Ulrike M. Lüdtke · Edward Kija
Mathew Kinyua Karia *Editors*

Handbook of Speech-Language Therapy in Sub-Saharan Africa

Integrating Research and Practice

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To Zukhanye

—Ulrike M. Lüdtke

Foreword 1: Regaining a Voice

Communication is a very important need for each one of us. Without it a person can suffer in silence. With no one to talk to, and in silence, a piece of you gets broken day by day. In every minute and second there is something happening in your life. But one problem: you have no ways of communicating. All you can say or ask in your heart is: Why? Where? Who to talk to and how do I say it?

The story of my life turned around when I was introduced to the Centre for Augmentative and Alternative Communication (CAAC) at the University of Pretoria, South Africa. Life seemed so meaningless and captured by my unknown illness. Slowly my brain was suffering and my future was dying in silence. I did not know where to go and who to turn to for help. And one day I gave up, feeling that I will never be like any other human being. Then that is when I saw a little light as I approached that light. It is when I got closer to it that it expanded into more light.

I met a person who opened each and every possible door for me to enter and discover. What life had for me to see and speak about anything I could not do before. I got to understand the meaning of having a voice. That is something valuable and precious at the same time. I told myself that this is one part of me I never want to let go of anymore.

I gave up so much when I was 11 and I became a victim, because I had no one to talk to. I suffered voicelessly and I had people say and make decisions on my behalf. Even if it was not what I wanted at the time, I had to sacrifice and accept things as they were. That is how my life was when I did not have my communication. The importance of having a voice has provided me with protection and a friendly environment to live in.

Life now is so good, and I have met people who started in familiar places to me, in the dark. But together with the people who opened doors for me, we are now working together in bringing more light to a voiceless person. Our voices may not come out of our mouth. But it sure comes out of our synthetic voices written by us. My mind is ok and it functions very well. I can hear all that is said to me; I am not deaf. All I ask for is time and patience so my voice can be heard.

Looking in the mirror now, who do you think I am seeing? Well, I will answer your thought. I see a strong beautiful independent young lady with a voice and the passion to make a change in people's lives. I believe I have been given an opportunity to speak again and to live with confidence to use my synthetic voice to teach others about the new developments technology has to offer.

University of Pretoria
Centre for AAC Pretoria, South Africa
Constance Ntuli

Foreword 2: Revealing the Person Within

Communication has the astounding ability to reveal the person within – enabling us to connect with others and share our thoughts, ideas and experiences. We communicate in many ways; most of us never think about what that ability brings to our lives. Unfortunately, often it is only when that ability to communicate is impeded that we begin to realize the fundamental role it plays in the human experience – this I discovered through the path my life has taken.

I was born in Johannesburg, South Africa, in 1975. I grew and developed as most children do. Playing, exploring, getting up to mischief with friends and attending school – life was good. At the age of 12 everything changed. I contracted a brain infection. Doctors treated me to the best of their ability. However, I progressively got worse. Eventually, I lost my ability to control my movements, make eye contact, and finally, my ability to speak. Assumed to have the intelligence of a 3-month-old baby I was trapped with my body, surrounded by people yet utterly alone, spending 14 years in care institutions.

My personality was entombed within a seemingly useless body, a vibrant mind hidden in plain sight within a chrysalis. To some I was Martin, a vacant shell, the vegetable. To others, I was the tragically brain-damaged boy who had grown to become a man. Someone, like a pot plant, they cared for.

It took someone new to see me in a different way. Whether through intuition or her attention to details that others failed to notice, she became convinced that I could understand what was being said. Having seen a television program on augmentative and alternative communication (AAC), she urged my parents to have me tested by experts at the Centre for AAC (CAAC) at the University of Pretoria.

An AAC consultation in 2001 at the CAAC helped me to communicate for the first time. From that moment my dull, mundane existence burst into a vibrant and fulfilling life. I made friends, found a job, obtained an education, met the love of my life, emigrated to the United Kingdom, started my own business and wrote an international bestselling book.

My journey to becoming a proficient communicator using AAC, while life-changing, was not an easy one. Living in Africa presented many challenges – a lack of AAC knowledge, awareness and expertise; limited and/or expensive AAC solutions; many social, cultural and societal barriers; and little support for the AAC user and their family.

While AAC solutions need to be tailored to the individual to meet their needs, opting for dedicated AAC software on a standard off-the-shelf laptop was highly unusual at the time. Consequently, we couldn't find anyone willing to help or support me. Thankfully my mother took on the responsibility of helping me to develop my communication system.

I will forever be grateful to the therapists who looked beyond the preconceived ideas and saw potential where others saw none. I am extremely excited about the truly groundbreaking *Handbook of Speech-Language Therapy in Sub-Saharan Africa*. This book is a valuable and unique resource to support the development of the speech-language therapy profession and the successful inclusion of individuals with complex communication needs in sub-Saharan Africa. It provides the reader with important insight on the perspectives, problems, challenges, ideas, concepts and models concerning communication disability within the African context.

My hope is that this book will promote the ongoing research and development of AAC in sub-Saharan Africa and in so doing make a real and significant impact on the lives of people with complex communication needs.

IT-ELF,
Sawbridgeworth, UK

Martin Pistorius

Foreword 3: My Journey with Aphasia

My name is Mary Aol Musungu. I have a Bachelor of Education degree (Home Economics) from Kenyatta University, Nairobi, Kenya. I was a high school teacher for 7 years, teaching home science, English and biology. I later left the teaching job to work as a humanitarian worker, dealing with children's and women's issues.

On Sunday, September 16, 2001 at around 8 pm, I felt dizzy and couldn't answer my daughter's question "Mum, what is the matter?" because I was clutching my head and foaming from my mouth. My daughter (a high school student at the time) rushed me to the nearest hospital where they confirmed that I had just suffered a stroke. My blood pressure was high at 140. After several hours, I felt calmer but I couldn't "feel" the right side of my body and I couldn't see through my right eye. I was "asking" questions that were not being answered. I found out later that I was not voicing my question aloud. I had lost my speech!

The doctor said that I will survive the stroke. However, I was not prepared for my new life. This meant that I will have to take medicine for life, hours of physiotherapy, drooling like a baby, having swallowing difficulties and the worst of all was I couldn't talk. It also dawned on me that I might not work again.

After 3 weeks in the hospital, I was able to count one to ten and utter a few words, though with difficulties. Then "hope springs eternal." When I was in this state of despair, my friends and family told me about speech-language therapy. I believed that since I was a fast learner, I could work hard, speak and resume work. So, I started speech-language therapy at Aga Khan University Hospital with the amazing Emma Shah.

I was diagnosed with aphasia, dysarthria (slurred speech), apraxia and swallowing problems. I learned to my horror that the new condition called aphasia is lifelong. That my language centers in my brain were damaged and anything languages related would be impaired. That's why I couldn't read, too. You make one step forward and two backward. You can see a word but you cannot recognize it. There was nothing about being a fast learner!

As a children's rights advocate and a manager of a child center program, communication was a key competency for that job: Speaking engagements, reading and writing programs, report writing and analysis were language intensive. Reading and writing, speaking and listening are key skills in the society and even very important to a teacher or a manager. So, I had to convince my employer that, although I was language impaired, I had not lost my intelligence. I was convinced that I would compete with my more able colleagues.

Back to Work

I received a letter from my employer that if I was not back in 6 months my service could be terminated. I panicked because I was the sole breadwinner. How will I pay my rent and school fees for my daughter? All this time, I was on half pay for 3 months and no pay for 3 months. Although I felt fine, I could barely talk and write. After 6 months, my doctor gave me a letter to go back on light duties.

So, I went to the office and asked to resume my duties. My boss called an ad hoc committee that comprised the organization executive secretary and the technical health advisor to make a decision on whether I was fit to go back to work. The verdict was that in that organization, there was nothing that could be called light duties. I feared I might have another stroke due to this decision. I was devastated by the verdict delivered by the committee. I wondered what to do with the rest of my life.

My only hope was in a fellowship group from my church that used to visit and pray with me and encouraged me that with God, everything was possible. My doctor advised me to work on my speech by reading a newspaper aloud, every day. A month later, I was called back to work and resumed my position as the program manager. Although I was able to perform and reached targets, I struggled with my language. I had a good secretary who helped me do my emails and report writing.

After about 1 year, I increased my responsibilities at work. So, I now managed more programs. I wanted to prove that I was not disabled. Unfortunately, 3 years after my stroke, I was terminated from my employment on a technicality. The organization was restructuring and asking managers to re-apply for their positions. We had to go through an interview where they picked some predetermined candidates.

Usemaji Aphasia Support Group

I realized that my life had changed for good. I continued with the speech-language therapy for another year. Meanwhile, with Emma Shah, my speech-language therapist, we founded an aphasia support group and named it Usemaji (meaning “to speak”). As stroke survivors, we used this group to share our experience, providing emotional support and educating each other about the acquired condition. We used to meet every second week of the month at Aga Khan University Hospital. We invited neurologists, occupational therapists, counselors, speech-language therapists and other experts. We also held several social events at Christmas, had picnics at City Park and Nairobi Arboretum, as well as awareness raising functions with supermarkets and media houses.

The Usemaji Support Group has benefited many people immensely. We have realized that communication disability is not only an issue of health but a human rights issue too. We have made friends, unlike many people who lose friends after suffering a stroke. Other support groups such as the Stammering Support Group and Kenya Association of Laryngectomies come from Usemaji meetings.

A Silent Disability

When people see us, they don't see a disabled person unlike in other disabilities. Yet, we suffer in silence. Communication disability is not seen but its effects are felt. The stigma is more because people confuse speech disorders with mood swing disorders. We feel like we are in a different world where people speak in a different language. Whereas the blind are recognized with a white cane, the aphasics have nothing.

We also waged a bruising battle with the Kenyan National Council for Persons with Disabilities (NCPWD) for recognition of aphasia as a disability and getting the same rights as the "big 5" (blindness, deafness, intellectual disability, physical disability, albinism). One of the achievements of the Usemaji Group is that aphasia is now recognized as a disability.

Before this recognition, I went to work with a lot of humiliation as I tried to convince my colleagues that I was not disabled. Many said, "A speech problem is not a disability, are you just looking for tax exemption?" To which I answered that I asked what I was entitled to. I just wanted my colleagues and I to be registered as per the Kenyan laws. I was not working to benefit from tax exemption. It is an irony that when I was working, I had to convince my colleagues that I was not disabled and after accepting my condition, then I had to convince the NCPWD that my disability is real.

Today, as a person with aphasia, my right is guaranteed as per the Kenya Constitution, 2010, and the Persons with Disabilities Act, 2003.

"New Normal"

People who thought I was drunk when I talked with my slurred speech think I am not normal. I still find it difficult to memorize Bible verses as a good Christian should. To pronounce a big word, I cut it into small syllables and then read slowly. As part of my therapy, I read aloud whether I understood or not, though I got much better with time.

I still read aloud to understand, much like a child learning how to read. When I write, I do the same. I talk out the word I want to write and repeat words until I get them. If somebody is nearby, I ask for help. The dictionary and spell check in the computer didn't help in the beginning because you could not recognize the sound. I have to depend on others to edit my work. My daughter usually does it for me. As for this write-up, Dr. Mathew Karia from Kenyatta University has helped me.

I still do speeches and presentations with a lot of preparation and help. Spur of the moment speeches or off-the-cuff talk are out for me. I must talk slowly or my words stumble over each other. When I start talking, I hear a lot of "pardon?" and "sorry?" so I talk again slowly.

I don't hear well in my right ear and listening is also tiring. So, after a few hours concentrating it gets difficult.

My Takeaway

Aphasia is a communication disability like any other disability and you get work done like any other person, just maybe slower. Our intelligence remains intact. I lost a job, not because I was an incompetent worker, but because of stigma that came with the disability. My journey has been on for 15 years. It is a journey to remember.

Watching *The King's Speech*, I am inspired. If a King of Great Britain can do it, why not you? If you can afford a speech-language therapist, it is worth it. But excellent support is vital. I had my child and my mother to help me.

Aphasia Support Group
Nairobi, Kenya Mary Aol Musungu

Foreword 4: Supporting Children at Risk

Most children growing up at Irente Children's Home (ICH) near Lushoto, Northern Tanzania, and the surrounding villages are at risk of having, or have, disorders in communication.

Likely reasons for this are, firstly, that speech and language difficulties have not received attention in general in most of our communities. This is due to the fact that difficulties in communication overlap with other disabilities. This makes it difficult for most people in our communities to identify children who need support particularly in this area and the required services to address the problem.

Secondly, there is a lack of enough professionals to deal with children. At ICH there are only two qualified professionals. The rest have just attended very basic programs relating to early childhood education. This has a great impact on the provision of appropriate and adequate services to those children growing up at the institution. With this very limited number of professionals, currently the present ratio is 11 children for one personnel. Hence, the children do not receive the best services which can facilitate communication development or support those who are already facing communication difficulties.

Thirdly, children growing up at ICH lack interaction with their families and other community members. Growing up in a family has a positive impact on a child's communication development as well as other crucial aspects of early childhood development because a child can interact with more people than here at the institution. Our African way of living (extended family) plays a big role in a child's development. In a family, it is common to find the parents, older children, relatives of other family members, grandmother or grandfather. If there is a baby in a family, all family members interact with the baby in different situations.

Fourthly, there is a deficit of funds to run the institution. Due to this situation, the two professionals spend much time supervising projects: small shop, hostels, cow keeping and gardening. More time is spent to secure income for running the institution than serving children.

Fifthly, in most surrounding villages, women are the ones taking care of children. It must be borne in mind that the women in villages are overwhelmed with many tasks because they are the ones who make the family survive. They have to spend the day on farms or other income-generating projects. With this situation, children are left to care for themselves.

Sixthly, the services that do exist for children with speech and language difficulties in the country have no central planning or formal policies. Hence, the issue of *who should develop services, where and by whom should they be provided* has not been addressed. For the present, there is no formal policy in the country regarding persons or children with speech and language difficulties.

A lack of formal policy makes it difficult to provide services. Besides this, the few units in the country which offer those services are located in urban areas. This means the majority of people living in rural areas are left out.

Training for the Prevention of Communication Disorders in Children Growing Up at Irente Children's Home and Surrounding Villages

Over the past 6 years, ICH and the Department of Speech-Language Therapy at Leibniz University Hannover have established a concept for training personnel at ICH as well as women from surrounding villages to support the language development of children and recognize risks for communication disorders. The training that we have received has motivated the personnel working here at ICH to be closer to children than before. Before training, it was common to observe them ignoring what children were doing, including playing. But now they are very much sensitive even when they hear a child crying. They are much more concerned with children's affairs than before.

They are eager to learn more and to spread the knowledge and skills they have obtained from the training to other women in communities around the Lushoto region.

In my opinion, we need to train more people in the basics of prevention and intervention in communication disorders. It will take time to have well-planned programs in this field here in Tanzania as well as many qualified speech-language therapists that can provide those services across the country. I would suggest that we find a way to build the capacity of the communities to handle those difficulties by themselves. The few professionals available in the country should be used to train other people in communities or for consultations.

We need to provide culturally appropriate services that are wanted by our local communities. In respect to this, the views of the whole community should be considered. More research studies should be available to inquire about the community's views on the issues relating to speech-language disorders. It should be borne in mind that there are some services provided unintentionally by people in communities. They should be tested because they can also assist in prevention and intervention.

We need to create awareness in people on all issues of communication disorders.

Irente Children's Home
Lushoto, Tanzania

Enna M. Mdemu

Foreword 5: Living with Stuttering

No one understands stuttering as well as the person who stutters. Growing up stuttering was like having a long-life painless pain. One of the basic human abilities is to speak and when one is not able to speak "well" you cannot avoid feeling incomplete, especially when you compare yourself with your peers.

I am now an adult, born in Kenya in the late 1970s. I can remember very well when my ability to speak was compromised. I was fluent but at 9 years old I realized I was having difficulty in saying some words; I opened my mouth, but some sounds didn't come out. By the age of 12 years my stuttering increased. This didn't bother my parents; this could be because my two maternal uncles were stuttering too. My mother and aunties used to make fun of my uncles when they stuttered; sometimes I would feel as if it was directed at me.

In class six the pupils were required to read aloud in class during English reading lessons. This was my dreaded lesson. I would do anything possible to avoid reading aloud. During one lesson I pretended to have a nosebleed just to escape reading aloud. I could not understand how I was able to read the words well but I could not say them; it was like the words were choking me, and when they came out, I automatically repeated some sounds over and over – I felt helpless. A lot happened while reading: sweating, increased heartbeat, anxiety, excessive facial grimaces and stamping my feet. Stamping my feet helped in getting words out.

My teachers could not understand why I was performing well in written exams and failed to actively participate verbally during the lessons. Little did they know that I was just afraid to involve myself with any activity which involved speaking. I would stutter less when I was out of the classroom. I tried to maintain the same friends who were not bothered by my speech as I didn't want people discovering my stutter. I mainly feared people's reactions when I stuttered while speaking with/to them.

Secondary school life was terrible; moving away from home and meeting new faces made it worse. I had to make new friends. Teenage life emerged and the demand to verbally express myself increased. At this time I realized I was not able to say some words starting with the sounds /t/, /p/, /d/ and /b/. I learned how to substitute words in conversations, switching from one language to another and using short words and/or short sentences. These really worked for me as I was able to camouflage my stutter. My two younger brothers also started to stutter and I realized my stutter had a genetic origin. During

the extended family gatherings stuttering was okay as the number of stutterers was increasing. There was no known treatment and we were resigned to fate.

Life in university was better as people were mature and I can't remember anyone making fun of my stutter. I became more social but still would stutter more while talking to a stranger and especially female students. Speech and language disorder was a unit in the course I was pursuing – Special Needs in Education. This was the time I came to realize what was "wrong" with my speech. I read about stuttering beyond the given scope. My feeling about myself changed – I didn't feel guilty, I didn't blame myself and I realized what I had heard before were myths. Some interesting beliefs were that when there is a full moon people stutter more. I was also told I needed to have my uvula "chopped" because it was blocking the sounds from coming out.

From the literature I read I started to talk slowly while relaxing my shoulders. This worked for me as I was more fluent. However, people started to complain that I was avoiding eye contact, especially the college girls. As I said before, I was afraid of their reaction, especially facial reaction in case I stuttered.

I graduated and secured a job as a teacher in a special school. I do remember my boss once introduced me to their parents as a shy guy. It was in the year 2004 that I joined Nairobi Stuttering and Cluttering Support Group. I came across influential adults who had a stutter. I felt relieved psychologically seeing other people who were even less fluent. The patron who was a speech-language therapist trained me on how to have eye contact, appropriate breathing while speaking and using prolonged speech within the first 3 months in the support group. I become more fluent, more social and I was no longer the "shy" guy.

We were trained on block modification techniques and desensitization. In desensitization we would stutter voluntarily in public and cope with negative feedback from people. I am still an active member in the support group and my role is mainly to welcome new members and create awareness in schools and colleges by giving talks. I have talked about stutter in local dailies and TV shows.

This experience together with working in special schools has motivated me to go back to school and pursue a master's degree in speech and language pathology. One question I am still looking for an answer to is "Why do I stutter more when using my mother tongue while speaking?"

The most FRUSTRATING thing is when I am stuck in a word or sentence and people try to complete it for me but end up saying the unintended words.

It's a long journey I am travelling to help myself and others.

Kestres Manor School
Nairobi, Kenya

Asaph Mwangi Irungu

Foreword 6: The Potential of Rehabilitative Care

Experiences at the Centre for Education and Community Based Rehabilitation (CERBBc), North-Eastern DR Congo

The audiology clinic located in Aru, North-Eastern Democratic Republic of Congo, provides very limited services supported by US volunteers to provide rehabilitative care and clinical assistance to persons who have speech-language disorders.

One of the beneficiaries is Alio Adjio, a 43-year-old man, who was consulted at the CERBC clinic in April 2016 with hemiplegia on his left side and with language disorder for about 6 months. Alio fell abruptly in his house after falling into a state of unconsciousness.

Alio's Testimony

I was paralyzed on one side; it happened suddenly. When I came back home from work in the evening, after a shower, I washed some of my clothes then hung them in the bathroom. So in the morning when I woke up, I went to take my clothes that I had left in the shower. Suddenly, I felt a discomfort followed by a sudden weakness; I could not lift my hand and mouth, I was forced to sit down but I was not able to maintain my balance. It was in October 2015.

I spent the whole day at home and the next day the family and my wife decided to take me to the Yuku Hospital about 30 km from the house. I had only been given medicines, which I took. I could not speak, eating and even swallowing was difficult, the food passed by and I was not able to remember and think properly. I forgot everything; even when I put my phone on the table, I was not able to know where I put it. My tongue was heavy, drinking water was difficult, saliva passing by. Life was very difficult; I thought I was going to die and my whole family had lost hope.

After an unsuccessful 2 weeks in the Yuku Hospital, it was decided to change to another hospital and I was taken to the hospital in Ariwara about 80 km away, where I spent a month but without a good evolution. From there I was taken to the traditional care, where I spent another month, still without change and my small means were already at an end. One evening, we followed the communication on the radio that there are white specialists who deal with language problems at Aru at the CERBC. My wife and I decided to

go see these white people as maybe they are going to give me the best medicines, because we had gone through many hospitals and there was no change. Arriving in Aru at the CERBC center, we were well received, but, curiously, during the consultation and after that, the whites only prescribed exercises and talked about massage. I had been given some tablets for my muscles and some painkillers and I had also bought the ointment for the massage. I was a little disappointed as I expected a lot of medication; I was even thinking of an operation, etc.

But after a week I started to observe a slight change. I did the memory and language exercises three times a day for 45–60 minutes and also the massage sessions for 45 minutes, then a bit of gym, etc.

I think if I had been brought to CERBC in time, I would not have lost a lot of money elsewhere. So ignorance is a problem when you do not know exactly where to go when you have a health problem and you live in remote areas. I thank God because in the time I spent at CERBC I had comfort, I recovered language and now I have a good memory. When I got home I found my old notebook containing the names of the people who owed me money before I got sick. I recharged my phone to remind them of my debts; one of them told me that he did not believe that it was me, he must be speaking to a demon or a ghost because it was said that I was dead.

I thank the CERBC team for having organized such a service and to have brought to our land the white specialist from the USA, who consulted me and they helped me a lot with the memory exercises, face massage, etc. Even though I did not fully recover the function of my arm and leg, I recovered my memory and I can speak now, I eat without much difficulty, I communicate easily; I am very happy because I can still coordinate my activities for the survival of my children.

Note: Alio Adjio gave his testimony in French, and it was translated into English by Ismael K. Byaruhanga, who has acted as his guardian.

Centre for Education and Community Based Rehabilitation
Aru, Democratic Republic of Congo

Alio Adjio
Ismael K. Byaruhanga

Introduction

Motive

As editors, we are more than happy to release the first *Handbook of Speech-Language Therapy in sub-Saharan Africa*. For the first time ever, a huge compilation of research and practice in this important discipline from all ends and corners of this vast continent is presented to the local and global community, material which was hidden and even dormant until today. The chapters collected represent the fascinating diversity of the subject, from broad historical and pan-African reflections of the emergence of professional services for persons with communication disorders to the precise description of developmental milestones in multilingual language development within the specific region of Uganda, from thoroughly arguing for the need to develop culturally sensitive assessment materials, for example for isiXhosa and isiZulu, to the empirical evaluation of the effectiveness of augmentative and alternative communication (AAC) teaching strategies in inclusive classroom settings in Namibia.

Due to the joint effort of 90 experts from 17 different countries covering disciplines such as pediatrics, neurology, speech-language therapy (SLT), linguistics, language teaching, ear-nose-throat medicine (ENT), AAC, information technology (IT), and, of course, special needs education (SNE), this handbook represents not only knowledge and skills but also political and ethical considerations which all persons with communication disability in sub-Saharan Africa (SSA) deserve: the isolated, stigmatized mothers with children diagnosed with cerebral palsy who experience dysphagia, the unrecognized men and women in rural areas with aphasia after strokes, the deaf, dyslexic, or autistic children in preschools and schools without sufficiently trained personnel, or the hidden, locked away, and sometimes even killed babies with severe or multiple organic disorders such as cleft lip and palate, spina bifida, or hydrocephalus.

We hope that this handbook will serve to support the growth of the SLT profession throughout the African continent and worldwide.

History

Looking back over the last 7 years, we can say that the book developed in three main phases.

The initial spark was ignited in 2015 when, due to unexpected difficulties, the planned 6th congress of the East African SLT Society in Arusha, Tanzania, had to be canceled at the last minute, after the venue, catering, and hundreds of flights had already been booked. Voices were raised that instead of being disappointed about this long-anticipated and lost opportunity of getting together, the already prepared keynotes, lectures, and seminars should be compiled in a written format. Having agreed on this, an additional call for papers went out through an email snowball system to ask each and every speech-language therapist (SLT) to contribute—trying not to miss anyone.

It quickly became clear that the task ahead was bigger than climbing Kilimanjaro and that a joint effort was needed to succeed. Fortunately, in 2015, a substantial 4-year grant was given to the editors to establish an SLT network in East Africa. This meant that the financial and human resources became available to support the editing tasks. Nevertheless, many times during this second phase, we considered giving up, and there were times when one author or another thought that this book project would never become a reality. We are, therefore, very grateful to all the individual authors for their patience and to the personnel at Springer Publishing for their encouragement.

For more than 4 years, we continued to edit the book eagerly, inviting as many authors as possible to create a representative picture of SLT in SSA (see list of authors), setting up a global peer-review network to ensure the highest professional quality (see list of reviewers), constantly communicating with all contributors about the 1001 fine details involved in publishing a chapter—from higher photo resolution to consent for publication, to missing references and so on—while all the time distracted by our normal duties of clinical service delivery, teaching obligations, or attending conferences in Europe, the US, and Asia.

And then…??, the COVID-19 pandemic started. Unreal in early 2020, unbelievably long by Christmas 2020 and New Year 2021, and shockingly persisting in successive waves with multiple dangerous mutants, with lockdowns and curfews, and the ugly spectacle of the unfair global distribution of vaccines. How did this global crisis impact on our handbook? Strange as it may seem, this totally unprecedented situation boosted our motivation and energy as it became clearer and clearer that (1) sharing professional information had to move beyond face-to-face meetings and to become virtual, (2) boundaries between countries and continents do not exist, although there may be attempts to impose barriers like high data cost, and (3) the vulnerability of all of us was revealed; it is no longer restricted to only persons with a disability, or—in our profession—persons with a communication, swallowing, or hearing disability. Finally, against this background, we delivered the completed manuscript to the publisher.

Structure

Book Sections

We are very proud that the book starts with touching forewords written by persons with communication disorders and those who provide services to them (see v–xiv), allowing us to gain insights into the sensitive, even intimate, issues that the rest of the book addresses scientifically. These introductory insights are followed by 35 original chapters. The chapters are organized into four major parts: (I) Professionalization, (II) Development and Prevention, (III) Assessment and Treatment, and (IV) Inclusion.

Part I, Professionalization, opens the book with a wide and thorough compilation of chapters reflecting on the complex multi-layered processes of the emergence, growth, and development of the relatively new profession of SLT in SSA, pointing out pitfalls, evaluating lessons learned, and highlighting best practice.

Part II, Development and Prevention, focuses on multilingual communication and language development and its support as well as early prevention of developmental communication, language, and hearing disorders. Topics specifically related to the context of SSA such as bilingualism and biliteracy, communication disorders concerning HIV/AIDS, developmental milestones in indigenous languages, and community-based prevention projects in rural areas are examined.

Part III, Assessment and Treatment, contains a variety of chapters sharing experiences and presenting models, aids, and practices for children with language and communication disorders, multilingual children, and adults with dysphagia and aphasia. It provides deeper theoretical and practical insights into the assessment and treatment of communication, language, and hearing disorders in SSA.

Part IV, Inclusion, outlines recent challenges, opportunities, developments, and directions for the successful inclusion of persons with communication disabilities at the interface of education and health in SSA. Topics range from teaching strategies for children with (social) communication disorders to sign language interpretation services. The chapters discuss the implications and the need for future actions.

Each section of the book starts with a short introduction to the section-specific topic, always aiming to combine the latest state-of-the-art and current topics from a global perspective with Africa-specific insights. This is followed by a brief overview of all the chapters in that particular section, the abstracts of the chapters, and a critical review by the editors.

An epilogue summarizes the main topics and highlights their value and impact on science and society. Finally, a comprehensive index and a table of abbreviations are provided.

Distribution of Chapters

An in-depth approach to structuring the 35 chapters is to analyze their distribution according to different parameters—from the more or less obvious ones, such as the country and discipline of the authors, to the more profound ones, such as the research method applied. This analysis provides important insights into the status quo of the emerging SLT profession all over SSA, as well as its current desiderata, which need to be worked on in research and practice over the coming years.

If we first consider the chapter distribution according to the *book sections* (Fig. 1) it is clear that we have an equal distribution (27.78% each) across three of the four parts (i.e., Professionalization (I), Assessment and Therapy (III), as well as Inclusion (IV). This seems to indicate that despite the fact that it is an emerging profession a lot of interesting, relevant work has already been conducted in these areas. In contrast, Part II, Development and Prevention, at 16.67%, is much smaller. This indicates that, in the future, topics related to this area of the theory and practice of the profession should be encouraged. One reason for the current under-representation of such topics might be that children's communication and language development is the key research domain of psycholinguistics with application to speech-language therapy (e.g., developing language-specific standardized tests for African languages based on linguistic norm data), and these interdisciplinary challenges are yet to be explored. Another possibility—even if this might not appear reasonable from an economic or from a sustainable perspective—is that prevention is always one of those areas of SLT service delivery which comes last, because the pressure and demand for immediate action is much higher in the areas of assessment, therapy, and inclusion. On a positive note, it is encouraging that the number of chapters that deal with aspects of professionalization is so high, given the fact that SLT is a relatively new profession.

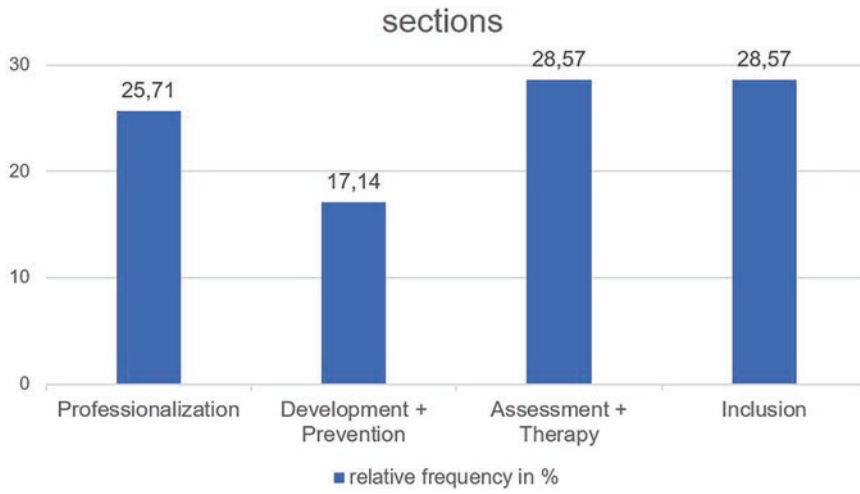

Fig. 1 Chapter distribution according to book sections

One explanation might be that almost all chapters in this section are the result of joint reflections of "insiders" and "outsiders," which is not so much the case in the other three sections. Another explanation could be that SLT in SSA does not need to reinvent the wheel; it is embedded in a global community, which shares—as documented here—the lessons learned.

In a second step, if we look at the chapter distribution according to *countries* or the broader regions which are addressed (Fig. 2), one-fourth of the contributions address SSA as a whole. As these are the chapters mainly discussing quite broad, comprehensive topics concerning professionalization, this number is not surprising. Further investigation of the country distribution reveals that the individual countries, Kenya, Namibia, Rwanda, South Africa, Tanzania, and Uganda, represent 6 out of 49 countries on this huge continent. If we also consider the region of East Africa, a possible explanation for the visibility of this small percentage of countries could be that these are the countries that have universities with SLT departments engaged in research and training (see Figs. 2 and 22), and/or that have local or regional SLT associations, and/or that have strong roots in the colonial past with mostly European SLT collaborations. The vast underrepresented regions and countries of Central and West Africa (at only 2.78%) can be explained by the roots of this book being in an East African conference.

In a third step, looking at the chapter distribution according to *discipline* (Fig. 3), unsurprisingly the vast majority of our chapters (71.79%) originate in the SLT discipline, and a remarkable 12.82% of chapters come from one of the closest neighboring disciplines, namely SNE. The remaining number of chapters (ENT = 2) or just single chapters (n = 1), representing other disciplines, such as linguistics, neurology, psychology, or even IT, or interdisciplinary

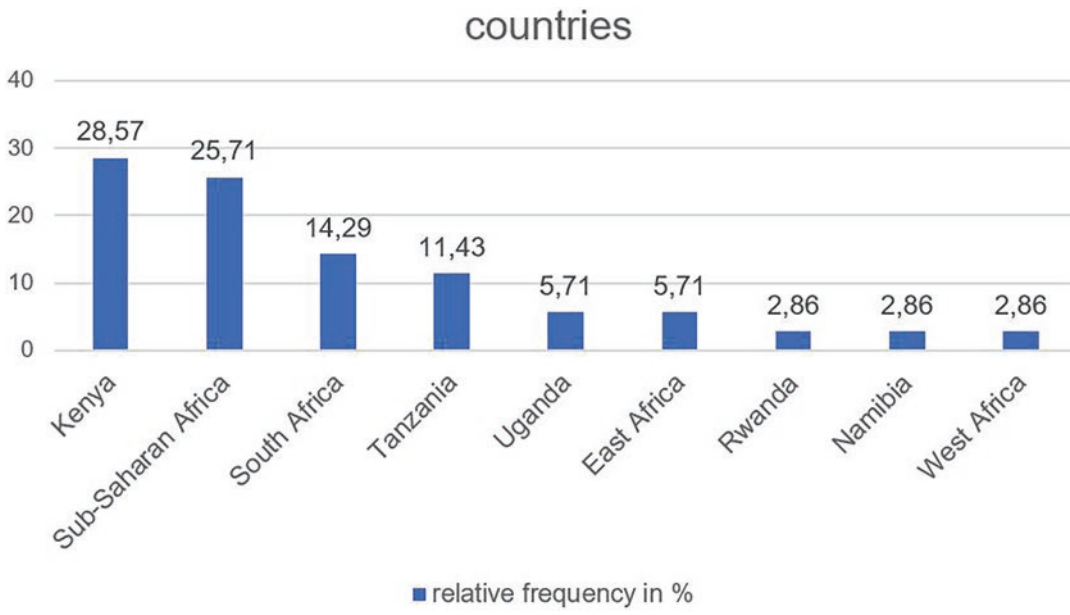

Fig. 2 Chapter distribution according to either specifically addressed African countries or broader regions

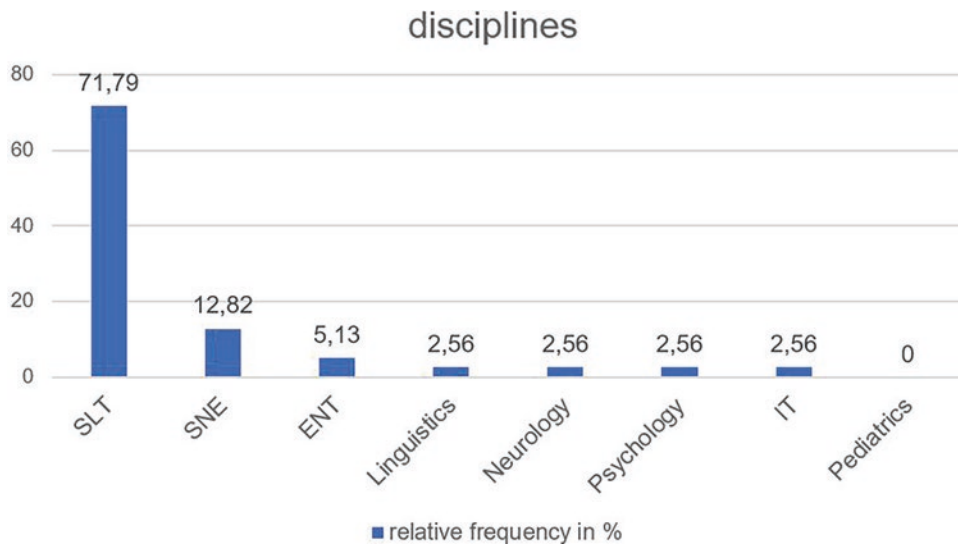

Fig. 3 Chapter distribution according to discipline ($n = 39$ due to authors from different disciplines in one chapter)

research, can be evaluated in two different ways. A positive view of the situation could indicate that there are small signs of interdisciplinary collaborations supporting the complex challenges of a young SLT profession. A more pessimistic interpretation could bemoan the fact that the disciplines that are traditionally strong in basic, well-funded research do not seem to be interested in collaboratively researching topics of specific interest to the SLT discipline. We should be optimistic and hope that this handbook will indicate interesting avenues for future transdisciplinary studies.

The *research methods* applied by the contributing disciplines are set out in Fig. 4. The distribution of the chapters according to research methods shows a majority of 41.67% using qualitative methods, followed by noticeably less using quantitative methods (19.44%) and project reflections (16.67%). Other approaches include 11.11% using mixed-method designs, theoretical chapters (8.33%), and systematic review approaches (2.78%). There are no contributions of practical reports. From our point of view, the clear dominance of qualitative methods represents a research approach that is mostly found in the social and educational sciences, whereas quantitative methods are more favored in psychology and medicine. The distribution of our chapters may indicate that SLT researchers in SSA could explore other types of methodologies and strengthen the less frequently applied methods.

As the *qualitative research methodology* is most prominent currently, it seems necessary to examine it in more detail (Fig. 5). Based on the methods applied as labeled by the researchers, 20.00% of the chapters do not specify the nature of the qualitative methodology. Further investigation reveals that the vast majority of chapters are based on literature reviews (33.33%), literature analysis combined with case studies (13.33%), or literature analysis (13.33%). Few chapters (6.67% each) used specific renowned qualitative

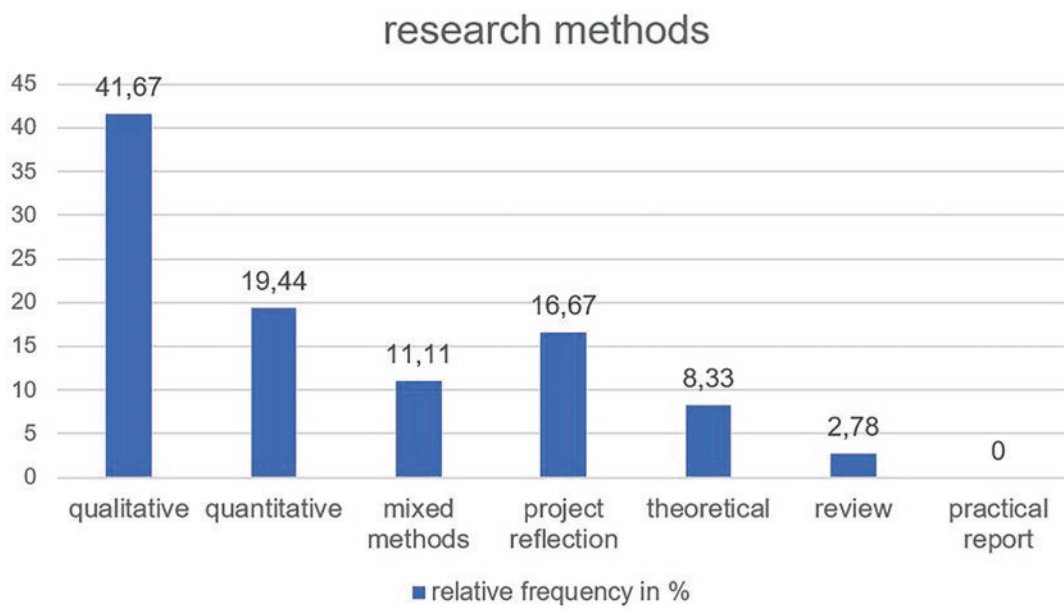

Fig. 4 Chapter distribution according to research methods

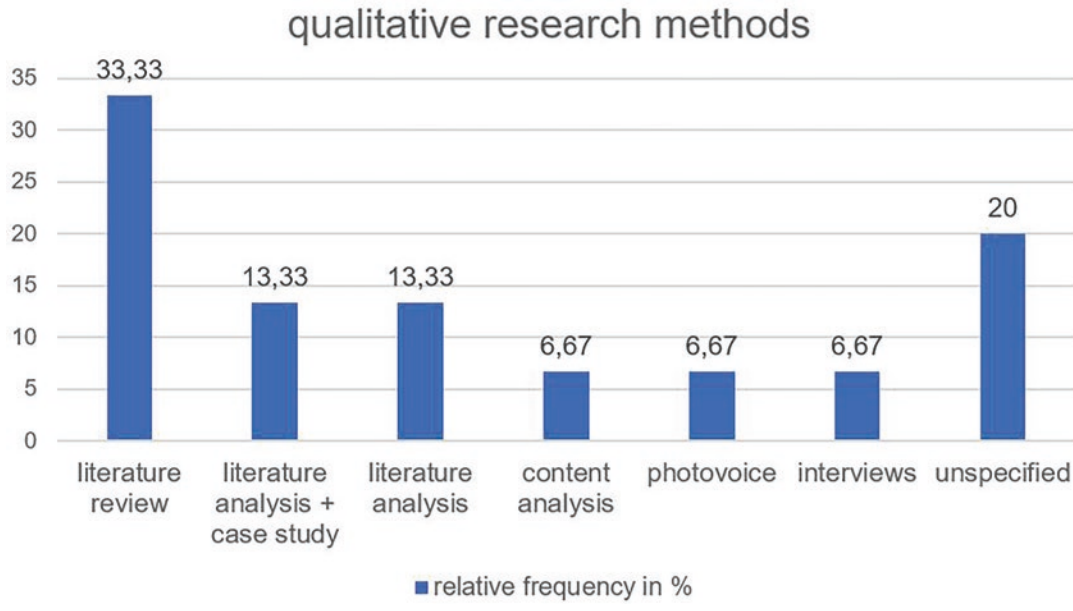

Fig. 5 Chapter distribution according to qualitative research methods

methods, such as interviews, content analysis, or Photovoice. There is a possibility that the label "qualitative research" is being used to include literature reports rather than specific qualitative research methodologies (e.g., focus groups, in-depth interviews, thematic analysis). If this is the case, while it is understandable in a young profession, it should be supplemented by studies with more rigorous research methodologies—quantitative, qualitative, or mixed. There is a need to recognize that the development of a profession should involve thorough research that builds up the data for the profession, for example epidemiological data or results of intervention studies. This process is of the utmost importance because evidence-based practice is a prerequisite for the development of SLT.

Shifting from research methods to the key subject of research in our handbook, we first look at the distribution of chapters according to *age group* (Fig. 6). Apart from the 37.14% of chapters that deal unspecifically with the whole life span of persons with communication, hearing, and swallowing disorders—the ones mostly reflecting issues of SLT professionalization—there is an impressive number of chapters (51.43%) that focus on children. This is noteworthy and might reflect that more than half of Africa's populations are youth, as well as the high value this generation places on the SLT profession and society in general. The focus on children goes hand in hand with another interesting number, as 5.71% of the research focused on newborns. In contrast, adults and older people, at 2.86% each, are very much under-represented, even if we take the very specific age structure of most sub-Saharan countries into account. Future research may further explore these two very important age groups.

As children, in general, are the most studied age group, it might be interesting to take a closer look at this large age cohort (Fig. 7). First, more than half of the chapters (55.00%) do not give precise information on their target group. The distribution of chapters within the remaining half is very interesting. The biggest group focused on are preschool children from 3 to 6 years (20.00%), followed by newborns and very young children from 0 to 3 years (10.00% each). In contrast, there is no chapter explicitly focusing on primary school children, and only a small number (5.00%) targeting secondary school children aged between 10 and 17 years. One explanation for the missing group of primary school children might be that the chapters, focusing on "children," without any further specification of age, mainly dealt with the 6–10-year age group and did not feel a need to specify it as such. It is also evident that the considerable majority of chapters focus on the three age groups before school entry, namely newborns, 0–3 years, and 3–6 years. This again emphasizes the importance of this generation. Accordingly, as mentioned before, secondary school children are very much underrepresented. This creates a research gap that needs to be addressed as this age group has unique profiles and needs related to the SLT profession.

In addition to age, it is also interesting to identify the *institutions* that are the key subjects of research. Apart from the one-third of chapters that do not focus on a specific institution—again, mostly the general chapters in Part I, Professionalization—the distribution of chapters according to institution

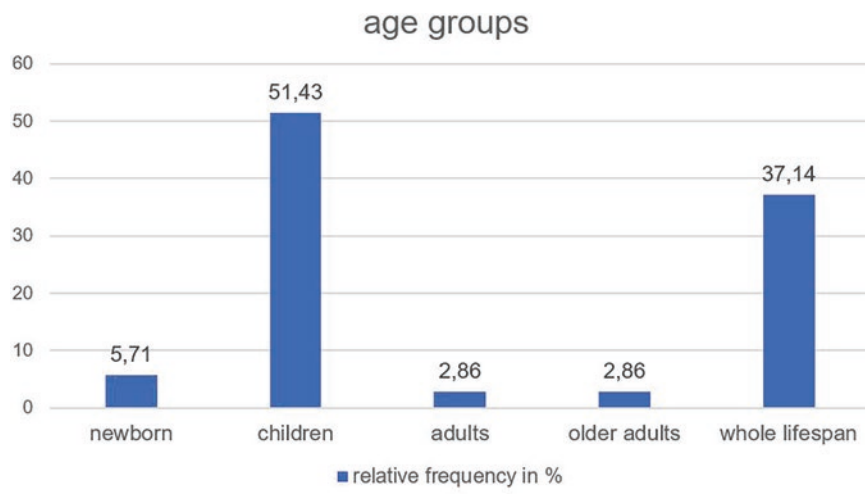

Fig. 6 Chapter distribution according to age group

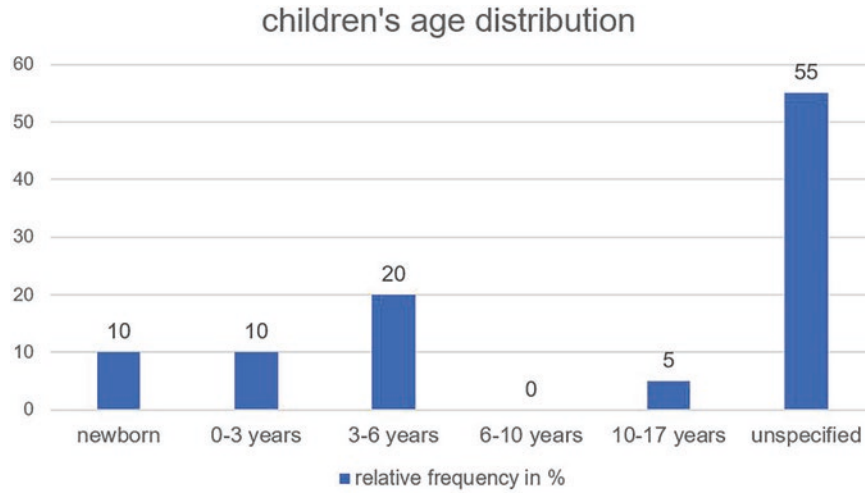

Fig. 7 Chapter distribution according to children's age group

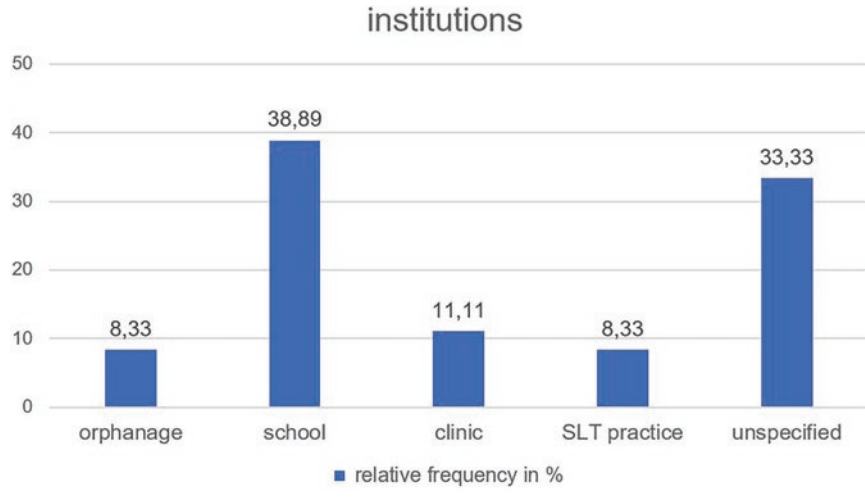

Fig. 8 Chapter distribution according to institution

(Fig. 8) shows the dominance of school-centered studies (38.89%). In contrast, the other specifically addressed institutions of orphanages, clinics, and SLT practices are much less represented, accounting for between 8.33% and 11.11% of contributions. Even though SLT in school is a very important area, it must be pointed out that for the profession as a whole, it is very important that the other institutions of service delivery, such as clinics, hospitals, and SLT practices, should not be neglected. Otherwise, the spectrum of service delivery is not complete. The current imbalance represented here might originate in the large number of contributions from special education, as pointed out above. Therefore the medical institutions should be expanded. At present, on the vast African continent, there are only a few SLT units in hospitals and very few SLT practices—mostly private ones—in some major capital cities. Recognizing and including SLT as part of a public health system is an absolute prerequisite for service delivery. Service delivery in schools is more established, as the institutions already exist, and SLT in the educational sector is even boosted by the global wave of implementing inclusion for children with disabilities, including communication disabilities.

A closer look at the dominating educational sector reveals that the chapter distribution by *school type* (Fig. 9) mirrors previous results. In 60.00% of the chapters, no specific information is provided, but it can be assumed that most of them focus on the primary school context. In line with the age group distribution, again a considerable number of chapters focus on the preschool context (33.33%). Only a few studies focus on secondary schools (6.67%). As already pointed out, the younger age groups are of the utmost importance, and the neglect of this sector is a major research gap that needs to be filled.

The third and perhaps most important trend in an SLT handbook is to analyze the chapter distribution according to specific disorder (Fig. 10), even though "diagnosis" is just a label and a more descriptive approach in line with the ICF (World Health Organisation, 2001) is perhaps more appropriate.

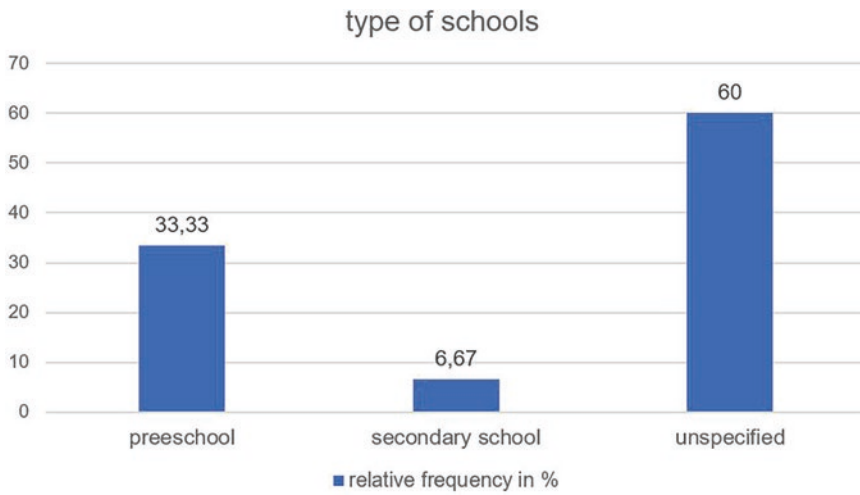

Fig. 9 Chapter distribution according to school type

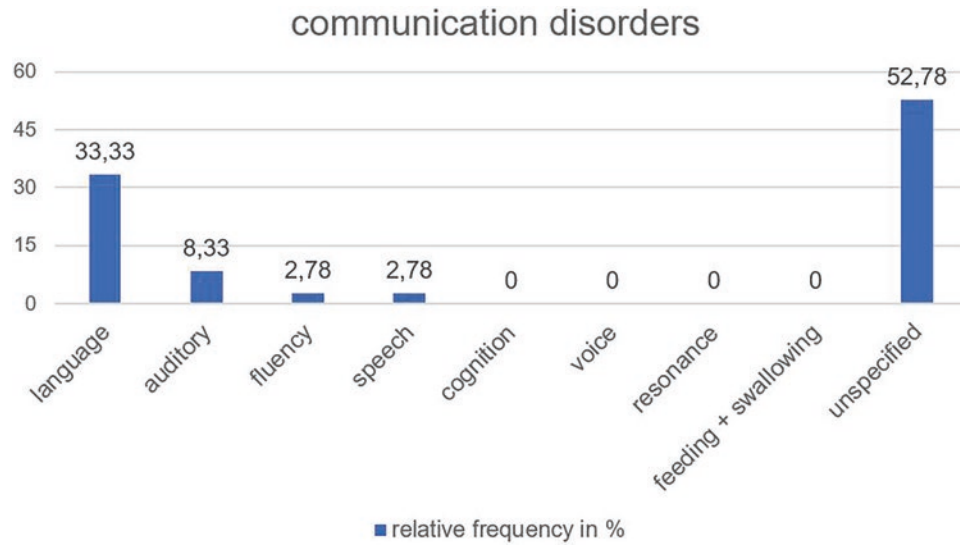

Fig. 10 Chapter distribution according to communication disorder

Again, more than half of the chapters (52.78%) do not focus on specific disorders. The authors took the perspective of focusing on professionalization of SLT in SSA for all disorders in general. In the remaining chapters, it is noteworthy that only one area of service delivery is prominently identified, namely language disorders, which accounts for 33.33% of contributions. Other areas, such as auditory, fluency, and speech disorders, are each mentioned in one, two, or three chapters (2.78–8.33%). Cognition, voice, resonance, and feeding and swallowing disorders are not represented at all. These results can be explained by the fact that, for example, although no chapter explicitly focuses on feeding and swallowing disorders, this subject is considered as part of a neurological disorder in some chapters that cover more than one disorder or area. Therefore, the conditions are coded as "unspecified." However, it is significant that dysphagia, and similar disorders, is not the exclusive focus of any chapter. The focus on language disorders can be interpreted in various ways. First, it is surprising that from the whole spectrum of disorders, the one that needs thorough and specific linguistic expertise is so prominent in a part of the world where not only every country but every region and every family is multilingual. It might be easier for a young profession to deal first with language disorders. Fluency, speech, and voice disorders would appear to be global and, to a large extent, independent of language and culture. Perhaps the correlation between the distribution of chapters according to disorder and the targeted age groups could provide an answer. In the dominant age group, children, language disorders and auditory problems seem to predominate. If this is the case, then our argument is worthy of repetition. Although the substantial current interest in language disorders is a

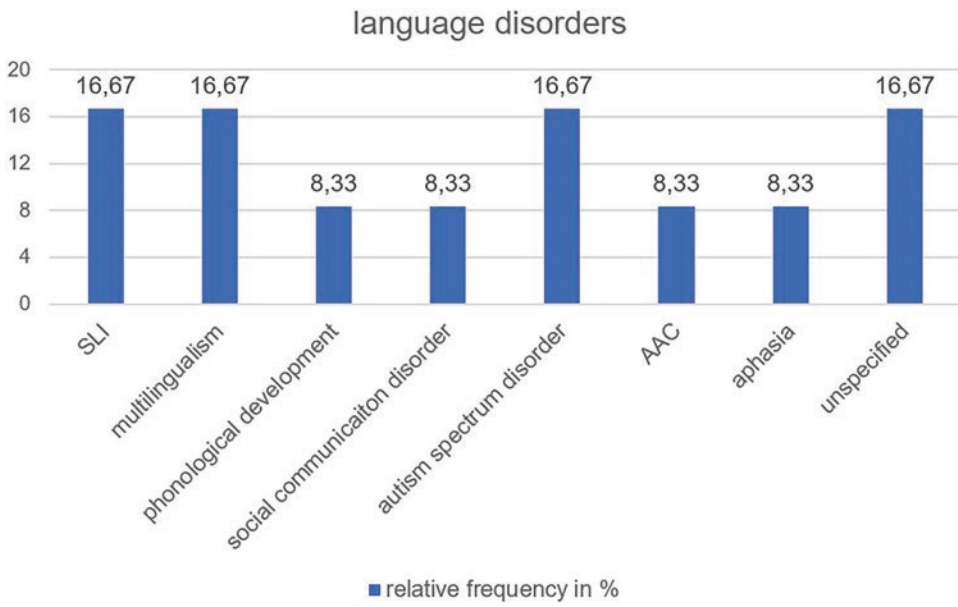

Fig. 11 Chapter distribution according to language disorder

strength of the rising profession, in the future, to complete the spectrum of SLT research and service delivery, the focus must shift to other disorders.

Close examination of the chapter distribution according to *language disorder* (Fig. 11) gives the impression that the relevance of the age variable seems to be supported. Aphasia is the only disorder featured (8.33%), which is typically related to adult age. Apart from a small number of unspecified studies (16.67%), the whole rich spectrum of language disorders related to children and/or their specific service delivery areas is quite evenly distributed at 8.33–16.67% for the specific language impairment (SLI), multilingualism, phonological development, social communication disorder, autism spectrum disorder (ASD), and AAC areas. A great strength of SLT in SSA seems to be that children's language disorders are recognized in all their manifold facets. This seems a good entry point for deeper exploration of more complex areas, such as dyslexia.

Finally, we thought it would interest the reader of this handbook to look at the chapter distribution according to *professional level* (Fig. 12) (see Lüdtke, 2023). Based on a model that divides professions into five different levels ranging from grassroots to meta-theory, this book has more contributions from the more abstract than from the more concrete pole of the continuum. The majority of the chapters represent SLT research and/or SLT theory development (34.29%), followed by 25.71% contributing to meta-theoretical and/or ethical considerations of SLT, as well as 20.00% studying in one way or the other SLT concepts of service delivery or assessment development. The more day-to-day level of SLT practice accounts for 17.14% of contributions, and there are few chapters representing the lifeworld of persons with com-

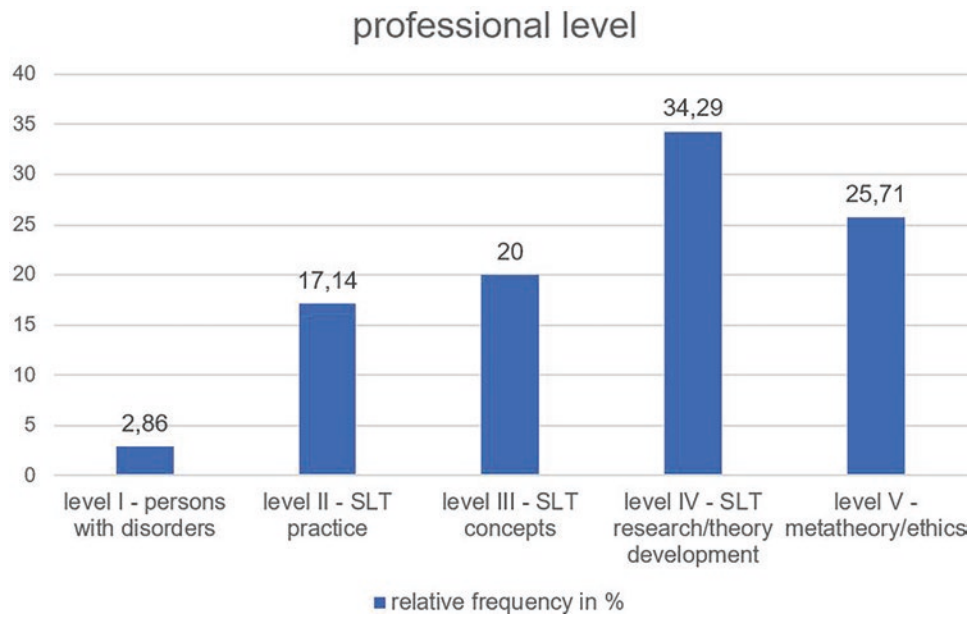

Fig. 12 Chapter distribution according to SLT professional level

munication, hearing, and swallowing disorders (2.86%). As this very last point is not just an essential aspect of our profession but represents its foundation, motive, and heart, as editors, we invited five persons with a communication disability to not only fill this gap but to feature prominently in the Forewords of this handbook (see v–xviii).

Transdisciplinary, Global, and Multi-Level Approach

Returning to a broader perspective, we would like to share our overall approach in compiling this handbook, which is based on three pillars.

Transdisciplinarity

First, as SLT is mainly an applied science, integrating knowledge from many different neighboring sciences (see Fig. 13), we planned to reflect this transdisciplinarity by inviting authors from a variety of related disciplines. Now, looking at the final manuscript, we are very pleased that the chapters—though small in number—represent most of the related disciplines (see Fig. 3).

Global scope

Second, our aim was to compile the first-ever handbook uniting all the efforts of the young, growing SLT profession in SSA and relating all this to the surrounding global community. Evaluating the final list of contributing authors

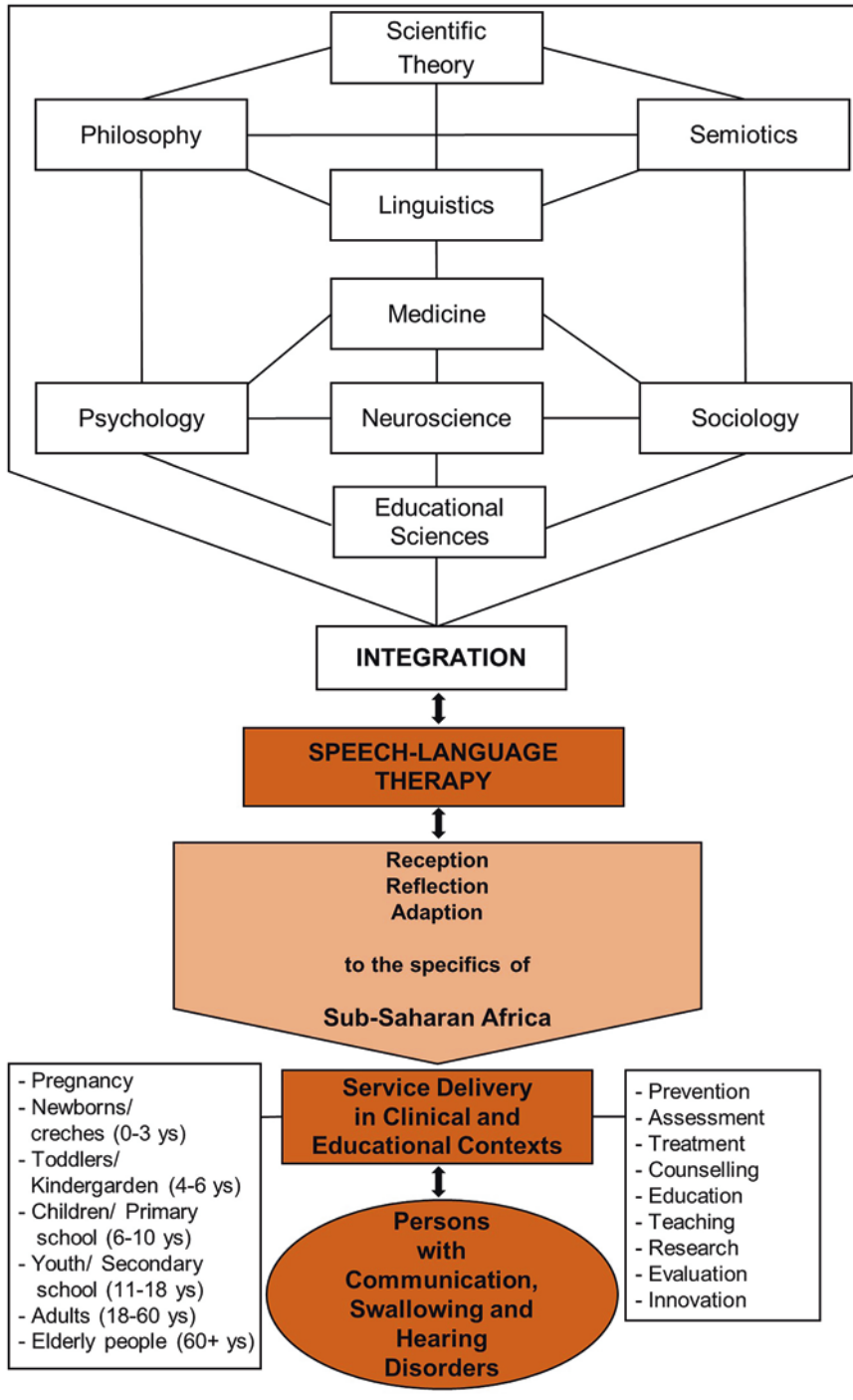

Fig. 13 The integrating character of SLT and its adaptation to the specifics of sub-Saharan Africa. (Adapted from Lüdtke & Stitzinger, 2015, used with permission)

as well as the table of contents, we are very satisfied that the uniqueness of SLT in SSA and the global scope are equally and jointly represented.

Multi-level conceptualization

Finally, in this handbook, we also intended to give a platform to all the different kinds of SLT projects throughout Africa as a whole, not excluding any projects, for example by judging them as "unscientific," but ensuring their quality in a criteria-based peer-review process (see section "Peer Review, Terminology, and Up-to-Dateness of Data"). Therefore, we are satisfied that the final assessment of the chapter distribution in the handbook according to professional level (see Fig. 12) reveals a wide variety of projects representing our multi-level conceptualization (see Lüdtke, 2023).

Peer Review, Terminology, and Up-to-Dateness of Data

As previously mentioned, when planning this handbook, we started by setting up a mixed African/international review board with more or less equal numbers of members from the US, Asia, Europe, and SSA (see list of reviewers), whereby we invited colleagues with outstanding expertise from the involved disciplines (see Fig. 3). With great effort, and with sensitivity to our pioneering endeavor, they took part in a double-blind peer-review process, where each chapter was reviewed by two experts in the specific subject. The evaluation criteria of the review sheet, with a 5-point Likert scale rating and additional open comments, were chosen according to current criteria of highly acknowledged international SLT journals and the peer review and manuscript guidelines of Springer Publications (Springer Nature, 2021a, 2021b). Two important issues were adapted due to the specific scope of the handbook. First, we included criteria for non-empirical research chapters. Second, we developed new criteria to strengthen the African perspective and context; for example the research questions and methodology had to be precise and specific to SSA conditions, and, wherever possible, a third of the cited references related to African research literature.

When the first manuscripts were submitted, some terminology issues were challenging. On the one hand, they occurred due to general international differences or different wording within SLT. On the other hand, they raised sensitive questions about preventing a "western" Anglo-American or Eurocentric paradigm. After intense discussion with many authors and the review board, we set the following author guidelines (excerpt):

- *chapter* not *paper*
- *speech-language therapy/therapist*, not *speech-language pathology/pathologists*
- *grade* not *standard* (school context)
- *disability*, not *disabilities*

- *disability* in the context of a long-term personal change within an individual regarding education and participation, *disorder* when dealing with biological dysfunction in specific disorders such as stuttering, dysphagia and dyslexia.
- no use of *PWCD/PWD* abbreviations but spelled out as *persons with communication disability/persons with disability* (not people with communication disorders/disabilities)
- *Majority/Minority World countries*, or *high-/middle-/low-income countries*, and *global north/global south*, not *developing/undeveloped countries*
- original names of languages, not the English name, for example *Kiswahili* not *Swahili*, *isiZulu* not *Zulu*
- *indigenous languages*, not *minority languages* or *tribal languages*

Finally, a major challenge was the up-to-dateness of data across the different chapters. As the process of compiling and editing this handbook had a long time span, we are aware of the issue that data quoted or presented might be slightly out of date. We, therefore, want to assure authors and readers that all data were correct at the time of authorship even though rapid change in many contexts, for example refugee populations or patient: SLT ratios, means that the data would need to be updated almost daily or monthly.

Target Readership

When planning the book, we also discussed at length the target readership we are trying to reach. Finally, we identified at least four major relevant groups:

1. SLTs from all different professional levels within all countries in SSA, for example students enrolled in the different SLT programs across the continent (see Fig. 22), or researchers designing an important study in the educational or clinical SSA context
2. SLTs from outside Africa, mainly scientists or students, who are interested in the specifics of the profession on another continent
3. Experts from the neighboring SLT disciplines within and outside Africa, who want to link their expertise with this young emerging profession in SSA
4. The interested SSA public, for example stakeholders in politics, health, and education, who will implement the new SLT research results in their various areas of service and policymaking

The heterogeneity of this target readership requires a short general introduction to our SLT subject (see section "Speech-Language Therapy"), as well as to some major relevant specifics of the African context (see section "Sub-Saharan Africa").

Key Subjects

Speech-Language Therapy

It is imperative to provide a clear definition of the scope of the discipline at the beginning of this short general introduction to our SLT subject. This requirement poses an enormous challenge because of the different historical, paradigmatic, and disciplinary backgrounds that cause the key terminology to differ widely. We aim not to align this handbook close to the specific position of one country, for example the UK, or to one professional body, for example the American Speech–Language–Hearing Association (ASHA). Therefore, we provide general, even vague, descriptions and explanations. Our decision to do so might be criticized or considered unscientific. However, it reflects our overall attitude of supporting the decolonization of the SLT profession in SSA, and this process begins with independent decisions on definitions, classification, and terminology.

Therefore, very generally, the term "speech-language therapy" describes the theory and practice of providing therapeutic treatment and educational support for persons with communication disabilities (including language, speech, and voice difficulties) as well as swallowing disabilities (including feeding difficulties). In this handbook, the therapeutic treatment and educational support of persons with hearing disorders are also included, although in many countries, the discipline of "audiology" is a separate one. We also decided to use the term "speech-language therapy" instead of "speech-language pathology" in this handbook. This is because in some parts of the world SLT does not belong exclusively to a medical paradigm but is also very close to SNE. In such cases, the providers of services to persons with communication disorders are not health professionals but rather teachers or other teaching personnel in schools who, in addition to therapy, provide special educational services, especially in inclusive settings.

Integrating Character, Africa-Specific Adaptation, and Areas of Service Delivery

In general, SLT is an applied science at the interface of medicine and education, affiliated to either one, or even to both, depending on the country, or—referring to the UN's Sustainable Development Goals (SDGs) (United Nations, 2015)—at the interface of SDG 3 (Good Health and Well-Being) and SDG 4 (Quality Education). It is an interdisciplinary yet independent science, integrating the latest expertise from the relevant neighboring disciplines (see Fig. 13).

- *Scientific theory*

  Latest discourses on epistemological and meta-theoretical questions are taken into consideration for reflections, for example on paradigm changes or methodological development in SLT research.

- *Philosophy*

Advances in anthropological reflections, for example on vulnerability as a sine qua non of humankind, are incorporated into accepting diversity and the participation of persons with communication disorders.

- *Semiotics*

The groundbreaking knowledge about the nature of communicative signs in all the human senses—hearing, seeing, touching, smelling, tasting—works as a continuously updated source, for example, to develop tools for nonverbal communication in AAC, recently also in a digital mode.

- *Psychology*

Advances in various psychological approaches, for example in clinical psychology, are adopted for the treatment of stress- or anxiety-based communication disorders, for example mutism.

- *Sociology*

Continuing sociological research serves as a source especially for up-to-date sociolinguistic reflections, for example on standard language and its normative use in language tests versus the acknowledgment of African American Vernacular English.

- *Linguistics*

Basic research in various African languages is a prerequisite for, for example, constructing linguistic assessment tools for patients with aphasia or children with phonological disorders in their specific African first language(s).

- *Medicine*

The latest research in the different relevant medical subdisciplines, for example ENT and plastic surgery, and maxillo-facial and oral surgery, guarantees the provision of SLT clientele with innovative care, for example a deaf newborn with a cochlear implant or infants with cleft lip and palate combined with speech therapy.

- *Neuroscience*

Continuously updated brain imaging techniques enable a better understanding of unsolved phenomena in communication disorders, for example language processing in multilingual speakers with brain injuries.

- *Educational sciences*

Up-to-date models of inclusive education can serve as a blueprint to benchmark school-based interventions for learners with speech, language, and hearing disorders.

The integration of the latest expertise from various disciplines into SLT is necessary. However, it is only a stepping-stone to the next complex building block in establishing the SLT discipline in SSA: the reception, reflection, and adaptation of these prerequisites to the unique specifics of the SSA context in regard to contextual relevance and social responsiveness to the needs of the community. These specifics are not only manifold but also encompassing, ranging from the Africa-specific etiology and epidemiology of communication, swallowing, and hearing disorders (e.g., the impact of poverty or of difficult access to health care), to the multitude of languages spoken on the African continent (see Figs. 20 and 21), to the very specific life and work conditions of persons with communication, swallowing, and hearing disorders (e.g., in rural areas), up to service delivery in Africa-specific clinical, hospital, educational, and community-based rehabilitation contexts (e.g., the separation of private and public sectors).

The main functions of service delivery have to consider these Africa specifics in targeting all age groups across the life span in various settings (see Fig. 13).

- *Prevention*

  One major aim of SLT services is to use professional anticipatory actions to prevent all communication, swallowing, and hearing disorders. One example could be eliminating the ototoxic medication of mothers during pregnancy (e.g., related to the treatment of malaria), a practice aimed at preventing children being born with a congenital hearing impairment.

- *Assessment*

  At the core of SLT service delivery is, of course, the assessment of all kinds of communication, swallowing, and hearing disorders throughout the life span. Africa-specific challenges are, for example, related to the assessment of language disorders in a highly diverse multilingual clientele or the specifics of early assessment and early intervention in contexts of limited access to health care services.

- *Treatment*

  Assessment is twinned with the other core element of the intervention process, the treatment of all kinds of communication, swallowing, and hearing disorders throughout the life span. Here similar Africa-specific challenges range from a lack of broadly institutionalized early intervention programs to the lack of broadly available highly skilled surgical and prosthetic care, for example cochlear implants for babies (0–3 years) and voice prostheses for adults (18–60 years), or electronic larynxes mostly needed for older people (60+ years).

- *Counseling*

  An important function of service delivery is the counseling of family members or other professionals supporting persons with communication dis-

orders. For example, mothers from rural villages, caring for older children with cerebral palsy and dysphagia, need to be trained, once they are able to visit a referral hospital, in how best to feed their child, and how to position and transfer them.

- *Education* and *teaching*

The various approaches of school-based intervention for children in primary school (~6–19 years) or young people in secondary school (~11–18 years) is another important setting in SLT. Africa-specific challenges here are, on the one hand, the qualifications of school personnel to provide adequate services, and on the other hand, the broad provision of inclusive school contexts, with special regard to admitting children with (severe) communication, swallowing, and hearing disabilities to school, instead of keeping them at home.

- *Research* and *evaluation*

The demand to include research and evaluation in the spectrum of the discipline is an often overlooked necessity. In the SSA context, it is essential to start at a general level to provide large-survey, current, epidemiological data on almost all kinds of communication disorders. This should be complemented, on a more refined level, by building a reliable body of evidence-based SLT practices for all areas of service delivery, for example assessment and treatment of orofacial dysfunctional disorders.

- *Innovation* and *telehealth*

Finally, innovation is a significant task within SLT, as new models and techniques of service delivery are constantly being developed, and they need to be adapted to improve the well-being of all learners and clients. Digitalization and telehealth is a recent rapidly growing area, for example in support of children with dyslexia or adults with aphasia. Digitalization can also increase the communicative participation of persons with ASD or other severe cognitive impairments.

Persons with Communication, Swallowing, and Hearing Disability and Forms of Classification

Taking a closer look at the target group of the described SLT services, we first wish to emphasize our overall personified approach, which according to the ICF paradigm (World Health Organization, 2001) implies that our focus is not on disorders as intrinsic attributes of the persons, but always on the persons being affected by communication, swallowing, and hearing disorders as well as their families, and their social participation in relevant life situations. In line with that, as previously mentioned, we decided not to use the common terms people with communication disorder/people with disorder but instead person(s) with communication disability/person(s) with disability. In this regard, we make a terminological difference between disorder and a disability as described in section “Peer Review, Terminology, and Up-to-Dateness of Data” of this chapter.

Another challenge concerning the phenomena of communication, swallowing, and hearing difficulties is the issue of their terminology, which depends on their classification and its underlying paradigm. For example, the term phonological disorder implies a linguistic paradigm—the term dyslalia for the same disorder implies a medical paradigm.

A first approach to outlining the scope of disorders treated by SLTs is a descriptive classification, briefly structuring the different phenomena according to their apparent symptoms. However, bearing in mind that the classification might differ from country to country or from profession to profession, the main groups are as follows:

- *Hearing disorders*: Difficulties in perceiving and processing sounds affecting speech reception and production, language development, and/or communication
- *Language disorders*: Difficulties in the comprehension and/or expression of meaning across any of the five language domains (i.e., phonology, morphology, syntax, semantics, and pragmatics), either in a verbal or in a written form negatively affecting communication
- *Speech disorders*: Difficulties in creating or forming speech sounds (the domain of phonetics) affecting intelligibility in communication
- *Voice disorders*: Difficulties with pitch, volume, tone, and other qualities of voice affecting speech production and/or communication
- *Fluency disorders*: Interruption in the flow of speaking characterized by atypical rate, rhythm, and disfluencies, which may be accompanied by excessive tension, speaking avoidance, struggling behaviors, and motor movements affecting speech production and/or communication
- *Swallowing disorders*: Difficulties in sucking, chewing, and moving different consistencies of food and/or liquid into the throat and/or difficulties swallowing different consistencies of food and/or liquid affecting eating, nutrition, weight, and/or general health
- *Feeding disorders*: Non-age-appropriate refusal to or avoidance by children of eating certain food groups, textures, solids, or liquids, affecting eating, nutrition, weight gain, growth, development, and/or general health

This type of classification can be complemented by:

- a *quantitative* approach, where the symptomatology is rated as single, multiple, or total, for example in articulation disorders, where the number of affected sounds is counted;
- a *qualitative* approach, where the symptomatology may be classified according to its severity ranging from mild to profound

Another much more nuanced approach is the etiological classification, which structures the various communication, swallowing, and hearing disorders according to their underlying causality. Here, also, the classification might differ and is a subject of constant discourse around the globe, for example due to the underlying paradigm of the classifying discipline, for example medicine vs. linguistics. One example is the recent international discourse about criteria and terminology for children's language difficulties (Leonard, 2020). Nevertheless, the two main groups are:

- *Congenital disorders*, meaning a person is born with a disorder, for example SLI;
- *Acquired disorders*, meaning the disorder occurs after birth, for example aphasia following traumatic brain injury.

Furthermore, disorders are described in the literature—not mutually exclusively—as follows:

- *Organic*, suggesting a physical cause of the disorder, for example cleft lip or palate as an impairment of the peripheral functions;
- *Functional*, suggesting a behavioral cause of the disorder, for example a deviation in how the vocal apparatus is used causing functional voice disorders;
- *Genetic*, suggesting a genetic cause of the disorder, for example Down syndrome as a change in the DNA sequence away from the normal sequence (in this case, an extra full or partial copy of chromosome 21);
- *Psychological*, suggesting an emotional cause of the disorder, for example anxiety as an etiological component in selective mutism.

Additionally, adverse social living conditions, for example poverty, very low socio-economic status (SES), or substance abuse of parents, might aggravate the above disorders, and the cumulative effect of these risks either as causal or contributing factors should be considered as well.

In short, a communication disorder is the individually restricted ability to use verbal and nonverbal symbolic systems limiting participation in relevant, everyday life contexts. In addition, communication, swallowing, and hearing disorders can also be secondary to another primary—often genetic—disorder, in which the communication, swallowing, and hearing disorders occur as part of a more complex pattern of difficulties. For example, severe developmental language disorders and/or swallowing disorders may be associated with Down syndrome or hearing loss may be associated with Waardenburg syndrome. Additionally, different communication, swallowing, and hearing disorders may be associated with each other. For example, some children with selective mutism may also meet the diagnostic criteria for a developmental language disorder.

Sub-Saharan Africa

At the beginning of a short general introduction to the second subject of our handbook—introducing some major relevant specifics of the African context, within which the above-outlined SLT discipline is placed—there is a need for a clear definition, or at least a description, of SSA.

Geography, Politics, Economics, and History

The African continent is divided by the enormous Sahara desert, which forms a climate zone that separated the north from the south of the continent geographically from 4000 to 6000 years ago (Claussen et al., 1999) (see Fig. 14). Because of its harsh climate and low population, the large desert, only interrupted by the Nile River, was a barrier for people, cultural exchange, and economic trade (New World Encyclopedia, 2020). Politically, the term SSA was established to name the south of the continent without any colonial bias. Previously, the area was often called "Black Africa" in Minority World countries. However, the term SSA is also criticized because it is similarly rooted in western colonialism, and the prefix "sub" might connote inferiority (Ekwe-Ekwe, 2007) (Fig. 14).

Fig. 14 Sub-Saharan Africa

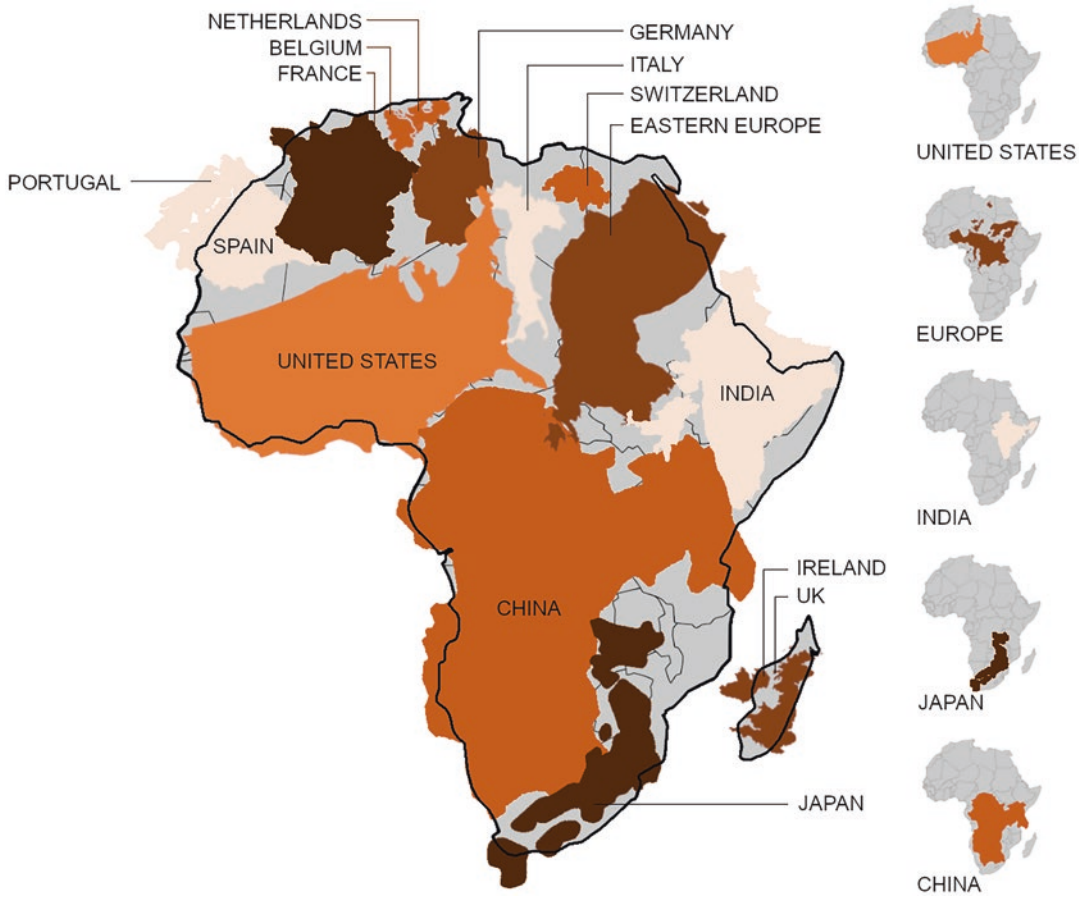

Fig. 15 Size of Africa in relation to other continents. (Adapted from Desjardins (2020))

In this handbook, we use the term SSA whenever the whole continent is addressed in general. Nevertheless, in regard to the situation of SLT in SSA it should always be kept in mind that the status of South Africa is a little different from the rest of SSA due to its longer history of SLT professional development (Pillay & Kathard, 2015; Wylie et al., 2016).

In the context of colonial bias, it is always enlightening to become conscious of the true size of Africa relative to other continents or leading Minority World nations (see Fig. 15). Europe, the US, China, India, and Japan combined are the same size as this one single continent.

In 2021, SSA consists politically of 49 nations (including Sudan, which is excluded in some definitions, e.g., the United Nations Statistics Division, 2021) (see Fig. 16). It has a size of 24.3 million km^2 (18.1% of the world's land) (von Carlowitz & Röndings, 2016). In 2019, the population was 1066 bn (United Nations, 2019). These facts should always be kept in mind when reflecting on the development of a profession as young as SLT within the African continent. On the one hand, the situation might differ widely from country to country. On the other hand, the number of people in need of SLT

services—especially outside the capital cities—is enormous. The task of building SLT capacity across all countries in SSA must also be considered.

The vastness of the continent is not only mirrored by the fact that, currently, approximately 14% of the world's population live in Africa (United Nations, 2021) but also that Africa encompasses four different climate zones and is spread over five time zones. Despite its richness in an amazing natural and cultural heritage, combined with a lively modern scene of innovative digital start-ups and entrepreneurship in many capitals, all major global indices rank Africa as being in the most difficult of positions.

Economy

Some key indicators reflect Africa's often precarious position in the global economy, despite its immense potential. Countries in SSA account for only 2% of global economic activity, although the region is home to 14% of the world's population (Usman & Landry, 2021).

While the gross domestic product (GDP) of all so-called industrialized states added up to 50.6 bn USD in 2020 and the countries of the European Union reached a sum of 15.17 bn USD in the same year, those countries summarized as SSA generated a joint GDP of only 1.62 bn USD despite their geographical vastness and high population density. Also, most of those 20 countries with the lowest per capita GDP in 2020 worldwide were countries in SSA (Statista, 2020). The seriousness of the situation is also emphasized by the information that with an approximate rate of 70%, SSA had the highest worldwide number of underage workers in 2016 (International Labor Organization, 2016), a fact that does not encourage hope for increased economic stability in the region.

Corruption

In addition to the economic considerations of concern, SSA does not show better results for the dissemination of corruption. The region scores the lowest among all other regions in the world, according to the Corruption Perceptions Index (CPI) (Transparency International, 2019). Due to the high number of countries summarized in this region, there is a wide bandwidth of different scores and main fields of corrupt activities, ranging between scores of 66/100 for the Seychelles with a comparably good result and 9/100 for Somalia. However, the average regional score of 32/100 shows the widespread impact of corruption in the region (Transparency International, 2019).

Infrastructure

Infrastructure is considered a major need of SSA. Calderón et al. (2018) have examined transportation as a field of infrastructure, as well as water and sanitation, electric power, and telecommunications/internet. Infrastructure has shown slower development in this region than in the rest of the world. An increase in infrastructure development would contribute to increased economic growth not only regionally but worldwide (Calderón et al., 2018).

Armed Conflicts and Political Instability

Amnesty International names a manifold number of African countries with armed conflicts in all regions of the continent, accompanied by grave violations of human rights. These were, however, in many cases, also committed by state organs. Human rights violations included torture, kidnap, injuries, or killing. In several places, opposition or human rights activists were arrested, disappeared, or even killed in 2020, such as in Mozambique, Tanzania, or Mali, to name only a few. Amnesty International also reports the postponement or even the suspension of a high proportion out of a total of 22 elections on the African continent. Another problematic topic is the restriction of media and press freedom (Amnesty International, 2021), which could recently be observed in regard to the emergence of the COVID-19 crisis.

Migration

The study by Flahaux and De Haas (2016) examined migration flows of African migrants from 1960 to 2010 and found that, contrary to the widespread opinion of African migrants leaving their continent, many of these people emigrated to other African countries. It also found a mainly decreasing migration rate, excluding West Africa. Nevertheless, extra-African emigration has also increased (Flahaux & De Haas, 2016). For the period between 2014 and 2019, the Africa Center for Strategic Studies reported 78,000 clandestine migrants from Africa who reached Southern Europe (Africa Center for Strategic Studies, 2020). According to the Global Migration Data Analysis Centre (GMDAC), an increase of 7% from 2010 to 2015 has been identified regarding the number of inhabitants of West Africa who wanted to migrate to another place, making West Africa "the region with the highest migration potential in absolute terms" (GMDAC, 2018, p. 50). However, it is not only the migration of people that is of concern but also the impact of displacement on those migrating, those staying behind, the infrastructure, and all aspects of social life. These are issues to be considered as they can lead to serious and sustainable consequences (Internal Displacement Monitoring Centre (IDMC), 2019).

Health

There are various widely spread infectious diseases and communicable diseases, such as tuberculosis, HIV/AIDS, and malaria, in the SSA region. In comparison to other regions of the world, SSA countries showed the lowest increase in the average age of death between 1970 and 2013 (Institute for Health Metrics and Evaluation, Human Development Network, 2013). In 2018, the average current health expenditure of sub-Saharan countries was reported to be only about 5.094% of GDP (World Bank, 2021).

It has been stated that, in 2015, about two-thirds of all maternal deaths worldwide occurred in SSA (World Health Organization (WHO), 2015). However, an average annual change of 2.4% in the maternal mortality rate between 1990 and 2015 has been reported. According to the WHO, "the proportion of AIDS-related indirect maternal deaths in SSA is 2.0%, yielding an AIDS-related indirect MMR (maternal mortality rate) for SSA of 11 maternal deaths per 100,000 live births" (WHO, 2015, p. 16).

In 2016, 90% of global malaria cases occurred in SSA, as well as 91% of all malaria-caused deaths. Malaria causes a decrease in economic growth, although medical possibilities and prevention measures against malaria have improved, and some countries were identified as theoretically capable of eliminating malaria completely in the near future (WHO Regional Office for Africa, 2019). The WHO also reports on the accompanying risks of malaria, for example infections during pregnancy (WHO, 2020).

In the current COVID-19 pandemic, the African continent is not receiving an equal share of vaccines. It is, yet again, a victim of global injustice (Ritchie et al., 2021).

Education

Another problematic topic is the rate of children who drop out of school early, thereby missing the opportunity to reach a basic education level and to have long-term economic stability. SSA is the region with the highest number of children who do not attend school—32 million, a devastating share of more than 50% of out-of-school children worldwide—and this already applies at the primary school level. According to the United Nations Educational, Scientific and Cultural Organization (UNESCO), over "one-half of all youth are out of school in sub-Saharan Africa" (p. 7), amounting to 58% (UNESCO Institute for Statistics, 2019). The share of students who enroll in the tertiary

Fig. 16 African nations today

education sector was 9.444% for the region (UNESCO Institute for Statistics, 2019). In contrast, an estimated 22.4% of children in SSA were affected by child labor in 2016, which means an increase of 1% compared to 2012 (International Labor Organization, 2017).

As this handbook is published against the backdrop of the COVID-19 crisis, it also needs to be emphasized that, according to the World Bank (2010, 2021), the macroeconomic instability resulting from the pandemic will increase poverty, further endanger lives and livelihoods, and negatively affect household welfare dramatically (International Bank for Reconstruction and Development, 2020). In the emerging SLT sector in SSA, the pandemic impacted heavily on the health and well-being of persons with communication disorders. The lack of a telemedicine infrastructure meant that service delivery almost stopped in many places. There was also an increase in crimes perpetrated on persons with severe disability.

When political considerations are put to one side, there is unanimous scholarly agreement that most if not all of the challenges facing Africa, as outlined in the previous sections, have their main roots in the colonial past when the major European countries ruled the whole continent (see Fig. 17).

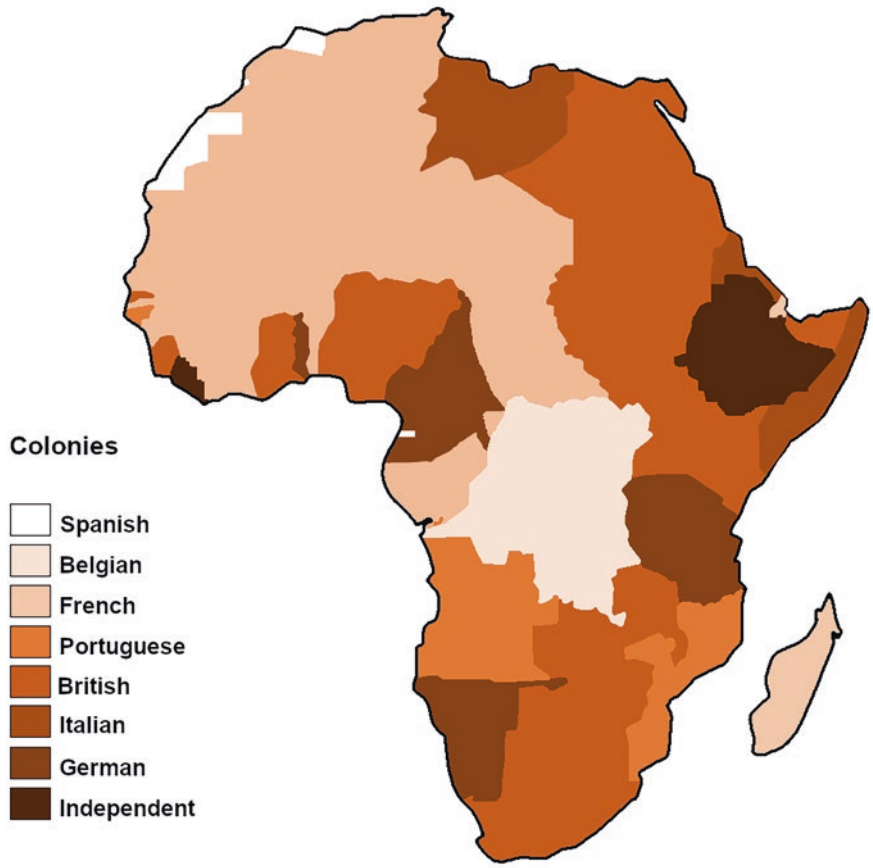

Fig. 17 Africa under colonial rule (1913)

The key features of that historical period were the slave trade, the exploitation of human and natural resources, political centralization, co-optation of traditional authorities, and arbitrary borders.

As a backdrop for our SLT context, a thorough reflection of this shared colonial past is an indispensable prerequisite. This is because the development of the SLT profession in SSA is part of a global professional context and often seeks the support of international collaboration in research and teaching. Therefore, reminders of the colonial past, such as experienced power imbalances, as well as conscious or unconscious prejudices or alienation, should be addressed professionally.

Languages

The next topic is integral to the SLT area. It is very important—especially for the non-African readership—to obtain some basic knowledge about the linguistics of Africa, although, yet again, we can only scratch the surface given the scope of our book.

Basic Language Domains

An American or European reader would find it difficult to believe that, in Africa today, there are approximately 2154 languages spoken (Simons & Fennig, 2018): 890 in Western Africa, 678 in Middle Africa, 438 in East Africa (including Madagascar), 100 in Northern Africa, and 48 in Southern Africa.

From a linguistic point of view, there are six language domains identified by different authors (e.g., Simons & Fennig, 2018) (see Fig. 18, where Güldemann (2018) classifies four domains and the Austronesian and Indo-European language families under the "others" category):

- the *Niger-Congo* domain with 1551 living languages with three subgroups (Atlantic-Congo, Kordofanian, Mande, and one unclassified language), each with several sub-categories;
  - *Bantu*, as a sub-category of the Niger-Congo family, encompasses 547 living languages (separately depicted in Figs. 6 and 7).
- the *Nilo-Saharan* domain with 207 living languages with four sub-groups (Kuliak, Saharan, Satelite-Core, and Songhai), each with several sub-categories;
- the *Afroasiatic* domain with 382 living languages with six sub-groups (Berber, Chadic, Cushitic, Egyptian, Omotic, Semitic, and one unclassified language);
- the *Khoisan* (Khoesan) domain including the Tuu, Kx'a, Khoe-Kwadi, Sandawe, and Hadza language families (Güldemann, 2018);
- the *Indo-European* domain with Afrikaans;
- the *Austronesian* domain with the languages of Madagascar and of Mayotte.

From a sociolinguistic perspective, it is interesting that many of the ex-colonial languages have a very high status and are used, for example, in administration and higher education. Figure 19 indicates how mainly English,

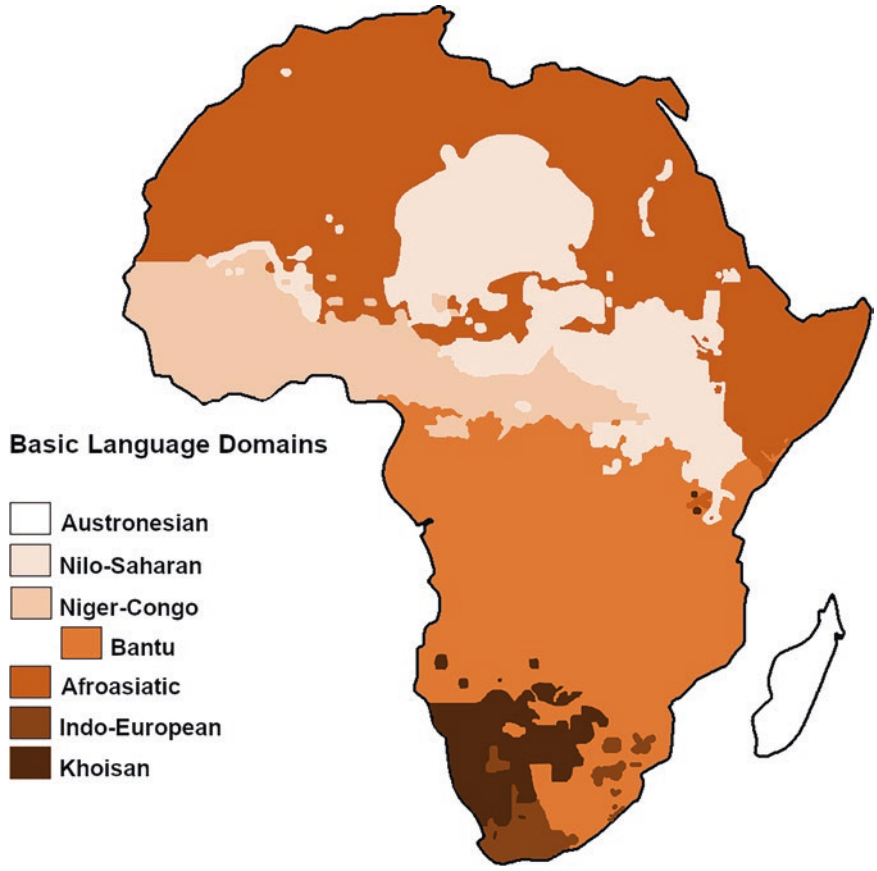

Fig. 18 Linguistics of Africa: Basic language domains. (Based on Wikimedia Commons (2017) and Güldemann (2018))

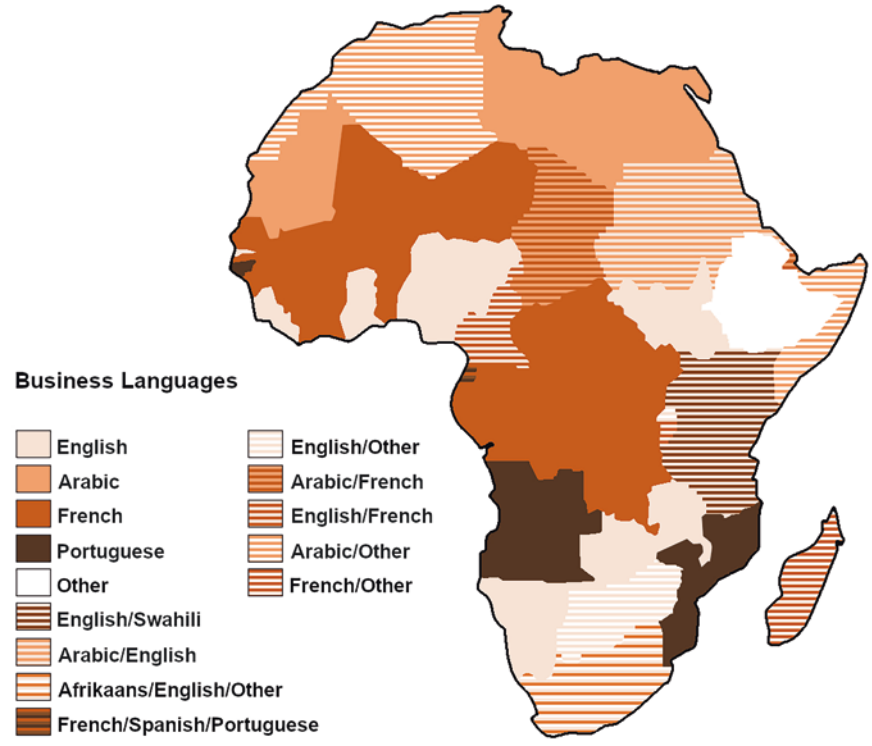

Fig. 19 Sociolinguistics of Africa: high status of former colonial languages in business

French, Portuguese, and Arabic alone, combined or mixed with Kiswahili in East Africa and Afrikaans in South Africa, are used as prestigious business languages.

It is often argued that one of the main reasons why many SSA countries have kept their ex-colonial languages as official languages is to avoid ethnic and linguistic conflict. This shows that, across all countries, language policy-making is a very sensitive issue due to the intermingling of linguistics and politics. There are many examples of how these underlying conflicts impact everyday life, for example questions as to which language university programs are delivered or in which language(s) SLT services are provided to the diverse clientele.

The above linguistic and sociolinguistic facts provide a snapshot of multilingualism across the continent. In everyday life, this means that children are raised in families in which all family members and those living in the neighborhood speak many different languages depending on the communication partner, the topic, and the context. The children are constantly experiencing multilingual language use, trans-languaging, and code-switching, and they are exposed to a highly diverse linguistic input from the media. Figure 20

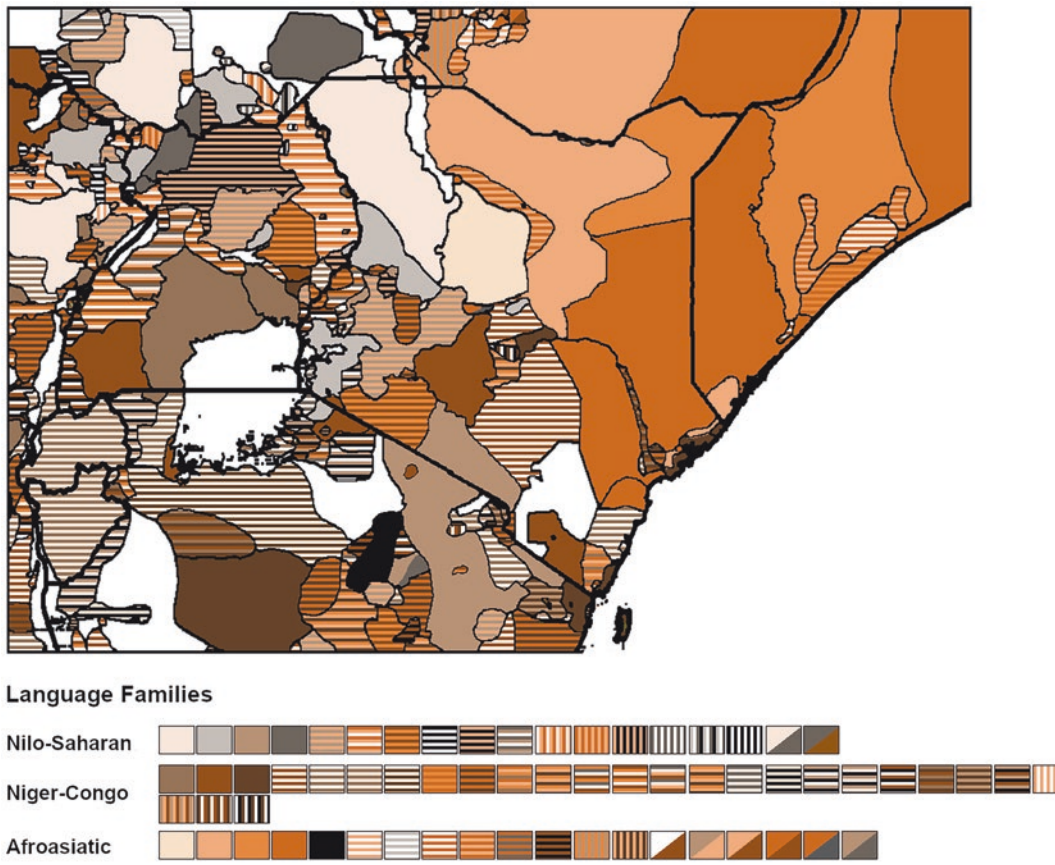

Fig. 20 Linguistics of East Africa: Major language families in Uganda and Kenya. (Adapted from Muturzikin (2007))

shows this complex multilingualism in a linguistic map of East Africa, where four major language domains, with many sub-groups, are spoken.

Figure 21 shows a similar linguistic complexity for South Africa, where the 11 official languages of the country are already quite diverse for first-language distribution, but where the linguistic diffusion is exponentially heightened when it comes to second-language distribution.

Due to their unique multilingual nature, all countries in SSA have embraced language diversity and, in general, strive for a balance between linguistic and political issues. However, this complex multilingual context is an overwhelming challenge for the young SLT profession in SSA: In which language should SLT services be provided to an adult with aphasia in Kenya? In which language should a South African child with symptoms of delayed communication development be assessed? In which language should information brochures or video clips be distributed in Tanzania? In addition, how can linguistically and culturally appropriate assessment and intervention materials be developed according to national, regional, and individual language status in SSA? Where should the focus of Africa-specific SLT research be? How can knowledge transfer from African linguistics to SLT science be emphasized, for example in providing standard norms in Setswana or Kiswahili for developmental test scales? Readers from countries with more or less monolingual SLT services, such as France and Germany, or with growing bilingual service delivery, as is the case in the US, can only imagine the enormous task ahead in SSA.

History and Status of Speech-Language Therapy in Sub-Saharan Africa

A full account of the history and current status of SLT in SSA is not yet achievable because the facts and data are limited or unavailable. As a vague outline, it can be said that compared to the Minority World, the SLT profession in SSA is quite young—only a couple of decades' old—but steadily rising and growing. As previously mentioned, the situation is different in South Africa, where SLT is an established field with a long history.

In line with the general challenging situation in the health and education sector (see overview in section "Sub-Saharan Africa"), rehabilitation services, in general, are small and often not accessible. Up-to-date epidemiological data on the prevalence of communication, swallowing, and hearing disorders in specific countries or in the African continent as a whole are not yet available. Rehabilitation services are still relatively small. It was estimated that the ratio of SLTs was 0.0008 to 10,000 population in SSA (Fagan & Jacobs, 2009). These statistics may not have changed much in recent years.

Therefore, besides providing epidemiological data and building a broad research base, the issue of building up a professionally trained SLT workforce in all of SSA is a priority. In the past, only a handful of SLTs from Africa (some trained locally and some trained in Europe or the US) and from abroad

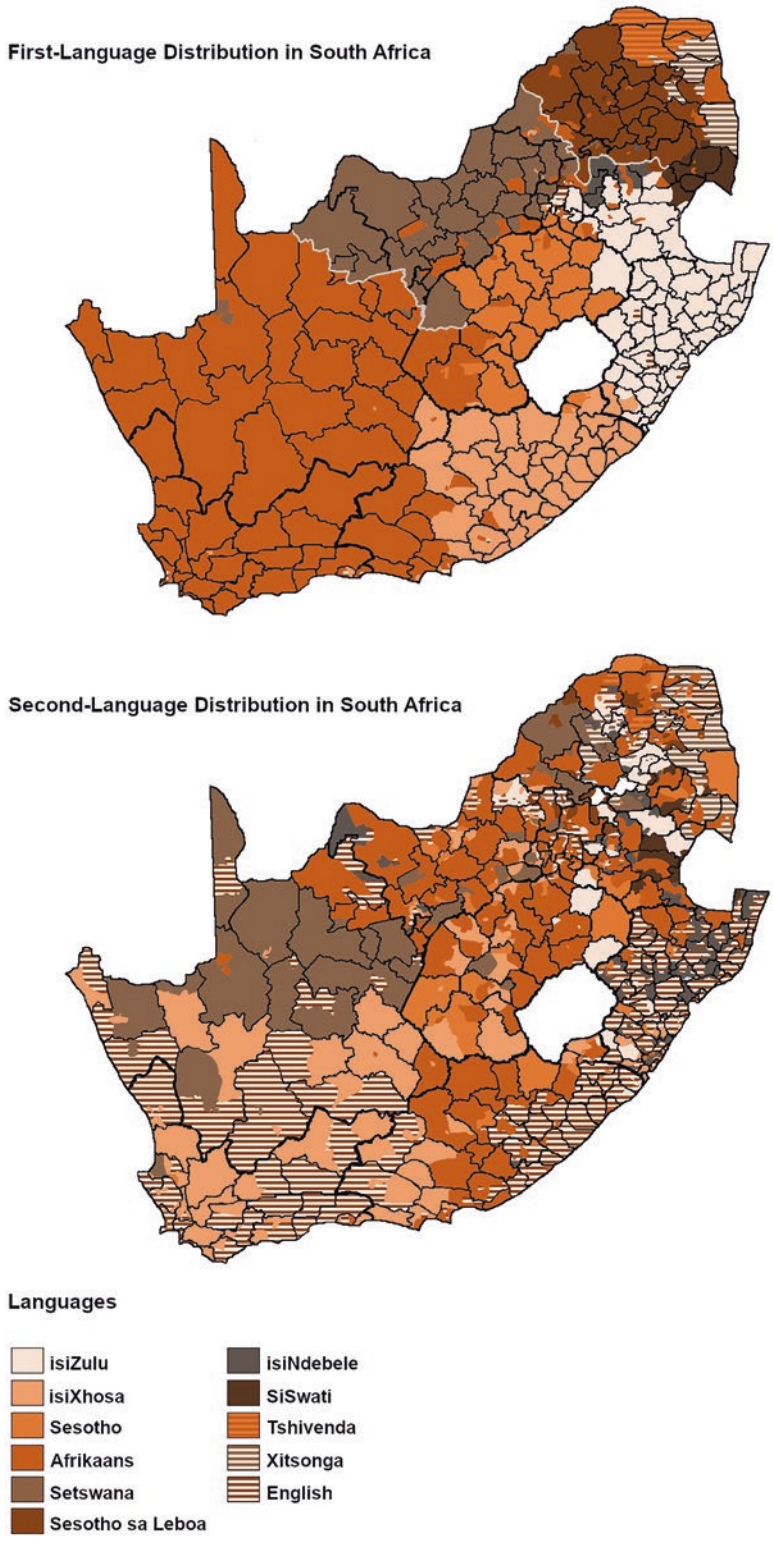

Fig. 21 Linguistics of Africa: First- and second-language distribution in South Africa. (Adapted from Alexander (2021), licensed under a Creative Commons Attribution 4.0 International License)

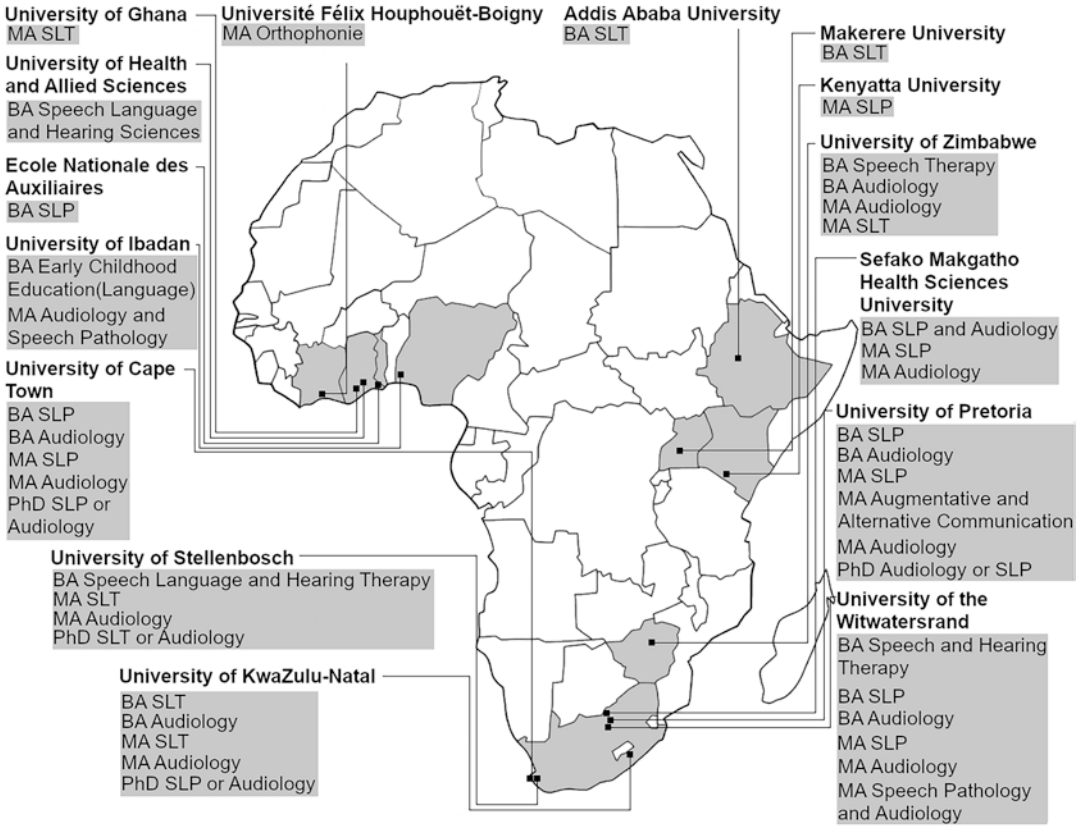

Fig. 22 Speech-language therapy in sub-Saharan Africa: Distribution of current SLT and audiology university programs across the continent

delivered these services, mostly in the capital cities. Some had trained locally, while a significant number had trained abroad.

Regarding professional training, a number of university-based training programs have been developed in the region, some with support from European or US partnerships. In the long run, African-based university programs will boost the SLT workforce and the communication of disability awareness in politics and society. They will encourage research projects and the founding of professional associations. As shown in Fig. 22, many universities currently provide SLT and/or audiology training at Bachelor, Master, and PhD level. While South Africa is leading with at least six universities training SLTs, some recent programs are taking place in Côte d'Ivoire, Ghana, Kenya, Nigeria, Togo, Uganda, and Zimbabwe. These local training programs are essential due to their cultural and linguistic appropriateness (Barrett & Marshall, 2013; Ndung'u & Kinyua, 2009).

As Fig. 22 shows, the distribution of these current SLT programs across the continent is not yet balanced, so the main task ahead is the implementation of professional training programs in all the countries still lacking in training courses. A major support in this endeavor seems to be the establishment of SLT networks—not only within the continent but also around the globe. This handbook aims to be a stepping-stone in this process.

Thanks

In line with the African saying that it takes a whole village to raise a child, it took many, many people to finally succeed in realizing this handbook. First, we thank the many contributors from all over the African continent who, often jointly with their fellows from the global community, willingly took the opportunity to record their long-term experience and give their outstanding expertise a written form. It can be said with pride that on a continent with an oral tradition and a still struggling university system in many regions, the transition from thought and practice to scientific publishing was a challenge. This challenge was overcome by, for example, hosting writing workshops and providing author mentoring. Therefore, our thanks go to all the facilitators of this process and in particular to the international review board, which accompanied all the authors throughout the last 4 years in a double-blind peer-review process. Our special thanks go to Prof. Fatuma Chege, Ph.D. (Ministry of Education-Kenya, Formerly, Kenyatta University, Kenya), Prof. Dr. Kirsty Donald (University of Cape Town, South Africa), Dr. em. Ad Foolen (Radboud Universiteit Nijmegen, Netherlands), Dr. Dana Gaigulo (Leibniz University Hannover/Ludwig-Maximilians Universität, Germany), Prof. Agnes W. Gathumbi, Ph.D. (deceased) (Kenyatta University, Kenya), Meugnet Georgiou (University of Pretoria, South Africa), Dr. Rodrick Kisenge (Muhimbili University of Health and Allied Sciences, Tanzania), Prof. Dr. em. Gisela Klann-Delius (Freie Universität Berlin, Germany), Dr. Chantal Polzin (Leibniz University Hannover, Germany), Prof. Dr. med. Dr. h. c. Martin Ptok (Medizinische Hochschule Hannover, Germany), Prof. Dr. Savithri Rajaratnam (All India Institute of Speech and Hearing, India), Prof. Prema Rao, Ph.D. (All India Institute of Speech and Hearing, India), Prof. Mary Beth Schmitt, Ph.D. (University of Texas, Austin, USA), Prof. Dr. Bart Vinck (University of Pretoria, South Africa/Ghent University, Belgium), and Prof. Jo Wilmshurst (University of Cape Town, South Africa) for their effort and support.

A very important figure in making this book a reality was our dear colleague and friend Prof. Juan Bornman, Ph.D., from the University of Pretoria's Centre for Augmentative and Alternative Communication, South Africa, who for many years encouraged this project in many ways—from supporting young scientists in writing workshops to clarifying terminological issues, to enlarging the numbers of contributing authors by reaching out to the SLT community in the whole of SSA. More than that, her greatest gift to our editorial team was raising her strong pan-African voice whenever we asked her for a critical review of a chapter, persistently pointing out that all SLT science must have an impact, and make a significant difference for the persons with communication disorders living in every nook and cranny of this vast continent.

Another key component of this process was the tremendous work of our editorial assistant, Julia Wu, who, behind the scenes, took care of author and reviewer communication, gently pushing for meeting deadlines and organizing the enormous amount of data to be managed. Without her help, we would have been lost. In the graphics and editorial department she was supported by

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Finally, we are more than happy that Constance Ntuli, Martin Pistorius, Mary Aol Musungu, Sr. Enna Mdemu, Asaph Mwangi Irungu, and Adjio Alio welcome the readers to embrace this book not just intellectually but with head, hand, and heart by sharing their specific experience with AAC, aphasia, dysarthria, apraxia, swallowing difficulties, prevention of communication disorders in the most vulnerable and orphaned children, stuttering, and hemiplegia. They represent the voices of all those with communication disorders on the African continent. May our wish to improve SLT services by setting a first baseline with this book, from which further improved research and practice will flourish, come true.

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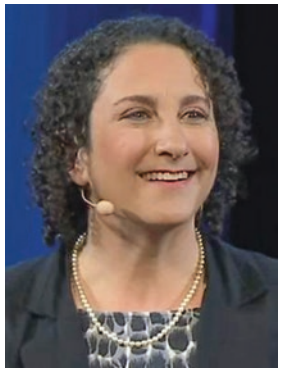

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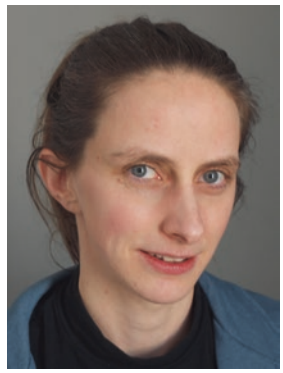

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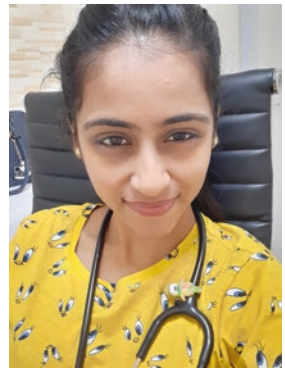

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List of Abbreviations

AAC	Augmentative and alternative communication
ABR	Auditory brainstem response
ACDH	A-chain deficit hypothesis
ADHD	Attention deficit hyperactivity disorder
AIDS	Acquired immune deficiency syndrome
AiLgS	Aided Language Stimulation
AJOL	African Journals Online
AKUH	Aga Khan University Hospital
ALS	Amyotrophic lateral sclerosis
ANOVA	Analysis of variance
APA	American Psychiatric Association
APDK	Association for the Physically Disabled of Kenya
ART	Antiretroviral therapy
ARW	Afrikaanse Reseptiewe Woordeskattoets
ASD	Autism spectrum disorder
ASHA	American Speech-Language-Hearing Association
ASLTK	Association of Speech and Language Therapists Kenya
ASPOT	Association des Professionnels Orthophonistes du Togo (Association of Professional Speech Therapists of Togo)
ASQ	Ages and Stages Questionnaires
BERA	Brainstem electric response audiometry
BOG	Board of governors
BSAE	Black South African English
CAP	Compound action potential
CARS2	Childhood Autism Rating Scale – Second Edition
CBO	Community-based organization
CBR	Community-based rehabilitation
CCBRT	Comprehensive Community Based Rehabilitation in Tanzania
CEO	Chief Executive Officer
CFCS	Communication Function Classification System
CI	Cochlear implant
CIIL	Central Institute of Indian Languages
CLD	Cultural and linguistic diversity
CNS	Central nervous system
CP	Cerebral palsy
CPD	Continuing professional development

CRPD	Convention on the Rights of Persons with Disabilities
CSR	Collaborative Strategic Reading
CSR-HS	Collaborative Strategic Reading-High School
CT	Computed tomography
DAAD	Deutscher Akademischer Austauschdienst (German Academic Exchange Service)
DANIDA	Danish International Development Agency
DD	Developmental disability
DELV-A	Diagnostic Evaluation of Language Variation – Afrikaans
DLD	Developmental language disorder
DMIS	Developmental model of intercultural sensitivity
DOOHICHE	Democratically Open, Outstanding Hybrid of Internet-aided, Computer-aided, and Human-aided Education
DRC	Democratic Republic of the Congo
DSCC	Diversity-sensitive clinical competence
DSM	Diagnostic and Statistical Manual
EARC	Educational Assessment and Resource Center
ECD	Early childhood development
ECochG	Electrocochleography
EDACS	Eating and Drinking Ability Classification System
ENT	Ear, nose, and throat
ERA	Electrical response audiometry
ESL	English as a second language
F0	Fundamental frequency
FEES	Flexible endoscopic evaluation of swallowing
FIFO	Fly-In-Fly-Out
FOAF	Fédération des Orthophonistes d´Afrique Francophone
GFT	Gastric feeding tube
GMDS-ER	Griffiths Mental Development Scales – Extended Revised
GMFCS	Gross Motor Function Classification System
HA	Hearing aid
HI	Handicap International
HIV	Human immunodeficiency virus
IALP	International Association of Logopedics and Phoniatrics
ICF	International Classification of Functioning, Disability and Health
ICH	Irente Children's Home
ICS	Intelligibility in Context Scale
ICT	Information and communication technology
IE	Inclusive education
IEC	Information, education and communication
IEP	Individualized educational program
IQ	Intelligence quotient
IRS	Irente Rainbow School
ISHA	Indian Speech and Hearing Association
IT	Information technology
KCMC	Kilimanjaro Christian Medical Centre

KFPE	Kommission für Forschungspartnerschaften mit Entwicklungsländern (Commission for Research Partnerships with Developing Countries)
KISE	Kenya Institute of Special Education
KNAD	Kenya National Association of the Deaf
KNH	Kenyatta National Hospital
KNSPWD	Kenya National Survey for Persons with Disability
KSDC	Kenya Society for Deaf Children
KSPH	Kenya Society of the Physically Handicapped
KU	Kenyatta University
KUB	Kenya Union for the Blind
L1	First language
L2	Second language
L3	Third language
LD	Language disorder
LI	Language impairment
LNFS	Little or no functional speech
MDAT	Malawi Developmental Assessment Tool
MG	Myasthenia gravis
MGLSD	Ugandan Ministry of Gender, Labour and Social Development
MIGEPROF	Ministry of Gender and Family Promotion, Rwanda
MINEDUC	Ministry of Education, Rwanda
MINEMA	Ministry for Emergency Management, Rwanda
MLU	Mean length of utterance
MND	Motor neuron disease
MNH	Muhimbili National Hospital
MoEST	Ministry of Education, Science and Technology Kenya
MRI	Magnetic resonance imaging
MT 86	The Montreal Toulouse Test
MUHAS	Muhimbili University of Health and Allied Sciences
NC	Noun class
NCPWD	National Council for Persons with Disabilities
NGO	Non-governmental organization
NGT	Nasogastric tube
NMD	Neuromuscular disease
NRDLS	New Reynell Developmental Language Scales
NSL	Namibian Sign Language
OAE	Otoacoustic emission
OdM	Orthophonistes du Monde
OECD	Organisation for Economic Co-Operation and Development
OVCs	Orphans and vulnerable children
PAELT	Phonological Awareness and Early Literacy Test
PAR	Participatory action research
PCC	Percentage of consonants correct
PD	Parkinson's disease
PECS	Picture Exchange Communication System
PEG	Percutaneous endoscopic gastrostomy

PESST	Patterned Elicitation Syntax Screening Test
PI	Principal investigator
PiNG	Picture Naming Game
PNS	Peripheral nervous system
PRS	Protracted refugee status
PRT	Pivotal Response Training
RCSLT	The Royal College of Speech and Language Therapists
RDLS	Reynell Developmental Language Scales
REALt	Receptive and Expressive Activities for Language Therapy
SAC	Speech-Language and Audiology Canada
SADiLaR	South African Centre for Digital Language Resources
SAE	South African English
SALT	Systematic Analysis of Language Transcription
SARIR	South African Research Infrastructure Roadmap
SASLHA	South African Speech-Language-Hearing Association
SCA	Sickle cell anemia
SCD	Social communication disorder
SCIP	Social Communication Intervention Program
SDGs	Sustainable Development Goals
SDQ	Swallowing Disturbance Questionnaire
SEP	Special education professionals
SLAP-R	Spoken Language Assessment Profile – Revised
SLP	Speech-language pathology/speech-language pathologist
SLT	Speech-language therapy/speech-language therapist
SLTA	Speech-language therapy assistant
SNE	Special needs education
SPSS	Statistical Package for Social Sciences
SSA	Sub-Saharan Africa
TELD-2	Test of Early Language Development – Second Edition
TRIP	Turning Research Into Practice
TROG	Test for Reception of Grammar
UDPK	United Disabled Persons of Kenya
UG	Universal grammar
UN	United Nations
UNAD	Uganda National Association of the Deaf
UNCRC	United Nations Convention on the Rights of the Child
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNHCR	United Nations High Commissioner for Refugees
UNHS	Universal newborn hearing screening
UNICEF	United Nations Children's Fund
UNISE	Uganda National Institute of Special Education
UNZA	University of Zambia
USE	Universal secondary education
VFSS	Videofluoroscopic swallowing study
VOT	Voice onset time

VSO	Voluntary Service Overseas
WAB	Western Aphasia Battery
WHO	World Health Organization
WRC	Women's Refugee Commission
WSAE	White South African English
ZERLA	isiZulu Expressive and Receptive Language Assessment

Part I

Introduction: Professionalization

The first section of this book deals with the professionalization of speech–language therapy (SLT) in sub-Saharan Africa (SSA). Professionalization, as understood in the most condensed way, is the process of the becoming and forming of a profession. However, even the definition of "profession" is complex. Some authors highlight the social function of professions such as in health care, for example, when a therapist deals with the complexity of people's problems to transform or "heal" them by interacting with them in addition to drawing on their expert knowledge (Münte & Scheid, 2017). Hence, there are various conceptualizations of the process. Further, there is still no "comprehensive picture of the genesis and dynamics of professional actions" (Vogd, 2017, p. 1614). Within this section, we outline the topics discussed in SLT in SSA to mirror the professional actions taken by researchers, educators, and practitioners in this relatively new and uprising profession.

Although the discipline of SLT is a profession that roots in rehabilitation paradigms of Minority World contexts (Pillay & Kathard, 2015), it has grown slowly and developed in differing African contexts over the last century. Therefore, the cultural contexts and linguistic specifics of practitioners and educators have informed the development of SLT as a profession on the African continent. In a narrative study about professional development, Eisenstat and Bohecker (2018) describe four aspects essential to the development of a profession: quality accredited education; professional identity; a link between accreditation, national certification, and state licensing; and united advocacy. Although these aspects are currently in the early stages of development in SSA, some first steps have been taken. For example, the "Association of Speech and Language Therapists in East Africa" attempts to host an annual conference for speech–language therapists (SLTs) in the region and speaks about building united advocacy within the profession as well as a professional identity.

The processes of professionalization run at a different pace across different countries in SSA. For example, South Africa has a longer history of SLT as a profession than in other countries on the continent. Different social and historical conditions shape the profession in different ways: In South Africa, "colonisation and apartheid as political acts" shaped the forming of the profession (Abrahams et al., 2019, p. 3286). In other SSA countries and regions, due

to their history of colonization and ongoing collaborations with former colonial countries, a similar influence of experts on the SLT discipline in the Minority World can be assumed. For example, in Kenya, among the practicing professionals, there exist a considerable number of SLTs from former colonizing countries who have shaped rehabilitative services over the years. In addition, most of the current qualified SLTs have been trained abroad.

These issues and the many cases of fruitful collaborations need to be discussed and reflected upon. Decolonization is part of the debate, especially in the training of SLTs in South Africa (Pillay & Kathard, 2015), but can also be considered as an intrinsic issue relating to the African SLT profession itself.

Nevertheless, the African SLT profession, with its extensive international networks, can be considered as part of the global SLT community. Hence, current global issues arising from the creative processes of professionalization form part of the debate in Africa as well and are reciprocally fruitful for all participants. Considering the important goals in professionalization, both Minority World contexts (with their long history of practice and established professional identity) and Majority World contexts (with their more fluid, flexible professional identities and culturally diverse contexts) can add gainful insights for one other. Objectives such as establishing interprofessional collaborations (Abbott-Anderson et al., 2019), acquiring and effectively using digital technologies in practice and training, and addressing cultural and linguistic diversity can enrich the discourse between both "worlds" in the SLT profession (American Speech–Language-Hearing Association, 2019; Georgeta et al., 2017; Morris et al., 2019). For example, Khoza-Shangase and Mophosho (2018) explicate "the danger of a single story" in the professional development of SLT in South Africa, thereby addressing the wide cultural and linguistic diversity across the African continent. Abrahams et al. (2019) point out the inequality in the South African context arising from the lack of linguistic and cultural diversity of practitioners and resources, resulting in SLTs serving a privileged minority. In the same way, SLTs from the Minority World recognize the need for linguistically and culturally diverse practitioners to serve a diverse clientele. For instance, the American Speech–Language and Hearing Association also faces the need to accommodate cultural and linguistic diversity and has formulated the goal to increase the cultural competences of SLTs in their Strategic Objectives "Pathway to Excellence" document (American Speech–Language-Hearing Association, 2019).

Besides these current global issues, another profound challenge that SLTs face in SSA is that existing rehabilitation systems cannot meet the peoples' needs – neither the general needs nor the specific needs of persons with communication disability. Concerning the needs of individuals who require SLT, there is an adverse professional-client ratio across the different countries in the region (Khoza-Shangase & Mophosho, 2018).

This section tries to link these different strands of SLT professionalization in SSA in order to draw a cohesive picture of the abovementioned ongoing debates. There are chapters concerning the development and history of the profession in different nations and regions. Authors reflect on intercultural

collaborations with foreigners and on how to deal with cultural and linguistic diversity in professional practice in multilingual societies. One chapter discusses a way of facilitating access to SLT training by using the digital approach "NextGenU." To outline these chapters, abstracts and critical reviews are presented below.

1 Ulrike M. Lüdtke

Speech–Language Therapy in Sub-Saharan Africa: The Emergence of a Profession in a Diverse Multilingual and Multicultural Context

Abstract *Background*: All over sub-Saharan Africa (SSA), evidence of the emergence of the profession of speech–language therapy (SLT) can be detected. This development can be illustrated through the availability of SLT in some major capitals, the implementation of university-based SLT training programs in several countries, and the execution of small research projects often in cooperation with internationally recognized SLT departments. Besides that, the founding of national and regional SLT associations and the hosting of SLT conferences attended by hundreds of practitioners and researchers from the whole continent as well as abroad can be observed. *Methodology*: In a meta-theoretical reflection based on scientific theory and supported by the findings of group discussions conducted alongside two conferences, this chapter analyzes the specific needs, chances and challenges, tasks, and opportunities that characterize this very special historic process and the driving forces behind it. *Results*: Within the current process of professionalization, one of the most important outcomes seems to be that of a sustainable balance between copying the models and blueprints of the Minority World and reinventing the wheel for the Majority World all over again. With the aim of establishing an independent but still globally connected SLT profession, the following leading key concepts could be identified, a grounding in an Africa-specific linguistic identity, the adaptation to a genuinely diverse multilingual and multicultural context, and the overcoming of the often subconscious collective processes of abjection, which are barriers to the inclusion of people with communication disorders. *Discussion*: A multilevel approach for the systematization and further professionalization of SLT in SSA at the interface of Sustainable Development Goals 3 (health) and 4 (inclusive education) is proposed and discussed. The levels of this approach range from evidence-based concepts for SLT service delivery in underserved rural areas, to the decolonization of SLT curricula, to the ownership of data in international research projects.

Critical Review This chapter broadens the perspective on the professionalization of SLT in SSA to a meta-position where the potentials, challenges, and – most importantly – future trajectories can be detected. This bird's eye view of the scientific theory is essential for an upcoming profession. One

could argue that an African expert should take such a meta-perspective and not a European one. However, this coherent chapter tries to provide a view from above and outside of the system. Expertise in SLT in Minority World contexts is combined with a more than 10-year-long experience of collaboration with the aim to support the development of SLT as a profession in Majority World contexts; the author is qualified to hold the balance of perspectives and provides a systematic approach of key concepts. The key concepts can be understood as a first attempt to systematize the processes of professionalization. These appropriate hypotheses need to be investigated and validated to elaborate upon this systematization until another paradigm shift opens new perspectives. If these concepts are applicable, they could be completely clarified over the next one or two decades, when a stabilized SLT profession has been developed in SSA. But for now, this exceptional chapter helps to push the processes of professionalization in SSA by setting focus, describing potentials, and outlining viable pathways for service delivery practice, training, and research.

2 Karen Wylie, Lindy McAllister, Bronwyn Davidson, and Julie Marshall

Speech–Language Therapy in Sub-Saharan Africa: Development and Sustainability of Services for Persons with Communication Disability

Abstract *Background*: Speech–language therapy (SLT) is an emerging profession in sub-Saharan Africa (SSA). Recent developments in SLT training in several countries including Uganda, Togo, Ethiopia, Kenya, Tanzania, and Ghana will gradually improve the regional availability of speech–language therapists (SLTs). However, for this relatively small number of therapists to effectively develop and influence services for persons with communication disability, consideration needs to be given to how the profession can develop in ways relevant to African contexts. This chapter raises issues surrounding the development and sustainability of the SLT profession in SSA and considers the potential contributions of the profession to the rehabilitation services for persons with communication disability. *Methodology*: An in-depth mixed methods survey combining both open- and closed-ended questions regarding the SLT workforce in SSA was employed between April 2012 and March 2013. A review and synthesis of the relevant literature including workforce development and rehabilitation models in the region is also included. *Results*: Thirty-three respondents provided information regarding availability, accessibility, acceptability, and challenges for the development and sustainability of rehabilitation services for persons with communication disability, such as job insecurity and opportunities for professional support. *Discussion*: The discussion integrates the implications for an emerging SLT scope of practice in SSA, issues influencing this workforce sustainability in the region, and original research from an SLT workforce survey in SSA, as well as the challenges to the development and sustainability of rehabilitation services for persons with

communication disability. Recommendations are made for SLT development in countries in SSA, such as job creation in equitable service sectors.

Critical Review As stated by the authors, "addressing the enormous unmet need for rehabilitation may require speech–language therapists to think more holistically." Such holistic thinking is interlaced throughout this chapter. Through sketching the current landscape of service provision and the challenges faced by SLTs in SSA, the authors promote an awareness of the fact that SLT service delivery models from Minority World countries cannot simply be imitated in these countries. Instead, a ground-breaking model is suggested, where SLTs transform their service delivery to include taking on vital roles in training, lobbying, and advocacy. The authors illustrate how the expansion of the role of SLTs in SSA can improve the sustainability of services and ensure that services are culturally and contextually relevant as well as economically, geographically, and structurally accessible and that there is adequate workforce support as well as job availability. This information will prove to be imperative for SLTs across countries in SSA, as the profession expands and makes its mark. The authors emphasize the need for Afrocentric SLT services which are suited to the context and that can be used by driven SLTs across SSA when lobbying for services, enacting health-care policies, and advocating for the profession.

3 Julie Marshall, Nana Akua V. Owusu, and Ryann Sowden

Maximizing the Benefits and Minimizing the Risks from the Contribution of "Outsiders" to the Development of Services for Persons with Communication Disability in Sub-Saharan Africa

Abstract *Background*: Services for persons with communication disability are scarce in many low- and middle-income countries, including most countries in sub-Saharan Africa (SSA). Speech–language therapists (SLTs) from high-income countries have long been involved in supporting service developments in SSA. This has often been through short-, medium-, or long-term posts (e.g., through individuals being employed by nongovernmental organizations, working as volunteer expatriates, or being locally employed), delivering direct services to clients and their families, training other professionals, and/or educating SLTs. Consultants working on a short-term basis advise universities and government ministries on the establishment of speech–language therapy (SLT) services and educational programs. There is some professional literature guiding SLTs from high-income countries on how to prepare for such work, but little has been written about what low- and middle-income country-based professionals, clients, or their families think about or would like from outsider SLTs. Furthermore, there is little or no evidence indicating what makes outsider support successful. *Methodology*: Two SLTs, with a combined experience of over 40 years (a Ghanaian SLT and an SLT

based in the United Kingdom with considerable experience working in low- and middle-income countries), present a written dialogue about insiders and outsiders working together in low- and middle-income country contexts. Four fictitious case examples of outsider-insider experiences of collaboration are then given, illustrating points made in the dialogue. The third author then reports on part of her Ph.D. study of an SLT insider-outsider collaboration in Uganda. *Results/Discussion*: Learning from all three sections and the previously published literature is then used to generate recommendations for maximizing the benefits of insider-outsider SLT collaborations in low- and middle-income countries.

Critical Review This pioneering chapter provides one of the first African narratives from the perspective of "insiders" relating to "outsider" contributions to SLT services in SSA. In contrast to the literature which has historically been dominated by outsiders' experiences (a narrative of European benevolence and expertise as opposed to local ignorance and passivity), these authors shine light on the perspective of the African experience in these partnerships, acknowledging the equal importance of insiders. The authors provide a vivid description of the reality of these collaborations from the perspective of the insider, allowing readers the opportunity to consider multiple perspectives and reflect on how collaborations are carried out to ensure sustainability and cultural competence. The authors assist in this personal growth and reflection by offering a practical list of suggestions at the end, which can act as a map that insiders and outsiders alike can use to ensure that these collaborations provide the maximum benefit for all involved, regardless of which country in SSA they might be situated in. There are many cases of SLTs visiting on various exchange programs, sabbatical leave, medical missions for hearing and cleft repairs, and so on. All outsiders are faced with cultural and linguistic dilemmas when working in SSA. Thus, this close collaboration with an insider would enable a comprehensive outcome. We highly recommend the use of an insider cultural informant and a language interpreter/translator. This chapter seeks to equal the power imbalance between insiders and outsiders by sharing perspectives that may aid in the understanding of the different outlooks, creating increased unity and partnership between SLTs from both sides.

4 Ulrike Schütte, Chantal Polzin, Afizai Vuliva, and Ulrike Lüdtke

Clinical Competence of Speech–Language Therapists in Culturally and Linguistically Diverse Contexts: A Qualitative Study of Intercultural Work Experiences Abroad

Abstract *Background*: A growing number of speech–language therapists (SLTs) face the challenge of working professionally with students or clients from diverse cultural and linguistic backgrounds, and diversity-sensitive clinical competence has become particularly important in the professionalization

of SLTs worldwide. Therefore, the aim of this study is to examine closely the effects of working or studying abroad on the professional growth of speech–language therapy (SLT) students. *Methodology*: The diversity-sensitive clinical competences of SLT students are investigated in a qualitative analysis of 14 biographical self-reflections on their experiences abroad. This chapter particularly focuses on the self-reflections of one student from Germany and another from Tanzania. *Results*: First, we were able to identify the most challenging experiences of work stays abroad that are relevant for the professionalization of SLT students working in the context of cultural and linguistic diversity (CLD). They can be clustered around three main themes: strangeness, heteronomy, and identity conflict. In addition, we analyzed the inter- and intrapersonal growth of the 14 participants in their diversity-sensitive clinical competence on a 6-point scale between denial of communicative diversity and integration of culturally different communicative perspectives and habits. *Discussion*: As the findings demonstrate, there is a strong potential for professional stays abroad to increase diversity-sensitive clinical competence for service delivery in CLD contexts. We propose recommendations for SLT training programs worldwide.

Critical Review As discussed in other chapters in this section, "insider-outsider" collaboration projects are prevalent throughout sub-Saharan Africa (SSA). This chapter makes a vital contribution to the discussion on this collaboration for both Minority and Majority World contexts by illuminating the opportunity that these projects provide for increasing diversity-sensitive clinical competence. Increasing this competence involves changing one's own point of view and taking another communicative perspective. The authors argue for the importance of using foreign stays as opportunities for speech–language therapists (SLTs) to develop this competence, especially for student SLTs around the world. The authors take a remarkable constructivist approach to constructing, deconstructing, and reconstructing experiences to gain deeper insights. They further present an innovative circular process of professionalization that relies heavily on critical self-reflection. This process makes the reader aware of the importance of personal growth in developing professional competence and may assist the reader in reflecting critically on his or her own level of diversity-sensitive clinical competence. The chapter points out the need for the development of tolerance and understanding as SLTs rise to the challenge of working with an ever-diversifying population, which is a challenge not exclusive to SSA but to the whole globalized world.

5 Bea Staley and Emma Shah

The History of Speech–Language Therapy in Kenya: A Collective Memory

Abstract *Background*: This chapter describes the developments in the speech–language therapy (SLT) profession in Kenya. It maps the people and activities which have contributed to the development of the discipline in notable ways. *Methodology*: This history was drawn primarily from written

responses to a questionnaire that went out to all members of the Association of Speech and Language Therapists Kenya in 2016, as well as personal networks of speech–language therapists (SLTs) who have lived and worked in Kenya over the years. Information from unpublished documents, written communication, conversations, and memories of the professionals who have been working in Kenya is drawn upon to document both the time and feeling behind the development of SLT in the region. *Results/Discussion*: The narrative co-created here provides insight into the ways in which the profession grew over the years in one specific country context. This may serve as a useful resource for those involved in future developments in Kenya, as well as clinicians working in other Majority World countries that are starting to develop their own SLT services.

Critical Review True to the deeply rooted oral history tradition of Africa, the authors of this chapter creatively combine different methodologies to vividly bring this developmental story to life. The chapter serves as a true inspiration for clinicians globally and in other SSA countries, who may be faced with comparable restraints but nonetheless have the drive to forge a path for the development of the profession in their own countries. The history described here is also critically important for clinicians residing in Kenya, for as the poet Maya Angelou has said, "If you don't know where you have come from, you don't know where you are going." This history initiates an important conversation about the inspiring future possibilities for SLT as a profession in Kenya. The creativity and unique perspective that Kenyan SLTs have developed as they have responded to being required to practice with such a wide variety of disorders and populations in difficult circumstances are highlighted. This is a testament to the flexibility and adaptability of these SLTs. In addition, their reflections offer some insights into navigating a new profession where both public awareness and health-care policies are limited. Through the storytelling in this chapter, insightful ideas for service provision are shared which can be adapted to other SSA countries, for example, establishing support groups in the community with the partnership of religious leaders. Sharing these creative solutions with the SLT community echoes the importance of sharing within SSA communities, making this a truly Afrocentric work.

6 Sylvia Topouzkhanian and Palakiyém Abalo

The Development of the Speech–Language Therapy Profession in West Africa: Over 10 Years of Experience

Abstract *Background*: This chapter provides important insights into the professional developments in speech–language therapy (SLT) in West Africa. A long-term involvement of a partnership between two humanitarian institutes allowed the implementation of the first SLT qualifying course in West Africa (Togo) in 2003. In 2006, sub-Saharan Francophone Africa saw its first locally trained speech–language therapists (SLTs) graduate in Lomé, Togo. The

Speech, Language and Hearing Sciences Department at the Ecole Nationale des Auxiliaires Médicaux (National School for Medical Auxiliaries) has since become a focal point for the training of SLTs within sub-Saharan Francophone Africa. Most of the SLTs practicing in Benin, Burkina Faso, Congo-Brazzaville, the Ivory Coast, Mali, and Togo were trained at the Lomé School. In order to elaborate and enact a series of collective projects, to share experiences, and to advocate for the profession in general, SLTs from several of these countries gathered their strengths under associative organizations at first and later formed a federation in 2016. *Methodology*: This chapter consists of a qualitative literary analysis of repositories such as Association des Professionnels Orthophonistes du Togo and the European CPLOL Congress, to name but a few. *Results/Discussion*: Over the past 10 years, African SLTs have been confronted with many challenges, for example, finding ways to adapt evaluation tests and tools for each country, culture, and language. These and other challenges are discussed in this chapter.

Critical Review This chapter delves into the creation of a unique Francophone African SLT profession which can exert real influence in West Africa. A vision of working toward the formation of a profession that can open up significant future opportunities and a genuine integration of people with communication disabilities is shared. The authors consider the individual challenges faced by SLTs in West Africa and look closely at how these can be countered, bravely driving the profession forward in the face of difficult circumstances. Although the chapter focuses on French-speaking countries, the information shared will also benefit clinicians from other SSA countries whose SLT profession is still in the process of growth. Of particular importance is the value of establishing organizations and a federation, such as FOAF (Fédération des Orthophonistes d'Afrique Francophone), to offer support and guidance to SLTs in SSA countries. The strength of this chapter lies in disclosing how therapists from various Francophone countries in SSA have come together to encourage and assist one another, building a stronger profession that truly succeeds in the West African context.

7 Abbie Olszewski, Verena Rossa-Roccor, Veronic Clair, Kate Tairyan, and Erica Frank

A Revolution in Training Speech–Language Therapists in Sub-Saharan Countries and Globally

Abstract *Background*: There is a substantial and still growing need for trained speech–language therapists (SLTs) in sub-Saharan Africa (SSA) to work with persons with communication disability. Unfortunately, there are very few university-level speech–language therapy (SLT) training programs in SSA, making it difficult for individuals interested in working with persons with communication disability to obtain the necessary skills. NextGenU.org offers a revolutionary model to address the shortages of well-trained SLTs in

both SSA and globally. *Methodology*: A qualitative literary analysis of the current state of SLT education in SSA combined with a project report on the development of the Democratically Open, Outstanding Hybrid of Internet-aided, Computer-aided, and Human-aided Education (DOOHICHE, pronounced as "doo-hickey" or gadget) model of NextGenU.org. *Results/Discussion*: This chapter discusses the need for trained SLTs concentrating on the challenges of SSA, the e-learning history of NextGenU.org's DOOHICHE model, the DOOHICHE model in practice, and the DOOHICHE SLT program in SSA. This model is based on workforce capacity building, focusing on training individuals independently or with university/organizational partners. The aim is to train individuals who remain in their local communities, developing a network of local and global professionals working with persons with communication disability. As a free, accessible, customizable, and sustainable online portal to higher education, this model has the potential to rapidly increase the number of trained SLTs in SSA and strengthen partnerships between universities, institutions, and local governing agencies.

Critical Review Innovative solutions are essential in a context such as SSA where there is approximately 1 SLT per 2–4 million people and only 12 universities offer SLT training. Through an exploration of the current training offered, this chapter illuminates the fact that continuing at the current rate of training is not enough to bring the basic human right to communication to all. However, it boldly offers a creative solution to the shortfall in trained SLTs: one which combines e-learning, access to information, and the empowerment of community members. By removing some of the barriers to accessing higher education, the DOOHICHE model is a beacon of promise which can help to bring SSA countries another step closer to realizing the human rights of the African people. The focus on local training is an important strength of this project, as there is a profound need for local SLTs in SSA countries to provide culturally and linguistically relevant interventions. This can also be complemented by collaboration with experts from the Minority World who can offer online modules. This exciting endeavor offers hope and something to look forward to for the future of SLT on the African continent.

8 Ulrike Lüdtke and Chantal Polzin

The Demands of Context: Development of a Relational In Vivo Methodology for Participative Speech–Language Therapy Research in Sub-Saharan Africa

Abstract *Background*: The young speech–language therapy (SLT) profession in sub-Saharan Africa (SSA) needs to develop research at different levels to reflect theory and practice. In general, in SSA, a lack of research investment and output brings many challenges for research development. Often research collaborations with researchers from Minority World contexts are entered into with potential intercultural and (neo-)colonial conflicts with subsequent

power disparities as well as the danger of a lack of cultural adaptation. However, the current early stage of professional development in research offers many opportunities for the SLT profession, such as the chance to create a unique African methodology. *Methodology*: In this chapter, we focus on a concept of a multilevel approach to SLT research development and connect it to the specific SLT research context in SSA. We discuss methodological necessities, challenges, and opportunities to propose and explicate a participative and relational in vivo approach – conceptually and practically illustrated with our own research examples following this approach. *Results*: Different forms of implementation of such a relational research paradigm, and the related research questions and methods, are exemplified at the five levels of SLT research. A research checklist at the end of the chapter gives recommendations to reflect on research strategies and designs in the proposed relational approach. *Discussion*: This relational research approach, which considers the needs of participating people and the demands of the context, offers an opportunity to create unique SSA research methodology by building a body of evidence-based practice, which is culturally appropriate with and for persons with communicative disorders in SSA.

Critical Review This chapter outlines the current situation of SLT research in SSA and reflects the needs against the background of a multilevel framework of the SLT profession. With its practical references to persons with communication disabilities and daily service delivery, the abstract levels of research become comprehensible. The authors suggest a participative, relational in vivo methodology to give one example to target Africa-specific research in SLT. This approach lays the focus on the SLT context, the relations of participating people to the context, and their relations among each other. The crucial aspect of this relational methodology, especially for the SLT profession in SSA, is to enable SLT researchers to find their own culturally and linguistically appropriate research methodology. Plausibly, the authors explain the theoretical approach that substantiates this methodology and give examples from their own experience, which were successfully implemented in transdisciplinary cross-cultural projects. This approach is promising for gaining more insights into communication, speech, and language development and practices of service delivery in clinical and educational contexts in SSA because it considers the reciprocity of the Africa-specific contexts. Moreover, it may help to mitigate the lack of research in the field of communication and language development and disabilities in SSA. Decolonizing curricula is a permanent challenge all over Africa; decolonizing assessment and therapy concepts/materials and changing the research approach to a more culturally appropriate one is another big task for the SLT profession. The influence of research approaches from Minority World contexts may not be apparent at first sight, but mainstream SLT research also needs to be thought out and classical methodological principles should be adapted when necessary.

9 Purity M. Nthiga and Eunice A. Nyamasyo

Speech–Language Therapy in Kenya: Trends, Challenges, and Opportunities

Abstract *Background*: Communication disability has led to the emergence and development of the interdisciplinary profession of speech–language therapy (SLT). Yet, as with many other professions, the development of SLT has not been uniform across the world. This is despite the fact that communication disability affects people of all races, ethnicities, and geopolitical regions. In many African countries, the emergence of SLT can be traced to the colonial past, and its development since then has been checkered. *Methodology*: A descriptive/scoping review was conducted that sought to qualitatively interpret and synthesize information relating to the development of the SLT profession in Kenya from various sources. *Results*: This chapter presents the socioeconomic and political factors that have shaped the emergence and development of SLT in Kenya. In addition, it looks at the role of governmental and nongovernmental agencies in the development of SLT services in the country. The chapter also highlights the challenges that have determined the development of SLT as a profession. *Discussion*: Despite the challenges, opportunities abound for SLT as a profession in Kenya. These are discussed in the chapter, and future recommendations are made.

Critical Review Although progress has been made in terms of the professionalization of SLT in Kenya, it has not yet bloomed as a professional area or a scientific area of study. However, the authors assert that, despite how gloomy this assessment may seem, there are boundless opportunities amidst the challenges. This optimism weaves through the chapter, viewing challenges as possibilities for growth. Furthermore, the authors provide a succinct timeline and summary of all the policies relevant to persons with communication disability in the Kenyan context, as well as the development of advocacy groups in Kenya. This information can equip Kenyan clinicians with tools for advocacy and may provide some insight for clinicians in other SSA countries into the types of advocacy groups and policies which should be established. The importance of collaboration comes through strongly in this chapter, not only between government and clinicians but also professional bodies and donor organizations. The authors argue the need for impactful, relevant African research related to the SLT profession. The chapter traces the steady development of SLT training in Kenya, which gives hope for the further growth of the profession. The chapter also discusses other creative possibilities, such as entrepreneurial opportunities for local hearing aid development and corporate social responsibility programs. This type of imaginative thinking is just what SSA countries need to propel the SLT discipline forward, to meet the unique needs of people with communication disability on the African continent.

10 Bea Staley, Ellen Hickey, Rachael Gibson, David Rochus, and Martin Nafukho

Obulala Na-maani: Unity Is Strength – Speech–Language Therapy and Community Engagement in Three Kenyan Communities

Abstract *Background*: Speech–language therapy (SLT) services are emerging and expanding throughout much of sub-Saharan Africa (SSA) using a variety of local, national, and global strategies to meet the identified needs of individuals with communication disability. *Methodology*: This chapter provides an interpretive description of three SLT community projects in order to share the successes, failures, and lessons learned by one nongovernmental organization working in Kenya. *Results/Discussion*: Examples are provided that contribute to the larger international discussion about the current work that is occurring in SSA for persons with communication disability. Considerations are made regarding how the models of service provision provided by this organization fit into the global context and align with the United Nation's Sustainable Development Goals. Reflection on these projects and lessons learned using ideas and frameworks of cultural competence and global engagement is shared so that other similar organizations working with people with communication disability may benefit from the development of this unique perspective. The question driving the narrative of this chapter is: What were the challenges and successes in developing community-based SLT services in three Kenyan communities? In conclusion, the main lessons learned are shared, namely, that context is imperative and community partners are key.

Critical Review "Unity is strength" – this slogan was perfectly chosen for the title of this chapter, as the authors reflect on the success that can be found in partnership with communities. The importance of context in SSA cannot be undervalued. It is within this context that the way SLT services are provided cannot simply be transposed from Minority World countries. Rather, there is a necessity for SLTs in Africa to develop their own Afrocentric service delivery models. In addition, cultural tendencies in the African context dictate all ways of life in the community; thus community-based rehabilitation is the best way to impact on people's lives. The authors of this chapter share success and failure stories that can be used to help prepare clinicians wishing to work in communities in various SSA countries for the possible challenges and opportunities that may arise. The stories also invite reflection on the way in which short-term volunteers are used within communities, so as not to promote neocolonialism. Community work within the Kenyan context is complex. However, this chapter succinctly and clearly communicates what has worked and what has not by analyzing and reflecting on each of the projects. This brings the reader a step closer to understanding these complexities and assimilating the lessons learned from these projects. By sharing this information, the authors allow the next clinicians who may read the chapter to progress even further with their own projects, beginning a cycle of shared

learning and unity among clinicians who all strive for the same achievement of the sustainable development goals. This chapter concurs with Marshal et al.'s insider-outsider evaluation of what is needed in an African context for effective service delivery.

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1 Speech-Language Therapy in Sub-Saharan Africa: The Emergence of a Profession in a Diverse Multilingual and Multicultural Context

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Evidence: Speech–Language Therapy Emerges in Sub-Saharan Africa

All over sub-Saharan Africa[1] (SSA), the following signs of the emergence of speech–language therapy (SLT) as a new profession can be detected:

- The availability of SLT services in some major capitals (e.g., Nairobi, Accra, Dar es Salaam, Windhoek, Abuja, and major South African cities)
- The implementation of university-based SLT training programs in several countries (e.g., Kenyatta University, Kenya; Makerere University, Uganda; University of Ghana, Ghana; and University of Pretoria, South Africa)
- The execution of research projects often in cooperation with internationally recognized SLT departments
- The founding of national and regional SLT associations (e.g., the Association of Speech and Language Therapists Kenya, Association of Professional Speech Therapists of Togo, South African Speech–Language-Hearing Association) and the hosting of SLT conferences attended by hundreds of practitioners and researchers from the whole African continent as well as abroad

In a meta-theoretical reflection based on scientific theory and supported by the findings of group discussions conducted alongside two African SLT conferences (the 5th EastAfrican Conference on Communication Disability in Mombasa in 2013 and the 6th EastAfrican Conference on Communication Disability in Nairobi in 2017), this paper tries to analyze what specific needs (section "Needs: The Basics of Africa-Specific Professionalization"), challenges (section "Chances and Challenges: Cultural Uniqueness in a Global World"), tasks (section "Tasks: Systematic Establishment of a Sustainable, Multilevel, Cross-Sector Speech–Language Therapy Approach"), and opportunities (section "Opportunities: International Speech–Language Therapy Research Cooperation Within a Global Ethical Framework") characterize this very special historic process and the driving forces behind it.

[1]Even though South Africa has a longer history in the establishment of the SLT profession, this paper will address sub-Saharan Africa as a whole.

Needs: The Basics of Africa-Specific Professionalization

From an observational, reflective perspective, the current main needs of the emerging SLT profession in SSA can be summarized with the following assertion:

> The SLT profession in SSA needs to define, expand, and consolidate itself in a unique, proud, independent, and sustainable way.

Inherent in this assertion is the need for SLT science in SSA to undergo an intense and long-lasting process of professionalization to reach this overall aim. Looking at the history of SLT from a global point of view (e.g., Braun, 2012; Duchan & Felsenfeld, 2016; O'Connell, 1990), such transformation processes are quite natural and occur at all times, moving from one continent to the other:

- For ancient Sanskrit scholars in India, speech and language were important aspects of communication, as observed in written texts between 2000 B.C. and 1300 A.D. (Savithri, 1987). Hence, different disorders were mentioned even at that time: voice, articulation, speechlessness as a form of mutism, loss of speech as a form of aphasia, dysarthria, and stuttering. The following causes of disorders were also discussed: "(1) hereditary, (2) congenital, (3) chemical, (4) traumatic, (5) seasonal, (6) parasitic, and (7) natural" (Savithri, 1987, 440).
- Presumably, in Europe, the roots of SLT science can be dated back to ancient Greece, where different sources describe different kinds of speech and language disorders and also recommend treatments. Herodotus (490–430 B.C.) reports in his writings about the stuttering

Bathos and the dumb son of King Croesus, and in the Corpus Hippocraticum (500–300 B.C.), almost all major disorders are mentioned (Gagarin & Fantham, 2010). Aristotle (384–322 B.C.) provides the first known classification of articulation disorders into "babbling," "stammering," and "stuttering," and a little later, Plutarch (46–125 A.D.) described the first treatment of stuttering practiced by Demosthenes (384–322 B.C.), as brought alive again in the famous contemporary movie "The King's Speech" (2010). Demosthenes was said to have used stones or pebbles in the mouth of the patient while he recited speeches.

- In Central Europe, the science of SLT underwent a long process of professionalization over many centuries, during which changes in epistemology and thought (e.g., the Age of the Enlightenment), along with advances in technology (e.g., ear, nose, and throat surgery), helped to improve diagnostics and therapy of all major syndromes. In the seventeenth and eighteenth centuries, two major works in phonetics emerged that should be mentioned: "Grammatica Linguae Anglicanae" by John Wallis (1653) and "Dissertatio de Loquela" by Johann Conrad Amman (1700).
- In the nineteenth and twentieth centuries, alongside the rise of psychoanalytic psychology (e.g., Sigmund Freud, 1856–1939) and Russian neuropsychology [e.g., Lev Vygotsky (1896–1934) and Alexander Luria (1902–1977)], a preliminary peak in SLT professionalization in Europe was reached, marked by the establishment of the Berlin and Vienna schools of thought, with major insights into the psychodynamic etiology and treatment of stuttering and mutism and the neuropsychological etiology and treatment of central disorders such as dysarthria, dyslexia, and especially aphasia [Paul Broca (1824–1880) and Carl Wernicke (1848–1905)].
- The era of Europe being the cradle of SLT abruptly came to an end by the shocking events of World War II, in which leading Jewish scientists were forced to escape from Nazi persecution and immigrated to the United States, having a major impact on the founding period of the professionalization of American SLT. The most influential scientists at this point were Emil Froeschels (1884–1972) from Vienna, who wrote more than 23 books on clinical SLT practices, and Kurt Goldstein (1878–1965) from Berlin, famous for his studies of patients with aphasia.
- Since then up to now, the US and the Anglo-American tradition, in general, can be more or less seen as the place where prominent scientists have constantly fueled the growth of SLT science (see, e.g., Duchan, 2011, Duchan & Felsenfeld, 2016). Important schools of thought have shaped the linguistic era (1965–1975), especially the works of Noam Chomsky and Van Riper, and the pragmatic era (1975–2000) in which John Austin's Speech-Act Theory strongly influenced interactional therapy approaches as well as interactionalism in a very broad sense (Jerome Bruner, Daniel Stern, and Colwyn Trevarthen). These advancements are reflected as well in the rise of the American Speech–Language-Hearing Association (ASHA), which takes a global lead in the professionalization of SLT science, supporting its birth and growth worldwide. One outstanding example of a genuine SLT development is India, where speech and hearing science became a distinct field in the 1960s (Chengappa, 2001), with several important institutions being established, e.g., the All India Institute of Speech and Hearing in Mysore.

Having this very briefly sketched global history in mind and coming back to the proposed assertion, what does it mean exactly that the SLT science in SSA has to undergo an intense and long-lasting process of professionalization to be properly established and flourish? Before answering this question, the concept of "professionalization" along with some key terminology needs to be defined in general.

What is a "profession"? A profession is a group of individuals who have undergone the same type of education and training and adhere to ethical standards. This group positions itself as possessing special knowledge and expertise in a widely recognized body of learning derived from research,

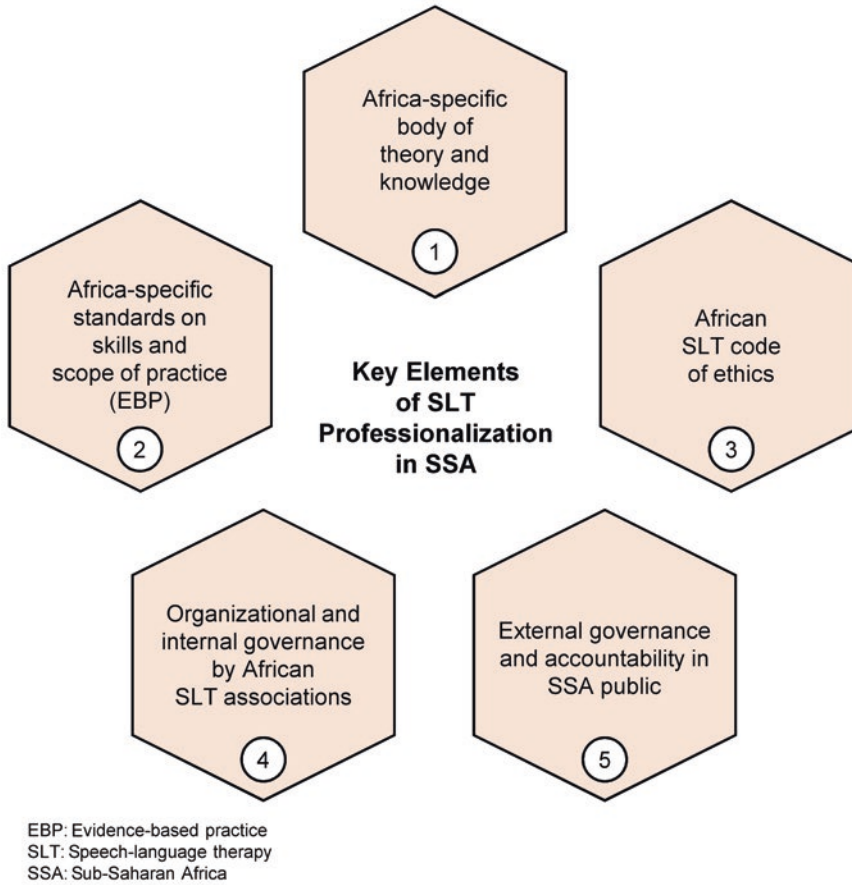

Fig. 1.1 Five key elements of speech–language therapy professionalization in sub-Saharan Africa

education, and training at a high level and is recognized by the public as such. A profession is also prepared to apply this knowledge and exercise this expertise in the interest of others. From a functional perspective, a profession sets and maintains the standards in relation to competence and ethics (Faulconbridge & Muzio, 2012). Another perspective is to look at a profession as an occupational group that creates legal boundaries to determine who is an insider and outsider (Saks, 2012).

What is a "professional"? A professional is a member of a profession. Professionals are governed by codes of ethics and profess commitment to competence, integrity and morality, altruism, and the promotion of the public good within their expert domain. Professionals are accountable to those served and to society.

What is "professionalization"? Professionalization is the pattern of how a profession develops, as well as the process of becoming a professional. It can be seen as a sociopolitical process, which includes the formation of a specific form and legal regulation that hence creates insiders and outsiders (Saks, 2012).

In order to identify the key elements of professionalization, several disciplines and different perspectives have discussed the issues that distinguish professions from other occupations. Examples of these discussions can be found in the papers by Gargan (1993), Freidson (2001), Saks (2012), and Egetenmeyer et al. (2019). For the purposes of this chapter, the core of these general discussions on key elements of professionalization can be specified to the SLT profession in SSA as follows (see Fig. 1.1):

1. Create a systematic *body of theory and knowledge* by research and base the African SLT profession on it.
2. Implement this theory and knowledge to daily service and develop professional *standards on skills and scope of practice* for it. Educate African SLT groups on regularly evaluated and updated *evidence-based practice* (EBP) and, ultimately, enforce this.
3. Develop an African *SLT Code of Ethics* and bind individual practitioners to it by commitment.
4. Ensure professional *organizational and internal governance* within African SLT groups, e.g., by setting rules and regulations for SLT associations.
5. Gain *external governance* and *public accountability* in the educational and health system, e.g., by advocacy.

Chances and Challenges: Cultural Uniqueness in a Global World

Having identified the basics of an Africa-specific professionalization as the main need of the emerging SLT profession, it is next essential to look at the chances and challenges of this process. We try to shed light on these by drawing on a meta-perspective of scientific theory.

Excursion in Scientific Theory

A groundbreaking and still relevant work in scientific theory is Thomas Kuhn's (1962) concept of the cyclic structure of science, which helps us to understand how any science is progressing in time and in what specific phase a science is in at any given moment. The central element is the notion of "paradigm" which describes the coherent framework of concepts, procedures, and theories that are guiding science at a specific time.

In his book *The Structure of Scientific Revolutions* (1962), Kuhn explains how the process of scientific change, as the result of various phases of paradigm change, works (see Fig. 1.2).

1. *Pre-Science* – This pre-phase exists only once and characterizes the pre-paradigm phase, in which there is no paradigm as of yet to successfully guide the work of the widespread members of the community. This phase is characterized by mere fact gathering, individual trial and error, several incomplete and incompatible concepts, and no shared consensus on standards of research methods, terminology, or any particular theory.
2. *Normal Science* – This first phase begins when the different actors in the scientific community have agreed on a scientifically based coherent model of understanding – the dominant paradigm – that helps to solve the problems of the field and answer the research questions.
3. *Model Drift* – This second phase begins when the leading paradigm is no longer able to give stability to problem-solving and newly arising phenomena cannot be explained. The scientific community enters a crisis period as more and more anomalies occur and, despite increased efforts, the normal paradigm fails.
4. *Model Crisis* – The third phase is reached when the model drift has become so extreme that the old classic paradigm bursts. The scientific community is disturbed and shaken and even might dissolve as there is no longer a reliable framework to solve the problems.
5. *Model Revolution* – This fourth phase begins when the basic assumptions and cornerstones of the old paradigm are radically reexamined and reframed, and totally new ideas, concepts, and theories are proposed – even by newcomers – and accepted by the scientific community. A paradigm shift – or scientific revolution – takes place as the new model for problem-solving is established in the field.
6. *Paradigm Change* – This fifth post-revolutionary phase is characterized by the dominance of the new paradigm for problem-solving, and the scientific community returns to the phase of normal science, and the completed cycle starts again.

Having this meta-theoretical excursus on scientific evolution and revolution in mind, this model can be helpful in analyzing the status quo of SLT in SSA as well as possible future trajectories and challenges that might occur in the process of Africa-specific professionalization to create a unique, proud, independent, and sustainable science.

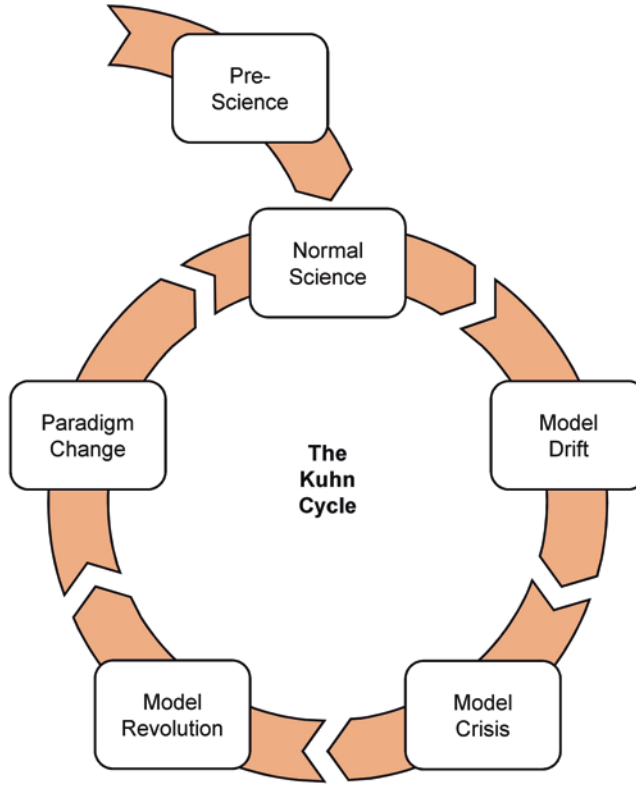

Fig. 1.2 The process of scientific change according to Kuhn's scientific theory

Establishing Speech–Language Therapy in Sub-Saharan Africa as a Science: The Danger of a Neocolonial Approach

As with any newly established profession in the world, SLT in SSA has come a long way being a pre-science initially (see Fig. 1.3a). In the beginning, only in a few countries did speech–language therapists (SLTs) start to practice on a widespread basis, having been trained in Europe or the United States or being ex-pats (Barrett et al., 2023; Crowley & Baigorri, 2011; Jochmann, 2006; Staley & Shah, 2023). Their pioneering work was guided by Western concepts, theories, and practices they brought with them from outside, each being of its own kind, and not united by a coherent framework.

Over the course of time, the numbers of professionals grew, the numbers of involved countries increased, and the multiplication of knowledge and skills by partnership programs and the initiation of university programs started on a larger scale. Over the past years, it could be said that SLT in SSA has entered the phase of normal science as the small but quite stable scientific community of the whole continent has agreed on a paradigm as a coherent model of understanding which promises to help solve the problems SLTs face (see the conference proceedings of the 4th East African Conference on Communication Disability in Barrett in 2012).

Nevertheless, from a critical point of view, the way of establishing SLT in SSA as a science needs to be questioned, as the danger of a neocolonial approach needs to be observed and checked. In general, neocolonialism is defined as the practice of using globalization, economic and scientific power, cultural imperialism, and financial aid to influence a country, which means to replace the classical previous colonial methods of direct military control (imperialism) or indirect political control (hegemony) by new means, but still resulting in a relationship of dependence, subservience, or obligations (see, e.g., Nkrumah, 1965; Rahaman et al., 2017). In our case, the challenge of a neocolonialist approach may exist in the phase of becoming a profession given that the very well-established

"Western" paradigm of SLT as a normal science was imported and implemented into the "developing" countries by "outsiders" (Marshall et al., 2023) – being it European or American SLTs demonstrating approaches to service delivery, SLT projects funded by "Western" nongovernmental organizations, or the assistance of universities in copying SLT programs from Minority World countries – with too little critical reflection of an ethnocentric perspective or the necessities of cultural adaptation. From our point of view, one important example of this dependence of many African countries from the West, that was created, are the several attempts to establish SLT university programs which suffer in the long run from being sustainable due to the lack of own African academic personnel. This often may result in either collapsing or becoming dependent on Western visiting lecturers.

Speech–Language Therapy in Sub-Saharan Africa in Crisis: Mismatch Issues in Problem-Solving

If we assume that SLT in SSA is in the phase of a normal science more or less based on an imported Western paradigm, then the risk is high that the profession is entering the phase of model drift or even model crises because the "outsider" paradigm is no longer able to solve the arising problems or occurring anomalies of the field (see Fig. 1.3b). From our point of view, the core cause of a possible failure is that of mismatch issues between the proposed solutions of the Western paradigm and the Africa-specific requirements of the field. Some observable examples at different levels of the profession are:

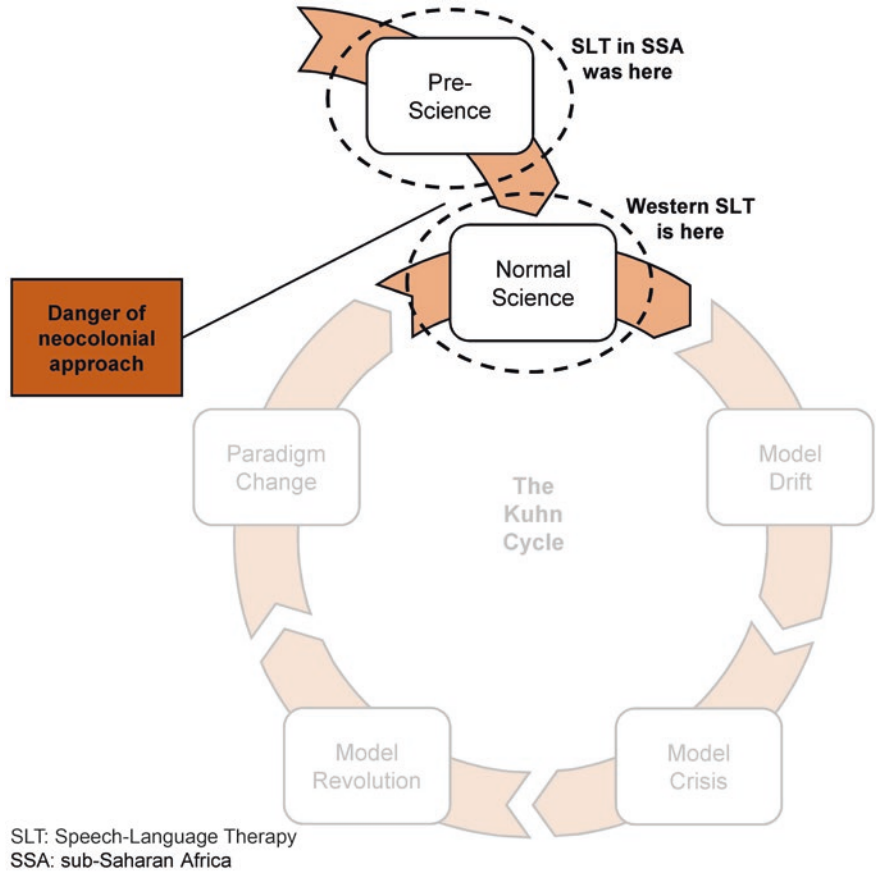

Fig. 1.3 (**a**) Establishing speech–language therapy in sub-Saharan Africa as a science: the danger of a neocolonial approach.

- Donated usable materials, e.g., hearing aids that sometimes are not fitted.
- Donated highly technical equipment, e.g., for fiber-optic endoscopic evaluation of swallowing (FEES) that cannot be maintained properly due to an absence of long-lasting funding as well as the lack of sustainable securement of capacity building to operate it.
- Application of Anglo-American assessment tools for language disorders, e.g., assessments for aphasia or dyslexia in Kiswahili that are not applicable for non-English native speakers.
- Imported media for SLT that is not culturally adequate, e.g., displaying photos of white children or families, as well as using Westernized items irrelevant or even unknown to the African clients.
- Imported models of service delivery that do not match the necessities of many rural areas in most African countries.
- Many implemented projects that do not take into account the contextual needs of the public health sector, e.g., insurance for SLT services.

If these mismatch problems accumulate, the model drift might become so extreme that the "outsider" paradigm bursts because it no longer serves as a reliable framework for daily problem-solving. This is a big danger as the scientific community might become so shaken that the SLTs look for other professional options and the profession itself even starts to dissolve due to disappointment.

Speech–Language Therapy in Sub-Saharan Africa in Model Revolution: Emergence of a Genuinely Independent Paradigm

Finding the way out of the expected model crisis leads us to the proposed need and aim of establishing SLT in SSA in a unique, proud, independent, and sustainable way (see section "Needs: The Basics of Africa-Specific Professionalization"). As said before, the model revolution begins when the basic assumptions and cornerstones of the old Western SLT paradigm are reexamined and

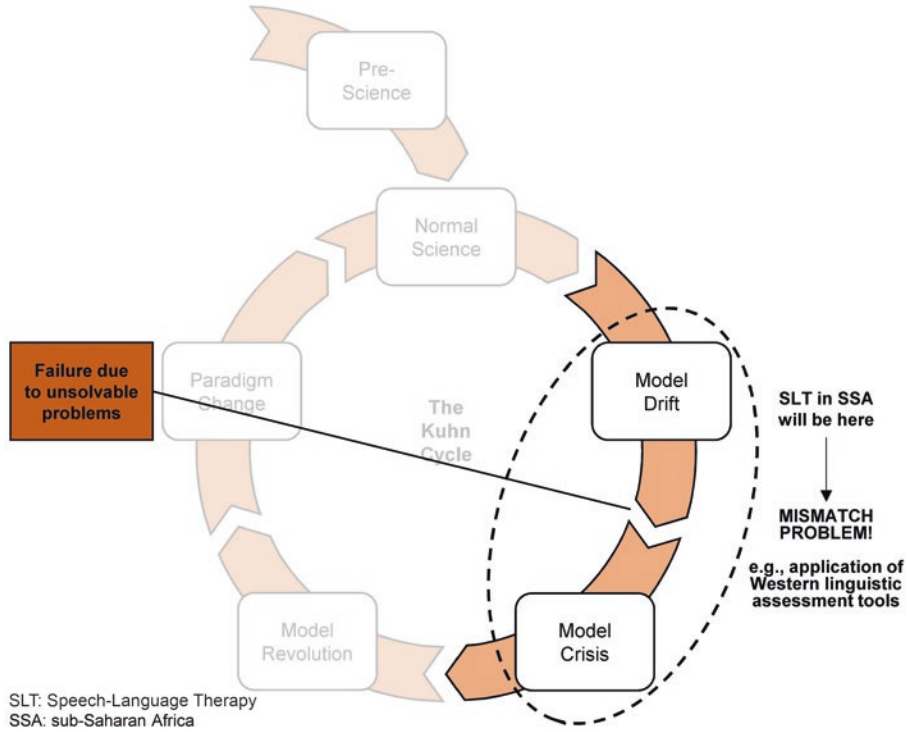

Fig. 1.3 (**b**) Speech–language therapy in sub-Saharan Africa fails as a science: mismatch issues in problem-solving

reframed and new Africa-specific ideas, concepts, and theories are proposed and accepted by the scientific SLT community. The challenge within this paradigm shift is that the change toward a genuinely independent SSA paradigm should not be a total breakaway or condemnation of the outside influenced past, as this is a natural part of the history, but the vision could be more harmoniously the establishment of a paradigm characterized by "Cultural Uniqueness in a Global World" (see Fig. 1.3c). The emergence of this genuinely independent paradigm still takes place within a global professional community and can be supported by three aspects:

- Recognition that there is no need to reinvent the wheel;
- Building on lessons learned;
- Initiating sensitive global exchange, adaptation, and transfer processes.

A model to help to support the paradigm shift is sketched below (see Fig. 1.4). First, it structures the exchange, adaptation, and transfer processes into the three main dimensions of SLT (Lüdtke, 2012):

- The individual *self* in communication with others, especially within the *family*;
- The *society* with its language norms and communication rules;
- The *culture* with its traditions and beliefs, e.g., about communication disability.

Second, it provides a key concept for each dimension which may serve to guide the emergence of a unique, independent, and sustainable SSA-specific SLT paradigm. Based on community discussions, we propose Africa-specific "linguistic identity," "cultural and linguistic diversity," and "inclusion" as described below.

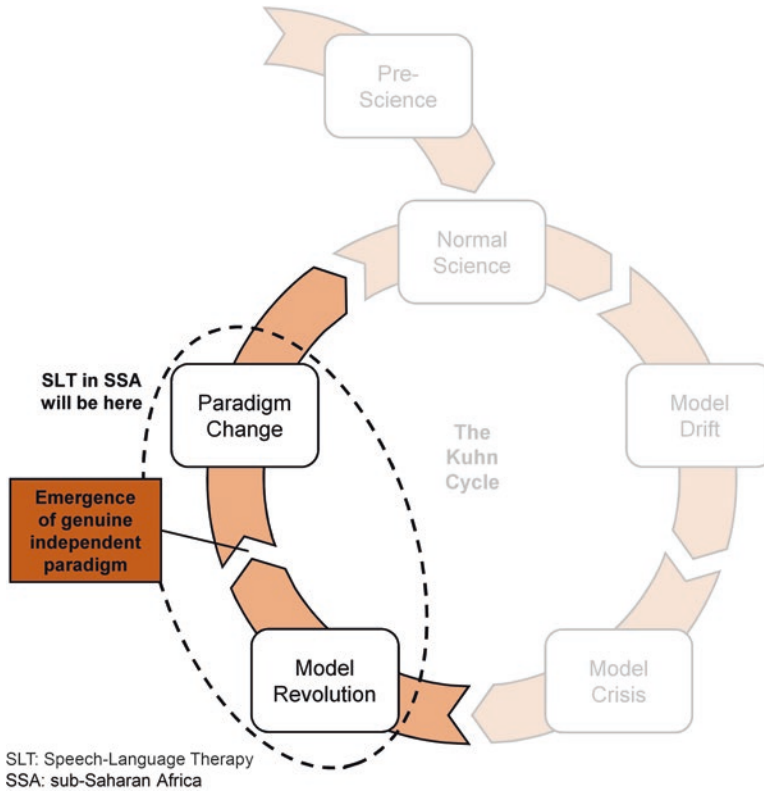

Fig. 1.3 (**c**) Speech–language therapy in sub-Saharan Africa in model revolution: emergence of a genuinely independent paradigm

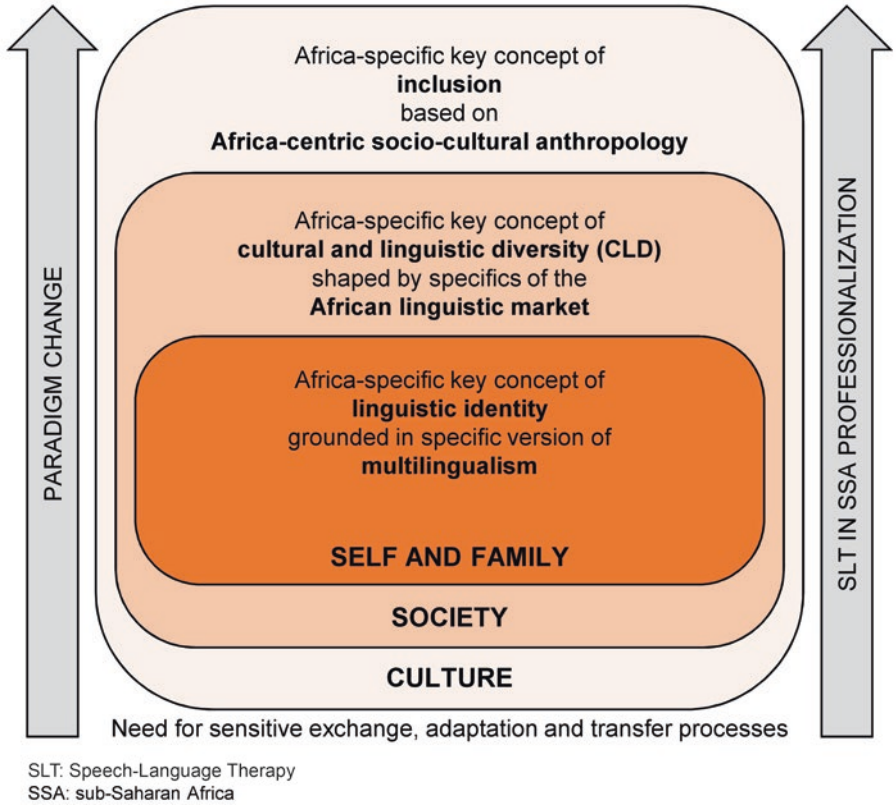

Fig. 1.4 Guiding Africa-specific key concepts for the dimensions of self and family, society, and culture to develop and establish a unique, independent, and sustainable Africa-specific speech–language therapy paradigm

Key Concept for the Speech–Language Therapy Dimension of the Individual Self and Family: Africa-Specific Linguistic Identity Grounded in a Specific Version of Multilingualism

The first dimension of SLT is that of the person throughout the whole life span in communication with others: babies and mothers or caretakers who need professional support in case of swallowing disorders or delayed language development, students in primary or secondary schools who need professional services due to dyslexic or hearing problems, adults at home or in the workplace who need professional intervention due to aphasic and dysarthric symptoms, and elderly persons who need professional support to delay their language disintegration due to dementia syndromes. Central to this dimension is not so much the diagnosed communication disorder but the internal self and, in particular, linguistic identity as an important constituting factor.

In general, the concept of "linguistic identity" (see Crystal, 2007) is important for SLT as, on the one hand, it describes how the personal functions of language – meaning being a human being that is able to talk and communicate with others – shape the identity through the psycho-emotional processes of belonging and delineation. On the other hand, it helps SLTs to understand how communication disorders or even disability can hurt, disrupt, destabilize, or even disintegrate the linguistic identity of a client and the family by feelings of

being shattered, lost, alien, and rejected (Lüdtke, 2012).

For a paradigm shift toward a genuinely Africa-specific professionalization, this concept, originated in Western psychology and linguistics, needs to be reconceptualized by African researchers in the future in an Africa-specific way as well to be able to match aspects of the profession which occur on this dimension in SSA contexts. A key element of such a specification seems to be the condition of a very vivid, natural, and multifaceted multilingualism (Di Carlo et al., 2013; Zsiga et al., 2014), which permeates as a condition sine qua non the shaping of the linguistic identity in African people and which is very different from monolingual or even multilingual contexts in the West.

Key Concept of the Speech–Language Therapy Dimension of Society: Africa-Specific Cultural and Linguistic Diversity Shaped by Specifics of the Linguistic Market

The second dimension of SLT is the society (Fig. 1.4) with its inherent specific language norms and communication rules. These determine the context, institutions, and settings in which service delivery takes place: the power of giving or denying permission to access to the education and health system; the implementation of language norms that are used for standardized language tests, e.g., in preschools or hospitals; or the decisions regarding language politics for the authorization of specific languages in schools and universities. Central to this dimension is not so much the "do's and don'ts" of service delivery conditions but the underlying language norms and their value, which are transported or implemented by SLTs – like teachers or professors as well – via their reigning role to be a personification of "good," accepted, high-standard language, and via their execution of power to assess the value of language capacities of students and clients, and setting and helping language aims to be reached (Lüdtke, 2012).

This last point of the social function of linguistic norms and the social value of different language capacities is, in general, very important for SLT as it helps us to understand that according to sociolinguistic concepts, e.g., Bourdieu's model of the linguistic market (Bourdieu, 1991). In this, when linguistic capital is exchanged, there are two possibilities: As society aims at stabilizing their linguistic norms, those speakers are allowed to participate in the heights of society whose language capacity – or linguistic capital – is of high value or even exceeding the set standard norms. In contrast, those speakers who fail to represent the language standards and have a low linguistic capital are marginalized to the edge of society by regulating processes of the linguistic market, e.g., by gate-keeping functions of the school system. For SLTs, this sociolinguistic framework is helpful in understanding three aspects of their professional role (Lüdtke, 2012). First, SLTs play a crucial role in the linguistic market as they can help students or clients of any age to increase the linguistic capital they need for society in general or an institution like the school or workplace, specifically by improving their language capacities. Second, it serves to gain insight into the processes of how persons with communication disorders might be devaluated and marginalized due to their linguistic and communicative deficiencies. And last but not least, they should take it as their foremost professional duty to help that society is interpreting linguistic variations or differences not as "deficits" but as "diversity".

For a paradigm shift toward a genuine Africa-specific professionalization, these concepts, originated in Western sociology and sociolinguistics, need to be reconceptualized by African researchers in the future in an Africa-specific way to be able to match aspects of the profession which occur on this dimension of society in SSA contexts. A key element of such a specification seems to be the concept of cultural and linguistic diversity (see Garcia & Kagan, 1991), which – based on the above-described African version of multilingualism – needs to be reframed by taking into

account first the specifics of the African linguistic market (e.g., the role of former colonial languages) and, second, the specifics of African ethnic diversity and the broad cultural heritage.

A Key Concept for the Speech–Language Therapy Dimension of Culture: Africa-Specific Inclusion

The third dimension of SLT which has to be considered as part of a paradigm shift is culture (see Fig. 1.4), as this is where processes and decisions regarding the inclusion or exclusion of persons with communication disability take place (Lüdtke, 2012): Do newborns with severe impairments have a right to live? Should severely disabled persons, unable to articulate themselves, be given a voice to talk about abuse and injustice? Do patients in a long-term coma have the capacity to communicate via heart rate, breathing patterns, or skin resistance?

For SLTs, this dimension might, at first sight, seem to be a quite rare issue as the abovementioned phenomena occur only seldomly in the course of professional life. But on closer examination, processes of the exclusion of persons with communication disability happen almost on a daily basis in a more subtle sense: the isolation of the mother of a child with cerebral palsy from the community, stigmatizing of a deaf student in class, or feelings of alienation and repulsion toward a person with a laryngectomy. To understand such subtle processes, the psychoanalytic concept of "abjection" is helpful, in which one's confrontation with an "abject" body or with "abject" language creates first feelings of shock, disgust, and repulsion, which then turn into rejection and exclusion of the alienating "source" to eliminate one's own feelings of being in danger to disintegrate and to realize one's own vulnerability.

For a paradigm shift toward a genuinely Africa-specific professionalization, this concept, originated in Western psychology, also needs to be reconceptualized by African researchers in an Africa-specific way to be able to match aspects of the profession which occur on this dimension of culture in SSA contexts. Even though somehow all cultures draw a demarcation line between "culture" and a sphere without culture, most existing concepts inhabit a very ethnocentric European perspective going back to the antique anthropocentric idea that the ability to talk and have the capacity of language differentiates between animal and man or between humans and "the wild." An Africa-centric reconceptualization in sociocultural anthropology would have to take genuinely non-European concepts, such as the pansemiotic nature of the universe, into account. It then could serve as a base to help SLTs in SSA to make people reflect on cultural stereotypes about communication disability and turn the stigmatization of persons with communication disability into cultural inclusion.

Tasks: Systematic Establishment of a Sustainable, Multilevel, Cross-Sector Speech–Language Therapy Approach

After reflecting at length on the opportunities and challenges of an Africa-specific professionalization, next, in a more practical way, the corresponding tasks lying ahead for the emerging SLT profession need to be pointed out. Overall, the vision would be to take this opportunity for the systematic establishment of an innovative, sustainable, multilevel, cross-sector SLT approach for SSA.

As the basis for a systematic approach in an abstract conceptualization, the profession of SLT can be structured into five different levels (see Fig. 1.5; Lüdtke & Polzin, 2023):

I. *Diversity of Persons with Communication Disorders*. The first level describes the diversity of persons with communication disorders throughout the whole life span, from newborns to elderly persons, displayed in manifold linguistic and communicative varieties.
II. *SLT Practice.* The second level encompasses SLT practice with service delivery in different contexts, institutions, and settings like crèches,

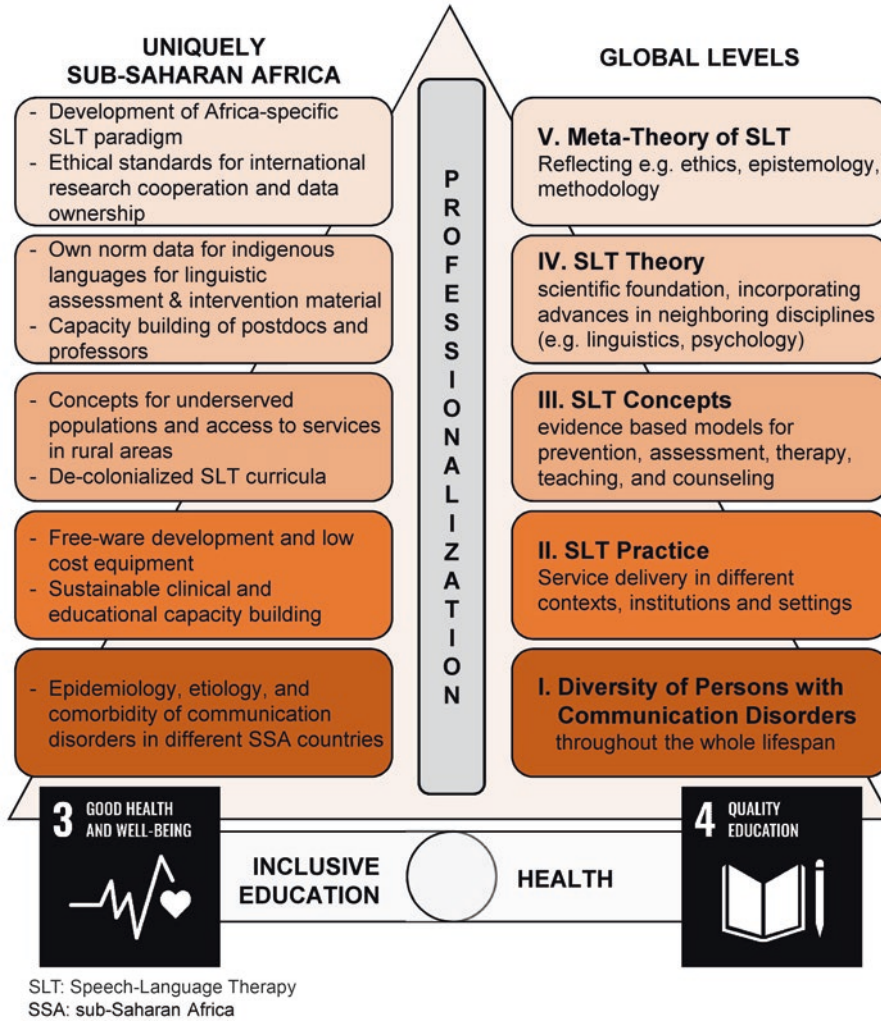

Fig. 1.5 Systematization of the professional establishment of a sustainable multilevel, cross-sector speech–language therapy approach in sub-Saharan Africa at the interface of Sustainable Development Goals 3 and 4[2]. Content of this publication has not been approved by the United Nations and does not reflect the views of the United Nations or its officials or Member States)

preschools, schools, and hospitals and private clinics, using different materials and media.

III. *SLT Concepts.* Further, the third level of the profession provides evidence-based SLT concepts for prevention, screening, assessment, therapy, teaching, and counseling, which guide daily practice and bind them together by coherent schools of thoughts or paradigms, e.g., behavioristic, neurolinguistic, socio-constructivist, and interactionist approaches. From these frameworks, clinical methods and language didactic models can be derived.

IV. *SLT Theory.* As mentioned, the fourth level of the profession stands for SLT theory, which is constantly developed and renewed from neighboring disciplines on which the

[2]The content of this publication has not been approved by the United Nations and does not reflect the views of the United Nations or its officials or Member States.

SLT profession relies on, such as pedagogy, linguistics, psycholinguistics, sociolinguistics, and medicine. Advances here need to be taken into account, and basic research can contribute to new findings and insights.

V. *Meta-theory of SLT*. On the highest level, there is the meta-theory of SLT. This concerns the philosophical discourse on scientific theories and basic philosophical questions like how the nature of human beings is understood and what role stimulating communication plays for infant development. Epistemological reflections on the pros and cons of different methodological approaches that allow insight into communication disability are placed here.

Based on this systematization on each globally employable level, tasks ahead can be identified for an Africa-specific professionalization, placed at the cross-sector interface of Sustainable Development Goal 3 (Health) and Goal 4 (Education) (United Nations, 2019, 2016).

(I) Uniquely Sub-Saharan African Tasks for the Diversity of Persons with Communication Disorders

On the first level, one major task would be to be able to describe the diversity of persons with communication disorders and their manifold linguistic and communicative varieties in an Africa-specific way, as their reality throughout the whole life span – from newborns to elderly persons – is very different from people in Minority World countries, e.g., due to living conditions for large parts of the SSA population living under the impact of poverty, malnutrition, or crime. Epidemiological studies, as well as disability studies, can help to detect and understand this specific complexity and prepare the ground for appropriate Africa-specific SLT practice, e.g., assessment and intervention relating to one of the manifold African languages. Other examples include:

- Research on the prevalence rates and etiology of all different kinds of hearing, speech, language, voice, swallowing, and communication disorders in different SSA countries
- Research on Africa-specific comorbidity (e.g., HIV/AIDS, substance abuse, sickle cell anemia)
- Setting up of SLT databases and digital client management systems

(II) Uniquely Sub-Saharan African Tasks for Future Speech–Language Therapy Practice

On the second level, an important requirement seems to be the need to adopt the Western SLT practice of service delivery to the very different Africa-specific contexts of major institutions and settings, like preschool, schools, hospitals, and private clinics. Specifics such as service delivery in extremely vulnerable places, like children's homes and places of safety or refugee camps, as well as for underserved populations, e.g., children with HIV/AIDS, have to be worked out. In particular, the materials and media applied in assessment and intervention need to be newly invented and/or adopted in a culturally sensitive way. Evaluation studies in the field can examine, e.g., the quality and results of the services and help to build up professional standards of service delivery for different target groups as well as guidelines for clinical reasoning and a body of EBP. Other examples include:

- Creating sustainable budgets for costly technical diagnostic equipment (e.g., FEES, brainstem-evoked response audiometry) and rehabilitative tools (e.g., Servox electrolarynx speech aid, talker, hearing aids, cochlear implants);
- Development of freeware and low-cost equipment;
- Increasing professionalization of untrained/minimally trained personnel in interdisciplinary contexts;
- Sustainable clinical and educational capacity building for SLT services;
- Enabling access to services in rural areas;
- Enabling SLT services for underserved populations;
- Different work settings;

- Eliminating undiagnosed clients due to missing or ineffective assessment tools.

(III) Uniquely Sub-Saharan African Tasks for Future Speech–Language Therapy Concepts

Further, on the third level, the SLT profession needs to strengthen Africa-specific existing good practice, for example, as it has been developed in the area of developmental language disorders. Based on that, Africa-specific concepts for prevention, assessment, therapy, teaching, counseling, and advocacy should be provided, which can guide daily practice and take the specifics of the abovementioned workplaces into account. They then can be proven by intervention studies and can add, as well as enlarge and adjust, the new body of Africa-specific EBP, which is also the base for professional clinical reasoning. For further binding of these concepts together by coherent schools of thoughts or paradigms, a major task is to reconceptualize "Western" approaches, e.g., those of behavioristic, neurolinguistic, or interactionist origin, and blend them with African theory. From these modified frameworks, SLT methods and language didactic concepts adjusted to the needs of the continent as well as to single continents or regions can be derived. Other examples include:

- Development of concepts for underserved populations and access to services in rural areas (e.g., by mobile clinics, telehealth options, remote health services such as hearing aid fitting);
- Enforcement of clinical and educational capacity building by university-based SLT undergraduate and graduate programs;
- De-colonialization of imported SLT curricula and redesigning genuinely African curricula;
- Creation of service delivery models for different clinical and educational settings;
- Establishment of legal and financial concepts to balance the public and the private health and education sector.

(IV) Uniquely Sub-Saharan African Tasks for Future Speech–Language Theory

The main task on the fourth level of the profession would be to acknowledge the existing wealth of contextually relevant knowledge on the African context, which can contribute to new findings and insights and the development of an SLT theory for SSA. Africa-specific research from neighboring disciplines on which the SLT profession relies on, such as pedagogy, linguistics, psycholinguistics, sociolinguistics, and medicine, has to constantly be taken into account and readjusted. Other examples include:

- Increasing Africa-owned research for fueling Africa-specific SLT databases;
- Increasing capacity building in a large variety of research methods;
- Development of an Africa-specific SLT paradigm with its own terminology and systematization;
- Development of large-scale research programs, including securing independent funding, e.g., to collect own normative data for indigenous languages for the development of highly specific linguistic assessment and intervention materials;
- Strengthening the infrastructure at African SLT universities for research management;
- Capacity building of postdoctoral researchers and professors by increasing publications and boosting scientific co-publishing with internationally renowned scientists;
- Development of scope with African SLT journals, scientific conferences, and professional networks.

(V) Uniquely Sub-Saharan African Tasks for a Future Meta-theory of Speech–Language Therapy

Finally, yet importantly, on the highest level, the task on the meta-theory is the development of an overall Africa-specific SLT paradigm, which is based on the practice, concepts, and theory of the previous levels described (I–IV). Epistemological

Table 1.1 Ethics of research and developmental cooperation

Ethics of research cooperation	
Guide for Transboundary Research Partnerships (Swiss Commission for Research Partnerships with Developing Countries, KFPE, 2012) in Stöckli et. al., 2012)	As a milestone in international research cooperation, the Guide for Transboundary Research Partnerships offers support to researchers who aim to conduct research in bi- or multilateral, intercultural settings. It includes 11 principles to follow in order to support those research relationships which, according to the authors, can require individual solutions for the cooperation, as well as questions that are intended to enable target-oriented discussions for improvement (Stöckli et al., 2012). They focus on *(1) setting the agenda together, (2) interacting with stakeholders, (3) clarifying responsibilities, (4) accounting to beneficiaries, (5) promoting mutual learning, (6) enhancing capacities, (7) sharing data and networks, (8) disseminating results, (9) pooling profits and merits, (10) applying results, and (11) securing outcomes*
Guidelines to Conflict Sensitive Research (Bentele, 2020; KFPE, 2020)	In 2020, the above general document was deepened by guidelines for research projects taking place in conflict-affected contexts – an issue becoming increasingly important for all disciplines including SLT, e.g., research in refugee contexts. The main intent of the document is to create an awareness that research is always part of the context in which it takes place. Additionally, this "conflict sensitive approach to research helps to understand the interaction of research with multiple layers of overt or latent conflicts" (KFPE, 2020, para. 3)
UNESCO Science Report: Towards 2030 (Schlegel, 2015; UNESCO, 2015)	Twice a decade, the UNESCO Science Report releases an overview on "science, technology and innovation around the world on a regular basis" (UNESCO, 2015, 3). Besides topics of current main interest, for example, the current report puts one of its spotlights on the consideration of indigenous knowledge for policy development, the report looks at changes on a global level and focuses on different regions and countries. Looking at the 2030 Agenda for Sustainable Development, UNESCO emphasizes the changes concerning the slow approximation of efforts in the science of "developed" and "developing" countries and their subsequent growing competitiveness (UNESCO, 2015). In its recent regional overview of SSA, it was pointed out how the still small scientific productivity is related to the relatively low resources devoted to research and development and how scientific publication output and trends are distributed across the continent
Ethics of developmental cooperation	
The Paris Declaration on Aid Effectiveness (OECD, 2005a, b)	As a first but important global document, in 2005, the Paris Declaration on Aid Effectiveness was signed by "Ministers of developed and developing countries responsible for promoting development and Heads of multilateral and bilateral development institutions" (OECD, 2005a, b, 1), following the Millennium Development Goals. The declaration focuses on increasing the effectiveness of aid for development with regard to the main topics of *Ownership*, *Alignment*, *Harmonisation*, managing for *Results*, and *Mutual Accountability* to ensure useful and target-oriented support to developing regions
Accra Agenda for Action (OECD, 2005a)	In order to "accelerate and deepen the implementation of the Paris Declaration on Aid Effectiveness" (OECD, 2005a, b, 15), the Accra Agenda for Action was signed in 2008. Predominantly, the agenda commits developing countries to taking responsibility for their future and, thus, gain more influence on the outcomes. Therefore, *Ownership*, *Inclusive Partnerships*, *Delivering Results*, and *Capacity Development* with greater impact are emphasized, for example, strengthening civil society organizations, developing financial and administrative efforts in the target countries themselves, or conjoining efforts in order to reach greater success
The Sustainable Development Goals (SDGs) (UN, 2016)	The SDGs are the core part of the 2030 Agenda for Sustainable Development, agreed to in 2015 by all Member States of the United Nations. The Agenda includes the conjoint aim for "peace and prosperity for people on the planet" in order to combat poverty and improve the life situation in all regions of the world. Among the 17 SDGs, which focus on all parts of life such as, among others, water and food supply, economy, and sustainability, the Agenda also emphasizes *Good Health and Well-Being* (SDG 3) as well as *Quality Education* (SGD 4). These two goals, together with Peace, Justice, and Strong Institutions (SDG 16), aim to ensure inclusion and equal opportunities for people of all ages and are of utmost importance for SLT and special education

and methodological reflections can pave the way here. One cornerstone might be the development of national ethical standards of SLT service delivery as well as ethical standards for international research cooperation and data exchange from an SSA perspective (see section "Opportunities: International Speech–Language Therapy Research Cooperation Within a Global Ethical Framework"). Other examples could be reflections and research on African conceptualizations of communication disability and their creolization with Western concepts, e.g., the concepts of "possession" and "punishment by God."

Opportunities: International Speech–Language Therapy Research Cooperation Within a Global Ethical Framework

Finally, after identifying the needs (see section "Needs: The Basics of Africa-Specific Professionalization"), exploring the opportunities and challenges (see section "Chances and Challenges: Cultural Uniqueness in a Global World"), and briefly discussing the tasks ahead (see section "Tasks: Systematic Establishment of a Sustainable, Multilevel, Cross-Sector Speech–Language Therapy Approach") of the emerging SLT profession in SSA, we conclude by having a brief look at the opportunities that international SLT research cooperation may offer within a global ethical framework. We propose that the professionalization of the African SLT community can profit from finding a balance between exploring its unique, proud, independent, and sustainable way and also shaping its cultural uniqueness within the existing and evolving global SLT world.

As in all partnerships, to find, keep, and sustain such a balance is a highly demanding, fragile, and evermore sensitive effort. Moreover, collaborations between the Minority World and Africa require concerted efforts in addressing the power imbalances between partners by focusing on aspects such as trust and resilience (Kerasidou, 2019). The history of cooperation in general, and research cooperation specifically, between SSA and the rest of the world has been a tragedy of among others corruption, exploitation, and power abuse. Therefore, to stop this infinite chain of imbalance, the cooperation of SLT in Africa with other countries should be guided and secured by a global ethical framework, which we sketch below (see Fig. 1.6). This figure tries to illustrate how at the intersection of two global ethical dimensions – the ethics of research cooperation (left) and the ethics of developmental cooperation (right) – three different levels of SLT cooperation (global, bi- or multinational, and national) are guided. As major references, we refer to these in chronological order (see Table 1.1).

More precisely and related to our profession, there are three different levels of SLT cooperation guided by ethical frameworks (see Table 1.2).

To conclude, we hope that these reflections may assist the SLT profession in SSA to grow and blossom and be of service to the millions of persons with communication disorders across the whole continent.

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Table 1.2 Levels of SLT cooperation guided by ethical frameworks

Global level	
International Classification of Functioning, Disability, and Health (ICF) (World Health Organization (WHO), 2001)	Globally, the International Classification of Functioning, Disability, and Health (ICF) is a document released by WHO in 2001 in order to deliver a guideline and concept of the reciprocal influence and interfaces of a human's (dis-)ability and their surroundings and offers support in terms of a conjoint language concerning health and disability. According to WHO, "the functioning of an individual in a specific domain reflects an interaction between the health condition and the contextual domain, conceptualized as environmental and personal factors. There is a complex, dynamic and often unpredictable relationship among these entities" (WHO, 2013, 7). It can be valued as a first step away from a deficit individualistic perspective on disability toward a holistic paradigm of diversity, inclusion, and participation
Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006)	In 2020 signed by 164 and ratified by 183 nations, the CRPD strengthens and boosts this paradigm by being the first global agreement intended to protect the rights and dignity of persons with disabilities. Full equality under the law is focused on in detail *regarding Civil and Political Rights*; *Economic*, *Social and Cultural Rights*; and *Independent Living*
Bi- or multilateral level	
For SLT cooperation on a bi- or multilateral level, the specific national implementation of the global documents has to be taken into account, and details have to be discussed and agreed on between the two or more SLT partner institutions according to these frameworks. One valuable reference for European countries involved could be:	
Ethics for researchers (European Commission, 2013)	The ethics for researchers was published by the European Commission in order to provide bi- and multinational networks of researchers attempting to apply for funding from the European Union with a guideline on ethical aspects to follow when developing research designs. Besides embedding the guideline into the European Union legal framework, it names the ethical principles and procedures to follow, as well as ethical issues, in order to provide the research subjects with protection (European Commission, 2013)
Country level	
SLT Code of Ethics (e.g., ASHA, 2016)	As an outstanding example of ethical guidelines for the SLT profession on a national level, the Code of Ethics of the American Speech–Language-Hearing Association (ASHA , 2016) can be recommended. This framework is intended to reflect "what we value as professionals and establishes expectations for our scientific and clinical practice based on principles of duty, accountability, fairness, and responsibility" (ASHA, 2016, para. 1) and to guide "professionals in support of day-to-day decision making related to professional conduct." The four major principles of ethics for professionals are (I) "to hold paramount the welfare of persons they serve professionally or who are participants in research and scholarly activities" (ASHA , 2016, para. 31), (II) "to achieve and maintain the highest level of professional competence and performance" (ASHA, 2016, para. 52), (III) "to honor their responsibility to the public when advocating for the unmet communication and swallowing needs of the public and shall provide accurate information involving any aspect of the professions" (ASHA, 2016, para. 61), and to (IV) "uphold the dignity and autonomy of the professions, maintain collaborative and harmonious interprofessional and intra-professional relationships, and accept the profession's self-imposed standards" (ASHA, 2016, para. 69)

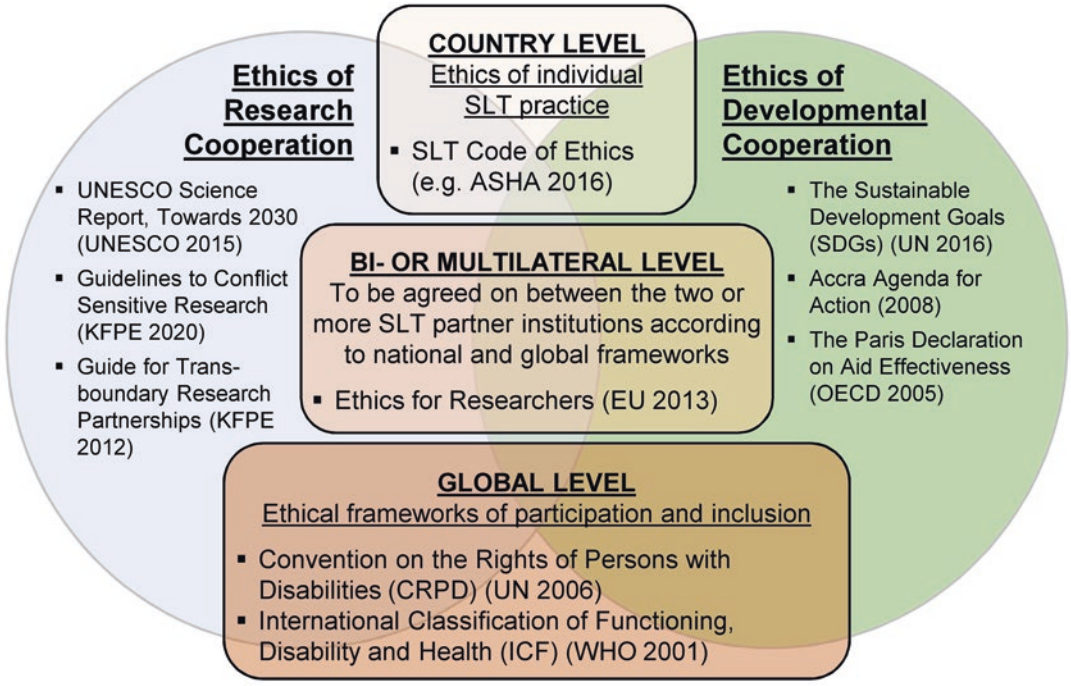

Fig. 1.6 Map of the global ethical framework for international speech–language therapy cooperation

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2

Speech-Language Therapy in Sub-Saharan Africa: Development and Sustainability of Services for Persons with Communication Disability

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Speech–Language Therapy and Rehabilitation Services in SSA

Despite overwhelming need, the profession of speech–language therapy (SLT) is largely unknown in sub-Saharan Africa (SSA). While the profession is growing, there continues to be few speech–language therapists (SLTs) offering services in the region. Broad estimates of the SLT workforce suggest that countries in SSA may have between zero and six SLTs per million population[1] (Fagan & Jacobs, 2009; Mulwafu et al., 2017; Wylie et al., 2012). This contrasts markedly with estimated population ratios of approximately 200–400 SLTs per million population in Minority World countries such as the USA, UK, Australia, and Canada (Wylie et al., 2012). Following developments in SLT training programs in several SSA countries including Uganda, Togo, Kenya, Ethiopia, and Ghana (Hussain et al., 2018; Wylie et al., 2016a), numbers of SLTs in SSA are slowly increasing. It will, however, be centuries before a workforce approaching current ratios in Minority World countries is possible.

Estimating how many people have a communication disability is complex. Global rates of disability are estimated to comprise 15% of the population (World Bank and World Health Organization (WHO), 2011); however, it is difficult to determine what proportion of these people may experience communication disability (Wylie et al., 2013). Estimates for the prevalence of communication disability in the Majority World are particularly difficult to establish. Hartley and Wirz (2002) analyzed data from reported studies in Pakistan, Uganda, and Zimbabwe and suggested that between 38% and 49% of persons with disabilities seeking help from rehabilitation services may have communication difficulties. Data from a disability prevalence survey in central Ghana (Biritwum et al., 2001) suggested that 25% of children identified with disabilities experienced some form of communication difficulty. However, caution is required in extrapolating these figures to a population level because we do not know if individuals accessing rehabilitation services are representative of all persons with disabilities in these countries. It is clear that a small SLT workforce will struggle to have a meaningful impact with such a large number of people requiring services, unless the way in which SLTs work evolves to meet the specific needs of the region.

Availability of rehabilitation services is critical for persons with communication disability, as communication disability can have far-reaching societal impacts. For example, the Ugandan Ministry of Gender, Labour and Social Development (MGLSD, 2011) reports that 29.2% of children with communication disability are unable to attend school at all and 50.1% of adults with communication disability are unable to work. Rehabilitation services for persons with communication disability play an important role in addressing the impact of com-

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[1]With the exception of South Africa, where training has been long established.

munication disability on the individuals themselves, their families, and communities.

Rehabilitation services for persons with communication disability may need to develop differently in SSA from the models used in Minority World countries. Originating from a lack of rehabilitation workforce and the need to shift rehabilitation into community settings, community-based rehabilitation (CBR) has been widely adopted in SSA and uses CBR workers and volunteers to offer a broad approach to rehabilitation at the community level. Despite the use of CBR, systems are continuing to fail to meet the need for rehabilitation in the region. In a series of research with persons with disabilities, only 26–55% of persons with disabilities across four Southern African nations reported receiving any medical rehabilitation at any point, with the majority of this rehabilitation being for physical disabilities (Eide & Kamaleri, 2009; Eide & Loeb, 2006; Eide et al., 2003; Loeb & Eide, 2004).

CBR workers have great potential to provide communication disability rehabilitation, especially as the system develops and expands, but their training may have gaps which limit their ability to address the needs of persons with communication disability. CBR workers are trained to provide a range of rehabilitation services. Despite the development of early resources to support the training of CBR workers on communication (e.g., Wirz & Winyard, 1993; World Health Organization and United Nations Children Fund and Ministry of Health, Zimbabwe, 1997), few receive specific training in intervention methods for communication disabilities (Nganwa et al., 2013). Formalized and extended training is required for all CBR workers to effectively increase services for persons with communication disability (Mannan et al., 2012).

There appears to be increasing awareness of the need for communication disability rehabilitation services in SSA, as evidenced by the development of new SLT training programs across Africa (Wylie et al., 2016a). Yet SLT services in SSA may need to evolve differently from SLT services in Minority World countries (Pillay & Kathard, 2015). SLT in high-income countries has historically adopted a predominantly medical model approach, focused on impairment-level services for individuals. In the context of few available therapists, such an approach will continue to fail to meet the significant population and development challenges in the region, even with gradually increasing numbers of SLTs.

The World Report on Disability (World Bank and WHO, 2011) highlights the importance of a range of approaches in providing rehabilitation for persons with disabilities. These include health-related rehabilitation services, CBR services, and services provided in other sectors such as within the education or employment sectors (Wylie et al., 2020). The key role of family and friends of persons with disabilities in providing and supporting rehabilitation is also identified in the report. In the background briefing paper to the meeting *Rehabilitation 2030: A Call for Action*, the WHO (2017a) describes the need for a well-integrated continuum of approaches to service delivery. When planning SLT services in SSA, considering the most effective approaches to meet the population needs should be a part of the critical dialogue.

If SLTs are to truly be part of the development of sustainable rehabilitation services for persons with communication disability, careful consideration needs to be given to both (a) how services are developed and supported and (b) the roles SLT will play in the mix of services. Simply replicating service models from Minority World countries may not provide equity or meet population demands in low- and middle-income countries (Law et al., 2013; Pillay & Kathard, 2018; Wylie et al., 2014) and may create systems that are unsustainable in the African context, compromising the needs of future generations of persons with communication disability.

SLT Workforce Sustainability Issues in SSA

Sustainability is a commonly used term in literature focused on development and services in low- and middle-income countries. Originating from the environmental literature, the concept of

sustainability has been long touted in development literature as "development which meets the *needs of the present* without *compromising the ability of future generations* to meet their own needs" (World Commission on Environment and Development, 1987, p. 41; emphasis added).

This chapter focuses on two interrelated issues: (1) the development and sustainability of rehabilitation services for persons with communication disability and (2) the development of, and contributions to, rehabilitation by the SLT workforce in SSA. If rehabilitation services for persons with communication disability are to grow and thrive, the primary dimension of "sustainability" must include consideration of durability, including support for, and relevance of, services.

SLTs and rehabilitation services for persons with communication disability are not synonymous. SLTs are just one component of the workforce of a complex network of providers who could play a role in delivering and supporting rehabilitation for persons with communication disability (Wylie et al., 2016a, 2018, 2020). Others, such as teachers, CBR workers, community health workers, therapy assistants, carers, and family members, provide important services in the provision of rehabilitation services for persons with communication disability in the region. Self-help and help provided by family members and other key community members have particularly significant potential for supporting and contributing to the range of existing rehabilitation services in SSA (Wylie et al., 2017, 2020).

Building the capacity and effectiveness of these broader groups to contribute to rehabilitation for persons with communication disability is particularly important in SSA, where more specialized rehabilitation for communication disabilities such as SLT is rarely available (Fagan & Jacobs, 2009; Mulwafu et al., 2017; Wylie et al., 2012). Addressing the enormous unmet need for rehabilitation (WHO, 2017a) may require SLTs to think more holistically, including their roles in training, lobbying, and advocacy (Wickenden, 2013; Wylie et al., 2017, 2018).

People drive rehabilitation services,[2] and without a suitable workforce, rehabilitation services are not sustainable. The imperative is to have the "right workers, with the right skills, in the right places, doing the right things" (WHO, 2006, p. x). The availability, skill mix, and functioning of the workforce must be a principal focus in improving the sustainability of health and disability services (Chen et al., 2004; WHO, 2015). The development and support of a sustainable workforce for rehabilitation is one of the priority actions identified in the Global Disability Action Plan 2014–2021 (WHO, 2015).

Establishing a workforce for rehabilitation is a challenging issue. There is a global shortfall in health and rehabilitation workers, particularly in low- and middle-income countries, including those of SSA (Anyangwe & Mtonga, 2007; Gupta et al., 2011; Liese & Dussault, 2004; WHO, 2017b). The limited available literature provides indications of the extreme scarcity of SLTs in SSA (Fagan & Jacobs, 2009; Mulwafu et al., 2017; WHO, 2017a, b; Wylie et al., 2012), despite indications of recent growth in training (Wylie et al., 2016a).

A sustainable workforce to deliver quality services requires more just adequate numbers of workers. A range of other factors have been identified as contributing to creating a sustainable workforce, including having the appropriate mix of workers, positive work environments, appropriate levels of remuneration, effective support systems, availability of ongoing training, and effective leadership (Chen et al., 2004; Mathauer & Imhoff, 2006; Willis-Shattuck et al., 2008).

There is increasingly explicit appreciation that health and rehabilitation services can only be effective if the workforce is available, appropriate, skilled, and stable. Campbell et al. (2013) adapted the original Tanahashi (1978) model of health service coverage to describe four stepwise dimensions of workforce factors impacting the provision of relevant and accessible ser-

[2]The health and rehabilitation workforces are linked and difficult to separate. This chapter combines the evidence from both the health and rehabilitation literatures to consider workforce implications.

vices – availability, accessibility, acceptability, and quality. For the remainder of this chapter, we frame our considerations of workforce and service sustainability using the first three of these dimensions. We then present original data from a workforce study of SLTs in SSA using the first three dimensions of availability, accessibility, and acceptability.

Our conceptualizations of the issues contributing to availability, accessibility, and acceptability of SLT services are provided below and illustrated in Fig. 2.1.

SLT Workforce Availability

Availability of an SLT workforce is inherently linked to two main factors: (a) how the workforce is established/created and (b) how the workforce is retained. Both training and net inward migration have the potential to grow the workforce, and historically SLT services in SSA have been supplemented by volunteers and other expatriate SLTs (Wylie et al., 2016a). Net gains in the workforce, through migration, may increase services if jobs, and the right to work, are available for migrant workers (WHO, 2006). The availability of local training programs has also been shown to enhance size and retention of the workforce (Anyangwe & Mtonga, 2007). Migration (both inward and outward) may also impact availability of services. A variety of push-pull factors exist, driving inward and outward migration. Push factors driving health workers out of the region may include lack of a career path, poor leadership and management, workload, poor facilities and infrastructure, and low salaries (WHO, 2006).

Factors such as job availability and stability and job attractiveness are key to establishing and sustaining services. Once the workforce is

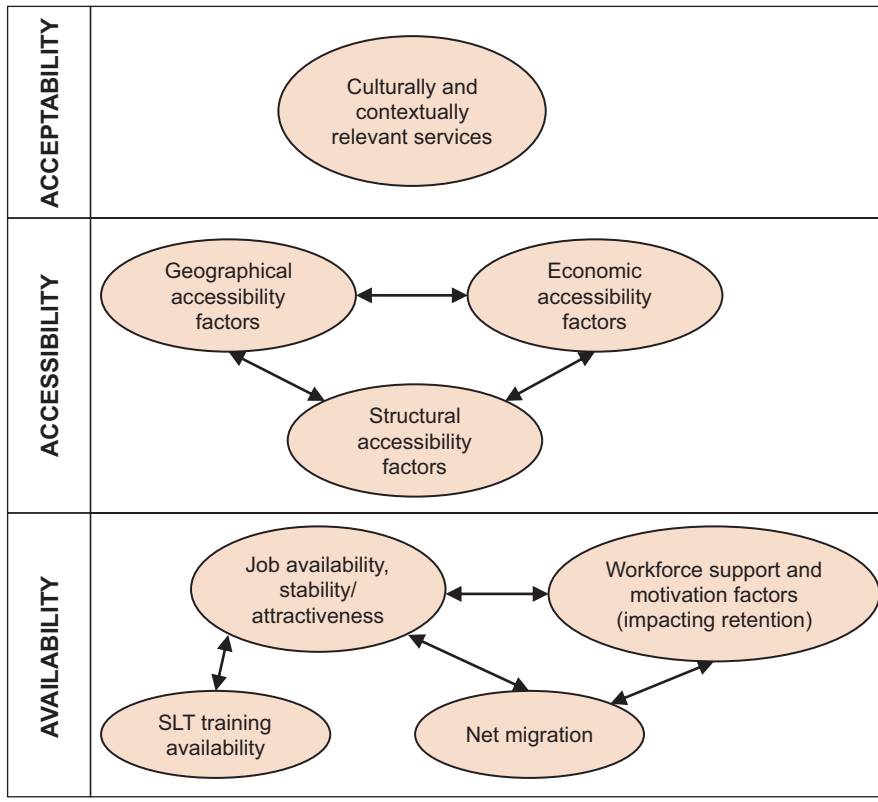

Fig. 2.1 Dimensions of availability, accessibility, and acceptability – SLT workforce. (Authors' Original Work, Based on Dimension of Health Service Coverage, Campbell et al. (2013))

trained, jobs or work opportunities need to be available for graduates. Without jobs, graduates may move into other fields of employments (WHO, 2006), and the opportunity for increased services is lost.

A range of working conditions have also been linked to motivation, performance, and retention of the workforce. Examples include supervision, continuing professional development, and organizational communication (Chen et al., 2004; Mathauer & Imhoff, 2006; WHO, 2006; Willis-Shattuck et al., 2008). Such factors may influence service availability, as both productivity and retention may be impacted if the workforce is poorly motivated and supported.

Accessibility of SLT Services

Following the establishment of the workforce and services, there remain a variety of factors which limit equitable access to SLT services, even when services are available. Barriers to services are frequently classified into structural, geographical, and financial elements (Verdon et al., 2011). For example, services located in urban settings only present geographical barriers to those living in rural and remote areas. Services which have high fees present financial barriers to those on low incomes. Structural barriers result from the ways in which services are organized and may include factors such as waiting times, operating hours, or limitation in types of clients accepted by the service. For further exploration of issues around accessibility of services and underserved populations in low- and middle-income countries, please refer to Wylie et al. (2013).

Acceptability of SLT Services

Culture shapes how we perceive and respond to circumstances in our lives. Even once services are available and geographical, structural, and economic barriers have been addressed, they need to respond to the needs and beliefs of the community. Campbell et al. (2013) used this dimension to refer to the sociocultural elements of services. African societies hold an enormous diversity of languages and cultures. While countries have frequently adopted the language of colonizers as their national unifying languages, commonly spoken languages are often indigenous languages. The ability of persons with communication disability and their families to be treated in a language in which they feel competent and comfortable, or in ways that fit with their culture and beliefs, may influence service accessibility (Bourke-Taylor & Hudson, 2005; Leadbeater & Litosseliti, 2014).

SLT is a "Western" profession (Abrahams et al., 2019; Pillay & Kathard, 2015) most commonly focused on the biopsychosocial model of disability. It considers communication disability to be an interaction of biomedical condition, personal factors, and societal expectations/environments. Cultures may not, however, all perceive communication disability in this way. A myriad of beliefs about disability exist in SSA, with disability frequently attributed to spiritual causes (Groce & Zola, 1993; Mpofu & Harley, 2002). For example, if communication disability is perceived as spiritual, it is likely that populations will seek spiritual support for the condition. If services do not attempt to address the cultural context, then even available and accessible services may only result in uptake by certain sections of the community who adopt a more "Western" view of disability and find this model of service acceptable (Groce & Zola, 1993; Hartley, 1998; MacLachlan, 2006).

Accessibility, Acceptability, and Availability of SLT Services: A Workforce Survey

We will now consider aspects of the development of SLT in relation to the following three dimensions: availability, accessibility, and acceptability.

Within this section, we present findings from a subset of data from a workforce survey of SLTs in SSA to report on issues in the sustainable development of the profession.

Aim and Objectives

The research aimed to explore the workforce of SLTs in SSA, by describing a sample of SLTs in the region (excluding South Africa) across five domains: workforce characteristics, SLT education, language and culture, employment and work roles, and continuing education. Other data from this study have been reported in Wylie et al. (2016a, 2018). Relevant results from these papers will be interwoven with original results presented in this chapter to provide cohesive information linked to the sustainability of services provided by SLTs. Data that have been reported previously are *italicized*.

Methodology

A purpose-designed, mixed methods survey was used to collect information from SLTs in SSA. The methodology for this research is detailed in a previous publication (Wylie et al., 2016a). The 186-item survey instrument included both open and closed questions. Survey development and piloting followed the process described by Punch (2003). Due to resource limitations, the survey was produced only in English.

The survey was offered in four modes: online (SurveyMonkey), email attachment (form) in Microsoft Word, paper copy, and via a telephone/callback service. The survey took 45–60 minutes to complete. It was not compulsory to complete all questions.

Data were collected between April 2012 and March 2013. Twenty Anglophone or partially Anglophone countries were included in the survey. South Africa was excluded given its long-established SLT education (Pillay & Kathard, 2015).

Selection criteria for respondents included self-identifying as an SLT and residence in a target country for 6 months or longer. Snowball sampling was used to recruit potential participants. Contact was made with relevant professions and groups including SLTs, disability workers, voluntary organizations, and professional bodies, either known to the team or identified via the Internet. Initial contacts were asked to forward survey information to other possible respondents.

Descriptive statistics were used to explore numeric data where sample size permitted. Qualitative content analysis (Shreier, 2012) was used to explore open-ended question data. Inductive coding was developed and reviewed; a coding frame was developed and applied to the data from each open question. Internal consistency was checked by reviewing data cohesion within coding groups. The coding frame, coding, and code hierarchies were reviewed by a second researcher experienced in qualitative research. Data are presented descriptively and must be interpreted with caution.

The study received ethical clearance from the University of Queensland, Australia, where the lead author was enrolled for a PhD at the commencement of the research. The ethical approval reference was 2011-SOMILRE-0018.

Results

Demographics of Respondents

Thirty-three completed surveys were received. All respondents held qualifications in SLT with qualifications ranging from Bachelor's degree to doctorate. Two-thirds (n = 22, 67%) of respondents were African nationals, while non-African nationals comprised one-third of the sample (n = 11, 33%).

Availability

Respondents reported holding 44 jobs (with some respondents reporting holding 2–3 jobs).

Job Availability: Permanent and Full-Time Jobs

In previously reported data from this survey (Wylie et al., 2016a)*, less than half of all jobs reported in the survey* (*41%*) *were full time, and less than half of relevant jobs* (i.e.*, not self-employed private practice or independent/self-organizing volunteers*) *were reported to be permanent* (*n = 12, 39%*). *Descriptive data suggested that the government sector offered the*

greatest job security with two-thirds of these jobs (n = 6, 67%) reported as being permanent. In comparison, both not-for-profit (17% permanent roles) and private sectors (36% permanent roles) offered less job security. Lack of subject numbers precluded statistical analysis.

Service Stability

Respondents were asked to describe the work roles they undertook and consider whether services were likely to continue if they were to leave their present position. Half of the respondents (*n* = 19, 50%) were uncertain or felt it unlikely that services would continue. Half of the participants who responded to this question (*n* = 19, 50%) indicated that it was likely that some level of SLT service may be available if they left their current position. Likely scenarios detailing how services would continue are outlined in Fig. 2.2.

Motivation and Support Factors: Working Alone

In previously reported data from this survey (Wylie et al., 2018)*, respondents were asked if they had a professional peer or colleague in communication disability within their workplaces. Just over a third (n = 16, 38%) of respondents indicated that they did, while 62% (n = 26) indicated being the only SLT or similar in their workplace.*

Motivation and Support Factors: Mentoring Availability and Location

To consider mechanisms of professional support, respondents were asked if they considered themselves to have an SLT mentor or support person. Responses are provided in Table 2.1.

Approximately one-third (*n* = 8, 35%) of mentors were reported to be formal arrangements; the same proportion were a mix of formal and informal arrangements (*n* = 8, 35%), and the remainder (*n* = 7, 30%) were informal arrangements. Of note, approximately half of the respondents had mentors resident outside of Africa.

Motivation and Support Factors: Strategies for Continuing Professional Development

Respondents were asked to list the strategies they used to access continuing professional development (CPD). Three overarching categories were evident in analysis of the responses: organized events and training, seeking information individually, and using networks of support (see Table 2.2).

Motivation and Support Factors: Successes and Challenges in Continuing Professional Development

Respondents were asked to describe successes and challenges in accessing CPD. These data were analyzed using qualitative content analysis

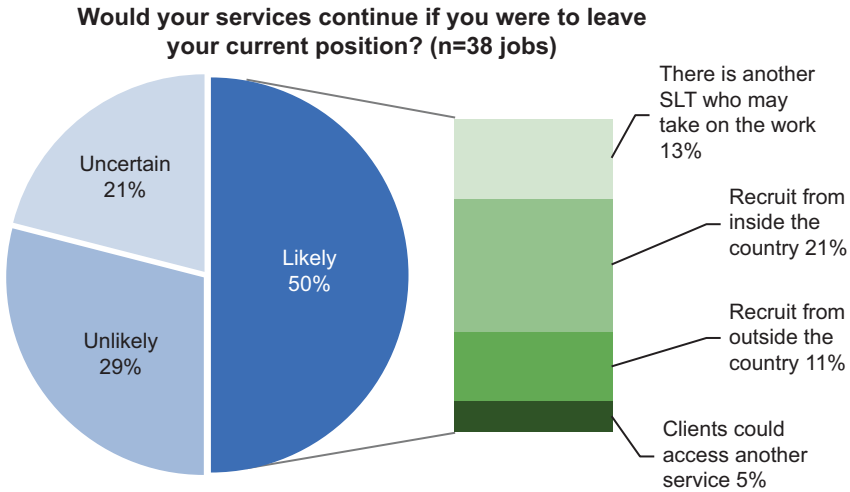

Fig. 2.2 SLT perception of service continuity

Table 2.1 Availability of an SLT mentor or support person, and location, by nationality group

	With SLT mentor		Without SLT mentor		Total	Missing data
All respondents	23 (79%)		6 (21%)		29	4
African nationality respondents	17 (85%)		3 (15%)		20	2
Non-African nationality respondents	6 (67%)		3 (33%)		9	2
	Same town	Same country	Another African country	Outside Africa	Total	
All respondents	9 (32%)	5 (18%)	1 (4%)	13 (46%)	28[a]	
African nationality respondents	6 (27%)	5 (23%)	1 (5%)	10 (45%)	22[a]	
Non-African nationality respondents	3 (50%)	0 (0%)	0 (0%)	3 (50%)	6	

[a]Some respondents reported having more than one mentor

Table 2.2 Continuing professional development: categories and subcategories

Organized events and training	International training courses, workshops/presentations, regional conferences, formal study
Seeking information individually	Textbooks, journals, internet searches
Using networks of support	Case discussions, multidisciplinary team meetings, mentoring processes, peer discussion, support groups

(Shreier, 2012). Comments about successful CPD were classified according to the location of activities: accessed locally (within country), accessed internationally (outside the country), and location unspecified.

Local CPD included training from international visitors or via the Internet, access to journals, local SLT meetings or support meetings, local mentoring/supervision, accessible Internet and email, and having access to a local colleague in the workplace.

International CPD included international colleagues, international professional associations, and attending training internationally. One reported activity that did not specify location was conferences. Examples are provided in Table 2.3 and include illustrative quotes from participants.

Challenges faced in CPD are clustered into six categories: availability and accessibility factors, cost, time, need for a community of support, relevance of training, and specific local barriers. Categories and subcategories are presented in Fig. 2.3, with examples of data provided in Table 2.4. A range of illustrative quotes have been included to enable the voices of participants to be clearly represented.

Accessibility

Wylie et al. (2018) *outlined data representing structural, geographic, and economic factors and factors impacting service accessibility. Key findings relating to these factors are summarized below.*

Structural Barriers: Employment Sector and Service Setting

SLTs worked in a range of settings including hospitals, schools, special schools, preschools, private clinics, universities, rehabilitation centers, and disability centers. SLTs were employed in the private (*n* = *20, 45%*), *not-for-profit* (*n* = *15, 34%*), *and government* (*n* = *9, 20%*) *funding sectors* (Wylie et al., 2018).

Geographic Barriers: Location of SLT Services

The SLT workforce was largely situated in urban areas, with 94% of respondents indicating they were based in a city, large town, or regional center (Wylie et al., 2018). *Limited visiting services to rural or remote areas were noted by 6%* (*n* = *2*) *of respondents, and qualitative data indicated that persons with communication disability traveled to receive services* (Wylie et al., 2018).

Table 2.3 Successes in continuing professional development and support: categories and subcategories with illustrative quotes from participants (*italicized*). Brackets () indicate amendments by the authors for clarity

Local activities	International activities
Visiting training (from another country) • *Once in a while, professionals come from outside (country omitted) to organize (a) workshop* • *We have also done two online (international speaker name omitted) seminars in the past…* • *(Country omitted) being a tourist destination is lucky to attract some international/overseas SLTs*	**International training** • *I am very fortunate to be able to attend workshops in (foreign country)* **International colleagues** • *A large network (of contacts) worldwide* • *…Research work reports obtained from friends from overseas* **International associations** • *…Regular updates about articles from (international professional association)*
Accessible internet and email • *Not challenging for me as I have easy access to the internet* • *Most of my research is on the internet as it is free and easily accessible*	
Mentoring supervision • *Mentorship program* • *Local SLT support meetings* • *Our monthly meetings of SLTs…where everybody is sharing their skills and expertise are great*	
Access to journals • *I also have university access to journal databases* • *Research papers are readily available through…hospital network and Hinari is great*!	
Local colleagues • *…Colleagues who are able to pass on information* • *I feel very fortunate to have…a local colleague*	
Unspecified location of activities	
Conferences • *Looking forward to the upcoming Speech and Language Therapy Conference*	

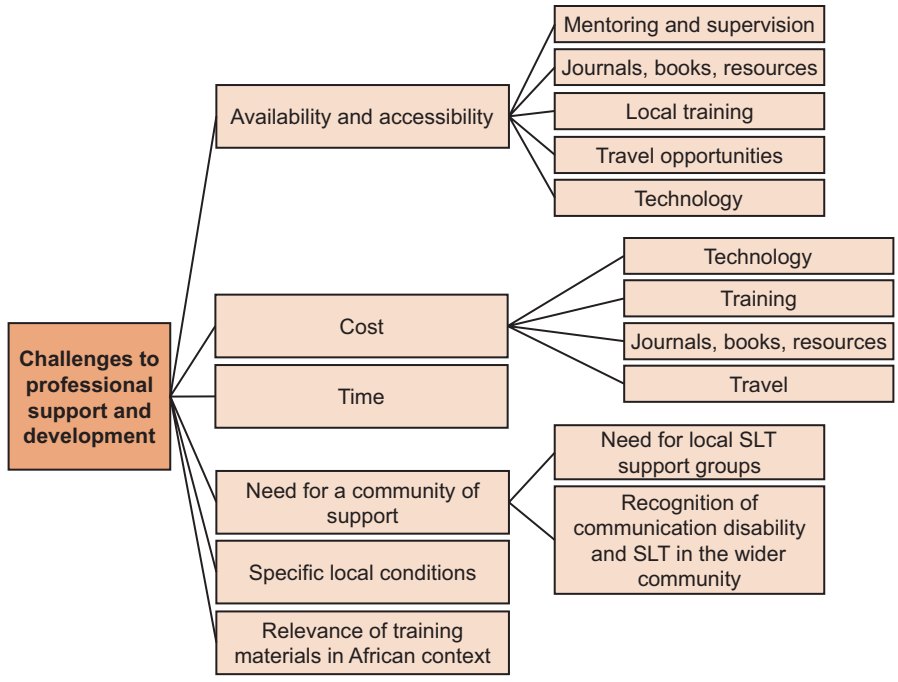

Fig. 2.3 Barriers to CPD: categories and subcategories

Table 2.4 Challenges to CPD and support, by category and subcategory. Illustrative quotes are included *in italics*

Categories	Subcategories and examples
Availability and accessibility factors	**Availability of infrastructure** • *Slow internet speeds and power cuts can be a frustration* • *How do you pay memberships from here*? • *…Unless it is an eBook it is difficult to actually get your hands on*
	Availability of mentoring and supervision • *I am able to discuss with doctors…BUT they are not used to being questioned hence not receptive/successful* • *Experienced therapists are busy with running the clinic and coordinating the course*
	Journals, books, and clinical resources • *There are very few resources concerning* (*persons with communication disability*) • *Limited access to journal articles*
	Local training • *There are limited training sessions here* • *Sometimes I look at relevant courses that would help me professionally but they are very far*
	Travel opportunities • *It is difficult. I have to travel to the UK for any course in speech and language therapy* • *…It is also difficult* (*and not always possible*) *to travel to the capital, where most training sessions are held*
	Technology • *Skype is almost impossible in* (*country name omitted*) • *Limited access to internet* • *Internet is not always working*
Cost factors	**Journals, books, and clinical resources** • *The cost of up-to-date assessments is very pricey so I rarely use official tests* • *… Journal access is very expensive*
	Local training • *Cannot afford to get there*
	Travel opportunities • *I suppose I could pay for online* (*organization omitted*)*-approved materials, but I have a feeling I might then end up going backwards financially*
	Technology • *Emailing is the only option though expensive*
Time	**Time limitations** • *Time to set aside to read due to heavy work demands* • *Due to caseload, no time to write notes, reports, or even read the articles and books etc.*
Need for a supportive community	**SLT community knowledge network** • *…Difficult to keep up to date since our university does not have a speech therapy department* • *It would be great to have a group of SLTs…who meet once a while to exchange ideas and experiences*
	Wider community knowledge • *There are not the local opportunities for continuing education in this field, speech therapy being a poorly recognized field in this country* • *Being a developing country, speech and language therapy is not known to many. Interestingly, health professionals are themselves lacking this information that there are professionals who work with persons with communication difficulties*
Local conditions	**Specific issues** • *Unable to register with allied health professions council* • *The key to the resource room is usually not available*
Appropriate information	**Relevance of information** • *All the information seems so far away and comes mainly from outside Africa*

Economic Barriers: Fee Structures

In previously reported data (Wylie et al., 2018), *SLTs reported that 82% (n = 27) of clinical SLT services charged fees to clients, with almost two-thirds (64%, n = 21) of services requiring fees considered commensurate with private-level fees in that country. Private sector services had the highest proportion of payment with 80% (n = 16) of all jobs reporting clients paying commercial-level fees for services. In contrast, 50% (n = 4) and 20% of government services (n = 1) required commercial-level fees for services.*

Conversely, SLTs reported that the government services charged provided free or low-cost services (80%, n = 4), followed by not-for-profit groups (50%, n = 4) and the private sector (20%, n = 4). This element requires further exploration.

Acceptability

Cultural Distance

Previously reported data from this survey (Wylie et al., 2016a) indicated that one-third of respondents were from non-African nationalities. To examine the concept of cultural distance, which is a subjective perception of the similarity and difference between cultures (Shenkar, 2001), respondents were asked to reflect on their own culture and that of persons with communication disability to whom they would typically provide services. Results are provided by nationality grouping in Fig. 2.4.

Multilingualism and African Languages

Data previously reported on this survey (Wylie et al., 2016a) *indicated that African nationality respondents were significantly more multilingual (median of number of languages spoken 2, mean 3.5) than their non-African nationality peers (median 1, mean 1.7) and that African nationals spoke significantly more African languages, with only two non-African nationality respondents self-reporting fluency in an African language.*

Language of Service Provision

SLTs were asked to indicate the languages typically spoken in the communities they provided services to. The average number of languages commonly spoken within their community, as identified by respondents, was five (median 5, mode 6, range 2–8). SLTs were asked to indicate if they provided services in each of those languages using a range of categories (e.g., work directly in the language; use a trained interpreter; use family or other staff to interpret; work in an alternative language). Categories were clustered into three response types: (a) positive responses (indicating services in that language), including categories for speaking the language fluently, working via family

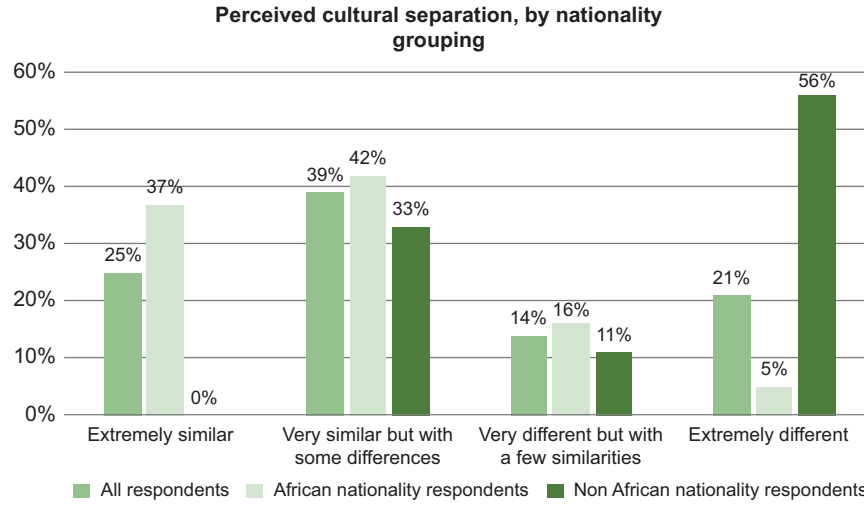

Fig. 2.4 Perceived cultural separation, all data and by nationality grouping

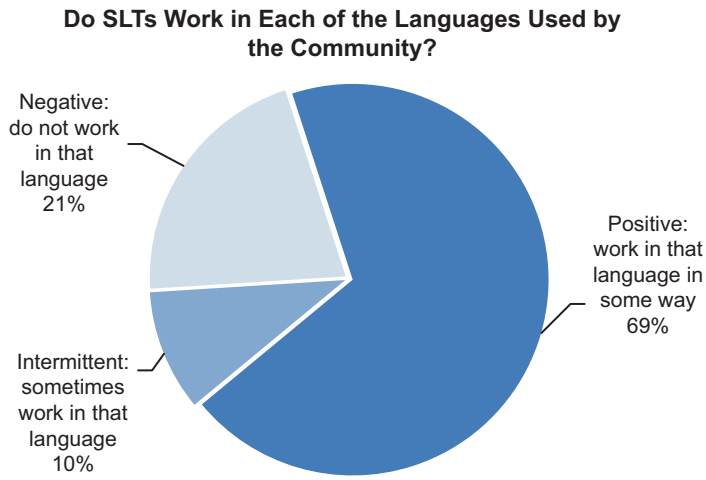

Fig. 2.5 SLT services in languages spoken in the community

or a non-professional translator, and using a professional translator; (b) negative responses, indicating services were provided in another language or services were not provided to individuals who speak a particular language; and (c) fluctuating conditions, with the language sometimes used as part of a mix of languages within an individual's service. No respondent indicated not providing services to clients who spoke a particular community language. Responses are outlined in Fig. 2.5.

Challenges for the Development and Sustainability of Rehabilitation Services for Persons with Communication Disability

In this final section, findings from the workforce survey of SLTs in SSA are discussed in relation to literature on the availability, accessibility, and acceptability of services for persons with communication disability. Major challenges to the development of appropriate and sustainable services for children and adults, their families, and communities in SSA are identified and discussed.

The existing literature and survey findings confirm a paucity of services for children and adults in SSA with communication disabilities. A significant part of this picture concerns the limitations identified within the current services provided by SLTs. It is also of note that there are limited government services that employ SLTs and those services that do exist are mainly centered in urban areas. Existing services are provided mainly by nongovernmental organizations (NGOs), private organizations, or private practitioners. While CBR programs in Africa have sought to respond to the needs of persons with disability within rural areas to ensure involvement of local communities and persons with disabilities, issues concerning the management of CBR programs and coordination of services have been identified (Kuipers et al., 2008). However, while there is preliminary evidence for the effectiveness of CBR programs (Iemmi et al., 2016), further training of CBR workers in supporting persons with communication disability is also required to ensure CBR meets the needs of people with a wide range of disabilities (Nganwa et al., 2013).

As described by Campbell et al. (2013), sustainability issues can be framed through investigation of the *availability*, *accessibility*, and *acceptability* of the services that are provided. Findings from the reported survey of SLTs in SSA provide a baseline for informing understanding of the *availability* of SLT services. Survey results indicate that many SLT jobs are not full time or permanent, although the small percentage of government jobs seem to offer greater stability of workforce and service availability. In addition to the temporary nature of roles, half of the respondents considered that, if they left, their

position would not be maintained. Such data are an important illustration of the lack of sustainability in the structures supporting the development of the profession and influence the availability of rehabilitation services involving SLTs.

If the profession of SLT is to be part of the future of services for persons with communication disabilities, there is a clear and urgent need to both build the SLT workforce and to establish strong structures in employment to ensure availability and continuity of services. Integral to ensuring robust and relevant SLT services is the provision of continuing education and mentoring for SLTs. At present, many SLTs are working in relative isolation, and this contributes to their need for ongoing support. While a number of SLTs reported having mentors from outside of Africa, a substantial proportion of external mentoring may have been supported by a temporary, funded program which was offered during the period of data collection (Marshall & Wickenden, 2018). Questions remain about how such potentially valuable mentoring or support programs can be offered more sustainably in the long term. Further research is required to explore the influence on mentors based outside of Africa (likely to be in HICs) on the practices and processes used by SLTs in SSA. This is of particular importance given the impetus to develop Afrocentric forms of SLT practice and the potential of mentors from HICs to perpetuate approaches in HICs (Pillay & Kathard, 2015).

SLT is a relatively "young profession" in SSA. Continuing education and support for professional development is particularly important to enable continued growth. Access to other forms of CPD is challenging for SLTs in SSA. For example, costs of international conferences are often prohibitive, and existing webinars or workshops may not be responsive to the African context.

With regard to *accessibility* of services, educating more SLTs is only part of the picture and certainly not sufficient. Strategic job creation is necessary. Collaborative planning across sectors and consultation between grassroots communities and government are required if recommendations from the *World Report on Disability* (World Bank and WHO, 2011) are to be enacted. Another key factor related to *accessibility* of services is financing. Services provided by respondents were overwhelmingly in urban settings and were not free or low cost at the point of use. The cost of services, and eligibility for subsidized services, inevitably has an impact on accessibility of services, particularly for people on low incomes.

A key consideration in service *acceptability* is whether health and education information and intervention programs are offered in local languages. Although many community languages were used by respondents and, encouragingly, two-thirds of respondents reported working in local community languages, there is still an urgent need for services to be available across all languages. The availability and cost of interpreting and translation services need to be factored in to provision of services in linguistically diverse communities.

Survey responses record that perceptions of cultural distance are understandably greater among foreign/non-African SLTs. What will be interesting to observe, as new graduates emerge from African universities and SLT grows in SSA, is how the profession of SLT adapts in ways specific to the culture and context in Africa.

Findings from this initial survey highlight workforce challenges that need to be addressed in an integrated manner if services are to be developed in an equitable and sustainable way. Four key issues have been identified and are discussed below:

1. Embedding SLT in the political agenda
2. Developing intervention models that respond to individual/family and population needs
3. Committing to the development of SLTs and community workers in SSA
4. Ensuring cultural relevance

In addressing each of these issues, it is imperative that persons with communication disability, their families, and communities in SSA countries need to be at the heart of these developments.

Embedding SLT and Communication Disability in the Political Agenda

The *World Report on Disability* (World Bank and WHO, 2011) and the recent presentations about communication disability at the Conference of States Parties to the Convention on the Rights of Persons with Disabilities (CRPD; United Nations, 2019) shine a clear light on the need for governments to play a key role to improve public awareness, create change, and develop effective systems to support persons who experience communication disabilities. The side event highlighting issues for persons with communication disability within the United Nations, initiated through the mandate of the International Communication Project (2019), was a key turning point in raising awareness about the need to address the urgent need for communication disability rehabilitation services, particularly in low- and middle-income countries. The WHO Global Disability Action Plan 2014–2021 (WHO, 2015) contains three key objectives focusing on improving access to health services, strengthening rehabilitation systems, and improving comparable disability data. Engagement of SLTs in partnership with persons with communication disability, such as within presentation to the United Nations (2019), should facilitate lobbying for an increased spread of accessible services, toward government or not-for-profit sector provision and away from urban centers.

Such political engagement is vital for any significant systemic change to occur. Government lobbying, in partnership with persons with communication disability, can effect improvement in services, to attempt to make them increasingly available and accessible. An example may include increasing locally filled, permanent, public sector government posts (in health, education, and social care) to provide broadly accessible and equitable services to persons with communication disability, with a focus on training of others in the community, such as CBR workers and teachers, so that they may learn about how to support persons with communication disability and their families.

Prevention and Intervention Models

It is clear that models of service development in SSA should not mimic the "traditional" intervention model used in Minority World countries, for example, a focus on one-to-one individualized treatment by an SLT. The unique contexts in SSA invite creative responses that demonstrate the complementarity of public health and family- and community-centered intervention services for children and adults with communication needs. Central to this response is to recognize and act on the need to decentralize service delivery and to utilize coordinated multidisciplinary teams that link closely with community efforts, such as CBR projects (Nganwa et al., 2013). To reach more of the population, SLTs should consider a broader scope of practice, with a focus on areas including prevention and public health, training and capacity building within the community, activism, lobbying, and awareness raising (Abrahams et al., 2019; Wickenden, 2013; Wylie et al., 2014, 2018, 2020).

Committing to the Development of SLT and Community Workers in SSA

SLTs, with their specialized knowledge of communication, have a role to play in raising community awareness and in training a range of community members to work with persons with communication disabilities, including health workers, CBR workers, family members, and others.

SLTs in SSA need to be responsive to the need to support communities and build their capacity to respond to communication disability. Thus, a challenge exists for SLTs to act as advocates, to train CBR workers and other community members, to carry out awareness-raising campaigns, and to lobby governments. To do this effectively, it will not be adequate to simply transplant educational curricula from Minority World countries with already-established models of service delivery. Professionals in Minority World countries need to

stand ready to support projects *led* by people on the ground in SSA and by people with experience of developing successful, equitable services and training in low- and middle-income countries. Funding for research to evaluate new programs, to establish data on the prevalence of communication disability in SSA, and to develop and explore models of best practice is required to inform the establishment of services focused on need in SSA.

Ongoing professional development programs are required to address the challenges outlined in this chapter. SLT programs in SSA frequently receive international support (Wylie et al., 2016b). "Insiders" and "outsiders" working together have the opportunity to explore creative solutions to ensure the sustainability of existing and future services. All those who are involved in the organization or delivery of ongoing professional support (whether mentoring, books, research, equipment, or short courses) need to critically appraise the appropriateness and sustainability of the supports offered and be willing to reject offers that may not help (Wylie et al., 2016b).

International professional SLT organizations should give serious consideration to the role they play in supporting practitioners from low- and middle-income countries to have an equal chance of accessing CPD, such as short courses and conferences. Listening to the voices of SLTs from the Majority World about challenges and successes, such as the data in the survey reported in this chapter, is a good start. Mentoring programs are vital for all SLTs to receive support from a knowledgeable and locally experienced SLT. Evidence from a recent mentoring project in Uganda suggests that such programs require significant inputs of time and other resources to be successful (Marshall & Wickenden, 2018) and that mentors require specific knowledge and skills in working in Majority World countries to provide relevant support (Rochus et al., 2014).

Ensuring Culturally Relevant Services

Creating a system of rehabilitation that is culturally relevant to the populations they service and contexts in which they operate is crucial. While a knee-jerk reaction to the limited SLT workforce would be the direct importation of SLT training and curriculum from outside of Africa, this would constitute yet another form of neocolonialism (Bleakley et al., 2008; Nixon et al., 2015; Perold et al., 2013) and ultimately offer services which may struggle with acceptability and sustainability. Programs that have been operating in the region, including those in South Africa, where services have long been established, may offer more contextually relevant approaches to training and workforce development, although recent publications highlight issues of neocolonialism in the profession in South Africa (Abrahams et al., 2019; Khoza-Shangase & Mophosho, 2018; Pillay & Kathard, 2015).

A more nuanced approach would be more appropriate, with the emphasis on developing culturally and linguistically acceptable services. First, it would involve building the *knowledge base* of SLTs about the aspects of language and culture that may impact on services for persons with communication disability and their families (e.g., child language development, language socialization, attitudes and beliefs about communication disability, etc.) (Marshall, 2000). Clearly, the graduation of more African SLTs will increase the number of SLTs with local linguistic skills (if they remain in or near their countries of origin). This in turn may increase the opportunities for research into community languages.

Second, it would engender debate and dialogue among SLTs and other stakeholders about the aspects of culture that may require *reconsidering how services are best offered* within the cultural and linguistic context. Strong emphases on cultural responsivity and cultural safety are required. The debate about the most appropriate terminology is outside the scope of this paper but will involve an *ongoing* development of SLTs globally in knowledge, attitudes, and skills in relation to effective cross-cultural practice and dialogue about the best ways to engage with persons with communication disability, to address their needs, and to structure services which are acceptable and appropriate in the context.

Limitations

This chapter synthesizes both original and previously reported data (Wylie et al., 2016a, 2018) to explore sustainability issues for the development of the profession of SLT in SSA. Due to the lack of country-based or regional data on the SLT workforce, non-probability sampling in the form of snowball sampling was used to recruit respondents. Response rates from each country are unable to be determined. There is a risk of selection bias associated with snowball sampling as respondents may have been more likely to be willing to participate if they were familiar with the research team, had easier access to the Internet/email, or had strong professional networks. Due to resource constraints, the survey was presented in English only, which may have influenced participation. Results presented are specific to the sample described and should be interpreted conservatively.

Conclusion

There is little doubt that developments in rehabilitation services for persons with communication disability in SSA are urgently required. Findings from an SLT workforce survey in SSA raise issues relevant to the development of accessible and equitable services for persons with communication disabilities. The data presented within this chapter demonstrate that, for a sample of SLTs in the region, there are a range of workforce challenges that impact dramatically on sustainability of services. Rather than simply increasing the number of SLTs through growth in training, attention also needs to be directed to the variety of workforce-related challenges demonstrated in the data. These include job creation; positioning jobs in equitable service sectors (e.g., government); addressing geographical, financial, and other service barriers; developing effective systems of career paths; and increasing long-term opportunities for support, supervision, and CPD.

Reflecting on the availability, accessibility, and acceptability of services, including how services are organized, funded, located, and provided, is critical if the objective is to offer sustainable and equitable services. Sustainable communication disability services in SSA may ultimately emerge in ways that differ from services in Minority World countries and adopt a wider view of rehabilitation and multidisciplinary and multi-sectoral practice that will be likely to include training and capacity building with others, activism, awareness raising, and public health/prevention (Wickenden, 2013; Wylie et al., 2014, 2018).

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3

Maximizing the Benefits and Minimizing the Risks from the Contribution of "Outsiders" to the Development of Services for Persons with Communication Disability in Sub-Saharan Africa

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Motive

Many speech–language therapists (SLTs) from high-income countries – "outsiders" – are motivated to help develop services for persons with communication disabilities in low- and middle-income countries. The chapter provides information that will assist outsider and "insider" SLTs to work positively together. A brief background to SLT work in low- and middle-income countries, focusing on sub-Saharan Africa (SSA), is given. Three sets of data are presented: a written dialogue between an insider and an outsider SLT, fictitious case examples of insider/outsider collaboration, and data from a study of insider/outsider SLT collaboration in Uganda. These data sets are used to generate considerations/recommendations to maximize the benefits of future SLT insider/outsider collaborations.

Introduction

In this chapter, we concentrate on the role played by outsider SLTs who work in low or middle-income countries, in order to consider how to maximize the benefits and minimize the risks, of outsider SLT contributions. For the purposes of this chapter, we have defined an "insider" as a person or institution native to and operating within a low- or middle-income country. We have defined an "outsider" as a non-native person or institution operating within a low- or middle-income country. The reason outsider and insider were selected as appropriate terminology (as opposed to, e.g., "African" and "non-African") is that the terms needed to be specific enough to fit the context while also remaining wide enough to encompass the internal complexity and heterogeneity of each group.

We hope that this chapter will provide useful insights and increase mutual understanding for outsider SLTs considering working in low- and middle-income countries and for insider organizations and individuals in low- and middle-income countries, who work with outsider SLTs. We hope that it will provoke reflection in outsider SLTs who have already worked in low- and middle-income countries and for their low- and middle-income country hosts. We acknowledge that some SLTs from low- and middle-income countries might also be outsiders from another low- and middle-income country, but we have not addressed the possible different issues that may apply to that group in this chapter.

Background

The development of services for persons with communication disability in sub-Saharan low- and middle-income countries has been documented for the past five decades (Hartley, 1998). These services have not been delivered exclusively by SLTs; services for persons with communication disability in sub-Saharan Africa (SSA) have also been provided by professions including teachers, special educationists, community-based rehabilitation workers, etc. (Hartley & Wirz, 2002). These are generally more established professions compared with SLT, which is a relatively new profession in SSA.

SLT services in SSA, while growing in size and scale, have typically served only small sections of the population (Barrett, 2010), often around major cities, where wealth is more abundant and health care more accessible. Elsewhere, in high-income countries such as the UK, Australia, and the USA, the proportion of the population served by SLT services is much higher, with more SLT personnel and significant

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diversification within the profession. Typically, there have been small numbers of SLTs working in many of the countries of SSA (Wylie et al., 2016). These SLTs have included outsiders (who may be expatriates/immigrants or volunteers working on short-, medium-, or long-term placements) and, in smaller numbers, insider SLTs who are indigenous and have traveled abroad to qualify as SLTs (before returning to practice locally) or, in more recent years, trained in-country, on newly developed SLT education programs.

Looking broadly at the topic of insiders/outsiders working to provide services for persons with communication disability in low- and middle-income countries, the literature has historically been dominated by outsiders' experience of working internationally: a narrative of European benevolence and expertise, contrasted with local ignorance and passivity (Wilson & Van Gilder, 2011).

Over the past 15 years, there has been a shift in some low- and middle-income countries from an outsider-dominated service model toward a more collaborative approach. Due to the perceived lack of sustainability of services for persons with communication disability that are provided by tiny numbers of outsider SLTs, collaborative educational programs for insider SLTs have begun in several SSA countries. These include Uganda's Makerere University, which began educating SLTs in 2008 (Barrett, 2010; Barrett & Marshall, 2013), with the first cohort of SLTs graduating in 2012. This program arose from a collaboration between outsider SLTs, an outsider institution and a nongovernmental organization (NGO, Voluntary Service Overseas [VSO]), and insider institutions, namely, the Ugandan Ministry of Health and Makerere University. Similarly, programs have started in Kenya, at Kenyatta and Moi Universities (Association of Speech and Language Therapists Kenya, 2016), and in Ghana, at the University of Ghana. In Mozambique, an SLT education program has been developed in collaboration with universities in Mozambique and Portugal (Velho et al., 2015). The profession in Ethiopia has expanded from outsider-led short-term SLT trips (Domsch, 2012) to the development of a training program (Transforming Faces, 2016). A course is also being planned in Rwanda (Crowley et al., 2013; University of Rwanda, 2016). Personal communication also suggests several SLT programs have been established and closed after a few years, such as in Zambia. Even where there has been success in implementing collaborative SLT training programs, graduates may have to work at translating theory into appropriate local practice (Pickering & McAllister, 2000).

Although the benefits of such outsider-led contributions to services for persons with communication disability may appear obvious (such as intervention where there is apparently no one else able to provide it), Domsch (2012) suggests that there are many potential risks that need to be considered. Considering the risks specifically of outsider volunteer work, Hickey et al. (2012) raise ethical concerns about such work, identifying the following points:

1. Projects may focus on providing an attractive volunteer experience rather than addressing local needs.
2. Poor preparation from outsiders may result in a risk of persons with communication disability being unintentionally harmed, through inadequate clinical practice or poor service delivery.
3. Poorly planned or administered services risk undermining broader (potentially long-term) relationships between insiders and outsiders.
4. The neocolonial assumption that clinical approaches common in high-income countries can be imported wholesale into new contexts (with no regard or adaptation for differing culture and differing infrastructure) is both culturally imperialist and clinically ineffective.

Understanding risks can facilitate reflection on how to minimize them. For example, Hickey et al. (2012) suggest that potential outsiders should be screened in relation to the risks listed above. Outsider training may also reduce the risk of inadequate preparation, therefore reducing the risk of ignoring local concerns and needs. There is some professional literature guiding SLTs from

high-income countries on how to prepare for work in low- and middle-income countries (ADAPT, Communication Therapy International and OT Frontiers (2014); the Speech Pathology Association of Australia (2015)). In the UK, the National Health Service has published a toolkit for outsiders and their hosts to collect reflective data on outsider placements (Longstaff, 2015).

Hyter (2014) suggests that outsiders can work toward minimizing risks and maximizing the benefits of support services for persons with communication disability by developing responsive global engagement. Hyter's recommendations for reducing this outsider risk include developing strong collaborations with insider colleagues and building knowledge of the unique cultural and political local context. The collaboration between outsider and insider can also make use of cultural interpretation, whereby each party seeks to work together to identify, understand, and work with their cultural differences, in order to deliver more effective services (ibid.). Hickey et al. (2012) also suggest that reflection on the relative positions of power and privilege can also allow an outsider to avoid causing risk through neocolonial, patronizing, or self-serving attitudes. Furthermore, Stephens et al. (2015) suggest that research should focus on the concerns of insiders within a community and acknowledge local knowledge and structures, rather than defaulting to the views of outsiders.

Understanding of this complex area of insider/outsider collaborations is incomplete. By presenting three sets of writing, the authors hope to contribute to increasing this understanding. Part 1 is a written dialogue between two expert SLTs, a low- and middle-income country insider and a high-income country outsider; Part 2 is made up of four fictitious examples of insider/outsider collaboration; and Part 3 presents selected data from a recent study on insider/outsider SLT collaboration in Uganda. In the final section, the authors use the learning from Parts 1–3 and the background literature to develop a set of considerations/recommendations to help maximize future SLT insider/outsider collaborations. The authors have relied not only on their own insider/outsider collaborative experiences but also on those of many colleagues and friends, both insiders and outsiders, with whom they have worked, observed, emailed, written letters to, and shared many cups of tea.

Part 1: A Written Dialogue Between Two Expert Speech–Language Therapists

In this part of the chapter, the first two authors pose a series of questions to one another, about SLT insider/outsider collaborations. Their answers principally reflect their views and experiences – although they do not claim to have all the answers and they have also drawn on others' experiences and opinions.

The two authors worked together for 3 years. Julie Marshall is a British-born and trained SLT who has been teaching and researching about communication disability for over 30 years. She has worked in SSA for periods ranging from 10 days to 2.5 years, teaching, training, researching, and supporting colleagues who are developing services for persons with communication disability. The second author, Nana Akua Owusu, is a Ghanaian-born SLT who was educated as an SLT in the UK and who lived and worked in the UK for 24 years. She has worked as an SLT in Ghana since 2007, where she established an NGO; is a partner in a private SLT/audiology clinic; and is involved in disability issues and collaborates with other stakeholders to raise the profile of the needs of persons with communication disability. She led the newly established SLT Master's program, in the School of Biomedical and Allied Health Sciences at the University of Ghana.

Julie: *What has been your involvement with outsider SLTs while you have been working and living in Ghana?*

Nana: Since returning to Ghana in 2007, I have worked as an SLT and encountered many volunteers, mostly outsiders. I have a number of different roles in which I encounter outsider volunteers. They include being the founder

of AwaaWaa2 (an NGO assisting children with communication disabilities); being a member of Inclusion Ghana (an umbrella organization for persons with intellectual disability) and of the Cleft Lip and Palate Management Group at Korle Bu Teaching Hospital in Accra; and working in a private speech and hearing clinic and as a clinical tutor at the School of Biomedical and Allied Health Sciences, University of Ghana. I have worked with many outsider professionals, including SLTs, physiotherapists, occupational therapists, special needs teachers, academics, and others with legal, policy, and organizational management expertise. Their levels of experience range from new graduates up to those with many decades of experience. Some outsiders come as individuals and others with organizations, and they stay for varying lengths of time, ranging from a week to a year.

They have assisted with a range of activities, from the formulation of policy and organizational development to implementation and evaluation of projects. My involvement with volunteers has been varied and has shaped my views and perspectives about insider/outsider collaborations. I have, however, sometimes wondered whether there are hidden reasons why anyone, especially a young person, would leave the comfort and security of their home and country and go and volunteer in a place about which they know nothing.

Nana: *I'm interested in your ideas about outsiders' reasons for volunteering in low- and middle-income countries.*

Julie: This is an interesting question. I am not sure that every outsider deeply examines their motives or is necessarily honest with themselves, let alone others, about why they want to work in a low- or middle-income country. Motivations appear to range widely and include the (outwardly at least) very altruistic intentions, religious reasons, a wish to travel with an added purpose, a desire to understand their profession in a different context, to have an adventure, to occupy themselves usefully while their partner is working in a low- and middle-income country, or as a stepping stone in their career. I do not regard most motivations as problematic, provided the person is honest with themselves and that they think carefully about (a) how that motivator might influence their work expectations/activities and (b) what they should tell their insider hosts. I become more concerned when outsiders see working in a low- and middle-income country as an opportunity to escape an unhappy life/life event. It is natural and healthy to want to make changes when life has been challenging, but it is very important to consider whether working and living in a very challenging and unfamiliar environment and in isolation from friends, work colleagues, and family is fair on your new colleagues, on your clients, and on yourself.

Julie: *What have been the biggest challenges for you in receiving outsider volunteer SLTs working with and for you in Ghana?*

Nana: I work in the only public SLT service in Ghana, and, if we have an outsider visitor, we often have to close that service for up to a week, in order to spend time with the visitor. Clients may travel long distances and may not receive cancellation messages and so they waste time and money traveling to Accra. The SLT department also loses money, as clients pay a contribution toward the services they receive. Unreliable Internet service, power, transport, and other system failures regularly interrupt work that has been planned in advance and impact upon planned work with outsiders. Such dis-

ruptions, uncommon in countries such as the UK, can make insiders appear not to be "up to the job" or able to work to strict timelines. In Akan, we say, "*ye di nam na eyi nam*" meaning "you need meat (as bait) to catch (fresh) meat." These challenges need to be understood and overcome, as they are the bait for bigger and better services.

"Fly in and fly out missions" pose a challenge to the local SLT service. Local contact with outsider SLTs who come with such missions is usually minimal. Clients often wait for the next mission for follow-up or, alternatively, might appear for an emergency appointment at a local SLT clinic. Outsider SLTs working on projects such as these should liaise with and understand local services in advance, in order to serve clients better. Many outsiders would not accept the kind of service in their own countries that they are prepared to provide in low- and middle-income countries.

Equally challenging are outsiders who arrive with very little knowledge about the country or host organization but who want to implement new ideas in very short time frames and/or require someone to be with them as they work, because they lack confidence in a new environment, appropriate language skills, and cultural competence. It is challenging to meet such needs for attention, without negatively impacting the very services that the volunteer is there to improve. Some of these challenges point to the need for insiders to work more closely with outsiders and to prepare them adequately before they arrive.

Nana: *How do outsider SLTs from the UK typically prepare for working in low- and middle-income countries, for example, how do they select the organizations and countries, and how do they learn about the country and organization for whom they will work?*

Julie: In my experience, of being an outsider volunteer and of training, advising, and supporting SLT outsiders before, during, and after their international work, there is a vast range in the amount and type of preparation that people do. Some SLTs see working in a low- and middle-income country as part of a medium- to long-term plan. They think about what kinds of work and continuing professional development (CPD) opportunities in their own country might best prepare them to work in a low- and middle-income country. They learn about international development, particularly relating to disability and the politics of international aid, and about low-resource setting work; they read academic literature in the field and learn about where and how SLTs have worked in low- and middle-income countries. They familiarize themselves with specific cultural, political, linguistic, health, education, social care, and other issues related to the country in which they will work. They try better to understand the history of the relationship between their own country and where they plan to work (for many, this includes learning about colonialism, slavery, racism, etc.). They understand that critical evaluation of the sending and host organizations and the specific job for which they are applying, are important. This leads to early communication with the host organization, about the organization's expectations of the SLT's role and potential achievements. Additionally, this communication can result in guidance about appropriate resources for the SLT to bring.

At the other extreme, some outsiders simply decide that they would like to "go abroad." Someone from an orga-

nization with whom they have a connection (often a church or a small charity) may invite them to volunteer. The sending/host organization may not be familiar with the role of an SLT and what is feasible for an outsider SLT to achieve, particularly in an isolated setting. Neither the outsider SLT nor the sending/host organization may have thought about how sustainable the proposed work is nor what an SLT could realistically offer in a country that may be unfamiliar to them: where people speak languages that they do not know; where there may be no multidisciplinary team and limited diagnostic equipment/services; where people are unfamiliar with SLT; and where carers may not typically play with children. They do not find out about the history of SLT involvement in the country (or similar countries) or the other issues outlined above.

Ready access to the Internet and social media means that there is no excuse for not finding out as much as you can!

Julie: *Do you have any advice about how outsider SLTs should best work with host organizations, before, during, and after work in a low- or middle-income country?*

Nana: Outsiders and their insider host organization must start communication early and keep it going until their arrival. Both should set time aside to discuss mutual goals and work together to prepare an orientation and exit plan for the outsider's visit. The outsider may have to prompt this, as some organizations may not be familiar with doing so. It is helpful if the outsider learns about the country and the host organization. In my experience, volunteers involved in clinical work should aim for a minimum stay of a month, while those assisting with policies and administration could do a couple of weeks. Arrival and departure dates should be jointly negotiated and not imposed, and the outsider may request to be picked up and helped to settle in. Having local phone numbers, email, and a local phone also help.

It is important for the outsider to follow the jointly devised plan for the visit and control the impulse to make major changes after meeting new locals and others. Be bold enough to ask questions and clarify anything that is not clear. Outsiders should ask the staff at the host organization to check that others can understand the outsider's accent and what they say. Set up regular meetings with key members of the host organization, to evaluate and give feedback and to discuss any changes in plans. It is important for outsiders to be honest about their knowledge, skills, and experience and to resist the urge to take charge; rather, use the opportunity to build local capacity. Be patient with any conduct or attitude that is difficult or feels unacceptable. Regular meetings with the host organization should be used to discuss how best to deal with them to enable work to progress.

Local guidelines on photos or videos should be respected, even if they are needed for a visitor's portfolio. Host staff should be included and involved in any blog or tweeting that refers to work at the organization. Accept any invitations by staff to social functions, as it is a great way to learn more about the country and its culture. Finally, the collaboration should be jointly evaluated following the visit, and it is important to maintain active links with the organization, including helping future outsiders to prepare to work with the host. Stay on their WhatsApp platform or use other modes of contact.

Julie: *What are the resource implications for host organizations, of having a volunteer from a high-income country?*

Nana: Resource implications for the low- and middle-income countries vary, depending on whether one outsider or a group is visiting. A first visit usually takes considerable local resources, in terms of staff time, often taken up by the initial preparation for hosting and once the outsider(s) arrive. Making time to communicate with the outsider, sending information, agreeing dates, helping to identify suitable accommodation, arranging pickup transport, and contacting local organizations where the outsider(s) may visit as part of orientation, may also have financial implications.

When an outsider is not visiting to carry out clinical services, then clinical services may need to be cancelled. When large groups of outsider students visit, for example, as part of a clinical internship, organizing the clinical program creates a considerable administrative burden. Clients have to be contacted well in advance, by telephone. Many pay for the cost of travel, as well as for the SLT, as it is not covered by the national health insurance. Availability of clinical space can also be a challenge when large numbers of clients are invited in all at once. Although a few outsiders may come predominantly for their own benefit, it is accepted that the costs of supporting outsiders should be seen as the "little sacrifices" that insiders make to encourage an outsider with significant knowledge, skills, and expertise in a particular area of need and who may have left a comfortable environment to assist with service provision for little or no monetary reward.

Nana: *What could locals do to improve their relationships with outsider SLTs?*

Julie: Once an outsider arrives, if your organization has the capacity to do so, offer support and tips for survival (accommodation, shopping, travel, leisure). Give them ideas about how to entertain themselves over long weekends – what is safe, interesting, and affordable to do? If you feel comfortable, invite them to your home. Try to help them to understand something about what life is like for the insiders in the host organization. Make implicit aspects of the culture explicit. Take them to your home by the same form of transport that you use to get to work. Explain if your organization pays tiny wages and everyone has three jobs in order to survive. Who do you support or care for in your family and what does that entail? Tell them about whether you have consistent access to water, electricity, and a bathroom and Internet access. Explain all this, and then they may understand why sometimes you are tired, arrive at work "late" and go home "early." Instead of thinking you "aren't up to the job," they might be amazed by the number of balls that you juggle! Similarly, find out about your outsider's life and for whom/what they are responsible.

Ensure that the volunteer knows what resources have been and are being used to support their presence. Set up regular supervision and agree its rules. Have explicit discussion about what both sides want to achieve from the partnership and what is required from each partner. Set goals with measurable outcomes.

Try to look at your work as an outsider might and then share with and explain to your visitors any behavior that you imagine might be puzzling, upsetting, or irritating to them. Organizations will build their wisdom about this the more that they do it. Talk to your outsiders about how you would like them to behave if they see practice that they do not agree with. Finally, share with them

any linguistic, language socialization and broader cultural practices and beliefs that might impact on the success of their probably high-income country-centric understanding of intervention.

Julie: *What are the behaviors/qualities that you think are most important for an outsider SLT, in order to maximize the chance of working successfully with colleagues in sub-Saharan Africa?*

Nana: Volunteers must be honest about their competence, what they think they can realistically achieve, and draw up clear boundaries before the label of "super-therapist" is conferred upon them. It is important to be able to remain flexible, calm, and patient when the power goes off, just when you were about to print those individually selected pictures for a parent. Be quick to come up with alternative plans for a happy conclusion.

Know how to work independently while recognizing when support is needed. It is important for outsiders to have the cultural competence to help them make the desired impact. Many Ghanaians think it is rude to say they do not understand when they know you are trying to assist them. So, they will listen and smile at the right times but do nothing you asked them to do because they simply did not understand what you were asking of them. As long as your actions show good intentions, it is accepted that you mean well and that you are planning something positive. It is important for outsiders to recognize when clients struggle to express themselves in English and so are unable to ask questions or make comments.

Volunteers need strong interpersonal and communication skills, together with a sense of humor and a spirit of boldness, to ask questions that will challenge clients to open up. Clients connect better when professionals show genuine interest, for example, by sympathizing about the distance traveled and the long wait before being seen. Finally, the least valuable traits are being "all-knowing" or superior, being a poor listener, inflexibility, and showing pity without actual support.

Nana: *What do you think are the biggest challenges for outsider volunteers?*

Julie: It may seem obvious, but culture shock can be huge, and it applies to all aspects of life. Frequently, the most significant impacts are not the obvious things such as language, food, and dress codes. They need opportunities to develop their cultural understanding and competence, and someone acting as a "cultural bridge" can help a lot. Loneliness can be a big challenge. Working out what outsiders can offer and what is realistic can be hard. For many of us, learning to watch, listen, be patient, and not to try to change things we do not understand and instead waiting for people to ask for support, are huge challenges.

Julie: *What do you consider to be the best ways for host and outsider volunteers to maximize the chances of volunteers' contributions being sustainable?*

Nana: Agree and write down goals and intended gains from the partnership at the start of the project. Set up times to review goals. Be clear on what you intend to teach or impart at the beginning and how you hope to measure any outcome at the end. Share this and plan together how to measure impact. Learn to understand how things work in the local area and adjust advice, methods, and ways of working to suit the environment. Make sure you have the support of the person in charge or the most influential person in the team to further explain and sell any new idea

or way of working and to be able to ensure its continuity even after outsiders depart. Share an exit evaluation session together; exchange what has been challenging and positive for both parties; and give ideas on how hosts might tackle any outstanding issues for future volunteers and vice versa. This process can be extremely useful and revealing. Agree renewed guidelines and review processes on how to carry on with a project or any new ideas introduced.

Make some effort to stay on the organization's WhatsApp platform or any other means they are using to keep members informed about various happenings at the organization.

Nana: *How do you think an outsider's contribution should be evaluated?*

Julie: If, as Nana has suggested, joint goals are set when the outsider arrives, then it is easier to evaluate the impact of the outsider's work. If possible, set up a dual evaluation: one in a format that the volunteer is familiar and comfortable with and one using a format with which the organization is familiar and comfortable. That provides familiar information, as well as opportunities for people to learn new ways to evaluate. Ask for the opinions (with evidence) from as many different groups as possible (balancing that with the effort and resources that this activity might use). It is possible to think about evaluation from various perspectives, including the impact on the host organization, specific individuals in the organization, persons with communication disability and their families, other professionals, the public, policymakers, the sending organization, the outsider's home country employer, and the individual outsider's knowledge, skills, and attitudes. Finally, having evaluated the impact of the outsider's contribution, decide what changes can or should be made in the future and set them into motion.

Julie: *After an outsider SLT has left a project, are there things that outsider SLTs and hosts could do to ensure a mutually acceptable continued relationship?*

Nana: Both parties should agree on how they would like to remain in contact. Assign a named person in the host organization to ensure that the volunteer is updated about new developments. Outsiders can also update themselves on the organization's Facebook page or website. Take advantage of modern technology and keep each other updated on the continued gains and challenges of what has been planned together. Outsiders who maintain good contact often act as a real source of information for other volunteers who may want to visit in the future.

This conversation has highlighted a number of key considerations for insider/outsider working.

Part 2: Fictitious Case Examples of Insider/Outsider SLT Collaboration

In this part of the chapter, the authors draw on their own and others' experiences of insider/outsider collaboration, to generate four fictitious case examples of SLTs from high-income countries working in low- and middle-income countries, two of them more successful and two less successful. These illustrate some of the pitfalls, benefits, and consequences of outsider work.

A Successful Example of an Outsider Joining an SLT Education Program in Sub-Saharan Africa

A country in West Africa has ten SLTs who have qualified outside their country. There is a small, but powerful, organization of persons with communication disability, their carers, SLTs, and other professionals that support persons with communication disability. They persuade the Ministry of

Health that in-country education of SLTs is needed, as it should be designed to meet the needs of their country and its health, linguistic, cultural, and social context. Funding is obtained to design a curriculum, to identify assumptions and risks about the program, and to map out, more than 2 years in advance, what external support is needed to upskill the existing SLTs and to supplement their capacity to run a program until several cohorts of local graduates are working. Clear role profiles are created for each external visitor, and outsiders are interviewed by local SLTs and university staff. Outsiders are given orientation reading (covering the topics suggested in Part 1) and are required to contact previous outsider visitors and to prepare some of their work before they arrive. They watch interactive videos of the students in workshops and in clinical education settings, in order to develop awareness about students' levels of knowledge, skills, and learning styles and the context of typical placements. Outsiders are encouraged to sign up for two visits and, for the first visit, to shadow a more experienced outsider as an "apprentice." Each outsider is also assigned a local mentor. Each visit is evaluated by the local team and the outsider, and development plans are agreed and actioned jointly.

An Unsuccessful Example of an Outsider Joining a Service Delivery Project in Sub-Saharan Africa

An SLT qualifies in the UK, aged 26, and works for a locum agency as an SLT for 6 months. She decides to "go abroad" for a year before "settling down." A friend fundraises for a charity supporting a small day nursery for children with disabilities, in Tanzania. When her friend hears she wants to work abroad, she is delighted and emails the charity, who immediately says "please come and work for us." She flies to Tanzania 2 months later, having saved 2000 GBP and with lots of donations of therapy toys and old assessments from SLT clinics in the UK. She is the nursery's first SLT, and they tell her that many of the children do not talk. The children have been exposed to a number of languages, but not English, and none of the nursery staff speak English fluently, apart from the manager. Many of the children have cerebral palsy and feeding/swallowing difficulties, but staff and parents seem resistant to feeding advice, for instance, to position children differently. It is hard to work with the children, as the SLT only speaks English. Instead, she decides to write some advice leaflets about communication (based on parent-child interaction therapy) and feeding. After 6 months, her money has run out and, reluctantly, she resigns. She returns home, reporting that she had a great time. The leaflets stay in the nursery as most of the parents cannot read, and those who can are bemused by the idea of playing with their child and do not have the time or money to feed their child who has cerebral palsy differently from how they have always done it.

A Successful Example of Bringing SLT Students in from a High-Income Country to Volunteer Short Term in a Sub-Saharan African Country

A high-income country university has engaged in a global exchange program and now arranges for students to receive part of their practical training in an NGO for children with disabilities, in Rwanda. Students go on placement for 4 weeks in their penultimate year, when it is expected by the university that they will have sufficient skills, knowledge, and experience to benefit their host. Detailed discussions to set objectives for host and students take place with the students' representative and a named contact in the host organization. The university runs orientation sessions, including inviting previous volunteers. The host agrees how many students it can support and when they will come. It assists students in arranging local accommodation and meets and settles them on arrival. An orientation session takes place at the host center, with opportunities for familiarization. They observe insider SLTs, assess and work with clients on day 1, and swap places with the insider SLTs from day 2. There is a 30-minute debriefing

session at the end of each day, and each group notes down new learning points. Students are on placement for 3 weeks. One week is devoted to visiting other organizations, learning about the country, and engaging in other social activities. A general meeting of all students and host staff takes place jointly to evaluate the collaboration. Host and volunteers complete an evaluation to assess their time together and make development suggestions. The evaluation is shared with the university and informs the next visit. A continuous flow of students each year ensures continuity and effective collaboration.

An Unsuccessful Example of a Fly-In-Fly-Out (FIFO) Short-Term Project

One of a handful of local SLTs, serving a population of approximately 26 million people, receives general information on a WhatsApp platform about an organization coming in to offer free intervention to clients with cleft lip and palate. Clients are recruited from particular areas in the country and are asked to assemble at certain locations, to be bused to a center for surgery. Publicity information only makes reference to surgery and not to SLT. Two weeks after seeing the notice, the SLT receives an email from an outsider SLT on the FIFO team. The outsider SLT expresses a wish to meet and invites the insider SLT to a training program at a town some 3 hours' drive from where insider SLT lives. Accommodation or transportation costs to the training venue are not offered. The SLT cannot attend and is offered another chance to meet with the outsider SLT at more central location, but is unable to attend. The outsider team complete their visit and leave. The local SLT has no idea what happened to any of the children seen by the FIFO team or who might require SLT. Later, a bag of resources is left by the FIFO team for the local SLT. Some 8 months later, the local SLT encounters a client who benefited from the FIFO surgery but who has considerable speech needs. This client knows nothing about the SLT services available and is waiting for the next FIFO visit.

The four examples above illustrate some of the ways in which well-intentioned collaborations may be more or less successful.

Part 3: Insider/Outsider Research in Uganda

In this part, the third author (Ryann Sowden) reports on selected findings from her PhD study: "An investigation into the perceptions of 'outsider' contributions to sustainable services for people with communication disabilities, in Majority World countries" (Sowden, 2018).

Background

The overall aim of this study was "to explore, describe and interpret the process and perceptions of the development of services for persons with communication disability in Majority World countries, with a particular emphasis on the contribution and roles of 'outsiders'." The study was split into two phases, with the first phase being a case study based in Uganda. In this chapter, we draw on data generated to achieve one of the research objectives, "to interpret insiders' perceptions and experiences of the contributions of outsiders and outsider support," to explore the risks and benefits of outsider contributions to services for persons with communication disability in Uganda.

This topic is important as outsider contributions to (and insider/outsider collaborations in) Majority World countries occur in many different ways, often with little sharing of outcomes. There is a need to record and understand the range of perspectives and views about the perceived effects and effectiveness of these approaches. Uganda was chosen as an appropriate research setting because it has a long history of outsider contributions to services for persons with communication disability and because there was an opportunity to reflect on ongoing outsider-led projects in the country.

Methods

This research was qualitative, and data were collected using semi-structured interviews with 14 Ugandan stakeholders (SLTs, student SLTs, faculty staff, NGO coordinators, parents of persons with communication disability) and 9 outsiders (SLTs, teaching staff, and NGO coordinators). Interviews were conducted face to face, by telephone, and using Skype. The interviews focused on outsider involvement in development of services for persons with communication disability (historically, currently, and anticipated). Interviews were transcribed verbatim and analyzed using thematic network analysis (Attride-Stirling, 2001) and supported by the use of NVivo software (version 10.2.2). Thematic network analysis is a form of thematic analysis in which themes are organized into a hierarchy, made up of basic, organizing, and global themes. These are arranged in a network in a web-like diagram to summarize the main themes (Attride-Stirling, 2001).

Seven thematic networks were produced from data from the 23 interviews: 3 for insiders and 4 for outsiders. In order to focus on risks and benefits for this chapter, the three insider thematic networks were revisited, searching specifically for what Ugandan (insider) participants said about the risks and benefits of outsider contributions. Initially, the interview transcripts were searched for the terms "risk" and "benefit" and revealed two mentions of "risk," only one of which was relevant. This concerned one insider's view that outsiders may not have the skills or experience to work in an educator role to pass on information and knowledge effectively. The word "benefit" did not appear anywhere in the insider transcripts.

The organizing themes of all three insider thematic networks were then searched using the lens of risks and benefits, in other words, looking for their synonyms as well as specifically for the words "risk" and "benefit." Exploration of these three insider thematic networks revealed that the global theme "mother-child relationship" contained organizing themes that were relevant to risks and benefits. It is therefore this global theme that is presented in this chapter.

Results

The global theme "mother-child relationship" explores the relationship between insiders and outsiders. This network covers the tensions of insider/outsider relationships. The metaphor of "pulling ropes" was used by one participant to describe this tension, which was often also described as being similar to the mother-child relationship. Such comparisons represent power struggles, the need for Ugandans' independence from outsiders, and how outsider support is experienced by insiders.

The "mother-child relationship" global theme has three organizing themes, with six basic themes below them. Figure 3.1 illustrates these themes. The three organizing themes are explored briefly, and then risks and benefits that were referred to in these organizing and basic themes are described in relation to:

- Ugandan persons with communication disability.
- The provision of services for persons with communication disability.
- Ugandan professionals.

Although there are data relating to risks and benefits for outsiders, these have not been included unless there are direct consequences for Ugandan people or services.

Organizing Theme 1: "Unstable Support"

This theme suggests that outsider support is seen as transient and unstable. This is because outsiders generally do not stay in Uganda long term. As such, outsiders have a reputation for a lack of commitment to partnerships, and their support is typically viewed as inconsistent and not making a difference.

Organizing Theme 2: "Developing Relationships"

This theme describes how having a wide network of insiders and outsiders is seen to increase the amount of support available to insiders. A wide network appears to provide greater potential or increase the likelihood of future opportunities for

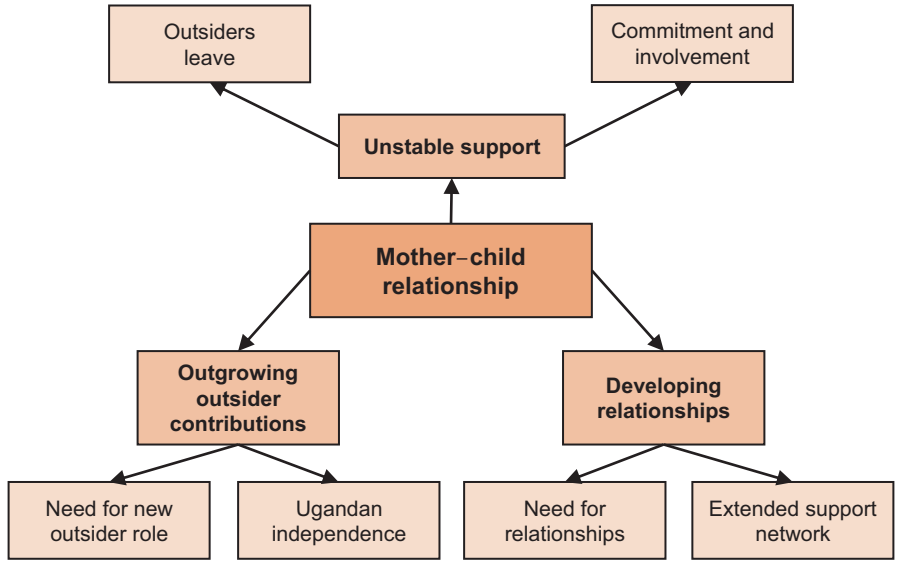

Fig. 3.1 Insider thematic network "mother-child relationship"

jobs, further study or resources, as well as personal support.

Organizing Theme 3: "Outgrowing Outsider Contributions"

This theme reveals that insiders see achieving independence from outsiders as natural. Although outsiders are welcome to contribute, Ugandans feel that Ugandans should lead the future of services of persons with communication disability in Uganda.

Risks

Risks to Persons with Communication Disability

Participants considered that there is a risk that outsider intervention will make no difference to persons with communication disability. This may be through inappropriate identification of communication disability, following an inappropriate assessment, or the use of inappropriate resources.

> So what happens is a foreigner especially a *mzungu*[1] comes in and doesn't really give that help … a *mzungu* comes with … different resources – bubbles and all that … they will only leave that impact on them – you brought fancy things – bubbles.

Risks to Ugandan Services

The main risk identified was a lack of sustainability and consistency that threatens the development of the SLT profession and services. This was partly due to a shortage of outsiders. Where outsiders were available, the Ugandans had little input into which outsiders they wanted, what skills they wanted from them, or when/if outsider programs of support ended.

> So sometimes there was a gap. The challenge before is like those ones who would come in because they would give like a period of six months, eight months something like that, so these people they would go before we did exams!

Risks to Ugandan Professionals

Ugandan SLTs discussed how persons with communication disability and their carers would often prefer an outsider to a Ugandan SLT.

> So if you put someone – you and I doing the same work [with] patients and we have two different rooms, patients will line up more [for] you than for me here in Kampala … they actually choose.

[1] *Mzungu* is Kiswahili for foreigner or stranger.

Benefits

Benefits to Persons with Communication Disability

Participants felt that outsiders were an integral part of developing the SLT program at Makerere University.

> [Outsiders] definitely helped us run this program which is a very clear success with graduated students … they will very soon improve the service in this country.

Outsiders were considered to have helped to increase the number of SLTs in Uganda who are culturally aware and adapted to a Ugandan setting. This, in turn, helps increase the number of persons with communication disability able to access appropriate SLT services.

Benefits to Ugandan Services

Ugandans expressed a preference for longer-term outsiders.

> Certainly, people who come because they want to give, tend to have a longer commitment … Even when they go, they are looking for others who can come … they are looking for support, they are writing back … it makes it better. It's better if they come for a longer time, all other things being constant: they are planning, they are fitting in with the other people.

Outsiders who worked long-term in Uganda were considered to doubly benefit services for persons with communication disability: first, by being more familiar with the local culture and, second, by offering consistency.

Benefits to Ugandan Professionals

Ugandans felt that appropriate continuing professional development offered by outsiders for Ugandan SLT graduates helped develop their skills.

> People who … are new, they don't know exactly what they should do … they are still crawling, they are not yet standing, so if those people come and help us stand, and help us walk, I think it will be better!

Discussion

The risks and benefits identified suggest a range of views and/or experiences and perhaps some ambivalence about outsider input. It may be challenging to avoid or minimize some of the risks of insider/outsider collaboration, for example, some clients' preference to receive support from outsider rather than insider SLTs. This is somewhat supported by findings from previous research looking at Kenyans' attitudes toward white volunteers in Kenya, that indicated that Kenyans perceived white volunteers to have superior knowledge and experience, as well as more resources (Lough & Carter-Black, 2015). They also perceived organizations of white volunteers to be more trustworthy (ibid.).

Some views may be influenced by politico-historical power differences. Cultural competence and consistency of support are important considerations for future collaboration.

Recommendations and Considerations for Future Insider/Outsider Work

The written dialogue, fictitious case examples, and research data, in addition to the literature reviewed earlier, all strongly emphasize the need for outsiders to be aware of how their presence may affect insiders. We conclude this chapter with a number of recommendations for maximizing outsider contributions to the development of services for persons with communication disability in low- or middle-income countries. These are divided into suggestions for low- and middle-income country host organizations and outsiders to do together, responsibili-

ties for host organizations, and responsibilities for outsiders.

Low- and Middle-Income Country Host Organizations and Outsiders Should:

- Establish communication as early as possible before an outsider arrives.
- Agree clear, written goals for collaboration and plan ahead.
- Be honest about agendas, motivations, commitment, goals, and expectations.
- Do not assume that *any* outsider help is better than none.
- Challenge stereotypes.
- Resolve differences before they become damaging.
- Consider sustainability at every step.
- Establish regular review meetings.
- Agree evaluation processes and resulting recommendations.
- Agree on how/if to maintain links after an outsider leaves.
- Use social media collaboratively to increase learning and awareness.

Low- and Middle-Income Country Host Organizations Should:

- Set up an orientation plan for outsiders and provide information about the organization: vision, mission, how it started, activities, achievements and future goals, protocols for working, and where the organization sits relative to similar local and national groups.
- Assign a named individual to support the outsider.
- Create a welcoming environment and ensure all staff are aware of the outsider's arrival and role.
- Aim to learn from the outsider, rather than relinquish all responsibility and power because an outsider is seen as an expert and more competent than the host organization's staff.
- Arrange some social/fun activities with/for the outsider.

Outsider SLTs Should:

- Critique any invitation received to work as an SLT in a low- or middle-income country, including the length of visit requested.
- Read everything possible about the country, the culture(s), the history, the development politics, the policies, etc.
- Seek to determine if SLTs are wanted/needed and, if so, by whom, for how long, and on what basis.
- Find out about present and past services for persons with communication disability, their success, or otherwise.
- Learn from others who have worked in the same or similar situations.
- Respect the resources devoted to supporting outsiders and the other demands on hosts' resources.
- Listen, watch, and ask questions – before proposing any changes.
- Be flexible.
- Keep aims modest – do not promise what cannot be delivered.
- Ensure that ideas and resources are useful and sustainable and that insiders know how to take ideas, make them sustainable in a local context, and gradually work more independently.
- Work out how to compromise and what are deal-breakers (and why).
- Share successes and failures with future outsiders, to ensure continuity and to accumulate expertise.
- Consider if/how support can continue to be offered after the end of a visit.

Truly open, trusting, and collaborative relationships between outsiders and host organizations and individuals have the potential to improve services for persons with communication disability and their families in low- and middle-income countries. Continued dialogue, with shared learning and reflection, should allow everyone to continually learn from one another and to improve SLT practice and its impact.

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4

Clinical Competence of Speech-Language Therapists in Culturally and Linguistically Diverse Contexts: A Qualitative Study of Intercultural Work Experiences Abroad

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Introduction: Service Delivery in Culturally and Linguistically Diverse Contexts

> As the global community becomes closer, the education of all speech–language pathologists (SLPs) must be relevant to this new world order of a multicultural and multilinguistic client base. […] SLPs need to develop culturally and socially responsive clinical skills and to become culturally competent communicators. Cultural competence goes beyond knowing the language used by the client; it involves establishing trust and listening to the concerns of the client. (Cheng et al., 2001, p. 121)

In an era of globalization and related worldwide migration, the mobility of people has increased along with the uncertainty experienced by individuals. In light of these interrelated phenomena, encounters and interactions with foreigners have now become commonplace, and this is also true in the work experience of speech–language therapists (SLTs). Hence, the educational as well as the health system in the realm of speech–language therapy (SLT) has to deal with this issue professionally to secure service delivery in culturally and linguistically diverse (CLD) contexts. The challenges that arise from CLD contexts are located on two levels: the external and the internal. On the external level, diagnostic and therapeutic materials mostly do not exist for minority languages (Schütte & Lüdtke, 2013). Another external issue would be the therapist's lack of knowledge regarding the structure and developmental processes of the minority language. On the internal level, we locate intra- and inter-psychological processes like feeling alienated because of differing communicative rules or the occurrence of misunderstandings. Kristeva (1991) examined the psychological aspects (and related emotional processes) when foreigners meet with the term "strangers," including "internal and external strangers." We use Kristeva's concept of "strangeness" to reflect on the challenges of working in CLD contexts as an SLT in this chapter and offer a short excursus on this concept in section "Theoretical Background: Diversity-Sensitive Clinical Competence and Its Acquisition".

One way to include the challenges of CLD contexts in the SLT profession would be to cover this topic in the training curricula. However, how could we implement the internal level of challenges in particular in a viable SLT curriculum? This is the question we try to answer in this chapter by presenting our findings from a qualitative study that emphasizes the importance of intercultural experiences acquired abroad by SLT students for fostering diversity-sensitive clinical competence (DSCC) in working with "strangers." Given that the study was the outcome of a collaboration between Tanzanian and German researchers, we focused especially on experiences in these two countries relating to the cultural and linguistic diversity in each.

Cultural and Linguistic Diversity Due to a Natural Broad Heritage of Indigenous Languages: The Case of Tanzania

Tanzanian society has been multiethnic and multilingual from the beginning. A survey conducted to assess the linguistic situation in Tanzania found that over 120 ethnic languages are spoken in the country by about 53 million people (Simons & Fennig, 2018). The languages spoken by those ethnic groups represent four major African lan-

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guage groups: the Khoisan (known for the "click" consonants), Nilotic, Cushitic, and Bantu languages (Kimambo & Temu, 1969). The Sandawe and Hadza in northern Tanzania speak Khoisan languages, whereas traces of Cushitic languages are found among the Iraqw (or Wambulu) and Mbugu groups. The Tatoga (also called the Mang'ati), Wataturu, and Maasai are descendants of Nilotic speakers, while most of the ethnic groups in coastal, western, and eastern Tanzania are Bantu-speaking populations (Odhiambo et al., 1977).

Despite the tremendous linguistic diversity that exists among Tanzanians, Kiswahili is the predominant language in terms of the number of speakers who speak it as a second or third language (Rubagumya, 1990), and it serves as the political lingua franca as well. It is, however, noteworthy that although a large population across the country speaks Kiswahili, a very small population speaks a "pure" version of the Kiswahili language. The majority of speakers still code-mix and code-switch with their ethnic languages or English. Generally, the separate population groups preserve and apply their languages and customs within their social realm. Therefore, Tanzania is evidently a land of genuine ethnic, cultural, and linguistic diversity. This particularity needs to be considered from the outset within the relatively newly developing Tanzanian SLT profession in terms of its service delivery. An external challenge for this highly diverse context is the lack of appropriate diagnostic and therapeutic materials for all languages—even for those with a large number of speakers. Internal challenges could also occur when people from different cultural contexts interact, such as when a Kiswahili-speaking SLT from Dar es Salaam counsels an Iraqw mother from the Arusha region speaking Kiswahili code-mixed with the Iraqw language. These challenges might also result from different living conditions in urban and rural areas, but they could still interfere with communication during counseling.

Cultural and Linguistic Diversity Due to Recent Migratory Movements: The Case of Germany

The German Federal Office for Migration and Refugees (Bundesamt für Migration und Flüchtlinge [BAMF], 2020) recorded a population of approximately 21.2 million people with migrant backgrounds in Germany in 2019. This figure represents 26% of the total German population. More than half of this group of people are German citizens. On average, they live in Germany for more than 21 years (BAMF, 2020). For example, a large Turkish population arrived in Germany in the 1960s to work; they stayed and began a new life. An increase in 2015 can be explained by the arrival of numerous asylum seekers due to several crises in the world (e.g., the Syrian war). The number of applications for asylum rose in 2015 by 135% compared with the previous year (BAMF, 2016). In 2019, the main languages spoken in bilingual German households were Arabic, English, French, Italian, Polish, Russian, Spanish, and Turkish (BAMF, 2020). These languages come from fundamentally different linguistic families and use three different writing systems.

Consequently, CLD is increasingly being discussed within German society in recent years and requires individual professional reflection in light of this new situation and consideration. These social changes affect service delivery in SLT. The expansion of a clientele with diverse cultural and linguistic backgrounds in speech and language clinics or private practices in Germany has been reported (see, e.g., Benholz et al., 2016). However, the overall shift from a monolingual to a multilingual habitus (Schütte & Lüdtke, 2013) in the SLT workplace is a slow process because the traditional monolingual and monocultural perspective has prevailed in Germany for decades. Students and clients from diverse cultural and linguistic backgrounds are still treated in a manner that has been tailored for monolingual German speakers (Schütte &

Lüdtke, 2013; Schütte, 2018). This seems to be consistent with the perception of multilingualism as being associated with linguistic deficiencies, given that an understanding of differences in equality has not yet evolved. Therefore, clarification and information on these topics is of primary importance.

Dealing Appropriately with CLD in the SLT Profession: The Global Perspective

Despite differing conditions in Tanzania and Germany, namely, the former's implicit multilingual history and the allegedly monolingual history of the latter, the SLT profession in both countries faces similar challenges in having to deal appropriately with CLD in the work context. Global attempts have been made to change the situation. Some countries have a number of SLTs from CLD backgrounds (see Barratt et al., 2012; Bellon-Harn & Weinbaum, 2017; Southwood & van Dulm, 2015) along with a repertoire of appropriate multilingual assessment and intervention methods for this field of work. For example, the United States' migrant history could be placed in the middle of the two extremes of Tanzania and Germany. From the beginning, its national identity has been defined by migratory movements. Although patterns of immigration are shifting, from largely European immigrants in the early twentieth century to more Hispanic and Latino immigrants in recent years, there is a longer tradition in the United States in the research and teaching of bilingual language development. In 1995, the American Speech–Language-Hearing Association (ASHA) founded Special Interest Group 14 "Communication Disorders and Sciences in Culturally and Linguistically Diverse Populations" to advance knowledge in the field of CLD. In 2010, the ASHA created a self-reflection checklist for the cultural competence of SLTs (ASHA, 2010). Basically, recognition of the importance of diversity-sensitive competences has increased worldwide (Crowley et al., 2015; Leadbeater & Litosseliti, 2014). Nevertheless, external and internal challenges for service delivery in CLD contexts remain in most countries. In this chapter, we focus on the latter by examining internal emotional challenges.

This leads to this chapter's guiding question: How can an SLT acquire diversity-sensitive competences that guide him/her to treat or teach persons with communicative disabilities who are bilingual and/or have a different cultural background? Before we try to answer this question by presenting our empirical study, we investigate what DSCC could look like as a part of the SLT's individual professionalization (see section "Theoretical Background: Diversity-Sensitive Clinical Competence and Its Acquisition"). To illustrate this, we present a qualitative research study on the self-reflections of SLT students and practitioners on their work stays abroad (see section "Constructivist Method: Relational Biographical Self-Reflections"). Finally, we discuss how the results of this study (see section "Results") could be transferred and support the professionalization and service delivery of SLT in CLD contexts in SSA (see sections "Discussion and Study Limitations" and "Recommendations for SLT Curricula Worldwide").

Research Findings on Work Stays and Diversity-Sensitive Competences in SLTs

One way of strengthening intercultural competence—or, to be more precise, diversity-sensitive competence—could be through work or study stays abroad. Numerous studies have shown that stays abroad influence the personal as well as professional development of diversity-sensitive competence and facilitate greater proximity to what aroused feelings of alienation before. Lee et al. (2012) have provided evidence that studying abroad strengthens complex cognitive processes underlying creative thinking. Moreover, a study by Nguyen (2017) found an increase in individuals' intercultural competence after a short period of study abroad. Ballestas and Roller (2013) and Richards and Doorenbos (2016) have demonstrated the effectiveness of a study abroad program in increasing the cultural competence of students in the health disciplines. In the field of SLT in particular, there are only single reports about the

effects of stays abroad (Crowley & Baigorri, 2011; Johnson & Hitchins, 2011) and a few research-based studies that mainly rely on students' self-reported affective benefits (Stanford & Gay, 2017).

Lüdtke et al. (2003) were among the first scientists to consider the impact of work stays abroad in the context of SLT based on systematic research. In their constructivist methodological approach, the authors generated findings based on the guided reflection of their own emotional experiences in a foreign country. They argued that shifting away from an ethnocentric habitus toward a culturally sensitive perspective cannot be achieved by gaining purely theoretical expertise (e.g., through a literature review). Instead, a holistic change—and reconstruction of the professional personality—is needed. In their study, the authors emphasized that it is necessary for prospective SLTs to acquire and analyze experiences in a foreign country by questioning and reflecting on their own emotional processes involved in intercultural work encounters. In the context of such stays in "foreign countries," it becomes essential for them to identify their own ethnocentric and mono- or bilingual habits. In particular, Lüdtke et al. (2003) stressed the importance of shifts in perspective through processes of deconstructing the professional identity, which are eventually initiated within the intercultural conflicts that arise.

In section "Theoretical Background: Diversity-Sensitive Clinical Competence and Its Acquisition", we offer a definition of DSCC, which is the competence needed in the therapeutic treatment or teaching of persons with communication disabilities from CLD backgrounds. We embed this competence in the other professional competencies an SLT should acquire in their individual professionalization.

Theoretical Background: Diversity-Sensitive Clinical Competence and Its Acquisition

Clinical Competences in SLT in CLD Contexts

"Competence" is a broad term that can be understood from different perspectives associated with particular academic disciplines. In our specific didactic context of SLT, we refer to the basic relational language didactic model proposed and adapted to the context of CLD by Lüdtke (2012, 2017) (see Fig. 4.1). It is a "relational" model

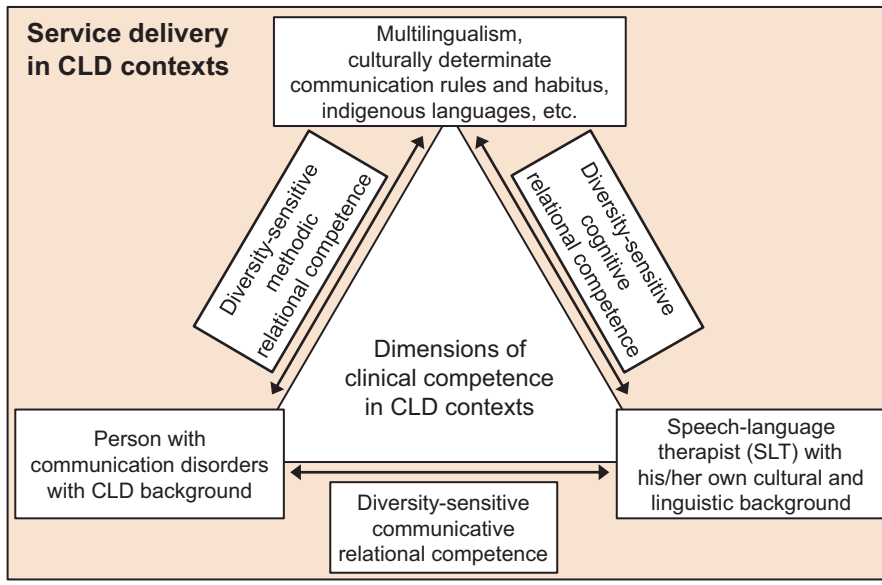

Fig. 4.1 Triangle of relational language didactics in culturally and linguistically diverse contexts focusing on diversity-sensitive clinical competence (Based on Lüdtke, 2017)

because it is based on a philosophical and psychological approach that focuses on the felt or unconscious relational emotions and sociopolitical, cultural, and historical contexts of the interacting subjects—SLTs, clients, and students. The emotional processes and contextual conditions of the setting of SLT service delivery are seen as crucial and constitutive factors of didactic situations (see Lüdtke & Polzin, 2023).

As stated above (see section "Introduction: Service Delivery in Culturally and Linguistically Diverse Contexts"), in the context of globalization with an emphasis on inclusion, SLTs have to manage the challenges of increasing diversity and encountering clients or students from CLD backgrounds, which may cause external and internal challenges to arise. We want to explicate the kinds of internal challenges (such as feelings of irritation, alienation, and rejection) SLTs face by referring to Kristeva's (1991) concept of "strangeness" before outlining our understanding of DSCC.

Excursus: *Strangers to Ourselves*—**Strangeness in Kristeva's (1991) Psychoanalytic Approach**

In her book *Strangers to Ourselves*, Kristeva (1991) described the experience of meeting other people from different cultural backgrounds from a psychoanalytic perspective. In service delivery in CLD contexts, SLTs experience these situations in different ways (e.g., in their clients' different models of thinking and acting, as well as in their different appearances) that can lead to feelings of alienation and further rejection or avoidance. Kristeva described this situation in general (not specifically for SLTs) and the possible feelings of alienation associated with it (e.g., "I am feeling insecure and confused about the way this person talks to me") as a construction that is an integral part of the inner Self—an "internal stranger" as opposed to the "external stranger" (who is the actual other person). The "Other"—as the internal stranger—is subsequently incorporated into the individual's own "unconscious" (Kristeva, 1991, p. 183). Thus, the "internal stranger" is created through the mechanism of repression, which needs to be revealed and reversed through reflection (see Fig. 4.2). The feeling of "strangeness" or alienation should be reflected on constantly and not suppressed. Ultimately, whether the "external stranger" induces a reaction of anxiety or an active involvement with the irritation of strangeness lies within the individual. The outcome is mostly based on how familiar each individual is with their own Self (Kristeva, 1991, p. 191).

What is experienced as being "foreign" and "strange" is determined by an individual's history and their personal and social identity (Schäffter, 1991, p. 12). This implies that the

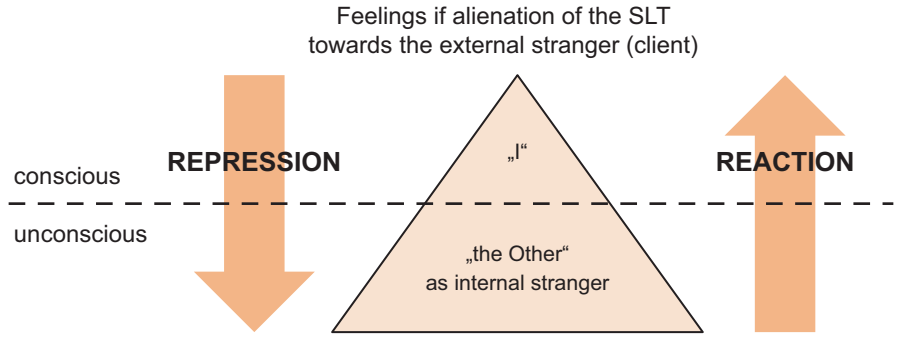

Fig. 4.2 Processes of repression and reaction when SLTs meet clients as external strangers

"internal stranger" is always re-experienced (Ntourou, 2006, p. 61) in encounters. In the SLT context, students or clients with CLD backgrounds—from within one's own country or abroad—can be viewed as one manifestation of the "internal stranger" of the SLT. Such a perception is determined by different biographical factors such as the SLT's acquired personal and professional experiences and his or her professional ability to self-reflect. This ability is part of the DSCC we present in the following:

The relational didactic model tries to encompass these complex sets of competence. It reflects on the three points of the triangle in Fig. 4.1. These constituents form the crucial aspects of teaching, treating, and/or learning language within a CLD context (Lüdtke, 2017). The constituents are interdependent in the process of teaching, treating, and learning and reciprocally influential:

1. The first constituent describes a *person* from a culturally and linguistically diverse background with communication and/or language disorders. This includes the person's mind, emotions, and linguistic and sociocultural background.
2. The second constituent describes the *SLT* and his or her cultural and linguistic background. This includes the biographically and/or professionally acquired competences in contact with CLD, his or her feelings about and attitude toward CLD, and knowledge about other languages and cultures apart from his or her own.
3. The third constituent refers to *languages* and forms of communication (e.g., the person's first language and the local language, the mismatch of languages, and the multi- vs. monolingualism of a client).

The SLT needs to combine effectively the components in the triangle of relational language didactics from which clinical competences are derived (Lüdtke, 2017). These competences should be seen as reciprocally related and not independent of each other:

1. Cognitive relational competence entails profound interdisciplinary knowledge of how didactic therapeutic decisions are linked to the linguistic specifics of the language learning process. A *diversity-sensitive cognitive relational competence* includes cultural knowledge about specific ethnic groups, a country- or region-specific knowledge, and culturally based theoretical knowledge. Further, this competence embraces knowledge about the existence and impact of cultural differences as well as cognitive abilities to reflect on self-constructions and other "foreign" *constructions* of reality. This requires the individual to self-reflect on their own culturally inflected attitudes and behavior. *As an SLT working with a child with a different and not entirely familiar cultural and linguistic background, you need to ensure that therapeutic content is (emotionally) meaningful for the bilingual child in relation to their cultural and linguistic identity and reflect on that.*
2. Methodic relational competence entails the ability to apply acquired techniques in given language learning contexts when dealing with individuals who have communication and language disorders. *Diversity-sensitive methodic relational competence* encompasses an extensive repertoire of various codes of communication and resolution strategies along with the ability to use each of these in culturally appropriate ways. Among other things, this includes a comprehension and appreciation of different communicative forms of expression. This entails direct personal communication between the SLT and the student/client in a professional context. *As an SLT working with individuals from CLD contexts, you should consider the bilingual environment, the individual's social position within this environment, and their developmental level regarding both languages when you decide on methods and ways of communication* (Isaac, 2002).
3. Communicative relational competence entails the ability of the SLT to make and maintain an appropriate dialogical connection with the client. This competency facilitates the progress of an affective relationship with the client, which supports the pedagogical or therapeutic process. *Diversity-sensitive communicative relational competence* includes the

ability to empathize and have emotional open-mindedness toward different perspectives and tolerance relating to the ambiguity of cultural conflicts. Key components of these competences entail an ongoing consideration of the contradictions between an individual's own system of values and the "strange" ones of personal feelings of alienation. *Within the context of CLD, as an SLT, you should be interested in students' or clients' stories regarding their attitudes and emotions relating to their own multilingualism. This openness can serve as the basis for reliable cooperation.*

In this chapter, we focus on the reflective part of these three constituents of DSCC because we understand reflection to be an essential element of the SLT's acquisition of DSCC for working in CLD contexts, whether the reflection of "other" and "own" constructions of reality, communication styles, or emotions involved when working with clients from CLD contexts. Further, we explicate the acquisition of DSCC in connection to individual professionalization.

Acquisition of Diversity-Sensitive Clinical Competence

When individuals belonging to different cultures interact, not only can the feeling of alienation interfere with the process of service delivery but so too can different individual experiences, ways of thinking, and behavioral patterns, which can lead to misunderstandings and misinterpretations (see Bührig & ten Thije, 2006). Each partner in the communication considers his or her worldview to be the only appropriate one (Spencer-Oatey & Franklin, 2009). Ethnocentrism plays a particularly influential role in intercultural encounters. Hence, an individual perceives his or her own culture as the measure of all things, which is also then applied in relation to other cultures. This is where the DSCC comes into play, enabling an individual to change his or her own point of view and take on another perspective in professional SLT contexts. Intercultural encounters in which new things can be experienced, some of which are unexpected and irritating, can be a basis for critical self-reflection (Crago et al., 1997). This does not just include the realization of these irritations but also an attempt to discover the underlying causes. Knowledge that is appropriately integrated leads to more tolerance of "external strangers" and a reduction in ethnocentric attitudes (Ott & Michailova, 2018), whereas unprocessed as well as fragmented knowledge might lead to misunderstandings and strengthen prejudices.

Here, we consider the ideal acquisition of reflective DSCC with reference to the developmental model of intercultural sensitivity (DMIS) created by Bennet (1994, 2004). We applied the DMIS as a template and adapted it to the SLT context. The DMIS is based on the constructivist approach and can be divided into the following six stages: (1) denial, (2) defense, (3) minimization, (4) acceptance, (5) adaptation, and (6) integration. These occur within broader ethnocentric and ethnorelative stages (see Table 4.1). The modified model describes the different stages in terms of the professionalization of SLTs, first, as it applies to the acquisition of DSCC and, second, as it applies to the potential promotion of cultural understanding. We see the acquisition of DSCC as a part of the individual professionalization process of SLTs. These processes are dynamic and permeable as opposed to being chronological and fixed.

Circular Process of Professionalization of SLTs in the CLD Context

Processes of understanding between "others" and "oneself" are always processes of self-formation and self-education (Wulf, 2003). Using work stays abroad as a way to strengthen DSCC, our study—presented in the following section—is based on a circular process of DSCC acquisition as part of professionalization in the CLD context, subdivided into four steps (see Fig. 4.3):

- SLTs worldwide face the challenge of an increasing number of students/clients from

Table 4.1 Levels of reflective DSCC acquisition of SLTs in CLD contexts. Adapted from Schütte (2016)

Stages	Levels of reflective DSCC	Description	Prototypical phrases of SLTs about their work experience in CLD contexts
I. Ethnocentric stages	1. Denial	Communicative diversity does not exist: • Denial of communicative differences • Stereotyping	*Children from CLD backgrounds do not need specific instruments for assessment and treatment of language development disorders*
	2. Defense	An individual's own communicative behavior is experienced as the best way, whereas another communicative behavior is perceived as a threat: • Awareness of communicative differences that are negatively judged • Devaluation of communicative differences	*Children from Turkey cannot learn the use of articles in the German language because these do not exist in the Turkish language*
	3. Minimization	Communicative diversity is no longer perceived as a threat but rather as being almost similar, whereas the communicative point of reference depends on the particular individual: • Awareness of superficial communicative differences • A perception that everybody communicates like the individual, interpreting linguistic signs in the same way	*In order to help my students/clients with CLD backgrounds better understand me, I pronounce words clearly and speak slowly*
II. Ethnorelative stages	4. Acceptance	The SLT's own form of communication is no longer the center of the world, with a corresponding increased interest shown in other forms of communication demonstrated by: • Valuing communicative differences • There is no good or bad—only different • No blind adoption of communicative expressions	*Naeku often uses Maasaii words during practice sessions. That is a good opportunity to converse with her about her village life*
	5. Adaptation	Extension of the SLT's own repertoire of thinking and acting demonstrated by: • Flexibility predominating in contrast to other categories of communication • Increasing competencies with the handling of other forms of communication (and one's own) are evident • Adoption of another communicative perspective	*To work effectively with children from CLD backgrounds, I have to change and adapt my methods*
	6. Integration	Adoption of different communicative perspectives and points of view demonstrated by: • Development of the SLT's communicative identity • Integration of elements from different cultural forms of communication • Being cultural and linguistic communicative mediators • Self-reflection	*When I greet Mrs. Takahashi, the mother of a Japanese student, I try to provide a self-reminder not to extend a hand in greeting*

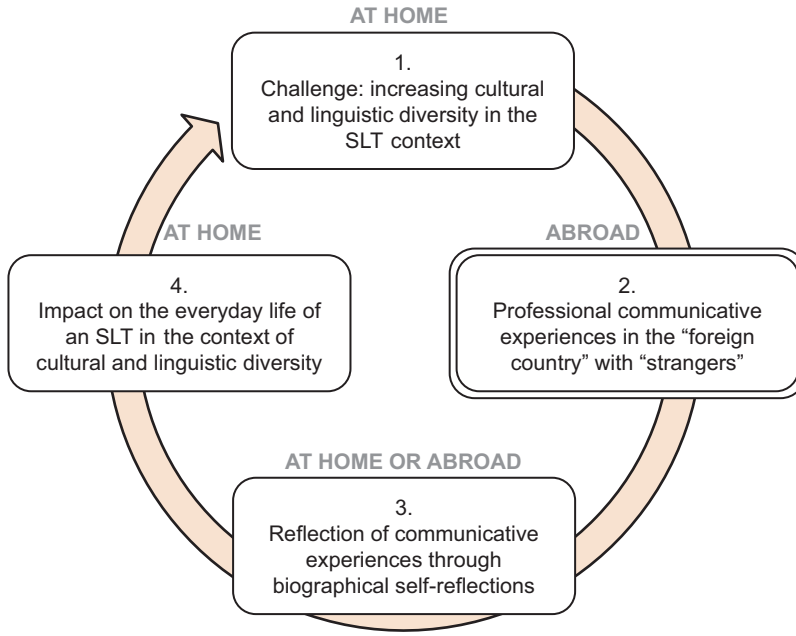

Fig. 4.3 The circular process of SLT professionalization in the CLD context focusing on diversity-sensitive clinical competence. (Adapted from Schütte, 2016)

diverse cultural and linguistic backgrounds in their daily work practice (Guiberson & Atkins, 2012; Schütte & Lüdtke, 2013; Southwood & van Dulm, 2015).

- Due to the exposure to "strangers" and a feeling of alienation in a foreign country during work experience abroad, the SLTs themselves become "strangers" in an unknown cultural and linguistic environment (Kristeva, 1991). Being abroad, the safety net of using own communicative habits has to be abandoned.
- Confrontation with a disconcerting experience can be processed instructively within the scope of biographical self-reflection, for example. A reflexive state of consciousness can be achieved.
- This, in turn, leads to various impulses prompting a possible transfer of the communicative intercultural experiences into the everyday life of an SLT in the context of CLD.

The participants in the qualitative research study described in the following section underwent this process of professionalization. In this study, the participants engaged in self-reflection on their difficult intercultural experiences during their work stays abroad. We explicate the method and results by focusing on two participants: one SLT from Germany and one SLT from Tanzania. Each has acquired experiences in the other's respective country. Because none of the other study participants had such counterparts, these two individuals were selected as illustrative case studies.

Constructivist Method: Relational Biographical Self-Reflections

In this section, we outline the qualitative research study on work stays abroad, which is based on Lüdtke et al. (2003), v their influence on DSCC acquisition.

Research Questions

For this study, we identified and analyzed the communicative intercultural encounters of SLTs who had studied or worked abroad between 2012 and 2014. Specifically, we explored their diverse experiences in a foreign country with foreign col-

leagues or clients, and the significance of these experiences for their individual professionalization, through the following research questions:

- What are the main themes raised by SLTs when reflecting on their challenging experiences during a professional stay in a foreign country?
- To what extent does their reflection on experiences with "strangers" in a foreign country allow SLTs to develop their DSCC and their individual professionalization?

Research Method and Design

The present study was developed based on the initial concept of Lüdtke et al. (2003) and strengthened with a qualitative design because the intention was to obtain insights into how the study's participants made sense of their experiences with the "stranger" in a foreign country. In the area of education and health care especially, it is crucial to understand people's experiences from their own perspectives (Atieno, 2009; Flick, 2014; Liamputtong & Ezzy, 2005). This understanding is not easily investigated through quantitative research.

Participants

The sample comprised 14 SLTs (11 women and 3 men, 13 from Minority World countries and 1 from a Majority World country), who were either practicing or still studying in Turkey, India, Tanzania, or Germany. The duration of their work stays abroad ranged from 7 weeks to 3 years. We attempted to portray a wide range of cross-cultural experiences through the inclusion of Minority and Majority World countries as work stay destinations.

Individuals who expressed a willingness to participate in the study were recruited. The selection criteria were the duration of the work stay abroad (with a minimum of 3 weeks) and an affiliation to the SLT profession as a student or practitioner.

Instruments

Qualitative research designs are interpretative and ethnographic in nature and are based on different philosophical approaches. Hence, there are diverse qualitative research methodologies. We chose the following methods for data collection and data analysis because they fit well with our relational approach. Both methods help to include emotional processes and the subject's relationship to the context and other people (Lüdtke, 2012).

Relational Biographical Self-Reflections for Data Collection

Relational biographical self-reflections are self-reflections with biographical elements and are rooted in a constructivist paradigm[1] (Lüdtke et al., 2003). The main aim of conducting biographical self-reflections is for the individual to develop an understanding and realization of their own communicative experiences from which new possibilities for communicative acts could be derived (Lüdtke et al., 2003). In this study, the biographical self-reflections on communicative behavioral patterns relating to intercultural conflicts should be questioned (and possibly extended) as well as integrated into new communicative patterns. This kind of professional analysis and reflection of intercultural encounters will help to understand that many misunderstandings with students or clients from different backgrounds are culturally determined. The SLT interprets these encounters from his or her own social, institutional, and cultural background (Lüdtke et al., 2003).

Qualitative Content Analysis for Data Analysis

The self-reflections were analyzed using qualitative content analysis (Mayring, 2000, 2014). Qualitative content analysis is defined as an empirical methodology that allows for a controlled analysis of texts within the context of their communication. With this instrument, key themes can be identified to answer the research questions. Specific rules are applied for analyzing content (e.g., analyzing the

[1]For a recent introduction to the constructivist paradigm, see Ayukawa (2020).

material step by step, following procedural rules, and organizing the material into analytical units) without engaging in rash quantification (Mayring, 2000). The core aspect of the analysis entails the establishment of categories to which the sections of interpreted text are assigned. These categories are carefully developed and revised during the process of analysis (see section "Data Analysis").

Data Collection

Following the methodology developed by Lüdtke et al. (2003), the biographical self-reflections—which were produced in a written form by the participating SLTs—were divided into four phases. The constructivist stages of knowledge (deconstruction, reconstruction, and construction) served as a guiding framework.

Following Lüdtke et al. (2003), we applied the following scheme for this process:

- *Phase 1—Deconstruction*: In this phase, the individual describes a communicative intercultural conflict in a professional, but culturally different, context, and the spontaneous emotional experience is described. The reflecting person has the chance to become aware of the need to remove self-constructed boundaries to culturally different ways of communication.
- *Phase 2—Reconstruction I*: In this phase, the individual describes similar conflictual communicative experiences they previously experienced in their own culture. The individual has the chance to understand that cultural communicative differences are based on his or her own standards.
- *Phase 3—Reconstruction II*: In this phase, the individual compares the communicative discrepancies between the foreign culture and their own culture. He or she has the chance to develop an awareness of their own standards. Personal values can be compared with the communicative cultural differences that are experienced.
- *Phase 4—Construction*: In this phase, the individual is asked to transfer his or her insights from the comparison of cultural differences (phase 3) to their work or study in SLT. He or she has the chance to establish an additional value and to move toward a shift in perspective.

For clarification purposes, we present excerpts from two biographical self-reflections in the following sections. The first biographical self-reflection is that of Husani,[2] a Tanzanian SLT student who studied in Germany. The second biographical self-reflection is that of Claudia, a German SLT student who took part in a Tanzanian-German research project.

Husani's Biographical Self-Reflection

Husani is a Tanzanian SLT student who spent 3 years in Germany studying SLT at a German university. Husani's communicative intercultural conflict occurred during seminar sessions at the university.

Phase (1) Husani's Deconstruction: My Experience of Being Excluded Because of Missing Language Skills *Although I was able to understand people and respond to some complex conversations, I still had difficulties in some aspects of communication. When I made mistakes, I sometimes recognized negative expressions on the faces of people with whom I was conversing. Some would say, "Please say that again," or "Oh! That is not correct." I sometimes felt as if I had lost the ability to communicate with people. Gradually, I began to hesitate to speak up even in class or in a group discussion.*

Besides this, in group assignments, some students sometimes refused to let me join their working groups. One of the assignments from which I was excluded was an assessment. In this assignment, each group had to find a client from school or within the community and conduct an assessment using the tools/materials that suited the client's condition. […] After the students had divided themselves into groups, two claimed that they were missing one partner, even though they were aware that I was present. One of the students asked the others, "Why don't you include the man over there?" They simply responded that I would

[2] All names have been changed.

fail to do the task because I did not speak German. This situation was difficult for me because of three issues: their refusal to include me, the reason given for excluding me, and having to do the assignment alone. […]

In the classroom situation, and especially in this foreign country, it was painful when one or a group of fellow students segregated me based on wrong judgments or prejudices. In fact, my good performance during this interaction with the client proved that my fellow students had been wrong in saying that I would fail to carry out an assessment.

Phase (2) Husani's Reconstruction I: My Previous Experiences of Making Mistakes in Language Tasks in My Own Culture *When I was in secondary school in Tanzania, I faced similar experiences, with a few exceptions. As is the case in most secondary schools in the country today, everybody was forced to speak in English from the first day of attending school. Those who were chosen as student leaders were required to make all announcements in English during the assembly. […] As the prefect, I faced a difficult situation, especially when I was in the first form. Whenever I made a mistake, my fellow students would joke about the words that I had spoken incorrectly. Hence, whenever I was the prefect on duty, I had to ask a friend among the prefects who could communicate better in English to make the announcements. […]*

In the classroom, this situation was tolerable because most teachers used to teach or read the English texts and elaborate on the concepts within the texts in Kiswahili. […] For students, when one failed to answer a question orally using good English, this did not draw too much attention. In fact, it was difficult for the majority of students to recognize those language errors.

In our communities, when a foreigner from Europe or America is learning or speaks a tribal language or Kiswahili, people do not care much if she or he does not speak it fluently. […] It is rare to see them showing irritation regarding this situation. Generally, linguistic proficiency is not taken as seriously as it is in Germany.

Phase (3) Husani's Reconstruction II: My Comparison of Different Recognitions of Failing in Communication Tasks *If I were to compare the two cultures in terms of the communication aspect in light of the above experiences, I would say that people in Germany take this aspect seriously. My experiences have shown that they have a very strong preference for doing things in a precise way. In Tanzania, this is not the case. This is perhaps because many languages are spoken across the country. However, in schools, especially in English-medium primary and secondary schools, the correct use of the English language is strongly emphasized.*

Furthermore, people in Germany are very direct communicators when someone fails to perform a task as required or expected. Telling people something negative about their performance, especially adults, is still taboo here in Tanzania. […] In my opinion, being direct when someone fails to do something could be helpful in some situations. In my situation, it forced me to learn to speak the language correctly. The strategies I used to prepare for my seminar presentation enabled me to learn the German language more effectively than I would have done at a German language school. […]

Our Tanzanian culture, which does not take the communication aspect seriously, affects us in different ways. It appears that some of our academics here in Tanzania, who are Ph.D. holders, fail to communicate correctly in English, even though they passed through this system. […]

The way I was sometimes mistreated because I could not speak German like a native speaker was painful for me in some situations. However, I still believe that if the majority of native speakers had tolerated my language difficulties at the university, I would not have succeeded in significantly improving my spoken communication skills.

Phase (4) Husani's Construction: My Take-Home Message Is Put Yourself in Another Person's Position! *Taken together, the above experiences have led me to recognize the important role that culture plays in the teaching–learning process. In fact, one cannot escape the fact*

that the communication process reflects the cultural backgrounds of the communicators. Much of what we say or do, the way we say it, and our relationships are deeply influenced by how we have been socialized. Accordingly, when we compare cultures, we should not look for differences that make us better or worse than each other. What is actually needed is for a person to have the ability to act in accordance with the local culture, to understand the structures and functions of the systems operating within a given society, to understand different viewpoints, and to tolerate ambiguities.

For me as an SLT, it is very important that before communicating information, I think about how it might be received and check on the cultural issues about which I am unsure. It is wise to put myself in another person's position, comprehending feelings from the other person's point of view rather than making evaluations based on my own cultural perspective. We all hold stereotypes; the important thing is not to allow them to disappoint others.

Claudia's Biographical Self-Reflection

Claudia is a German SLT student who took part in a Tanzanian-German research project in the field of SLT. One goal of the research project was the joint preparation, implementation, and analysis of interviews conducted in tandem by German and Tanzanian students. Claudia's communicative intercultural conflict occurred during her excursion to Tanzania in the context of this research project.

Phase (1) Claudia's Deconstruction: My Description of an Exciting but Still Confusing Experience Abroad *I was sitting on the bus beside my tandem partner, Safiya, on our way to conducting interviews with some people in a small village. […] Safiya told me that she sometimes has headaches and problems with her eyes. I asked her if she was still able to join in the interviews, and she said yes. The interviews went well.*

On the way back, Safiya told me that she had to go to the hairdresser. I was very confused and asked her why she wanted to go to the hairdresser during what was our working time. For me, it was incredible to do something like that while working. She said that she wanted to remove her braids. Therefore, we went to the hairdresser. […] I found it very exciting to learn more about the Tanzanian culture. […] The procedure took a very long time. After one and a half hours, I said to Safiya that I would go back to the university. She agreed, but she was uncertain whether I could manage to get back on my own. I convinced her that this was not a problem and that she did not need to worry.

[…] At the university, my lecturer was confused to see me returning without Safiya. She asked me skeptically why I was alone. So, I told her the whole story about the interviews, the hairdressing salon, and my decision to return to the university on my own. After that conversation, I went to my room to get some rest. It had been a very long day.

Phase (2) Claudia's Reconstruction I: My Description of Possible Irritations at Work in My Home Country *I had not experienced a similar situation in Germany. For sure, in Germany, we also have different attitudes and approaches concerning work ethics. Also, at the university, you can find different approaches. However, I have never experienced anything like this within such a close group work session. Among my friends […], we have the following motto: "You scratch my back and I'll scratch yours." When somebody is unable to do their tasks, there is usually a convincing reason. And if it is possible, someone will then assist. Being aware of time constraints, people are generally willing to work more than is usually required. […] Nevertheless, an honest and transparent dialogue will occur. In addition, irritation can arise in the course of a cooperative effort. This can be eliminated by being transparent.*

Phase (3) Claudia's Reconstruction II: My Comparison of My Own and Different Ways of Facing Difficult Situations *If I compare my experiences of working in Germany and in Tanzania, I can see significant differences. […] It is difficult to compare this situation with one in which two people share the same background and cultural experiences and speak the same lan-*

guage. A common impression is that Germans grit their teeth together compared with Tanzanians. However, problems arise because of the complexity of conditions involving multiple factors, which result in misunderstandings. Depending on where the collaboration takes place (in Tanzania or in Germany), one of the collaborating partners feels uprooted and has to face many new things. The other one is in the position of a host and an expert in his or her culture. Sympathy and empathy are required from both sides. Transparency could clear up misunderstandings, and the provision of clarity and safety could also help in engaging with the collaborative partner. It seems that comments like: "I do it this way because of…" or "What do you think if we first do this and then go on to do that?" are not appreciated within the Tanzanian culture. Here we can see the uncertainty in dealing with the other culture. In Germany, I would have raised the issue clearly. I would have said that I would go back to the university and continue working.[…] So, I was also slowed down, and I felt left out of the process.

In the situation with Safiya, I decided to stay calm and convey to her that I was fine; I could cope with the situation by myself, and she should take her time. On the one hand, I wanted to be polite and avoid potentially jeopardizing the collaboration. On the other hand, I felt like a novice in the foreign culture, and I thought it would be inappropriate to change the cultural circumstances as a result of my presence and activities. Could this be absolutely normal here?

Afterwards, I was annoyed at myself. When I left Safiya, I could express my real emotions and my anger resulting from this situation. In Germany, I would have definitely vented my anger earlier.

Phase (4) Claudia's Construction: My Conclusion for My Understanding of My Own Role *Empathetic cooperation is very important and is part of intercultural competence. For me, becoming familiar with foreign cultures can be seen as an absolute enrichment, and it may be deemed necessary to integrate within a particular culture. From my point of view, you can create links that lead to further mutual discoveries. I could imagine that meeting each other on the same level creates a good foundation for a fruitful collaboration. To realize my own position in contrast to those of others is also very important. How does my counterpart feel about being in the foreign country? What do they need? What information should I give them?*

You should always reflect on your own role. You need to ask yourself: How should I deal with a strange situation? Do I change myself in the interaction? Am I the person who has to provide a sense of security? […] Certainly, talking to each other will be a very important aspect of getting to understand the other person.

Especially as an SLT in schools, these issues essentially entail bringing foreign students on board, giving them the opportunity to demonstrate their own culture, and familiarizing them with the value of this culture. As a teacher specializing in speech–language didactics, you have to create opportunities for the students to be motivated to get to know each other. […] Appreciation of a foreign culture increases the motivation of foreign students to participate more in class. Could this be one way to achieve better class participation?

Data Analysis

The specific rules for our data analysis can be briefly described. Initially, we summarized the textual material comprising all of the biographical self-reflections in a process referred to as an "inductive development of categories" (Mayring 2014, p. 3). The material was divided into single coding units and paraphrased through (1. generalization). Afterward, we summarized the paraphrases through a process of reduction (2. reduction; see Table 4.2).

In a third step, we analyzed the material based on the scaling system in relation to the degree of DSCC using our scale (for levels of reflective DSCC, see Tables 4.1 and 4.2).

Results

In this section, we present the results from the qualitative content analysis (Mayring, 2014). Initially, we addressed the first research question regarding challenging experiences that are

Table 4.2 Extract of a summary of Husani's inductive category application and scale structuring during phase 4 (construction)

Line number		1. Generalization	2. Reduction	3. Levels of reflective DSCC
170–171	*"When we compare cultures, we should not look for differences that make us better or worse than each other"*	Every culture has special features which should not be rated	There is no better or worse	4. Acceptance
172–174	*"To understand different viewpoints and tolerate ambiguities"*		Tolerance of diversity	5. Adaptation
172–174	*"It is wise to put myself in another person's position"*	If you self-reflect and try to reflect on the other, you will succeed	Reflection	6. Integration
	"We all hold stereotypes; the important thing is not to allow them to disappoint others"		Reflection	6. Integration

acquired during professional stays abroad in a foreign country and are relevant for the professionalization of SLTs. Subsequently, we illustrate the interindividual growth of DSCC throughout this professional stay in a foreign country (see Fig. 4.3). To provide an overview of the study results in their entirety, alongside the focus on Husani and Claudia, we present the results for all participants.

Identification of the Most Relevant Challenging Experiences Gained Through Professional Stays in a Foreign Country

Our analysis of the 14 biographical self-reflections revealed a variety of challenging experiences that were found in the reduction phase of the qualitative content analysis. These could be clustered around three main themes: strangeness, heteronomy, and identity conflict.

Strangeness: "I Am a Stranger!"

The most frequently mentioned theme in the biographical self-reflections was the feeling of strangeness. In particular, statements reflecting communicative uncertainty ("I still had difficulties in some aspects of communication" [Husani]) and discomfort ("the time pressure, which the Tanzanian students probably did not feel, made me sick in the pit of my stomach" [Mia]) occurred quite frequently. This aspect is underpinned by the participants' incomprehension of many things, regardless of language (e.g., "I could not understand what was going on" [Mia]). Consequently, communicative misunderstandings and irritation arose that could result in a withdrawal from the communicative situation ("to escape as quickly as possible" [Mike]). Therefore, the feeling of not belonging to the group often recurred ("it was painful when one or a group of fellow students segregated me based on wrong judgments or prejudices" [Husani]).

Heteronomy: "I Am Powerless!"

The second most important theme in the biographical self-reflections was heteronomy—being determined to do something based on a given situation or another person. Not knowing who they were in the foreign country (see section "I dentity Conflict: "I Am Not Myself!"") or how to behave, the participants started to feel dominated by others in their interactions ("I felt left out of the process" [Claudia]). As a result, they experienced a

feeling of communicative dependency and helplessness ("I could not change the situation, so I had to accept it" [Mia]). Moreover, their feeling of communicative helplessness increased ("I did not know how to help myself" [Mike]). A different understanding of time ("short time scheduling was hard for me to endure" [Mia]) and acting spontaneously continued to be prominent ("the work meeting I initiated did partially happen [the way I had imagined], even if spontaneously and in a rather informal way" [Barbara]).

Identity Conflict: "I Am Not Myself!"

Through their intercultural encounters, many SLTs began to reflect deeply about their own identities and their communicative roles. How they desired to present themselves ("to realize my own position in contrast to those of others" [Claudia]) and how they were perceived by others ("the children saw me as the rich white man—a role I never wanted to take on" [Mike]) were significant questions. In addition, they experienced self-doubt ("an enormous destructive self-doubt" [Mike]), resulting in a different communicative behavior compared with their normal styles ("In Germany, I would have definitely vented my anger earlier" [Claudia]).

Professionalization of Diversity-Sensitive Clinical Competence as a Result of Reflecting Challenging Experiences in a Foreign Country

The analysis of the four phases of the biographical self-reflection (deconstruction, reconstructions I and II, and construction) shows that phase 1, the deconstruction phase, was the participating SLTs' starting point for acquiring DSCC and phase 4, the construction phase, was the meaning-making phase relating to the current state of their acquisition of DSCC.

The analysis, which was based on the scaling structuring system proposed by Mayring (2014) (see section "Data Analysis"), showed that as a result of their professional stays in foreign countries and their subsequent reflection, 11 participants improved their reflective DSCC, including Claudia and Husani. Three participants showed no difference in their reflective DSCC after experiencing meeting the "stranger" in a foreign country. Furthermore, there was no decrease in any of the participants' reflective DSCC (see Fig. 4.4).

Discussion and Study Limitations

The aim of the current study was to investigate SLTs' intercultural experiences abroad and their significance for their individual professionalization to gain DSCC for working in CLD contexts. For this reason, the biographical self-reflections written by 14 participants in the study after experiencing a conflicted intercultural situation were analyzed. The first research question asks about the main themes of SLTs experiencing challenging situations during professional stays abroad. The second research question concerns the individual increase in the level of reflective DSCC.

The findings relating to the first research question on challenging experiences caused by professional stays in a foreign country revealed the relevance of the three major subject areas: strangeness, heteronomy, and identity conflict. These themes imply mostly negative emotional states. Working and communicating in foreign countries can be challenging and painful for the individual in a given situation. This reveals the necessity for professional reflection on these crises to develop a professional clinical competence that is sensitive to diverse cultural formats. With the concept of the "internal stranger" (Kristeva, 1991) in mind, one fruitful way of reflecting on these experiences is through the method of self-reflection, which guides the reflection through the four phases of construction (see section "Data Collection").

Lüdtke et al. (2003) have suggested that the experiences acquired in a foreign country are relevant for the development of professional identity. Professional identity can only advance to the level of professional competence when the experiences abroad are reflected on holistically. It is important to reflect on the emotional part of the experience, especially when the main themes are mostly negative and could result in avoiding or suppressing the feelings and perpetuate these

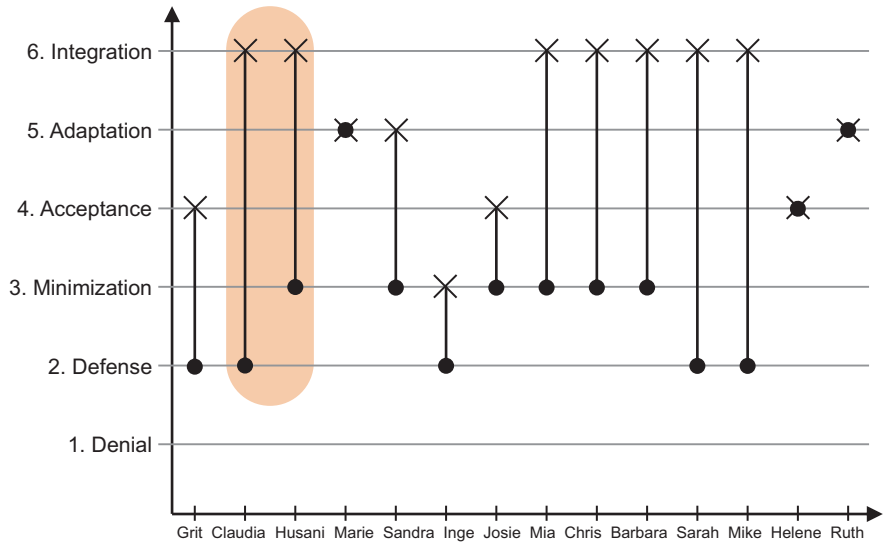

Fig. 4.4 Acquisition of reflective DSCC of all the participants (highlighting the cases of Claudia and Husani): phases 1 (•) and 4 (×). (Adapted from Schütte, 2016)

clinical situations. Therefore, a comprehensive process of preparation, mentoring, and follow-up actions is essential (Nguyen, 2017; Stanford & Gay, 2017). Engaging in biographical self-reflection, as recommended in this study (see section "Instruments"), could facilitate reflection on professional experiences of feeling alienation in a foreign country. It could help SLTs to understand better the "internal stranger."

We believe that stays abroad in a foreign country should be professionally supervised. Otherwise, they could have negative impacts on SLTs by reinforcing rather than reducing their prejudices. These conflicted experiences significantly influence the communication flow in intercultural encounters between SLTs and students/clients. Based on the results, it can be assumed that a change of perspective occurs that enables SLTs to put themselves in the position of their students/clients from CLD backgrounds. This would enable them to understand better their needs, feelings, and ways of thinking and acting, which improves service delivery in a CLD context. Therefore, study or work stays abroad and a curriculum-embedded reflection could benefit the professionalization of SLTs in multiethnic and multilingual countries in SSA. Although there might be the danger of a brain drain of SLT professionals to Minority World countries, which already occurs in other health professions when studying abroad, it could be a chance to strengthen the reflective and practical parts of DSCC on all three facets (cognitive, methodic, and communicative).

However, the benefits of work or study stays abroad for SLTs in SSA still need to be investigated. Future research should include participants from more diverse contexts. Thirteen of the participants in this study came from Minority World countries. Therefore, this study inadequately represents the views of sub-Saharan African SLTs. Whether feelings of alienation arise in SLTs from countries in SSA when they treat clients from different ethnic groups speaking different languages is not clear. The fact that clients and SLTs share an "African" identity can be a unifying factor. Nevertheless, it must be assumed that other factors like growing up in rural or urban regions or practicing different religions potentially result in feelings of alienation in SSA.

Considering the second research question, the intraindividual comparison shows that 11 out of 14 participating SLTs increased their level of DSCC through the reflection on their professional stays abroad in a foreign country. There

was no decrease in the DSCC of any of the participants. This finding indicates that a stay in a foreign country is valuable for acquiring or improving DSCC.

In light of this, interindividual differences can be identified. Reasons for these differences can only be assumed and would need to be determined through further investigations. For now, one reason could be that they are related to the individual personalities and socialization of the participating SLTs as well as to their previous intercultural experiences. The length of their stays could also have an impact. In addition, the initial conditions of the participants could play an important role. Another limiting factor is that we only collected data about the duration of the stay without analyzing the correlation between the duration and the level of DSCC. In this context, an investigation into whether previous challenging intercultural experiences influence the acquisition of DSCC would yield further insights.

Recommendations for SLT Curricula Worldwide

This study has shown that professional stays in a foreign country have a positive impact on the development of DSCC in SLT students and practitioners. The following recommendations can be made based on the study's findings with regard to the professionalization of SLTs in light of their exposure to "strangers" in CLD contexts.

Implementation of Professionally Supervised Practical Internships Abroad for Promoting Direct Exposure to "Strangers"

A professionally supervised internship abroad should be implemented in the study program of SLTs to enable them not only to acquire theoretical knowledge about CLD within their classes but also to gain direct exposure to challenging intercultural situations. This should be reflected in the circular speech–language therapeutic process of professionalization (see Fig. 4.3).

The establishment of international (research) projects in which students are given the opportunity to discover foreign countries and cultures through project work provides opportunities for them to become acquainted with foreign professionals or clients (and their different professional communication habits). This would simultaneously provide them with an opportunity to cultivate a reflective engagement with the "internal stranger" (feelings of strangeness).

Implementation of a Module to Promote DSCC in SLT Training Programs

The idea of a compulsory stay abroad that entails professional supervisory mentoring as part of SLT study programs could be difficult to implement for structural and financial reasons. Therefore, we recommend—at the minimum—the establishment of modules to foster DSCC (Horton-Ikard et al., 2009) in a way that professionally addresses issues of "strangeness," "heteronomy," and "identity conflict." These three main themes emerged in the biographical self-reflections presented in this study (see section "Identification of the Most Relevant Challenging Experiences Gained Through Professional Stays in a Foreign Country") and are relevant issues for dealing with conflicting situations in CLD contexts.

It must be borne in mind, however, that only a few previously conducted empirical studies have demonstrated the effectiveness of modules or training to promote DSCC within the health sector (Chipps et al., 2008, p. 92). Therefore, further research is urgently needed.

Toward Intensive Self-Reflection for Dealing Appropriately with "Strangers"

As discussed in this chapter, biographical self-reflections can lead to a modified understanding of strangeness. Therefore, prospective SLTs should deal with their own feelings of alienation

and reflect intensively on these processes. Accordingly, the ASHA has created "culture competence checklists" (ASHA, 2010) for prompting self-reflection. Our work with the biographical self-reflections presented in this chapter represents possible instruments that would enable SLTs to recognize their own cultural communication and interactional patterns and to detect the strangers within themselves (see section "Clinical Competences in SLT in CLD Contexts"). For the SSA context, future research needs to show whether these tools are also appropriate to support reflection of difficult situations in CLD contexts as well.

Toward Ethnorelativism for Promoting Acceptance Rather Than Suppression of "Strangers"

The modified DMIS developed by Bennet (1994, 2004; see section "Acquisition of Diversity-Sensitive Clinical Competence") illustrates the possible steps for a shift from ethnocentrism to ethnorelativism. This process also plays a decisive role in the examination of "feeling alienated." A conscious perception of ethnocentric modes of thinking and behavior is needed for engaging with "strangers." This perception is fostered through an understanding of the culturally determined imprint and interpretation of concepts, such as health, illness, or even disability. In our view, the development of information sheets on selected cultures could be helpful in enabling SLTs to relate their own (communicative) behavior patterns to those of "strangers." As a result, they would start thinking about what constitutes presumably "proper" clinical behavior in service delivery situations, like the shaking of hands as a gesture of greeting. As part of their professionalization, students would be expected to critically integrate the contents of these information sheets within their practical work in CLD contexts.

In conclusion, we assert that the feeling of alienation should not be ignored or suppressed. Instead, we should ensure that the appropriate conditions are provided for SLTs to reflect the feeling of alienation and acquire professionalization through higher education didactics. We should acknowledge that feeling alienated is part of being human, and finally, we should recognize that we are all "strangers." This learning process is a lifelong biographical process.

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5 The History of Speech-Language Therapy in Kenya: A Collective Memory

Bea Staley and Emma Shah

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Introduction

Motive

This chapter provides a description of the history of the speech–language therapy (SLT) profession in Kenya. It is intended to map the people and activities which contributed to the development of the discipline in notable ways. We anticipate this work will inform those working with clients with communication disorders in sub-Saharan Africa about the development of SLT in Kenya. We expect that the narrative created here will provide insight into the growth of the profession over the years and serve as a useful resource for those involved in future developments in Kenya, as well clinicians working in other Majority World countries that are starting to develop their own SLT services. In line with the words of Wylie et al. (2013), who "suggest that SLTs in Minority World countries have much to learn from service developments in Majority World countries" (p. 9), we anticipate that this work will also contribute to the larger global conversation about the development of the SLT profession in Majority World contexts (e.g., see Staley & Hopf, 2016).

This chapter documents a largely oral history that is otherwise unaccounted for in the literature and which may serve as inspiration for clinicians globally who are forging a similar path, with comparable constraints. The chapter is intended to mark history and also initiate a conversation about alternative visions, futures, and possibilities for the profession in Kenya.

Problem Background

There is a notable dearth of SLT services in sub-Saharan Africa (e.g., Wylie et al., 2016), particularly of clinicians who reflect and represent the diversity of clients presenting with communication disorders (Southwood & van Dulm, 2015). Given the discrepancy between the suspected numbers of persons with disability (Wylie et al., 2013; Zuurmond et al., 2016) and the number of health and education professionals trained to work with this population (Hartley & Wirz, 2002), the ongoing conversation about how the field of SLT is being developed remains relevant and important (Pillay & Kathard, 2015).

Methodology

Methods: A Qualitative Methodological Pastiche

Storytelling is ubiquitous (Ochs & Capps, 2001), and it is a function of human storying and restorying that we recreate the past in sequential and temporal order to help make meaning of our experiences (and indeed our lives). While the SLT profession has typically taken a quantitative stance to documenting and accounting for practice, qualitative methodologies generally, and storytelling methods specifically, are proliferating in various disciplines including medicine (see Charon, 2006; Frank, 1995; Kleinman, 1988). We need lived experience in our clinical practice theories. As Mattingly (2010) notes, "it is essential to be reminded of the way moments of possibility and community are cultivated, reality needs to be exposed as a space of possibility" (p. 39); this work is one such space of possibility.

Although this chapter might be considered an oral history (Errante, 2000), we describe the methodology guiding this work as a methodological pastiche. We selected the word *pastiche*, because it derives from a French word that means "a mixture of diverse ingredients." Perhaps we might have used the Swahili term *pamoja* instead, which can mean "collective" or "together." In this work, we use the term as a metaphor to encapsulate how this "picture" of the oral history of SLT in Kenya was formed: by balancing a combination of perspectives, rememberings, interpretations, ideas, and stories that have been brought together in this text.

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The data were drawn primarily from written responses to a questionnaire (see Table 5.1) that went out to all members of the Association of Speech and Language Therapists Kenya (ASLTK) in 2016, as well as our own SLT networks of friends and colleagues who have lived and worked in Kenya. We also drew from emails and other documents in an attempt to generate a picture that most accurately reflected the development of the SLT profession in Kenya. Woven together, the information from written communication, conversations, and memories create the narrative shared in this chapter.

As questionnaire responses were returned to the primary authors and the text for this chapter was developed, we distributed and redistributed various drafts to contributing authors so that they could edit and add to the history in ways that best reflected their personal accounting of the history of SLT in Kenya. This chapter therefore provides an interpretation of history based on the comments we received from the emerging versions of the chapter as they circulated through the Kenyan SLT community. We found that as the manuscript progressed, so too did the feedback and details. We have attempted to account for all of them and have used footnotes at times to add richness to the text without distracting from the primary story.

This chapter may be considered a creative arts methodology as we draw together the remembering of the professionals who have been working in Kenya over the years, to document both the timeline and the feeling behind the development of SLT practice in the region. Thus, we formed a history of our collective viewpoints, with the benefit of hindsight. There is a notable relationship here between history and our biographies, personal stories, and a collective one. This text in many ways represents the varied relationships that exist between the authors as friends and colleagues (Errante, 2000). This does not necessarily mean the versions of events recounted here, or the conclusions we have drawn, have been unanimously agreed upon. Just as an artist paints a picture, or a photographer takes a photo, the result is manipulated through their lens. Ultimately, the primary authors of the chapter, as historians perhaps, selected the tone and the emphasis to communicate a perspective which was intended to encapsulate the community's contributions.

Table 5.1 Questionnaire distributed to the Kenyan SLT community

History of development of SLT in Kenyan questionnaire
Please fill out the questionnaire with as much detail as you are able. The submitted chapter will endeavor to reflect everyone's views equally – the more you write, the more information will be in the submission! Have a think about the history of SLT in Kenya from your perspective and then type up your story. This can be fragments, thoughts, ideas, memories, bullet points, etc.; the more, the better. Don't labor too much if it is going to put you off! Please contribute to the following questions – and let us know of anything we have missed out! • Past history of SLT as it relates to Kenya – this may include the influence of historical events in Kenya (e.g., independence/colonialization, democracy, post-election violence). • What is unique about SLT in Kenya? (e.g., different languages/cultures, services being mainly based in cities currently with much of the population being rural). • The stages you think the profession has passed through in the last 40–50 years – these stages may or may not correlate to development of SLT in other countries. • The key events/organizations (e.g., SEP, Usemaji, Cerebral Palsy Society, VSO) or people that have developed the profession (in your opinion) – within and outside the country. • The role of government organizations (e.g., KISE, Ministries/Ministers). • The role of local and international universities in setting up training courses. • Innovative/different working practices that have developed in Kenya due to local needs/circumstances. • Role of ASLTK – registration of the profession, Schemes of Service, and so on. • Influence of East African SLT conferences. • Influence/support from other professions (physio, OT, teaching, nursing, medicine, audiology, dietetics, etc.). • How did *You* specifically contribute – what were your successes and failures to the development of our profession in Kenya? What did you learn from the failures? What needed to be in place for the successes? • What are the next steps/goals for the future, in your opinion? • What will be the future challenges?

Situating the Authors

In order to provide clarity about our positions as authors (and "rememberers"), the authors will now be briefly introduced, alongside their roles and experiences in Kenya.

Bea Staley is an Australian SLT, who first came to Kenya in 2006 as a volunteer and returned to Kenya in 2007 with Voluntary Service Overseas (VSO), training special education teachers to use language and literacy strategies in their classrooms. Bea was one of the primary organizers of the 2008 East African conference and remained actively involved with the Kenyan SLT community until 2012. Bea has remained affiliated with Yellow House Children's Services,[1] an organization she founded to provide SLT services both on the Coast and in Western Kenya.

Emma Shah is an English SLT who married and moved to Kenya in 1999, spending 15 years living and working in Nairobi. Together with Reyhan Erguden (an SLT from Turkey), she set up new pediatric and adult SLT services at Aga Khan University Hospital and Nairobi Hospital. Emma also set up four self-help/support groups: "Usemaji" (for persons with aphasia), "Kenya Association of Laryngectomees," "Nairobi Stammering and Cluttering Support Group" (together with Reyhan), and the "Parkinson's Support Group" (after Reyhan left Kenya). Emma coordinated student clinical placements with the ASLTK members, arranged continuing professional development opportunities, and was the co-coordinator of the 2009 East African SLT conference along with Laura Gomersall. Emma returned to England in 2014 and maintains links with colleagues and clients in Kenya.

The remaining clinicians who contributed to this work will be introduced in the text, and their biographies will appear in the footnotes as they appear in the history. We refer to the clinicians by their first names throughout the text to denote the personal nature of the work.

[1]Now Yellow House Health and Outreach Services.

The Development of the Speech–Language Therapy Profession in Kenya

A Collective Remembering

From 1970 to 2000: An Overview

Elisabeth Kruger[2] recounts: "I came to Kenya in 1989 and I had the pleasure of meeting with retired SLT Mrs Betty Couldrey," a woman who we have since remembered as the first SLT in Kenya. Couldrey's husband was a High Court judge, and the couple were known for their community activism before independence in1963.

Betty was both an influential and progressive social thinker. She started the "Kenya Society for the Deaf" and had some involvement in the design of Kenyatta National Hospital (KNH), orchestrating the inclusion of an SLT room, as a part of the audiology suite, into the hospital plans. This literal signposting of the SLT profession in the 1970s undoubtedly helped keep SLT in the minds of staff at KNH.

While there were possibly other SLTs during these early years, Betty was probably the only SLT in the country for a considerable period. When Reyhan Erguden and Emma Shah met her,[3] she noted that she had people queueing up at her kitchen door at her home in Karen even after she had officially retired. Betty's son Nick Couldrey recounts:

> My mother trained as a speech therapist in London starting towards the end of the war (she was born in 1925). She came to Kenya to marry my father in 1948. My father was born in Kenya but was in England during the war and they met in England after it ended. I think that there was no speech therapy at all when she arrived in Kenya, but she was fully trained.
> She got together with Mrs. Hughes to start what became the "Deaf Society of Kenya" sometime in

[2]Elisabeth Kruger is a Dutch SLT who worked privately in Nairobi, Kenya, for 23 years. Elisabeth is a founding member of the Cerebral Palsy Society of Kenya and co-supported the Usemaji Aphasia Support Group. Elisabeth worked at Nairobi Hospital and various health clinics and schools in Nairobi. Together with Emma Shah, Dr. Omamo-Olende, and Prof. Macharia, Elisabeth initiated the first joint Voice Clinic in Kenya at Nairobi Hospital.

[3]Betty Couldrey has since passed away (circa 2005).

> the fifties I think, but I could not tell you when. She had four children between 1951 and 1958 so that must have taken up some of her time. The Society was a charity that provided some support for deaf people – mostly children. The money was raised locally, and it was almost entirely staffed by Kenyans who had some training locally although how many obtained British qualifications, I don't know; there were of course no relevant Kenyan qualifications.
>
> In the 1960s I think that she managed to get a number of VSOs[4] to work in the clinics. I remember her saying how useless they were to begin with and how good they became after a year, bemoaning the practice of sending them only for a year. Mrs. Hughes was the wife of the guy who owned the Ford franchise in Kenya called Hughes Motors. I think that she did most of the administration and fundraising. My mother concentrated on training the staff and the clinical side. By independence there were something like 50 clinics,[5] some residential. They were taken over by the government shortly after independence. My mother also had a small private practice, mostly children, that she continued after independence and she also did a fellowship with the relevant professional body in the UK (Royal College of Speech Therapists). It was inevitably about problems particular to Kenya, but I don't know what.
>
> Betty continued to work in the public sector after independence although I don't know what her status was or whether she was still working under the auspices of the Society. She never took Kenyan citizenship but lived in Kenya until she died about ten years ago.

Maartje Rosenstok, a Dutch SLT, was another early SLT who worked in Western Kenya at Nyanza General Hospital from 1979 until 1981 and then in Nairobi from 1990 to 2003. Maartje worked at several Nairobi schools including Kestrel Manor, Acorn Special School, and Oshwal Primary School in Parklands, which had a special needs department (among others). In addition to her school-based work, Maartje ran her own SLT clinic at home in Karen, where she reportedly saw clients of all ages, with "all the problems an SLT can dream of."

These school-based SLT services really were (and still are) relatively scarce. However, this was also true of other services delivered through community-based health organizations. While there are still fewer than optimal SLT provision options in Nairobi today, thanks to the work of SLTs like Elisabeth and Maartje, there *are* options. Elisabeth highlights the shortage of SLT services for clients with communication disorders in the late 1980s and early 1990s in her stories about starting the Cerebral Palsy Society of Kenya (founded in 1994):

> A group of us, including a lawyer who had a son with cerebral palsy (CP), a woman in marketing who had a daughter with CP, and a father of a child with CP who worked at the United Nations, formed a preparatory committee for awareness of cerebral palsy. We had to keep a low profile and we met in a small upstairs bar, because in those days the president did not allow unofficial gatherings. However, our work paid off and in the end we managed our own clinic for CP. We lobbied for equipment and quality toys from a large store in town, and luckily we got everything for free since the owner had a child with CP himself!

Elisabeth's story provides a glimpse into the political context of the time, as well as the way in which many of the early associations were founded in Kenya, including the Autism Society of Kenya (founded in 2003).

As Elisabeth's quote attests, for families of individuals with communication disorders, much of the drive for societal inclusion, education, and services has come from small groups of like-minded individuals that often included parents and family members. Elisabeth describes some of the difficulties the early association faced:

> It wasn't an ideal situation. Water had to be ferried up the stairs for the toilet and had to be boiled for drinking and cleaning. Also the children and their wheelchairs had to be physically lifted to access the space. Parents came mainly from the surrounding area, and we attracted a diversity of families… the families cooperated enthusiastically, used to the lack of conveniences and appreciative of the services.

During these early years, with the exception of Betty, the SLT services in Kenya were mainly provided by expatriate therapists (Elisabeth and Maartje included) who trained overseas, came to Kenya, and eventually returned to their

[4]Voluntary Service Overseas (VSO) volunteers.

[5]We wonder, but cannot verify, if these are the clinics that became the district Education Assessment Resource Centers.

home countries. The discontinuity of professional expertise continued and contributed to the challenges of sustainability for the developing profession.

From 1990 to Present: Special Education Professionals (SEP)

Special Education Professionals (SEP)[6] was set up in 1990 due to the efforts of Belgian psychomotor/occupational therapist Karolien Tuts together with special educators Eva Nyoike, Theresa,[7] and Christel Roick and occupational therapist Stella Nduba. SEP has one central office with a library and materials on special needs in Gertrude's Children's Hospital, Nairobi. SEP employs therapists who run monthly consultations and workshops for therapists, teachers, caregivers, and family members at hospitals, schools, day care centers, and orphanages, usually at the request of parents or teachers. They are supported by a group of SEP volunteers who are all professionals (therapists and teachers). Throughout the years, SEP has offered a much-needed multidisciplinary service to children who cannot afford private SLT services, as well as professional development and support for community members.

One of the challenges SEP has faced includes not having consistent and adequate SLT support. SEP has managed to get full-time SLT volunteers through VSO at times (e.g., Natalie Myles, 2013) but does not consistently have a full-time SLT. SEP places emphasis on demonstration and advice for parents, or primary caregivers, of children with special needs, rather than individual diagnosis and treatment.

One of the reported difficulties of client care in Kenya is that children are often only seen intermittently. Families will be referred to a clinic or for an assessment and then not return for follow-up (for various reasons including differing expectations, cost of travel, etc.). It is essential then for therapists to provide as much information as possible to families in the initial session together.

SEP's slogan is "Helping you to help your child," and this is evident in their work. SEP professionals together with families and teachers identify the needs of individual children, families, schools, or organizations and then work toward supporting them with adapted furniture, therapy materials, educational equipment and/or toys, and the training of applicable staff. Furthermore, parents and community volunteers can receive training to become peer educators in their communities.

From 2000 to 2014: A Building of Momentum

After 2000, services grew slowly with a burst of involvement by expatriate SLTs, partly due to the vision of VSO, which supported a number of SLTs working in the disability sector. At this time, there were also a number of Kenyan SLTs who had trained overseas and returned home from their studies in Britain, the USA, Australia, and India. These included Poonam Shah,[8] Laura Gomersall,[9] Doris Kwenda, Grace Macharia,[10] Pauline Muhoho, and Lorna Muthamia.

In 1996, Nuala Alibhai had been working at Aga Khan University Hospital in Mombasa setting up the hospital-based services on the coast. In 2001, Emma Shah and Reyhan Hosgor Erguden did the same in Nairobi, establishing hospital-

[6]SEP was only named in 1998. In 1990, it was simply a professional support group.

[7]Last name unknown.

[8]Poonam Shah is a Kenyan SLT who trained in India and the UK and has been practicing in Kenya since 2013. She worked at Aga Khan University Hospital (AKUH) providing an acute and clinic-based SLT service. She helped further develop the acute inpatient SLT service to include critical care and ward-based input. Along with this, she ran the videofluoroscopy clinic at AKUH, the first such clinic in East Africa.

[9]Laura Gomersall (née Dykes) is a British-trained Kenyan SLT, who lived and worked in Nairobi and Naivasha as an SLT before relocating to England. Laura Dykes was the second Kenyan-born SLT to have studied abroad and returned to practice in Kenya.

[10]Grace Macharia is a Kenyan SLT who trained at the University of Reading in the UK. Previously, Grace trained as a special needs teacher and then worked as lecturer at the Kenya Institute of Special Education (KISE). Following her SLT qualification, Grace continued to work at KISE for 3 years and then moved to private practice.

based SLT services at Aga Khan University Hospital and Nairobi Hospital. 2014 saw the founding of the first SLT service at MP Shah Hospital in Nairobi by Jainee Shah and Risha Joshi.[11]

Because there is no precedence for government SLT roles, there is no funding structure to pay for SLTs in schools or hospitals. Consequently, SLTs operate as private practitioners or as consultants even within these public settings. This means SLTs often have to provide their own equipment, materials, space, and transportation, making the costs of providing SLT services relatively high compared to the general population's ability to pay. Because of the relationship between disability and poverty, often individuals who need SLT services the most are the least able to afford either the service or the travel required to access the service.[12] This will be an ongoing challenge for the profession in the Kenyan context.

Voluntary organizations, such as VSO (globally) and SEP (locally), expanded their programs and services during this time period. While this had minimal impact on the dearth of services available to the average Kenyan, it was a notable attempt to alleviate the situation. VSO placed numerous SLTs within Kenya during this time including Heidi Witte (circa 2006), Mike Terry (2007–2008), and Heather Hayes (2010–2011) who were based at the Association for the Physically Disabled of Kenya (APDK). VSO also supported SLTs Claire Leadbeater (circa 2006–2007), Bea Staley (2007–2008, 2010), and Marie Fahy (circa 2010) who provided services at the district Education Assessment Resource Centers around the country. Rachael Tuckley (2008–2010) was placed at the Kenya Institute of Special Education.

Whether volunteers or private practitioners, most SLTs working in Kenya have donated significant portions of their time and energy to free clinical services, as well as the development of the profession. Poonam reported that "On returning to Kenya in 2013, I found it challenging to manage my clinical caseload, volunteer my services at SEP, and run support groups." Poonam went on to suggest that:

> In order to sustain and support groups and reduce the load for SLTs, experienced group members need to be encouraged to take on a lead role, so that once funding is sourced, support groups can employ these members.

According to Emma, this has already happened in some support groups for people with laryngectomy and also in groups for persons who stutter. Poonam's quote highlights the multiple demands on clinicians who are working, volunteering, fundraising, and often advocating for the profession, as well as the establishment of university training programs.

Local universities such as the University of Nairobi, Kenyatta University, Kenya Medical Training College, Aga Khan University Hospital, and Moi University all expressed varied interest in starting SLT training courses during the period of 2000–2012. A curriculum was developed by the Kenyan SLT group based on the program that started at Makerere University in Uganda in 2008. But staffing such courses requires academics with appropriate qualifications as well as practicing SLTs, and so a program in Kenya was not a viable proposition at that time.

Meanwhile, Kenyan-based SLTs were supporting and mentoring international SLT students (mainly from Australia, the UK, and Canada) who came to Kenya as a part of their studies. Clinicians received some support from those universities in return for clinical supervision. Clinical placements were developed with the involvement of David Rochus[13] and Rachael Gibson at Yellow House Health and Outreach

[11] Risha Joshi was born and raised in Nairobi, Kenya. She went to the UK to study speech and language therapy at the University of Reading and returned to Nairobi in 2014 to work as an SLT. Risha chose to move back home due to the apparent need for the services and the sparse number of service providers.

[12] But Kenya is a diverse place, and Laura recounted an experience where she was offered the opportunity to "hop on a plane and assess some children of a more financially able family in the middle of the bush"!

[13] David Rochus is a graduate of the first cohort of Ugandan SLTs trained at Makerere University. David has been working for Yellow House Health and Outreach Services in Western Kenya almost exclusively since he graduated in 2011.

Services in Western Kenya, Jenny Cox in Mbita, and Nuala Alibhai and Rehana Pasta[14] in Mombasa to include rural/coastal experiences in addition to the urban setting of Nairobi.

The East African Conference on Communication Disability: 2005–2018

Throughout the years, the East African Conference on Communication Disability (also known as the East African Speech Therapy Conference) has grown and developed as the primary event to provide professional development to East African SLTs as well as showcase the work that is happening in the region.

SLTs in Kenya from 2000 onward collaborated in planning and organizing the conferences which occurred in Nairobi (2005, 2008, 2009); in Kampala, Uganda (2012); and in Mombasa (2013). The sixth East African Conference on Communication Disability, which was to be held in 2015 in Lushoto, Tanzania, was postponed due to elections that same year. This conference finally took place in Nairobi in 2017. Yellow House Health and Outreach will sponsor a conference on communication disorders in Kisumu in 2018.

The conference was born from a need for professional development and a desire to connect with professionals across the region. It was founded by individuals and has grown over the years because of the efforts and dedication of SLTs who gave up countless hours finding suitable locations, negotiating the cost of lunches, and organizing speakers (both local and international). Attendance at the conference has grown and continues to both attract and involve a wider variety of SLTs and related professionals globally, with attendees coming from Australia, Cameroon, Canada, France, Germany, Ghana, New Zealand, Senegal, South Africa, Tanzania, Uganda, the UK, and the USA. The African (and global) representation at the conference has facilitated networking between SLTs working in remote locations in East, Central, and West Africa and has helped to bring together individuals and institutions interested in SLT training in Africa, together with persons with communication and swallowing disorders and their families.

At the first East African Conference, there were only four SLTs from Kenya. At subsequent conferences, other professionals such as teachers, doctors, occupational therapists, and nurses also presented and participated. Attendees also included individuals with communication disorders and their families and Kenyan organizations such as the Kenya Institute of Special Education and the APDK. This meant that alongside academic presentations, there were opportunities for local clinicians, students, self-help groups, clients, and their families to present their work and perspectives. This has given the East African Conference on Communication Disability a welcoming, joyful atmosphere of respect between professionals and stakeholders committed to sharing knowledge.

Risha wrote that the conference led to improved connections with other related professionals, so that after the event, she was able to apply a multidisciplinary perspective for her clients' goals when needed. In addition, she noted an increase in the number of referrals received as a result of the conference. The SLT community generally reported that the conferences had an impact on their professional lives because each conference provided a forum where varied health and education specialists came to learn, connect, and share knowledge and contacts with each other about communication disorders.

For many East African SLTs, participation in the conference is their only access to continuing professional development. Costs for local attendees are typically kept low to allow as many interested individuals as possible to come. Rehana commented that "it provides a very useful platform for those in the related professions to meet, mingle and share experiences/expertise, something that doesn't happen enough here."

[14] Rehana Pasta is a Kenyan-born and raised SLT. Rehana has a Master of Science in SLT from City, University of London. The great need for SLT services in Kenya made her return to her hometown of Mombasa where she practiced for 5 years.

Others also believe interdisciplinary teamwork has improved in Kenya as a result of the conference. The conference has served to draw international attention to the work occurring in East and West Africa. Woody Rule[15] notes:

> The development and implementation of the East African SLT conference has really publicized the work that SLTs are doing in East Africa. This event has been featured in conferences and smaller professional networking meetings in the United States.

This has resulted in an increase in international attendees bringing a wealth of specialist knowledge with them. Rehana comments that "making contacts with highly specialized international SLTs has been helpful in gaining support for the work we do here."

The shared experience of international SLTs reportedly provides useful ideas that can be adapted to SLT practice in Kenya. Overseas professionals visiting for the conferences frequently bring resources for the local SLTs, including materials that are both expensive and difficult to obtain in Kenya, for example, glycerin swabs, laminating sheets, Velcro, or technology such as an amplifier for a person with dysphonia. SLTs typically receive old and outdated textbooks and culturally invalid assessments that Minority World clinicians do not want anymore and decide to donate. Through the international collaborations forged at the conference, SLTs have been able to request and receive specialist feeding bottles for babies with cleft palate, an E-Tran frame (the only one in Kenya), and current, relevant textbooks on various therapy techniques that have been purchased for local SLTs based on their wants and needs.

[15]Woody Rule is an American SLT who lived in Kenya from 2014 to 2015. Woody was based at Tenwek Mission Hospital (Bomet County), where he supported local efforts in the development of a community-based rehabilitation program for children with disabilities. In partnership with hospital administration, Woody also helped implement swallow screening practices and a low-resource inpatient management protocol.

There is general consensus that the conference is a highlight for many Kenyan SLTs. Laura notes:

> I personally loved the impact the conferences had from the general buzz from all those who attended, great speakers and the opportunity to allow SLTs and others to get their thinking caps on and not only think together as a small team but with SLT friends and colleagues on a much wider circle. This has provided the building blocks and planted the seeds for where SLT is now in Kenya.

The conferences have had a big impact on the SLT community in East Africa, as they provided an opportunity to come together over a common cause to share ideas, beliefs, and experiences. The events have also led to the formation of a global group of SLTs with a wide range of clinical interests and expertise supporting the long-term development of the profession and the SLTs in Kenya, which has further made a significant contribution to the production of this handbook.

Establishing the Association of Speech and Language Therapists Kenya (ASLTK)

While the conferences are a professional development highlight, there has long been a group of SLTs who met in Nairobi on a more regular basis to share case studies, to discuss professional issues, and to provide support for one another in relation to their work. Bea recalls:

> I lived in Kisumu, but I often tried to schedule my work travels to coincide with the monthly SLT meetings in Nairobi (a nine-hour bus journey). I enjoyed the shared expertise, as well as getting to know the other clinicians. It certainly helped me contextualize the work I was doing in rural communities.

The eventual establishment of this group as the ASLTK was a major milestone and achievement heralded in by Jessica Halley. The association's constitution was submitted in November 2012 to the Registrar and celebrated at the fifth East African Conference in Communication Disability in Mombasa in 2013.

In 2014, Poonam Shah formulated the "Newly Qualified Practitioner Competency Checklist," based on similar documents from other countries. In order to make membership accessible, ASLTK is committed to keeping membership costs as affordable as possible. ASLTK as yet does not have any administrative support for the running of the organization, meaning that all duties are carried out by members in their free time.

At present, ASLTK does not regulate the profession, and it is not mandatory to be registered with ASLTK to practice in Kenya. ASLTK is now mainly comprised of Kenyan SLTs that have trained in the USA, the UK, India, Australia, and New Zealand. Member SLTs join ASLTK to participate in the professional SLT community in Nairobi. Through ASLTK, members run professional development events, support and supervise each other, and work toward increasing awareness of the profession and getting it recognized by the government. Risha notes that:

> ASLTK has been at the forefront of widening the perception of SLT in Kenya through spreading awareness, aided by the representation of ASLTK members at community events. For example, a number of members of ASLTK have participated in awareness campaigns for various types of disorders as well as communication difficulties (e.g., autism, Down syndrome, voice, aphasia, stuttering etc.) by presenting talks or workshops and carrying out radio/TV interviews usually with individuals with communication disabilities and their families.

Some of these media spotlights have been in local languages other than Kiswahili/English. Emma also remembers a committee member of the Nairobi Stammering and Cluttering Support Group being interviewed about stuttering by a national newspaper, which published both their mobile numbers – resulting in continual calls on both phones for several days, reflecting the strong need for SLT services. A group of people (mainly rural farmers) with laryngectomy were also on the national evening news during their intensive residential therapy course.

Having a properly registered professional organization in place was the first step toward SLT becoming formally recognized as a profession within Kenya. Building awareness about the association and the profession has since been ongoing. The ASLTK Facebook page and blog has certainly made it easier for people to find out about SLT and the availability of services in their area. Bea recounts:

> It is easy to take your professional association for granted when you always had one you could rely on. I had a newfound appreciation for the work of the American Speech and Hearing Association when I lived and worked in Kenya, where we could not rely on a professional association for advocacy, best practice guidelines, or as a general resource. Starting an association is a tremendous amount of work, and I regard it a remarkable achievement by all those who made it happen.

The required bureaucratic work is ongoing. Grace Macharia (current chair of ASLTK), Doris Kwenda, and Nancy Mwangi have worked on the Scheme of Service with officials from the Ministry of Health and Department of Personnel Management (Kenya government). This Scheme of Service will enable professional recognition in Kenya. The aims and objectives of the Scheme of Service are:

- A well-defined career structure which will attract, motivate and retain suitably qualified SPEECH AND LANGUAGE THERAPISTS in the civil service;
- To provide for well-defined job descriptions and specifications with clear definition of duties and responsibilities at all levels within the career structure to enable SPEECH AND LANGUAGE THERAPISTS to understand the requirements and demands of their jobs;
- To establish standards for recruitment, training and advancement within the career structure on the basis of qualifications, knowledge, merit and ability as reflected in work performance and results;
- To ensure appropriate career planning and succession management. (ASLTK, 2016)

Coordination with the Ministry by Dr. Mathew Kinyua Karia, Grace Macharia, and Doris Kwenda is ongoing. Per reports, the Scheme of Service can only be accepted once there are greater numbers of qualified clinicians working (around 200). The government has promised to take into consideration a projection of the SLT students who will graduate from the SLT training courses at Kenyatta University and Moi University and who will need to be employed. SLT is on the government's radar, evidenced by the Minister of Health reportedly voicing his concern about the

lack of SLTs when launching the Ministry's strategic plan.

It will be essential for ASLTK to lobby for the creation of government-funded SLT positions in urban and rural settings. Having government positions that cover a basic salary for SLTs will mean that families who cannot afford private therapy will have greater access to services. In an era when SLT services are increasingly being privatized (e.g., in Australia, the USA), advocating for publicly funded allied health services is likely to be an ongoing challenge for the profession.

The registration of ASLTK was a major achievement for the clinicians working in Kenya, though it was not the beginning of the story. The first conference happened 7 years prior to the registration of the association and 9 years before the start of the first training course. ASLTK's registration happened before there was a training course. We reiterate this timeline to highlight that there was no linear progression of activities for the development of the profession in Kenya. During some time periods, professional activities accelerated, and at other times, there was little activity and/or it was difficult to get responses from stakeholders. Furthermore, most professional activities have been organized with very little funding, and monies were typically gleaned from individual donors or organizations.

Establishing SLT Training Programs: 2014 Onward

Emma Osei-Mensah[16] arrived in Kenya in 2014; she writes: "given the ratio of SLTs to population, it is surprising how many people knew what SLT was by the time I got there…There must have been a lot of good PR going on!" She continues: "during the two years between 2014 and 2016 there was a notable shift from SLT being something that foreigners come in and do, to something that Kenyans want to do for themselves."

This is a poignant quote that captures the change in perspective that has occurred in the profession in recent years. SLT is increasingly seen as a Kenyan profession. With this altered view and ownership came the opportunity for the discipline to develop in a way that truly reflects and responds to the unique context in which SLT clinicians are working, as advocated for by Wylie et al. (2013).

In 2018, there are two established Masters-level SLT training programs in Kenya. The first SLT training program was started at Kenyatta University in Nairobi in 2014. Kenyatta University currently has 37 enrolled students and 3 students interested in a PhD program. Kenyatta University is collaborating with Prof. Ulrike Lüdtke from Leibniz University Hannover, Germany, to provide foreign SLTs to help in training and staffing a hospital clinic for Kenyatta University's students. Clinical supervision is also being provided by Kenyan SLT Lorna Muthamia at Gertrude's Garden Children's Hospital.

There is a second SLT training program at Moi University, located in Eldoret (Western Kenya), in partnership with Linkoping University (Sweden). Janna Aanstoot (an SLT and lecturer from Linkoping University) is coordinating the program and started this postgraduate SLT course with three students, who were all experienced at working with children with special needs. All three students were close to completion of their degrees in 2018.[17] One of their soon-to-be graduates has been hired by the Kenya Institute of Special Education to teach speech therapy, another is completing further training in head and neck cancer in India, and the third has returned to their role at Moi Teaching and Referral Hospital in Eldoret as an occupational therapist. The future of this program is uncertain as Janna has returned to Sweden and no further students have been enrolled in the program.

One of the main challenges of the program at Moi University was getting clinical training for students, given the few SLTs in Kenya. In

[16] Emma Osei-Mensah is a British SLT who moved to Nairobi with her husband in 2014. During her 2 years in Kenya, Emma was able to provide some mentoring for her Kenyan colleagues and input into the training of Kenyan SLT students. She was also involved in drafting various documents related to the registration of the profession, as well as working at Nairobi Hospital and Aga Khan University Hospital.

[17] One student has submitted her dissertation; the other two students had not submitted their research at the time of writing.

February 2016, the SLTs in Nairobi organized a week of hands-on clinical experience for these students. Emma Osei-Mensah shares that it was a "thoroughly enjoyable and stimulating experience, helped by generous patients and their families."

Both these courses are imperative for growth of the profession, as they will graduate the future SLTs who may in turn be called on to support and develop the programs, as well as act as the clinical lecturers.

Speech–Language Therapy in Kenya: A Contemporary Perspective

Ongoing Challenges

Issues of Language

One of the biggest challenges for the profession of SLT in Kenya, like other multilingual societies, is the diversity of languages and dialects spoken in the country. Although Kiswahili and English are the official languages of Kenya, and most people who have been primary school educated speak both, estimates about indigenous languages vary from more than 30–60 (Bunyi, 1997; see section "Introduction"). Members of ASLTK speak Kiswahili, English, Luganda, Dholuo, Kikamba, Kutchi, Kikuyu, Gujarati, and Hindi. The SLTs working in Kenya typically try to accommodate their clients' mother tongues where possible by referring among themselves.

The presence of the United Nations and other international aid organizations in Nairobi, as well as health tourism as a developing sector, and Nairobi's position as a tertiary health referral center for the entire East African region, means that expatriate clients arrive with a whole array of global languages. Hospital-based SLTs commonly encounter the need to speak French, Kinyarwanda, Somali, and Sudanese Arabic. Unfortunately, there are very few resources[18] that we know of which have been standardized in an East African context, let alone translated (both linguistically and culturally) to serve as appropriate assessment tools or treatment materials.

While a majority of urban Kenyan families are multilingual, it is always likely to be a challenge to provide services and materials in a client's mother tongue. SLTs working in Kenya often have to engage informal translators, as certified translators are rarely available. Family members usually accompany clients to appointments with SLTs and act both as translators and informal SLT assistants, carrying out much of the therapy at home.

Building Awareness About the Profession

Working in the SLT profession in Kenya can be challenging given the many roles and responsibilities clinicians are expected to take on. Building awareness about what SLTs do has been an ongoing task occurring in tandem with the increasing demand and availability of SLT services. Risha notes that people generally think SLTs have a limited role, namely, "helping someone who cannot talk properly, like a person who stammers."

General knowledge about the profession and the ways SLTs work is only partial and often inaccurate. The lack of awareness surrounding the profession includes:

1. Limited understanding about the significance of speech and language as components of a child's overall development
2. Knowledge about the challenges faced by individuals with communication difficulties
3. The knowledge that communication disorders can be acquired (e.g., epilepsy, due to stroke, etc.)
4. The knowledge that SLT support exists.

Emma carried out a survey in response to a worldwide request for World Voice Day 2011 and found there were not even words in Kikuyu, Kiswahili, or Gujarati for "vocal cords." Thus, when translating the survey, they had to describe the vocal cords and what they did, which defeated the purpose of one of the questions.

What we do and how we do it will be an ongoing project in educating community members as well as health and education professionals. Bea

[18] SLT Lynne Masaki did develop a Kiswahili articulation screening tool and began the process (circa 2008).

remembers that when she was training teachers from the Kenya Institute of Special Education in 2007–2008 about the use of speech and language strategies in the classroom, there were frequent requests for a "speech kit." This seemingly mysterious speech kit was something that had been developed and distributed many years earlier. It was basically a big wooden box that contained a mirror, some straws, feathers, and a few other bits and pieces. Even after a week-long training about speech and language disorders, there were still requests for this speech kit. The idea of a tool or kit that could fix problems was just too compelling to be achieved with a week of training about strategies to promote speech and language development.

In the hospitals in Nairobi that have had a longer SLT presence, a variety of medical professionals (e.g., nurses, allied health therapists) now refer to SLT appropriately. Risha notes that:

> [I]n the past, speech therapy had been sought mainly in private hospitals through referral from a doctor. They are starting to come in now because clients and their families find out about the work of SLTs through colleagues, friends or the internet.

SLTs will need to continue with advocacy work for individuals with communication disorder. For example, Reyhan and Emma had to intervene for someone with a stutter who was refused a visa to study overseas as their dysfluency was misunderstood as dishonesty about their reasons for traveling. At other times, SLTs have been called upon to intervene for individuals who were rejected for jobs due to their stutter. Hospital-based SLTs often have to advocate for young people who have suffered a stroke or head injury and wish to return to work or study.

There is clearly work to be done in building awareness about the profession, but we are making progress with each year that passes. For example, the implementation of accreditation processes has led hospitals to follow guidelines set by the International Organization for Standardization or the Joint Commission International, and this has led to an increased number of referrals to SLTs, for persons with stroke and dysphagia.

Furthermore, as the variety of services SLTs provide in Kenya increases, so does the visibility of the profession and hence awareness about what SLTs do. For example, Grace Macharia is a part of a cochlear implant team, which is also comprised of three Kenyan surgeons (Prof. Macharia, Dr. Din, and Dr. Asmeeta Patel), three audiologists (Serah Ndegwa, Zachary Wanjohi, and Joseph Ayiego), and one auditory rehabilitationist (Natasha Nanji). Between 2012 and 2018, there have been 30 successful cochlear implants, with local rehabilitation services provided since 2012. This is a developing area with increasing referrals which crucially need SLT support.

Reportedly, many children are going to India for implants and presumably requiring rehabilitation and follow-up when they return home. Starkey Hearing Foundation, which donates hearing aids to children with hearing impairment, has started using local SLTs to train teachers and parents to develop verbal communication, with the aim of mainstreaming these children in schools and society.

Issues of Access

Even if a client with a communication disorder knows about the SLT profession and knows where to find a practicing SLT, most Kenyans will have to travel extremely long distances to get help if they can afford it. Because SLT services tend to be clustered around Kenya's urban centers (Nairobi, Mombasa, and now Kisumu), this limits access to services, and even those who are able to commute are unlikely to do so regularly for ongoing therapy. Lack of funding for services and transport are major factors impacting an individual's ability to access help for their communication disorders.

For those living in urban centers, the challenges of access may be due to the increasing costs of living and the unpredictability of traffic, which means travel times can vary widely. SLTs often have to continually rearrange their schedules for clients arriving very early or very late (sometimes days late if they are coming from rural areas).

However, things look bright for the future, as newly qualified practitioners from the university training programs will certainly bolster the available workforce. Furthermore, graduates of the

Moi University course may remain in Eldoret or other parts of Western Kenya supplementing services already available in that region through Yellow House Health and Outreach Services (who see clients in Kisumu, Kakamega, Vihiga, and Mumias).

Also, Internet services continue to improve with individuals increasingly able to use their phones as small computers. Even when families do not have their own mobile phone, they are relatively cheap in Kenya, so they may have access to one in the community. Elisabeth reported she was able to follow up with voice therapy clients using Skype to save 4 hours of travel time. Also, for voice therapy practice, she often used to record on patients' mobile phones, so they could rehearse voice exercises while in the ubiquitous Nairobi traffic jams. It was imperative for Elisabeth's SLT role to include encouraging self-monitoring and responsibility for progress. Younger patients came with their USB sticks, onto which she saved video recordings of their sessions.

Creative solutions aside, in the absence of SLT services, there has been a history of unqualified practitioners offering "SLT services." Examples noted by ASLTK members include an occupational therapist carrying out oral-motor exercises as the primary therapy for both a child with autism and with an adult with aphasia! Rehana comments:

> Cultural/traditional practices still have a big impact on way of life and hence healthcare/healing. As a result, SLT intervention may be sought at a later time, after more "traditional practices" have been exhausted. For example: I once had the mum of a child with cerebral palsy come to me for advice. She had been told that cutting his frenulum would solve his speech difficulties. This mother had seen improvement in her son's speech with SLT support and had access to SLT services, so was able to make a more informed decision about cutting her child's tongue.

Because most Kenyans do not have access to professional advice and services, Rehana notes that families "will do whatever it takes in an effort to help their child." Emma reiterates this point:

> People without access to services may spend whatever they have available on whatever is suggested to them in the hope to find an answer. For example, a lady living in Nairobi (from a very educated family) with LIS (locked-in syndrome). Her family had spent all their money on Chinese herbs to heal her instead of seeking help from a SLT (which would have been considerably cheaper).

Issues of Payment

When Elisabeth first came to Kenya, she noted that:

> [A]t Kenyatta National Hospital only basic inpatient and outpatient healthcare was available, and all patients had to pay for medication and therapies out of their pocket. Clinics had (and still have) very full waiting rooms from very early in the morning. The most difficult situation was/is upcountry where patients are dependent on well-wishers (basically family, friends and neighbors) to pay for their medical care. But in Kenya there is a tradition of "Harambee" where communities get together and share stories, and collect the money needed to cover the cost of doctor's expenses, or a funeral, or a child's therapy.

It wasn't until much later that financial health insurance companies started to come on the market to provide financial coverage for physiotherapy, occupational therapy, and SLT. This meant that some clients with health insurance cover through their employment were able to access inpatient care in private hospitals. Doctors would keep patients with communication- or swallowing-related issues in hospital for an extra day or two to allow them to access SLT services.

For individuals with long-term communication disorders (e.g., individuals with cerebral palsy, hearing impairment, stroke, Parkinson's disease, or laryngectomy), it is an ongoing challenge to find the funds for services, medications, and equipment/devices (e.g., hearing aids, batteries, and percutaneous endoscopic gastrostomy tubes which need to be replaced every few weeks). Often parents, partners, or family members have to negotiate the financing and thus the course of therapy on behalf of the patient.

This is particularly challenging for SLTs in private practice and requires creative approaches to treatment to maximize the effectiveness of the treatment while minimizing the equipment, medical costs, and time taken. For example, while appointments with the SLT might occur monthly,

additional daily "sessions" are carried out by a family member or friend.

Poonam reiterates that the challenges presented for SLT clinicians are many, when the majority of Kenyans are not able to afford SLT services and few insurance companies cover SLT services (and limited sessions even if covered). As a practicing professional SLT, she notes that it is difficult to plan for and predict her income and working in multiple sites certainly has an impact on clinical efficiency and viability.

Resources and Innovations

Dynamic and Creative SLT Practices

Working in Kenya has revealed a wide variety of disorders and difficulties, yet because there are so few SLT clinicians, clinicians typically lack the opportunity for specialization (e.g., focusing as a voice therapist). This is born from the need for therapists to be able to deal with everyone who walks through their door, including a range of ages and diagnoses. Emma Shah reports having multiple diagnoses to contend with such as human immunodeficiency virus (HIV)-related infections (e.g., cerebral toxoplasmosis or cytomegalovirus) prior to the use of antiretroviral medication, gunshot injuries, and other functional/non-organic presentations (e.g., aphasia or elective mutism). Most Kenyan-based clinicians have to have a mixed bag of therapeutic strategies as well as tools to work with different languages and cultural groups. This has necessitated strong connections and communication between clinicians, so that SLTs can support each other informally with resources and shared learning.

The Kenyan context provides opportunities for SLTs to think about their professional work and support individuals with communication disorder and their families to maximize impact. Wylie et al. (2013) made a call for "new approaches to service delivery," which are "culturally relevant, holistic, accessible, sustainable, and responsive and give due consideration to the types of service recipients, the level of intervention targeted and the agent of service delivery" (p. 9). We see ASLTK members are doing the kind of work suggested by these authors.

Support groups have been developed as one of the ways the SLT community can help meet the needs of adults with communication and swallowing disorders (e.g., Kenya Association of Laryngectomees). Due to the importance of religion for many Kenyans, it is common to have religious leaders involved in self-help groups, which builds group cachet and increases an individual's desire to participate. Some groups have meetings in church buildings – for example, the Nairobi-based Parkinson's Group meeting at Consolata Shrine in Westlands, which includes senior Muslim and Christian religious leaders as well as Christian, Muslim, and Hindu members from all backgrounds. The accessible location and clerical involvement in services supports members and builds community awareness about communication disorders.

Lorna Muthamia-Ochido has set up the Centre for Child Development and Education in Nairobi offering services at a variety of locations. Lorna has addressed the lack of SLTs by hiring and training speech–language therapy assistants (SLTAs). Emma notes that good SLTAs are invaluable, both clinically and as cultural brokers. Emma reports there were times when the SLTAs helped correct SLTs' use of Kiswahili and taught strategies to families in more culturally appropriate ways. For example, Grace Kagiri (SLTA) taught diaphragmatic breathing to an older lady from a rural area (with dysphonia) by using the analogy of blowing on a fire. As the number of SLT clinicians increases in Kenya, it will be interesting to observe the ways in which services are implemented, particularly as access to technology improves, as discussed below.

Harnessing Technologies

Technology has typically been one of the challenges of SLT practice in Kenya. For example, recounting her earlier years in Kenya, Elisabeth writes:

> I learnt the value of shifting from high tech to low tech materials for patients. This was crucial given the intermittent access to electricity and internet.

> Despite these difficulties, my parents and patients were very understanding, versatile and patient.

To get a sense of the challenges faced, Emma recounts a story about some of her clients with laryngectomies. These clients could be given a Servox[19] (an electrolarynx) but would often have to travel some distance from home (e.g., to a local church) in order to charge it. Consequently, for people in rural areas, the artificial larynx may be used for "best occasions" rather than as a daily communication device. Bishop Mbogo (Chair of Kenya Association of Laryngectomees) recounts a story of buying milk from a kiosk (a small informal shop). When he raised his Servox to talk, everyone hurriedly ducked as they thought it was a gun!

Improved technology has greatly facilitated communication between clinics and their patients now that mobile phones are relatively cheap. SLTs in Nairobi often communicate with organizations and educators in the home community of children and families. For example, a clinician might directly communicate with district-level Education Assessment and Resource Centers about children who will be under their jurisdiction and also appearing in their schools. Elisabeth recounts:

> I once sent a text about a child via a special needs teacher upcountry … In that message, I asked her to discuss the situation with the parents in their own local language. In Holland this would have been considered unprofessional; in Kenya it was necessary and effective.

Bea remembers that there were colleagues she communicated with primarily via text:

> When I called them, they often couldn't understand me, a result of my accented English, and the poor telephone line. If we made plans by text, I knew they would understand when I was arriving and what I intended to do while I was there!

This fast and relatively inexpensive technology has also made it easier for the SLT community to liaise. For example, ASLTK has a WhatsApp group which enables the members to arrange meeting dates and carry out tasks such as collaborating on documents (e.g., the standards of practice).

Kenyan-based SLTs report a need for visiting specialists to provide training when they are in Kenya, expressing an appreciation for the efforts of the foreign visiting clinicians who do provide professional development when they travel to Kenya. However, it may be that as webinars and trainings become available via the Internet, technology will provide a new avenue for high-quality, continuing professional development. The Internet may therefore be able to override the tyranny of distance for Kenyan SLTs and enable them to access professional development, by breaking down the barrier of high costs associated with travel and training abroad. Currently, webinar services are not available everywhere, as they depend on access to fast Internet speeds and availability of computers and electricity (even in Nairobi!). However, technology will certainly be a key part of SLT service delivery and professional development in the future.

Looking to the Future: Considering the Next Steps

Research and Material Development

As we consider the future of the profession in Kenya, it is clear that more local clinical research is needed. The SLT profession assumes that the milestones of language development are universal, and yet language socialization scholars argue that language develops to service the social communication needs of an individual in a community. Therefore, we might expect differences for children learning different languages, in different communities in Kenya. It would also be extremely helpful to have better incidence data for communication disorders. It is likely that this data exists in hospital records, as well as the intake data for the district-level

[19]These are usually secondhand and reconditioned by the Servox company in Germany. They are typically donated by international laryngectomy associations.

Educational Assessment Resource Centers. Funding is needed, however, to enable the collection and analysis of this information.

Given the service provision constraints described, SLTs in Kenya have historically been stretched for time and energy to devise new assessments and therapy materials. SLTs working in Kenya have to be extremely adaptable and flexible in using available tools; this has often meant quick translations of assessments borrowed from other languages, cultures, and countries, which may not be the best option for the client. Often, donated materials from other countries have culturally inappropriate pictures and items unfamiliar to people living in Kenya. Children have never seen the types of toys, bubbles, or children's books used in the assessment protocols and so may be better assessed with typical household items. Past students commented on their amazement at seeing American SLT Jenny Cox working in a rural area assessing children's language with just a plastic bottle.

There is much work to be done in developing standardized assessments for Kenyan clients, as well as producing replicable evidence-based therapy materials that can be cheaply and easily distributed to therapists who may be in rural areas as well as urban contexts. This will involve partnering with the new university training programs, as well as non-SLT organizations that are already developing culturally appropriate educational resources and translating materials into local languages (e.g., SIL Kenya).

Strengthening and Supporting the Kenyan SLT Community

By the year 2018, there were ten SLTs practicing in Nairobi, one working on the coast and three SLTs practicing in Western Kenya (Kakamega, Vihiga, Mumias, and Kisumu).[20] There are a further three qualified SLTs who are not currently practicing while home with their young children. Though the majority of these SLTs are now Kenyan citizens (of African and Indian descent), the profession is not yet representative of the Kenyan population. Compared to 10 years ago, however, this is a vast change in professional demographics where the majority of clinicians were foreigners.

The two Masters-level university courses are training small numbers of SLTs. While these may not be sufficient to effectively provide services for the country in the short term, Kenya will be in a position of having larger numbers of locally qualified SLTs to plan services appropriately for the future.

Despite previous efforts of individual SLTs, it is only in recent years that the SLT profession in Kenya has gained the traction needed to establish itself as an integral component of the health and education systems of Kenya. This has likely happened because finally there is a small but stable cohort of Kenyan SLTs and their insistent voices are being heard and recognized. The active advocacy of the SLTs currently running ASLTK and the establishment of the SLT training programs have all contributed to SLT becoming a profession that is making an important contribution to the well-being of Kenyan citizens.

A small group of Kenyan SLT advocates was necessary for each of the developments in the profession to become a sustainable reality. That said, there has also been crucial involvement from Kenyan and East African academics in related fields such as special education at Kenyatta and Moi Universities (Dr. Nelly Were Otube and Prof. Geoffrey Kamau Karugu), linguistics (Prof. Hilary Sang and Dr. Tom Abuom), and neurolinguistics/phonetics (Dr. Mathew Kinyua Karia), some of whom have returned from studies overseas, while others have had a long career in Kenya. Furthermore, senior university staff at Kenyatta and Moi Universities have enabled courses to become a reality.

This is not to completely discount the involvement of foreign professionals, including professors

[20] Overall, we know of these 14 practicing SLTs and 4 non-practicing SLTs. Throughout the years, there have never been more than 16 practicing SLTs in Kenya, at any one time, to our knowledge.

such as Dr. Julie Marshall.[21] As Risha says, she would "urge SLT professionals in countries where the profession is developed to continue their work in Kenya through organizations and events, to further education and awareness of the profession."

Furthermore, Risha notes that "there is a great opportunity for universities willing to exchange students between Kenyan universities and other countries universities for experiential placements."

What is most interesting about Risha's suggestion is that she highlights reciprocity between Kenyan and international universities. In the past, international SLT students have come to Kenya, yet their universities have not opened a dialogue about supporting Kenyan SLT students in Canadian, Australian, and British clinical settings. This kind of thinking and action would undoubtedly help develop the skills of student clinicians in both contexts.

Likewise, reciprocal clinical experiences between the developing SLT programs in Uganda, Tanzania, Ethiopia, and Rwanda may also be possibilities for the region in the future. Dialogue between African training programs seems essential as, for example, it is likely that there is much to be learned from the experiences of the Makerere University SLT graduates in Uganda that could direct some decision-making within Kenya's program development.

With SLT training courses now in place in Kenya and the East African region, there will be further developments in the area of research, development of new more relevant assessments in different African languages/"mother tongues" and perhaps new methods of treatment and delivery models which are more suitable and sustainable to the country context. This is anticipated to lead to better-quality SLT services, which are more relevant from a Kenyan perspective. Over time, increasing SLT access across languages, geographical area, and sociocultural groups should become an achievable goal while maintaining quality and standards of practice, which is of paramount importance to members of ASLTK.

Historically, there have been Kenyan SLTs that trained overseas and then stayed in the country of qualification. As SLT becomes economically viable as a profession and more mainstream within the health and education professions, it is reasonable to assume that the internationally qualified diaspora may return to work in Kenya. The presence of ASLTK is also likely to assist such clinicians.

Conclusions

Over the last 45 years, there have been increasing SLT developments within the profession both in Kenya and indeed globally. While there is still only a small SLT presence, some major achievements have occurred in recent years, including the formation of the ASLTK, the development of a Scheme of Service, and the start of two Kenyan SLT university training programs.

Although there has been a great amount of effort put into initiatives and projects by foreign individuals and organizations, which have helped mold and shape the development of SLT in Kenya, the time has come whereby there is enough of a Kenyan professional presence that it will be these Kenyan clinicians who will shape the future. The Kenyan SLT community now have the knowledge and expertise to carve out a different direction for their future if they want to: be it adapting technology, or through the support of religious institutions, and thus creating their own locally distinctive profession that is suitable to meet the unique challenges of the Kenyan context.

While Kenyan clinicians appreciate the support and resources provided by foreign individuals and universities, particularly when it involves specialist knowledge, they too look forward to the opportunity to figure out what the future brings. As the profession develops, the sentiment is one of independence and a firm belief that the direction

[21] Dr. Julie Marshall is on faculty at Manchester Metropolitan University in the Research Institute for Health and Social Change. Dr. Marshall's work involves communication disorders and cross-cultural competence, evidence-based practice, and services for persons with communication disorders in underserved countries. Dr. Marshall has been working with services and clinicians in Kenya and East Africa since 1995. She is currently engaged in research with Yellow House Health and Outreach Services.

will be set by current ASLTK members and the coming generation of newly qualified practitioners.

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6

The Development of the Speech–Language Therapy Profession in West Africa: Over 10 Years of Experience

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Introduction

In 2003, the Ecole Nationale des Auxiliaires Médicaux (ENAM; National School for Medical Auxiliaries) of Lomé (TOGO) launched a training program with an academic degree and a clinical certificate in speech–language therapy (SLT) in Togo. This BA is currently under the administration of a public national health higher education institution and was created in collaboration with many European non-profit organizations (Orthophonistes du Monde and Handicap International) and Togolese ministries. This three-year training program (after the baccalaureate) is located in the only academic medical assistant training center in Togo. The department that provides the training is regionally based and aims to train French-speaking African students. Since 2006, 63 speech–language therapists (SLTs) have been taught in Togo.

African SLTs are facing many challenges. Two major challenges are identifying language disorders and the possible treatment methods (other than traditional therapies) and finding ways to adapt the evaluation tests and tools of SLT for each country, culture, and language.

Project Genesis and Course Design

In West Africa, as in many other parts of the world, persons with disability are largely excluded from the development process and have limited opportunities to get involved in consultation and public decision making. The social representations of persons born with an impairment result from the cultural perceptions of the society they belong to and in which they have multifaceted relationships (N'Diaye, 2000). In West Africa, although persons with disability are rarely excluded from their families or communities, they are consistently considered as unproductive and as having no future. Differences among disabilities are significant. Persons with intellectual or physical impairments are often rejected by others, while those with a communication disability are generally excluded from the development process because their distorted communication impedes their social inclusion (Wylie et al., 2013). It is difficult to believe that their intellectual development could be preserved. Communication in African societies is mostly by word of mouth, where culture and knowledge are usually passed down verbally and social exchanges are based on oral conversations. Telling one's name to a stranger is like giving a present and initiating a real exchange (Manteau, 2001). Deafness and mobility impairments have direct consequences on oral language learning and thus create a real disability. According to the World Health Organization (2012), more than 275 million people are deaf or hearing impaired, 80% of them live in low- or middle-income countries. Malaria, mishandled medicine, noise pollution, and serious accidents are the main causes of deafness in these countries.

Considered as secondary care, sometimes SLT improves access to education and the social integration of persons with language and other communication disorders.

The association known as OdM (Orthophonistes du Monde; Worldwide Speech and Language Pathologists) was established in December 1992 by the Fédération Nationale des Orthophonistes (French National Federation of Speech and Language Pathologists) management board members.

Since its establishment, OdM has contributed to the setting-up of two initial training centers (at professional diploma level) in Lebanon and Togo. These have led to the starting of a local SLT profession, completely adapting to the needs of the countries and indeed the relative regions involved. As a consequence, the Speech and Language Pathology School at Lomé in Togo trains SLT professionals for the entire region of francophone West Africa.

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One non-governmental organization (NGO), Handicap International (HI), has been active in Togo since 1997 and has chosen to focus its work on the training of professionals. The first project was entitled "Capacity Construction in ENAM's Three Departments" and focused on physiotherapy, orthoprosthetics, and SLT. This project also received lots of support from other partners and was considered to be a milestone achievement in the improvement in professionals training in Togo.

OdM has been working on training in Togo since then. A partnership between OdM and HI was initiated in 1999. In October 2000, this partnership gradually became a leader in SLT projects, and this position was eventually filled by an expatriate French SLT. A two-year awareness campaign was then implemented to develop SLT services (hitherto absent from the country) for persons with various disabilities.

The two partners' long-term involvement was conducive to the implementation of another large-scale project in 2003: the first SLT qualifying course in West Africa, inside ENAM, in Lomé, Togo (see Table 6.1).

The initial course curriculum was a copy of the French model; this has evolved over the years and is now adapted to the local context and the specific needs of patients (Topouzkhanian & Mijiyawa, 2013). The teaching missions led to very deep exchanges between the students, who got to discover the reality of their future professional practice, and the teachers, who had to adapt their courses to the local realities they discovered in Togo. It was important to introduce and develop knowledge and skills in the students' frame of reference.

> Training only works if it allows the teachers to wonder about their goals and the way they operate. Humanitarian help can only be considered as a mutual transformation. (Gagnayre & d'Ivernois, 1994, p. 51)

Perhaps more than other humanitarian missions, because they work with communication and language, the SLT missions require knowledge and know-how, the ability to reduce this information, and break and rebuild it according to the human framework: cultural, linguistic, socioeconomic, and ecological (Manteau & Topouzkhanian, 2006).

Implantation of a New Profession Within Western and Central Africa

ENAM on the other hand, since its creation in 1945, has always been the only official and normative academic training center for paramedical staff in Togo and also the only training center for second-level orthoprosthetic technicians and SLTs in the entire West and Central Africa.

At present, ENAM has eight departments, including registered nurses, laboratory technicians, hygiene assistants, massage therapists and physiotherapists, orthoprosthetic technicians, SLTs, sanitation auxiliaries, and pharmacy assistants. The training length has increased steadily and is now set at 3 years. Teaching staff in ENAM are either permanent (these trainers are recruited through a competitive process) or temporary staff. The teaching program is organized into a semester structure, with two assessments during the year.

It is also important to emphasize the international role of ENAM. Take, for example, initial training in massage therapy and physiotherapy, orthoprosthetics, and SLT. Students at ENAM are from several different countries in West Africa (Cape Verde, Sénégal, Burkina Faso, Ivory Coast, and Benin) and Central Africa (Chad, Burundi,

Table 6.1 Funding sources for speech–language therapy trainees at ENAM-Lomé ($N = 63$)

Sources of funding for training	Workforce	Percentage (%)
Government	45	71.5
International organizations	11	17.4
Parents	3	4.8
Specialized centers	4	6.3

Table 6.2 Distribution of speech–language therapists trained by ENAM-Lomé according to country and year of promotion ($N = 63$)

Country	2003–2006	2007–2010	2010–2013	2013–2016	Total
Benin	0	0	7	0	7
Burkina Faso	0	2	0	1	3
Cameroon	0	1	0	1	2
Congo	0	0	0	0	1
Gabon	0	0	1	1	2
Mali	0	0	2	1	3
Togo	10	11	12	12	45
Total	10	14	22	16	63

and Cameroon; see Table 6.2). The impact of a high-quality training course is therefore expended both in Togo and elsewhere in the region, which means treatment to disabled persons can be accessible both in Togo and beyond. Students from outside Togo can also benefit from bursaries from their home countries to support their 3 years' study in Togo. These bursaries are awarded by the authorities in those countries or by NGOs working in the region.

This training department has a national role inside Togo and also an international role around French-speaking sub-Saharan Africa. The programs that train communication disability professionals already have many graduates. All ten Togolese students from the first class graduated in July 2006 with an SLT degree. The second class graduated in 2010. The third class graduated in July 2013 and the fourth in July 2016. The number of SLTs who are practicing in West Africa is increasing steadily (Gascoin et al., 2015). Of these, 63 were trained by ENAM. These trained professionals, who are from different countries in French-speaking Africa, have concretely formed the sub-regional vocation of the ENAM (see Table 6.3 for more information about sex ratio).

From 2007 onwards, HI began a process of gradual withdrawal. By putting in place a number of activities, HI intended to safeguard the long-term impact of training at ENAM. As part of this process, and thanks to the financial support from Co-operation and Cultural Action of the French Embassy in Togo, from 2007 to 2010, the partners were able to set up a series of workshop activities

Table 6.3 Distribution of speech–language therapists trained by ENAM-Lomé according to sex ratio ($N = 63$)

Sex	Workforce	Percentage (%)
Men	46	73
Women	17	27

for ENAM's future, to guarantee autonomous management of the School. The workshop brought together the external partners who had contributed to the maturing of ENAM over the previous years (Topouzkhanian & Mijiyawa, 2013).

The SLT department currently operates autonomously with four qualified Togolese trainers, all of whom have partnerships with French training establishments. They have regular access to high-quality continuous professional development opportunities either in Africa (Institut de Recherche en Santé Publique [IRSP]; Ouidah-Benin) or in France (training of trainers, training in audioprosthesis, doctorate training, and so on), and even in Canada.

This department has gradually gained reputation and fame through its particularity and exemplarity. It is also the first department at ENAM to have a special curriculum that trains students to complete ready-to-submit research work before obtaining the diploma. This was an innovative idea that was later extended to other departments (Koré et al., 2016).

Following the restructuring process of higher education in Togo, since 2013 the ENAM has affiliated with the Faculty of Sciences from the University of Lomé to complete the mission of training professional, graduate paramedics in health sciences. The considerations of setting up a specific master's degree in SLT are in process.

Professional Development and Growth

Over the past 10 years, the SLT profession has become more structured so as to become better known and recognized by local authorities, medical and educational professionals, and the general population (see Table 6.4). SLTs have been actively lobbying the ministries in order to create an official status for their profession and to allow the

Table 6.4 Distribution of speech–language therapists according to their place of professional practice in French-speaking Africa ($N = 100$)

Country	Graduates of ENAM-Lomé	Graduates from other institutions	Non-graduates	Total
Benin	7	2	0	9
Burkina Faso	6	1	0	7
Cameroon	2	3	2	7
Congo	2	0	0	2
Côte d'Ivoire	2	6	0	8
Gabon	3	2	0	5
Mali	3	0	2	5
Niger	0	0	1	1
RDC	0	4	2	6
Sénégal	0	8	4	12
Togo	34	2	0	36
France and Canada	4	0	0	4
Total	63	28	09	100

Table 6.5 Distribution of speech–language therapists trained at ENAM-Lomé according to their place of professional practice ($N = 63$)

Country	Public service employees	Salaried in specialized institutions	Liberal work	Benevolent	Total
Benin	0	3	4	0	7
Burkina Faso	0	3	2	0	5
Cameroon	0	1	1	0	2
Congo	0	0	2	0	2
Côte d'Ivoire	0	1	1	0	2
Gabon	0	3	0	0	3
Mali	0	1	2	0	3
Togo	22	5	0	5	32
Total	22	17	12	5	63

creation of jobs within public health institutions (see Table 6.5). SLTs have also been actively training and raising awareness through non-profit organizations. They are in close contact with medical professionals, social workers, and teachers with whom they are progressively building strong interprofessional collaborations. Furthermore, awareness is being raised toward local populations about SLT through media events and community-based health fairs (Gascoin et al., 2015).

There are currently six professional organizations in the West and Central Africa region, all of which were created recently. In those countries where there are only a few SLTs, such associations welcome other healthcare and health education professionals who also wish to promote the benefits of SLT. These associations manage numerous operations.

In order to have the profession recognized, they contribute to the drafting of official documents that define and frame its scope of practice. Then, those documents are submitted to relevant authorities. They defend the profession's interests and lobby the institutions so that new publicly funded SLT positions are created and that health insurance companies better cover therapy sessions. They develop activities and events that increase the population's knowledge and sensibility toward our field (Gascoin et al., 2015).

Each year, these associations get together and organize the African Speech and Language Days on September 4. They appear on radio and TV to provide information about the field. They also lead awareness campaigns: Each association goes and meets the public in towns and villages in order to explain what SLT is and what types of

disorders it can treat. They usually have early identification clinics on those days to detect pathologies in children.

They also organize events directed toward teachers and medical professionals such as doctors, nurses, and so on. During those events, they explain what language and communication disorders are and how they can be treated. SLTs are sometimes present at international conventions (e.g., ear, nose, and throat conventions), also raising awareness about the field.

Finally, those associations strive to develop and improve the quality of care that they provide as SLTs. They organize meetings during which they discuss clinical practice and set up training sessions designed for licensed SLTs that cover new methods and research findings in order to reinforce skills.

Creation of the Fédération des Orthophonistes d'Afrique Francophone

In July 2016, SLTs from five different countries gathered in Togo to celebrate the first 10 years of SLT in the region. On that day, the Fédération des Orthophonistes d'Afrique Francophone (FOAF; Francophone-African Federation of SLTs) was created (Association of Professional Speech Therapists of Togo [ASPOT], 2016).

Today, the FOAF, headquartered in Lomé, is composed of ten SLT associations from ten different Francophone African countries. Its goal is to promote SLT by coordinating its members' initiatives. It thrives toward better recognition and grounding for the profession, toward promoting the quality of care provided by SLTs, toward reinforcing SLTs' scope of practice, and toward adapting diagnostic and therapeutic tools to the African culture.

Upon its creation in 2016, it recommended the following guidelines:

- Reinforce SLTs' scope of practice and skills by creating a structured continuing education program and by analyzing each country's specific practices.
- Provide adapted diagnostic and therapeutic tools that match the African sociocultural context.
- Set up, in each country, a technical committee in charge of monitoring the quality of its practice.
- Set up, in each country, a public awareness program.
- Conduct lobbying and advocacy campaigns geared toward each country's authorities in order to increase the profession's recognition and grounding.

As practitioners started taking off in the field and with the various events organized by ASPOT, SLT has become increasingly better known, and the requests for SLT training are continually increasing. However, the Togo's school can only offer a limited number of registrations (Koré et al., 2016). This emerging problem is discussed in the section below along with further challenges.

Challenges to Take On

African SLTs have to face many challenges because the context in which they work has several specificities:

1. Oral tradition and the significance of cultural beliefs
2. Importance of raising awareness about language and speech disorders
3. Advocating for the recognition of the profession of SLTs by the governments of French-speaking African countries
4. Regulating SLT practice in Africa
5. Working in bilingual and multilingual settings
6. Adapting diagnostic and therapeutic materials
7. Promoting scientific research on SLT in Africa.

Oral Tradition and the Significance of Cultural Beliefs

Oral tradition is very much alive in Western and Central Africa. A speech and/or language disorder

very negatively impacts one's social life. Additionally, alternative modes of communication are only seldom accepted and integrated (Ate, 2006).

Furthermore, traditional beliefs still shroud many handicaps or speech/language disorders with spiritual connotations. Disorders such as stuttering or a stroke are believed to be linked to dark spells cast by malevolent family members. Shame weighs heavily on those families with handicapped children, sometimes to the point of completely hiding a child away from sight.

Traditional medicine is still very present: Families are taken care of by healers who cure those evils that manifest themselves through language disorders or strokes. It is not rare for traditional and modern medicines to be used simultaneously. In relation to the transmission of medical knowledge, health education may frequently clash with beliefs, behaviors, or values conveyed by popular wisdom (e.g., cutting the lingual frenulum when a child starts talking late and inserting hot stones under the tongues of children with a stammer).

Education may be perceived as incursions from an unfamiliar medical system (Masse, 1995; Tison & Hervé Desirat, 2007; Chapron, 2002). Popular wisdom needs to be considered by health professionals, including SLTs, for them to be able to strategically and culturally adapt their direct and indirect practices regarding prevention, detection, family guidance, and aid for the helper, to the context (cf. Empowerment Theory, Talbot, 2003).

Finally, many handicaps such as autism or dementia are usually detected later in life. Our fellow SLTs from Africa are challenged by several difficulties in their everyday practice.

Importance of Raising Awareness About Speech–Language Disorders

In order to weave a perennial collaboration between SLTs and other healthcare professionals and to enable the latter to appropriately refer their patients who present with language or speech disorders, the first awareness events led by the ASPOT were at first conducted alongside medical and paramedical professionals. It was a long and arduous path given the fact that some of these healthcare professionals were still used to such cultural practices as cutting the lingual frenulum. Lingual frenulectomies were indeed systematically practiced whenever a language or speech disorder was suspected. This is how the attitudes adopted by certain physicians toward children presenting with language or speech disorders prevented early language and/or speech therapy services to be delivered.

Healthcare professionals were therefore educated about speech and communication disorders, their etiologies, manifestations, and the best approaches used to support a child who has a speech disorder.

In order to raise awareness about the domain of SLT and speech and communication disorders, the ASPOT organized several meetings and produced promotional items displayed during events happening on the African Day of Speech and Language Pathology (Journée Africaine de l'Orthophonie), which takes place on September 4 (see section "Professional Development and Growth"). It was indeed on the September 4, 2003, that an official bill was validated by the Ministry of Education, officially opening Togo's first SLT school. To this day, it is still the only such school within the entire sub-Saharan Francophone Africa. The first African day of SLT happened in 2014.

Awareness ventures were also designed specifically for teachers to help them better understand what language, speech, communication, and learning disabilities are. That way, they would be able to refer those students who might need to be seen by an SLT.

Within the context of raising awareness about SLT, screening "fairs" were set up in two different regions of the country (the Central and Kara areas). These fairs offered screening for speech, language, and communication disorders as well as parent counseling sessions. They identified around 551 children who presented with speech, language, or communication issues. They also provided follow-up appointments so that these children could keep improving their communication skills.

Access to care is difficult, because of the few practicing clinicians as well as because of the low financial status of most of the population. It is

necessary here to remind you that few people there have any sort of medical insurance that could alleviate the cost of going to a therapy session and of the session itself. Setting up a recurring, month-long therapeutic plan is therefore arduous.

As mentioned earlier in this chapter (see Table 6.5), to this day, few SLTs are publicly employed. Such positions are rare and only exist in Togo, with the exception of Congo Brazzaville, where a position for one publicly funded SLT practitioner was recently established.

Advocating for the Recognition of the Profession of Speech–Language Therapy by the Governments of French-speaking African Countries

SLT associations in West and Central Africa face numerous challenges: First, a lack of financial means limits their reach. The associations all lead their events without any kind of public funding. The work they do is important, but it is sometimes difficult to recruit willing therapists who want to get involved.

Despite all of those hurdles, the associations are led by strong dynamics and oversee ambitious projects. They have succeeded in implanting SLT in their respective countries and across the African continent. They meet whenever possible in order to exchange knowledge and ideas and to work together.

In fact, apart from Togo, where the state officially recognizes the corporation of SLTs, Benin, Burkina Faso, Cameroon, Congo, Gabon, and Mali have not yet formalized SLT in public health establishments. This does not allow them to pass public service competitions as is the case with other health professions.

Regulating Speech–Language Therapy Practice in Africa

SLT procedures are, for the most part, paid for directly by patients. However, these acts are more and more recognized by private insurance that reimburses up to 80% of the rate of each session. In Togo, in addition to private insurance, public insurance, set up by the government, recognizes and reimburses 80% of the cost of SLT services.

All SLTs have noted the need to have an appropriate nomenclature of speech procedures. This will make it possible to have the same language, to better express the speech–language diagnosis to standardize our practices and to make African SLT better known to the decision-making and reimbursement bodies of the SLT profession.

Working in Bilingual and Multilingual Settings

One of the foremost challenges is clearly multilingualism: Numerous languages are spoken in each of these countries. For instance, in Togo, a small, seven-million people country, 42 vernaculars are daily used. Schooling is provided in the official state language, a language that is rarely the children's native tongue. Different ethnicities cohabit in each country, each with its own unique culture. SLTs must include this factor in their practice (Abalo & Topouzkhanian, 2007).

SLTs are therefore faced with numerous pitfalls in this very particular linguistic situation and with recurrent questions about the acquisition and mastery of the languages involved: In which language(s) should one assess a bilingual or multilingual patient? How can one provide therapy to a patient with whom one does not share a common language? Is a complete mastery of the patient's language necessary to offer therapy? How should SLTs conceptualize the presence of the interpreter as a third person within a therapeutic situation? Is it sufficient to rely on an interpreter for the translation of the tests used in an SLT assessment? How should SLTs proceed in the case of lexical differences between the two languages? (Topouzkhanian & Mijiyawa, 2013).

Working in bilingual and multilingual settings requires SLTs to involve families in these educational projects; educationalists who themselves

originate from these various ethnic groups can of course also help with this development (Manteau & Topouzkhanian, 2006).

Adapting Diagnostic and Therapeutic Materials

The SLT assessment tools available from African SLTs are all imported from Europe, particularly from France. These tools being developed on monolingual populations have not been adapted for the African populations. Their use would lead to biased diagnoses. Together, these SLTs work toward the creation and adaptation of screening methods, diagnostic tools, and therapy items which are adapted to their own cultures and to the languages that are spoken in each country:

- The first tool "Oral Language Evaluation Togo" (BILOTO; Abalo et al. in prep.) is in its final phase. It will be used to assess language skills in children up to 6 years of age, in three languages (French, Kabyè, and Mina; see Figs. 6.1 and 6.2).

Fig. 6.1 Sequencing task adapted to the African context. (BILOTO; Abalo et al. in prep.)

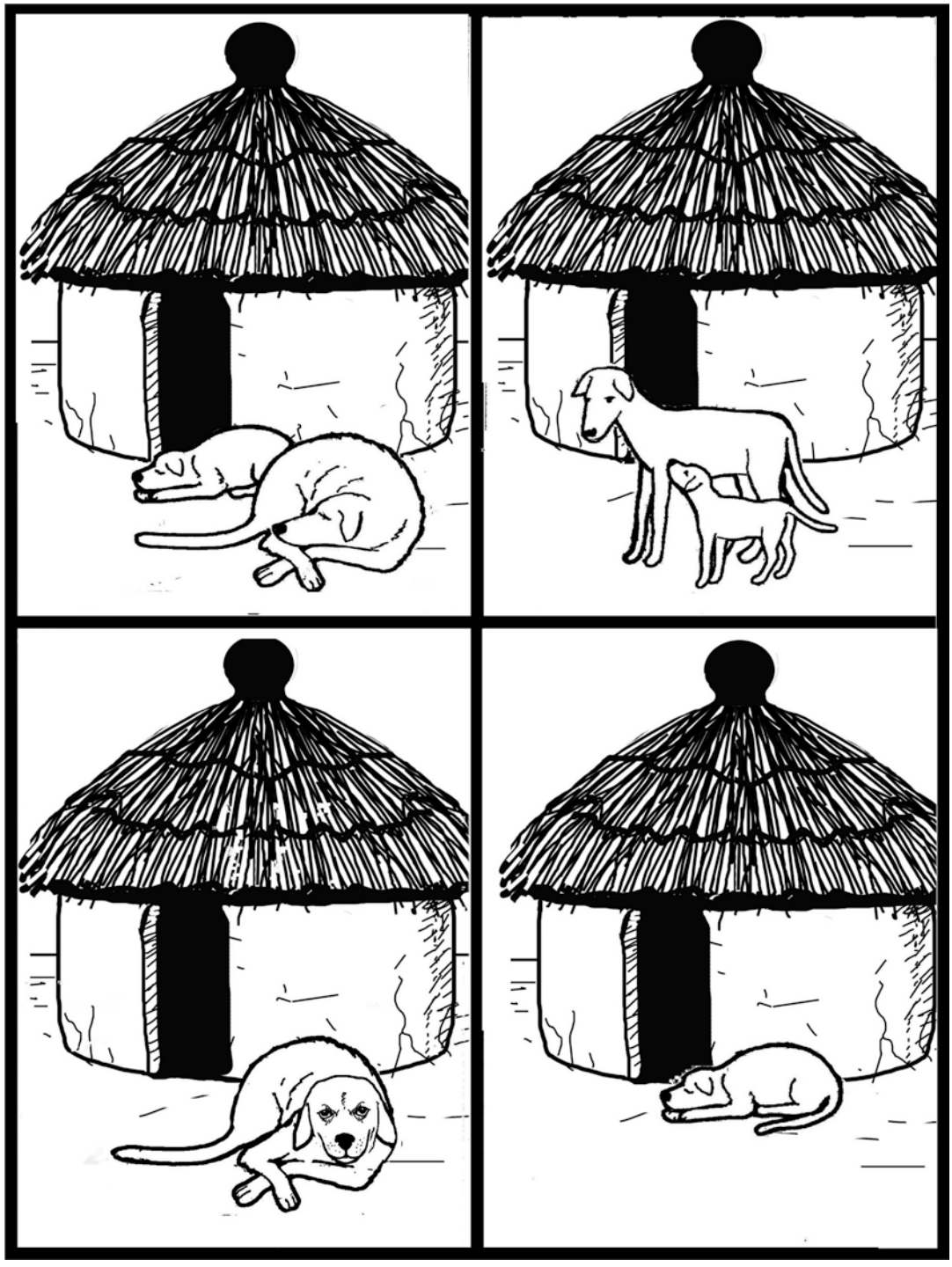

Fig. 6.2 Naming task adapted to the African context. (BILOTO; Abalo et al. in prep.)

- The Montreal Toulouse test (Protocole Montréal-Toulouse 1986, MT 86; Nespoulous et al., 1986) used to evaluate aphasia is in the calibration phase.
- The Oral Language Evaluation (Evaluation du Langage Oral, ELO; Khomsi, 2001) test that assesses the oral language of children aged 4–9 years is in the phase of the adaptation of items and illustrations.
- The Boston Diagnostic Aphasia Examination (BDAE; Goodglass & Kaplan, 1972) is being assessed in relation to use with the Togolese population.

Promoting Scientific Research on Speech–Language Therapy in Africa

This research will collect and centralize data on SLT. The processing of this data will provide relevant information for setting up future projects, advocating, and making decisions. It is from this perspective that ongoing training is organized periodically with our French partners (Orthophonistes du Monde, Claude Bernard Lyon 1 University, French SLTs' Research Association UNADREO, and so on).

In August 2018, the first international scientific congress of SLTs in Africa took place. This conference looked at the issues and challenges of specific language and learning disorders in Africa. This first international scientific congress was a great success because of the quality of the 250 conference participants and the relevance of the discussions. At the end of the congress, several challenges were formulated as described below.

FOAF should encourage the creation of associations promoting the SLT profession in other African countries. It must accompany the efforts to create, adapt, and disseminate SLT assessment and intervention materials.

The governments of African states must make efforts to regulate the practice of the SLT profession in African countries by adopting regulatory texts and by ensuring compliance with the rules of ethics and professional conduct. They also need to implement inclusive education strategies, including those concerning communication disorders.

Universities and training institutions in SLT must closely involve FOAF and local SLTs in the process of creating new schools and courses in SLT. The FOAF must, in turn, establish partnerships with universities and training institutions in SLT to develop training curricula adapted to the African sub-region. They must also plead for the evolution of the career of SLT by creating a Master's course SLT in African countries where initial training in SLT is accredited and well linked.

Conclusion

The FOAF is also intent on raising awareness about the profession across the whole African continent to boost its development. New schools that train SLTs will probably open their doors in the upcoming years throughout Western and Central Africa. Consequently, the number of SLTs will increase, and patient care will develop.

Creating an African SLT profession (according to its own standards), which proceeds to have a real influence in West Africa, opens great future opportunities in favor of the schooling, social, and occupational integration of persons with communication disabilities.

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7

A Revolution in Training Speech-Language Therapists in Sub-Saharan Countries and Globally

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Introduction

Tragically, many individuals with a communication disability in sub-Saharan Africa (SSA) are not being served because there are not enough trained speech–language therapists (SLTs) to provide services. There are only 12 universities in the whole of SSA that offer higher education training in speech–language therapy (SLT): one program in West Africa, four programs in East and Central Africa, and another seven in Southern Africa. These programs do not graduate nearly enough SLTs to work with persons with communication disability across SSA. For example, SLTs are essential for children with hearing loss to ensure age-appropriate language development, and in SSA, there are approximately 180,000 children each year born with permanent bilateral hearing loss (Swanepoel et al., 2007). Recent research has found an enormous need in SSA for trained SLTs to work with persons with communication disability. A study conducted by Wylie et al. (2012) demonstrated the stark shortage of SLTs in sub-Saharan countries where there is a ratio of one SLT per two to four million people. This compares to high-income countries of the USA, UK, Australia, and Canada where there is a ratio of one SLT per 2500 to 4700 people. Without a marked growth in related higher education training programs, trained SLTs will not be able to sufficiently serve persons with communication disability, who then may be denied the opportunity to communicate effectively.

There are many challenges in training SLTs in low- and middle-income country settings such as SSA, including access to higher education, affordability, customizability to local communities, and sustainability of an educational model. At NextGenU.org, we have created a training model to address these challenges while substantially increasing the number of trained SLTs. We use a workforce capacity-building approach that focuses on training individuals, while engaging in partnerships with individuals, institutions, and universities.

Specifically, we created a Democratically Open, Outstanding Hybrid of Internet-aided, Computer-aided, and Human-aided Education (DOOHICHE) training model. This training model is *Democratically Open*, as it is available to anyone interested in learning more about SLT. It is *Internet-aided and Computer-aided*, as the content of the didactic material and many interactions are accessed through computers and the Internet. It is also *Human-aided*, as the courses are developed by volunteer experts and staff, and professional skills are practiced through peer and mentor activities.

This training model is also useful as it can serve as an entire, separate training program, it can be readily subdivided into modules and other sizes to supplement current training models, and it can be immediately translated into any language offered through Google Translate. The competency-based DOOHICHE training model is uniquely designed to train and accredit individuals for free, through the online transfer of didactic knowledge and by providing professional skills training through peers and mentored interactions in the local or global community. This self-paced model eliminates barriers of affordability, customizability, and sustainability.

We expect to rapidly increase the number of much-needed, well-trained SLT providers in SSA who can work with the growing number of persons with communication disability. Our goal is to train SLTs across SSA and around the world, especially in places where few higher education SLT training programs currently exist.

It is expected that this solution will face some challenges. It is also likely that some of those completing the training will mentor new learners, become agents of change in their country and

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across SSA, gain ground in making policy about persons with communication disability, and form/strengthen professional SLT organizations. In this chapter, we aim to describe how NextGenU.org can create sufficient capacity in the provision of SLT care in SSA.

Problem Background

The World Health Organization and World Bank (2011) reported in their *World Report on Disability* that the global prevalence of disability has increased 10%. While it is unclear how many of these individuals are persons with communication disability, they are included in this global figure. Concurrently, there is also an international shortage of more than four million healthcare workers (Chen et al., 2004). For example, SSA, which comprises 11% of the world's population and has 24% of the global disease burden, only has 3% of global healthcare workers and spends less than 1% of the world's financial resources on health (Anyangwe & Mtonga, 2007). To put this in perspective, USA and Canada together, which comprise 14% of the world's population and have 10% of the global disease burden, have 37% of global healthcare workers and spend 50% of the world's financial resources on health (Anyangwe & Mtonga, 2007). The need for healthcare workers is particularly steep for SSA countries, which would need to triple the number of all healthcare workers, an equivalent of one million, to approximate the Millennium Development Goals (Chen et al., 2004).

SLTs are among the most critical healthcare providers serving persons with communication disability. Recent research has documented the number of persons with communication disability across SSA. SLTs in the sub-Saharan face many heavy challenges in treating persons with communication disability, including healthcare issues such as HIV infection, cerebral malaria, and meningitis that can cause brain dysfunction and affect language development (Alcock & Alibhai, 2013). For example, cerebral malaria has impacted 575,000 children below 5 years of age annually (Bangirana et al., 2006). It is known that speech and language services can improve these children's language skills (Goorhuis-Brouwer & Knijff, 2002). However, there is a lack of qualified healthcare workers such as SLTs to provide these services (Olness, 2003).

Likewise, data have been collected in Uganda and Nigeria showing the presence of persons with communication disability in these sub-Saharan countries. In Uganda, there are five million people with disability, equaling 16% of the population (Ministry of Gender, Labour, & Social Development, 2011). Although no exact number of persons with disability have been reported, we do know that 29% of children with communication disability are unable to attend school and 50% of adults with communication disability do not work (Ministry of Gender, Labour and Social Development, 2011). Furthermore, the overall incidence of newborn babies born in Uganda with clefts is 1.73 of 1000 live births in a 1-year period (Van Lierde et al., 2013).

In Nigeria, it is estimated that 8–30% of individuals have a speech impairment (Nwosu, 2015). A handful of studies have documented these speech impairments. For example, 65% of children with communication disorders (among children aged 0;6 to 15 years) had hearing loss, 30% had a speech disorder, 2% had a nasal speech quality, and 2% exhibited a stutter (Somefun et al., 2006). Additionally, Aremu et al. (2011) conducted an epidemiological study over a 5-year period from January 2005 to December 2009 in north central Nigeria to describe speech and language disorders. There were 89 patients under 5 years, 32 were between 5 and 10 years, 20 were between 11 and 20 years, and two were between 21 and 34 years. Findings revealed that 58% of the clients were diagnosed as deaf or hard of hearing, 21% had delayed speech, 4% had slurred speech, 13% had impaired speech, 3% stuttered, and 1% had aphasia.

Fagan and Jacobs (2009) conducted a survey of ear, nose, and throat (ENT) surgeons in 18 sub-Saharan countries who were asked questions regarding availability of and training programs for ENT, audiology, and speech therapy professionals. Applying the density of SLTs in the UK to the 18 SSA countries would yield a total of 85,525 SLTs. At the time of the survey, there

were 1182 SLTs in these nations. Thus, using this logic, there is an estimated shortage of 84,343 SLTs (Fagan & Jacobs, 2009). Out of these 18 countries, the ENT surgeons estimated that SLT professionals existed in only 13 countries. Of the countries with any SLT professionals, the total numbers were only one, two, three, four, or twelve professionals, with an outlier in South Africa of 1144. This was also the only country where the ENT surgeons stated that there was a training program in SLT (Fagan & Jacobs, 2009).

Many SSA countries face the challenge of insufficient training for professionals locally. In Ghana, approximately ten SLTs had received training in the USA and the UK as of 2013 (Crowley et al., 2013). Additionally, there are non-Ghanaian SLTs who temporarily provide SLT services, primarily private services in Accra (Ghana's capital). There is a total of approximately one SLT per 2.5 million people in a population of 25 million (Ghana Statistical Service, 2012).

Until recently, Kenya depended mainly on US and European expatriates and Kenyans who received training outside of Kenya to provide SLT services (Alcock & Alibhai, 2013). As of 2013, there were nine SLTs in Kenya, all located in the major cities of Nairobi and Mombasa, and who provided SLT services to children. Voluntary Service Overseas paid for two of the nine SLTs (Alcock & Alibhai, 2013). Kenyan SLTs were based in non-governmental organizations (NGOs) and community-based rehabilitation or Education Assessment Resources Centers. Persons with communication disability in need of SLT services are often required to pay privately; this is difficult, as the prices are steep and the professional shortage is sharp. Although approximately 300 children are seen in Mombasa by an SLT and an assistant per year (Jochmann, 2006), children may wait up to 6 months to be seen (Alcock & Alibhai, 2013).

As of 2019, the Kenyan Association of Speech and Language Therapists posted their members on the Internet. This included nine practice SLTs, two SLT assistants, six students at either Moi University or Kenyatta University, and three affiliated SLTs overseas (Association of Speech and Language Therapists Kenya, n.d.).

In Uganda, although SLT services have been available since 1986, non-Ugandans were providing these services (Barrett & Marshall, 2013). Volunteer Service Overseas sent early volunteers to Uganda and expatriates as well as short-term residential SLTs providing SLT services. Even though some Ugandans were being trained in a SLT program at a Ugandan university created in 2008, this small group of trained professionals is not enough to accommodate all Ugandans in need of SLT services (Barrett & Marshall, 2013). For example, a study by Luyten et al. (2016) further supports the need for more trained SLTs, clarifying that the 19 existing Ugandan SLTs cannot meet the needs of Ugandans who live long distances from these clinicians and may require overnight stays to get appropriate services. More recently, an NGO, *Hope Speaks*, with roots in the USA and Uganda, has begun serving children with disabilities and their families across Uganda (Hope Speaks, 2019).

In Tanzania, Comprehensive Community Based Rehabilitation in Tanzania (CCBRT) was established in 1994 and is an NGO providing rehabilitation services to children and adults with disabilities (University of Toronto, 2019). CCBRT grew out of a partnership between rehabilitation professionals at the University of Toronto's International Centre for Disability and Rehabilitation and professionals and Tanzanian community rehabilitation providers. CCBRT serves around 120,000 children and adults with disabilities at a disability hospital in Dar es Salaam and community programs in and around Dar es Salaam and Moshi. In Dar es Salam, it was reported that two internationally certified SLTs were working at Muhimbili Hospital in 2011 (Bowen, 2019). In Moshi, CCBRT refers clients to the Kilimanjaro Christian Medical Centre (KCMC, n.d.; University of Toronto, 2019). Services at KCMC started in 2015 when the KCMC hired an SLT to work in the ENT department. The SLT provides services to children and adults (Kilimanjaro Christian Medical Center, n.d.).

Additionally, Project Abroad provides SLT internships at a rehabilitation center in Moshi that serves children who are disadvantages and is run by an NGO (Project Abroad, n.d.). Interns are

required to have 2 years of relevant studies and are supervised by a qualified local Tanzanian SLT.

Although South Africa has the best infrastructure for health care among SSA countries, particularly for training of SLTs and treatment of persons of disability, it still falls short in its ability to serve children with hearing loss (Swanepoel et al., 2007). Using the United Nations Children's Fund's (UNICEF) estimated prevalence rates of hearing loss, one study determined that 17 children are born every day in South Africa with congenital or early-onset hearing loss (Swanepoel et al., 2009). Yet despite this high incidence, in a country with considerable SLT capacity compared with its immediate neighbors, the average age of hearing loss diagnosis in South Africa is at 2 years of age, well after the typical time of identification in high-income countries (Swanepoel et al., 2009) and well after many ideal early intervention points in infant and toddler development.

In summary, the majority of persons with communication disability needs in SSA are not met by the current number of SLTs, which requires a remedy.

State of Speech–Language Therapy Higher Education in Sub-Saharan Africa

Unfortunately, the shortage of SLTs cannot be efficiently remediated by the very few university traditional training programs in SSA. These university programs require fees and residence in a few major cities in SSA, making training inaccessible for those living in poverty or at a distance. A summary of programs that offer higher education in SLT is provided in Table 7.1. Details are described below by region.

West Africa

Professional SLT training opportunities in West Africa are growing. The first university program was established in 2003 at the École Nationale d'Auxiliaries Médicaux (ENAM; National School for Medical Auxiliaries) in Togo under the partnership between Handicap International and Orthophonistes du Monde (Speech and Language Pathologists of the World; Topouzkhanian & Mijiyawa, 2013). The French SLT program is a post-baccalaureate 3-year program, consisting of 16 modules and practicum placements. In addition to Togolese attendees, students attending this program come from West Africa (Cape Verde, Senegal, Burkina Faso, Ivory Coast, and Benin) and Central African (Chad, Burundi, and Cameroon). As of 2013, ENAM had trained 22 SLTs, who were from Benin, Gabon, Mali, and Togo. Graduates from the second graduating class were selected to become lecturers, and the SLT program now is autonomous (Topouzkhanian & Mijiyawa, 2013).

Since 2008, a Professor and Clinical Supervisor from Teachers College (in New York, USA) has collaborated with Ghanaian educators to provide clinical services and to build SLT capacity (Crowley et al., 2013) using a biopsychosocial model to train teachers to improve the communication skills of children with intellectual disabilities. In January 2012, Crowley and colleagues also presented a workshop on alternative and augmentative communication to Ghana's Unit school teachers. Additionally, in 2009, a SLT taught some speech–language courses within a 2-year master's program in disabilities study at Kwame Nkrumah University of Science and Technology. After several years of discussions with stakeholders, the University of Ghana began planning in 2013 to create a Speech–Language Pathology Program in Ghana (Crowley et al., 2013). In 2016, the University of Ghana accepted its first group of 12 master's students in Speech and Language Therapy (Wylie et al., 2019).

East and Central Africa

There are more university programs in East and Central Africa combined compared to West Africa. Uganda and Kenya are among the first countries in East and Central Africa to have a program or to be in the process of creating a program.

Uganda started a bachelor's degree in Speech and Language Therapy at Makerere University in

Table 7.1 Summary of higher education programs in sub-Saharan Africa

Region and country	University	Name of program	Number of students trained
West Africa			
Togo	École Nationale d'Auxiliaries Médicaux	Speech–Language Pathology Post-baccalaureate	22 (reported as of 2013)
Ghana	University of Ghana	Speech and Language Therapy	12 (reported as of 2016)
East and Central Africa			
Uganda	Makerere University	Bachelor of Science in Speech and Language Therapy	12 (reported as of 2013)
Kenya	Moi University	Master of Science in Speech and Language Pathology	NR
Kenya	Kenyatta University	Master of Speech and Language Pathology	NR
Southern Africa			
Zambia	University of Zambia	Master of Education in Speech, Language, and Communication Disorders	18 (reported as of 2015)
South Africa	University of Cape Town	Bachelor of Science in Audiology and Speech–Language Pathology Master of Science in Audiology Master of Science in Speech–Language Pathology Doctor of Philosophy in Speech–Language Pathology/Audiology	37 24 8 NR (reported as of 2015)
South Africa	Sefako Makgatho Health Sciences University	Bachelor of Speech–Language Pathology	NR
South Africa	University of Pretoria	Bachelor of Art in Speech–Language Pathology Bachelor of Art in Audiology Master of Audiology Master of Speech–Language Pathology Doctorate in Communication Pathology	130 126 NR NR NR (reported as of 2015)
South Africa	Stellenbosch University	Bachelor in Division of Speech–Language and Hearing Therapy	30 each year
South Africa	University of KwaZulu-Natal	Bachelor of Communication Pathology	NR
South Africa	University of Limpopo	Bachelor of Science in Speech–Language Pathology	NR
South Africa	University of Witwatersrand	Bachelor of Art in Speech Hearing Therapy	NR

NR not reported. Dates are reported as of when they were reported online. Information is gathered from online resources and may not be up to date. Partnerships and programs continue to develop

2008 (Merkley, 2010). As of 2013, Makerere University in Uganda graduated 12 SLT students, five were awaiting graduation, and nine were in training. Students from Tanzania, Rwanda, and Uganda were all trained in this program (Barrett & Marshall, 2013). This program has relied heavily on international volunteer lecturers, and a collaboration with the UK's Manchester Metropolitan University provided mentorship and additional professional training for program graduates.

There are now two university programs in Kenya. In a 2010 exchange program with Sweden's Linköping University, three students participated in a 6-week exchange program with Moi University (Eldoret, Kenya) during 2010 (Mwenda, 2012). Since then, these universities have collaborated to

offer a Master of Science in Speech and Language Pathology at Moi University, described as a full-time, four-semester, 2-year program where the first two semesters are coursework-intensive, the third semester is a clinical practicum, and in the fourth semester, students conduct a research project (Lingua Tinga, 2015). Recruitment for the first class began in July 2015 (Lingua Tinga, 2015), with admissions ongoing as of publication (Moi University, 2019).

In 2013, Connective Link Among Special Need Program (CLASP) International based in Austin, Texas, collaborated with Kenyatta University in Nairobi, Kenya, to offer a 3-year Master of Speech and Language Pathology (Kenyatta University, n.d.). Requirements for this program include 18 hours of courses, a thesis and a 1-year full-time clinical internship. This program can be taken full-time, institutionally based, or part-time.

A collaboration of four international universities in the project "PAGEL—Knowledge Transfer by Global Unity" (2015–2018) aimed to strengthen the profession of SLT in East Africa. Beside the work on culturally sensitive assessment and intervention materials, East African university programs and curricula for SLT were developed and re-developed within the project. Frequent workshops and meetings to specific topics took place at Muhimbili University of Health and Allied Sciences (Dar es Salaam, Tanzania), Kenyatta University (Nairobi, Kenya), Kyambogo University (Kampala, Uganda), and Leibniz University (Hanover, Germany). In that context, external experts from different countries were invited for lectures. This exchange of lecturers, scientists, and students supported the national and international collaboration of SLT professionals and created a sustainable international network in the field of SLT (Leibniz University Hannover, n.d.).

Southern Africa

There are several established university SLT programs in Southern Africa. CLASP International has partnered with the University of Zambia (UNZA) to create the country's only master's degree in SLT (CLASP International, n.d.), an intensive 2-year Master of Education in Speech, Language, and Communication Disorders, from which 18 students graduated in 2015.

There are seven universities in cities scattered across South Africa that train speech–language pathologists and audiologists. The University of Cape Town in South Africa offers 4-year Bachelors of Science in Audiology and in Speech–Language Pathology and three graduate programs: Masters of Science in Audiology and in Speech–Language Pathology and a combined Doctor of Philosophy in Speech–Language Pathology/Audiology (University of Cape Town, n.d.a). In 2015, 37 students graduated with a bachelor's degree in SLT, 24 in audiology, eight with a master's in SLT and two with a master's in audiology (University of Cape Town, n.d.b, n.d.c).

South Africa has two universities offering programs to train professionals to work with persons with communication disability in Pretoria. Sefako Makgatho Health Sciences University, formerly the Medical University of Southern Africa, offers a 4-year Bachelor of Speech–Language Pathology (Weddington, 2002). The University of Pretoria in South Africa offers two 4-year Bachelor of Art degrees, one in SLT and one in audiology (University of Pretoria, n.d). At the University of Pretoria, the 2015 SLT program had 32 students in year 1, 26 students in year 2, 30 students in year 3, and 42 in their final year totaling 130 students. The 2015 audiology program had 31 students in year 1, 29 students in year 2, 43 students in year 3, and 23 in their final year totaling 126 students (Vinck & Kritzinger, 2015). They also offer graduate programs—a Master of Audiology, a Master of Speech–Language Pathology, and a Doctorate in Communication Pathology.

There are four other university SLT training programs in South Africa. Stellenbosch University offers a 4-year bachelor's degree in the Division of Speech–Language and Hearing Therapy (Stellenbosch University, n.d.) with approximately 30 students selected each year. The University of

KwaZulu-Natal offers a 4-year Bachelor of Communication Pathology (University of KwaZulu-Natal, n.d.), the University of Limpopo offers a 4-year Bachelor of Science in Speech–Language Pathology (University of Limpopo, n.d.), and the University of the Witwatersrand offers a 4-year Bachelor of Art in Speech and Hearing Therapy (University of the Witwatersrand, n.d.), along with a Master of Arts in Speech Pathology, a Master of Arts in Audiology, and a Doctor of Philosophy.

eLearning

The amount of information on the Internet has expanded dramatically (Dudding & Drulia, 2013), normalizing for over a decade the use of high-quality Web-based learning objects and activities in health science undergraduate, graduate, and postgraduate education (Cobb, 2004).

Online learning has become more accepted as a tested means for transferring knowledge (Dudding & Drulia, 2013). For example, the Massachusetts Institute of Technology (MIT) offers all of their undergraduate and graduate courses online for free (though they charge for credentials) through their OpenCourseWare (MIT OpenCourseWare, n.d.). MIT OpenCourseWare includes over 2300 courses, addressing many areas, but there are no specific courses dedicated SLT (MIT OpenCourseWare, n.d., 2006). There is also a steady increase of SLT courses offered online in conjunction with universities located in North America and Australia. As of 2013, 13 North American universities offered online master's degrees in SLT and at least 46 offered online SLT coursework (Dudding & Drulia, 2013). However, none of these SLT programs are free.

There are numerous websites offering continuing education units for SLTs, though most are private organizations offering fee-based continuing education that is approved by specific national organizations. On SpeechPathology.com, SLTs can earn continuing education units for 99 USD per year. The Northern Speech Services also provides online seminars, workshops, and courses (Northern Speech Services, n.d.) with 1-hour courses ranging from 24 to 34 USD, 2 to 4-hour courses ranging from 31 to 79 USD, 5 to 9-hour courses ranging from 89 to 129 USD, and a 10-hour course ranging from 149 to 600 USD, amounts unaffordable to most potential sub-Saharan users. There are also national professional organizations that offer professional development opportunities in person and online. Speech Pathology Australia offers continuing professional development workshops and live online events for their members (Speech Pathology Australia, n.d.). The American Speech–Language-Hearing Association (ASHA) offers some free courses and webinars as well as other courses, webinars, and online conferences for a fee (ASHA, n.d.a). Speech–Language and Audiology Canada (SAC) offers SLT webinars, lunch and learns, workshops, and webcasts to earn continuing education equivalents (SAC, n.d.). It is clear that the Internet has become a widely accepted source of continuing education training for SLTs and healthcare workers alike.

SLTs are also using the Internet to better serve their clients. For example, the ASHA has developed a Practice Portal for SLT clinicians. The Practice Portal provides clinicians with curated and peer-reviewed web pages devoted to clinical topics and professional issues. Clinicians can read material that covers specific disorders with an overview, incidence and prevalence data, signs and symptoms, causes, roles and responsibilities, assessment, treatment, resources, and references (ASHA, n.d.b). The Royal College of Speech and Language Therapists (RCSLT) also has web pages devoted to clinical resources organized by disorder, organized into introductions, role of therapy, prevalence and incidence, evidence and research, guidelines and resources, useful contacts, reference list, and contributors (RCSLT, n.d.).

The World Health Organization (WHO) conducted the first global (2005–2006) survey on eHealth. In 2005, the African Region showed the lowest percent of electronic journals available and the least provision of health information to the public electronically, providing 60% of health information compared to 90% of health information in high-income countries of Europe. As a result of this survey, a guiding principle of the WHO's eHealth agenda is that higher- and lower-

income countries work together to lessen the "digital divide" in eHealth, with lower-income countries developing programs based on lessons learned from successes and failures in higher-income countries (World Health Organization, 2006). Online health information, eJournal services, and eLearning are the areas of greatest related adoption thus far (World Health Organization, 2006).

History of the DOOHICHE Model

In 2001, NextGenU.org and its predecessor (Health Sciences Online [HSO.info], n.d.), were invented by co-author Dr. Frank, a creation of the opportunity presented by the burgeoning amounts of online professional content, and a global need to provide organized access to free, high-quality, educational resources for learners interested in health sciences and (eventually) other disciplines (Tairyan & Frank, 2011). The American College of Preventive Medicine, Grand Challenges Canada, U.S. Centers for Disease Control and Prevention, and the World Health Organization are among the founding collaborators and funders for the Health Sciences Online (HSO.info) and NextGenU.org websites. HSO.info was designed to be a library of online learning materials that were curated by experts in the fields of medicine, public health, pharmacy, dentistry, nursing, basic sciences, and other health sciences disciplines. The website has over 50,000 learning resources, from medical professional societies, accredited continuing education organizations, and governments, and from highly ranked universities such as Columbia University, Harvard University, Johns Hopkins University, Massachusetts Institute of Technology, University of California San Francisco, and the University of Pennsylvania. The website allows for search and browse functions in any language within Google Translate.

NextGenU.org was an outgrowth of HSO.info. The purpose of NextGenU.org was to essentially become the world's first free university. NextGenU.org organizes health science information from (and similar to) materials on HSO.info that build on traditional and modern (e.g., distance learning and flipped classroom) training methods of healthcare workers. They offer this information, coupled with mentored and peer interaction, as a globally free unprecedented institution that transforms access to high-quality, higher education: NextGenU.org is the world's first portal to free, accredited, higher education (Next GenU.org, n.d.).

Courses are created by first identifying expert-created, published competencies on the subject matter. Free, high-quality resources found on the Internet are aggregated into learning modules that address these knowledge-based competencies, and peer and mentored interactions address skills/practical competencies. NextGenU.org partners with universities and professional societies to offer credit for courses and programs with demonstrated learner proficiency.

NextGenU.org's DOOHICHE (Democratically Open Outstanding Hybrid of Internet-aided, Computer-aided and Human-aided Education) model is thus far unique, but is grounded in the workforce capacity-building framework (Goldberg & Bryant, 2012; Somerville et al., 2015). Capacity building in the healthcare setting can be defined as improving programming and service delivery (Goldberg & Bryant, 2012). SLTs provide both programming and service delivery to individuals with communication disabilities. In resource-poor settings, organizations may not have the means to advance their missions to serve these individuals. Organizations may have difficulty conducting activities such as strategic planning, performing needs assessments, or training individuals to deliver educational or clinical services (Goldberg & Bryant, 2012). This situation can be an opportunity for resource-poor organizations to partner with external organizations to focus on key activities to facilitate capacity building. Following current best practices in workforce capacity building (Goldberg & Bryant, 2012), NextGenU.org partners with interested parties (e.g., individuals, universities, hospitals, Ministries of Health) who wish to have access to SLT training (and other

training). NextGenU.org focuses on the training of individuals as healthcare workers because they are the backbone and hands of healthcare systems (Anyangwe & Mtonga, 2007; Goldberg & Bryant, 2012). The DOOHICHE model addresses some of the challenges in building global workforce capacity in SLT. Specifically, the DOOHICHE model confronts issues of quality, accessibility, affordability, customizability, and sustainability.

High Quality

One challenge in building capacity is providing access to high-quality content for knowledge transfer. Training in SLT requires specialized training in many topic areas, challenging SLT teachers globally. Training individuals through the DOOHICHE model resembles other current training models in terms of quality assurance. However, the DOOHICHE model is not dependent on specialized trainers having local availability and skills, but instead scalably addresses many areas in depth, as it is created by experts in the field, and guided by course-specific Advisory Groups, working with experts from and using resources from (and only from) the reliable sources of governments, peer-reviewed journals, specialty societies, and universities.

Accessibility

Accessibility can pose challenges for both trainers and learners, but DOOHICHE's Web-based didactic content is constantly available and offered in the >100 languages used by Google Translate, leading to more education for learners, and more capacity for trained SLTs.

Affordability

Another challenge in building workforce capacity is affordability. NextGenU.org's DOOHICHE model provides training for free; learners need only to gain access to a tablet or computer and mentor. As course creators are volunteers, and the resources are freely available on the Web, the DOOHICHE model is unusually (perhaps uniquely) inexpensive to implement, and we have found that this training can benefit many (Clair et al., 2016a, b, c; Frank et al., 2016; Galway et al., 2014).

Customizability

A challenge for training models is to be able to fit into a wide variety of organizational needs (Goldberg & Bryant, 2012). The DOOHICHE model addresses individual and organizational customizability, acknowledging the considerable variety in needs between and within countries, through choices of appropriately diverse and generalizable materials and by designing tailored peer and mentored activities. Peer and mentored activities address skills-based competencies and enhance the didactic content by requiring interactions between learners and with mentors who are serving persons with communication disability and better understanding local standards and expectations. These connections will promote future working relationships and build a global community of SLT professionals.

Sustainability

Creating sustainable training programs can be challenging, but the DOOHICHE model has good potential to be sustainable, as a one-time investment of building such a course can (with slender operating costs) be infinitely scalable. Using NextGenU.org's 16 million USD endowment (sustainably covering core expenses), NextGenU.org aims to build sufficient capacity globally of individuals who understand the person with communication disability community's needs and who can continue to develop and take ownership of building SLT workforce capacity (Goldberg & Bryant, 2012). Subsequently, local communities, policymakers, organizations, and governments can take leadership of course development and customization and further develop other aspects of capacity building (Goldberg & Bryant, 2012). NextGenU.org data can support local authorities to determine the training's value to learners and the populations they serve and how best to incorporate these newly trained individuals into the workforce.

The DOOHICHE Model in Practice

As of 2019, NextGenU.org has registrants in every country but North Korea and South Sudan. NextGenU.org's DOOHICHE model has been used to train senior medical students in North America with an Emergency Medicine (EM) course based on competencies from the Clerkship Directors in Emergency Medicine, and co-sponsored by the Emory University Center for Injury Control, International Federation of Emergency Medicine, and Society for Academic Emergency Medicine.

Frank et al. (2016) provided training to US medical students in the class of 2013 (n = 202) at our two test schools, the Uniformed Services University of the Health Sciences (USUHS,) and University of Missouri (UM). A two-sided t-test comparison was used to compare national Emergency Medicine test scores offered by the Society of Academic Emergency Medicine of NextGenU.org users versus traditionally trained students. Students who were trained using NextGenU.org's DOOHICHE model performed almost identically to traditionally trained students: USUHS NextGenUsers (n = 167) averaged a score of 80.9% (±6.4 SD) vs. the prior year's class of 2012 USUHS control students' (n = 163) averaging 80.9% (+6.8 SD) on the 2011–2012 SAEM exam. Likewise, UM NextGenUsers averaged 71.2% (±5.7 SD, n = 35) vs. the national comparison population's 71.4% (±8.6 SD, n = 415; p = 0.8) on the 2012 SAEM exam. Both sites' Clerkship Directors reported NextGenUsing students enjoying the asynchronous, site-independent readings.

Furthermore, NextGenU.org's DOOHICHE model has been successfully used in public health education in a flipped classroom setting, where content and material were primarily delivered online and class discussions were used for problem solving. Galway et al. (2014) examined the effectiveness of using NextGenU.org as a flipped teaching model for an Environmental and Occupational Health course (EOH). Eleven graduate students in a Master of Public Health program at a Canadian university in the spring session of 2013 participated. Learners accessed the online content, discussion forums, peer activities, and quizzes, and in-class discussions were held once every 2 weeks. Self-perceived knowledge was assessed before and after the course by a 12-question survey that was on a five-point Likert scale (1 = strongly disagree; 5 = strongly agree), and ten additional items and one open-ended question were added to this survey after the course to assess learning experiences. Mean knowledge examination scores for the 2013 NextGenU/Flipped classroom students were 88.8% compared to 86.4% for traditional students. Most (82%) students "agreed" or "strongly agreed" that they would rather take a flipped course compared to a traditional lecture-based course, and all (100%) students "agreed" or "strongly agreed" that they felt comfortable with learning material through a self-paced online learning environment. The open-ended question yielded mostly positive feedback including changed perceptions of online courses and how much they enjoyed the class. Overall course ratings from the NextGenU.org/flipped EOH course were compared to ratings from a traditional lecture-based course on a five-point Likert scale (1 = lowest rank; 5 = highest rank), with a substantially higher mean overall rating of the NextGenU.org/flipped course of 4.75/5 vs. traditional lecture-based EOH course scores from 2012 (3.7), 2011 (4.3), 2010 (4.1), and 2009 (3.9).

NextGenU.org's DOOHICHE model has also been used in SSA to train health care workers in administering screenings and brief interventions for alcohol, tobacco, and other substance use disorders. Clair et al. (2016a, b, c) evaluated stigma scores in 99 healthcare workers working in 11 primary healthcare facilities in rural Kenya, and in Nairobi. This online training was based on competencies outlined in the WHO Mental Health Gap Action Program and the WHO Alcohol Smoking and Substance Involvement Screening Test, with participants interacting with peers and mentors through formalized learning activities. The Opening Minds Scale for Health Care Providers (OMS) was administered before and after the training. Results indicated that there was a significant decrease in OMS stigma scores in those receiving the training (n = 52), with alcohol

use disorder stigma decreased by 7.7%, other substance abuse disorder stigma by 9.2%, and tobacco use disorder by 9.3% vs. those not receiving training ($n = 42$).

The DOOHICHE Model for Speech–Language Therapy

Since there is a substantial shortage of SLTs globally and specifically SSA (McAllister et al., 2013; Wylie et al., 2013), we determined that a full program (vs. a single course) was needed to train individuals interested in working with persons with communication disability. We systematically followed eight steps to form the Speech–Language Pathology Program using the DOOHICHE model to provide both the transfer of content knowledge and skills in the field of SLT.

Step 1: Perform a Needs Assessment

We reviewed the literature to determine if there was a need for creating DOOHICHE-based SLT courses to increase the capacity of SLTs globally. As anticipated, we found shortages in countries where there were no SLT training programs, particularly in SSA (Fagan & Jacobs, 2009; Wylie et al., 2013), but also found a shortage of SLTs in countries that offer traditional higher education in SLT (Wylie et al., 2013), suggesting a need to train individuals who were interested in serving persons with communication disability worldwide.

Step 2: Competencies

We aligned the coursework with competencies from long-established professional SLT organizations. The DOOHICHE courses were designed to have learners fulfill expert-created competencies, which were based on the standards and competencies of the Canadian Alliance of Audiology and Speech–Language Pathology Regulators (2018), the College of Audiologists and Speech–Language Pathologists of Ontario (2018), and the Canadian Association of Speech–Language Pathologists and Audiologists (2004) due to their high level of specificity. We anticipate that our learners will be well-qualified for further training, internships, and certification by the countries who have mutual recognition agreements with Canada including Australia, Ireland, New Zealand, the UK, and the USA (ASHA, n.d.c).

Step 3: Locate Resources

Each content area (e.g., phonetics, speech, and language development) is being further developed to identify key concepts, becoming our targets for locating available authorized learning objects for the didactic portion of the learning modules. With the supervision of a doctorally trained SLT associate professor, SLT undergraduate students from the University of Nevada, Reno, have been curating the course content, using only cost- and advertisement-free online learning resources that did not require log-in (all to keep barriers as low as possible). Resources were identified as essential or supplementary resources, with essential resource content coming only from .org websites that offer continuing education units, .edu sites, or .gov sites.

Step 4: Review with Advisory Group

We selected an Advisory Committee of master's and doctoral-level trained SLTs to provide feedback regarding the courses. All Advisory Group members have taught SLT courses at the university level and had also provided SLT services outside of the USA, in countries including Nicaragua, Brazil, and Senegal. Advisory Group members review courses on the teaching platform in English and in other languages, review content for appropriateness, review the competencies selected, help us identify and address challenges to implementation, and make recommendations for organizational co-sponsorship of the training program.

Step 5: Creation of Learning Modules

NextGenU.org learning modules are competency-based. This means the framework for each course is modeled after an existing, expert-derived, peer-reviewed set of competencies. Once individual SLT

resources are located, they are matched with course competencies and learning objectives and organized in modules. The courses are developed in a spreadsheet format; introductions to courses are written to provide an overview of the course content, and the learning objectives for the learners before courses were stringently edited by NextGenU staff and were transferred onto NextGenU.org's open-access teaching platform, Moodle.org.

The "Internet-aided and Computer-aided" portions of the course were then complemented by the "Human-aided" portions of the DOOHICHE: peer activities, mentored activities, and case studies. Peer activities are written by the course creators and aim to address specific competencies. They are created to enhance the didactic learning process by adding an applied component and by contextualizing the content to the student's community. Students enrolled in courses perform activities that are graded by their peers; the course creators provide a scoring guide for peers.

Competency-based mentored activities, likewise written by course creators, help solidify and apply knowledge from the didactic session, with learners working directly with mentors on activities that require a higher level of knowledge and familiarity with local practices and practical skills. Mentors pass students on skills-based knowledge.

The last learning activity is the case study. Learners enrolled in courses write about a specific case they have encountered while taking the course. The learners include information about the patient, case history, and management of the client. Three peers read the case study and assess it against explicit criteria; the learners each do likewise for three peers. The learners then respond to the peer comments and edit the case study as necessary until the criteria are fulfilled. The goal is to accumulate and freely publish, with attribution, a globally available, peer-reviewed atlas of cases.

Learners enrolled in courses complete both summative and formative assessments in the form of objective knowledge assessments and self-assessments for each course.

After resources are approved, course creators write an average of three multiple-choice questions for each essential resource used, in order to create pre- and post-test quizzes and a final exam. Students take quizzes after each lesson and complete self-assessments to reflect on the knowledge gained through the model and to help them learn more deeply from their course experience.

Summative assessments are delivered in the form of objective knowledge assessments, peer assessments, and mentored assessments. Learners apply their knowledge to activities and write about these experiences, and a peer then assesses this learning. Learners also work with mentors throughout the module with the mentor evaluating the student's skills, knowledge, behaviors, and attitudes using a standardized assessment. Learners take post-tests after each course and earn a certificate of completion. Through its university partners, NextGenU.org awards a certificate of completion to students who earn greater than or equal to 80% on the post-test for each SLT course and who pass the peer and mentored activities. Passage of these courses does not imply competence in the practice of SLT; such assessments (as always in licensure) should come from local jurisdictions, with which NextGenU.org is pleased to collaborate.

Step 6: Teaching Platform

Course creators work with NextGenU.org technical and quality assurance staff to transfer modules from a spreadsheet format onto a teaching platform that houses the didactic and human-aided learning modules. Equipment requirements for users of any NextGenU.org course are merely an internet connection and any computer platform; students may individually (or collectively) participate in an online, self-paced didactic learning environment, and the teaching platform uses Google Translate to present course content in >100 languages.

Step 7: Locating Potential Students

When completed, the NextGenU.org SLT program will be open to any learner or professional who already works with persons with communication disability or who is interested in doing so in the future. Recruitment of learners is spread through professional social networks by the course creators, Advisory Group, participating organizations, students, and other interested individuals.

Step 8: Refine and Research

Each course in NextGenU.org's Speech–Language Pathology Program will be refined and updated over time, with content adjusted based on feedback from students, mentors, and interested institutions and organizations, and results reviewed from learner evaluations with members of our Advisory Group who give feedback and provide organizational co-sponsorship of the training.

Current State of the NextGenU.org Speech–Language Pathology Program in Sub-Saharan Africa

When we first endeavored to create the Speech–Language Pathology Program, we were uncertain if there would be enough learning resources to create a single course, but were pleased to be able to find materials sufficient for ten courses thus far (see Table 7.2 for a list of the courses). We also identified the University of Nevada, Reno, as our first university co-sponsor and welcome other governmental agencies, professional organizations, and universities as additional co-sponsors. Because of the extensive training needed for SLTs, additional courses beyond the initial ten courses will be created to meet the training needs of highly qualified professionals.

As of 2019, the SLT DOOHICHE model is about to enter its piloting stage with students in Nairobi, Kenya. We welcome new collaborations with individuals, professional organizations, and universities throughout SSA and beyond. Table 7.3 demonstrates a competency set and how it is used to establish the framework of a course, instancing stuttering as an example. Table 7.4 provides further examples of peer and mentor activities that are included in the course to guarantee training of clinical skills.

Since these courses are only now being completed, we are in the initial stages of collecting research on the vitality of the SLT application of the DOOHICHE model. We expect to encounter challenges as the program grows, and NextGenU.org will follow current best practices in determining the quality of online education by examining four pillars of quality: learning effectiveness, cost effectiveness, access, and student satisfaction (Dudding & Drulia, 2013). Specifically, quality data measures will be collected regarding accessibility, sustainability, affordability, and effectiveness of customization of our first SLT courses with pilot students. This process will be ongoing for each course and courses will be continually refined based on metrics and feedback. These pilot studies will follow processes and procedures used in other courses and programs that evaluated the NextGenU DOOHICHE model (Clair et al., 2016c; Frank et al., 2016).

Regarding the quality of the DOOHICHE model when applied to SLT training, we will assess the transfer of knowledge by evaluating the scores on the pre-/post-tests and peer activities, as well as collecting mentor and student feedback. To ascertain accessibility, we will review student feedback regarding the ease of use of the website, how quickly the websites loaded, the navigation of the website, and the translation of the content of the website. To determine the sustainability of the DOOHICHE model, we will evaluate the efficiency of the time and effort required to complete the courses, peer activities, and mentor activities. For example, learners may encounter time conflicts in meeting with their mentors and learners may have difficulty accessing computers or connectivity. We are eager to determine if the SLT application of NextGenU.org's DOOHICHE model, including the peer and mentored activities, can be successfully implemented.

Table 7.2 Resources found for ten speech–language therapy courses

Course	Course title
1	Introduction to Communication Disorders
2	Phonetics
3	Speech Language Development
4	Introduction to Audiology
5	Anatomy and Physiology of the Speech Mechanism
6	Speech Sound Disorders
7	Stuttering
8	Speech Science
9	Foundations of Assessment
10	Advanced Audiology

Potential Impact

Our purpose is to aid in the training of SLTs worldwide to help meet the shortage of more than 13 million healthcare workers globally by 2035 and specifically to train individuals in SSA where there is limited access to formal training programs (World Health Organization, 2019). The DOOHICHE training model has the potential to reach sub-Saharan audiences of potential SLT professionals interested in working with persons with communication disability because it is accessible, affordable, and sustainable (Clair et al., 2016a, b, c). This training model can avoid the "brain drain" of sending individuals outside of their communities where they may stay to work. Individuals can be trained locally and begin to establish professional networks focusing on working with persons with communication disability. This workforce can contribute to the number of SLTs who belong to professional organizations and can help germinate the seeds of these organizations where they do not yet exist. With an expanding SLT workforce in SSA, there should be increased opportunities for trained professionals to serve more persons with communication disability. Furthermore, with more trained professionals, the ability to produce research increases, which can not only improve services of sub-Saharan SLTs but can impact SLTs worldwide.

Summary

There is an overwhelmingly large population of persons with communication disability across SSA who are not getting needed services because of the abject and chronic SLT shortage. Regions in SSA suffering from this shortage of trained SLT professionals include West, East, Central, and Southern Africa.

One of the main challenges in addressing the dearth of SLTs is the paucity of training programs available to individuals living in SSA. NextGenU.org has created a solution to create sufficient capacity in provision of SLT care in SSA. NextGenU.org's model breaks barriers of cost, accessibility, customizability, and sustainability and is being used to create a free, high-quality SLT program that can be used as a stand-alone training program or one that can supplement traditional programs.

NextGenU.org's DOOHICHE model is unique as individuals may be credentialed for free after acquiring knowledge competencies through self-paced computer didactic lessons, and practicing skills through peer, mentor, and case study learning activities. The goal of the model is to build local SLT capacity as learners are able stay in their local communities to be trained. This model will make it possible to treat persons with communication disability even in rural areas, which suffer an even greater need for SLTs than urban areas. Learners access the materials online and

Table 7.3 Course on Stuttering—Based on Practice Standards and Guidelines for Developmental Stuttering from the College of Audiologists and Speech–Language Pathologists of Ontario

Module 1: Screening for Stuttering
Lesson 1: Demonstrate knowledge and skills to select or develop appropriate screening measures, administer them, interpret the results in order to identify the presence or absence of signs of emerging or persistent stuttering, and recommend further assessment.
Lesson 2: Demonstrate knowledge of roles and responsibilities of other professionals who are involved in early identification of speech and language disorders.
Lesson 3: Demonstrate knowledge and skills required to supervise support personnel (if applicable) as outlined in the Position Statement on Use of Support Personnel by SLTs: (a) Ability to train and supervise support personnel involved in screening.
Lesson 4: Demonstrate knowledge and skills required to supervise support personnel (if applicable) as outlined in the Position Statement on Use of Support Personnel by SLTs: (b) Know when it is appropriate to utilize support personnel.
Module 2: Assessment of Stuttering
Lesson 1: Demonstrate knowledge and skills to differentiate stuttering from other disorder of speech and language: (a) Determine features that may differentiate between normally non-fluent speech and established stuttering.
Lesson 2: Demonstrate knowledge and skills to differentiate stuttering from other disorders of speech and language: (b) Determine features that may distinguish developmental stuttering from cluttering, neurogenic stuttering, psychogenic stuttering, disorders of language, articulation, and learning with an understanding of the manner in which such disorders may interact.
Lesson 3: Demonstrate knowledge and skills to differentiate stuttering from other disorders of speech and language: (c) Relate the findings of language, articulation, voice, and hearing tests to the impact on stuttering.
Lesson 4: Demonstrate knowledge and skills to differentiate stuttering from other disorders of speech and language: (d) Recognize the degree of variability in observable stuttering and ability to investigate further, especially when reported stuttering is not evident.
Lesson 5: Demonstrate knowledge of associated factors affecting stuttering such as language, phonology, articulation, voice, hearing, cognition, behavior, and communication dynamics.
Lesson 6: Demonstrate accurate selection, administration, and interpretation of assessment procedures in order to identify the presence, nature, and functional implications of stuttering: (a) Recognize the risk factors for persistent stuttering in children, e.g., family history, length of time from onset, and severity.
Lesson 7: Demonstrate accurate selection, administration, and interpretation of assessment procedures in order to identify the presence, nature, and functional implications of stuttering: (b) Recognize features that assist in differentiating between primary (core) stuttering behaviors and secondary behaviors.
Lesson 8: Demonstrate accurate selection, administration, and interpretation of assessment procedures in order to identify the presence, nature, and functional implications of stuttering: (c) Identify dysfluencies by type (prolongation, repetition, blocks, etc.).
Lesson 9: Demonstrate accurate selection, administration, and interpretation of assessment procedures in order to identify the presence, nature, and functional implications of stuttering: (d) Identify avoidance behaviors, struggle behaviors, and escape behaviors.
Lesson 10: Demonstrate accurate selection, administration, and interpretation of assessment procedures in order to identify the presence, nature, and functional implications of stuttering: (e) Identify additional features of fluency such as prosody, speech rate, effort, and continuity of movement.
Lesson 11: Demonstrate knowledge and skills to communicate the results of an assessment, the characteristics of stuttering disorders, the current theories regarding etiology, and the possible intervention options.

(continued)

Table 7.3 (continued)

Module 3: Management of Stuttering
Lesson 1: Demonstrate knowledge and skills to formulate a program of direct treatment of stuttering: (a) Know appropriate treatment techniques and procedures and the benefits and risks of each.
Lesson 2: Demonstrate knowledge and skills to formulate a program of direct treatment of stuttering: (b) Know the features that contribute to perceptually fluent speech.
Lesson 3: Demonstrate knowledge and skills to formulate a program of direct treatment of stuttering: (c) Be aware of the interaction and potential compromise between a monitored speech pattern and natural-sounding speech quality.
Lesson 4: Demonstrate knowledge and skills to formulate a program of direct treatment of stuttering: (d) Know principles and procedures of conditioning and learning as they apply to modifying speech behaviors.
Lesson 5: Demonstrate knowledge and skills to formulate a program of direct treatment of stuttering: (e) Know the principles of transfer/generalization and maintenance of fluency.
Lesson 6: Demonstrate knowledge and skills to develop and implement an indirect treatment for stuttering: (a) Know appropriate indirect treatment approaches and strategies and the benefits and risks of each.
Lesson 7: Demonstrate knowledge and skills to develop and implement an indirect treatment for stuttering: (b) Identify environmental factors that influence the patient's/client's fluency
Lesson 8: Demonstrate knowledge and skills to develop and implement an indirect treatment for stuttering: (c) Identify internal factors that may influence the patient's/client's fluency.
Lesson 9: Demonstrate knowledge and skills to counsel and develop the skills of family, support personnel, and other communication partners: (a) Know mediator training techniques to assist individuals in the patient's/client's environment to facilitate fluency.
Lesson 10: Demonstrate knowledge and skills to counsel and develop the skills of family, support personnel, and other communication partners: (b) Know how and when to incorporate support personnel (when applicable).
Lesson 11: Demonstrate knowledge and skills to counsel and develop the skills of family, support personnel, and other communication partners: (c) Know how to assist others in facilitating the patient's/client's generalization of gains made during intervention.
Lesson 12: Demonstrate knowledge and skills to counsel and develop the skills of family, support personnel, and other communication partners: (d) Know community resources in order to facilitate referral to self-help groups.
Lesson 13: Demonstrate knowledge and skills to evaluate a treatment program: (a) Assess objectively the efficacy of treatment continuously, including input from the patient/client.
Lesson 14: Demonstrate knowledge and skills to evaluate a treatment program: (b) Apply necessary modifications to treatment program to reflect unique needs of patient/client.
Module 4: Discharge Planning
Lesson 1: Demonstrate the ability to determine the need for, and arrange for, appropriate follow-up at discharge.
Lesson 2: Demonstrate knowledge of additional available services that may be appropriate.
Module 5: Continuing Education
Lesson 1: Demonstrate continued acquisition of knowledge and skills necessary to provide quality assessment and management of developmental stuttering disorders: (a) Know the current literature and research in the area of stuttering intervention.
Lesson 2: Demonstrate continued acquisition of knowledge and skills necessary to provide quality assessment and management of developmental stuttering disorders: (b) Know the current stuttering screening, assessment, and management approaches.

Speech–Language & Audiology Canada (2004); used with permission

can begin the program at any time of the year; they do not need to wait for an academic calendar year to begin or for an international professional to come to their country and be available to them to teach a course. All resources are from .edu, .gov, or .org sources that offer high-quality, accredited degrees and continuing education units and are matched with internationally respected and published competencies. The program uses local mentors, so learners are able to understand local culture and expectations regarding persons with communication disability and receive guidance in acquiring practical skills. There are currently ten courses being made available to cover a broad range of content in SLT. At the moment, this training will work best for English-speaking learners, but as openly accessible translating services (such as the Google Translate button now built into the

Table 7.4 Peer and mentored activity examples

Directions for Peer activity:
There are two different approaches for treating stuttering: stuttering modification (strategies: cancellations, pull-outs, preparatory sets) and fluency shaping (strategies: slower rate, relaxed breathing, easy initiation of sounds, and smooth transitions between words). For each approach, select two strategies and complete the following: • Define two strategies for each approach. • Write one measurable goal/objective for each approach.
Evaluation criteria for authors:
Criterion 1: The paper should be 250–500 words. *Criterion 2*: Clearly define two therapeutic strategies for stuttering modification. *Criterion 3*: Clearly define two therapeutic strategies for fluency shaping. *Criterion 4*: Write a measurable goal/objective for stuttering modification. *Criterion 5*: Write a measurable goal/objective for fluency shaping.
Directions for mentored activity:
Observe a child or adult who stutters (either in person or recorded). As you listen to this speaker, take data on how many syllables (or words) are typical of stuttering (repetitions, prolongations, and blocks). Determine the following Total Disfluency Index based on your language sample: 1. Count the total number of syllables (or words) in the sample that are repetitions, pauses, and sound prolongations. 2. Count the total number of syllables (or words). 3. Divide the total disfluencies by the total syllables (or words). 4. Change to a percentage (multiply by 100). Discuss if you would categorize this person as a stutterer and if so, the level of severity.

site) continuously improve, the translation and adaptation of materials in other languages will also advance.

Although this program anticipates that learners could become highly trained, NextGenU.org believes local authorities should create their own regulations regarding the practice of SLTs. It is expected that more countries around the world and specifically sub-Saharan countries will start to build their SLT capacity using NextGenU.org's DOOHICHE model as their designated training program or in partnership with current programs. Especially, if governments can support improved internet accessibility to its individuals, this model can quickly increase the number of trained SLTs because it is constantly available and limitlessly scalable. NextGenU.org believes that its Speech–Language Pathology Program can provide a much-needed answer to the devastating shortage of SLTs in SSA. The development of customized programs in collaboration with readers of this chapter will be an important issue for the future.

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8

The Demands of Context: Development of a Relational In Vivo Methodology for Participative Speech–Language Therapy Research in Sub-Saharan Africa

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Introduction: The Necessity of Multilevel Research for Development of the Speech–Language Therapy Profession in Sub-Saharan Africa

Scientific research is an inherent part of every profession, and manifold research activities secure the ongoing professionalization of disciplines. It should cover all profession-specific issues, blank spots, insecurities, and needs. Accordingly, the young speech–language therapy (SLT) profession in sub-Saharan Africa[1] (SSA) also has an enormous need for research as it forms a critical part of developing evidence-based practice. In this chapter, we propose a concept to reflect on the development of future research of SLT scientists in regard to research strategies, key areas, and methodologies. We are limited in our SSA-specific knowledge, as we are two outsiders from Europe. However, based on a conceptual work, which is evolved in line with our research experience in collaborative and participative research projects in SSA, we outline a general framework of multilevel research in SLT (section "Framework of Multilevel Research in Speech–Language Therapy"). To fill this abstract concept with practical impact, it will then be applied to identify some proposed SLT research needs in SSA (section "SLT Research Needs in Sub-Saharan Africa"). As our aim is to propose a relational research methodology, which may inspire STL scientists in SSA to develop SLT research, which includes the people and the context and strives to initiate significant change, we subsequently outline opportunities and challenges for SSA-specific SLT research from our point of view. Different aspects of the situation are discussed as well (section "Background: Opportunities and Challenges for Research in Sub-Saharan Africa"). This leads us to propose a relational research paradigm, which addresses the needs and challenges and supports researchers from SSA to strengthen an Africa-specific perspective within SLT research—with and without international partners. First, we explicate the theoretical foundation and key elements of such a relational in vivo research methodology (section "Proposing a Relational In Vivo Methodology for Participative Speech–Language Therapy Research in Sub-Saharan Africa"). Then, we fill these more abstract statements with examples of applied methods from our collaborative research projects on different research levels for further discussion (section "Studying Persons with Communication Disorders Within the Sub-Saharan Africa Context: The Range of Relational Methods in a Multilevel Research Approach"). Concluding, we present a checklist for the implementation of a relational in vivo research approach in SSA, which needs to be elaborated by future research teams (section "Steps Toward a Relational In Vivo Methodology: An Everyday Participatory Research Checklist for Decolonizing SLT Research").

Framework of Multilevel Research in Speech–Language Therapy

In an abstract conceptualization, a general framework of multilevel research in SLT can be outlined. This is based on Lüdtke's (2023) model, which structures the profession into five different levels (Fig. 8.1). These levels are not hierarchal organized. Instead, they merely follow the general multilevel framework of the SLT profession, starting from research, which is close to the daily life and practice of the people involved (e.g., SLT practitioners and persons with communication disorders) based on the pyramid, to research which is more abstract and theoretical on the pyramid's peak. The value of the research is high and inevitable on each level and is always interwoven with all other levels. Nevertheless, each of these levels still requires an individual research approach,

[1]Even though South Africa has a longer history in the establishment of the SLT profession, this chapter will address sub-Saharan Africa as a whole.

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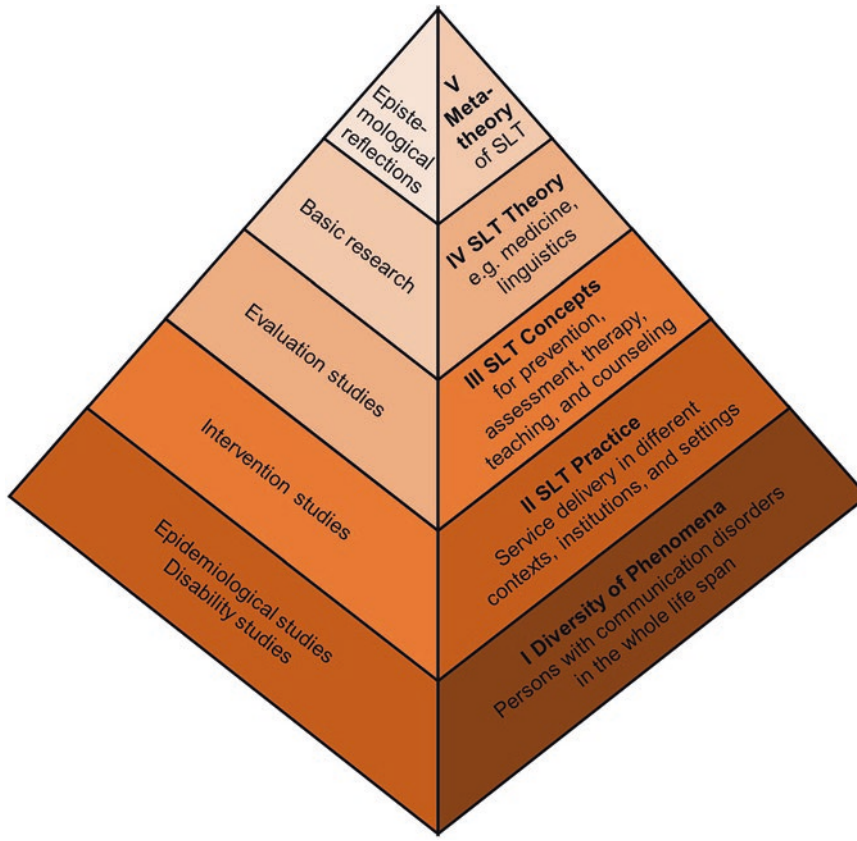

Fig. 8.1 Levels of the SLT profession and corresponding research approaches in general

which includes specific designs suited to specific groups:

I. The first level encompasses the *diversity of phenomena of persons with communication disabilities* throughout the whole life span, displayed in manifold linguistic and communicative varieties. *Epidemiological* studies, such as prevalence studies, and *disability studies* can help to detect and understand this complexity and prepare the ground for appropriate SLT practice, e.g., diagnostics and intervention.
II. At the second level, there is the *SLT practice* with service delivery in different contexts, institutions, and settings such as schools or private clinics using different materials and media. For example, *intervention studies* with a pre–post-test design in the field can examine aspects such as service quality and results using specific methods or tools to help to build up a body of evidence-based practice (EBP) for different target groups and ideas for clinical reasoning. Another example is *comparative studies*, which compare different approaches and thus help to evaluate which practices work best.
III. Further, the practice needs guiding *SLT concepts* for prevention, assessment, therapy, teaching, and counseling, depicted at the third level. These concepts bind together different practices of Level II by coherent schools of thought or paradigms, e.g., behavioristic, neurolinguistic, or interactionist approaches. From these frameworks, methods and didactics are derived. These can be proven by continuous *evaluation studies* and expand and adjust the body of EBP as a base to develop professional standards of service delivery to different target groups and guidelines for clinical reasoning.

IV. As mentioned, the concepts are derived from *SLT theory*, which is constantly developed and renewed by neighboring disciplines on which the SLT profession relies, such as pedagogy, linguistics, psycholinguistics, sociolinguistics, or medicine. Advances in these disciplines need to be taken into account, and SLT *basic research* can contribute new findings and insights.
V. At the peak of the pyramid (see Fig. 8.1), there is the *meta-theory of SLT*. This concerns the philosophical discourse on scientific theories themselves or basic philosophical questions such as how the communicative nature of human beings is understood or what role communication plays in infant development. *Epistemological* and *methodological reflections* can pave the way here.

As mentioned above, these levels of research are interwoven and relate to each other. Therefore, research on all these levels has a cyclic character, which is in one direction *inductive* research (from the manifest problems of the individuals with communication disorders at the base of the pyramid to the abstract meta-theoretical reflections at its peak) and in the other direction *deductive* research (from the very general issues at the "top" of SLT science to the very specific individual needs at the "bottom"). One important example for this reciprocal process is prevalence or comorbidity studies (e.g., through Universal Newborn Hearing Screening, UNHS), which can be transferred into policymaking for a specific target group (e.g., newborns), and where in turn the implemented policies have a strong impact on the daily lives of persons with communication disorders and their families (e.g., parents with newborns who might have a hearing disorder). Therefore, the impact of research for the persons with communication disorders should be planned and discussed on every level.

SLT Research Needs in Sub-Saharan Africa

In real life, these abstract levels of the framework are inseparably interwoven and always embedded in a very specific cultural, institutional, socioeconomic, emotional, and linguistic context. SLT research particularly tailored to fit the SSA context could start by reflecting on the Africa-specific needs of every professional level and determining corresponding research questions and research methods, as shown in the following examples from a (1) clinical and (2) educational background, respectively.

Multilevel Research Needs in a Sub-Saharan Africa Clinical Context: Adults with Aphasia

In the clinical context of SSA, one example could be the target group of adults with aphasia. The following research needs, questions, and methods could be proposed.

Level I: Clinical Diversity of Adults with Aphasia in Sub-Saharan Africa

The research need at this first level is to better understand how this clinical target group is defined with regard to SSA-specific factors, as this is a prerequisite for effective SLT service delivery.

- *Research questions* could include the following: How many persons acquire aphasia in SSA? What are the main etiology and risk factors? What is the age and gender distribution?
- *Epidemiological studies*, such as those with large samples in urban and rural areas of the continent, could be an adequate research method to answer this range of questions. Further, by generating more knowledge about the prevalence of aphasia, society and policymakers can be informed. A change in the situation of persons with aphasia, e.g., in better health care and SLT service delivery, can be initiated.

Level II: Clinical Service Delivery to Adults with Aphasia in Sub-Saharan Africa

At the second level of SLT practice, the research need is to design different forms of clinical service delivery to adults with aphasia adapted to varying contexts, institutions, and settings in SSA, and to prove their effectiveness and efficiency in supporting language rehabilitation and daily living.

- *Research questions* could include the following: To what extent is this newly designed

assessment tool in Swahili a valid, reliable, and objective tool to identify adults with aphasia in Uganda? How effective is the inclusion of family members into the therapy sessions with regard to the communicative improvement of the aphasic patient?
- *Intervention studies* with pre–post designs could evaluate these service-related research questions and set the base for clinical reasoning and evidence-based clinical SLT practice within SSA.

Level III: Speech–Language Therapy Concepts for Diagnosis and Therapy of Adults with Aphasia in Sub-Saharan Africa

To enlarge this body of EBP in SSA, the research need at this third level is to design broader Africa-specific concepts for diagnosis and therapy of adults with aphasia and evaluate these conceptual frameworks on a long-term basis.
- *Research questions* could include the following: To what extent is the concept of supplementing personal service delivery with media-based approaches more effective than without media-based approaches? In what ways do the patients at home use a newly developed app with neurolinguistic-based training of word memory in IsiXhosa? What are the effects of this specific mixed conceptual approach on sentence production in the respective mother tongue? To what extent does the newly implemented concept of stroke prevention reach the majority of the rural population in this respective country?
- *Continuous evaluation* studies—formative or summative—can steadily help to improve these broader SLT concepts for SSA.

Level IV: Theory Development in Adults with Aphasia in Sub-Saharan Africa

In the case of aphasic syndromes, the practical work and SLT concepts in SSA need to be based on and supported by a theoretical and empirical background on the processes of language loss and language processing, which takes the cultural and linguistic specifics of the African context into account.
- *Research questions* could include the following: Which recent findings from psycho- or neurolinguistic research can help in understanding the language processing of multilingual persons with aphasia, as the majority of the SSA population are multilingual? To what extent does affective prompting based on the individual family context enhance the quantity of word retrieval in one or the other spoken language of the aphasic patient?
- *Basic research*, such as experimental laboratory studies or observatory field studies with adults with aphasia, can contribute new findings and insights specific to the African (multi)-linguistic context, which in turn helps to enhance service delivery for multilingual persons with aphasia.

Level V: Meta-Theoretical Reflections on Speech–Language Therapy and Adults with Aphasia in Sub-Saharan Africa

Further, theories and derived concepts of service delivery are based on specific scientific paradigms. The need at this level when working with adults with aphasia could be to become aware and reflect on the underlying beliefs and paradigms, which influence the individual speech–language therapist (SLT) in SSA and the profession as a whole in his/her daily practice.
- *Research questions* could include the following: What are the differences between the medical paradigm of eradicating aphasic symptoms and the inclusive "International Classification of Functioning, Disability and Health" paradigm of enabling social participation with regard to the SLT's goals in service delivery? How are these two paradigms conflicting for different relevant groups of society?
- *Epistemological reflections*, including paradigm conflicts between the SLT and the aphasic patient and/or the family, or between the SLT profession and prejudices within the society of a specific SSA country, can improve SLT professionalization and the well-being of the clients.

Multilevel Research Needs in the Sub-Saharan Africa Educational Context: Children with Autism Spectrum Disorder

In the SSA educational context, an example could be the target group of children with autism spectrum disorder (ASD). The following research needs, questions, and methods could be proposed.

Level I: Educational Diversity of Children with Autism Spectrum Disorder in Sub-Saharan Africa

At this first level, the research need is to better understand how this educational target group of children or adolescents with ASD is defined with regard to SSA-specific factors, as this is a prerequisite for appropriate SLT service delivery in schools or other educational institutions.

- *Research questions* could include the following: How many learners with ASD are educated in regular primary or secondary schools in different African countries? At what age are the children diagnosed with ASD? Are children diagnosed before or after entering the school system? What is the age and gender distribution of children diagnosed with ASD? What terminology is used: Is the general label "ASD" used or have more specific sub-syndromes been described?
- *Epidemiological studies*, such as with large samples comprising families, schools, or assisted living in a specific African country, could be an adequate research method to answer this range of questions. With these kinds of questions and their manifold answers from research, society can be informed and policymaking processes can be initiated, which lead to change for the children with ASD and their families.

Level II: Educational Service Delivery to Children with Autism Spectrum Disorder in Sub-Saharan Africa

The research need at the second level of SLT practice is to design different forms of service delivery for children or adolescents with ASD adjusted to varying educational contexts, schools, other institutions, and settings in SSA. The research needs to prove their effectiveness and efficiency in supporting language acquisition and rehabilitation and daily living.

- *Research questions* could include the following: How effective is a broad supply of icon-based augmentative and alternative communication (AAC) technologies in an educational context with regard to enhancing the quantity and quality of learner's communication? How effective is a daily training session of 30 minutes in ASD-specific learning strategies in optimizing the learners' competence of basic math operations such as addition and subtraction of two-digit numbers?
- *Intervention studies* with pre–post-designs could investigate these service-related research questions and set the base for evidence-based SLT practice within varying SSA educational contexts.

Level III: Speech–Language Therapy Concepts for Assessment and Teaching of Children with Autism Spectrum Disorder in Sub-Saharan Africa

To enlarge this body of educational EBP in SSA, the research need at this third level is to design broader Africa-specific concepts for assessment, teaching, and intervention of children with ASD and to evaluate these frameworks on a long-term basis.

- *Research questions* could include the following: What are the features of a teacher training program on classroom-based intervention that are effective in enhancing learner participation in different subjects? What features of the program successfully reduce teachers' prejudices toward learners with ASD?
- *Evaluation studies*—formative or summative—can steadily help to improve the application of these broader SLT concepts and programs to the SSA educational context.

Level IV: Theory Development in Children with Autism Spectrum Disorder in Sub-Saharan Africa

SLT concepts for practical work with children with ASD in SSA need to be based on and supported by a theoretical and empirical background of the processes of communicative and language development and its impairment.

- *Research questions* could include the following: What recent finding in psychological research can help in understanding the etiology of ASD in the African context? What theories of communication help in understanding the social impact of ASD, taking into account the Africa-specific relevance of family? To what extent does contingent responding by parents or siblings accelerate the process of noun acquisition in IsiZulu? What positive impact on different levels of language development in the respective first language(s) of the learner has the teacher's emotional reward, e.g., specific lexical or pragmatic competences?
- *Basic research*, such as observational in vivo studies with children and adolescents with ASD at home or in schools, can contribute new findings and insights, such as those specific to the African family context. The findings of such a basic research can help to create new tools for service delivery for learners with ASD.

Level V: Meta-Theoretical Reflections on Speech–Language Therapy and Children with Autism Spectrum Disorder in Sub-Saharan Africa

The theories and derived concepts of service delivery in schools are based on specific scientific paradigms. The need at this level for working with children and adolescents with ASD could be to become aware and reflect on the underlying beliefs and paradigms, which influence the daily practice of the individual SLT, special need teachers, and the profession as a whole in SSA.

- *Research questions* could include the following: (a) from an anthropological perspective: What is human communication? Is the learner's way of expressing his/her intentions in a "different" way valued as communication or devalued as he/she just making vital "noise"? Or (b) from an ethical perspective: Is a child with severe autism worth being schooled and educated?
- *Epistemological reflections*, such as on paradigm conflicts between the SLT and family members or teachers, or between the SLT profession and prejudices within the society of a specific SSA country, can improve SLT professionalization and the well-being of learners with ASD. It can initiate a significant change for the learners with ASD.

Background: Opportunities and Challenges for Research in Sub-Saharan Africa

Having outlined a multilevel research framework and indicated how it could be applied to two areas of SLT, a short summary of the background of the SLT research context in SSA seems necessary to reflect on the inherent opportunities (section "Opportunities: Uniqueness and a Fresh Start!") and challenges (section "Challenges: Lack of Cultural Adaptation and (Neo)colonial Shadows"), because—as the proverb says—every coin has two sides.

Opportunities: Uniqueness and a Fresh Start!

In minority world countries, SLT research has grown over decades and with it power-related traditions and research paradigms, including the still prevailing dominance of quantitative studies over qualitative ones, or the subordination of educational and linguistic research under the medical realm. In contrast, in SSA all five levels of SLT research need to be more or less built up from the ground. For the young emerging profession (see Lüdtke, 2023), one major opportunity is exactly this fresh start, as the not (yet) existing traditions guarantee an openness to a new and innovative research paradigm, while at the same time the growing scientific community of African SLT researchers can build on the lessons learned from their Western colleagues.

Additionally, another opportunity can be seen in the need for a genuinely Africa-specific research paradigm and, as was pointed out in the previous examples, in the clinical and educational domains (see section "Introduction: The Necessity of Multilevel Research for Development of the Speech–Language Therapy Profession in Sub-Saharan Africa"). The uniqueness of the African context is reflected in different key concepts, such

as the Africa-specific concept of linguistic identity grounded in a specific version of African multilingualism, the Africa-specific concept of cultural and linguistic diversity (CLD) shaped by the specifics of the African linguistic market (see Lüdtke, 2023), or the philosophical Pan-African concept of Ubuntu with its focus on community, which have to be considered when planning SLT research within SSA.

Last but not least, this uniqueness alongside the ability to draw on a rich heritage of genuine knowledge poses another opportunity as it might lead to African research expertise that is sovereign in international research collaborations in the SSA fields of health and education, which are nevertheless relevant for a high research output (Adams et al., 2014; see section "Challenges: Lack of Cultural Adaptation and (Neo)colonial Shadows"). There is the opportunity that the inherent advantage of knowing the context in combination with inherited knowledge could lead to more equality in international SLT research collaborations and to improved research output for African scientists.

Challenges: Lack of Cultural Adaptation and (Neo)colonial Shadows

Bearing the above opportunities in mind, the other side of the coin reveals the challenges inherent in the SLT research context in SSA. The major challenge is that the young SLT profession has to develop its research uniqueness while being embedded in the global context under the strong influence of the outside(r) SLT research community. Research in general is confronted with many obstacles in the African continent. Ngongalah et al. (2018) developed a questionnaire survey on research challenges facing African researchers. The results show that the research conditions in SSA are not encouraging for engaging in research. Research is mostly unpaid. The main areas for improvement named in this survey are training, awareness of the importance of research, and increasing the number of collaborations with other African researchers. The overall situation in the SLT profession—lacking research traditions, a small or no scientific community in many countries, a small or no body of methodology and high-cost equipment, and small or no supportive research infrastructure at universities—can be briefly outlined from significant to subtle in their impact by examining the following detailed aspects.

Lack of Research Output and Research Investment

In general, the lack of a broad research tradition is reflected in SSA's research output over the years. Even though research output in SSA is increasing, as Adams et al. (2014) described, it has done so to an extremely low extent: The total research output from 2000 to 2012 in SSA increased from about 13,000 publications to about 35,000 publications indexed on Thomson Reuters Web of Science. However, Adams et al. (2014) stated that the total output of the African continent is similar to the output of the Netherlands—a relatively small country in Europe. However, some low-income countries such as Benin and Gambia are as scientifically productive as middle-income economies (measured by articles per million inhabitants) (UNESCO, 2015). In health-related research, biomedical publications by SSA researchers have a share of research output of less than 1% of the global output. Though exact numbers are unavailable, this picture will be about the same for SLT research in SSA—it is likely that SLT output might even be lower as the profession is young (Adams et al., 2014).

Research output is closely related to research investment. In most SSA countries, the government is the main source of research and development funding. However, in the Gabonese Republic and Uganda, the business enterprise sector contributes more than 10% of the gross domestic expenditure to research and development (GERD). In East African countries like Burundi, Kenya, Tanzania, and Uganda, foreign sources contribute a substantial share of the GERD from 40% up to 57%. Looking at gender gaps, women are not equally likely to be researchers in SSA countries. In 2012, the highest proportions of female researchers were found in Namibia (43.7%), South Africa (43.7%), and Mauritius (41.9%) (UNESCO, 2015).

The Danger of One-to-One Adoption Rather Than Adjusting Research Approaches

Another significant challenge seems to be the danger of adopting well-established research approaches from the minority world context without adapting them to the Africa-specific requirements. The following are some observable examples at different research levels of the profession.

I. *Epidemiological studies* for different communication disorders that apply standardized Western questionnaires without taking into account differing Africa-specific parameters for etiology, comorbidities, and risk factors or that conduct sample stratification based on the criteria of minority world countries.
II. *Intervention studies* with pre–post-designs were conducted using Western assessment or intervention tools without any culturally sensitive and/or linguistic adaptation. Examples include the application of Anglo-American assessment tools for language disorders, e.g., assessments for aphasia or ASD that are not applicable to non-English native speakers, or imported media for SLT that are not culturally adequate, e.g., displaying photographs of white children or families, as well as using Westernized items that are irrelevant or even unknown to African clients.
III. *Evaluation studies* that examine imported models of service delivery that do not match the needs of many rural areas in most African countries, e.g., the accessibility of SLT services in remote places. Another example is the evaluation of imported teaching models that do not consider possible cultural stereotypes and cultural beliefs on communication disorders in SSA.
IV. *Basic research* is conducted by intrusively collecting data even in very sensitive areas without considering and acknowledging Africa-specific cultural norms, e.g., within a neonatal unit of a referral clinic, a refugee camp, or a children's home in a rural area.
V. *Methodologies and meta-theories* are drawn from a philosophy, which is rooted in minority world culture and is widely spread in Anglo-American and European research contexts. Africa-specific epistemological perspectives or philosophical concepts are not utilized as a base for theory and knowledge generation (see section "Epistemological Reflections").

From our point of view, this one-to-one adoption of research approaches might lead to a dangerous mismatch effect (Lüdtke, 2023) between the applied solutions of the Western research paradigm and the Africa-specific research requirements of the field, which could weaken the young profession's establishment of research.

Intercultural Conflicts Instead of Cross-Cultural Partnerships

As mentioned previously, the situation often requires that African scientists—including SLTs—collaborate with scientists from minority world contexts such as Europe or the United States. Boshoff (2009) revealed that 80% of Central Africa's research papers are produced in collaboration with a partner from outside the region. Moreover, 46% of papers are produced in collaboration with European countries as the only partner. Nevertheless, these relationships are not always without any conflicts—be they intercultural conflicts or conflicts about power relations (e.g., about data ownership or publication authorship position).

Intercultural challenges in intercultural collaborative research are manifold. Intercultural tensions can also result from different communication styles or rules. For example, some cultural specifics include a more direct form of addressing work issues than is found in other cultures (Okech et al., 2016). People who are not used to a direct form of communication might feel offended by their fellow researcher. On the other hand, from a Western point of view, some cultures seem to "ignore" conflict, or discussing challenging issues seems to be a taboo. As these intercultural conflicts may affect collaboration at different levels of the research process, training research teams in cross-cultural partnerships seems to be a must.

Research Collaborations Against the Background of Subconscious Colonial Trauma

Returning to Boshoff's study (2009), an interesting finding was that 35% of African research papers had been produced in collaboration with researchers whose countries were past colonial rulers or former slave traders. In the case of collaborations with European and North American researchers, one part of the abovementioned tensions within multinational research teams cannot only be explained by general intercultural misunderstandings but may be related instead to unconscious influences of this harmful past. From a psychoanalytical perspective (e.g., Fanon, 1952; Kristeva, 1991), the shared background of racism and exploitation can be seen as a trauma that more or less continues to resonate as an inherent part of every international research collaboration. Further, current researchers may still feel, or act, subconsciously driven by the past, for example, feeling ashamed as a European researcher or feeling subordinated as an African researcher.

Even though colonization and Apartheid lie in the past, at a time of progressive globalization the power relations within research collaborations are still not balanced and new neocolonial shadows crawl in. One way of analyzing these conflicts within the SLT science is to look closer at the joint past. Schütte et al. (2023) therefore argue that these collective experiences are important to reflect on not only in international SLT research collaborations, but also in any SLT workplace worldwide with a context of cultural and linguistic diversity (CLD). As a way to address this—especially for the next global SLT generation—they propose implementing work and research stays for students abroad along with a professional reflection on social, cultural, and psycho-emotional experiences as part of any SLT curriculum worldwide.

Proposing a Relational In Vivo Methodology for Participative Speech–Language Therapy Research in Sub-Saharan Africa

With the above background in mind, in this section we outline one possible research methodology in the field of SLT in SSA, "the Relational In Vivo Paradigm for Participative Research" (Lüdtke, 2023), which is based on multiple collaborative research projects we conducted over the last decade. Before we dive deeper into some of them (see section "Studying Persons with Communication Disorders Within the Sub-Saharan Africa Context: The Range of Relational Methods in a Multilevel Research Approach"), we first outline the paradigm's conceptual dimensions (section "Conceptual Dimensions of a Relational and Participative In Vivo Research Paradigm"), followed by a description of the practical key elements of such an approach (section "Practical Key Elements of a Relational In Vivo Approach").

Conceptual Dimensions of a Relational and Participative In Vivo Research Paradigm

Our proposed research approach can be called a paradigm because it draws on some fundamental theoretical positions, which act to demarcate it from other methodological paradigms, e.g., the positivist approach (Popper, 1935). Its key elements—"relational," "participative," and "in vivo" (Lüdtke et al., 2022)—are grounded in the following theoretical and epistemological assumptions. These concepts are rooted in "Western" scientific discourse. It is an urgent request that all SSA researchers discuss or even discard these, and exchange, add, or ungird these ideas with African-specific concepts and ideas.

Social Constructivism: There Is No Objective Reality

First, we refer to the overall basic consensus of the constructivist epistemology that there is no objective reality, which can be detected by empirical studies. Instead, all "truth" is constructed by the participants of a research study, who also influenced by their mere presence in the research field (Berger & Luckmann, 1966; von Glasersfeld, 1984; von Förster, 1981; Maturana & Varela, 1992). Therefore, a research methodology should take into account the relations within the studied field as an inherent part of gaining knowledge about it.

Relational Sociology: The Real Is Relational

Based on the above, we expand this epistemological cornerstone, agreeing with Bourdieu's famous saying: "The real is relational" (1998, p. 3); as this sine qua non of his relational sociology points out, any feature of a research phenomenon cannot be studied in isolation as an inherent part of it, but has to be valued instead as relationally differing from other studied phenomena within the field. Therefore, a research methodology needs to dive "in vivo" into the field and study the inherent power mechanisms and attributions made by the "market" to the studied subjects to understand the specific creation of "difference."

Intersubjectivity: Relational Emotions Are the Driving Force

A relational approach cannot be called "relational" without acknowledging emotions as a constitutive factor of epistemological insight—be they relational emotions between collaborating researchers, relational emotions between the researcher and participants within the field, or relational emotions between two or more research participants themselves. Relational emotions are understood as emotions felt toward the communicating partner, such as pride or shame. Based on the concept of "intersubjectivity" (Habermas, 1987; Trevarthen, 1979, 2001), a relational research methodology value relational emotions in general as the driving force of many relevant processes—epistemology, development, communication—and therefore seeks to prioritize participative research structures.

Semiosphere and Intertextuality: Speakers as Embedded Subjects in Process

Having said this, and most relevant to research of the SLT profession, our target group—persons with language and communication disorders throughout the whole life span—cannot be depersonified and devalued as mere "objects of investigation"; instead, as "speakers," they have to be conceptualized as embedded "subjects in process" (Kristeva, 1984, 1998). Drawing on this psychoanalytic concept means implementing the dimension of "time" into our research approach, resulting in a real-time in vivo methodology. Researching living, evolving, and developing speaking subjects in process in SLT studies mean on the one hand considering the past and future of the studied person(s) at the intersection of the present studied moment. On the other hand, it draws the researcher's attention to the dimension of (a) the surrounding "semiosphere" (Lotman, 1992)—the communicative space of never-ending semio-genetic processes, and (b) to the phenomenon of "intertextuality" (Kristeva, 1980), where "texts" and features of any communication resonate in the studied speaker(s). A relational research methodology therefore has to study those traces through participative in vivo approaches and the semiosphere itself, in which the participants are embedded.

Performativity: Every (Spoken) Action Has an Impact

In addition to the socially co-constructed, relational, intersubjective, and intersemiotic aspects of reality, performative aspects add to the relational research paradigm the scientists' impact on the subjects of interests. Rooted in different epistemological approaches, the concept of performativity in the form of performative utterances was first named by Austin (1962). He described the power of utterances to change social reality, such as when a priest says, "I pronounce you husband and wife," and through these words, two persons are married. His thoughts were discussed and enhanced by different thinkers of the twentieth century like Derrida (1988), Bourdieu (1991), and Butler (1996). One core thought of this wide concept of performativity is the reiteration of every communicative sign from the past: Every communicative sign, be it a word or a gesture, has already

been said or executed before. For example, a word of greeting such as "habari yako" in Kiswahili has a history and encompasses traces of preceding greetings within its historical and cultural context as it is used in casual meetings of people of the same age and prestige. However, when repeated in communication, the communicative sign creates a new context. The word of greeting changes the situation. "Habari yako" acts as an opener for communication in Kiswahili-speaking communities only when the situation is appropriate. Greeting an elder in Kiswahili requires saying "shikamoo." Otherwise, it might be offensive and disturb the communication. In other words, every spoken action has an impact on the actual situation, while the impact is still connected to the past. Therefore, this approach requires reflection on researchers' actions and how these impact on the participants (Polzin, 2019).

- In vivo investigations
- Participative discussion
- Inclusion of emotion
- Widening the focus

Practical Key Elements of a Relational In Vivo Approach

From our point of view and derived from the above conceptual dimensions, the following features of a relational in vivo research are crucial:

Leaving the Laboratory—Diving into the Field

To gain Africa-specific insights on the reality of persons with communication disorders (Level I) or the effectiveness of practical SLT concepts or programs (Level II and III), research needs to access the SSA field. Otherwise, research will not meet the complexity of real life and practice. In a quantitative design, this might not be viable in every step, but even quantitative research can include perspectives or specific contexts before commencing the research. Meeting the people with communication disorders and obtaining insights on how they live (see section "Epidemiological Studies (Level I): Getting Access to the People and the Field") is vital before starting to create the research design—whether it is quantitative or qualitative. According to a relational in vivo approach, this is as important as studying theoretical papers or the state-of-the-art research in a given specific topic.

Stopping Top-Down Implementation—Starting Participative Negotiation

Closely related to the need to step into the field is the feature of participation. Both should bring research closer to the people. Implementing research designed by privileged academics living outside the person's reality, e.g., a scientist working at a university and living in an urban area, or, when collaborating, scientists from minority world countries, could easily fail as they might neglect the needs of the persons with communications disability who are less privileged, living in rural areas in SSA countries. In research practice, participation of the people includes meetings, discussions, and hearing their voices and acting accordingly. Participative research needs to be designed in an open way to adopt changes. This consumes time and labor that is not always given. However, participation can start with small steps in every research design, such as by identifying and discussing the relevance of the research questions with the persons concerned beforehand (see sections "Epidemiological Studies (Level I): Getting Access to the People and the Field" and "Intervention Studies on Speech–Language Therapy Practices (Level II): Obtaining Different Perspectives on Daily Service Delivery").

No Suppression of Affective Reactions—Cultivating Inclusion of Emotion

As mentioned above, emotions are seen as an intricate part of the way humans receive and understand the world and other persons. Therefore, the inclusion of emotions in research needs to be cultivated. Reflecting on the affective reactions of research participants and the research team during the data collection or analysis or in participative discussions could be one way to include emotions (see sections "Intervention Studies on Speech–Language Therapy Practices (Level II): Obtaining

Different Perspectives on Daily Service Delivery" and "Evaluation Studies: Promoting Standards for Evidence-Based Practice in Specific Contexts of Speech–Language Therapy Service Delivery"). This requires an openness to speak freely about personal feelings. Community participants may speak more openly because they are not as restricted to typical formal research attitudes compared to academically trained members of the research team. However, building relationships and mutual trust is a major task in cultivating the inclusion of emotion, which again needs time, effort, and continuous meetings.

Complementing the Microscopic Lens—Widening the Focus for Traces of History and Culture

In an innovative SLT research approach, power relations in society, traces of the past, and cultural and contextual specifics need to be recognized and reflected on. Even when research investigates specific aspects of language development, such as the transference of linguistic structures in multilingual development (which would be the view through the microscopic lens), the context—be it situational, cultural, or socioeconomic—should be reflected on (see sections "Epidemiological Studies (Level I): Getting Access to the People and the Field", "Intervention Studies on Speech–Language Therapy Practices (Level II): Obtaining Different Perspectives on Daily Service Delivery", and "Basic Research Studies: Investigating Early Communicative Dyads in a Non-Intrusive and In Vivo Way"). This wider perspective should also include reflection on the impact of the research itself and the performance of the researchers in the field. In a relational approach, it is important to think about how to address the people and how to act in the field. For SLT research in SSA, the overall aim should include the perspective of improving the situation in health care and education for persons with communication disorders as a kind of participative *action* research.

Studying Persons with Communication Disorders Within the Sub-Saharan Africa Context: The Range of Relational Methods in a Multilevel Research Approach

In this final section, we would like to show how the proposed relational in vivo paradigm for participative SLT research in SSA has already come alive in different intercultural and collaborative research projects which Leibniz University Hannover and different sub-Saharan universities carried out. We organize the portrayal of our experience by returning to our multilevel framework of SLT research (see Fig. 8.1), adding the description of concrete examples of research projects as illustration of the possible range of participative methods in a relational in vivo approach (see Fig. 8.2).

I. At the first SLT research level of getting to better understand the diversity of persons with communication disorders in SSA, the necessity of manifold epidemiological studies is illustrated by the example of conducting interviews with relevant stakeholders of the Tanzanian research context as part of a *participatory construction of a questionnaire*. This questionnaire was developed to gain epidemiological insight into the broad topic of the diversity of multilingual children and their language development in this particular rural area.
II. At the second research level of examining the quality of SLT practice, the demand for many intervention studies on service delivery in different SSA contexts, institutions, and settings to build up a body of EBP for different target groups, as well as ideas for clinical reasoning, is described by a research project on community-based prevention of speech, language, and hearing disorders in remote rural areas. Leading women located in villages with well-

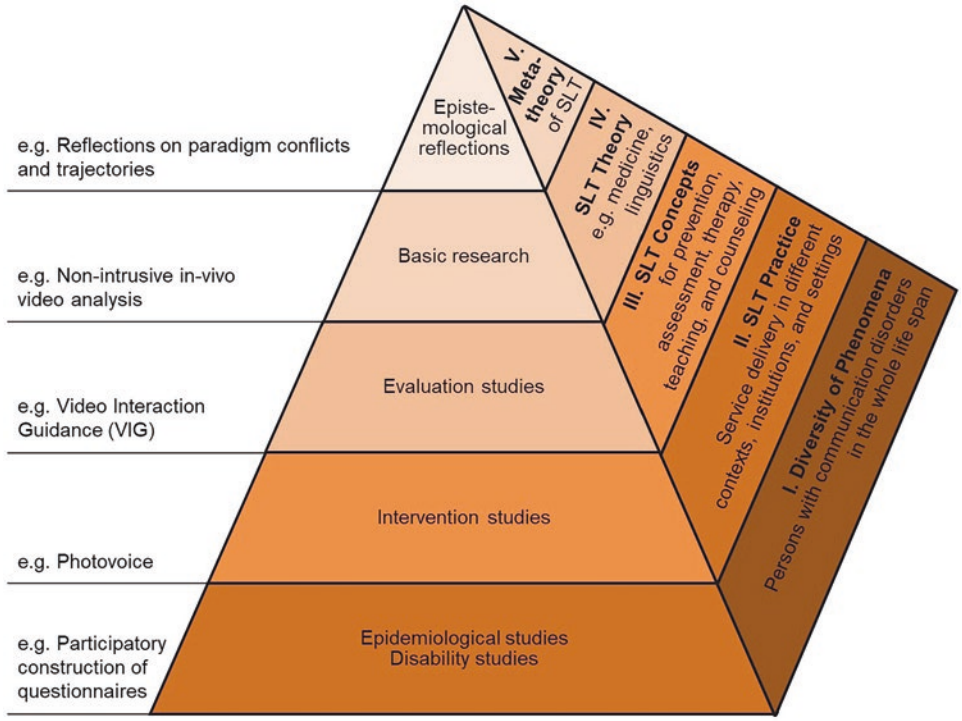

Fig. 8.2 Range of methods in a relational in vivo approach for participative multilevel speech–language therapy research in sub-Saharan Africa

respected local knowledge have been collecting, reflecting on, and evaluating different perspectives of the rural community on beneficial and challenging conditions and practices of child development and early communication using the method of photovoice as a means of community-based SLT capacity building.

III. At the third research level of developing guiding SLT concepts for prevention, assessment, therapy, teaching, and counseling in the SSA context, the high need for continuous evaluation studies is demonstrated by a project where the staff and management of an orphanage developed their own professional standards of service delivery to the orphans in the four areas of (1) infant intersubjectivity, (2) communicative musicality and play, (3) child language development, and (4) respectful caretaking based on group reflections of their daily concepts of service delivery using own recordings inspired by the method of *video interaction guidance (VIG)*.

IV. At the fourth research level of developing and renewing SLT theory for SSA, the request for Africa-specific findings and insights based on Africa-specific empirical data is exemplified by a basic research study, which aimed at investigating the processes of emotional regulation of early caretaker–newborn communication in a highly vulnerable SSA context by using non-intrusive participative in vivo (micro)video recording and analysis.

V. Finally, at the fifth research level of also establishing a meta-theory of SLT in SSA, the urge for Africa-specific reflections on paradigm conflicts and trajectories or epistemological reflections is described by referring to this chapter and proposing references to Africa-specific philosophical approaches when developing a meta-theory for Africa-specific SLT.

Epidemiological Studies (Level I): Getting Access to the People and the Field

One example from our relational SLT in vivo research in the area of epidemiological studies (Level I) is the participatory development of a questionnaire, which was jointly developed by master's level students from both Tanzania and Germany to gain epidemiological insight into the broad topic of the diversity of multilingual children and their language development in a particular area of rural Tanzania (Ellerbrock, 2014). This collaborative research project illustrates how the need of the first SLT research level—gaining better understanding of the diversity of persons with communication disorders in SSA—can be targeted. The main guidelines of the project were the methodological features shown in Table 8.1 regarding the relational research method, research question, and research paradigm.

Implementation

The key element of the implementation of these relational features in the research project was conducting interviews with relevant stakeholders of the Tanzanian research context, e.g., with members of the Maasai community (see Fig. 8.3), or

Table 8.1 Example for features of a relational participative in vivo SLT research methodology in SSA at the level of the diversity of persons with communication disorders (Level I)

Level I: Diversity of phenomena *Epidemiological studies*	
Relational research method	Participatory construction of a questionnaire, which is also appropriate for the people who answer it, as part of SLT epidemiological research grounded in the particular Africa-specific research context
Relational research question	How can the Africa-specific cultural, socioemotional, and linguistic research context become transformed into the construction of the epidemiological questionnaire?
Relational research paradigm	Questionnaires need to be constructed within the Africa-specific research context and together with its stakeholders— – not from an "alien" outside(r) perspective.

Fig. 8.3 Epidemiological studies: visiting relevant stakeholders for interviews as part of a participatory construction of a questionnaire

Fig. 8.4 Epidemiological studies: obtaining various perspectives from the context to do field-based research in a participatory way

with parents of small children in the surrounding villages (see Fig. 8.4). Obtaining different perspectives in the interviews, which cover a wide range of people working or living with young children and supporting them in their (multilingual) language development, was the aim but also the main challenge. First, the groups of participants needed to be defined and, second, they needed to be found, contacted, and visited at their home. For the development of the questionnaire, this was a time-consuming process, compared to listing questions based on ideas from classic minority world literature. Only if this outsider knowledge is complemented by local knowledge can the people relate to the questions in the questionnaire, and the research becomes Africa-specific, innovative, and meaningful.

With a valid research instrument, as such a participative developed questionnaire, which is constructed for the persons involved, more information on the perspectives of a wide range of people from diverse contexts could be gained. This could help to improve and adjust methods and tools in SLT and assessment.

Intervention Studies on Speech–Language Therapy Practices (Level II): Obtaining Different Perspectives on Daily Service Delivery

One example from our relational SLT in vivo research in the area of intervention studies (Level II) has been the application of the method of photovoice (Wang & Burris, 1997), which was used by the management and staff of a Tanzanian children's home to collect, reflect, and evaluate different perspectives of the neighboring rural community on

Table 8.2 Example for features of a relational participative in vivo speech–language therapy research methodology in sub-Saharan Africa at the level of speech–language therapy practice (Level II)

Level II: SLT practice *Intervention studies*	
Relational research method	Photovoice is used for collecting, reflecting on, and evaluating different perspectives of the rural African community as a means of intervention for community-based SLT capacity building.
Relational research question	What are the different context-specific perspectives of the members of the rural African community on beneficial and challenging conditions and practices of child development and early communication?
Relational research paradigm	Knowledge on SLT issues needs to be derived from within the Africa-specific research context and together with its stakeholders— – not from an "alien" outside(r) perspective.

beneficial and challenging conditions and practices of child development and early communication (Beta et al., 2023). This collaborative research project illustrates how the demand for manifold intervention studies examining the quality of practical SLT service delivery in different SSA context institutions, and settings for different target groups, can be met by using photovoice as a means of community-based SLT capacity building. The project shows how community-based prevention of speech, language, and hearing disorders in remote rural areas is based on the context-specific local knowledge of the leading women of the local villages. The main guidelines of the project were the methodological features shown in Table 8.2 regarding the relational research method, research question, and research paradigm.

Implementation

In a field study on practices of early child communication development, the participatory method photovoice was used. In this method, the participants' views on different topics can be gained from discussing photographs they took within the African SLT context about important aspects of a specific subject: here, early communication development in rural Tanzania (Beta et al., 2023). Using photographs instead of written texts also allows team members with reduced writing skills to participate and express their voices. However, the visual method can pose challenges for unexperienced participants. The use of a camera and shooting expressive relevant photographs is a skill that needs to be taught and trained (Fig. 8.5). Another merit of this method is the more direct access to the participants' lives, thoughts, and emotions. When discussing the photographs in groups, the participants learn from each other and connect for future collaborative work (Fig. 8.6). Main challenge of such a method is that it is more expensive and time-consuming. For reducing costs and enhancing the applicability of this method, existing resources such as cameras of mobile phones could be used.

Nevertheless, this method brings the voices of the people into the core of the intervention study and has the potential to make the intervention sustainable because the intervention becomes their project and the participants are intrinsically motivated to implement the intervention program. Thus, it also could change the perspectives on communication development and disorders of the community members, which might affect the lives of persons with communication disability for the better.

Evaluation Studies: Promoting Standards for Evidence-Based Practice in Specific Contexts of Speech–Language Therapy Service Delivery

At the third research level of developing guiding SLT concepts for prevention, assessment, therapy, teaching, and counseling in the SSA context, we refer to a method from a broader evaluation research and training project as an example (Polzin, 2019; Schütte, 2016). In this project, group reflections of daily concepts of service delivery were implemented using *self-taken*

Fig. 8.5 Intervention studies: training on the use of cameras for the photovoice method

video recordings, which were inspired by the method of *video interaction guidance (VIG)* (Kennedy et al., 2011). The high need for evaluation studies is demonstrated by this project, where the staff and management of an orphanage developed, with the help of Tanzanian students, their own professional standards of service delivery to the orphans in the four areas of (1) infant intersubjectivity, (2) communicative musicality and play, (3) child language development, and (4) respectful caretaking (see Table 8.3).

Implementation

In a training project (Polzin, 2019; Schütte, 2016; Schütte et al., 2016), the concept of video interaction guidance (VIG) (Kennedy et al., 2011) was used to reflect on the communicative behavior of caregiver staff in an orphanage (see Fig. 8.7). This specific method uses self-recorded videos (via a camcorder) from communicative situations between parents and children or professionals and clients to reflect on specific significant moments in this situation. The aim is to identify and show the parents or professionals moments of successful communication. This should lead to them becoming more self-aware and self-reflective in situations when communication fails. Video reflections are a powerful tool to reflect on communicative structures and behavior as well as SLT sessions in an almost natural setting. In our project, VIG was implemented in the form of group discussions, in which not only were the successful communicative moments of the caregivers with the orphaned children part of the discussion, but reflection on theoretical knowledge in the four conceptual areas (infant intersubjectivity, communicative musicality and play, child language development, and respectful caretaking) was also

Fig. 8.6 Intervention studies: obtaining different perspectives on daily practices in the context of child development and early communication using photovoice

Table 8.3 Example for features of a relational participative in vivo speech–language therapy research methodology in sub-Saharan Africa at the level of speech–language therapy concepts (Level III)

Level III: SLT concepts *Evaluation studies*	
Relational research method	Inspired by the method of VIG, self-taken video recordings collected in almost natural SSA working setting were used by staff and management of an orphanage as a base for group reflections on their daily concepts of SLT service delivery.
Relational research question	How can professional standards of service delivery to orphans in SSA be developed by the SLTs themselves based on own reflection, evaluation, and improvement of the everyday concepts of service delivery built on self-generated data of daily practice?
Relational research paradigm	Guiding SLT concepts for prevention, assessment, therapy, teaching, and counseling in the SSA context need to be derived from the practitioners themselves not from an "alien" outside(r) perspective.

correlated with these approachable examples. These video discussions and relations to concepts led to their own standards for best practice (see Fig. 8.8).

However, this video approach also poses challenges. The discussion and reflection on the short video clips also needed some practice. For the caregivers, it was challenging to watch themselves,

Fig. 8.7 Evaluation studies: discussing criteria for successful caregiver–child communication with the head of the institution and her representative as renowned experts

Fig. 8.8 Evaluation studies: promoting standards for evidence-based practice in specific contexts of service delivery based on group reflections of caregivers to evaluate their daily service delivery using own recordings (VIG)

as it was often the first time they had seen themselves on video, and to talk about positive moments, they were having with the children. It took some time for them to become used to talking about what they see and to overcome being ashamed. Afterward, though, they even felt proud to share these moments. Another challenge was to encourage the non-academic caregivers to take the concepts as a base upon which to reflect on their own daily practice in their institution, and not to entirely adopt them as standards from outside. To achieve this, their videos were a fruitful reference to connect their reflection to their daily service.

The use of such a method in this evaluation study influenced the way of communication to especially one child with a severe communication disorder who lived there. Subsequently, the child changed her communication as well and became more intelligible for the caregivers (Polzin, 2019).

Basic Research Studies: Investigating Early Communicative Dyads in a Non-Intrusive and In Vivo Way

At the fourth research level of developing and renewing SLT theory, the request for Africa-specific findings and insights based on SLT researchers' own empirical data is exemplified by a basic research study, which aimed to investigate the processes of emotional regulation of early caretaker–newborn communication (Lüdtke, 2012) in a highly vulnerable SSA context by using a non-intrusive participative in vivo video technique and analysis (Frank & Trevarthen, 2015; Lüdtke & Polzin, 2015; Polzin et al., 2017, see Table 8.4).

Implementation

In our basic research study, the research team consisting of Tanzanian and German researchers took the first steps to build a child development laboratory in Tanzania, implementing a technique of an automatic recording system of three cameras recording synchronously (one for the infant's face, one for the caregiver's face, and another one recording from the side for the movements) in an orphanage (Figs. 8.9 and 8.10). The purpose was to gain more insights into this specific communication context, the communicative and emotional process, and the structures of communication and language development under at-risk conditions. In such a vulnerable setting, it became evident that these investigations need to be as non-intrusive as possible. Therefore, the caregivers could decide whether to record a specific situation or not by using a remote control (Fig. 8.10).

A major challenge for our research team was to gain the trust of the head of the institution, the caregivers, and finally yet importantly, the representatives of the church who administer the orphanage. For this, the Tanzanian researchers had several meetings with all the persons who are responsible for the children or took part in our research. In addition, the German researchers needed to become familiar with all the participants as well. We all needed to know more about the daily struggles in the orphanage like the time-consuming chores of the caregivers, which take time off the time for childcare. In this process, also the head of the institution became an active and driving part of the research team. Our team needed to be clear and intelligible to the participants, especially on the topics of data security, and to reassure them that there would be no mis-

Table 8.4 Example for features of a relational participative in vivo speech–language therapy research methodology in sub-Saharan Africa at the level of speech–language therapy theory (Level IV)

Level IV: SLT theory *Basic research*	
Relational research method	Non-intrusive in vivo video or audio sampling and analysis in a natural context.
Relational research question	How can in vivo data of emotionally regulated communicative dyads be collected in a non-intrusive way? How can it be analyzed?
Relational research paradigm	Data of communicative dyads, e.g., caregiver and vulnerable newborns, need to be collected with respect for the highly sensitive research context and not from an "intruder" perspective.

Fig. 8.9 Basic research studies: investigating emotional regulation of early caretaker–newborn communication in highly vulnerable contexts by using a non-intrusive participative in vivo video technique. (Frank & Trevarthen, 2015)

Fig. 8.10 Basic research studies: set-up of the automatic camera system with a remote control (marked with circle) for self-determined operation by the caregivers during their everyday communication with the babies during nappy changing

Table 8.5 Example for features of a relational participative in vivo speech–language therapy research methodology in sub-Saharan Africa at the level of speech–language therapy meta-theory (Level IV)

Level IV: meta-theory of SLT *Epistemological reflections*	
Relational research method	Participative group discussions or theoretical examinations on philosophical and epistemological thoughts and narratives from SSA on topics such as communication, emotion, and knowledge generation.
Relational research questions	What value has verbal communication to the people in SSA? What is an Africa-specific methodology for SLT research?
Relational research paradigm	Meta-theoretical and methodological thoughts should be connected to philosophical approaches from SSA.

use as a surveillance technique. Only when the caregivers felt safe could the caregivers themselves and the research team obtain natural insights into their daily lives. The analysis of the video was done jointly in the research team with other professionals and the participants themselves. In particular, because we were investigating emotional processes in the caregiver–infant dyad, the reflection of the participants' and the researchers' emotional involvement revealed important information on the situation.

With these research efforts, not only the childcare in this orphanage was supported by video feedback sessions, but also basic knowledge about language and communication development could be gained.

Epistemological Reflections

Finally, at the fifth research level of establishing a meta-theory of SLT in SSA, there is the need for Africa-specific *reflections on paradigm conflicts and trajectories* or *epistemological reflections*. This chapter tries to address this need by referring to methodological reflections at every research level.

For future research, we propose reference to and examination of philosophical positions from SSA, which can give insights into Africa-specific views on philosophical research questions on areas such as communication, emotion, and knowledge generation (see Table 8.5).

Implementation

Epistemological reflections at the fifth level can be initiated in different ways. However, all epistemological reflections are about knowledge and how we generate it—whether it is about the external world or other people's perspectives. These reflections about how knowledge is produced are an inherent part of philosophy from minority world contexts. When doing research at every level (I–IV), we think it is relevant to reflect on the way this research generates new knowledge. In our examination in this chapter, we have gone through different levels of the SLT profession and initiated reflection on the uniqueness of the SSA context.

In a relational approach, it is relevant to relate the reflection to thoughts of African philosophers. Venter (2004) describes two conceptions in the debate on African philosophy: academic and traditional concepts. The academic concept is seen as a rational and critical understanding of African philosophy and the traditional concept would be a philosophy that is constituted by Africa-specific worldviews. Both conceptions are viable for Africa-specific epistemological reflection. From a relational point of view, especially, the understanding of traditional philosophies on Africa-specific concepts on topics like knowledge, communication, and emotions would be fruitful to reflect on for methodologies in SLT research.

For example, Senghor (1984), Mbiti (1966), and Anyanwu (1987) are authors who stand for the traditional conceptions of philosophy (Venter, 2004). In the concept of Négritude, Senghor highlights emotion for an African epistemology: "Emotion is Negro, as reason is Hellenic" ("L'émotion est nègre, comme la raison héllène") (Senghor, 1984, p. 288). He was criticized for this statement, because reason and intellect are usually seen as superior to emotion. However, from a relational perspective, emotion is as important as cognition and those two factors cannot be viewed separately. As a current example of Africa-specific epistemo-

logical reflection, Jimoh (2017) can be consulted. He outlines an African theory of knowledge that also includes more than the cognition of a subject. Jimoh (2017) claims that the object, the context, and the subject's disposition are parts of understanding reality, which is also a relational kind of understanding.

Discussing concepts from African philosophers and relating those to activities in SLT research have the potential to develop SSA-specific methodologies.

Steps Toward a Relational In Vivo Methodology: An Everyday Participatory Research Checklist for Decolonizing SLT Research

Following a relational approach includes having a type of research attitude or research habitus (Bourdieu, 1998) that accepts the valid perspectives and realities of the persons who are part of the research. The researcher him- or herself should be open to the situation and context they want to investigate. For conceptualizing research, we propose the following questions which help to reflect own research attitudes. We chose to address the questions not to a singular person but to a research team, because in participatory research, research should be a team effort. With these questions, research teams from SSA (e.g., SLTs from Moshi with academics from Dar es Salaam, scientists from South African universities with scientists from Togo, or also scientists from Nairobi with scientists from Berlin) could reflect on how much their research is Africa-specific and appropriate to the situation and context of the people with communication disorders. However, some of these questions are especially valid for researchers who are part in international collaborative research projects in SSA.

In Vivo Investigations

- Do we research in our intervention study, evaluation study, or basic research questions which are important for the persons with communication disorders in SSA?
- How can we be part of their situation to understand them and their life experiences in a more detailed way?
- From where can we get more information on their situation, e.g., when investigating developmental trajectories of dysphagia in children, is it possible to talk to the parents or relatives?
- What is the most natural environment for investigating our research questions, e.g., on communicative barriers for participation of persons with ASD?
- How can we design the research setting of our study in a most natural environment so that we are not disturbing natural communication?
- What are the communicative rules in this institution or in the family, e.g., rules about who is allowed to talk in the classroom?

Participative Discussions

- Do we need a diverse research team to obtain insights that are more diverse?
- Are we flexible to changes in our plan, e.g., when the participants express their doubts on planned steps?
- Do we value and integrate the perspectives of all members of the research team, e.g., in giving them the opportunity to speak in an open and trustful setting?
- Do we meet regularly to reflect on past phases and to discuss further steps?
- How can we include persons with communication disorders in doing research, e.g., in constructing a questionnaire?
- What are the relationships of the participants to each other; e.g., are there any conflicting positions or interests when students and teachers join a research team?
- To what extent are they bound to their professional position, e.g., as head of an institution?

Inclusion of Emotion

- How do the participants respond when we pitch our ideas on their involvement in the research process?
- How do the participants respond to the question of expressing their feelings?
- Do we communicate in a non-offensive way?

- What emotional processes lie beneath disturbances or problems in the participative research process; e.g., when one participant refuses to meet for participative discussions, how is he feeling?
- What role could emotions play for the person with communication disorders in a specific SSA context, e.g., when a student who stutters speaks in front of a classroom?

Widening the Focus

- Do we reflect on research in the SSA context from different perspectives?
- Does the research have an impact on the lives of persons with communication disorders or policymaking processes?
- Do we communicate in a culturally and situationally appropriate way in this specific SSA context; e.g., when interviewing an Iraqw mother of a child with communication disorder for getting her perspective on service delivery in her region?
- What changes when we implement this method in this SSA context, e.g., video recordings in a rural area where the participants are not used to video recording?
- What changes when we ask this question; e.g., what happens to the peer interactions when we investigate the situation of a student with ASD in a case study? Or what happens to the perception of persons with aphasia in the society?

Some of these questions on the researcher's attitude and actions are more or less important for specific research questions. There might be only reduced possibilities for the researcher themselves to be involved in the situation in a quantitative experimental research setting. Nevertheless, we understand this more as a question of attitude toward the researcher's own role. Even in quantitative experimental designs, persons with communication disorders can be part of designing the setting or formulating the research questions. Therefore, and in the light of a relational approach, which has the potential to create an Africa-specific methodology, these questions are important to ask in every research design.

In this way, we think that a relational approach can contribute to decolonizing research in SLT and its underlying paradigms. While decolonizing curricula is already a topic in several papers or books (e.g., d'Abdon, 2016; Heleta, 2018; Pillay & Kathard, 2015; Winberg et al., 2021), decolonizing research methodology and practice is another important step, which needs to be taken by future SLT researchers from SSA countries and by collaborating researchers from minority world countries. With this in mind, we would like to open a scientific dialogue on decolonizing research and encourage all researchers from SSA to respond critically to our proposed relational in vivo approach.

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9

Speech-Language Therapy in Kenya: Trends, Challenges, and Opportunities

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Background

Defining Communication Disorders and Speech–Language Therapy

Communication disorders or impairments, defined as delays or difficulties that interfere with the normal flow of speech or language in the day-to-day communication of a person, have led to the emergence and development of the interdisciplinary profession of speech–language therapy (SLT) (Newfoundland Division of Student Support Services, 2000). SLT grew from the integration of disciplines including elocution, education, psychology, linguistics, communication, and medicine (Lubinski, 2010). SLT is a field of expertise that deals with the evaluation and treatment of communication disorders including speech, language, and swallowing disorders (American Speech–Language-Hearing Association [ASHA], 1997–2019). SLT deals with speech problems relating to articulation, phonology, apraxia, fluency, and voice disorders, such as hoarseness. It also deals with language disorders such as receptive language problems, expressive language problems, and pragmatic problems. Other disorders that are of concern to SLT include deafness/hearing loss, oral–motor disorders and swallowing or feeding disorders (Loraine, 2008). Overall, both speech and language problems and related problems that interfere with communication all fall under the broad area of communication disorders. This chapter is concerned with the broad field of communication disorders and the persons whose lives are affected by these disorders—that could result in long term communication disabilities.

Practitioners in this field are known as speech–language pathologists (SLPs) or speech–language therapists (SLTs). The practitioners are trained in techniques, strategies and interventions to assess and rehabilitate persons with communication disorders and disabilities. SLTs work collaboratively with multidisciplinary teams consisting of audiologists, physicians, dentists, nurses, occupational therapists, dieticians, teachers, and parents, among others. Such collaborative working is important because the underlying causes and effects of communication disorders can be related to different aspects of an individual and their functioning. Speech and language disorders may be due to a range of factors including physical, mental, social, neurologic, organic, and genetic causes (DeThorne et al., 2016, Hamed et al., 2018).

Communication disorders, just like other forms of disorder including physical and mental disorders, affect people of all races, ethnicities, and geopolitical regions. However, as with many other professions, the development of SLT has not been uniform across the world. In many African countries, the emergence of SLT can be traced to the colonial past and its development since then has been checkered. It has been stated that in many Majority World countries such as Kenya, SLT either does not exist or is in the early stages of professional development (D'Antonio & Nagarajan, 2003; Munyere, 2004, Mwihaki, 2002/2003; Wylie et al., 2017).

First, it must be pointed out that, in Kenya, there is no clear demarcation between communication disorders and other disorders. Communication disorders have often been found to occur either with or as a result of other disorders such as learning difficulties, hearing impairment, autism, and Down syndrome. Second, in Kenya, any developments, policy-wise or otherwise, have been instituted for persons with disability in general and not specifically for persons with communication disability. Furthermore, in Kenya, people are more aware of other forms of disorders compared to communication disorders. Therefore, in discussing issues relating to SLT or communication disorders, this chapter will inevitably touch on disorders more generally. With this in mind, the following sections highlight some of the developmental trends, challenges, and opportunities relating to SLT in Kenya. Where possible, a distinct and specific focus on communication disorders is provided. In the next section, a brief overview of the demographics of persons with communication disability whose activities and participation in social life are affected by communication disorders in Kenya is presented.

Persons with Communication Disability in Kenya: A Demographic Overview

From the pre-colonial period, there was no evidence-based data on the extent of disabilities and other factors affecting persons with disabilities in Kenya, making it difficult to plan for this minority segment of the population (Kenya National Bureaus of Statistics, 2012). The 2007 Kenya National Survey for Persons with Disability (KNSPWD) was the first attempt at a comprehensive nationwide survey aimed at providing data on the population of persons with disabilities. The 2007 survey recorded that 3.8% of the persons with disability had a speech impairment of some form.

The Kenya 2009 Population and Housing Census collected data on disability for the second time in the history of the country's census undertaking, the first attempt being in 1989. In collecting the data, the 2009 census categorized disability into seven groups, namely visual impairment, hearing impairment, physical disability, mental disability, self-care difficulties, speech impairment, and other forms of disabilities. It was found that 1,330,366 (3.5%) of the Kenyan population had some form of disability. Out of the total population of persons with disability, 12.2% were found to have a speech impairment. Clearly, there is a disparity between the findings of the 2007 KNSPWD survey and the 2009 national census regarding the figures for those with speech impairments.

Figure 9.1 shows the proportions of different forms of disability as enumerated in the 2009 census (Kenya Bureau of Statistics, 2012).

These data show that the population of Kenyans affected by communication disorder continues to grow and/or is becoming better identified. The increase in communication disorders has been associated with factors such as cerebral malaria, cleft palate, cerebral palsy, Down syndrome, accidents, and injuries to the brain or other articulatory organs (Gill, 2009). With such increasing populations of persons with communication disabilities, the need for SLTs cannot be underestimated.

With this difficult background in mind, the following sections broadly discuss SLT in relation to the following key socioeconomic factors: (1) the conceptualization of disorder and disability, (2) the legal framework that has shaped the development of SLT, (3) advocacy and professionalization, and (4) resources and facilities. In doing so, this chapter aims to trace developmental trends, challenges, and opportunities with a view to raising awareness about the need for increased attention toward communication disorders in Kenya.

Research Questions

This chapter seeks to answer the following questions with a view to identifying the important milestones and gaps relating to SLT provision in Kenya:

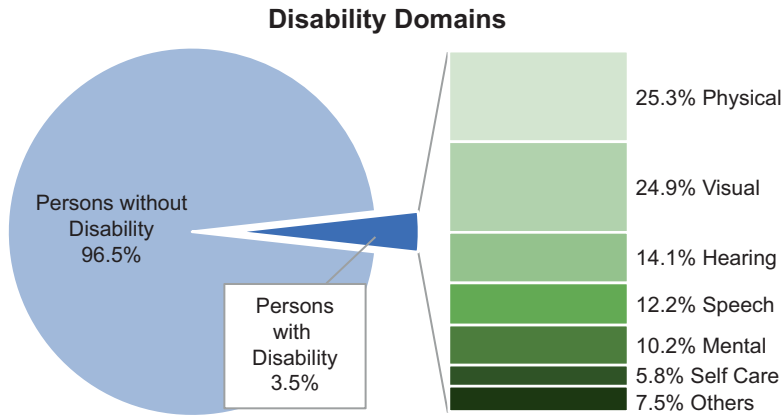

Fig. 9.1 Proportion of persons with disability in Kenya per disability domain. (Based on Kenya 2009 Population and Housing Census: Analytical Report on Disability; Kenya Bureau of Statistics, 2012)

1. How has SLT been conceptualized in Kenya?
2. Which factors and agencies have shaped the emergence and development of SLT in Kenya?
3. What challenges does the development of the SLT profession in Kenya face?
4. What are the opportunities for the SLT profession in Kenya?

Methods

The aim of this review is to highlight the socioeconomic and political factors that have shaped the emergence and development of SLT in Kenya, outline some key challenges that have accompanied the development of SLT as a profession, and highlight the opportunities yet to be exploited.

To address these issues, a descriptive/scoping review was conducted to qualitatively interpret and synthesize information related to the research questions from various sources (Schlagenhaufer & Michael, 2015). Based on an (online) library search using the keywords *speech–language pathology, language disabilities, communication disorders, speech–language pathology trends, speech–language pathology policies*, in combination with the word *Kenya*, online research, scholarly publications from professional bodies, government and nongovernmental policy documents and reports, theses, dissertations, and other material relevant to the topic were critically reviewed. The search yielded 70 documents. From these, the content of a sample of 53 documents, including policy documents, reports, theses, journal articles, and web pages, was analyzed.

The selection of the 53 documents was guided by three themes related to the research questions. The themes were key definitions related to communication disorders and SLT, development trends in SLT in Kenya, and studies on SLT in Kenya.

Results

SLT Development Trends: Factors and Agencies

In this section, we highlight some important factors and agencies that have influenced the development of SLT in Kenya, addressing as mentioned above the following four themes: (1) the conceptualization of disorder and disability, (2) the legal framework that has shaped the development of SLT, (3) advocacy and professionalization, and (4) resources and facilities.

Conceptualizing Communication Disability in Kenya

Although communication disorders are one form of barrier afflicting human beings since ancient times, the development of SLT as a profession is yet to take root in Kenya. This state of affairs can be traced back to the way in which disability has been conceptualized in the country. This conceptualization has been influenced by cultural as well as religious beliefs. Jochmann (2006, p. 3) observed that "the devil is in that child," "This is the result of adultery," and "God punishes you for your sins" are phrases that are made with regard to disabilities in Kenya.

Ndung'u and Kinyua (2009) further observed that there are many cultural stereotypes and beliefs used to explain speech and language disorders in Kenya. Citing from the Operation Smile Mission Reports for 2006 and 2007 conducted in different parts of Kenya, Ndung'u and Kinyua give examples from the Boran, Rendile, and Samburu peoples, who believe that a pregnant woman who looks at a camel giving birth is likely to give birth to a child with a cleft lip since the camel's nostrils are split. The Ameru, Luo, and Kisii peoples see cleft lip as a result of curses for social wrongdoing, such as disobeying one's parents. The Agikuyu, on the other hand, associate cleft lip with family planning methods such as the pill or coil. Ndung'u and Kinyua (2009) conclude that such beliefs are likely to discourage people from seeking professional correction for cleft lips.

Religious beliefs have also influenced views about persons with a disorder or disability and, as such, determine whether or not those with communication disorder seek treatment. For example, where it is believed that a cleft lip is a punishment from God, the patient would not seek correction for fear of offending God any further (Ndung'u & Kinyua, 2009).

Semela (2001) reports that the birth of a disabled child usually causes various types of con-

flict in families as well as guilt, regret, grief, and anxiety. The emotional and psychological stress, as well as the increased financial burden on the family, causes significant strain in families. It has also been stated that traditionally in African society, children and adults with disability have been viewed as bad omens to the society, being *oloibe enkai*, meaning "one hated by God" (Munyere, 2004, p. 31). Consequently, those with communication disorders have been hit or beaten as a result of speech that is dysfluent, while others have had their lingual frenulum cut as a treatment for not speaking (Marshall, 2003).

Generally, in Kenya, as in many other parts of the world, disorders have been understood and associated with factors such as curses, witchcraft, and punishment from gods (James, n.d.; Munyere, 2004; Mwihaki, 2002–2003; Ndung'u & Kinyua, 2009). Therefore, persons with speech and language disorders, like those with many other types of disorders, were ignored, feared, pitied, mimicked, laughed at, considered helpless, rejected, hidden, or killed (Munyere, 2004; Ndun'gu & Kinyua, 2009). This conceptualization has arisen primarily out of ignorance about the real causes of communication disorders and, consequently, has led to the mismanagement of persons seeking professional help for them.

Even from an educational perspective, communication disorders have not clearly been understood and appreciated. Mwihaki (2002–2003) records that up until 1998, the Kenya Ministry of Education did not recognize language disorders as a special learning need. Special needs were categorized into hearing impairment, visual impairment, physical handicap, and mental handicap. Children with communication disability were slotted into any of these categories depending on the observable characteristics. Language and speech disorders were first addressed by the Koech Report of 1999 under the heading "Communication disorders." The report went on to recommend that speech therapy, music, counseling, and articulation of sounds should supplement the regular curriculum as a way of supporting children with communication disability. This highlighting of communication disorders was a commendable effort although, according to Mwihaki (2002–2003), the report still admitted that communication disorders are a complex area without services or programs in Kenya at that time. We hasten to add that the situation does not seem to have changed much and also note that negative attitudes and stigma associated with persons with disability have, to date, impacted negatively on the development of resources, facilities, and other necessary infrastructures for the advancement of persons with disability in various spheres of life.

Legal Framework for Disability in Kenya

The relevant government policies and legal frameworks affecting persons with communication disability in Kenya will be those that apply more generally to persons with disability. The government of Kenya has, over time, put in place a number of policies and programs to address issues concerning persons with disability. Some of these programs are anchored on global conventions, while many others are local. The area of legislation, policies, and programs for persons with disability has witnessed tremendous growth. We shall therefore only discuss some of the key developments in this regard.

Provision and Coordination of Services

The earliest government policy for the provision and coordination of services for persons with disability arose out of the recommendation of an education taskforce set up by the government, the Ominde Commission of 1964 (Kihoro, 2010, see Table 9.1 for an overview). The commission recommended more job training and education for persons with disability. This recommendation saw the birth of the Parliamentary Sessional Paper Number 5 of 1968 and the establishment of the Vocational Rehabilitation Division in the Department of Social Services (National Council for Persons with Disabilities, 2009). These initiatives led to the establishment of the Industrial Rehabilitation Centre in Nairobi in 1971 to train disabled persons in artisan skills such as carpentry, dressmaking, and leatherwork. Ten other rural vocational centers were later developed nationwide (Association for the Physically Disabled of Kenya (APDK), n.d.; Korpinen, 2009).

Table 9.1 Timeline of government policies for provision and coordination of services to persons with disability relevant to the Kenyan context

1960–1965	1966–1970	1971–1975	1976–2000	2001–2005	2006–2010
1964	*1968*	*1971*		*2003*	*2008*
Ominde Commission	Parliamentary Sessional Paper Number 5	Industrial Rehabilitation Centre in Nairobi		Persons with Disabilities Act	UN Convention on the Rights of Persons with Disabilities
		1975			*2009*
		UN Declaration on the Rights of Disabled Persons			Vocational Rehabilitation Division in the Department of Social Services

The 1975 UN Declaration on the Rights of Disabled Persons (United Nations, 2017), to which Kenya is a signatory, saw, for the first time, the creation of a special education division in the Ministry of Education to coordinate a special curriculum for children with special needs. Further impetus with regard to legislation on persons with disability arose out of recommendations of the Disability Taskforce set up by the attorney general to review laws relating to persons with disability. The taskforce recommended the need for legislation to support the marginalized community, and this bore the Persons with Disabilities Act, 2003 (Grut, 2007). The Act provides for the rights and rehabilitation of persons with disability in order to achieve equalization of opportunities. The Act also established the National Council for Persons with Disabilities (NCPWD). Some of the functions of NCPWD include:

- To formulate and develop measures and policies to deal with disorder issues;
- To advise the government during the national census to ensure that accurate figures of persons with disability are obtained in the country, for purposes of planning;
- To advise the minister in charge on the provisions of any international treaty or agreement relating to the welfare or rehabilitation of persons with disability and its benefits to the country;
- To carry out the registration of persons with disability, as well as institutions, associations and organizations of persons with disability, and to raise public awareness regarding persons with disability. (NCPWD, 2009)

In 2007, one major achievement of the NCPWD was to conduct a national survey to estimate the approximate number of persons with disability, the types of disorders, the prevalence of disorders, geographical coverage, and age distribution.

Another significant international policy that has impacted on persons with disability is the UN Convention on the Rights of Persons with Disabilities, which came into force in 2008 and to which Kenya is again a signatory. The convention seeks to promote, protect, and ensure the enjoyment of all human rights and fundamental freedoms of persons with disability. Furthermore, the convention also clarifies that discrimination on the basis of disability refers to any distinction, exclusion, or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil, or any other field (United Nations, 2017). The member states which have signed the convention agreed to promote, protect, and ensure the full and equal enjoyment of the human rights and fundamental freedoms of persons with disability and the prompt respect for their inherent dignity (United Nations, n.d.).

Assessment and Rehabilitation

With regard to the assessment, referral, and rehabilitation of persons with disability, the Community-Based Rehabilitation (CBR): Joint Position Paper of 2010 is a very important document. The CBR guidelines for the rehabilitation, equalization of opportunities, poverty reduction, and social inclusion of persons with disability were launched by the World Health Organization (WHO), United Nations Educational, Scientific and Cultural Organization (UNESCO), International Labor Organization (ILO), and International Disability and Development Consortium (IDDC). The key goals of this program are to ensure early identification, referral, and rehabilitation of persons with disability (WHO, 2004; WHO, 2010). Implementation of the CBR is through the combined efforts of persons with disability, their families and communities, and representatives of the appropriate health, education, and vocational and social sectors. CBR, therefore, provides an important additional tool to implement the Convention on the Rights of Persons with Disabilities and strengthen community-based development involving persons with disability (KNBS, 2012).

The Special Needs Education Policy provides the anchor for Special Needs Education (SNE) in Kenya (Ministry of Education, 2009). SNE is a provision of the Education for All policy that looks at issues relating to assessment and intervention, conducive environment, health and safety (adaptation of facilities), specialized facilities and technology, and access to quality and relevant education of persons with disability (KNBS, 2012). The Special Needs Education Policy targeted the following 15 key areas of intervention (Ministry of Education, Science and Technology (MoEST), 2009):

- Assessment and intervention
- Access to quality and relevant education
- Conducive environment, health, and safety (adaptation of facilities)
- Specialized facilities and technology
- Inclusive education
- Curriculum development
- Capacity building and development
- Participation and involvement
- Advocacy and awareness creation
- Partnerships and collaboration
- Gender mainstreaming in SNE
- Research and documentation
- Disaster preparedness
- Resource mobilization—finance, human, and material resources
- Guidance and counseling

This policy, though in draft form, set the stage for a number of gains for persons with disability including the establishment of Educational Assessment and Resource Centers (EARCs) in every district, inclusive education, as well as the adaptation of facilities such as ramps and disability-friendly toilets in public institutions.

Most importantly, the Constitution of Kenya, 2010, in Chapter 4, Article 27 and 54, emphasizes the rights of persons with disability, which include dignity, right to education, access to places, communication, and access to materials and devices to overcome constraints due to disability (KNBS, 2012). In addition, Article 7 of the constitution recognizes sign language, braille, and other communication formats accessible to persons with disability as part of the official languages in Kenya (see Table 9.2 for an overview).

Due to the awareness created as a result of these legal frameworks and programs, SLT has also started gaining roots in Kenya to address the needs of persons with communication disability.

Other relevant local legislative, policy, and institutional frameworks that have contributed to improvement in the lives of persons with disability include the Draft National Policy on Disability (2005), the Social Assistance Policy (2011), the National Guidelines on the Identification and Referral of Children with Disabilities and Special Needs (2010), Public Service Commission Code of Practice on Mainstreaming (2015), Disability Policy and Guidelines for the Public Service (2018), National Gender and Equality Commission Act (2011/2012), and the Ministry of Labor, Social Security and Services in general.

Advocacy and Professionalization of SLT

A notable development with regard to persons with disability is in advocacy. Advocacy involves attempts to improve the lives of persons with dis-

Table 9.2 Timeline of government policies for the assessment and rehabilitation of persons with disability relevant to the Kenyan context

2005–2009	2010–2014	2015–2019
2005	*2010*	*2015*
Draft National Policy on Disability	Constitution of Kenya, Chapter 4, Articles 7, 27, 54	Public service Commission Code of Practice on Mainstreaming
2009	*2010*	*2018*
Education for All (EFA) policy: The Special Needs Education Policy	Community-Based Rehabilitation: Joint Position Paper (CBR guidelines, WHO)	Disability Policy and Guidelines for the Public Service
	2010	
	National Guidelines on the Identification and Referral of Children with Disabilities and Special Needs	
	2011	
	Social Assistance Policy	
	2011/2012	
	National Gender and Equality Commission Act	

ability through, among other activities, creating awareness, lobbying for policy and legislative changes, and supporting persons with disability to live sustainable livelihoods. Various advocacy groups for different types of disorders have been registered (see Table 9.3 below). Although there are only a few specific groups to advocate for persons with communication disability, more often they benefit from gains made by these advocacy groups. The most notable gain from advocacy efforts is the enactment of the Persons with Disability Act of 2003, and the entrenchment of the rights of persons with disability in the Kenya Constitution, 2010. Others that are very specific to SLT are support groups. They include, for example, the Kenya Association of Laryngectomees, *Usemaji* Aphasia Support Group, Stammering Support Group (Nairobi), and Parkinson's Support Group, Nairobi (ASLTK, n.d.).

Persons with disability require specialized and professionalized services in education, health and community interaction. One major development toward the professionalization of services to persons with disability was the establishment of the Kenya Institute of Special Education (KISE) through the Legal Notice no.17 of 14th February, 1986. KISE is a semi-autonomous government agency of the Ministry of Education whose mandate includes conducting teacher training courses for teachers of children with special needs, conducting in-service courses for personnel working in all fields of special education, and running documentation and resource centers on special needs and disabilities, among others (KISE, 2020). The institute has trained many professionals working with persons with disability in Kenya, among them SLT assistants.

Another group that has contributed to the professionalization of SLT is the special education professionals (SEP), a homegrown organization for Kenyan-based speech therapists. The organization started in 1990 as a support group and has been offering free monthly consultation days at Gertrude's Children's Hospital since 1998. According to Staley (2013), in that year, there were 25 volunteer member SLTs, occupational therapists, special needs teachers, and an educational psychologist. SEP offers free assessments, runs training sessions in the community and schools, and partners with other organizations.

With regard to SLT practice, the registration of the Association of Speech and Language Therapists Kenya (ASLTK) in 2013 was a development that has made SLT work more visible in the country. ASLTK, though without a legislative anchor such as an Act of parliament, has registered some SLTs and assistant SLTs in Kenya and has published details of their current members on their website to help those searching for SLT services. In addition, the association holds monthly seminars for members and others interested in or working with persons with disability to educate them on various aspects related to SLT.

The most recent development in the professionalization of SLT has been the commencement of SLT courses at master's level at Kenyatta

Table 9.3 Timeline of advocacy groups and professionalization activities related to persons with disability relevant to the Kenyan context

1955–1960	1961–1985	1986–1990	1991–2000	2001–2005	2006–2010	2011–2015
1959		*1986*		*2003*	*2006*	*2013*
Kenya Union for the Blind (KUB)		Kenya Institute of Special Education (KISE)		Autism Society of Kenya	Albinism Society of Kenya	Association of Speech and Language Therapists Kenya (ASLTK)
		1986		*2004*		*2014*
		Kenya Society of the Physically Handicapped (KSPH)		Association for the Physically Disabled of Kenya (APDK)		SLT courses at master's level in Kenyatta University
		1987			*2009*	*2015*
		Kenya National Association of the Deaf (KNAD)		Kenya Society for Deaf Children (KSDC)		SLT courses at master's level in Moi University
		1989				
		United Disabled Persons of Kenya (UDPK)		the National Council for Persons with Disabilities		
		1990				
		Special Education Professionals (SEP)				

University in 2014 and Moi University in 2015. The first cohort of three students from Kenyatta University graduated in July 2019, and, meanwhile, more are approaching the completion of their studies. These programs will go a long way in addressing the great need for professional SLTs in the country.

It is important to note at this point that most of the gains made for persons with disability in general, and SLT in particular, are the result of nongovernmental and civil society organizations.

Another recent development is the establishment of a scheme of service for speech therapists, which was developed in the year 2016. This meant that the Kenyan government, through the Ministry of Health, could establish a cadre for speech therapists within the public services (Yellow House, n.d.).

Resources and Facilities for Persons with Communication Disability

Persons with communication disability require specialized services, resources, and facilities, especially in education, health, and for daily living in the community. Therefore, we trace some of the significant developments in the areas of education, health, and community for persons with disability.

One important principle of special needs education is that "if rehabilitation is to be effective and lasting, disabilities must be detected as early as possible and followed by training and education" (Kristensen et al., 1987, p. 1). The need for proper early assessment of children with disorders had been recognized by the Ministry of Basic Education from as far back as 1981 (Kihoro, 2010). With regard to the early identification, assessment, intervention, and placement of learners with disorders, the establishment of EARCs was a major developmental milestone in Kenya. EARCs were first established in Kenya in 1984 as part of a program supported by the Danish International Development Agency. The EARCs are managed by officers under the Ministry of Education. At the time, 17 EARCs were established in the country. In 1987, an agreement was signed between the Danish government and the Kenyan government to extend the EARCs project. It was anticipated that by 1988, each of the 41 districts in the country would have an EARC and 150

sub-centers would be established (Kihoro, 2010). By 2003, there were 72 EARCs in Kenya according to the Taskforce on Special Needs Education. The taskforce reported that before the establishment of EARCs, training of children with disorders began at school-going age. Additionally, about half of all children with disorders were incorrectly placed due to lack of assessment, while many others did not receive any training or formal education (MoEST, 2003).

The development of the EARCs slowed down with the withdrawal of funding by the Danish government. Notwithstanding this, the available centers have greatly improved the screening, assessment, and placement of a good number of persons with disability.

A second significant development is the establishment of special schools and units for children with disability throughout the country. As at 2014 there were 3464 special needs institutions in the country. Out of these, 2713 were integrated, while 751 were special schools. In total, 17 of these institutions were secondary schools (KNCHR, 2014). Although not sufficient, the increased numbers of institutions served to significantly open up access to education for the disadvantaged population of persons with disability.

The general improvement in the provision of health care to the general population has also been beneficial to persons with disability. It is also important to note that with the introduction of free primary education in 2003, the government introduced a capitation fee of 2000 Kenya shillings (approximately 20 USD) to every child with disability. Although this is still not enough, it is a move in the right direction with regard to funds allocation for SNE. It should, however, be noted that communication disorders are not given the special attention they deserve, as teachers are not trained to easily identify and address them, and neither are schools or hospitals supplied with specialized facilities and/or the required resources for those with communication disorders.

It becomes clear that SLT in Kenya faces a number of challenges. These will be discussed in the next section under the following areas: professional development, legislative and policy frameworks, inadequate resources and facilities, language and culture, as well as awareness, access, and cost.

Challenges Facing SLT in Kenya

Professional Development

Training of SLT professionals has been and continues to be a big challenge in Kenya. As noted under the section on trends of development, before 1986 and the establishment of KISE, there was no institution training professionals to provide services to persons with disability in general, let alone those with communication disability. The KISE curriculum, however, shows that all trainees choose areas of specialization, such as visual impairment, hearing impairment or physical disabilities (KISE, 2020). However, they all complete a course on SLT because communication disorders are often a result of other conditions such as autism or hearing loss. Those specializing in audiology and hearing impairment gain some important knowledge related to SLT. Thus, they can assist in the assessment and placement of children with communication disorders but are not fully equipped to provide SLT. It is also important to note that KISE is only able to train a small number of students.

A review of available literature indicates that the earliest training of SLTs in Kenya was through a European Union funded program supported by Voluntary Service Overseas from around 2004 (Jochmann, 2006). At that time, there were only seven SLT practitioners in East Africa. These therapists were all trained in foreign countries and practicing in different big cities within East Africa, e.g., Mombasa and Nairobi. The SLTs then began organizing conferences as forums to discuss challenges they were facing and training each other in therapy methods (Jochmann, 2006). According to Jochmann (2005), the first of these conferences was attended by the following six of the seven SLTs at that time: Emma Shah (trained in the UK; working in Nairobi, Kenya), Reyhan Hosgor Erdugon (Turkey; Nairobi), Elisabeth Scheltema-Kruger (Netherlands; Nairobi), Nuala Alibhai

(Mombasa; Kenya), Clemence Aryanyijuka (SLT assistant, Kampala; Uganda), and Angela Jochmann (Germany; Kampala). The conferences became an annual event, but due to the enormous workload of organizing a conference, it was decided at the third conference that the conference would become a bi-annual event (Staley, 2013). Staley records that the second conference in 2008 held in Nairobi was attended by a small group of American professors who provided professional development in their areas of expertise to a group of approximately 20 SLT clinicians and related professionals (e.g., doctors, nurses, special educators, occupational and physical therapists). The third conference in 2009 (also in Nairobi) had a different group of foreign therapists and professors who provided continuing education opportunities to the audience of 20 to 30 participants (Staley, 2013). It is evident that the numbers continued to grow but professional trainers continued to be foreign to the country. Another conference was held in February 2017, at Kenyatta University in Nairobi, Kenya, co-hosted by Kenyatta University, Leibniz University of Hanover, Germany, and the ASLTK.

It was not until 2014 and 2015, respectively, that Kenyatta University and Moi University started offering courses in SLT. In fact, as at the time of writing this chapter, only the first cohort of three students from Kenyatta University had graduated.

The lack of facilities for professional development in SLT means that for proper qualification, one needs to seek training internationally, an expensive affair that discourages many potential SLTs. It is no wonder then that the number of registered practitioners in the country is very small. The ASLTK website showed about 17 members of the association as of February 2016. These are SLTs and assistant SLTs working in different parts of the country.

Legislative and Policy Frameworks

The government of Kenya has no specific legal framework addressing issues relating to SLT. Persons with communication disorders are all handled under the umbrella legislation for persons with disability. With regard to the registration of SLTs, for example, there is no government policy or legislation for guidance.

The Kenya Medical Practitioners and Dentists Act CAP 253 of 1977, revised in 2012, is the only framework in place for the registration and regulation of medical practitioners (Medical Practitioners and Dentists Act Chapter 253 (n.d); National Council for Law Reporting, 2012). However, due to the wide field of medical practice, different sub-fields have formed their own associations in a bid to regulate registration and accreditation of their members. As such, SLTs register under the ASLTK. This organization was registered by the Kenyan Registrar of Societies in February 2013 with the primary objective to represent its SLTs and assistant members. It also aims to promote the profession and the rights of persons with communication difficulties in Kenya. Furthermore, the ASLTK checks members' qualifications and requires them to maintain membership with a foreign professional body such as the Royal College of Speech and Language Therapists, ASHA, or the Indian Speech and Hearing Association (ISHA; ASLTK, n.d.).

The fact that the ASLTK lacks any legislative anchoring poses a number of challenges. First, the association has no capacity to control practice. It is clear that registration into the association is optional. This opens an avenue for anyone to practice SLT without any legal repercussions. Practice by doctors and dentists, for example, is strictly controlled by the Kenya Medical Practitioners and Dentists' Board. The board has the legal authority to register and regulate professional practice and also discipline errant practitioners. Second, ASLTK lacks the capacity to influence government policies relating to SLT. An association of 17 members in an area that is hardly known or appreciated within the country has very little power to lobby or push for any meaningful policy changes. A third challenge is the lack of capacity to monitor training. The Kenya Medical Practitioners and Dentists' Board, for example, is actively involved in vetting any institution that purports to train medical practitioners. The board vets the curriculum, facilities,

and personnel involved in the training to ensure quality and compliance with the legal requirements. Unfortunately, this is not possible for SLT practitioners. This leaves open the question of the quality of upcoming training programs for SLTs.

Inadequate Resources and Facilities

Resources and facilities available to persons with communication disability, in particular, continue to be a significant challenge. By resources, here we refer to both financial and human resources available for the provision of services to persons with communication impairments. Under facilities, we look at infrastructural provisions available to individuals, institutions, and organizations working with persons with communication impairments. Persons with disorders of any form require special services, especially in education and health, and this, in turn, requires great investment.

Education

The Koech Education Commission of 1999 identified the following resource-related challenges to the provision of SNE: lack of equipment, technical and training tools for proper diagnostic assessment of disorders, lack of financial resources for the implementation of programs for persons with disability, as well as lack of proper training for teachers, trainers, therapists, and supervisors in special education needs.

Over ten years down the line, these challenges continue to haunt the provision of assessment and education services to persons with disability. The KNCHR (2014) Status Report on the Implementation of Rights of Persons with Disabilities records that the National Special Needs Education Policy (2009) clearly states the important role of EARCs and outlines proposals for ensuring their efficiency in service provision. Unfortunately, the proposals remain unimplemented to date. The report further points out that many EARCs in the country remain nonfunctional because of lack of funds, noting that the centers have not received funding since 2008—a factor that limits the officers' work on assessment, sensitization, and mobilization. More so, the report observes that the EARCs lack sufficient and proper equipment and trained personnel for assessment.

The problem of assessment of communication disorders is especially affected as it is an area that is not yet clearly understood even by personnel manning the EARCs as well as teachers and parents of persons with communication disability (Mwihungi 2010; KNCHR, 2014).

Health

With regard to facilities for health, the Kenyan government has made an effort to provide health facilities to the entire population. This has also benefited persons with disability. However, some challenges continue to be experienced with regard to specialized equipment and tools needed for assessment and treatment. Carter et al. (2012) observe that there is a lack of appropriate speech and language assessment tools in majority world countries like Kenya, yet such tools are necessary given the prevalence of different disabilities, many with related communication disorders. SLTs in Kenyan contexts mostly have to translate or modify the assessment tools from the west (Carter et al., 2012) However, it is opined that translation of assessments from the source language to a second "target" language is complex and often does not overcome the problem of bias (Lindau et al., 2014; Howard & De Salazar, 1984; Miller et al., 1984). Carter et al. (2012) note that test directions, which are often technical, are difficult to translate to ensure equivalence of meaning. This then calls for several back-and-forth translations between languages.

Another problem relates to the non-universality across cultures of psychological constructs underlying the assessment as well as variations in test-taking behavior and orientation toward assessment procedures between cultures (Sperber et al., 1994). Carter et al. (2012), however, argue that development of completely new tools is often not practical, due to time and resource constraints because such an endeavor would require ethnographic research on the language and culture of the target population to generate a developmental model for assessment (Ochs, 1983; Schieffelin & Ochs, 1986). The clinicians thus must adapt existing

assessments, a task which is a big challenge. It is also evident that the number of SLTs in the country is too small compared to the reported prevalence of communication disorders. Jochmann (2006) observes that the prevalence of diseases like cerebral malaria, meningitis, German measles, and malnourishment predispose children to cerebral palsy, deafness, or blindness, which have related communication disorders. On the other hand, cases of accidents and assault causing brain injuries, poor feeding habits, environmental pollution, and HIV/AIDS are predisposing factors for adults to speech and language disorders. Therefore, the caseloads for the available clinicians are very high.

Language and Culture

SLTs face several challenges and ethical dilemmas in the treatment of persons with communication and feeding disorders. Jochmann (2006) highlights a challenge in the treatment of Muslim patients with dysphonia and dysarthrophonia. She notes that the treatment of these conditions includes physical contact. Consequently, female clinicians are faced with the problem of how to check muscle tone and to train breathing and/or relaxation without touching male Muslims. Jochmann cites a case where one Muslim Imam with a laryngectomy treatment had to stop because he refused to take advice from a white non-Muslim woman.

The patriarchal system in Kenya where the male dominates can interfere with SLT. Jochmann (2006) cites two cases where male relatives became an impediment to the treatment of females. In one case, a dysphonic woman was advised not to carry loads that are too heavy and talk at the same time in order to avoid straining her neck muscles. In another incident, a female patient was advised to do her breathing exercises in a prone position in order to train costo-abdominal breathing. This led to the remark of a man that "These women try to make my daughter idle" (Jochmann, 2006, p. 4). Jochmann concludes that finding a balance between obeying cultural taboos and providing effective treatment is often a tricky affair.

Another cultural-related challenge has to do with non-verbal communication such as facial expressions, gestures, and eye contact. The interpretation of non-verbal communication is highly dependent on cultures. The same non-verbal signal may convey different meanings in different cultures. This then poses a challenge when communicating through gestures with patients from a different culture. The training in gestures is an important feature in aphasia treatment, but the clinician needs to know the meaning of the gestures. Establishing and maintaining eye contact are considered very important in Western speech and language treatment of dysfluencies, for example. But the possibility of establishing eye contact depends on the hierarchical position of the person in Kenya. People of low social status are not allowed to establish eye contact with their superiors in some communities. Patients considered to be of such status will therefore not look at the clinician who is considered superior, making it difficult to administer therapy that requires eye contact (Jochmann, 2006).

A related problem arises from the fact that Kenya is multilingual. Kenya has 42 ethnic groups, and, in addition, English is the official language. There are also foreign languages such as German and French. As noted elsewhere in this chapter, most of the current SLT practitioners in Kenya are foreign, mostly using English as their working language. Assessing and treating patients who speak only in the vernacular then becomes a challenge. For example, the patient may name a picture in a language the clinician does not understand and the accompanying caretaker, not wishing to embarrass the patient, tells the therapist that the word is correct. With regard to giving advice and instructions to such patients, the clinician must ensure that the interpreter understands the instructions first and also must ensure they have been interpreted correctly for the patient. Staley (2013) advises that, in Kenya, some knowledge of Kiswahili may be necessary for foreign therapists not only for communication but for identification with the local communities.

SLTs also face linguistic challenges relating to phonology, morphology, syntax, and even orthography. Jochmann (2006) observes that SLTs can-

not apply some of the treatment strategies of cueing words because the morphology of languages spoken in Kenya is different from that of Indo-European languages. Jochmann further notes that cueing a word via the initial sound does not lead to the desired effect, and neither does cueing the word via the first letter because many people do not know how to read or write their tribal language or English.

Jochmann further contends that the assessment and treatment of writing can be problematic in aphasic patients as it may not be clear whether the issue with spelling is idiosyncratic, phonetic, functional dyslexia, acquired dyslexia, or lack of formal education.

Access, Awareness, and Cost

Persons with disability face various challenges relating to awareness and access to facilities and information.

Access to SLT is beyond the reach of many persons with communication disorder. SLT services are not available in public hospitals. Currently, the SLT practitioners in Kenya are in private practice, and their charges are quite high. Those attached in hospitals are in expensive hospitals like Aga Khan, Nairobi Hospital, and Gertrude's Children's Hospital. Two major institutionalized SLT providers are the Yellow House Children's Service in Kisumu and the Centre for Child Development and Education in Gertrude's Children's Hospital, Nairobi (Centre for Child Development and Education (n.d.)), both of which are quite expensive for the average person.

Conclusion

From the foregoing discussion, it is obvious that SLT has not fully bloomed as a professional area or a scientific area of study in the Kenyan context. Whereas this might seem a gloomy assessment, we assert that amid all the challenges highlighted opportunities abound. There are opportunities for collaborations at various levels. SLT practitioners can actively seek collaborations with the well-established national associations in the minority world. Areas of collaboration can include sharing of best practices with members from the well-grounded organizations who have the benefit of experience that may be lacking in the majority world. In addition, local practitioners could get assistance in setting up a legally recognized professional national body whose mandate could include registering SLT practitioners in Kenya, establishing and upholding a professional code of ethics, as well as advising the government on policy matters with regard to SLT. There are opportunities for collaborative projects by the government, practitioners, and international donor agencies to establish more EARCs to meet the growing demand for assessment services and to meet the capacity of the existing ones by equipping them with modern assessment tools as well as developing the human resource capacity of the EARC officers through in-service courses, hence expanding their knowledge on communication disorders.

Another area of opportunity is in research. There is still much to understand about SLT in Kenya. Research by universities, field practitioners, advocacy groups, and special interest associations as well as by the national and local government can generate much-needed evidence to inform decision making. It would be important, for example, to determine ways in which the country could adopt CBR programs to complement the current model that mainly is focused on taking learners away from their social setup and placing them in special schools for some form of intervention. Findings from such research could form the bedrock of policies on all matters touching on SLT. Research could also inform the development of contextualized tools for the assessment of speech and language disorders in Kenya. Such tools could be utilized in the different languages spoken in Kenya.

There is room for entrepreneurs to come up with innovative resources that can be produced locally to serve various needs in SLT. For instance, hearing aids, ear molds, and audiometers need not be imported goods. Locally produced

ones could be cheaper and create employment opportunities. In the same vein, social entrepreneurs could come up with innovative ways of using existing emerging social media platforms to spread awareness about communication disorders with the aim of eliminating persistent biases against persons living with such disorders. Social entrepreneurs can create platforms for private–public partnerships by suggesting innovative ways in which corporates could enhance their social responsibility programs by supporting the assessment, treatment, and inclusion of persons living with communication disorders.

There is also the opportunity of creating new career paths. The huge demand for SLTs has the potential to absorb many persons choosing to specialize in the area. A new generation of professionals could emerge with a defined scheme of service to be deployed in hospitals, schools, and community outreach programs. In addition, there is an opportunity for affirmative action policies at national and local government levels to create employment opportunities for persons with disability who have graduated from special schools or vocational training institutions. This would ensure that the functionalism they are assisted to acquire becomes a means of personal growth and development.

Impact

This chapter has brought to light the challenges faced by persons with communication disorders and also communication disability. Equally important is the fact that the chapter has shown there are opportunities in the area of SLT. Persons living with communication disorders stand to gain if these challenges are dealt with and the areas of opportunity are explored. The foregoing discussion has also revealed new areas of research in the area of SLT in Kenya. Apart from this, the chapter has added to the body of knowledge of SLT as a scientific area.

Future Research

The challenges facing the development of SLT in Kenya identified here are by no means exhaustive. Research could unearth others or bring to the fore new perspectives regarding the challenges discussed in this chapter.

The chapter began by acknowledging the multidisciplinary nature of SLT. In line with this, there is a need for multidisciplinary research that brings together researchers from diverse fields such as linguistics, sociology, medicine, and education to look at various aspects that go into defining disability as well as account for distribution patterns of communication disorders across geographical areas, gender, and age groups.

Comparative research on trends and developments in SLT in the minority world and the majority world is also important and would inform the borrowing and adaptation of resources as well as practices.

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10

Obulala Na-maani: Unity is Strength

Speech-Language Therapy and Community Engagement in Three Kenyan Communities

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Introduction

Motive

This chapter describes three speech–language therapy (SLT) community projects in order to share the successes, failures, and lessons learned of a non-governmental organization (NGO) working in Kenya. We provide these examples to contribute to the broader international conversation about the current work taking place in sub-Saharan Africa for persons with communication disability. In this chapter, we consider how the models of service provision provided by Yellow House Children's Services (Yellow House), an NGO, fit into the global context and align with the United Nations' (2015) Sustainable Development Goals (SDGs). Furthermore, we reflect on these projects and the lessons learned, applying ideas and frameworks of cultural competence and global engagement. We aim to share the experiences of Yellow House so that other similar organizations working with persons with communication disability may benefit from the developments in our thinking. The question driving the narrative of this chapter is: What were the challenges and successes in developing community-based SLT services in three Kenyan communities? We conclude by answering the question: What have we learned from our experiences?

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Problem Background

The World Report on Disability (World Bank and World Health Organization, 2011) estimates that more than a billion people, or 15% of the world's population, live with a disability, and 95 million of those individuals (or 5.1% of the world's population) are children. Despite the current paucity of published data regarding the prevalence of communication disability specifically, SLT services are emerging and expanding throughout much of sub-Saharan Africa. Such services are using a variety of local, national, and global strategies to meet the identified needs of individuals with communication disability.

There is consensus on the need for the development of more communication-related interventions in the Majority World (Carter et al., 2005; Hartley & Newton, 2009; Olusanya et al., 2006; Wylie et al., 2013, 2014). Speech–language therapists (SLTs) are developing global networks to advocate for increased availability of services for individuals with communication disability (Staley & Hopf, 2016).

In Kenya, a handful of foreign-trained SLTs who are permanent residents or citizens have been actively developing the profession for over two decades. They have established the Association of Speech and Language Therapists Kenya (ASLTK), which meets regularly and is, alongside others, involved in running the East African Conferences on Communication Disability. This event brings together a diverse array of national and international educators and therapists every two years. There are also two fledgling university-based training programs that have been established to train Kenyan SLTs. Yet, for those individuals with a communication disability, SLT services remain predominantly available in urban locales only.

In 2009, Yellow House Children's Services was founded by Bea Staley. It was registered as an NGO with the goal of providing Kenyan-based SLT services to children with communication disability, as well as training and support for special education teachers, particularly in rural districts. All of the Yellow House project sites were chosen because of good working relationships between the primary author and Kenyan educators. These

relationships were established during participation in the Children with Disabilities Project (2006–2010) administered by Voluntary Service Overseas (VSO) and funded by the European Union.

The aim of this chapter is to describe and reflect on three Yellow House SLT projects: (1) Bahari,[1] which ultimately failed as a successful and sustainable collaboration between Yellow House and the affiliated community agencies in that locale; (2) Kilima, which was initially unsuccessful, but was able to adapt and relocate to a more successful community partnership; and (3) Sukari, which comprises the ongoing work in which we are presently engaged. The goals and outcomes of these projects are described with consideration of the 2030 Agenda for Sustainable Development (United Nations, 2015) and the subsequent Sustainable Development Goals (SDGs). We also reflect on these experiences using ideas related to cultural competence that have been proposed by other SLTs with experience working in sub-Saharan Africa (Barrett, 2016; Hyter et al., 2017; Wylie et al., 2016). The SDGs and notions of cultural competence are used to discuss the complexities of establishing and delivering community-based services in Kenya. We share the moments where we failed and stumbled, and ultimately succeeded so that the lessons learned from our experiences can inform practicing clinicians who may embark on SLT work in other Majority World contexts.

In order to situate the authors so that the reader can understand our relationship with the projects and our way of "seeing" the work (Ely et al., 1997), a brief introduction follows about us and our roles in the projects described. Bea Staley came to Kenya with VSO in 2007 to work as an SLT on the Children with Disabilities Empowerment Project. She then founded Yellow House and initiated the Bahari project in collaboration with a Kenyan colleague. Bea continued to work with the projects while residing in the United States for the duration of the time described here. Ellen Hickey has had experience in SLT development in Malawi, Tanzania, and Kenya. Yellow House was one of the organizations with which she worked in Kenya. Rachael Gibson came to Kenya to work as an SLT with Yellow House in 2011 and is the Yellow House chief executive officer (CEO). David Rochus was also hired by Yellow House in 2011, after graduating from the first cohort of Makerere's University's SLT program. Both Rachael and David remain integral to the projects in Kilima and Sukari. Martin Nafukho is an occupational therapist who has been an informative and supportive colleague to all the co-authors throughout their time in Kenya. He remains a knowledgeable and indispensable part of the project work in Sukari. Whereas four of us are not Kenyan, we take seriously the responsibility to work with cultural and contextual competence (Wylie et al., 2016). This is at the forefront of our thinking as we learn and navigate our SLT projects in Kenya.

[1]Bahari, Kilima, Sukari, and all of the names used in this chapter are pseudonyms.

Method

This chapter is non-empirical, providing an interpretive description of three SLT projects that have been conducted by Yellow House, along with reflection on the experiences and the lessons learned. We consider this a narrative approach (Sandelowski, 1991), as the focus is on storytelling (Ochs & Capps, 2001) as a way to formulate meaning and theorize about experience. The data were derived from Yellow House records, email communication, stories, and recollections.

As we reviewed documents and wrote about our experiences, we came to understand the events and factors that supported or hindered the work. A description of the projects will be provided along with reflections on the failures, successes, and lessons learned within these projects, situated within the context of the SDGs and cultural frameworks, as described below.

Theoretical Background

The Sustainable Development Goals

As the time frame for the Millennium Development Goals came to a conclusion in 2015, the

United Nations (UN) initiated a new global conversation, which is documented in their post-2015 Development Agenda (UN, 2014) and in A million voices: The world we want (UN, 2013). This process led to the 2030 Agenda for Sustainable Development (UN, 2015) and 17 Sustainable Development Goals (SDGs), focusing on economic, social, and environmental dimensions of development. The ultimate purpose of the goals is to ensure the eradication of poverty in the world. Furthermore, the SDGs aim to enable human rights, dignity, and gender equality for all. This vision for realizing full human potential includes a proclamation to strive for "a just, equitable, tolerant, open and socially inclusive world in which the needs of the most vulnerable are met" (UN, 2015, p. 2). The 2016 Global Sustainable Development Report was created to inform a high-level political forum on sustainable development, "ensuring that no one is left behind." The emphasis on social inclusivity is significant for framing the work with a focus on just, equitable outcomes for persons with disability. To enable this to happen, the report indicates that marginalized groups should be brought into the planning and implementation process sooner rather than later (UN, 2016).

Furthermore, the 2016 Global Sustainable Development Report (UN, 2016) discusses the interconnections among infrastructure, inequality, and resilience. The report indicates that access to infrastructure is linked to measures of inequality and resilience. For instance, differential access to infrastructure (e.g., health services) in rural versus urban communities is related to inequality, with reduced access to infrastructure disproportionately increasing inequality in rural areas. Lack of access to infrastructure and inequality of opportunity (e.g., based on discrimination) have also been linked to lower levels of resilience. We have seen some of these issues at play in Kenyan communities and will address them accordingly in the descriptions of our SLT projects.

This recognition of the need to focus on marginalized populations is essential, as disability and poverty remain inextricably linked (Elwan, 1999; Mitra et al., 2013). Disability often occurs in contexts where there is poverty, and the consequences of having a disability may be more severe in the context of poverty. For example, disability often removes individuals from opportunities for education and employment and may also remove their caregivers from the workforce, thus perpetuating poverty. The cycle of poverty and disability also has an impact on an individual's food security (Pillay et al., 2016; Quarmby & Pillay, 2016), as well as access to health care and education (World Bank and World Health Organization, 2011). Therefore, the following SDGs are applicable to Yellow House's work:

1. End poverty in all its forms everywhere;
2. End hunger, achieve food security and improved nutrition, and promote sustainable agriculture;
3. Ensure healthy lives and promote well-being for all at all ages;
4. Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all;
5. Reduce inequality within and among countries. (UN, 2015)

In particular, in this chapter we focus on SDG 4 in reflecting on our work.

Frameworks for Cultural Competence and Cultural Humility

The development of SLT programs in sub-Saharan African countries has often involved Minority World SLTs traveling to those countries for short-term or long-term involvement in these development projects (Staley & Hopf, 2016; Wylie et al., 2016). In many instances, these SLTs work alongside local partners to develop services, as with the work of Yellow House in Kenya. While there is no question that Minority World SLTs get involved with good intentions, there is heightening awareness that good intentions are not enough without cultural competence (e.g., Hickey et al., 2012). These Majority–Minority World partnerships are more likely to flourish when Minority World SLTs come to the projects ready to learn about the local cultures and contexts and to reflect on their cultural competence. Our own reflective process is inspired, in particular, by the cultural competence and humility framework proposed by Barrett

(2016), the ideas of cultural and contextual competence proposed by Wylie et al., (2016), the framework for responsive global engagement proposed by Hyter (2014), and the idea of the need to decolonize the SLT and audiology professions (Pillay & Kathard, 2015).

One notion that these frameworks and concepts share is cultural humility, which is the acceptance that one culture is not superior to another culture and that, as outsiders, we will never have the same level of understanding of a culture as one who was born into that culture (Barrett, 2016; Hyter, 2014). Barrett proposed that most theories of cultural competence are lacking by not including cultural humility. Furthermore, SLT as a discipline and SLTs as professionals need to come to these development projects and to international services with a greater understanding of broad contextual factors that underlie the experiences of our clients, families, communities, and partners (Hyter, 2014; Pillay & Kathard, 2015; Wylie et al., 2016). These authors all emphasize the need for transdisciplinary knowledge and engagement that extend beyond our traditional SLT or interprofessional collaborations and education. For example, in each context, it is important to understand the types of beliefs circulating in the local community and held by your client and their family about the conceptualization of disability, how stigma impacts persons with communication disability, and whether or not there are notions of rehabilitation and types of help-seeking behaviors. We will address some of these issues in this chapter.

Results

Description of the Projects

Bahari Children's Therapy Centre

Experience

The earliest Yellow House services were envisioned and developed in partnership with a Kenyan colleague, Grace,[2] who had years of experience working with Kenyan-based SLTs and had worked alongside the primary author in a formal capacity for several years. As a result of the collaboration with Grace, Yellow House hired a business manager, who found a site for a standalone center that could provide multidisciplinary therapy services, as well as a day care facility for children with special needs. The center's broad mission was to promote inclusion for children with disabilities through community outreach, training, therapy, and consultation to ensure full community participation of children with disabilities and their families. An SLT, occupational therapist, physiotherapist, and early childhood educator were also hired to the team, and in April 2011, the Bahari Children's Centre (BCC) was officially opened. All members of the BCC team were Kenyans, trained in Kenya, and experienced in their professional capacity. The exception was the SLT who was British (and professionally trained in Britain), and had been residing in Kenya since 2007.

The Center

Bahari Children's Centre was innovative in two capacities. The first innovation is that it was the only center at that time in the region (and indeed in most of Kenya) that had three therapy disciplines providing services under one roof, and at a nominal cost for families (approximately 1 USD per session). The second innovation was that there was a day care facility (with one teacher and a teaching assistant) for children with special needs. The day care space accommodated five children, enabling their mothers to work outside the home. There was also room for simultaneous outpatient therapy sessions. The day care facility was a significant matter for Grace, because there were no day care options for children with disabilities in Bahari at the time. As a mother of a now adult daughter with special needs, Grace felt that families needed an option for childcare as well as therapeutic services.

Five months after opening, clinic records showed that BCC was providing 89 therapy sessions per month and had 77 children in the district on their caseload. These children presented with a variety of diagnoses such as cerebral palsy, autism spectrum disorders,[3] hydrocephalus, club foot, rickets, and epilepsy.

[2]Pseudonym

[3]Often diagnosis was informal and unofficial.

The SLT was working for BCC two-and-a-half days per week and records indicate that he provided 29 SLT sessions per month. These sessions involved 18 clients, of which eight were described as having autism, seven having either cerebral palsy and/or seizures,[4] and three had general developmental delays. Further, 15 of the 18 clients were under the age of seven years. This was notable given that in 2007–2008, the average age of initial referral to the government system was ten years. This meant that children's first access to education and or allied health services (where available) was happening well after the optimal years for nurturing their development had passed.

Emerging Issues

While the plans for BCC were reasonably well conceived (albeit somewhat idealistic), a few problems emerged as it was rolled out: program cost, program competition, and use of space. First, this model overall was top-heavy in terms of operational costs (e.g., rent, electricity, a business manager). The money spent was disproportionate to the number of therapy sessions actually being provided. Running costs for the service exceeded 1000 USD per month; therefore, Yellow House was spending 11 USD per individual therapy session, which seemed unsustainable for long-term operations.

Second, due to the proximity of the clinic (same neighborhood) to the nearby government facility, BCC inadvertently became a competitor to existing therapy services. Reports were trickling back from area colleagues that children were attending BCC instead of the government center because parents thought the services must be better, potentially because BCC had a foreign-trained SLT. However, the government facility was the formal school gateway for children with special needs. The government center ensured that children with disabilities were served in schools and created the special education classrooms to provide for these children as demand required. Furthermore, it connected families with the appropriate school for enrolment based on the needs of the child and the services available in the district. While the staff at BCC could and did train teachers and work with schools, they were in no way the appropriate educational avenue for families. Our presence added complexity and confusion for parents, who were already experiencing difficulty understanding the system and accessing inclusive education services for their children with additional needs.

Third, there were issues relating to how the clinic space was divided for the various activities. The biggest room in the center (which was essentially a two-bedroom flat) was being utilized as an office for the business manager, with a large desk and computer dominating the entrance/living room area. The three therapists shared one small bedroom for outpatient services while the day care facility ran in the other small room. Despite several formal discussions between the Yellow House board, BCC leadership, and staff, the division of space was not resolved.

Though we may have been able to manage the space and budget in ways that better aligned with our vision and goals for the center, the only way to prevent competition with the government facility was to relocate BCC. This was not considered as a viable option for the team in Bahari, and Yellow House decided to cease their support for the clinic.

Reflection

The project in Bahari aimed to support the fourth SDG on quality education for all (specifically part 4.5, UN, 2015). While the project did address part 4.a of the goal, "education facilities that are child, disability and gender sensitive and provide safe, non-violent, inclusive and effective learning environments for all," the project inadvertently undermined the local government services. This was contrary to the SDG Dialogue of "strengthening capacities and building effective institutions" (UN, 2014, p. 8). This was crucially important to realize, as the government services were also the educational gateway for children with additional learning needs. Due to the proximity of the two facilities, and BCC's staffing (we had trained therapists from three allied health disciplines), fami-

[4]Seizures and epilepsy are common and often related to malarial events in a child's life.

lies were not coming to BCC as well as the government services; they were choosing BCC instead of the government services, which was highly problematic if the intent was to support capacity in the community. The efforts of the government center and BCC needed to align to make this a viable model. The context was such that the interests of stakeholders were at cross-purposes and the needs of the children and their families were not being met in a way that would best support them through the health or education system.

We share this anecdote because this situation arose despite firm relationships in the community and a thorough understanding of the context. The services were seen by us as complementary. However, despite our views of how this should and would work, families saw things differently and acted otherwise. Through their experience in Bahari, Yellow House staff learned that things do not always go as intended, that differing motivations shape outcomes, and that going forward we would try to find a more cost-effective model for providing services to children with special needs.

Kilima Children's Community Centre

Experience

Occurring somewhat simultaneously to the project in Bahari, Yellow House's partnership in Kilima developed with a completely different trajectory from that of Bahari. The work and the relationship between Yellow House and local collaborating community partners at Kilima blossomed.

The Kilima partnership was set in motion after the first author, alongside a Kilima colleague, wrote and applied for an industry grant (June 2009) to fund the refurbishment of a vacant government building in the community. The building was being used to dry and store maize, and local authorities had given permission for transformation of the building into a therapeutic community center for children with disabilities. The grant provided 20,000 USD to make structural renovations to the building, including repairs to the roof, doors, windows, walls, finishes, and plumbing. Upon completion of the building work, a foreign government grant was obtained (May 2011) to provide an additional 5000 USD to buy furniture, therapy resources, and equipment for a cerebral palsy clinic. These funds also allowed for the building of two wheelchair-accessible pit latrines on the property.

Alfred,[5] a local colleague, led the work to build community awareness about disability and to develop the cerebral palsy clinic in the space, including regular occupational therapy services. A formal community-based organization (CBO) was set up to run the projects and potentially solicit community funds. As a result of this work, Yellow House became a formal partnering organization, providing the monthly operating costs of the project through the CBO bank account. The funds were used to pay the occupational therapist to deliver services to the cerebral palsy clinic and to pay for fuel for the motorbike for outreach activities, electricity bills, and parent trainings.

In June 2011, two SLTs were hired by Yellow House to live and work in a neighboring community. With their clinical expertise, Yellow House began to provide free SLT services in and around the community, as well as provide continuing education around communication disability to employees in the local education and health institutions.

Emerging Issues

While the small Yellow House team began to work with schools in Kilima county as well as parents at the center, there were unanticipated leadership changes. The newly appointed manager who oversaw disabilities services at the district level, and thus the refurbished therapy center, was not in favor of the Yellow House collaboration.

In 2012, the Yellow House SLTs had plans to continue building the capabilities of the center, including a multipurpose library with computers and internet access that could be used by parents and special educators. However, an audit completed that year found that resources earmarked for these activities could not be accounted for. The plans were aborted due to lack of funds, and a resolution was not pursued to avoid adding to the political tensions brewing within the partner organization.

[5] Pseudonym

With the formal dissolution of the partnership, Yellow House moved their SLT services to a local medical clinic where the project appears to have had greater traction within the community. The clinicians report more effective community impact as measured by the increased numbers of referrals over time, and increased numbers of individuals seen for SLT. This move proved beneficial in slashing the monthly overhead costs since Yellow House now only had to pay salaries and the public transport costs for the SLTs to travel around the community. Additionally, the new location allowed for skill-building of the medical practitioners in the clinic who were often seeing children and adults with communication impairments.

Initially, Yellow House shared therapy space with the occupational therapy department. Later, the organization was allocated a SLT room for the provision of free outpatient-based services. This model of working within a medical clinic has also been expanded to two other counties, with the SLTs holding regular clinic days at different sites.

Yellow House's strategy for the professional development of educators changed over time from large one-off trainings, to regular, short, and focused "in house" trainings. This meant the SLTs spent less time training in a general capacity, and more time working alongside professionals coaching the targeted skills. Working directly with the teacher in the classroom enabled the SLT to demonstrate how to implement strategies in "real time" and discuss what works best with a particular child, rather than giving generic strategies. SLTs reported specific improvements in the ways children with disabilities are accommodated in their classrooms by their teachers. This type of work has also resulted in an increase in appropriate referrals from teachers in education settings, and from doctors, physiotherapists, and occupational therapists in medical settings.

Due to ongoing concerns about the small number of education-related referrals from community professionals relative to the large numbers of children with SLT needs, a position was created in 2013 for a Parent Liaison Officer (PLO). This position was filled by a parent of a child with a disability who had been receiving SLT services and could speak to the experience and merits of SLT services. The PLO role includes sharing her personal experiences with parents who have been referred for SLT services, and/or are attending clinics for SLT and/or occupational therapy for the first time. Furthermore, the PLO also uses her community networks to identify any children that may have been overlooked for referral, and runs a regular parent support group for those who have children with communication disability. The PLO has proven to be a crucial piece in the organizational puzzle that was previously missing when engaging parents in the therapeutic process. Since employing the PLO, there has been an increase in the number of return appointments as well as new referrals.

Reflection

The Kilima project had a vision which aligned with SDG 4.5 to provide equal access to education, as well as part 4.a of the SDGs, which states "…upgrade education facilities that are child, disability and gender sensitive and provide safe, non-violent, inclusive and effective learning environments for all" (UN, 2015, p. 17). The refurbished facility provided a space that families wanted to participate in, as well as two wheelchair-accessible pit latrines. The outreach of the service improved teacher practices, and there were reports of better educational outcomes for children with disabilities. We also addressed SDG 10.2 of empowering social inclusion of all, as well as the UN's 2016 challenge of leaving no one behind, by engaging the PLO.

Although we were also able to honor SDG 16.7 and generate some "responsive, inclusive, participatory and representative decision making" (UN, 2015, p. 25) with the creation of the Yellow House CBO, we did not manage to "develop effective, accountable and transparent institutions at all levels" (UN, 2015, p. 25) as indicated in SDG 16.6. So while the Kilima project supported the UN's SDG Dialogues around engaging civil society and the private sector, our shortcomings around the UN-recommended participatory monitoring and accountability ultimately unraveled what was a close community partnership (UN, 2014).

We share this experience because, once again, this situation emerged despite strong relationships in the community and a thorough understanding of the context. As a partnering organization, Yellow House staff had to acknowledge that they could never foresee all the complexities and dynamics that might arise in a CBO. Once it was clear the collaboration was unsupported within the partnership, a shift of energies and focus was initiated to work with a partner who did want the services on offer. This was only possible due to the links with the broader community, a strong commitment to the work, and a solution-oriented outlook. By making a relatively swift decision and change, it ensured a continuity of services for most of the families with whom we were working.

Sukari

Experience

The affiliation between Yellow House and the center in Sukari, which began in 2007, has had a much more meandering relationship. The partnership has gradually built over the years, with both teams increasingly understanding the other's perspectives, and trusting in a mutually compatible view of disability and community-based service provision. Though Yellow House has never funded ongoing project costs for Sukari, the organization has provided them sporadically with resources for specific needs (e.g., computers), ongoing SLT support, as well as short-term SLT expertise in the form of volunteers. Yellow House also funded a study tour for Martin to present his work at a regional conference and to observe clinical practices in the United States. What has developed out of the collaboration between the Yellow House team and the team in Sukari is a small but consistent SLT program. As a result, Sukari staff report that they have families traveling significant distances for SLT services at their site.

The Center

Health care services in Sukari, like elsewhere in Kenya, are often planned based on models of care designed to address only acute medical issues (e.g., malaria, diarrhea, the terminal stages of HIV/AIDS, accidents, and emergencies), and there is little attention paid to issues related to life skills and quality of life, such as the ability to communicate. Like at the other centers, the team at Sukari frequently work with families who are experiencing additional serious issues around poverty, malnutrition, and disability. Unlike other teams, the professionals (teachers and occupational therapists) in Sukari were always quite explicit about their need for expertise in the area of communication disability.

To satisfy this urgent need for general information about speech and language disorders, trainings were presented to the team to increase their knowledge and clinical skills. These workshops led to the team simultaneously building community awareness about the SLT profession. In addition, they demonstrated and utilized techniques they had learned from volunteer SLTs in the region. Most significantly, Sukari staff reported that the parents, caregivers, and teachers they worked with began to emphasize the integration of language and literacy experiences in children's everyday routines, including eating, playing, and learning.

Volunteers

The team at Sukari noted that the most beneficial aspect of the collaboration with Yellow House was the ongoing provision of volunteer SLTs to their community center, which is in contrast to Yellow House's perspective about short-term volunteers generally. From Yellow House's experiences in Sukari (and to a lesser extent in Bahari and Kilima, as well as two other communities), short-term volunteers often come with little clinical experience in their home country, or experiences that would help them to understand the cultural context of the work.[6] Additionally, although short-term volunteer SLT clinicians with long work histories in a specific area (e.g., swallowing, augmentative and alternative communication) can provide useful bursts of expertise, they rarely have a long-term impact on services

[6]Formal interviews with volunteers completed in 2010 revealed that often volunteers have not even purchased a travel guide or done any related reading about the country prior to departure. Volunteers reported they most typically prepare for their time in Kenya by gathering clinical materials and donations to take with them on their trip.

due to issues of continuity and/or issues of cultural or contextual relevance.

That said, the integration of short-term SLT volunteers into Sukari's program was relatively successful because the long-term SLTs (authors Rachael and David) were in the region to provide support for short-term visitors as well as the follow-up needed for long-term service implementation. Rachael also spent a considerable amount of time planning for volunteers, and setting up the projects they would work with while in Kenya. This time spent preparing for and mentoring visitors likely exceeded the time it would have taken for David or Rachael to complete the work themselves, as Wylie et al., (2016) noted is common.

Volunteers also use other resources, both human resources and financial. They are typically accompanied to schools, homes, and clinics by members of the Sukari team, including Martin (author), who serves as a cultural broker for the visitors to the area. Furthermore, the Sukari team members bolster the skills of visiting SLTs by increasing their cultural awareness, translating the needs of Kenyan families and their communities, and informing them of gaps in resources. Volunteers, too, share skills and expertise with the Sukari team.

What we have seen in this partnership is the growth of skills in the team and an increased confidence to respond to community demands about communication disabilities. Though there have been many challenges amid successes in Sukari, each year that passes brings an increase in the number and types of different programs the team has been able to provide, such that greater numbers of community members and volunteers are more involved, in various ways, than ever before. Many additional projects have arisen in response to identified needs and volunteers have often secured funds to pay for children's surgeries (e.g., club foot, cleft palate, burns), medical expenses, household goods (e.g., mattresses for children sleeping on dirt floors), water holes, education materials (e.g., desks, books, pens), and educational expenses for children with special needs (and their siblings). Additionally, volunteers have often been useful in funding the alleviation of immediate issues (e.g., money to fund transport to hospital).

Sukari now boasts an adult program that cares for disabled adults, which is implemented and supported by a visiting psychologist. They also formed a parent support group that raises funds for disability-related projects by making and selling jewelry. The team reported that "the weary faces and dusty feet of parents have disappeared, replaced with smiling faces of energized women getting their share, feeling part and parcel of community development."

Reflection

The work at Sukari aligns with the UN's SDG 4.5 (2015) on equal access to quality education for all. This project extends to address other goals as well, such as SDG 1.1, reducing extreme poverty, and SDG 10.2, empowering and promoting social and economic inclusion, through its fundraising and income-generating projects. What seems to work well at Sukari are the transdisciplinary and holistic elements of the way that the team addresses problems, examining various aspects of what affects quality of life and inclusion for the clients and family members and finding innovative solutions. Perhaps it is the participatory engagement and accountability (UN, 2014) seen here that is keeping things moving forward.

To ensure that our work at Sukari continues to move forward with the voices of the local community remaining strong, we must continue to reflect and improve on how we engage with short-term Minority World volunteers. Wylie et al. (2016) noted that there are two types of expertise needed to successfully volunteer in Majority World contexts: clinical skill and proficiency in providing services that are culturally and contextually competent. Our experiences with volunteers sometimes reflect concerns that have been reported in other literature, such as the lack of adequate preparation and use of human and financial resources that could be used for the programs (Hickey et al., 2012; Wylie et al., 2016). One reason that short-term volunteers have been a source of strength in the Sukari project likely reflects the excellence that Martin exudes as a cultural broker. With his wealth of information about the political, historical, and economic issues that affect the community and our clients and families, as well

as his generosity with time and patience, he is able to help volunteers to navigate this new context so that they may make meaningful contributions to the program. We must continue to reflect to ensure that we are not promoting neocolonialism with our use of short-term Minority World volunteers.

Lessons Learned

Analyses of these experiences in Bahari, Kilima, and Sukari suggest that there are two primary factors that ultimately drive the decision-making around how, where, and when services will be provided. The lessons learned will be described within these two factors: context and community members.

Context Is Imperative

Culture is not a static or fixed concept, and even within a country, cultural norms vary with place or context (Barrett, 2016; Hyter, 2014). There are diverse beliefs and values that underpin what is often summarily termed culture, without interrogation of the actual local context that impacts on the actions, events, and interpretation in the moment. For example, in one town, there was a reoccurring belief that parents shared: giving eggs to young children prevents them from learning to talk.[7] It is unlikely that this belief generalizes beyond the region; that is, it exists only in the culture of that specific locality.

While this example is small, understandings or misunderstandings can pervade the work that is done in communities, and impact on project development, implementation, and ultimately success. For example, in introducing a new clinical service, uptake might depend on how the team understands community beliefs about the cause and meaning of disability (or even if they understand community beliefs about the cause and meaning of disability). It is critical to understand a family's beliefs about disability generally and their child's disability specifically (they may genuinely be uncertain if there is a relationship between their child's communication disability and eating eggs). We have observed that families will attribute the disability to an event or a cause (e.g., seizures being related to a malevolent spirit rather than a result of poorly treated malaria) and it is easier to work with a family once you understand their beliefs.

In another community in which Yellow House has worked recently, there is a widely held belief that all children with speech difficulties also have cognitive impairment. Yellow House SLTs found that giving information to parents in a way that they could understand, and by allowing them to deduce whether or not it accurately relates to their child, was more effective for treatment outcomes than transmitting generic facts about disability and communication.

At a community level (including communities of the different professionals involved), it is important to be aware of the historical context of services. Many community members will tell you about agencies and projects that have been and since gone, and these stories recount the promises that went undelivered. You must be present in a locale, and available to listen to hear these tales. It is not just helpful, but imperative, to have an understanding of the roles (past and present) of educators, schools, health clinics, community leaders, and foreigners in the community. It is critical to understand the cultural perceptions, beliefs, and past practices in the area of disability if the service plans to introduce a new idea or seeks to alter the perceptions of the community.

Community Partners and People Are Key

The project trajectories briefly described in Bahari, Kilima, and Sukari illustrate that there is no one-size-fits-all service model even within a single country and that projects must respond to the unique needs of their communities given the resources available at their disposal, and their beliefs and perceived needs. However, we must

[7] According to one explanation of the tale, this was a story perpetuated by fathers to stop the mothers giving eggs (a protein-rich source in the diet of a resource-poor community) to their young children. If the father came home from work and the child already had spoken language, he could just ask the child if they had been eating eggs. This was not true of a child too young to speak. The item of value in the story is the eggs.

not overlook the human resources, in terms of skills and expertise on the ground. People are the key to all successful projects. The examples presented here reveal that even given a responsive approach to a situation, the project may still not succeed, or may develop in ways that were unanticipated. This work is dependent on individuals who leave from and arrive in communities, taking and bringing their skill sets, attitudes, influence, and motivations with them, to the benefit and sometimes the detriment of the work.

Yellow House has found that it is essential to invest in the people who were already doing the work prior to the onset of the project. Many granting agencies want to pay for buildings and other tangible items. However, our experience has shown that when we invest in people, we are able to leverage funds in a way that has greater long-term effects. It is important to assemble a team of people who are already working passionately in the community, and whose actions align with your mission and goals. When community members, and education and health professionals work together to view children with disabilities and their families holistically, and take a functional approach to the individual's communication issues, there is a greater chance of success.

Volunteer narratives suggest that short-term volunteers gain more from their time working in foreign communities than the community does in return. As we think about the necessity of globally minded clinicians, however, this is important too, for these SLTs may be more empathetic and responsive to the immigrant and refugee clients they find in their caseloads at home (Cheng, 2014; Hyter, 2014). More research is needed on the use of short-term SLT volunteers from the Minority World in Majority World contexts.

As an organization, Yellow House takes a hopeful stance that short-term volunteers will want to continue a long-term relationship with the project. These ongoing volunteer relationships, where clinicians return over the years, have been both beneficial and fruitful for Yellow House and the communities they work in because they have greater cultural awareness, and thus are able to be more effective SLTs. Returning volunteers also develop and maintain relationships that can support the skill development of our Kenyan colleagues and community members.

Discussion

Impact

In countries where systems for SLT service are established, the scope of practice is well defined and fairly uniform. In countries like Kenya, where the profession is emerging, these parameters are often in development by the professional associations, if there is one (e.g., Association of Speech and Language Therapists Kenya). This chapter aims to contribute to the literature on what the work can look like in situ so that others doing similar work may consider if there are elements of Yellow House's projects that could be adapted for inclusion (e.g., hiring a PLO) or purposeful exclusion (e.g., setting up an independent clinic facility). Such decisions would have to be made taking into account a wide range of factors, including cultural and resource factors (Barrett, 2016; Wylie et al., 2016), as well as broader political and historical factors (Hyter, 2014; Pillay & Kathard, 2015).

Over the years, the Yellow House team has taken a multifaceted approach to service provision. The organization has implemented a variety of SLT services: as an outpatient model; as an adjunct service to special needs day care; group training of teachers, parents, and health professionals; and working alongside and coaching teachers, parents, and health professionals. Additionally, we have developed workshops, a training manual, supported staff at orphanages, and provided clinics for specific diagnoses (e.g., cleft palate). Despite the challenges, overall Yellow House projects have seen growth in terms of numbers of individuals seen, the numbers of people trained, and the numbers of schools and hospitals accessed, as well as increased efficiency in the way the organization works.

In this work, we emphasize that SLT clinical services must be firmly situated in the context of the community in a broad sense (Barrett, 2016;

Hyter, 2014; Wylie et al., 2016). Furthermore, as noted in our experiences in Bahari, the services must complement existing community services, taking place within the current health and education structures, rather than replacing or competing with services that already exist. The intention is to support and supplement current resources for individuals with disabilities, not to create competition with the existing services, as we unwittingly did. The danger here is that if a government center loses their funds because the service is not being fully utilized, they are unlikely to be able to get that financial support back again.

Given the nexus of infrastructure–inequality–resilience emphasized in the 2016 Global Development Report, our work must add to or support infrastructure and resources for these communities so that we may have a positive impact on reducing inequalities and increasing resilience. For example, when families access government services in Kenya, their children with disabilities are "counted." When children are seen by NGOs, the data are often invisible to government systems, and it can appear like there are fewer children in the community needing and accessing services. It is counter to our mission to reduce the number of families accessing government services by taking them out of the system that documents their needs.

The experiences described here support the notion that it is essential for SLT projects to be tailored around local contexts and community needs (Barrett, 2016; Hickey et al., 2012; Pillay & Kathard, 2015; Staley & Hopf, 2016; UN, 2014, 2016; Wylie et al., 2016). Here, we have described three projects along with the challenges and successes of each project in their community context. We emphasize the importance of working with local colleagues and families to develop service delivery that best meets the needs of the community. In countries where the SLT profession is emerging, there are dual professional roles, where clinicians need to educate and inform about communication disability and advocate for persons with communication disability, as well as provide clinical services to those who need SLT. By sharing stories of varied conceptualizations and delivery of clinical SLT, we bolster the literature and provide a fertile space for a global discussion around varied considerations of clinical implementation in Majority World contexts.

Considerations for the Future

As membership in the Association of Speech and Language Therapists Kenya (ASLTK) grows in number, and the association works toward developing and implementing professional policies, they will be challenged to address the contextual diversities in national service delivery. A best practices framework for service provision that allows practitioners considerable flexibility for implementation will likely be most useful in guiding how SLT services might look in Kenya. Our experiences support the notions by others involved in global SLT development that public health approaches and other non-traditional SLT professional practices are an essential component to addressing communication disability in the Majority World (Pillay & Kathard, 2015; Wylie et al., 2014). Our experiences also suggest that considerations be made about the ways that SLT university training programs are educating future SLT professionals, including non-traditional transdisciplinary issues and promoting independent and flexible thinking (Hyter, 2014; Pillay & Kathard, 2015). This would serve both new Kenyan professionals in developing contextually based services and Minority World volunteers who travel to Kenya and other Majority World contexts to participate in SLT development.

As Yellow House proceeds into the future, the organization is dedicated to ongoing reflection on the ways of working with communities that vary according to their contexts and needs. We are always striving to improve and maximize the benefits of our services as we continue to learn with and from our partnerships and communities. As with many other organizations for persons with disabilities throughout the world, we believe in "nothing about us without us" and continue to strive for strong multi-stakeholder partnerships that are participatory and inclusive (UN, 2015). Yellow House is also committed to formalizing its data gathering about ongoing clinical work, as

well as publishing its data to bolster the available literature on SLT in Majority World contexts. Documentation of the ways in which development of SLT and reduction of communication disability contributes to meeting the SDGs, particularly around nutrition, health care, and education, is essential in communicating with other rehabilitation and education professionals as well as policymakers at various levels. Yellow House will continue to be involved in advocating to policymakers and communities for more inclusiveness and supports for persons with communication disability to maximize their potential. We encourage research that is participatory and emancipatory to ensure that SLT projects continue to develop in locally desired ways that do not promote colonialist thinking in the profession or the programs we develop.

Conclusion

Our failures, successes, and lessons learned echo the calls for actions, policy, and research that are both transdisciplinary and participatory to ensure that the needs of communities and persons with disabilities are being met (Barrett, 2016; Barrett & Marshall, 2013; Hyter, 2014; Pillay & Kathard, 2015; UN, 2016). We have been striving to move past traditional schemes of SLT research and practice, and agree with SLTs who are suggesting the need to expand our thinking to allow a broader worldview in SLT, which includes factors such as politics, economics, and history. Such participatory and transdisciplinary work would ensure that economic, social, and environmental elements (UN, 2016) are accounted for in further SLT development. This would allow for culturally responsive and emancipatory SLT programs that fit the needs of local contexts (Barrett, 2016; Hyter, 2014). As seen in our three examples, the projects where there was good communication and accountability within teams and across partners resulted in everyone working together for the good of the clients and families in their community. Our work cannot be about bolstering individual professional identity or capacity. Our most successful work demonstrates *obulala na-maani: unity is strength*. We plan to continue to grow our projects with these lessons in mind, and we hope that others may learn from our lessons too. We hope to continue to share information with other SLT programs that are culturally and contextually relevant and sustainable so that we may all learn together. We have benefited from recommendations from international documents, such as the World Disability Report (World Bank and World Health Organization, 2011) and the UN reports on sustainable development (e.g., UN, 2014, 2015, 2016) to create sustainable, accessible, and contextually relevant solutions for communities and for persons with communication disabilities (Cheng, 2014).

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Part II

Introduction: Development and Prevention

Research in Minority World contexts has focused on language and its ontogenesis as a singular human faculty for thousands of years, starting in ancient Greece. Theoretical discourse on language development has moved for decades between the poles of nature and nurture: Are language development processes induced and shaped by innate linguistic acquisition structures or are these processes acquired extrinsically, learned, and shaped in experienced contexts? In the recent past, the strict distinction between these poles has become blurred. The "Emergentists Coalition Theory" proposed by Golinkoff and Hirsh-Pasek (2006) sets the basis for a vast number of hybrid theoretical approaches that acknowledge both innate linguistic learning strategies and the importance of social experience. Today, no one disagrees that communication and language development are deeply interwoven into the social context. In fact, it is a social process from the very beginning (e.g., Trevarthen, 2001).

The influence of social context in communication and language development is a topic currently being investigated globally. Communicative input and uptake, like child-directed speech, parental socioeconomic status, and the social contexts of bilingualism, are some of the examined themes (e.g., Dave et al., 2018; Elmlinger et al., 2019; Kalashnikova & Burnham, 2018; Kheirkhah & Cekaite, 2015; Ramírez-Esparza et al., 2017).

In sub-Saharan Africa (SSA), one of the most intriguing issues concerning communication and language development might be the high diversity in culture and ethnicity all over the continent and the impact thereof on development. In addition, there is a high correlation between culture and communication disorder and/or disability for example seen in the definition of what is deviant communicative behavior. Therefore, there is a general tendency for a cultural stereotypical perspective toward the prevention and management of communication disorders in SSA (e.g., Ndung'u & Kinyua, 2009). Thus, speech and language therapists (SLTs) in the region are faced with the huge task of creating awareness and distinguishing between genuine communication disabilities and peoples' cultural and linguistic tendencies. Moreover, there is a need to develop assessment protocols that are culturally sensitive, effective, and acceptable in the region.

As Buzasi (2016) shows in her survey on the linguistic situation of 20 SSA countries, and especially in Benin, Liberia, Mozambique, Nigeria, South Africa, Tanzania, Uganda, and Zambia, there is a high fragmentation of linguistic and ethnic diversity. Expressed in numbers (calculated as one minus the Herfindahl index of concentration), linguistic diversity in these countries lies between 0.82 and 0.95, where 1.00 is highly fragmented (Buzasi, 2016). For example, in a country like Tanzania, there are 125 established living languages (117 of which are indigenous), while English and Kiswahili form two of the principal languages (Lewis et al., 2016), the linguistic fragmentation is calculated to be 0.95 (Buzasi, 2006). This implies that nearly everybody in Tanzania can at a minimum be considered to be bilingual. This situation could easily be implied for almost all countries in SSA.

The preservation and valuation of one's heritage language can be seen as a human right in itself (Luca, 2018; United Nations, 2007). This is also put on record in the Asmara Declaration of the African Union (2000), which highlights the importance of African languages in the light of empowerment and dialogue of the people of Africa. Herein, African children have the "unalienable" right to be educated in their heritage language (African Union, 2000). Nevertheless, the current position of indigenous languages in education is frequently debated (Buzasi, 2016) and the violation of language rights is also discussed (Namyalo & Nakayiza, 2015). Kamwangamalu (2015) reports the use of colonial languages as the language of learning and teaching in Southern Africa (including Angola, Botswana, Eswatini, Lesotho, Malawi, Mozambique, Namibia, South Africa, Zambia, and Zimbabwe) and an English-only policy. That is due to different arguments against multilingualism, e.g., too many languages to include in education or favoring one African language at the expense of another, which would entrench tribalism.

The diversity of languages not only holds challenges for the educational system, but it also implies significant challenges with far-reaching consequences for SLTs. Knowledge about the structures of heritage languages, cultural embeddedness, and developmental processes is essential to prevent speech and language delays, and to appropriately assess and intervene when communication disorders are present. Heritage languages are crucial against the backdrop of communication disorders. First, this applies to the consideration of differential diagnostics (for example, the identification of whether variabilities in language development are due to bilingual language development or delayed or altered language development). Second, it applies to establishing identity as a person's first and emotionally marked access to the social world. In order to increase information on the influence of the first language on bilingual development, current research from Minority World contexts sets foci on the heritage language and its value for bilingual development (e.g., Daskalaki et al., 2020; Flores et al., 2020; Schmid & Karayayla, 2020; Seals, 2018; Sun et al., 2020). This shows that research on bilingual development is not only an African research desideratum. As a result of migration, researchers from historically monolingual countries in Europe (e.g., Caloi et al., 2018; Curdt-Christiansen & La Morgia, 2018; Fleckstein et al., 2018; Kaltsa et al., 2019) set their research foci more and more on bilingual language development.

Besides the vast multilingualism of SSA, the consideration of risk factors—both general and region-specific risks—are crucial when discussing communication and language development and its contexts. Moreover, risk factors for communication and language development vary in different countries. For example, in their research conducted in São Paolo, Brazil, Molini-Avejonas et al. (2017) describe the following risk factors: "being male gender, prematurity, shyness, being an only child or youngest child, presenting deleterious oral habits, having a family history of speech–language disorders, and use of licit or illicit drugs during pregnancy" (Molini-Avejonas et al., 270). While some of these aspects may pertain to other countries as well, additional risk factors, such as HIV/AIDS, malaria, and malnutrition should be considered in the SSA context.

This section discusses these challenges and opportunities. For example, there are chapters on the role of bilingualism in the discipline of SLT, research on developmental processes in heritage languages, and the support of early developmental processes in indigenous languages through community-based projects, as well as HIV/AIDS as a risk factor for communication development. In the following paragraphs, abstracts and critical reviews of the chapters of this section are provided.

11 Prema K. S. Rao

Paradoxical Reflections on Bilingualism and Biliteracy: Relevance for Speech–Language Therapists in Sub-Saharan Africa

Abstract *Background*: The paradox of bilingualism and biliteracy for speech–language therapists (SLTs) may be treated as "old wine in a new bottle." The socio-cultural-linguistic diversity across the majority of countries has been upscaling in recent decades with migrating populations. Sub-Saharan Africa (SSA), comprising 49 countries, is home to 1.05 billion people and is well known for its ethnic diversity with 160 different population groups speaking 2,000 different languages. India, one of the South Asian countries, has a population of 1.35 billion with 1,576 rationalized mother tongues grouped into 114 languages. The socio-historical origins of ethnicity and language attitude toward language variety of both SSA and India, similar to many countries in the Global South, dates back to colonial dominance by European powers. The idea of "one nation, one language," once advocated for political unity, is a misnomer which in reality poses several challenges to SLTs. *Methodology*: A qualitative literary analysis of information related to bilingualism and biliteracy was conducted. *Results/Discussion*: This chapter focuses on certain aspects of bilingualism and biliteracy that are of concern to SLTs, in addition to providing an overview of the discipline of speech–language therapy (SLT), language and literacy acquisition by bilinguals, and the challenges to be met by the SLTs while serving bilingual-biliterate children with communication disorders. The chapter concludes with a proposal

or roadmap for SLT services to bilingual-biliterate children with communication disorders. The ultimate aim of this chapter is to facilitate SLTs in SSA as well as other bilingual countries to develop better knowledge regarding the logistics of services to bilingual children with communication disorders.

Critical Review In this chapter, parallels are drawn between India and SSA, which are both part of the Global South. In both regions, the colonial legacy of "one nation, one language" is a misnomer as bilingualism and multilingualism are accepted as the norm. However, multilingualism is not reflected in many SSA policies. This poses a challenge to SLTs, who are tasked with designing culturally and linguistically relevant strategies for assessment and intervention in a biliterate and bilingual population. Taking into consideration contextual challenges such as culture, languages and scripts, parental awareness, national policy, the educational system, and available training and resources, the author suggests the need to re-invent the policies and strategies for providing services to bilingual-biliterate children in SSA. The chapter also shares beneficial information about the developmental processes occurring in bilingual children, which helps contribute to an increased knowledge base for SLTs practicing in SSA. Using successful examples from the Indian context, the author proposes useful models for partnership and human resource development, which could help guide SLTs advocating for culturally and linguistically relevant services for children with communication disorders living in SSA. The need to conduct cross-cultural and cross-linguistic research to understand the skills of bilingual-biliterate children is also highlighted. This chapter thus highlights not only the value of developing SLT practice and advocacy for policy change, but also developing Afrocentric research to strengthen the profession.

12 Precious Ahabwe and Sara Howard

Typical Phonological Development in Ugandan Language: A Case of Rukiga—A Pilot Study

Abstract *Background*: Speech–language therapy (SLT) is a young profession in Uganda and studies on typical phonological development in any of the 41 languages in Uganda, including Rukiga, are lacking. This has been a challenge for speech–language therapists (SLTs) in making effective clinical decisions in the management of speech difficulties in children. The challenge is further exacerbated by a lack of speech assessments in Ugandan languages. The study aimed to identify patterns of speech sound development in ten typically developing Rukiga-speaking children aged 2;4 – 4;1 years. *Methodology*: A cross-sectional design was used to identify patterns in children's speech development with two groups of five children: a younger age group (2;4 – 3;4 years) and an older age group (3;7 – 4;1 years). Phonological development is described in terms of scores for the percentage of consonants correct, phonemic acquisition, and phonological patterns. *Results*: Older children had a

higher percentage of consonants correct scores than younger children. Sounds acquired earlier include /m, n, p, b, t, k, v, ʧ, w, j, h/ by 3;4 years and consonant acquisition is complete by 4;1 years, although vowels are still undergoing reduction by this age. Older children had fewer error patterns compared to younger children. *Discussion*: This chapter suggests a clear trajectory in phonological development as children increase in age from 2;4 to 4;1 years. Rukiga-speaking children showed cross-linguistic similarities and differences to other languages. This provides a basis for further studies in Uganda and developing culturally and linguistically appropriate assessments.

Critical Review There is a dearth of research on typical phonological development in African languages. This chapter focuses specifically on speech development in Rukiga, one of the 41 living languages in Uganda and which has not previously been studied. Having no normative data upon which to base clinical judgments, just like many other SSA countries, is a major challenge for SLTs working in Uganda when diagnosing speech difficulties in children. The unavailability of published assessment tools in children's native languages further challenges SLTs, as the assessment of children in their native language is best practice and standardized speech assessments outside of their original context should be used with caution, as they may be influenced by factors such as cultural and linguistic differences. This chapter describes in close detail the methodology that the researchers used when conducting the study to obtain the normative data on phonological development in Rukiga, which can serve as a detailed map for future studies on different languages. The results of this study could also assist SLTs working in Uganda in assessing and diagnosing phonological difficulties of Rukiga-speaking children and children speaking related languages by providing normative data to base clinical decisions on. Although the authors mention that the study needs to be repeated on a larger scale, this is the first step toward developing standardized phonological assessment tools in an African language that are linguistically and culturally appropriate.

13 Kirsten Beta, Chantal Polzin, Afizai Vuliva, Julia Wu, and Ulrike M. Lüdtke

The Participatory Potential of Photovoice as a Relational In Vivo Research and Training Method: The Case of a Community-Based Prevention Program on Early Communication and Language Disability in Underserved Rural Sub-Saharan Africa

Abstract *Background*: In rural areas of sub-Saharan Africa (SSA), many children are at risk of developmental disorders because of poverty, illness, and other obstacles related to their care and nurturing. Providing children living in rural underserved areas in SSA with support and resources, and reduc-

ing barriers in early communication and language development to prevent speech, language, and hearing difficulties are vital tasks for speech–language therapists. To achieve a sustainable prevention program, projects need to consider community perspectives. To include the voices and perspectives of the rural community, we implemented photovoice as a participatory research and training method in a community-based and participatory project in Northeast Tanzania. In this project, nine well-respected women with local knowledge about child care and development were trained as counselors of early communication and language development in villages. *Methodology*: In this chapter, we ask whether photovoice can increase community participation. We present the phases of the photovoice method and evaluate the method using criteria gleaned from the literature. *Results*: The photovoice method revealed and extended the women's understanding of communication and language development, their training, their work, and their future aims to disseminate the knowledge they acquired. *Discussion*: Photovoice, as an in vivo and participatory research method, can effectively increase participation in culturally appropriate training and community-based counseling networks that can reach underserved rural areas. The participants' and community involvement is discussed in light of power-related aspects focusing on the aspect of joint decision-making in the context of community-based projects.

Critical Review Prevention of speech–language delay, disorder, and eventually disability is a challenging field for SLTs, because, in the case of primary prevention, it starts before any disturbances in communication can be recognized and before their clinical expertise can be effective. Hence, there are less tangible concepts relating to prevention than assessment or treatment. Nevertheless, it is an important field, especially in regions where children are living in at-risk conditions. This distinctive chapter, being the only one to focus on prevention in this handbook, offers an impressive and comprehensive concept that includes local women as multipliers who spread their knowledge in their villages. This culturally appropriate approach utilizes photovoice. It is an exceptional method that allows trainers (and also researchers) to understand the views and indigenous knowledge from locals. Because the topics arise from internal motives, results can be practicably implemented without any help from outsiders. Therefore, photovoice helps to make trainings sustainable. Further, photovoice, as described in this chapter, can easily be implemented across the world. Due to the low threshold of access to budget digital photo cameras, e.g., on mobile phones, copy shop printers, or simply using a laptop to look at photos in small groups, monetary costs are low. Hence, this valuable chapter delivers a practicable concept for the service-delivery of prevention in rural and underserved areas—a task of outstanding importance.

14 Julia Wu, Chantal Polzin, Afizai Vuliva, Enna M. Mdemu, Kirsten Beta, Kirsten Beta, and Ulrike M. Lüdtke

A Network of Knowledge: Participatory Development of Culturally Sensitive Information, Education, and Communication Materials for the Prevention of Communication Disability in Rural Tanzania

Abstract *Background*: The first years of life are the most crucial in children's communication and language development. To prevent early communication and language disability, parents and caregivers need counseling on communication development and responsive caregiving. This is particularly important for children living at risk in rural sub-Saharan Africa (SSA). However, the lack of culturally appropriate materials in SSA impedes the development of fruitful counseling settings in this field. Abundant knowledge is present in local communities but not always accessible to community members in need. *Methodology*: To confront the provision gap, this chapter depicts a culturally sensitive process of developing information, education, and communication (IEC) materials in the field of early child and communication development from within communities. Twelve women from four villages and seven staff members from a children's home in rural Tanzania formed a network of multipliers, developing IEC materials and counseling strategies that reflect cultural specifics. In this chapter, this process and its results are evaluated in terms of the successes, challenges, and indicators for long-term sustainability. *Results*: The results of the project are a structured, participative method of IEC material development (*activity*), a set of materials that specifically match local conditions (*output*), and a variety of counseling strategies and settings (*output*). *Discussion*: The identified successes show that the presented method is a reliable and appropriate tool for creating culturally and contextually matched IEC materials and promising counseling activities. The challenges indicate that although a lasting impact can be assumed, long-term sustainability has not fully been reached yet and must be addressed through major effort.

Critical Review Counseling in the field of early communication development and disability, and spreading such knowledge in rural areas are important tasks for the SLTs in SSA. Due to the adverse ratio of people in need and at risk to SLTs, networks of multipliers can be appropriate tools. This remarkable chapter illustrates the creative development of material for counseling at the grassroots level. The authors selected a longer but more fruitful road to the culturally sensitive development of materials with community participants from villages. The counseling materials were also used in the project by the participants to advise and inform families in their villages. This is an extraordinary aspect of this procedure that guarantees their identification with this project and their counseling. The chapter, with its impressive photo pre-

sentation, offers valuable insights into this process. The term "culturally sensitive" is often criticized because of its blurriness, but in this illustration, it becomes practical and tangible. This procedure is even transferable to other kinds of material development: e.g., assessment or therapy materials. Often money is needed for buying assessment inventories or therapeutic resources, but the authors show that useful materials to start with can be developed even with limited financial opportunities. Hence, this approach can be seen as a flagship example of the development of culturally appropriate materials.

15 Elise Davis-McFarland

Pediatric HIV/AIDS and Communication and Developmental Disorders in South African Children

Abstract *Background*: Sub-Saharan Africa has more people living with HIV/AIDS than any other region in the world. A total of 87% of the world's children living with HIV/AIDS are in this region. In South Africa, there are approximately 350,000 children living with HIV/AIDS. Although great strides have been made in the diagnosis, treatment, and longevity of South African children who are HIV-positive, the serious and sometimes fatal effects of the infection can be debilitating. As HIV has a shorter incubation period in infants than in adults, the neurocognitive symptoms of the infection often manifest during a child's infancy. *Methodology*: This chapter comprises a qualitative literary analysis of studies related to the medical background of HIV, the developmental and cognitive manifestations of pediatric HIV as well as the World Health Organization's pediatric clinical staging system for the African region, as well as a case study. *Results/Discussion*: Information relevant for the provision of speech–language therapy services to this population is disseminated, namely oral-motor development and oropharyngeal lesions and infections, dysphagia and feeding, otologic and hearing issues, as well as preverbal and language development associated with HIV/AIDS. The case study illustrates the intervention and rehabilitation strategies that can be used for speech and language development in children with HIV infection.

Critical Review In a country such as South Africa where the burden of pediatric HIV/AIDS is excessive, information is empowering. According to a study mentioned in this chapter, South African physicians may not be aware of the need to refer children with HIV/AIDS for neurodevelopmental assessments and therapies, highlighting the need for SLTs as well as other professionals to make every effort to educate healthcare providers about the importance of their role in dealing with HIV/AIDS. To do this, SLTs should be equipped with information regarding profession-specific symptoms that children with HIV/AIDS may experience. The author shares this relevant information through a thorough literature review, empowering SLTs to have the necessary information to advocate for the profession as well as have a

basis of knowledge that can contribute to better serving this population in practice. The inclusion of a case study further strengthens the chapter by making the lived experience of a child living with HIV tangible to the reader. Although the treatment of children with HIV/AIDS may be interrupted by factors such as poor access to health facilities or stigma associated with the diagnosis, the influential combination of antiretroviral drugs and therapies should be advocated for. Although this chapter focuses specifically on South Africa, SLTs in all SSA countries will benefit from the information. With such high numbers of cases of pediatric HIV/AIDS in SSA, this also highlights the importance of increasing the number of SLTs who are trained to provide these services.

16 Ulrike M. Lüdtke, Angelika Illg, Louisa Johanningmeier, Enica Richard, Reema Ruparellia, Lars Rumberg, Jörn Ostermann, Thomas Lenarz, and Anke Lesinski-Schiedat

Hear Africa! Improving Language Development, Education, and Participation of Children with Severe Sensorineural Hearing Loss in Tanzania

Abstract *Background*: In Minority World countries, up to 5 in every 1,000 newborns are congenitally affected by hearing impairment. Due to the physiologically irretrievable loss of maturation in untreated hearing impairment in early childhood, language development fails to take place and serious consequences occur. Thus, the participative and educational opportunities of the affected child are minimized. An interdisciplinary approach, including special needs education, otorhinolaryngology, speech–language therapy (SLT), and information technology (IT), is necessary to face the challenges of delayed social, cognitive, and emotional development by implementing diagnosis and treatment of infant sensorineural hearing loss in Tanzania. This interdisciplinary project aims to implement an early diagnostic approach in sub-Saharan Africa (SSA) to detect and treat infant hearing impairment. *Methodology*: A multi-centered cross-method project to improve educational and participation opportunities of children with severe sensorineural hearing loss is described. As a first step, universal newborn hearing screening (UNHS) was implemented and monitored in a clinical context in Tanzania. Telemedical applications will be adopted with the provision of hearing aids and cochlear implants (CI). Additional training of speech–language therapists (SLTs), audiologists, and other field-related professionals in hearing impairment will take place in a digital, transnational way. *Results*: UNHS was successfully implemented at Muhimbili University of Health and Allied Sciences (MUHAS), Dar es Salaam, Tanzania, which provided the first audiological and UNHS training of trainers and screeners. The obtained data were evaluated concerning prevalence, risk factors, and comorbidities of newborn hearing impairment. As the next step, more screenings will be conducted and informational material will be developed. The focus will be on materials for

the support and education of hearing-impaired young children because they can benefit most from early diagnosis as well as further treatment, e.g., technical devices such as hearing aids or CI. *Discussion*: This multi-centered study enables the first epidemiological assessment of childhood sensorineural hearing impairment in Tanzania. Alongside pedagogical and medical-therapeutic measures, this study increases the future educational and participation chances of hearing-impaired children in Tanzania.

Critical Review In this article, the reader obtains an overview of the globally widespread health condition of infant hearing impairment in the shape of a comprehensive tutorial on the topic from an interdisciplinary medical and speech–language therapeutic (SLT) perspective. As hearing loss goes hand in hand with delay or even a loss of language and communication and therefore needs scientific as well as medical and pedagogic attention, this chapter offers basic knowledge for all practitioners on the interface of health and education. In addition to information on different types of infant hearing impairment from a medical perspective, this chapter offers information on the outcomes and consequences of hearing impairment for affected children and their environment and gives an overview of an interdisciplinary research project named "HEAR Africa! Extending Life and Educational Opportunities for Hearing-Impaired Children in Tanzania" as a practical example. In this project, universal newborn hearing screening (UNHS) was implemented as a primary prevention measure to screen the hearing ability of a large number of newborns to secure language and communication development. It is profoundly important to screen newborns' hearing capacity as the foundations for language development are laid at this very young age. Implementing UNHS in a sub-Saharan African (SSA) country on a large scale provides a glimmer of hope because SSA regions often lack these screenings and consequently, hearing impairment is detected much too late at school age. Also, the fact that a large epidemiologic study has been realized in this project is remarkable, as such studies are both very challenging and expensive. The authors impressively show that more research with preventive aims should be implemented with newborns, and in the future in other medical areas including during pregnancy. Through early intervention, secondarily induced speech delay is preventable. Further, this chapter helps to realize that "hearing" as a topic in SSA should shift from the exclusive private sector to public health care by pointing out that medical care for hearing impairment needs a far further scope into rural areas. In the global sense of inclusion, early diagnosis, and, consequently, fewer therapeutic needs lead to realistic chances for the inclusion of children with communication disorders in education and employment. Another unique and outstanding feature is the unconventional interdisciplinary work in this project: the cooperation of speech–language therapists, ear nose throat professionals, and information technology (IT) experts. In particular, the collaboration with IT opens up new opportunities for epidemiological studies in different fields, telemedicine, and speech–language telepractice in SSA.

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11

Paradoxical Reflections on Bilingualism and Biliteracy: Relevance for Speech-Language Therapists in Sub-Saharan Africa

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Introduction

Socio-cultural-linguistic diversity is apparent across the majority of countries. The root causes for the multicultural and multilinguistic diversity of a country date back to its history. For centuries, this diversity has been viewed as a 'problem' as well as an 'asset' (Rao et al., 2010) in socio-cultural, political, and educational domains. However, for speech–language therapists (SLTs), linguistic diversity can be an 'asset' if the nuances are understood from a multilingual perspective but a 'problem' if viewed from a monolingual perspective. The dilemma of this paradoxical situation suggests an urgent need in the discipline of speech–language therapy (SLT) to realize the 'assets' in order to plan and strategize mechanisms to manage all spheres of assessment and intervention. The empirical evidence that is offered in this chapter emphasizes the 'assets' of bilingual-biliterate children. However, there may be exceptions that ensue in view of the nature of bilingualism. This calls for SLTs to be trained and 'tuned-in' to develop sensitivity as well as the requisite skills to serve this unique population. The various aspects of language and literacy skill acquisition, development, and learning are discussed in brief along with empirical evidence from research. Given the similarities in the socio-cultural-linguistic dimensions of sub-Saharan Africa (SSA) countries and India, the strategies and mechanisms adopted in India for SLT services are expected to be relevant to the context of the SSA countries as well. The majority of countries in SSA are multilingual (Kamwangamalu, 2013). Thus, the contents of this chapter are particularly relevant for SLTs working in SSA countries. It is hoped that the theme of this chapter, besides addressing the concerns and challenges of SLTs, will kindle the interest of educators and special educators who play a crucial role in children's literacy development.

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The Discipline of Communication Disorders

Consequent to World War II, the influx of defense personnel from a diverse ethnography into civilian society with an inability to communicate called for specialized professionals. The birth of the specialized discipline of speech and hearing to offer rehabilitation services dates back to the demand that arose to serve the injured defense personnel with communication disorders. The socio-cultural and linguistic barriers for rehabilitation were as prevalent then as they are in the 2020s. However, the emergence of SLT and audiology programs across 51 nations and territories (Ndigirwa, 2006) has given much impetus to bilingualism in relation to communication and its disorders with the aim of developing appropriate services to for the population. As an update to the above, the International Directory of Communication Disorders (n.d.) lists around 55 nations or territories (approximately one-quarter of the world's nations) that have professional associations at the national level, among which 24 are also international professional associations. The amount of attention that the population with communication disorders receives within specific countries is influenced by the history of the country, economic climate, cultural views, and availability of relevant services (Kotby, 2006; McLeod & Bleile, 2007). The enigmatic nature of the bilingual population across cultures calls for intensive research to understand its complexities. Owing to the paucity of empirical knowledge, services for bilingual children with communication disorders are yet to be validated with a convincing rationale.

Components of Communication

It is well known that communication disorders cut across physical, psychological, emotional, socio-cultural, and linguistic dimensions. Children

acquire language, a system of arbitrary symbols, to communicate with parents, siblings, family members, friends, and society. Irrespective of the social context (monolingual or bilingual society), the essential vehicle for communication is language, which is used either in verbal, written, or gestural mode. The modality (Table 11.1) through which a child communicates depends on his/her potential and the demands of the communicative context.

From the perspective of SLTs, communication may be viewed as comprising the major components and sub-components shown in Fig. 11.1.

SLTs working with bilingual children should gain a clear understanding of all the components of communication, and the language component in particular, as there are variations in its features across different languages. To illustrate the components with examples from the English language, the study of speech sounds is phonology (for example, production of /p/, /b/); word structure is morphology (/is/ vs. /as/); sentence structure is syntax (/books are thick/vs. /book is thick/); meaning of words is semantics (/hair/ vs. /air/); and use of language in a meaningful context is pragmatics (/he dropped her home/ vs. /he dropped a book/). Depending on the nature of bilingualism (elaborated in the following section), often children with communication disorders manifest difficulties in any one or a combination of the features of the language components. The difficulties may surface in either receptive or expressive language, or both these domains.

Table 11.1 Modalities of Communication

Receptive Modality	Expressive Modality
Hearing	Speech
Seeing	Writing
Touch	Gestures
Smell	Body language

Theoretical Background: Bilingualism and Biliteracy

Bilingualism

'Bilingualism' refers to being proficient, to varying degrees, in two languages (Edwards, 2013). Based on the way in which languages are learned, as early as 1953, Weinreich proposed three types of bilingualism:

1. *Compound bilingualism* where a child learns two languages in the same environment and acquires one concept with two verbal expressions.
2. *Coordinate bilingualism* where a second language (L2) is learned in a different environment with the mediation of the first language (L1). For example, when a child learns the Kannada language in Karnataka, India, and Spanish in Mexico during their developmental period, the child is likely to have a separate system for each language in his/her mental map with separate locations for words and concepts of each language.
3. *Subordinate bilingualism* where a child learns a second language but fails to understand it without the help of L1 unless (s)he translates the words in the second language into his/her first (dominant) language, as the concepts in the mental map function as only one system.

Later, in 1994, Bialystok and Hakuta made a distinction between simultaneous bilingualism (L1 and L2 learned about the same time) that par-

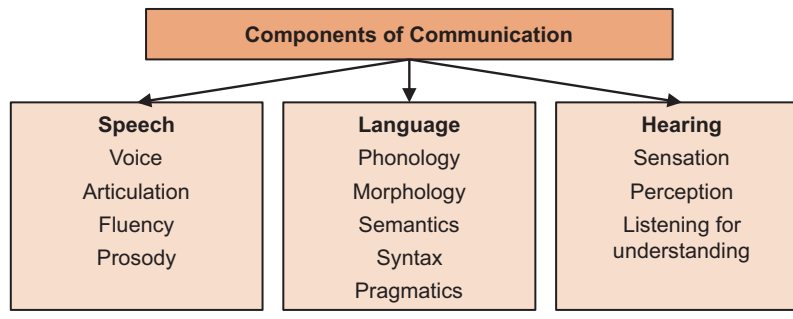

Fig. 11.1 Components of Communication

allels compound bilingualism; early sequential bilingualism (L1 learned first and L2 relatively early in childhood); and late sequential bilingualism (from adolescence onwards) that can be considered fairly equivalent to coordinate and subordinate bilingualism. In general, when a language is learned after the first or the native language is relatively well established, the term 'second language' is used. As we advance our knowledge on bilingualism in this section, we come to realize that the types described in the earlier decades may not hold true, particularly for the bilingual population of SSA countries and India. Owing to the heterogeneity in the bilingual population across diverse cultures, it may appear absurd to embrace the fixed categorical terms given by a few bilingual theorists. In the present era of a changing global scenario, a rigid definition of terminology is, however, highly speculative. Strict adherence to the above terminologies by the SLTs in SSA countries as well as India and other bilingual countries seems all the more absurd in view of the differences in the process of bi-/multilingualism happening in the specific community. While in some communities it may be a naturally occurring phenomenon by virtue of its ethnographic status, such as in the Global South where bi- and multilingualism is often the norm (Shoba & Chimbutane, 2013), in a few other countries it may be developed through educational immersion programs such as those developed in Canada and the USA (Wright, 2013).

Biliteracy

Bilinguals and second-language learners who develop literacy in two languages are termed 'biliterates' (Perez, 2004). In the process of acquiring language(s) and literacy by bilingual-biliterate children, although it may appear that the receptive skills (listening and reading) and expressive skills (speaking and writing) are acquired like any other monolingual child, they are likely to go through a stage of mixing and switching the codes of the languages and scripts (be it in the oral mode or written mode). Therefore, in addition to resolving the terminological debate, SLTs should also analyze features of languages and scripts to understand the communication difficulties of bilinguals and biliterates.

Relationship Between Language and Literacy

Several studies have found a considerable relationship among the components of language and literacy, the complexities of which are compounded by the structure of language and the system of writing, as well as the nature of the script of a given language (Geva & Siegel, 2000; Karanth, 1992; Katz & Feldman, 1983; Wimmer & Goswami, 1994, among others). To reiterate the above with examples of language structure, a bilingual-biliterate child learning to speak, read, and write English and Kannada (a South Indian language spoken in the State of Karnataka, India) would need to internalize the differential syntactic rule for use of a preposition in a sentence in the two languages. For example, in a sentence 'book is on the table', the preposition is positioned before the noun 'table' in English, whereas in the Kannada language it is positioned after the noun 'table' and expressed as /table mele book ide/ /'table' 'on' 'book' 'is'/. Similar differences occur in some African languages; when considering the same sentence in Zulu, it translates as /incwadiisetafuleni/ /'book' 'on table'/. Here, the preposition occurs in the form of a prefix (ise-) to the word 'table' (tafuleni).

With reference to the nature of the script of a language, the child requires skills to convert speech sounds (phonemes, such as /s/ or /k/) to letters (graphemes, such as <c> in 'ice' or in 'cat') by recruiting the meaning of the word (lexicon) while learning to write in English (an alphabetic script with deep orthography, explained in Section "Literacy Acquisition in Non-Alphabetic Orthography"), whereas, while writing in Kannada (semi-syllabic script with transparent orthography), a child need not aim for conversion as the speech sounds and letters (called as aksharas) have a direct relationship and therefore letters are written as they are heard (/ka/ as /ಕ/ for /ಕರ/ 'palm' and /sa/ as /ಸ/ for /ಸರ/ ('necklace'). The differences in linguistic structures and features of speech sounds of Indian

languages and English (the language that is learned in school) invariably turns out advantageous to the bilingual children in India as biliterate children learn to exercise additional cognitive skills (metalinguistic in nature for this task) while learning two or more languages (Bassetti, 2013). This may also be true for children learning English/French at SSA schools in addition to their first languages. Exposing children to English (or to additional languages) from an early age, therefore, should be viewed positively for cognitive enhancement that supports language and literacy acquisition.

In view of the societal and academic demands for communication and literacy learning placed on a bilingual child, rehabilitation services for such children with communication disorders should embrace several dimensions including literacy-related skills. Given the enigmatic picture of bilingualism and biliteracy, SLTs, educators, and special educators are often in a dilemma over whether to choose one language or more than one language in their service. Such a complex scenario poses challenges to professionals when designing strategies for assessment and intervention services for bilinguals and biliterates. It also signals an urgent need for empirical studies and evidence-based practice to find solutions to this paradoxical situation.

Bilingualism and Language Acquisition

Bilingualism vis-à-vis Language Acquisition

Bi-/multilingualism is a natural product of language spread and development. Migration, as a consequence of globalization and transnational job markets, has created a sociolinguistic environment in which individuals and communities have been exposed to one or two languages besides their mother tongue vernacular (Hulstijn et al., 2003). Recognition of cultural differences and bi-/multilingualism has been treated as a sign of ethnic identity in recent years. As a result, young children often find themselves in an environment where more than one language is used. The majority of the documented literature views the acquisition of speech and language in bilingual children from a monolingual perspective and, therefore, several concerns have been raised about language acquisition in bilingual children.

Since the 1960s (for example, MacNamara, 1966), there have been several reports on language acquisition in bilingual children. Bialystok (1988) reported that bilinguals show a slower rate of vocabulary development in following the same stages of speech and language development as monolinguals. The order of morpho-syntactic and phonological development, strategies used for acquisition of lexical-semantics such as overextension and under-extension of lexical items, substitutions, and direction of acquisition from unmarked to marked linguistic structures are essentially the same for both monolingual and bi-/multilingual children (Meisel, 1986). Consequent to the impetus given to research in bilingualism in recent decades, the focus of study has shifted from gross linguistic units to finer metalinguistic units indicating higher metalinguistic skills in bilinguals. Goswami (2010) reported that the characteristics of speech sounds vary across languages, such as the temporal features (i.e., the durational component, for example, /a/ vs. /a:/) and the spectral features (i.e., the frequency component, for example, /s/ vs. /ʃ/) of phonemes as well as the script features (for example, the alphabetic, syllabic, or morphemic nature of scripts). These temporal, spectral, and script features of each language influence metalinguistic skills, including phonological awareness. Schuele et al. (2007) have discussed the special considerations required when assessing phonological awareness in children from linguistically diverse regions. This dimension has been largely explored in bilingual children with studies reporting a consistent advantage for bilinguals over their monolingual peers.

Bi-/multilingual children also tend to develop additional communication means that a monolingual child lacks by switching between the languages in a systematic fashion, suggesting flexibility in language use. (S)he uses each of the language(s) in different contexts, reflecting the

ability to shift on a continuum ranging from a monolingual to a truly bilingual or multilingual mode. With rapid changes in globalization, coupled with the naturally occurring phenomenon of bilingualism as seen in the SSA countries and India, SLTs need to develop sensitivity to view the acquisition of language by bilingual children as a unique process that differs from that described for monolinguals. This also cautions against using norms developed on monolingual children in the language assessment of bilinguals. For example, in South Africa, English is the main language of instruction and healthcare services. However, the vast majority of the population are not English first-language speakers. Language assessments are either conducted in English or are translated by interpreters, as the majority of SLTs do not speak the same first language as their clients (Barratt et al., 2012). This calls into question the validity of language assessment results.

SLTs need to be skeptical about viewing a bi-/multilingual child as one who has linguistic knowledge of perfectly equal parts and behaves like a respective monolingual from that linguistic community. To date, the reports from studies on speech–language development in bilinguals, however, appear to be equivocal, suggesting the need to explore the issue across countries with diverse ethnicity.

Despite these findings, apprehension among SLTs and educators about the effects of bi-/multilingualism on a child's acquisition and development of language prevails as the nature and type of bilingualism are also taking different directions, unlike those traditional types described in earlier decades. SLTs should arrive at a consensus to assess bilingual children based on their 'knowledge' of language instead of 'use' in a specific language to determine language development. Support for this premise is drawn from a comparative study conducted at the All India Institute of Speech and Hearing, Mysore, India (Rao & Yelimeli, 2005). In this study, a questionnaire was administered to the parents of 100 monolingual children exposed predominantly to one language (the word predominant is used here as the naturally occurring bilingual environment in India does not allow the choice of an ideal monolingual population for the study) and to 100 parents with multilingual children (exposed to two or more languages). The findings revealed that multilingual children scored significantly better in their language comprehension and cognitive domains when compared to monolingual children. The results revealed that the expressive skills of multilingual children were comparable to those of monolinguals when the scores were considered irrespective of the language of expression but poorer when the scores for each language were considered separately. The findings support the view that 'knowledge' and not the 'use' of linguistic codes should be taken into consideration when assessing bi-/multilingual children. Since children learning to speak two or more languages together go through a stage of mixing and confusing the languages, the structural differences of the language(s) as well as the proficiency of children in L2 (and third language, L3) are likely to contribute to the nature and degree of delay in expressive skills.

From the literature on language acquisition in bilingual children, it can be said that there is no causal relationship between a bi-/multilingual environment and the development of language disorders. The fact that many children across the world grow up with two or more languages from birth without developing language delays or disorders also offers support for the above. If SLTs develop sensitivity to the nuances in bilingual language development in the development of empirical methods for assessment, the percentage of bilingual children labeled as 'children with communication disorders' would be automatically reduced. In the case where a typical profile of communication disorder is confirmed in such children, intervention should be planned and executed by SLTs with a clear understanding of the way the language is acquired/learned, the structure of the two languages, and the mode of communication, in addition to many other individual factors.

Bilingualism vis-à-vis Literacy Acquisition

Literacy acquisition is considered a secondary language skill. Literacy, which is traditionally

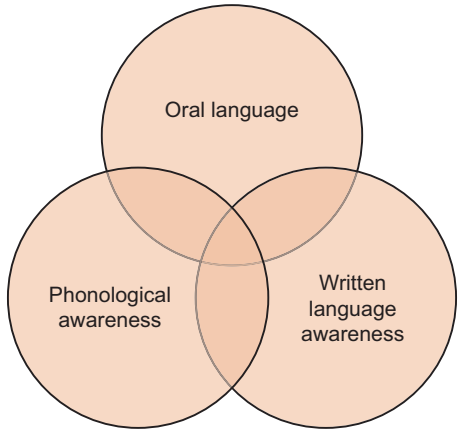

Fig. 11.2 Precursors to Alphabetic Literacy

defined as the ability to read and write, develops with the help of meaning derived from a given language. While reading is defined as the ability to obtain meaning from print, writing is the ability to use print to communicate with others. The National Reading Panel (2000) emphasizes oral language, phonological awareness, and written language awareness as precursors to the acquisition of alphabetic literacy in the English language by native English-speaking children (Fig. 11.2).

However, a word of caution should be mentioned here, in that these precursors should not be considered as universal, as the writing system and the nature of the script employed in a language (alphabet, syllabaries or letters, morphemes, or other logographs) will have a differential impact on literacy acquisition, as detailed in the following section.

Literacy Acquisition in Non-Alphabetic Orthography

Studies on non-alphabetic orthography have reported that reading development is linked to the nature of orthography (transparency vs. opaque). According to the Orthographic Depth Hypothesis by Katz and Frost (1992), the less transparent orthographies (deep orthography) have more complex relationships between letters and sounds, leading to slower development of word recognition skills, while the more transparent ones facilitate word recognition as there is a simple direct one-to-one correspondence between letters and sounds of words. The reading process is different for different orthographies (Ellis et al., 2004). Accordingly, a child who is learning to be biliterate in languages with differing scripts (for example, one with an alphabet that is less transparent and another with syllabaries or letters that are more transparent) is likely to develop additional skills and strategies required for reading two types of orthography, thus enhancing his/her cognitive resources in comparison to monolingual children (Karanth, 1992; Karanth & Prakash, 1996; Rao, 1998; Rao, 2006; Rao et al., 2010, among others). For example, the letter 'c' in English is pronounced as either sound (phoneme) /s/ as in 'ice' or /k/ as in 'cream', making the task of reading or writing difficult for a child learning to spell the word 'ice cream'. However, in the Kannada language with a syllabary script, the sound (syllable) /sa/ is written as /ಸ/ and /ka/ as /ಕ/ as heard by the child with no other competitors as the orthography is transparent.

The understanding gained from these observations suggests that the structure of a language and the script-specific features influence the development of precursors for literacy acquisition (for example, phonological processing, phonological sensitivity, phonological naming, and phonological memory, as described by Bialystok et al., 2005). Since the languages differ in terms of the regularity between written symbols (letters/graphemes) and sounds/phonemes, a bilingual-biliterate child may require specific skills to process the scripts of different languages (for more details, see the script-dependent hypothesis by Geva & Siegel, 2000). One such process that is largely examined in the literature is the development of phonological awareness skills that are considered as prerequisites for the acquisition of alphabetic literacy (Katz & Feldman, 1983). However, studies on non-alphabetic scripts report that phonological awareness develops as a consequence of exposure to the alphabetic scripts, provided that one of the languages of the biliterate child happens to be English or any other language with an alphabetic script. Phonemic awareness, in particular, emerges as a consequence of learning alphabetic script (for example, English) and therefore is not a necessary skill for literacy acquisition in syllabic/semi-syllabic scripts. Alternatively stated, unless there is exposure to an alphabetic system,

literacy in a syllabic/semi-syllabic system does not facilitate the development of phonemic awareness and phonemic awareness is not crucial for literacy acquisition in such a system.

The momentum seen in research on non-alphabetic literacy helps to gain a clearer understanding of the issues related to script specificity as related to literacy. In this context, from a bilingual-biliterate perspective, there is a need for SLTs to address the following questions in extensive studies on different types of scripts.

Key Questions for Research with Bilingual-Biliterate Children

1. Does literacy develop without the precursor of phoneme awareness skills?
2. Are the precursors to literacy governed by script features?
3. Is training certain skills that are not precursors in a given language/script necessary?
4. Does exposure to an alphabetic script restructure the cognitive system to facilitate phoneme skills?
5. Does written language awareness govern the precursor to literacy-oral language and phonological awareness in English as a second-language learners?

On the basis of the studies conducted in Indian languages, a hypothetical model is proposed (Fig. 11.3) that gives direction to those interested in investigating literacy in English as a second-language (ESL) learners. The thin, dotted line connecting phonological awareness to phoneme skills implies that this relationship is not strong. This model may be validated with data from different languages and scripts by conducting research on ESL learners.

These findings are crucial for bilingual-biliterate children in SSA countries since the nature of the script used by the children ranges from the Roman script (alphabetic) commonly adopted in Africa, the Arabic script (written from right to left) used in North Africa, to the autochthonous scripts designed by linguists in West Africa (Pasch, 2008). The diverse nature of these scripts gives an edge to bilingual-biliterate children in SSA over their monolingual peers, encouraging them to use their cognitive resources as an 'asset' for learning.

At this juncture, it can be said that biliteracy and multiliteracy is an upcoming trend in literacy instruction. Literacy in the first language and bi-/multilingual approaches to literacy teaching in early childhood education are now widely accepted as the most effective ways to ensure educational achievement for children in multilingual

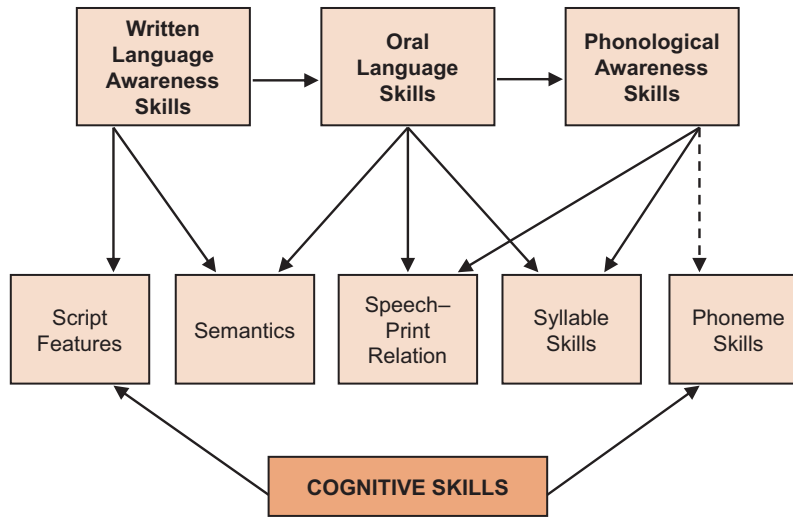

Fig. 11.3 Hypothetical Model of Precursors to Literacy for ESL Children. (Based on Rao, 2011)

societies. Hence, children undertaking bilingual education, particularly in languages with widely differing features of speech sounds and scripts, are likely to exercise differential skills depending on the demands placed by the linguistic and script features. Since there are studies that point to phonological awareness acquisition being dependent on many factors, including exposure and experience with languages and scripts, SLTs, as well as teachers, need to consider the relevance of particular skills that are prerequisites for the literacy acquisition of selected languages and scripts. While instruction in alphabetic languages and scripts demands an intensive focus on phonemic skills as a part of phonological awareness activities, the non-alphabetic languages and scripts require a different set of instruction methods to enhance written language awareness (for example, orthographic sensitivity), suggesting that there is no single rule of thumb for literacy instruction across languages and scripts.

Cross-Language and Cross-Script Skill Transfer in Bilingual-Biliterate Children

The studies on second-language acquisition have heightened awareness of the influence of one language and script over the other (cross-language and cross-script transfer) in a bilingual-biliterate child learning to speak, read, and write two different types of languages and scripts. The studies in this field reflect on the role of language proficiency in bilinguals, the distance between the languages and orthographies for transfer of skills between/across languages and scripts (Chen et al., 2015).

While cross-language transfer research shows an exponential growth with studies conducted on several pairs of languages (Stuart-Smith & Martin, 1999: Punjabi-English; Geva and Wang 2001; Turkish-English; Shanbal & Rao, 2006: Telugu-English; Shanbal & Rao, 2007: Kannada-English), knowledge about cross-script transfer is often derived from studies on bi-/multiliterate children with dyslexia (Zaretsky & Shwartz, 2016). Depending on the structure of language(s) and the nature of script(s) employed by the bilingual-biliterate children, evidence is documented for either facilitation or interference from languages and scripts in some of the aspects of their verbal or written communication. The studies suggest that when the scripts are common across the languages (for example, French-English; Punjabi-Hindi), bilingual children are facilitated in literacy. Even when the scripts are different (for example in Kannada and English), bilingual children appear to have an edge over monolinguals by recruiting additional metalinguistic skills as mentioned in Section "Bilingualism vis-à-vis Language Acquisition". Although the studies on cross-script transfer are scant, the findings from the above studies are very encouraging since in both the contexts (similar or dissimilar scripts) bilinguals fair better. Therefore, the naturally occurring diversity in languages and scripts in SSA and India offers a promising picture for bilingual-biliterate children.

The issue of cross-language transfer of literacy skills in bilingual-biliterate children is of direct concern to SLTs, be it in oral or written language communication. Although research on this aspect is not very extensive, the available information to date emphasizes the importance of SLTs as well as educators understanding the subtle characteristics of languages and scripts in order to deliver quality services to bilingual-biliterate children.

Service Delivery for Bilingual-Biliterate Children

As mentioned earlier in this chapter, migration of populations is increasingly viewed as a norm in society, more so with the advancement of technology and the need for skilled personnel. As a result, bi-/multilingualism happens as a naturally occurring phenomenon. Speciale (2013) lists ten countries across the globe as multicultural and multilingual in nature. Among these, SSA and India are taken as good examples of naturally occurring multilingual countries for discussion in the present chapter. Societal bi-/multilingualism is quite common in both SSA and India where the majority of people have at least two to three languages in their communication habits. The advantages of the use of more than one language for cognitive enhancement have motivated several other countries (for example, the USA, Spain, France, Italy, to name a few), where bilingualism is not a naturally occurring phenomenon, to initiate a movement toward language immer-

sion or dual-language programs in schools to teach foreign language to children. Table 11.2 presents an overview of the ethnographic status of a few bilingual countries.

The statistics on languages as shown in Table 11.2 come from *surveys conducted by governmental sectors* (including children and adult populations) and are not aimed at evolving strategies for service delivery to bilingual children. A word of caution to be mentioned here is that *SLTs should view the statistics as only a cursory guideline* to estimate the quantum of preparedness necessary to serve bilingual-biliterate children. There are several factors that contribute to optimum service delivery (by SLTs as well as educators) but a few significant ones are listed below:

(a) Availability of qualified professionals to offer services in the given language(s)
(b) Availability of resources for assessment and intervention
(c) Parental acceptance of the language of assessment and intervention
(d) National vs. official vs. state languages
(e) Home vs. academic languages
(f) The language(s) of prestige for a given family, state, or country
(g) Educational policy
(h) Availability of empowered teachers and many more factors depending on the nature of bilingual children being served.

SSA and India are considered major multilingual regions and therefore are often taken either as examples or for purposes of comparison in this chapter to discuss a few of the above factors.

Language Policy for Service Delivery in Bilingual Countries

The policies adopted for service delivery in a few bilingual countries with reference to language(s), availability of service providers as well as educational policy are presented for comparison with the objective that SSA countries will examine the prevailing practice to draw input for service delivery with the motto of implementing the best practice.

An overview of the linguistic situation in India presents 1652 languages, more than 2000 dialects, 31 official languages, 44 languages taught in various state schools at primary level, and more than 20% bilinguals (often trilinguals or multilinguals as explained in the subsequent paragraph), among whom more than 70% are bilinguals in view of the lack of script to write in their native language. In such a complex situation, India embraces a pluralistic principle that is language development oriented as well as language survival oriented (Ministry of Human Resource Development, 2016). In India, Hindi and English (colonial influence) are the official languages with each state permitted to have its own official language. Therefore, a majority of educated Indians are at least trilinguals or multilinguals with a working knowledge of additional languages when they move between states.

Table 11.2 Overview of Ethnographic Status of Bilingual Countries

Country/ Continent	States	Population	Ethnic Groups	No. of Languages	Bi-/Trilinguals
SSA Countries	49	1.01 billion	160	Approx. 2000	Majority of population are complex multilinguals (5 to 450 languages per country)
India	29 & 7 UT's	1.34 billion	>2000	1576 >2000 dialects	Approx. 25%
Australia	6	23 million	270	300	Approx. 22%
European Union	28	741 million	87	>60	Approx.54%
USA	50	327 million	6	350	Approx.12–54%

Based on Australian Bureau of Statistics (2018), European Union (2018), Federal Ministry for Economic Co-operation and Development (2018), India Online Pages (2019), Maps of India (2018), Population Pyramid (2017), United States Census Bureau (2015), Wikipedia contributors (2018)

With reference to the number of persons with communication disorders and the qualified SLTs and audiologists (Indian Speech and Hearing Association, 2017) (1.8% of the total population estimated by the Rehabilitation Council of India, 2016), India has a ratio of 1:32,000 persons in a population of 1.37 billion (as of May 2019) with 28 States and nine Union Territories (as of August 2019). This indicates the need to intensify methods and strategies for which studies are being done that are detailed in the following section.

The picture is not much different for SSA countries except for the use of a foreign international language as an official language irrespective of their true linguistic diversity. Pereltsvaig (2011) remarked that the colonial languages are embraced as official languages in SSA to avoid an awkward situation that ensues with multiple languages in governance.

With reference to the available data on the number of qualified SLTs, for a population of 1.01 billion people in the 49 countries of SSA, the ratio of the SLT workforce is one SLT per 2–4 million persons with communication disorders across four countries in SSA (Wylie et al., 2012).

While India and the SSA countries may be viewed as those influenced by colonial governance in their historical developments, there are no clear models as exemplars even from high-income countries such as the USA and the EU. The USA is largely monolingual with 75% of Americans speaking in English, the remaining primarily being Spanish-English bilinguals. In recent years, there have been dual-language programs and language immersion programs in schools to build a multilingual society (Wright, 2013). On the contrary, the EU has 24 official languages but English and French are the major languages used by its citizens. However, the EU has always designated language learning as an important element for success in global competitiveness and, therefore, two foreign languages are taught in schools.

When compared with the EU and the USA, the linguistic diversity that prevails in SSA countries and India facilitates language and literacy learning without requiring extra efforts toward immersion programs or dual-language programs. The language immersion and exposure to dual or multiple languages happen right from childhood. The bilingual society in these countries offers a rich ground for learning languages but the language policy is embedded in the economic, political, and ideological interests of the social groups. In view of the relatively recent emergence of the discipline of communication disorders compared to the educational domain, there is no clear-cut policy for service delivery by SLTs for bilingual children. However, there appear to be some policies for the language of education although this has been a debated issue for a long time.

Tracing the history of language policy in education for SSA, Bamgbose (2001) reflects on the diversity emerging from teaching French, Portuguese and English languages in schools at the expense of native (vernacular) languages. While the British and Belgian colonies initiated policies that supported the use of African languages, French and Portuguese colonies imposed the colonial language as the primary language of instruction. Buzasi (2016) remarked on the linguistic situation and the prevailing thoughts on bilingual children in the SSA countries as follows:

- Informal language acquisition in the prevailing multilingual contexts in SSA creates a conducive factor which needs to be used and nurtured.
- Bilingual education is best achieved when it is based on literacy in a language familiar to the learner.
- Almost all prevailing models of bilingual education existing in SSA fail as real transfer of learning is not happening.
- There is a body of research evidence to support mother tongue literacy and education and to dispel the confusions and myths dominating the field.

In contrast, India embraced the Three-Language Formula (TLF) as the language policy for education consequent to independence. As per the National Curriculum Framework for School Education: 2000, the TLF includes the study of a modern Indian language, preferably one of the

South Indian languages, apart from Hindi and English in the Hindi-speaking states, and Hindi along with the regional language and English in the non-Hindi-speaking states at the secondary stage (Subhash, 2013).

Although the TLF policy has been mostly well-received for decades, it has generated apprehension with reference to the proficiency of teachers in the regional language and the language(s) of instruction in schools. The international meeting held with the National Multilingual Education Resource Consortium and many other organizations in September 2011 in Mysore, India, allowed discussion of issues relating to the Mother tongue-based Multilingual Education (MLE) policy adopted by many states in India (Central Institute of Indian Languages, CIIL 2011). One of the major issues discussed was 'capacity building' for a large number of MLE teachers since the number of teachers available from within a given language community is disproportionate to the number of children from that region. A few small-scale studies carried out on this topic are summarized below with the hope that similar studies will be taken up on a large scale to build more evidence before re-inventing service delivery methods, strategies, and policies for bilingual children.

Stuart-Smith and Martin (1999) developed one of the first documented resources for the assessment of bilingual populations. They developed a battery of tasks for the assessment of phonological processing skills in Panjabi-English bilingual children in west Birmingham in the UK, with the understanding that phonological awareness is to a certain extent language-specific and dependent on the phonology of the language of assessment. Sensitivity towards the need for language-specific tasks heightened consequent to the work of Stuart-Smith and Martin (1999). The issue of service delivery was viewed diligently across the globe to examine the issue of intervention for bilingual children. The following paragraphs highlight two significant studies that further enlighten this issue.

A survey was conducted in 13 countries with 99 SLTs as respondents with data from 157 children by Jordaan (2008) for the International Association for Logopedics and Phoniatrics (IALP). The focus of the survey was to obtain biographical details, including language background of the children, type of communication disorder, language competence of the therapists, the language of intervention, use of interpreters, advice given to parents regarding the use of each language, and the possible outcomes of the intervention. The results indicated that very few therapists provided bilingual intervention and were unable to provide quantifiable intervention results due to a paucity of assessment materials for bilinguals. The results of the survey indicated major limitations in the service, and as a result, the IALP developed guidelines for working with multilingual populations with communication disorders.

Williams and McLeod (2012) elicited 128 Australian SLTs' perspectives and experiences of multilingualism with a focus on assessment and intervention practices, and service delivery methods. Among the 28 languages listed in the study, only 12 SLTs (9.4%) reported that they were proficient in another (second) language apart from their native language. The majority of SLTs reported that they always used informal speech (76.7%) and language (78.2%) assessments and, if standardized tests were used, typically they were in English. The SLTs sought additional information about the children's languages and cultural backgrounds but indicated that they had limited resources to discriminate between speech and language difference versus disorder.

Although there are limited studies documented that examined the status of service delivery for bilingual-biliterate children, the limitations faced by the SLTs reported in the above research should help to re-frame therapeutic practices for bilingual-biliterate children. Given the diverse status of bilingualism across the major bilingual countries, to arrive at a consensus on uniform service delivery methods and policies appears to be too theoretical without a plausible solution to the challenges. The need to re-invent the policies and strategies for bilingual-biliterate children will be an ongoing process for bilingual countries as it is highly likely that periodic changes in socio-cultural-linguistic diversity might ensue in the years ahead.

A Few Studies on Bilingual Teachers in India

Very few studies have explored the effect of bi-/multilingual teachers who are non-native language speakers imparting education to children who are native language speakers of that region. Rao and Mekhala (2013) examined the proficiency of bilingual (for example, Tamil-English) teachers imparting education in language and other curricular subjects in their non-native language to bilingual (Kannada-English) children. Language proficiency in 15 schoolteachers was assessed using an online bilingual test for language proficiency (Kannada-English, Rao & Mekhala, 2013). The results indicated that although teachers were non-native speakers of Kannada and English with lower proficiency in both the languages, they were able to communicate with children using multiple modes. The bilingual children showed flexibility to be able to respond to differences in social or pragmatic expectations in either more familiar or less familiar interactions. These findings are promising for the academic outcomes of young transnational children.

Flexibility in bilingual children is also reflected in a cross-cultural study conducted by Rao et al. (2017). The bilingual (Kannada-English) preschoolers enrolled in English-medium preschools were engaged in a shared book reading session. Two investigators, one of whom was a native speaker of English from a different culture (Less Familiar Adult, LF), the other a second-language learner of English from the same culture (Familiar Adult, F) read an English storybook and asked children scripted questions in English. The linguistic output of preschoolers for scripted questions was analyzed with the help of the Systematic Analysis of Language Transcription (SALT; Miller, 1981) software. The results did not show significant differences either in the number of utterances, question formulation, or percentage of total number of questions. However, the data suggested that the children's participation in shared book reading sessions with the familiar (F) and less familiar (LF) adults was similar and that even very young bilingual children were able to adapt to different language partners. These findings are encouraging, as young children are likely to be adept at interacting with LF adults regardless of their linguistic and cultural familiarity. The findings are encouraging for the SLTs and teachers working with bilingual children.

Despite the flexibility to adapt to linguistically diverse communication situations, bilingual children often encounter difficulties with cognitive subjects such as mathematics and science in their non-native language if they have low proficiency in the second language. While monolingual children learn cognitive subjects with the help of their well-established native language, bilingual children learn language through cognitive subjects. Cross-language studies on digits and number word processing (Anitha et al., 2007; Anjali et al., 2006; Bernado, 2001) suggest that there are differences in the processing of digits and number words at the semantic level between monolingual and bilingual children. The bilingual children fared poorly on statement problems and homophonous words (for example, 'some' and 'sum'; 'tense' and 'tens'), suggesting a high possibility of interaction between the language vocabulary and math vocabulary. In order to plan and evolve adequate methods for developing language teaching, it is necessary for SLTs to interact with language teachers as well as teachers of cognitive subjects to help them understand the paradoxical nature of language processing in bilingual children.

Challenges for SLTs with Bilingual-Biliterate Children

Multi-culturalism, bi-/multilingualism, and bi-/multiliteracy are accepted as a norm for countries in SSA as well as in India, in addition to a few other countries that are striving hard to nurture bilingual societies. However, the bilingual population is complex in SSA countries, with a minimum of 40 different languages in each African country (Speciale, 2013). Given the fact that bi-/multilingualism is a norm associated with the ethnic diversity of SSA countries as well as in India, and the disproportion in the number of

qualified professionals who are service providers to the number of persons with communication disorders who are service receivers, the challenges posed to develop strategies cannot be addressed with a rule of thumb. This should not, however, discourage SLTs from planning and strategizing their services to the group of bilingual-biliterate children even though the challenges are multifold. From human resource development with qualified professionals at various levels to offering services, countries need to plan and develop resources for assessment and intervention in multiple languages, field-tested with culturally fair pictures and in different contexts, and develop norms for the specific culture(s), language(s), and writing system(s).

The most challenging situation for SLTs (and teachers) is when a child is learning to read an alphabetic and a non-alphabetic language that is prevalent in the majority of the school system. SLTs and teachers should design common programs that could apply to both (or all) the languages in question as well as specific programs for specific languages. In view of this, it is extremely important to sensitize bilingual SLTs and language teachers to the differential skills needed for each of the languages and scripts. They should receive training on methods to enhance the cognitive resources of children learning two or three languages and scripts to achieve optimum outcomes in communication and education. This, however, calls for intensive efforts to empower SLTs and teachers to meet the needs of bilingual-biliterate children. The nature of these challenges, although changing with time, is complex. An attempt is made to depict the existing challenges in Fig. 11.4 to convey that the road ahead for bilingual countries is very long if they are to reach that goal.

There is a critical shortage of highly skilled professionals (0.5 workers per 10,000 inhabitants in many countries in SSA, such as Burundi, Cameroon, Central African Republic, Chad, Congo, Gabon, Guinea, Niger, Burkina Faso, Cote d'Ivoire, Gambia, Senegal, Tanzania, Madagascar, Mali, Ghana, and Uganda) and also in several countries across Asia (Bangladesh, Nepal, Pakistan, Myanmar, and India) as reported in a study carried out by Gupta et al. (2011). They further remark that lower-income countries tend to have a lesser supply of human resources for rehabilitation, posing additional challenges in designing strategic policies and actions.

Conclusion: Roadmap of Services to Bilingual-Biliterate Children in the Future

The research findings presented in the earlier sections of this chapter highlight the need to develop a comprehensive model for service delivery to meet the challenges posed by bilingual-biliterate children. The discussion presented in this chapter suggests that bilingual countries should prepare to build human resources, bilingual tests, and

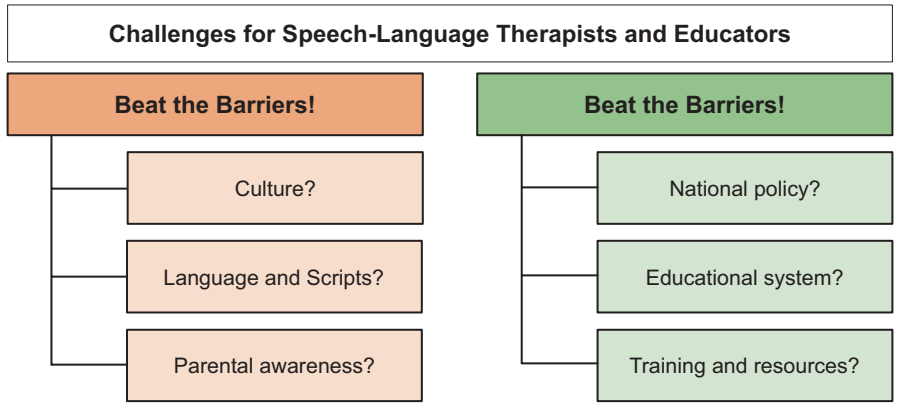

Fig. 11.4 Challenges for Speech–Language Therapists and Educators in Bilingual Countries

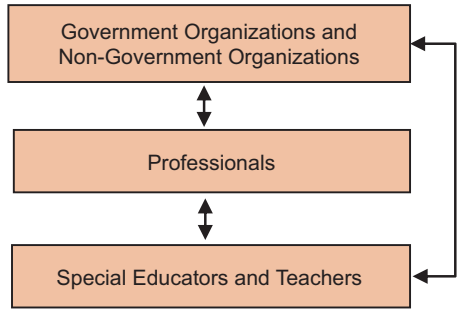

Fig. 11.5 Three-Tiered Partnership Model

appropriate measures for assessment, strategies, and methods for intervention, and develop policies for decision making on the language of intervention including educational language. To strategize mechanisms for the above, a simple three-tiered partnership model is proposed (Fig. 11.5). The model proposes that there is a need to establish interaction among SLTs, teachers, and special educators. The government organizations and the non-government organizations should establish networks at the national level because the obligation to deliver services to bilingual-biliterate children cut across several disciplines.

In order to achieve this goal, bilingual countries need to generate human resources at an affordable cost by adopting the cost-effective phase-model (Fig. 11.6). This is self-explanatory in meeting the large requirement for human resources in serving bilingual-biliterate children.

(a) Recognize different themes (unique) from those that apply to monolingual-monoliterate groups.
(b) Develop conceptual clarification of their language and literacy processing.
(c) Develop language-specific and language-free tests and resources as applicable to various linguistic and literacy parameters.
(d) Empower caregivers and volunteers or village and district level community field workers to have a sustainable model for SLT services.
(e) Encourage and accept immersion in languages from early childhood to enhance cognitive potential.
(f) Establish a network of parents and caregivers, teachers, aides, and volunteer helpers who are fluent in the child's native language. Empower them to assist in testing the child's native language under the supervision of a tester.
(g) Have knowledge of the similarities and differences between the languages and the nature of the writing systems to facilitate the transfer of skills during language and literacy acquisition.
(h) Empower in-service early childhood educators and school teachers with additional skills through specially designed short-term courses to sensitize about specific skills of bilingual-biliterate children through correspondence mode (conventional distance education and learning) or virtual classrooms with the help of technology.
(i) Advocate with policymakers for bilingual children to restructure the system of literacy development in schools.

The following list of 'to do' activities envisioned for SLTs strengthens the roadmap of service to bilingual-biliterate children.

Cross-cultural and cross-linguistic research should be conducted to understand the skills of bilingual-biliterate children. This could be treated as a priority as well as a potential area of study under language, literacy, and cognitive science initiatives.

In view of the roles and responsibilities of SLTs in early intervention, as described by the American Speech–Language-Hearing Association (2008), it is imperative that SLTs accept the onus and implement the above suggestions to realize the dream of 'communication for all' and 'literacy for all'.

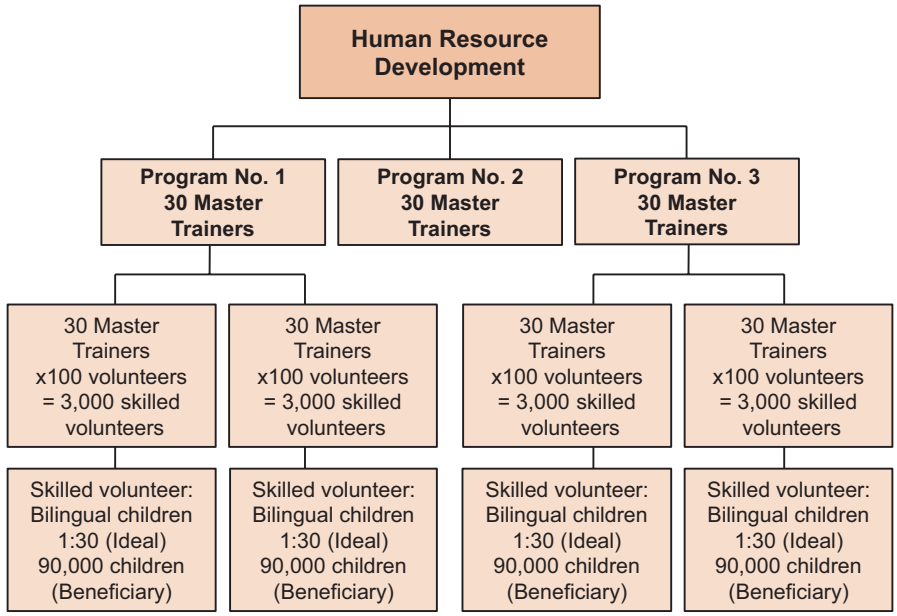

Fig. 11.6 Phase-Model for Human Resource Development in Bilingual Countries

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12

Typical Phonological Development in Ugandan Language: A Case of Rukiga – A Pilot Study

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Introduction

Uganda is a diverse country linguistically with 41 living languages, Rukiga included (Lewis, 2009). Rukiga is relatively under-researched, and there have been no previous studies on speech development in Rukiga. Speech–language therapy (SLT) is a new profession in Uganda whose pioneers qualified in 2010 and no study has been conducted on the speech development either of Rukiga or other Ugandan languages. Speech–language therapists (SLTs) working in Uganda face a major challenge in diagnosing speech difficulties in children given the lack of normative data upon which to base such clinical judgments. According to Miccio and Scarpino (2011), an effective phonological assessment requires knowledge of typical phonological development. Therefore, a study on Rukiga would not only contribute to an understanding of typical speech development in Rukiga-speaking children but also to that of the sister languages in Uganda, including Runyankole, Runyoro, Rutooro and the other related languages of Nyambo, Zinza, Haya, and Kerewe in Tanzania (Lewis, 2009). This preliminary study establishing speech developmental norms would also contribute greatly to professionals working in Uganda.

Theoretical Background

Rukiga Language

Rukiga /ruʧiga/, also referred to as Chiga, is one of the interlacustrine Bantu languages classified by the Guthrie classification of Bantu languages as E.14 (Lewis, 2009). Bantu is a tribal group classified as originating in sub-Saharan Africa, whose members speak more than 500 languages, Rukiga inclusive, with related linguistic features (Guthrie 1948 as cited in Lewis, 2009).

Rukiga is spoken in southwestern Uganda in the districts of Kabale, Kanungu, Rukungiri, north Kisoro, Ntungamo, and Kibaale (see Fig. 12.1). It is part of a language group known as Runyakitara, which according to an analysis by Bernsten (1998) is spoken by the largest group of Uganda's population (more than 20%). According to the Uganda Bureau of Statistics (2014), Uganda has a population of 34.9 million people. Runyakitara consists of four languages, namely: Rukiga, Runyankole, Runyoro, and Rutooro, which are mutually intelligible (Lagefoged et al. 1972 as cited in Bernsten, 1998). The four languages have a lexical similarity between 68% and 94% such that Runyankole–Rukiga use the same standard of orthography and so do Runyoro–Rutoro. Rukiga has four dialects, as indicated by Lewis (2009): Ruhimba, Runyaifwe-Hororo, Runyangyezi, and Rusigi.

Phonology of Rukiga

Consonant System

Twenty-one consonant phonemes have been identified for this study from an inventory of Runyakitara phonemes listed by Ndoleriire and Oriikiriza (1996): /p, b, m, f, v, t, d, n, r, s, z, ʒ, ʃ, ʧ, ʤ, k, g, ŋg, j, w, h/. The phoneme /ŋg/ was added for purposes of assessing velar-nasal sound acquisition considering that Rukiga does not contain the phoneme /ŋ/. However, Rukiga also contains sound combinations such as /n/: nt, nd, ns, nz, nʒ, nʧ; /m/: mb, mp; /ŋ/: ŋk, ŋg; /w/: bw, tw, nw, ʃw, kw, gw, mbw, ntw, nʃw, ŋkw, ŋgw; and /j/: sj, zy, tj, dj, which are treated as individual sounds since they function as single phonemes and when combined with other phonemes they form words.

Vowel System

Conventionally, Rukiga has been treated as having a five-vowel system, where each short vowel is paired with a long vowel of similar quality (Ndoleriire & Oriikiriza, 1996). The vowels are /a, e, i, o, u/ and have qualities close to the cardinal vowels. The distinctive feature of vowel length leads to change in the meaning of a word (e.g., *okutuma* [to send] versus *okutuuma* [to heap up]). However, this distinction raises the question of whether or not short versus long vowels should be treated as separate phonemes such that instead of five vowels the vowel inventory would comprise ten vowels. Rukiga also has three diphthongs /ai, ei, oi/. In Rukiga orthography, the long vowels are indicated as double letters and short vowels as single letters. In this discussion, short vowels will

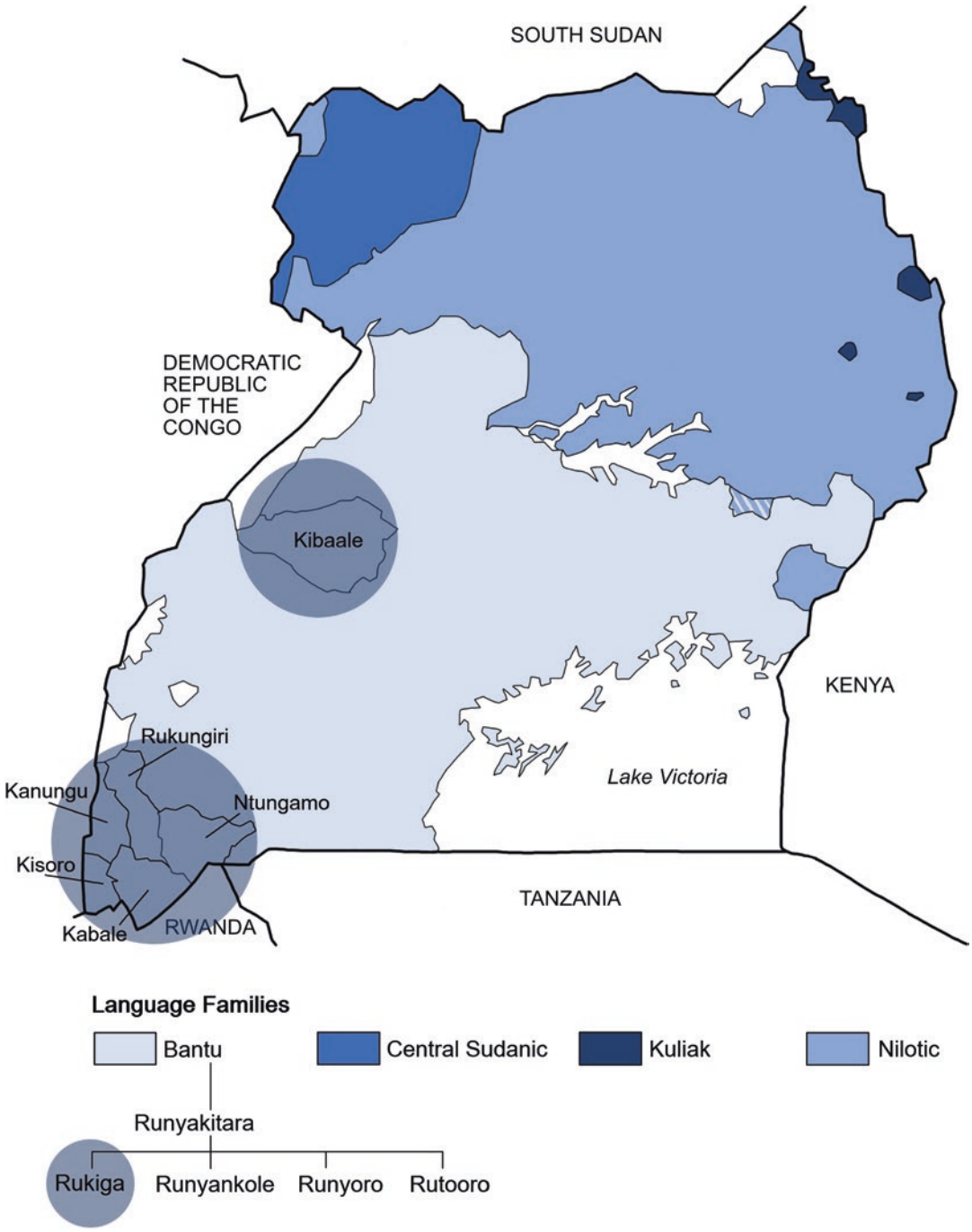

Fig. 12.1 Map showing language families and the distribution of Rukiga language in Uganda. (Based on Bernsten, 1998; Eberhard et al., 2020; Lewis, 2009)

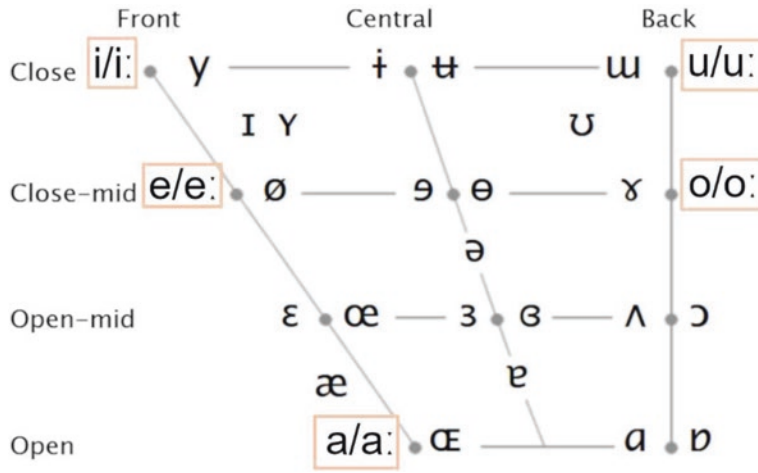

Fig. 12.2 Rukiga vowel chart. (Adopted from Ndoleriire & Oriikiriza, 1996)

be indicated by a single letter (e.g., /a/) and long vowels will be indicated using the International Phonetic Alphabet (IPA) symbol /ː/ (e.g., /aː/) (Fig. 12.2).

Syllable Structure

Rukiga has polysyllabic words that can take on the syllable shape of VCVCV (*vowel–consonant–vowel–consonant–vowel*) or CVCVCV (*consonant–vowel–consonant–vowel–consonant–vowel*). All words in Rukiga end in a vowel; thus, no consonants exist in word-final position. A syllable can consist of a single vowel and most Rukiga words have a vowel in word-initial position. A cluster of two or three consonants with a vowel is also considered as a syllable, e.g., *ente* (cow) = {e*(V)*nte*(CCV)*}; omwana (child) = {o*(V)*mwa*(CCV)*na*(CV)*}; *embwa* (dog) = {e*(V)*mbwa*(CCCV)*}; and *engwe* (leopard) = {e*(V)*ngwe*(CCCV)*}. The shortest word has two syllables and longer words have six or more syllables. There are no monosyllabic words in Rukiga.

Tones

Rukiga makes use of lexical tones but the tonal system appears to be in a state of change, with young speakers using a different system from that of old speakers (Ndoleriire & Oriikiriza, 1996). The current phonological study will focus on sound segments and not on tones.

Speech Development Including Phonological Development

General Overview

In the process of speech development, children learn to recognize and use the distinctive features of the speech sound segments in their native language. In addition, they learn how to combine the speech segments into well-formed linguistic units to convey meaning. A review of the literature indicates that speech development follows a gradual progression (Stackhouse & Wells, 1997; Stoel-Gammon & Vogel Sosa, 2007). Stoel-Gammon and Vogel Sosa (2007) indicate that from birth, children are using non-speech-like expressions such as cries, coughs, wheezes, burps, and at around 2–3 months, speech-like sounds emerge which are vowel-like vocalizations. At around 6–7 months, children start to use non-meaningful consonant-vowel (CV) productions that resemble adult-like syllables. Stackhouse and Wells (1997) note that by 9 months, children's babble includes a greater range of CV sequences that have characteristics of their native language. At around 12 months, they start to say their first meaningful words, and this is followed by a period of rapid expansion in vocabulary, sound repertoire, and syllable shapes. Stoel-Gammon and Vogel Sosa (2007) indicate that at around 18 months, they start to use two-word utterances and multi-word utter-

ances emerge at around 24 months. Syllable structures also develop from simple or shorter syllabic structures to longer or more complex syllabic structures. Development continues in later years until they have acquired all distinctive speech segments of their native language in an adult-like manner (Stoel-Gammon & Vogel Sosa, 2007). Studies on vowel development indicate that most vowel quality development takes place before 3 years of age (Donegan, 2013).

English has been the most researched language in speech development (including several cross-sectional studies on English-speaking children) (see Table 12.1). Relatively fewer studies have been done on other languages of the world. Such studies include those on Arabic, Cantonese, Dutch, Filipino, Finnish, French, German, Greek, Hebrew, Hungarian, Israel, Japanese, Korean, Maltese, Norwegian, Portuguese, Putonghua, Sesotho, Spanish, Thai, Turkish, Vietnamese, and Welsh (McLeod, 2007).

Regarding English, differences in the age of acquisition of sounds have been reported by different authors. For example, Prather et al. (1975) found an earlier age of acquisition compared to other studies. However, similarities are also noted: For example, children acquire /m, n, p, b, w/ earlier than other sounds while /θ, ð, z, ʒ, ʤ/ are among the last sounds to be acquired.

Several studies have described phonological processes in English-speaking children (e.g., Dodd et al., 2003) and relatively fewer in other languages. As cited in Hua and Dodd (2006), such studies include those focusing on Arabic (Ammar & Morsi, 2006), Maltese (Grech, 2006), Putonghua (Hua, 2006), and German (Fox, 2006). Although some patterns are similar across the languages of the world, some are different. For example, the sound /r/ has different replacement patterns in the languages analyzed by Hua and Dodd (2006): in English, /r/→[w/ʊ], in Putonghua /r/→[j], in Turkish /r/→[j/vowel], in Maltese and Arabic, /r/→[l], and in Welsh, /r/→[ð/ɪ]. Phonological patterns in English typical speech acquisition include gliding, de-affrication, cluster reduction, fronting, weak syllable deletion, and stopping (Dodd et al., 2003).

The literature regarding the acquisition of phonological structures in languages whose majority words are multisyllabic, such as Finnish and French, suggests that children attempt to use multisyllabic words as early as in their first 50 words

Table 12.1 Overview of studies on phoneme acquisition in English

Author	Sample size	Age range	Word position[a]	% of age group[b]	Speech[c]	Sounds acquired first (age)	Sounds acquired last (age)
Wellman et al. (1931)	204	2;0–6;0	I, M, F	75%	S and I	m, n, b, f, w, h (3;0)	ŋ, θ, ð, ʒ, ʤ (6;0)
Poole (1934)	65	2;6–8;6	I, M, F	100%	S and I	m, p, b, w, h (3;6)	θ, s, z, ɹ (7;6)
Templin (1957)	480	3;0–8;0	I, M, F	75%	S	m, n, ŋ, p, f, w, b, h (3;0)	ð, z, ʒ, ʤ (6;0)
Olmsted (1971)	100	1;3–4;6	I, M, F	50%	S	p, b, n, k, g, z, f (3;0)	ŋ, ð, ʒ, ʧ, ʤ (>4;0)
Prather et al. (1975)	147	2;0–4;0	I, F	75%	S	m, n, ŋ, p, h (2;0)	v, θ, z, ʤ (>4;0)
Arlt and Goodban (1976)	240	3;0–6;0	I, M, F	75%	I	p, b, t, d, k, g, m, n, f, v (3;0)	z, θ, ð, ɹ (>6;0)
Smit et al. (1990)	997	3;0–9;0	I, F	75%	S	m, n, p, b, d, w (3;0)	ŋ, s, z, ɹ (>7;0)
Dodd et al. (2003)	684	3;0–6;11	I, F	90%	S and I	p, b, t, d, k, g, m, n, ŋ, f, v, s, z, h (3;5)	θ, ð, ɹ (>6;0)

[a]I, M, F refer to word-initial, word-medial, and word-final positions
[b]Minimum percentage of an age group required in deciding acquisition of a phoneme
[c]S and I refer to spontaneous production or imitation

(MacLeod et al., 2011; Saaristo-Helin et al., 2011). Phonological patterns reported in Finnish-speaking children include syllable reduction, initial consonant deletion, and vowel harmony (Saaristo-Helin et al., 2011). Finnish has some linguistic features that are similar to Rukiga, such as sharing features of open syllables, longer words, and a phonological contrastive feature of vowel length (every short vowel is paired with a long vowel).

For languages that use vowel length as a contrast feature (with little associated quality difference), such as Japanese and Swedish, other studies indicate that children learn to distinguish short and long vowels by 2 years of age (Donegan, 2013). Thus, it can be predicted that similar patterns may be observed in Rukiga. However, different patterns may also arise due to language-specific variations.

Speech Development (Including Phonology) in Bantu-Speaking Children

No speech development study has been conducted on any of the languages in Uganda, Rukiga included. The studies that have been conducted have focused on syntax and morphology in Runyakitara (Katushemererwe & Hanneforth, 2010a, b).

SLTs working in Uganda tend to compare the phonological development of Ugandan children to norms applicable to English children because there are no normative data for native speakers of the local languages. Yet it is known that different languages differ in terms of segmental and suprasegmental features and developmental patterns. Reilly et al. (2004) argue that SLT practice should be linked to research. Hence, establishing the phonological development norms of Ugandan languages, Rukiga included, will inform evidence-based practice in identifying speech sound disorders.

Although research on other Bantu languages is growing (Pascoe et al., 2018), relatively few studies have investigated phonological development, most of which have been on South African languages, such as Sesotho, Setswana, Xhosa, and Zulu (see Pascoe & Norman, 2011, and Mahura & Pascoe, 2016 for an overview). Only one study has been conducted on one of the East-African languages (Swahili; Gangji et al., 2014).

Swahili

Gangji et al.'s (2014) study on Swahili speech development focused on 24 children acquiring Swahili as a first language between the ages of 3;0 and 5;11 years. In a cross-sectional design, children were divided into six age groups of four children each, with a difference of 6 months between groups. Each child produced 48 target words in a picture-naming task designed to elicit a specific range of consonant and vowel phonemes in Swahili. A phoneme was considered acquired if 75% of children in an age group produced it correctly. Results indicated that vowel acquisition was complete by 3 years. The order of consonant acquisition followed a gradual progression starting with plosives, nasals, laterals, approximants, affricates, fricatives, and finally trills. Most consonants were acquired by 3 years except the fricatives /s, z, h/ which were acquired at 4 years and the trills /θ, r/ at 5;11 years. Phonological patterns found included cluster reduction, weak syllable deletion, lateralization, sound preference substitution, initial consonant deletion, and metathesis. However, the population size was quite small, and determining whether a sound had been acquired was based on only three children (75% of the sample of four children in each age group). This may have resulted in variability in the developmental trends reported: for example, children in the group 4;6–4;11 performed below the youngest group (3;0–3;5) on percentage of consonants correct (PCC) scores. The investigators argued that two children in the age group 4;6–4;11 had inconsistencies that dragged down the group mean.

Zulu

Naidoo et al. (2005) investigated the speech development of 18 Zulu-speaking children between the ages of 3;0 and 6;2 years, divided into three age groups (3;0–4;0, 4;1–5;1, 5;2–6;2). Each child's speech sample of 100 words was elicited from spontaneous conversation. Data were transcribed

and the study utilized the software packages of UBINET and the Phonetic Calculator Program (PCP) in the analysis. A speech sound was considered present in an age group if at least five to six children produced it correctly at least once in their speech. Findings indicated that vowels and most consonants were acquired by 3 years although the speech sound system was not complete by 6;2 years. Nasals, plosives, approximants, and fricatives developed earlier than affricates, clicks, and prenasalized consonants. In addition, shorter syllable structures developed earlier than longer syllable structures. For example, children in the age group 5;2–6;2 years were the only ones who could manage to produce six to seven-syllable words.

Xhosa

Several studies have been carried out to investigate isiXhosa speech development (Pascoe & Smouse, 2012). A longitudinal study by Tuomi et al. (2001) investigated speech development in ten Xhosa-speaking children between the ages of 1;0–3;0 years. Children's spontaneous productions were recorded and analyzed. A phoneme was considered fully emerged if 75% of children in the age group produced it correctly at a criterion frequency of 66.6%. Results indicated that all vowels were acquired by the age of 1;6 and most consonants by 3 years. Nasals, stops, and the glide /j/ were among the earliest to be acquired whereas fricatives and liquids were acquired last. It is also noted that the sibilant fricatives /s, z/ were acquired from the ages of 1;6–2;0. However, some findings from this study contradicted those from an earlier study by Mowrer and Burger (1991) in which the fricatives /s, z/ were acquired from the ages of 3;0–3;5. The investigators in this study argued that the difference in findings could have resulted from the different criterion measurements used in the two studies.

This earlier study on Xhosa, by Mowrer and Burger (1991), investigated the phonological development of 70 Xhosa-speaking children from the ages of 2;6–6;0 years, divided into seven groups of ten children each. The aim of this study was to compare the Xhosa phonological development with that of English-speaking children. Further, they matched the Xhosa-speaking children with 70 English-speaking children. A picture-naming test was used to elicit 41 target words. Mastery of a sound was considered complete if 80% of the children produced the sound correctly in word-medial position. Results indicated that 80% of the phonemes were acquired by 3 years in Xhosa-speaking children while only 48% of phonemes were acquired by 3 years in English-speaking children. Plosives, nasals, and clicks were the earliest to develop in Xhosa. Sounds acquired late in English were also found to be the last ones to be acquired in Xhosa-speaking children, namely /s, z, ʃ, r, tʃ/. The investigators also compared 20 consonants in the two languages that were similar. Results indicated that on sounds that Xhosa shares with English, English-speaking children made twice the number of errors that the Xhosa-speaking children made.

Sesotho

Finally, an analysis of Sesotho speech acquisition (Demuth 1992 as cited in Demuth, 2007) indicates that most consonants are acquired by the age of 2;6 years and attributes the early acquisition to the simple syllable structure of the language. Nasals and plosives are acquired earliest while the trill, lateral affricates, and clicks are the last sounds to be acquired. However, the findings on the development of clicks in Sesotho contrast with those in Xhosa, where clicks are among the earliest sounds to be acquired (Mowrer & Burger, 1991). This is attributed to the higher frequency of clicks in Xhosa than in Sesotho (Gxilishe 2004 as cited in Demuth, 2007).

Summary

Comparing these studies, it is clear that there are some similarities in the speech sound acquisition reported in Bantu languages; for example, vowels are acquired before the age of 3 years and children have acquired most consonants by this age, including nasals and plosives. However, discrepancies are also noted; for example, Swahili-speaking children acquire affricates earlier than in South African languages. Also, clicks are acquired earlier in Xhosa than in Sesotho. Hence, such a discrepancy in language variation in the age of acquisition of sounds is in contrast with the phonological universals. Although the Bantu-language groups are categorized by origin, they

vary in terms of the phonological system and in the frequency of sound use across different languages: for example, South African languages have clicks, ejectives, and prenasalized consonants, which are not present in Rukiga. Thus, every language needs to be considered independently when studying speech development.

Speech Assessments Including Phonological Development

There are several formal speech sound assessments designed for assessing monolingual English-speaking children (McLeod & Threats, 2008). These include standardized assessments and word lists, which may or may not be standardized. However, the majority of speech assessments are in English or other majority languages and there are few in minority languages (McLeod & Goldstein, 2012).

In terms of each of the Bantu languages, van der Merwe and le Roux (2014) and Van Biljon et al. (2015) note that articulation assessment protocols need to be developed. Writing about sub-Saharan Africa, Alcock et al. (2015, p. 764) note that "the current lack of appropriate tools is associated with a dearth of systematic studies of typical development." There are no formal or published speech assessments in Rukiga and this has challenged SLTs in Uganda working with this group of children. McLeod and Goldstein (2012) highlight the unavailability of assessment tools in a language as a major challenge and urge SLTs to be cautious in using standardized speech assessments outside their original context due to several factors such as cultural and linguistic differences. They further note that the assessment of children in their native language is best practice and recommend creating an assessment tool if none are available.

However, when creating an assessment tool, some guidelines need to be followed (Van Biljon et al., 2015; Van der Merwe & Le Roux, 2014). McLeod (2012) provides some general considerations to note when creating an assessment tool and specific guidelines on how to develop a single-word test of consonants, which the current study utilized in the creation of the assessment tool.

Independent Analysis

An independent analysis allows one to investigate consonants, vowels, syllable shapes, and patterns in a child's speech regardless of accuracy and relationship to the adult target. For phonological acquisition, several criterion measures are used. A frequently used criterion in cross-sectional studies is that proposed by Sander (1972 as cited in Amayreh & Dyson, 1998), categorizing children's speech acquisition into customary, acquired, or mastered levels. Consonants are defined as: (a) *customary* if they are correctly produced in a minimum of two-word positions by at least 50% of children in a given age group; (b) *acquired* if they are correctly produced in all word positions by at least 75% of children in a given age group; and (c) *mastered* if they are correctly produced in all word positions by at least 90% of children in a given age group. However, although independent analysis has its strengths, the current study will adopt more of a relational approach as highlighted below.

Relational Analysis

In contrast to an independent analysis, a relational analysis allows comparison of a child's productions to the adult target when investigating speech development. A phonological process analysis is one commonly used in identifying patterns in children's speech (Miccio & Scarpino, 2011).

Other commonly used quantitative metrics in assessing children's phonological performance are the percentage of consonants correct (PCC) and percentage of vowels correct (PVC) (Pascoe et al., 2018; Shriberg et al., 1997). PCC is scored based on the number of consonants correct against the total number of consonants in the sample. PVC is scored similarly based on the number of vowels correct against the total number of vowels in the sample. Although these metrics have been useful for demonstrating the accuracy of speech production, they have also

been criticized for lacking standardization measures (for example, they are not adjusted for differences in age or gender).

Research Questions

Taking the problem background and the current state of research into consideration, the study aimed to address the following research questions:

1. At what age do Rukiga-speaking children acquire the different speech sounds of Rukiga phonology?
2. Do Rukiga-speaking children develop speech sounds similarly to children acquiring other languages more commonly reported in the speech development literature or differently?
3. What phonological patterns are identifiable in Rukiga-speaking children's speech?
4. At what age do Rukiga-speaking children exhibit specific developmental phonological patterns?

Methods

Research Design

The study employed a descriptive cross-sectional design to identify patterns in children's speech development. A cross-sectional design enables a picture of children's speech to be captured at one point in time. The study was carried out in a rural nursery school located in Kikenkye, Bukinda subcounty in Kabale district, southwestern Uganda. It is located approximately 420 kilometers from Kampala, the capital city of Uganda.

Participants

The study involved ten typically developing monolingual Rukiga-speaking children between the ages of 2;4 years and 4;1 years. The sample consisted of seven girls and three boys. Children were selected if they met the inclusion criteria and were recruited if their parents consented to their participation in the study (see sections "Selection Criteria" and "Ethical Considerations").

In addition, two adult native Rukiga speakers who were both teachers were recruited to name the pictures used in the analysis to compare children's productions with the adult target.

Selection Criteria

The study included typically developing children who were native Rukiga speakers, aged between 2;0 years and 4;6 years attending the nursery school. The study excluded children who spoke Rukiga as a second language, children suspected of delayed or disordered speech development, and children with a medical diagnosis of a disorder such as autism, hearing impairment, visual impairment, or any kind of disability. One teacher at the school and two research assistants who are native Rukiga speakers were recruited for the purposes of identifying the children and collecting the speech data.

Ethical Considerations

The approval to conduct the study was obtained from the University of Sheffield Ethics Review Panel and the study adhered to the requirements of the panel. Informed consent was obtained from the headteacher of the nursery school, the children's parents, and the adult participants to participate in the study. The headteacher was given an information sheet explaining the purpose and giving information about the study and a consent form to indicate the school's approval to participate in the study. The parents of identified children were invited to school and given an information sheet and a consent form to indicate their children's approval to participate in the study. To ensure informed consent, the information sheet and consent form were written in Rukiga and all explanations were given in Rukiga. The adult participants were given an

information sheet and a consent form to indicate their approval for participation in the study. To ensure confidentiality of the participants, pseudo Rukiga names were used in the report.

Procedure

Stimuli

A picture-naming task was used to elicit the target words. The single-word test was devised by the researcher following guidelines by McLeod (2012). A list of 98 words was generated from Rukiga vocabulary, from which 42 words were selected. These were selected considering whether they would be highly frequent and familiar to children, culturally appropriate for a rural setting, and picturable (McLeod, 2012). The final word list consisted of 42 target words that represented all consonants and vowels of Rukiga and a few clusters, in two-word positions: syllable initial word medial (SIWM) and syllable initial word final (SIWF) (see Table 12.2). The two-word positions were selected because the majority of Rukiga words contain vowels in word-initial and final positions. There was only one target word /wakame/ that contained a consonant in the syllable initial word-initial position (SIWI). The target words varied in length from three syllables to six syllables. The words were nouns that could be represented with a picture. Colored pictures of real objects were used considering they would be easier for

Table 12.2 Word list of Rukiga words used in the assessment

No.	Phoneme	SIWM[a] and SIWI[b]	SIWF[c]
1	/p/	*ball* **omupiira** /omupiːra/	*cup* **ekikopo** /ɛʧikopo/
2	/b/	*basin* **ebafu** /ebafu/	*chair* **entebe** /entebe̤/
3	/m/	*key* **ekishumuruzo** /ɛʧiʃumuruzo/	*sheep* **entaama** /entaːma/
4	/f/	*hoe* **efuka** /efuka/	*basin* **ebafu** /ebafu/
5	/v/	*avocado* **ovakedo** /ovakedo/	*earthworm* **omuhova** /omuhova/
6	/t/	*car* **emotoka** /emotoka/	*tree* **omuti** /omuti/
7	/d/	*window* **edirisa** /edirisa/	*bell* **ekide** /ɛʧide/
8	/n/	*kettle* **ebinika** /ebinika/	*child/baby* **omwana** /omwana/
9	/r/	*pencil* **ekaraamu** /ekaraːmu/	*egg* **eihuri** /ihuri/
10	/s/	*plate* **esohaani** /esohaːni/	*pineapple* **enanaasi** /enanaːsi/
11	/z/	*water spring* **eiziba** /iziḇa/	*table* **emeeza** /emeːza/
12	/ʒ/	*smearing vaseline* **amajuta** /amaʒuta/	*boy* **omwojo** /omwoʒo/
13	/ʃ/	*watch* **eshaaha** /eʃaːha/	*eye* **eriisho** /eriːʃo/
14	/ʧ/	*bottle* **ecupa** /ɛʧupa/	*banana* **ekitookye** /ɛʧitoːʧe/
15	/dʒ/	*spoon* **ekigiiko** /ɛʧidʒiːko/	*door* **orwigi** /ogwidʒi/
16	/k/	*pencil* **ekaraamu** /ekaraːmu/	*hen* **enkoko** /eŋkoko/
17	/g/	*bicycle* **egaari** /egaːri/	*jug* **ejaaga** /edʒaːga/
18	/ŋg/	*shoes* **engaito** /eŋgito/	*pot* **enyungu** /enjuŋgu/
19	/w/	*rabbit* **wakame** /wakame/	*green ibis* **enyawaawa** /enjawaːwa/
20	/j/	*mango* **omuyembe** /omujembe/	*dress* **ekiteteeya** /ɛʧitetːja/
21	/h/	*panga* **omuhoro** /omuhoro/	*bag* **eshaho** /eʃaho/

Words are indicated first by the English name in *italics*, followed by the orthographic Rukiga version in **bold** and the phonemic transcription in slant brackets //

[a]Syllable initial word medial

[b]Syllable initial word initial

[c]Syllable initial word final

children to identify, and these were compiled into a picture booklet. There were two pictures per page each of 15 × 10 cm in size.

Task Administration

The nursery teacher who was familiar with the children and a native Rukiga speaker assessed each child individually in a quiet room. The assessor first established rapport and informed the child of what was required of him/her, before the test was administered. The assessor and the child were seated side by side with a book placed at a table appropriate for the child's height. The research assistant sat at the opposite side of the table in order to be able to clearly capture the child's speech production and video-recorded the speech productions of children and adult participants using a Canon VIXIA HF G10 HD recorder.

The administration procedure was the following:

1. The child was shown the picture and asked to name it. An appropriate prompt was given to elicit the response, whereby the assessor pointed to the picture and asked the child "*Eki'nenki?*" (What is this?).
2. If the child did not produce the correct target word or did not respond, the assessor gave another prompt in which the name of the picture was given and the child was asked to name it again: "*Ekibarakyeta ekikopo, barakyeta' ki?*" (This is a cup, what is it?).
3. Imitation was allowed to increase the data set, especially for the youngest age group of 2;4–3;4 years.

   However, allowing imitation poses theoretical implications, considering that imitation and spontaneous speech use different speech processing mechanisms from a psycholinguistic perspective (Stackhouse & Wells, 1997); for example, unlike spontaneous productions from a picture-naming task, imitation does not require a child to access their own representations of the word.

Data Analysis

The video recordings were transferred to an encrypted memory stick, which was sent to the researcher at the University of Sheffield through the post for analysis. Based on the video recordings, the children's productions were transcribed by the researcher, who is a Rukiga native speaker and an experienced SLT, using phonetic transcription. To ensure validity and reliability, video recordings were listened to several times. The researcher sought a second opinion from a second researcher (an experienced SLT) where there were concerns in transcription. Due to the lack of a second Rukiga speaker at the University of Sheffield where the data were analyzed, inter-rater reliability was not possible.

Analysis of each child's speech took into consideration which sounds existed in the child's repertoire at the given age and the phonological patterns exhibited. A phoneme was considered acquired if 80% of the children (at least four out of five children) in an age group produced the sound correctly in two-word positions: syllable initial word medial (SIWM) and syllable initial word final (SIWF), regardless of whether the response was spontaneous or following a model. To profile phonological development, children were divided into two age groups consisting of five children in each group: the younger age group (2;4–3;4) and the older group (3;7–4;1). To ensure proper data management, data forms adopted from the Phonological Assessment of Child Speech (PACS) were used (Grunwell, 1985). The percentage of consonants correct (PCC) was calculated using the following formula (according to Shriberg 1997 and Pascoe et al., 2018)[1]:

[1]The study also intended to identify the percentage of vowels correct (PVC) but due to a pattern observed in all children regarding vowel production, it rendered PVC calculation challenging. This will be discussed in the next sections.

Table 12.3 PCC scores for the younger age group (2;4–3;4)

Pseudo name	Age (years)	Sex	PCC scores (%)
Byamugisha	3;4	M	88.14
Rukundo	2;11	F	46.61
Natukunda	2;10	F	53.39
Abaasa	2;9	F	46.61
Ariho	2;4	F	83.05

Table 12.4 PCC scores for the older age group (3;7–4;1)

Pseudo name	Age (years)	Sex	PCC scores (%)
Tumuheki	4;1	F	97.46
Abeneitwe	4;0	F	94.92
Kyomuhendo	3;7	F	97.46
Tumwesigye	3;7	M	99.17
Musinguzi	3;7	M	96.61

$$\frac{\#\,C'\text{scorrect}}{\#\,C'\text{stargeted}} \times 100$$

A phoneme was considered acquired if 80% of children (at least four out of five children) in an age group produced the sound correctly in two-word positions, syllable initial word medial (SIWM) or syllable initial word initial (SIWI) and syllable initial word final (SIWF), regardless of whether the response was spontaneous or following a model. The 80% criterion was used for this study as compared to Sander's 1972 (as cited in Amayreh & Dyson, 1998) 75% criterion, which is frequently used in cross-sectional studies because there was an uneven number of children in each age group (five children) which meant that it was not possible to meet the 75% criterion. A phonological pattern was considered present if it affected a class or a set of sounds with features in common (e.g., fricatives, alveolars, approximants, voiced sounds, etc.), rather than a single sound. Superscript letters […]$^{S \text{ or } M}$ are used to indicate spontaneous production (S) or a production following a model (M), respectively (see e.g. Table 12.7). The majority of children in the younger age group required a model for their productions.

Results: Phonological System-Segmental

The results presented are from ten children who participated in the study. The results will be presented for two age groups: the younger group of children (2;4–3;4) and the older group (3;7–4;1). The results in each age group will be presented in three categories: (1) phonological system-segmental, (2) phonological structure, and (3) variation, starting with the younger group and followed by the older group.

Consonant Production

Younger Age Group (2;4–3;4 Years)

Children in this age group had a range of consonant accuracy between 46.61% and 88.14%. Table 12.3 shows the accuracy of consonant production as measured by the PCC.

Older Age Group (3;7–4;1 Years)

Children in this age group had a range of consonant accuracy between 94.92% and 99.17%. Table 12.4 shows the accuracy of consonant production as measured by the PCC.

Phoneme Acquisition

Younger Age Group (2;4–3;4 Years)

In this age group, children had acquired 62% of consonants including nasals, stops, glides, fricatives, and affricates, as indicated in Table 12.5.

One child Byamugisha (3;4 years) had acquired all the consonants except /ŋg/, which is categorized as a cluster in Rukiga.

80% of the children in this age group did not produce a consonant in syllable initial word-initial position.

Older Age Group (3;7–4;1 Years)

In this age group, children had acquired all the consonants of Rukiga phonology, as indicated in Table 12.6.

Table 12.5 Phoneme acquisition for the younger age group (2;4–3;4)

Manner	Nasals	Stops/plosives	Glides	Fricatives	Affricates
Phonemes	/m, n/	/p, b, t, k/	/j, w/	/v, h/	/ʧ/

Table 12.6 Phoneme acquisition for the older age group

Manner	Nasals	Stops/plosives	Glides	Fricatives	Affricates	Liquid
Phonemes	/m, n, ŋg/	/p, b, t, d, k, g/	/j, w/	/f, v, s, z, ʃ, ʒ, h/	/ʧ, dʒ/	/r/

Table 12.7 Patterns and processes for the younger age group (2;4–3;4)

Consonant production		Vowel production
Phonological system-segmental	**Phonological structure**	
Context-sensitive voicing, e.g., /b/; /ebafu/→[epafu]^{M}	Consonant/syllable addition, e.g., /enjuŋgu/→[edʒijindu]^{S}	Vowel deletion, e.g., /efuka/→[fuka]^{S}
Assimilation/reduplication/con-sonant harmony, e.g., /emotoka/→[emotota]^{S}	Initial consonant deletion, e.g., /wakame/→[akame]^{M}	Vowel harmony, e.g., /ekaraːmu/→[ataja:mu]^{S}
Affrication of fricatives, e.g., /z/; /emeːza/→[emeːdʒa]^{M}	Weak syllable deletion, e.g., /eʧikopo/→[kopo]^{M}	Vowel substitution, e.g., /iziβa/→[eduβa]^{M}
Deaffrication, e.g., /ʧ,dʒ/; /eʧidʒːiko/→[eʃiʒiːko]^{S}	Cluster reduction, e.g., /entaːma/→[etaːma]^{M}	Vowel reduction, e.g., /ekaraːmu/→[kəhəːm]
Gliding, e.g., /r/; /ekaraːmu/→[ataja:mu]^{S}		
Backing, e.g., /n/; /omwana/→[oŋaŋa]^{M}		
Stopping, e.g., /z/; /emeːza/→[emeːta]^{M}		
Fronting, e.g., /k/; /efuka/→[efuta]^{S}		
Glottal substitutions, e.g., /n/; /enanaːsi/→[enahaːʧi]^{M}		
Glottal reinforcement, e.g., /eʧiʃumuruzo/→[ʔŋʔŋjudʒo]^{M}		
Lack of alveolar and post-alveolar sound contrast, e.g., /enanaːsi/→[enanaːʃ]^{M}		

Patterns and Processes

Younger Age Group (2;4–3;4 Years)

Table 12.7 shows patterns and processes for both consonant and vowel production for the younger age group children.

Older Age Group (3;7–4;1 Years)

Table 12.8 shows patterns and processes for both consonant and vowel production for the older age group children.

Variation

Younger Age Group (2;4–3;4 Years)

There was inter-speaker variation, where different children varied in the production of the same word. There was also intra-speaker variation, where the same child varied in their production of the same word. However, not all children were variable in their own production.

A model was required in this age group for more than 60% of their productions. The number

Table 12.8 Patterns and processes for the older age group (3;7–4;1)

Consonant production		Vowel production
Phonological system-segmental	**Phonological structure**	
Gliding, e.g., /eʧitete:ja/→[eʧitete:ra]^{S}	Consonant deletion, e.g., /eʧiʃumuruzo/→[eʃ:umuruzo]^{M}	Vowel deletion, e.g., /emotoka/→[em:tka]^{S}
Lack of alveolar and post-alveolar sound contrast, e.g., /amaʒuta/→[amazuta]^{S}	Consonant addition, e.g., /omupi:ra/→[omufpi:ra]^{S}	Vowel reduction, e.g., efuka→[efukə]^{S}
Affrication of fricatives, e.g., /omwoʒo/→[omwodʒo]^{S}	Cluster reduction, e.g., /omwoʒo/→[uwoʒo]^{M}	Vowel substitution, e.g., /eʧito:ʧe/→[eʧito:ʧi]^{S}
Backing, e.g., /n/→/ŋ/; /omwana/→[oŋaŋa]^{M}		

of models reduced with age and the number of words produced was 100% for all age groups.

Older Age Group (3;7–4;1 Years)

There was inter-speaker variation, where different children varied in the production of the same word. There was also intra-speaker variation where the same child varied in their production of the same word. However, variation was not common in this age group.

Discussion and Conclusions

The discussion of findings will focus on three aspects: first, the developmental trajectory of speech; second, the cross-linguistic similarities and differences; and finally, the word structure of Rukiga.

Developmental Trajectory

It was hypothesized that Rukiga-speaking children would develop their phonological skills with age as reported in the literature regarding speech development (Stackhouse & Wells, 1997; Stoel-Gammon & Vogel Sosa, 2007). The data obtained from the children in this study indicate a clear developmental trajectory with increasing age. This is demonstrated by the huge difference of observations in the younger age group (2;4–3;4) compared to the older age group (3;7–4;1). Children in the younger age group had acquired few consonants (52%) while children in the older age group had acquired all consonants of Rukiga phonology. The first consonants to be acquired before 3;4 years were /m, n, p, b, t, v, h, k, ʧ, w, j, h/ and the last sounds to be acquired before 4;1 years were /d, g, ŋg, f, s, z, ʃ, ʒ, dʒ, r/. The fact that nasals, glides, and stops are acquired before fricatives by Rukiga-speaking children is consistent with more recent research (e.g., Dodd et al., 2003 and the "phonological universals" by Jakobson, 1941/1968). However, the affricate /ʧ/ is acquired before fricatives.

The age of acquisition of some phonemes is similar to other languages: for example, some of the sounds acquired early are the same as in English. However, variation is also apparent, which will be discussed in the next section on cross-linguistic issues. For example, the phoneme /ʧ/ is acquired from the ages of 4;0–4;5 years in English-speaking children (Dodd et al., 2003), but it is acquired from the ages of 2;4–3;4 years in Rukiga. This finding is supported by reports of Swahili-speaking children who acquire /ʧ/ by 3;0 years (Gangji et al., 2014). Furthermore, some sounds that English-speaking children acquire early (3;0–3;5), for instance, /d, g, f, s, z/ (Dodd et al., 2003), have been found to be acquired after 3;4 years in Rukiga. Also, /h/ is acquired before 3;4 years in Rukiga as compared to Swahili where it is acquired after 4;0 years and /r/ is acquired by 4;1 years yet is acquired at 5:11 years in Swahili. Most of these variations could be attributed to the frequency of phoneme distribution in Rukiga: for example, /ʧ/ is highly distributed and frequent in most Rukiga words (appearing in most Rukiga words and commonly used words).

Older children had more accurate productions as indicated by the PCC measures ranging from

94.92% to 99.17% compared to the younger children with PCC measures ranging from 46.61% to 88.17%. Children in the younger age group exhibited more variability in their speech production (both intra-speaker and inter-speaker variability) compared to the older group of children. Variability has been reported in young typically developing children (Stoel-Gammon, 2007, for English-speaking children). As cited in Stoel-Gammon (2007), children still exhibited high rates of inter-speaker variability in CVC productions until 30–33 months.

Children in the younger age group also had a significant number of patterns in their speech production, including context-sensitive voicing, reduplication/assimilation, affrication of fricatives, deaffrication, gliding, backing, stopping, fronting, glottal substitutions, lack of alveolar and post-alveolar sound contrast. The younger children also had shorter syllabic structures due to several patterns that affected the word structure, including consonant/vowel/whole syllable deletions and cluster reductions. In contrast, the older children had few error patterns in their speech and these occurred occasionally. The older children were most of the time able to produce longer and appropriate word structures up to the six-syllable word /eʧiʃumuruzo/ as assessed in the study unlike the younger children, where only two (40%) managed to produce the five-syllable word /eʧitete:ja/. However, most of the younger children's productions followed a model. It is uncertain whether similar or different findings could be obtained from spontaneous productions since imitation and spontaneous speech use different speech processing mechanisms (Stackhouse & Wells, 1997).

This finding of a clear developmental trajectory is similar to what has been found in other studies of English (e.g., Dodd et al., 2003, Swahili; Gangji et al., 2014, Zulu, Sesotho, Xhosa, French, Finnish, and other languages of the world).

Cross-Linguistic Similarities and Differences

Some of the patterns found in Rukiga-speaking children are similar to what has been reported in other languages such as English (Dodd et al., 2003) and Putonghua (Hua & Dodd, 2000): for example, assimilation, consonant/syllable deletion, backing, stopping, and gliding. Although there were similarities with the mentioned languages and other Bantu languages such as Swahili (Gangji et al., 2014), cross-linguistic differences in the use of patterns were observed in this study, as will be discussed below (see the summary in Tables 12.9 and 12.10).

Context-Sensitive Voicing

Context-sensitive voicing, a pattern that has been reported in English-speaking children, was also found in Rukiga-speaking children although the pattern found was different from that occurring in English. Whereas in English, a voiceless sound preceding a vowel would become voiced, in Rukiga, voiced sounds preceding vowels become voiceless (e.g., the word *kettle* /ebinika/→[epinika] or *basin* /ebafu/→[epafu]). The pattern in Rukiga is similar to the examples reported in Maltese-speaking children where /b/→[p] (Grech, 2006). This pattern has not been reported in Swahili (Gangji et al., 2014). Hence, this finding suggests that this pattern may be a language-specific one to Rukiga. Alternatively, it could be that it was not found in the Swahili-speaking children because they had resolved it, since the study included children above 3 years unlike the current study which included younger children.

Gliding Pattern

The gliding pattern found in Rukiga was similar to that found in Putonghua (Hua & Dodd, 2000), where the liquid /r/ was replaced with the glide /j/: for example, the word *pencil* /ekara:mu/→[ataja:mu]. However, in Rukiga, the reverse pattern also occurred where /j/ was replaced with /r/ (e.g., the word *dress* /eʧitete:ja/→[eʧitete:ra]). There were no examples of /r/→[w], a pattern which is common in English (Dodd et al., 2003). Furthermore, the pattern in Rukiga is different to that found in Swahili (Gangji et al., 2014), whereby /r/ was lateralized to /l/. The reason for the difference is attributed to the fact that Rukiga has only one liquid /r/. Hence, this is a clear indication that although the two languages are linked by a common

Table 12.9 Summary of the cross-linguistic comparisons in phonological patterns

Phonological pattern	Similarities	Differences
Context-sensitive voicing	Similar to findings in Maltese-speaking children /b/→[p] (Grech, 2006).	In Rukiga, voiced sounds preceding vowels become voiceless. In contrast to English where a voiceless sound preceding a vowel would become voiced.
Gliding	Similar to findings in Putonghua /r/→[j] (Hua & Dodd, 2000).	In Rukiga, the reverse also occurred /j/→[r]. No examples of /r/→[w] as common in English (Dodd et al., 2003). Different to Swahili (Gangji et al., 2014) where /r/→[l].
Backing and fronting	Similar to findings in Putonghua where the alveolar sounds are replaced by post-alveolar sounds, e.g., /s, z/→[ʃ] (Hua & Dodd, 2000). Similar findings reported in Swahili; backing of alveolar fricatives to post-alveolar /s, z/→[ʃ, ʒ] (Gangji et al., 2014)	In Rukiga, the reverse also occurred where post-alveolar sounds were realized as alveolar sounds, e.g., /ʒ/→[z]. Also backing of nasal /n/ to velar-nasal [ŋ] No findings of backing of alveolar stops /t, d/→/k, g/ as in English-speaking children. In Rukiga, fronting was not common, only observed in one child; fronting of /k/→[t] and /g/→[d].
Initial consonant deletion	It was a common pattern. This is similar to what has been reported in Swahili (Gangji et al., 2014), Finnish (Saaristo-Helin et al., 2011), and in Maltese (Grech, 2006) as a common process.	In Rukiga, initial consonant deletion was common, in contrast to English where it is not a common pattern (Grunwell, 1987).
Vowel and syllable deletion	In Rukiga, weak syllable deletion was common. This is similar to what has been reported in most languages, as a common process, e.g., English, Maltese, Putonghua, Swahili.	Vowels in SIWI positions were deleted; this has not been reported in other languages.
Assimilation/ reduplication	In Rukiga, the pattern was common in the younger age group (2;4–3;4 years). Similar to what has been reported in English-speaking children.	In Rukiga, there is a delay in resolving the pattern as compared to English-speaking children who resolve the process at approximately 2;0–2;6 years (Grunwell, 1987).
Affrication and deaffrication	Affrication was a common pattern in Rukiga, also reported in English-speaking children. Deaffrication was also a common pattern. Similar patterns have been reported in English /ʧ/→[ʃ].	In Rukiga, it affects fricatives /s, z, ʃ, ʒ/ In contrast to English where it affects stops (Dodd et al., 2003). Other examples of deaffrication found in Rukiga, /ʧ/→[t, tj]. In contrast to English where /dʒ/→ /dz./, in Rukiga, it is realized as [ʒ].
Cluster reduction	A common pattern, as reported in English. Similar findings to what has been reported in Swahili; a cluster of a nasal + an approximant→nasal, e.g., /mw/→[m] Early acquisition of homorganic clusters, similar to what has been reported in Finnish.	In clusters that had a stop and a nasal sound /nt, gw, ŋk, mb/, children retained a stop, e.g., /ŋk/→[k].
Vowel development	Children could maintain a distinction between the target short vowels and target long vowels. This is similar to reports from other languages that use vowel length as a contrastive feature. e.g., Japanese, Swedish (Donegan, 2013). Patterns included vowel reduction, vowel harmony, and vowel deletion. Similar patterns have been reported in Finnish (Saaristo-Helin et al., 2011).	Rukiga-speaking children have not developed the adult vowel quality by the age of 3 years (vowels were produced with a more centralized quality). In contrast to reports from English and other Bantu languages that most vowel development is complete by the age of 3 years.

Table 12.10 Summary of cross-linguistic comparison in word structure patterns

Word structure	
Similarities	Differences
• Younger children (2;4–3;4 years) used shorter syllabic structures. This is similar to what has been reported in Zulu-speaking children (Naidoo et al., 2005). • Rukiga-speaking children exhibited a variety of patterns, e.g., deleting whole syllables, or individual consonants or vowels. • Saaristo-Helin (2009) as cited in Saaristo-Helin et al. (2011) reports similar findings of children truncating polysyllabic words in Finnish. • The younger children also used compensatory lengthening of consonants to realize the vowel in the syllable: for example, /ebafu/→[ebaf:]^{S}. This is similar to what has been reported in Finnish-speaking children (Saaristo-Helin et al., 2011).	• Rukiga is very different to lots of western European languages. • It contains a high number of polysyllabic words. Shortest words have two syllables and are very rare. • Structure for words that have no clusters contains a variety of CV syllable shapes that pose different challenges to those reported in other common languages. • Children use glottalization as a reinforcement for the sounds at the beginning of very long words, e.g., /eʧiʃumuruzo/→[ʔŋʔŋjudʒo]^{M}.

origin (Bantu), they are different languages that need to be addressed independently in studies of speech development.

The Backing and Fronting Pattern

The backing pattern found in Rukiga was also similar to that reported in Putonghua (Hua & Dodd, 2000) where the alveolar sounds are replaced by post-alveolar sounds (e.g., /s, z/ were realized as [ʃ], as in the word *pineapple* /enanaːsi/→[enanaːʃ]). However, in Rukiga, the reverse pattern also occurred where post-alveolar sounds were realized as alveolar sounds (e.g., the word *boy* /omwoʒo/→[mozo]). There was also backing of the alveolar nasal /n/ to velar-nasal [ŋ] (e.g., the word *baby* /omwana/→[oŋaŋa]). Unlike in English-speaking children, where the alveolar stops /t, d/ would also be backed to /k, g/, this was not observed in Rukiga-speaking children. Instead, what was observed was fronting of /k/→[t] and /g/→[d] and this was observed in only one child (Rukundo, 2;11) in the younger age group.

Fronting of velar sounds to alveolar was also found in a small number of children in Putonghua. Hence, fronting is not a common process in Rukiga unlike the reports for English. Backing of alveolar fricatives to post-alveolar position has been reported in Swahili using the term "palatalization" where /s, z/→[ʃ, ʒ] (Gangji et al., 2014). It, therefore, seems a common process in Bantu languages. Fronting is not reported in Swahili, suggesting it may not be a common process in Bantu languages.

Initial Consonant Deletion

As reported in the English literature, initial consonant deletion is not a common pattern in English-speaking children (Grunwell, 1987); in contrast, it was found to be common in the younger age group of Rukiga-speaking children. This could be attributed to the fact that most words in Rukiga have vowels in SIWI word position. Words with a consonant in SIWI position are not frequent words that children would use, such as names of places and some people's names. Hence, it is not surprising that only one word /wakame/ (*rabbit*) appeared on the test with a consonant in SIWI position and was realized without a consonant by 60% of children in the younger age group (e.g., [atame]). Initial consonant deletion has also been reported in Swahili (Gangji et al., 2014), Finnish (Saaristo-Helin et al., 2011), and in Maltese (Grech, 2006) as a common process.

Vowel and Syllable Deletion

Similar to the above finding, vowels in SIWI positions were also deleted, and this was common in the younger age group (e.g., the word *hoe* /efuka/→[fuka]). This pattern has not been

reported in other languages, possibly because most languages have a consonant in SIWI position; hence, this is a language-specific variation.

Weak syllable deletion, a pattern that has been reported in most languages including English, Maltese, Putonghua, and Swahili, was also common in Rukiga-speaking children (e.g., the word *cup* /eʧikopo/→[kopo]). This pattern was only observed in the younger age group, suggesting that it resolves before 3;7 years, earlier than expected in English. In English, this process may occur up to approximately 3;6–4;0 years (Grunwell, 1987).

Assimilation/Reduplication

Assimilation/reduplication was another pattern common in the younger age group of Rukiga-speaking children similar to that reported in English-speaking children (e.g., the word *car* /emotoka/→[emotota]). Since the pattern was not observed in the older age group, it is presumed that it resolved before 3;7 years. However, Rukiga-speaking children seem to delay resolving the pattern compared to English-speaking children who resolve the process at approximately 2;0–2;6 years (Grunwell, 1987); the younger age group in the current study was 2;4–3;4 years.

Affrication of Fricatives

Another common pattern in Rukiga-speaking children was affrication of fricatives. Affrication has been reported in English-speaking children although it affects stops (Dodd et al., 2003), while in Rukiga it affected the fricatives /s, z, ʃ, ʒ/ (e.g., the word *table* /eme:za/→[eme:dʒa]). Deaffrication was also common in Rukiga-speaking children and similar patterns have been reported in English /ʧ/→[ʃ] (e.g., the word *bottle* /eʧupa/→[eʃupa] and in other cases, the affricate /ʧ/→[t, tj]). However, unlike English-speaking children who realized /dʒ/→/dz./, in Rukiga, children realized it as [ʒ]. Hence, such findings suggest cross-linguistic variation.

Cluster Reduction

Cluster reduction, commonly reported in English, was also apparent in Rukiga and the patterns observed are language specific due to the Rukiga-specific clusters. However, for clusters that are common with Swahili as reported in a recent study by Gangji et al. (2014), when a cluster has a nasal and an approximant (e.g., /mw/), a nasal /m/ remains. In the other clusters examined which had a stop and a nasal sound /nt, gw, ŋk, mb/, children retained the stop (e.g., the word *hen* /eŋkoko/→[koko]). An important finding in the current study is that out of the seven clusters examined, all children in the older age group realized six (86%) correctly except /mw/. Early acquisition of homorganic clusters (clusters in which the place of articulation of both consonants is the same such as /nt, ŋk, ŋg/) has been reported in Finnish.

Vowel Development

Finally, despite reports in the literature from many languages such as English and other Bantu languages that most vowel development is complete by the age of 3 years, Rukiga-speaking children have not developed the adult vowel quality by 4;1 years of age. In the current study, it was found that all children produced vowels with a more centralized quality (e.g., the word *ball* /omupi:ra/→[om:pi:rə]). However, all children could maintain a distinction between the target short vowels and target long vowels. This finding is similar to reports from other languages that use vowel length as a contrastive feature such as Swedish and Japanese, where children were found to acquire this distinction by 2 years of age (Donegan, 2013). The majority of vowels affected by the reduction pattern were those in word-medial and final positions, suggesting that children possess appropriate vowels for Rukiga phonology at 2;4 but because there are so many vowels in words, they stand a high chance of being reduced as a compensatory strategy. The vowel–consonant ratio is higher for vowels than consonants in most Rukiga words. For example, in the current study, the test used contained 141 vowels (54.4%) compared to 118 consonants (45%). The other vowel patterns included vowel harmony and deletion, although vowel harmony was only found in the younger age group. Similar patterns in vowel production have been reported in Finnish (Saaristo-Helin et al., 2011).

This suggests that word length is an important factor to consider for such vowel patterns commonly found in languages with long words, as discussed in the section below.

Word Structure

Rukiga is very different to lots of western European languages because of the high number of polysyllabic words that it contains; the shortest words in Rukiga have two syllables, although there are very few words of this length. Examples include *mother* /mama/ and *father* /tata/. Hence, it is not surprising that the shortest words examined in the current study were three syllables long. Rukiga seems to have a simple structure for words that have no clusters. There are a variety of CV syllable shapes but because there are quite a lot in a word, it poses different challenges from what has been reported in many of the most common languages in the speech development literature.

As found in the current study, children in the younger age group could produce mostly three- to four-syllable words and only two children (40%) produced the five-syllable word. Children in the older age group could produce up to six syllables: for example, the word *key* /eʧiʃumuruzo/ with a structure VCVCVCVCVCV. This finding of younger children using shorter syllabic structures is supported by findings from Zulu-speaking children (Naidoo et al., 2005).

However, in contrast to what was found in Zulu-speaking children where the six-syllable VCVCVCVCVCV structure occurred with a frequency of 0.33% in the group of children ranging 3;0–4;0 years, 80% of Rukiga-speaking children in the older age group (3;7–4;1) produced the six-syllable word with the same syllable shapes.

This comparison needs to be treated with caution since the two studies used different methods: the study by Naidoo et al. (2005) elicited speech samples from spontaneous conversation, unlike the current study that used picture naming. Findings from Rukiga-speaking children are supported by reports from Finnish which utilizes polysyllabic words by Saaristo-Helin (2009) as cited in Saaristo-Helin et al. (2011), who noted that children stop truncating long words by the age of 3;0–3;6 years.

To cope with polysyllabic words, Rukiga-speaking children seem to be employing a variety of patterns as discussed in the previous section, such as deleting whole syllables, or individual consonants or vowels. The sounds that were mostly prone to deletion were those occurring in the word-medial position: for example, Rukundo (2;11) realized the word *cup* /eʧikopo/→[epu]^{S}.

The younger children also used compensatory lengthening of consonants to realize the vowel in the syllable (e.g., /ebafu/→[ebaf:]^{S}). Compensatory lengthening has been reported as one of the patterns in Finnish-speaking children (Saaristo-Helin et al., 2011). Also, glottalization was used as a reinforcement for the sounds at the beginning of very long words (e.g., /eʧiʃumuruzo/→[ʔŋʔŋjudʒo]^{M}).

Impact of this Study

The study, being the first one to research children's speech development in Uganda, serves as a basis for future research in studies of speech development and should be repeated with a higher number of participants. Furthermore, results from this study will help SLTs working in Uganda in assessing and diagnosing phonological difficulties of Rukiga-speaking children and children speaking related languages in Uganda such as Runyankole, Runyoro, Rutoro, and the other related languages of Nyambo, Zinza, Haya, and Kerewe in Tanzania.

Considerations for Future Work and Research

Future studies should focus on establishing the typical phonological development of the native speakers of other languages of Uganda and other countries in sub-Saharan Africa considering the cross-linguistic differences between these languages. It will also be paramount to establish standardized phonological assessment tools for SLTs to use for the effective assessment of children with speech difficulties.

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13

The Participatory Potential of Photovoice as a Relational In Vivo Research and Training Method: The Case of a Community-based Prevention Program on Early Communication and Language Disability in Underserved Rural Sub-Saharan Africa

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Introduction: Presenting Photovoice as an In Vivo Research and Training Method

In this chapter, we introduce the use of "photovoice" (Wang & Burris, 1997) as a research and training method in a binational German–Tanzanian project called Preventive Community-Based Work in Early Education and Communication Development in Irente.[1] Photovoice and its possible use in relational in vivo research is the main theme of this chapter, while the project serves as a vivid example of implementing photovoice in participatory research projects in sub-Saharan Africa (SSA).

The intervention in this project focused on community-based capacity building at a grassroots level related to the specific cultural and environmental needs and demands in the rural village communities of Irente in Northeast Tanzania. Head of the Irente Children's Home (ICH), Sr. Enna M. Mdemu, suggested this focus as an option to support children at risk in the Irente region. The overall objective of the project was to prevent communication disabilities in early childhood. It comprised a training course on early childhood and communication development and the joint development and publication of basic information, education, and counseling materials on this topic (Wu et al., 2023) (for an overview of the project combining intervention and research, see Table 13.1). Alongside training, photovoice was introduced as a tool aiming to integrate the community participants' local perspective on child development conditions and to initiate activities at a grassroots level in this field (the strand focused on in this chapter is marked in gray in Table 13.1). According to Wang and Burris (1997), photovoice enables people to present and jointly reflect the strengths and concerns of their community through integrated group discussions that promote critical dialogue, share knowledge about important issues, and facilitate change.

Providing resources on early child care and reducing barriers in early communication and language development to prevent speech, language, and hearing difficulties in children living in rural underserved areas in SSA are generally vital tasks for all health and education professionals working in this context and is a specific mission for speech–language therapists (SLTs) working in this area. The intervention aimed to raise awareness in rural communities in general and to build the capacity of (extended) families to support early communication development from the very beginning. It focused on newborns and other vulnerable children to provide reliable home-based care and support even in critical life situations.

To reach the village communities, the project team (consisting of SLTs and early child development researchers) worked together with the management of ICH and 9 well-respected women from four villages in the Irente region, with five of the women working at the ICH as caregiving staff.

In this process, photovoice was an important component as a relational in vivo research and training method in community-based work aiming to understand the participants' perspectives and to facilitate change in the participants' daily lives at

[1]The project was funded by the Lower Saxony Ministry for Social Affairs, Health, and Equal Opportunities, Germany, and it was based on the longstanding cooperation between the Department of Speech–Language Therapy and Inclusive Education at Leibniz University Hanover, Germany, Sebastian Kolowa Memorial University in Tanzania, and Irente Children's Home, as a regional practice institution of the North Eastern Diocese of the Evangelical Lutheran Church in Tanzania. The head of project management was U. Lüdtke. Since 2012, a concept for training personnel at Irente Children's Home and community members from the surrounding villages has been developed and continuously adapted to local needs and demands (e.g., Frank & Trevarthen, 2015; Polzin et al., 2017; Schütte, 2016).

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Table 13.1 Project Profile

Preventive Community-Based Work in Early Childhood and Communication Development in Irente, Tanzania (June 2017–February 2019)

Aims of the intervention:

- Preparation and conduction of culturally sensitive training on early childhood and communication development
- Research on community perception and needs (this chapter)
- Joint conception and development of information, education, and communication (IEC) materials (Wu et al. 2023)
- Conception and implementation of low-threshold learning and counseling services to raise awareness in the local village communities

Project participants:

- German–Tanzanian project team (two German SLTs, one Tanzanian SLT lecturer and researcher, two Tanzanian early child development lecturers and researchers)
- Management of ICH (two trained and experienced nurses)

Community participants:

- Five trained caregivers at ICH
- Four women from four surrounding villages (12 women after expansion of participants)

Training schedule:

- Four training modules (adapted from Schütte 2016; a fifth training module was added):
  - Child language development
  - Caregiving
  - Musicality and play
  - Basics in first aid
  - (Hearing impairment)
- Two training courses on early child care and speech language development at ICH
  - November 2017–April 2018
  - November 2018–February 2019

Project strand A: Accompanying research (this chapter)	**Project strand B: IEC material development (Wu et al. 2023)**
• Photovoice study (November 2017–August 2018) • Focus of the accompanying research: *"Community listening" (Aslam et al. 2013)* • Research question: What kinds of challenging conditions and situations for newborns and young children in the village community do the participants describe and discuss in the photovoice sessions? *Needs analysis* • Research question: Which activities do the participants suggest, plan, or perform to improve challenging conditions for newborns and young children regarding their development in general and early language and communication development in particular?	Development of IEC materials: • Flyers and posters for each module • Workbooks for the participants Development of further equipment: • First care bags • ID badges

the same time. Besides the training course, we intended to jointly plan and implement activities that were supportive and relevant from the participants' point of view. Participatory involvement plays a key role within this process. Von Unger (2014) describes three prerequisites to fulfill this demand. The first is to involve participants in data collection and analysis, the second is to support processes of self-empowerment and strengthening, and the third is to create practical benefits for the participant's community in addition to gaining knowledge. This chapter asks to what extent did photovoice support the active involvement of the community participants in meeting the objectives of this project. Therefore, we explicate the theoretical background of photovoice (Section "Background of Project Implementation: Situational Context and Methodological Approach") and how to use it in projects that combine intervention and in vivo research (Section "Method: Evaluation of Photovoice Implementation"). We present results on the levels of participatory involvement of the community participants that were enabled through the photovoice process (Section "Results: Identified Participatory Involvement of Community Participants"). To discuss these results, we apply literature-based criteria to evaluate our findings (Section "Discussion: Successes and Limitations of the Participatory Involvement").

Background of Project Implementation: Situational Context and Methodological Approach

In this section, we explicate the background of this project on two distinct levels. As an understanding of the context of a situation—with all its political, traditional, and social dimensions—is a prerequisite for successful project implementation, we first give a short overview of the situation of orphaned and vulnerable children (OVCs) and the efforts to support their development from the beginning.

Afterward, we present the theoretical embeddedness of photovoice as a method to investigate the needs and perspectives of the people who care for OVCs in the communities.

Context of the Project: The Situation of OVCs and Concepts on Facing Their Needs

Over the years, the management of ICH has observed the local need to increase awareness and practical knowledge of the frequently difficult situation of orphaned newborns and other young and vulnerable children after a critical event like the death of the mother. Based on their experience in the district of Lushoto, it is not unusual for newborns or OVCs to remain in inadequate emergency care for weeks because families are overwhelmed and lack the capacity to overcome organizational issues and financial challenges in order to care for them. Eventually, a lack of attentive care is likely. The urgent need to prevent these situations is evident (personal communication with Enna Mdemu, November 2017). Consistent with this description of a local problem, general observations can be made for SSA. For generations, the extended family has offered caregiving support in times of need and crisis (Monasch and Boerma 2004). However, demographic and socioeconomic changes have affected the traditional family system and have "contributed to family circumstances that are characterized by economic fragility, debilitating poverty and weakened family support for household chores and care-giving responsibilities" (Mokomane, 2012, 248).

The training course within the intervention focused on different aspects of early child development and aimed to increase the participants' understanding and competencies in this area in a personal and context-relevant way. The overall aim was to prevent newborns and OVCs from enduring these difficult situations and finding themselves in inadequate living conditions. However, creating and implementing a program meeting these expectations is challenging and presents difficulties.

Up to now, the importance and the extent of socio-cultural differences within early child development concepts and practices have rarely been the focus of research and program development in this field (Cole, 2003; Pence & Nsamenang, 2008; Serpell & Nsamenang, 2015). In addition, research on and programs for early child development are dominated by ideas and values of childhood, and child development from

a Minority World background and perspective (Pence & Hix-Small, 2007). Hence, the dominance of particular research methods in developmental science correlates with a particular type of finding "that privileges certain understandings and perspectives while restricting other, diverse forms of knowledge" (Pence & Nsamenang, 2008, 10).

This consolidates the current dominance of an education model and related (academic) curriculum mainly based on normative values and objectives from Minority World societies and strongly influences the focus of "early intervention as a corrective to the disadvantage suffered by children from low-income families, which in Africa are predominantly located in rural areas or urban slums" (Serpell & Nsamenang, 2015, 232). Serpell and Nsamenang (2015) are critical of the lack of integration of traditional African songs and games in early intervention programs, despite the richness of these resources.

For international project staff, time is often too short to gain a deep and comprehensive content-specific knowledge and understanding of the various local stimulation practices in the field of early child development and early communication and language development, in particular. Only by working in a binational project team and including the perspectives of all participants and local stakeholders from the very beginning can this be partially offset. We agree with Serpell and Nsamenang (2015, 236) that there is "a powerful foothold from which to collaborate with family members in the design, implementation and monitoring of health and educational interventions for young children at risk for developmental disabilities."

Theoretical Approach of Photovoice: A Participatory Method for Relational In Vivo Research

In this section, we outline the method photovoice and its methodological roots. Photovoice as a method uses self-taken photos of participants of a project or study to initiate verbal explanation, narrations, and/or discussions. "Photo elicitation" was first mentioned in the late 1950s by the photographer and researcher John Collier (Collier & Collier, 1986). This research method might count as one of the precursors of the later photovoice method. Collier's findings were followed by other studies that also discovered that photos stimulate narratives and group discussions in a fruitful way as compared to settings based on verbal accounts and discussion only (Harper, 2002). According to Harper (2002, 13), the "potential usefulness [of photo elicitation] is huge and now largely unrecognized." Wang and Burris (1997) and their colleagues (Wang, 1999, 2006; Wang & Pies, 2004) developed the actual photovoice method in the mid-1990s, and "the importance of Wang and Burris's seminal work cannot be overstated, as it is difficult to locate any subsequent piece of writing about Photovoice that does not reference these two scholars" (Catalani & Minkler, 2010; Latz, 2017, 3).

Interventions and research using this method show that it is a flexible tool that can be successfully adapted to diverse cultural contexts, geographical locations, community settings, and groups of participants (Catalani & Minkler, 2010; Latz, 2017). Interventions from Kenya and Canada give a very first impression of the existing variety regarding the number and characteristics of community participants, ranging from eight women to 122 teenagers (Alaca et al., 2017; Bisung et al., 2015; Wilson et al., 2008). In the first systematic literature review of this approach, Catalani and Minkler also found wide disparity in the duration of photovoice projects, ranging from two weeks to several years, with a median duration of three months (Catalani & Minkler, 2010). Besides, the review analyzed the correlation of group size and project duration with the quality of community participation. No relationship was found regarding group size, but "the quality of participation appeared to increase with project duration" (Catalani & Minkler, 2010, 439).

Photovoice can be placed under the methodological umbrella of participatory action research (PAR). PAR is a research approach that originated from different disciplines and philosophical theories investigating social practices. Community-based PAR has an interdisciplinary research tradition that originated in Africa, Asia,

and South, Central, and North America (Torre et al., 2018). Hall (2005, 9) traces the first articulation of participatory research in Tanzania to the early 1970s and describes how this method of social investigation originates in the expanding networks of non-governmental organizations in the 1980s and 1990s: "It was clear to me that many people in the majority world and people working with or for marginalized persons in the rich countries were actively engaged in research projects which were very different from the standards of the day in most of the universities of the world."

This approach does not stipulate strict steps for the research inquiry. It is connected to a reflexive and participative account and attitude toward the research process in which every person is involved and affected by the research (Kemmis & McTaggart, 2005). Kemmis and McTaggart (2005, 563) name the key features of PAR that illustrate this account:

- "*Planning* a change,
- *Acting* and *observing* the process and consequences of the change,
- *Reflecting* on these processes and consequences,
- *Replanning*,
- *Acting* and *observing* again,
- *Reflecting again*, and so on."

Besides the PAR methodology, photovoice can be included in a relational research approach that integrates the role of emotions in the process of co-constructing knowledge (Lüdtke 2012; Frank & Trevarthen, 2015). In this approach, emotional processes play a key role in understanding other people's minds and the social world in general. For the purposes of including emotional processes felt by people in the most natural environment in research, photovoice is a method that uses self-collected images as offering access to others' thoughts, perspectives, and emotions. Photovoice's visual element and the use of iconic meaning especially can elicit emotional responses from and the involvement of participants and research team members, which needs to be reflected and investigated in a systematic way (for further discussion of a relational research approach, see Lüdtke and Polzin 2023).

Among feminism and participatory documentary photography, Latz (2017) sees the "education for critical consciousness" of Paulo Freire (1974) as one of the sources of photovoice as a method. Freire is a Brazilian pedagogue in theory and practice who worked in SSA literacy projects as well (Gerhardt, 2000). In these projects, he tried to design a democratic way of teaching reading and at the same time creating a culture of critical consciousness (Freire, 1974). His approach can be seen as a precursor of photovoice because he uses visual images as a tool for initiating critical thinking (Freire, 1970).

Method: Evaluation of Photovoice Implementation

As we aim to discuss the leading question of this chapter, whether the use of photovoice in this project enhanced the participants' involvement, we present how we implemented photovoice as a method in this section. In the discussion section (Section "Discussion: Successes and Limitations of the Participatory Involvement"), we explicate the criteria based on von Unger (2014), Catalani and Minkler (2010), Wright et al. (2008), and Wright et al. (2018), which we use to evaluate the method and reflect on the power-related aspects of the participatory involvement. For this, we need to outline first the planned phases of the process by referring to other literature about photovoice and the adjustments we made because of the unexpected challenges we faced and what we learned along the way.

Phases of the Photovoice Process

As explained in Section "Theoretical Approach of Photovoice: A Participatory Method for Relational In Vivo Research", variations in structuring the photovoice process are a characteristic feature of the method. Nevertheless, the general procedure and key elements are remarkably similar throughout the literature; differences in application occur more from dividing the phases differently (Latz, 2017; Von Unger, 2014; Wang, 2006). Usually, the photovoice process contains

seven to nine phases which structure the process. Depending on the study and the degree of participation, the beginning and the end of the process may differ (Latz, 2017).

In the following, we describe the phases of the process in line with Wang and Burris (1997) and Wang (1999, 2006) together with the planned context-related adaptations in this intervention (for an overview, see Table 13.2, which shows the adaptations in italics). These typical phases of a photovoice study are not usually carried out in the strict chronological order presented here. Most of the time, and in this project, certain phases repeat and overlap.

Phase 1: "Planning"

The first steps of planning and organizational preparation were done by the Tanzanian and German project members in close consultation with the management of ICH. We planned to get in contact with the leaders of the four villages involved and to introduce the project objectives to them, but it took longer to approach them than expected. Therefore, the first joint meeting took place after the preparation phase (phase 2) had already been conducted.

Phase 2: "Preparation"

The community participants received an introduction to the study's aims, process, and ethical issues. Further, they were trained to use the digital camera provided by the project team (Fig. 13.1). The community participants found that using a camera was new and unfamiliar. Training was repeated over multiple days to ensure their technical and practical preparation.

Taking photos that depict people is always a very sensitive process, especially when children or other vulnerable persons are involved. With this in mind, we obtained informed consent in close cooperation with the data protection department of Leibniz University Hannover. While preparing and discussing the issue in our team and with the community participants, two themes became evident. First, obtaining the village leaders' approval of the process was a necessary requirement. Second, while the community participants understood and fully embraced the ethical implications of photographing other people, they rejected the signature forms as inadequate and not culturally sensitive in this context. To them, obtaining verbal consent seemed more appropriate. Both the approval of the village leaders and verbal consent from those being photographed were obtained in this study.

Phase 3: "Shooting Photos"

For ten days, the participants had time to explore the use of the camera and to take pictures in their village area by focusing on the content of the training and representing their individual perspectives on beneficial and challenging child development and early communication conditions (Fig. 13.2). We decided to do a trial for the "photo presentation" (phase 5) during this phase. This turned out to be a helpful intermediate step. In the trial of the "photo presentation," the participants showed the first pictures they had taken after a few days of shooting. It helped to point out some technical aspects (e.g., image sharpness, light) that needed to be considered and to refine the concept of the possible expressive dimension and the power of a photo. For this session, we used the digital pictures and presented them to the group with a projector.

Phase 4: "Selecting Significant Pictures and Printing"

Afterward, each participant selected up to 20 photos to be printed out with technical assistance from a member of the project team. From the printed photos, the participants chose from one to three photos to present for further discussion (Figs. 13.3 and 13.4). We aimed to complete this phase within a few days, which was challenging because of the infrastructure available for printing photos. The suggested number of up to 20 printed photos for each participant worked well in this setting. Two participants selected more than 20 photos, but the average was 14. When selecting the photos to print, we applied a few exclusion criteria in the process, such as very blurry pictures and series of almost identical images.

Table 13.2 Overview of the Photovoice Process (adaptations in *italics*)

Photovoice process	
Phase 1 "Planning" *(four months)*	Joint planning of project members and management of ICH Organizational preparation in Germany *Approval of the village leader and verbal ethical consent* Necessary documents: ethical clearance
Phase 2 "Preparation" *(one day and ongoing)*	Explain aims and content of the method Introduce informed consent Preparatory instruction in terms of data protection law, ethical aspects, and property situation Distribute cameras and explain and practice the functionality Necessary documents: informed consent, permission forms from people who are photographed
Phase 3 "Shooting photos" (seven to ten days)	Practice using the camera (ongoing) and start taking photos *Practice presenting and discussing photos in a trial* Ongoing (according to demand) Proposal or discussion regarding possible locations and situations in which to take photos Time for questions and discussion (technical and ethical aspects, etc.)
Phase 4 "Selecting significant pictures and printing" (two days)	Jointly select and save up to 20 photos to print out Print photographs with pseudonymization numbers Return photographs (printed) to participants Participants select one to three of the personally most meaningful photographs
Phase 5 "Photo presentation and moderated group discussion" (one to three sessions)	Participants present selected picture(s) and related stories Questions and moderated group discussion on each picture Data collection: Audio recordings (in Kiswahili and with simultaneous translation in English), report from field notes
Phase 6 "Reflection and plan for further action" (one session)	Group work: Discussion of own experiences along with guiding questions Each group: Create a poster with results Each group: Present discussion results Joint discussion and suggestions for further action Data collection: Audio recordings (in Kiswahili and with simultaneous translation in English), report from field notes, posters (in Kiswahili), and translation (in English)
Phase 7 "Follow-up" (evaluation) (four half days)	Tanzanian project team visits each village and reflects with participants from the villages and communities on the outcome of the intervention and discusses benefits, challenges, and possible next steps Tanzanian team and participants discuss feedback from the four villages and evaluate similarities and differences Data collection: Report from field notes and meetings with community participants
Phase 8 "Accompanying research" (four to six months)	Transcription and translation of audio recordings and field notes Data analysis based on qualitative content analysis (Mayring, 2014)
Cycle II: Phases 1–7 New photovoice study (starting September 2019)	Second cycle of photovoice with the first and an additional second group of community participants

Fig. 13.1 Learning How to Take Photos Properly

Fig. 13.2 Photo of a Caregiver and a Newborn taken by a Community Participant during Phase 3

Phase 5: "Photo Presentation and Moderated Group Discussion"

In the next step, within a moderated group session, the participants presented selected photos to the other participants and the project team by telling the group about the connected story and answering and discussing questions from the group (Figs. 13.5 and 13.6). We planned to facili-

Fig. 13.3 Participants Selecting Photos for Presentation

Fig. 13.4 Participants Deciding Which Photos to Discuss

tate the discussion by asking questions according to the SHOWeD guidelines[2] (Wang, 1999), but the SHOWeD technique was not as actively used because the setting and sequence of the questions seemed to restrict rather than facilitate the discussion in our setting.

It turned out that it was more appropriate in terms of time to only present one photo per participant since it was difficult for the group to concentrate and discuss more photos in each session. Repeating this phase with additional photos was a productive and important step in the process. Because the participants became more practiced and confident, their narrations became longer and

[2]The acronym covers the following questions: S—What do you *s*ee? H—What is really *h*appening? O—How this relates to *o*ur lives? W—*W*hy does this concern, situation, or strength exist? E—How can we become *e*mpowered through our new understanding? D—What can we *d*o? (Wang, 1999)

Fig. 13.5 Photo Presentation via Projection

Fig. 13.6 Moderated Group Discussions

more detailed. At some points, several weeks passed between shooting the photo and presenting it. Here, the photos served as a fruitful visual anchor for the participants to recall single situations or experiences.

Phase 6: "Reflection and Plan for Further Action"

The moderated group discussions were followed by another group meeting in which the participants jointly summarized the different activities

they had performed in the villages since the start of the intervention. Together with the project team, the participants reflected on the content of the training and their experience. We jointly developed a plan for action with possible and practicable further activities.

Phase 7: "Follow-Up" (Evaluation)

In this phase, Tanzanian project team members visited the four villages involved for a follow-up with each community participant and their community. In different settings (visits with families, village leaders, and community members), they asked about the intervention and the associated benefits and challenges from the community's point of view. Afterward, the feedback from the village communities was jointly discussed with all participants and considered within the further planning. In this phase, we underestimated the amount of organizational work, time resources, and flexibility required. Sufficient time capacities of all participants are likely to be a compounded problem in participative projects when parts of the project team can only be on-site for short intervals. From the planning phase, this must be taken into account.

Phase 8: "Accompanying Research"

After the discussion and evaluation with the participants, the project team translated, transcribed, and analyzed the audio recordings from phases 5 and 6, which were enhanced by further field notes from the whole photovoice process. The methodological procedure and the results of the analysis will be published separately.

Results: Identified Participatory Involvement of Community Participants

In this section, we present the levels of active involvement of the community participants and outline our observations about the impacts facilitated through the photovoice process by focusing on the time period from data collection to evaluation. As in other studies on participative interventions, the term "impact" is broadly understood in this context (Catalani & Minkler, 2010; Wihofszky et al. 2020).

Regarding the results, we partly distinguish between the two groups of community participants and concentrate on the four women from different surrounding villages. The five community participants who work as caregivers at ICH are more involved in activities in the orphanage than in the villages (for an overview of community participants, see Table 13.1).

All community participants supported the intervention on different levels. First, in the shooting photos and group discussion phase, they gained insight into and shared knowledge with the whole team about the situation, the challenges, and the concerns of many families in the villages.

Example village context: Extract from a translated photo presentation (February 21, 2018)

"Thank you for this opportunity to talk about the child I'm standing with in the photo. He is a child who is beyond the age we have been dealing with in this training. What attracted me was the problem the child has. […] When I asked the family about the condition of the child, they said that after birth, the child had sitting, crawling, standing, and speaking delays. I asked them which measures they had taken. They told me that they didn't take any measures. They were just waiting to see if the child could himself adopt the stages of development like his peers. However, it didn't work; that's why he was the same when I met him. [...] I'm attracted by this lesson that some of our children have disabilities due to lack of knowledge."

Example ICH context: Extract from translated photo presentation (April 12, 2018)

"This is a small baby. […] She is one week old. […] When I was feeding her, she fell asleep; she couldn't swallow the milk properly. Then I stopped giving her some milk and continued with the other children.

When I finished feeding the other children, I went out. When I went out, I heard one crying behind me. When I went back, it was this child in the photo. Then I recalled what we were learning in this training. When I was feeding her, she was still sleepy, and crying was a signal that she was calling me. This means she was ready to eat this time."

Second, starting in the photo presentation and group discussion phase, the participants developed ideas and plans to facilitate supportive actions. Those ranged from vague ideas which needed further conceptual planning and preparation to be put into action to specific plans. In the case of the latter, some plans were carried out during the intervention while others could not yet be realized because they required additional financial, time, or personnel resources and therefore remained on the level of suggested actions. See Table 13.3 for an overview of the suggested and reported activities of the community participants. In addition, the following extract from a photo presentation may provide more detailed insight.

Extract from translated photo presentation (April 12, 2018)

Presenting participant: "As you can see in the picture, here is a ward. It is the maternity ward there in the hospital. I met this mama there and this was the second day after birth. The baby was born through an operation. And this mama has a health problem. […] Later, I was able to visit her home, and I was glad to see them both doing well. […]"

Question from the group: "You said you met her in hospital. Was she alone or were there some people to assist?"

Presenting participant: "Yes, the grandmother was around. But I took the photo of just the mother and baby."

Question from the moderator: "Which challenges do you think the child is going to face considering the situation of the mother?"

Presenting participant: "[…] if you have a very difficult situation, like this one, you cannot be interested in the child. You cannot smile. […]"

Question from the moderator: "Is it common here to find a mother who has delivered a baby when she is sick?"

Presenting participant: "Yes, but whenever it happens, there is usually a caregiver behind who takes care of the baby. In this situation, one can educate the caregiver on how to care for the baby. If you live near, you can visit the family and do a kind of monitoring."

Third, along with the experience and increasing self-confidence they gained in their new role, the participants faced new challenges which they first shared and jointly discussed within their group (phase 6).

During the follow-up (phase 7), challenges were voiced and discussed on a broader level with the participants, community leaders, and some members of the village. The main challenges identified were the long distances for the participants to cover in order to reach some families for consultation, lack of funding to compensate them for transport and work-related costs, unrealistic expectations regarding their medical competence and resources, and, in some villages, the lack of support from the village leaders.

Alongside the challenges, the village communities discussed different options to support the work of the community participants by concentrating on the challenge of providing services to large and partly hard-to-reach areas and the associated time and financial challenges. The suggested way forward included plans for action for the village communities as well as further support from the project (see Table 13.4). After offering this brief insight into the impacts of the project on the village community level, we end this chapter with closing remarks on its achievements, limitations, and necessary changes to extend the participatory involvement of the community participants.

Table 13.3 Suggested and Reported Activities

Suggested activities from all community participants	Reported activities of four participants from the village
Extend the counseling activities to other specific groups: • Men—especially husbands • Grandparents • Youths who are expecting to become parents • Families with children with disabilities Extend the counseling activities to other locations to increase the reception: • Meet mothers directly in hospital • Inform the communities after Sunday services at church	Establish contact and perform initial counseling activities: • Visited 60–70 mothers with newborns and OVCs • Ten interactions related to health problems (advice and basic treatment) • Two cases of counseling and care of pregnant women • Two cases of counseling and supporting grand-mothers who took care of the grandchildren • Distributed clothes from ICH to two newborns and one older child • One participant met with a group of three women on a weekly basis to discuss issues of childcare and support • One participant talked to the community about the project after Sunday service at church
Increase visibility of the project: • Distribute information material	• In the four villages, the participants put up posters at the community halls and at some shops • Guests of honor from the regional church institution involved were invited to hear their learning outputs and their new tasks within the village community
Hold a graduation ceremony at the end of the training with official guests	• The husbands of the community participants were invited to attend this occasion as well

Table 13.4 Follow-up: Challenges and Related Actions

Identified challenge	Related actions of the project team	Related actions of village communities
Large and partly hard-to-reach districts to cover for one community participant.	A second training session for eight additional women from the four villages was organized and conducted within the same year.	To make the workload more manageable, one village community established a network of nearby contact persons who acted as a link between the advice-seeking village members and the trained community participant.
Too little financial compensation for the community participants to cover their transport costs and allowance for the time they cannot work because they are attending to community issues.	The community participants received further allowances to cover transport costs for counseling visits in their area.	Some village communities planned to make financial contributions.

Discussion: Successes and Limitations of the Participatory Involvement

In light of this chapter's research question—to what extent did photovoice support the active involvement of the community participants in this project—we would like to discuss the successes and limitations of their participatory involvement.

The observed and reported plans and activities of the community participants and village communities highly correspond with von Unger's (2014) three prerequisites for participative interventions and research: "participation in data collection and analysis," "support of self-empowerment," and "creation of practical benefits" (as outlined in the introduction). The findings provide a first impression of the beginning of community-based participation in the prevention of early communication and language disabilities at the grassroots level in rural SSA.

According to Catalani and Minkler's (2010) photovoice impact model, we can show results on all mentioned levels. The model consists of three categories: "(a) enhanced community engagement in action and advocacy, (b) improved understanding of community needs and assets […] and (c) increased individual empowerment" (Catalani & Minkler, 2010, 443). Based on a review of photovoice studies, the authors identified these three

typical categories. As applied to this project, the results in Table 13.3 may count as outcomes on the level of individual empowerment (c) and enhanced community engagement (a); the results in Table 13.4 mainly belong to categories (a) and (b).

The participants' process from being increasingly involved to becoming empowered agents resembles the results from Foster-Fishman et al. (2005) and Hannay et al. (2013). Their findings show that participants were "significantly affected by their experience" (Foster-Fishman et al., 2005, 281). This ranged from articulating "local and cultural dimensions […] that led to unexpected new insights" (Hannay et al., 2013, 221) into the feeling of empowerment and the opportunity to bond with other community members to discuss important community issues to "becoming community change agents" (Foster-Fishman et al., 2005, 275).

Nevertheless, there were also some barriers in this project that would need to be overcome in order to extend the participatory involvement of the community participants. Although the project strived to follow a bottom-up rather than a top-down approach (Laverack & Labonte, 2000), during the project design period (including phase 1), only the management of ICH participated in the process. Due to the project's structure and timeframe, which was set by the funding stakeholder, the community participants were not introduced to the project in detail along with the opportunity to actively engage in the process during the planning phase. If some of the community participants had been part of the planning process, some procedures might have been different from the start. For example, we might have chosen different methods in the moderated group discussions in phase 6.

Looking back, we think it would be worthwhile to try different, more creative, and innovative methods. The selected methods of using "group work and creating posters" could be fruitful with a group of university students who are familiar with this kind of academic work, for example. However, for the participants in this project, this method did not fit well. For future projects, this phase could benefit from additional ideas about how to proceed here in a way that is sensitive to the context and oriented to the target group, making it fruitful for all. Ultimately, the design and preparation of the intervention and photovoice process clearly corresponded with a top-down approach regarding the participatory involvement of the community participants. This is still typical of concept development phases in the field of prevention and health promotion (Wright et al., 2018) despite the fact that community empowerment and participation have been considered prerequisites for successful community-based interventions according to the World Health Organization's (WHO) guideline on health promotion for the past 30 years (WHO 1987). Nevertheless, tension exists between the academic discourse on bottom-up programming and the continuing practice of top-down processes within the programs (Ledwith & Springett, 2010; Wright et al., 2018).

A corresponding and important aspect regarding participatory involvement is the question of the distribution of decision-making power. The greater the decision-making power of a person or a group, the greater the degree of participation. This definition relates again to a central demand of the Ottawa Charter to realize the self-determination of citizens as the core tenet of health promotion (Wright et al., 2008). Based on Arnstein's (1969) "ladder of participation," Wright et al. (2008) distinguish several successive steps which lead from preliminary stages of participation to "real" participation.

The "circles of influence" open up a new perspective on participation as a form of shared decision-making power, referring to having power over the decisions related to the project's objectives as well as power relating to financial or time resources (Wright et al., n.d., see Fig. 13.7). Looking at the involvement of the community participants in this project, as presented in Section "Results: Identified Participatory Involvement of Community Participants", it becomes clear that the existing participation mainly reached the degree of involvement and codetermination. More advanced stages of partial decision-making power and decision-making authority are related to elements like the choice of project objectives as well as the distribution of financial or time resources. However, there were also areas in which the community participants in this setting lacked power. To achieve "real" participation in this sense is a

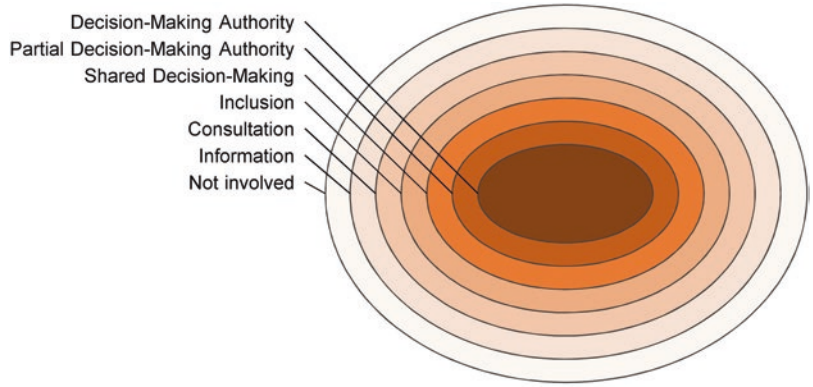

Fig. 13.7 Circles of Influence (translated from Wright et al., n.d.; we gratefully thank M. Wright for permission to reprint)

long way off and includes overcoming various challenges, learning lessons, and reorganizing both structures and processes for the project team and funding agency. Evaluating the potential and possible impact of photovoice interventions on these power-related aspects of participation could be a worthwhile next step, because decision-making power can only be shared when there is clarity about who wields it.

The results and experiences in community-based work using photovoice described in this specific setting can serve as a strong foundation for future projects and preventive interventions and offer a starting point from which to further increase community participation in all stages of a project "to strive for the highest levels of involvement that are feasible or practical" (Catalani & Minkler, 2010, 448). This project shows that photovoice can be effective in supporting culturally appropriate training and community-based counseling networks that can reach underserved rural areas, which is of the utmost importance in the field of speech–language therapy in SSA.

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14

A Network of Knowledge: Participatory Development of Culturally Sensitive Information, Education, and Communication Materials for the Prevention of Communication Disability in Rural Tanzania

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Introduction: Generating Local Knowledge and Resources for the Prevention of Communication and Language Disability

Project Outline

This chapter describes the process of information, education, and communication (IEC) material development in the context of a binational German–Tanzanian project[1] in the field of early communication and language development in the rural areas surrounding Lushoto in northeastern Tanzania between 2017 and 2019. As can be seen in Table 14.1, the project contained two strands, one of which was to develop sustainable, locally appropriate IEC materials to support the participants' counseling activities in the local communities. This included several weeks of training for the participants on selected topics in the area of early childhood and communication development. In order to gain insight into the specific local conditions, a second strand of the project sought to identify the participants' understanding of communication and language development and their reflections on their work within the network of multipliers and needs in the communities (Beta et al., 2023). This was done through a study using photovoice (Wang & Burris, 1997), which is a participative and creative method that can be used to directly reflect the participants' point of view.

This chapter asks which successes, challenges, and indicators for long-term sustainability can be identified in the IEC material development for the prevention of communication disability within a network of multipliers in Irente, Tanzania. This question is answered by (a) defining criteria to evaluate the success of the program, (b) presenting the method used in the material development, (c) discussing the results in light of the previously defined criteria, and (d) discussing the challenges encountered and providing recommendations for necessary further steps on the path to full sustainability.

The Role of Prevention in Underserved Regions

Fifteen years ago, Jochmann (2006) stated that speech–language therapy (SLT) services in East Africa were scarce and only available in very few cities. Although the profession has undergone a development of growth in sub-Saharan Africa (SSA) in recent years and services have improved and spread since then, it is still evident that most—particularly rural—areas in East African countries continue to lack access to SLT services. In this context, it is clear that the prevention of speech, language, and communication disability is enormously important in underserved communities.

From the viewpoint of these communities, capacity building, training, and education of community members are key to prevention. For many years, Sr. Enna M. Mdemu, who is the head of

[1]The project was funded by the Lower Saxony Ministry for Social Affairs, Health, and Equal Opportunities, Germany, and it was based on the long-standing cooperation between the Department of Speech–Language Therapy and Inclusive Education at Leibniz University Hannover in Germany, Sebastian Kolowa Memorial University in Tanzania, and Irente Children's Home, as a regional practice institution of the North Eastern Diocese of the Evangelical Lutheran Church in Tanzania. The head of project management was U. Lüdtke. Since 2012, a concept for training personnel at Irente Children's Home and community members from the surrounding villages has been developed and continuously adapted to local needs and demands (e.g., Frank & Trevarthen, 2015; Polzin et al., 2017; Schütte, 2016).

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Table 14.1 Project profile

Preventive Community-Based Work in Early Childhood and Communication Development in Irente, Tanzania (June 2017–February 2019)

Aims of the intervention:

- Preparation and conduction of culturally sensitive training on early childhood and communication development
- Research on community perception and needs (Beta et al., 2023)
- Joint conception and development of information, education, and communication (IEC) materials (this chapter)
- Conception and implementation of low-threshold learning and counseling services to raise awareness in the local village communities

Project participants:

- German–Tanzanian project team (two German speech–language therapists [SLTs], one Tanzanian SLT lecturer and researcher, two Tanzanian early child development lecturers and researchers)
- Management of Irente Children's Home (ICH; two trained and experienced nurses)

Community participants:

- Five trained caregivers at ICH
- Four women from four surrounding villages (12 women after expansion of participants)

Training schedule:

- Four training modules (adapted from Schütte, 2016; a fifth training module was added):
  - Child language development
  - Caregiving
  - Musicality and play
  - Basics in first aid
  - Hearing impairment
- Two training courses on early child care and speech–language development at ICH:
  - November 2017–April 2018
  - November 2018–February 2019

Project strand A: **Accompanying research** (Beta et al., 2023)	**Project strand B:** **IEC material development (this chapter)**
• Photovoice study (November 2017–August 2018) • Focus of the accompanying research: *"Community listening"* (Aslam et al., 2013) • Research question: What kinds of challenging conditions and situations for newborns and young children in the village community do the participants describe and discuss in the photovoice sessions? *Needs analysis* • Research question: Which activities do the participants suggest, plan, or perform to improve challenging conditions for newborns and young children regarding their development in general and early language and communication development in particular?	Development of IEC materials: • Flyers and posters for each module • Workbooks for the participants Development of further equipment: • First care bags • ID badges

Irente Children's Home (ICH), which is located in a network of rural villages around Lushoto, has promoted the importance of generating local resources for the prevention of communication disability through the training and education of community members and local pedagogic staff. Her experience has indicated that offering education in the villages on early child development could prevent many cases of children being brought to the children's home and thereby being exposed to potential developmental risks.

A highly valuable resource for prevention is the abundance of locally and culturally specific knowledge within the local communities. Therefore, in

this chapter, we seek to discover whether a prevention initiative organized from within a community and targeted specifically at community members can be a sustainable way of making local resources accessible to community members in need.

Background: Participatory Development and the Creation of Information, Education, and Communication Resources

Participatory Development and Sustainability

Creating sustainable outcomes and outputs was one of the main aims and a leading principle of the project. Achieving sustainability through an intervention is based on various factors. An approach that profoundly shaped this project by following an underlying philosophy of actively involving communities in an intervention was that of participatory development. Mohan (2014, p. 133) explained that "in rejecting the statism and top-downism of 'normal' development, the focus for participatory development has become the grassroots level which permits a plurality of developmental goals to be realized as well as giving communities the self-determination they need." The basic principles of participatory development therefore enable interventions to become *community-based* and *culturally specific*. In the context of the present project, two statements can be made in accordance with the principles of participatory development:

- Interventions need to be *community-based* and led by the intrinsic motivation of the participants in order to have a long-term sustainable perspective.
- The developed resources can only be *culturally specific* if they are developed in a culturally specific and appropriate way.

Keough (1998) reflected on his experiences and outlined the lessons learned while working in development cross-culturally, as well as within his own cultural context. He concluded from his reflections that there is no better way of generating knowledge in a community than collecting it directly from its members, and he emphasized that only locally applicable knowledge will be of any sustainable use to the community. The reality on the ground, according to Keough, is true even if it cannot be scientifically validated, as knowledge systems differ culturally and contextually. Since the reality found in the individual context might differ significantly from what was previously expected or theorized, Keough (1998, p. 191) advised maintaining flexibility and accepting that plans might fail or change, and he suggested always maintaining "a sustainability vision."

With regard to the principles of participatory development, Keough (1998, p. 189) suggested using them as a guideline to evaluate if "the promise of participatory development" was met. In this chapter, the principles of participatory development were used to orient the evaluation criteria used to rate the success of the project (see section "Methodological Background of IEC Material Development in the Project").

Information, Education, and Communication Materials in the Context of Communication and Language Development in SSA

IEC materials is a catch-all term used to refer to a variety of resources created to be used in educational or counseling settings, such as printed materials (like posters or brochures) and digital resources (like videos or podcasts). The World Health Organization Regional Office for the Eastern Mediterranean (WHO EMRO, 2014) has further specified that IEC initiatives, which usually aim at promoting certain desired—and mostly health-related—activities or behaviors in a population, should ideally have a clearly defined objective, audience, target topic/problem, and timeline in order to be successful. While there have been numerous successful IEC campaigns in SSA, in healthcare (often concerning the topic of HIV/AIDS), challenges have arisen because many of the provided materials

intended to reach wide swaths of society have often failed to respect the variety and diversity of the targeted populations (Kiiti, 2008; Mbananga & Becker, 2002). In addition, the content provided in these materials is not always relevant for the reality found in the targeted communities, and it is often merely based on knowledge of the Minority World. Moreover, indigenous knowledge and communication channels are often disregarded, potentially lowering the relevance of IEC materials (Kiiti, 2008).

Cherie et al. (2005) assessed the perceived sufficiency and usefulness of IEC materials for youth HIV/AIDS education in Addis Ababa, Ethiopia, and found that only half of the participants (51%) believed that the IEC resources presented through various channels had helped them become sufficiently informed about HIV/AIDS; even fewer (42%) felt that those materials had helped them develop the necessary practical skills to prevent HIV infection. The authors argued that youth (when they are the target group) should be involved in the development of IEC materials in order to include their perspectives and expectations. An example of implementing this approach can be found in the HEART (Helping Each Other Act Responsibly Together) campaign in Zambia at the beginning of the 2000s. HEART took a peer-to-peer-approach to HIV/AIDS education via IEC resources, involving both HIV-positive and HIV-negative youth in their development team, and they found that doing so had positive effects through their evaluation of the IEC consumers' prevention skills (Underwood et al., 2001).

In another project, Leshabari et al. (2006) developed resources for health workers to counsel HIV-positive mothers in safe breastfeeding techniques in Tanzania. The materials were based on international guidelines and counseling materials provided by the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF), which were then adapted according to the results of an investigation among community members regarding infant feeding and HIV. The adapted materials were field tested and reviewed to ensure appropriateness. Meanwhile, Birhanu et al. (2011) investigated the production, distribution, and utilization of printed IEC materials in Ethiopia and found that the majority of materials were not perceived as culturally sensitive and therefore not consumed by most community members. In addition, poor management of the materials was reported. The materials had been produced mainly at the federal level in Ethiopia, which indicates an existing gap between the reality of the producers and the reality of the target group—despite the fact that both producer and recipient shared the same cultural context. All these examples indicate that the individual needs of a target group can best be defined by the group itself. Many similar examples can be found, revealing the great potential for improvement through IEC materials generally.

When considering communication and language development, in particular, the fundamental role of the cultural context becomes evident as communication and language development is a deeply socially and culturally embedded process. While on the one hand language itself and the ability to speak is a key function of cultural participation, and its loss can lead to social exclusion (Lüdtke, 2012), culture, on the other hand, determines specific parameters of communication and defines, for example, how children are encouraged to speak or how children are spoken to (Obiegbu, 2016). In terms of IEC materials and child (language) development, resources such as training manuals and counseling guidelines are available in the packages provided by the WHO and UNICEF (WHO, 2012, 2015), for example, which could be a starting point for programs. However, in order for materials (especially on communication and language development) to be suitable for a certain cultural context, their adaptation to such is unavoidable.

Methodology: Project Background and Evaluation Criteria

The following section will first describe the methodological background of the IEC material development within the project. Then, the methodological outline for the evaluation of this process in this chapter will be presented.

Methodological Background of IEC Material Development in the Project

Participatory Feedback Loops

The development of IEC materials took place in consecutive phases, each of which included multiple "culturally sensitive feedback loops" (Schütte, 2016) within the project team and participants to ensure the appropriateness of the content. The procedure of working in feedback loops was developed based on the practice of action and reflection cycles in participatory action research (PAR). Bradbury (2015, p. 1) described action research as "a democratic and participative orientation to knowledge creation" and "a pragmatic co-creation of knowing *with*, not on *about*, people." Instead of following a linear research process of hypothesizing–collecting data–analyzing–concluding, PAR is conducted in cyclical processes of acting–observing–reflecting–planning before moving on to new actions and repeating the cycle (Wadsworth, 1998, 2015). This reflective procedure enables the researcher to continuously (re)evaluate the process and, where necessary, (re)adapt to the given circumstances.

For the process of training and material development, distinctive phases with smaller steps were designed to accommodate working in cyclic feedback loops. On a broader level, each of the four phases (see Fig. 14.1) can be defined as one cycle; on a deeper level, the four phases contain multiple feedback loops within the consecutive steps. Each of the phases and steps will be further described in section "Results: IEC Materials from and for the Local Communities".

Project Team and Participants

The network of multipliers that formed the project group initially consisted of 4 and then eventually (after an expansion of the participants) 12 women from the local village communities within the Irente region, 5 trained staff members, and the management (comprising 2 trained and experienced nurses) of ICH, 1 Tanzanian SLT lecturer and researcher, 2 Tanzanian early child development lecturers and researchers, and 2 German SLTs and research fellows. Project coordination was done by the two German research fellows and the Tanzanian SLT, who had years earlier acquired a master's degree in SLT at Leibniz University Hannover, Germany, and had been involved in former projects within the same research group. The training participants (12 local women and 5 ICH staff members) were recruited by the management of ICH. ICH, as one of the main initiators of the project, hosted the training sessions.

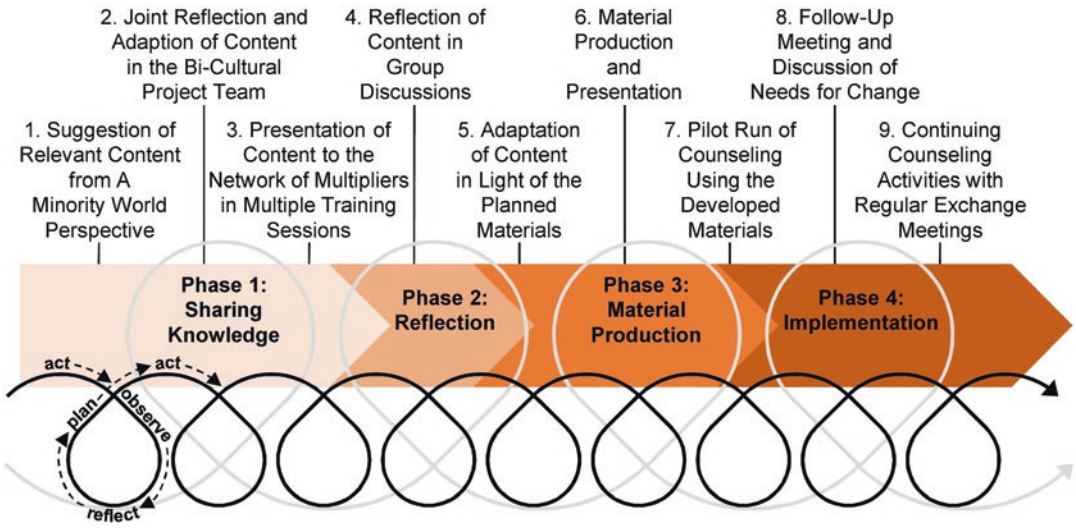

Fig. 14.1 Consecutive phases and steps in the IEC material development, accompanied by participative feedback loops

Methodology for the Evaluation of IEC Material Development in This Chapter

To answer the leading question of this chapter, the process of IEC material development is presented, and its results will be reflected on following a set of pre-defined criteria. The results will be analyzed on the three levels of activity, output, and outcome. The following section describes how the evaluation criteria were derived and how the evaluation levels were defined.

Leading Question

Which successes, challenges, and indicators for long-term sustainability can be identified in the IEC material development for the prevention of communication disability within a network of multipliers in Irente, Tanzania?

Derivation of Evaluation Criteria

The evaluation criteria for determining the project's success were derived by following two consecutive steps. First, the principles (Keough, 1998) were grouped and summarized into broader categories. Some of the categories were excluded from the grouping as they were not rated suitable for evaluation or could not be grouped with other principles. Second, the defined categories were transformed into concrete questions forming the evaluation criteria. Table 14.2 shows an overview of Keough's principles and the derivation of evaluation criteria. In summary, it was concluded that the success of the activities in terms of participatory development could be rated by how much the *local knowledge*, *local ways of knowing*, *local needs*, and the *local reality* were respected.

Table 14.2 Evaluation criteria in the context of participatory development

Participatory development principles (Keough, 1998)	Group/ category	Evaluation criteria to rate the success of the project activities
Understand the potential of local knowledge	Local knowledge	1. Was local knowledge included?
Acknowledge diverse ways of knowing	Local ways of knowing	2. Were local knowledge systems respected?
Adhere to democratic practice	Local needs	3. Were local needs met?
Maintain a sustainability vision	Local needs	
Exercise an option for community	Local needs	
Put reality before theory	Local reality	4. Was the local reality met?
Embrace uncertainty	Local reality	
Recognize the relativity of time and efficiency	Local reality	
Approach each situation with humility and respect	--	
Take a holistic approach	--	

Definition of Result Levels

The results of the project, which will be evaluated using the pre-defined criteria, can be identified on multiple levels. Based on the quality standards for development evaluation and the glossary of key terms in evaluation and results-based management by the Organisation for Economic Co-operation and Development (OECD, 2009, 2010), these levels include input, activity, output, outcome, and impact. Following the definition of those terms, connections to the results of the projects were drawn (see Table 14.3). Activity, outputs, and outcomes of the project will be presented in section "Results: IEC Materials from and for the Local Communities", while the potential impact of the project—meaning long-term sustainability, including successes and challenges following the evaluation criteria as defined in section "Derivation of Evaluation Criteria" —will be discussed in section "Discussion: Successes, Challenges, and Indicators for Long-Term Impact and Sustainability". The level of inputs will not be covered in a separate section but will be included where relevant.

Table 14.3 Evaluation levels for the results of the project activities

Level	Definition	Related results of the project
Input	Resources (e.g., financial, personnel, material)	–
Activity	Actions taken to produce specific outputs	Proposed method of IEC material development in the project
Output	Products resulting from an activity	IEC materials and resources developed in the project
Outcome	Short-term or medium-term effects resulting from the activity's output	Counseling strategies and activities using the IEC materials developed
Impact	Long-term effects of an activity and its outputs and outcomes	Long-term sustainability of IEC material development, IEC materials developed, and counseling strategies/activities

Based on OECD (2009, 2010)

Results: IEC Materials from and for the Local Communities

This section presents the results of the training and material development on the three previously defined levels of activity, output, and outcome as follows:

- In terms of the presented *activity*, one main result of the project is a structured, participative method of developing IEC materials (section "Activity: Phases and Steps of Material Development in Participatory Feedback Loops").
- Looking at the *output* of the project, the materials developed that specifically match the local conditions and demands are another major result (section "Output: Information, Education, and Communication Materials Developed in the Project").
- As for the *outcome* of the project, another result is the variety of counseling strategies implemented by the participants using the IEC materials developed (section "Outcome: Counseling Settings and Strategies Based on the Developed Materials").

Activity: Phases and Steps of Material Development in Participatory Feedback Loops

A primary result of the presented project activity was the method of IEC material development. As the procedure was structured following the outlined phases and steps (see Fig. 14.1), it can be seen as a model for projects with similar aims. The process of material development stretched over a total period of 1 year and contained the production of materials for four different topics, followed by a second cycle with one additional topic. Material development was conducted in four consecutive phases, while each of these phases consisted of consecutive steps as described in the following sections.

Phase 1: Sharing Knowledge (Steps 1–3)
The first phase focused on *sharing knowledge* between all network members. This was done in three steps: first, project team members made a suggestion for relevant training content from a Minority World perspective. In the second step, the bi-cultural project team reflected on and adapted these topics according to the needs of the target group. In the third step, the prepared training content was presented to the training participants in multiple training sessions over several weeks.

Step 1: Suggestion of Relevant Content from a Minority World Perspective

The initial suggestion of relevant topics for the IEC material development and the respective training of the participants was based on an ear-

lier project between the same project partners in which ICH caregiver students were trained to create and enhance meaningful communication in order to support the language development of young children (Lüdtke et al., 2021; Schütte, 2016). It was composed of four modules: (a) innate intersubjectivity, (b) child language development, (c) respectful caregiving, and (d) communicative musicality and play.

Innate intersubjectivity (e.g., Trevarthen, 1998) is based on the view that children are born as actively communicating individuals with a strong and innate desire for communication, expecting an emotionally responsive, communicative partner right from the outset. The module on innate intersubjectivity taught the basic principles and ideas of this theory and further included insight into how the language and communicative development of a child can be impaired when there is no such communication partner.

The module on *child language development*, based on the theory of innate intersubjectivity, covered the steps and milestones relating to children's language and communication development from birth to the age of 2 years, and it gave recommendations for how the language development of a child can be supported.

The module on *respectful caregiving* was mainly based on the approach of Pikler (1979), who, instead of seeing children as helpless, incompetent, and dependent creatures, presented a view of an infant as a competent and skilled human being who must be actively involved in their caregiving. Not only will this help them grow awareness of their independence and develop a feeling of their own capacity, but it will also support their language development through using everyday activities to immerse themselves in emotional dialogue.

The fourth module, *communicative musicality and play*, was based on research in neuropsychology that found distinctive rhythmical or musical patterns in the communication between infants and caregivers (e.g., Gratier & Apter-Danon, 2009; Gratier & Trevarthen, 2008; Malloch, 1999; McGilchrist, 2015), leading to the concept of "communicative musicality" (Malloch, 1999; Trevarthen, 2012) as "the vehicle which carries emotion from one to the other" (Malloch, 1999, p. 48). The module described the developmental stages of play in children and gave caregivers recommendations and inspiration for how to communicatively and emotionally engage with children using rhythm, music, and play.

Step 2: Joint Reflection and Adaptation of Content in the Bi-cultural Project Team

In the first meeting, the four topics were discussed among the bi-cultural project team in terms of their appropriateness for the training leading to material development. Involved in the meeting were the ICH management, the Tanzanian lecturers and project coordinator, and the two German project coordinators. Two main criteria for the evaluation of the topics were their practical relevance for the target group of training participants and the appropriateness of the content in terms of its complexity and comprehensibility. The meeting concluded with the decision that the first two modules were to be combined into one module due to their proximity and that generally all four modules should reduce the theoretical information offered and focus more strongly on the practical implications. Further, the ICH management suggested the addition of a new topic of first aid based on their knowledge of a very high demand for the village communities to learn about the most common diseases and injuries in children and how to appropriately respond to them. As a trained and highly experienced nurse, this topic would be covered by the leader of ICH. The final four topics of the training and material development were *child language development*, *caregiving*, *musicality and play*, and *basics in first aid*.

In the second meeting, the bi-cultural team discussed the content of the four topics in detail and developed an outline for the training sessions. The Tanzanian lecturers took responsibility for didactically preparing the training sessions to ensure the appropriateness and effectiveness of the teaching methods.

Step 3: Presentation of Content to the Network of Multipliers in Multiple Training Sessions

A few weeks after the initial meetings, the entire project group got together for the first training session at ICH (see Fig. 14.2). The first block of training took place over a period of 3 weeks, with training sessions taking place 3 days a week for 4 hours each, based on the recommendations and experiences of the local project team. Each module was discussed for 2 to 3 days.

The presentation of content was done by the Tanzanian lecturers and project coordinator (see Fig. 14.3). The language of the training was Kiswahili, with occasional switchovers to Kisambaa, the local language. The German project coordinators were present. While two of the lecturers took turns in leading the training, one of the Tanzanian team members translated between the foreign team members and the group.

Phase 2: Reflection (Step 4)

The second phase, *reflection*, focused on the reflection of the content presented by the training participants in the context of the local conditions and target group.

Step 4: Reflection of Content in Group Discussions

Each training session was accompanied by a set of reflective questions prepared by the trainers. In the first step, the reflective questions were openly discussed in the training group (see Fig. 14.4). The discussion was moderated by the trainers. In the second step, the trainees were split into small groups of 2 or 3 and were assigned the task of noting down the most important aspects of one of the previously discussed reflective questions on posters. The notes collected were then presented to the

Fig. 14.2 The network of multipliers at the beginning of the first training session in February 2018

Fig. 14.3 Presentation of content to the network of multipliers in multiple training sessions

Fig. 14.4 Through group discussions, the lecture content was adapted, extended, and culturally reflected on

group, and they were given the chance to add to them or revise them. After all the posters had been approved, they were collected by the project coordinators and backed up in digital files. For transparency, a translation into English was done for the benefit of the German project members. The content of the posters was included in the so-called workbook that the project team designed for the trainees as a collection of the training content and the trainees' own notes for future counseling purposes.

Phase 3: Material Production (Steps 5–6)
The third phase was the *material production* phase. It included the step of first defining the most relevant content with regard to the planned IEC materials and their adaptation, followed by the production of materials and their initial presentation to an audience of invited guests.

Step 5: Adaptation of Content in Light of the Planned Materials

A few weeks after the initial training session, the whole group reconvened for the material development and production phase. The aims of the meetings were to define which content was most relevant to be included in materials for the specific target group of parents or other family members with small children and to develop strategies on how to teach the information to the community members. The discussions therefore also included the selection of appropriate formats for the IEC materials, of which flyers and posters were chosen. In addition, the group decided to include in the flyers, posters, and workbook "practical guidelines," meaning advice and recommendations for parents and relatives on how to support the communicative development of the child or, in case of the topic of first aid, guidance on how to act in case of injury or sickness of the child.

The preparation and summary of content followed the same procedure as in the first training sessions. The specific content that was to be included in the posters and flyers was defined in an open group discussion and then distributed to small groups, then relevant content was summarized on handwritten posters (see Fig. 14.5), and this was followed by a final discussion with the whole group.

In terms of the topic *basics in first aid*, the group proposed the idea of putting together a "first care bag" with basic items that could be necessary when visiting families in need. Following the proposal, five bags were prepared—one for each village and one to remain at ICH with some spare items for replacement.

Another question that was posed by the network members was how they would be identified as qualified for their work. The group decided that a recognizable symbol—a badge—would make them recognizable within the villages.

Step 6: Material Production and Presentation

The summarized posters from both training sessions were processed into a digital form and simply laid out by the project coordinators. English versions of all materials were produced, too. For the illustration of the content, the network members suggested specific photos to be taken. For this purpose, the group spent one afternoon at ICH, while the project team took photos of their interactions with the children, always ensuring that the children would not be identifiable in the photos to protect their anonymity. Other photos (not including children) were taken based on the participants' ideas. In addition to the photos, hand-drawn illustrations were made (Fig. 14.6).

The workbook for the trainees was completed with the additional content produced through the second training session. The first batch of flyers and posters was then printed and distributed among the trainees.

The first opportunity to present the newly produced materials opened up during the graduation celebration for the trainees, which was organized by ICH and the project coordinators at the end of the second training session. Among the guests were high-ranking members of the local diocese, the chiefs of the participating villages, the husbands and families of the training participants, and the local press. In the ceremony, the trainees were handed their certificates, ID badges identifying them as counselors and graduates of the train-

Fig. 14.5 Content for IEC materials are summarized on posters as a preparative step for the production of flyers and posters

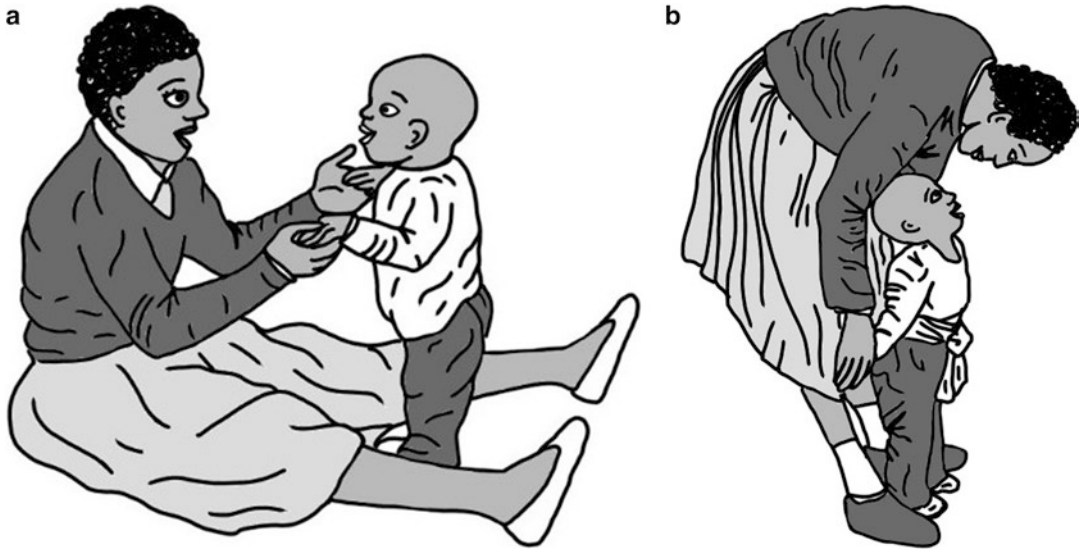

Fig. 14.6 Hand-drawn illustrations for the IEC materials

ing program, and the first care bags. The ceremony also included a detailed presentation of the materials, training content, and use of the first care bag to the guests.

Phase 4: Implementation (Steps 7–9)

In phase 4, the focus was placed on the *implementation* of all activities involving the developed materials. The first step toward implementation was taken through a pilot test of counseling activities using the developed materials. This was followed by meetings for exchanges and discussions of the training participants' initial experiences. This phase also included the continuation of counseling activities with regular exchange meetings.

Step 7: Pilot Test of Counseling Using the Developed Materials

The graduation ceremony was followed by the first test run of the counseling activities in the villages using the newly developed materials. The participants were provided a basic guideline in the form of the workbook; in addition, the group had previously worked out further frameworks, such as a structured way of documenting family visits in a notebook, ideas on how to approach families, and ideas on how to make use of the developed materials. The counseling activities ran for a period of 2 months before the group reconvened with the lecturers for their first supervision and exchange meeting.

Step 8: Follow-Up Meeting and Discussion of Changing Needs

In the supervision meeting, the counselors shared their experiences based on their activities and discussed not only the positive moments but also the first obstacles they encountered in their communication with families. As all of the participants were conducting the counseling on top of their jobs or other daily duties, a big part of the discussions centered on the practicability of the activities. The participants also shared the structures they had established in their villages to facilitate the counseling work. The participants reported that the counseling was well received in the villages and that there was no shortage of work. Consequently, they strongly agreed that they felt unable to cover the counseling work all by themselves, and they emphasized the need for an expansion of the network by training additional participants. The participants also expressed their desire for further training on other topics related to child development that they could include in their counseling activities. In terms of the developed materials, the participants noticed that some topics were more popular than others. While the topics of musicality and play and caregiving were less popular, flyers soon had to be reprinted for basics in first aid and child language development. In the weeks following the meeting, steps were undertaken to meet the demands of the counselors. First, the participants—together with the ICH management—recruited two additional women from each of the four villages to receive training. The training was quickly organized and took place 3 months later at ICH. The new participants were trained in the four topics and were advised by the more experienced group members.

A few weeks after the first block of training of the new participants, the group reconvened to conduct a second full cycle of training and material development for a new topic: hearing impairment. The second cycle followed the same model as described above and also included a small graduation ceremony for the new counselors.

Step 9: Continuing Counseling Activities with Regular Exchange Meetings

Counseling activities are ongoing. At first, the group regularly came together for exchange meetings, enabling the participants to share their experiences with the counseling activities on a regular basis; however, as the group is also connected via phone and other media, and as there is now a small group of participants in each village that can reflect on the activities among themselves, meetings have become less frequent.

Output: Information, Education, and Communication Materials Developed in the Project

The major *outputs* of the project are the developed IEC materials, namely, the flyers and posters for each of the five training modules and the workbook, and the additional materials for the members of the network of multipliers, including the ID badges and the first care bag, which support the network members in their work.

Primary Materials: Flyers, Posters, and Workbook

Primary materials refer to the materials that are directly used in counseling activities or information campaigns within the local communities according to the definition of IEC materials. The final output comprised five posters (Figs. 14.7, 14.8, 14.9, 14.10, and 14.11) and flyers (Fig. 14.12), one for each training module, and a summary of the training content on all five topics in the workbooks (Figs. 14.13 and 14.14). The flyers, posters, and workbook further include practical guidelines for the network members to give advice to clients on how to support children in their development or ensure their health.

Secondary Materials: First Care Bag and ID Badge

Secondary materials refer to the output produced in the course of the training to support the counseling activities using the primary materials. This included the first care bag, which contained various items such as a thermometer, a scale, clean drinking water, soap, wound disinfectant, honey (as an alternative disinfectant), some baby clothes and towels, a notebook and pen, a first aid kit including some common medications (like paracetamol, eye drops, and antibacterial cream), and gloves (see Fig. 14.15). The composition of the first care bag was done under the supervision of the ICH management, who as trained and experienced nurses ensured that the trainees understood that their support was not an adequate replacement for medical assistance and that they should always encourage community members to seek proper medical treatment in the event of severe injury or illness.

To identify the participants as counselors, the group agreed to design an ID badge with their photo, name, and information about the training in which they had participated (Fig. 14.16). The badge carried important meaning for the participants as it showed their qualifications and status to the community.

Outcome: Counseling Settings and Strategies Based on the Developed Materials

Looking at the use of the developed materials as reported by the training participants in informal group discussions during the follow-up meetings, a variety of creative approaches can be found as *outcomes* of the project.

One of the participants, for example, explained how she would meet up with a family, inform them about the project and her intentions, and then briefly summarize the information on the flyers to them. She would then leave the flyers with the family and give them the task of picking the topics they would like to learn more about. One week later, she would return and discuss the topics with them. In some cases, she would even take the flyers back, as oral culture is dominant and some families would not have any further use for the printed materials.

Another participant described a similar procedure, although she followed a slightly different approach. While she also left the flyers with the families, she would not explain the content to them in detail; instead, she would let the parents read and learn and then return to discuss with them what they understood and what they found most interesting. She added that she had noticed that interest was increasing not only from other mothers but also from male community members on the topic of early childhood development after seeing the flyers in her own home as well as in the homes of other families.

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IRENTE CHILDREN'S HOME

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UKUAJI WA LUGHA WA MTOTO

NJIA ZA MAWASILIANO:

- Zipo njia mbalimbali za kuanzisha/kuchochea mawasiliano na watoto au kujibu kile watoto wanachotaka kuwasiliana nasi tangu wakiwa wachanga. Kwa mfano:
  - *kuongea*
  - *kugusa*
  - *kuimba*
  - *kutazama (machoni)*
  - *kutumia ishara mbalimbali usoni*
  - *ishara/vitendo mbalimbali*
  - *kubadili sehemu/mazingira ya mtoto*
  - *kutembea*
  - *mirindimo ya sauti na midundo kama vile kuimba,kupiga makofi*
  - *kutabasamu*
  - *kucheza*
  - *kumuiga mtoto nk.*
- Mara zote inashauriwa kutumia njia ambayo inafaa kutegemeana na uwezo wa mtoto au hali aliyonayo mtoto kwa wakati huo.
- Mfano: Kutumia sauti ya utulivu pale mtoto anapotaka kulala au pale anapolia, AU kutumia sauti ya juu au kupiga makofi/kuonyesha hali ya uchangamfu pale mtoto anapokuwa katika hali ya furaha au anapenda kucheza.

MAHITAJI YA KUWASILIANA:

- Mara zote ujibu kile afanyacho mtoto katika kuwasiliana nawe kwa makini sana na huruma (Mfano, kwa kuongea, kumgusa, kutumia ishara mbalimbali usoni, kutumia ishara/vitendo mbalimbali vya kimawasiliano).
- Chochea mawasiliano na mtoto (Mfano kumuongelesha, kumgusa gusa, kumtazama machoni, kumwimbia nk).

KUWASILIANA KWA NJIA/MILANGO YA UFAHAMU:

- Unaweza kuwasiliana na mtoto kwa kutumia njia/milango mbalimbali ya ufahamu au kuchochea ukuaji wa njia/milango ya ufahamu kwa watoto.
- Kuchochea kuona kwa mtoto kwa njia ya kutazamana na mtoto machoni, kutabasamu, kuchezesha ulimi, n.k.
- Kuchochea hisia mbalimbali za mwili kwa kumkuna kuna kwa uangalifu au kumgusa, au kumfanyia masaji, nk.
- Kuchochea ukuaji na ufanyaji kazi viungo mbalimbali vya mwili kwa kumrusha rusha, kumchezesha chezesha mikononi kama vile anabembea.
- Kunusa.

HALI AU TABIA ZISIZO ZA KAWAIDA:

- Kuzungusha kichwa.
- Kukaa kimya kwa muda mrefu.
- Kujitenga na wenzake.
- Uwe makini na tabia zisizo za kawaida kwa watoto. Unapoona mtoto anaonyesha tabia zisizo za kawaida ni vizuri kumtazama kwa makini sana.
- Usidharau tabia zisizo za kawaida kwa sababu zinaweza kuwa ishara ya kuchelewa kukua kwa mtoto.

KUKUA KWA LUGHA:

- Anzisha/chochea mawasiliano na mtoto kadri unavyoweza.
- Watoto wanaweza kuchelewa kuzungumza na kwamba kila mtoto ana wepesi wake katika kujifunza lugha.
- Endapo unapenda kumsaidia mtoto kuzungumza mwonyeshe mawasiliano yenye hisia chanya katika kutengeneza maana za maneno.
- Mara zote msaidie mtoto katika jitihada zake za kuwasiliana na muonyeshe kuwa unajali kile anachojaribu kuwasiliana nawe hata kama si sahihi.
- Mfano: Matamshi kama 'mma' tamka 'mama' 'maji'.

MIEZI 0-3:

- Uwe msikivu/mfuatiliaji wa karibu sana wa ishara mbalimbali za kimawasiliano anazozionyesha mtoto.
- Mfano: Kulia kwa ukali kusiko kwa kawaida kwa mchanga.

MIEZI 4-6:

- Cheza na mtoto michezo yenye kuhusisha mtu na mtu, yenye midundo ya kimuziki (mfano, kupiga makofi) na nyimbo ambazo zinajenga mahusiano na kukua kwa lugha.
- Kuwa muangalifu na hali/hisia za mtoto pale unapochagua namna ya kucheza au wimbo.

MIEZI 6-9:

- Msaidie mtoto kutafuta vitu mbalimbali katika mazingira (mfano kumuonyesha vitu au kufikia vitu) kwa hisia chanya.
- Msaidie mtoto pale anapojaribu kusogea lakini umwache ajaribu kutatua changamoto anazokutana nazo mwenyewe (mfano, kugeukia tumbo).
- Mpatie michezo yenye kuhusisha mtu na mtu yenye midundo ya kimuziki na kuhusisha mwili mzima.

MIEZI 9-13:

- Msaidie mtoto katika kutafuta/kuona vitu mbalimbali katika mazingira yaliyo nje na aliyoyazoea.
- Mwonyeshe mtoto kile unachofanya pale unapomuona anapendelea kuona kile ufanyacho (mfano kuwaonyesha namna ya kutumia vitu hivyo).

MIEZI 13-24:

- Wapatie watoto mazingira ya kuwawezesha kushirikiana (mfano waache washiriki kwenye kazi mbalimbali ufanyazo).
- Wapatie watoto mazingira ambayo kwayo wanaweza kujifunza juu ya mazingira. Mfano, kuonyesha na kutaja vitu mbalimbali.

MAFUNZO YA MALEZI YA AWALI NA MAKUZI YA MATAMSHI NA LUGHA KITUO CHA WATOTO YATIMA IRENTE, FEB 2018 – SEP 2019

Tunawashukuru washiriki wote wa mafunzo kwa kutunga maudhui na kupigapicha mbalimbali zilizomo kwenye bango hiki.

Kwa sababu za kimaadili, tunadiriki kutoonyesha sura za watoto walioko kwenye picha.

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Niedersächsisches Ministerium für Soziales, Gesundheit und Gleichstellung

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Fig. 14.7 Poster for the topic Child Language Development

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MALEZI YANAYOMJALI MTOTO

USHIRIKI WA MTOTO:

- Mara zote jitahidi kumshirikisha mtoto katika malezi yake na shughuli nyingine zinazomhusu (mfano kumuambia anyanyue mkono/mguu wakati ukimbadilisha).
- Kwa mtazamo chanya, saidia jitihada/juhudi za mtoto katika kushiriki.
- Mruhusu mtoto kutatua changamoto zake kadri iwezekanavyo (mfano anapotaka kugeuka: kugeukia kulalia tumbo badala ya mgongo). Msaidie tu pale inapobidi!

UMAKINI TIMILIFU:

- Mpatie mtoto usikivu/umakini uliokamilika hata kama ni kwa muda mfupi.
- Kuwa muangalifu na hali ya hisia za mtoto wakati wa kufanya shughuli na mtoto.
- Kutana na mtoto ukiwa na umakini, utulivu na uzingativu.

MUANDAE MTOTO:

- Zungumza na mtoto kabla ya kumfanyia jambo mf kumbeba.
- Mtazame mtoto machoni kabla ya kufanyia jambo kama kumbeba.
- Kuwa muangalifu na mapokeo ya mtoto.
- Mbebe mtoto pale unapohisi aekutambua.

ZUNGUMZA NA MTOTO:

- Elezea kile utakachofanya (mfano: Ndio, sasa umeniona, nitakubeba!).
- Tumia kila shughuli inayowezekana, pamoja na zile za kumjali mtoto kama fursa ya kuwasiliana kuzungumza na kumjibu mtoto.
- Pokea/itikia kwa kujali jitihada za mawasiliano ya maneno na yasio ya maneno.

MAFUNZO YA MALEZI YA AWALI NA MAKUZI YA MATAMSHI NA LUGHA KITUO CHA WATOTO YATIMA IRENTE, FEB 2018 – SEP 2019

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Fig. 14.8 Poster for the topic Caregiving

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IRENTE CHILDREN'S HOME

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MICHEZO NA MUZIKI

NAMNA YA KUJIFUNZA MUZIKI TANGU KUZALIWA KWA MTOTO:

- Mpatie mtoto nyimbo na ala za sauti au michezo ya ala za sauti ambayo inachochea kinachopendelewa na ushiriki/uguswaji wa hisia.
- Cheza michezo ya ala za sauti na nyimbo pamoja na mtoto ambayo inamfaa mtoto.
- Wezesha ala za sauti za kimuziki na kimawasiliano kwa mtoto yakiwa na hisia chanya na kuwepo pamoja.

MAWASILIANO YA ALA ZA ZAUTI:

- Kama mtoto anaonesha ala ya sauti, Unaweza ukamwitikia mtoto kwa ala ya sauti ile ile (mfano, kupitia sauti au kumgusa kwa mapigo ya sauti yaliyo sawa).
- Kwa njia hii, unaweza kupata hadi majibizano ya hisia yasiyo ya kuongea na mtoto.
- Kila mara msaidie mtoto kwa upole katika majaribio ya kuwasiliana kwa ala za sauti au mapigo ya sauti.
- Unaweza kutumia ala za sauti kurekebisha hisia za mtoto (mfano, kumbembeleza mtoto kimapigo ya sauti taratibu na kwa upole pale anapolia.

NYIMBO:

- Unapoimba wimbo kwa mtoto, kuwa makini na hisia za mtoto.
- Mtoto anapolia, au anapoenda kulala, imba wimbo kwa sauti laini ya chini taratibu.
- Mtoto anapokuwa na furaha au anataka kucheza, imba kwa sauti ya juu wimbo wa haraka unaosikika.

MICHEZO KATIKA UKUAJI WA MTOTO:

- **Mpatie mtoto michezo inayowezesha:**
  - Mawasiliano/matamshi ya ukuaji wa **lugha**, mfano, Kuimba nyimbo kwa pamoja.
  - Ukuaji wa **akili**, mfano, kucheza na vibao vyenye namba.
  - Ukuaji wa **viungo**, mfano, kupiga makofi.
  - Ukuaji wa **hisia**, mfano, kuendeleza kucheza kutokana na desturi au uzoefu.
  - Ukuaji wa **kijamii**, mfano, kucheza pamoja na watoto wengine.

- **Itikia kwa upole kwa:**
  - Majaribio ya mtoto kuongea wakati wa mchezo.
  - Majaribio ya mtoto kutatua matatizo yao wakati wa mchezo.
  - Majaribio ya mtoto kusogea wakati wa mchezo.
  - Kujieleza kwa hisia kwa mtoto wakati wa mchezo.
  - Majaribio ya mtoto kwenda kukutana na wengine wakati wa mchezo.

AINA ZA MICHEZO:

- Wajengee watoto hali ya kujizoesha aina mbalimbali za michezo kutokana na hatua ya ukuaji wa michezo.
- Zingatia kwamba kila mtoto ni tofauti katika ukuaji na watoto wanaweza kuchelewa katika ukuaji wa michezo yao.

HATUA ZA UKUAJI WA MCHEZO:

- Mpe mtoto mchezo wa mtu na mtu, mfano, mchezo wa kuficha na kuonesha sura.
- Mpe mtoto mchezo wa mtu na mtu kwa kutumia vitu.
- Mjengee mtoto mazingira ambayo yatamu-wezesha kucheza mwenyewe.
- Mjengee mtoto mazingira ambayo yatamu-wezesha kuwaangalia watoto wengine.
- Mjengee mtoto mazingira yatakayomuwezesha kucheza sambamba na watoto wengine.
- Mjengee mtoto mazingira yatakayomuwezesha kuiga wengine.
- Mjengee mtoto mazingira yatakayomuwezesha kucheza na wengine.

- **Msaidie mtoto katika:**
  - kujaribu kugundua vitu na mazingira yaliyo nje na aliyoyazoea.
  - hitaji la kucheza mwenyewe.
  - hitaji la kuangalia uhalisia.
  - Hitaji la kucheza sambamba.
  - Kuiga.
  - Majaribio ya ushirikiano.

MAFUNZO YA MALEZI YA AWALI NA MAKUZI YA MATAMSHI NA LUGHA
KITUO CHA WATOTO YATIMA IRENTE,
FEB 2018 – SEP 2019

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Kwa sababu za kimaadili, tunadiriki kutoonyesha sura za watoto walioko kwenye picha.

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Fig. 14.9 Poster for the topic of Musicality and Play

Sebastian Kolowa Memorial University SEKOMU

IRENTE CHILDREN'S HOME

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HUDUMA YA KWANZA

HUDUMA YA KWANZA NINI?

- Huduma ya kwanza ni ule usaidizi unaotolewa kwa haraka mara tu mtu anapopatwa na ajali, jeraha ama anaposhikwa na ugonjwa wa ghafla kabla kufikishwa hospitali. Huduma hii inatolewa kwa kutumia vifaa vilivyo karibu nasi.
- Zingatia: Huduma hii hutolewa kabla ya mjeruhiwa kupelekwa hospitali au kituo cha afya kilicho karibu.

TUNATAMBUAJE MTOTO AKIWA MGONJWA?

- Joto kali.
- Kulia sana.
- Kukosa amani/kunyong'onyea/ kukosa ucha-ngamfu.
- Kukosa hamu ya kula au kunyonya.
- Kutetemeka mwili.
- Kutapika na kuhara.
- Kulala mara kwa mara pale inapotokea sio kawaida ya mtoto.
- Kudidimia utosi, macho (kwa watoto wachanga).
- Kukauka mdomo.

MWANDAMO WA MWEZI UNA ATHARI YOYOTE KWA AFYA YA MTOTO?

- **HAPANA** - Hakuna uhusiano wowote kati ya mabadiliko ya afya ya mtoto na mwandamo wa mwezi. Haijathibitika kisayansi.

SHERIA KUU ZA KUTOA HUDUMA YA KWANZA?

- Fanya jambo la kwanza kwa haraka bila kubabaika.
- Mwondoe mgonjwa katika enao la ajali.
- Msaidie mgonjwa kupumua iwapo anashindwa.
- Mfariji mgonjwa kwa ukaribu ili kumuondoa wasiwasi.
- Usijaribu kupita kiasi.
- Usimvue mgonjwa nguo bila sababu, ila legeza nguo zilizobana.
- Andaa kumpeleka hospitali kwa uchunguzi wa tiba sahihi.

HOMA KWA WATOTO WADOGO

Tunatambuaje hali ya homa kwa mtoto?

- Homa ni pale joto linapokuwa juu zaidi ya vile mama alivyomzoea mtoto wake. Katika hali hii joto linakuwa zaidi kuliko kawaida yaani zaidi ya nyuzi joto 37.
- Mara nyingi akina mama hugundua hali hii kwa kupima watoto wao kwa kutumia mikono nyuma ya kiganja.

Je huduma ya kwanza kwa mtoto mwenye homa ni ipi?

- Kumvalisha mtoto nguo nyepesi.
- Kumpa kinywaji baridi kinachopatikana (kisicho na kilevi):
- Kumfariji mtoto ukimweleza kile unachomsaidia kama vile kumpunguza nguo.
- Kuendelea kumlisha mtoto chakula kama kawaida yake
- Kumpa mtoto dawa ya kutuliza maumivu (mfano Paracetamol) - kulingana na umri wa mtoto na uzito wake kama itakavyoagizwa na mtaalam (angalia uzito kwenye kadi ya mtoto ya klinik).
- Mpeleke mtoto kituo cha afya au hospitali iliyo karibu na kueleza yote uliyoyafanya.

HALI ZA MARA KWA MARA ZINAZOWEZA KUHITAJI HUDUMA YA KWANZA

- Kuumwa/kung'atwa na wadudu, nyoka, wanyama, nyuki, nyigu, ng'e, siafu nk.
- Kuungua
- Kujikata (mfano wembe)
- Kuhara na Kutapika
- Chakula chenye sumu
- Mzio (allergy)
- Mafindofindo (tonsillitis)
- Kuumia jicho/macho
- Kupaliwa/kukwama na kitu

MAFUNZO YA MALEZI YA AWALI NA MAKUZI YA MATAMSHI NA LUGHA KITUO CHA WATOTO YATIMA IRENTE, FEB 2018 – SEP 2019

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Fig. 14.10 Poster for the topic of Basics in First Aid

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IRENTE CHILDREN'S HOME

Leibniz Universität Hannover

ULEMAVU WA KUSIKIA

NI DALILI ZIPI ZA ULEMAVU WA KUSIKIA KWA WATU WAZIMA NA WATOTO?

- Mtu anaweza kuwa na Usikivu hafifu au Uziwi. Hali hii inaweza kujitokeza kwenye Sikio moja au Masikio yote mawili
- Ulemavu wa Kusikia hauna Athari yoyote kwenye mfumo wa Akili ya mtu
- Watu wazima: Mtu anaweza kushindwa kusikia sauti yoyote vizuri au kumsikia mtu anayemuongelesha. Hali hii inaweza kutafsiriwa vibaya na mzungumzaji.
- **Watoto:**
  - ***Kushindwa kujibu au kuonesha hali dhaifu ya Muitikio wa Sauti yoyote inayosikika kwenye Mazingira***
  - ***Kutomgeukia Mlezi pale anapoongeleshwa***
  - ***Kutoiga sauti au Matamshi (kuanzia Umri wa wa miezi 3-6)***
  - ***Kubwabwaja kusiko kwa kawaida au kushindwa kutamka maneno ya awali (kuanzia Umri wa miezi 6-10)***

UNAWEZAJE KUSAIDIA MAKUZI YA LUGHA NA MATAMSHI KWA MTOTO MWENYE ULEMAVU WA KUSIKIA?

- Kama ilivyo kwa Watoto wengine, Watoto wenye Ulemavu wa Kusikia wana uhitaji wa Kuwasiliana na wengine
- Watoto wanajifunza Lugha kwa njia ya kucheza na kuzungumza na Walezi wao. **Usiache kuzungumza na Mtoto wako hata kama hakusi-kii vizuri!**
- Mlezi anaweza kutumia njia mbalimbali za kimawasiliano ili kumsaidia Mtoto mwenye Ulemavu wa Kusikia kumuelewa na kufuatilia kwa usahihi kile anachomuongelesha.
- **Njia hizi za kimawasiliano zinaweza kutumiwa tunapowasiliana na Watu wenye Ulemavu wa Kusikia kwa ujumla:**
  - ***Kumgusa*** *Mtoto/Mtu mzima unapotaka kuwasiliana naye ili kumuwezesha kuwa makini na kile unachotaka kuwasiliana naye*
  - ***Kuwa karibu*** *na Mtoto/Mtu mzima unapowasiliana naye*
  - ***Kumtazama usoni*** *Mtoto/Mtu mzima unapowasiliana naye*
  - ***Kupunguza au kuondoa Sauti yoyote*** *(kwenye Mazingira) ambayo inaweza kuondoa Utulivu kati yenu*
  - *Kuzungumza pole pole*
  - ***Kuzungumza kwa namna tofauti tofauti*** *ambazo zitamfanya Mtoto/Mtu mzima kukuelewa (sauti, melodi)*
  - ***Kukata kata Mazungumzo*** *ili kumuwezesha Mtoto/Mtu mzima kutafakari kile ulichozungumza*
  - ***Kutumia Alama mbalimbali usoni na vitendo*** *ili kuwezesha kile unachozungumza kueleweka*

NI KWA JINSI GANI UWEZO WA KUSIKIA UNASAIDIA MAKUZI YA LUGHA NA MATAMSHI KWA MTOTO?

- Uwezo wa Kusikia una mchango mkubwa katika Makuzi ya Lugha na Matamshi kwa Mtoto
- Usikivu unamuwezesha Mtoto kushirikiana na Mlezi kwa njia mbalimbali na mazingira kwa ujumla, Mambo ambayo ni muhimu sana katika Makuzi ya Lugha na Matamshi
- Kwa njia ya Kusikia, Mtoto anaweza kutambua na kujifunza kutumia:
  - ***Sauti mbalimbali***
  - ***Melodi ya Sauti***
  - ***Sauti za Matamshi yao wenyewe na kubwabwaja***
  - ***Kanuni na Miundo mbalimbali ya Lugha mama***
  - ***Sauti na Matamshi kuzungumzia mahitaji yao***

NI KWA JINSI GANI ULEMAVU WA KUSIKIA UNAWEZA KUATHIRI MAKUZI YA LUGHA NA MATAMSHI KWA MTOTO?

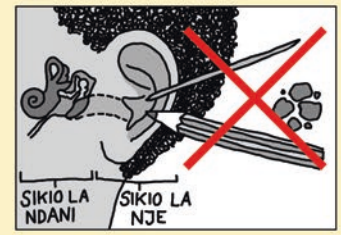
- Ulemavu wa Kusikia unaweza kucheleweshe makuzi ya Lugha na Matamshi kwa Mtoto. Hii inategemea ukubwa wa tatizo na aina ya Ulemavu wa Kusikia
- Ulemavu wa Kusikia unaweza kumfanya Mtoto kushindwa:
  - *Kujifunza jinsi ya kuwasiliana au kuwasilisha Mahitaji yake kwa wengine*
  - *Kujifunza na kutamka Sauti za Maneno, Melodi na Maneno ya lugha yake*
  - *Kujifunza jinsi ya kutofautisha/kutumia Sauti katika Mawasiliano*
  - *Kushirikiana na watu wengine katika Mazingira yake (mf. Mlezi au Mgeni)*

NI MAMBO GANI YANAWEZA KUSABABISHA ULE-MAVU WA KUSIKIA?

- Kuumia sikioni (mf. Vitu vyenye ncha kali, kumpiga mtu kofi (kwa nguvu) sikioni)
- Maambukizi Masikioni/Koromeo (kwa muda mrefu)
- Maambukizi ya Magonjwa na Virusi (wakati wa ujauzito)
- Madhara ya Dawa (kwa Mtoto au Mama wakati wa Ujauzito)
- Athari za kurithi (genetic)
- Kelele zilizo kithiri
- Uchafu, Wadudu au Vitu ndani ya Sikio
- Uchafu/Asali sikio iliyokithiri

NIFANYE NINI ILI KUEPUKA ULEMAVU WA KUSIKIA?

- **Epuka kuumia sikioni**
- **Uwe mwangalifu unaposafisha Sikio: Usitumie vitu vyenye ncha kali**
- **Epuka kelele zilizokithiri**
- **Utafute Ushauri wa kitaalamu (hospitalini) endapo Mtoto wako ana Maumivu ya Sikio, Puani au kwenye Koromeo**



NI WAKATI GANI WA KUTAFUTA USHAURI HOSPITALINI AU WA KIDAKTARI?

- Pale unapogundua kuwa Mtoto wako hasikii vizuri
- Sababu nyingine ni:
  - ***Maumivu ya Sikio yaliyokithiri***
  - ***Majimaji (Damu, Usaha) unaotoka sikioni***
  - ***Harufu mbaya sikioni***
  - ***Maambukizi sikioni, kuuumia sikioni, vitu visivyotakiwa sikioni)***
  - ***Kupoteza Usikivu gafla***
  - ***Maumivu ya Sikio, Puani au kwenye Koromeo***

MAFUNZO YA MALEZI YA AWALI NA MAKUZI YA MATAMSHI NA LUGHA KITUO CHA WATOTO YATIMA IRENTE, FEB 2018 – SEP 2019

Tunawashukuru washiriki wote wa mafunzo kwa kutunga maudhui na kupigapicha mbalimbali zilizomo kwenye bango hiki.

Kwa sababu za kimaadili, tunadiriki kutoonyesha sura za watoto walioko kwenye picha.

ulrike.luedtke@ifs.uni-hannover.de

Niedersächsisches Ministerium für Soziales, Gesundheit und Gleichstellung

Bango hiki kimetengenezwa kwa msaada wa Wizara ya Ustawi wa Jamii, Afya na Fursa Sawa ya Jimbo la Lower Saxony, Ujerumani

Fig. 14.11 Poster for the topic of Hearing Impairment

Fig. 14.12 The first printed batch of flyers for the topics of musicality and play, child language development, basics in first aid, and caregiving

Fig. 14.13 The workbook containing a summary of the training content, recommendations on how to support the healthy development of a child, and copies of the produced IEC materials

MATOKEO YA MAFUNZO KWA UFUPI

MODULI: MICHEZO NA MUZIKI

MICHEZO

1. Faida za michezo katika makuzi ya mtoto
2. Namna/aina mbalimbali za michezo
3. Umuhimu wa michezo katika makuzi ya watoto

MUZIKI

1. Ni nyimbo za namna gani zinafaa kuwaimbia watoto na ni namna ipi inafaa kuimba nyimbo na watoto?
2. Kama mlezi elezea jinsi utakavyochochea tabia ya kuimba kwa watoto.
3. Nyimbo mbalimbali za watoto
4. Nyimbo zina mchango gani katika makuzi ya mtoto?
5. Ni katika mazingira gani mlezi anaweza kumuimbia mtoto?

MICHEZO

Fig. 14.14 Excerpt from the workbook for the topic of musicality and play, including ideas for toys made from locally available materials

In another case, the participant reported that she had tried to expand her services to other villages by sending out flyers and posters and then visiting these places a few days later to hold a small event presenting the content. These meetings were held even in distant places where she sometimes even had to stay overnight.

The posters were hung at popular and highly frequented places around the village (see Fig. 14.17), and the flyers were laid out in shops and market stalls. Each participant added her phone number so she could be contacted in case anyone had any questions or needed her support.

Fig. 14.15 First care bag with various items relating to newborn care

Fig. 14.16 ID badge of a training participant as an item for recognition

The methods of approach varied among the participants. While some would spontaneously address people on the street, others preferred scheduling appointments with families, while again others would use gatherings such as church or village meetings to open up discussions. According to their personal preference and experience, some participants worked alone while others preferred to counsel in a team or even in a small group.

In terms of the topic *musicality and play*, one woman reported that her village was working on producing typical toys (as shown in the workbook)

Fig. 14.17 The poster on basics in first aid on the door of one of the villages' community center

out of local materials as additional resources to give to the families or to put on display while talking about the topic.

As for the first care bag, the participants all reported its frequent use and high appreciation for it by community members. The fist care bag was mainly reported as being used while the participants were on call, which most offered as a service in their community. The ID badge was reported to be a great help in ensuring they were recognized. Table 14.4 summarizes the reported activities and the materials used.

Table 14.4 Outcome: counseling strategies and activities reported by the training participants

Counseling strategy or activity	Materials used
Counseling in oral form, topics selected by counselor according to the individual context	Flyers
Counseling based on the parents'/families' main interest after reading the flyers	Flyers
Organizing information events in other communities to spread knowledge about the selected topics and counseling services	Flyers, posters
Hanging posters and distributing flyers at popular and highly frequented places around the villages	Flyers, posters
Including additional resources to give to the families or to have on display while talking about a certain topic	Workbook, additional (e.g., toys)
On-call duty within the community	First care bag, ID badge

Discussion: Successes, Challenges, and Indicators for Long-Term Impact and Sustainability

The following section will discuss the results previously presented. For each of the presented levels of results, the successes and challenges will be outlined. The successes and challenges will be evaluated using the evaluation criteria regarding respecting *local knowledge*, *local ways of knowing*, *local needs*, and *local reality* (see Table 14.2). The following section will discuss the results in light of these aspects and will conclude by evaluating the potential long-term impact of the project by indicating its directions toward sustainability. A summary of the evaluation will be provided in Table 14.5.

Table 14.5 Evaluation results: identified successes and challenges

Evaluation criteria	Successes	Challenges
Local knowledge	• Feedback loops ensured the inclusion of local knowledge in all phases and steps • Local knowledge was included in all materials	• Potential bias due to content being initially suggested from a Minority World perspective
Local ways of knowing	• Involvement of local press and village officials • Formats for materials accepted in the communities • Counseling settings were designed based on local knowledge and information systems	• Disregard of oral tradition in selected formats • Support from village officials differed among the communities and influenced publicity of the project
Local needs	• Dual-level expansion of the program: additional participants, additional topics • Materials included only relevant content for the communities • Additional materials were developed in the process (first care bag, ID badge)	• Increasing demand and unrealistic expectations from community members regarding the types of services provided
Local reality	• Training participants appreciated and acknowledged as counselors in their communities • Increasing interest and knowledge of community members in early child development	• Struggles to fulfill other daily duties during training episodes • Lack of financial compensation for time spent in training • Limited possibilities for reproducing materials in rural areas (lack of access to printing materials, devices, technical skills) • Limited effectiveness of printed materials for illiterate community members • Local infrastructure (seasonal weather, bad road conditions, unsafe means of transportation) limits counseling work

Activity: A Structured, Participative Method of Developing Information, Education, and Communication Materials

Successes

The IEC material development presented respected the inclusion of *local knowledge*, *local ways of knowing*, and *local needs* at all stages of the process. Any changes needed were addressed along the way. Clear indicators of the success of the method are outputs and outcomes regarding the developed materials and counseling settings. While it does not necessarily need to be part of the material production process, the graduation ceremony that was held for the training participants was considered a great success. The presence of the village chiefs was a great symbolic gesture of their support for the project and the future activities of the participants, and the appreciation of and support received from the local diocese played an important role in legitimizing the project activities. The involvement of the local press helped spread the word about the program through different channels, both in print and on the local radio station. The confidence gained by the participants was very evident.

Further successes can be noted in the dual-level expansion of the program after completion of the first successful cycle. First, the network was extended by two additional members for each of the four villages. Second, the full cycle of IEC material development was repeated with the addition of a new additional topic. The fact that both processes derived from the needs communicated by the participants is a strong indicator of their involvement and motivation in the program.

Challenges

Although the approach of suggesting knowledge from a Minority World perspective as a starting point for the training preparation was desired by all involved parties, a potential bias due to the pre-selected content cannot be completely ruled out. This might have limited the quantity and quality of input regarding relevant content by the training participants. Further challenges encountered during the material production process mainly concerned the training schedule and the availability of the training participants. The training sessions were organized in blocks to allow the German project coordinators to be present and to ensure an intensive working process. While the benefit of working in blocks was that it produced a rather quick material production process, this did not fully meet the needs of the *local reality*. As all the participants attended the training on top of their daily duties, they encountered challenges in finding free time to participate in the project and sometimes failed to attend. Unfortunately, the project was not able to provide any financial compensation for the time spent in the meetings and could only cover the meals and transportation costs for the participants. Organizing the material development in a slow and steady process instead, meaning shorter but more frequent and continuous meetings, could help avoid these problems in future interventions.

Output: Culturally and Contextually Appropriate Information, Education, and Communication Materials

Successes

The materials resulting from the project can be grouped according to primary materials, meaning the flyers, posters, and workbook, and secondary materials, meaning the ID badge and first care bag. While the flyers, posters, and workbook were initially based on content provided from a Minority World perspective, the resulting materials included only content that was relevant in the specific local context, thereby respecting *local knowledge*, *local reality*, and *local needs*. This indicates that the method of reflection in feedback loops was successful. Further, the communities' acceptance of the materials indicates that appropriate formats were chosen by the training participants and hence met the criterion of reflecting *local ways of knowing*. The need for reprints of the materials was an indicator of the communities' acceptance and usage of the materials.

The idea to use secondary materials in the form of an ID badge and first care bag originated entirely

from within the group of participants. This can be seen as an indicator of their identification with the program and their involvement in it. However, the crucial role these items play in acknowledging and appreciating the participants' services in the villages is an aspect that must not be overlooked when planning similar interventions.

Challenges

One of the challenges encountered is related to local limitations affecting the ability to reproduce materials. While the nearby town of Lushoto is equipped with plenty of options for reprinting and copying materials, these services are very costly. Although new batches of flyers and posters were shipped from Germany regularly, a sustainable way of ensuring possibilities for material reproduction on the ground, respecting the *local reality*, has not yet been established and is therefore an important challenge to overcome.

When repeating the training and material production cycle, sustainability would be achieved if the network of multipliers could produce new materials on additional topics completely independently. Since limitations could arise relating to a lack of technical skills or access to technical devices for the production of new posters and flyers, solutions must be developed to overcome such obstacles.

Last, a challenge can be identified regarding illiteracy which thereby raises questions regarding the effectiveness of the printed materials. In addition, judging from the reports of the network members, oral tradition seems to dominate in the rural areas. Both these facts raise the need to expand the training content to other forms of media with a stronger respect for *local ways of knowing* and *local reality*.

Outcome: Fruitful Counseling Strategies Based on the Developed Materials

Successes

As the results demonstrate, the participants produced a variety of counseling strategies and settings in accordance with the *local ways of knowing* and the *local needs*. The participants reported that while the training prepared them for their future role as counselors, they learned from practice that this was only the beginning and that the real learning process would be being on the job through the experiences they encountered.

One particular area of success regarding the *local reality* can be found in the community members' growing interest in early child development. Some of the participants reported aiming their services at certain target groups, such as young expectant mothers and fathers, as this group was seen by the counselors as a risk group due to a potential lack of interest in matters pertaining to early child development. Some of the network members observed a growing interest among male community members in early child development, although they are often reported as not typically overly involved in caregiving. For the counselors, this was seen as an encouraging development because it not only showed increasing interest but also increasing knowledge. Some participants made suggestions for how to involve male community members in the training and material development when repeated.

In terms of the *local reality*, it can be noted that the training participants were quickly acknowledged and appreciated as counselors within their communities. This is indicated by the high (and rapidly growing) demand in the communities for their services.

Challenges

While the participants all reported that their services were appreciated and acknowledged in the communities, some of the participants reported being asked more questions about (and even facing unrealistic expectations from within the community regarding) the treatment of disorders, such as hearing impairment, or certain types of disabilities. They felt overburdened by these queries because they could not give any in-depth advice. Some clients had reportedly even expected to receive medical services equal to that of medical doctors from the participants. Improvements could be made by expanding the network professionally and includ-

ing further steps for affected persons to take in order to seek treatment in order to optimally meet the *local needs*.

Challenges could also be found regarding local infrastructure concerning the *local reality*. Some participants reported that seasonal rains and bad road conditions made it hard for them to visit families. While one of the villages had started to raise some money for the counselors to use the motorcycle taxi to visit distant families, most other network members relied on travel by foot. As some of the villages are spaced far apart, this can be an exhausting task and could even pose a risk to network members if vast distances need to be covered after sunset.

As for the individual villages, the support that was provided by the village leaders seemed to have an impact on the successful delivery of the services. While some villages organized meetings and events for the community to inform them about the program, others did not strongly act on the network members' behalf, which reportedly had an influence on the initial status and recognition of the participants when visiting clients. This indicates that more effort could have been put into publicizing the program to strengthen the villages' support of it and incorporate the program into *local ways of knowing*.

Finally, financial struggles comprised a large part of the identified challenges and extended beyond transportation costs, as some of the participants decided to sometimes pay others to cover their farming work in order to enable them to carry out their counseling work, meaning that they sometimes spent their savings in order to free up time to engage in counseling.

Conclusions: Directions Toward Sustainability

Sustainability is a hardly measurable variable. Therefore, this chapter can only outline indicators and directions for sustainability. While we can identify single results on each level, the bigger picture shows how the three levels—activity, output, and outcome—are interwoven in a way that they support and enhance each other. As the structured and participative method of developing IEC materials presented will lead to culturally and contextually specific and appropriate resources, these resources will foster fruitful counseling strategies. However, the existence of such resources closes the loop as it again has a great impact on the activity, if repeated, while the same can be said about the materials developed that are an important resource for new training and material development activities. Figure 14.18 illustrates the interplay of the three components, forming a long-term sustainable impact.

Despite the challenges encountered, successes are recognizable on all levels. The identified achievements show that the presented method is a reliable and appropriate tool for creating culturally and contextually matched IEC materials as well as for fostering promising counseling activities by the network members. Looking back at the leading question for this chapter—*Which successes, challenges, and indicators for long-term sustainability can be identified in the IEC material development for the prevention of communication disability within a network of multipliers in Irente, Tanzania?*—the discussion of the results showed that local knowledge, local ways of knowing, local reality, and local needs were mostly met. Further, from the interplay of activity, output, and outcome, it becomes evident that the presented method was successful in bringing about fruitful and appropriate IEC materials and counseling strategies. However, the discussion also made clear that challenges regarding one or more of these aspects could not be avoided on all levels, hence showing that full sustainability has not yet been achieved.

As can be concluded from the discussion, most of the identified challenges relate to the sustainability and continuation of the network's counseling activities rather than the material development process or the materials themselves. The following recommendations—which describe work still in progress—can help the network of multipliers achieve sustainable independence and support the continuation of their work:

- Financial stability based on local resources must be reached. Costs must be covered for safe

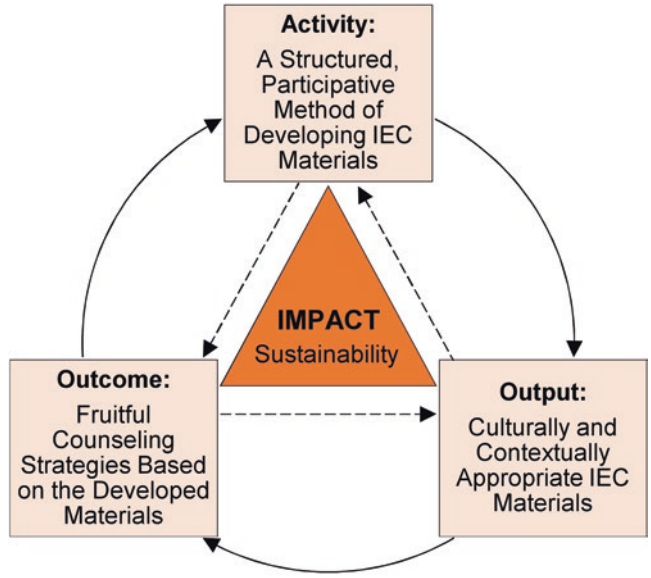


Fig. 14.18 Results of the project: an interplay of activity, outcome, and output forms the basis for future work within the network of multipliers and recurrence of the procedure

and effective transportation, work compensation, carrying out future follow-up meetings, and the reproduction of materials. For example, funds could be provided by the villages or local stakeholders such as the local diocese.

- Network members must be provided with the necessary technical skills and access to technical equipment in order to be able to produce new materials. This could be organized in further training courses. If this exceeds the capabilities of the network members, a sustainable alternative infrastructure must be developed.
- Network members must be further trained in their functions to deliver training to future network members and thereby expand the network by taking a "train-the-trainer" approach.
- The network of multipliers must continue to be extended on three levels: the expansion of the network in a personnel capacity, a geographic extension of the services, and an extension of the content covered. New topics must be defined according to the needs of the community. New network members must not only include village members but should also seek to involve other professional groups such as pedagogic staff, teachers, or other groups related to early child development. Other neighboring communities must be informed and involved in order to extend the network.
- Finally, the program must be better publicized not only to support finding funding options but also to encourage other communities to get involved.

Outlook: Future Perspectives for Sub-Saharan Africa

This chapter presented a method of developing culturally and community-specific IEC materials on the topic of early child and communication development within a network of multipliers in rural Tanzania. Results and successes, but also challenges and needs for change, have been identified. While the presented activity can be seen as a pilot for the proposed model, the approach can also be seen as a starting point for many future activities in the field of IEC material development. As this approach is not bound to any specific topic or cultural context, it can be flexibly

transferred to any other. Researchers, SLTs, teachers, community workers, health professionals, and other groups are highly encouraged to engage in further material development.

IEC materials, as this chapter has shown, can be a highly valuable resource for health development and prevention, particularly in underserved rural communities in SSA, and can lead to fruitful and effective counseling activities within the communities. While the presented method largely focused on printed materials, future activities could expand the spectrum of materials and media in order to strongly embrace oral tradition, which is dominant in many communities in SSA. Efforts can be made in the future to broadcast information via radio or television, which would also serve to increase the reach of the developed materials.

Finally, an important aspect to consider in future work is to give the communities and their valuable resources a forum and a voice in the rapidly expanding digital world. A good example can be found in the project "SpeechBase—Speech, Language, and Hearing Resources for Sub-Saharan Africa," which is a 4-year (2020–2023) project funded by the German Academic Exchange Service (DAAD) aimed at supporting the development of the SLT profession in SSA. The project comprises a partnership between Kenyatta University in Nairobi, Kenya; Kilimanjaro Christian Medical Centre in Moshi, Tanzania; Leibniz University Hannover in Germany; Muhimbili University of Health and Allied Sciences in Dar es Salaam, Tanzania; and the University of Pretoria in South Africa. One of the project's main aims is to develop an online platform called "SpeechBase" to provide various information and educational materials in the context of SLT. Such platforms carry a great potential to spread information about the existing materials and encourage communities to develop their own materials and counseling structures according to their individual interests and needs. Most importantly, there is a need to join forces and share knowledge in order to strengthen communities in their ability to engage in the prevention of communication disability.

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Pediatric HIV/AIDS and Communication and Developmental Disorders in South African Children

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Introduction

> "We won't end AIDS as a public health crisis if we don't end AIDS in children first."
>
> Michel Sidibe, UNAIDS Executive Director
> 21st International AIDS Conference
> Durban, South Africa, July 2016

HIV/AIDS is a global issue, but African children have been especially vulnerable to the epidemic. Eighty-seven percent of the world's children living with HIV/AIDS are in sub-Saharan Africa (WHO, 2015) (see Table 15.1). Most of those children are in South Africa where approximately 260,000 children suffer from the infection (UNAIDS, 2019). Although the number of new HIV infections diagnosed in children aged from birth to 14 years old fell from 88,400 in 2003 to 5053 in 2015 (UNICEF, 2016), mother-to-child transmission rates in South Africa are still 25–35% compared to 2% in North America and Europe (WHO, 2015). Even within South Africa, there is a difference in the incidence and prevalence of the disease. There is a 13.6% infection rate among Africans, while Coloreds (people of mixed-race ancestry)[1] account for 1.7%, Indians 0.3%, and white people 0.3% (UNICEF, 2016).

Table 15.1 Prevalence of HIV infection in Southern African countries (adapted from UNAIDS, 2019)

Country	Incidence (%)
Angola	2.0
Tanzania	4.6
Uganda	5.7
Malawi	9.2
Mozambique	12.6
Zambia	11.3
Namibia	11.8
Zimbabwe	12.7
South Africa	20.4
Lesotho	23.6
Botswana	20.3

[1]The term "Coloreds" is officially recognized as a racial designation in South Africa.

The toll of HIV/AIDS has been especially high in South Africa where several factors combine to exacerbate the issues related to the disease. In addition to the realities found in many low-income countries where there is a lack of access to readily available HIV care, not enough healthcare personnel, and poverty, South Africa also has a history of AIDS denial, which shaped the country's response to the AIDS crisis from 1998 to 2004 (Bosley, 2008).

In the late 1990s, South African government officials refused to accept that acquired immune deficiency syndrome (AIDS) resulted from the progression of the human immunodeficiency virus (HIV). Instead, the government insisted AIDS was the result of poverty, bad nutrition, and general ill health. Consequently, the government delayed launching an antiretroviral medication program (Fassin, 2002). The government even withdrew funding from clinics that used medications to prevent mother-to-child transmission of HIV. This meant that many people who suffered from the disease did not have medications that could have improved their health, extended their lives, and prevented the transmission of the virus from mothers to their newborn infants. It took a Constitutional Court judgment in 2002 to bring about change, ordering the government to make nevirapine universally available to pregnant women infected with HIV. The court's ruling was followed shortly by a cabinet statement supporting wider access to antiretrovirals (Fassin, 2002).

This sense of denial can also be present in people who may themselves be HIV-positive. In a study by Shipalana and Ntuli (2016) to determine why mothers decline testing for their children, the authors interviewed 30 women who participated in prenatal care at Mankweng Hospital, Limpopo Province, South Africa, who declined to have their infants (median age 13 months) tested for HIV infection (see Fig. 15.1). The reasons they gave for denying testing were the following: they did not want to be stressed with a positive result (66%); they did not want to know their status (7%); they could not consent as their partners had declined tests for both baby and mother (7%); and other reasons include fear of HIV stigma (20%). Seventy percent of the children were discharged home without testing or treatment.

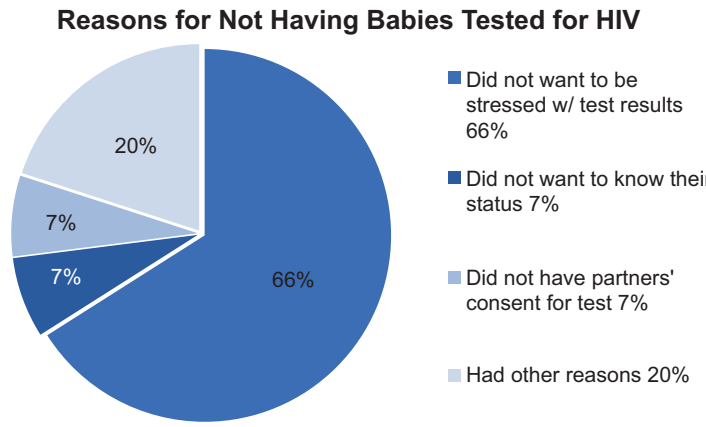

Fig. 15.1 Reasons mothers declined HIV testing. (Based on Shipalana & Ntuli, 2016)

The AIDS crisis in South Africa has resulted in approximately 3.5 million children being orphaned (UNICEF, 2016). Another 150,000 children may be living in child-headed households (UNICEF, 2016). At times, the need to get care and services to orphans has overwhelmed the country's social services agencies (Baldauf, 2010). Government and nongovernmental organizations have responded by building orphanages and developing community-based care programs; however, it often falls to relatives to care for these children. In addition to the loss of guidance and protection often experienced by children following the death of their parents, multiple hardships may be placed on relatives or others who assume the care for these children. In South Africa, Madhavan (2004) wrote that children have historically been fostered by a variety of kinfolk, so child fostering has been a part of South African culture, with working mothers leaving children with adult relatives or older siblings.

A study of persons caring for AIDS orphans found they face significant challenges from parental deaths and the responsibilities of caring for the orphaned children (Hlabyago & Ogunbanjo, 2009). The researchers conducted one-on-one interviews with nine caregivers at the Hoekfontein Clinic in North West Province, South Africa. Six of the women were grandmothers, and the orphans were between 5 and 20 years of age. The caregivers said their most prevalent challenges in caring for the children were poverty and lack of money; bureaucratic difficulties and lack of assistance from the social services agencies; lack of financial, physical, and emotional support from family members; the frustrations of coping with rebellious orphans; the pain of caring for terminally ill family members; feelings of despondency; conflicts in the family; and the rejection of maternal orphans by their fathers. It is obvious that even under the best circumstances, the challenges associated with nurturing and caring for children orphaned by AIDS represent a monumental task.

Medical Background

The virus that causes HIV is a retrovirus which uses an enzyme to encode its RNA into the DNA of host cells (Young, 1994). HIV replicates very quickly, and without medication the infection progresses to AIDS, resulting in severe immune system compromise (Young, 1994). Pregnant women have a higher risk of acquiring HIV infection than do non-pregnant women (Gray et al., 2005). For South African children, transmission of the HIV antibodies is most likely to occur prenatally in utero, perinatally during birth through the newborn's contact with vaginal fluids during the delivery, or postnatally during breastfeeding if the mother is not on an antiretroviral therapy (ART) regimen and has a reduced viral load (CDC, 2016). Nearly 30% of pregnant women in South Africa are HIV-positive (UNICEF, 2016). The highest prevalence of HIV-positive pregnant women is in KwaZulu-Natal where 37% of women are HIV-positive (UNICEF, 2016). Today, approximately 95% of pregnant South African women receive antiretroviral medications to prevent transmission

of HIV to their infants, which is an increase from only 46% receiving prenatal medications in 2002 (CDC, 2016). The result has been a dramatic reduction in the number of children between birth and 14 years who are diagnosed with HIV.

KwaZulu-Natal also has the highest incidence of infants who are HIV-positive (16%) (UNICEF, 2016). Gauteng and KwaZulu-Natal account for 30% of HIV-positive children aged from birth to 24 months and 29% of the HIV-positive children aged from 2 to 14 years (UNICEF, 2016). The lowest HIV-positive populations among children are in the Western Cape (4.9%), Northern Cape (8.2%), and Limpopo (11.3%) (UNICEF, 2016).

Children born to HIV-positive mothers are usually HIV-positive themselves because the mother's antibodies are in the infant's blood and can remain there for up to 15 months (Maldonado & Petru, 1994). It can be difficult to make a definitive diagnosis of a child's HIV status prior to 15–18 months, as most children lose the maternal HIV antibodies (serorevert) (Lepage et al., 1992), but once an HIV diagnosis is made, antiretroviral drugs must be started to slow the progression of the virus (WHO, 2007).

It is imperative that children who are HIV-positive or who are born with maternal HIV antibodies be put on antiviral medication immediately. ART is the standard of care for these children (Rabie et al., 2007a, b). ART medications are given to prevent the proliferation of HIV, to suppress and eradicate bacterial infections, and to treat the debilitating side effects associated with HIV/AIDS. Progress in the reduction of infection rates among South African children is due, in large measure, to the availability of antiretroviral drugs. In 2010, 33% of children in need of antiretroviral medications received the drugs they needed. By 2015, this had increased to 74% of children receiving the necessary drugs (UNAIDS, 2016). The mortality rate of South African children under the age of 5 years fell by 46% between 2006 and 2015 (UNICEF, 2016). In addition to antiretroviral medications, effective medical care, nutritional support, improved living conditions, and rehabilitation programs have contributed to these children's improved developmental outcomes and longevity (UNICEF, 2016).

The increased availability of antiretroviral medications has made a significant impact on the incidence of HIV in children; however, challenges remain. Purchase et al. (2016) found that 42% of the children being followed in a peri-urban medical clinic in a South African province were lost to follow-up because they discontinued their medical appointments and medications. Interviews revealed the discontinued appointments were largely due to long pharmacy lines, fear of the stigma associated with the disease, and unpalatable medications. Without antiretroviral medications, the progression of HIV infection in children is particularly aggressive, exacerbating the neurological, cognitive, and developmental issues which can accompany the disease (WHO, 2015).

Developmental and Cognitive Manifestations of Pediatric HIV

Much attention has been given to the progression of HIV in adults and the disorders and disabilities that result. In children, the disease can be accompanied by severe illness and disability, but the infection can manifest differently in children than in adults (Mintz, 1994; Pavia, 2001; see Table 15.2). The infection has a much shorter incubation period in children, who can begin to exhibit developmental and neurocognitive symptoms of infection as early as 3 months old (Coplan et al., 1998; Gay et al., 1995; Kandawasvika et al., 2011; Pressman, 1992; Moss et al., 1996; Whitehead, 2014), while adults can harbor the virus for years before symptoms become evident (Aberg et al., 2014; Mintz, 1994; Schacker et al., 1996). Opportunistic infections are less common in children than in adults. Children are more likely to suffer central nervous system involvement, while adults are more prone to peripheral system symptoms (Mintz, 1994). This may be due to the projection of pediatric HIV onto a developing central nervous system in children, while adults are more likely to have achieved all developmental milestones prior to infection (Mintz, 1994; Pavia, 2001).

Children with HIV can suffer from various disorders. The disease can be progressive with different symptoms and disorders manifesting over

Table 15.2 Comparison of pediatric and adult neurological symptoms (Mintz, 1994; Copyright 1994 by Elsevier Science Ltd., adapted with permission)

Children	Adults
Vertically acquired infection	Horizontally acquired infection
Short latency period from infection to symptom manifestation	Long latency period from infection to symptom manifestation
Growth impairment of an immature CNS	Deterioration of a mature CNS
Impaired brain growth	Brain atrophy
Seizures usually associated with fever	Seizures common
Progressive motor dysfunction/neurodevelopmental decline	Motor deterioration/cognitive decline/dementia

Table 15.3 AIDS-defining conditions most commonly reported in children in sub-Saharan Africa (Jamison et al., 2006)

Condition	Occurrence (%)
Lymphadenopathy	59
Encephalopathy	52
Recurrent fever	51
Progressive weight loss	51
Chronic otitis media	42
Chronic diarrhea	38
Dermatitis	37
Persistent cough	32
Oral candidiasis	19

time, especially as children's infections progress to AIDS. Signs and symptoms may increase in number and severity as a child's viral load increases. Children with mild symptoms may experience swollen lymph nodes, infections of the spleen or liver, or skin infections. Children who are moderately symptomatic can experience anemia, enlarged heart, hepatitis, cytomegalovirus, diarrhea, or bronchitis. Severe immunosuppression results in serious bacterial infections (esophageal or pulmonary), cytomegalovirus, candidiasis, encephalopathy, cancer, and wasting syndrome (Ferguson & Jelsma, 2009; Govender et al., 2011; Whitehead, 2014; see Table 15.3).

World Health Organization Early Diagnosis

In 2005, the World Health Organization (WHO) published a new pediatric clinical staging system for the African region to increase children's access to antiretroviral medications (see Tables 15.4 and 15.5.). The scale delineates signs and symptoms in each of the four stages of HIV infection and allows healthcare practitioners to make a presumptive diagnosis of HIV infection and progression without confirmatory laboratory testing. The WHO guidelines allow organization of the pediatric and adult staging systems, which facilitates a smooth transition from pediatric to adult medical care (Hattam et al., 2014). The staging system also provides guidance on diagnosing stage IV clinical disease in infants younger than 18 months of age.

In addition to the illnesses that can accompany HIV/AIDS, indirect effects of the infection such as mental retardation, attention-deficit/hyperactivity disorder, and cerebral palsy have been reported extensively (Cohen & Diamond, 1992; Hanna & Mintz, 1992; Hoare et al., 2012; Levinson et al., 1992; Lowick et al., 2012; Potterton et al., 2009). Many of these conditions are associated with encephalopathy, which can be progressive and is a defining condition of pediatric HIV infection and progression to AIDS. Other conditions that are very prevalent in children who are HIV-positive and those with AIDS are speech, swallowing, and hearing disorders.

Oral-Motor Development and Oropharyngeal Lesions and Infections

Oral-motor development is one of the most important aspects of development in a young child's life. The infant's mouth is an important organizing mechanism for development (Morris & Klein, 2000). In addition to being the child's

Table 15.4 Clinical staging of HIV/AIDS in infants and children (WHO, 2005; adapted with permission)

Stage I
- Asymptomatic
- Persistent generalized lymphadenopathy (PGL)

Stage II
- Hepatosplenomegaly
- Papular pruritic eruptions, seborrheic dermatitis
- Extensive human papilloma virus infection, molluscum contagiosum
- Herpes zoster
- Fungal nail infections
- Parotid enlargement
- Recurrent oral ulcerations, lineal gingival erythema (LGE), angular cheilitis
- Recurrent or chronic RTIs (otitis media, otorrhea, sinusitis)

Stage III

Conditions where a presumptive diagnosis can be made based on clinical signs or simple investigations
- Moderate unexplained malnutrition (between the third percentile and 60% of expected weight)
- Unexplained persistent diarrhea (14 days or more)
- Unexplained persistent fever (intermittent or constant, for longer than 1 month)
- Oral candidiasis (outside neonatal period)
- Oral hairy leukoplakia, acute necrotizing ulcerative gingivitis/periodontitis
- Severe recurrent presumed bacterial pneumonia
- Pulmonary TB

Conditions where confirmatory diagnostic testing is necessary
- Chronic HIV-associated lung disease, including bronchiectasis
- Lymphoid interstitial pneumonitis (LIP)
- Unexplained anemia (<8 g/dl) and or neutropenia (<1000/mm^3) and/or thrombocytopenia (<50,000/mm^3) for more than 1 month

Stage IV

Conditions where a presumptive diagnosis can be made based on clinical signs or simple investigations
- Unexplained severe wasting or severe malnutrition
- Pneumocystis pneumonia
- Extrapulmonary TB
- Esophageal candidiasis
- Recurrent severe presumed bacterial infections (excluding pneumonia)
- Chronic herpes simplex infection (orolabial or cutaneous of more than 1 month of duration)
- Kaposi's sarcoma
- CNS toxoplasmosis (outside the neonatal period)
- HIV-associated encephalopathy

Conditions where confirmatory diagnostic testing is necessary
- CMV infection (CMV retinitis or infection of organs other than the liver, spleen, or lymph nodes; onset at age 1 month or more)
- Extrapulmonary cryptococcus including meningitis
- Any disseminated endemic mycosis
- Cryptosporidiosis, isosporiasis
- Disseminated non-tuberculous mycobacteria infection
- Candida of trachea, bronchi, or lungs
- Visceral herpes simplex infection
- Acquired HIV-associated rectal fistula
- Cerebral or B-cell non-Hodgkin's lymphoma
- Progressive multifocal leukoencephalopathy (PML)
- HIV-associated cardiomyopathy or nephropathy

Table 15.5. Presumptive diagnosis of clinical stage IV HIV in children aged under 18 months (WHO, 2005; adapted with permission)

Presumptive clinical stage 4 in infants and children aged under 18 months where virological confirmation of HIV infection is not available
A presumptive diagnosis of stage 4 clinical disease should be made if: • An infant is HIV antibody-positive (ELISA or rapid test), aged under 18 months and symptomatic with two or more of the following: – Oral thrush – Severe pneumoniae – Severe wasting/malnutrition – Severe sepsis • CD4 values, where available, may be used to guide decision-making; CD4 percentages below 25% require ART • Other factors that support the diagnosis of clinical stage 4 HIV infection in an HIV-seropositive infant are: – Recent HIV-related maternal death – Advanced HIV disease in the mother • Confirmation of the diagnosis of HIV infection should be sought as soon as possible.

conduit for nutrition, the child explores objects and begins to make some sense of the world through her or his mouth. The suck-swallow-breathe synchrony allows the child to suck from the nipple and to bite, chew, and swallow foods and liquids of progressively changing textures and tastes (Davis-McFarland, 2000). Achieving oral-motor milestones also supports aspects of sensorimotor and cognitive as well as speech and language development, feeding and eating behavior, eye-hand coordination, and ego development (Morris & Klein, 2000). As oral-motor development progresses over the child's first 3 years of life, the fine oral-motor movements necessary for the development of babbling and then oral language and speech articulation are overlaid on the system that supports normal nutritional intake (Morris & Klein, 2000).

Encephalopathy is a central nervous system disorder commonly associated with pediatric HIV (Baillieu & Potterton, 2008; Drotar et al., 1997; Hanna & Mintz, 1992; Hattam et al., 2014). HIV-related encephalopathy can cause abnormal oral-motor patterns that interfere with normal oral-motor development and result in atypical oral-motor patterns, which can include jaw thrusting, tongue thrust, tonic bite reflex, lip retraction, tongue retraction, and nasal regurgitation (Davis-McFarland, 2000).

Oral lesions are less common in children than adults, but at least 19% of South African children who suffer from HIV will develop some type of oropharyngeal lesion (Rabie et al., 2007a, b). The compromised immune system is not able to fight the bacteria that cause conditions that impede oral-motor development. Candidiasis (thrush) of the oral cavity and pharynx is common among infants up to 12 months of age, and manifests as small white patches on the tongue, palate, cheeks, or gums, and can also be found in the esophagus (Rabie et al., 2007a, b). In children with HIV, thrush can be severe and long-lasting. Children with HIV are also vulnerable to the herpes simplex virus, which causes cold sores in the mouth and palate (Behardien, 2006), and chronic aphthous ulcers or canker sores, which occur on the tongue and cheek (Lal & Chussid, 2005). In addition to these conditions, children with HIV may also be vulnerable to xerostomia (dry mouth), which can be caused by salivary gland disease (Rabie et al., 2007a, b), or the medications children take to treat their HIV infection. Lesions in the mouth, pharynx, or esophagus can cause children to experience odynophagia, which is painful swallowing. Table 15.6 shows an overview of conditions causing oral-motor dysfunction. Any of these conditions can impede a child's oral-motor development, affect their ability to develop speech and language skills, or compromise previously developed skills.

Dysphagia and Feeding

Neurological pathology as well as bacterial and viral infections and other conditions described above can compromise a child's ability to chew, suck, and swallow (Davis-McFarland, 2000). In a study of 150 children between the ages of 4 months and 17 years, Pressman (1992) found that 20.8% of children reported eating difficulties characterized by coughing on foods or liquids, slow feeding, failure to thrive, and gagging on solids or chewable foods. All phases of swallow

Table 15.6 Oral-motor dysfunction (Davis-McFarland, 2000; used with permission)

Cause/condition	Disorder
I. Neurological disease	
1. Encephalopathy	• Poor oral-motor development • Delayed oral language development • Loss of language milestones • Dysphagia
2. Stroke	• Dysarthria • Oral apraxia • Dysphagia
II. Oropharyngeal lesions	
1. Candidiasis (thrush)	• Impaired sucking, chewing, swallowing • Excessive drooling
2. Herpes simplex virus	• Impaired sucking, chewing, swallowing • Excessive drooling
3. Aphthous ulcers	• Impaired sucking, chewing, swallowing • Excessive drooling • Impaired swallowing
III. Dysphagia	
1. Dysphagia	• Impaired swallowing
IV. Other conditions	
1. Xerostomia (dry mouth)	• Impaired sucking, chewing, swallowing • Excessive drooling
2. Odynophagia (painful swallowing)	• Impaired sucking, chewing, swallowing • Excessive drooling

(i.e., oral preparatory, oral, and pharyngeal) were affected in most of the children she studied. Encephalopathy, neuromuscular incoordination, and odynophagia caused by candidiasis esophagitis were the origins of the children's swallowing issues.

A study by Nel and Ellis (2012) at Tygerberg Children's Hospital in Cape Town, South Africa, revealed that most of the children who were HIV-positive and referred for possible swallowing disorders experienced dysphagia. The referral complaints included recurrent respiratory complaints, poor growth, or poor feeding. The 25 HIV-infected children (median age 8 months; 2.8 months to 9.0 months) who were referred received feeding assessments, which included examinations for oral malformations or muscle weakness, poor posture, and the presence of swallowing reflexes during feeding and swallowing. A speech–language therapist (SLT) also observed the infants for signs of aspiration during feeding and swallowing. Subjects who were suspected of having swallowing abnormalities or aspiration were referred for a videofluoroscopic swallow study. Twenty (80%) of the children had clinical indications of swallowing disorders: 11 (44%) in the oral phase, 4 (16%) in the pharyngeal phase, and 5 (25%) in both oral and pharyngeal phases. Six (24%) of the children aspirated during the assessment. Sixteen (64%) of the children were on ART at the time of their assessments. Thirteen (81%) of those children had dysphagia. Seven (78%) of the nine children who were not on ART also had swallowing disorders. The study children were in various stages of HIV infection. Thirteen (52%) of the 25 children had central nervous system disease: 8 (32%) had HIV encephalopathy, and 5 (20%) had cerebral palsy, seizures after meningitis, or developmental delay.

Gastrointestinal illness can also accompany HIV/AIDS infection. It is common for HIV-positive children to have diarrhea, constipation, and nutritional loss (Brenchley & Donek, 2008; Guarino et al., 2004). Children with HIV require proper nutrition with high-calorie, high-protein foods and vitamin supplements to ensure their health (Guarino et al., 2004). Poor nutrition contributes to malnourishment, further immunosuppression, and increased illness. Hattam et al. (2014) found that 96% of the children in their study were referred by physicians to a dietician and social worker for further management due to dysphagia or feeding difficulties that impacted their health and growth.

HIV-positive children must take medications, sometimes several times a day, to maintain their health. Once a child reaches school stage, most antiretroviral medications are pills and capsules, which must be taken orally. This requires good oral-motor function (Davis-McFarland, 2000; Sheppard, 2008). If oral intake, chewing and swallowing, and the ability to take medications are compromised by poor oral-motor function, tube feeding may be required to maintain the necessary nutrition and provide medication (Pressman, 2010).

Otologic and Hearing Issues

Otitis media along with other ear and nose ailments is very common in children who are HIV-positive (Bernaldez et al., 2005; Miziara et al., 2007; Singh et al., 2003). In their study of South African children, Hattam et al. (2014) found that 56% of the children with HIV who were seen in a hospital in Gauteng, South Africa, had chronic or acute otitis media with effusion. Otitis media was found in 46% of HIV-positive children in a study conducted in Great Britain (Singh et al., 2003). Even in children who do not have HIV, their ability to overcome otitis media is often compromised by Eustachian tube dysfunction or depressed cell-mediated immunity (Bernaldez et al., 2005). If untreated, chronic otitis media can worsen progressively, causing conductive hearing loss. Recurrent otitis media, especially at an early age, has been shown to impede phonological development (Scott & Layton, 2000).

Torre et al. (2012) conducted a study of 231 children aged 7–17 years who were HIV-positive and those exposed to HIV in utero but who were HIV-negative. The children were given hearing tests consisting of a tympanogram in each ear and pure-tone air-conduction threshold testing. The HIV-positive children had a significantly higher incidence of hearing loss than their HIV-negative peers. Both the HIV-positive and HIV-negative children had a higher incidence of hearing loss than non-exposed, non-infected children, indicating that exposure to HIV puts a child at risk for hearing loss. Sixty percent of the children with hearing loss had sensorineural hearing loss, which is a higher incidence of sensorineural hearing loss in HIV-positive children than found in previous studies (Hattam et al., 2014; Singh et al., 2003). This study did not report that any of the children suffered from encephalopathy, but CNS disease has been implicated in the development of a lesion on the eighth cranial nerve, causing sensorineural hearing loss (Torre et al., 2012).

Some drugs such as aminoglycoside antibiotics as well as zidovudine, azidothymidine, and lamivudine have been shown to be ototoxic when children are exposed in utero (when the mother takes the drugs during pregnancy) and when taken by children who are HIV-positive (Newton, 2006; Shibuyama et al., 2006). Any type of hearing loss can put a child at risk for poor speech and language development and has a deleterious effect on literacy development and academic achievement (Layton & Hao, 2010).

Preverbal and Language Development and Disorders

Studies by Condini et al. (1991), Pressman (1992), Havens et al. (1993), Wachtel et al. (1994), Wolters et al. (1995), Moss et al. (1996), Coplan et al. (1998), Davis-McFarland and Cowan (1998), Hodson et al. (2001), Brackis-Cott et al. (2009), Rice et al. (2012), and Granzotti et al. (2013) found varying degrees of delays in preverbal and speech and language development in populations of children aged 6 weeks to 17 years.

As antiretroviral medications have become available for HIV treatment, children are living longer, meaning there are adolescents and adults who are vertically infected with the virus. As children who are HIV-positive mature, language disorders may continue to develop or persist (Brackis-Cott et al., 2009; Granzotti et al., 2013; Layton & Hao, 2010; Lowick et al., 2012; Scott & Layton, 2000). Researchers have found that older children who are HIV-positive tend to have less well-developed language skills, vocabulary skills, and phonemic skills than their non-infected peers (Baillieu & Potterton, 2008; Brackis-Cott et al., 2009; Condini et al., 1991; Coplan et al., 1998; Davis-McFarland & Cowan, 1998; Lowick et al., 2012).

In several studies, children with HIV infection were found to have considerably poorer expressive language skills than receptive skills, indicating that the receptive-expressive discrepancy is a hallmark of communication disorders in children with HIV infection (Baillieu & Potterton, 2008; Brackis-Cott et al., 2009; Lowick et al., 2012; Tardieu et al., 1995; Wolters et al., 1995). This also appears to be the case as the HIV infection advances (Brackis-Cott et al., 2009; McNeilly, 1998; Whitehead, 2014; Wolters et al., 1995). One study of school-aged children found their

communication disorders might be more related to problems with information, semantics, or syntactic structure than to problems that affect motor or working memory systems (Rice et al., 2012; Wolters et al., 1997).

As the incidence of children born with HIV has decreased globally, fewer studies on developmental issues associated with the infection have been reported; however, the studies that are available indicate that children who are born with the virus are at high risk for delayed speech and language development (Baillieu & Potterton, 2008; Brackis-Cott et al., 2009; Davis-McFarland, 2000; Hodson et al., 2001; Layton & Hao, 2010; Lowick et al., 2012; McGrath et al., 2005; McNeilly, 1998; Moss et al., 1996; Whitehead, 2014). A child's preverbal development is influenced by his or her health, environmental stimulation, and parental modeling. Some of the most important milestones for speech and language development occur within the first 3 years of a child's life. Failure to achieve these necessary milestones can result in poor development of the communication skills that will determine the child's future communication ability. A study by Condini et al. (1991) of 36 HIV-exposed children (18 prenatally infected but asymptomatic and 18 seroreverters) aged 18–36 months found that the children with HIV evidenced delayed language development based on a shorter mean length of utterance (MLU) and less mature language production compared to their seroreverted peers.

Davis-McFarland and Cowan (1998) assessed the language development of infants aged 6–25 months at an outpatient pediatric HIV clinic in a regional teaching hospital. Fifty-four children who were HIV-positive or HIV-exposed in utero were evaluated with the Early Language Milestone Scale-2 (ELMS-2) (Coplan, 1993) three to six times during their visits to the clinic. The results indicated there were no statistical differences between the two groups of children at 6–9 months or 10–13 months on the expressive language, receptive language, visual language, and total language scores, but the data indicated some differences among the three HIV-positive groups: (1) there was a statistically significant difference between the receptive language scores of 6- to 9-month-old children and the 10- to 13-month-old children. The older children's scores indicated poorer receptive language ability for the older infants; (2) the 10- to 13-month-olds' receptive language scores were significantly higher than the 22- to 25-month-old infants' scores; (3) there was a significant difference in the total ELMS-2 scores for the children aged 6–9 months and 22–25 months; and (4) the total language subtest scores for the children aged 6–9 months were significantly higher than those for children aged 10–13 months. As both the HIV-positive and seroreverted infants increased in age, their scores decreased.

The study findings indicated that during the early stage of infection, HIV-positive children's communication development is near the level of their uninfected peers; however, as they get older, the children with HIV infection begin to fall behind in the developmental process, and language development is compromised. Analysis of individual items on the ELMS-2 revealed that the HIV-positive infants achieved some language milestones later than their seroreverted peers. The HIV-positive children exhibited reciprocal vocalization, polysyllabic babbling, and first word (other than "mama/dada") acquisition 6 weeks to 2 months later than their seroreverted peers. Receptive language subtest items showed HIV-positive infants followed one-step and two-step commands without gestures and pointed to a body part and named objects an average of 1–2 months later than their seroreverted peers.

In another study, McNeilly (1998) assessed 30 children aged 15–36 months using the Preschool Language Scale-3 (PLS-3) (Zimmerman et al., 1979). She assigned each child to one of three groups: HIV-positive with moderate symptoms, HIV-positive with mild symptoms, and seroreverters. The study results indicated that the children with more severe symptoms had poorer language development. McNeilly also found the seroreverters had some impairment in their language function.

Brackis-Cott et al. (2009) compared 206 HIV-positive African-American and Hispanic children aged 9–16 years with 134 seroreverters (children who were HIV-negative born to HIV-positive mothers) in New York City using the Peabody Picture Vocabulary Test-III (PPVT-III) (Dunn & Dunn, 1997) to assess receptive language ability and the

reading subtest of the Wide Range Achievement Test-3 (WRAT-3) (Wilkinson, 1993) to assess reading. The perinatally infected and exposed children scored poorly on the language function assessments; however, the HIV-positive children's scores were lower than their seroreverted peers' scores. Sixty-two percent of the HIV-positive children scored below average (<25th percentile), and 39% scored below the tenth percentile. Fifty-six percent of the seroreverters scored below average (<25th percentile), and 34% scored below the tenth percentile. The children's scores on the WRAT-3 were similar to their scores on the PPVT-III with the HIV-positive children scoring significantly lower than their seroreverted peers. The authors suggested that the children's language and reading ability may have been related to the stresses associated with having lost a parent to HIV, living with and perhaps having to care for a parent who is HIV-positive, the stresses of inner city living, the impoverishment that often accompanies HIV infection, and attending poor-performing schools. Seroreverters are also subject to similar family, living, and community conditions to their HIV-positive peers, and the researchers suggested that this may account for their poor language and reading skills.

Rice et al. (2012) completed a comprehensive study of language development and disorders in HIV-positive children and children who were HIV-negative but born to mothers who were infected. The subjects were 468 children aged 7–16 years (306 HIV-positive and 162 seroreverters) who were involved in a cohort study at 15 sites in the United States and Puerto Rico. The children's language functioning was evaluated using the Clinical Evaluation of Language Fundamentals-4 (CELF-4) (Semel et al., 2003). Language impairment (LI) was classified as primary LI (Pri-LI) (LI with no cognitive or hearing impairment) or Con-LI (LI with cognitive or hearing impairment). Thirty-five percent of the children scored more than one standard deviation below the general population mean for the CELF-4. The rates of LI were comparable between the HIV-positive and the uninfected groups. The mean core language scores were also similar. The Pri-LI and Con-LI scores were similar across the two groups with 10% versus 12% for the Pri-LI and 24% versus 25% for Con-LI, respectively. Sixty-one percent of the children assessed did not have any LI at all. The children with Con-LI were more likely than those with Pri-LI or no LI to have had a detectable viral load and started on an ART regimen by 6 months of age. Early ART initiation may have been associated with Con-LI because those children experience more severe neurologic compromise from an early age. The study results are an indication that exposure to HIV in utero without infection puts children at risk for compromised language development.

Some of the first studies on language development and disorders in children with HIV were conducted in the United States and Europe. Given the differences in availability of medical care, income, living conditions, child-rearing practices, and other cultural variables, it should not be taken for granted that those study results can be generalized to the African population; however, studies of children living with HIV in the Democratic Republic of Congo (Van Rie et al., 2008), Rwanda (Msellati et al., 1993), and Zimbabwe (Kandawasvika et al., 2011) found neurodevelopmental deficits that included the failure of receptive and expressive language development in children with HIV from infancy to adolescence.

Many of the studies on language development in South African children have been done in the context of comprehensive neurodevelopmental studies. Baillieu and Potterton (2008) conducted a study with 40 children at Harriet Shezi Pediatric HIV Clinic at Chris Hani Baragwanath Hospital, Gauteng, South Africa. The children were aged 18–30 months and were not receiving antiretroviral medications. Their viral load count was 12% of normal, indicating they were severely immunocompromised. The children were assessed using the Bayley Scales of Infant and Toddler Development-II (Bayley, 1993). Raw scores for the mental scales indicated the children's mean chronological age was 25 months, while their mean cognitive developmental age was 17.7 months, which was 7.63 months lower than their chronological age. The researchers provided a descriptive analysis of the children's language which revealed global language delay in 83% of the children.

Whitehead (2014) used the Bayley Scales of Infant and Toddler Development-III (Bayley, 2005) to assess a group of 27 HIV-positive and 29 HIV-negative children who were less than 12 months old and receiving care at the Empilweni Clinic at Rahima Moosa Mother and Child Hospital in Johannesburg, South Africa. The HIV-positive infants were assessed prior to beginning of ART and then for 12 months while on medication. The HIV-positive infants scored significantly lower when compared to the HIV-negative infants for language development at baseline, 3-, and 6-month follow-ups. By the second visit, 45% of the HIV-positive infants had a language delay. The HIV-positive infants' composite scores did not change over time. Whitehead suggested that the lack of change in the composite scores may have been due to improved care or possibly because ART preserved the infants' language function. Although the infants' developmental scores did not decrease over time, there was no significant improvement in language function.

Neurodevelopment of children with HIV was the focus of a study by Lowick et al. (2012) in Soweto, South Africa. The subjects were 5- and 6-year-olds who were HIV-positive and receiving ART. The comparison group consisted of 30 HIV-positive and 30 children whose HIV status was unknown but who were healthy and receiving routine immunizations at the Lilian Ngoyi Primary Health Care Clinic in Soweto. The children were assessed using the Griffiths Mental Development Scales-Extended Revised (GMDS-ER, Griffiths, 1996). The majority of children in both groups (90% of HIV-positive and 76% of HIV-negative children) had overall z-scores two standard deviations below average, but the HIV-positive group had a consistently higher proportion of children with low z-scores in all domains and overall. The children who were HIV-positive also had significantly lower scores on the hearing and speech subtests which assess receptive and expressive language.

In addition to communication disorders, school-aged children with HIV may exhibit learning deficits characterized by attention-deficit/hyperactivity disorder, learning disability, dyslexia, and difficulty with concentration (Brackis-Cott et al., 2009; Lewis et al., 1994). They may also have social-emotional deficits which can be evidenced by irritability, anxiety, and depression (Lewis et al., 1994). The previously mentioned study by Brackis-Cott et al. (2009) illustrates this. Thirty-five percent of the study children had been retained in school, 33% were currently attending special education classes, and 47% had a history of special education placement. Across groups, special education placement was most frequently attributed to problems with reading or math.

A summary of the studies on language development in HIV-positive children indicates that these children are at risk for poor language development (see Table 15.7). Specifically, the studies' results indicate the following:

A. Acquisition of preverbal and language milestones may be delayed in HIV-positive infants and toddlers as well as adolescents (Baillieu & Potterton, 2008; Brackis-Cott et al., 2009; Condini et al., 1991; Coplan et al., 1998; Davis-McFarland & Cowan, 1998; Lowick et al., 2012; Pressman, 1992).
B. The severity of a child's symptoms is likely to indicate the severity of the language development delay (Baillieu & Potterton, 2008; Coplan et al., 1998; McNeilly, 1998; Wachtel et al., 1994).
C. As children who are HIV-positive mature, they continue to be at risk for poor expressive language development (Brackis-Cott et al., 2009; Granzotti et al., 2013; Lowick et al., 2012; McCardle et al., 1991; Meyers et al., 2012; Tardieu et al., 1995; Wolters et al., 1995; Wolters et al., 1997).
D. As children who are HIV-positive mature, language deficits may increase (Coplan et al., 1998; Davis-McFarland & Cowan, 1998; Kandawasvika et al., 2011; Msellati et al., 1993; Wachtel et al., 1994; Whitehead, 2014).
E. Expressive language deficits are more common than receptive language deficits in children with HIV (Brackis-Cott et al., 2009; Condini et al., 1991; Coplan et al., 1998; Davis-McFarland & Cowan, 1998; McNeilly, 1998; Moss et al., 1996; Rice et al., 2012).

Table 15.7 Studies of language development and disorders in children with HIV

Study	Country	Participants	Ages	Assessments	Findings
Condini et al. (1991)	Italy	36 • 18 HIV+ • 18 seroreverters	18–30 months	• Observation of natural mother-child interactions for language samples • Brunet-Lezine Scale	• HIV+ children had shorter MLUs and poorer cognitive development • HIV+ children had "greater production difficulty" in the second year of life.
Pressman (1992)	USA	96 HIV+	4 months–17 years	• Preschool Language Scale • Peabody Picture Vocabulary Test • Expressive One-Word Test	• 69% had expressive and receptive language deficits.
Havens et al. (1993)	USA	60 • 26 HIV+ • 14 seroreverters • 20 controls	5–12 years	• Gardner One-Word Picture Test Reception and Expression	• All groups had low average language scores with expressive scores lower for HIV+ children • Seroreverters' scores are also low but not as low as HIV+ children's scores
Msellati et al. (1993)	Rwanda	436 • 50 HIV+ • 218 seroreverters • 168 HIV status unknown	Assessed at 6, 12, 18, and 24 months	• Bayley Scales of Infant and Toddler Development-II	• HIV+ children had higher incidence of high risk of neuro-developmental impairment (including oral-motor involvement) than other children
Tardieu et al. (1995)	France	33 HIV+	6 years	• Brunet-Lezine's Test • Examen pour L'Evaluation Du Language	• 44% of children had language delay or articulation disorders
Wolters et al. (1995)	USA	• 27 HIV+ vertically infected children • 9 HIV+ infected via blood transfusion • 21 symptomatic	1–10 years	• Reynell Developmental Language Scale • Clinical Evaluation of Language Fundamentals-Revised	• 55% had receptive-expressive language score differences of 12 points or greater with expressive language scores significantly lower than receptive score on both measures
Moss et al. (1996)	USA	83 HIV+	2–60 months	• Rated 16 variables representing five behavior domains including receptive and expressive language	• 55% of children had delayed receptive or expressive language with expressive language more delayed. Severity of delay was related to the stage of HIV infection

(continued)

Table 15.7 (continued)

Study	Country	Participants	Ages	Assessments	Findings
Davis-McFarland and Cowan (1998)	USA	• 54 HIV+ and seroreverters	6–25 months	• Early Language Milestones-2	• HIV+ group had lower receptive language scores at 6–9 months and 10–13 months. At 10–13 months, receptive language scores were higher than at 22–25 months. • Significant difference in total scores for 6–9 months and 22–25 months. Total language scores for 6–9 months were significantly higher than for 10–13 months.
McNeilly (1998)	USA	• 30 HIV+ w/ mild symptoms • HIV+ w/ moderate • symptoms • Seroreverters	15–36 months	• Preschool Language Scales-3	• Children with more severe symptoms had poorer language scores. • Seroreverters also had some LI.
Coplan et al. (1998)	USA	• 9 HIV+ • 69 seroreverters • 6 unknowns	6 weeks–45 months	• Early Language Milestones-2	• ELMS scores were lower for HIV+ subjects.
Hodson et al. (2001)	Scotland	• 4 HIV+	3–10 years	• Spectrographic analysis of speech onset time • Reynell Developmental Language Scale • Language samples	• Each child scored at least 1 SD below normal on the language test and had inconsistent motor control regardless of their symptomology.
Baillieu and Potterton (2008)	South Africa	40 HIV+	18–30 months	• Bayley Scales of Infant and Toddler Development-II	• 83% of HIV+ children had global language delay.
Van Rie et al. (2008)	Democratic Republic of Congo	160 • 35 HIV+ • 35 seroreverters • 90 controls	18–72 months	• Bayley Scales of Infant and Toddler Development-II • Rossetti Infant-Toddler Language Scale • Snijders-Oomen Nonverbal Intelligence Test • Peabody Developmental Motor Scales – second edition	• 85% of HIV+ children had delays in language expression. • 77% had delays in language comprehension and cognitive and motor development. • Seroreverters also exhibited delays in each area. • All delays for the HIV+ and seroreverters were significantly higher than for the control group.

(continued)

Table 15.7 (continued)

Study	Country	Participants	Ages	Assessments	Findings
Brackis-Cott et al. (2009)	2009	• 340 • 206 HIV+ • 134 seroreverters	9–16 years	• Peabody Picture Vocabulary Test-III • Wide Range Achievement Test-3	• Both groups scored poorly on the PPVT, but HIV+ children's scores were significantly lower than HIV- children's scores on both tests.
Kandawasvika et al. (2011)	Zimbabwe	• 598 • 65 HIV+ • 188 seroreverters • 287 unexposed • 58 unknown status	assessed at 3, 6, 9, and 12 months	• Bayley Scales of Infant and Toddler Development-II	• HIV+ infants showed higher risk for poor neurodevelopment at 3- and 6-month assessments than study infants. • At 12 months, pre-language development was poorer for HIV+ infants than for others in the study.
Rice et al. (2012)	United States and Puerto Rico	• 468 • 306 HIV+ • 162 seroreverters	7–16 years	• Clinical Evaluation of Language Foundations-4	• 35% of HIV+ children scored more than 1 SD below the CELF-4 mean. • Scores for Pri-LI and Con-LI were similar across both groups. • 61% had no language impairment
Lowick et al. (2012)	South Africa	• 30 HIV+ • 29 HIV−	5–6-years	• Griffin Mental Development Scales-Extended Revised	• 90% of HIV+ and 76% of HIV- children had overall z-scores <2, but HIV+ children had significantly lower scores on the hearing-speech subtests.
Granzotti et al. (2013)	Brazil	31 HIV+	3;4–7; 11 years	• ABFW – Children's Language Test	• 77% of children exhibited impaired phonology and receptive language. • Expressive language was not assessed.
Whitehead (2014)	South Africa	• 29 HIV+ • 27 HIV−	<12 months assessed at 3, 6, and 12 months	• Bayley Scales of Infant and Toddler Development-III	• The HIV+ infants scored significantly lower when compared to the HIV- infants for language development at baseline, 3, and 6 months. • No significant improvement in language function occurred over time, but developmental scores did not decrease.

F. Seroreverters are at risk for delayed language development (Brackis-Cott et al., 2009; Condini et al., 1991; Davis-McFarland & Cowan, 1998; Havens et al., 1993; McNeilly, 1998; Scott, 1994; Rice et al., 2012; Wachtel et al., 1994).
G. Language skills may continue to develop in children with HIV but at a slower rate than in their seroreverted peers (Brackis-Cott et al., 2009).
H. HIV/AIDS has the same effect on Southern African children's speech and language development as in American and European children (Baillieu & Potterton, 2008; Kandawasvika et al., 2011; Lowick et al., 2012; Msellati et al., 1993; Van Rie et al., 2008; Whitehead, 2014).
I. ART may prevent further language deterioration (Whitehead, 2014).
J. Encephalopathy is a precursor to language compromise (Coplan et al., 1998; Moss et al., 1996).

Neurodevelopmental Studies of South African Children

As children mature, a decline in expressive language function may be a precursor to general cognitive decline. Coplan et al. (1998) noted that "Language deterioration is seen frequently in the absence of abnormalities on neurologic examination or CNS imaging and may precede evidence of deterioration in global cognitive ability" (p. 8).

Studies conducted in South Africa provide important information about neurodevelopmental challenges faced by children with HIV infection and indicate that delays in neurocognitive and language development are hallmarks of HIV infection. Encephalopathy is common in children with HIV. Conditions associated with the disorder include impaired brain growth, delays in or loss of developmental milestones, muscular weakness, loss of fine motor coordination, and delayed and poor language development or deterioration of communication skills (Baillieu & Potterton, 2008; Davis-McFarland, 2000; Drotar et al., 1997; Ferguson & Jelsma, 2009; Hattam et al., 2014; Whitehead, 2014). In a study conducted by Hattam et al. (2014) at a large regional hospital in Gauteng, South Africa, 19% of children between the ages of birth to 5 years and 11 months had static or progressive encephalopathy. Drotar et al. (1997) noted that motor coordination, muscle tone, and reflexes are most consistently and strongly affected by HIV infection and poor motor development may be a sign of encephalopathy. Cerebral vascular accident (CVA) is another neurological disorder that can occur in children who are HIV-positive or have AIDS. Children who survive CVAs can suffer hemiparesis, paralysis, dysarthria, oral and verbal apraxia, and dysphagia (Larsen, 1998).

In Whitehead's (2014) study using the Bayley Scales of Infant and Toddler Development-III (Bayley, 2005) to evaluate a group of HIV-positive and HIV-negative infants in Johannesburg, South Africa, she found the HIV-positive children scored significantly lower than the HIV-negative subjects on motor development at each assessment period with no improvement in motor function over time. The percentage of infants with delays in motor development increased from 29% at the beginning of the study to 41% at the 6-month follow-up. The infants' composite scores did not change, indicating that they continued to develop new motor skills, but they were still more delayed than their HIV-negative peers. Cognitive development of the HIV-positive infants was significantly slower compared to the HIV-negative group on their first clinic visit, but by the 6-month follow-up, only 30% of the HIV-positive infants had cognitive delay. At the 12-month assessment, there were no significant differences between the two groups in cognitive development, which may indicate that ART cannot reverse developmental delay, but it may prevent further delay.

Potterton et al. (2009) used the Bayley Scales of Infant and Toddler Development-II (Bayley, 1993) to evaluate 122 children, in Soweto, South Africa, who were under the age of 30 months (mean age 18.5 months). Only 16% of the children were receiving antiretroviral medication. Seventy-two percent of the children had severe motor delay, while 52% had severe cognitive delay. Motor skills were more severely affected than cognitive development. The authors sug-

gested that poverty, in the face of HIV infection, might pose an additional risk factor for the children's development.

To document the motor performance of a group of HIV-positive children aged 6 months to 31 months in Cape Town, South Africa, Ferguson and Jelsma (2009) assessed 51 HIV-positive children and age-matched controls whose HIV status was unknown using the Bayley Scales of Infant and Toddler Development-II (Bayley, 1993). Thirty-four of the HIV-positive children were receiving ART. Sixty-seven percent of the HIV-positive children exhibited significant motor delay as opposed to 6% of children in the control group. Ferguson and Jelsma noted that in addition to different outcome scores, the children with HIV also had significantly more hospital admissions, single parents, and differences in housing environments. They considered these intervening variables that could contribute to cognitive development related to environmental stimulation and opportunities for learning. The researchers recommended that HIV-positive children be monitored over time to determine whether motor development delay can be minimized with treatment.

Strehlau et al. (2016) studied the effects of pre- and post-ART on a group of 195 HIV-positive children in South Africa who were less than 24 months old (median age 8.8 months). They were assessed with the Ages and Stages Questionnaires (ASQ) (Squires & Bricker, 2009) before they began ART and at various age-appropriate intervals after beginning therapy. ASQ assesses functioning in five domains: communication, gross motor, fine motor, problem solving, and personal-social development. The mean time to viral suppression was 9.4 months. Better outcomes were reported on tests after medication therapy than prior to therapy with fewer children failing the gross motor, fine motor, problem solving, and personal-social domains, but there was no change in the communication domain. ART can lead to significant improvements in neurodevelopment, but developmental delays may persist.

Lowick et al. (2012) used the GMDS-ER (Griffiths, 1996) to assess HIV-positive and non-exposed children. The developmental z-scores on GMDS-ER for the HIV-positive children indicated severe delay in 90% of the children, while 76% of the children in the control group also had low z-scores. Forty-seven percent of the HIV-positive children exhibited developmental delay as evidenced by their scores, compared to only 10% of the comparison group. The two groups differed significantly in the locomotor domain which assesses eye-hand coordination: fine motor skills, manual dexterity, and visual monitoring skills. The assessment revealed that 47% of the HIV-positive children had very low z-scores in this domain, while only 7% of the HIV-negative children had scores at the same level.

Govender et al. (2011) used the Denver Developmental Screening Test-II (Frankenburg et al., 1990) to document the range and extent of neurological and neurobehavioral complications associated with pediatric HIV infection. They evaluated 78 children who were HIV-positive and receiving medical care at War Memorial Children's Hospital and Groote Schuur Hospital in Cape Town, South Africa. Seventeen of the children were not receiving ART. Forty-six children (59%) had abnormal neurological findings characterized by HIV encephalopathy, pyramidal long tract signs, cerebrovascular events, proximal weakness, distal weakness, and epilepsy. In addition to the neurological findings, 39 (50%) of the children had behavioral problems as assessed by the Aberrant Behavior Checklist Scale (ABCS; Aman & Singh, 1985). Twenty-one (27%) children had features of hyperactivity; 13 (17%) scored in the mild-moderate range for lethargy; six (17%) children scored high on the irritability scale; and six (17%) children were evaluated to have stereotypical behaviors.

A neuroimaging study by Hoare et al. (2012) of 12 asymptomatic (slow progressors) HIV-positive children aged 8–12 years in Cape Town, South Africa, revealed they had significantly poorer visuospatial processing, visual memory, and executive functioning scores on the Wechsler Abbreviated Scale of Intelligence (Wechsler, 1999) than their matched controls. The "slow progressors" also scored lower on tests of executive function and attention than did their non-infected peers. The

research suggested that nerve demyelination may be a prominent disease process in pediatric HIV infection.

A summary of studies on neurodevelopment in children with HIV indicates they are at risk of neurocognitive challenges as infants, which continue as they mature (see Table 15.8). Specifically, the studies indicate the following:

A. Motor function appears to be the most severely compromised aspect of development in children with HIV (Drotar et al., 1997; Govender et al., 2011; Potterton et al., 2009).
B. HIV infection can result in decreased intellectual function and compromised development of cognitive functions, including visuospatial processing, visual memory, and executive function (Hoare et al., 2012; Lowick et al., 2012).
C. HIV infection can result in neurological abnormalities, including encephalopathy, stroke, lymphoma, and epilepsy (Govender et al., 2011; Hoare et al., 2012; Lowick et al., 2012; Whitehead, 2014).
D. Exposure to HIV in utero without infection can result in the same neurodevelopmental delay and compromise as seen in children who are HIV-positive (Hoare et al., 2012; Lowick et al., 2012).
E. Older children with HIV may be at higher risk for repeating grades or special education placement (Brackis-Cott et al., 2009).
F. ART may prevent further neurocognitive compromise, but does not reverse developmental delay (Strehlau et al., 2016; Whitehead, 2014).
G. A significant percentage of children who are HIV-positive will develop encephalopathy (Govender et al., 2011; Hattam et al., 2014; Hoare et al., 2012).
H. Cognitive development in children with HIV can be compromised by poverty, poor housing, parenting by ill parents, poor nutrition, and poor educational opportunities (Brackis-Cott et al., 2009; Govender et al., 2011).
I. In addition to neurocognitive and motor delay and disorders, children with HIV may exhibit behavior deficits characterized by hyperactivity, irritability, and stereotypical behaviors (Govender et al., 2011).

Intervention Services for Children with HIV/AIDS

Antiretroviral medications have a positive and compelling effect on the health and longevity of children born with HIV (Russel et al., 2007). Given the debilitating effects of HIV infection and AIDS, it is imperative that children have appropriate medications, habilitation, and rehabilitation services, because medications alone cannot reverse the debilitating effects that accompany HIV infection (Koekkoek et al., 2006; Strehlau et al., 2016; Whitehead, 2014). Medications in combination with other habilitation approaches can be successful in improving children's developmental progress and well-being. In Rwanda, researchers investigated strengths and sources of resilience in Rwandan children and families at risk of psychosocial difficulties due to HIV/AIDS (Betancourt et al., 2011). They found there were five resources such as perseverance (kwihangana), self-esteem/self-confidence (kwigirira ikizere), family unity/trust (kwizerana), good parenting (kurera neza), and collective/communal support (ubufasha abaturage batanga) that when found within the individual child as well as the family and community systems supported children's development of personal resilience, which in turn prevented mental health problems. Programs for developing resilience in children with HIV can also lead to beneficial developmental outcomes. According to Boivin et al. (2008), computerized cognitive rehabilitation therapy may be a useful approach for supporting cognitive development in children with HIV. Their study indicates that computer games increased attention span and maze learning in HIV-positive children in Uganda. In addition, training caregivers on how to enhance their children's cognitive and emotional development appeared to be successful in increasing their children's receptive and expressive language as well as their overall cognitive ability (Boivin et al., 2013). Home environment appears to have a role in children's cognitive development. Coscia et al. (2001) found that home environment was predictive of IQ and cognitive development in children living with HIV. Educating parents about how to develop a stimulating home environment to encourage learning, and playing with their chil-

Table 15.8 Studies of neurocognitive development in children with HIV

Study	Country	Participants	Ages	Assessments	Findings
Drotar et al. (1997)	Uganda	436 full-term babies • 79 HIV+ • 241 seroreverters • 116 HIV−	<6 months (assessed at 6, 9, 12, 18, and 24 months)	• Bayley Scales of Infant and Toddler Development-II	• HIV-infected infants had greater deficits in motor development and neurological status, and more frequent and earlier onset of motor and neurological abnormalities than uninfected and seroreverted infants.
McGrath et al. (2005)	Tanzania	327 • 246 HIV+ • 53 seroreverters	6–18 months (assessed at 6, 12, and 18 months)	• Bayley Scales of Infant and Toddler Development-II	• 25% of HIV+ and 12% of seroreverters were developmentally delayed • BSID scores for all children decreased with increasing age
Ferguson and Jelsma (2009)	South Africa	52 • 1 HIV+ • 51 HIV−	6–31 months	• Bayley Scales of Infant and Toddler Development-II	• 67% of HIV+ infants versus 6% of controls had significant motor delay.
Potterton et al. (2009)	South Africa	122 HIV+	<30 months (median age 18.5 months)	• Bayley Scales of Infant and Toddler Development-II	• 72% had severe motor delay, while 52% had severe cognitive delay. • Motor skills were more severely affected than cognitive skills
Brackis-Cott et al. (2009)	United States	340 • 206 HIV+ • 134 seroreverters	9–16 years	• Peabody Picture Vocabulary Test • Wide Range Achievement Test-3	• 35% had been retained in school; 33% were in special education classes; and 47% had a history of special education placement.
Govender et al. (2011)	South Africa	78 HIV+	8–12 years	• Aberrant Behavior Checklist Scale • Denver Developmental Scales-II	• 49% had abnormal neurological exams (encephalography, strokes, distal weakness, and epilepsy); • 50% had behavioral problems; and 27% were hyperactive.
Hoare et al. (2012)	South Africa	24 • 12 HIV+ asymptomatic • 12 HIV−	9–16 years	• Wechsler Abbreviated Scale of Intelligence (WASI) • Brain imaging	• The "slow progressors" performed significantly worse than controls on the WASI Verbal and Performance IQ scales and on visuospatial processing, visual memory, and executive functioning tests. • The HIV+ children's brain images also showed corpus callosum abnormalities.

(continued)

Table 15.8 (continued)

Study	Country	Participants	Ages	Assessments	Findings
Lowick et al. (2012)	South Africa	30 HIV+ 30 HIV−	5 and 6 years	• Griffin Mental Development Scales-Extended Review	• Developmental scores revealed 90% of HIV+ children had severe delay and lower mean scores in all domains.
Hattam et al. (2014)	South Africa	N/A	Birth–5;11 years	• Medical record review	• 19% of HIV+ children had encephalopathy.
Whitehead (2014)	South Africa	29 HIV+ 27 HIV−	<12 months (assessed at 3, 6, and 12 months)	• Bayley Scales of Infant and Toddler Development-III	• HIV+ infants scored lower on motor development than HIV- infants. • Impaired infants increased from 29% to 41% at the 6-month assessment. At 6 months, 30% of HIV+ infants had lower cognitive development scores than HIV- infants, but by 12 months, there was no difference between the groups. An indication that ART was preventing further delay.
Strehlau et al. (2016)	South Africa	195 HIV+	<24 months (median age 8.8 months)	• Ages and Stages Questionnaire	• Post-ART assessment showed improved motor scores for 18% of the infants, but most continued to exhibit motor delay.

dren to enhance their learning, can support and encourage cognitive development in children.

Care for a child with HIV can be complex and must be continuous. When children have access to the required care and intervention, the progression of the disease may be slowed, thereby extending the child's longevity and quality of life, but prevention of complete debilitation may not always be possible. Children who suffer poor oral-motor development or dysphagia because of lesions, infections, or CNS compromise must have treatment as well as nutritional support. Some children may require oral-motor therapies to support their development of chewing, sucking, and swallowing as a precursor to oral speech development. Long-term speech–language therapy may be necessary to help the child develop communication skills that will allow successful interaction and socialization with family and peers. Support for literacy development may also be necessary. Appropriate educational placement and supplemental instruction, as needed, can serve to support literacy development and learning.

Physical and occupational therapies can facilitate progress with muscular development and/or strength and counteract the debilitating potential of HIV infection. The child may also need the use of augmentative communication systems and strategies if they are unable to develop or use oral speech. Regular hearing screenings should also be part of the constellation of services the child receives. In addition, screenings to monitor intellectual development and interventions to prevent intellectual deterioration should certainly be planned.

Challenges

In poorly resourced communities, there are many challenges in the care of children with HIV infection. If there are no local or accessible health facilities equipped to serve children with HIV infection, children may go without much-needed medical attention and medication. Long commutes to distant medical facilities are impossible for some because of financial and transportation constraints. In these situations, families are at risk of not having the care their children require. Even when resources and care are available, the shame and stigma associated with HIV infection in some communities may prohibit parents from seeking assistance for their children.

Outlook: Tasks Ahead for Speech–Language Therapists Working with Children with HIV/AIDS

An additional barrier to the care and treatment of children who are HIV-positive may be lack of information on the part of health professionals about the need for therapies in addition to medication (Hattam et al., 2014). In their study of communication development in 204 children aged from birth to 5 years in a regional hospital in Gauteng Province, South Africa, Hattam et al. had medical practitioners complete a questionnaire to survey their perceptions and practices regarding general and communication development of HIV-positive children who were seen in the clinic. In addition to the completed questionnaires, the researchers also reviewed the medical charts of the 204 children in their study. Their review indicated that although it was obvious from the children's medical charts that they were suffering many of the developmental challenges and illnesses that are common in children with HIV, there was no documentation in the children's charts of referrals for physical, occupational, or speech therapy or audiological evaluations. The questionnaire respondents indicated that physicians may not be aware of the need to refer children for neurodevelopmental assessments and therapies. The study points to the need for SLTs as well as other professionals to make every effort to educate physicians and other healthcare professionals about the importance of their role in ensuring children with HIV get the necessary developmental assessments and therapies.

SLTs are primarily concerned with habilitation and rehabilitation of communication; however, when working with children with HIV, there must be an additional priority. Without proper and continuous use of antiretroviral medication, children will not be able to benefit from speech–language therapy. SLTs have the responsibility to advocate for proper medication for their clients. They must also work with parents and caregivers to help ensure that children are compliant with their medications, taking them as they should and impressing upon them the relationship between their physical and communication health and their medications.

Case Study

The following case study provides an "up close and personal" description of a South African child with HIV, the neurocognitive and communication challenges that accompany the disease, and the habilitation and rehabilitation strategies that can be used to persuade and support development.

Kwanele was born in KwaZulu-Natal province. His mother made her first visit to the regional prenatal and pediatrics clinic, which was 56 miles from her home, during her second trimester of pregnancy. A lack of transportation had prevented her from coming to the clinic earlier in her pregnancy. She was tested for HIV during her prenatal visit. Test results were negative.

Kwanele was delivered at term at home by a midwife. His mother brought him to the clinic when he was 9 months old. She was breastfeeding him, but he was not gaining weight as her other two children had at his age. He had a recurrent fever and was lethargic. Kwanele and his mother were tested for HIV. His mother was HIV-positive, and Kwanele's test was positive for HIV antibodies. Kwanele's mother reported that her husband had recently died of AIDS. The staff arranged for Kwanele and his mother to stay at the clinic overnight so she could receive counseling and medications.

During the clinic visit, Kwanele was evaluated by the SLT, Anna, and a pediatric nurse. The nurse found that Kwanele had weak muscle tone in his legs and lower back. He seemed alert to his environment, he followed objects visually, he could hold his head upright when placed on his stomach, and he swiped at a brightly colored triangle the nurse dangled in front of him. A physical examination and blood work indicated that Kwanele was suffering from lymphadenopathy. He had a fever of 101 degrees. He had stage I HIV infection.

Anna asked Kwanele's mother what sounds Kwanele made at home. She said he cooed occasionally, but he was not babbling as her other children had at his age. When Anna tried to stimulate Kwanele to vocalize by talking to him, putting toys in his hand, and singing to him, he looked at her but did not vocalize. His mother said he looked in her direction when she spoke to him. Based on her evaluation and his mother's input, Anna surmised that Kwanele's hearing was adequate, but he did not have age-appropriate preverbal language skills. She knew his language skill development was at risk if future tests confirmed his HIV-positive status. Anna questioned Kwanele's mother about the language development of her 6-year-old son and 8-year-old daughter. According to his mother's report, his siblings' development appeared to be age appropriate. Anna gave Kwanele's mother a simple chart of speech and language and other developmental milestones for infants' first year of life. She told her she could encourage Kwanele's language development by talking to him, telling him stories, singing to him, and having his brother and sister play games with him. She also told her it was very important that she and Kwanele take their medications each day as directed.

Kwanele's mother received counseling about her HIV status, the medications, and the importance of adhering to the dosage schedule. They were scheduled for a return visit in 6 months.

The next time Anna saw Kwanele and his mother, Kwanele was 18 months old. They had not been able to return to the clinic because they did not have dependable transportation and his mother had to work on her neighbor's farm each day to provide food and shelter for her family. She had been getting their medications by sending her prescription to the clinic with a neighbor.

Kwanele appeared to be doing well. His mother reported that she was giving him his medications regularly and he seemed to have a normal appetite. His weight and height were at the 85th percentile. He was crawling, but not walking. He appeared to have normal hearing as he responded to his mother's voice by looking at her when she spoke to him and by giving an affirmative head nod when she asked him if he wanted his toy. Anna gave Kwanele a language evaluation. He used four words consistently ("yes," "toy," "give," "bottle"); he followed simple directions from his mother ("give me the toy," "sit down," "look at the book"); he understood "no"; he waved his hand for "goodbye"; and he combined syllables with intonation as if talking. Anna determined that Kwanele was approximately 6 months delayed in his language development. Kwanele's mother told her she did not know when she would be able to return to the clinic, as transportation was not regularly available. Anna gave her a home program to encourage Kwanele's speech and language development. She encouraged her to point to and tell Kwanele the names of objects, tell him stories, and direct his attention to her face whenever she spoke to him. She said she could encourage Kwanele's speech by encouraging him to name the things he wanted. She told her to teach Kwanele to imitate her actions such as clapping her hands and playing hand games. She said she should talk to Kwanele about what she was doing while she bathed, fed, and dressed him. She said she should identify colors and count items for Kwanele and use gestures such as waving goodbye to help convey meaning. She advised her to expand Kwanele's utterances by adding two words to his single words when he spoke. She told her to have his older brother read to him each day. As Kwanele and his mother were departing, Anna praised her for making sure Kwanele took his medications, and she encouraged her to continue to do so.

Kwanele and his mother did not return to the clinic, and when Kwanele was 48 months old, his mother died. Kwanele's aunt Thandie brought Kwanele and his brother and sister to Soweto to live with her. She took Kwanele to Baragwanath

Hospital. He had not had his antiretroviral medication during the later stages of his mother's illness. He had developed hepatosplenomegaly and parotid enlargement. He was at stage II HIV infection. He was hospitalized for 2 weeks for treatment and then discharged in his aunt's care. When he returned to the hospital for his 1-month checkup, his condition had improved significantly. A pediatric SLT, Maggie, and physical therapist evaluated him. At 48 months, his receptive language development was at a 24-month level, and his expressive language was at an 18-month level. He did not exhibit consistent articulation of any phonemes, and his expressive vocabulary consisted of 12 words. He could follow simple commands ("get the toy," "give her the cup," "look at the picture"), and he seemed to understand the names of familiar objects. He was enrolled in speech–language therapy and physical therapy at the hospital. He was still not walking independently.

Kwanele's physician recommended that Thandie take advantage of a six-session parenting class the hospital's social workers offered to parents of HIV-positive children and children with other chronic illnesses. She could learn strategies for teaching Kwanele and encouraging his learning. Thandie took advantage of the class. She enrolled Kwanele in a community childcare center near their home, which he attended 3 days a week. Maggie began activities to build Kwanele's speech and language skills. Because Kwanele had such a poorly developed phonemic system, she targeted the developmentally earliest developing sounds for remediation, progressing from auditory discrimination to imitation, and then production of single phonemes in isolation. Kwanele eventually progressed to articulation of sounds in syllables and then words. As each phoneme group was mastered, they moved on to the next phoneme group. For language development, Maggie used play themes to model language and speech and incorporated scaffolding activities to help Kwanele move from one-word utterances to two- and three-word phrases. As his physical therapy progressed, Kwanele's speech and articulation improved. By age 6, Kwanele's receptive language skills were age-appropriate, and his expressive language skills were at the level of a 5-year-old. He could point to and name colors. He used four-word sentences, but his expressive vocabulary consisted of approximately 600 words.

When Kwanele was aged 7, he began school. He continued to receive speech–language therapy and to make progress with expressive language development. In preparation for his enrollment in school, Maggie began to expose Kwanele to books by having him "read" the pictures and tell her about the stories. He could give her the sense of the stories, but he sometimes could not remember what he told her when she asked him about the stories later. At school, Kwanele had difficulty learning to read and exhibited typical symptoms of dyslexia. He reversed letters and sometimes put letters and syllables in the wrong order. He spelled phonetically. Maggie visited Kwanele's school and spoke with his teacher about the curriculum so she could plan therapy activities to support his literacy development. She worked with Kwanele on phonemic awareness and word recognition as well as speech articulation and development of higher-level language concepts. He made slow but steady progress. Maggie also taught Kwanele to slow his rate of speaking to increase his intelligibility. He was an enthusiastic student. He enjoyed school and his schoolmates. Despite his language deficits and literacy limitations, he was well-liked by his classmates and was always included in their activities.

By age 12, with the help of Maggie and his teachers, Kwanele was able to read well enough to learn from his textbooks if he read slowly and asked questions to clarify points he did not understand. His speech was intelligible enough for him to be understood by an attentive listener. He was very outgoing, and despite his reading and communication limitations, he made friends. He was well-liked in his community and became an altar boy at his church.

Kwanele continued to go to Baragwanath Hospital regularly for treatment of his HIV infection and for his speech and physical therapies. Over the years, he became a volunteer with a national non-profit AIDS advocacy organization. He completed school at 18. It had taken him an extra 2 years to complete his schooling, but he had a good academic background and some vocational training in consumer services. Upon graduation, Kwanele was offered a job with the

advocacy organization as a community AIDS advocate. He was responsible for raising community awareness about HIV/AIDS, explaining infection prevention strategies, and finding medical and community services for people with HIV.

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16

Hear Africa! Improving Language Development, Education, and Participation of Children with Severe Sensorineural Hearing Loss in Tanzania

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Introduction

When the World Health Organization (WHO) published recent key data on deafness and hearing loss, once again a severe global health issue came to light. An estimated 466 million affected persons worldwide, many of them children, suffer from hearing loss at disabling levels. The suggestion that the majority of cases could be prevented or provided with hearing aids or cochlear implants (CI) at an early stage is even more devastating (WHO, 2021). Scientific and medical endeavors to comprehend data on the prevalence, risk factors, and impact of hearing impairment for those affected focusing on sub-Saharan Africa (SSA) are manifold, some of which efforts focus on hearing impairment in Tanzania and are therefore presented exemplarily in the following.

Research to date has focused on the prevalence of hearing loss and hearing impairment at different ages, some of which has investigated hearing impairment in children in different Tanzanian regions. Bastos et al. (1995) examined the prevalence of middle ear diseases and hearing impairment among school children in rural and urban Northern Tanzania. The results showed that in the urban areas, children were more often affected by high-frequency hearing impairment and speech impairing hearing loss than in the rural areas (Bastos et al., 1995). Minja and Machemba (1996) carried out a study among 802 primary school students in different parts of Dar es Salaam, Tanzania, with regard to the prevalence of otitis media, sensorineural hearing loss, and cerumen impaction. They found that more than one-fourth (27.7%) of all examined children had ear disease, 8.7% of whom had sensorineural hearing loss. Rural areas were more impacted by chronic otitis media and sensorineural hearing loss than urban areas. A connection has been drawn between certain causes of hearing loss and insufficient medical treatment opportunities (Minja & Machemba, 1996). A more recent study focusing on different primary schools in the rural Kilimanjaro region found hearing impairment among 7.1–16.7% of the examined children, depending on the respective school. Tympanic membrane perforation, otitis media, and cerumen impaction were the most common causes. The need for identification, prevention, and treatment opportunities with regard to the impact of hearing impairment on the affected children's further development is emphasized (Solvang et al., 2020).

Another topic of interest has been the risk factors that are presumed to cause and/or aggravate the affected persons' hearing capacity. Freeland et al. (2010) examined risk factors for sensorineural hearing loss in Zanzibarian children. Besides infections and other causes, the ototoxic impact of medication given to children in inappropriate amounts has been suspected to be a common risk factor for hearing impairment among children (Freeland et al., 2010). Besides, the impact of noise in certain working environments, for example, in mines (Musiba, 2015) and industry (Abraham et al., 2019; Mndeme & Mkoma, 2012; Nyarubeli et al., 2019), on the workers' hearing ability has been examined.

Regarding the diversity of studies, study designs, and different approaches and forms of data collection, the current chapter is concerned with the topic of hearing impairment from an interdisciplinary point of view. Therefore, the research question of this chapter is to investigate how an interdisciplinary project with an early diagnostic approach could be successfully implemented in SSA to detect and care for children with hearing impairment. For this, hearing impairment is outlined first concerning frequency, clinical appearance, and classification in section "Hearing Impairment". Different types of hearing impairment and its various possible causes and risk factors are briefly explained, and the complexity of a

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health limitation which is common yet often preventable or at least a treatable condition in many parts of the world is expounded. Currently, different options exist for the detection and measurement of hearing impairment, its severity, and location.

Sections "Impact of Hearing Impairment on Language Development, Education, and Participation" and "Speech–Language Therapy for Hearing Impaired Children as an Interdisciplinary Care Approach" contextualize the consequences of hearing impairment for affected persons, taking into account regional and cultural backgrounds. Explanatory approaches are discussed to draw us closer to understanding why hearing impairment can have an especially heavy impact on life in structurally weak regions. In addition, the idea of an interdisciplinary therapeutic approach and the expected benefit for patients, in general, is presented; hearing-impaired persons in culturally different contexts could possibly benefit from such approaches. Desiderata for SSA with regard to facing the described challenge are then derived.

Finally, section "Methodology of a Multicentered Cross-Method Project: Hear Africa!" gives an overview of the project "Hear Africa!" which has been developed to face the challenges that hearing impairment poses to those affected. Over the course of 5 years, Hear Africa! aims to investigate the prevalence of an underrepresented yet high-impact condition in newborns in Tanzania to determine and expand local expert staff capacities and enable a region to adopt self-sufficiency in facing hearing impairment. An interdisciplinary, multi-centered, and culturally sensitive approach has been chosen to suggest possible methods and to collect the first data about severe infant hearing impairment in SSA. Regarding the aforementioned data on the prevalence of hearing impairment in school children, Hear Africa! also aims to examine the prevalence of hearing impairment in newborns to reveal the commonness of innate hearing loss. Consequently, hearing impairment should be detected at the earliest age possible to diminish negative influences on the affected children's development.

Background

Hearing Impairment[1]

Frequency and Clinical Presentation

Hearing impairment denotes loss of auditory function and may be mild, moderate, severe, or total. Hearing impairment is one of the most challenging health disorders with high prevalence globally. In Minority World countries, up to 5 newborns in every 1000 are affected congenitally. The early childhood prevalence of bilateral sensorineural hearing loss is described in the international literature as approximately 0.1–0.2% and for unilateral sensorineural hearing loss approximately 0.1% (Lieu et al., 2012; Morton & Nance, 2006; Smith et al., 2005; Watkin & Baldwin, 2011). Some children develop hearing loss in later childhood, so the prevalence of bilateral sensorineural hearing loss rises to 0.27% for children under 5 years of age and 0.35% during adolescence. School children show unilateral hearing loss at a prevalence between 3% and 6% (Ross et al., 2010). According to the WHO's "Global Burden of Disease Study 2017" (James et al., 2018), hearing disorders are among the eight most common diseases in all participating regions that most impair the quality of life. Worldwide, hearing disorders, along with oral disorders, headache disorders, anemias, and visual disorders, are among the most common diseases (James et al., 2018) although prevalent rates of hearing loss vary between regions. Rates are significantly lower in higher-income countries (0.5%) than in SSA (1.9%) and South Asia (2.4%), because of lower rates of infection, combined with better access to preventative measures and healthcare services (Graydon et al., 2019; WHO, 2017).

Hearing impairments are symptoms of various failures or functional losses. If a hearing loss occurs progressively in adulthood, it can be compensated for a long time but has insidious negative cognitive and social consequences. Often audio devices, such

[1]For a basic background to ear, nose, throat medicine (ENT), see Maqbool and Maqbool (2007).

as radio or television, are simply turned up, the better ear is turned toward the sound source, and in personal conversations, the visual sense is used by reading lips. Frequent questions or the wrong answers to questions as regards to the content as well as the tendency to use a louder speaking voice are further possible conspicuous features. If hearing loss occurs in children from birth or in early childhood, the entire development of the child is affected. Language may not develop at all or only very poorly, cognitive, and emotional development is delayed, and the child has greatly reduced educational opportunities. In society, this leads to the loss of taxpayers. However, almost every form of permanent hearing loss can be treated nowadays.

Classification and Causes of Hearing Impairment

Hearing impairments can be classified according to their degree and also their etiology (and the WHO classification of degrees of hearing loss can be viewed at the WHO (2021)).

The classification based on etiology is explained below. Hearing impairments are classified as (1) conductive, (2) sensorineural, (3) mixed, (4) neural, and (5) central hearing impairments based on the topographic and functional cause of the hearing loss (Fig. 16.1).

(1) Conductive hearing impairment

This type of hearing impairment occurs when the mechanical sound conduction in the middle ear is disturbed. In these cases, there is a lesion between the external auditory ear canal and the stapes footplate. Conductive impairments can be congenital or acquired. Congenital abnormalities in the middle ear can be, for example, atresia of the external auditory canal, tube blockades, ossicular anomalies, or the absence of the oval window. Acquired conductive impairments can have the following causes: wax or foreign bodies in the external canal; inflammatory diseases like external, acute, or chronic otitis; traumatic stenosis; tympanic membrane perforations; ossicular disruptions; tumors; or otosclerosis. The treatment of conductive hearing impairments depends on the causes and includes conservative, surgical, and technical (hearing aids) care. In a typical audiometric measurement, a sound conduction disturbance is represented by the difference of the measurement in air and bone conduction (Fig. 16.2). Audiometric measurement is explained further in section "Audiometric Diagnostics".

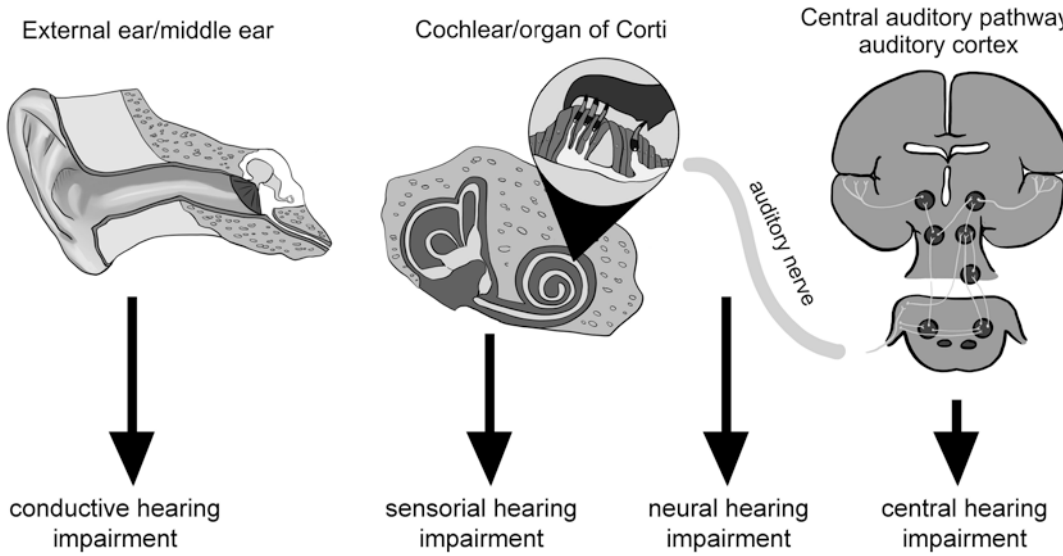

Fig. 16.1 Topographic functional classification of hearing loss according to the different levels of the hearing organ

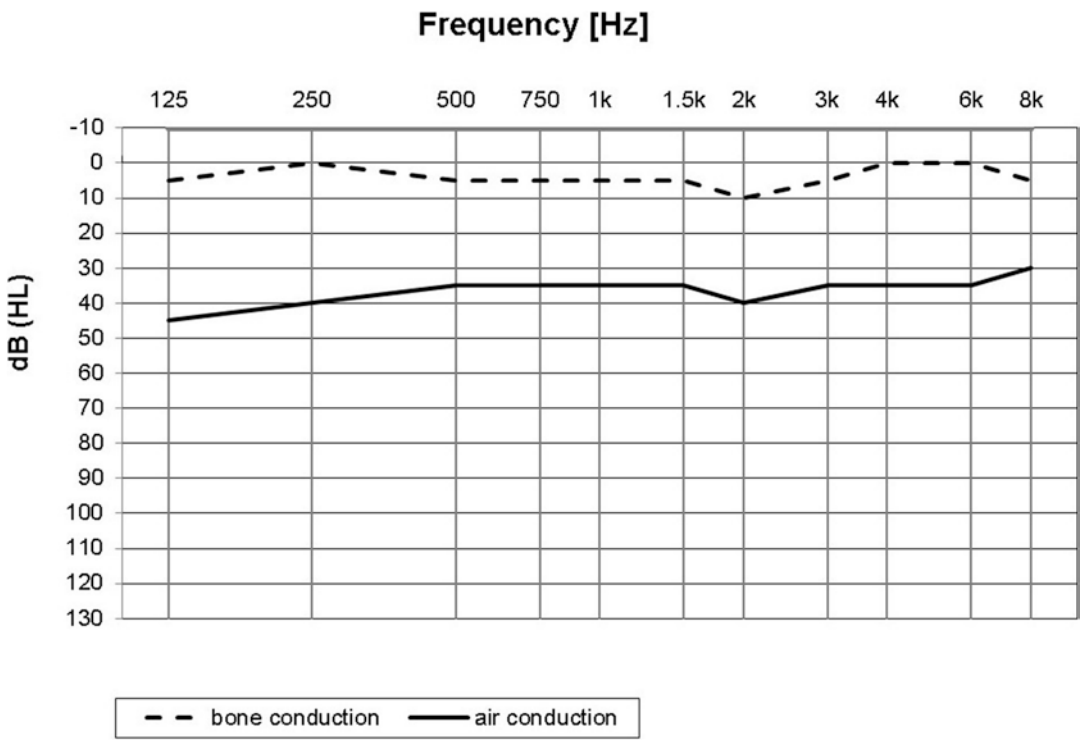

Fig. 16.2 Audiometric representation of a sound conduction disorder, measurement via air conduction (headphones) and bone conduction (bone conduction receiver)

(2) Sensorineural hearing impairment

In all sensorial hearing losses, the function of the organ of Corti is disturbed (see Fig. 16.1), that is, the outer or inner hair cells (or both) are affected. This means that the sound cannot be transformed and transmitted to the auditory nerve. Sensorineural hearing impairments can be congenital or acquired. Acquired hearing loss is defined in terms of pre-, peri-, and postnatally acquired hearing loss in relation to the date of onset. Acquired hearing impairment is systematically described as congenital (meaning from birth on) and progredient during childhood: In a typical audiometric measurement, a sound conduction disturbance is represented by no difference in the measurement of air and bone conduction (Fig. 16.3).

Congenital sensorial hearing impairments have the following causes:

- Genetic
  - Non-syndromal: autosomal recessive, autosomal dominant, X-linked chromosome
  - Syndromal: Alport's syndrome, Pendred's syndrome, Cogan's syndrome, Waardenburg's syndrome, Usher's syndrome, Goldenhar's syndrome, and others
- Acquired during pregnancy or birth:
  - Infections: toxoplasmosis, cytomegalovirus, meningitis, sepsis, herpes, mumps, rubeola
  - Metabolic: hyperbilirubinemia, hypothyroidism
  - Toxic: alcohol, thalidomide, quinine
  - Birth trauma: asphyxia, intracranial hemorrhages, cranial trauma, noise

However, unknown congenital reasons are the most common.

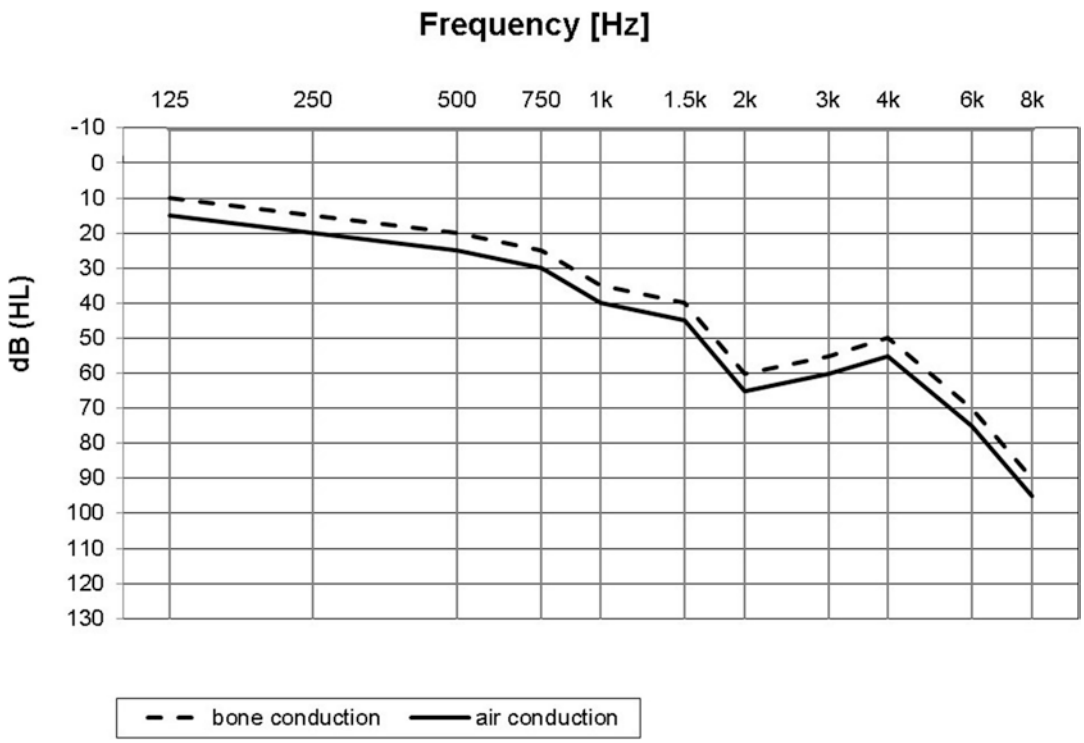

Fig. 16.3 Audiometric representation of a sensorial, neural, or central disorder, measurement via air conduction (headphones) and bone conduction (bone conduction receiver)

Acquired sensory hearing disorders often have mixed causes. The most common ones are as follows:

- Idiopathic sudden sensorineural hearing loss
- Infections: meningitis, herpes zoster infection
- Trauma: noise-induced trauma, skull base fracture
- Cardiovascular causes
- Presbyacusis

(3) Mixed hearing impairment
Conductive and sensorineural hearing impairments can be mixed. The audiometric measurement provides a graph as shown in Fig. 16.4. Typically, a cholesteatoma comes with a mixed hearing impairment.

(4) Neural hearing impairment
Neural hearing loss includes all forms of hearing loss affecting the auditory nerve (see Fig. 16.1). The main causes are tumors such as meningiomas, chordomas, chondrosarcoma, or inflammatory destruction of the petrous bone (cholesteatoma, cholesterol granuloma). A non-applied auditory nerve can also be the cause. The audiometric image is similar to that of a sensory hearing loss (Fig. 16.3) and requires further diagnostic clarification.

(5) Central hearing impairment
The perception, processing, and coding of acoustic signals occur in different structures of the brain. Trauma, bleeding, and tumors in these areas can lead to central hearing loss (see Fig. 16.1). The audiometric image is similar to that of a sensory hearing loss (Fig. 16.3) and requires further diagnostic clarification.

Audiometric Diagnostics

A number of diagnostic tests are currently available in the field of audiology. The specific tests will be chosen based on the symptoms and age of the person. Audiological tests are divided into subjective and objective tests. In subjective tests, the result depends on the cooperation of the tested per-

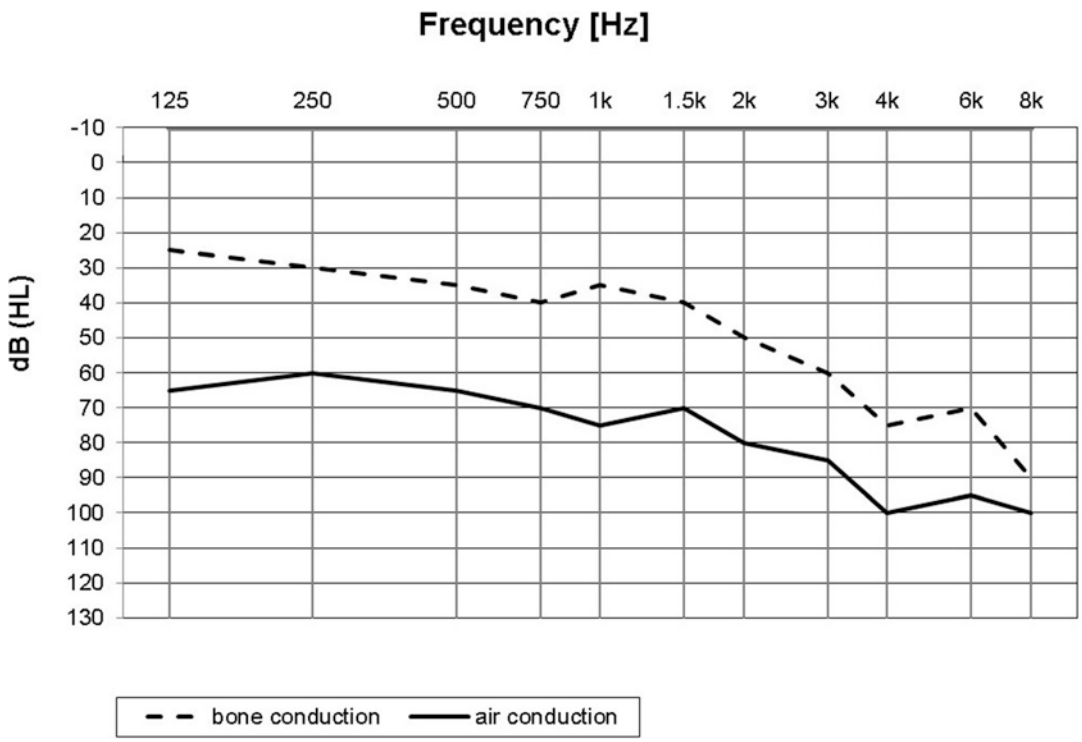

Fig. 16.4 Audiometric representation of a mixed conductive and sensorial disorder, measurement via air conduction (headphones; solid line) and bone conduction (bone conduction receiver; dashed line). Neither line is in the normal range

son. In objective tests, the equipment measures independently and the tested person must be present in silence. The most common tests are briefly described below. Further diagnostic test methods for differentiating between different clinical presentations can be found in the audiological literature (see, e.g., Hoth & Baljić, 2017).

Subjective Tests

(1) Pure tone audiometry

The purpose of this test is to check the different thresholds of hearing for the person at a variety of frequencies (see Fig. 16.5). The test requires the person to wear a pair of headphones for the measurement of air conduction and a bone conduction receiver for the measurement of bone conduction. The person has to press a button every time a sound is heard.

(2) Speech audiometry

This is a hearing test designed to check if the person is able to perceive and understand speech. A set of words (numbers, monosyllables) is presented to the patient which they must repeat back to the audiologist. The word lists are also presented at different intensities.

Objective Tests

Tympanometry

This test evaluates the middle ear condition. A probe tone is generated via a loudspeaker within an inserted tip into the external canal, and the reflected tone (from the eardrum) is measured after reaching the microphone in the tip.

Stapedius reflex measurement

Probe tones of different loudness and frequencies are generated triggering the stapedius reflex. The reflex includes the auditory nerve, parts of the brainstem, and the facial nerve.

Otoacoustic emissions (OAE)

This is a test of the outer hair cell function of the cochlea into the inner ear. The person can sleep or

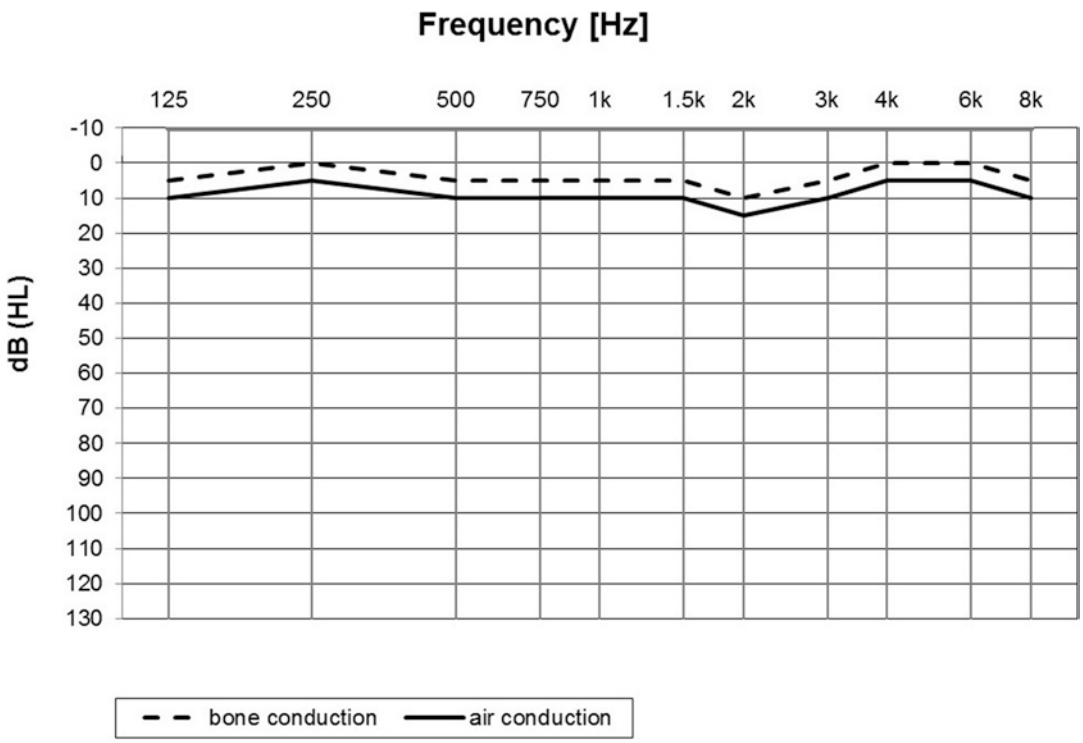

Fig. 16.5 Audiometric representation of a normal hearing measurement via air conduction (headphones) and bone conduction (bone conduction receiver). Both lines are in the normal range between 0 and 20 dB without distance

sit quietly and listen to the sounds. The results are recorded automatically. OAE is a method that is also used in universal newborn hearing screening (UNHS). Likewise, auditory brainstem response (ABR) screening can also be used for this purpose.

Auditory brainstem response (ABR)
This audiological test helps verify that the auditory nerve and auditory pathway are functioning normally. The person hears clicking noises, and electrodes are used to record the responses of the neural and central structures on a computer. One specific form of the auditory brainstem response screening is brainstem electric response audiometry (BERA) which will be discussed later.

Impact of Hearing Impairment on Language Development, Education, and Participation

Due to the physiologically irretrievable delay in maturation in untreated hearing impairment in early childhood, language development fails to take place, and serious consequences for the emotional, cognitive, and social personality development of a child can occur (Lüdtke, 2012). This minimizes the participation and educational opportunities of the affected child as now discussed.

Decreased hearing ability leads to a higher risk for limited participation in social contexts, for example, at school (Dobie & van Hemel, 2004). In many cases, teachers are not aware of problems such as hearing impairment which cause lack of participation and the perceived disintegration of their students or the solutions for such difficulties. For this reason, certain needs for support stay undetected. Consequently, both teachers and students need to be involved in the transfer of knowledge about hearing impairment and support for social participation and educational success (Schwab et al., 2019).

A study among students in randomly chosen primary schools in Nigeria (Olusanya, 2004) showed that common tests for hearing impairment as well as the WHO criteria for the classification of

hearing impairment levels are insufficient to uncover the full range of hearing impairment in children. The inability to perceive certain frequency levels can, for example, be problematic in the classroom. Especially in Minority World countries, classroom equipment is often rudimentary and therefore offers poor acoustics and high noise levels which deteriorate the learning environment for hearing-impaired students. Furthermore, the teacher is supposed to convey information verbally which can pose another high burden for students with severe hearing problems. As Olusanya (2004) states, "[it] is unlikely that the acoustic environment in many schools can be improved sufficiently to make the listening conditions more conducive because of the cost implications" (p. 1226) which makes the early detection of decreased hearing ability as well as the deliberate consideration of simple measures, such as positioning hearing-impaired children in front and closer to the teacher, even more important.

A study on the supply of hearing-impaired adults with hearing aids and therapeutic health care in Sweden (Turunen-Taheri et al., 2019) detected that hearing impairment had a stronger negative effect on the lives of affected women than men. Whereas both women and men achieved equally good results in audiological treatment, fewer women than men received this type of health care. In addition to gender differences concerning impaired hearing frequencies and the need for one- or both-sided hearing aids, the study also showed some gender-specific social impacts, for example, hearing-impaired women were more likely to live alone (Turunen-Taheri et al., 2019). The gender-specific increased negative impact of hearing impairment on social participation means creates an even more severe problem for many low-income countries as females are often underprivileged compared to males, which deteriorates precarious life situations even more.

Finally, the country as a whole suffers from the limited participation of persons with disabilities such as hearing impairment who are much less likely to achieve high academic levels and thus will not be able to contribute to the country's economy as taxpayers (Graydon et al., 2019). Early intervention measures, some of which are presented in the following chapter, help treat hearing impairment and enable children to become an active part of society.

Speech–Language Therapy for Hearing-Impaired Children as an Interdisciplinary Care Approach

As speech and language development starts to take place at a very young age, hearing-impaired children should receive their diagnosis and speech–language therapy (SLT) as early as possible to optimally accompany the process of language building and relationship building (Kovačević et al., 2010). The general aim of an individual and interdisciplinary long-term therapeutic approach to serve the needs of hearing-impaired children's language development from newborn to adult is shown schematically in Fig. 16.6.

The interdisciplinary approach includes SLT, ear, nose, throat (ENT) medicine, information technology (IT), as well as special needs education (SNE) and starts with the UNHS, followed by language development; emotional, social, and communication development and education, leading to the participation of the hearing-impaired person; and, finally, their inclusion as taxpayers. In the following sections, a short overview of the different components of an interdisciplinary therapeutic approach is given.

Speech–Language Therapy

Besides hearing and listening, the ability to use spoken language is the central component of sound-based communication. Especially for severe hearing impairment, SLT is necessary for appropriate language acquisition (Estabrooks et al., 2016). The training of auditory skills such as recognition, discrimination, identification, and understanding of a stimulus together with the development of the ability to use the voice for spoken communication will stimulate spoken language, which can be trained in all different linguistic fields. The use of hearing support devices such as hearing aids and/or CI is an important component of auditory-verbal therapy and aims to amplify language acquisition as much as possible (McCreery & Walker, 2016). Cochlear implant use, even from a young age, does not ensure that spoken language will develop normally. Comorbidities, age, social, and other factors influ-

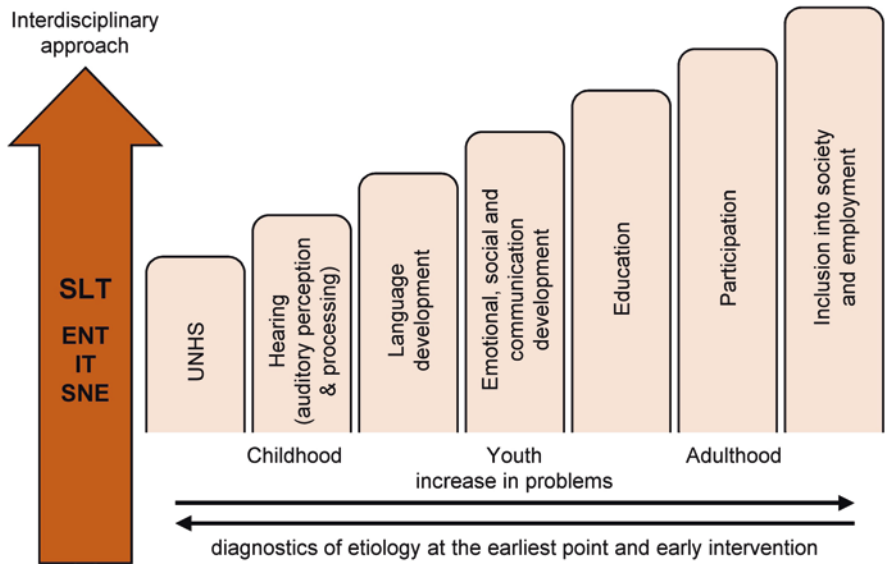

Fig. 16.6 Schematic presentation of the impact of an interdisciplinary approach to face hearing impairment across the life span

ence the quality of the development of spoken language. The use of sign language can add to the rehabilitation process, but whether sign language in combination with spoken language provides greater benefit from a CI than spoken language alone has not yet been demonstrated (Geers et al., 2017). Because of the complexity of the situation, the SLT profession necessarily has an integrating function. The different agents in the process of supporting the persons with hearing impairment need to be coordinated and integrated into therapy plans: for example, ENT professionals, who take care of early and confirmatory diagnostics; audiologists, who are experts for technical devices for hearing support; SNE professionals, who reduce barriers in educational settings and provide access to education; and IT professionals, who facilitate remote assessment or therapy.

Technical Devices for Hearing Support: Hearing Aids and Cochlear Implants

Nowadays, various technical devices can enable or support hearing perception. Technical devices can amplify a child's audibility range significantly, while the outcomes of hearing aid supply depend on the individual residual hearing capacity of the child. The consideration of technical hearing support should occur as soon as possible, for example, fitting hearing aids or CI during early childhood to minimize the negative impact of hearing impairment on speech and language development and overall personality development. By starting the use at an early age, such devices can support an increased sound perception, jump-start cognitive skills, and, thus, contribute significantly to the speech and language development of hearing-impaired children (McCreery & Walker, 2016). A late start to the use of technical hearing support or a long period of time between diagnostics and start of hearing aid/CI use leads to decreased hearing and language development, and deficits can be difficult to overcome (McCreery & Walker, 2016).

Cochlear Implants[2]

CI bypass non-functional hair cells in the cochlear by directly stimulating the auditory nerve (see Fig. 16.7). The externally visible part of the device is connected to the implanted part via a magnet. CI are "generally considered to be the standard of care for children and adults with severe to profound sensory hearing loss" (Wolfe & Neumann, 2016, 162), whereas the individual degree of hearing loss can be

[2]For further information and a medical perspective on cochlear implantation, see Lesinski-Schiedat et al. (2023).

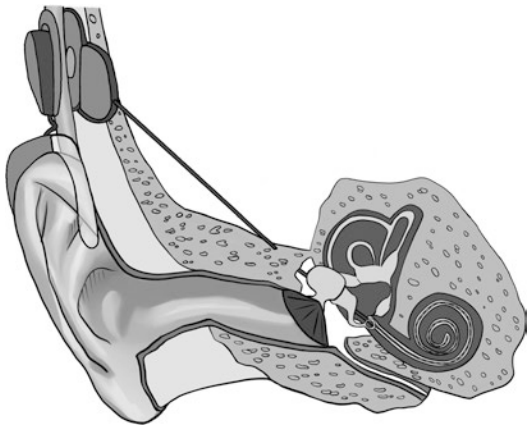

Fig. 16.7 Schematic visualization of a cochlear implant, showing the inner part of the implant in the bone and leading into the inner ear, as well as the outer part connected to the implant via magnetism

Fig. 16.8 Schematic visualization of a hearing aid including electronic amplifier fixed behind the ear cone, wire for transmitting amplified sounds, and ear piece individually fitted in the ear canal

caused differently, and affected children can have very different physiological and anatomic bases (Lenarz, 2018; Wolfe & Neumann, 2016).

Hearing Aid

Hearing aids are sound-conducting devices externally attached to the child's auricle. The sound caught by the hearing aid is amplified and led to the middle ear via an individually fitted so-called earmould (McCreery & Walker, 2016, 131 f.; see Fig. 16.8). Hearing aids amplify auditory signals depending on the individual's hearing function (Ching, 2013). Such devices contribute to both auditory and language development (McCreery & Walker, 2016, p. 132).

Special Needs Education

Since the "Convention on the Rights of Persons with Disabilities" of the United Nations (2006), the standard inclusion of children with hearing impairment in the regular school system is the aim of the many countries that have ratified or signed the convention. In Tanzania, the overall aim is to secure quality education for all children and youth (United Republic of Tanzania, 2009). Focusing on children with hearing impairment, Wang et al. (2011) state that early placement in mainstream pre-schools is one of the predictors of good auditory performance. When schools are financially and personally equipped well, SNE teachers are the professionals who meet the needs of children with hearing impairment or hearing loss in inclusive schools. Nevertheless, in Minority World contexts, different school systems have different supporting professionals from different disciplines, for example, "hearing resource teacher" in the USA (Fitzpatrick & Doucet, 2013) or "special needs teachers specialized in hearing impairments" in Germany. However, the educational inclusion of students with hearing impairment itself should be an interdisciplinary effort. Different professionals working with the children like speech–language therapists (SLTs), classroom teachers, or educational audiologists, as well as the children themselves and their parents, have to work together to support and strengthen the students to follow the general curriculum, if possible, and to reduce the barriers that hinder learning processes (Kisanga, 2019; United Republic of Tanzania, 2017).

The main tasks of SNE teachers are (1) preparing individualized education plans, (2) identifying children with hearing impairment when the children with hearing impairment are in contact with an educational institution for the first time, (3) counseling of classroom teachers and other educational personal in reducing barriers, and (4) cooperating with different disciplines and parents (Rhoades et al., 2016). The main aim is to reduce barriers in the general curriculum, the methods, and didactics of class-

room teaching as well as in the acoustic environment. For the latter, Rhoades et al. (2016) name the following factors, which improve the acoustics in classrooms: decreasing background noise (e.g., closing windows when noise comes from outside traffic or heavy rain), increasing the signal-to-noise ratio (e.g., using hearing technology like wireless remote microphone systems), reducing reverberation time (e.g., covering up hard surfaces using putting rugs or drapes), and reducing speaker-to-listener distance (e.g., allowing the students with hearing impairment to move around to increase the proximity to the important sound source). The intervention can be indirect like these adjustments of the setting or direct in working on specific tasks with the student outside of the classroom (pull-out) or adjusting the methods in the lesson (push-in) (Rhoades et al., 2016).

Information Technology Support for Remote Service Delivery

The application of communication and IT for service delivery in SLT and audiology has become more important in recent years and especially in the context of the COVID-19 pandemic. Assessment, intervention, and/or consultation when client and practitioner are at distance can be implemented by using modern communication technologies. The American Speech–Language-Hearing Association (ASHA) sums up these activities under the term "telepractice" (ASHA, n.d.). To implement and to innovate telepractice, SLT and audiology professionals need support from experts in technology.

In the field of CI aftercare, there is the possibility of remote fitting. One exemplary project is a project of the German Hearing Centre (DHZ) in which CI for patients from all over Germany can be fitted at their hearing aid provider by consulting the experts via real-time high-definition video conference between the patient and audiologist (DHZ, n.d.). In the future, such a remote care system could help overcome the broad distances between patient and practitioners in SSA as well. Such a real-time remote care system requires reliable Internet access at a speed of at least 1 Mbit/s. In the case of low-quality video communication, a rate of 200 kbit/s might be sufficient. In remote areas, medical doctors may use databases on their mobile devices and synchronize these databases to a central site when an Internet connection becomes available. Databases may contain patient data as well as instructional videos and information.

Advantages of an Interdisciplinary Approach

With regard to the perspectives discussed above on how to face hearing impairment and improve affected children's communicative abilities, an interdisciplinary approach including medical, pedagogic, and technological components seems likely to facilitate optimal therapeutic care for children with hearing impairment. ENT specialists and audiologists, pedagogues, and SLTs should be included in preventive and therapeutic approaches. Also, the need to involve those in the environment of hearing-impaired children has been highlighted. Rhoades and MacIver-Lux (2016) emphasize the importance of parental involvement in the auditory-verbal therapy of their hearing-impaired child. Strategies for everyday interaction between child and parents enhance speech and language developmental disorders caused by hearing impairment (Rhoades &

Desiderata for Tanzania and Sub-Saharan Africa

So far, no extensive database exists on the prevalence, comorbidities, and risk factors for infant hearing impairment in the SSA region or Tanzania specifically. A reasonably suspected number of affected children as well as factors that might lead to an increased risk of hearing impairment need to be examined on a standardized and systematic scientific level to gain a realistic overview and to find adequate approaches for treatment. Besides, the region lacks the necessary amount of audiology specialists for therapeutic care. Building up databases and enlarging staff capacities to confront hearing impairment in Tanzania are two main aims of the project Hear Africa! and are presented in the following section.

MacIver-Lux, 2016). This includes the use and maintenance of the technical device of their children at home but also support for successful language development. In addition, school teachers should be informed about hearing impairment and its effects on the everyday lives of affected persons to help improve learning environments and enable participation, for example, in school contexts (Olusanya, 2004; Schwab et al., 2019).

Methodology of a Multi-centered Cross-Method Project: Hear Africa!

"Hear Africa!" is an interdisciplinary and cross-cultural project aiming to identify congenital hearing impairment in newborns and improve language development, education, and participation of hearing-impaired children in Tanzania. The international cooperation between the German and Tanzanian project partners is carried out by a variety of experts from different work fields such as researchers and medical staff with broad expertise. The project was developed and is led by Prof. Dr. habil. Ulrike Lüdtke, Department for Speech Pedagogy and Therapy of the Leibniz University of Hannover.[3] The current project team consists of the Institute for Information Processing (tnt), Leibniz Lab for Relational Communication Research, the ENT Clinic of the Medical University of Hannover (MHH), the DHZ, Muhimbili University of Health and Allied Sciences (MUHAS), Muhimbili National Hospital (MNH) in Dar es Salaam, and Kilimanjaro Christian Medical Centre (KCMC) in Moshi, Tanzania. The integration of rural Tanzanian clinics is planned for the upcoming years to gain insight into the possibly differing regional statuses in the provisions for infant hearing impairment in Tanzania. The financial efforts of Hear Africa! are covered by the Lower Saxony Ministry of Social Affairs, Health and Gender Equality, Germany.

The structure of the project involves different parties in Germany and Tanzania (see Fig. 16.9). At the core of the project are the birth clinics with screeners and the parents of hearing-impaired newborns. The newborns at the clinics undergo UNHS, and their medical data are collected at the birth clinic. The data are submitted to the central headquarters where UNHS trainers then contact the parents of newborns with "refer" results from the first UNHS to invite them for a second screening. The patient data are also submitted to the German project partners Leibniz University of Hannover (LUH) and MHH for scientific evaluation. Other fields of activity of the German project partners are supervision of all project activities and organizational aspects, as well as monitoring, controlling, and technical support, for example, concerning data collection and data storage. A data cloud for safe submission of patient data can be accessed by both Tanzanian and German project partners and follows the highest regulations and restrictions for data safety.

Aims

Hear Africa! aims to improve the language development, education, and participation of children with hearing impairment in Tanzania through the implementation of UNHS. The aims were developed in the context of the universal rights of persons with disabilities to participation and the claim for sustainability. The project especially refers to Goals 3 and 4 of the Sustainable Development Goals of the United Nations 2030 Agenda for Sustainable Development (Division for Sustainable Development Goals, 2020). These goals aim to ensure healthy lives and promotion of well-being

- Aim 1: *Clinical research* and *data collection*
- Aim 2: Professional *education* and capacity building
- Aim 3: Building up an SLT and audiological *infrastructure* including remote care
- Aim 4: Political work and *community empowerment*

[3]This project is funded by the Lower Saxony Ministry of Social Affairs, Health and Equal Opportunities.

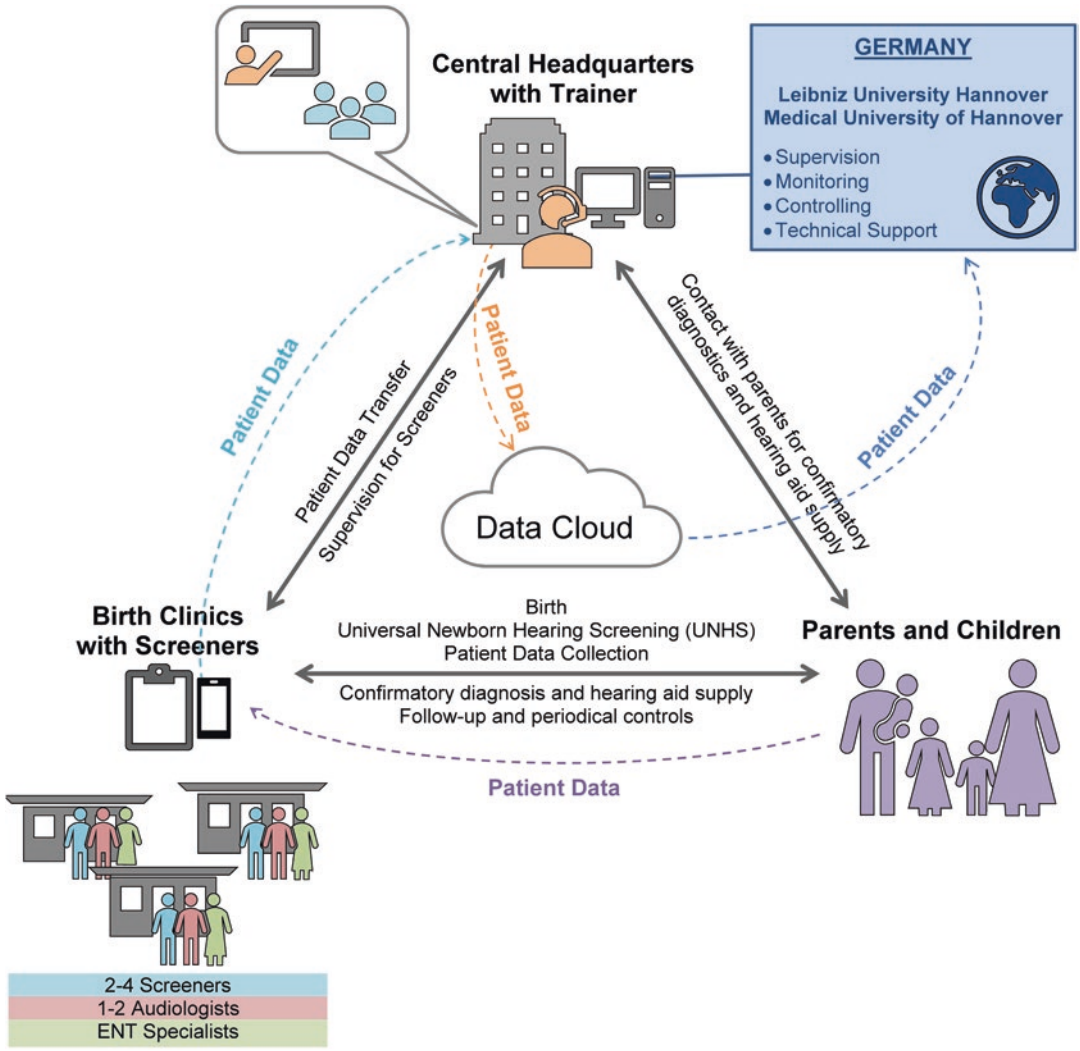

Fig. 16.9 Schematic visualization of the different parties involved in, and affected by, project measures of "Hear Africa!"

for all at all ages (Goal 3) and to ensure inclusive and equitable quality education and promote lifelong learning opportunities for all (Goal 4) (see https://sdgs.un.org/goals). Based on these, Hear Africa! aims to meet the following major aims:

The project follows a 5-year schedule and includes the education of trainers and screeners as well as the implementation of a pilot study to screen 5000 newborns in Tanzania in addition to the diagnosis and adequate treatment of children with potential sensorineural hearing impairment. Early diagnosis is crucial for successful treatment, for children's speaking ability, and for their educational participation. Table 16.1 shows the partial goals for every project.

Sustainability

The sustainable impact of all project activities is the inherent aim of Hear Africa! and builds the base for all project targets of the 5-year plan. One example is the "Train-the-Trainer" approach for capacity building in UNHS (see Fig. 16.10). The approach

Table 16.1 Partial goals matched to the respective project years

Year	Aims
Year 1	• Site and needs assessment and analysis of the existing infrastructure for UNHS • Building educational structures for UNHS • Clarification of the institutional and political frame for the implementation of UNHS • Development of the first ideas for education and sensitization of the Tanzanian society to hearing impairment
Year 2	• First screenings and evaluation in a pilot study • Education of trainers to supervise and control the screeners and for local data management • Conception and testing of modules for the medical and speech therapeutic care of hearing-impaired children • Development and testing of pilot measures for the education and sensitization of Tanzanian society concerning hearing impairment
Year 3	• Sustainable implementation of structures for confirmatory diagnosis and the supply of hearing aids and cochlear implants • Stabilization and expansion of the UNHS • Building up therapeutic care supply for hearing-impaired children in Tanzania by establishing a digital learning platform "SpeechBase – Speech, Language and Hearing Resources for Sub-Saharan Africa"
Year 4	• Solidification and expansion of extensive newborn hearing diagno sis • Intensifying the education of professional staff via the digital platform "SpeechBase – Speech, Language and Hearing Resources for Sub-Saharan Africa" • Expansion of the structures for cochlear implant and hearing aid supply, remote care, and therapeutic care supply of hearing-impaired children focusing on e-health • Continuous educational and sensitizing work with Tanzanian society
Year 5	• Continuation of newborn hearing diagnosis • Building up structures for cochlear implant and hearing aid supply (continuation) • Expansion of medical and technical cochlear implant and hearing aid supply with speech therapeutic care and aftercare • Continuous educational and sensitizing work with Tanzanian society

was chosen to enable the participants to act as screeners and also to carry out screenings independently. Knowledge and expertise are passed on to medical and therapeutic staff in Tanzania, and, thus, further training can be offered by local staff. Furthermore, the early identification of severe hearing loss in newborns followed by precise diagnosis and individual treatment facilitates undisturbed language development. Therefore, affected children gain access to education and participation which is of high economic importance for Tanzania.

First Steps and Outcomes

Aim 1: Clinical Research and Data Collection

UNHS was successfully implemented in MUHAS, Dar es Salaam, Tanzania. The method utilized was the measurement of OAE. Using a smartphone-based OAE measuring method enables registration of the result and transfer to a centralized database.

One main interest relates to eventual differences in the prevalence and comorbidities of infant hearing impairment in other regions, for example, Western Europe. The data obtained can be evaluated and can also give insight into risk factors and comorbidities associated with failed hearing screenings in newborns in the study sample at MNH which is examined from a therapeutic and medical perspective. The results of the first hearing screening cohorts of 1000 newborn children in Tanzania showed a variety of the first results which both require and enable further research. Among those are organizational and structural problems on the local level. Children with atypical findings in both screenings are handed over to a confirmation diagnosis to precisely assess their hearing impairment, grade, and cause followed by initiation of therapy. Trainers, audiologists, and ENT professionals are responsible for providing hearing aids to affected children. The intended long-term effect of the newborn hearing screening is an improved health situation and educational participation for children with hearing impairment in Tanzania. While the first screening showed a comparatively low rate of insufficient data (e.g., missing values),

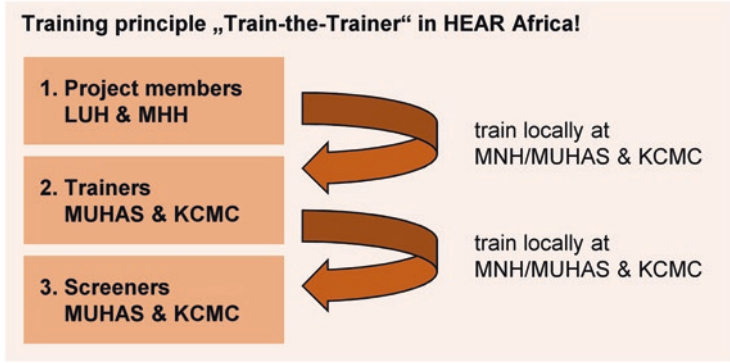

Fig. 16.10 “Train-the-Trainer” approach to support capacity building in universal newborn hearing screening (UNHS)

the second screening showed a high drop-out rate which means that a certain number of newborns who participated in the first screening did not receive a second screening. Individual reasons for dropping out of the screening process remain unknown. Obvious reasons could be organizational misunderstandings between parents and medical staff, financial or infrastructural problems concerning the transport to the hospital, or fear of stigmatization in the case of confirmed hearing impairment. Figure 16.11 shows the UNHS in three phases, starting with the training of UNHS screeners (see Fig. 16.12).

Aim 2: Professional Education and Capacity Building

A training phase with the first and second training (see Fig. 16.11) took place in the Tanzanian partner clinics in the second project year. In advance of the training sessions, the medical locations in Dar es Salaam and Moshi were visited to examine personnel, technical, and medical supplies for the diagnosis and treatment of infant hearing impairment in the region. Workshops enabled the further establishment and solidification of the existing interdisciplinary and intercultural cooperation. The Tanzanian and German project partners participated in the development of the different project parts and the scope of the pilot study. The training phase itself was divided into two subphases. In the first step, experts from MHH trained local trainers in Tanzania (see Fig. 16.13). These local trainers mediated their newly gained expertise to the medical staff that will, later on, carry out the hearing screening. The Tanzanian trainers chosen in the first year also received education as well as instruction to form a supervisory and controlling entity for the executing screeners and the local data management.

The first results showed that all 22 participants (principal investigators [PI], trainers, screeners) had a good theoretical basis to perform OAE with a screening device. Multiple-choice testing after training showed no significant difference between the six PI and trainers and 16 screeners ($p = 0.066$). All of the participants (PI, trainers, screeners) were able to correctly explain the basic principle of the measurement to parents, carry out the measurement independently, and explain and document the results and outstanding consequences. All participants trained the OAE measurement on each other and on at least one baby during the training period (see Fig. 16.14). Cognitive relational competence, methodic relational competence, and communicative relational competence (Schütte et al., 2023) were successfully developed during training.

Aim 3: Building Up Speech–Language Therapy and Audiological Infrastructures Including Remote Care

To collect and save the patient data, an app for mobile devices (see Fig. 16.15) was developed using the MIT app inventor: For each screening, the medical personnel is supposed to enter the patient data. These data are temporarily stored in a local database on the device and can be edited.

When an Internet connection becomes available, the medical personal can transfer all tempo-

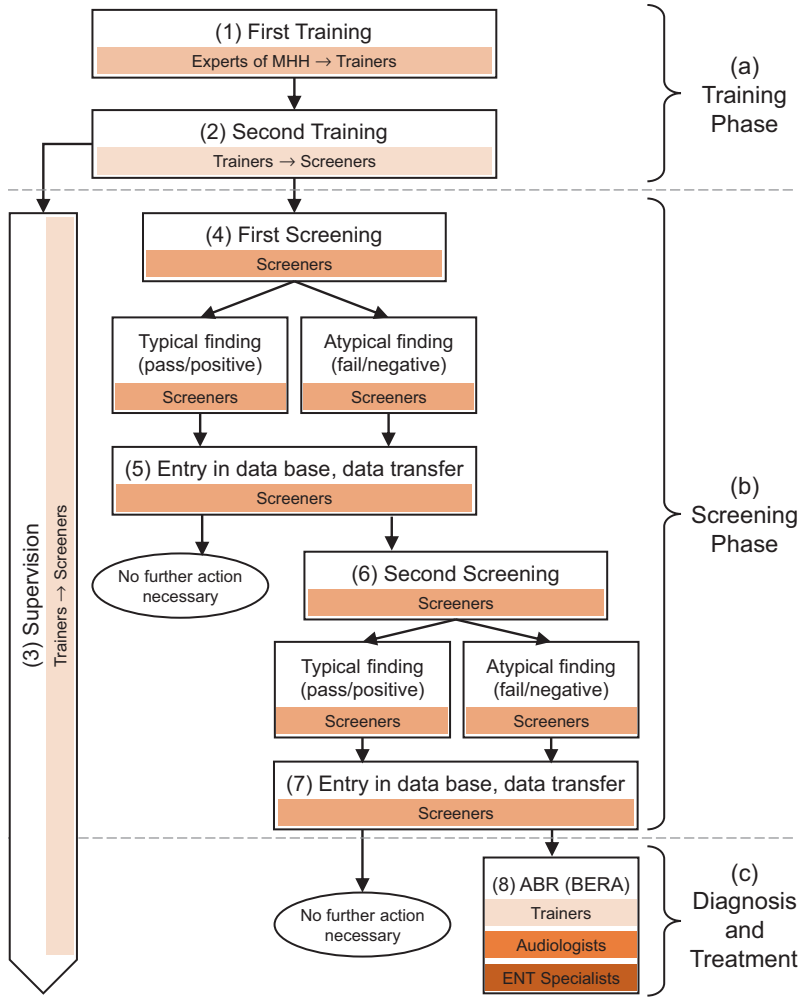

Fig. 16.11 The three project phases of universal newborn hearing screening

Fig. 16.12 Screening a newborn in the clinic to diagnose possible hearing impairment

Fig. 16.13 Universal newborn hearing screening training in Dar es Salaam

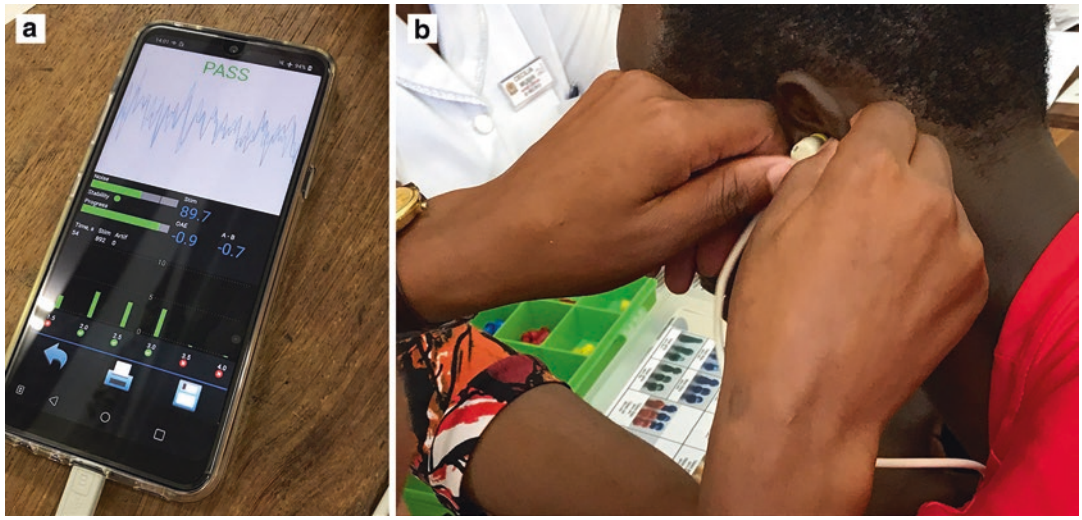

Fig. 16.14 Testing the technical apparatus for universal newborn hearing screening in Tanzania

rarily stored data from the device to a central server using a secure connection. For data privacy reasons, the local data is removed from the device after upload to the central server. By first storing the data locally, no continuous Internet connection is required.

Aim 4: Political Work and Community Empowerment

Aiming at community empowerment to strengthen the position of hearing-impaired persons, information material has been and will further be developed. This material comprises different media, for

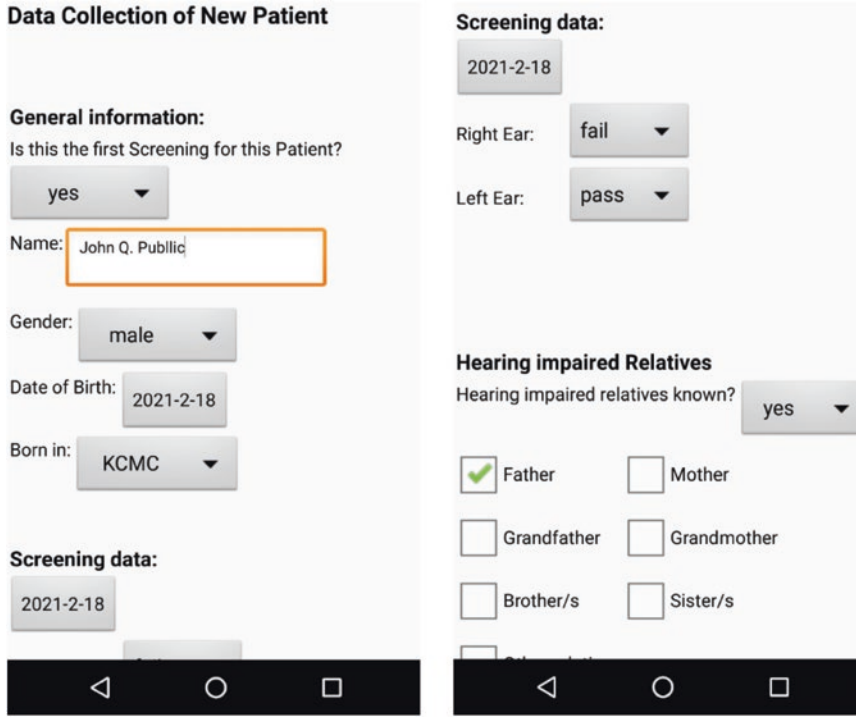

Fig. 16.15 Screenshots of the app developed by tnt, Hanover, for the inquiry of patient data

example, printed flyers or screencasts, to explain certain topics concerning hearing impairment to inform the population and impart knowledge about hearing impairment and its consequences. So far, different material has been developed, and further flyers, screencasts, and additional material will be developed throughout the course of the project.[4]

The project "SpeechBase – Speech, Language and Hearing Resources for Sub-Saharan Africa" is a cooperative project with five partner institutions in Germany and SSA. These partners are LUH in Germany; University of Pretoria in South Africa; Kenyatta University in Nairobi, Kenya; and MUHAS in Dar es Salaam and KCMC in Moshi, both in Tanzania. One central aim of the project is the development of a web platform on different topics concerning SLT (see Fig. 16.16), for example, hearing impairment, language development disorders, neurology, audiology, and support communication, and to offer improved access to different target groups. Informational material and curriculum-supporting material for academic education in SLT will be offered on the platform in a culturally sensitive and demand-responsive way. Moreover, the project aims to develop conjoint curricula for SLT practice and strengthen the scientific and academic network in SSA via South-South cooperation of the African project partners.

Challenges

With the help of this multi-centered study, the epidemiological assessments of infant sensorineural hearing impairment in Tanzania are now available. In combination with pedagogic and medical-therapeutic measures, this study can increase the future educational and participative chances of hearing-impaired children in Tanzania. Providing epidemiological data on the prevalence and comorbidity

[4]For information and examples of informational material for community empowerment, see Wu et al. (2023).

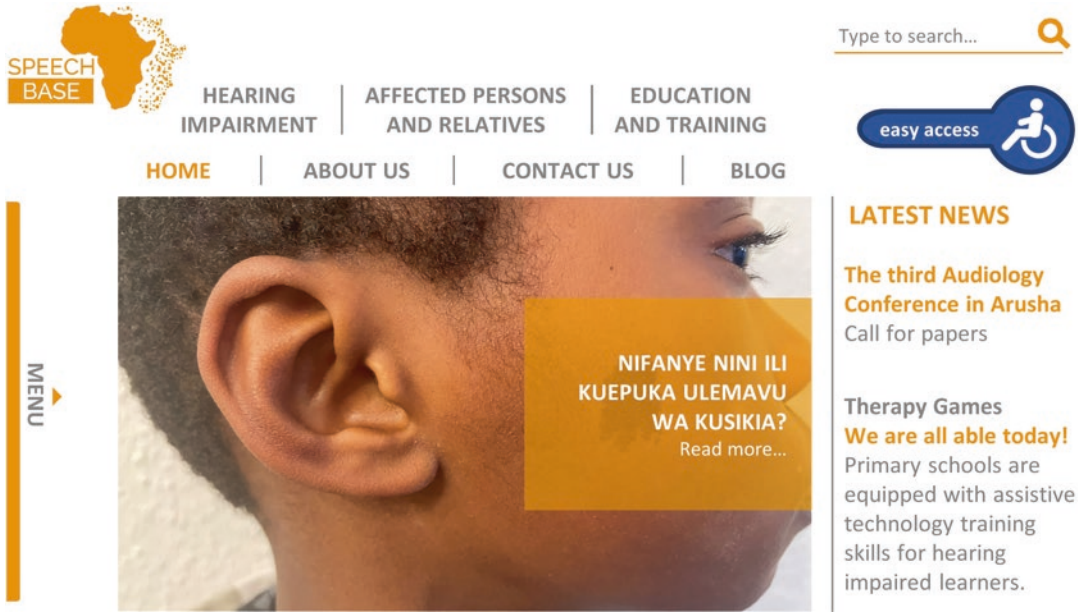

Fig. 16.16 Screenshot of the web platform SpeechBase developed in the project "SpeechBase – Speech, Language and Hearing Resources for Sub-Saharan Africa" http://speechbase.org

of infant hearing impairment in Tanzania is highly important for further scientific research.

During the process, some aspects came to light that need further attention. The obtained data on newborn hearing impairment allows insight into a field of disability in SSA that has not yet received much scientific attention. The first part of the study shows that the implementation of UNHS combined with the training of trainers and screeners in advance is feasible. The scope of the training proved to be sufficient for the execution of the intended action: the implementation of UNHS in the Tanzanian partner clinic. Integrating parents into the diagnosis and therapeutic process for their children (see section "Speech–Language Therapy for Hearing Impaired Children as an Interdisciplinary Care Approach") was part of the training, and the participants showed good results. Thus, the obtainment of further data concerning infant hearing impairment and ototoxic medication in Tanzania is to be expected. The number of children suspected to be hearing impaired (the first step of UNHS) gives the first epidemiological data for potentially hearing-impaired children in Tanzania. The integration of both pediatrics and gynecologists into a suitable interdisciplinary approach to confront hearing impairment in Tanzania in the future could prove to be very useful.

Whereas the sub-studies turned out to be successful, some logistic, as well as financial aspects, appeared to be challenging. First of all, a high drop-out rate was apparent. A high number of those newborns testing positive in the UNHS and thus at high risk of hearing impairment are either still awaiting confirmation diagnosis (BERA) and therapy or are not reachable anymore. Investigating the reasons for the drop-out rate along with the accessibility of SLT services in rural areas will be major tasks in the continuous project work in cooperation with the Tanzanian partners.

The Way Forward: Digital and Remote Alternatives for Care Supply and Culturally Sensitive Adaptation

With regard to the needs and challenges of a digitalized medical environment worldwide, a fully digitalized and remote care system is indispensable. The need for these remote structures is also relevant given the recent pandemic for education,

training, medical care, and therapy. This applies especially to regions that become hardly accessible because of pandemic restrictions or being far afield rural areas. Therefore, digital and remote solutions are a superior goal of Hear Africa! activities and have been followed throughout the project so far.

First, digitization is applied in the field of education and training in SLT. The aim of SpeechBase is to provide a digital platform for the education and sensitization of both professional staff and affected persons in the field of SLT in SSA. The platform is a joint project to produce education and training materials for the target groups. This includes SLTs and other professionals, as well as parents and community-based healthcare workers. The material focuses on the education on infant hearing impairment and the support of hearing-impaired young children who benefit most from audiological technology such as hearing aids or CI. Materials for all other age groups and adults can also be derived. Digitization could also prove to be supportive in other areas. SLT and audiology diagnostics should consider the possibilities of integrating digital solutions for remote care approaches, especially in those regions with a low number of SLT and ENT specialists.

Second, it is of superior importance to develop digital solutions for data management. In addition to the collection of a high amount of data, the reliability of data collection is essential. A shared digital data storage tool collects data in a centralized and comparable way. Options to feed and co-work the storage from any location, at any time, and from authorized persons are available. Thus, an app specifically designed and developed for international co-working projects to transfer knowledge and enablement in developing countries to perform scientific work on epidemiology would be in the crucial interest of the WHO.

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Part III

Introduction: Assessment and Treatment

This section focuses on the assessment and treatment of speech, language, and hearing disorders in sub-Saharan Africa (SSA). These two core topics have a reciprocal link in speech–language therapy (SLT): assessing the communicative and linguistic competence of a client is the basis for making decisions about treatment, while treatment outcomes have to be assessed in an ongoing way to determine future treatment. As such, one cannot say at which point the one stops and the other starts.

Globally, the gold standard of assessment and treatment is discussed with the term "evidence-based practice" (EBP), which is rooted in the scientific influence of medical professions including SLT from Minority World contexts (Justice, 2008). Contemporary thinking now describes EBP as comprising three forms of evidence (giving rise to the E_3BP acronym), namely, (i) research findings on assessment tools and strategies (E_1), (ii) professional expertise stemming from therapeutic concepts and methods (E_2), and (iii) the inclusion of the client's perspectives on their health status, well-being, and participation (E_3) (Dollaghan, 2008). Such a practice substantiated by research can act as decision-making guidance in clinical reasoning on such matters as choice of (standardized) assessment tools, dosage, intensity, or selection of treatment methods and stimuli that have been validated for the context (e.g., Justice et al., 2017; Meyers-Denman & Plante, 2016; Storkel et al., 2017; Turkstra et al., 2016).

SLTs in SSA need to trust their own knowledge and skills and feel confident to provide services within the demanding contexts they serve. They also need to understand the value of joining external evidence (i.e., research) with internal evidence, namely, their therapeutic experience, values and ethics, and the client and family's needs and goals related to SLT (Bornman, in press). Furthermore, significantly more research evidence needs to be generated focusing on SSA.

The diverse ethnic and linguistic fragmentation in SSA poses a challenge when it comes to the assessment and treatment of a client's communicative and linguistic abilities. Since most assessment and treatment concepts come from Minority World contexts, there is an unconditional need for culturally and linguistically appropriate diagnostic and therapeutic tools in SSA (Mdladlo et al., 2016; Romski et al., 2018). A "client-tool- or client-concept-mismatch"

will lead to misinterpretations and misunderstandings that hinder successful treatment (Mdlalo et al., 2019). Preparing SLTs to assess and treat multilingual clients in SSA using E_3BP is a complex and demanding process as it encompasses an extensive number of different languages (Buzasi, 2016). One possible way to deal with this situation is through using computer-assisted tools. In speech assessment or aphasia therapy, in particular, digital solutions have been investigated recently (e.g., Lee & Cherney, 2016; Liu et al., 2018; Qin et al., 2018).

The paucity of research on SLT in Majority World contexts means that it is currently challenging to achieve the EBP standard in SSA. However, the implementation of E_3BP is not always successful in Minority World contexts either (Campbell & Douglas, 2017). For example, Fulcher-Rood et al. (2020) investigated the attitude of 25 school-based SLTs toward EBP. These SLTs from the United States articulated challenges in transferring research findings into practice; they named barriers such as insufficient time, limited funding, and restrictions imposed by employment settings.

The American Speech–Language-Hearing Association (ASHA) provides digital tools for initiating and implementing EBP into the daily routines of SLTs. For instance, ASHA offers "Evidence Maps" for communication disorders that summarize the latest research findings from Minority World contexts (American Speech–Language-Hearing Association (ASHA), 2020). With this in mind, research on assessment and treatment in the SSA context needs to be pushed to aim for applicable outcomes. It shows that research should be culturally appropriate and sensitive to diverse contexts. Thus, as we discussed in Section II on Professionalism, SLTs in SSA need to consider the linguistic and cultural diversity in their practice. All SLTs should be encouraged to have a critical, inquisitive attitude regarding the specific SLT outcomes aimed for in a client, as well as a willingness to rate the existing evidence by researching different strategies and asking piercing questions without blindly relying on previous experience and training (Bornman, in press). Otherwise, implementation of E_3BP will fail.

Besides the reinforcement of research, SLT in SSA has to overcome harmful modes of traditional healing in the realm of communication disorders, e.g., uvulectomy in swallowing disorders in Nigeria or Tanzania (Adoga & Nimkur, 2011; Kawia et al., 2014). However, to develop culturally appropriate assessment and treatment for the best practice that is person-centered, SSA spiritual and holistic access should not be denied. Some psychotherapy authors try to include traditional practices in counseling situations (van der Merwe, 2019; Ngozi & Odigwe, 2018). As stated by the International Classification of Functioning, Disability and Health (ICF), religion and spirituality are aspects of a person's activity and participation, and spiritual norms and rituals influence people's lives and health (World Health Organization (WHO), 2001, ICF codes d930 and e465).

Another region-specific issue that needs to be addressed is the vast distances involved in SLT service delivery combined with an insufficient client-practitioner-ratio (see Sect. I on Professionalization) as well as poor literacy skills in some communities, high unemployment rates, and widespread pov-

erty (Bornman et al., 2020). There is a need to think outside the box when it comes to service delivery in rural regions: multiplier networks in community-based services, mobile clinics that allow travel and treatment around the countries, or forms of "telepractice" or "telehealth." Telepractice is becoming increasingly important because of innovations in the information technology industry and the uptake of mobile technology – smartphones and tablets – in Africa (Bridgman et al., 2016; Walker et al., 2018; Weidner & Lowman, 2020). Assessment and treatment via video conferencing on smartphones is a promising concept for SSA and is currently being implemented due to the COVID-19 pandemic in several SSA countries. However, it also brings challenges associated with the high-speed Internet infrastructure and the costs of data.

Taking these topics together, this section presents different sub-Saharan ways of assessing and treating persons with communication disorders. It discusses and describes creative ways to deal with the high cultural and linguistic diversity of the context, the lack of linguistically and culturally adapted assessment and treatment tools, and the vast distances between clients and practitioners. The following abstracts and critical reviews give an overview of the examined topics.

17 Michelle Pascoe and Shajila Singh

Development of Speech–Language Therapy Assessments for the Languages of South Africa

Abstract *Background*: South African speech–language therapists (SLTs) practice in a richly diverse setting characterized by many languages and cultures. This environment creates opportunities for research and development but also brings with it challenges for clinical practice. In this chapter, it is argued that the profession needs to increase its relevance for all the people of South Africa. One way in which this can be done is by focusing on assessments. Valid and reliable assessment is essential for the identification of children and adults with communication difficulties and is the first step in providing services to address their needs. To date, there are only a few assessment tools designed and validated for use in the South African context. *Methodology*: This chapter comprises a literary review documenting the context of the SLT profession in South Africa as well as considering the available contextually relevant assessments. *Results*: The context and challenges faced by SLTs in South Africa are described, followed by an overview of the official languages of the country, suggesting that expanding the knowledge of the local languages is an important first step toward improving the relevance of services. Contextually relevant assessments currently available in South Africa are discussed to better understand the developmental work that has been undertaken, specifically focusing on screening tools, diagnostic assessments, and the collection of normative data. *Discussion*: Brief suggestions are offered for future work that may help to increase the relevance of SLT services at both an individual/clinician level and in a more systemic way.

Critical Review Formal assessment tools form an important part of most SLT assessments. However, as this chapter clarifies, most tools developed in Minority World contexts are not relevant for Majority World contexts such as South Africa. This leaves the reader questioning which tools *are* relevant and in which areas/languages more tests need to be developed. The chapter authors generously answer these questions by providing an in-depth list of all the assessment tools available in various languages of South Africa, as well as suggestions for further tests which need to be developed. This makes the chapter an essential resource for clinicians working in South Africa. The focus on providing assessments in the client's first language comes through strongly in this chapter, highlighting the need for access to relevant assessment materials to move the profession forward. Although this chapter is specific to South Africa, the underlying message is relevant to all clinicians working in SSA countries with similar multicultural and multilingual clients. The information shared by the authors contributes meaningfully to the nationwide movement toward providing relevant, sustainable SLT services to all.

18 Mellissa Bortz

Assessing Language in South Africa: Use of the Passive Construction

Abstract *Background*: Tools that are linguistically and culturally diverse are needed to explore language acquisition and impairment in Africa. The development of a tool in any of the over 500 Bantu languages would be useful for sub-Saharan Africa (SSA). Controversy exists about the age of acquisition of the passive construction. Research indicates that the passive develops earlier in Bantu languages than in Indo-European languages. The hypothesis for this chapter is that if these were the results of this study, the passive would be a useful construction to determine language impairment in the first language (here: Setswana) and English as a second language. *Methodology*: Using a mixed methods design combining a quantitative cross-sectional design with a qualitative service -learning component, comprehension, and production of the passive was examined in terms of age (2.6–5.6 years), passive categories, and length variables. Comprehension, elicited production, and elicited imitation tasks were examined in 62 participants in Pankop, South Africa. *Results*: The results of the elicited imitation tasks indicate a developmental effect. Results on the comprehension picture selection task are at chance, while elicited production is an unsuccessful task. *Discussion*: The passive may not be an early acquired structure in Setswana. The results of the study, therefore, support the A-Chain Deficit Hypothesis, i.e., that the passive is a late-acquired structure with difficulties with non-actional categories. Despite the original hypothesis being refuted, elicited imitation may be a viable and relevant measure for assessing language in South Africa. These findings concur with current literature supporting the usefulness of elicited imitation tasks.

Critical Review This chapter contributes significantly to the drive for language-specific assessments, which has been building momentum in SSA countries. The detailed methodology section makes the study which the chapter is based on easily replicable, acting as an example for future researchers to follow. Furthermore, the discussion section of the chapter skillfully links the results of the study to relevant literature, creatively finding explanations and possible solutions to the research findings. This chapter is a prime example of how to conduct thorough, ethical research that contributes significantly to the collective knowledge surrounding African languages. The finding that elicited imitation tasks are meaningful and contextually relevant means to be used during assessment could be useful for clinicians in various SSA countries and opens up the possibility for further research. Despite the original hypothesis being refuted, this chapter provides a clear outline of how to conduct research of this variety and illustrates the fact that the development of contextually relevant assessment measures is a complex process.

19 Mellissa Bortz

Methods for Devising a Standardized Language Assessment for isiZulu Preschoolers: Implications for Sub-Saharan Africa

Abstract *Background*: Standardized language assessments are one of the most effective methods to diagnose language disorders. Using standardized language tests to identify a language problem at an early age can help to prevent both the permanent and long-term effects of language disorders. Standardized language assessments, therefore, play an important role in primary health care. Over 500 Bantu languages are spoken in Africa, spreading from Southern Cameroon eastward to Kenya and then to the southern tip of Africa. Bantu languages are characterized by noun classes, agreement, and verb suffixes. *Methodology*: This chapter describes the process of developing a standardized language assessment in isiZulu, using a mixed design with an emphasis on a quantitative (cross-sectional) design. The pre-standardization phase of the process involved 108 participants aged between 2.6 and 5.5 years old, and the standardization phase involved 303 participants aged 3.9 to 4.3 years old, residing in Soweto, South Africa. *Results*: The development, pilot testing, and standardization of a linguistically and culturally appropriate expressive and receptive isiZulu language assessment are described. This includes extensive pilot testing and norming, as well as obtaining mean scores, standard scores, percentile ranks, measures of validity, and reliability. *Discussion*: The motive for the chapter is to provide colleagues with methods of how to devise standardized language assessments in Bantu and other African languages, taking linguistic and cultural factors into account.

Critical Review This chapter provides the reader with a succinct yet detailed framework for conceptualizing the development of a language assessment in

Zulu, which can be applied to other African languages across SSA. The authors provide seminal information on the features and psychometric criteria necessary for standardized language tests, which would be applicable across languages. They also provide an in-depth step-by-step procedure for the development and piloting of the language test, which can be replicated in different languages. This chapter is thus an irreplaceable tool for any clinicians or researchers in SSA wishing to develop a culturally and linguistically relevant language test for any of the other African languages. The authors also use the platform to share the formation of a project in which they are involved, called the African Connections Partnership (by the South African Speech Language and Hearing Association). This project aims to develop and provide a database with information and resources for SLTs across Africa. This project would undeniably revolutionize the currently isolated way in which many SLTs work and offer much-needed support to those who do not have access to materials or relevant information. It is through projects such as this that African SLTs can come together to form a virtual community and develop the profession from strength to strength.

20 Mathew Kinyua Karia

Using Acoustic Phonetics in the Assessment and Treatment of Speech Disorders

Abstract *Background*: Traditionally, behavioral/perceptual-based therapy techniques have been used in speech–language therapy (SLT). However, acoustic phonetic-based assessment and therapy tools may provide huge benefits in clinical practice in the assessment and treatment of speech disorders. Acoustic phonetics is concerned with the acoustic properties of human speech such as frequency, duration, pitch, intensity, and so on. By using acoustic cues and a phonetic-based computer software program such as PRAAT, speech–language therapists (SLTs) can screen and analyze their clients' impaired speech. PRAAT can be used to visualize, play, annotate, and analyze sound objects in terms of their acoustic properties. This chapter discusses how SLTs can make use of acoustic phonetics to assess speech impairments caused by dysarthria. *Methodology*: The voice onset time (VOT) and fundamental frequency (F0) of ten Kenyan participants with dysarthria as a result of traumatic brain injury were recorded and analyzed using PRAAT software. *Results*: Acoustic analysis showed deviation in VOT as well as incomplete closure for plosives. Prosodic deviation with a lowered F0 was found. *Discussion*: Acoustic data about VOT and F0 can be analyzed acoustically to complement a perceptual-based assessment. The information gained from acoustic analysis can help guide the clinician toward a treatment plan that addresses the underlying speech problems.

Critical Review Multilingualism and language complexity can result in many challenges for SLTs working in SSA. However, the author of this chapter considered this challenge and devised a creative way to work around it:

using acoustic phonetics to objectively analyze the speech of dysarthric patients in Kenya. This is the type of inspired thinking that moves SLT in SSA forward by finding solutions rather than being caught focusing on the challenges. The discussion section of the chapter illustrates how the analysis of the voice onset time and fundamental frequency (F0) using software programs such as PRAAT can assist in diagnosing the underlying muscular difficulties which may contribute to speech errors. This exciting finding would be relevant across SSA contexts, regardless of the language of assessment, which opens up better avenues for assessment where the language of the client and clinician may not be the same. The author also suggests the need for further research on the use of acoustic phonetics to assess a wide range of articulatory disorders. This chapter is the first step in unlocking many undiscovered possibilities for those working with the speech of clients who may not share the same language as them. The information is also useful for those clinicians throughout SSA who provide services to patients with dysarthria as it illuminates the underlying reasons for speech impairments, informing intervention goals appropriately.

21 Phyllis W. Mwangi and Gatitu Kiguru

The Capacity to Assess and Treat Communication Disability in Kenya: Field-Based Evidence

Abstract *Background*: Communication is central to human existence. Unfortunately, due to physical and neurological conditions such as autism spectrum disorder, Down syndrome, and cerebral palsy, not everyone has the ability to communicate through speech. The disability may be phonetic/phonological, grammatical, or semantic/pragmatic. Depending on the severity of the condition, communication disability may be total or partial. It therefore follows that the persons affected cannot be helped unless their condition, and the attendant communication disability, is assessed and the appropriate treatment administered. However, in Kenya, adequate expert assessment and intervention mechanisms, not to mention resources, may not be easily available. Determining the extent to which this is true is the concern of this chapter. *Methodology*: Speech–language therapists (SLTs) and other field- related professionals (n = 18) were interviewed, and the materials used were reviewed in order to gain insight into the current status of assessment and treatment of communication disability in Kenya. The questions covered five main areas of interest such as training of different cadres of professionals handling children with special needs; facilities, equipment, tools, and resources for assessment/intervention; cost and funding; access; and existing networks. *Results*: The findings show that professionals in the field of communication disability are inadequately funded and therefore largely lack the necessary facilities and equipment. Access to assessment and treatment is also limited to a large extent. *Discussion*: Although there is a dearth of qualified SLTs, the staff in the other cadres are fairly well-trained and experienced and have established strong networks that benefit those with communication disability

Critical Review This chapter provides a bird's-eye view of the current situation SLTs in Kenya find themselves in, providing useful insights to help the reader understand their context. This context bears many similarities to other SSA countries, where SLTs may be faced with similar challenges. In this chapter, the authors illustrate how the assessment and intervention of children with communication disability is not only the responsibility of the few SLTs working in Kenya; the responsibility is shared with a variety of professionals including EARC officers, SNE teachers, and assistant SLTs. Given the high demand paired with the low availability and affordability of SLT services, it becomes apparent that creative solutions are necessary for service provision in SSA contexts. The authors also look deeper into the challenges facing all of these professionals, trying to determine *how* they can be better supported and making detailed suggestions for this. It is worth noting that these professionals only have basic training in communication disorders; however, they assist in providing basic management of communication disorders. In addition, with their basic knowledge, these education officers provide educational placement and referral services to the few SLTs in Kenya. In this way, the chapter contributes meaningfully to the development of solutions which may assist more people with communication disability in accessing relevant, quality services.

22 Ulla Licandro, Tom Abuom, and Dennis Omari

Linguistically and Culturally Diverse Children with Language Disorders in Sub-Saharan Africa: Approaches to Service Delivery

Abstract *Background*: Working with linguistically and culturally diverse children with language disorders, including developmental language disorders, is part of the daily professional life of speech–language therapists (SLTs) in sub-Saharan Africa (SSA) and also increasingly common worldwide. For young children with language disorders, in particular, the support of the home language(s) in addition to the academic language is important to facilitate language growth and overall development, even though it may present significant challenges. In cases of cultural and linguistic clinician-client mismatches and limited resources, SLTs may want to apply indirect approaches to service delivery, for example, by involving peers from similar linguistic and cultural backgrounds in the intervention process. *Methodology*: This chapter provides a qualitative literary analysis of research evidence related to multilingual learners. *Results*: Language practices in educational settings in SSA countries and their consequences for multilingual learners are critically discussed. International research evidence regarding peer-assisted SLT services is reviewed. *Discussion*: Practical examples which point to important clinical implications when providing peer-assisted services for linguistically and culturally diverse children in SSA are given.

Critical Review In line with the pursuit of innovative solutions to challenges faced by SLTs in SSA, this chapter provides an imaginative solution to working with multilingual children with language disorders, backed up by international research. The application of peer-assisted SLT services is approached with cautious optimism, as a possible means to improving the language development of multilingual children in SSA. The authors offer compelling evidence from studies conducted in Minority World countries, which hold a promise for application to the SSA context. Particularly where the client and clinician do not share the same cultural/linguistic background, this solution may assist in the efficacy and relevance of services. The chapter also sparks conversation about the educational language policies in Kenya as well as the availability of SLT services in children's home languages. Despite the fact that language education and intervention are not "ideal," this chapter shares with the reader a positive prospect that can fit into the cultural and linguistic perspective of SSA.

23 Ines Said, Anke Bulsink, and Marieke Dekker

Speech, Language, and Swallowing Difficulties in Neurology: A Sub-Saharan African Perspective

Abstract *Background*: Brain, nerve, and muscle disorders are extremely prevalent in sub-Saharan Africa (SSA) and are often chronic. Awareness of and insight into oropharyngeal disorders in neurological disease are the most important factors for optimal functional outcome. Due to the complexity and hierarchy of neurological systems, functional (psychogenic, non-organic) neurological disorders pose a particular challenge: their clinical presentation is often dramatic and gives rise to insecurity in patients as well as in health workers. Furthermore, myths about the oropharyngeal region and unfamiliarity with its neuroanatomy and neurophysiology may lead to unnecessary and even harmful treatments. *Methodology*: This qualitative literary review describes a selection of common neurological disorders associated with speech and swallowing difficulties. *Results/Discussion*: Stepwise, the reader is guided through these disorders, their associated neuroanatomy while noting helpful clinical features, reader-friendly figures, and treatment suggestions. The glossary emphasizes the attribution of brain, nerve, and muscle dysfunction to speech, language, and swallowing pathology, allowing for renewed familiarization with specific issues and the speech and language therapeutic options in this multifaceted field.

Critical Review "This chapter is dedicated to Hilda, a young bright Tanzanian schoolgirl who sadly died from aspiration in juvenile myasthenia gravis, which is a treatable disorder." This dedication sadly is not the only story of its kind. In an attempt to have fewer African children such as Hilda who passed away due to preventable causes, the authors have shared detailed, clinically

relevant information about the most common neurological disorders. The authors provide culturally appropriate treatment suggestions, including pictures that reflect this cultural diversity. This is one of the first chapters where this information is shared with the SSA context specifically in mind, making it a pioneer in the field. The authors have also included some specific background information regarding traditional procedures such as frenulectomy and uvulectomy, which form part of the traditional healers' treatment of neurological disorders. This chapter thus provides a wide array of information that SLTs and other professionals from across SSA can use as a reference when working with neurologically involved patients. Through sharing this information, the incidence of the unnecessary deaths of children such as Hilda can hopefully be reduced, and clinicians and those working with people with disabilities can have some of the tools needed to help this population.

24 Stephen Musila Nzoka, Elizabeth Wangui Kamau, Paul Kamau Mbugua, Molly Merrab Ogalloh, and Joyce Achieng Ogogo

Active Aging with Aphasia: A Case of Kiambu County, (Kenya)

Abstract *Background*: Interpersonal communication can be described as an essential tool for life adjustment, linking people to their environment. This communication breaks down in the case of aphasia. The aim of this study was to investigate active aging with aphasia in Kiambu County, Kenya. Through participation and engagement with others, "'active aging" can take place. This paper aims to determine the gender most affected by aphasia in Kiambu County, establish how those in Kiambu County living with aphasia receive information and interact with others without aphasia and the community participation of those with aphasia, and to determine economic influences on disability in the participants. *Methodology*: A questionnaire was administered to 28 persons with aphasia between the ages of 51 and 68 years old in Kiambu County. *Results*: While 51% of participants used cellphones and media to assist in their communication, 46% relied on familiar communication partners. Access to assistive technology for communication was limited. There was a link between those with low levels of education and later economic difficulties. *Discussion*: Many participants found spontaneous solutions to their communication challenges, in the absence of formal supports. Results revealed that possession of education by persons with disability, including a person with aphasia, predicted better prospects of aging gracefully because education was a platform on which persons with disability could access many life benefits.

Critical Review With a steadily growing elderly population in many SSA countries, SLT services are increasingly needed to assist in cases such as post-stroke aphasia. This chapter examines aphasia in the context of Kenya; however, parallels can be drawn with other SSA countries as there is a high

prevalence of stroke across Africa. The chapter includes a discussion of aphasia specifically related to the African context, including a brief overview of the types of aphasia and some traditional beliefs surrounding it. This makes it one of the first of its kind as it considers the influence of African culture on this specific disorder. It also provides insight into the lived experience of patients with aphasia, particularly in terms of the means to communicate that they have developed. The fact that a large percentage of the participants made their own communication devices, such as using a cellphone to communicate, is a testament to the will and creativity that develops out of need when there are no formal supports available. This chapter resonates well with Mary Musungu's story in the foreword of this book. However, as the authors argue, increased formal supports must be advocated for. The information provided in this chapter can be used by a variety of professionals across SSA countries who work with aphasic clients but also by persons in positions of power when considering policies related to the elderly.

25 Lawrence Eron, Nelly Otube, Mathew Karia, Edward Kija, Becky Isanda, Charles Mugisa, Stuart Robert Oyesigye, Marlene Küthe, Rieke Meinen, Steffen Gremmelt, Geoffrey Karugu, and Ulrike M. Lüdtke

Development of a Mobile SLT Clinic: An Example from East Africa

Abstract *Background*: In SSA, the ratio of persons with communication disabilities to speech–language therapists is adverse. People living in urban areas of some countries are much more likely to receive treatment than those living in rural areas. Mobile health care is a community-based strategy that provides solutions to speech–language therapy (SLT) delivery to underserved at-risk populations. *Methodology*: This multinational project report elaborates on the culturally appropriate adaptation of the general concept of a mobile clinic to a mobile SLT clinic. The authors from Kenya, Tanzania, Uganda, and Europe outline a strategic methodology for developing, equipping, and using the mobile clinic. *Results*: Challenges, pitfalls, and prospects of developing a culturally sensitive practicing mobile clinic for SLT are discussed. In particular, the collaboration in a multinational project team of experts from sub-Saharan Africa and Europe is critically reviewed. *Discussion*: While developing a culturally appropriate and mobile SLT clinic, a cost-benefit analysis became one of the main tasks. SLTs need to question themselves over whether there is a need for expensive inventories or low-cost basic equipment for assessment and therapy or both.

Critical Review This chapter deals with a challenging field of SLT in SSA: service delivery in underserved rural areas. The authors present a persuasive concept of a mobile SLT clinic to face this challenge. Their intelligible approach of conceptualizing the mobile clinic to serve rural areas holds the

potential to be implemented in different areas while keeping the costs low. In particular, the very important debate on finances and the ideas to face it given by the authors are beneficial for readers. They plead to find a balance between necessary purchases from Minority World contexts and the usage of basic daily materials on the one hand and the development of SSA culturally appropriate materials on the other hand to avoid the classical dependence on outsider's funds and donations. Furthermore, this chapter reflects on an exceptional example of an international project collaboration where the expertise of therapists, medics, and special needs teachers from different SSA countries and Europe was brought together. As interprofessional and international collaboration – especially between Majority World countries – is vital for many fields of professionalization of SLT in SSA, this project reflection offers gainful insights to collaborate beyond borders and disciplines.

26 Anke Lesinski-Schiedat, Enica Richard, Rachel Mkumbo, Rukiya A. Mohamed, and Angelika Illg

The Organization of Cochlear Implant Programs in Tanzania: Assessment of Needs and Challenges

Abstract *Background*: The incidence of newborns, children, and adults who are hearing impaired is large, estimated to be about 360 million worldwide. In Majority World countries in particular, healthcare systems for the assessment, treatment, and rehabilitation of hearing-impaired persons are not typically available. As such, the global inclusion of persons with hearing impairment is far from being reached. *Methodology*: Universal newborn hearing screening (UNHS) will offer a starting point for providing hearing-impaired patients with hearing technology in Tanzania. As part of this, objective audiological and radiological examinations must be offered and performed as further diagnostic methods for profound hearing loss. While hearing aids amplify sounds and require sufficient residual hearing, cochlear implants bypass hair cells by direct stimulation of the auditory nerve in the case of deafness. The surgical experience for cochlear implantation will be performed by an interdisciplinary team. *Results*: The ear, nose, and throat specialist will be responsible for confirming audiological diagnostics and the introduction of therapy after positive UNHS. Objective audiological and radiologic evaluations will serve to define the hearing loss as well as the individual anatomy relevant to hearing. Generally in children, the indication exists for a threshold poorer than 80 dB HL in automated auditory brainstem response (ABR). Implantation will be performed within the prelingual phase of neural maturation in congenitally deafened children before the age of 12 months. *Discussion*: It is known that hearing impairment has an immense and negative biopsychosocial impact. Hearing impairment without adequate therapy does not allow an education leading to tax-relevant employment. The development of a new hearing program based on the experiences of professionals reported in the literature and through personal discussions with and guidance from experienced professionals can increase the success of the development of a new center.

Critical Review In this chapter, readers obtain comprehensive information on the topic of treating hearing impairment through cochlear implantation and the necessity of implementing cochlear implant (CI) programs. This chapter offers basic knowledge for all practitioners on pathophysiology, therapy options, and outcomes in terms of speech and education. Although this basic information comes from the Western European medical tradition, it illustrates pathways for the development of a sub-Sahara African program for hearing loss diagnostics and therapy. This chapter outlines precisely and concisely specific guidelines for the implementation of a speech–language therapy (SLT) program for children that is focused on CI, such as universal newborn hearing screening (UNHS), as a primary prevention program, hearing aid fitting, and CI-based SLT, and argues for the necessity of maintaining lifelong care. Again, these standards come from a Minority World perspective that is filled with a long experience in diagnostics. Nevertheless, these guidelines have the potential to assist speech–language therapists (SLTs) from Majority World countries in implementing an SLT program focused on CI. Implementing an SLT program with a focus on CI on a large scale in a sub-Saharan country would be a huge step for people with hearing disorders or hearing loss in sub-Saharan regions. The authors discuss carefully different facets of the need and challenges of the implementation of such a program. Furthermore, this chapter emphasizes how hearing as a topic is crucial for SLTs in sub-Saharan Africa (SSA). From a global perspective of inclusion, early diagnostics and appropriate therapy programs in SSA will lead to the realistic inclusion of children with communication disorders in education and employment.

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17

Development of Speech-Language Therapy Assessments for the Languages of South Africa

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Background

> "After almost two decades of official multilingualism in South Africa, SLTs' practices remain a poor reflection of the multilingual and multicultural realities of the population. This is especially striking given that the focus of our work is on this very aspect: language."
>
> Van Dulm and Southwood (2013, p. 55)

South Africa is a richly diverse, multilingual, multicultural country with a progressive constitution that recognizes 11 official languages: nine indigenous languages from the Bantu[1] group and two West-Germanic languages. The Bantu languages include isiZulu, isiXhosa, Sepedi, Setswana, Sesotho, Xitsonga, siSwati, Tshivenda, and isiNdebele. The West-Germanic languages are English and Afrikaans. In addition to these official languages, people in the region speak a range of other indigenous languages, together with languages spoken by immigrants from the rest of Africa and beyond. South African Sign Language is also used across the country, although not yet recognized as an official language. The linguistic diversity of the region is accompanied by similar cultural variety, which coupled with the country's often-troubled history and social and economic challenges, creates a dynamic and complex environment rich in opportunity.

Speech–language therapists (SLTs) and audiologists working in this context are tasked with providing equitable services to all people of the country. They face innumerable challenges in doing so, variously described by authors such as Jordaan and Yelland (2003), Pascoe and Norman (2011), and Van Dulm and Southwood (2013). In this chapter, we focus specifically on challenges faced by SLTs in carrying out reliable and valid clinical assessment of the communication of children and adults in this context. It is widely acknowledged that there is a lack of assessment instruments designed for and standardized on the South African population (Jordaan & Yelland, 2003; Mdlalo et al., 2016; Penn, 1998; Van Dulm & Southwood, 2013). Here, we aim to describe the challenges faced by SLTs in assessment and focus in particular on assessments that have been developed for the context, the methodologies that underpin their development, and future work that needs to be done. Alongside these assessment-related challenges, opportunities abound to study under-researched languages, develop new assessment materials and protocols, and set standards for the clinical training of SLTs and audiologists that speak directly to the multilingual, multicultural environment and place us at the forefront of the profession in terms of embracing this diversity.

There are many different ways in which South African SLTs might increase the relevance of their practice for the people of the country. These have been discussed from epistemological (Kathard & Pillay, 2013; Penn, 2014), clinical training (Singh et al., 2015; Watermeyer & Barratt, 2013), and curriculum (Seabi et al., 2014) perspectives. There is an urgent imperative to recruit and train more multilingual SLTs, specifically speakers of African languages who will ensure that the demographics of the SLT workforce better match that of the population. In this chapter, we limit our focus to just one of the ways in which this increased relevance might be achieved, namely, through the development of culturally and linguistically appropriate assessments.

Current Challenges

Contextually relevant resources have been described as any tools (assessments, intervention programs, or guidelines) used with a specific population in a specific setting that were developed with that population and setting in mind (Pascoe & Norman, 2011).

[1]The word "Bantu" has negative connotations for many South Africans who associate it with the apartheid regime and derogatory usage. In this chapter, we use the term in a linguistic sense to describe the language family to which many of our indigenous languages belong, in keeping with international usage.

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Given the limited range of contextually relevant assessments available for children and adults in South Africa, how do clinicians typically proceed? Van Dulm and Southwood (2013) carried out a national survey of SLTs working with children in South Africa. Results suggested that English-speaking South African children are often assessed with British or American instruments, with or without replacement of inappropriate vocabulary items. For Afrikaans-speaking children, translated versions of some of the British/US-based assessments are used. Informal assessments are also frequently administered with clinicians sometimes devising their own assessments or making their own translations of tests. Van Dulm and Southwood's survey indicated that there are a few tests available in some of the Bantu languages (e.g., Sepedi and isiXhosa translations of some tests), but for most of these languages, there is nothing at all.

Simply translating an assessment from one language into another does not make it appropriate. Languages are not always equivalent to each other in terms of lexical items or structure. Furthermore, the culture and context of the target population need to be considered to avoid misinterpretation of results (Van der Merwe & le Roux, 2014). There is a growing drive to develop or adapt assessment tools and procedures to match the needs of populations and take different worldviews into account. Carter et al. (2006) emphasized the need to develop culturally appropriate materials that take cultural variation and potential cultural bias into account. Their work in Kenya led to suggestions for clinicians assessing or treating children from a culture different from their own. These included a focus on the influence of culture on performance, familiarity with the testing situation, the effect of formal education, and picture recognition. Gladstone et al. (2010) used focus groups to identify important local concepts and developmental milestones when creating a developmental assessment for children in Malawi. This was done in preference to simply translating and adapting available tools from other settings. The focus groups highlighted social milestones and social intelligence as important components of development for the community, aspects which existing tests may have emphasized less. It should be noted that for many cultures the idea of assessment or testing is itself peculiar and "…a particularly Western middle-class phenomenon as the manner, content and criteria for evaluation are firmly embedded within middle-class culture and standards" (Solarsh & Alant, 2006, p. 2).

One of the problems with the administration of assessments developed for different populations may be the inaccurate identification of individuals with communication difficulties, leading to either over or under referral. Pascoe et al. (2015) assessed English-speaking children in Cape Town, South Africa, using the Diagnostic Evaluation of Articulation and Phonology (Dodd et al., 2002). Before considering the adaptations necessary to account for dialectal differences (as advised by the developers of the test), the prevalence of speech difficulties was noted to be 21% of the 3-year-olds sampled. However, this figure fell to 6.66% once dialectal differences were taken into account. South African English is the variety of English spoken in South Africa, and it contains distinguishing vowel and consonantal features that must be considered in a phonology assessment (see section "The Languages of South Africa" for further details). Another example of the dangers of using unadapted materials comes from Wilson and Moodley (1999). These authors showed that the use of the Central Institute for the Deaf, Test W-22 wordlist (a speech discrimination test developed in the USA and widely used by South African audiologists), is problematic. The participants spoke South African English as their home language and had hearing thresholds within normal limits yet still performed more poorly than their US counterparts on whom the norms are based. If an assessment is inappropriate or inaccurate and does not take cultural variation and the potential for cultural bias into account, results will not be accurate, and intervention may be inappropriate or even harmful (Carter et al., 2006).

Similar to an earlier survey by Jordaan and Yelland (2003), Van Dulm and Southwood's (2013) survey reported that all SLT respondents were fluent in English. However, the proportion able to provide services in an indigenous African language was 15%, lower than the figure estimated by Jordaan and Yelland 10 years before (25%).

Less than one-fifth of the SLTs surveyed could serve clients in a Bantu language, although approximately 80% of South Africans speak languages from this group as their home language (Statistics South Africa, 2012). This disparity between the languages in which SLTs can provide services and the country's demographics is striking and remarked on with increasing frequency (Jordaan & Kunene Nicolas, 2016; Mdlalo et al., 2016; Pascoe & Norman, 2011; Van Dulm & Southwood, 2013).

This issue of language mismatch between clinician and client is, of course, not a uniquely South African problem. At an international level, the profession has increasingly focused on the need to serve multilingual, multicultural populations and ways in which this might be done (Leadbeater & Litosseliti, 2014; Legg & Penn, 2013; Verdon, Wong, & McLeod, 2015; Verdon, McLeod, & Wong, 2015). The International Expert Panel on Multilingual Children's Speech (McLeod et al., 2016) drafted guidelines for addressing this very issue, irrespective of context. The principles detailed in that document are helpful in framing assessment as a broad information-gathering process comprising of case history taking, informal observations, and formal assessment that should ideally include all languages spoken by a child. Although access to formal assessments is mentioned as a key part of the process, the document is a helpful reminder that formal assessment tools are just one part of a larger assessment process. In terms of formal assessment tools, the authors detail a step-by-step process which begins with "1: [SLTs should] familiarize themselves with the language and assessment tool/test" (p. 11). Using this as a guide, we have structured the remainder of the chapter as follows: section "The Languages of South Africa" describes the official languages of South African in further detail, section "Assessment" gives an overview of assessment principles in general, and in section "A Review of Current Assessments", we review assessments that have been developed or adapted for use in the South African context.

The Languages of South Africa

A deeper knowledge of all the local languages is essential if we are to provide the same level of service to all people in South Africa. To reach a greater level of understanding will require multidisciplinary research teams comprising linguists, psychologists, and SLTs (Jordaan & Kunene Nicolas, 2016). In the section that follows, we focus on the official languages of the country and describe them in further detail.

IsiZulu is the most widely spoken language in South Africa, with 22.7% of the population speaking it as a first language. This is followed by isiXhosa (16%), Afrikaans (13.5%), and English (9.6%). Figure 17.1 summarizes the first-language distribution of the population of South Africa (based on Statistics South Africa, 2012).

Although English has one of the smaller home language bases in South Africa, it is generally thought to be the country's lingua franca and the dominant language of trade and industry, science and technology, politics, and education. English is widely favored as the language of learning and teaching in many South African schools, especially from Grade 4 (Lafon, 2008; Posel & Zeller, 2016). Many children thus have home languages

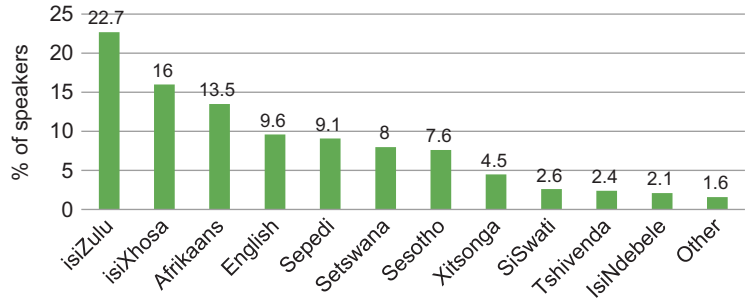

Fig. 17.1 Percentage of the first-language speakers in South Africa. (Based on Statistics South Africa, 2012)

different from their language of instruction in school, which may affect their academic development. The language situation is a complex one where the majority languages of isiZulu and isiXhosa actually have a minority status when considering aspects like education and availability of clinical resources and personnel.

Multilingualism is widespread in South Africa with most people being able to speak a mix of different languages. The many languages (official and unofficial) influence each other widely so that, for example, isiXhosa contains words borrowed from Afrikaans, and most South Africans, irrespective of their first language, will know words like *hayibo*! (an expression of surprise deriving from isiZulu) and *braai* (an Afrikaans word meaning barbecue). The distribution of languages varies by region, with, for example, isiXhosa being the main language spoken in the Eastern Cape and isiZulu being the dominant language in KwaZulu-Natal. isiZulu is also the most frequently spoken language in Gauteng, although by a smaller proportion of people. Afrikaans is the most widely spoken home language in the Western Cape.

The Bantu languages of South Africa are divided into two main groups: the Nguni group comprising isiZulu, isiXhosa, Siswati, and Ndebele and the Sotho-Tswana languages comprising Northern Sesotho (Sesotho sa Leboa or Sepedi), Southern Sesotho, and Setswana. Although the languages within these families are separate in their own right, the languages of the Nguni and Sotho-Tswana families are closely related, especially in terms of syntax and lexicon, and, for the most part, are intelligible to a first-language speaker of one of the languages in the group. They all have a subject-verb-object (SVO) structure and agglutinative verb structure and are tone languages (Zerbian & Krifka, 2008). One of the most widely known and well-described features of the Bantu languages is the noun-class system where each noun is assigned to a specific class (ranging from 12 to 20 depending on the language) and creates a system of grammatical agreement (for further information, see Demuth, 2000; Smouse et al., 2012). Each of the languages comprises a range of dialects deserving of further study and consideration in clinical contexts. For example, isiXhosa is characterized by a number of dialects described in detail by Gxilishe (1996) including the Thembu, Gcaleka, Cele, and Bhaca dialects. Each dialect is linked to a specific geographical region of the country, and although mutually intelligible, the differences between the dialects can be marked.

Focusing on the two Germanic languages of English and Afrikaans, South African English comprises two main varieties commonly referred to as L2 Black South African English (BSAE) and L1 English, formerly known as White South African English (WSAE) (De Klerk, 1999; Lass, 2004; Mesthrie, 2017). These well-documented world English varieties are in a state of flux that mirrors the dynamic socio-political environment of South Africa. Mesthrie (2017) describes the way in which "traditional" features of these varieties are changing and how the prestigious former WSAE is no longer the preserve of whites only, as South African society deracializes following the demise of apartheid. BSAE is the dialect spoken by first-language speakers of Bantu languages and may also be a regional dialect for some first-language English speakers (De Klerk, 1999; De Klerk & Gough, 2004; Van Rooy, 2008). Defining features of the variety include reduced contrasts between short and long vowels; the use of fewer central vowels; realization of /θ, ð/ as plosives /t, d/; and palatal fricatives /ʃ, ʒ/ produced as alveolars /s, z/ (De Klerk & Gough, 2004; Van Rooy, 2008). Devoicing processes are frequently reported (Lass, 2004; Van Rooy, 2008). In light of the variations within South African English, and the features that define it as a variety distinct from other varieties of English, including those in which the majority of standardized tests are normed, it is essential that assessment and therapy materials are adapted for the South African context. South African English (SAE) is described as morphologically impoverished when compared to Bantu languages such as isiXhosa, although it does have subject-verb agreement, making it less morphologically impoverished than Afrikaans which has no noun classes, noun prefixes, or overtly marked subject-verb/object-verb agreement (Potgieter & Southwood, 2016). Afrikaans,

the third most widely spoken language in South Africa (Statistics South Africa, 2012), derives from Dutch and has been influenced by other languages such as English, Malay, German, Portuguese, French, and some of the Bantu languages. It is a dominant language in the Western and Northern Cape regions of the country and, like all of the languages, has a range of different dialects linked to different socioeconomic groups and geographical location.

Van der Merwe and le Roux (2014) discuss the notion of language-specific symptoms of speech, language, and hearing disorders. They suggest that while there are likely universal language-independent symptoms associated with specific communication disorders, there will typically also be a set of characteristics specific to a given language. Thus, for example, developmental phonological processes are thought to be universal across all languages, but cluster reduction may apply only to languages that contain consonant clusters and final consonant deletion only to those where words end in consonants. Salient features of disorders are often described based only on English language investigations. We need to view these studies critically, with an awareness of how the difficulty would be experienced by speakers of other languages and cultures. Since English and Afrikaans are both Germanic languages, the difficulties could be similar for these languages but are likely to be very different for the Bantu languages. Van der Merwe and le Roux (2014) describe the idiosyncratic features of the sound systems of some of the indigenous languages, suggesting that the first step for SLTs working in South Africa is to understand the reality of Bantu language-specific symptoms. We should be aware that the languages contain sound characteristics that do not occur in the Germanic languages and the features are not always represented orthographically. These authors suggest that stimuli selection for assessment and therapy has to be considered carefully. Diemer et al. (2015) provide an excellent example of this careful consideration in their paper on phonological awareness assessment in isiXhosa. They provide a critical review of what is known about phonological awareness in the Bantu languages and note that "In adapting a phonological awareness test from a structurally very different language, such as English, a number of decisions must be made about what tasks to use, what linguistic segments to target, how the test relates to the linguistic structure and how to administer the test" (p. 332).

Assessment

Assessment is a key component of clinical practice in SLT. The use of valid and reliable tools is vital for the accurate identification of speech and language difficulties. Once such difficulties have been identified, assessment of an individual's strengths and weaknesses is needed to plan appropriate intervention. Dockrell and Marshall (2015, p. 116) note, "Effective targeted interventions and the ability to monitor progress require tools that are reliable, valid and fit for purpose." Although such steps are fundamental in the training of SLTs, being able to undertake such assessment presupposes that valid and reliable tools are available for the particular setting and that the use of the tools will mean that best practice for management can be adopted. Reviews and critiques of available assessments have been undertaken by Friberg (2010), McLeod and Verdon (2014), and Dockrell and Marshall (2015). These papers highlight the psychometric properties that need to be considered when evaluating assessments and emphasize the complex nature of human language and interactions. Dockrell and Marshall (2015) emphasize the value of dynamic assessment as a means of fairly evaluating the skills of individuals from a range of different language and cultural backgrounds. McLeod and Verdon's (2014) review focused on speech assessment in languages other than English. They described 30 speech assessments covering 19 languages. Approximately half (53.3%) were norm-referenced, with the number of children in the normative samples ranging between 145 and 2568. Many of the assessments met the psychometric criteria for operationalization, although only a small number provided sensitivity and specificity data. These authors noted that in situations where bilingualism is typical, norms should include data for bilingual children.

Norm-referenced tests involve a comparison of an individual's score in relation to the scores obtained by a sample of the population. The indi-

vidual's score is compared to the performance of the sample and placed in relation to it, that is, it is better than most, poorer than most, comparable to the average score obtained by the sample. Most speech and language assessments use this approach. Kester and Brice (2010) suggest that when evaluating an assessment, the norm group be carefully considered. Aspects that should be considered include representation and the extent to which the group is characteristic of a particular population. The factors considered most important are age, grade level, gender, geographic region, ethnicity, and socioeconomic status. Guidelines suggest that the number of participants should be at least 100 per cell for standardizing a test (Vergouwe et al., 2005).

For some purposes, national norms may be most relevant. In other cases, the norms of a specific subgroup may be more relevant.

Criterion-referenced assessments are different in that they compare an individual's performance to a predetermined standard or desirable level. Many educational assessments follow this format in which learners must meet an acceptable standard to pass an examination or grade. An example of a communication assessment that follows a criterion-referenced approach is the Rossetti Infant-Toddler Language Scales (Rossetti, 1990). As such, it does not matter how learners perform in relation to one another, rather than they meet the grade (or not).

Validity is an estimate of whether a test measures what it intends to measure. Reliability refers to how consistently the test measures what it measures. Standardized assessments usually involve large-scale studies providing an estimate of validity and reliability. These constructs are linked to each other since a test that measures what it purports to measure is more likely to yield consistent and reliable results. Kester and Brice (2010) note that a test must have a high reliability if it is to achieve high estimates of validity. Estimates of reliability and validity can range from 0.0 to 1.0 with 0.6 and above being considered as high. There are multiple types of validity, discussed in detail by Kester and Brice (2010). In brief, content validity refers to whether an instrument takes all content into consideration. For example, a speech assessment that only included two consonants would not cover the entire domain of phonology. Judgments about content validity are usually made by experts in the field. Criterion-related validity involves a comparison of the tool to another instrument that measures the same thing. Criterion-related validity would look at the correlation between scores on similar tests. Predictive validity refers to an assessment's ability to predict something. For example, a high score on a single-word speech assessment may predict high levels of intelligibility. Concurrent validity is an estimate of the ability to distinguish between groups that are different. For example, when assessing two groups of children (those diagnosed with speech difficulties and those who are judged to be typically developing), we would expect the assessment to yield very different scores for the two groups.

If we are to move forward in the development of assessments appropriate for the different languages and people of South Africa, we need to start by gathering sets of normative data. Writing about sub-Saharan Africa more generally, Alcock et al. (2015, p. 764) note "the current lack of appropriate tools is associated with a dearth of systematic studies of typical development." The collection and analysis of normative data will lead to a database of what is typical and thus a better understanding of the difficulties that may occur. Since this knowledge of what to expect may inform the way in which assessments are designed, it is reasonable to ask whether the collection of normative data should happen before the development of assessments – or alternatively, is it only possible to obtain data once an assessment has been developed for this purpose? Different researchers have taken different approaches in their work, but in general, it seems as if the two areas need to advance together in parallel. Normative data is typically collected using an early version of an assessment tool. The data collected – and the process of collecting it – then leads to refinement of the tool, and so on, in a spiral process.

A Review of Current Assessments

In this review, we focus specifically on assessments in the official South African languages designed for use by SLTs in South Africa. There are many unpublished studies (e.g., honors and postgraduate student projects; informal assessments by clinicians), which have an important contribution to make and have been included in the reviews by Penn (1998), Mphahlele (2006), and Mdlalo (2013). However, for the purposes of this review, we have selectively limited our focus to published projects in SLT and therefore cannot claim to be exhaustive. We have included assessments based on parental questionnaires and screening tools. In the following sections, we analyze the assessments by language, clinical domain, and methodology. This is followed in section "Discussion and Future Plans" by a discussion of the findings and implications for future work.

Description of Assessments by Language

Table 17.1 details the available assessments by language. There are 27 assessments that met the criteria set in our review. Of these the greatest number (10) was for Afrikaans, followed by five assessments for isiXhosa, and four for isiZulu. Sepedi and SAE both have three assessments, whereas Setswana has one. The other languages, Sesotho, Tshivenda, Siswati, Xitsonga, and isiNdebele, do not have any known/published assessments – aside from the Intelligibility in Context Scale (ICS) that was adapted for all of the South African languages (see Pascoe & McLeod, 2016). It is interesting to note that although Sesotho does not have any freely available assessments, it is one of the Bantu languages that has been relatively well studied, especially in terms of children's language acquisition. There is a fairly substantial body of knowledge about the nature of children's acquisition in this language (e.g., Demuth, 1990, 2007), and although an assessment tool remains to be developed, Sesotho is ahead of some other languages that have early versions of assessment tools but very limited associated normative data.

Description of Assessments by Clinical Domain

Table 17.2 shows that the language assessments that have been developed or translated cluster in a few specific areas. It is clear that more work has been conducted relating to children than adults. There are just four assessments described here that focus on adults with acquired speech and language difficulties: the adaptations by Mosdell et al. (2010) of the Boston Naming Test and Cookie Theft Test which form part of the Groote Schuur Neurocognitive Assessment Battery (see also Balchin, 2008), preliminary work around a translated version of the Western Aphasia Battery by Barratt et al. (2012), and Fouche and Van der Merwe's (1999) speech intelligibility test designed for use with Sepedi adults with dysarthria or other acquired neurogenic speech difficulties. The development process described in these papers is a complex one, detailing work in progress rather than fully validated tools complete with psychometric data. There is much other work being undertaken in the development of assessments for adults with communication impairments in South Africa such as that by Allie et al. (2015) focusing on apraxia of speech in isiXhosa-speaking adults and work describing alternative methods to assessment using ethnographic approaches and narratives to more completely grasp the socio-cultural background of individuals (Legg, 2010; Legg & Penn, 2013; Penn, 2014).

For children, the assessments in Table 17.2 cluster around the domains of speech (four assessments), literacy and phonological awareness (two assessments), lexical development (eight assessments), language (seven assessments), and general development (including language). Van der Merwe and le Roux (2014) and Van Biljon et al. (2015) note that the development of articulation assessment protocols is needed for each of the Bantu languages and provide some guidelines that might be used in developing these, as well as potential research questions that this type of work might address. Although there is no children's speech assessment included for isiZulu, Naidoo et al. (2005) have undertaken studies of isiZulu phonology, which have added considerably to our knowledge of isiZulu speech development. Parent-administered scales (such as

Table 17.1 South African speech and language assessments by language

Afrikaans	1. Language Impairment in a Multilingual Society: Multilingual Assessment Instrument for Narratives (LITMUS-MAIN-Afrikaans, Gagarina et al., 2012) 2. Language Impairment in a Multilingual Society: Cross-Linguistic Lexical Tasks (LITMUS-CLT-AF, Southwood, 2012a; Klop et al., 2012)
	3. Receptive and Expressive Activities for Language Therapy (REALt, Southwood & Van Dulm, 2012)
	4. Mullen Scales of Early Learning (Bornman et al., 2010 based on Mullen, 1995)
	5. Ages and Stages Questionnaires (ASQ, Bornman et al., 2010 based on Squires et al., 1999)
	6. Boston Naming and Cookie Theft Tests (Mosdell et al., 2010)
	7. Diagnostic Evaluation of Language Variation (DELV-A, Van Dulm & Southwood, 2008)
	8. Phonological Awareness and Early Literacy Test (PAELT, Adnams et al., 2007 based on Nadler-Nir, 1997 and Byrne & Fielding-Barnsley, 1993)
	9. Afrikaanse Reseptiewe Woordeskattoets (ARW, Afrikaans Receptive Vocabulary Test, Buitendag et al., 1998)
	10. Peabody Picture Vocabulary Test (Alant & Beukes, 1986)
isiXhosa	1. Phonological Awareness Tasks (Diemer et al., 2015)
	2. Masincokoleni Speech Assessment (Maphalala et al., 2014)
	3. Language Impairment in a Multilingual Society: Cross-linguistic Lexical Tasks (LITMUS-CLT-XHO, Southwood & Potgieter, 2013)
	4. Receptive and Expressive Activities for Language Therapy (REALt, Southwood & Van Dulm, 2012)
	5. Boston Naming and Cookie Theft Tests (Mosdell et al., 2010)
isiZulu	1. Picture Naming Game (PiNG, Kunene Nicolas & Ahmed, 2016 based on Bello et al., 2012)
	2. Western Aphasia Battery (WAB, Barratt et al., 2012)
	3. Test of Ability to Explain (Solarsh & Alant, 2006)
	4. IsiZulu Expressive and Receptive Language Assessment (ZERLA, Bortz, 1997)
Sepedi	1. Non-Word Repetition Test (Wilsenach, 2016)
	2. Speech Intelligibility Test (Fouche & Van der Merwe, 1999)
	3. Peabody Picture Vocabulary Test (Pakendorf & Alant, 1997)
Setswana	1. Setswana Speech Assessment (Mahura & Pascoe, 2016)
South African English	1. Language Development Survey (LDS-SA, Gonasillan et al., 2013)
	2. Language Impairment in a Multilingual Society: Cross-linguistic Lexical Tasks (LITMUS-CLT-SAE, Southwood, 2012b)
	3. Receptive and Expressive Activities for Language Therapy (REALt, Southwood & Van Dulm, 2012)
All official languages	1. Intelligibility in Context Scale (ICS, Pascoe & McLeod, 2016)

the ICS, Language Development Survey, Mullen Scales of Early Learning, and Ages and Stages Questionnaires [ASQ]) have not always been included in reviews of assessments because they do not always test children directly and are more likely to be criterion rather than norm-referenced. We consider that they have a very important place in the assessment of young children and their families, and the growing number of tools of this nature testifies to this. Outside the parameters of our selective review, Abdoola (2015) describes a project translating the ASQ (Squires et al., 1999) into Hindi, one of the local Indian languages.

There are lexical assessments for five of the South African languages (isiXhosa, isiZulu, Sepedi, Afrikaans, SAE). Earlier projects describe the adaptation of the Peabody Picture Vocabulary Test (revised, Dunn & Dunn, 2007) into Afrikaans and Sepedi. This was followed by the development of the Afrikaanse Reseptiewe Woordeskattoets (ARW, Afrikaans Receptive Vocabulary Test) by Buitendag et al. (1998). This well-validated test is still widely used by clinicians in South Africa (including 30% of the respondents in Van Dulm and Southwood's survey of SLTs) and has been cited in local research studies focusing on

Table 17.2 South African speech and language assessments by domain

Speech	1. isiXhosa: Masincokoleni Speech Assessment (Maphalala et al., 2014)
	2. Sepedi: Non-Word Repetition Test[a] (Wilsenach, 2016)
	3. Setswana: Speech Assessment (Mahura & Pascoe, 2016)
	4. Ten South African Languages: Intelligibility in Context Scale (ICS, Pascoe & McLeod, 2016)
Phonological awareness/literacy	1. Afrikaans: Phonological Awareness and Early Literacy Test (PAELT, Adnams et al., 2007 based on Nadler-Nir, 1997 and Byrne & Fielding-Barnsley, 1993)
	2. IsiXhosa: Phonological Awareness Tasks (Diemer et al., 2015)
Lexicon/ vocabulary	1. Afrikaans: Language Impairment in a Multilingual Society: Cross-linguistic Lexical Tasks (LITMUS-CLT-AF, Southwood, 2012a; Klop et al., 2012)
	2. Afrikaans: Peabody Picture Vocabulary Test (Alant & Beukes, 1986)
	3. Afrikaanse Reseptiewe Woordeskattoets (ARW, Afrikaans Receptive Vocabulary Test, Buitendag et al., 1998)
	4. isiXhosa: Language Impairment in a Multilingual Society: Cross-linguistic Lexical Tasks (LITMUS-CLT-XHO, Southwood & Potgieter, 2013)
	5. isiZulu: Picture Naming Game (PiNG, Kunene Nicolas & Ahmed, 2016 based on Bello et al., 2012)
	6. South African English: Language Impairment in a Multilingual Society: Cross-linguistic Lexical Tasks (LITMUS-CLT-SAE, Southwood, 2012b)
	7. Sepedi: Peabody Picture Vocabulary Test (Pakendorf & Alant, 1997) 8. South African English: Language Development Survey (LDS-SA, Gonasillan et al., 2013)
Language (expressive and receptive)	1. Afrikaans: Receptive and Expressive Activities for Language Therapy (REALt, Southwood & Van Dulm, 2012)
	2. Afrikaans: Diagnostic Evaluation of Language Variation (DELV-A, Van Dulm & Southwood, 2008)
	3. isiXhosa: Receptive and Expressive Activities for Language Therapy (REALt, Southwood & Van Dulm, 2012)
	4. isiZulu: Test of Ability to Explain (Solarsh & Alant, 2006)
	5. isiZulu: isiZulu Expressive and Receptive Language Assessment (ZERLA, Bortz, 1997)
	6. South African English: Receptive and Expressive Activities for Language Therapy (REALt, Southwood & Van Dulm, 2012) 7. Language Impairment in a Multilingual Society: Multilingual Assessment Instrument for Narratives (LITMUS-MAIN-Afrikaans, Gagarina et al., 2012)
General development, including language	1. Afrikaans: Mullen Scales of Early Learning (Bornman et al., 2010 based on Mullen, 1995)
	2. Afrikaans: Ages and Stages Questionnaires (ASQ, Bornman et al., 2010 based on Squires et al., 1999)
Acquired neurogenic difficulties (adult assessments)	1. Afrikaans: Boston Naming and Cookie Theft Tests (Mosdell et al., 2010)
	2. isiXhosa: Boston Naming and Cookie Theft Tests (Mosdell et al., 2010)
	3. isiZulu: Western Aphasia Battery (Barratt et al., 2012)
	4. Sepedi: Speech Intelligibility Test (Fouche & Van der Merwe, 1999)

[a]This assessment could also have been included under the phonological awareness/literacy category since non-word repetition tasks yield information about both speech production and phonological awareness

Afrikaans-speaking children (e.g., Southwood & Van Dulm, 2016). More recently, Southwood and her team at the University of Stellenbosch developed lexical assessments for isiXhosa, Afrikaans, and SAE which are linked to each other and other languages studied as part of a bigger cross-linguistic project. This type of study is effective in showing both the applied value of a newly developed tool and the theoretical value that can be obtained when languages are compared and contrasted with each other. The Picture Naming Game (PiNG, Bello et al., 2012) is a relatively new assessment of

lexicon in children, initially devised for Italian and now adapted for isiZulu (Kunene Nicolas & Ahmed, 2016).

Some assessments have been designed to comprehensively assess children's expressive and receptive language: Bortz's (1997) isiZulu Expressive and Receptive Language Assessment (ZERLA) is a comprehensive test battery for isiZulu; and Southwood and Van Dulm's (2012) Receptive and Expressive Activities for Language Therapy includes isiXhosa, Afrikaans, and SAE activities for informal assessment and therapy. The Diagnostic Evaluation of Language Variation (Seymour et al., 2003) is an assessment developed in the USA to distinguish language disorder from language difference. It does this by focusing on universal aspects of linguistic knowledge, which do not vary across dialects. An Afrikaans version of this assessment was created by Van Dulm and Southwood (2008) with a view to being able to assess a range of universal language skills in Afrikaans. Solarsh and Alant (2006) adopted an innovative approach in their development of an isiZulu assessment of verbal reasoning entitled: Test of the Ability to Explain. This assessment was designed to assess the verbal reasoning skills of isiZulu-speaking children in a way that is culturally fair but at the same time able to evaluate universal cognitive skills.

Description of Assessments by Methodology

In our final table (see 17.3), we look behind the scenes at each of the 27 assessments focusing on the methodologies used in the work. We analyzed each assessment using four main descriptors which are now described in turn:

A. *Description of the assessment:* We considered information about each assessment and aimed to provide an overview of the main characteristics and purpose for each.
B. *Assessment development process*: Where the information was available, we attempted to give an overview of the approach that was taken to the test development and to describe phases or steps that were taken in developing the material.
C. *Pilot/s overview*: Where applicable, pilot studies that were undertaken with the assessments were described. Where possible we aimed to include details about the number of pilots undertaken, the number of participants, and any other pertinent characteristics of the participants.
D. *Results/psychometric data:* Finally, we were interested in the psychometric properties of the assessments and aimed to share these if they were available or provide summary statements about the progress toward achieving validation and documentation of psychometric properties.

Table 17.3 shows that some of these assessments have been adapted and translated from other existing assessments, for example, Mosdell et al.'s (2010) adaptation of the Boston Naming Test and Bornman et al.'s (2010) adaptations of the two parent-administered scales. There are other assessments that have started fresh from a blank page – possibly because there were no appropriate models suitable for adaptation. Diemer et al. (2015) and Mahura and Pascoe (2016) focused on understanding the language structures of isiXhosa and Setswana, respectively, and used this knowledge to shape assessments that are different from the available materials for other languages, as suggested by Van der Merwe and le Roux (2014).

A range of different methodologies has been used in the development of these assessments. As shown in Table 17.3, several of the research teams started with focus groups where the opinions of "experts" or first-language speaking adults could be obtained as a first step, for example, Kunene Nicolas and Ahmed (2016) solicited the opinions of first-language isiZulu speakers for their preliminary PiNG test items, and Maphalala et al. (2014) undertook a focus group with an expert panel required to critique stimuli items in terms of specific criteria pertinent to the language. Other studies focused more heavily on the literature, theoretical models of test design, and stimuli selection. Several of the tests involved a parallel process of test development and pilot work with multiple versions of an assessment

created and updated. Normative samples ranged from small groups (e.g., the 24 participants used by Maphalala et al. (2014) and only four participants used by Fouche and Van der Merwe (1999) to the larger studies of Solarsh and Alant (2006) with 292 participants and Bortz (1997) with 303 children).

Discussion and Future Plans

This chapter has emphasized the importance of assessments for SLTs that are valid and reliable for the given context. This focus on assessments should not detract from the need for the development of culturally and linguistically relevant interventions. Assessment is a means to an end so that relevant intervention can be provided if needed. Much of what has been written about therapy strategies and interventions is based on English speakers in high-income countries. A simple example of this is cueing words using initial consonants as for English. This would not work well with languages such as isiXhosa or Sesotho that typically begin with a vowel (Gxilishe, 2004). Intervention is more valid when it is relevant and culturally acceptable, and it must be tailored specifically to the culture of the community in which the individual resides (Hartley et al., 2009).

Tables 17.1 and 17.2 clearly indicate that there are many gaps in the languages covered by assessments as well as the domains addressed. Table 17.2 includes only a small number of literacy and phonological awareness assessments, which, given the educational crisis in South Africa (Spaull, 2013), must surely be a key focus area to be addressed. Diemer et al. (2015) review a larger set of work (both published and unpublished) that has focused on phonological awareness in the Bantu languages, not only limited to South Africa. There are likely many informal assessments of children's literacy and phonological awareness being used by SLTs and educators, which were not included in our review. Linked to this point is a caution about the limitations of this review. Our review focused on published studies only, but there are many unpublished resources that we did not describe here, and we may have inadvertently omitted assessments that our search strategy did not find.

It is apparent from the summary provided in Table 17.3 that assessment development is a process usually occurring over the long term with multiple phases and iterations. There are some complete assessments included in Table 17.3 (e.g., Bortz's [1997] ZERLA and Buitendag et al.'s [1998] ARW), but many of the assessments described are in the early stages of development. The authors acknowledge that these materials will change over time, becoming more valid and reliable and growing together with a larger body of normative data against which individual children can be compared.

In section "Assessment" of this chapter, we described the psychometric qualities of the assessments and gave an overview of the ways in which validity and reliability can be considered. Table 17.3 shows that we have some way to go in ensuring that the available assessments meet psychometric criteria. There are assessments that show, either through the assessment manual or related publications, psychometric data and rationales underpinning the test design, collection of normative data, and standardization (e.g., Solarsh & Alant, 2006; Bortz, 1997; Buitendag et al., 1998). However, these assessments are the exceptions, and there is much work to be done in strengthening the validity and reliability of the tools presented in this paper – as well as developing new tools to plug the gaps in areas (languages and domains) in which there are few assessments at all.

SLTs should be driven by their own day-to-day needs. What is it that is needed to make our roles more relevant? Without doubt, we must expand research leading to linguistically and culturally appropriate assessment and intervention material for which clinician and researcher partnerships are critical. A collaborative national speech and language project could support a coordinated agenda of strengthening research in progress, developing networks of researchers, and acting as a clearinghouse for published materials. In parallel with this

Table 17.3 South African speech and language assessments – description and methodology

Assessment	A Description of assessment	B Assessment development process	C Pilot/s overview	D Results/ psychometric data (if available)
Speech				
1. isiXhosa: Masincokoleni Speech Assessment (Maphalala et al., 2014)	Single-word picture-naming task covering all sounds of the isiXhosa speech inventory	Focus group with an expert panel	24 children aged 3–6 years	Not available
2. Setswana: Speech Assessment (Mahura & Pascoe, 2016)	Single-word picture-naming task covering all sounds of Setswana speech inventory	Focus group with an expert panel	36 children aged 3–6 years	Not available
3. Sepedi: Non-Word Repetition Test (Wilsenach, 2016)	20 non-word items, ranging in the number of syllables, presented in a pre-recorded format	Not detailed	120 Grade 3 children (mean age, 9 years)	Normal distribution of scores; moderate to strong correlations with other measures, e.g., digit recall and reading
4. Ten South African languages: Intelligibility in Context Scale (ICS, Pascoe & McLeod, 2016)	Parent-administered questionnaire that asks ten questions about a child's speech intelligibility in a range of different settings	Adapted into ten official languages of South Africa by a team of translators/ clinicians. Forward and back translations and community checking	Piloted with 23 SLTs in South Africa; focus groups with five SLTs to evaluate usefulness of tool	Not available
Phonological awareness/literacy				
1. Afrikaans: Phonological Awareness and Early Literacy Test (PAELT, Adnams et al., 2007)	16 subtests focusing on phonological awareness and early literacy (e.g., includes subtests of rhyming, blending, reading, spelling)	Based on an English test of phonological awareness and literacy (Byrne & Fielding-Barnsley, 1993) that was adapted by Nadler-Nir (1997) and translated into Afrikaans	Used as part of an intervention study with 105 Grade 3 children in the Western Cape	Able to distinguish between different diagnostic groups; a sensitive outcomes measure although sensitivity varied for subtests in the study (See Adnams et al., 2007)
2. isiXhosa: Phonological Awareness Tasks (Diemer et al., 2015)	Blending, segmenting, and substitution are targeted at a variety of levels (phoneme, syllable)	Detailed consideration of linguistic and cognitive factors	31 learners in Grade 4	Syllable awareness is stronger than phoneme awareness; syllable substitution was the most difficult task at syllable level; phoneme segmentation was the most difficult phoneme task

(continued)

Table 17.3 (continued)

Assessment	A Description of assessment	B Assessment development process	C Pilot/s overview	D Results/ psychometric data (if available)
Lexicon/vocabulary				
1. South African English/isiXhosa/ Afrikaans: Language Impairment in a Multilingual Society: Cross-linguistic Lexical Tasks (LITMUS-CLT, Southwood, 2012a, b, Southwood & Potgieter, 2013, Klop et al., 2012)	Each assessment consists of four sections (noun production, noun comprehension; verb production, verb comprehension). Each section contains 32 test items	Items were selected for each language based on a fixed list of candidate words rated for difficulty ensuring that tests for different languages are not the same but are equivalent in difficulty	41 low SES 4-year-olds including 11 trilingual speakers of SAE, IsiXhosa, and Afrikaans and ten monolingual speakers of each of the languages	See Southwood et al. (2012, 2013), Potgieter and Southwood (2016), and Potgieter (2016)
2. Afrikaans and Sepedi: Peabody Picture Vocabulary Test (Alant & Beukes, 1986; Pakendorf & Alant, 1997)	Adaptation of English Peabody Picture Vocabulary Test into Afrikaans and Sepedi	Not available	Not available	Not available
3. isiZulu: Picture Naming Game (PiNG, Kunene Nicolas & Ahmed, 2016 based on Bello et al., 2012)	Picture format game with 40 target pictures of nouns (20 for comprehension and 20 for production) and 40 of verbs/adjectives (20 for comprehension and 20 for production)	Translation into isiZulu by a small team and pilot study with adult first-language speakers. Changes to some items were made following this pilot	Study 1: 15 children aged 25–36 months Study 2: 26 children aged 25–36 months	Age was shown to affect children's performance
4. Afrikaanse Reseptiewe Woordeskattoets (ARW, Afrikaans Receptive Vocabulary Test, Buitendag et al., 1998)	Assesses children's Afrikaans vocabulary using two alternate forms	Not available	970 children aged 7 and 10 years	The test forms (A/B) have been shown to be equivalent, reliable, and valid; referred to in recent research studies (e.g., Southwood & Van Dulm, 2016)
5. South African English: Language Development Survey (LDS-SA, Gonasillan et al., 2013)	An expressive vocabulary checklist designed to ascertain vocabulary of young children	An expert panel was used to determine appropriateness of LDS for South Africa. Twenty-two items from the original scale were replaced with more relevant items	Presented to 40 middle-class parents of 2-year-old children in one region of South Africa	Significant correlations found between LDS-SA and original LDS for 12 of 14 vocabulary categories
Language (expressive/receptive)				
1. SAE, isiXhosa, Afrikaans: Receptive and Expressive Activities for Language Therapy (REALt, Southwood & Van Dulm, 2012)	Consists of informal assessments and an intervention program specifically designed for work with children who speak these languages	Focuses on aspects of language known through literature and clinical expertise to be challenging for children in the respective languages	93 typically developing children aged 4–9 years	Not available

(continued)

Table 17.3 (continued)

Assessment	A Description of assessment	B Assessment development process	C Pilot/s overview	D Results/ psychometric data (if available)
2. Afrikaans: Diagnostic Evaluation of Language Variation (DELV-A, Van Dulm & Southwood, 2008)	A comprehensive language assessment. Consists of 11 subtests organized into four domains (syntax, pragmatics, semantics, and phonology)	Based on the original DELV which aims to assess aspects of language that are known to differ between children with typical and atypical language	64 typically developing children between 6 and 9 years	The first version was not able to identify all participants as typically developing. Further adaptations were made, and a second version of the test was developed
3. isiZulu: Test of Ability to Explain (Solarsh & Alant, 2006)	Children are presented with pictures and asked questions about them. Measures verbal problem-solving skills; five categories of abstract thinking skills: (a) explaining inferences, (b) determining cause, (c) negative why questions, (d) determining solutions, and (e) avoiding problem	Based on the Test of Problem Solving (TOPS, Zachman et al., 1984) using principles of non-biased assessment	Three studies were undertaken with children aged 7.6–12.11 Pilot 1: 6 children Pilot 2: 60 children Main study: 292 children	Described as a reliable and valid test for the target population
4. isiZulu: isiZulu Expressive and Receptive Language Assessment (ZERLA, Bortz, 1997)	Subtests focusing on morphology, syntax, semantics, and pragmatics	Multiple phases for development, piloting, pre-standardization, and standardization	Pre-test sample: 188 children, aged 2.6–5.5 Standardization sample: 303 children aged 3.0–4.3 years	Test items found to have appropriate levels of difficulty and can discriminate effectively between children of different ages and those with language impairment
5. Language Impairment in a Multilingual Society: Multilingual Assessment Instrument for Narratives (LITMUS-MAIN-Afrikaans, Gagarina et al., 2012)	Comprehension and production of narratives in children aged 3–10 years	Part of a large multilingual project using principles of narrative development and looking at a range of different languages	Pilot tested with more than 500 children for 15 different languages and combinations of languages	The stories used in this assessment have been controlled for cognitive and linguistic complexity. It has not been normed yet, but its standardized procedures can be used for evaluation, intervention, and research purposes

(continued)

Table 17.3 (continued)

Assessment	A Description of assessment	B Assessment development process	C Pilot/s overview	D Results/ psychometric data (if available)
General development including language				
1. Afrikaans: Mullen Scales of Early Learning; Ages and Stages Questionnaires (ASQ) (Bornman et al., 2010)	Mullen scales comprehensively assess all aspects of development (including expressive and receptive language). ASQ covers five developmental domains (communication, gross and fine motor, cognitive, and social) using a Likert scale	Four steps were followed to adapt these tools into Afrikaans: (1) linguistic translation, (2) cultural adaptation, (3) teacher review, and (4) pilot testing	Forty-seven typically developing preschool children aged 3.6 years. Mullen scales completed by SLTs; ASQ completed by parents	Both measures yielded similar results and compared favorably with each other
Acquired neurogenic difficulties (adult assessments)				
1. isiZulu: Western Aphasia Battery (WAB, Barratt et al., 2012)	Translated versions of the Western Aphasia Battery (WAB)	Five first-language isiZulu speakers translated the WAB	Exploratory study which aimed to describe differences in the translation of the WAB from English to isiZulu by five first-language speakers	Notable differences between translations especially with regard to vocabulary
2. isiXhosa and Afrikaans: Boston Naming and Cookie Theft Tests (Mosdell et al., 2010)	Adapted versions of English assessments	Adaptations using quantitative and qualitative converging lines of evidence, which included consultation with clinicians and translators knowledgeable in Afrikaans and isiXhosa, qualitative feedback from the research participants, and the results of the tests	Thirty typical participants (equal numbers of Afrikaans, English, and isiXhosa speakers) comparing scores to their performance on the original tests. Three aphasic patients were also tested	Adaptations made to the tests improved the performance of controls over the original versions and tentatively suggest that the adapted tests should be able to screen for aphasia
3. Sepedi: Speech Intelligibility Test (Fouche & Van der Merwe, 1999)	Contains four wordlists each comprising 27 words and a set of 12 multiple-choice items for each word. Aims to evaluate the intelligibility of speech	Wordlists compiled based on phonetics of language; qualitative analysis was undertaken	Four adult speakers with dysarthria	Not available

project, we also need to address other areas such as the training of SLTs and updating practice frameworks.

> "If you talk to a man in a language he understands, that goes to his head. If you talk to him in his language, that goes to his heart."
>
> Nelson Mandela

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18

Assessing Language in South Africa: Use of the Passive Construction

Mellissa Bortz

The chapter is based on author's doctoral thesis, Bortz, M.A. (2013).

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Motive

A much too often repeated lament in the South African speech–language therapy (SLT) profession is the critical need for the development of language assessment tools in all the languages spoken in the country (Barratt et al., 2012; Pascoe & Norman, 2011; Southwood & van Dulm, 2015). Generally, language assessments are not based on the structure of the nine Southeastern Bantu zone languages spoken in South Africa, and they do not take cultural or environmental conditions into account (Bornman et al., 2018; Bortz, 1995).

Tools are urgently needed to explore language acquisition and language impairment in Africa and must focus on issues of poverty and diversity. The research methods used should be suitable for the communities being explored and inform the delivery of appropriate services. Endeavors should be made to provide information that improves scientific research in terms of language acquisition and access to SLT services (Romski et al., 2018).

Traditionally, SLT research has been conducted in English on Western middle-class populations (Kathard et al., 2007). However, most of the world's populations is neither English speaking nor Western nor middle class. Most of these populations live in abject poverty (Soludo, 2001). It is therefore vital for speech–language therapists (SLTs) to change the focus of their research and begin to meet the urgent need of developing a research basis for the African languages. As van Rooy and Pienaar (2006, p. 60) note, "linguistic inquiry is under pressure in South Africa. Such a situation is unexpected in a country where such a rich collection of languages is used, and ostensibly supported by a very enabling language policy." However, research is not being conducted, due to problems within the university environment and lack of funding (Penn, 2007).

This study was motivated by the fact that the passive is an important and unique structure to examine as it could provide SLTs working in Africa with a tool to assess children in their first language. This is because if the passive was found to be acquired early in Setswana and if a child performed poorly on the passive assessment, then it would be an indication that the child has a language acquisition problem.

Demuth (personal communication, October 26, 2009) described the rationale to study the passive in Setswana as a test that would be useful as a diagnostic of language delay in the Sesotho languages, facilitating early identification and intervention:

> Given that South Africa's Bantu languages are closely related, tools that are developed in one language can be relatively easily adapted to another language. This is particularly true for grammatical constructions such as the passive in the very closely related languages, such as Setswana, Southern Sesotho and Northern Sesotho. The findings could then be easily applied to the Nguni languages Xhosa and IsiZulu.

Children in South Africa are required to learn English. Therefore, an assessment of the passive in Setswana and English would be extremely useful to assess children's bilingual abilities with respect to the passive. As mentioned previously, if a child performed poorly in the passive in her/his first language, this would indicate a language problem. However, if a child performed well on a Setswana assessment of the passive but poorly in English, the SLT would be able to utilize the child's knowledge with the passive in her/his first language to develop the passive in English. Hence, the main aim of this research was to investigate the understanding and expression of the passive construction in Setswana-speaking preschoolers aged 2.6 (meaning 2 years and 6 months)–3.5 years, 3.6–4.5 years, and 4.6–5.5 years old. Answers to these questions will thus help to evaluate the usefulness of the passive construction as an assessment tool for Setswana-speaking children.

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Theoretical Background

Passive Constructions

The passive has been found to be sensitive to various language impairments such as aphasia (Faroqi-Shah & Thompson, 2012), hearing impairment (Schmitt, 1969), and language learning impairment (Van der Lely, 1996).

Several studies have been conducted to determine whether elicited imitation tasks are useful in diagnosing language disorders. Useful results were obtained from Conti-Ramsden et al. (2001), Redmond et al. (2011), and Riches et al. (2010). The passive is a very important construction for SLTs and appears in many standardized language assessments such as the Preschool Language Scales (Zimmerman et al., 2011).

The passive transformation has been termed the "Granddaddy of them all" (Ross, 1974, p. 64). There are many different reasons for this statement. For example, Deen (2011) states that the passive voice is the most well-studied phenomenon in child language. From the earliest days of the modern era, it has been noted that children appear to have difficulties with the passive, both in terms of comprehension and production (p. 155).

One of the reasons for Ross's statement is crosslinguistic controversies. Menn and Obler (1990, p. 8) claim that "cross-language comparisons play the essential role of making it possible to distinguish valid from spurious generalizations, by permitting the examination of a wide variety of combinations of linguistic devices." Slobin (1992, p. 3) contends that "there is far more to be done in the Americas, Africa…" in terms of crosslinguistic research. Until 1985, crosslinguistic studies which found the passive to be used more frequently in languages other than in English were almost nonexistent (Slobin, 1985).

Jespersen (1965 [1924], p. 167) states that "we use the active or passive turn accordingly as we shift our point of view from one to the other primaries contained in the sentence."

According to Ud Deen (2011), the passive is used when (i) one wants to de-emphasize or hide the identity of the agent, (ii) to place emphasis on the patient of the action, and (iii) to retain the topic of conversation in subject position across multiple clauses or (iv) when the speaker wishes to express a sense of adversity or distress (p. 157).

The following list shows the various verbal passive categories that will be examined in this study (Table 18.1). All of these categories can be short or long passive constructions.

Table 18.1 Verbal passive categories (Bortz, 2013, p. 27)

Category	Reversible	Negative	Non-actional	Inanimate	Impersonal	Reversible	Negative	Non-actional	Inanimate	Impersonal
Length	Short passives					Long passives				

Reversible Passives

According to De Villiers and De Villiers (1985), reversible passives are sentences with two animate noun phrases. In passive sentences, the subject and object can be interchanged while continuing to maintain a syntactically and semantically acceptable construction (Baldie, 1976), for example, *the soldier was carried by the Captain → The Captain was carried by the soldier.*

Negative/Malefactive Passives

Negative passives occur when the patient is negatively affected by the action in verbs, for example, *hit*.

Non-actional Passives

Non-actional passives denote experience or non-action. Examples include "see, hear, like" (Deen, 2011). Parramon Chocarro (2009) describes non-actional passives as "those that cause or provoke a change or transition from one mental state to another mental state (*frighten*), or express the state after a mental process has taken place (*fear*)" (p. 5). Usually instead of an agent, the object is an experiencer.

Inanimate Passives

Inanimate passives do not allow the maneuvering permissible for reversible passives, for example, *the timber is planed by the carpenter → The carpenter is planed by the timber* (Baldie, 1976, p. 331).

Impersonal Passives

In the Bantu languages, the impersonal passive construction is a particular variant of the passive. The impersonal passive "refers to constructions that lack a grammatical subject and show invariable agreement on the verb" (Zerbian, 2007, p. 1). The impersonal passive performs the function of *it* or *there* in English.

Short and Long Passives

Table 18.1 also shows the length variable for passives. Therefore, the table shows that the verbal passive categories and length are interlinked and need to be considered together.

An example of a short or truncated passive in English is *the boy was hugged. The boy was hugged by the girl* is an example of a long passive sentence. The long passive, therefore, contains the optional *by*-phrase *the girl*. Ud Deen (2011, p. 162) explains that because the purpose of the passive is to "de-emphasize or hide the identity of the agent, the *by*-phrase is often omitted."

Passive Constructions in Bantu Languages Spoken in South Africa

Bantu Languages in South Africa

South Africa has 11 official languages. Nine of these languages are the Southeastern Bantu zone languages, as can be seen in Fig. 18.1.

Passive Constructions in Sesotho[1]

Demuth (1989, p. 73) claims that the passive "is a very basic canonical grammatical construction in Sesotho." In fact, "without the passive the grammar of Sesotho would have to radically be restructured." Thus, Demuth (1989, p. 73) claims that Sesotho "forces the use of passive constructions where other languages may use active constructions."

Topic orientation is the reason why passives are used more frequently in Sesotho than in English (Demuth, 1989). This is a discourse principle that prohibits new information from occurring in subject position. Only old information is allowed in subject position. Topic orientation does not permit question words in initial position, if a subject is questioned. This can only occur with a passive construction containing a *by*-phrase, as can be seen in Example 1. Answers to questions also cannot be given in subject position, for example:

Demuth et al. (2010) suggest that "Sesotho-speaking children achieve early competence with passive syntax due to the relatively high use of the passive in child-directed speech, often accompanied with a *by*-phrase" (p. 248).

(1) The child is drinking a corn drink and the grandmother asks:
'*O- o nk-il -e kae?*'
sm-obj-get-prf-m-where?
'Where did you get it from?'

The child replies:
'*Ke-o -f- uo e ke ausi Linaese*'
sm-obj-give-prf-PASS-m by sister Linaese
'I was given it by sister Linaese'

In Sesotho, Demuth (1989) found that the passive is used in a range from 0.4% of utterances by 2.1-year-old children to a maximum of 2.1% of utterances in 3.10-year-old children. However, the early spontaneous use of the passive by Sesotho-speaking children is approximately three times greater than in English-speaking children, according to Demuth (1989). The passive is used in approximately 2% of the isiZulu and Sesotho populations (Demuth et al., 2010; Suzman, 1985, 1987, 1991).

Brown (1973), in his seminal study examining children's first 13 morphemes, found that the passive construction was used infrequently. Gordon and Chafetz (1990) found that the passive is only used in 0.1% of English child-directed speech.

The passive construction in Setswana is formed, like in other languages such as English, by the subject of the passive clause corresponding to a direct object in the corresponding active.

[1]Languages within one group, such as Setswana and Sesotho, have close linguistic ties. If information about Setswana, the language of interest in this chapter, is missing, the description will refer to Sesotho in the following.

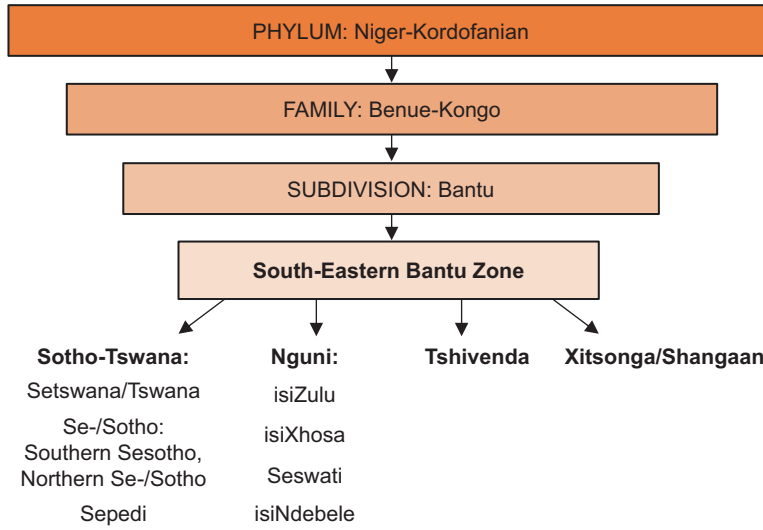

Fig. 18.1 Classification of Setswana. (Based on Gowlett (2006), Greenberg (1963), and Gregersen (1977))

Grammatical subject (patient)	Verb	Agentive group (patient)
Ngwana	*o-romiwa*	*ke mosadi*
The child	is sent	by the mother
	(Kruger & Pretorius, 2006)	

The subject of the active clause is expressed in the passive with a *by*-phrase. The *by*-phrase "takes the form of an agentive adverb with the prefixal formative ké-" (Cole, 1955, p. 192). The verb is then marked as passive with a passive extension by suffixing *-w* or *-iw* instead of the final vowel *-a* (Cole, 1955; Kruger & Pretorius, 2006), for example, *ngwana wa mosetsana o a gakilwe (ke ntatemogolo)* "the baby girl is being hugged (by the grandfather)."

The Bantu languages have the impersonal passive construction as a particular variant of the passive (Cole, 1982; Zerbian, 2007). Cole (1982, p. 195) considers that one of the reasons why "passive verbs are used much more commonly in Setswana than in English is due to the impersonal construction."

Age of Passive Acquisition in Bantu Languages

Another area where there has been much emphasis on the study of the passive is in terms of age of acquisition. Table 18.2 is a summary of some acquisition studies of the passive conducted in the Bantu languages.

Suzman (1985, 1987, 1991) found that passives were used early by isiZulu-speaking children. She also found that parents used passive forms in *who*-subject questions when speaking to children as young as 1.10 years. It must be noted that Suzman conducted all her research with naturalistic data using three children in rural Kwa isiZulu Natal.

Stephen (1988) examined developmental trends in the acquisition of the passive in 3–4-year-old isiZulu-speaking children. She also investigated the categories of reversible, negative, and inanimate passives. Her results indicated that there was a developmental trend in which participants' performance improved from age 3 to 4. In addition, they responded best on inanimate categories. She also found that participants' understanding of the passive was better than their expression.

Respondents scored the highest for the passive construction on the isiZulu Expressive and Receptive Language Assessment (ZERLA, Bortz, 1995).

Demuth found that children use the passive productively by age 2.8 in Sesotho (Demuth, 1989) and impersonal passives first appeared at ages 2.8–2.9 years. Demuth confirmed her initial findings, which were disputed by some because

Table 18.2 Studies examining the acquisition of the passive in Southeastern and Eastern Bantu zone languages (Bortz, 2013, p. 42)

	Early passive development (by age 3)	Developmental pattern of acquisition	Late passive development (after age 6)
Sesotho	Demuth (1989) Demuth et al. (2010)	Bortz (1998)	Crawford (2008, 2012)
IsiZulu	Suzman (1985, 1987, 1991)	Bortz (1998)	
Kiswahili[a]	Alcock et al. (2012)		
	Used passive sparingly (Deen, 2002)		
Kigiriama	Alcock et al. (2012)		
IsiXhosa	Used passive sparingly by age 3 (Gxilishe et al., 2008)		

[a]Based on the same data as Alcock et al. (2012)

naturalistic data was used for this research (Deen, 2011). Demuth et al. (2010) investigated the passive using 16 first language Sesotho-speaking children aged between 2.11 and 3.5 years using picture selection tasks, choosing between two pictures, eliciting production tasks, and generalizing novel verbs to passive frames.

The results of Demuth et al.'s (2010) study showed that children comprehended active sentences (82%) better than passives (73%). The difference between reversible passives (77%) and non-actional passives (69%) was not significant. This difference was also found with the ten adult controls who scored 99% for reversible passives and 89% for non-actional passives.

Alcock et al. (2012) investigated 15 children who were speakers of Kiswahili and Kijirami aged between 1.9 and 3.4 years using spontaneous speech samples. They examined two dialects of Kiswahili, one spoken on the coast of Kenya and the other in Nairobi. In these languages, there was no use of topicalization as there is in Sesotho. Their findings showed that the children used the passive:

> productively very early (2.1 years) in these languages, regardless of the method used to measure productivity. Kiswahili and Kijirami children used short and long passives. In addition, non-actional passives, particularly rare in English and some other European languages, were seen at these early ages. (Alcock et al., 2012, p. 1)

Interestingly, in other naturalistic studies of Bantu languages such as Swahili (Deen, personal communication, January 21, 2008) and isiXhosa (Gxilishe et al., 2008), the passive was found to be used very sparingly by 3-year-old children. However, Alcock et al. (2012) used Deen's data (2002) to show that children as young as 2.1 years used the passive productively with non-actional verbs in Kiswahili.

Bortz (1998) conducted a study to investigate the acquisition of the passive in 26 bilingual Sesotho/English and isiZulu/English children. Results showed that participants performed better on passive tasks in Sesotho/isiZulu than in English and better on comprehension than production tasks. The results also indicated that the children's ability to understand the passive improved at age 4 and even more by 5 years. However, the passive was not fully acquired by 5 years.

Crawford (2008, 2012) replicated Hirsch and Wexler's English study (2006) in Sesotho, using a two-picture selection computerized task. Her results showed that Sesotho-speaking children did not perform any differently to English-speaking children on long passives or passives of non-actional verbs. These results occurred even though there is "increased passive frequency" in Sesotho (Crawford, 2012, p. 13). Also, children did not perform like adults on passive tasks. They also performed worse on non-actional passive tasks.

Based on the data summarized above, Table 18.3 provides a summary of differences in ages of acquisition of the passive in Bantu languages and English.

Methods for Assessing Passive Constructions

The studies included in the overview of passive acquisition were based on different assessment

Table 18.3 Difference in ages of acquisition of the passive in Bantu languages and English (Bortz, 2013, p. 47)

Age (years)	Sesotho/isiZulu		English	
	Early development	Late development	Early development	Late development
2–3	Comprehension and production of early development reversible passives		Comprehension of short and long passives (Crain et al., 1987; O'Brien et al., 2006)	First emerges
	Begins to use impersonal passives (2.8–2.9)			
	(Demuth et al., 2010; Suzman, 1985, 1987, 1991)			
3.6			Produces reversible passives (Bencini & Valian, 2008; Messenger et al., 2009; Shimpi et al., 2007)	
4–5				Comprehension of passive (Armon Lotem et al., 2015)
6		(Crawford, 2008, 2012)		Passive still developing (Stromswold, n.d.)
9				Infrequent *by*-phrase (Horgan, 1978)
10				Frequency of spontaneous passive and *by*-phrase (Horgan, 1978)
11				Uses reversible and inanimate passives (Horgan, 1978)

methods and settings, the most common of which are comprehension picture selection tasks, elicited production tasks, and elicited imitation tasks. The latter need to be further discussed after a brief summary of each method.

Comprehension Picture Selection Tasks

Picture selection tasks are very useful in situations where participants do not produce particular linguistic forms and to determine whether they understand linguistic contrasts, particularly if they do not use these in their own speech (Gerken & Shady, 1998).

Elicited Production Tasks

In these tasks, pictures/cards are mostly used to depict an action that is taking place. The child is then prompted to say what is happening. The patient in each picture is often demarcated so that the research assistant can prompt the child how to begin the sentence.

Elicited Imitation Tasks

Historically, as early as 1924, Allport suggested that language is acquired through an imitative process. Lust et al. (1998, p. 63) state that elicited imitation tasks should be used with a "repeated measures design." They also recommended that the elicited imitation tasks should "tax" the child's processing ability, for example, by their length.

Prutting and Connolly (1976, p. 415) define elicited imitation as "those imitations which occur when a child responds to an examiner's request to 'say what I say' and repeats a model sentence or phrase."

Elicited imitation provides "overt, direct evidence of child's grammar construction for particular targeted aspects of grammar" (Lust et al., 1998, p. 63). The sentences that the child utters are according to the child's rule for the linguistic structure. The utterances are not necessarily the same as the adult's rules (Lust et al., 1998). During elicited imitation tasks, the child reduces the imitation to fit her/his own linguistic knowledge of a particular linguistic principle (Mumm et al., 1980).

The original elicited imitation studies were carried out to determine whether imitation of sentences works through comprehension or is the mere rote repetition of an acoustic image, produced regardless of whether the subject has understood its meaning or not (Vinther, 2002, p. 57).

Historically, elicited imitation tasks were a powerful tool used to inform about the theory of transformational grammar (Menyuk, 1963) as well as being a method of assessing language (Slobin, 1968). Regarding elicited imitation, Menyuk (1963, p. 429) hypothesized that from a very young age, "language is not an imitative function and that the child has indeed, the grammatical capacity for generating an infinite number of sentences of the language…".

In order to test this hypothesis, Menyuk (1963) conducted a study to examine "the hypothesis that children have incorporated the generative rules of their grammar and are able to understand and produce sentences in accordance with these rules and to extend systematically their behaviour without additional instruction…" (p. 438).

Menyuk studied 14 children aged from 2.10 months to 3.8 years as well as 50 kindergarten children. A short reversible passive sentence was one of her stimuli. Ten of the participants in each age group scored correctly on the passive sentence, which was a score that did not achieve significance. However, generally the results of Menyuk's study showed "that children, even at the age of 3, have incorporated the rules of the grammar and are able to understand and produce sentences" (p. 437) using the rules of universal grammar (UG).

Elicited imitation tasks (Lust et al., 1998) can be used to assess children's expressive knowledge of the passive. According to Lust et al. (1998, p. 56), elicited imitation allows researchers to assess children's knowledge of precise grammatical factors or "precise testing of children's knowledge of specific hypothesized grammatical factors involving UG" (p. 59). Klem et al. (2015) confirmed this statement.

Other experiments have been performed to examine children's passive abilities on elicited imitation tasks. An example is that Baldie (1976) found that 3–8-year-old subjects produced truncated and inanimate passives equally. Reversible passives began developing poorly but by 8 years "had surpassed the two other passive forms" (p. 338). Baldie also concluded that in the acquisition of the English passive, imitation precedes comprehension and comprehension precedes production.

Budwig (1990) also conducted a study using elicited imitation. She tested adults as well as ten 4-year-old subjects. The adult subjects scored 100% on the tasks and the children 97%. The pattern of errors showed that children mismatched "get" and "be" passives. Results of a study conducted by Lempert (1990) showed that 14 subjects imitated full and truncated passives.

A combination of a semi-elicited production task was used on Spanish-speaking 3.5–6-year-old children (Pierce, 1992). Results indicated that, as predicted, children made more errors in subject–verb order than in verb–subject order. (In Spanish, there are multiple constructions for verbal passives. There was also significant developmental improvement in verb–subject order.)

Verrips (1996) pilot tested an elicited imitation task for the impersonal passive in Dutch. She found that 51% of 24 children aged 4–7 years performed successfully on the elicited imitation task.

SLTs also use elicited imitation tasks in language assessment. Mumm et al. (1980) claim that elicited imitation has been used repeatedly as a valuable tool for language assessment. The aim of using elicitation during testing is for the child to minimize her/his imitation behavior to use her/his own linguistic knowledge. Tests such as the Patterned Elicitation Syntax Test (PEST, Young

& Perachio, 1993) assess syntactic structures using a delayed imitation task.

Young and Perachio (1993) were some of the first test authors to utilize a delayed imitation device in testing. The method they used to assess children was to have them listen to three consecutive modeled sentences with the same syntactic pattern but different vocabulary "while looking at pictures that depict these sentences" (p. 3). The child was then required to describe all three pictures to the examiner. Young and Perachio (1993) describe delayed imitation as a procedure which requires the following competencies of the child: (1) processing the information with the help of his/her acquired meaning system, (2) perceiving the rule of the utterance, and (3) repeating the sentences which is facilitated by using the pictures. The important point is that the sentences that the child utters are according to the child's own rule for the specific linguistic structure and not according to adult rules (Kim et al., 2016).

Methods

Research Questions

The specific aims were the following:

1. To describe the development of the passive in 2.6–5.5-year-old Setswana-speaking preschoolers
2. To examine the children's understanding and production of the reversible, negative nonactional, inanimate, and impersonal verbal passive categories
3. To assess the children's capabilities in terms of the length of passives, that is, short and long passives

Design

Swanepoel (2007, p. 11) recommends that when conducting research in South Africa, in order to address previous inequalities, "a holistic or eclectic approach which combines positivist and phenomenological research paradigms and applies both quantitative and qualitative methods" should be used. This recommendation is reiterated by both Alant (2007) and Singh (2007), the latter of whom states that "both quantitative and qualitative modes of research are umbrellas that accommodate a range of research methodologies within their ambit" (p. 18). The above approach was also considered appropriate for the present study.

For the quantitative method, a cross-sectional design was used as different participants from a number of age groups can be selected.

A variant of service-learning was the qualitative aspect used in this study (research assistants were not volunteering). *Service-learning* is a pedagogy which provides an opportunity to collect and evaluate data, to relate seemingly unrelated matters and ideas, and to investigate a self-directed learning including inquiry, logical thinking, and a relation of ideas and experience by volunteerism. It is a transference of learning from one context to another that will allow for the opportunity to reflect, conceptualize, and apply experience-based knowledge (Brevard Community College, 1994). Service-learning is an excellent method of conducting research for the South African population, "[w]hen considering the nature of the relationship between practice and research" (Kathard et al., 2007, p. 6), particularly in populations who live in poverty as research inadequately supports the needs of people in societal "black holes" (Soludo, 2001). *Service-learning reflection diaries* were kept by the research assistants.

Research Materials

In order to answer the three generated research questions, three different tasks for assessing passive constructions were developed (see below). To ensure that the materials were culturally and linguistically appropriate, a South African graphic artist was commissioned to produce drawings which were specifically aimed to suit the Pankop community. He photographed people and animals from Pankop as reference.

Comprehension Picture Selection Task

According to the stipulations of the picture selection task, four pictures on each page were organized according to an adaptation of the Test for

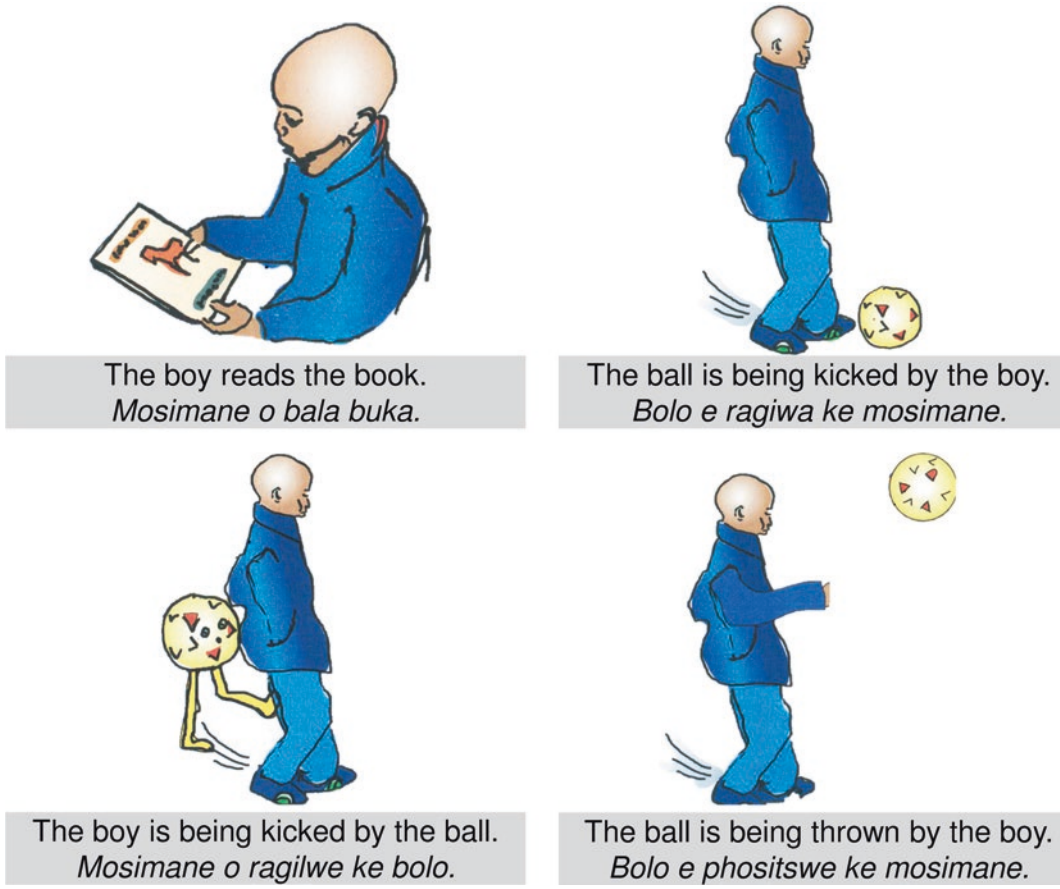

Fig. 18.2 An example of the picture selection task (Bortz, 2013, p. 234)

Reception of Grammar (TROG, Bishop, 1983). The participants were required to point to one of four pictures which assessed the understanding of passive verb categories and short and long sentences. An example of an inanimate passive can be seen in Fig. 18.2.

Elicited Production Task

A card game was used for this task. The cards depicted an action taking place such as *ngwana wa mosetsana o otilwa (ke ntatemogolo).* "The baby girl is being hugged (by the grandfather)." The child was then prompted to *Mpontse gore go diragalang* "tell me what is happening." The patient in each picture was demarcated with a gold star, and the research assistant pointed to it to prompt the child how to begin the sentence with that word.

Elicited Imitation Task

Considering the mentioned challenges, the difficulty of this assessment should be just enough so that children can and do attempt reconstruction without overtly involving their grammar. Young and Perachio (1993) recommend that sentences should be approximately nine syllables long and not vary by more than two syllables. In this study, sentences, therefore, consisted of an average of 8 syllables for short passives and 11 syllables for long passives. Pilot testing (see section "Pilot Testing") showed that both standard forms and nonstandard forms of verbs had to be used on occasion, for example, *kgarameditswa*, "pushed" standard form, and the nonstandard form *pushiwa* "pushed." Standard forms of a language are the "purest" form of the language and generally spoken in rural areas. The reason for

this is that these areas are isolated and therefore there is little opportunity for code-switching or influence from other languages. However, Pankop is a peri-urban area, and so there is influence from other languages.

Additional Qualitative Data Sources

Parent's and teacher's reports were administered to obtain biographical material and determine whether the respondents met the selection criteria. An *adult verifier* protocol was also administered. In this chapter, however, the focus is on the quantitative results.

Pilot Testing

Thornton (1998) states that "pilot work is essential if the experiment is to achieve its goal. In fact, pilot work often takes more time than conducting the actual experiment" (p. 85). Seven different phases of pilot testing occurred in this study. The results of the pilot studies formed the basis for the comprehension and production tasks. Three different versions of the elicited production task were piloted due to the participants experiencing difficulties with this task.

Criteria for the Selection of Children

All the children were required to be healthy and to present with no obvious physical, cognitive, hearing, or visual impairments that may have impacted on language development. Child participants were required to have attended Setswana-speaking crèches in Pankop.

Discharge from the ear and gastroenteritis have been identified as "at-risk" medical factors for language impairment in the South African population (Penn & Segal, 1982). Therefore, both teacher's and parent's reports enquired about these conditions for the child participants.

Table 18.4 shows the number of participants in the study and their categorization into different age groups.

Seventy-nine percent of the participants were Setswana speaking. All of them were proficient Setswana speakers according to the teacher's report. They lived in Pankop, mostly with their unemployed grandmothers. Teachers reported that 7% of the children had hearing problems and 4% of the children had difficulty with understanding. These children were referred to the closest speech and hearing clinic in accordance with ethical requirements.

Setting

Children were tested at three preschools in Pankop, Chief Maluke Trust in Mpumalanga Province. Adult verifiers were also resident in Pankop, which is a peri-urban area. In South Africa, peri-urban areas are beset by massive poverty (Thornton, 2008).

In the preschools, children either sat on the floor or on a carpet. There were few books and stationery and no toys. No preschool had waterborne sewerage. The children were taught through rote learning and singing, which is common in preschools in South Africa (Prinsloo & Stein, 2004).

Due to the differences in sample size shown in Table 18.4, the elicited imitation task was admin-

Table 18.4 Participant sample (Bortz, 2013, p. 86)

Age	Number of children: comprehension and elicited production tasks	Number of children: elicited imitation task	Description of age group
2.6–3.5 years	18	15	Group 1
3.6–4.5 years	18	20	Group 2
4.6–5.5 years	26	17	Group 3
	$n = 62$	$n = 52$	
21–65 years	$n = 11$	$n = 11$	Adult verifiers

istered on a separate occasion from the comprehension and production tasks.

Ethical Clearance

Ethical clearance was obtained from the Human Research Committee (Medical) of the University of the Witwatersrand, protocol number: HO 90214. In addition, informed consent was obtained from the principals of the preschools and parents/legal guardians.

Data Analysis

All the research instruments yielded interval levels of measurements; the appropriate parametric statistical procedures were selected for between- and within-group comparisons and correlations (Schiavetti & Metz, 2006).

Descriptive statistics in the form of means, medians, minimums and maximums, and standard deviation were calculated for all participants. Significance was determined using post hoc Scheffe tests. An inter-rater reliability of between 93% and 98% was obtained.

Results

Developmental Passive Abilities in Different Assessment Tasks

Elicited Imitation Task

Figure 18.3 depicts the mean results of the participants' scores on the elicited imitation task.

All participants scored high on the elicited imitation task, as Fig. 18.3 shows. According to the post hoc Scheffe comparison, the performance of the youngest group is significantly different from Age Groups 2 and 3 on elicited imitation, with the younger group scoring the lowest (mean = 0.68) of the three age groups ($F = 10.382$; df = 4236; $p = 0.00379$).

Age Group 3 participants differed significantly from the adults on each elicited imitation task, with mean performances of elicited imitation at 81% for Age Group 3 and 91% for adult participants ($p < 0.05$).

Comprehension Picture Selection Task

Figure 18.4 shows the significant results in the comprehension task which were obtained between Age Group 1 (mean = 0.36, youngest children) and Age Group 3 (mean = 0.48, oldest children)

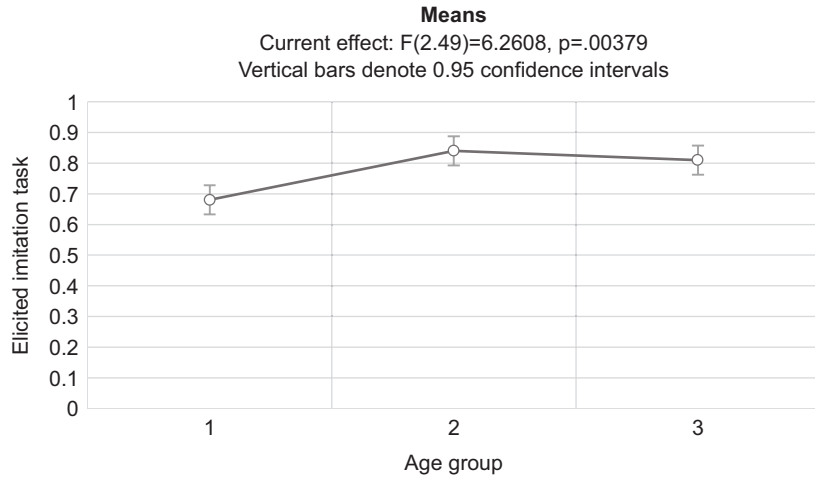

Fig. 18.3 Mean performance of the three age groups on the elicited imitation task (Bortz, 2013, p. 118)

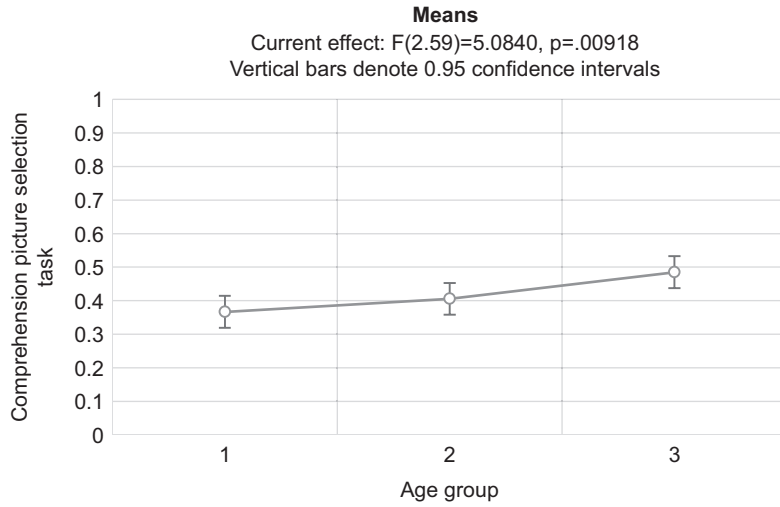

Fig. 18.4 Mean performance of the three age groups on the comprehension picture selection task (Bortz, 2013, p. 131)

Table 18.5 Scores for participants' understanding and production of passive categories

Tasks	Passive categories				
	Reversible (%)	Malefactive/negative (%)	Non-actional (%)	Impersonal (%)	Inanimate (%)
Elicited imitation	80	76	83[a]	72[a]	83[a]
Comprehension picture selection	40	45	38	Could not be depicted	45
Elicited production	9	10	7	6	12

[a]Significance

($p = 0.009$). Therefore, a significant developmental trend was found with children performing better as they got older. These scores approach 50%, which is chance.

Elicited Production Task

In the elicited production task, there was no significant difference between the mean performance levels of the three age groups on elicited production ($F = 2.6869$; df = 2.59; $p > 0.05$). The youngest group scored at 8% while the oldest group scored 12%. The adult verifiers' performance did not exceed 40%. Therefore, the results of the elicited production task showed poor performance by the participants on this task.

Understanding and Production of Various Passive Categories

Table 18.5 shows the performance results for participants' understanding and production of various passive categories on the three tasks presented in this study.

Regarding the elicited imitation task, a significant category effect ($F = 5.9628$; df = 3177; $p < 0.001$) was also found on the comprehension task. A post hoc Scheffe test showed that performance on the non-actional category (mean = 0.35) was significantly worse than negatives (mean = 0.46) and inanimate categories (mean = 0.47). The participants scored the best on the inanimate category (mean = 0.52). On the elicited production task, there was a significant category effect across the five passive categories ($F = 10.382$; df = 4236; $p < 0.0$). The post hoc Scheffe comparison showed that the mean for the inanimate passive category (mean = 0.15) was significantly different from the means of the reversible passive category (mean = 0.9), non-actional passive category (mean = 0.6), and impersonal category (mean = 0.4). The mean of the negative passive category (mean = 0.11) was significantly different from the impersonal category (mean = 0.4).

Table 18.6 Scores for participants' understanding and production of short and long passives

Tasks	Length	
	Short (%)	Long (%)
Elicited imitation	85	80
Comprehension	47	45
Elicited production	10	4

These results show that participants performed the best on inanimate categories, followed by negative categories.

Children's Capabilities in Terms of Short and Long Passives

Table 18.6 shows that the performance of the participants was found to be significantly better on versions of the elicited imitation task with short sentences (mean = 1.96) compared to long sentences (mean = 1.25). Error patterns on long sentences involved the omission of the *by*-phrase, for example, *ke malume* "by the uncle."

In the results of the comprehension task, a mean score of 0.47 for all short sentences was obtained. The results for long sentences were almost identical as participants scored a mean of 0.45. No significant results were obtained on the elicited production task.

Adult Verifier Protocol

The adult verifier protocol was also administered to a Setswana and IsiZulu teacher from an institution who teaches these languages. The teacher reported the following in response to the protocol that was used for adult verifiers:

> … you requested to know how children speak the Setswana language with specific reference to the passive form. According to Owen and Selinah, young children ignore the passive form until a certain age. Selinah visited her sister this weekend to speak to her 3-year-old nephew. Even though she led him to use the passive tense, the boy didn't use it and couldn't even reproduce it. Children acquire the use of the passive form in Setswana at a later stage, around school-going age, according to Setswana mother-tongue speakers. Selinah also showed me some questionnaires you gave her. I discussed all of this with Owen, our African languages resource developer. Over the weekend, he visited a Setswana mother who has two children to ask about her experience. The information he received was the same as what Selinah obtained. Further, Selinah informed me that she spoke to a principal of a middle school which teaches Grades 6 to 8. He reported that he believed that children would only begin to use the passive in Grade 8. He also reported that the passive was a form of language used mostly for writing and by adults.

Service-Learning Reflection Journals

The service-learning reflection journals provided valuable information regarding the frequency and use of the passive by the participants. One of the research assistants commented that the youngest group of participants could not cope with the elicited production task. She stated that these children:

> are not exposed to the passive sentences, as they are very young. Most Setswana people don't teach their children passives when they are still toddlers. Children learn as they grow through their parents when they talk to them using passive sentences. (K. M., reflection journal, August 1, 2009)

The second research assistant reported:

> I was working with kid's age from 3–6 years. My experience while working with this kids is that I've found that most kids age 3–4 years were struggling with the Reversible long and Reversible short sentences and the Negative long and short sentences on Comprehension tasks but especially Elicited Production tasks.
>
> (L. M., reflection journal, August 1, 2009)

Discussion: Usefulness of the Passive Construction as an Assessment Tool for Setswana-Speaking Children

One of the primary aims of this study was to devise a test battery that would be appropriate and useful for communities in South Africa that has previously not been investigated.

The results show a developmental trend of the acquisition of the passive on all three tasks developed for this study, despite the relatively low scores achieved. The results of this study therefore indicate support for the ACDH (A-chain deficit hypothesis) because the development of

the passive was found to be a gradual process in Setswana-speaking preschoolers.

Differences in age groups were also found in terms of different passive constructions. Results of the elicited production tasks show that participants performed the best on the inanimate category, followed by the negative category. Both the Williams syndrome and typically developing participants in Bartke's (2004) study performed better on "irreversible sentences [inanimate]" (p. 356) than reversible sentences. Bartke argues that this is because "reversible sentences are more vulnerable to misinterpretation than irreversible sentences" (p. 355). The poor results on the impersonal category were surprising due to Cole's (1955) contention that the use of the impersonal category is one of the reasons that the passive construction is used so frequently in Setswana. The fact that the participants in this study performed the worst in the non-actional category on the comprehension tasks is backed up by other studies such as Crawford (2008), Demuth et al. (2010), and Maratsos et al. (1985). In addition, Fox and Grodzinsky (1998) and Hirsch and Wexler (2004, 2006) found that children experience problems with understanding non-actional full passives at age 5. In addition, it must be considered that memory is a factor that affects performance on long sentences. Naturally, it is easier to remember shorter sentences than longer ones even though the difference between the short and long sentences in the present study was only three syllables.

However, the comprehension task also provided some useful results, particularly regarding the adults and the fact that they had not fully acquired the passive. Due to additional challenges with the elicited production tasks experienced by all participants (even adult verifiers), the author of the present study therefore drew the conclusion that participants cannot perform elicited production tasks on the passive. This conclusion is substantiated by the fact that all Setswana-speaking research assistants and verifiers who participated in this study claimed that the passive and the impersonal passive were not an often-used structure in Setswana. They reported that currently in the Pankop region, people do not speak using the passive. Taking participants' responses on comprehension as well as elicited production tasks and the research assistants' qualitative comments and findings into account, Cole's claim might be put into question. The author visited Professor D.T. Cole in 2008 (personal communication, March 5, 2008). He was asked why passive verbs were used more frequently in Setswana. His response was that he did not really have a reason for this. Rather, he just knew this from learning to speak Setswana in his boyhood while growing up in Botswana. Taking both quantitative and qualitative data together, they negate the original hypothesis for this study, that is, that Setswana-speaking children develop the passive construction early in their language acquisition.

The results of this study also showed that devising such a battery is a multidimensional but simultaneously a subtle process. This process is particularly true of the comprehension task where all participants achieved relatively low scores. On one level, the picture selection task was a difficult task for the children as they, similar to those in Demuth et al.'s (2010) study, were not familiar with pictures. This result is not surprising considering that the participants do not have access to these books either at home or at school.

The production task was the most difficult for the participants, which was also found to be the case by Baldie (1976). Only 3 out of 45 crosslinguistic studies about the passive used production tasks. Rubin (2009) suggests that these low scores indicate that participants may have interpreted passive sentences as active sentences. These results differ from those of Demuth et al. (2010), who found that 98% of their 3-year-old Sesotho-speaking participants could produce passive verbs.

Demuth et al. (2010) suggest that "some of the lower performance on non-actional verbs often reported in the acquisition literature may, therefore, be due to experimental artefact (less than ideal depiction) rather than due to incomplete syntactic competence" (p. 19). In order to get help with devising an effective elicited production task, the author observed Demuth et al. testing some of their participants in Lesotho (May 2008). The elicited production task was similar to Demuth et al.'s task. But still, the results for production were much more clear-cut, yet on opposite ends of a usefulness continuum. The elicited production

task was completely unsuccessful. It presented difficulties both in the pilot testing and the test phase of this study.

Elicited imitation, on the other hand, proved to be a sensitive task for this study and, therefore, should be used in the future. Such assessments of the passive indicate that Setswana-speaking preschoolers can be assessed on their comprehension and production of the passive.

Impact

Examination of the Passive in All Bantu Languages

Due to the fact that all Bantu languages have the same language structure, it would be very useful to perform the elicited imitation task in all Bantu languages. These results would contribute to devising the beginning of an essential child language repository for Bantu languages.

It would also be useful to replicate this research in rural areas where more standard forms of a language are spoken (Otlogetswe, 2008). The linguistic aspects of the passive in the rural context such as topicalization, impersonal passives, and frequency of use of the passive should be examined. Results obtained in the rural context would show more definitively whether or not the passive is a frequently used structure.

The Development of Appropriate Assessment Materials

This study had positive implications for the development of language materials. SLTs should consider various methodologies for devising assessment materials very carefully.

Elicited Imitation

The elicited imitation task was very successful as it showed significant developmental trends. It was very well suited to the way of learning of the participants and in South Africa. As Prinsloo and Stein (2004) describe in their research, rote and chant learning are very common in South Africa. A child's ability to perform elicited imitation tasks is a useful measure to determine whether or not the child's language is intact.

Jordaan (2011) also found correlations between passive comprehension and sentence repetition, digit repetition, listening recall, and processing listening for English second language participants. The current study has already determined that sentence repetition is a very useful tool for Setswana-speaking children. It would, therefore, be useful to conduct further research investigating 8–10-year-old Setswana-speaking children's abilities with digit repetition, listening recall, and processing skills.

It was interesting to note that both when other forms of pilot testing occurred and during the testing phase, the children often responded to the instructions by imitating the research assistants. This is despite the fact that the research assistants had repeatedly given different instructions such as *Mpontse kolobe e a latswiwa.* "Show me the pig is being licked." The authors believe that these responses occurred because rote learning is so entrenched in children's performance at crèche. It is almost as if this is the child's "default setting." Therefore, this is the only method of responding children know and when they are faced with an unfamiliar task they revert to their "default setting."

Due to the fact that elicited imitation tasks form the basis of priming tasks, future research should expand elicited imitation tasks to priming tasks like those conducted by Messenger et al. (2009) and Bencini and Valian (2008).

Elicited Imitation and Parent's and Teacher's Report

When constructing a parent's and teacher's report in Bantu languages, it is very important to ask parents and teachers to report on their children's imitation abilities. Information would need to focus on any child who had difficulty repeating what the teacher was teaching.

Considerations for Future Work, Research, and Politics

It is very important for SLTs to assist preschool/crèche teachers and assistants to stimulate language and identify language problems as early as possible for preschoolers. This is important to prevent the long-term effect of speech–language disorders (Marge, 1991). Due to the limited number of SLTs in South Africa, and Africa, it is important to partner with government departments such as of health and social welfare, education, and nongovernmental organizations that empower teachers and facilitators. SLTs need to focus on educating about the importance of language development and how to stimulate and encourage language.

Regarding the present study investigating whether the passive would be a useful construction to determine language impairment in the first language (Setswana), continued verification of whether the passive is an early and often-used structure seems to be needed. The literature review has shown that researchers such as Demuth et al. (2010) and Suzman (1991) describe the passive as being both early developing and an often-used structures in Sesotho and IsiZulu, respectively. However, the results of this study show that it is necessary to tease apart the two notions of early development and frequency of the passive.

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19

Methods for Devising a Standardized Language Assessment for isiZulu Preschoolers: Implications for Sub-Saharan Africa

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Motive

The rationale for this chapter is that the methods used to devise this assessment as well as other processes such as the Delphi technique can be applied to different Bantu languages. Speech–language therapists (SLTs) would then be able to assess preschool children to ensure that they receive required language assistance. This assistance needs to be provided as early as possible in a child's life to prevent the long-term consequences of language disorders.

Research Questions

The aim of the study was to devise an expressive and receptive isiZulu language assessment for preschool children. The sub-aims were the following:

- To establish the necessary components of language assessment in isiZulu
- To determine the expressive and receptive language ability of preschool isiZulu children living in Soweto as measured on the language assessment
- To determine the appropriateness of the assessment tool devised, using quantitative and qualitative analysis

Problem Background

> One of the major problems facing the speech therapist in South Africa today is the absence or inadequacy of tests available for use with the black population. Factors such as educational, cultural, linguistic and environmental considerations mean that the tests that are available, generally standardized in England or the United States, standardized on western white middle class populations are found to be inappropriate in the accurate evaluation of the black South African population. Therefore, new tests must be created so as to overcome the limitations of translated imported tests and to fill the need for assessment tools for the black population.
>
> (Ballantine et al., 1976, p. 5)

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The above plea has been reiterated many times over the last four decades (Bortz, 1995; Southwood & van Dulm, 2015). It has begun to be heeded by some researchers and therapists. Morgan and her team at the Chris Hani Baragwanath Hospital began working on these kinds of material during the 1970s and 1980s. Other South African authors who have devised multilingual and multicultural materials include Maphalala (2012), Gonasillan et al. (2013), Mdladlo (2014), Tshule (2014), and Mazibuko (2018).

Normed African assessments have also been devised. These include the Spoken Language Assessment Profile-Revised (SLAP-R, Kramer & Hartley, 2013) and Malawi Developmental Assessment Tool (MDAT, English and Chichewa), whichis now translated into Kinyarwanda (Gladstone et al., 2010). In addition, Tchoungui Oyono (2016) has developed a Cameroon Speech and Language Assessment, the Evaluation du Language Oral.

Pascoe and Norman (2011) wrote a powerful editorial asking whether there were contextually relevant resources in speech–language therapy (SLT) and audiology in South Africa. In this editorial, they also asked where this research was hiding.

And yet, the plea continues to be made. As recently as 2015, Southwood and van Dulm explain that there "is still an absence of appropriate assessment and remediation material for Afrikaans and African languages" (Southwood & van Dulm, 2015, p. 1). These authors studied the challenge of linguistic and cultural diversity with a sample of 71 South African SLTs with over 20 years of experience (more experienced group) as well as 79 less experienced therapists with at least 5 years of experience. The results showed that most SLTs, regardless of level of experience, were aware of the need to consider the underlying linguistic base of the assessment instruments they used, but few considered the cultural and linguistic appropriateness of these instruments (Southwood & van Dulm, 2015).

Southwood and van Dulm suggest that standardized tests are possibly not devised for South Africans due to challenges with translation. Other difficulties they reported included that the need to standardize the translated instrument on a representative sample was expensive. However, we do not agree with this view. The majority of South

Africans and Africans have been deprived of essential assessment materials for far too long. It is hoped that this information will motivate and assist SLT colleagues to devise much-needed methods for their communities.

Therefore, the purpose of this chapter is to provide details about how a standardized isiZulu Expressive and Receptive Language Assessment (ZERLA) was devised (Bortz, 1995).

One of the reasons for the necessity of a standardized language assessment is that unsuccessful attempts have been made to address the absence of standardized tests by translating existing standardized tests into one or more of the Bantu languages. Masiloane (1983) performed a literal translation of the Reynell Developmental Language Scales (RDLS, Reynell, 1977) into isiZulu. Results showed difficulty with the translated version as the children did not know linguistic items such as Santa Claus.

The challenge of literal translation is that although it ensures that the basic meaning is retained, it results in a structure which differs in syntactic complexity, semantic form, and pragmatic implications from the original (Paltiel, 1990). Literal translation also ignores cultural and linguistic differences (Hartley, 1986). Pascoe and Norman (2011) report on unsuccessful studies which found that "simply translating the language of a test does not make it appropriate for another population group, as the cultural and context of the target population needs to be considered to avoid misinterpretations of the results" (p. 3).

Another alternative to address the lack of standardized language assessment in South Africa has been to use criterion reference tests. Second-year SLT students at the University of the Witwatersrand (2015) completed an assignment where they adapted standardized tests to suit the South African population. They focused on providing vocabulary items that were more linguistically and culturally appropriate for the South African population. An example was using the item "engine" for "caboose" on the Peabody Picture Vocabulary Test (Dunn & Dunn, 1997). However, ultimately standardized language assessment is the most powerful tool available to assess children effectively and prevent the long-term sequelae of language disorders.

Theoretical Motivation

Importance of Standardized Language Assessment

> The use of formal testing instruments in speech and language pathology derives from a simple concern within the profession – to provide an orderly, systematic, and convenient basis for tapping the language capabilities of a population of speakers. (Wolfram, 1983, p. 21)

Standardized language assessments are one of the most effective methods to diagnose language disorders (Lund & Duchan, 1993). However, language assessment is not an easy task.

Weiss et al. (1987) state that the most important aspect of clinical management is assessment. Standardized tests are also important for therapy because "they can be used to guide interventions and measure treatment outcomes" (Weiss & Zureich, 2009, p. 4).

Standardized language tests can take the form of diagnostic tests which detect the nature of the language disorder so that appropriate therapy programs can be devised for a client (Dale & Henderson, 1987). They can also take the form of screening tests. Screening tests provide a sample of broad-based language behaviors for the purpose of selecting children who need further language assessment (McCauley & Demetras, 1990).

Another advantage of standardized SLT tests is that they are objective. These tests can also compare the skills of a child to a larger group of similar children, and test administration is "usually efficient," according to Shipley and McFee (2015).

Hyter and Salas-Provance (2019) recommend developing a new test if the "person's ethnic and/or language background is represented in the normative sample" (p. 231).

Epidemiology of Language Problems

In the SLT field, prevention is defined as "the elimination of factors which interfere with the normal acquisition and development of communication skills" (American Speech–Language-Hearing Association [ASHA], 1982, p. 425). Prevention occurs at the primary, secondary, and tertiary levels

(Gerber, 1990). The ASHA Committee on Prevention of Speech, Language, and Hearing Disorders (1988) strongly recommended increased development and implementation of primary prevention strategies, particularly for low-income populations who are at the greatest risk for conditions that can lead to communication disorders. Secondary prevention is the early detection of a communication challenge and aims at reducing the prevalence of a communication disorder (Gerber, 1990). Tertiary prevention relates to treatment of disorders, which is the traditional focus of attention for SLTs.

From both epidemiological and clinical perspectives, it is imperative to identify language problems as early in a child's life as possible so that the child will receive therapy in a timely manner and thereby obtain maximal benefit from therapy (Wetherby 1985 in Wetherby et al., 1989). If communication problems are not treated during the critical language learning period (Lenneberg, 1967), then "the deficiencies in communication skills result in academic failure, social maladjustment, and the need for special care programs, often at considerable cost to society" (Ehrlich et al., 1973, p. 522).

Early identification could also prevent more serious and long-term repercussions of language delay, such as problems with education and social or vocation opportunities (Aram & Nation, 1980; Bernstein & Tiegerman, 1993; Wetherby et al., 1989).

Features and Psychometric Criteria Necessary for Standardized Language Tests

McCauley and Swisher (1984) conducted a seminal study which outlined ten essential criteria that are required in any standardized language test. Therefore, when devising a standardized language test, the SLT needs to ensure the following:

- "A consideration of cultural factors. This factor is extremely important in multicultural South Africa, and Africa. There are varying communication rules among different cultural groups… and diagnosis of a person with a communication disorder is more likely to be effective if one uses instruments, interpersonal interaction, testing and interpretation of findings that are consistent with the communication rules of the group from which the person comes" (Taylor & Payne, 1994, p. 164). The New Reynell Developmental Language Scales (NRDLS) includes a Multilingual Toolkit (Edwards et al., 2011). This toolkit assists with concepts and materials of linguistic diversity for children who speak English as an additional language.
- A specific set of instructions and stimuli to elicit the required behavior (Bernstein & Tiegerman, 1993).
- A specific set of standards for scoring and interpreting the elicited behavior (ASHA, 1989). Traditionally, language tests such as the RDLS (Reynell, 1977) score responses as correct or incorrect. McCartney (1993) suggests that this form of scoring be used because "yes-no" answers are not representative of "normally developing children" (p. 41). McCauley and Swisher (1984) state that it is necessary for test administration to be described in sufficient detail to ensure replication of the administration and scoring procedures for norms to be based on. Means and standard deviations are derived from raw scores (Kinsey, 2010; McCauley & Swisher, 1984).
- A sample test population, encompassing a general geographical area and standardized for a broad range of social class, intelligence, and dialect (Emerick & Hatten, 1979).
- A reliable and valid measure of language. Reliability and validity are dependent on each other, in that making judgments on whether an assessment is valid depends on whether the assessment is reliable. The opposite also holds true (Beech et al., 1993; Plante & Vance, 1994).
- Item analysis. This is a method used to identify the best items within a pool of potential items (Hresko et al., 1991). Anastasi (1990, p. 202) states that performing item analysis is an alternative indication of validity and reliability and that "high reliability and validity

can be built into a test in advance through item analysis."

- Description of tester qualifications. The general background and training required for the people who are to administer and score the test should be described.
- McCauley and Swisher (1984) reviewed 30 language and articulation tests according to the psychometric criteria described above. They found that only 20% of tests met at least half of these criteria, while most tests met only two. Plante and Vance (1994) repeated this review a decade later and found that 38% of tests met at least half of the criteria. The modal number of criteria met increased to four. Most recently, Kinsey (2010) used 15 norm-referenced tests which were published after 1998. She found that the reliability and validity of tests have improved since McCauley and Swisher's original study.
- Friberg (2009, p. 78) describes the additional criterion of identification accuracy: "Identification accuracy refers to an assessment tool's ability to accurately diagnose the presence or absence of a speech and/or language disorder."

Structure of isiZulu

isiZulu was selected as the language to use to devise the standardized language assessment. isiZulu is the most commonly spoken first and second language in South Africa (spoken by 22.4% of the population) (Statistics South Africa, 2011). isiZulu is also the lingua franca of cities like Soweto (Crawhall, 1994), as shown in Fig. 19.1.

The structures described below are those that were included in this standardized language assessment. isiZulu is a partially agglutinating language where words typically consist of more than one morpheme, for example:

a-ngi-m-bon-anga
Neg-I-him-see-negative
"I didn't see him."

Typologically, isiZulu and Bantu languages are characterized by noun class systems, extensive agreement, and a suffixal system of verbal derivatives (Doke, 1990).

Noun classes can be singular or plural prefixes, "where the nominal stem is invariant" (Demuth, 1992, p. 560). Nouns in isiZulu are composed of two formatives, a prefix and a stem, for example:

umntwana NC1 > um + ntwana "child"

Prefixes vary to express number and the noun class (NC) to which the noun belongs, while the stem remains constant (Taljaard & Bosch, 1988):

abantwana NC2 aba + ntwana "children"

There are six singular/plural noun classes, with two noun classes and their prefixes (Cope, 1984). Noun class prefixes determine the semantic content of noun classes as well as control extensive concordial agreement (Cope, 1984).

Semantic Origin

Historically, Bantu noun classes were assumed to be semantically based (Kunene, 1979). The term "semantically based" refers to similar nouns being categorized into corresponding meaning classes. An example is that noun classes 1 and 2 are referred to as the "human classes."

Agreement

The noun class system determines alliterative agreement that links nouns to other words in the sentence (Taljaard & Bosch, 1988). Adjectives, relatives, possessives, and verbs are inflected to agree with the head noun.

Subject and Object Prefixes

Taljaard and Bosch (1988, p. 30) state that "the subject concord always bears a close relationship to the class prefix of the noun which is the subject

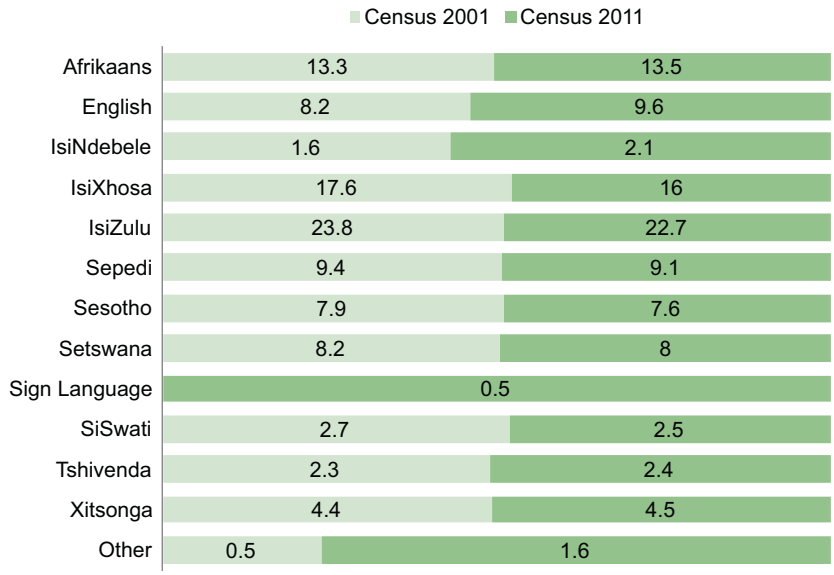

Fig. 19.1 Percentages of languages spoken in South Africa. Note: Data on "sign language" were not collected in 2001. Slight differences exist on how the question on language was asked in the two censuses. (Based on Statistics South Africa, 2001, 2011)

of the clause. Object concord has a similar structure to subject concord."

Adjectives and Relatives

Adjectives are composed of stems and adjectival concordial prefixes and can only be used when there is agreement between the stem and the concord. The adjective follows the noun in the sentence, for example:

in-gubo en-khulu
NC9-blanket AP9-large
"the big blanket"

However, adjectives are not common in isiZulu and Bantu languages. Instead, relative stems are used. An example is that, in English, colors are represented as an adjective but, in isiZulu, colors are represented by relative stems (Doke, 1990).

Verb Morphology

As Table 19.1 shows, verbs in isiZulu may have a very complex structure as a range of tense, aspect, concordial, and derivational affixes occur with the basic verb stem. The meaning of the verb is carried in the radical (Doke, 1990). Verbs can be distinguished from nouns in that their stems end in a consonant and the final vowel is an inflection, for example:

u-ya-hamba
SP1-tense-go-present tense
"he travels"

Tenses are marked with verbal affixes, which are prefixal yo- or zo- in the future tense, the suffix -a in the present tense, and -e/ile in the past tense (Doke, 1990). Passivation is a productive grammatical category in Bantu languages, and

Table 19.1 Aspects of isiZulu verbal morphology (Bortz, 1995, p. 62)

	Example	Verb marker
Present tense	*u-ya-hamb-a* SP1-tense-go-present tense "he travels"	*-a*
Past tense	*ba-hamb-ile* SP2-go-past tense "they went"	*-e/ile*
Future tense	*u-zo-hamb-a* SP1-future tense-go-tense suffix "she will travel"	*zo*
Negative (present)	*a-ka-sebenz-i* negative-SP1-work-present tense negative "he doesn't work"	*a- -i*
Passive verbal extension	*ku-phek-iwe* SP-cook-passive extension "it has been cooked"	*w-*

isiZulu language makes much use of the passive voice (Doke, 1990). The verb is marked with a passive extension -w.

Varieties of isiZulu

Urbanization, immigration, and migration are all factors in the emergence of urban varieties of isiZulu. Because of these processes, much contact between isiZulu and English and Afrikaans took place (Calteaux, 1992). Similar processes have occurred with other Nguni and Sotho languages.

Standard isiZulu is spoken in the rural areas of Kwa IsiZulu Natal (Doke & Vilakazi, 1958). G.K. Schuring (personal communication, April 1, 1993) states that standard varieties tend to be based on a form of language that was spoken about five decades ago. IsiZulu speakers in rural areas are slower in accepting innovations.

In contrast to the standard variety, different varieties of isiZulu are spoken by Sowetans. These can be called isiZulu B, Soweto isiZulu, Township isiZulu, or Colloquial isiZulu (G.K. Schuring, personal communication, April 1, 1993).

Methods

Research Design

This study used a mixed design, with emphasis on a quantitative design. The quantitative aspect of the design was cross-sectional. According to Bordens and Abbott (2013), different participants from a number of age groups can be selected. Focus groups and in-depth interviews formed the qualitative aspect of the design to determine items for structures of isiZulu to be examined.

Ethical Clearance

Ethical clearance was obtained from the Human Research Committee (Non-Medical) of the University of the Witwatersrand. Informed consent forms were obtained from parents and the principals of the preschools that the participants attended.

Participants

Table 19.2 shows the number of participants in both phases of the study. Participants were required to be first-language isiZulu speakers who attend preschools. They were aged between 2.6 and 5.5 years for the pre-standardization phase and 3.9–4.3 years for the standardization phase. Regarding the participants' language, when teachers were asked "what language do the children speak at preschool?," their answers were "Soweto language." Soweto language is a mixture of languages spoken at home together with isiZulu. The participants attended full-day preschools belonging to the African Self Help Association.

Research Assistants

Tester bias has a strong influence on a child's language ability (ASHA, 2004; Leaders Project, 2013). To ensure that the children would be comfortable to interact with the research assistants, the research assistants were isiZulu first-language speakers. They were also required to live

in Soweto to ensure that their sociolinguistic environment was consistent with that of the participants. A total of 12 research assistants participated in this study.

Research assistants' tasks included administering, scoring, coding, and analyzing data. The researcher did not fit these criteria, and due to a possible difference in the results obtained when a person from a different culture is present, she did not take an active part in testing (Taylor & Payne, 1983).

Data Collection

To devise the standardized language assessment, a pre-standardization phase and standardization phase occurred as shown in Fig. 19.2. The standardized language assessment was called the isiZulu Expressive and Receptive Language Assessment (ZERLA).

Procedure

The most important aspect of the pre-standardization phase was to define the principles upon which the ZERLA was based. Vaughn-Cooke (1986) suggested that the test should be based on valid assumptions about language and that the test should provide an adequate description of some aspect of the child's knowledge of language and the results of the test should provide principled guidelines for language intervention.

Table 19.2 Description of subjects in the standardization phase (Bortz, 1995, p. 98)

Standardization sample		
Number of subjects	$N = 303$	
Dominant language	98% isiZulu ($n = 298$)[a]	
Residence	Soweto	
Schooling	Although this was not a criterion, 32% ($n = 96$) of the sample attended nursery school	
Parents/caregiver, present in the home	All respondents	
Age range	3.9–4.3 years	
Gender	Female	54% ($n = 165$)
	Male	46% ($n = 138$)

[a]Three subjects were dominant isiXhosa speakers and two were Sotho speakers

The ZERLA was based on an adaptation of Lahey (1988) and Bloom and Lahey's (1978) model of language. In this model, language consists of three separate but interrelated components: form, content, and use. These components operate together and need to be regarded together when assessing language (Bloom & Lahey, 1978). This model of language also forms the basis for other recognized language assessments such as the Test of Early Language Development—Second Edition (TELD-2, Hresko et al., 1991).

Regarding the use of language, Hresko et al. (1991, p. 2) report that language use was not used as a dimension of the TELD-2, because operationalizing language use is extremely challenging in that the concept does not lend itself easily to standardized test formats.

The ZERLA does not formally assess pragmatics for similar reasons. However, attempts were made to devise the ZERLA in a pragmatically sensitive manner (Lund & Duchan, 1993), through assessing language in context. Examples include adjectives and relatives being assessed within the theme of dressing a doll.

Given the enormous complexity of language, it would be unrealistic for a test to evaluate in detail every aspect of a speaker's linguistic knowledge. An adequate test should have a clearly defined focus, that is, it should be specifically designed to assess the grammatical, semantic, or pragmatic systems or subcomponents of these systems (Vaughn-Cooke, 1986, pp. 43–44). The ZERLA was, therefore, specifically designed to evaluate children's knowledge of the morphology and syntax of isiZulu through the use of expressive and receptive subtests. The purpose of each subtest was to provide an indication of the participant's knowledge of a specific component of her/his language.

Expressive language was assessed using spontaneous language sampling. According to Gallagher (1983, p. 2), "spontaneous language sampling is

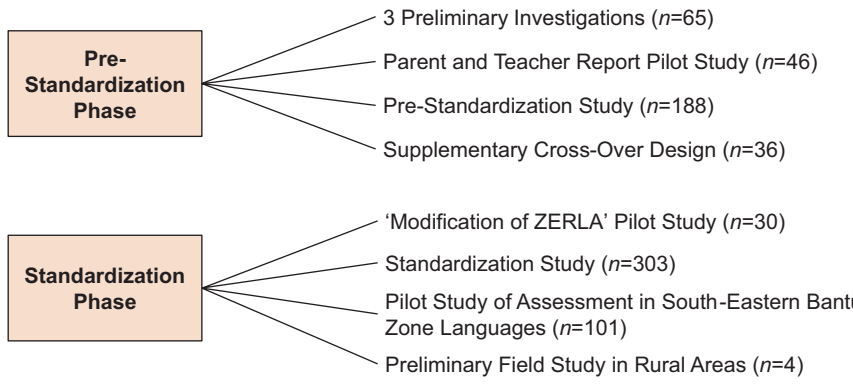

Fig. 19.2 Pre-standardization and standardization phases of the ZERLA development. (Adapted from Bortz (1995, p. 17))

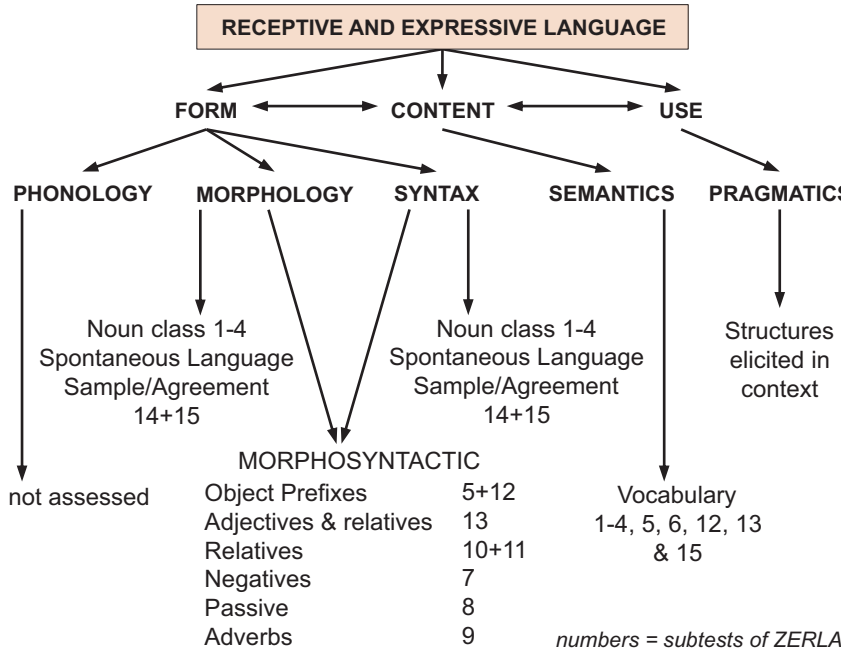

Fig. 19.3 Components of the ZERLA. (Adapted from Bortz (1995, p. 112))

the centerpiece of child language assessment." The ZERLA utilized a semi-structured language sample which assessed the participants' expressive vocabulary. Research assistants asked questions which required responses from the participants. The conversations included descriptions of concrete "hereand-now topics" (Snow, 1981), for example, *ugqokaninamhlanje* "what are you wearing today?" The participants' knowledge of agreement and relative stems were also elicited in this manner. The subtests of the ZERLA can be seen in Fig. 19.3.

One aspect of the Bloom and Lahey's (1978) model that was not used in the ZERLA was phonology. Tone, an integral part of isiZulu, is also not assessed. This omission is a limitation of the study.

ZERLA Materials

Using objects for ZERLA materials was based on the same principles as the RDLS-2 (Reynell, 1977). However, efforts were made to ensure that these materials were suitable for the Soweto population via an informal focus group of Soweto mothers, who had come to the Chris Hani Baragwanath Hospital for a routine developmental follow-up for their children. They were questioned about what their children played with at various ages. Examples of items provided by the mothers included household items and toys. In addition, stimuli that were commonly seen in Soweto, such as *ihashi* "horse" (Dellatola, 1990), were used. Items were also selected according to a list that Reynolds (1989) found that Black South African children commonly played with, such as combs and plastic bottles.

An activity mat was designed by an art student living in Soweto and studying in a local college. The mat depicts a "typical" Soweto neighborhood with characteristic "matchbox" houses and *groundini* "sports field." Items not common in Soweto, such as flowers, were thus sadly excluded (Dellatola, 1990).

Treatment of Data: Coding and Analysis

On the ZERLA, correct responses marked with a tick were given a score of 1. Incorrect responses indicated with a cross received a score of 0. In the pilot test phase, the research assistants had to provide the response that the child had made.

Statistical Analysis

Descriptive statistics were applied to analyze the results. For each participant, the total number of correct responses out of the total number of possible responses on each subtest of the ZERLA was calculated as percentages. Frequency counts of all the responses for subtests were addressed to obtain composite scores for each participant.

Norms were obtained by transforming the raw scores to means, and standard deviations were also calculated. Measures of internal consistency, test-retest reliability, and mark-remark reliability were determined. Different measures of validity such as concurrent and internal validity were also determined.

Analyses of variance (ANOVAs), t-tests of significance, and Bonferroni t-tests have a weakness. Therefore, chi-square goodness-of-fit tests were administered. These tests indicated that the receptive language and the composite score of the ZERLA showed good fits with the normal distribution.

Qualitative Analysis

As many of the measures of reliability and validity are not empirical, qualitative analysis was used. Qualitative analysis provides a comprehensive description and rationale for the results, particularly reliability (Marshall & Rossman, 1989; Patton, 1988). Participant observation, in-depth interviews, and focus group interviews were used.

Results and Discussion

Item Analysis

Items were analyzed according to discriminating power (the discriminating power of each item was determined by using the point biserial correlation technique Howell (1989)). Item difficulty is defined as the "the proportion of examinees who got the item correct" (Hresko et al., 1991, p. 40). Good test items should range in difficulty between 15% and 85%. Although this is a fairly wide dispersion, Anastasi (1990) argued that items should have an average percentage of difficulty.

The results of the ZERLA showed that 37% of the items met the criteria of discriminating power. Fifty-one percent of the ZERLA items had appropriate item difficulty. Thus, not all items included in the ZERLA met the criteria for appropriate discriminating power or item difficulty. The fact that these criteria were not met was a limitation of this study. However, Anastasi (1990) stated that having only items with good discrimination can lower the validity of a test.

Norms

Means, standard deviations, standard sores, and percentile ranks made up the norms for the

ZERLA. The means and standard deviations contributed to developmental norms for the ZERLA while percentile ranks provided within-group norms. These normal distributions provided additional indicators of the validity of the ZERLA.

However, the chi-square goodness-of-fit test showed that a poor fit was obtained for expressive scores, as a significant difference from the normal curve was obtained. Poor results on expressive measures of language assessment are not unusual. According to Letts et al. (2010), the expressive scales of the first two versions of the RDLS (Reynell, 1969, 1977) were difficult to administer objectively and yielded uninformative results. This resulted in the development of the Reynell III.

The results of standardization demonstrate that the ZERLA can be utilized to assess the language abilities of isiZulu-speaking preschoolers. SLTs can compare a child's performance with that of the participants assessed in the standardization sample of the ZERLA, in order to determine if the child has any language challenges. The ZERLA can be used as a standardized language test because it contains sufficient items which have discriminating power and appropriate item difficulty. The ZERLA is also a norm-referenced instrument. The fact that scores obtained on the ZERLA are representative of a normal distribution is an additional verification that the ZERLA can be used for the identification of language difficulties. The standardization process also showed that the ZERLA is a reliable and valid measure (see Table 19.3).

Impact

Language Acquisition

The findings of the ZERLA reflected the universal nature of language; for example, noun classes were found to develop earlier than verbs and receptive language abilities predominated over expressive abilities (Bloom & Lahey, 1978; Lahey, 1988). Studies of isiZulu and Sesotho language acquisition, such as those conducted by Demuth (1989, 1992), Demuth et al. (2010), and Suzman (1985, 1991), indicated that children acquired their noun class systems and concordial morphology, passive, and relatives by age 3 years. The present study verified these findings regarding noun class and agreement. However, it found that the children tested on the ZERLA still had difficulty with their relative structures even at the age of 5 years.

There were also sociolinguistic and cultural findings from this study. All languages undergo continuous changes (Aitchison, 1991; Hickey, 2003; Kamwangamalu, 1989). However, in South Africa, change has been influenced due to the transformation of the political situation and changes in the education system. These changes in education have resulted in a strong influence of spoken English on isiZulu. English is becoming a lingua franca of Soweto, as this is the language which people use to gain employment. Parents also want their children to be educated in English as they view this as a language of increased opportunities (Jordaan, 2011).

Vaughn-Cooke (1986, p. 38) states that "forms of language used to code concepts can vary as a function of age, sex, social class, ethnicity and geographical region." The effects of language shift in isiZulu and geographical region certainly influenced the ZERLA in a myriad of ways; for example, preliminary investigations showed that standard isiZulu agreement using subject prefixes had to be omitted, for example, *-thatha aba-ntwana* take NC2 children "take the children" instead of *bathathta aba-ntwana* SP2 take NC2 children "take the children." The variety and inconsistency of Soweto IsiZulu and code-switched responses that subjects used when naming colors or numbers also showed the influence of language shift. Table 19.4 shows how features of the ZERLA can be compared to criteria of standardized language assessments (McCauley & Swisher, 1984; Plante & Vance, 1994; Vaughn-Cooke, 1986).

Epidemiological Implications

South Africa has adopted the primary health-care system, which consists of primary, secondary, and tertiary prevention (Gerber, 1990). This assess-

Table 19.3 Z-scores and percentile ranks of the ZERLA (Bortz, 1995, pp. 463–464)

Raw ZERLA score	Z-score	Percentile rank	Raw ZERLA score	Z-score	Percentile rank	Raw ZERLA score	Z-score	Percentile rank
0	−5.87	0.0	30	−2.98	0.1	60	−0.10	46.2
1	−5.77	0.0	31	−2.88	0.2	61	0.00	50.0
2	−5.67	0.0	32	−2.79	0.3	62	0.10	53.9
3	−5.58	0.0	33	−2.69	0.3	63	0.19	57.7
4	−5.48	0.0	34	−2.60	0.5	64	0.29	61.4
5	−5.38	0.0	35	−2.50	0.6	65	0.38	65.1
6	−5.29	0.0	36	−2.40	0.8	66	0.48	68.5
7	−5.19	0.0	37	−2.31	1.0	67	0.58	71.9
8	−5.10	0.0	38	−2.21	1.3	68	0.67	75.0
9	−5.00	0.0	39	−2.12	1.7	69	0.77	78.0
10	−4.90	0.0	40	−2.02	2.2	70	0.87	80.7
11	−4.81	0.0	41	−1.92	2.7	71	0.96	83.3
12	−4.71	0.0	42	−1.83	3.4	72	1.06	85.6
13	−4.62	0.0	43	−1.73	4.1	73	1.15	87.7
14	−4.52	0.0	44	−1.63	5.1	74	1.25	89.5
15	−4.42	0.0	45	−1.54	6.2	75	1.35	91.2
16	−4.33	0.0	46	−1.44	7.4	76	1.44	92.6
17	−4.23	0.0	47	−1.35	8.9	77	1.54	93.9
18	−4.13	0.0	48	−1.25	10.5	78	1.63	94.9
19	−4.04	0.0	49	−1.15	12.4	79	1.73	95.9
20	−3.94	0.0	50	−1.06	14.5	80	1.83	96.7
21	−3.85	0.0	51	−0.96	16.8	81	1.92	97.3
22	−3.75	0.0	52	−0.87	19.3	82	2.02	97.9
23	−3.65	0.0	53	−0.77	22.1	83	2.12	98.3
24	−3.56	0.0	54	−0.67	25.0	84	2.21	98.7
25	−3.46	0.0	55	−0.58	28.2	85	2.31	99.0
26	−3.37	0.0	56	−0.48	31.5	86	2.40	99.2
27	−3.27	0.1	57	−0.38	35.0	87	2.50	99.4
28	−3.17	0.1	58	−0.29	38.7	88	2.60	99.5
29	−3.08	0.1	59	−0.19	42.4	89	2.69	99.7
						90	2.79	99.7

ment can be used at all levels of prevention as can be seen in Fig. 19.4.

An example at the primary level of prevention, the screening version of the ZERLA, can be used. At the secondary level, the ZERLA can be used to detect and identify language problems. The ZERLA can therefore be used to identify children with language difficulties. It thus fulfills the criterion of identification accuracy mentioned by Friberg (2009).

The ZERLA can also be used at a tertiary level of prevention, by assisting with tertiary prevention (Marge, 1991). Lahey (1988) and Vaughn-Cooke (1986) state that language tests should be able to determine what form of intervention and remediation of a child is required. The ZERLA can also be used while the child is receiving therapy. It can also be readministered to assess progress.

Psychometric Results of the ZERLA

An often-leveled criticism against standardized language assessments is that they "do not report impressive validity data, if any at all" (Lund &

Table 19.4 Features of the ZERLA compared to criteria of standardized language tests (Bortz, 1995, p. 267f; derived from Hresko et al. (1991), Lund and Duchan (1993), McCauley and Swisher (1984), Vaughn-Cooke (1983, 1986))

Features and criteria of formal tests	ZERLA
When necessary, a new test that is able to provide an appropriate assessment should be devised.	Prior to the ZERLA, no test was available for isiZulu speakers, the majority of South Africa's population. Previous attempts to devise tests included unsuccessful translations of assessment normed on non-South African cultures.
The test should provide an adequate description evaluating aspects of a child's knowledge of language.	Characteristic features of isiZulu noun class, agreement system, and verb morphology were assessed.
Assessment should provide information about a child's receptive, expressive, syntactic, and semantic abilities.	Receptive and expressive morphological and morphosyntactic, syntactic, and semantic subtests were designed.
The test should be based on a normative sample that is representative of a child's language and culture.	Sociolinguistic and sociocultural factors were taken into account when the ZERLA was developed. The ZERLA was normed on a sample of 303 isiZulu speakers.
The assessment requires a specific set of instructions and stimuli to elicit the required behavior.	Instructions were included on the ZERLA Test Booklet, and research assistants were trained to administer the assessment; an inventory of culturally appropriate test stimuli was devised.
Evaluations can be administered in a short time without creating fatigue for the child.	Pilot testing determined that test time needed to be shortened. Current administration time is 30 minutes. The ZERLA is not a timed test.
The test can be used by persons skilled in assessment who are not experts in child language.	An important implication for South Africa due to the shortage of speech–language professionals. Teachers and linguists can be trained to administer the ZERLA. Parents and other nonprofessionals can administer the ZERLA in conjunction with a speech–language therapist.
A specific set of standards for scoring and interpreting the elicited behavior should be provided.	A range of responses that take the diversity of child language and sociolinguistic variables into account is provided. Research assistants are trained to use these when performing evaluation.
The tool is sufficiently reliable for an examiner to have confidence in the findings.	Good internal consistency and mark-remark reliability coefficients were obtained. Poor test-retest reliability was achieved. Qualitative analysis indicated the effects of sociolinguistic variables on reliability. An additional study was devised to improve results.
The assessment is valid to the extent that the examiner can have confidence in the findings.	Various measures of validity were obtained.
The score obtained enables an intra-individual comparative index of child's strengths and weaknesses—this should provide principled guidelines for language intervention.	Analysis of individual subtests provides this.
Uses normative information and fosters comparisons among age-mates.	Means, standard deviations, standard scores, and percentile ranks provide this information.

Duchan, 1988, p. 289). The ZERLA determined several aspects of validity, as shown in Fig. 19.5.

Scoring on the ZERLA was done by creating a pool of responses to deal with language variation. One of the criticisms traditionally leveled against standardized language assessments is the manner in which they are scored. Scoring is usually done in a binary fashion using a right-wrong system with correct responses counted as correct, 1 point, or incorrect, 0 points. Authors such as McCartney (1993) are concerned that this kind of coding is not representative of developing children's language.

Clinical Implications: Examiner Qualifications

An important consideration during this study and regarding future use of the ZERLA is who is

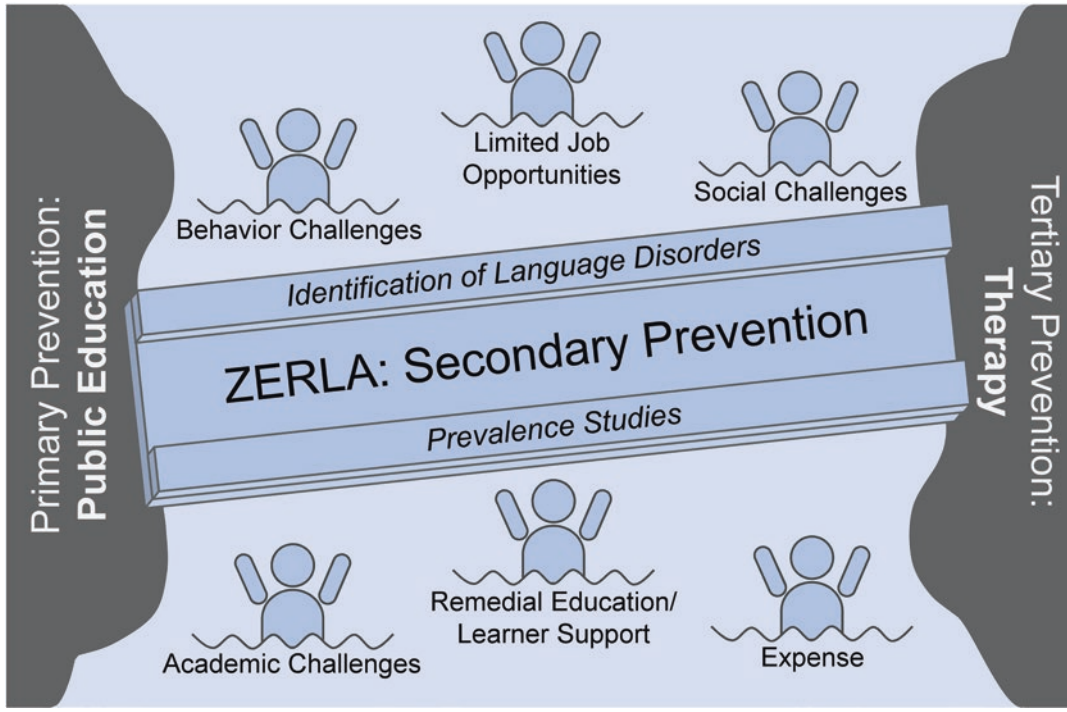

Fig. 19.4 The use of the ZERLA for prevention of language disorders. (Adapted from Bortz (1995, p. 275))

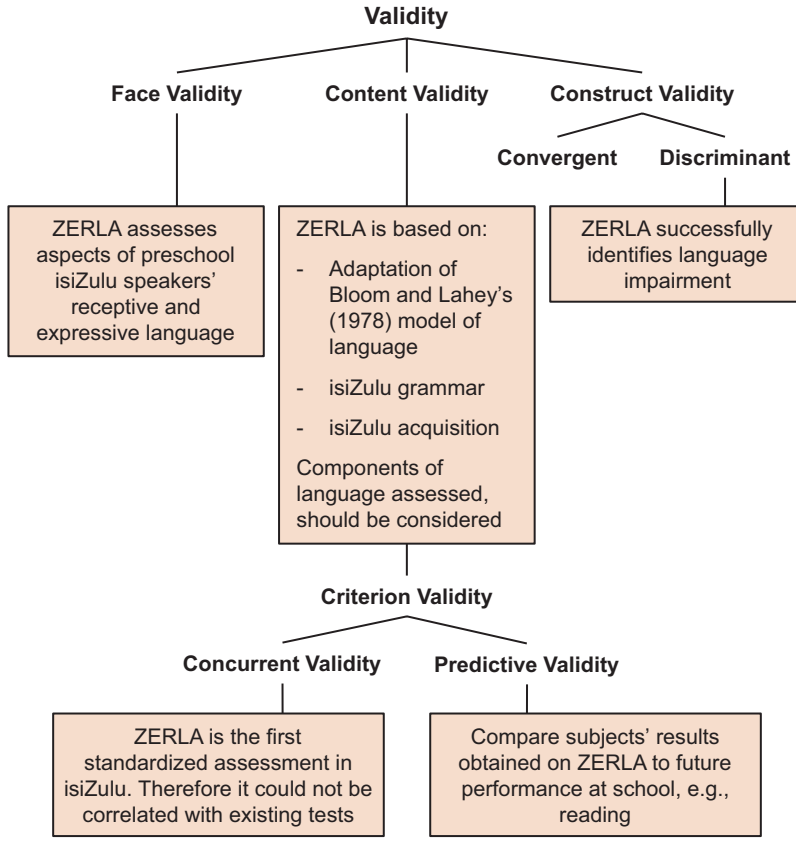

Fig. 19.5 Aspects of validity determined on the ZERLA. (Adapted from Bortz (1995, p. 270))

qualified to administer and score this assessment. There is a shortage of suitably trained SLT personnel in South Africa as well as Africa (Tuomi, 1994; Bortz et al., 1996; Barratt et al., 2012; Southwood & van Dulm, 2015, Enwefe, A. and S. personal communication; Wiley personal communication, October 9, 2016). However, as SLTs who specialize in communication, we need to empower ourselves to deal with the linguistic situation that presents itself during assessment.

In the case of the ZERLA, when no isiZulu speaker is available, a recommendation is that the SLT should work with an isiZulu speaker such as the parent or an interpreter. Using the parent can be an added advantage if the child is shy or uncooperative. The SLT needs to train the isiZulu speaker on the purpose of the test and method of administration. The therapist needs to observe that the test is being administered according to the detailed instructions required (McCauley & Swisher, 1984).

A criterion for the selection of a person to administer the test is literacy, as this would facilitate transcription of the child's responses. The range of responses would be used to score the responses.

Utilizing test personnel in this manner would also be beneficial when using the ZERLA to screen large populations. The facilitator could train a number of examiners on test administration and scoring. She/he could then coordinate the process.

Considering the current composition of the SLT profession in South Africa, another alternative for test administration is for an English or African speaker to administer and score the ZERLA. The major drawback to this alternative is that isiZulu is a tonal language (Doke, 1990) and difficulty with tones is often experienced by non-isiZulu speakers.

Despite these issues, the non-isiZulu-speaking therapists would be able to administer the ZERLA on the proviso that they did considerable preparation prior to test administration. They could practice with an isiZulu speaker.

Considerations for Future Work, Research, and Politics

Standardization of Assessments in Bantu Languages

Due to the similarities within the languages of the Southeastern Bantu zone language group, the ZERLA can be translated into other languages such as the Sotho language group (Setswana, Northern Sotho, Southern Sotho). These assessments should also be standardized and normed so that they can effectively evaluate the languages of all children in South Africa. Similarly, the principles used for devising the ZERLA can be applied to other Bantu language zones due to the similarity of structures in the Bantu languages. Normed language assessments for the African population would assist in the prevention of long-term consequences of language delay.

Rural Areas

There is a need to adapt the ZERLA for use in rural environments, as approximately half the population lives in these areas (Hlophe, 1993). Standard dialects of the language are spoken in the rural areas. Therefore, linguistic changes would have to be reflected in the standardized tests. In addition, results of preliminary testing in rural environments revealed that vocabulary and activities such as the activity mat would need to be modified. The Delphi technique, which according to Hsu and Sandford (2007) is a method used to build consensus, can be used for this purpose.

Development of a South African Multilingual and Multicultural Database

Many authors have spoken about the urgent need for the development of appropriate speech, lan-

guage, and hearing materials for a multilingual and multicultural South Africa (Ballantine et al., 1976; Bortz, 1995; Southwood & van Dulm, 2015; Tuomi, 1994). For decades, South African SLTs working in hospitals and universities have devised these kinds of materials. Unfortunately, much of this work is unpublished and not shared among colleagues.

Efforts have been made to compile a list of these resources (Professor Shajila Singh, personal communication, 2010–2014). The South African Speech–Language-Hearing Association (SASLHA) discussed this issue at the 2016 SASLHA Conference (October 2016). At this conference, an African Connections' partnership using email was set up. SASLHA also set up an African Connections' committee. The aim is to partner and assist speech–language and hearing therapists working in Africa with any challenges and needs they may have. A specific aim is to devise a database listing any resources. This email group already assisted in informing this chapter in terms of the assessments used in Africa, as described previously. Such a database would consolidate the materials and prevent "reinventing the wheel." Clinicians would know what resources are available. An added benefit of such a library would be that clinicians could comment on their experience of the materials, adding to the materials' reliability and validity. Such a resource would also prevent results such as those of Southwood and van Dulm (2015) who found that SLTs with the most experience persist in using assessments that are not linguistically or culturally appropriate for South Africa.

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20

Using Acoustic Phonetics in the Assessment and Treatment of Speech Disorders

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Introduction

Over the years, speech–language therapists (SLTs) have had a tendency to favor the traditional auditory-based or segmental-based approach to assessment and treatment of speech disorders, as originally proposed by Rosenbeck and La Pointe (1985). In addition, many of the published assessment tools for pathological speech, for example, the "Frenchay Dysarthria Assessment" (Enderby & Palmer, 2008), are psychosocial in basis. In many of these approaches, phonological processes such as substitution, omission, deletion, and distortion of segments are used to describe speech production in therapeutic procedures. An example is the sound substitution of a voiceless alveolar plosive /t/ for the voiced bilabial plosive /b/, for example, saying "tin" when a person meant to say "bin."

However, these are not the only approaches that can be used in clinical practice. This chapter demonstrates that in addition to this traditional segmental-based approach, there is a gestural approach in which speech can be analyzed using speech acoustics. This can be a major advantage in sub-Saharan African (SSA) countries, where language complexity is a major challenge in the assessment of speech disorders.

Background

Speech–Language Therapy Services in Kenya

Kenya, just like other SSA countries, is underrepresented in terms of speech–language therapy (SLT) services (Karia, 2007; Ndung'u & Kinyua, 2009; Wylie et al., 2016). In addition, there is a short supply of SLTs in this region (Barrett & Marshall, 2013; Jochmann, 2006; Wylie et al., 2013). Furthermore, foreign nationals represent a significant proportion of SLTs in SSA countries like Kenya. In a 2016 study by Wylie et al., up to 36% of therapists in SSA countries (excluding South Africa) were found to not be of the same nationality as the country in which they work. Considering the polyglot nature of Africa, this poses a challenge for providing services in patients' home language(s). Furthermore, there are few universities offering training of SLTs in SSA countries, which results in Kenyan SLTs mostly being trained outside of Africa (Wylie et al., 2016).

In addition, assessment tools (many of them standardized for US and European populations) are adopted in SSA, with little or no changes. Therefore, there is a need to develop diagnostic tools that would make it easier to work in challenging environments, especially regions with few assessment tools (Carter et al., 2012).

Perceptual Assessment of Dysarthria

Perceptual-based assessments are widely used in clinical practice, not only in Minority World countries such as the USA but also in Majority World countries such as those in SSA. Perceptual evaluation involves a listener who judges the production of speech and usually transcribes the production orthographically (Sussman & Tjaden, 2014). This type of evaluation is dependent on accurate perception by the clinician, and there is a difference between the accuracy of perception by experienced versus non-experienced listeners (Munson et al., 2012). Furthermore, there may be "wide subjective variability in assessment of dysarthria between different clinicians" (Thoppil et al., 2017, p. 352). When considering the fundamental frequency (which relates to the perception of pitch), listeners have been divided into *fundamental* and *spectral* listeners, depending on whether they focus on the higher harmonics or lower harmonics of a complex sound signal. This may lead to differing interpretations of the perceived pitch values in different listeners (Postma-Nilsenová & Postma, 2013). It is possible to lack objectivity in the screening and diagnostic process, especially in patients with motor speech disorders (Karia, 2014).

Acoustic Assessment of Dysarthria

Acoustic analysis has been widely used in the analysis of speech production, especially in persons with dysarthric speech (Özsancak et al., 2001; Ziegler & Hartmann, 1996). Dysarthrias

are motor speech disorders which result in impaired speech production due to a neurological condition, such as traumatic brain injury (TBI) or Parkinson's disease, to name a few (Mefferd, 2015). As stated by Mefferd (2015), the speech acoustic signal is changed by articulatory movements, particularly movements of the tongue; thus, articulatory deficits can be inferred by using speech acoustic measures. For example, speech acoustic methods have found that the acoustic vowel space is smaller in dysarthric speakers than non-dysarthric speakers, which could suggest smaller-than-normal articulatory movements (Mefferd, 2015). Acoustic analysis can be said to have additional benefits because as well as the assessment of speech production, it can also be used to evaluate the motor and sensory function of speech organs (Kirkham & Nance, 2017; Ouattassi et al., 2015). For example, dysarthric speech is characterized by very poor breath control (Spencer & Yorkston, 2002), which could be partly assessed through acoustic analysis.

PRAAT is a free and relatively easy-to-learn and easy-to-use program (Boersman & Weenink, 2011). This is a computer-based software that can be used to visualize, play, annotate, and analyze sound objects in terms of their acoustic properties. By using their knowledge in phonetics and phonology, which is usually part of their training, SLTs can analyze and interpret speech samples of their clients.

The use of an acoustic measure may thus assist SLTs in objectively analyzing pathological speech. This chapter discusses an alternative and objective technique of analyzing pathological speech in a clinical setting.

Articulatory Gestures

This chapter adopts the articulatory phonology approach as originally postulated by Browman and Goldstein (1989). According to Browman and Goldstein (1990, p. 346), there are three oral tiers for the oral gesture in articulatory phonology (AP), namely, the lips, tongue tip, and tongue body. These can be equated to the traditional place of articulation (i.e., labial, lingual, and dorsal) as described by phoneticians (Halle, 1982; Ladefoged & Maddieson, 1986). Also, autosegmental phonologists have described tiers which correspond to the articulatory system such as the larynx (for tone and voicing), the velum (for nasality), and the oral articulators (Clements, 1980; Goldsmith, 1976). In AP, the main tenet is the articulatory gesture. Gestures are "units of action that can be identified by observing the coordinated movements of vocal tract articulators" (Browman & Goldstein, 1989, p. 202). They constitute basic phonological units that can be identified by movements within the vocal tract.

In contrast to a segmental approach, articulatory gestures capture inaccuracies in speech in terms of gestural target undershoots (the speech organ not attaining full constriction in production of speech). According to AP, the use of gesture in pathological speech provides an alternative descriptive in phonological variation. This can be based on the argument that gestures are the basic units of phonological contrast. As stated by Browman and Goldstein (1990), the presence or absence of a given gesture will explain phonological variation.

Research Question

The research question was the following:

- Which acoustic cues can be used in the analysis of pathological speech in the assessment of dysarthria as a result of traumatic brain injury?

Methods

Study Population

The study population comprised ten participants, who were recruited from the caseload of the patients in the neurology and speech/occupational therapy department at the Kenyatta National Hospital (KNH); Nairobi. This is the biggest referral and teaching hospital in Kenya. Therefore, the sample was assumed to be adequately representative. These participants had different ages, social

backgrounds, as well as education levels. In addition, they spoke different first languages. The selection criteria were based on a medical diagnosis of TBI by a neurosurgeon, and clinical evaluation was performed by an SLT who confirmed the presence of a motor speech disorder.

Ten healthy controls were also sampled. Judgmental sampling was used to match each participant with a healthy control. They reported no history of speech or language disability and were matched in terms of age, gender, first language/mother tongue, and level of education.

Research approval from the hospital's ethical board was obtained. In addition, all participants selected for the study or their parents/guardians (for minors) provided written informed consent. The participants' mean age was 21;8 years.

Speech Materials

Oral Diadochokinesis Test (DDK)[1]

The participants carried out a DDK test which comprised six plosives, each repeated five times. A total of 300 tokens were recorded (6 plosives × 5 repetitions × 20 participants).

Telephone Number Test

The telephone number test was used to investigate prosodic deviation. The participants were instructed to repeat two sets of fictitious telephone digits. These were 0721-222-989 (coded as _a) and 0721-989-222 (coded as _b). These digits were produced at both a normal and fast speaking rates, as instructed by the researcher. A total of 40 tokens were recorded (2 digits × 2 speech rates × 20 participants).

Recordings and Data Annotation

The participants were acoustically recorded using an EDIROL (R-09HR) wave 16 bit/44.1 kHz digital recorder, using an AV-JEFE TCM 141 condenser microphone. The headset microphone was set at a mouth-to-microphone distance of 10 cm. The recorded data was then normalized and converted from stereo to 16-bit mono using the Cool Edit 96 digital editor. The recordings were done at the Kenyatta University (KU 99.9 FM) soundproof recording studio.

Thereafter, the data was labeled by the hand in the PRAAT speech analysis software package, version 5.3.56 (Boersman & Weenink, 2011), by the researcher. The annotations were carried out using a wide-band spectrogram.[2]

Measurements

Voice Onset Time

After annotating the speech sample for DDK, the voice onset time (VOT) of the plosives was measured. This chapter adopts Cho and Ladefoged's (1999) definition of VOT as "the interval between the release of an articulatory gesture … and the beginning of vocal fold vibration" (p. 225). VOT is the most important acoustic feature for distinguishing voiced and voiceless plosives. A voiced plosive has a positive VOT value, while a voiceless one has a negative VOT value. The positive voice onset value (VOT) is the interval between the beginning of the release burst and the onset of the first formant[3] as observed in the spectrogram. Positive VOT values indicate that the glottis is open after the release of the consonant. Negative VOT (prevoicing) is measured from the beginning of voicing during closure to the release burst. Negative VOT values indicate the presence of voicing during the closure phase. These measurements are illustrated in Figs. 20.1 and 20.2.

[1] According to Ziegler (2002, p. 557), oral diadochokinesis involves "rapid repetitions of a monosyllables, usually one of /pa/, /ta/, /ka/ or /ba/, /da/, /ga/ and it is used to measure performance of the muscular system required for speaking."

[2] A spectrogram is a visual representation of the spectrum of frequencies in a sound.

[3] A formant refers to a spectral shaping which is the result of an acoustic resonance within the human vocal tract.

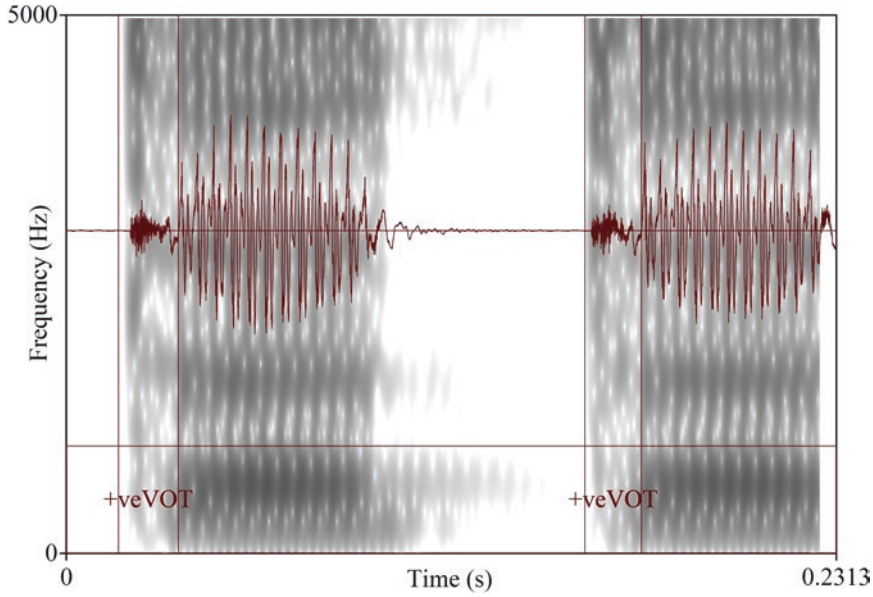

Fig. 20.1 Oscillogram and spectrogram showing the positive VOT measurement for the voiceless bilabial plosive /p/ (spoken by a healthy control)

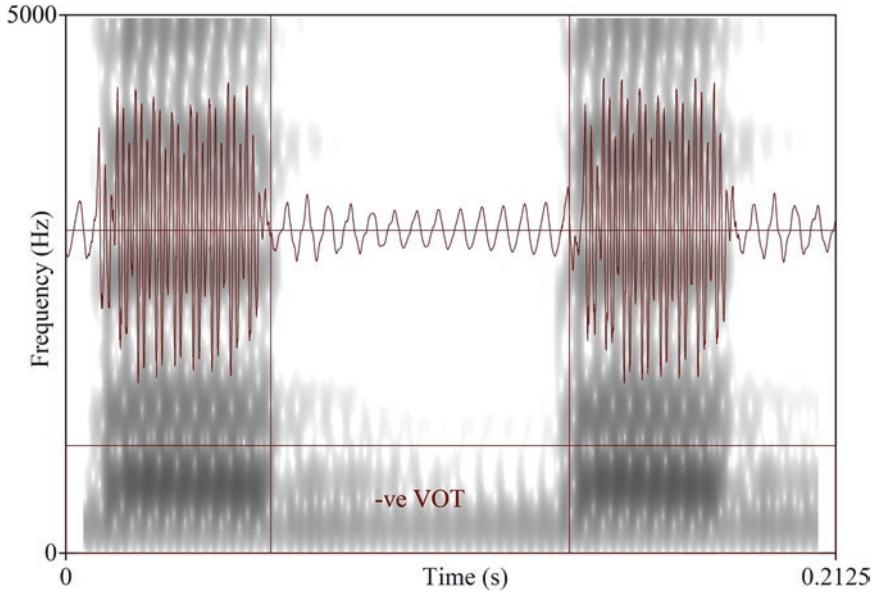

Fig. 20.2 Oscillogram and spectrogram showing the negative VOT measurement for the voiced bilabial plosive /b/ (spoken by a healthy control)

Fundamental Frequency (F_0)

Fundamental frequency (F_0) is the lowest tone produced in an oscillation or a waveform. The fundamental frequencies (F_0) were generated using PRAAT, and the pitch contours were drawn in the PRAAT picture window as shown in Fig. 20.3. The rising (H) and the falling (L) F_0 movements were analyzed.

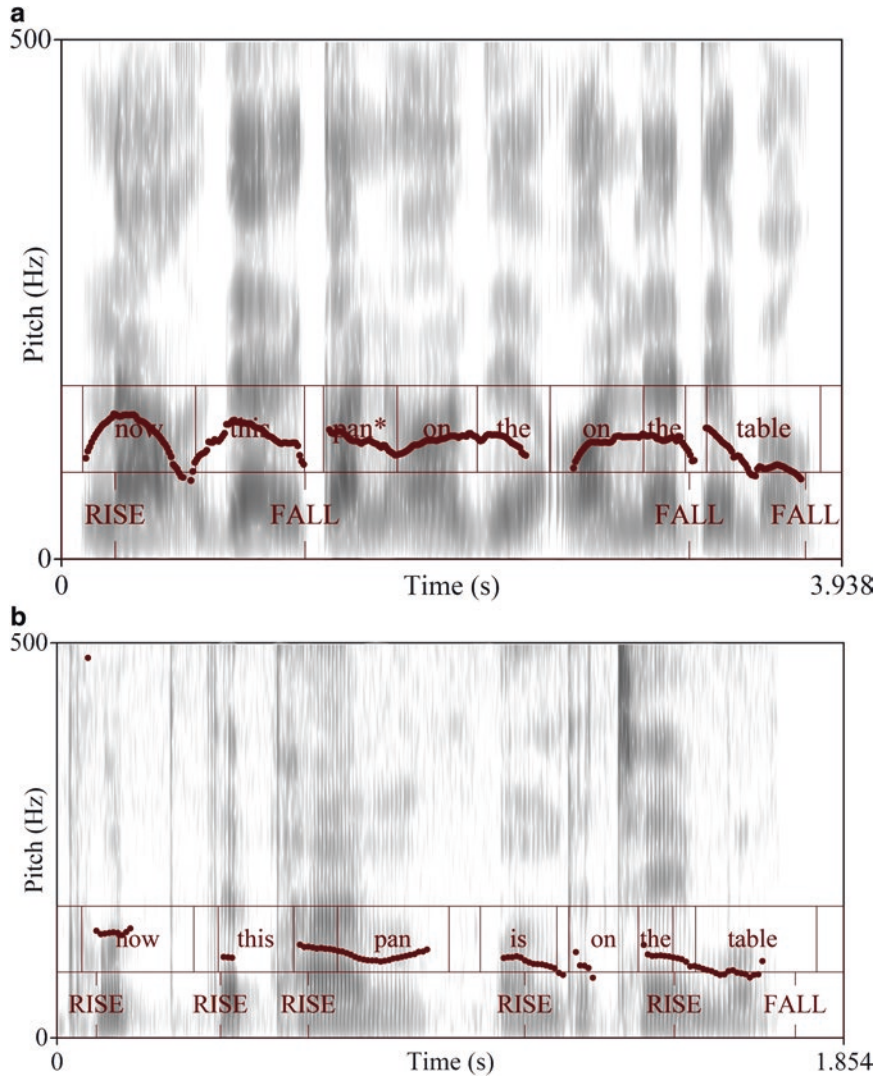

Fig. 20.3 F_0 and spectrogram for digit sequence 0721-222-989 at a fast speaking rate; (**a**) spoken by a healthy control and (**b**) a participant

Results

The research question was which of the acoustic cues can be used in analyzing speech, specifically in assessing pathological speech, in patients with dysarthria. The results show that measurement of the following acoustic cues can be used to analyze impaired speech.

Voice Onset Time

As illustrated in Figs. 20.1 and 20.2, VOT is one of the acoustic cues that can be used to distinguish different sounds, specifically plosives. As shown in Figs. 20.4, 20.5, and 20.6, a pathological speech sample can show that there is a deviation in the participants' VOT.

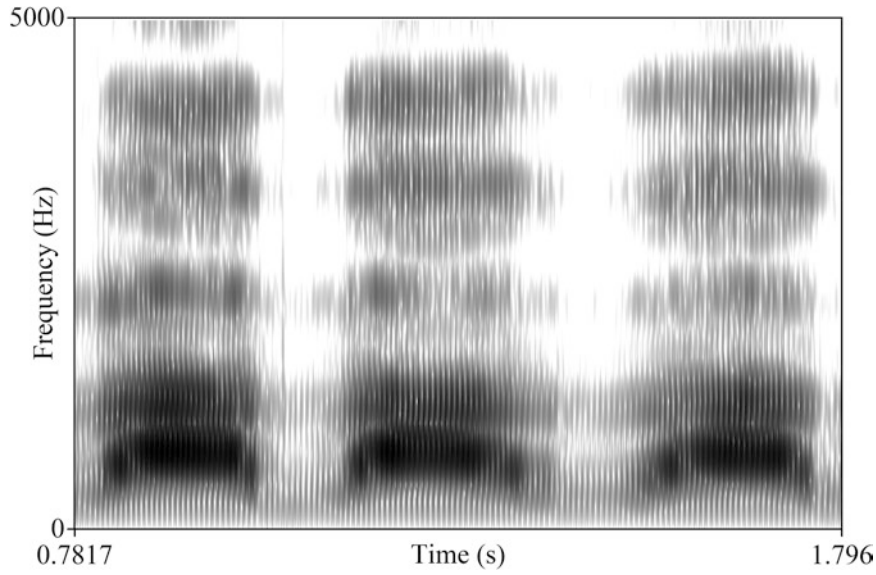

Fig. 20.4 Spectrogram showing incomplete closure for the voiceless alveolar plosive /t/ (spoken by a participant)

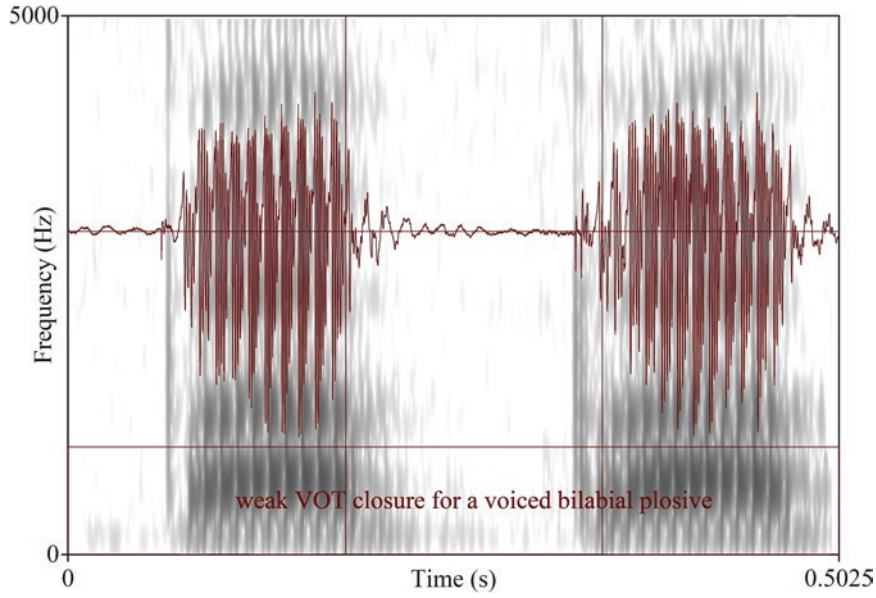

Fig. 20.5 Oscillogram and spectrogram showing weak closure for the voiced bilabial plosive /b/ (spoken by a participant)

Figure 20.4 shows a weak or incomplete closure where the intended voiceless alveolar plosive /t/ is produced as an approximant.

Figure 20.5 shows some evidence of a weak closure coupled with loss of voicing where the intended voiced plosive sounds like a voiceless fricative.

Figure 20.6 shows some loss of voicing and frication during the closure phase where the intended voiced plosive sounds like a voiceless fricative. From the results of the study, it is evident that participants' VOT are characterized by very weak or incomplete closure (undershoot of closure gesture), especially where the production

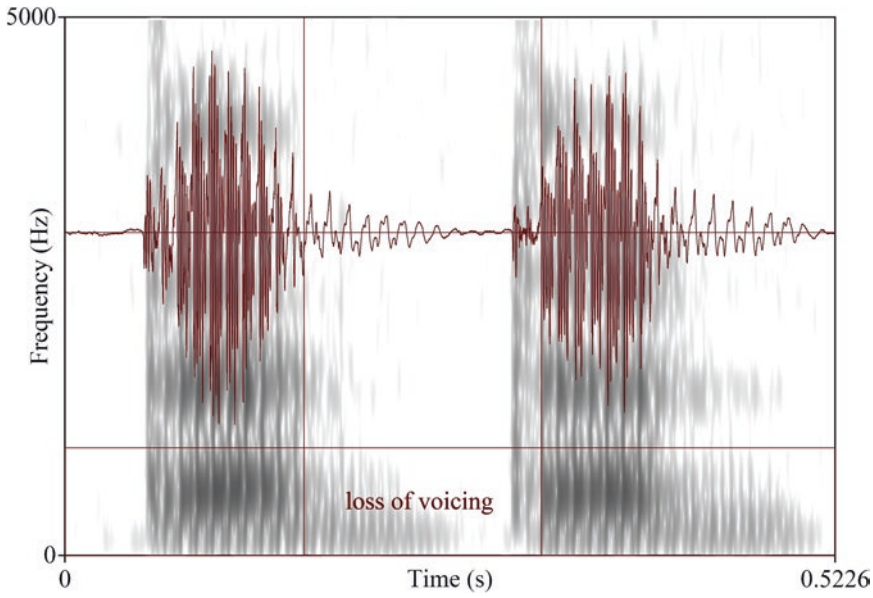

Fig. 20.6 Oscillogram and spectrogram showing loss of voicing for the voiced alveolar plosive /d/ (spoken by a participant)

of a plosive is intended. Also, there are multiple closures (incomplete gestural undershoot), which make a plosive sound like a fricative, and loss of voicing (glottal abduction gesture) during the plosive closure phase, which makes an intended voiced plosive sound like a voiceless plosive.

Fundamental Frequency (F_0)

It is possible to diagnose deviant prosody using computer software such as PRAAT. Prosody refers to the patterns of stress and intonation in a language. As mentioned previously, dysarthric speech is characterized by very poor breath control. This can be seen in the pitch picture window in PRAAT. Pitch is the degree of highness or lowness of a tone. Acoustically, it can be seen to have an effect of lowering fundamental frequency (F_0). This is shown in Fig. 20.7.

As evident in Fig. 20.7, the use of acoustic analysis can assist an SLT in understanding the nature of a client's suprasegmental features such as prosody. Normally, one should start an utterance with high pitch, as well as on phrasal boundaries (pauses midway), but end in a low pitch. This is referred to as the "production code" where high pitch is associated with the utterance beginning, while a low pitch marks the utterance end and high endings signal continuation (Gussenhoven, 2004, p. 89). The evidence from pitch contours shows that participants did not follow this production code. The pitch pattern indicates some prosodic deviations. Acoustic analysis not only makes it possible to play the speech sample but also displays the visual feedback where the pitch contour is shown.

Discussion

The study set out to analyze the acoustic clues that can be used to assess speech disorders such as dysarthria. VOT (for plosive production) and fundamental frequency (for deviant prosody) were measured.

Voice Onset Time

VOT has previously been used to differentiate plosives across different languages (Cho & Ladefoged,

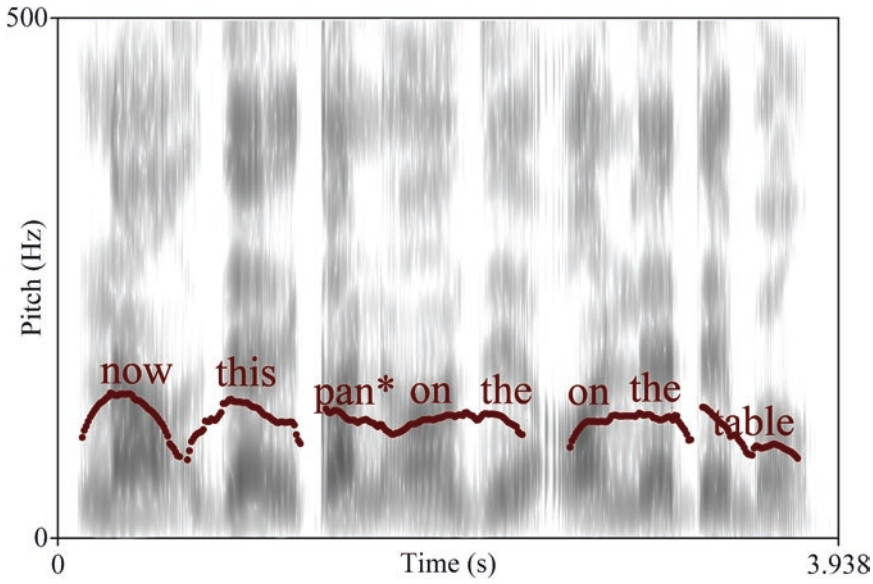

Fig. 20.7 F_0 and spectrogram for digit sequence 0721-222-989 at a fast speaking rate (spoken by a participant)

1999). Although many of the studies where VOT has been used are on healthy subjects, this study advocated the use of this acoustic measure in clinical practice in the assessment of speech disorders. Phonetic measurements have also been used in the assessment of patients' speech production (Niesler et al., 2005; Ouattassi et al., 2015). From the results of the study, it is evident that participants' VOT is characterized by very weak or incomplete closure (undershoot of closure gesture) or multiple closures (incomplete gestural undershoot). In these scenarios, it would be concluded that the participant did not attain the target for a full constriction.

In the segmental approach, phonological processes such as substitution, omission, and distortion of sounds would be used to explain this occurrence. However, through acoustic analysis, the change in sound would rather be interpreted as a result of weakened speech muscles, particularly a weak phonation phase.

Therefore, instead of concluding that a plosive is substituted with an approximant, the SLT would work on muscle stimulation as well as breath control. This could include improving respiratory support, improving respiratory/phonatory control and coordination, as well as improving phonatory function (Spencer & Yorkston, 2002). This can also inform the referral process where such a client would require a multidisciplinary team for total rehabilitation. That is, the composition of a multidisciplinary team would be needed in reference to the areas where a client needs rehabilitation. An occupational therapist may be involved in a case where muscle stimulation is needed.

Fundamental Frequency

Pitch contours in the telephone number test provide sufficient evidence of deviant prosody. This is because participants have poor breath control, which has the effect of lowering their fundamental frequency. Using this kind of acoustic analysis, it is possible to display the F_0 movement, which paints a clear picture of lack of variation in pitch accent. This would necessitate a therapy program that includes breath control exercises to improve the monotonous pitch. When an SLT is relying solely on a perceptual-based assessment, she/he may hear a monotonous pitch but may not have access to the visual contours of prosody provided by acoustic analysis.

As illustrated in this chapter, computer-based software may assist SLTs in the objective analysis of clients' pathological speech using acoustic

measures of their VOT and F_0. Therefore, it is suggested that SLTs move from the traditional approach to a dynamic approach to assessment, which includes acoustic analysis. Information gained from acoustic analysis can help guide the clinician toward a treatment plan that addresses the underlying speech problems, such as focusing on respiration and phonation rather than on a mislabeled articulation error.

Impact on Speech–Language Therapy Practitioners and Researchers in Sub-Saharan Africa

Although perceptual-based assessment is most commonly employed by SLTs, this method relies heavily on SLTs' auditory perception in the screening process. As discussed previously, SLT services in SSA are often conducted by expatriate SLTs from abroad. Therefore, due to linguistic complexity in the region, SLTs sometimes offer their services to clients who do not speak their language (Barrett, 2016; Jochmann, 2006; Wylie et al., 2016). Although they usually depend on translators, acoustic analysis would be helpful in the screening and diagnostic process as acoustic cues are the same in all languages. This makes it easier to interpret pathological speech patterns, even in a language you do not speak.

In addition, information gained from acoustic analysis may provide meaningful insights into the underlying causes of speech errors, which can help SLTs plan an intervention which will have the required effect. In a context where the ratio of SLTs to clients is so disproportionate, it is imperative that the assessment effectively diagnoses the problem so as to make the most of the resources available.

The discussed acoustic approach provides a non-biased analysis of speech. The therapist just needs to record a speech sample with the specific sounds that need to be analyzed acoustically. This approach is also vital for researchers of communication disorders and those in other related fields such as speech science and linguistics. Most of these studies would ordinarily need a well-equipped acoustic laboratory, which is very expensive to set up. However, the use of computer-based software, such as PRAAT, could solve this problem. PRAAT is a freeware that can be used with any Windows or Mac computer. Furthermore, it can be used in almost all environments as long as the recording parameters are favorable.

Considerations for Future Work, Research, and Politics

Future work should help to address the major limitation of this research, which is the specific focus on dysarthria. Although it can be argued that the techniques described in this chapter can be generalized to other speech disorders, especially those which are articulatory in nature, more research should be conducted on different speech disorders and in different populations.

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21

The Capacity to Assess and Treat Communication Disability in Kenya: Field-Based Evidence

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Introduction

Communication Disabilities as Secondary Disabilities

The following discussion focuses on the evidence-based status of the assessment and treatment of communication disorders in Kenya. We begin by noting that current official statistics on the number of persons affected by communication disorders in Kenya are hard to obtain. Carter et al. (2012) also note that there are few comprehensive descriptions of speech–language disorders in Kenya. A possible explanation for this could be the fact that, in Kenya, such disorders are taken to be secondary disabilities. This means that they are considered symptomatic of other primary disabilities such as hearing impairment, autism, cerebral palsy, or Down syndrome or a combination of these disabilities. Therefore, a discussion of communication disorders in Kenya must necessarily keep "straying" into other disabilities that have a speech or language component.

Indeed, as this chapter will show, the assessment of communication disorders in Kenya is always conducted in the context of determining an underlying disability which, in turn, affects a person's ability to fit into the regular educational system. To further underscore this fact is the observation that, whereas there is a healthy volume of postgraduate theses and dissertations focusing on learning disabilities in the Kenyan educational context, there is a hiatus when it comes to research that narrows down on speech and communication disabilities in Kenya. For example, a survey of the repository of one public university in Kenya shows 126 theses in the different areas of special needs education (SNE), but only a few of these have the words *language* or *communication* in the title.

High Incidence of Communication Disabilities Versus Only Nascent Growth of Speech–Language Therapy Services in Kenya

One of the objectives of the 2009 Kenya Population and Housing Census was to determine the number, types, and distribution of persons with disabilities in Kenya. To this end, the census adopted the International Classification of Functioning, Disability and Health categories (World Health Organization [WHO], 2001) to determine disability types, one of which was speech impairment. The census report arguably contains the most comprehensive figures on language and communication disabilities in Kenya, albeit indirectly (Kenya XE "Kenya" Bureau of Statistics, 2012).

The Kenya 2009 Population and Housing Census Analytical Report on Disability (2012) reported that 3.5% of Kenyans have some form of disability. In terms of the prevalence of the various types of disabilities reported, speech impairment was fourth with a prevalence rate of 12.2%. The third was hearing impairment at 14.1%, while visual disability was the second at 24.9%, and the leading with a prevalence rate of 25.3% was physical disability. It is notable that both speech and hearing impairments fall within the definition of communication disorders adopted in this chapter. Moreover, the report indicates that mental disabilities had a prevalence of 10.2%, while "other types of disabilities" (operationalized to include albinism, epilepsy, cerebral palsy, autism, learning difficulties, and multiple disabilities) had a prevalence rate of 7.5%. It is important to note that the definition of mental disabilities, cerebral palsy, autism, learning difficulties, and multiple disabilities could all include a communication disorder. Even without exact figures, one can safely deduce that communication disorders constitute a huge percentage of the total persons with disabilities in Kenya. The UK Department for International Development (as cited in Gill 2009) estimated that in 2003, around half a million children in Kenya had communication disabilities and, sadly, noted that speech–language therapy (SLT) services were at the nascent stage.

Page and Quattlebaum (2012) assert that "communicating confidently is a cornerstone of a positive self-image" (p. 24). Added to this is the fact that communication disorders have a negative impact on learning. The ability to communicate has been linked to a sense of well-being (Enderby, 1997) and a cornerstone of social, cognitive, and emotional growth. Helander (1993) goes further to assert that the ability to communicate is a basic human need. Given such sentiments, there is a

need to document and evaluate the assessment and treatment measures in place to help persons with such disorders to overcome or mitigate the social and educational challenges these disorders cause in their lives.

Theoretical Background

Conceptualizing (Communication) Disabilities with Particular Focus on Kenya

Communication disability as a long-term state of a person is an encompassing term that includes difficulties in all aspects of language use as well as communication. Thus, such difficulties manifest in, inter alia, difficulties in articulating sounds, stammering, forming words, constructing sentences, understanding words and sentences, as well as using language in a social context. The American Speech–Language-Hearing Association (ASHA) further notes that communication disability exists in a continuum, varying from mild (difficulty with certain aspects of speech or communication) to profound (total inability to produce and/or understand language) (ASHA, 1993).

As Page and Quattlebaum (2012) point out, a typical human being has a repertoire of communication options. These include speech which is augmented by a range of nonverbal signs such as eye contact, gaze, posture, body movement, and gestures, as well as the prosodic features of pitch, intonation, rhythm, pace, and appropriate stress patterns. One can also communicate via writing or signing. Competence in communication is seen in the ability to use a wide range of communication resources as well as to understand and respond to the same from others.

A deficiency in any of these areas that hinders intelligibility or the ability to understand and respond to communication and that cannot be tied to differences between languages and dialects or the developmental process of first or second language acquisition would constitute a communication disability. We hasten to add that not all modes of communication are available to everyone. As Hartley and Wirz (2002) note, writing as a mode of communication is not available to illiterate people in the same way signing is not available to the majority of people. It would be wrong to conclude that those who cannot write or sign have a communication disability. We can only talk of a language and communication disability in a context where one is unable to receive or send information using the primary modes of communication available to him/her.

From the offset, it is important to unpack some of the terms to be used in this chapter. The wider field of SLT, within which communication disabilities fall, has been described as a minefield of terms and careful navigation is called for if one is to remain intelligible.

ASHA (1993) identifies two types of communication disorders, namely, speech disorders and language disorders. Speech disorders affect one's ability to articulate sounds, control voice, or speak fluently. They, therefore, manifest as articulation disorders, voice disorders, and fluency disorders. Language disorders affect language use at the levels of form, content, and function. Form deals with phonological, syntactic, and morphological structures, while content refers to meaning. Disorders affecting language function touch on the pragmatic aspects of language.

In addition, communication disorders can be receptive or expressive. The former is related to receiving language through hearing or reading, while the latter relates to language production. We will use the term "communication disabilities" for situations where "communication disorders" have a long-term and sustainable effect on action and participation of the person.

Hartley (1998) defines persons with communication disabilities as "a population whose ability to communicate is affected by their response to an impairment and/or social and contextual factors which interrelate with each other and the person themselves resulting in limited communication skills and ability" (p. 227). Critical in this definition is the fact that communication disabilities are not just clinically determined. Their determination and grading should also take into consideration the social and contextual factors. It has been argued, for instance, that the definition of dysgraphia and dyslexia as communication disorders

is dependent on a person being in a literate society. The impact of social and contextual factors on the definition of communication disabilities is seen if we attempt to define the disability of a person who is deaf. A person who is deaf but can use sign language to fulfill his/her communicative needs in a given setting may not be said to have a communication disability. However, if the same person needs to communicate in the dark, he/she becomes profoundly disabled given that communicating using sign language has a mandatory visual component. In addition, if a person who is deaf visits a place where no one understands sign language, the same upscaling of disability occurs as the person may be without any other means of communicating (Barnes, 1996; Hartley & Wirz, 2002; Morris, 1995). It is therefore a fact that disabilities and the help extended to persons with disabilities are shaped by prevailing sociocultural factors.

This is particularly applicable for the Kenyan context where, in many communities, disabilities attract a lot of stigma. Whereas gains have been made in highlighting the need to realize that disability does not equal inability, there are still many stereotypical explanations for disability, some with deep cultural roots. Munyere (2004) reports that a disabled child is seen as one hated by God and grows up ostracized by both family and peers. Mwihaki (2002) reports that many parents resort to hiding children with speech disorders as they consider them "a curse or an unbearable reflection on their social image" (p. 243). Jochmann (2006) also details the cultural- and religious-based explanations for disability which lead to stigmatization. For many, communication disorders are a sign of a curse from God, evidence of the workings of the devil, or a sign that the parents are being punished for a sin committed. The overall effect of such views is that they exert a lot of undue pressure on the parents as well as the person with the disability. They can lead to rejection and hiding away instead of seeking professional help. All these are factors that could impact on assessment.

Assessment and Treatment of Communication Disabilities

In the context of disability, assessment is the use of direct and indirect procedures to determine the characteristics of an individual with a view to documenting them to arrive at a diagnosis of a disorder and facilitate intervention and treatment (Simeonsson & Bailley, 1992). To minimize erroneous diagnosis and placement, Scholl (1986) recommends regular and complete assessments conducted by qualified personnel using appropriate equipment. Ideally, the assessment should be conducted by a group of experts. Assessment, in the case of Educational Assessment and Resource Centers (EARCs), normally leads to referral to a hospital for a medical diagnosis after which the EARCs determine whether to place the child in a special unit in a regular school or a special school.

According to Barkoukis et al. (2008), the treatment of communication disorders in children aims at assisting them to do the following:

- Develop and improve the ability to communicate
- Acquire coping strategies and alternative or different ways of communicating
- Use their communication skills and coping strategies in their daily lives in settings such as the school and the home

The authors note that some of the interventions used in the treatment of communication disorders in children include one or a combination of the following:

- SLT: To help children develop or improve their language in terms of vocabulary and grammar as well as organize their thoughts logically.
- Behavior therapy: To encourage desirable communication behaviors and interpersonal skills while discouraging the reverse.
- Stimulant medications may be used to treat impulsivity or hyperactivity symptoms. This is mainly used in those children who exhibit atten-

tion-deficit and hyperactivity disorder, often seen in autism spectrum disorder.
- Environmental modification: This may involve providing extra time during school activities for children affected by communication disorders.

The SLT program for children is based on the subtype of communication disorder detected and their intellectual ability, behavior and personality.

Educational Assessment and Resource Centers in Kenya

According to Hartley and Wirz (2002), the interventions provided for persons with communication disabilities are through education, health services, or community development programs. This chapter will focus on education services with some mention of health services. This is because it is at the level of facilitating access to education that assessment and treatment of speech and communication disorders can be said to be active. Mwihaki (2002–2003) notes that "the management of speech disorders in Kenya would best be investigated in relation to the running of the special education sector" (p. 242), which further underscores the emphasis on the education angle as an intervention measure for persons with disabilities in Kenya. The next subsection details the formal structure established under the Ministry of Education to facilitate the assessment and placement of children with disabilities in Kenya.

From 1984, the Government of Kenya, with assistance from the Danish International Development Agency (DANIDA), began establishing EARCs as a means of ensuring equitable access to education for children with disabilities (Kihoro, 2010). The overall mandate of EARCs was to help identify children with disabilities, assess their disorder, place them in schools, and offer follow-up services. The plan was to have at least one functional assessment center manned by a coordinator in each of the administrative districts in Kenya. All the coordinators were trained at the Kenya Institute of Special Education (KISE), again with Danish support. The EARC coordinators' job description includes community outreach to sensitize the community on the causes of disability, intervention measures, and services available for children with special needs. The coordinators also conduct the assessment of children with special needs and the referral and placement of children with special needs. EARCs are also mandated with organizing courses for parents of children with impairments and teachers working with children with impairments, providing guidance and counseling of parents of children with special needs, and organizing home visits and care for severely disabled children. Other functions include training teachers of newly established special schools and units, offering itinerant and peripatetic services, producing learning materials, and advising on their use. By whichever measure, these are ambitious goals. As already mentioned, DANIDA funded the training of the EARC coordinators as well as the equipping of EARCs and the national training center, KISE, with equipment for assessment of various types of disorders. However, in 1998, DANIDA pulled out. The running and funding of the EARCs, as well as the national training center, fell squarely on the Government of Kenya. The performance of the EARCs since then has been wanting.

Perhaps the most damning assessment of EARCs was by the Task Force on Special Needs Education, whose Task Force Report (Ministry of Education, Science and Technology [MoEST], 2003) reported that 90% of EARCs were making erroneous placement decisions due to lack of appropriate assessment equipment and properly trained personnel. The Kenya National Commission on Human Rights, in its Occasional Report (2007), noted that EARCs are "under-resourced, and they have insufficient funding, lack adequate trained personnel or even transport for follow up or to enable them undertake interventions…" (pp. 31–32). In 2009, Kenya launched the National Special Needs Education Policy Framework which spells out strategies for improving assessment and intervention, part of which is the strengthening of EARCs through funding. Seven years down the line, there

is a need to determine whether the envisioned strategies have borne fruit specifically in the assessment and treatment of communication disorders.

Research Questions

Taking the background information into account, the present study sought to answer the following questions:

- What are the levels of training of the professionals handling children with communication disabilities in Kenya?
- Which are the tools and equipment used in the assessment and treatment of communication disabilities?
- To what extent is there synergy among the different players in the field of special needs?
- What are the challenges facing the assessment and treatment of communication disorders?
- What opportunities exist in the assessment and treatment of communication disorders in Kenya?

Methods

Research Design

The present study adopted a qualitative research design to investigate and explain how communication disorders in children are assessed and treated in Kenya. This was achieved by analyzing data from interviews and questionnaires and then describing how EARCs and teachers in SNE assess the said disorders. It also examined how speech–language therapists (SLTs), as well as SNE teachers, treat communication disorders. In addition, a document analysis of the assessment tools and the syllabi used by those in the field of special needs was completed.

Study Population

The study was carried out in two counties: Nairobi and Kiambu. The rationale for this is that the two have a higher concentration of active EARCs, special schools/schools with special units, and SLTs than other parts of the country. The research targeted EARC officers, primary school teachers in special schools, and special units in regular schools, as well as SLTs.

Inclusion Criteria

With the help of the County EARC coordinators in the two counties, the researchers selected only the EARCs that were manned and active. Another major consideration was the presence of schools that handled children with communication disorders in the sub-counties chosen. Also included were primary school teachers in special schools and special units in regular schools. The teachers targeted were those with training in SEN (special educational needs) and with eight or more years of teaching experience. The last category of respondents was that of Kenyan SLTs in Nairobi County with over eight years' worth of experience. From these three groups, only those willing to participate were included.

Exclusion Criteria

The following were excluded: EARCs that had no personnel or were said to be inactive; EARCs located in sub-counties without schools handling communication disorders; SLTs that were not Kenyan; and those dealing exclusively with adults and those with less than eight years of experience. Also excluded among the three categories of respondents were those outside the study areas as well as those unwilling to participate even after they were assured of the confidentiality with which the data would be handled.

Methods of Data Collection

Interview Schedule

Interviews were conducted with EARC officers, SNE teachers, and SLTs. The interview schedule for EARC officers contained items that sought to establish the levels of professional qualification and experience of the officers in charge of assessment at the centers. In addition, there were questions on additional in-service training as well as

the gender of the officers. The majority of the interview questions focused on establishing how the officers classify disabilities, the tools and equipment used for assessing and treating communication disorders, and the process of assessing such disorders. The interviews also helped establish the kind of links that exist between EARCs and schools and other professionals such as SLTs. Also addressed was the issue of outreach and awareness creation. To this end, there were questions about the ways in which the officers create awareness about the assessment centers. The officers were also asked about the challenges in their daily work and opportunities they saw for the future.

The interview schedule for teachers included items on the biometrics of gender and age, as well as questions on training and experience. The teachers were asked about their areas of specialization and the categories of disabilities they dealt with. There were also questions focused on communication disabilities. Specifically, teachers were asked to state the communication disorders they encountered and the intervention they made for each case. Furthermore, there were questions about their collaboration with EARCs and other professionals. Other questions touched on how they would assess communication disorders in their learners and how they would measure improvement after intervention.

Questionnaire

The questionnaire for SLTs helped determine the levels of awareness about SLT in Kenya, as well as the cost and access to the service. The questions for the therapists also focused on the prevalence of communication disorders and the interventions that exist for these forms. There were also questions on the collaborations between these professionals and other professionals, such as teachers and EARC officers.

Observation Schedule

Observations of lessons were conducted during visits to the sampled special schools. The observation schedule focused on determining how the streaming or the lack thereof of learners as per their disabilities impacted on the teachers' ability to give individualized attention to learners. In addition, the schedule allowed for the observation of the intervention measures teachers adopted for learners with communication disabilities.

Document Review

The assessment manual that guides assessment at the EARC center was studied with a view to establish whether any focus was given to communication disorders. The manual was obtained from one of the sampled EARCs. This analysis also helped establish the descriptions given of communication disabilities and their assessment procedures.

Data Analysis

The data analysis was conducted at two levels. The items for the demographic data of the respondents were coded to reflect the gender, age, professional qualification levels, and experience of the respondents. These responses availed data to address the first research question of the study which dealt with the levels of training of professionals handling children with communication disabilities.

The other items in the questionnaires and the interview schedule were analyzed thematically. The themes were derived from the remaining research questions. The research method adopted a qualitative, mainly inductive approach, which aimed to generalize categories and their systematic linkage from collected data segments, guided by the following four sections of interest: tools and equipment, collaboration, challenges, and opportunities. Data from the classroom observation added to the themes of tools and equipment and the theme of challenges. The document analysis was mainly oriented to the theme of tools and equipment.

The four broad thematic areas that informed the analysis are presented in the subsections below as follows:

- Training of different cadres of professionals handling children with special needs

- Facilities, equipment, tools, and resources for assessment/intervention
- Cost and funding
- Access
- Networks

Where applicable, results relating to both assessment and treatment are presented and discussed below.

Ethical Clearance

The researchers started by requesting the Deputy Vice-chancellor (Research, Innovation and Outreach) of Kenyatta University to issue a letter of introduction to the County Director of Education, Kiambu County, and another to the counterpart in Nairobi County. With these letters, the researchers were able to obtain clearance from the county education offices to visit schools and EARC centers. Through phone calls, the EARC officers in charge of the two counties introduced the research team to the EARC officers manning the sampled data collection sites. When it came to the schools, the team would present the letter from the county office to the head teacher who would then grant permission to proceed.

From the onset, all the study participants (teachers, EARC officers, as well as SLTs) were fully briefed about the study and their consent individually obtained. They were assured of the utmost confidentiality regarding their identity and that of their institutions. The wishes of those who requested not to be tape-recorded were respected, and note-taking was used instead. Finally, the researchers committed to availing the study findings to the institutions where data was collected and the county education offices.

Results

Sample Size Determination

Following the inclusion criteria outlined above, four sub-counties in Kiambu County were purposively sampled. These were Thika West, Thika East, Githunguri, and Kiambu (the last sub-county shares a name with the county). Two of these sub-counties had two officers, and both were interviewed because of their varied expertise. The same purposive technique was used to pick two of the three active sub-counties in Nairobi County (a hospital-based one was omitted). This left Makadara Sub-county and Kasarani Sub-county. The selection of the latter sub-county was particularly crucial because it is the home of KISE, which is the national and therefore referral EARC. Given this fact, three EARC officers handling different disability areas associated with communication disorders were interviewed. Thus, a total of ten EARC officers were interviewed.

As for teachers, one teacher per school was interviewed following the recommendations of the head teacher and the EARC officer in the sub-county. This came to a total of six teachers. Two SLTs, a male and female, were chosen on the basis of working closely with schools as well as meeting the other inclusion criteria mentioned earlier. Table 21.1 summarizes the study sample characteristics.

Training

The qualifications of the sampled respondents, the quality of those qualifications, and years of field-related work experience are considered here. The information is presented in Tables 21.2 and 21.3.

EARC Officers

Starting with EARC officers, Table 21.2 reveals that all ten had a diploma from KISE. In addition to the diploma, four of them had a bachelor's degree in SNE from either a public or private university in Kenya, while the other six held a master's degree from a public university in one area of impairment or another. Of these six, two of them were pursuing a Ph.D. at a public university. None of the ten were trained specifically in speech and language disorders although they covered one unit in the area at the diploma level.

Concerning the quality of training, the officers unanimously observed that the curriculum at the diploma level, adapted from that of the University of Manchester, was more comprehen-

Table 21.1 Study sample characteristics

Counties	Nairobi County		Kiambu County				Total
Sub-counties	Makadara	Kasarani	Thika East	Thika West	Githunguri	Kiambu	
EARC coordinators	1	3	1	2	1	2	10
Teachers	1	1	1	1	1	1	6
SLTs	2						2

Table 21.2 Participants' highest qualifications in Special Needs Education/Speech–Language Therapy

Cadre	Diploma	Bachelor's degree	Postgraduate degree	Total
EARC officers		4	6	10
Special needs Education teachers	2	2	2	6
SLTs		1	1	2

Table 21.3 Length of service in Special Needs Education/Speech–Language Therapy

Cadre	8–10 years	11–15 years	16–20 years	21+ years	Total
EARC officers	2	3	4	1	10
Special needs Education teachers	1	3	2	–	6
SLTs	2				2

sive and practice-oriented than any other they have been exposed to. The respondents reported relying heavily on the training acquired at the diploma level at KISE to assess clients and perform related duties. They all reported that they have not benefited from any in-service training in SLT but have attended infrequent workshops and seminars on different areas of disability. It is clear from Table 21.3 that their experience in the field of special needs ranges from 8 to 26 years, with half of them having served for over 15 years.

Teachers (SNE)

Like their EARC counterparts, all the sampled teachers held a minimum of a KISE diploma. Four of them had university qualifications, with two currently pursuing doctoral studies. Their attendance at relevant workshops and seminars in SNE was not regular. They singled out the KISE diploma as being most useful in their assessment of children for class placement and the application of various intervention strategies to alleviate communication disorders. Most had served in special education for over 12 years (see Table 21.3).

SLTs

The two SLTs trained at university level in Western countries had practiced in Kenya for over eight years in a private capacity. One had a clinic in a learning center for children with special needs. The other was a researcher who also offered consultancy services in public and private hospitals and also to clients in their homes. They mainly worked with children. Both professionals actively participated in many professional development activities. They pointed out that the only institutions in Kenya currently offering SLT training are Kenyatta University and Moi University, both of which provide a master's program offered jointly with European universities.

Facilities, Equipment, Tools, and Resources for Assessment/Intervention

Facilities

In two centers, the EARC officers reported sharing one large room with other sub-county education

officers. This means that officer–client confidentiality in such a setting was unlikely to be achieved. One such affected officer, who reported sometimes sharing the local chief's premises, was often forced to work under a tree or out in the open to protect the said confidentiality. The other centers had their own offices but shared compounds with schools or civil servants. The downside of this, it was reported, was that children brought for assessment sometimes "invaded" the adjacent rooms and "wreaked havoc." KISE was the only center reported as having a compound of its own, but the assessment area was usually crowded on assessment days. Again, the center boasted the only acoustically conducive audiology room.

Technical Equipment

The assessment center at KISE also had equipment not found in any of the other centers. For example, none of the others have basic equipment such as computers, printers, scanners, or photocopiers that would make assessment and outreach work easier. In terms of SLT-related equipment, none of the six centers had any special equipment to assess swallowing disorders, yet these are closely linked to communication disorders. Three of the EARC officers also reported that they did not have an audiometer, a machine used in the assessment of hearing impairment. They reported using ringing phones and other jingling objects for this purpose. In one center, the only audiometer, donated by DANIDA, was not in use because it needed to be calibrated and there was no technician to do so. In another center, a digital audiometer was donated by the Volunteer Services Overseas but not put to full use because the officer did not have a technician to operate it and he himself was overwhelmed by other duties. The National Education Assessment Center had an older generation calibrated audiometer as well as a digital one received from external donors, which was nonetheless insufficient given that KISE is a referral and teaching center.

Assessment and Intervention Methods

It was established that assessment at EARCs was completed through interviews and observations guided by a questionnaire. In schools, the teachers used a questionnaire as the main tool for class placement. The EARCs used an assessment questionnaire and an accompanying Functional Assess-ment Tool Manual for Learners with Special Needsin Education (Kenya Institute of Curriculum Development, 2016). Both the questionnaire and the manual are comprehensive documents that focus on identifying various forms of disability. The two have extensive sections dealing with communication skills. These are assessed in terms of expressive language skills, receptive language skills, and other observable cues. The expressive and receptive language skills are correlated to the chronological age of the child. A sample question assessing expressive language skills for children above 5 years is "Does the child modulate tone of voice, volume, and rhythm appropriately?" A sample question for receptive language skills for a child of the same age is "Does the child understand figurative language?" Of interest is that the tool, developed by the Kenya Institute of Education (now Kenya Institute of Curriculum Development), has remained in draft form since 2011. According to the EARC officers, the tool is not user friendly.

Moreover, the officers observed that assessment tools from the Ministry of Education were designed with the structure of the English language in mind, which the researchers were able to confirm. For instance, one of the questions in the checklist for receptive language skills is "Can the child understand prepositions?"

The SLTs agreed that the tools used to assess and treat communication disorders had been designed for the US and European countries. No specialized equipment was in use except one for assessing swallowing disorders. Specialized equipment was reported to be not easily available in Kenya.

Teachers added that in terms of intervention materials, drinking straws, balloons, and chewing gum are used to help with speech development and improvement; communication boards are also in wide usage. In some schools, radios are used for musical therapy to calm down autistic children. In others, computers were used in language activities (visual images to help children generate language structures).

Cost and Funding From the Government

Here we look at the cost of assessment and treatment as well as the funding available. Both at the assessment centers and in schools, assessment was said to be free. However, EARC officers hastened to add that clients often have to meet the cost of stationery and photocopying of assessment forms and referral letters. This is because what is supplied by the government is far from enough. Schools confirmed that each child with a special need is allocated 2000 KES (approximately 20 USD) over and above what other children get from the government. It is with this money that they buy the intervention tools and equipment already mentioned. This budget must be approved by the EARC officer concerned.

It emerged that EARCs do not have a head entitled to vote for these provisions or for outreach activities. The funding available is channeled through the county education office, making it difficult for EARCs to plan and execute their own budget. Furthermore, EARCs are expected to produce learning materials and advise teachers on their use. All the EARC officers interviewed were categorical that this is not practical, given constraints on funding and personnel. Some EARCs are a "one-officer-show," expected to do assessment, training, and offer outreach services. It must be noted that material production is a professional area by itself and cannot be completed by one person. One officer said that she at least does not allocate any budget that does not cater for speech and language development and promotion.

When it comes to therapy, KISE reported that they offer occupational therapy services at the cost of 100 KES (approximately 1 USD) per session. Kenyatta National Hospital was said to charge 300 KES (approximately 3 USD) for each session of occupational therapy, a figure too high for some of the clients who need the service. If a hearing aid is required, the prohibitive cost, which can go beyond one million shillings, is met by the client. Kenyatta National Hospital is, however, said to offer hearing aids at a subsidized cost.

Looking again at SLT, the two therapists were in agreement that their services were beyond the reach of most Kenyans. A 1-hour session of SLT was said to cost 3000 KES (approximately 30 USD) on average. Given that, according to the SLTs, such therapy can range from a few weeks to several years, the cost is far too high, and there are no government subsidies. It was pointed out that in most cases, only those with insurance cover can afford it. Unfortunately, very few insurers are willing to take the risk because of the treatment duration and the fact that it is a rehabilitative intervention. Also put across was the fact that SLT is cheaper when the client is handled by an assistant SLT (although of course, these assistants are not as qualified). The exception to the prohibitive costs of SLT was reported to be the provision by the Yellow House in Kisumu, a nonprofit organization serving the western Kenyan region. This community-based program was reported to offer free or affordable SLT services.

Access

Creating Awareness

One way of looking at access is in terms of the sensitization activities carried out to inform the public about the assessment and treatment services available. Indeed, this is one of the mandates of the EARCs. All the officers sampled reported using more or less the same forums to create awareness. These included local churches, annual general meetings, and board of management meetings in schools, chief's *barazas* (public forums organized by government officials in villages), and, in a few cases, processions through towns. One officer said she has taken advantage of seminars and workshops of whatever nature organized in her subcounty to "gatecrash" and spread the message. Another mandate is to organize home visits for children with severe special needs. However, none of the centers had a vehicle earmarked for these activities. The officers reported having to depend on pool transport at the county education offices.

Needless to say, this is not sufficient, and respondents said they could do a lot more if adequately funded. Most reported using public transport or their own vehicles without a mileage

allowance. These officers said they try to do their best in these circumstances because they see theirs as a higher calling beyond designated duty. One center in Kiambu County took pride in the fact that their services attract people from as far as Rwanda and Tanzania.

Concerning treatment, respondents reported referring clients to hospitals for the treatment of the underlying causes of communication disabilities, such as hearing impairment and epilepsy. They admitted honestly that, in most cases, they did not refer clients to SLTs because they knew the clients could not afford such services.

As for schools, respondents reported making use of events that bring parents together such as board of governors (BOG) meetings and prize-giving days to create awareness. They requested that parents sensitize people in their churches, neighborhoods, and places of work.

The SLTs lamented that there is very little awareness about their services since only those who can afford them bother to find the relevant information. To underscore this point, one of the SLTs said that she was forced by circumstances to get into SLT after her father lost speech through a stroke a couple of years back and the family did not know where to get help. The SLTs strongly believed there is a need to sensitize the government and the general public about the causes and management of communication disorders. To redress the situation, they reported working with EARC officers, schools, and hospitals. However, they noted that not much can be achieved given that there are very few SLT specialists in Kenya. This brings us to another way of looking at access – the easy reach of assessment and treatment services.

Easy Reach of Services

Ideally, each sub-county should have an EARC. The fact, however, is that this is far from the reality since the establishment is based on districts (there are more sub-counties than there are districts). In Kiambu, for example, four sub-counties do not have EARC officers. This is despite the fact that some in the same county have more than one officer. In Nairobi, many sub-counties do not have functional centers. The officers interviewed felt that given the high population in these counties, their services are not accessed as easily as they should. This suggests that there is a problem in the deployment of officers.

Equally, our data revealed that there are not enough special schools or special units in regular schools, particularly those handling mental challenges, to serve the existing needs. Not surprisingly then, it became evident from the interviews with teachers and classroom observations that most classes had more than 12 children. This was reported to be far from ideal given that children with different disabilities are put together in one class and the teachers do not have assistants. In one of the classrooms visited, one child had an epileptic seizure that took all the teacher's attention for quite some time. In the meantime, an autistic child had started tearing up textbooks.

When we take SLT into consideration, the situation is dire. It was learned that currently, there are only 15 qualified SLTs in Kenya: 8 Kenyans in Nairobi, 1 Kenyan in Mombasa, 2 Ugandans in Kisumu, and 4 foreigners in Nairobi. The number of foreigners keeps fluctuating. With the statistics on communication disabilities mentioned earlier, the point does not need belaboring.

Networks

We now consider networks in terms of professional associations and collaborations. All the EARC officers reported working closely with hospitals for medical assessment as well as special schools/special units in regular schools or inclusion classes for placement purposes. Sometimes, the collaboration was reported to go beyond placement in schools. In one instance, the officer said she used the equipment in a school for the hearing impaired to assess some of her clients. All the teachers interviewed confirmed that their schools engage with EARCs and hospitals. On their part, SLTs mentioned that they have close connections with EARC officers, schools, and hospitals, all of whom referred clients to them.

Several EARC officers reported having close collaborations with missionaries/churches, non-governmental organizations (NGOs), international agencies, and various associations for persons with

disability. Among the examples mentioned were the Sense International, Volunteer Services Overseas, Save the Children Kenya, Autism Awareness (Kenya), Orient Sacco, Association of the Physically Disabled in Kenya, and Eardrop. The benefits accruing from these networks include the donation of equipment such as hearing aids and audiometers, the funding of facilities such as classrooms and boarding facilities, and the sponsorship of seminars/workshops in the area of disability. Two teachers revealed that they have also benefited from some NGOs, banks, and churches in terms of equipment and physical infrastructure. In one school, a bank had put up a *posho* mill which generates income that is then used to support learning activities. Crucially, some of the international organizations also send volunteer experts on various disabilities, especially to KISE. However, KISE pointed out that some of the so-called experts posted had lesser qualifications than KISE staff and therefore their contracts were terminated. Others masqueraded as experts in autism while actually they were not. They too faced a similar fate. In one of the centers in Kiambu, we met an occupational therapist whose services were highly appreciated by the EARC officers. He was seconded there for one day a week by an NGO, and his services were in great demand. The same officers reported a close working relationship with the Autism Society of Kenya, which had trained them on dietary management for autistic children.

Discussion

The current study indicates that costs and financing options facing the assessment and treatment of communication disabilities in Kenya seem to be an important part of the discussion, interacting with all other areas of interest. In summary, the results revealed challenges as follows.

Facilities and Equipment

From the foregoing, it appears that one of the major challenges is inadequate facilities and equipment. Most of the equipment in the EARCs is outdated or inadequate. The EARCs are understaffed and underfunded in many cases. This makes it difficult for them, for example, to carry out field visits for the purposes of sensitization and assessment. Understaffing also affects special schools. As mentioned earlier, some teachers have more children than they can possibly handle. In this scenario, it is often difficult for such teachers to offer individualized interventions that would help in the development and improvement of communication. A lot more, therefore, needs to be done to invest in human capital, physical infrastructure, and modern equipment.

Accessibility of Speech–Language Therapy Services in Different Areas and at Different Ages

Concerning access, the study established that assessment and treatment SLT services are beyond the reach of the majority of those who need them. Even the very schools that are labeled "special" because they are expected to avail special interventions for learners do not offer SLT. This confirms the truth of Jochmann's (2006) observation that the treatment of speech and language disorders in East Africa consists of little treatment islands in major urban areas.

Another problem is that assessment is focused on placement in educational institutions. This means that for the population that is over the school-going age, there are no provisions for assessment and intervention. Moreover, whereas special schools and special units try to equip learners with prevocational skills, life skills, and social skills, there are no formalized plans for the total inclusion of learners into the wider society. Thus, a person with a communication disorder is likely to face stigma and discrimination in social and workplaces. Access to education by persons with communication disabilities on its own is not enough to create acceptance by the wider society. Indeed, a teacher in one of the special schools commented that she frequently has to remind people that she is a teacher and her institution is a school. This is in reaction to a common misconception in the Kenyan society that special schools are homes and those working there are caregiv-

ers. The mandate of the schools is to help learners achieve functionality, and it is up to the society to give those with communication disorders a chance to be functional.

Culture and attitude still remain huge obstacles for persons with various disabilities in Kenya (Gill, 2009). A catchphrase on the official webpage of the Hermitage Garden, a learning and therapy center in Nairobi for persons with communication disorders, is "Autism isn't the tragedy: ignorance is the tragedy." This tragedy of ignorance is true of all other disabilities, not just autism. Teachers in two of the sampled special schools told of cases of labeling of children with communication disorders as "retards" or "crazy." To many, a communication disorder is a sign that a person is mad or retarded.

According to the results of this study, creating awareness for communication disabilities has also been seen as an important part of the work of professionals and their networks. However, the lack of financing options inhibits further efforts.

Professional Speech–Language Therapists and Materials

The challenge in accessing professional intervention can be explained by the high cost of SLT sessions. This, in turn, is due to the small number of professional SLTs working in Kenya. As we have seen, there are only a few in Kenya. As for the other professionals who assess and treat persons with communication disabilities (SNE teachers, EARC officers, and assistant SLTs), the KISE diploma does not prepare them adequately to offer specialized therapy and the highly recommended additional training programs. That notwithstanding, the officers unanimously observed that, as far as the quality of training is concerned, the curriculum at the diploma level, adapted from that of the University of Manchester, was more comprehensive and practice-oriented than any other they have been exposed to. This is because all the areas of disability are covered in the first year of training before specializing in one area of disability in the second year. Both phases have adequate practical components that include attachments in special schools. It was noted that once on the job, SNE teachers and EARC officers have very limited access to further educational courses. For example, although the National Educational Assessment Center at KISE is mandated to organize in-service training for SNE teachers and EARC officers, such training is sporadic, and invitation to attend is extended to only a few who are expected to meet the cost. This further complicates matters.

Looking at the few SLTs operating in Kenya, they also lack proper and adequate resources. Even though collaboration with occupational therapists in hospitals, who work closely with EARC officers and SLTs, might help to bridge the gap in terms of an appropriate assessment (by sharing the assessment form used which covers the following general areas: brief history, general/physical examination, functional assessment, psychosocial assessment, and recommendations), specific SLT assessment tools are missing. This is corroborated by Jochmann (2006) who states that SLTs in East Africa are forced to depend on expensive SLT foreign journals, Internet resources, and books. There is, therefore, a need to develop tools and instruments that are culturally and linguistically responsive to the Kenya situation. As Carter et al. (2012) propose, it is desirable to have locally designed assessment materials. However, this is currently not the case owing to financial and time constraints as well as the unavailability of expert personnel.

To illustrate, we have seen that one of the ways of assessing receptive skills is through prepositions, yet in some African languages, prepositions are so few that they are far from the best items to test for spatial and temporal awareness. The assessor must, therefore, be resourceful enough to adapt the tool to each case assessed, given that some clients do not even understand English. This tallies with Staley's (2013) claim that SLT practices in East Africa are based on Western research that might not be locally applicable. Carter et al. (2012) concur, noting that there is a lack of appropriate speech and language assessment tools in Kenya. They note that these assessment tools have to be translated from English into local languages, often an arduous task that is fraught with bias. This is because test instructions are difficult to translate and, even more importantly, the psycho-

logical underpinnings of such tests are not culturally universal.

Fortunately, it can be noted that the issue of improving the professional training of SLTs is being addressed in the meantime: Two universities are training experts in SLT who will redress the situation. It is commendable that their programs feature local and international faculty. The expectation is that the students will receive the best from two worlds, all for the benefit of the development of the SLT profession in Kenya. Indeed, Wylie et al. (2016) confirm that this is increasingly becoming the case in sub-Saharan Africa.

Impact

The current status of the assessment and treatment of communication disorders in Kenya appears rather gloomy, but even with this state of affairs, opportunities abound. This study helped to identify current needs for improvement and to give further directions on how to address them by taking into account the interactions between key issues. The findings show that professionals in the field of communication disability are inadequately funded and, therefore, largely lack the necessary facilities and equipment. Access to assessment and treatment is also limited to a large extent. Although there is a dearth of qualified SLTs, the staff in the other cadres are fairly well trained, experienced, and have established strong networks that benefit those with communication disability.

A key issue to note is that the paucity of professional SLTs in Kenya and SLT as a scientific field of study is already being addressed. Two Kenyan universities have recently started pertinent programs at the master's level. This is bound to increase the number of SLT professionals in Kenya and in the region and proliferate graduate research in this area. There is potential for other universities to come up with similar programs and for graduates from such programs to transition to the Ph.D. level. The findings of the current study underline the relevance of the current efforts.

As noted, persons living with disabilities face rejection by family and the wider society. There is a need to explore more ways of entrenching community-based interventions for persons with communication disorders. Special schools and special units in regular schools have their role and place, but success in attaining inclusion for persons with communication disorders lies with the society appreciating that children with communication disabilities need help to become functional in communication and other areas. This paper tries to create more awareness on communication disabilities and the possibilities that SLT might offer for persons with communication disorders and their families.

Considerations for Future Work, Research, and Politics

Taking the results of the present study into account, there are various implications for future work. Research in the following areas should be addressed:

- There is a need for tracer studies to find out how persons with communication disorders fare after whichever intervention they complete in schools. It would be important to determine the levels of functionality such persons have acquired and whether this has translated into greater acceptance by society. A comparative study on the curricula of various institutions offering SNE programs would also help determine the extent to which communication disorders are being addressed.
- Research on persistent stereotypes about communication disabilities would also be important. As Gill (2009) aptly notes, it is only when we understand the role of culture and attitude in defining disabilities that we can determine the best interventions to put in place and how to proceed with such interventions.

- The last research area mentioned here reflects the need for developing appropriate assessment tools for the Kenyan context that enable the SLT to deliver high-quality services to the individuals affected. This issue has recently been corroborated by other African researchers and reflects an urgent need for SLT in Africa.
- Finally, it must be noted that these future tasks can only be tackled if finances and resources (particularly human) are available to conduct research.

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Linguistically and Culturally Diverse Children with Language Disorders in Sub-Saharan Africa: Approaches to Service Delivery

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Motive

Against the backdrop of the multilingual and multicultural reality of children growing up in sub-Saharan Africa, the rationale for this chapter is to explore ways to support children with developmental language disorders (DLDs) and language disorders (LDs) in improving their language skills. The general goal is to provide SLTs with information that will assist them in making clinical decisions relevant to the inclusion of peers in interventions with culturally and linguistically diverse learners.

Growing Up with Multiple Languages in Sub-Saharan Africa

Geographically speaking, the sub-Saharan Africa region lies south of the third largest desert in the world after Antarctica and the Arctic, namely, the Sahara Desert. This region, consisting of all African countries that are either fully or partially located south of the Sahara, displays the most linguistic diversity of any region in the world, with over 1000 languages spoken, which accounts for one-sixth of the world's total (Rob, 2007). However, it is important to note that in many sub-Saharan African countries, including Kenya, Uganda, Tanzania, Rwanda, South Africa, and Zimbabwe, to name but a few, either English or French is the official language of instruction in schools. As a result, a child growing up in this part of the world is generally exposed to a myriad of indigenous languages in addition to English (for English-speaking Africa) or French (for French-speaking Africa), both ex-colonial languages, at a relatively early stage in their education (Sonaiya, 2004).

For instance, a sub-Saharan country like Kenya with a population of over 40 million people from diverse ethnic backgrounds is a multilingual country in which approximately over 60 languages are spoken. English and Kiswahili are the most dominant as they are accorded official recognition while numerous other native languages are used for intra-communal communication. English is used in education, for official purposes, and international communication, while Swahili is the national language and is used in the political arena, parliament, and as a language of political unity and national identity (Kembo-Sure et al., 2006). Still, people are viewed differently depending on the language they use in their everyday communication. English is often seen as the language of the "elite," while Swahili and all local languages are referred to as languages of "a common man" meaning they are mostly spoken by the ordinary citizens (Kioko et al., 2008; Muthwii, 2007).

A large majority of Kenyan children speak one of the 60 native languages at home with their family members. However, after having entered the educational system at around the age of four, children will soon switch to English while in school, since English is the official language of instruction in all educational institutions from primary school to university. For most of their school life, Kenyan children use English to express their needs, play with their peers, and process complex learning material in school. Swahili, on the other hand, is the national language taught as one of the subjects from kindergarten through university and is widely used as a lingua franca for daily interactions of people from different ethnic backgrounds. As a result, the average Kenyan child speaks at least three languages, although this number can be even higher among children in multicultural rural settings.

This ability to speak multiple languages helps to create among African children a sense of strong cultural identity and belonging to a multicultural society. However, the fact that an ex-colonial language (English or French) has been made an official language and the language of instruction in most, if not all schools of sub-Saharan countries, has lately triggered a heated debate on language-in-education policies and practices across Africa. Successful participation in the academic setting depends on a child's proficiency in the language of instruction. For example, Ambatchew (2004) reported that most grade eight students in government schools in Addis Ababa, Ethiopia, displayed huge insufficiencies in their English reading skills. In South Africa, similar trends have been reported (for the case of Kenya, see Wangia et al. (2014)). The United Nations Educational, Scientific and Cultural Organization (UNESCO) argues that the best way to educate children is through their home

languages, in which they are generally assumed to have unparalleled mastery and competence much earlier in life (Ouane & Glanz, 2011). Along the same lines, Heugh (2007) linked low levels of achievement in both academic performance and literacy with slowness in enacting mother tongue-based bilingual education. Others have argued that children need to be taught as early as possible in a language that they will need for higher-level education (both nationally and internationally), particularly to access science and technology, to do business in a globalized world, and to engage actively as a citizen in wider society (Ouane & Glanz, 2011). Baker (2011) discussed that the greatest hindrance toward the implementation of bilingual education in African schools is the defense by African elites of their already established status as speakers of foreign languages and disinterested law makers. Interestingly, many parents are in support of the latter position; they do not want their children educated in any of the local languages. These conflicting positions are being experienced across sub-Saharan Africa every day, with no immediate solution in sight. For example, Owu-Ewie pointed out that the language of instruction in lower primary schools in Ghana had changed five times since independence in 1957 and the time of his report (2006).

Against this backdrop, the importance of the ability to acquire and use multiple languages for a sub-Saharan African child cannot be overemphasized. An impaired language acquisition and/or use is therefore not only a barrier to the acquisition of academic and interpersonal skills but also a huge drawback to the child's future development, especially in education and in the job market. This is further compounded by the fact that in Kenya, as in most sub-Saharan African countries, there is not only a scarcity of speech therapy services in local languages but also very limited assessment materials for the evaluation of language and communication skills in any of the native languages spoken (Schütte, 2014). The use of screening and assessment instruments developed for Western countries can easily lead to wrong diagnoses and hence no or inappropriate treatment.

Language Disorders in Multilingual Children

Both the pace and course of language development distinguish children with LD from their typically developing multilingual peers. In comparison, children with LD are usually late in producing their first words (Dale et al., 2003; Restrepo, 1998) and exhibit pronounced difficulties in various linguistic domains, including lexical semantics (Sheng et al., 2013), morpho-syntactical skills (Paradis, 2010), as well as language processing tasks, such as nonword repetition (Gutiérrez-Clellen & Simon-Cereijido, 2010; Windsor et al., 2010). In cases of DLD, those divergent patterns of expressive and/or receptive language acquisition cannot be readily explained by differences in sensory, cognitive, social, motor, or neurological development (Leonard, 2014). If the impairment is present beyond the age of 6, it often persists into adult life (Young et al., 2002; also see Johnson et al., 2010; McGregor et al., 2013). Those difficulties in acquiring and using language come at a high price and have been shown to negatively affect social interaction and acceptance (Fujiki et al., 2001), emotional health (Conti-Ramsden & Botting, 2008), as well as academic success (Catts et al., 2002).

While specific symptoms differ from child to child, they are also related to specific linguistic characteristics of the different languages at hand, the age at onset of language acquisition, changes in the developing language learner, and the environment. Especially in linguistically and culturally diverse children, different ages and exposure contexts (e.g., the home or academic setting) may result in high amounts of interindividual variability. It is certain, however, that LDs affect all languages that a child is acquiring. In other words, if at least one of the child's languages is developing typically, diverging developmental patterns in another language cannot be attributed to LD but rather to insufficient exposure contexts.

Importantly, research has shown that growing up with multiple languages neither causes nor further aggravates difficulties in language acquisition. For example, Paradis et al. (2003) found that French–English bilingual children with DLD

were relatively similar in their respective morpho-syntactic language skills compared to monolingual children with DLD acquiring either French or English. Consequently, there is no reason to assume that growing up with multiple languages puts children with LD – including children with impairments such as autism spectrum disorders (Drysdale et al., 2015) and Down syndrome (Bird et al., 2005) – at an additional disadvantage.

Issues in Language Intervention with Linguistically and Culturally Diverse Children with Language Disorder

The fact that LDs affect all languages that a given child acquires raises the important question of choice of language(s) targeted in the intervention. While the acquisition of the academic language is important for obvious reasons, the additional continued learning of the languages with which the child has significant experience supports the child's social–emotional development by allowing closer family relationships and supporting the development of a sense of identity. Children of preschool age in particular will need ongoing support in the language(s) of their primary caregivers to ensure language growth and overall development, while a lack of support of the home language(s) often results in incomplete acquisition or language regression (Håkansson et al., 2003). Such absence of a strong home language foundation may also negatively affect the acquisition of subsequent languages and thus place children with LD at an additional developmental risk (Kohnert, 2010). Therefore, this chapter shares the view that a "systematic support for the home language(s) of young children with language impairment (LI) is critical to the long-term success of language intervention" (Kohnert et al., 2005, p. 252).

Research evidence suggests that targeting multiple languages in an intervention can effectively stimulate language growth. Ebert et al. (2014) compared interventions for US school-aged children with DLD acquiring both Spanish and English and found that children in a bilingual treatment group displayed significant gains in both languages, as opposed to children who were only treated in English. This result is consistent with the literature comparing monolingual language intervention to bilingual treatment for bilingual children with DLD (Restrepo & Gutiérrez-Clellen, 2012).

The primary goal of language intervention for culturally and linguistically diverse children is to help them gain exposure to meaningful and developmentally appropriate use of their languages. Consequently, there is no "one-size-fits-all" approach. Intervention to support these children in reaching language goals can be administered directly (i.e., intervention implemented by the SLT) or indirectly (i.e., working together with intervention partners for implementing intervention strategies; see Fig. 22.1). Certainly, both approaches can also be mixed depending on the needs of the child as well as the available resources.

Where resources are limited, an indirect approach to language intervention may be used to increase the frequency and intensity of service delivery (Boyle et al., 2009). Moreover, an indirect approach may be especially useful when there is a linguistic and cultural mismatch between the clients and the SLT has to seek ways to facilitate exposure to meaningful language experiences (Licandro & Lüdtke, 2012).

The following sections will focus on indirect approaches to language intervention including peers as intervention agents. As almost all children strive after the initiation and maintenance of interactions with their peers, an intervention approach that includes peers may be especially motivating. Also, in some cultures, it is more appropriate for children to communicate with their peers rather than participating in adult-led conversations (Van Kleeck, 1994). Another important aspect to consider is that children with LD may struggle to establish relations with their peers; studies have shown that children with LD are less likely to establish sustained peer interactions and are more likely to be rejected by their peers (DeLuzio & Girolametto, 2011; Menting et al., 2011). Consequently, as a group, they have limited access to naturally occurring peer interac-

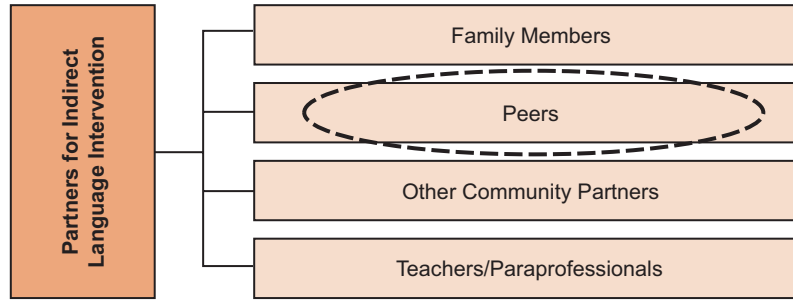

Fig. 22.1 Partners for indirect language intervention with culturally and linguistically diverse children with LD

tions with children with more advanced linguistic skills, which further underlines the potential benefits of peer-assisted learning approaches.

Approaches to Language Intervention Including Typically Developing Peers

Socioemotionally, from the child's perspective, one of the most enjoyable aspects of attending (pre)school is to engage in play and other interactions with their peers, where they express and discover similarities. This "joint experience of interests, ideas and actions" (Degotardi & Pearson, 2014, p. 95) creates a sense of belonging and togetherness.

Furthermore, peers' verbal interactions shape their use of linguistic features and directly influence children's language development (Hoff, 2006; Licandro, 2016). There are different approaches to peer-assisted intervention which are administered with or without previous training of the peer communication partner, as reviewed below.

Peer-Assisted Intervention with Trained Peer Communication Partners

Peer trainings have been used in interventions to improve the social and communicative interaction of children with developmental disabilities (DDs), such as autism (Chang & Locke, 2016). For example, Goldstein et al. (1997) implemented a peer-assisted intervention in the US preschool setting to improve communicative interaction and social inclusion of eight children with moderate DDs and LD. Typically developing peers were each paired with a "buddy" (i.e., a child with LD) and participated in a "buddy training" designed to teach the use of communication strategies, including the awareness of communicative attempts of their buddies, the use of facilitative strategies (i.e., instructions to stay, play, and talk to their assigned peer), and the distribution of those strategies across the school day. A multiple baseline design including different observation time points revealed quantitative and qualitative increases in peer interactions. Those improvements also generalized to interactions with newly assigned "buddies" and the social status of participating children with LD. Also, Bambara et al. (2016) reviewed peer-assisted strategies to enhance conversational skills of adolescents with autism. In their research, effective strategies implemented by peers included the support of overall conversational engagement, the increase of initiations to start conversations, and the increase of follow-up questions to sustain conversations.

Peer-Assisted Intervention with Untrained Peer Communication Partners

When interacting with their typically developing peers, preschool-aged children with DLD can benefit from their language models, as research by Robertson and Ellis Weismer (1997, study 1) suggests. They paired eight preschoolers aged 4–5 with DLD with typically developing preschoolers. Each play dyad was supplied with props and was instructed to play "house" for 15–20 minutes at four different time points within a 3-week period. While an adult did not get actively involved in the

play interaction, children were instructed to talk about things they knew about playing house and were prompted with "What else do you do?" when appropriate. Children with DLD who participated in such structured play interactions in the untrained peer model demonstrated significant gains in several areas, such as the length of their script reports (e.g., answering the question, "What do you do when you play house?"), the number of different words used, and the number of linguistic markers used.

In a subsequent study, Robertson and Ellis Weismer (1997, study 2) applied a single-case, multiple baseline design and paired 4-year-old children with DLD either with another child with DLD or with a typically developing peer model to participate in four play sessions (as previously described). Children with DLD paired with typically developing peers displayed gains in their total number of words and number of different words produced, verbalization of play-themed acts, as well as their use of linguistic markers (i.e., temporal, conditional, and other conjunctions), while children with DLD play dyads displayed little or no gain.

While these findings cannot be readily generalized due to the small sample sizes as well as the specific cultural and institutional contexts in which the research was conducted, the reviewed studies still suggest that carefully planned scripted play activities with typically developing peers may facilitate aspects of language growth in children with DLD. Furthermore, a study by Licandro and Lüdtke (Licandro, 2016; Lüdtke & Licandro, 2017) was designed to explore the effects of a peer-assisted intervention approach on the narrative generations of 24 children acquiring Turkish and German with a mean age of four and a half years. A pre-posttest design including a random assignment to either an intervention group, an intervention control group, or a nonintervention control group was applied to enable careful experimental control of multiple aspects of oral narration as well as an assessment of generalization and maintenance of narrative skills. After 10 weeks of clinician-prompted, peer-assisted intervention, children in the intervention group demonstrated greater growth in lexical diversity as well as narrative complexity than children in the control groups ($r = 0.06$). A maintenance probe 5 weeks after the intervention had ended revealed that narrative performance was also improved when generating a narrative in response to an unfamiliar picture book.

Finally, Schmitt (2013) investigated active ingredients in school-based speech–language therapy for 233 children in kindergarten and first and second grades with LD, provided by 73 SLTs in the US school system. While all treated children made considerable progress, children seen in therapy sessions that included typically developing peers made greater gains than those who were not. In fact, this was the only therapy ingredient, next to the group size (i.e., children seen in smaller groups made more gains) that emerged as a significant moderator on child language outcomes.

While these findings underline the use of peer-assisted learning approaches in targeted language support, the successful implementation of SLT-mediated peer interactions in sub-Saharan African contexts depends on several factors, as discussed in the next sections.

Applying SLT-Mediated Interactions to Clinical Practice

SLT services to children with LD from diverse cultural and linguistic backgrounds have been criticized as often being problematic and largely unsatisfactory (Van Dulm & Southwood, 2013).

In Kenya, for instance, the majority of the few SLT practitioners available offer therapy services in only English and/or, in a few instances, Swahili and English. This is problematic, because the consideration of only one language in the diagnostic process does not allow to paint a precise picture of a child's language competence and needs. Furthermore, the lack of support of the home language(s) in the therapeutic process puts children with LD at an even greater disadvantage. Therefore, to address some of

these challenges, the involvement of typically developing peers in the intervention process may produce promising results. As reviewed, peer-assisted interventions come in many forms, such as carefully planned scripted play activities with untrained peers or trained peer models to facilitate social communication and language growth. Already in early childhood, peer models can be used as a natural, effective, and economic approach to improve communication skills. Pairing a child with LD with a typically developing peer who speaks the same home language(s) and facilitating shared language use can yield language growth. However, for the successful implementation of peer-assisted intervention approaches in SLT practice in sub-Saharan Africa, especially in the Kenyan context, several factors should be carefully considered.

The need to tailor peer-assisted intervention approaches to meet the individual needs of a child within a multilingual and multicultural context in which he or she is receiving therapy services cannot be overemphasized. Studies in ethnically diverse countries like the United States have shown that children differ in interactional styles (see Awde, 2009; Tarman & Tarman, 2011; Wyatt, 1995). For example, in some African cultures, children speak only when spoken to and generally tend to be quiet in the presence of strangers. Therefore, to facilitate the most effective intervention outcomes, the peer should be carefully selected on the basis of his or her cultural and linguistic background, relevant social and interpersonal skills, shared interests, age, and previous contact with the child with LD. Also, the peer should be drawn from the same school and home locality as the child with LD to facilitate and encourage continuity of consistent and meaningful academic and social interactions that are geared toward enhancing the communication skills of the multilingual child in different settings. The ultimate goal is to support a child with LD in their use of both home and academic languages.

SLTs intending to include trained peers as communication partners should consider the provision of multiple sessions of training, targeting the primary needs of the child with LD as well as what a meaningful interaction entails, before the chosen peer(s) can reliably begin participating in the intervention process. Peer training can take different forms, depending on the type of approach to be used as deemed appropriate by the clinician. Throughout the implementation of peer-assisted intervention, regular positive feedback to peers by the SLT is vital to encourage and reinforce fruitful peer interactions for a successful intervention process (Bell & Carter, 2013).

Action Points for Practice and Research

Linguistically and culturally diverse children with LD display difficulties in language production and/or reception which put them at significant social and academic risk. Many reasons underline that language intervention should target their home language(s) in addition to the academic language. While – as with any case for SLT intervention – there is not always one perfect approach, including peers from similar linguistic and cultural backgrounds in the intervention process is one way to achieve the inclusion of their home language(s). It should be noted, however, that the available evidence on intervention with children who grow up with more than two languages is still very limited, such that the current knowledge base on bilingual language intervention can be used as a guideline until further research emerges (Patterson & Rodríguez, 2016).

Providing appropriate services for children with LD and conducting meaningful research require considering specific cultural, linguistic, and individual circumstances. When working with linguistically and culturally diverse children, clinical decision-making and service delivery can be challenging for different reasons. Several actions will have to be taken in future years to optimize speech–language services for children with LD in sub-Saharan Africa, among them:

- The establishment of language benchmarks and understanding of growth patterns in the respective languages in typically developing children as well as children with LD
- The development of culturally and linguistically appropriate and standardized assessments for local languages to avoid under- and overdiagnoses of LD in multilingual children
- The optimization of counseling for parents emphasizing the importance of home language support for the overall child development
- The conduction of intervention studies to investigate the efficacy and effectiveness of different approaches to intervention with children acquiring multiple languages

Until these actions have been taken, SLTs in sub-Saharan Africa will have to draw on the available resources, rely on their professional expertise, and utilize the existing evidence base to make informed decisions to provide their linguistically and culturally diverse clients with appropriate language support, so they can realize their full potential.

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23

Speech, Language, and Swallowing Difficulties in Neurology: A Sub-Saharan African Perspective

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Introduction

The brain and spinal cord form the central nervous system (CNS), while anterior horn cells, nerve roots, nerves, neuromuscular junctions, and muscles form the peripheral nervous system (PNS). Together, they constitute the most complex organ in the human body: the nervous system. In several conditions, minor or major interruptions to various pathways of the CNS can result in difficulties in language acquisition or production, speech, swallowing, and the planning of these movement patterns. Measuring only centimeters, the larynx, pharynx, and oral cavity are extremely intricate in their innervation and musculature and therefore very prone to dysfunction leading to significant morbidity. Most parts of the PNS can be affected by neuromuscular disorders, leading to dysarthria and dysphagia yet often leaving higher cortical functions, such as language production, language comprehension, and the planning of motor functions (e.g., articulation) untouched. Dysarthria and aphasia may lead to social and communicative disability. In the case of dysphagia, severe and preventable complications, such as aspiration pneumonia and malnutrition, may lead to increased mortality in this population.

In sub-Saharan Africa (SSA), the prevalence of neurological disorders is increasing (Howlett, 2015a) despite the relative reduction of the burden of infectious disease. In adult medicine, globally, noncommunicable diseases, such as stroke, are rising. Ironically, such diseases are indirectly caused by improved survival and economic resources (Howlett, 2015a). A new epidemic of chronic disease is in the making, and the burden of disease is frequently determined by neurological conditions (Mfinangai et al., 2011).

In pediatrics, cerebral palsy (CP) is still the most common chronic neurological disorder across the African continent (Donald et al., 2014; Karumuna & Mgome, 1990). The prevalence and incidence of CP have unfortunately not decreased as they have elsewhere in higher-resource settings, and this is despite several efforts to improve maternal and neonatal care (Donald et al., 2015; El-Tallawy et al., 2011). Overall, the burden of neurological disease in Africa remains significant (Howlett, 2015a) and is frequently complicated by problems with speech and/or swallowing.

This chapter features a glossary of neurological conditions, inspired by the sizable overlap and common principles between clinical neurology and speech-language therapy (SLT). Patients with neurological disorders substantially contribute to the client base of any SLT professional.

The professionals involved with these complex patients, however, are not exclusively SLT professionals. Medical doctors, nurses, occupational therapists, physiotherapists, and, importantly, the direct caregivers of a patient make up a patient's multidisciplinary team. The latter is essential in the SSA culture, where the extended family is the cornerstone of daily patient care in the home setting, frequently extending even to hospital wards when required. However, due to limited financial and material resources or long distances between patients' homes and the hospital, much of the rehabilitation may be in the hands of minimally trained individuals (World Health Organization [WHO], 2006). This leaves SLT professionals with the responsibility to educate both patients and caregivers, as they are likely to be the core of the rehabilitation process at home—and may be so for a much longer time than desired. By optimizing communication, SLT will positively impact quality of life. However, it is the optimization of swallowing by which SLT truly saves lives.

Due to the very limited capacity of neurologists (Howlett, 2015b) and SLT professionals in SSA,

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adequate recognition and management of these sometimes-subtle issues remain a challenge, often leading to delayed diagnosis and treatment (Fagan & Jacobs, 2009). Neurological deficits can furthermore be clearly visible or audible. Examples include the presentation of involuntary movements, an asymmetrical face, drooling, or a speech impediment. Across the world, at all socioeconomic levels of society, these disabilities unfortunately frequently lead to a degree of stigmatization. This may lead to psychosocial isolation and the underutilization of medical facilities. "Alternative" medicine practice has preceded "regular" medicine by centuries all over the world and is still widely utilized. This can lead to misdiagnosis and mistreatment, as well as a delay in seeking support in the more conventional medical system. In carefully selected mild to moderately severe mental health disorders, the effectiveness of alternative approaches can approach that of medical professional counterparts (Nortje et al., 2016; Schwarz & Snijdewind, 2010). Faith healers and witch doctors are often close by, respected, and recommended by proxies (Nortje et al., 2016; Schwarz & Snijdewind, 2010). This complex situation may result in reduced compliance with regular medical therapy and can be downright harmful.

Methods

The neurological basis of speech, language, and swallowing disorders is often intricate and challenging to diagnose precisely. For this, a systematic and methodical approach is needed. By gaining insight into neurological patterns, one may be able to widen the SLT scope for a particular patient. For instance, a patient presenting with motor aphasia (see also Section "Introduction" and Table 23.2) is likely to have an associated degree of dysphagia but may not be aware of this or may simply be unable to express this difficulty. By applying a framework of knowledge about common neurological disorders, a degree of "pattern" recognition will greatly help.

This chapter is a short neurology refresher and provides an overview of the neurological disorders of epidemiological significance. It aims to help the reader differentiate those conditions with and without a neurological (or even an organic) origin. After a brief introduction, SLT aspects are highlighted, aided by images, and where possible supported by the available published evidence base.

Neurological Disorders

In this section, we will describe some of the most common pediatric and adult neurological disorders in SSA, divided into three broad categories: (1) central nervous system disease, (2) peripheral nervous system disease, and (3) an intermediate group with the involvement of both the central and peripheral nervous systems (see Table 23.1). Per disorder, definition, pathogenesis, epidemiology, clinical features, and SLT therapies are discussed as separate sections categorized by neurological disability.

Table 23.1 A classification of neurological disorders

	Central nervous system (CNS)	Peripheral nervous system (PNS)
Anatomical structures	Brain, brainstem, and spinal cord (with the cortex, basal ganglia, and pyramidal tract (and more) lying within these structures)	Anterior horn cells (although strictly located in the central nervous system), nerves, neuromuscular junction, and muscles
Examples of diseases	Stroke, cerebral palsy, Parkinson's disease, and more	Polyneuropathy, myasthenia gravis, myositis, and more
Examples of disease (CNS + PNS)	Motor neuron disease such as amyotrophic lateral sclerosis (ALS)	Motor neuron disease such as amyotrophic lateral sclerosis
Examples of clinical features	Aphasia, one-sided muscle weakness, one-sided disorder of sensibility, one-sided spasticity, dysarthria, dysphagia, tremor, and rigidity	Dysarthria, dysphagia, muscle weakness, symmetrical sensibility symptoms, and painful muscles

Central Nervous System Disorders

Stroke

Stroke is an acute disorder of the CNS in which an interruption of blood supply to a certain part of the brain results in the loss of one or more neurological functions. The mechanism of injury may take the form of either blocking of the arteries (ischemic stroke) or rupturing of the arteries (hemorrhagic stroke). Stroke is one of the most important reasons for admission and death in urban hospitals throughout Africa with an annual incidence of 2–3 cases per 1000 persons (Howlett, 2015a; Owolabi et al., 2015). Depending on the region(s) of damage, patients can have one-sided weakness of the body and face (especially pharyngeal, tongue, and mouth musculature) with articulation and swallowing difficulties (dysarthria and dysphagia) or language impairment (Table 23.2). The damaged brain territory does not have to be large to cause disabling symptoms: a small infarct to a very eloquent structure of the brain, several small bilateral strokes, or a larger stroke affecting a greater brain volume may all result in significant speech and/or swallowing difficulties. Stroke in SSA appears to affect younger people more often than it does elsewhere (Walker et al., 2010). The diagnosis is made upon history (acute deficit) and imaging of the brain (computed tomography [CT] scan). Further, in a report from Tanzania, Walker et al. (2000) found high mortality and morbidity in patients with stroke and postulated this percentage to rise in the future due to aging.

Speech-Language Therapy and Dysphagia in Stroke

Apart from the eye-catching motor deficit in stroke patients, speech and language problems are readily noticed. Many patients with dysphagia are not aware of their problem or cannot express it due to motor aphasia (see Table 23.2). Caregivers as well as medical professionals often overlook the associated swallowing problems. A swallowing test is not a standard nursing assessment procedure in SSA hospitals, and unambiguous criteria suggesting referral to an SLT specialist or any other professional involved in swallowing are lacking (Blackwell & Littlejohns, 2010). It is important to identify swallowing problems within the acute phase after a stroke. It minimalizes complications and improves the outcome of oropharyngeal dysphagia (Ostrofsky & Seedat, 2016). About 50% of stroke patients have dysphagia in the acute phase (Mahawish & Heikinheimo, 2010).

The most important features of poststroke dysphagia are choking on fluids, difficulties in chewing, development of stagnant food bolus in the cheek, and food dribbling out of the paralyzed side of the mouth. Behavioral factors, including a lack of disease awareness and a tendency to stuff food into the mouth without regular swallowing, are

Table 23.2 A classification of aphasia

	Broca's Aphasia	Wernicke's Aphasia	Global Aphasia	Conduction Aphasia	Amnestic aphasia
Anatomical structure involved	- Broca's area; - frontal lobe dominant hemisphere	- Wernicke's area; - temporal lobe dominant hemisphere	- Diffuse dominant hemisphere	- Arcuate fascicules (connection between Broca's and Wernicke's areas)	- No clear localization, typical of more than one small lesion
Also called	- Expressive aphasia - Motor aphasia	- Receptive aphasia - Sensory aphasia	- Mixed-type aphasia	–	- Anomic aphasia
Speech	Nonfluent	Fluent	Nonfluent	Fluent	Fluent, impaired word retrieval
Comprehension	Relatively intact	Impaired	Impaired	Good	Good

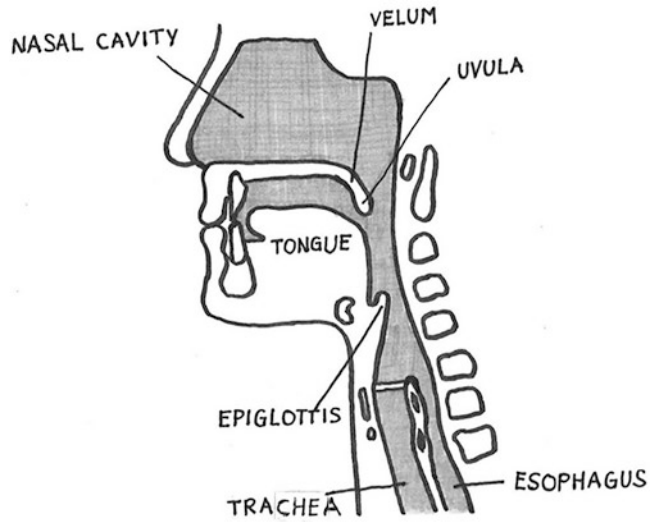

Fig. 23.1 Sagittal anatomy

mostly seen in right hemispheric stroke (Kalf et al., 2008) (Fig. 23.1).

Swallowing assessment by an SLT professional consists of a thorough history followed by various swallowing tests and an observation of chewing and swallowing. SLT screening tools developed elsewhere may not be adequate for SSA, further impeding any objective measurements. The South African dysphagia screening tool (SADS, Ostrofsky & Seedat, 2016) has been shown to be a more valid assessment in low-resource settings. In the case of doubt, the SLT professional can suggest an ear, nose, and throat (ENT) specialist to perform an additional videofluoroscopic swallowing study (VFSS) or flexible endoscopic evaluation of swallowing (FEES). As with ENT services, VFSS and FEES are very scarcely distributed in SSA (Fagan & Jacobs, 2009). In cases of impossible or inadequate swallowing, tube feeding should be considered, initially through a nasogastric tube, which is easily introduced at the bedside. For patients who need to be tube fed for a longer time, a gastric feeding tube (GFT), preferably an endoscopically placed percutaneous endoscopic gastrostomy (PEG), is a safer route (Rowat, 2015). The idea of a tube-fed patient, however, is not easily accepted for emotional reasons, and this seems to be even more the case in SSA. Treatment of oropharyngeal dysphagia can be divided into compensatory techniques and rehabilitation techniques (Kalf et al., 2008). The preventive value of compensatory mechanisms in stroke dysphagia is often overlooked. Therefore, both the patient and caregiver should be intensively involved in counseling about normal swallowing, so as to signal problems in a timely way. Eating and drinking are complex sensorimotor actions subdivided into four phases: the oral preparatory phase, oral transport phase, pharyngeal phase, and esophageal phase. Visually representing the process with a schematic sagittal diagram of oropharyngeal anatomy is indispensable, yet cheap and effective (Fig. 23.2).

There is a common tendency to feed ill people when they are supine, the reason being the reduced requirement for feeding time, as the food will easily run into the throat. Provision of education to caregivers and nurses about passive compensatory techniques is therefore essential, for example, posture, airway securing, spoon-feeding skills with adapted food textures (smooth and semisolid is often preferred over thin fluids), and pulverized drugs. This requires basic knowledge about a country's specific national dishes like *mtori* (a hearty soup with bananas) and *uji* (maize-based porridge), from which potentially balanced and safe diets can be composed. Furthermore, other everyday issues such as oral hygiene should not be overlooked, as adequate oral care reduces the risk of aspiration in oro-

Fig. 23.2 Four phases of swallowing

pharyngeal dysphagia (Seedat & Penn, 2016). There is a need for the monitoring of malnutrition due to the inadequate dietary components and texture of meals. A suboptimal nutritional status also increases aspiration risk (Kampman et al., 2015).

In order to prevent neck extension during drinking, which increases aspiration risk, a regular cup can be adapted so that it leaves the nose free (Fig. 23.3). These cups are easily made, for instance, in collaboration with occupational therapy. In addition, swallowing with the chin toward the chest can be a good compensation strategy to reduce aspiration risk (Fig. 23.4).

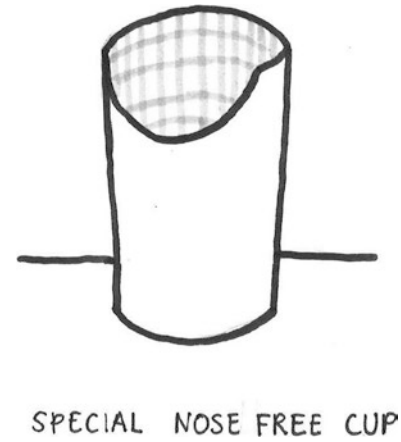

Fig. 23.3 Special nose-free cup

Speech-Language Therapy and Communication Disability in Stroke

Most paramedical professionals including physiotherapists and occupational therapists will know that aphasia is a disorder of language but not exactly what it encompasses. A grasp of the impairments to language and understanding (aphasia) versus those of articulation and pronunciation (dysarthria) is essential, as the disabilities can go together in many of the possible anatomical stroke locations (see Table 23.3).

Fig. 23.4 Chin toward the chest

Table 23.3 A schematic representation of processes from idea to speech and associated disorders. (Based on Dharmaperwira-Prins (2002, p. 15))

Process	Disorder
Idea	For example, dementia
↓	↓
Language (words, sentences, story)	Aphasia
↓	↓
Programming of speech	Verbal apraxia
↓	↓
Speech	Dysarthria

(This table is conceptual only and not intended to be a complete depiction of processes and associated disorders)

This knowledge also helps identify silent problems: an aphasic patient will not be able to express or indicate his or her dysphagia, but when there is also a right-sided weakness, the prior likelihood of concomitant swallowing involvement is high.

Aphasia usually manifests itself in productive language (speaking and writing) and in receptive language (comprehension of spoken language and reading). The linguistic impairments vary from patient to patient. Impairment of language production can occur at various linguistic levels, such as phonology, lexicon usage, and application of grammar. A common example of a mixed articulation impairment is verbal apraxia, where the motor cortex programming of articulation is impaired (Bastiaanse & Prins, 2011).

Definite advantages can be expected in SSA when students in paramedical disciplines are taught a solid basis in neurological disease (Fagan & Jacobs, 2009). An important obstacle can be a lack of investigative material in the patient's mother language. A layperson translator may come up with his or her own interpretation of what the patient means, not allowing for finer diagnostic differentiation (Barrat et al., 2012), or worse, giving rise to miscommunication and frustration.

Cerebral Palsy

In SSA as well as most other low-income regions, CP is the most common cause of childhood disability and the most common severe chronic neuropediatric condition (Krägeloh-Mann & Cans, 2009; UNICEF, 2006). CP consists of a number of complex permanent disorders of movement and posture, causing activity limitations. They are attributed to nonprogressive disturbances that have occurred in the developing fetal or infant brain prior to the age of 24 months. The greatest burden of CP is carried by low-income countries (El-Tallawy et al., 2011; Reddihough & Collins, 2003), but detailed demographic data on childhood disability in these settings is difficult to obtain and grossly underrepresented in the international literature (Darmstadt et al., 2005). Prevalence estimates from high-income countries indicate that CP affects one to six per 1000 live births (Reddihough & Collins, 2003). This prevalence seems to be similar in low-income countries, yet the literature from these regions is limited, and incidence and mortality may be higher, not being accurately represented in the prevalence estimates (Colver et al., 2014; El-Tallawy et al., 2011; Jacobsson & Hagberg, 2004; Reddihough & Collins, 2003). From the available literature from high-income regions, prenatal events likely account for 75% of all cases of CP, and postnatally acquired CP cases account for between 10% and 18% (Reddihough & Collins, 2003). In low-income countries, these figures are different, with multiple risk factors and an important, if not predominant, role for perinatal asphyxia (Donald et al., 2014; El-Tallawy et al., 2011). Recently, high-income country studies have reported that in 10–25% of cases, there is no identifiable risk factor at all, a phenomenon mostly seen in patients with mild dis-

Table 23.4 Types and clinical features of cerebral palsy (derived from El-Tallawy et al., 2011)

	Spastic CP	Dyskinetic CP	Ataxic CP	Mixed CP
In percent	65.4%	3.8%	3.8%	26.90%
subtypes	- Hemiplegic - Diplegic - Triplegic - Quadriplegic	- Dystonic - Choreoathetoid	- Cerebellar-type ataxia	- A combination of features constitutes the clinical phenotype
Examples of clinical features	- Abnormal posture and movement - High muscle tone - Pathological reflexes - Contractures	- Abnormal and involuntary posturing and movements; dystonic posturing with common truncal involvement - In sleep, such movements are not present	- Impaired balance - Coordination problems or problems of voice, arms, and legs - Eye movement disorders, most prominently nystagmus- and pontine-type eye movement disorder	- Combination of previously mentioned subtypes - Often present if neurological examination is completed in more details

ability or those with the ataxic type of CP, suggesting a genetic predisposition (Blair, 2010; Stoknes et al., 2012). El-Tallawy et al. (2011) found that the most common clinical CP syndrome was spastic type, accounting for 65.4% of the overall prevalence; the second most common was mixed-type CP, accounting for 26.9%; and the least common were dyskinetic and ataxic types, where each accounted for 3.8% of the overall prevalence (see Table 23.4). The mixed type of CP may consist of subtle contributions of both the spastic and dyskinetic subgroups, not appreciated or identified by non-neurologically trained medical professionals.

The severity of disability is graded using the Gross Motor Function Classification System (GMFCS, Palisano et al., 1997). It has been reported that a larger proportion of severe disability (corresponding to GMFCS levels IV and V) is reported in African studies compared to European and American cohorts (Donald et al., 2014). CP is defined according to its motor disability, but other disorders of cerebral function are strongly associated with CP: intellectual disability, epilepsy, behavioral abnormalities, and, last but not least, disorders of speech, swallowing, and language. Epilepsy and feeding and swallowing disorders (dysphagia) determine the morbidity and mortality of CP to a significant extent. With a high GMFCS grade being a surrogate marker for the severity of CP in SSA (Donald et al., 2014), many children with CP suffer from feeding and swallowing disorders and speech and language impairment. The diagnosis of CP is mostly made upon history and neurological examination, sometimes in combination with imaging of the brain.

Speech-Language Therapy and Dysphagia in Cerebral Palsy

In SSA, CP often presents with the higher GFMCS severities. In our center in Northern Tanzania, we have a multidisciplinary clinic which, apart from patient care, also provides a to-and-fro learning environment for the various disciplines. Almost all (99%) of children with GFMCS IV or V and/or cognitive impairment with IQ below 55 points have feeding and swallowing disorders, with 15% of these children being unable to handle food and fluids orally at all (Shevell et al., 2009). Swallowing problems are furthermore associated with regurgitation and drooling, pulmonary comorbidity such as coughing and airway aspiration of food, gastrointestinal reflux, vomiting, constipation, and dehydration (Erasmus et al., 2012; Hadders-Alga et al., 2015). Even "silent aspiration" is common and can eventually lead to pneumonia. In SSA, this often eventually culminates in malnutrition (Kakooza-Mwesige et al., 2015). Those children who can be fed orally often end up with an unvaried diet with, for instance, in Tanzania, exclusively *uji* (maize porridge), which is being tolerated and may thus become the mainstay of a diet. Cervical auscultation with a small bell stethoscope can be a way of detecting by ear whether and how there is swallowing capacity. It is highly sensitive for fluid swallowing although less so for solids. The validity of this assessment in adults, however, is limited (Frakking et al., 2013). In settings such as those seen in large parts of SSA, cervical auscultation may be an elegant and low-resource addition to a swallowing assessment and can be taught to other profession-

als, such as occupational therapists, physiotherapists, and nurses.

A valid and quick screening system to describe eating and drinking ability in persons with CP, analogous and complementary to the GMFCS, is the Eating and Drinking Ability Classification System (EDACS, Sellers et al. 2013). With respect to the optimization of feeding position, in recent years, the treatment of feeding and swallowing problems in children has focused on using motor learning approaches. From the literature, it is known that functional training is useful in improving motor skills (Sheppard, 2008). Isolated oral sensorimotor training methods, such as practice in the neurodevelopmental treatment (Bobath & Bobath, 1963), have proven ineffective (Arvedson, 2013; Rogers, 2004). The motor subtype of CP (spastic or dyskinetic, for instance) and body position strongly influence the success rate. For instance, swallowing with a flexed neck reduces aspiration risk (Harding & Cockerill, 2015). Many tend to feed a child with their neck hyperextended, especially as there is often limited neck control. Education is therefore of primary importance, as caregivers are often stressed young mothers without sufficient background knowledge about the disorder. Sometimes, having the caregivers undergo a feed while supine is an effective way to explain the hazards of inadequate feeding techniques (Fig. 23.5).

Again, compensatory strategies (such as those addressed in the chapter about dysphagia in stroke) can be used. The aforementioned cup prevents neck extension by its very design (also see Section "Stroke" and Fig. 23.3). Mouth and jaw training is effective when it is given during functional activities like eating, drinking, brushing teeth, and so on (Engel-Hoek van den et al., 2011) (Fig. 23.6). A feeding spoon, for instance, should ideally be shallow (small volume), short (less risk of gagging), and made of plastic (less irritative to the mucosa and teeth) (Fig. 23.7). Furthermore, oral and dental hygiene is often completed with a piece of cloth and some salt, rather than toothbrush and toothpaste, raising the risk of dental decay and superinfection (Nemutandani et al., 2013; Roberts et al., 2016). Counseling about the importance of daily intraoral hygiene is therefore part of the SLT workup.

Fig. 23.5 Good feeding position

Fig. 23.6 Mouth and jaw control

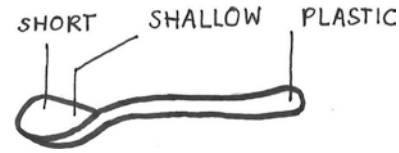

Fig. 23.7 Feeding spoon

In cases of persistently inadequate swallowing, a nasogastric tube (NGT) can be inserted temporarily, and the patient can be referred for a GFT. These procedures are usually by laparotomy and, less often, the elegant endoscopic technique of PEG (see Section "Stroke").

Speech-Language Therapy and Communication Disability in Cerebral Palsy

Communication in CP is strongly determined by cognitive performance. Communication disability is present in about 48% of children seen in high-income countries. About 35% of children in this same population have dysarthria (Watson & Pennington, 2015). In SSA, dysarthria is one of the most common comorbidities, directly related to GFMCS severity (Kakooza-Mwesige et al., 2015). SLT aims for the maximization of communication in children with CP and the world around them, albeit by facial expressions and gestures rather than ordinary speech (Pennington et al., 2013). Daily communicational abilities can be assessed and rated according to the GMFCS on a five-point scale, known as the Communication Function Classification System (CFCS, Barty et al., 2016). Hearing and visual (cortical) deficits always need to be ruled out, as they are rather common co-occurrences in CP (10% and 40–50%, respectively) and may be misleading during assessment (Adedeji et al., 2015; Smith & Hatcher, 1992). SLT testing and treatment tools are rarely available in SSA (see Section "Stroke"). Augmentative and alternative communication (AAC) is a valuable home-based intervention method for children with complex communication disabilities (Bunning et al., 2014; Watson & Pennington, 2015) (Fig. 23.8).

The importance of adequate language input is increased in disabled children (Hadders-Alga et al., 2015). Parents can learn to communicate according to the Hanen principles: follow (observe, wait, listen), adapt (sit at eye level and adequately react to the child's language level), and add (offering more language and experience) (Pennington et al., 2009). This approach should be subsequently adapted to cultural expectations within the family, as in collectivistic societies, such as in the United Republic of Tanzania, where there is an emphasis on politeness and respect (Peña & Fiestas, 2009).

Parkinson's Disease

Parkinson's disease (PD) is a chronic progressive neurodegenerative disorder caused by a loss of cells of the substantia nigra in the brain, resulting in decreased levels of dopamine. The PD age-adjusted prevalence rate in SSA is lower than in high-income countries with a rate of 40–67/100,000 (Dotchin et al., 2008; Howlett, 2015a; Winkler et al., 2010). PD typically begins

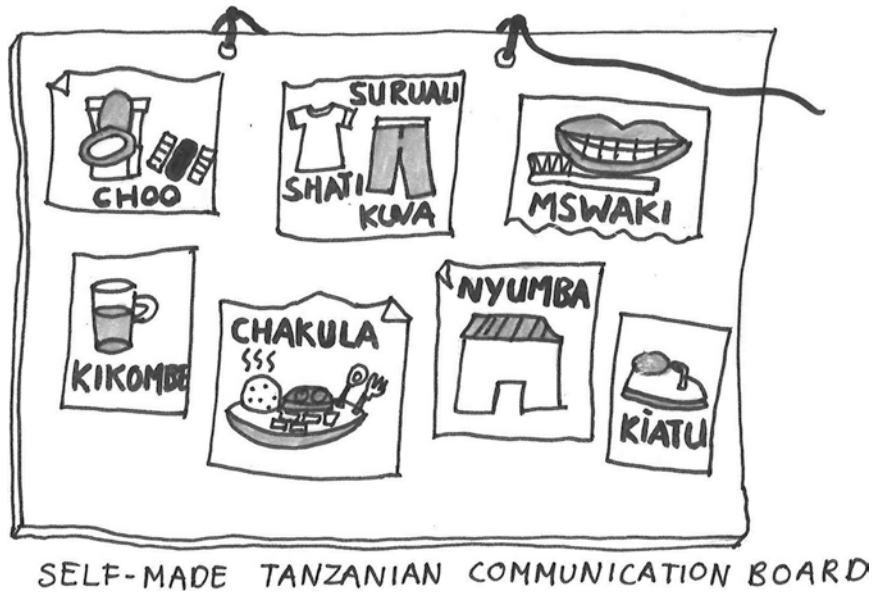

Fig. 23.8 Communication board

around 50–60 years of age. The disease is characterized by tremor, rigidity, and poverty of movement (bradykinesia). Bradykinesia, in particular, has a vast impact on the quality of life of patients, since it results in less frequent swallowing, which causes drooling and possible aspiration, as well as very low and slow speech (Howlett, 2015a).

Speech-Language Therapy in Parkinson's Disease

In PD, the hallmark SLT features are rigidity and cognitive impairment, which can interfere with chewing, swallowing, and speech and can lead to drooling. Of PD patients, 80% are estimated to have subclinical dysphagia in the early disease stages, rising to 95% in advanced disease stages (Lee et al., 2016). Symptoms are various, ranging from slow chewing and slow oral transport, lesser mobility of the esophagus and pharynx, oral food residue, and silent aspiration (Ayres et al., 2016). A structured swallowing assessment as in stroke patients should be conducted, using, for example, the Swallowing Disturbance Questionnaire (SDQ, Manor et al., 2007) for detecting dysphagia in patients with PD or the Munich dysphagia test–Parkinson's disease (MDT-PD, Simons et al., 2014), which are specialized assessments that can be feasibly administered in lower-resource settings (Wirth et al., 2016). Choking on fluids can be minimalized by the prevention of double tasks, swallowing with attention, thickening fluids, handling smaller volumes per time, or applying good neck flexion. Due to the characteristic delay in motor tasks, such as chewing and the initiation of swallowing, a special individually tailored "cue" for swallowing may be required. Patients with reduced pharyngeal transport are recommended to swallow harder in a conscious and consistent manner (Kalf et al., 2011).

Voice and speech quality (hypokinetic dysarthria) in PD is impaired in no less than 90% of patients and significantly impacts social interactions and quality of life (Ciucci et al., 2013). The general advice is to speak "loud and low" (de Swart et al., 2003) to prevent a tense and hoarse pitch. The treatment intensity of this method is very high, which is often not feasible for patients in SSA. As the disease progresses, drooling can pose an essential burden on PD patients. The causes are decreased spontaneous swallowing, hypomimia with insufficient lip closure, and a stooped posture. Usually, conservative SLT measures (good lip closure, adapted posture of the trunk and head, and swallowing more frequently) suffice, but occasionally, modification of dopaminergic or cholinergic medication is required. Botulin toxin injection of the salivary glands has proven efficacy (Srivanitchapoom et al., 2014), but in SSA, this is rarely available outside South Africa.

Peripheral Nervous System Disorders

Myasthenia Gravis

Myasthenia gravis (MG) is a chronic autoimmune disease that is caused by antibodies against the acetylcholine receptors at the junction between the nerve and the muscle (neuromuscular junction, part of the peripheral nervous system). MG has neonatal, child, juvenile, and adult forms and is a treatable disorder but when unrecognized or undertreated has significant morbidity and mortality. The incidence and prevalence in SSA are not well known, but studies performed in Tanzania and South Africa reported an incidence of between 3 and 8.5 cases per 1000,000 population, which is similar to that in high-income countries (Howlett, 2015a; Matuja et al., 2001; Mombaur et al., 2015). The age-standardized incidence rate for child and juvenile MG in South Africa is between 3 and 4.3 per 1000,000 (Mombaur et al., 2015). Transmission of nerve impulses to the muscle membrane is suboptimal, leading to muscle weakness and fatigability. These symptoms fluctuate depending on exercise and will be mostly worse after exercise or at the end of the day. The distribution of weakness can be generalized or more focal (ocular, bulbar). The latter causes weakness in chewing, dysphagia with nasal regurgitation of liquids, and dysarthria with hypernasal speech and a weak voice, especially after, respectively, eating or talking for a

while. Other symptoms can include drooping eyelids (ptosis), double vision (diplopia), and respiratory insufficiency. Diagnostics in high-income countries include blood sampling for antibodies, imaging of the chest, and electromyography. The clinical diagnosis can be confirmed by response to anticholinesterase drug treatment. Clinical management includes medication with a close follow-up of treatment effects and possible harmful side effects, as well as therapy from a speech-language therapist.

Speech-Language Therapy and Myasthenia Gravis

Patients with a CNS disease have a high risk of choking on thin fluids, whereas patients with neuromuscular diseases (NMD) lack the muscle power to swallow solids. The extent of this varies strongly between the NMD subtypes such as myasthenia gravis, myopathy, myositis, and motor neuron disease (MND). MND (such as amyotrophic lateral sclerosis [ALS]) can combine features of both. In CNS disease determined dysphagia, fluid thickeners are used, which can paradoxically worsen dysphagia in NMD (Engel-Hoek, van den, et al., 2015). Muscle weakness in MG generally worsens over the day (due to fatigue) and with sustained use of muscle groups. Chewing and swallowing can, therefore, worsen during one single meal, where typically jaw opening can be normal but jaw closure fatigable. Swallow training can, therefore, worsen complaints, and a patient is better resting prior to each meal (Kalf et al., 2008). Meals need to be adapted in terms of portion size and food texture. Helping to close the jaw can be achieved by placing a thumb under the chin (Fig. 23.9). Fluids can run back via the nose during swallowing, causing nasal regurgitation, and incomplete glottis closure can cause aspiration. The latter can be reduced by conscious swallowing followed by an "after swallow."

Many myasthenic patients have reduced facial expression and show the typical myasthenic "snarl" when they try to smile. The oropharyngeal muscle weakness causes dysphagia and hypophonic dysarthria by which articulation becomes less clear. Palatal muscle weakness brings about a hypernasal sound, increasingly audible when a patient needs to speak on end. In the case of severe muscle weakness, the tongue can show considerable atrophy (Juel & Massey, 2007). Neck flexors more than neck extensors are often also weakened, causing a "dropped head" syndrome. During meals and drinking, an optimal position is essential, which is in this case an elongated neck (Fig. 23.10). Sometimes a pillow will help support this posture (O'Rourke & Focht, 2013). If there is concern about safe swallowing, VFSS or FEES should be performed if available.

Fig. 23.9 The thumb under the chin

Fig. 23.10 The elongated neck

Myopathy/Myositis

Myopathy is a muscle disorder. The most common inflammatory myopathies are dermatomyositis and polymyositis. The prevalence in high-income countries is 5/100,000. Myositis causes pain and weakness of muscles and can involve the pharyngeal muscles causing dysphagia. Myopathy and myositis (or inflammatory/infectious myopathies) resemble one another strongly, but the painfulness in myositis is a conspicuous additional feature that should always be asked for in the case of muscle weakness. In SSA, inflammatory and drug-induced myopathies are more frequently seen in patients with HIV (Howlett, 2015a; Jowi et al., 2007).

Speech-Language Therapy and Myopathy/Myositis

Dysphagia occurs in 10–73% of patients with inflammatory myopathies/myositis (Mugii et al., 2016). As a result of oropharyngeal, laryngeal, and esophageal muscle weakness, pain may further impede function. For instance, one-third of polymyositis patients have dysphagia, with additional neck extensor weakness, difficulty in jaw opening, and facial weakness (Dimachkie et al., 2014). In dermatomyositis, muscle weakness often coincides with its typical skin lesions. In adults, skin lesions tend to precede muscle abnormalities. Dermatomyositis is a "red flag" in diagnosis, as it can be associated with a (sometimes unknown) malignancy, of which the chance is higher if there is significant dysphagia (Mugii et al., 2016). Patients with dysphagia often complain of weakness and pain in the masticatory muscles and have to swallow multiple times due to tongue weakness. Nasal regurgitation can also occur due to palatal weakness. Apart from adapted posture, food texture, and portion size, task-specific training can be considered in these disorders (Engel-Hoek, van den, et al., 2015). Even when a PEG has been inserted in cases of severe dysphagia, aspiration pneumonia may still occur (Carstens & Schmidt, 2014). In terms of speech quality, a hypotonic dysarthria with hypernasal speech and false air escape can be expected, also caused by profound facial and oropharyngeal weakness (Howlett, 2015a).

Combination of Central and Peripheral Nervous System Disorders

Motor Neuron Disease

MND includes a group of progressive neurodegenerative disorders that affect specific cells of the brain and spinal cord of which ALS is the most common entity. Patients with ALS present with slow but progressive pyramidal syndrome, peripheral-type weakness, muscle cramps, and muscle wasting, including the bulbar muscles. Typically, sensation will remain intact, although pain and entrapment neuropathies can occur in an advanced stage due to immobilization. The incidence rate is about 0.4–1.76 per 100,000 person years (Ropper & Samuels, 2009) in high-income countries and is not yet fully known in SSA (Quansah & Karikari, 2015). An estimated prevalence of MND in SSA is 5–15/100,000 (Lekoubou et al., 2014). Ten to twenty percent of patients with MND suffer from progressive bulbar/pseudobulbar palsy resulting in a spastic, immobile tongue with dysarthria, dysphagia, and relative hypersalivation progressing over months. Patients are usually over 60 years old, and survival is on average 3–5 years, with respiratory infection or failure being the most frequent cause of death (Howlett, 2015a).

Speech-Language Therapy and Motor Neuron Disease

ALS combines the dysphagia features with central and peripheral nervous system involvement. Dysphagia is a prominent symptom in the ALS patient, leading to aspiration, weight loss, and dehydration (Wijesekera & Leigh, 2009). There is an inadequate swallow reflex with an exaggerated gag as well as velar weakness. As a result of impaired arm and hand function, using cutlery or handling a toothbrush can be laborious (Offeringa et al., 2012). Again, an optimal posture with an elongated neck is essential. Additional tips in ALS are to avoid drinking right after eating solids, to clean the mouth after meals, to avoid conscious and forcible coughing, and to avoid lying down within 30 minutes after a meal (Schelhaas

et al., 2012). Drooling further increases the risk of oropharyngeal infections and aspiration. In the more advanced stages of the disease, a PEG can be considered. Speech problems occur in more than 60% of ALS patients and are a combination of low vital lung capacity and dysarthria due to both weakness and spasticity of oropharyngeal muscles (Green et al., 2013). Along with progressive motor problems, ALS patients can also develop cognitive impairment during the course of the illness, further impairing intelligibility and communication. If advice for optimization of voice use (dosage, speed) is not feasible due to the aforementioned combination of progressive features, then communication aides can be considered (gestures, writing and drawing, mimics, communication boards, or computerized assistance) (Wijesekera & Leigh, 2009).

Pitfalls

Unusual Speech and Swallowing

Background

In this section, we address nonorganic (also known as functional or psychogenic, see below) symptoms in two clinical entities, speech and swallowing. But in order to diagnose these, organic disease must be ruled out. There is a thin line between somatic complaints and psychologically determined experiences, which may present just like physical complaints. In the area of neurology, this line is even thinner. Commonly, neurologically imposing symptoms or signs are seen in individuals who unconsciously use this as a vehicle of their mental unwell-being (Schwarz & Snijdewind, 2010). This means that whether the cause reveals itself as organic or nonorganic, every patient should be taken seriously in his or her own right. In SSA, functional neurological disorders often present with abnormal movements or paralysis, unlike the pattern in affluent countries where pain syndromes occur more often—possibly indirectly facilitated by the higher rates of medical insurance allowing for ample additional investigations into a cause (Kellogg et al., 2016). However, genuinely neurological movement disorders can also cause difficulties with talking and swallowing and may be hard to differentiate. A solid grasp of mouth and throat anatomy and basic tips and tricks to tell apart functional (seemingly neurological but nonorganic) and real neurological phenomena is essential in the field of SLT. Importantly, if no anatomical cause can be demonstrated and a nonorganic cause is considered likely, it does not mean that a patient is not unwell. From transcultural psychiatry, it is known that mental health issues such as depression and anxiety or underlying psychotrauma often tend to translate themselves into disorders of speech, language, and swallowing (Kortmann, 2010). The presence of the above symptoms, however, obviously the psychogenic cause may be, warrants a serious assessment of the reasons why the patient presents with exactly this complaint at this moment (Schwarz & Snijdewind, 2010). In general, functional presentations are more often present with negative symptoms, like mutism and whispering, than positive signs like stuttering or vocalization. It is essential to assume an organic cause until proven otherwise and perform a full neurological examination (including gag reflex and tongue muscle bulk and agility) (Howlett, 2015a). The art is to actively hunt down clues for the dysfunction of neurological systems locally or elsewhere. If inconsistencies are found, patients with functional neurology also need to be taken seriously with counseling and feedback upon the findings, while trying to probe for underlying psychological stressors in the patient.

Mutism

Mutism is the absence of speech, whether due to a psychological cause or organic inability. It differs from aphonia, where one attempts to vocalize, but no sound is being produced. Organic causes can be a frontal syndrome due to pathology in the frontal lobes of the brain; acute vascular events of, for example, Broca's area in the motor strip of the dominant hemisphere (which is the left hemisphere in all right-handed and in the majority of left-handed people); and, especially in childhood, in cerebellar lesions such as after posterior fossa surgery (Catsman-Berrevoets et al., 1999). Mutism can also encompass a functional neurological disorder. Some differentiating features for functional mutism are an otherwise normal neurological and

local oral examination with intact comprehension and swallowing but often a history of psychotrauma, depression, or another psychosocial stressor. In children, specific attention should be granted to the possibility of child abuse (physical, emotional, or sexual) and whether there is any selectivity in whom they are mute with (selective mutism), and in adults, the concurrence of psychiatric disease such as schizophrenia or vital depressive symptoms should be considered.

Hypophonia/Aphonia

Hypophonia or even aphonia is the reduction or absence of sound in speech. In the case of a patient who can only whisper, it is important to test the sound produced when coughing. When someone can only whisper, this suggests incomplete or asymmetrical closure of the larynx by a mechanical or neurogenic cause. In SSA, it is particularly important to rule out vagus nerve dysfunction, which can be caused by compression by mediastinal lymphadenopathy due to, for instance, hilar pulmonary tuberculosis (Grange & Zumla, 2003) or malignancy. However, if the sound produced by a voluntary cough is normal, it implies that the vocal cords (Fig. 23.11) can close sufficiently through the vagus-mediated semiautonomic cough reflex and that sound production is organically possible. If the cough sound is absent or abnormal ("bovine cough," the sound of a cow coughing: hoarse and blowing), this supports the presence of an underlying organic cause. Furthermore, it is important to look for fatigability, where the voice sounds more or less normal initially but wears off into hypophonic whispering with false air escaping as speech is prolonged (e.g., when counting aloud from 1 to 30), implying fatigable muscle action as seen in the neuromuscular transmission disorder myasthenia gravis.

Stammer

Stuttering or stammering is a widespread problem in children and is thought to be a maturation problem of the basal ganglia circuits (Nass & Ross, 2009). It often wears off as the child grows older but can persist over the lifetime, causing substantial psychosocial suffering. A newly arisen stammer can be a functional neurological disorder resulting from psychological distress, and sometimes children who used to have a stammer will relapse when they experience psychologically stressful moments in their lives, like interviews or presentations. It might also be a sign of dysdiadochokinesia (the inability to sustain alternating movements with the limbs, tongue, or vocal cords) in an emerging extrapyramidal disease like parkinsonism. So, especially in adults with an acquired stammer, a neurologist must always look for pyramidality, parkinsonism, or dystonia in the neurological examination.

Vocal Tics

Vocalization and vocal tics (such as coprolalia) are often organic in etiology. The syndrome consisting

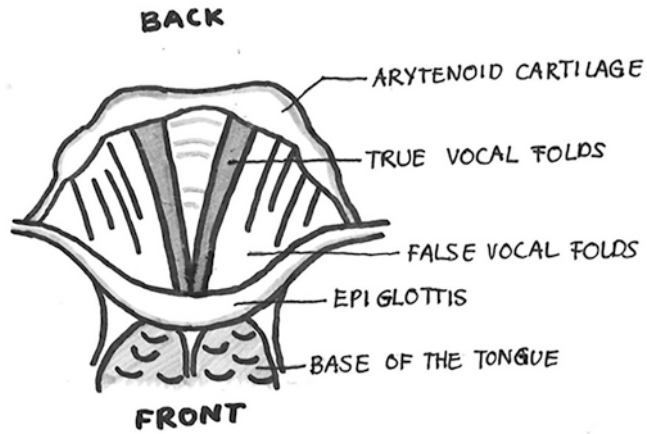

Fig. 23.11 Vocal cords

of compulsive and involuntary motor and vocal tics and behavior, Gilles de la Tourette's syndrome, is the most well known. An acquired, postinfectious mechanism (Sydenham's chorea) can cause a severe and subacute motor variant sharing neuropsychiatric features with Tourette's syndrome. When not recognized, the associated severe cardiac complications could be missed. Vocal tics and sounds can be functional when movements appear atypical for tics and chorea, but the concurrence of motor and vocal phenomena should be analyzed with care: odd vocalization should always prompt a motor exam.

Globus Sensation

Globus sensation is the experience that there is a lump in the throat despite clearing and coughing. It is of primordial importance to rule out mechanical obstruction in any age. In children, this can be a foreign body lodged in the pharynx, but in adults, this can be anything from an innocuous fishbone to an undetected malignancy. "Globus hystericus" is a rather old-fashioned term used for cases where this sensation persists despite ruling out mechanical obstruction, and other complaints of anxiety, somatization disorder, or depression are present. Insidious dysphagia, often presenting with chronic cough and the idea that the throat cannot be cleared sufficiently, can actually be attributed to a neurological motility disorder of the esophagus, so clues for underlying pyramidal signs or muscle weakness, connective tissue disease (like the CREST syndrome where multiple rheumatological symptoms and signs are associated with esophageal motility impairment), or achalasia are important. Concomitant speech problems or facial weakness will provide important clues to validate those largely subjective symptoms.

Dysphagia

Acute dysphagia can occur in isolation and may look functional by its absence of obvious other signs or symptoms. A classical pitfall consists of focal brainstem lesions, which can cause acute isolated dysphagia, or in combination with seemingly incoherent sensory, cranial nerve, or cerebellar signs. The most well-known example is Wallenberg's syndrome, an acute ischemia in the posterior inferior cerebellar artery (PICA) territory that can occur in persons with vascular risk factors but also in younger individuals with a traumatic or spontaneous vertebral artery dissection (Warlow et al., 2009). The vertebral arteries run through the foramina in the lateral cervical vertebrae where they are especially vulnerable to vessel wall injury, leading to ischemia distal of the dissection (PICA area) that may only be demonstrated by MRI, which is often unavailable in the African setting.

Culturally Determined Pitfalls

Background

Superstition and the desire for alternative treatment play a role in neurological disorders worldwide but particularly so in SSA regions. When you live far away from modern healthcare facilities, are not optimally informed, and have little or no money to spend on health, opting for culturally well-accepted local treatment strategies is natural and to be expected. By their sheer vicinity, traditional healers play an important role in first-line healthcare, and this is most pronounced in the rural regions in SSA (Njamnshi et al., 2010). In the arena of mental healthcare, some effectiveness, for example, for features of mild and moderate depression, has been demonstrated in a large meta-analysis (Nortje et al., 2016). The most important risk factor associated with traditional healers is the consecutive delay in obtaining established medical treatment options. Especially in organic disorders of the upper airways, applying traditional remedies may lead to critical patient treatment delay. Occasionally, the interventions may even be downright harmful due to their invasive or toxic nature.

Uvulectomy

In various parts of Africa and the Middle East, the practice of uvulectomy, surgical removal of the uvula, has been performed over many centuries (Mitke, 2010; Ravesloot & de Vries, 2011). Many of these take place in early childhood. Much of this invasive pharyngeal surgery is conducted not by medical professionals but by others such as traditional healers and barbers (Manni, 1984). The complications range from severe anemia and

shock, aspiration of the cut uvula, to infections such as tetanus. The idea that the uvula is an abnormal midline structure interfering with breathing and swallowing is widespread and has persisted through time in regions far beyond SSA. In previous years, this midline structure, which means "little grape" in Latin, had several myths associated with it (Fig. 23.12). A senior Tanzanian pediatrician describes his study in rural Northern Tanzania where an excess mortality of about 400 children was attributed to traditional medicine practice, ranging from the complications of uvulectomy to kidney failure by traditional herb administration. Upon further clinical analysis of the uvulectomy cases, many of the patients had evident treatable disorders like pulmonary tuberculosis or whooping cough (Olomi, 1982).

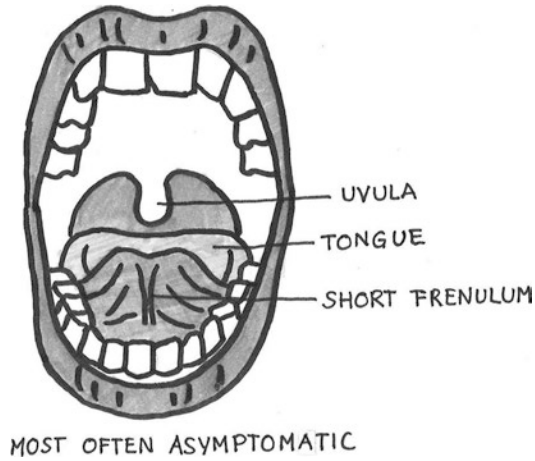

Fig. 23.12 Open mouth

Frenulotomy

An example of an intervention in later childhood based on neurological misperception is that of tongue frenulotomy, which is practiced all over the African continent. In this procedure, surgical release of the anterior frenulum is performed, which is the midline mucosal structure connecting the tongue to the bottom of the oral cavity (see also Fig. 23.12). This operation is often performed based on the incorrect belief that a shortened frenulum ("tongue tie" or ankyloglossia) causes mutism or speech and language delay. With intact higher cortical function, however, a mechanical restriction usually does not stop someone from producing speech altogether. Frenula have a wide anatomical variation in length (Wright, 1995). With a significantly short frenulum, genuine restriction of the tongue's range of motion would cause feeding problems long before the milestone of vocalization. Babies would already present during breastfeeding with difficulties in nipple latching and sucking. More often than not, however, a congenitally short frenulum, which is often a familial trait, will not cause any functional impairment. In the case of a symptomatic short frenulum, children may develop a mechanical speech impediment—but not a neurological dysarthria. Language delay is unlikely to occur, as the neurodevelopmental drive to speak and communicate is intact, even if there is a mechanical dysarthria. In case of a child with a seemingly short frenulum and a developmental delay leading to a speech and language deficit, the "tongue tie" is often blamed. A frenulotomy is already known to be of dubious significance in true ankyloglossia, with common complications (e.g., scar formation, torsion) and relapse (Suter & Bornstein, 2009). It will not change a child's speech and language delay, giving rise to disappointment in the patient's unchanged neurological performance, thus hampering acceptation and causing grief and stress. Moreover, there is a sizable risk of postoperative distortion and contractures of the tongue leading to secondary dysarthria.

Implications

Widespread traditional interventions in patients with speech, language, and/or swallowing problems bring unnecessary cost and high risks. In Northern Tanzania, we admitted neonates with severe anemia and infection due to excessive bleeding and infection after uvulectomy by traditional healers. Not all of those babies survived. Logically, we can reason against this, but the practice of uvulectomy and frenulectomy has persisted throughout centuries in large parts of the world and remains a current practice. With increasing global migration, these phenomena will be seen not only locally in SSA but also, perhaps unexpectedly, by health professionals in other parts of the world.

Discussion

This overview of the most common disorders presents only a representation of the overall burden of neurological disease in SSA. What all these diseases have in common is the extent of speech and swallowing dysfunction in their respective morbidities (Martins et al., 2012). In a resource-limited society, SLT may not appear the first priority in neurological patient care where many are still dying from the primary disease. But nothing could be less true. Every patient with a neurological disorder and his or her caregivers will know how time-consuming and dominating the problem of dysphagia is or the frustration of not making oneself understood.

If everyone in SSA had access to SLT, it would significantly reduce early death from aspiration pneumonia, malnutrition, and antibiotic resistance. It would leave patients and caregivers better informed about the "do's and don'ts" of feeding, making them feel more confident in providing home care. It would grant patients attention and acknowledgment of their speech impediments and communication disabilities without creating false expectations. The vis-à-vis interaction with neurological patients as such is already a boost for their mental well-being, as many turn out to suffer from depression as a by-effect of neurological disease (Hesdorffer, 2016).

Most importantly, we would be able to raise the standard of multidisciplinary care, such that the boundary is approached between untreatable deficits and those that can be optimized. This is the limit of optimal rehabilitation care anywhere in the world and obtainable by SLT in our setting. There is nothing more frustrating than uninformed, uninstructed patients and caregivers who, by means of some practical SLT sessions, could have improved quality of life for their neurological peers as well as for themselves. SLT is able to fill in this gap and has an important role to play in the upcoming silent epidemic of noncommunicable disease in SSA.

Acknowledgments This chapter is dedicated to Hilda, a young bright Tanzanian schoolgirl who sadly died from aspiration in juvenile myasthenia gravis—a treatable disorder. Credit is given to all our Tanzanian patients and our colleagues in the Kilimanjaro Christian Medical Centre, Moshi, Tanzania (Artwork and copyright: JB Bulsink 2016).

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Active Aging with Aphasia: A Case of Kiambu County, Kenya

24

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Motive/Research Question

This study investigated active aging with aphasia in Kiambu County, Kenya. The objectives of the study were the following:

1. To determine the gender most affected by aphasia in Kiambu County.
2. To establish how those in Kiambu County living with aphasia receive information and interact with others without aphasia.
3. To examine the community participation of persons with aphasia.
4. To determine economic influences on disability in the participants in Kiambu County.

Problem Background

While aphasia may occur at any age, the majority who acquire the disorder are older people. One reason for this is due to the high number of elderly individuals encountering strokes. There is a high incidence of stroke in Africa, aggravated by the fact that patients in Africa may be affected by stroke 10–15 years younger than those in high-income countries (Lemogoum et al., 2005). In fact, 23–35% of stroke survivors have aphasia (Flowers et al., 2013), causing it to be the primary cause of this disorder among older individuals. Other brain injuries resulting in aphasia include head trauma, brain tumor, and degenerative processes such as dementia or infections such as meningitis (Schoeman & Van der Merwe, 2010). Aphasia is an acquired impairment of language which can affect all language components across all modalities, such as the production and/or comprehension of speech and the ability to read or write (Papathanasiou et al., 2013). This occurs due to a focal lesion in the area of the brain that controls speech and language or when the neural pathways connecting them are damaged. Damage affecting speech and language can occur in Broca's area, Wernicke's area, angular gyrus, auditory cortex, motor cortex, or visual cortex (Schoeman & Van der Merwe, 2010). As aphasia is caused by a focal lesion to the language-dominant hemisphere of the brain, symptoms are not a consequence of cognitive impairments, such as those which are present after a closed head injury (Papathanasiou et al., 2013).

In Kenya, there is an urgent need to address the problems of cultural and language bias in assessing African persons with aphasia. There are few neuropsychological measures that have been properly validated for use among culturally and linguistically diverse individuals (Manly, 2005). Furthermore, due to widespread socioeconomic hardship in African low- and middle-income countries, appropriate psychological services are available to the minority, not the majority, of the population (Mosdell et al., 2010). The need for special care for the elderly is increasing over time and is expected to become much higher as the quality of life in Kenya improves and the population of the elderly increases. Gitonga (2013) indicated that as the quality of life improves, more people in Kenya are able to afford nursing services for their elderly, which includes placement in homes for the aged. Due to globalization, children are frequently moving abroad, leaving their aged parents with no one to care for them. The best option they have is then to place them in homes for the aged. The Kenya Vision 2030 is a long-term development proposal for economic, social, and political growth (Government of the Republic of Kenya, 2007). Within the social pillar of this plan, there is a flagship project focusing on vulnerable groups to which the aged belong. It is within this context that this study investigated active aging with aphasia in Kiambu County, Kenya.

Theoretical Background

Global Overview of Aphasia and Aged Adults

Aphasia is an acquired language disorder of neurological origin that impairs the expression and reception of language (Hallowell, 2016). This language disorder usually occurs in adults who already have well-developed language. Being able to use and understand language for their entire adult life and

losing this ability all of a sudden has, in a lot of cases, a severe and debilitating effect on a person's life. Given the acute onset of the disorder, persons with aphasia are confronted with life-changing impairments. Aphasia affects a person's ability to understand (reception) and produce language (expression) across all language modalities, causing communication activity limitations and participation restrictions (Davidson et al., 2013). It is important to know that aphasia is defined as a language disorder not "a sensory, psychiatric, or intellectual disorder" (Hallowell, 2016, p. 4). Although there is a scarcity of stroke incidence and prevalence studies in sub-Saharan Africa, the incidence in Nairobi Hospital may be as high as 3042 per 100,000 (Jowi & Mativo, 2008) while the incidence in a referral hospital in western Kenya was 568 per 100,000 (Oduor et al., 2015). It may be difficult for a person with aphasia to understand and fully grasp the meaning of written materials and spelling. Also, they might find it hard to understand number-based concepts like telling time or counting money (American Speech Hearing Association, n.d.). Persons with aphasia report difficulty participating in activities which require reading comprehension while adults without aphasia are involved in a variety of reading practices on a daily basis (Brennan et al., 2005). Aphasia may interfere with a person's ability to use and understand health-related information and forms in a medical setting. If persons with aphasia do not have access to health-related documents or have the ability to comprehend the material, they may withdraw from participating in their healthcare, which could impact their quality of life and their access to healthcare information (Davidson et al., 2005).

Aging by itself requires good management for all. Darling and Heckert (2010) assert that disability increases with age. Sheets (2005) recognizes that aging persons with disability are faced with age-related challenges such as fatigue, pain, and functional decline like muscle weakness and mobility limitations just like other persons, but theirs is superimposed on their disabilities. Sometimes there is premature aging in persons with disability, with the above symptoms occurring 15–20 years earlier than in most people (Hayes et al., 2010; Heller & Sorenson, 2013; Sheets, 2005). Environmental issues, access to medical services, and associated disability are some of the factors seen as related to earlier than normal deterioration of the quality of life in persons with disability (Heller & Sorenson, 2013). According to Sheets (2005), apart from discrimination against persons with aphasia in job placements, there are instances where aging early may force them to retire early, before they have made arrangements for their livelihood later in life. The need for health-promoting behaviors in aphasia, such as healthy nutrition, physical activities, and routine primary medical screenings, has been noted by Heller and Sorensen (2013).

It has also been noted that adults with aphasia and chronic conditions receive less preventive health services than those without aphasia, yet most of them are at high risk for high-cost debilitating conditions (Reichard et al., 2011). Furthermore, according to the World Report on Disability, physicians lack training about caring for persons with disability (Iezzoni & Long-Bellil, 2012). Although these authors state that efforts are being made in the United States to incorporate relevant skills in the training of physicians currently, there is not much information about this happening elsewhere in the world. Rather, medical nonuse in African countries such as Malawi has been linked to poor attitudes in health workers as well as communication barriers which result from a person with disability being unable to speak (Munthali et al., 2014). The lack of competence among physicians compromises the healthcare outcome of those with disabilities (Iezzoni & Long-Bellil, 2012), including those with aphasia. Iezzoni and Long-Bellil (2012) suggest that persons with disability should be involved in the design of training programs for future healthcare professionals. This should ensure that the competencies gained by the healthcare professionals are aligned with the management and care issues related to aphasia. For example, medical support staff will likely be enriched to support active aging in persons with aphasia and to significantly ameliorate possible risk factors.

Another factor which is increasingly recognized as important to support the health, independence, and life satisfaction in the elderly is active participa-

tion (Raymond et al., 2014). Since active aging with aphasia requires active participation within the community, relevant support is required to train staff working with these individuals (Riches et al., 2009). The depth and rigor of the training would depend on the severity of the aphasia. Riches et al. (2009) recognizes the importance of availing resources necessary to provide support that would result in persons with disability being active participants in their contexts (such as "staff doing *with* rather than *for* individuals," p. 327). Participating recurrently in religious, civic, and recreational activities may further buffer individuals with functional limitations from the negative psychological effects associated with declining functional health (Greenfield & Marks, 2007).

Ellison et al. (2011) compared the impact of allowing aged persons with aphasia to remain in the community and receive assistance rather than institutionalizing them. Findings indicated that those in community-based care were better off because they thrived on developing relationships, continued using their skills, and participated in community activities. Another factor to consider is obesity, caused mostly by sedentary lifestyles and type of diet, as it plays a role in increased difficulties with the physical functioning of aging persons with disability (Martin & Schoeni, 2014). In short, remaining active within the community – even if it means being given some level of assistance – is beneficial to aging persons with disability, especially those with aphasia.

Persons with aphasia younger than 50 years old may experience employment challenges and lower incomes compared to the able-bodied persons of the same age (Clarke & Latham, 2014). The aforementioned authors related poor health behaviors like smoking, obesity, and sedentary lifestyles to more functional restrictions to aphasia. They concluded that aphasia made individuals more vulnerable to poor health and a lack of financial independence. Agree (2014) observed that the health and quality of life can be improved in the aging population through technology.

Agree (2014) asserts that research into assistive technology devices for persons with disability signified a possibility for the development of powerful individualized tools to assist in meeting their needs. Cohorts growing older with these resources would have more assistance than their peers. For those with complex communication needs, augmentative and alternative communication (AAC) can provide access to functional communication (Beukelman & Mirenda, 2013). This may include the use of technology, such as voice output devices. There is currently a paucity of services that provide AAC for individuals with complex communication needs in low- and middle-income countries, possibly due to the large rural population, limited resources, and poor economies (Muttiah et al., 2016). Furthermore, there are only a small number of speech–language therapists (SLTs) in Africa, with a large burden of disability (Wylie et al., 2013). Thus, technological devices should receive more attention, and persons with aphasia should be trained to use them to foster a better quality of life.

The important question to consider therefore is how persons with disability such as aphasia in Kenya are positioned to achieve helpful behaviors and facilitation toward healthy aging. As seen by Raymond et al. (2014), the most important ingredient is what is located within the persons themselves. This raises the question of equipping the persons with disability such as aphasia for their entire life spectrum so that they take hold of healthy options for themselves. This study explored the position of the aged persons with aphasia as they transition to retirement years with respect to how well they are prepared to achieve healthy livelihood and life satisfaction in that stage of life. The study focused on how education influences and interacts with other factors in enhancing their graceful retirement (Raymond et al., 2014).

Types of Aphasia

According to the book *Aphasia and Related Neurogenic Communication Disorders* by Papathanasiou et al. (2013), various types of aphasia can be listed in relation to the part of the brain affected. A focal lesion in a specific area of the brain results in a spe-

Table 24.1 Types and subtypes of aphasia. Based on Papathanasiou et al. (2013), Schoeman and Van der Merwe (2010)

Fluency	Subtype	Brief description
Nonfluent	Broca's	Characterized by nonfluent, effortful speech in the presence of comparatively good comprehension of spoken language. Broca's aphasia may vary from a complete inability to speak to the use of telegraphic speech or mild word-finding difficulties. This may affect written language in a similar way.
	Global	Global aphasia includes severe deficits in all aspects of language, including naming, repetition, comprehension, reading, and writing. Speech is often reduced to only a few stereotypic utterances.
	Transcortical motor	While comprehension and repetition are preserved, phonemic paraphasias are present along with a lack of connective words. In some cases, passive echolalia is present.
	Mixed transcortical	This rare form of aphasia combines signs and symptoms of both transcortical motor aphasia and transcortical sensory aphasia. Despite a severe impairment in speech, comprehension, reading, and writing, the patient's repetition remains intact.
Fluent	Wernicke's	Despite the presence of a severe deficit in auditory comprehension, speech is fluent and spontaneous. This causes incoherent speech where patients are usually unaware of their language disorder. In severe cases, this is called jargon aphasia. Further impairments are present in repetition, writing, naming, and reading aloud.
	Anomic	Speech output is fluent and grammatically correct, characterized by word-finding difficulties, particularly when naming objects. Language comprehension and repetition are intact.
	Conduction	While spontaneous speech production remains relatively normal, phonemic paraphasias and word-finding difficulties are present. Repetition is compromised; however, comprehension is spared. Patients may also experience difficulties when reading aloud, naming, and writing.
	Transcortical sensory	Similar to Wernicke's aphasia, comprehension is impaired with fluent but meaningless speech. However, these patients have preserved the ability to repeat, which sometimes results in echolalia. Reading, writing, and naming are also severely impaired.

cific aphasic syndrome. These can be divided into two main categories, namely, fluent and nonfluent aphasia. Within these two categories, eight subtypes of aphasia exist (Schoeman & Van der Merwe, 2010). Table 24.1 summarizes the main symptoms of each of these subtypes (Papathanasiou et al., 2013; Schoeman & Van der Merwe, 2010).

Aphasia in the Sub-Saharan African Context

In South Africa, culture is a phenomenon which cannot be easily defined but rather is "enmeshed with ethnicity and socioeconomic status" (Mosdell et al., 2010, p. 250). Studies have shown that culture impacts the functioning of neuropsychological tests among patients with aphasia (Ardila, 2007; Rosselli & Ardila, 2003). Furthermore, the African perspective on the origination of aphasia is influenced by culture. According to Legg and Penn (2012), this may be reflected in a combination of ancestral, witchcraft and sorcery, social and biomedical explanations, which vary from individual to individual. As an example, "people did not only need to understand the medical nature of stroke; they were also concerned with questions of "why me/him/her?", "why now?", and "who did this?" This would seem to be central to the African conception of illness" (Legg & Penn, 2012, p. 14).

Fidel Castro of Cuba once asserted that a country is developed in the way it takes care of its citizens with disabilities and special needs (Kenya Institute of Curriculum Development, 2012). Many governments, Kenya included, would fully support this view today. From 2003 to date, the government of Kenya has endeavored to introduce vital legislative, educative constitutions, and economic changes that have tremendously benefited many Kenyans with disabilities (Gitonga, 2013). These changes include the

Disability Act of 2003 which established the National Council for Persons with Disabilities (NCPWD; Republic of Kenya, 2004), which is charged with the following responsibilities in relation to persons with disability: realization of rights, employment, reservation of employment, apprenticeship, prohibition of discrimination by employers, incentives to employers, records for job placement, sponsorship for formal education and special education, health, accessibility and mobility, modification of public buildings, public service vehicles, adjustment orders, denial of admission to premises, schools and other public places, sports and recreation, voting and polling stations, registration of organizations, national development fund, trustees to manage the fund, tax exemptions for workers with disabilities, incentives, credit, legal system, TV programs, telephone services, postal charge exemption, requirements of exemptions, regulations, concealment of persons with disability, negligence by doctors, giving false information to get registered, general offenses and penalties, and request for legal assistance for persons with disability by the Attorney General.

The government, through the NCPWD, encourages the establishment and registration of organizations for persons with disability including those with aphasia through the Ministry of Gender, Sports, and Social Services, which are economically empowered in a bid to eradicate poverty (Republic of Kenya, 2004). Through the cash transfer programme, the government has begun paying monthly allowances to the majority of persons with disability, including those with aphasia (Republic of Kenya, 2004). The Constitution of Kenya (2010) has also opened a lot of opportunities to all persons with disability including those with aphasia, which include nominations of members to national parliament and counties. Article 54 of the constitution clearly recognizes that dignity and respect for persons with disability should be accorded. The Persons with Disabilities Act, No. 14 of 2003, is a legislation that covers the rights of persons with disability, including the concept of equal employment opportunities (Republic of Kenya, 2004). Further enactment after the current review by the parliament is expected to increase employment opportunities for persons with disability, including persons with aphasia, in political as well as civil sectors (Mudora, 2016).

Methods

Research Design

A quantitative survey design was used. This method allows participants to answer specific questions about their behaviors, attitudes, and emotions (Mrug, 2010). Survey research designs allow researchers to deduce information about a large population based on a relatively small sample of that population (McMillan & Schumacher, 2010).

Participants and Sampling Methods

Snowballing sampling was applied with the following inclusion criteria:

(a) Participants with a diagnosis of moderate to severe aphasia;
(b) Participants residing in Kiambu County, Kenya;
(c) Participants over 50 years of age.

Initially, 50 participants were identified. However, only 28 participants were sampled for the study as they adhered to all of the inclusion criteria. The participants were 51–68 years old (10 females and 18 males). The participants had been discharged from hospitals and were living in the community.

Instruments

Questionnaires

A questionnaire consisting of 20 items was developed, consisting of both close-ended and open-ended questions. Close-ended questions allow the participants' responses to be coded and categorized (McMillan & Schumacher, 2014, 2010) while open-ended questions provide more in-depth, comprehensive information (Mrug, 2010). The questionnaire was divided into the following four sections:

(a) Section one contained items to collect data on demographic characteristics such as gender and age.
(b) Section two contained items to collect data on reception and interaction with others without aphasia.
(c) Section three contained items related to the advantages of effective social inclusion of persons with aphasia.
(d) Section four contained items related to the effectiveness of economic empowerment in persons with aphasia.

Data Collection

A research permit was obtained from the National Commission for Science, Technology and Innovation. Data were then collected using questionnaires over a period of 1 month. The participants were living in the community; hence, the data were collected in situ. The first interaction was to obtain the consent of the participants. This was obtained by filling and signing the consent form after explanation in local language for ease of understanding. The data were collected by the researchers with the help of trained research assistants. To ensure confidentiality, the participants were told that the information obtained would be used entirely for research, after which the evidence would be destroyed. To compensate for their time, a small token was offered. The information was recorded on paper as the respondents narrated and hence recorded immediately. To confirm accurate recording, it was read back to the respondents for their confirmation. The records were carefully filed and safely stored for future reference. During the first week, piloting of the instruments was carried out in Thika Sub-County with a separate group of five participants (three males and two females) to confirm the reliability of the instruments using the test-retest method. In the first week, the instruments were tested, and then administration was repeated 2 weeks later. The results were correlated indicating a reliability coefficient of 0.75, and hence the instruments were deemed reliable.

Data Analysis

Data were coded onto the scoring sheet and then entered into quantitative analysis software, the Statistical Package for Social Sciences (SPSS) version 22 (IBM Corporation, 2013). Descriptive statistics were used to determine the mean, range, and standard deviation of the scores. Analyzed data were then presented with graphical representations of frequency distribution tables and bar graphs.

Results of the Study

Demographic Information of the Respondents

Sampled Respondents by Gender

Findings revealed that 64% of those interviewed were male (n = 18) while 36% were female (n = 10). The sample captured a reasonable representation of each gender. Figure 24.1 shows the persons interviewed by gender.

Age of the Respondents

The respondents ranged from 51 to 68 years of age. These ages represent the ages within the population that tend toward retirement in the Kenyan context and were deemed capable of revealing the aging pattern among persons with disability such as aphasia. Two respondents did not indicate their age and were excluded from further analyses concerning age. Therefore, the sample size was 26 instead of 28. The mean age was 60.46 with a standard deviation of 4.961. In Kenya, the retirement age has been on average 55 years. It has recently been raised to 60 years for nondisabled workers but 65 years for persons with disability including aphasia (Republic of Kenya, 2004). An indication of engagement with life between the ages of 51 and 68 years can, therefore, be predictive of the nature of aging among persons with disability especially those with aphasia.

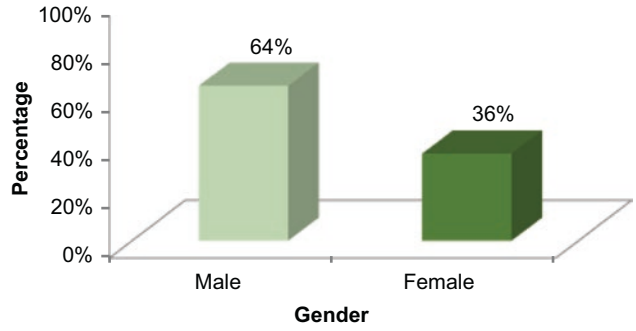

Fig. 24.1 Distribution by gender

Severity and Type of Aphasia by Gender

From Table 24.2, it is evidently clear that the males were more afflicted than females with aphasia across all types of aphasia. A study by Roberta and Ellen (1999) examined the effects of group communication treatment on linguistic and communicative performance in adults with chronic aphasia and found that the anomic type of aphasia was equally severe in both male and female participants aged above 60 years. These findings are also supported by a study by Yao et al. (2015), which explored the relationships between types of post-stroke aphasia by gender age and stroke types, and revealed that male patients (69.23%) had a significantly higher morbidity of aphasia than females (30.77%) after stroke ($\chi 2 = 11.57$, $P = 0.003$), especially those under 65 years old (73.38%).

Table 24.2 Types of aphasia by gender

Type of aphasia	Gender	$n = 26$	Total
Fluent	Male	07	10
	Female	03	
Global	Male	08	11
	Female	03	
Nonfluent	Male	03	05
	Female	02	

Ways in Which Aged Adults Receive Information and Interact with Others Without Aphasia

The respondents were also asked to respond to the question on how they receive information and interact with others. Life informants were relied on by 42% of the participants, while cell phones were used for this purpose by 46% of the participants. A further 4% of the participants used media while 8% indicated that they had no way of interacting with others or receiving information (see Table 24.3).

Age Variations and the Methods Used for Receiving Information and Interacting

The results of this question were further organized according to the participants' ages to reveal any variation. Of the 11 participants who reported relying on life informants, 7 were between the ages 60 and 64. One person was classified as 54 years or below, and three were classified as 65 years and above. It is important to note that these two categories consisted of the majority within the population, considering that the average mean was 60.46 years with a standard deviation of 4.961. Only the category of 60–64 years had two people who report that they lacked a way of receiving information and interacting with others. Therefore, this category (60–64 years of age) had 36% out of a total of 45% without a way of receiving information or interacting with others that were dependent on them. The remaining 9% of the total of 45% relied on cell phones to receive information and to interact with others.

Further, respondents were asked to identify the ways through which they received informa-

Table 24.3 Distribution of methods used to receive information and interaction by age category

Method of interaction/ information	50–54 years	55–59 years	60–64 years	65+ years	Total n = 26	Percentage
Life informants	1	0	7	3	11	42%
Cell phones	1	4	2	5	12	46%
Media	1	0	0	0	1	4%
None	0	0	2	0	2	8%
Total	3	4	11	8	26	100%

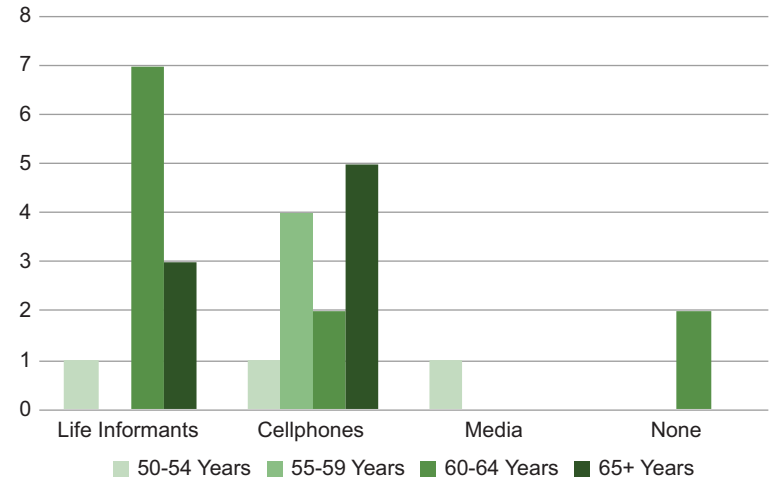

Fig. 24.2 Ways of receiving information from others without aphasia ($n = 26$)

tion from others without aphasia. The findings were discussed and presented based on age category as shown in Table 24.3 and Fig. 24.2.

The majority (13 people) relied on either media or cell phones to receive information. Among these, only one person reported using media, and they were in the age category of 54 years and below. Interestingly, of the majority of people who reported using cell phones, five people were of ages 65 years and above, and two people were of ages 60–64 years, totaling to a number of seven people aged 60 years and above using cell phones. This result could be an indicator that the pursuit by persons with disability, especially those with aphasia, to gain self-reliance through the use of technology may not be a factor of age but perhaps of personal and environmental factors such as education, the severity of aphasia, personality, or social climate around their nurturing. The other five who relied on cell phones for their interactions and reception of information were aged 59 years and below. All the persons sampled between 55 and 59 years reported to use cell phones, but of those 54 years and below, one person used life informants, one used cell phones, and another one used media. This distribution affirmed that more than the age factor was involved in determining the medium used by respondents for interactions with their world. The participants were allowed to give multiple answers, but each participant only gave one answer as shown in Table 24.3 and Fig. 24.2.

Participation in the Community

The results showed that only females (4%) participated in home care activities and only males (4%) did sports training. The 4% who provided company to others with disabilities were all males. The comparison of gender engagement in life shows that both males and females are equally

Table 24.4 Level of education

	Frequency	Valid percent
Primary level	5	17.85
Secondary school dropout	5	17.85
College	4	14.28
O level	3	10.71
University	5	17.85
Postgraduate	4	14.28
None	2	7.14
Total	28	100

engaged. The majority of respondents indicated that "business" was a preferred retirement activity, while 4% recommended "employment" as an activity.

Economic Determinants and Their Influence on the Participants

Out of the 28 participants with aphasia, 14 (50%) had adopted coping strategies to communicate with families. Coping strategies are learned patterns used to cope with and deal with new situations. However, only five participants (17.9%) had aided systems. This implied that a bigger portion of persons with aphasia in Kiambu County has not been economically empowered and thus could not afford these systems. Looking at the level of education of the participants, it varies from no or primary education to postgraduate degree (see Table 24.4). Furthermore, it was found that a number of participants resorted to begging as a way to survive. Although most of the persons begging (15%) were above 65 years, the others (10%) were younger, implying that their begging may be due to factors other than age. A comparison of the educational background of the respondents provided more insights. All the participants with no education, and a good portion of those with only primary-level education (14% of the total respondents), were the people begging. Table 24.4 represents the education level of the participants.

Discussion

Gender and Aphasia

Of the aged adults with aphasia who participated in this study, the majority were male. This finding is in disagreement with that of Davidson et al. (2008) who found no difference in gender concerning the prevalence of aphasia. This discrepancy shows that gender has no significance for the prevalence of aphasia among aged adults. Findings revealed that the majority of both male and female adults with aphasia had anomic aphasia. The numbers were lowest for the global aphasia subtype in both genders. A study by Elman and Bernstein-Ellis (1999) found that anomic aphasia was equally severe in both male and female participants at the ages of 60 years and older. These findings are also supported by a study by Yao et al. (2015) which explored the relationships between the types of poststroke aphasia with gender, age, and stroke types and revealed that male patients have a significantly higher poststroke morbidity of aphasia, especially those younger than 65 years old. Female morbidity increases after the age of 65. However, gender had no significant influence on the types of aphasia, with Broca's aphasia being the most prevalent in both males and females (Yao et al., 2015).

Ways in Which Aged Adults Receive Information and Interact with Others Without Aphasia by Age Group

The use of cell phones and media among 51% of the respondents is positive. In fact, Agree (2014) points out that assistive technological devices may be the way forward in enabling persons with disability such as aphasia to develop independent lives. In Kenya, this calls for the acquisition of the devices by the mandated bodies and the training of the persons with disability on how to take advantage of them. The range of what this sample

had access to was very limited. Although the great majority of participants relied on life informants in this sample, there is some correlation with age. The great majority of them were 60 years and above. Those who did not have any way of getting information were also above 60 years. However, there were younger individuals (54 years and below) who depended on other people for information. Therefore, there may be other factors that may determine whether individuals turn to technology to assist them with their communication.

Participation in the Community

This research reveals an inherent desire by the persons with aphasia sampled to interact with non-aphasic individuals and be as engaged in life as able-bodied individuals. Since active aging has been associated with positive participation in life (Ellison et al., 2011; Martin & Schoeni, 2014; Raymond et al., 2014; Riches et al., 2009), it is gratifying to see that the tendency found in this group reflected this healthy orientation. It is possible that preferences for specific activities, such as sport in men and housekeeping in women, were driven by personal interests, gender orientation among their communities, and demands from needs around the respondents. As the majority of respondents were still concerned with "business" and "employment," it may indicate that they may be unfamiliar with any other activity or insecure about transitioning out of formal employment. It also indicates a need to further investigate the possibility of a return to work for those who have had a stroke before the age of 65, particularly as there is a move toward equal employment opportunities for persons with disability in Kenya.

Economic Factors Influencing Persons with Aphasia

The majority of persons with aphasia have not been economically empowered despite the importance that economic empowerment has on the lives of persons with disability. The use of AAC devices, such as voice output systems, may be beneficial for those living with aphasia. However, all these are determined by the economic stability of a person with aphasia and his/her family members or friends (Estes & Bloom, 2011).

In South Africa, a study by Legg and Penn (2008) found that adults living with aphasia in Khayelitsha lacked resources such as information, coping strategies, support from their community and family, access to intervention, and material support (such as financial). These resources are vital for the management of disabilities within a social model, yet they are unavailable in low socioeconomic contexts due to overwork, poverty, and stress experienced by the community (Legg & Penn, 2008).

This research indicates that for persons with aphasia to age actively, it is an advantage to have had access to education and economic activities in their younger years. The data revealed that those who had a higher level of education were able to make provisions for their future and thus did not have to resort to begging.

Considerations for Future Work, Research, and Politics

Improving the Well-Being of Aging by the Government

Suggestions for improving the well-being of the aging are made below:

1. Hospitals should have the policy of assessing the aged patients' family background and situation, and if needed refer them to homes for the aged where they can get the necessary day-to-day assistance they require. Due to this, the government should assign a portion of the disability fund to the homes for the aged who are taking care of the disabled aged population. These homes would

then also require adequate training for working with persons with disability.
2. Community engagement is critical for active aging. There is a need to set a policy to include the vulnerable and the aged in sports and recreational activities, enhancing the health and participation of aging adults within the community. As some of the respondents in this study appeared to be insecure about transitioning out of formal employment, structured activities for the aged are recommended.
3. In Kenya, access to good health is a function of the economic power of the individual. This research touched on the link between education and economic freedom later in life; thus, access to education should always be considered a priority. Economically empowering individuals will allow them to raise their own resources and cater for their own medical services and other concerns. This may include return-to-work assistance.
4. The use of cell phones and media among 51% of the respondents is positive; however, it is not enough. In Kenya, there is a need for the acquisition of AAC devices by the mandated bodies and the training of the persons with disability on how to take advantage of them. Training of SLTs should also be a priority, to have a positive impact on the ratio of professionals to patients. Community-based healthcare workers could also be trained to assist.

Future Research

Further research is needed to better understand the experiences and implications of aging with communication disorders in low- and middle-income countries such as Kenya, in order to learn how to best minimize the associated disability.

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Development of a Mobile SLT Clinic: A Case of East Africa

25

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Background: Lack of SLT Service Delivery in Rural SSA

In most Minority World countries, speech–language therapy services are available everywhere for people of all ages. In contrast, in the majority of countries around the globe, East African countries included, such optimal SLT services are either nonexistent or quite inadequate (Jochmann, 2006; Stevenson, 2014). The few available services are usually located in urban areas, but still with a disastrous client-SLT ratio (D'Antonio & Nagarajan, 2003; Munyere, 2004; Mwihaki, 2003). Moreover, not much research that focuses on speech and language difficulties and interventions have been carried out. It is therefore possible that the prevalence and need for SLT service are even much higher in many sub-Saharan African countries with no scientific proof.

As an example, a survey of the ear, nose, and throat (ENT), audiology, and speech therapy services and training opportunities in 18 sub-Saharan African countries in 2009 stated that there are extremely poor, very inequitable, and limited training opportunities available (Fagan & Jacobs, 2009), leading to a lack of service delivery to the people affected. Availability of ENT and speech and language therapy services outside major African cities that were shown to be a problem in 2009 remains a concern a decade later (Mulwafu et al., 2017). There is also a lack of basic equipment, audiological rehabilitation, and awareness of the burden of ENT and speech pathology, as well as human resources management.

Besides that, speech and language therapy services have traditionally been offered in hospitals by professionals with a medical background. However, there is a growing global trend to provide SLT services in social and educational settings such as kindergartens, regular and special schools, and even homes. This is based on the notion that speech, language, and communication development and difficulties depend on multiple factors, such as cognitive, social, and emotional aspects (Johnston, 2010), which are either rooted in or best treated in a family or inclusive educational background (Valles-González & Rosell-Clari, 2017). Luterman (2017) advocates

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an integrated community-based approach where the therapist collaborates with the client as a team during assessment and intervention. Such recent community-based approaches are effective where the professional is able to reach out to the client, listens, and pays attention to their emotional needs through a collaborative approach rather than an expert service (Mutiso et al., 2018). Thus, for both background circumstances, the model of a mobile SLT clinic would be vital in improving the adequate availability of speech and language therapy services in sub-Saharan Africa, especially in the even more affected rural regions.

Taking medical services to where people are creates convenience for the people in need, especially for families. From an economic and time-effective perspective, a mobile SLT clinic helps parents to work and spend less time moving to a nearby designated place within the community (Law et al., 2012). Speech and language therapy service costs are a concern. This includes, among other costs, consultation as well as transport to and from the clinic usually a faraway referral hospital. A mobile clinic reduces the cost of transport and allows flexibility in meeting schedules. This gives opportunities to parents to continue engaging in gainful activities, sustain the family, and create unity within homes as well (Patricia, 2013). In instance where the clinics are in referral hospitals, which are in most cases far away, there is always limited family involvement. A typical speech and language therapy should involve the entire family. A mobile clinic will be nearby, and therefore more family members can be involved to the relief of the one parent, usually the mother, who may be having other family responsibilities.

In addition, mobile SLT clinics are usually closer to the client's indigenous community. It implies that the activities and materials to be used during therapy may be familiar and meaningful to the client in his/her comfortable surroundings instead of unfamiliar clinic-based activities/resources, even if imported from Minority World countries. This helps the parent or relatives to continue with the speech and language therapy at home with the familiar, easily available resources. This, too, makes clients, parents, and relatives reduce a notion that speech and language therapy is a preserve for medical practitioners or the "learned" only. Instead it promotes a community-based therapy and rehabilitation approach.

Moreover, the service provider can use the local language of the area, thus being more sensitive to the culture of the community. Mobile SLT clinics can be particularly relevant in reaching out to persons who are vulnerable with limited access to speech and language therapy services. Mobile clinic services travel to the communities and offer affordable or free services, removing logistical constraints experienced by poor rural communities. Logistical constraints include limited transport, complex administrative processes, and limited health insurance requirements. Mobile SLT clinics in this case will help to overcome discreet barrier challenges in maintaining trusting relationships between speech and language therapy providers and community members. Utilizing mobile clinics will improve screening so as to improve interventions.

In summary, the mobile speech and language therapy service approach has the benefit of supporting clients of all ages within their everyday environment. It makes the therapy relevant to the local situation and the local context relevant to the therapy provision and success.

The General Concept of Mobile Clinics for Underserved Rural Areas in Majority World Countries

Mobile clinics – sometimes referred to as mobile health care – are designed to the complement local health care system of a population (McGowan et al., 2020; Howe et al., 2009; Du Mortier et al., 2006). The general concept of mobile clinics has been adopted in many countries for different reasons. A report by SolidarMed (Drack et al., 2015) cites the implementation of a mobile clinic each in Lesotho, Tanzania, Zambia, and Mozambique. They report similar experiences in Cameroon, Congo DRC, Eritrea, Ghana, Kenya, Nigeria, Rwanda, Sierra Leone, Togo, South Africa, and Zambia. In Lesotho, the concept of a mobile

clinic is particularly used to offer all the services of the health center. The Afro-European Medical and Research Network (AEMRN) used the concept of mobile clinics to bring together a network of multidisciplinary professionals covering the fields of education, medicine, and engineering to work together to support people in need. According to Caterina et al. (2014), mobile clinics are facilities that reach out to the "heart of urban and rural communities" to provide prevention and health care services by "living with the people, sharing information, and providing support." In Mozambique, a mobile clinic was started in 2008 with the aim of providing access to health services and improving quality of life, particularly to facilitate access to maternal-child health care, antiretroviral therapy (ART) for people living with HIV and AIDS, tuberculosis, and other diseases (Alegría, 2007). To sum it up, mobile health care is a community-based strategy that provides solutions to health care delivery to underserved at-risk population. A mobile clinic facility should therefore provide easy access for outpatients and other clients to more professional examination, consultation, and prescription. Mobile clinics also dispense medicines and provide basic laboratory services and vaccination facilities.

This paper therefore presents the concept of a mobile clinic as a speech–language therapy clinic. An example is in the form of a converted van. The advantage of a van is that this mobile SLT clinic can be driven to the community and parked at a kindergarten, school, village, or home grounds, allowing for a distraction-free space. The mobile clinic could be stocked with a fully equipped SLT kit for assessment and intervention of most disorders. The kit could contain as well basic equipment and materials to carry out sensitization, screening, and counselling. There could be a (digital) documenting and referral mechanism for children and persons identified of all ages with a need for speech, language, hearing, swallowing, and communication intervention. The mobile clinic would also facilitate easy follow-up of clients who miss out on their therapy days.

Development of a Model Mobile SLT Clinic for the Rural East African Context

Since the early 2000s, a collaboration between different Tanzanian stakeholders and Leibniz University Hanover has been following the development of the speech and language therapy profession in East Africa. During this long collaboration history of now two decades, other major East African stakeholders joined in, namely, Kenyatta University, Kenya, and Kyambogo University, Uganda. Various international academic exchange programs and projects between the partners in Germany and East Africa have been engaged in. The exchanges involved ideas and expertise from international professionals in speech and language therapy in theory and clinical as well as educational practice. The aim of the collaboration was to develop an outstanding and unique East African approach to providing speech and language therapy services, considering the specific conditions and resources for the region in terms of infrastructure, staff, and equipment.

Initially, Leibniz University Hanover, Germany, and Sebastian Kolowa Memorial University (SEKOMU), Lushoto, Tanzania, started a collaboration in 2006 to provide speech and language therapy services and academic training in the rural areas of the Usambara mountains. The need for local expertise, equipment, and SLT service delivery was most obvious in the partner institutions implementing special needs education. This involved Irente Children's Home, Irente Rainbow School for the Disabled and the Irente School for the Blind, located in the Lushoto district and organized under the umbrella of the Evangelical Lutheran Church of Tanzania – North Eastern Diocese (ELCT-NED) (Lüdtke, 2009). The shortage of human resource expertise and distributional inequalities in the health workforce in many Majority World countries are acknowledged by Munga and Mæstad (2009). As such, stakeholder meetings brought up the impulse to search and apply for funds to start a first international project. This started with student

exchange projects in 2010, followed by the first German Academic Exchange Service (DAAD), funded 4-year project "Welcome to Africa." The continuous collaboration focused on exchange and capacity building of SLT staff.

As international exchange was one way to develop the area of speech and language therapy practice, finally, the next DAAD-funded 4-year project, Partnerships for the Health Sector in Developing Countries (PAGEL), brought an opportunity to implement and promote speech and language therapy practice in East Africa. The PAGEL project – or more specifically, "Knowledge Transfer by Global Unity Multilateral East African-German Partnership in Speech Language Pathology (SLP)" – gathered from 2015 to 2018 interdisciplinary expertise from professionals in medicine, special needs education, and speech and language pathology. The project framework laid the conclusive groundwork for the implementation of speech and language therapy practice.

Initially, the proposal aimed at establishing the fixed setup of an academic speech clinic at Muhmbili National Hospital, Dar es Salaam, Tanzania, for SLT service delivery and student training of the participating university partners in East Africa, comparable to the working SLT University Clinic at the speech and language therapy department at Leibniz University Hannover and other model clinics in Europe and the United States. But after thorough analysis of existing and missing infrastructure and staff, the original idea of an adaption of the LUH SLT clinic in East Africa was discussed and finally modified, as it was not meeting the needs, demands, and requirements of the regional medical services in Tanzania, Kenya, and Uganda. Instead, the idea of a mobile SLT clinic was born and followed.

Potential Outcomes and Functions

In general, there are diverse potential outcomes and functions of having a mobile clinic. A mobile clinic should contribute to the assessment of disabilities and other special needs in individuals and their learning competences and health-related ailments, provide treatment, and be used for training, research, and raising awareness in the local community.

For the purpose of the speech and language therapy program, the following are suggested to be major outcomes of a model mobile SLT clinic (see Hill et al., 2012; Fils-Aimé et al., 2018).

1. Sensitization
Speech and language therapists (SLTs) or other trained professionals move to different places, especially in rural regions of East Africa, to sensitize the community about communication, swallowing, and hearing disorders. The information would include what the problems are, possible causes, challenges associated with the difficulties, and what each member of the community can do when they suspect or identify a speech, language, or communication problem in a newborn, child, adult, or elderly person. Following the basic principles mentioned above, there must be information sheets for parents/caretakers and community members included during patient and community consultation, outreach, and education programs. To take into consideration the principle of cultural sensitiveness, the information should be designed either in local language, simple language, or picture-based. These information sheets should contain basic information about the epidemiology, progress, treatment, and perspective of the different SLT-related disorders to create awareness in society, reduce stigmatism, and promote the SLT profession in public services.

2. Early Identification
The mobile speech and language therapy clinic will assist professionals to identify communication, swallowing, and hearing problems in children early in their lives as suspected by parents. The clinic will also bring together parents of the identified children with speech, language, and communication problems within their localities to help them share experiences and identify more children whose parents and teachers are not informed. Early identification helps to miti-

gate the adverse problem that speech, language, and communication problems would bring as the child grows.

3. Assessment and Management
Because mobile speech and language therapy clinics are managed by well-trained professionals, they can carry out screening and sometimes proper assessment on the spot. The trained professionals will then manage, give advice on placement, and make appropriate referral if the case required so based on the assessment.

4. Collaboration
Members of the mobile speech and language therapy clinic will collaborate and build local and regional teams. A collaborative team is a group of medical, educational, and other practitioners from different speech and language therapy-related fields who work together to serve their clients and try to meet the care goals of the clients. Their responsibilities and tasks complement each other to meet the care needs of clients. Collaborative SLT teams include and are not limited to professionals in medical, special needs education, social workers, and regular school teachers. Each of the professionals will have defined role(s) to ensure that the problems of the clients are attended to. These roles include but are not limited to sensitization, screening testing, diagnosis, therapy, and counselling.

5. Outreach Activities
Mobile speech and language therapy clinics often offer screenings, primary health care, advice, and, in some cases, hospital-grade services as close as possible to where people live. In the East African context, this could imply that the services are taken to the poorest of the poor and in communities with more illiterate residents. A UNESCO (2013) report recognizes that literacy rates have worsened in some countries in the region despite global improvements in adult literacy rates. Poor literacy level has affected the quality and quantity of access to health care services. For the community therefore to accept to take the newborn child, young people, or even adults to attend medical, therapeutic, and rehabilitation services, the outreach program will focus among other activities sensitization, awareness raising, and training. These should be done in the local language. The staff working with the mobile SLT clinic should have a person who understands the local language to put into perspective the need of screening.

6. Training and Education of Students and Professionals
Speech and language pathology and therapy-related knowledge is not yet very well introduced in academic training programs. Professionals in medical services, special needs education, schools, and rehabilitation, as well as psychology, lack information manuals to introduce them to the topic of speech and language therapy. Within the mobile SLT clinic, manuals for different speech language disorders will have information on epidemiology, treatment, intervention perspective, and references for professionals. It should also include material lists and contact numbers for further information, and family members need to take part in some training as well. In a first draft, manuals from ASHA would be selected and put into the toolbox (see section "Conceptual Setup of a Mobile SLT Clinic"). Highly significant literature can be added after discussion about their relevance and usage.

While the mobile SLT clinic would have a relatively small space, there is a need to have training in the organization and management of the equipment used for screening. To facilitate community ownership of the mobile SLT clinic, there would be structured ways to take care of equipment. Therefore, some of the mobile clinic team should have training in basic maintenance skills.

7. Research
In all East African countries, there is limited data available on communication, swallowing, and hearing disorders. There is a lack of basic information related to speech and language disorders. A starting point would be basic epidemiological research through which data collection can be conducted through a standardized template on a form during the patient's registration. More infor-

mation would be collected from clear and easy understandable different speech, language, and communication disorders assessment results.

The mobile clinic will be an ideal tool for carrying out baseline surveys in speech, language, and communication disorders for intervention in the rural East African communities. Anecdotal information indicates that speech, language, and communication disorders have the highest incidences and prevalence among learning difficulties of all other disabilities in East African *communities*. Research is broadly needed to give accurate data on the magnitude of the problem. Through the mobile SLT clinic, there would be staff who will correlate the data to assist in future planning of therapy and rehabilitation exercises for speech, language, and communication disorders.

Having the mobile clinic in an educational institution will support the basic research projects that cover the causes, types, characteristics, parental and sibling stress, as well as involvement in interventions. Other aspects of research could include intervention strategies, teaching, rehabilitation, and community-based interventions. These research findings would strategically be disseminated within the communities where data is collected. Thereafter, for wider readership, the information validated would be published in academic journals.

Adapted Methodology

Generally, there are some basic procedures for starting a mobile SLT clinic as given, for example, by Mobile Health Map (2021), which need to be adopted to the East African context, for example, following some of the steps below:

1. Identify the community that needs the SLT service

In East Africa, not all communities will require the services of mobile speech and language therapy (SLT) clinics, and not all communities that require mobile SLT clinic services will receive them. It is important therefore that communities are identified and priority is made on which ones to start with.

2. Partner with community organizations

Other community organizations already working in the identified area especially those related to health can be of great help when it comes to needs identification, sensitization, and referrals in the speech and language therapy area. These organizations have information and data that should inform planning and intervention.

3. Identify and validate the community needs

There is a need to know the people who will benefit from the mobile SLT clinic services. In the case of East Africa, there is a need to identify persons with speech, language, communication, swallowing, and hearing disorders. A community-based approach to these people and their needs is recommended.

4. Obtain and refit the speech and language therapy van

Funds should be sourced and made available to buy and modify a van for mobility. Similar attempts have been made on community ambulances, making it easy to adapt SLT vans.

5. Identify convenient places to park the van

In some places where mobile clinics are used, they have very big vans that require a special accessibility and place for parking. But for the purpose of this speech and language therapy program, a small omnibus vehicle or a double-cabin pickup can be used. This does not require special arrangements for parking but would necessitate central locations where the SLT van can be conveniently reached by the communities to be served.

6. Publicity

People need to be informed about the coming mobile speech and language therapy services, especially underserved populations who need to be reached out to. This can be done through distributing fliers and communication through prayer

places, schools, and local FM radio stations that provide free airtime for community mobilization.

Requirements for Design and Setup of SLT Clinic

The design and setup of equipment in a mobile SLT clinic follow the framework of intended outcomes and functions, as well as the adopted methodology (see sections "Potential Outcomes and Functions" and "Adapted Methodology"). The framework will be arrived at following the results and outcomes of discussions from PAGEL meetings in Tanzania, Germany, and Kenya. These discussions were continued in Uganda during the 2018 workshop. In addition, some of the considerations for setting up the mobile SLT clinic could include information from Mobile Health Map (2021) and OCHA (2021):

1. Cultural adaption and sensitiveness
Most obviously, the promotion of the services of a profession of speech and language therapy in East Africa needs adaptation to the cultural, social, and economic environment.

The adaptation should include language patterns aimed at bringing about totally different needs in assessment and intervention materials and methods for East Africa. This involves research aimed at analyzing the particular characteristics of the East African languages. The multilingual nature of each East African country requires profound knowledge of linguistic and rehabilitation competences. The intention must be to develop the speech and language therapy profession through a culturally sensitive adaptation of speech and language therapy approaches. The Minority World approaches which have been proved to their benefit scientifically will have to be adapted based on the local contexts. It therefore calls for a well-designed academic and interdisciplinary perspective for the successful achievement of this target.

2. Cost-effectiveness
Lack of funds was a permanent concern during the PAGEL project's progress. Setting up a low-cost mobile SLT clinic will help to multiply the mobile clinic concept and strategy for a broad application in different areas. Coming up with a cost-effective equipment will be achieved by using open-source assessment and intervention materials as well as manuals provided by speech and language therapy associations on the web, for example, ASHA. Furthermore, materials for intervention in speech and language therapy clinical and educational practice will be easily produced and expanded through everyday life materials and common clinic and school equipment.

To reduce costs for administration and staff, the mobile SLT clinic will be linked to existing university structures. For example, lecturers in speech and language pathology can be committed to be in charge for the maintenance and administration of the mobile clinic equipment, as they use and adapt it continuously for their courses.

3. Mobility and accessibility
One essential outcome of the PAGEL project was to set up the speech and language therapy clinic for mobile use to enable application in different settings in and outside the university, which is primarily located in the cities of the three participating East African countries Kenya, Tanzania, and Uganda. As a result, the idea of creating specific toolbox/tool kit for different speech, language, and communication disorders was developed. In perspective, those toolboxes can be stored and combined in a mobile speech and language therapy van, specifically equipped for mobile speech and language therapy clinic use in community-based settings and rural areas. The principle of mobility allows for accessibility and application in a wide range of activities in speech, language, and communication therapy and connects other professions in social work. This advantage was prioritized ahead of the initial proposed stationary speech and language therapy clinic. Despite that fact, the mobile SLT clinic can be an essential part of the equipment of a planned stationary speech and language therapy clinic.

4. Education and awareness
The targeted aim of establishing a speech and language therapy profession is ambitious in

various ways. The great possibilities are that this pioneer approach is likely to face barriers as people would not be aware of the relevance, opportunities, and necessarily a speech and language pathology and therapy profession. As long as the profession is unknown among other medical and education professionals, civil society, and political decision makers, embracing the services would be challenging.

The mobile SLT clinic design and setup, therefore, needs to address approaches to awareness creation and education of parents, teachers, hospital staff, civil society, and politicians. In general, this requires strategic publicity through easy-to-read local language information and pictorial materials given out to patients and the general public. Scientific publications for professionals and decision makers will help to provide literature as well.

5. Human resources

Mobile speech and language therapy (SLT) clinical setup depends on recruitment and retention of committed staff. Different ideas suggested a linkage to existing departments or academic units to promote synergies and reduce costs. Because of limited numbers of graduates in speech and language therapy in some countries, there will be a dependence on expats for some time. To avoid this dependency and establish sustainability, logical steps and progress for implementation of speech and language therapy-related content in running programs and units are a first step. A consequent promotion and separation to an independent academic SLT profession for clinical and educational practice would be prioritized.

Identification of committed staff identified to take over responsibility for the speech and language profession is critical. The commitment is supported by a focus on training, clinical practice, research, and outreach to spread the skills among staff as a means of making the mobile clinic sustainable. The human resource requirements will grow with the extent of the speech and language profession in the different areas and universities of East Africa. Personnel for training, practice, research, outreach, and administration will be necessary for sustainable implementation.

Conceptual Setup of a Mobile SLT Clinic

Conceptual Areas

First, on a conceptual level, the setup of a mobile SLT clinic needs to consider at least four areas of professional service delivery:

1. *Administration and documentation*
   The administrative and documentation strategy should include a database for patient profiles. The center would administer and document epidemiological studies, protocols for clinical reasoning with colleges, database for service evaluation and evidence-based practice, as well as a network of referral hospitals.
2. *Screening and assessment*
   There should be a pool of hardware and/or software tools and techniques specified for the screening and assessment of preferably the whole range of communication, swallowing, and hearing disorders. User manuals for the same are needed.
3. *Therapy and intervention*
   These are a pool of hardware and/or software tools and techniques specified for the therapy and intervention of the whole range of communication, swallowing, and hearing disorders as well as user manuals.
4. *Community sensitization and family counselling*
   Involves information brochures on the symptoms and available mobile treatment options of the whole range of communication, swallowing, and hearing disorders, preferably modified in different local languages for the different target groups. The information brochures target family members, health care workers, teachers, and politicians.

How these four areas need to be practically equipped will be described in section "Equipment Setup of a Mobile SLT Clinic".

Clinical Guidelines: ASHA Manuals for Different Communication, Swallowing, and Hearing Disorders

Secondly, clinical guidelines on assessment and treatment of the major communication, swallowing, and hearing disorders need to be provided to those personnel working in the different areas of mobile SLT service delivery. Clinical capacity building in the trained or untrained staff should equally be prioritized within challenging circumstances of young professional development.

As a preliminary solution, for the basic information for those persons, who start with service delivery at the mobile SLT clinic, it was agreed to rely for the moment on the online available ASHA manuals on various clinical topics at the practice portal (ASHA, 2021), as they provide the most essential information for professionals in the field of SLT. ASHA here offers a collection of manuals for all relevant speech, language, and swallowing disorders as well as hearing disorders (see Table 25.1). Developmental disorders such as autism spectrum disorder and mutism are represented, too.

The manuals use scientific and evidence-based proven approaches for theory, assessment,

Table 25.1 Online ASHA manuals: clinical topics as a resource for a mobile SLT clinic (in alphabetical order)

Communication disorders	Swallowing disorders	Hearing disorders
• Acquired apraxia of speech • Aphasia • Apraxia of speech (childhood) • Augmentative and alternative communication (AAC) • Autism spectrum disorder • Cleft lip and palate • Dementia • Dysarthria (adult) • Early intervention • Fluency disorders • Head and neck cancer • Intellectual disability • Late language emergence • Orofacial myofunctional disorders • Resonance disorders • Right hemisphere damage • Selective mutism • Social communication disorder • Speech sound disorders: articulation and phonology • Spoken language disorders • Traumatic brain injury (adult) • Traumatic brain injury (pediatric) • Voice and communication services for transgender and gender diverse populations • Voice disorders • Written language disorders	• Aerodigestive disorders • Dysphagia (adult) • Dysphagia (pediatric) – feeding and swallowing • Tracheostomy and ventilator dependence	• Aural rehabilitation for adults • Balance system disorders • Central auditory processing disorder • Cochlear implants • Hearing aids (adult) • Hearing screening (adult) • Hearing screening (childhood) • Hearing screening (newborn) • Permanent childhood hearing loss • Superior canal dehiscence • Tinnitus and hyperacusis

and clinical intervention practice, research, and documentation as a brief overview for application in all areas of SLT practice (see Table 25.1). All manuals are structured with information about the following:

- Overview
- Incidence and prevalence
- Signs and symptoms
- Causes
- Roles and responsibilities
- Assessment
- Treatment
- Resources
- References

Furthermore, all manuals are linked with all kinds of further information available from ASHA or professional networks. In the PAGEL meetings, it was decided to use these free and online-based manuals from ASHA as print copies for basic information of the disorders mentioned in the table below as a preliminary solution, taking the utmost necessity of a thorough adaption into the local and cultural needs into account. This SLT library, stored either in a suitcase, a portable steel box, or available cars or rooms, meets the requirements of cost-effectiveness, accessibility, applicability, and the latest academic-based knowledge transfer among professionals and associated actors in the field of SLT (ASHA, 2021).

Equipment Setup of a Mobile SLT Clinic

Materials for a mobile speech and language therapy (SLT) clinic address the needs of the patients and clients of all ages and help them to appreciate and embrace the assessment and treatment. The mobile clinic approaches and the equipment should be selected for use in different areas of clinical practice and academia including classical, everyday, and media-based assessment and intervention. Before describing possible setup solutions for the conceptually identified four areas of (1) administration and documentation, (2) assessment and screening, (3) therapy and intervention, and (4) community sensitization and family counselling, the general setup for starting a mobile SLT clinic will be sketched based on our PAGEL team discussions.

General Setup for Mobile SLT Service Delivery

The mobile clinic needs to provide basic materials and tools for speech and language pathology assessment, therapy, and intervention for the most common speech and language disorders. During the PAGEL workshops, the relevance of proper and early hearing assessment was pointed out as critical, as proper hearing is the prerequisite for proper speech, language, and communication development as well as cognitive skills. Equipment for hearing and visual stimulation and specific screenings for each are needed. Of course, to start a mobile SLT clinic approach, the vision of incorporating all speech, language, swallowing, and hearing disorders is ideal, but not practical and not easily to be fulfilled. Therefore, following the particular PAGEL university hubs in East Africa, the first strategic direction for a mobile clinic equipment therefore targets swallowing disorders or dysphagia, speech and language acquisition or developmental disorders, and neurological disorders or aphasia. In other contexts, the disorders, to start with and to focus on, might change accordingly.

The PAGEL setup for the mobile SLT clinic and the required equipment was finally selected from a pool of materials for assessment tools and machines as well as interventions as they are known and used in speech language pathology approaches in the United States and the United Kingdom (see, e.g., Shipley, 2009; Roth & Worthington, 2016; Helm-Estabrooks et al., 2014). In the following sub-chapter, some useful equipment setup for a mobile clinic – digital and media-based as well as classical tools – is presented without any claim to completeness. The priority for the selection of equipment for the particular PAGEL mobile SLT clinic was availability, cost-effectiveness, and applicability to the local and cultural framework of the East African communities. Cultural sensitiveness and the need for adaptation to the specific linguistic and cultural

requirements of the rural East African context, as well as consideration of appropriate introduction to nonprofessional users in clinical practice and schools, show a current limit to the mobile speech clinic, which definitely needs to be addressed as soon as possible.

Finally, the basic decision was made that besides equipping a van, a mobile box, either a common suitcase or a wooden or steel box, would be purchased to keep all working tools needed handy.

(1) General Setup for Administration and Documentation

For the general setup for administration and documentation, the PAGEL teams decided that three aspects are always necessary:

- *Notebook/hardware*
  As discussed in the PAGEL plenary, the hardware should meet requirements to run assessment, intervention, and research activities, as well as data collection, for example, for epidemiological issues, and case documentation for patient follow-up and evidence-based practice (EBP). So far, all available tools and materials in the United States and the United Kingdom/Europe require midrange hardware specifications only. Therefore, an expensive and high-end hardware is neither necessary nor appropriate due to cost-effectiveness. Finally, hardware should be chosen to use the notebook most flexibly, in terms of the number and variety of slots for data storage devices, camera and speaker specifications, touchscreen, changeable battery slot, and shock/water resistance. In result, a Lenovo ThinkPad Notebook was selected with some extra hardware like spare batteries, external hard-disk drives, and a wireless mouse.
- *Operating system*
  Considering all advantages and disadvantages, the latest Windows 10 operating system was agreed to be the most suitable for the mobile SLT clinic. The main reason was compatibility with most of the available assessment and data management software.
- *Safe with case history forms*
  For data safety, it seems to be of the utmost necessity to have a safe to store all patient data most secure. Personal data could be collected and currently updated on case history forms, for example, from the local hospital, or in a software, where the hard disk needs to be locked as well.

(2) General Setup for Screening and Assessment

The general setup for the screening and assessment area of the mobile SLT clinic is of the utmost importance, yet a very challenging task, especially when no huge funding is available. Besides cost-effectiveness, linguistic and cultural appropriateness is an even bigger issue, especially in rural areas, and in speech and language disorders more than in motor dysfunctions. Therefore, the first strategy is to purchase a very basic audio and video equipment, which can be used for a variety of diagnostic issues, ranging from stuttering to aphasia (e.g., recording of language samples), as demonstrated in Table 25.2.

Next, it would be optimal, if there would be a pool of classic and media-based diagnostic equipment for all SLT-related disorders across all age groups. As this might not often be the case, there should be in the beginning of the mobile clinic setup a focus on one or two areas, and other areas could slowly be built up starting with a simple screening approach.

Table 25.2 Unspecified equipment for screening and assessment of various communication, swallowing, and hearing disorders

Unspecified training material	
• Digital voice recorder kit • Head mount microphones (USB portable) • Two pairs of headphones	• Mini DV camera kit

In general, the diagnostic equipment can consist of (1) classic tools, for example, an auriscope or a nasometer, (2) costly apparatus such as a fibro endoscope, (3) standardized tests with user manuals and statistic scales, or (4) software-based tools.

Standardized assessment tools are provided by publishers either completely media-based or with digital add-ons for evaluation and documentation. As the licenses for software are expensive, the tools have to be installed on one single computer and permanently stored within the mobile clinic. The abovementioned laptop will be essential equipment for every mobile clinic setup.

Among the variety of available standardized tools from the different publishers, the most common tools have been chosen by the PAGEL team to assess a broad range of communication, swallowing, and hearing disorders, with a focus on speech and language disorders. As the licenses are pricey in some cases, the tools are limited.

- *Aphasia screening (acute stroke)*:
  Aphasia Rapid Test (ART) (Azuar et al., 2013) or Language Screening Test (LAST) (Flamand-Roze et al., 2011)
- *Aphasia assessment*:
  Boston Diagnostic Aphasia examination (BDAE-3) (Goodglass et al., 2000) or Western Aphasia Battery – Revised (WAB-R) (Kertesz, 2006)
- *Developmental language disorder screening (prekindergarten)*:
  Parents' reports of vocabulary and word combinations such as the The Language Development Survey (LDS) (Rescorla, 1989) or the MacArthur-Bates Communicative Development Inventories (MB-CDIs) (Fenson et al., 2007) (both strongly need cultural adaptation)
- *General developmental screening (including language, motor, and concept) (kindergarten – elementary school age)*:
  Developmental Indicators for the Assessment of Learning (DIAL 4) (Mardell & Goldenberg, 2011)
- *Language disorder assessment (kindergarten to adolescence)*:
  Clinical Evaluation of Language Fundamentals (CELF-5) (Wiig et al., 2013)
- *Swallowing disorder/dysphagia screening (stroke/acute stroke)*:
  Toronto Bedside Swallowing Screening Test (TOR-BSST) (Martino et al., 2009) or Royal Brisbane and Women's Hospital dysphagia screening tool (Cichero, 2009)

Media-based intervention materials are more and more available for free on the Internet and obviously most appropriate for some particular patients. To serve the diverse individual speech and language needs of patients, such a diverse selection of materials digitally available would possibly be a viable solution. The digital copy on the laptop will help to store patients' case files and collect easy-to-access data materials for research activities.

(3) General Setup for Therapy and Intervention

Besides the diagnostic equipment, the general setup for therapy and intervention is the heart of a mobile SLT clinic. As in the area of screening and assessment, a balance between cost-effective everyday materials and the latest high-end tools has to be considered. For a quick setup and start, taking the rural East African context into account, the following tables may give a first practical idea and can be accompanied by online available intervention materials from professionals who founded open-source websites to share self-made interventions (see, e.g., https://www.speechandlanguagekids.com/).

First, as a base to freely choose whenever more specified tools are not available, a pool of

Table 25.3 Unspecified equipment for therapy and intervention of various communication, swallowing, and hearing disorders

Unspecified training material	
• Building blocks • Molding clay • Paint and art material • Talking toys • Sensory tubes • Mobile water play • Mobile sand pit	• Mobile trampoline • Dressing up frames • Puzzles • Memories • Toy cars • Jig saws • Writing boards • Mirror

Table 25.4 Equipment for therapy and intervention of attention and imitation disorders

Training material of attention and imitation skills	
• Different playing materials, for example, blocks, beads • Memory	• Different toys, for example, dolls, cars, domestic and animal toys • Edible paper and colored pens

Table 25.5 Equipment for therapy and intervention of swallowing disorders

Training material of swallowing skills	
• Oral tongue vibrator or massager • Thickener • Feeding spoons • Cutout cups	• Feeding plates • Angled spoons • Chewy tubes

manifold unspecified equipment for therapy and intervention of various communication, swallowing, and hearing disorders should be collected, whereby the local contexts should be considered (see Table 25.3).

As many child disorders treated by an SLT have attention and imitation dysfunctions as either a cause or a side effect, the following equipment should be provided in the mobile clinic as well (see Table 25.4).

Even though swallowing disorders, especially dysphagia in children with cerebral palsy, should best be treated in a hospital, the mobile clinic needs basic equipment for treatment as well (see Table 25.5). This is because many families in rural areas, especially mothers, have no access to high-end clinical SLT services and are in need of easy-to-reach mobile services for training on how to feed their children at home.

Table 25.6 Equipment for therapy and intervention of oral motor disorders

Training material of oral motor skills	
• Small torch • Gloves • Spatula • Blowing games (feathers, cotton balls, table tennis balls)	• Buttons • Blowing bubbles • Threads and strings • Straws

Table 25.7 Equipment for therapy and intervention of hearing disorders

Training material of hearing skills	
• Drums • Bells • Shakers	• Sounds cards

Hand in hand with the training of swallowing skills goes the training of oral motor skills, for example, for strengthening oral muscle tone. A set of appropriate training materials can be kept simple and might be based on cost effective materials of daily household use (see Table 25.6).

Another very basic area of service delivery, yet of utmost importance for the whole speech, language, and communication development, is the therapy and intervention of hearing disorders. The basic training of hearing skills needs as well a setup of cost-effective materials from local shops or self-made, culturally appropriate cards (see Table 25.7).

Moving from the basic area of hearing to the area of speech and language development, more elaborate materials are needed, both content- and cost-wise. A common way to arrange the general setup would be to organize it according to the four linguistic levels: (1) phonetic and phonological, (2) lexical and semantic, (3) morphological and syntactical, and (4) pragmatic.

First, on the sound level of language (phonetics), there should be a clear discrimination of the oral-motor training of phonetic pronunciation problems versus an auditory training of the mental reception, discrimination, and recognition of speech sounds. Accordingly, different materials are needed (see Table 25.8).

Table 25.8 Equipment for therapy and intervention of phonetic and phonological disorders

Training material of phonetic and phonological skills	
Phonetic training • Symbol cards for consonants • Phonetic memories	Phonological training • Minimal pairs (worksheets) • Discrimination of syllables

Table 25.9 Equipment for therapy and intervention of lexical and semantic disorders

Training material of lexical and semantic skills	
• Variety of picture cards (nouns + verbs) • Flash cards, e.g., for naming activities	• Reading books (Swahili and other local languages and English) • Picture books • Picture story cards

Table 25.10 Equipment for therapy and intervention of morphological and syntactical disorders

Training material of morphological and syntactical skills	
• Strip cartoons/ picture stories • Picture cards	• Card/domino games (e.g., for plural constructions) • Objects/toys (e.g., for prepositions or case constructions)

Second, on the word level of language (semantics), the variety of training material of lexical and semantic skills, ranging from simple picture cards to advanced text books, should be linguistically and culturally matched to the individual student. Yet, a general pool should be provided in the mobile SLT van (see Table 25.9).

On the level of grammar (morphology), a general pool of toys, cards, and games, which can be shared with other areas of service delivery, needs to be supplemented by more specific linguistic material, which helps to train either the morphological changes within a word (e.g., plural constructions in nouns) or the chronological order in sentences (see Table 25.10). Here of course arises the need of very specific linguistic adaptation according to the local language(s) spoken by the student.

Finally, for the training material of pragmatic language and communication skills, a setup seems appropriate, which combines general games and text-based material with audio and video recording (see Table 25.11).

Table 25.11 Equipment for therapy and intervention of pragmatic disorders

Training material of pragmatic skills
• Voice and/or video recorder • Story cubes • Strip cartoons/picture stories

Table 25.12 Equipment for therapy and intervention of reading and writing disorders

Training material of reading and writing skills
• Boards and markers, papers, pens, and pencils • Foam letters • Letter cards

Table 25.13 Equipment for therapy and intervention of cognitive disorders

Training material of cognitive skills	
• Sorting and matching activities materials, for example, variety of puzzle and memory games • Coloring books and crayons, paintings	• Communication board

An even more refined and specialized area of speech and language therapy service delivery, focusing mostly on primary and secondary school children, is the therapy and intervention of dyslexia. The general setup for the training of reading and writing skills can be basic school material (see Table 25.12), which needs to be adapted by the SLT according to the linguistic needs of the individual student.

Finally yet importantly, in many students or patients, the speech, language, and communication disorders are not the main problem, but rather a side effect of a much more severe mental, emotional, or physical disability. Therefore, the mobile SLT clinic needs a setup, where, for example, training material of cognitive skills is available as well (see Table 25.13).

(4) General Setup for Community Sensitization and Family Counselling

The fourth and often neglected area of community sensitization and family counselling needs to be equipped with information on the symptoms,

causes, side effects, diagnosis, treatment, family impact, and participation possibilities of the whole range of speech, language, swallowing, hearing, and communication disorders throughout the whole life span.

Besides considering the different target groups – for example, patients themselves, family members, teachers, health personnel, midwifes, community workers, political and religious stakeholders – the style and level of language used, the variety of local languages chosen, the cultural appropriateness of photos, pictures, and written content as well need to be considered.

The following formats – print, aural, and digital – could be chosen:

- Radio spots and interviews
- Brochures, leaflets
- Flyers for students and parents
- Videos displayed in waiting rooms of referral hospitals
- Social media
- Wall -painted information for illiterate groups

Sustainability of the Mobile SLT Clinics

The success of a program depends on its sustainability, that is, there should be enough funds and human capital both within the organization and externally to run the project (Oyugi et al., 2018). In this case, arrangements should be made to ensure that activities of the mobile clinic are sustained. For example, in America, United Neighborhood Health Services (UNHS) operated a Mobile Health Screening Unit (MHSU). A similar strategy is being developed in Kenya, Tanzania, and Uganda.

Policy Guidelines

In order to sustain such well-intended outreach activity, mobile clinic as an outreach activity should be included in the institutional outreach structures and national policy. The intention is to develop a strong leadership to maintain its activities over time. The lack of management structure, resources, and guidelines is a serious sustainability risk. The structure includes and not limited to staffing, management, and coordination with stakeholders and beneficiaries. It would involve the mobilization of health and other professionals to ensure a continued service delivery and strict planning at national level. Cooperation with decision-making entities at ministerial and local governments are essential strategy to efficient resource mobilization. The understanding is that resources for sustainability of a mobile clinic should be considered within the institutional and national framework.

The absence of a policy guideline on how it should be operated may result to a serious risk of early termination. A policy guide will facilitate having a mobile clinic as a national program rather than a private charitable activity as financing a private charitable activity is difficult to sustain and is often problematic. A structured national program would work with private initiatives using funds they receive from various sources. Institutional management systems protect the mobile clinic from the lack of the constant flow of resources arising from private initiatives. While private initiatives cannot be ignored as they often show the way forward by innovative approaches, relying on private program as part of community based regular activities is problematic. It is difficult to manage private resource flow with the timing and objectives of the program. It is possible to argue for the development of a regulatory framework as critical sustainability strategy.

Ensuring political will provides for national support as a factor for sustainability and success. Lack of political will and support, for this case, the mobile SLT clinic, can be a threat. In Uganda, surgical caps as a semblance of mobile clinics were reported as lacking regular activity because of the scarcity of financial resources until supported by the Ministry of Health. The absence of a centrally coordinated financial support impacted on the operation. While the eHealth network in Rwanda has been successful because of the strong commitment of the government.

There are many sustainability approaches that range from fee-for-service models, to third-

party payer sources, to grants, in-kind contributions, and local fundraising. In addition to the cost involved that can affect mobile SLT clinic sustainability, a flexible human resource management is crucial. Sustaining a mobile SLT clinic involved proper coordination of multidisciplinary team involving dentists, dental hygienists, health educators, special needs educators, and other social work providers. More than a decade ago, the World Health Organization (2006) already provided examples of rural mobile health program where resident doctors collaborate with local hospitals and rural clinic to provide health support to low-income and uninsured individuals. Services are offered at a reduced rate shared between the patient and the state. These cost sharing sustain mobile health care and also mobile SLT service delivery activities.

From insight gained from Health Cluster (2021), we can conclude that to sustain a mobile clinic project, the following need to be done:

1. Proper record management
There is a need to keep record of how many cases of persons with communication, swallowing, and hearing disorders each have been handled on a daily basis. The record should include statistical data of the types of cases handled and a narrative of the way they were handled. This will help the duty bearers to keep evidence of the SLT work done and make follow-ups. The statistical data and narrative information are an important leverage for attracting more funding as and when there is a need.

2. Immediate and frequent feedback to clients
Clients are always interested in knowing results from the tests conducted on them. Parents will want to have feedback on the assessment carried out on their children. Feedback will give full knowledge of the child's condition and way forward for the SLT intervention needed. The way forward will give recommendations to the parents on what to do when s/he is back home. If no feedback is provided, people will not see the value of the SLT services, and they will fall out of the support. This can affect the strategy intended for the intervention and the operation of the intended mobile SLT clinic services.

3. Working with existing structures
There are already existing structures like the village health teams that are used especially for mobilization and awareness creation in Uganda (Babughirana et al., 2016), millennium village structures at Dertu, Kenya, and council health management team in Tanzania (Republic of Tanzania, 2001). These structures are meant to use the health systems to improve health services. They work in decentralized health units and with community workers. As members of the community, they are respected, are listened to, and are able to follow up patients for compliance and are therefore important, experienced, and reliable partners for a mobile SLT clinic.

4. Cost sharing
Private health services, including speech and language therapy, are costly. General public hospitals are often crowded that impact on the quality of health service delivery. Mostly, no SLT professionals and service delivery is publicly available. The East African countries within the PAGEL project lack a structured health insurance system. In spite of the recognized poverty, patients utilize self-medication, attend to private health providers, or use traditional medicine.

Cost sharing as strategy where the beneficiaries contribute some little money for maintenance would be encouraged. The amount to be contributed should be mutually agreed upon and explained to the clients so as to reduce on disputes.

Reflection and Recommendation

Mobile Clinic Approach as an Outcome of an International Development Cooperation

International cooperation in the health sector always works at the interface with international development cooperation (DC). The DAAD funding line PAGEL, as mentioned before, is

also designed to build training structures for the health system, especially the promotion of the SLT profession, and thus to contribute to a central goal of development cooperation.

The objectives of development policy activities are defined in the 17 Sustainable Development Goals (SDGs) as globally recognized by the Agenda 2030 from January 2006 (UN, 2006) and recently updated at the SDG Summit 2019 (UN, 2019). The implementation of a mobile SLT clinic especially supports goal 3 and 4. In addition, OECD (2008) pointed out the basic principles of successful development cooperation, namely, ownership, inclusive partnership, delivering results, and capacity development.

From the perspective of development policy, it becomes clear that a mobile SLT clinic with its goals and potential can directly and indirectly affect many SDGs and make a decisive contribution to improving living conditions. At the same time, the principles of development cooperation also provide guidelines with regard to the project structure and practical cooperation between the participating international partners.

Work on the concept of a mobile speech clinic has been strongly influenced by these goals and principles throughout the PAGEL project. For an evaluation of the project results, an evaluation of the cooperation is important also with regard to a development policy perspective.

The conception of a mobile SLT clinic can already be seen as the positive result of ongoing project planning taking into account the above-mentioned guiding principles. The basic idea of a stationary model SLT clinic, as in Hannover, Germany, was jointly adapted to the specific conditions at the participating universities in Nairobi, Kenya, Kampala, Uganda, and Dar es Salaam, Tanzania. In the interests of an equal cooperation structure of all partners ("inclusive partnership") and the sustainable applicability of the goals to be established ("ownership"), the design of a model SLT clinic was adapted with regard to mobility, costs-effectiveness, equipment, and HUB-specific focus. This process was tedious and challenging as a result of different conceptual ideas in the practical implementation of setting up such a mobile SLT clinic.

On the other side, the project team also had to face conceptual differences, which sometimes could not be solved even though long and powerful discussions were held. One example can be the different views on the material setup of the SLT clinic especially in the areas of screening and assessment, as well as therapy and intervention. The German partner, representing Minority World perspectives, favored, for example, the approach of focusing on low-cost, everyday material, whereby the East-African partners strongly advertised to purchase high-cost apparatus and software solutions – a dispute deeply rooted in cultural bias.

Mobile SLT Clinics as a Promising CBR Approach for Underserved (Rural) Communities in SSA

In summary, despite the above-sketched challenges, the PAGEL team agrees that the concept of a mobile speech and language therapy clinic is a promising community-based rehabilitation (CBR) approach for underserved (rural) communities not only in East Africa, but in the whole of SSA.

The aim of a mobile SLT clinic is to take affordable and sustainable services nearer to the communities. The envisioned community-based mobile SLT clinics will create awareness on speech, language, communication, swallowing, and hearing disorders as an impairment at community level and provide opportunities for community members and policy makers to gain information on the screening and intervention strategies available. This information will reduce the stigma associated with speech and language pathology and communication disorders as well as provide available intervention and referral options for persons suffering from such challenges.

It is through the mobile SLT clinics that avenue for the much-needed research in communication, swallowing, and hearing disorders, which is currently very marginal, will be realized. Through the mobile SLT clinic as a com-

munity outreach activity, training institutions will conduct baseline surveys on the prevalence and status of speech, language, and communication disability for the future well-being of clients and patients from newborns to the elderly.

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The Organization of Cochlear Implant Programs in Tanzania: Assessment of Needs and Challenges

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Introduction

There is a large worldwide incidence of hearing-impaired newborns, children and adults, estimated to total about 360 million people. Most of them do not receive adequate therapy to enable them to participate in mainstream educational settings (GBD 2015 Disease and Injury Incidence and Prevalence Collaborators, 2016), to be involved in regular tax-paying employment, or to become integrated members of society (Hear-It AISBL, 2015). The global inclusion of hearing-impaired individuals is far from being realized.

A structured diagnostic audiological program combined with a clear hearing- and speech-language therapy (SLT) program are basic necessities for achieving the aim of helping a higher number of patients (Illg, 2017). Europe and the United States have learned from their initial mistakes in developing such a program. Recent pathophysiological knowledge has enabled historic faults to be avoided and for new programs to be more effective and less expensive to implement. In recent years in Tanzanian society, clinical and scientific interest has focused on the impact of hearing impairment on children, the elderly, and employees (Dotchin et al., 2015; Musiba, 2015). Experiences have revealed that hearing impairment without therapy can also negatively influence many other daily situations and living conditions.

This chapter outlines the infrastructure and logistics via which a hearing screening program in the sub-Saharan African region could be established. It is outlined based on the example of Tanzania. In October 2017, Tanzania had a population of 57,881,976 inhabitants. According to the Tanzanian Bureau of Statistics (2002), the incidence of disability was 2% of which 13.1% were deaf and blind and another 20% were hearing impaired in the ages 0–14 years. Universal newborn hearing screening (UNHS) (Ravi et al., 2018) is not yet established in Tanzania. Also, a cochlear implant program or a program to supply hearing aids is only available on a private clinical basis or in rare cases in government hospitals like Muhimbili National Hospital, Dar es Salaam. Education for hearing-impaired children is only offered by several schools of the deaf, which are not accessible to all sectors of society. Compared to other Majority World countries, in Tanzania about 60% of inhabitants pay for basic health insurance, covering basic healthcare such as pain treatment or minor surgery. Partial coverage from governmental health insurance is available for major medical treatments, oncology-related procedures, and treatment of children under the age of 5 years, pregnant women, diabetics, or HIV-positive persons.

This chapter describes potential solutions towards achieving an effective and generalized audiological-based diagnostic procedure with individualized hearing and SLT therapy that is dependent on age.

Theoretical Background

The theoretical background is based mainly on Western European standards that have been shown to be reliable and effective to use as an example to guide the development of a program in an African infrastructure and culture.

Pathophysiology

Hearing impairment is in most cases caused by an inner ear disorder. Only 20–30% of all hearing disorders are located in the middle ear. These middle ear diseases are caused by infections, tube ventilation malfunctions, ossicle trauma, or even congenital dysplasia. In most cases, these middle ear disorders can be treated by ear surgery.

Intracochlear hair cell damage is caused by a variety of genetic, degenerative, or traumatic disorders. Up to five out of 1000 newborns are already affected congenitally, and more than 20% of people worldwide are hearing impaired. Most of them have moderate hearing loss, but one to two out of 1000 newborns can have profound congenital hearing impairment (Maqbool & Maqbool, 2007).

Therapy Options

Physiological regeneration of hair cells is known to occur in some birds but has not yet been observed in humans. By the beginning of the twenty-first cen-

tury, treatment of hearing impairment with auditory prostheses was the only therapy concept for treating communication disorders. In the last 30 years, significant technical and surgical developments have taken place. Nearly all kinds and grades of hearing impairment can now be addressed with an adequate inner ear prosthesis, known as a cochlear implant. In particular, congenital deafness can be detected early by UNHS, and adequate therapy can be initiated to support sufficient neural plasticity in children.

The neural plasticity of the hearing system is evident from birth in which the auditory nerve generates electrical activation from the synaptic contacts between the hair cells and nerve fibers. During the first 2–4 years of life, mandatory maturation of the neural tissue must take place in order to enable normal hearing as well as appropriate speech and language development needed for sufficient integration into mainstream education (Kral & Sharma, 2012).

Hearing Systems

Within the last two decades, the technical development of conventional hearing aids (HAs) has improved substantially. Ease of use, low power consumption (meaning less battery consumption), simplified fitting strategies, and better understanding in noisy environments have become more readily possible.

Additionally, implantable hearing devices provide options to bridge the gap with combined hearing loss. Cochlear implants (CIs) provide solutions for deaf or profound hearing-impaired individuals. CI is an electrical hearing prosthesis that electrically stimulates the hearing nerve in cases of severe hair cell damage. The CI is implanted by experienced ear, nose, and throat (ENT) surgeons after a complete diagnostic audiological and radiological procedure (Lenarz, 2017). This is offered in a team after intense counseling from SLTs, audiologists, and ENT specialists. The postoperative therapy needs proper fitting of the CI system and a specialized therapeutic setting. This setting requires SLTs. The challenge is to identify those patients who need more specialized therapy and follow-up clinical sessions versus those who only need counseling as well as recognizing any changes in diagnosis and treatment in their ongoing hearing development.

Outcome in Terms of Speech and Education

The ENT-specialized CI surgeon bears the responsibility for the entire lifelong follow-up of the patient and has to properly manage the interdisciplinary team. One challenge is avoiding any medical or therapeutic complications. One can expect to integrate at least 70% of implanted children into mainstream education and about 90% of adult recipients into regular employment (Kerr et al., 2012; Illg et al., 2017; Schulze-Gattermann et al., 2002). Adult recipients who become deaf after the age of about 4 years are defined as postlingual deaf persons. They are able to communicate with spoken language.

Methods

To implement such an SLT program for hearing-impaired children (focused on the CI), special guidelines have to be respected – according to experiences based on the "state of the art" in Minority World countries and adapted to the needs of Majority World countries.

Universal Newborn Hearing Screening

Without UNHS at birth or some weeks after delivery, the mean diagnostic age in Europe and the United States is around 33 months of age (Moeller, 2000; Yoshinaga-Itano & Apuzzo, 1998; Yoshinaga-Itano et al., 1998). This timeframe is too late to address hearing impairment and for appropriate plasticity and development of the auditory system in the brain. It is proven that hearing screening via otoacoustic emission (OAE) or automated auditory brainstem response (ABR) is effective within the first 4 days after delivery. To ensure realistic chances of treating hearing impairment, effective and economic automated screening has to be con-

ducted by midwives or the nurses on the children ward. This is true for Minority World countries. Education of midwives and nurses and technical tracking is a duty of the ENT specialist. The ENT specialist is (after positive UNHS) responsible for confirming audiological diagnostics and the introduction of therapy.

Hearing Aid Fitting Observed by Speech-Language Therapists, Specialized in Hearing Impairment

HA fitting is done by a specialist, such as an acoustician. This is a process which can require evaluation over several weeks. In Germany, it is good practice for this process in children to involve SLTs as an early intervention. They provide counseling to parents, communicate with the acousticians, and observe the effect of the HA. This involvement is important to determine further diagnostic procedures and to establish whether a HA is sufficient.

Complete Audiological and Radiological Diagnostic Procedures, Independent from Age

In the case of a possible diagnosis of profound hearing loss, objective audiological and radiologic evaluations need to be performed. These serve to define the audiogram as well as the individual anatomy relevant for hearing. In order to exclude any additional negative influence from middle ear pathology, paracenteses are necessary before the audiological objective measurements.

The procedure includes the following:

- Bilateral paracenteses
- Subjective audiometry with HA in adults only, including promontory testing
- Objective audiometry
  - OAE
  - Electrical response audiometry (ERA), ABR; compound action potential (CAP); electrocochleography (ECochG); slow negative ten potentials (SN10)
- Radiology
  - High-resolution computed tomography (CT) on the temporal bone
  - High-resolution magnetic resonance imaging (MRI) on the temporal bone

These methods should be offered to children and performed by one interdisciplinary team, within a timeframe of 2–3 consecutive days, and as one procedure under general anesthesia. The advantage of an interdisciplinary team is the enhanced combined experience and quality of the results, reduction in the risk of multiple anesthesia sessions, and reduction in cost. More importantly, the interdisciplinary team can more successfully draw interpretations and make recommendations in an effective manner.

Cochlear Implant Indication

Severe hair cell disorder leads to elevated pure tone thresholds exceeding about 80 dB HL and monosyllables of less than 30%, which prevents speech recognition in noise, although is better amplified. Also, in high-frequency deafened patients, an indication exists for electrical-acoustic CI surgery. These indications are valid for postlingual deafened candidates.

In general, in children, CI indication exists for a threshold worse than 80 dB HL in ABR. Implantation will be performed within the prelingual phase of neural maturation in congenitally deafened children before the age of 12 months.

Cochlear Implant Surgery

CI surgery is not equivalent to middle ear surgery. The surgery is performed by an interdisciplinary team, requiring placement of a foreign body device into a crucial position into the head, and involving neural monitoring during the surgery and radiological confirmation of the finalized position of the implant. Currently, four companies offer the CI, so a surgeon should be familiar with all products to choose the most appropriate product for the patients. The products have different characteris-

tics, which is also important for postoperative use by the patients. Independent from this, reliable implantation is only possible if the surgical team undergo continuous training with the chosen product. If a given team or surgeon have implanted fewer than 100 recipients, then they should stay with one company to concentrate the experience for that given CI device.

After completing a mastoidectomy, a bony bed is drilled out to protect the implant device. A posterior tympanotomy opens the middle ear from a dorsal incision to gain access to the round window niche. In drilling out this area, the facial recess must be respected, and the procedure is electrophysiologically controlled by monitoring. Exposing the membrane of the round window gives access to the intracochlear structure. The implant is set in place, and the cable is pulled through a drilled tunnel down to the mastoid cavity. After sliding the membrane of the round window, the electrode is inserted slowly within the cochlea. The insertion depth is determined from the size of the cochlea and the residual hearing. Wound closure determines the surgery.

Cochlear Implant Basic Speech-Language Therapy

CI therapy is continued after diagnostics and implantation by fitting and hearing training and SLT. This postoperative therapy is dependent on age at implantation, duration of deafness and development with the CI (Illg, 2017; Percy-Smith et al., 2018).

Postlingual adults with progressive deafness (without any residual hearing) are fitted "directly" after surgery before leaving the hospital. During wound healing, electrical stimulation minimizes the development of scar tissue around the electrode. After 5 weeks of wound healing, the CI recipient returns for 5 consecutive days of intense fitting and hearing training, including education on the technical challenges of a CI.

In children implanted within the phase of maturation, CI stimulates the auditory nerve to accomplish maturation in a comparable period to that of normal-hearing children. This means that the intense phase of fitting lasts about 3–6 years after implantation. Within this phase, the children are fitted and receive hearing therapy and SLT regularly over 8–12 weeks for 2–3 consecutive days a week (Erber, 1982; Illg, 2017). At home, SLTs follow up these children and offer additional therapy (Suleiman et al., 2014). These phases of fitting and training initially occur in frequent sessions with short intervals between them, but with further hearing development these periods are more spaced out, such as up to twice a year.

Lifelong Care

After finalizing the basic therapy, only day-patient visits to the ENT clinic are necessary to monitor the expected use of the CI and appropriate development of speech recognition. The lifelong responsibility includes observing the technical integrity of the device, the societal, educational participation, and hearing development of the recipient, and identifying potential medical complications over time.

Due to recent technical developments in internet technology, online lifelong care with an experienced center and partners is possible (i.e., remote care).

Lifelong care in growing children, also after basic therapy, is characterized by continuous diagnostics of speech and language development, as well as passive and active speech and language training by SLTs. Any distinctive peculiarities should be diagnosed by a neuropediatrician, an immunologist, and/or a human geneticist to reveal additional disorders. These additional disorders can occur more frequently in hearing impaired than in normal-hearing peers (Häkli et al., 2014).

Lifelong care is characterized not only by technical, physiological, and medical questions but also by questions of appropriate inclusion. CI therapy experience is based only on 30 years of practice. Consequently, a generation of implanted children did not participate in education and employment. Additional postlingual implanted adults did not participate in employment and subsequent retirement, with some experiencing neurodegenerative disorders. Lifelong care has

huge potential for development after resolving known and unknown questions. A known question that has been resolved is the positive influence improved hearing has on slowing down the process of dementia (Bonfiglio et al., 2020).

From hearing aid use and recent studies on CI, it is known that hearing impairment and the quality of hearing systems and the fitting process determine the quality of employment and whether CI recipients pay tax (Dammeyer et al., 2019; Tehranchi & Jeyakumar, 2020).

Discussion

In 2012, the World Health Organization reported that 360 million people in the world (5.3% of the population) have disabling hearing loss. Among these, 328 million (91%) are adults, while 32 million (9%) are children. The greatest number of children are from Southern Asia and sub-Saharan Africa. It is estimated that two-thirds of hearing-impaired persons worldwide come from Majority World countries. Awareness of hearing impairment is continuously rising in Majority World countries, with the understanding that this is one of the major health challenges globally (Dotchin et al., 2015; Mushi et al., 2016).

Socioeconomic Aspects

It is known that hearing impairment has an immense negative biopsychosocial impact. Hearing impairment without adequate therapy does not allow education to lead to tax-relevant employment. Furthermore, the education system for hearing-impaired pupils and students is more expensive and less effective than the mainstream education participation of hearing-impaired students (Cheng et al., 2000; Kerr et al., 2012; Schulze-Gattermann et al., 2002; Shield, 2006). Compared to normal-hearing adults, hearing-impaired persons earn significantly less money than normal-hearing peers or are unemployed (Jung & Bhattacharyya, 2012). This is a strong argument for Majority World countries to establish an effective strategy to formulate solutions for hearing-impaired inhabitants.

Hearing Disorders and Hearing Systems

Hearing disorders pose global challenges, especially concerning diagnostic and therapy possibilities because the pathophysiology causing these hearing disorders is largely the same. A publication from Tanzania concerning otitis media was published in 1987 (Manni & Lema, 1987), which has been followed by several other studies in recent years (Freeland et al., 2010; Maro et al., 2016; Minja & Machemba, 1996; Mushi et al., 2016). These studies showed that otitis media is not only related to hearing impairment that reduces educational opportunities but also related to severe complications and economic pitfalls. Medical infrastructure can help reduce such complications because of early identification and therapy.

More than 80% of hearing disorders are not cured by middle ear surgery but need to be addressed by implementing a hearing screening and therapy program. This also offers an economic advantage by involving the hearing device industry in the national economy.

The basic requirements for implementing a hearing system for inner ear disorders are complete audiological diagnostics as well as the fitting of hearing systems or implantation of an auditory prothesis. Nowadays, besides fitting HAs for the majority of inner ear disorders, fitting a CI for profound hearing-impaired patients is an additional established solution. Nevertheless, the challenges associated with CI differ from those of HAs and are not completely known. This is the case because we have not yet followed up a whole generation of CI recipients in order to determine the success of a CI after 50–80 years of usage.

Development of a Countrywide Strategy

Initiating a new hearing program based on experiences reported from the literature or through personal discussions with and guidance from experienced professionals can enhance the efforts made to develop a successful new center. Initiating a program focused on children is extremely effec-

tive. Globally, experience has shown that early detection of congenital hearing impairment can only be realized in UNHS with proper tracking. Follow-up return, called "tracking," to facilitate the procedure of confirming diagnostics, has to be straightforward and effective. One tool to perform this easily is measuring the natural sleep of babies to achieve reliable audiometric results with ABR. This is essential to ensure the hearing maturation of children with early-fitted HAs or CIs. In a country such as Tanzania with a population of 57,881,976 inhabitants (as per October 2017), a landscape of 947,300 km^2 and an infrastructure of a Majority World country, establishing UNHS is a primary challenge. Only governmental policymaking to realize UNHS can enable professionals to identify existing resources and to establish the UNHS infrastructure needed for therapy. Governmental commitment to take over the costs of UNHS is the key issue to avoid a general refusal of screening. A high rate of follow-up return (tracking) is dependent on mandated UNHS, centralized data management, and quality control monitoring systems (Scheepers et al., 2014).

Challenges

The infrastructure for UNHS cannot be established without challenges. Therapy for hearing-impaired HA or CI recipients is lifelong and requires not only recurring device fitting but also long-term SLT. This has to be offered by SLTs. Because hearing with HAs is more similar to normal hearing than is the case with CIs, the therapy effort is less complex. Nevertheless, the growing auditory and technology updates need a reliable expert with easy access for the patient's family.

Cochlear Implant Therapy

CI therapy is more complex than HAs because of the potential surgical complications and unknown challenges of therapy given it has only been in use for the past 30 years. In adults, an initially intensive effort in fitting and speech therapy is needed, with less involvement over time. CI fitting in children, as with HA fitting, needs special experience and attention that can develop uniquely over time. SLTs have the duty to monitor the development in children's therapy. Dependent on the developmental milestones reached, related course therapy will be necessary or even not necessary at all. The main work of SLTs with children is to control their development and be aware when it differs. SLTs take over the therapeutic responsibility to differentiate between patients with a need for therapy and those without any need at a specific time. Depending on potential additional disabilities, the need can change during children's development. The incidence of additional cognitive pathologies in hearing-impaired individuals is higher than in normal hearing. Cognitive disorders need additional therapy, occupational therapy, or concrete neurological therapy.

Therefore, CI therapy is always interdisciplinary and dependent on a reliable and evolving infrastructure, which includes at the minimum ENT surgeons, SLTs, audiologists, and specialized CI and HA engineers/technicians. The medical responsibility for the entire process has to be taken by the specialized ENT surgeon.

With an increasing infrastructure in a Majority World country like Tanzania with a large landscape, one has to take into account that patients can be reached with new communication tools. Telemedicine and online fitting via mobile phones will be important tools for the care of hearing-impaired inhabitants. Academically founded developments, with which own experiences are collected and adapted in the African context, can be economic changes and chances there.

Conclusion

Drawing on the experiences of the last 30 years of structured audiological diagnostics, ensuring adequate therapy and transferring to a hearing screening system that identifies a huge number of potential candidates who can benefit from it is the baseline to design an effective infrastructure for sub-Saharan Africa. The next step is to address these challenges and transfer it to a culturally adequate strategy.

Increasing the number of hearing-impaired individuals involved in the socioeconomic system is the overall target (Grimby & Ringdahl, 2000). Further studies will reveal whether new technology and developments, such as hair cell regeneration, could enhance the hearing impairment outcome and ease of access to hearing impairment programs.

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Part IV

Introduction: Inclusion

This section highlights the intricate link between inclusion (typically regarded as a construct that belongs in the education field) and speech–language therapy (SLT); this link has been implicit in the previous sections. Inclusion as a principle is rooted in a World Conference on Special Needs Education held in Salamanca in 1994 (United Nations Educational, Science and Cultural Organization, 1994). It was there that the idea of inclusive education as education for all was first formulated. This was followed by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006), where important steps were taken to encourage the rights of persons with disabilities all around the world: to date, 164 countries have ratified and accessioned the CRPD. Concerning also persons with communicative disabilities, inclusion became more fundamental for their activation and participation in society independent from education. The International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001) could be seen as another big step toward the remodeling of speech, language, and hearing assessment and therapy in a person-centered way by keeping environmental resources (which act as facilitators) and barriers in mind. Nevertheless, inclusion is more than reducing barriers to participation in education or social life. Inclusion requires a change of attitude in society as a whole: In both Minority and Majority World contexts, this is a significant social challenge, albeit due to different reasons.

Observing inclusion from a scientific theory perspective, in Minority World contexts, the paradigms of rejection, segregation, and inclusion of persons with disability are in principle consecutive and historically grown. Nevertheless, rejection and segregation are still there, but in subtle forms of discussion. In sub-Saharan Africa (SSA), different paradigms can be recognized at the same time more perceptibly (Lüdtke, 2009). Synchronously, there are "traditional cultural attitudes which view people with disabilities as a punishment from God, cursed and a shame to the family" (Pather, 2019, p. 787) cultural stereotypes such as witchcraft and punishment by ancestors (Ndung'u & Kinyua, 2009), "colonial and postcolonial histories of medical

segregation" (Berghs, 2017, p. 292), and a philosophy of a shared collective humanness and responsibility called "Ubuntu" (ibid.). Berghs (2017) relates Ubuntu to an understanding of disabilities as an African concept.

Looking at the scientific discourse, the understanding of inclusive education differs from author to author, from Minority to Majority World contexts. Cultural and historical processes shape differences in the way of understanding. For example, South African authors' discourse of inclusive education is connected with the terms freedom, democracy, citizenship, and references to the experience of the apartheid system (Hummel, 2018). In Minority World contexts, the implementation of inclusive education differs from country to country (e.g. Sansour & Bernhard, 2018). For example, in the United States, inclusion is differently implemented than in Germany with its long tradition of a highly separated school system (Powell, 2009). The German-established system has had to overcome a fundamental practice – away from speech–language schools to co-teaching children with communicative disorders in general classes, while US school-based speech–language therapists (SLTs) are required to change from pullout to classroom-based approaches (Green et al., 2019). Both traditions continue to challenge obstacles. Hence, implementing inclusive settings needs to consider, among others, cultural appropriateness in SSA together with a range of other factors.

In SSA, the process of changing to an inclusive educational system has been slow. According to a more general global understanding of inclusion, there was also a shift from not only educating children with disability but rather to reaching all learners in SSA regions. Vulnerable groups of children need to be considered, such as the children who live in poverty, those in rural or remote communities or in urban slums, working children, those who belong to indigenous or to linguistic and/or ethnic minority groups, and those infected and affected by HIV/AIDS (Pather, 2019). In particular, for children participating in education and social life who belong to linguistic and ethnic minorities, the barriers they face are communicative in nature, implying that SLTs have a direct role to play in addressing and remedying these barriers. Thus, the SLT should use culturally and linguistic appropriate material for the proper inclusion of these children in service provision.

All over the world, SLTs work on the interface of two Sustainable Development Goals (SDG), SDG 3 "Ensure healthy lives and promote well-being for all at all ages" and SDG 4 "Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all," to encourage inclusive SLT (Division Sustainable Development Goals, 2020). This pedagogic and health care interface is, on the one hand, implicit in the daily work of SLTs. On the other hand, it is mirrored in the different modes of training: special needs education studies with a greater or lesser focus on speech, language, and hearing or medical training on SLT with a greater or lesser focus on pedagogical or school-related topics. But for the inclusion of persons with communicative disabilities – be it participation in education or society – a good balance is crucial. This is because in the Majority World, due to limited awareness of communication disability, less attention is given to communication disorders as compared to physical and visual disabilities. In this section,

the authors give insights into their work and research on this interface. An array of topics focuses on the inclusion of persons with different communication disabilities in societal and educational contexts. The following critical reviews outline these diverse projects.

27 Juan Bornman

Communication, Disability and Human Rights: Exploring the Role of the Sustainable Development Goals

Abstract *Background*: Good health and well-being, quality education, and peace, justice, and strong institutions are three of the 17 universal Sustainable Development Goals (SDGs) adopted by world leaders as part of a United Nations initiative. *Methodology*: Ten South African studies dealing with Goals 3 and 4, respectively, are reviewed in this chapter, and brief reference is made to the aims of the studies, methods used, results as well as the limitations, recommendations for future research, and implications for implementation. *Results/Discussion*: The goals and relevant studies are linked to the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) as this chapter frames disability as a human rights concern. By utilizing the CRPD to implement and monitor the implementation of the SDGs, progress can be made to ensure that the exclusion and inequality of persons with disability, such as policy, practice, knowledge skill, and attitudinal barriers, are not created or perpetuated.

Critical Review Serving as the keynote paper for this section of the book, this chapter introduces inclusion as a human rights narrative. The author shares valuable information from a number of quality South African studies, weaving them together under overarching themes guided by two of the SDGs. By portraying the ties between the different studies, the author projects the reader into a higher level of reflection on these research outputs. It is through this reflection that the reader comes to realize that inclusion is a complex, multifaceted phenomenon. By focusing on the SDG for Good Health and Well-Being, the reader is led through questioning how persons with communication disability are included in health settings, such as in hospitals. Similarly, the manner in which these persons participate and are included in the education sphere is raised when dealing with the SDG for Inclusive and Quality Education and Lifelong Learning. Although the studies discussed are South African, they reflect trends and human rights infringements which are prevalent throughout sub-Saharan Africa (SSA). This chapter thus meaningfully contributes to the drive for the realization of human rights in practice for all people with communication disability in SSA.

28 Helen Barrett, Julie Marshall, Juliet Goldbart, and Nathalie Bussien

Access to Early Childhood Development and Inclusive Education Services for Refugee Children with Communication Disability in Rwanda

Abstract *Background*: Rwanda is host to over 154,000 refugees, mainly from neighboring Democratic Republic of the Congo and Burundi, who have fled violent unrest in their home states. Most are unable to access the three "durable solutions" at the core of international protection: voluntary repatriation, local integration, or resettlement in a third state, for a number of complex reasons. They therefore remain under the protection of the Rwandan Ministry for Disaster Management and Refugee Affairs (MIDIMAR) with the support of the United Nations High Commissioner for Refugees (UNHCR) Rwanda Representation Office. People with communication disability are thought to be under-identified and underserved in East Africa. The provision of services is extremely limited, and communication disability is chronically misunderstood and often "invisible" to the onlooker. Lack of knowledge and skills about how to identify and manage communication disability is a key limitation to children accessing appropriate services. Research into communication disability and barriers to inclusion in extremely vulnerable refugee communities is required, in order to raise awareness of the significance of communication disability among key stakeholders, including those in the humanitarian sector. *Methodology*: This chapter describes in detail the background to ongoing research with refugee children in Rwanda, which follows a concurrent mixed-method approach using documentary analysis, focus group discussions and interviews, classroom observations, and a literature review. *Results/Discussion*: The opportunities and challenges facing refugee children with communication disability in accessing ECD and inclusive primary-level education services in Rwanda are discussed.

Critical Review In line with the human-rights framework introduced at the beginning of this section, this chapter illuminates the violations that refugee children with communication disability are faced with when they cannot access services in Rwanda. However, the reader also experiences a sense of hope and opportunity once background information is given regarding the current research being conducted into how they can be included in these services. The authors provide a detailed description of ethical considerations, which is particularly relevant to this vulnerable population and creates awareness of an additional level of complexity with regard to working with this population. This chapter successfully portrays the ethical dilemmas, human rights issues, and need for change in this specific population. Due to many civil strifes, guerrilla wars, and cross-border conflicts, many children suffer the most, affecting not only their education but also general communication skills due to trauma caused by war. This has been the case in many countries in SSA, especially in Western, Central, and Eastern Africa. The map provided

in this chapter showing the numbers of refugees exiting from various African countries also highlights the necessity for clinicians all over Africa to take note of these considerations surrounding refugee children with communication disability, as many African countries must absorb this population into their own. This chapter is thus an essential read for any clinicians working in Africa.

29 Joyce Achieng Ogogo, Molly Merrab Ogalloh, and Beatrice Bunyasi Awori

Inclusion of Children with Social Communication Disorder in Kenya

Abstract *Background*: This chapter aims to investigate the inclusion of children with social communication disorder (SCD) in the mainstream in Kenya. SCD is characterized by difficulty with the social use of both nonverbal and verbal communication. The deficits result in functional limitations, ineffective communication, a dearth in social participation, and low academic achievement. Children with such disorders require early identification and interventions to accommodate them in inclusive settings in Kenya. *Methodology*: This chapter involves a literature search on SCD as well as investigation into the accommodations made for learners in mainstream Kenyan classrooms. The literature review was guided by variables such as the definition and characteristics of SCD, possible causes, implications, and educational accommodations for children with SCD. *Results*: Findings reveal a paucity of research on SCD in Africa. Perceptions regarding the causes of neurodevelopmental disorders such as autism spectrum disorder and epilepsy are investigated, as well as the pluralistic view of these disorders according to Kenyan culture. Parallels are then drawn between these disorders and SCD. *Discussion*: Information on the requirements for inclusion of children with SCD in the mainstream in Kenya is then provided in an effort to assist teachers, speech–language therapists, parents, the learners with SCD, and their peers.

Critical Review This chapter is a testament to the resourcefulness that African academics must develop when facing a lack of resources. As noted in the results section, the authors merge scarce information on inclusive educational strategies employed in Kenya and perceptions related to similar disorders in the African context with information from Majority World contexts regarding social communication disorder (SCD). Chapters such as this are critical for developing awareness of "novel" diagnoses, which may not have been covered in training. The authors draw parallels between the way in which similar disorders such as autism and epilepsy are viewed and this relatively unknown disorder. In this way, this chapter presents the first-of-its-kind conception of SCD within the SSA context. In addition, there is a focus on educational inclusion for this population, as these are typically children who

will be placed in mainstream classrooms. This inclusive focus advocates for improved individualized education plans, which is a component of inclusive education that is applicable to many SSA countries and many different diagnoses. All clinicians working with the pediatrics population in SSA would thus benefit from the information presented in this chapter.

30 Diane Rodríguez and Geraldine Arquer Haddock

Promoting Social Communication: Teaching Strategies for Students with Autism Spectrum Disorder in East Africa

Abstract *Background*: Given the importance of teaching all children, it is very beneficial to use effective resources and for educators to learn how they can use them to best help their students with autism spectrum disorder (ASD) improve their communication skills. Effective teaching of children with ASD will ultimately enable them to participate in the community, which contributes to their self-esteem. *Methodology*: This chapter makes use of qualitative literary analysis paired with case studies to illustrate practical strategies to improve the communication skills of students with ASD in East Africa. *Results/Discussion*: Instructional methods for teaching are discussed, including assessment, community teaching, collaborative strategic reading, social stories, modeling, strategies for minimally verbal children with ASD, and the use of music combined with social narratives. Instructional activities designed to help students successfully transition to other educational settings or careers are also discussed. The strategies discussed bring multiple perspectives to issues concerning the effective teaching of communication skills to students with ASD. This chapter also discusses how teachers can involve family and community members in instructional activities in order to support students with ASD develop their communication skills. This chapter is intended to serve as a resource for educators of learners with ASD working in East Africa.

Critical Review With the growing number of children globally being diagnosed with ASD, it stands to reason that teachers universally need to have the necessary tools to work with children who may have this diagnosis. Unfortunately, teachers in SSA may not have ready access to this information, which is where this chapter comes in. The authors of this chapter aim to bridge this knowledge gap through sharing information which will most certainly assist teachers with the inclusion of children at any level of the autism spectrum in their classrooms. What makes this specific chapter distinctive is the fact that it is written from the perspective of Tanzania and East Africa, making it culturally and contextually pertinent for this context. The authors have further added reflection questions at the end of each section, guiding the reader through a deeper level of engagement with the content. The suggested methods are also each discussed in terms of cultural adaptation and transfer:

one of the first of its kind for SSA. This chapter is thus a necessity for any SSA clinicians providing support to teachers who have children with ASD in their class, as well as teachers who may wish to further their own research into how to include these children. Moreover, it is worth noting that this and the previous chapter on ASD offer critical insights into the management of children with spectrum disorders such as ASD in an inclusive setting. In addition, we note that in SSA, many parents, teachers, as well as speech–language therapists may have challenges in screening, diagnosing, and management of children with ASDs.

31 Martin C. Njoroge and Augustus Nyakundi

Navigating Communication Difficulties Faced by Children with Autism Spectrum Disorder: Evidence from Kenya

Abstract *Background*: On the one hand, the available literature on inclusive education reports that globally children with autism spectrum disorder (ASD) experience diverse communication difficulties in educational contexts. On the other hand, the same literature expounds on a variety of communication interventions to such challenges. It argues that if such strategies are employed early, these children with ASD, with time, will be able to communicate effectively and meaningfully and be able to lead fulfilled lives. *Methodology*: Using interviews and observation schedules, data were collected from 72 children and 6 teachers in three inclusive schools for children with ASD in Kiambu and Nairobi Counties, Kenya. *Results*: This chapter outlines the communication challenges faced by children with ASD learning in inclusive classrooms. Further, this chapter discusses the interventions that teachers of these children employ to navigate these difficulties, thus aiding the development of their communicative ability. *Discussion*: The findings show that children with ASD do face communication challenges, but quick interventions by their teachers support the slow but impactful development of language and communicative ability of these children.

Critical Review The inclusion of children with ASD in mainstream schools in SSA is ever-increasing. However, for various reasons, there is a paucity of research from Africa involving children on the autism spectrum, specifically in terms of educational inclusion. This chapter shares findings from a study that aims to bolster this research disparity by providing information on the educational strategies being employed by expert teachers in three Kenyan schools with specific autism units. By sharing the strategies employed by these highly qualified teachers who run the units, this chapter serves as an example to other schools in Kenya and other SSA countries who may wish to establish similar units or may have a number of learners on the autism spectrum in their mainstream classes. As is mentioned in this chapter, children

with ASD are often hidden away as a result of stigma associated with disability in the African culture. By publishing research such as this chapter, we can gradually increase awareness and acceptance of disorders such as ASD, starting with professionals who can advocate for this population. The ultimate anticipation is that this may lead to increased inclusion and a better realization of human rights for all.

32 Juan Bornman, Helindi Gouws, Enid Moolman, Anna Robberts, and Kerstin Tönsing

Using Augmentative and Alternative Communication Strategies in Schools in Namibia

Abstract *Background*: Attending school provides children with opportunities to socialize and form friendships, to develop and learn new skills – ultimately impacting on adulthood as it prepares one for life in the workplace. Active participation in the classroom is a prerequisite for learning to take place, but if a child has a significant communication disability, active participation is jeopardized. *Methodology*: This chapter comprises a qualitative literary review of some barriers that children with disabilities face, as well as augmentative and alternative communication (AAC) strategies which can be used in the classroom. *Results/Discussion*: Five opportunity barriers (barriers that lie outside of the individual), namely, policy, practice, attitudinal, knowledge, and skill barriers, are unpacked within the Namibian context. Next, AAC strategies, which involve the utilization of less frequently used modes and channels of communication to facilitate participation and learning in the school context, are discussed. These AAC strategies include unaided systems (gestural and signing systems) as well as aided systems (communication boards and communication technology). However, a combination of the different systems, called multimodal communication, is typically used. Keyword signing is described, and specific steps to teaching it are presented. This is followed by a clear illustration of representational skills which develop along a complexity continuum. A variety of specific school-based strategies such as visual schedules, remnant books, aided language stimulation activities, visual aprons, visual recipes, and place mats are described. Each of these strategies also contain clear pictures as well as step-by-step guidelines on how to design and implement them.

Critical Review Although this chapter is set within the context of Namibia, the story is applicable across SSA; a story of a small number of "special schools" or specialized units which cater for children with disabilities, necessitating that children have to travel great distances or stay in hostels and often be taught in a language which they do not know. On the other hand, there is a high percentage of children not attending any form of school at all and very

few mainstream schools practicing inclusive education. Within this context, many teachers are at a loss as to how to work with children who have complex needs. The barriers faced are immense. With this story in mind, the authors present a positive and achievable solution to helping such a variety of children in these classrooms: implementation of augmentative and alternative communication (AAC) strategies. This chapter provides practical solutions for facilitating communication in the classroom, which can assist children in terms of both understanding and expression. The authors provide culturally appropriate strategies and pictures, bearing in mind the reality of the SSA context, which makes this chapter a go-to resource for teachers working in SSA who need additional ideas and support when working with children with disabilities. The strategies provided in this chapter give insight into how teachers in SSA can be creative and improvise teaching and learning materials. This chapter also provides the necessary background information for SLTs wishing to use AAC strategies with their clients, helping to achieve better communication for all.

33 Nelly Were Otube and Mathew Kinyua Karia

Critical Components in the Inclusion of Learners with Cerebral Palsy and Associated Communication Disorders

Abstract *Background*: Rates of children born with cerebral palsy (CP) is higher in sub-Saharan Africa (SSA), while effective inclusive education remains a challenge in these countries. This chapter focuses on the critical components in the inclusion of students with CP with associated communication difficulties in learning institutions. *Methodology*: A systematic review was carried out to find, critically evaluate, and synthesize the available evidence on how the inclusion of students with CP can be fostered in regular schools. *Results*: A critical appraisal of 18 studies revealed significant gaps in research related to the inclusion of students with CP in SSA schools. The synthesized evidence is described in a narrative form in the following thematic areas: the learning environment, accommodation, attitude, therapy, and assistive technology. This chapter sampled studies that were aimed at providing meaningful information regarding the inclusion of children with CP in regular primary schools. *Discussion*: Conclusions are drawn for the SSA context, such as increased classroom engagement by therapists and the increased use of augmentative and alternative communication (AAC).

Critical Review Continuing with the theme of inclusion, this chapter looks specifically at the inclusion of children with cerebral palsy (CP) in mainstream schools in SSA. This chapter provides a succinct overview of the available global research, giving the reader access to the findings in an integrated, abridged manner, and then draws parallels to the SSA context. This

overview provides worthwhile information on how to accommodate learners with CP in the mainstream setting, with the SSA context in mind, which makes it a beneficial resource for clinicians and teachers throughout SSA. It may serve as a useful commencement point for research into practical strategies to use with this population. The authors divide the research into easily understandable categories that guide the reader through the different areas in a deliberate, systematic manner. In a context such as SSA where the rates of CP are so high, this chapter is an essential read for policymakers, teachers, and clinicians alike. It also opens the door for similar reviews to be conducted focusing on the inclusion of different diagnoses, exposing the need and opportunity for Afrocentric research related to educational inclusion.

34 Atieno Rose Opiyo

Stuttering's Hidden Side: The Need for an Empathetic School Climate for Disfluent School-Age Children in Public Primary Schools in Kakamega, Kenya

Abstract *Background*: Short-term psychosocial problems are common among school-age developing children, emanating either from individual child characteristics and/or factors within the school setting. Essentially, these problems reduce a child's chance for school adjustment and overall school success. Children who stutter may be at the highest risk of social adjustment difficulties and school failure when they find themselves in a non-empathetic school environment. Although there is anecdotal evidence about the adverse effects of disfluency, elsewhere, little systematic research has examined the psychosocial and academic challenges of disfluency within African school setups. This chapter explores prevalence, psychosocial effects, and coping strategies of children who stutter in Kakamega Municipality, Kenya. *Methodology*: Based on a qualitative approach, a retrospective analysis of school psychosocial experiences linked to disfluency was documented. Qualitative interviews were conducted with 11 disfluent pupils and their 22 non-stuttering peers aged 8–14 years and five teachers from one public primary school. Qualitative data were coded, thematically categorized, and analyzed in descriptive and narrative forms. *Results*: Disfluent pupils reported negative intra- and interpersonal adjustment difficulties as a result of bullying, teasing, rejection, ridicule, exclusion, low peer acceptance, shame, anxiety, anger, and loneliness. Psychological problems are a manifestation of their inability to communicate competently, difficulties in making friendships, and self-condemnation. *Discussion*: In response to the high incidence of psychosocial and academic challenges experienced by disfluent pupils, this chapter reiterates the need for awareness and sensitization programs to create a more empathetic school climate where differences are tolerated rather than assaulted.

Critical Review Applying the concept of inclusion to learners with disfluency, this chapter takes a look at the environmental and personal factors which impact on the psychological well-being of children who stutter. As stated in this chapter, there has been little research conducted into disfluency in schools in the African context. Seeing a need in this area, the author set out to fill the gap by conducting her own research in the Kenyan context. The results of the research illustrate the vital role that the environment plays, which could provide insights for school policymakers, educators, and SLTs collectively. As stated by the author, "there is a need for clear awareness programs that aim to create friendly atmospheres in schools, where diversity is tolerated and not assaulted." It is this sentiment that could positively transform the African education system for children with a variety of disabilities and differences. This also alludes to the fact that physical inclusion is not enough; the attitudes and perceptions of peers, staff, and community will always remain vital to successfully reducing the stigma of disability in Africa, where there is a large correlation between cultural beliefs and disability. This chapter is a first step in the conceptualization of a tolerant educational system in SSA where difference is celebrated.

35 Julius Patrick Omugur

Sign Language Interpretation Services for Learners with Hearing Impairment in Inclusive Secondary Schools in Uganda: Challenges and Successes

Abstract *Background*: The study aimed at establishing the provision of sign language interpretation services for learners who are deaf and/or hard of hearing in an inclusive secondary school that practices the policy of inclusive education in Uganda. This chapter assesses the work of sign language interpreters and the challenges they encounter during indoor and outdoor interpreting activities in an inclusive regular secondary school. Interpreters are believed to work closely with the teachers teaching in the school for learners with hearing impairment. *Method*: This chapter adopted a qualitative case study design, identifying six teachers and six sign language interpreters through purposive sampling. Data collection instruments were interview, observation, and focus group discussions. *Results*: Implementation of universal secondary education (USE) has had less impact on the teaching and learning of students with hearing impairment in secondary schools in Uganda. Findings of a communication disparity in such an inclusive environment are not conclusive enough to explain the challenges and successes investigated. Challenges appear to be rooted in the interpreters' level of qualification, from the learners with hearing impairments, from the teachers and school administration, as well as resulting from environmental and contextual factors. Educational and cultural diversity also have an influence. *Discussion*: There

is a need to develop a healthy inclusive school working environment, further training for sign language interpreters, and awareness campaigns to support the work of sign language interpreters.

Critical Review This chapter provides a unique opportunity to view inclusion from the perspective of sign language interpreters working with deaf/hard of hearing learners in Uganda. Providing this additional perspective is necessary for understanding the complexities of educational inclusion in the SSA context. Factors mentioned by the author which contribute to challenges faced by sign language interpreters correspond to factors influencing SLTs and children with disabilities themselves. This is echoed throughout the chapters of this handbook, and suggests that there are underlying barriers to inclusion in the SSA context. Although the focus of this chapter is on the Ugandan context, the findings are applicable to many SSA countries. By using well-qualified key informants in his research, the author also provides learning opportunities for other teachers and sign language interpreters in Uganda. By giving sign language interpreters and teachers an opportunity to have their voices heard, the author has made a strong contribution to the growing body of research which is helping professionals better understand disability in SSA.

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Communication, Disability, and Human Rights: Exploring the Role of the Sustainable Development Goals

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Introduction

The silence of speechlessness is never golden. We all need to communicate and connect with one another – not just in one way but in as many ways as possible. Communication is a basic human need, a basic human right. And much more than this, it is basic human power, according to Bob Williams, disability activist and himself a person who uses augmentative and alternative communication (AAC) (Williams, 2004). So what exactly is communication? It is derived from the Latin word *communicare*, which means to impart, to share, or to make common. In other words, to create a shared meaning of something between at least two individuals. However, research shows that approximately 1.3% of all humans have such significant communication disorders that they cannot rely on their natural speech to meet their daily communication needs (Beukelman & Light, 2020). Without access to speech, these individuals are severely restricted in their participation in all aspects of life – health, education, employment, family life, access to justice and citizenship. The use of AAC systems and strategies offers great potential to enhance the communication of individuals who have little or no functional speech. AAC involves multiple modes of communication, namely, unaided forms where only the body is needed, such as facial expressions, manual signs, finger spelling, and natural gestures, as well as aided forms such as real objects, pictures, line drawings, and orthography which can be displayed on either low-tech devices such as communication boards or on high-tech devices such as speech-generating devices.

British theoretical physicist Stephen Hawking, possibly the most celebrated AAC user of the modern world, said in an internet interview:

> Without my computer, I cannot communicate ... [It] has provided me with the means to continue working and researching ... [It] also allows me to keep in touch with my family and friends; I can e-mail and make phone calls at any time using the mobile technology ... It is vital for my security and safety that I can make calls for myself should the need arise.

Across the world, persons with disabilities have poorer health outcomes, lower education achievements, fewer employment possibilities, and higher rates of poverty than peers without disabilities. This is partly because of the difficulties they face in accessing health services, education, employment, transport, information, and communication. These difficulties are exacerbated in less-advantaged communities as disability disproportionately affects vulnerable groups. Within the sphere of disability, those individuals with a severe communication disorder are especially vulnerable, as participation in all aspects of life is restricted. Therefore, acknowledging the importance of human rights for individuals with disability cannot be overemphasized. Communication is essential for promoting, protecting, and ensuring the full and equal enjoyment of all human rights and guaranteeing fundamental freedoms for all persons with disabilities. "To deny people their human rights is to challenge their very humanity," said Nelson Mandela (1990).

Human rights are fundamental rights that are considered universal to humanity, regardless of ethnicity, gender, ability, or any other consideration, and they cannot be gained by or taken away from an individual or a group. The African continent boasts a strong normative framework for the protection, prevention, and preservation of human rights – and thus the United Nations Convention on the Rights of Persons with Disabilities (CRPD, United Nations, 2006) is of particular interest to the continent to ensure an integrated, peaceful, and prosperous Africa.

The CRPD specifically states that persons with disability should have "full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities" (Article 1), thereby underscoring the fact that these individuals should be seen as rights-bearers rather than as recipients of pity and charity. As such, the CRPD marks the migration of disability issues from the medical and charity models to the human rights arena (Degener, 2016).

Although all persons with disability are vulnerable to human rights exploitation, those with significant communication disorders are the most vulnerable members of society because their

impairments make them dependent on others. Furthermore, many persons with disability live in dismal poverty in Africa, and in almost all African towns and cities, one would find persons with disability begging in the streets for donations. Rural areas in Africa frequently do not have clean water, electricity, and indoor plumbing, which necessitates the sharing of community toilets. These barriers result in exclusion, marginalization, and serious human rights infringements for these individuals.

Since the United Nations' Millennium Development Goals (2000–2015) introduced eight Millennium Developmental Goals in 2001, the international human rights landscape for persons with disabilities progressed exponentially, largely due to the global adoption of the CRPD. These goals focused funding initiatives and aid toward ending extreme poverty, hunger, and preventable disease (United Nations, 2016), but unfortunately did not include disability and led to persons with disability not benefiting from these development initiatives. They remained less likely than their able-bodied peers to have access to health care and education, which in the long term makes it difficult to find employment, earn a living, and lift themselves out of poverty – a clear illustration of how disability can be seen as both a cause and a consequence of poverty. Today it is a well-known fact that as many as 80% of persons with disability live in poverty (World Health Organization and the World Bank, 2011).

The Millennium Development Goals were followed by the international acceptance of 17 universal Sustainable Development Goals (SDGs), for the period 2016–2030 (United Nations, 2015). The SDGs are a universal agenda, which explicitly embraces human rights for all, advocating that "no one will be left behind." They explicitly mention persons with disabilities seven times and reference "vulnerable populations" 18 times, providing real hope that persons with disabilities will tangibly feel the impact of development during this period. As such, the SDGs draw particular attention and commitment to empower persons with disabilities under a number of articles that are also found in the CRPD, and therefore the remainder of this chapter will focus on these two international mechanisms.

Methods

The SDGs give hope to many previously excluded individuals. The question now becomes: Which SDGs give hope for the biggest impact for persons with disabilities in low- and middle-income countries? What action is needed for that to happen by 2030? This chapter will explore the role of communication as a means to satisfy two of the SDGs, namely, Goal 3: Good Health and Well-Being and Goal 4: Inclusive and Quality Education and Lifelong Learning, and how communication can be linked to specific articles set out in the CRPD (Articles, 24 and 25). A brief introduction of the study, its aim, and the research methodology used will be explained for each of the ten studies in relation to the two SDGs. This will be followed by a summary of the results, a discussion on the limitations of the study, and future research suggestions as well as implications for implementation.

SDG 3: Good Health and Well-Being

Ensuring healthy lives and promoting well-being for persons of all ages is essential for sustainable development (SDG 3, United Nations, 2015). Good health is important to be able to work, to learn, and to participate in community life. Hence, the Sustainable Development Agenda aims to address access to the highest standards of health and health care for all individuals, irrespective of their income. Since access to good health and well-being is also a human right, the CRPD should serve as the guiding framework for implementing the SDGs. Article 25 of the CRPD reinforces the right of all persons with disabilities to attain the highest standard of health care, without discrimination, thereby echoing the sentiments of Goal 3 of the SDGs.

Four different studies that were conducted in South Africa to specifically address various aspects of Goal 3 of the SDGs are next discussed in more detail, following the above outline. Table 27.1 provides a conceptual map for this section.

Table 27.1 Four studies concerned with Goal 3 of the SDGs and Article 25 of the CRPD

SDG 3: Good Health and Well-Being (United Nations, 2019)[a] CRPD: Article 25 – Health	
Study 3.1: *Scoping Review of Children's Pain Vocabulary: Implications for AAC* (Johnson et al., 2017b)	
Study 3.2: *An Exploration of Pain-Related Vocabulary: Implications for AAC Use with Children* (Johnson et al., 2016)	
Study 3.3: *Nurses' Perspectives Towards Patient Communication Using a Low-Technology Communication Board in an Intensive Care Setting* (Gropp et al., 2019)	
Study 3.4: *Message Banking: Perceptions of Persons with Motor Neuron Disease, Significant Others and Clinicians* (Oosthuizen et al., 2018)	

[a]The content of this publication has not been approved by the United Nations and does not reflect the views of the United Nations or its officials or Member States.

Scoping Review of Children's Pain Vocabulary: Implications for AAC (Johnson et al., 2017b)

Introduction

Having access to vocabulary that enables a child to communicate about pain is an important developmental milestone. The ability to express pain allows parents and health care providers to understand the child's discomfort and act accordingly. Unfortunately, children with communication disorders are often unable to self-report pain and have to rely on proxies (e.g., parents or other caregivers) to report on the location, type, and intensity of their pain. Discrepancies between proxy reports and children's self-reports have been widely documented (Herr et al., 2011). A deeper understanding of children's use of language to express pain could enable health care providers to better understand children's pain and intervene when necessary.

Aim of the Study

The main aim of Study 3.1 was to conduct an interpretive scoping literature review to determine the available research on children's self-reported pain vocabulary by asking the question, "*What is the vocabulary that children themselves use to express pain?*" In the past, children's verbal expression of pain was overlooked during pain assessment.

Research Methodology

An inclusive systematic keyword search in six individual online journal databases (CINAHL, Medline Proquest, PsychInfo, PubMed, Scopus, and Web of Science) was conducted, as well as hand searches and a general internet browser search (Google Scholar). A total of 1435 records were identified through the database searching, which included 77 duplicates. Following the screening of all 1395 records at title level, 1258 were removed as they did not fit the inclusion criteria of being focused on children's vocabulary. A total of 137 records were read at abstract level, of which 106 were excluded as they did not meet the inclusion criteria for the study. Next, the full text of 31 records were read for eligibility, and 14 of them were excluded (mostly because they did not include children's own voices about pain). This resulted in a scoping review of 17 articles.

Results

Results identified a total of 403 words, with 133 words that appeared in at least three studies. When the 403 words were analyzed, two main themes emerged, namely, a description of pain and ways of coping with pain. Regarding the description of pain, the following four subthemes emerged: (i) use of interjections, graphic descriptors, e.g., "*ouch*," "*ow*," sensory descriptors, comparisons, and intensifiers; (ii) description of physical or sensory pain rather than emotional pain, e.g., "*ache.*" Young children who did not yet have the language skills to describe the pain would use concrete phrases like "*I lose my smile and feel bad*" (Jerrett & Evans, 1986) or "*I am not feeling well*" (Kortesluoma & Nikkonen, 2006). Older children used more abstract language, e.g., "*Sometimes it is worse and sometimes more like stabbing*" (Savedra et al., 1982); (iii) indication of the location of pain, e.g., "*I felt it all over my whole body*" (Kortesluoma & Nikkonen, 2006) or "*I have a pain in my willie*" (Wennström & Berg, 2008); and (iv) eecounting the causes of the pain, e.g., "*I was playing too rough; stress; bumps in the road; was hit in the head; bleeding; skin came off; it had dirt in it*" (Harbeck & Peterson, 1992) or "*I know I will feel sick when I eat sweets*" (Esteve & Marquina-Aponte, 2011).

Regarding the theme of coping with pain, six subthemes emerged: (i) asking for attention, support, or comfort, e.g., "*I want to sit on Mummy's knee*" (Johnson et al., 2016); (ii) using distractions or dissociations from pain, e.g., "*I want to play*" (Johnson et al., 2016); (iii) focusing on secondary gains or avoiding unpleasant activities, e.g., "*You can stay at home when there is an exam*" (Esteve & Marquina-Aponte, 2011); (iv) requesting treatment, e.g., "*Put on plasters/Band-Aid*" (Esteve & Marquina-Aponte, 2011); (v) employing fake bravery, e.g., "*I wasn't afraid*" (Wennström & Berg, 2008), or "*It's not sore at all*" (Johnson et al., 2016); and (vi) indicating a physiological need, e.g., "*I want to drink*" (Wennström & Berg, 2008) or "*I want to vomit*" (Johnson et al., 2016).

Limitations and Future Research

Only full-text papers published in English were included. This created a double-edged sword: some studies might have been excluded (despite the fact that their aim might have been relevant), while some studies were included which might not have been conducted in English but were published in English. Therefore, translation errors by the original authors in reporting the children's vocabulary might be possible. Furthermore, only studies that portrayed children's own voices of pain-related vocabulary were included, which considerably reduced the number of studies reported.

An empirical study that asks children about their pain vocabulary and compares that to proxy-reported vocabulary is recommended to determine if discrepancies do exist. This was undertaken in Study 3.2 by the same authors. Another future direction would be to determine how these pain-related concepts could be visually represented for young children and also for older, nonliterate individuals who use or could benefit from AAC, as well as for individuals who suffer a temporary loss of speech (e.g., persons in intensive care units).

Implications for Implementation

In conclusion, this study expanded the relatively small research base (only 17 studies) that focused on children's own voice in describing pain by providing a composite list of 133 pain-related words that might be useful for children talking about pain. However, Study 3.1 also warns that although this list is an important guideline in ensuring that the breadth and width of pain vocabulary is covered, vocabulary should be selected on an individual basis and consider the specific child, his/her unique needs, and the specific context.

An Exploration of Pain-Related Vocabulary: Implications for AAC Use with Children (Johnson et al., 2016)

Introduction

Self-report of pain is considered the gold standard for assessing pain (Hay et al., 2009); children need vocabulary to describe their pain and ensure that they receive appropriate treatment. Research has shown that children with disabilities often suffer more frequent pain episodes and more acute pain than their peers without disability (Ramstad et al.,

2011). For example, research has shown that children with cerebral palsy need more frequent treatment to stretch their still muscles, with potential associated discomfort or pain (Johnson et al., 2015). Comorbid speech and language difficulties often make it extremely difficult for them to express their pain (Barney et al., 2015).

Not being able to communicate pain verbally is terrifying and stressful for any individual and results in the pain being overlooked by parents and professionals and consequently not being treated. Children need to have the relevant vocabulary available that will enable them to communicate about the occurrence, nature, and intensity of the pain, as well as potential causes of the pain, strategies to avoid pain in future, and also self-comforting messages to calm themselves and cope with the pain. AAC strategies could be used to enable children to meet this gold standard of pain assessment by providing them with the means to self-report their pain.

Aim of the Study

This study aimed to identify the most common vocabulary that typically developing children would use to describe physical pain experiences (Johnson et al., 2016). A second aim was to socially validate the pain-related vocabulary list compiled from the responses in the first phase for children who use or who could benefit from an AAC system.

Research Methodology

Study 3.2 used a sequential, exploratory mixed-method design with a qualitative development phase. During the first qualitative phase, ten hypothetical pain scenarios were developed, which were used in the second, quantitative phase. Three different groups of participants were involved: children between the ages of 6;0 and 9;11 years ($n = 74$), parents of children in this age group ($n = 61$), and teachers who teach children in this age group ($n = 56$). In-depth interviews were conducted with all the children at their school or at the hospital, and they were asked to answer each of the questions related to the hypothetical pain scenarios. These interviews were all transcribed verbatim. Parents and teachers answered exactly the same questions, but in questionnaire format, at a time and location they considered convenient.

The words/phrases from the interviews with the children were recorded according to a predetermined set of transcription rules and were uploaded into an Excel spreadsheet along with the written responses obtained from the parents and teachers. Content analysis was done to categorize words/phrases. Thereafter, inferential statistics were calculated to compare the data between the children and parents; the children and their teachers; and the parents and the teachers. Pearson's chi-square test or Fisher's exact test was used to determine the frequency of the words/phrases in the different categories across the different groups.

Results

Some 629 pain-related words or phrases were suggested, which were divided into seven distinct categories, namely, (i) vocabulary to describe the pain (which includes exclamations, vocalizations, descriptors, sensory words, intensifiers, comparisons or metaphors, as well as evaluative words); (ii) vocabulary to direct others' actions in response to the pain, injury, or illness (which included actions, places, and possible remedies); (iii) vocabulary to describe the pain location and visible signs of the actual tissue damage as a result of the physical injury; (iv) vocabulary to describe the cause of the pain (which included both internal and external causes); (v) vocabulary to describe specific strategies to help cope with pain (which includes self-talk, actions to cope with pain, positive outcomes, and distractions); (vi) vocabulary to reflect on strategies of how the pain could have been prevented (which could also include a reflection on what had happened in the past); and, finally, (vii) vocabulary to indicate the consequences of pain or injury and its influence on activities and participation (which could include a physical outcome, a secondary gain, or an emotional response as a result of pain).

This study also clearly showed that children used different words or phrases when compared to adults. This supports the notion of always including the child's viewpoint or "*the child's perspective*" as opposed to "*a child perspective*," which is

obtained when adults act as proxies for children and reflect on children (Nilsson et al., 2015).

In order to meet the second aim of the study, a composite list of the 84 most frequently occurring vocabulary items was compiled and socially validated by three adults who use AAC. They suggested that only single words and/or phrases be used, as that would provide more message options. They also emphasized the need to individualize vocabulary items and provided valuable suggestions on how to organize the vocabulary on an AAC system. They proposed that a body figure should be added to eliminate the need for words to describe body parts as part of indicating the pain location.

Limitations and Future Research

The comparisons between the three different groups in the study were only done at group level (i.e., the parents in the study were not compared with their own children). Furthermore, only a few children in the hospital setting could be accessed, despite attempts at recruiting children from this context. Therefore, subsequent studies that investigate the pain experiences of children in the hospital context are suggested. Follow-up studies are needed to determine the best-suited visual representation (photographs or line drawings) as well as the most appropriate strategy for selecting vocabulary for children who require AAC.

Implications for Implementation

In conclusion, Study 3.2 highlighted the importance of including more than one perspective (particularly a child and an adult perspective) in generating a comprehensive vocabulary list. Moreover, it demonstrated the appropriateness of using hypothetical scenarios to elicit vocabulary for sensitive topics (e.g., abuse, violence, end-of-life topics). A follow-up paper was completed to address one of the suggestions from Study 3.2, namely, to propose a model for selecting vocabulary for sensitive topics such as pain (Johnson et al. 2017a). This model suggests a four-phase strategy comprising (i) using hypothetical scenarios, (ii) considering different perspectives that may affect vocabulary selection, (iii) involving direct stakeholders, and (iv) customizing vocabulary.

Nurses' Perspectives Towards Patient Communication Using a Low-Technology Communication Board in an Intensive Care Setting (Gropp et al., 2019)

Introduction

The emphasis moved from the primary stakeholder group (in this case children and their parents and teachers) in Studies 3.1 and 3.2 to the secondary stakeholder group (namely, nurses who work in intensive care units) for Study 3.3 (Gropp et al., 2019). Communication is of critical importance in an intensive care setting for both the patient and medical staff in order to ensure efficient care, to alleviate possible adverse effects, and to avoid possible medical errors (Patak et al., 2009). Persons with disabilities, specifically those with communication disorders, are particularly vulnerable in an intensive care setting, and apart from their need to communicate vital information (e.g., difficulty breathing), they also need to express basic needs (e.g., pain, discomfort, itching) (Ten Hoorn et al., 2016). Some patients without disability are also affected in the intensive care setting for a temporary period, for example, when they are intubated or have a tracheostomy, or when their hands are restrained, or if they have an intravenous drip inserted, to name but a few (Beukelman et al., 2007). AAC strategies can be used effectively in this context to provide additional communication support.

Aim of the Study

The aim of Study 3.3 was to determine the perspectives of nurses about communication with patients in an intensive care unit and their use of a paper-based communication board – the translated Vidatak EZ Board™ – before and after a training session.

Research Methodology

A quasi-experimental pre-test post-test group design with a control group was used in this study. Data were gathered using a custom-designed questionnaire that comprises a biographic section, as well as a section on different communication aspects and possible communication barriers between nurses and patients. A total of 30 regis-

tered nurses who had been working in the intensive care unit at a large 1650-bed public hospital in a semi-urban, low socioeconomic area participated in the study.

The aim, duration, and procedures of the study were explained to nurses during their tea break. This process was repeated on several days to recruit nurses from different day shift groups. Once the nurses agreed to participate, they received the pre-test questionnaires, and a time and date for training was negotiated with each participant. In order to not disrupt hospital procedures, the training was short (1 hour long) and focused on how to communicate with a patient using a translated Vidatak EZ™ communication board. Nurses were given 2 weeks to implement the board with their patients, after which they completed Post-test 1. Post-test 2 was completed 2 weeks after Post-test 1.

Nonparametric statistics were computed to analyze the data. Between-group comparisons were done (using the Mann-Whitney U test), as well as within-group comparisons (using a Friedman test).

Results

Results revealed general consensus about communication being a crucial component in the provision of appropriate patient care in an intensive care unit, and most nurses agreed that a communication board should be implemented. However, only limited success was observed when the board was implemented after a short training session. Scores on the second post-test (2 weeks after training) were also lower than the scores after the first post-test (directly after training), which might suggest that nurses did not implement the communication boards permanently, or that they had stopped using them. This might either have been due to the time spent on the initial training (too short to bring about permanent change) or because the training content focused more on knowledge than on skills.

Limitations and Future Research

The biggest limitation of the study was the relatively small sample size (n = 30) and the nonrandom assign of participants to the experimental and control groups. For logistical reasons, nurses in the day shift formed the experimental group, and nurses working the night shift constituted the control group.

It is recommended that future studies should use focus groups comprised of nurses to determine their perspectives regarding the content and layout of the proposed communication board in order to ensure that it is appropriate and valid for the context. Moreover, different types of training (e.g., case-based training spread over consecutive days using a problem-based learning focus) should be explored as this might impact positively on the maintenance and generalization of communication board use after training.

Implications for Implementation

Most nurses agreed that communication is crucial in the intensive case context and that a communication board can be implemented, although limited success was observed in implementing the board following a short training. The study concluded by recommending that different types of training (e.g., case-based training spread over consecutive days using a problem-based learning focus) should be explored in order to investigate the maintenance and generalization of communication boards after training. Nurses recommended specific adaptations to the communication board.

Message Banking: Perceptions of Persons with Motor Neuron Disease, Their Significant Others, and Clinicians (Oosthuizen et al., 2018)

Introduction

The last study (Study 3.4) that was related directly to Goal 3 of the SDGs investigated message banking (Oosthuizen et al., 2018). Message banking is a relatively new intervention strategy that has the potential to facilitate effective communication for persons with a degenerative disease such as motor neuron disease (MND) who gradually lose their ability to rely on speech to convey messages. As such, message banking involves the recording of whole messages by the person in their own natural voice and storing these messages electronically for

when the person is no longer able to use their natural voice. As message banking allows for recording legacy messages in one's own voice, its main purpose is to maintain social closeness between the person with MND and their significant others (Costello, 2014). The loss of speech and communication is often perceived as being stripped of humanity, and when someone is simultaneously facing this loss and a terminal illness such as MND, it is even more devastating (Brownlee & Bruening, 2012).

Inherent to message banking is the selection of vocabulary and messages to bank for future use. Although the speech-language therapist (SLT) can fulfill an important guiding role in this process, the person with MND themself as well as their significant communication partners all play a crucial role in planning and selecting the legacy messages that need to be banked. A collaborative approach, taking the concerns, skills, and preferences of all the parties involved into consideration, is essential to ensure the effective implementation of message banking as an intervention strategy.

Aim of the Study

The aim of Study 3.4 was twofold: first, to determine and compare the perceptions about message banking of the persons with MND themselves, their significant others, and practicing SLTs and, second, to determine the possible messages to record during message banking, based on the perspectives of these three stakeholder groups.

Research Methodology

A comparative, nonexperimental group survey design with a custom-designed questionnaire was used, and the questionnaire was independently completed by the three different participant groups. Prior to completing the questionnaire, all participants listened to a short presentation about message banking.

Following an extensive recruitment process, ten persons with MND, seven male and three female, were included in the study. Their ages ranged from 34 to 77 years, and they had all received their diagnosis less than 5 years prior to this study. Seven persons with MND were living with their spouses, partners, or former spouses, while two were living alone and one lived in a retirement home. Three persons with MND had reportedly consulted an SLT after being diagnosed with MND. The persons with MND were requested to identify one significant other with whom they spend at least 3 hours a week, to also participate in the study. One person identified two significant others, which meant that 11 significant others participated in the study: eight females and three males of ages ranging between 18 and 71 years. Six of the significant others were spouses and two former spouses; two were children and one a friend. The 17 SLTs who participated were all female, and ten reported that they had had experience with persons with MND, while seven had no experience in this area.

Results

Results indicated that although most participants, spread across the three participant groups, reported that they had never heard of message banking, they were all interested in it. It is of great concern that message banking was so unknown, given the fact that research indicates that 95% of individuals with MND would lose the ability to meet their daily communication needs using their natural speech (McKelvey et al., 2012). It was particularly worrisome that a third of the SLTs had never before heard of message banking, given the fact that they should be the primary informants to persons with MND regarding AAC options. They were also the participant group who were most negative toward message banking. It appeared as if the therapists in the study were emphasizing speech-strengthening exercises (e.g., improving articulation, respiration, phonation, prosody, and resonance), which is contrary to current evidence in the literature for MND (Hanson, 2014). Persons with MND regarded social etiquette as the most important communication function and information transfer as the least important, which is consistent with other findings in the literature that emphasize the need for vocabulary that will conserve "small talk" and maintain social closeness. The survey results also revealed statistically significant differences between the three participant groups regarding the types of messages to bank. Persons with MND themselves rated messages

about discussing finances and social closeness as most important, while their significant others rated messages about needs and wants as being the most important. SLTs selected messages regarding the sharing of information about spirituality and religion, children, comforting others, and being romantic as being the most important.

Limitations and Future Research

The generalizability of the results of Study 3.4 is limited, given the relatively small sample size. Furthermore, comparisons were drawn at group level, and not for individual triads.

Future research can include retrospective perception studies of persons with MND who have lost their speech and who therefore cannot use message banking any longer, to determine their perceptions about the messages they would have prioritized for banking. The results of such a study will provide invaluable guidance to persons who are in the early stages of such a degenerative disease. A crossover design comparing the attitudes of conversational partners to messages that are stored in the person's natural voice, using message banking as compared to synthetic messages, would provide insight into the value of message banking.

Implications for Implementation

The most important clinical implication of this study was that SLTs should become more aware of the value and importance of message banking and that they had an ethical responsibility in recommending its use as best practice. Furthermore, they should assist with the types of messages that should be banked, given that achieving social closeness through the banking of legacy messages (e.g., saying your loved one's/ones' names or characteristic utterances that are specific to the person) is of great importance and urgency. Similar to earlier studies (Fried-Oken et al., 2006), results from Study 3.4 also showed that persons with MND rate the transfer of information as the least important communication function, while maintaining social closeness is the most important function.

Impact of the Presented Studies on SDG 3: Good Health and Well-Being

Successful communication in the health context requires effective and competent interaction between the sender and the receiver of the specific message. The process becomes compromised from the moment when the message transmitted by the sender cannot be effectively interpreted and understood by the receiver. When a person has significant communication challenges, for a temporary period (such as individuals who are in intensive care units as described in Study 3.3) or permanently, and does not have access to relevant vocabulary (as described in Studies 3.1 and 3.2), or in cases where persons lose their ability to communicate due to a degenerative disease (such as the individuals in Study 3.4), the communication process becomes more challenging, ultimately compromising the quality of the service provided by SLTs. This can be seen in factors such as diminished trust in the health care provider, weakened patient and family satisfaction with the service they receive, reduced treatment adherence and thus symptom resolution, contracted access to and use of health services, negatively impacted quality of life, and even mortality. This may damage the well-being and health of the individual, thus compromising their ease of access to health services (Castro et al., 2012).

Health care providers, such as nurses, doctors, and therapists (including SLTs), need knowledge about different forms of communication such as AAC and message banking when trying to succeed in communication with individuals with communication challenges, in order to prevent the disability from affecting the exchange of information between the individual and the health care provider. Studies about the communication challenge between persons with communication disorder and health professionals such as the four studies mentioned, may create a greater awareness of the importance of communication and also hold benefits when it comes to planning actions aimed at training health care providers to assist persons with disability.

Therefore, the rights of all persons, including those individuals with significant communication disorders, to access safe, effective, quality, and affordable essential health care services following

the principle "*No one must be left behind*" – as described in SDG 3 and promulgated in Goal 25 of the CRPD – can only be assured for this group of individuals if training of health care providers is undertaken.

SDG 4: Inclusive and Quality Education and Lifelong Learning

Quality education is the foundation for improving individuals' general quality of life as it can be a powerful mechanism to break the cycle of poverty. As such, education can go a long way toward ensuring equality for all: equality between boys and girls, between children with and without disability, between poor children and rich children, etc. The United Nations estimates that in low- and middle-income countries, primary education enrolment has reached a level of 91% – however, in 2013, 59 million children of school-going age were still out of school (United Nations, 2015). Education outcome (in Goal 4.5 of the SDGs) specifically focuses on individuals with disability and states that by 2030 gender disparities in education should be eliminated and equal access to all levels of education and vocational training should be ensured for the vulnerable, including persons with disabilities (Martinho, 2016). However, simply creating a platform for children with disabilities to enrol/attend school is not enough: access to education for all requires that teachers have the capacity to teach these children with special educational needs. Therefore, SDG 4.5 clearly states that the in-service training of teachers to create the knowledge and skills to teach children with special educational needs must be increased and that all schools should be upgraded or built with the necessary adapted infrastructure and materials to accommodate children with disability.

This is in tune with Article 24 of the CRPD (United Nations, 2006), which recognizes the right of persons with disabilities to education. Education of children with disabilities is a human rights concern, and the inclusion of individuals with disability in mainstream society is the primary step toward obtaining a just and equal society. One of the main shifts toward raising disability awareness and creating positive attitudes toward persons with disability and their families should take place in schools, as they are the primary places where early attitudes are shaped.

The CRPD specifically highlights the importance of an inclusive education system with the necessary reasonable accommodations in place and argues that children with disabilities should not be excluded from free and compulsory education on the basis of disability. Similar to the SDGs, the CRPD also mentions teachers and specifically states that teachers, including teachers with disabilities, should be appropriately trained in disability awareness, the use of AAC modes, and sign language and/or Braille (United Nations, 2006).

Six different studies were conducted in South Africa to address Goal 4 of the SDGs. They are now described in more detail. Each study includes a brief introduction, followed by the aim of the study and the research methodology used. Next, the results are summarized, followed by a discussion of the limitations and suggestions for future research. Finally, the implications for implementation are provided. Table 27.2 provides a conceptual map for this section.

The Challenges of Realizing Inclusive Education in South Africa (Donohue & Bornman, 2014)

Introduction

Internationally, the Education for All initiative, which marked a global movement toward providing quality basic education for all children, was adopted by the international community in 1990 (UNESCO, 1990). Following the demise of apartheid, in 1994, compulsory education was implemented for all South African children and segregated schooling practices eliminated. Education White Paper 6, the policy document that promotes educational equality and pushes for the educational inclusion of children with disability (Department of Education, 2001), was released. This brought educational policies into line with the human rights-based South African constitution. White paper 6 was designed to transform the educational system in South Africa by building an integrated system for all children

Table 27.2 Six studies concerned with Goal 4 of the SDGs and Article 24 of the CRPD

SDG 4: Quality Education (United Nations, 2019)[a] **CRPD: Article 24 – Education**	
Study 4.1: *The Challenges of Realizing Inclusive Education in South Africa* (Donohue & Bornman, 2014)	
Study 4.2: *South African Teachers' Attitudes Toward the Inclusion of Learners with Different Abilities in Mainstream Classrooms* (Donohue & Bornman, 2015)	
Study 4.3: *South African Teachers' Attitudes Toward Learners with Barriers to Learning: Attention-Deficit and Hyperactivity Disorder and Little or No Functional Speech* (Bornman & Donohue, 2013)	
Study 4.4: *The Awareness of Primary Caregivers in South Africa of the Human Rights of Their Children with Intellectual Disabilities* (Huus et al., 2016)	
Study 4.5: *The Effect of an Aided Language Stimulation Programme on Subtraction Word-Problem Solving for Children with Intellectual Disabilities: A Preliminary Study* (Naudé et al., 2020)	
Study 4.6: *Comparing Two Response Modes in a Mathematics Test for Learners in Foundation Phase with Severe Physical Disabilities: A South African Example* (Bornman et al., 2016)	

[a]The content of this publication has not been approved by the United Nations and does not reflect the views of the United Nations or its officials or Member States

(i.e., no special and mainstream schools), using a more flexible and suitable curriculum for all (including children with disabilities), developing district-based support teams to provide support for all teachers in need thereof, and strengthening the skills of teachers to cope with more diverse classrooms.

However, despite the introduction of White Paper 6, most children with disability remain in separate "special" schools or do not attend any form of school at all.

Aim of the Study

This conceptual paper explored the reasons why so many children with disability and of school-going age do not attend school and why those who do attend typically still attend "special schools" for children with disability, despite the country's educational policy that promotes inclusion. This is not necessarily a South African problem alone, as it appears that many other countries have struggled with implementing inclusive education.

Research Methodology

This paper takes a top-down theoretical approach to policy implementation proposed by Matland (1995), which stresses the importance of policy clarity as well as the control and direction that is required by policy makers to systematically implement the policy, as stipulated in White Paper 6.

Results

It highlights two main factors that hinder the implementation of inclusive education in South Africa: first the lack of clarity, specificity, and detail in the education policy, as the policy only prescribes broad strategies that provide limited guidance on its implementation in practice, and, second, issues around the implementation and enforcement of the policy by the National Department of Education. The authors conclude that progress can be made with inclusion if procedures are clarified, directives are given, and the appropriate authorities assume responsibility for and control of implementation.

Limitations and Future Research

This is a conceptual paper and focuses on a top-down theoretical orientation, although a counter-argument for a bottom-up approach could also be made. More empirical research studies that investigate specific components related to the imple-

mentation of various components of White Paper 6 are needed as inclusion is a broad term involving a variety of stakeholders.

Implications for Implementation

The role of teachers in the inclusion process cannot be overemphasized and thus both the SDGs and CRPD specify appropriate teacher training to ensure successful educational inclusion. Teachers are the driving force in the enactment of the education policy as they are the gatekeepers of the classroom climate and activities (Bornman & Donohue, 2013; Bornman, 2021). Therefore, the next two studies (Studies 4.2. and 4.3) investigate different aspects of teacher attitudes – whether as facilitators or barriers – toward the inclusion process.

South African Teachers' Attitudes Toward the Inclusion of Learners with Different Abilities in Mainstream Classrooms (Donohue & Bornman, 2015)

Introduction

Inclusive education that focuses on one schooling system for a nation's children, irrespective of whether they exhibit disability or not, is globally accepted. As explained in Study 4.1, South Africa published Education White Paper 6 (Department of Education, 2001) outlining the transformative steps the schooling system would need to undergo in order to become more inclusive for all South African children. Political and policy changes, however, do not always translate to what happens in practice. Although various factors contribute to inclusion, teachers may be one of the most important facilitators, as they have the opportunity to advance or to deadlock its implementation in the classroom. Teachers' attitudes concerning inclusion are varied and influenced by, among others, factors related to the specific child (e.g., language, gender, ability, age), the school at large, the broader society and culture, as well as factors related to the teacher themselves (e.g., their attitudes, values, knowledge and skills). Accordingly, Study 4.2 attempted to describe the attitudes of South African teachers toward the inclusion of children with different abilities in mainstream classrooms.

Aim of the Study

This study specifically attempted to examine teachers' academic and social expectations of the children they teach and their attitudes regarding the amount of academic adjustments they believed would be needed to include the child with a specific disability. Several teacher-related variables (such as age, teaching experience, and experience with children with disability) were also examined in relation to the attitudes they held.

Research Methodology

Teachers were recruited from three of South Africa's nine provinces – some were teaching in special schools, while some (n = 27) were teaching in mainstream schools but were enrolled for an advanced certificate in educating children with severe disabilities. A total of 110 teachers consented, but only 93 teachers responded in full to the Teachers' Attitudes and Expectations Scale, a measure that was custom-developed for the purpose of this study. The scale contains four hypothetical vignettes that depict children with different types of disability in the classroom context (i.e., a child with congenital blindness but good verbal abilities, a child with autism spectrum disorder (ASD) who exhibits serious deficits in social skills but performs average with regard to academic skills, a child with spastic quadriplegia who has a mild intellectual disability and needs to wear nappies to school, a child with Down syndrome who has a mild intellectual disability without any challenging behavior). Content validity was established for the measure. Teachers responded using a five-point Likert scale (1 = *I don't agree at all*, and 5 = *I agree completely*).

Results

Overall, teachers reported that they thought that inclusion would benefit the social development of children with disabilities more than their intellectual development. This finding relates to concerns expressed by researchers that the focus of inclusion for children with disabilities is rather on caring, loving, and socializing, than on learning (Bornman et al., 2008; Zonious-Sideri & Vlachou, 2006). The classic 1968 experiment by Rosenthal and Jacobson showed that children live up to what

is expected of them – the so-called "*Rosenthal*" or "*Pygmalion effect*." Unfortunately, this effect is true not only for positive but also for negative expectations, thus creating a self-fulfilling prophecy. Low expectations from teachers toward children with disability are a double-edged sword (Bornman, 2021) as they have a negative impact on the teaching goals that are set and the strategies and energy teachers employ to meet these goals.

Study 4.2 furthermore found that teachers were overwhelmingly more confident about including children with Down syndrome into their hypothetical mainstream classrooms than including children with other types of disabilities, as they felt that the child with Down syndrome would need significantly less instructional time when compared to the other children. It was also noteworthy that teachers reported that the child with congenital blindness would make the least progress over the course of the year with reading, despite the fact that the hypothesis did not imply any intellectual disability for this child. This unexpected result was possibly due to the teachers' lack of knowledge of braille and their inability to understand how a child with a visual disability could meet the visual demands of learning to read in the conventional way.

Limitations and Future Research

The four vignettes provided to the teachers included brief descriptions of hypothetical children with disability who exhibited "typical behavior" often found in children with the specific disability type, yet we know that children are complex and their behaviors are varied. The great variability in children's behavior, skills, and abilities might therefore have impacted on how teachers completed the questionnaire. Furthermore, this research is more closely aligned with the medical model of disability (as it focuses on specific types of disability) rather than the social model. It would therefore be useful if future research could focus more on environmental aspects. It would also be useful to conduct longitudinal research in this regard and to track these teachers over an extended period of time (e.g., 5 years) to track possible changes in attitude over time. Attitudes might become more positive (if teachers gain more exposure and experience with children with disability) or equally become more negative (if they find themselves in a position with limited or no support to implement inclusion).

Implications for Implementation

The results from this study showed that providing teachers with sufficient resources in the classroom and providing them with hands-on training experiences with children with disability might influence their attitudes toward such children positively. Finally, this study showed that teachers still have many reservations and are ambivalent about inclusion: on the one hand, they strongly support the ideals of human rights for children with disability, but on the other hand, they have realistic concerns, given the lack of resources and infrastructure for support in the education system.

South African Teachers' Attitudes Toward Learners with Barriers to Learning: Attention-Deficit and Hyperactivity Disorder and Little or No Functional Speech (Bornman & Donohue, 2013)

Introduction

Teachers' attitudes influence their classroom and communication interactions with the children in their class, which, in turn, creates the basis for learning. Research has shown that one of the driving factors influencing the development of academic skills for children with disability in inclusive education is high expectations from teachers (Beukelman & Light, 2020).

Study 4.3 focused on two conditions: first, on children with attention deficit hyperactivity disorder (ADHD) and, second, on children with little or no functional speech (LNFS).

Children with ADHD can be disruptive in classrooms because of their inability to concentrate and focus on a single task. They have difficulty completing their classwork, have problems staying seated, misunderstand what is required of them to complete a specific task, and may also have difficulty forming and maintaining relationships with

peers (Kos et al., 2006). Children with LNFS, on the other hand, have considerable communication difficulties and typically have less than 30 words of intelligible speech (Beukelman & Light, 2020). Due to this, teachers sometimes feel uncertain about what these children comprehend, need, and prefer, and thus teachers place fewer demands on them, leading to reduced communication opportunities and little motivation to develop more effective communication skills. Learned helplessness may also be observed in these children when the teacher tries to anticipate what the child wants to communicate, thereby restricting opportunities for the child to autonomously communicate and participate in classroom interactions (Basil, 1992).

Aim of the Study

The attitudes of teachers toward two specific types of barriers to learning were explored in Study 4.3 by means of two different vignettes. Teachers' attitudes were assessed on five domains: the child's general academic abilities, the child's classroom behaviors, the child's communicative interactions in the classroom, their attitude toward the inclusion of the children in their classroom, as well as teachers' attitudes pertaining to their own capabilities to teach these children.

Research Methodology

A total of 118 foundation phase teachers (Grades one to three) from 12 different schools in a remote district of the Northern Cape province of South Africa participated. The Modified Teachers' Attitude Scale, with 32 items that tap five subscales and use a five-point Likert scale (1 = *Strongly agree* to 5 = *Strongly disagree*), was used. These subscales include teachers' attitudes about their own abilities, about the child's general academic abilities, about the child's classroom interaction, about the child's communication interaction, and about the inclusion of the specific child in their classroom. Two vignettes were developed to highlight the differences between the two types of children: one depicts a child with ADHD in which impulsivity, hyperactivity, and inattention are highlighted, while the other vignette shows a child with LNFS who uses a communication board to interact in the classroom and requires assistance in the classroom. A comparative crossover research design was used, and teachers completed the Modified Teachers' Attitude Scale for both vignettes.

Results

The results indicated that although teachers reported that the child with ADHD would be more disruptive in class and have a more negative effect on the classroom climate, they overwhelmingly favored including this child in their classroom over the child with LNFS. This might in part be attributed to their fear of the unknown as most of the teachers in this study had had experience of teaching a child with ADHD (being a learning barrier frequently seen in classrooms), while many of the teachers in the sample had never taught a child with LNFS. Although they rated the child with LNFS as more motivated to learn, they were concerned about the ability of that child to communicate effectively for both learning and social purposes. They were also significantly more concerned about their own ability to cope with the child with LNFS and felt that they would benefit from extra training. The results that emerged from this study are similar to those of another study carried out in Botswana, where teachers also reported, in the absence of additional training, anxiety about including children with academic barriers to learning (Chhabra et al., 2010). The results from Study 4.3 further showed that age was a significant predictor of teachers' attitudes toward the inclusion of children with LNFS and ADHD, where younger teachers held more positive views about children with either condition. This attitude might be indicative of the evolution of teacher training as teachers nowadays receive more positive information about inclusive education.

Limitations and Future Research

The low reliability estimates that were obtained on the Modified Teachers' Attitude Scale for two of the five subscales (Subscales 2 and 4) are of concern. Cronbach alpha estimates suggested that the reliability of Subscale 2 can be substantially improved with the removal of Item 9 "*This learner will need extra help to learn.*" However, the omission of none of the items on Subscale 4 (teachers' attitudes about communication interaction) would increase its reliability estimate. Future studies that

employ the Modified Teachers' Attitude Scale should therefore consider its reliability.

Another limitation of this study is that only a self-reported questionnaire was used, and no independent observations of teachers' behavior in their classrooms were conducted. This could have led to them responding to the questionnaire in ways that they thought were accurate but did not match their classroom behavior in actuality. Future studies of this nature could thus attempt to also obtain observational data to correlate with the self-reported questionnaires.

Implications for Implementation

In order to achieve educational inclusion of all children, a shift that promotes change is needed, a shift from a set of embedded assumptions and practices that encourage maintenance of current practices. Study 4.3 thus concludes with the need for ongoing inclusive education training for all teachers in South Africa to secure successful inclusion that is in line with Goal 4 of the SDGs and Article 24 of the CRPD.

The Awareness of Primary Caregivers in South Africa of the Human Rights of Their Children with Intellectual Disabilities (Huus et al., 2016)

Introduction

As explained earlier in this chapter, human rights as articulated in the CRPD (UN, 2006) can be seen as a basic requirement also for the maintenance of human dignity and the opportunity to thrive – particularly in the case of children with disabilities. However, the rights of children can never be considered separately from the rights of their parents or other caregivers (Klinck et al., 1999) as children are often unable to implement their own rights while parents are in a favorable position to either fulfill or restrict their children's rights. Therefore, parents of children with disabilities are obliged to be well informed when they take decisions concerning their children by carefully considering their children's rights.

Aim of the Study

Study 4.4 aimed to explore 219 parents' awareness of the human rights of their children with intellectual disabilities in light of the role the parents may play in either facilitating or restricting these rights.

Research Methodology

The aim of the study was fulfilled by means of a custom-designed close-ended question on a questionnaire with a yes/no answer that probed the parents' awareness of the fact that their children with intellectual disability actually had rights. If they answered "*yes*," they were requested to list and prioritize those rights they could think of. Participants were recruited from 11 special schools for children with mild to moderate intellectual disabilities in South Africa and included four schools in rural areas in South Africa and seven schools in urban areas. Results were analyzed using deductive content analysis.

Results

The majority (85.5%) of participants agreed that their child with intellectual disability had rights. Three broad kinds of rights were mentioned, namely, provision rights, which were mentioned 377 times, followed by protection rights (mentioned 172 times), and lastly participation rights, mentioned only 17 times. Participants from both urban and rural areas mentioned education (a provision right) followed by the right to an identity (which included nationality and family relations), the right to maximize the child's potential for development, and the right to privacy. This was followed by protection rights, namely, the right to protection by the state when maltreated and the right to no discrimination based on race, sex, disability, etc. The results also showed that participants from urban areas were more aware of the different rights that existed than their counterparts from rural areas.

Limitations and Future Research

Results are restricted to the primary caregivers (mostly parents) of children between the ages of 8;0 to 14;11 years old with mild to moderate intellectual disabilities who attend special schools. Given the fact that many children with disability

in South Africa do not attend school, the results should thus be interpreted with caution.

Qualitative research (i.e., data gleaned, for example, through in-depth interviews or focus group discussions) is recommended for future research in order to understand caregivers' understanding and thinking processes around their children's rights. This study could also be replicated in countries where there are large disparities between rural and urban areas to investigate the extent to which parents in those areas perceive that the basic rights of their children with intellectual disabilities are being met and how they prioritize the different kinds of rights.

Implications for Implementation

Parents of children with intellectual disabilities in both rural and urban areas are aware of their children's rights, particularly with regard to provision rights. However, parents from urban areas are more aware of the different possibilities that exist, and they are perhaps better equipped to provide opportunities for their children to exercise their rights than their counterparts from rural areas.

The Effect of an Aided Language Stimulation Programme on Subtraction Word-Problem Solving for Children with Intellectual Disabilities: A Preliminary Study (Naudé et al., 2020)

Introduction

The next two studies focus on reasonable accommodations in the classroom context. Study 4.5 was concerned with an aided language stimulation program that was used to teach mathematics to children with intellectual disabilities (Naudé et al., 2020), while Study 4.6 compares two response modes (oral responses vs. eye-gaze responses) as an assessment accommodation in a mathematics test for children with severe physical disability (Bornman et al., 2016).

Mathematics is an important part of the school curriculum and plays an important role in facilitating problem solving. However, word-problem solving has typically not been included in the mathematics curriculum for children with intellectual disabilities (Sileo & van Garderen, 2010). This might be attributed to the fact that many children with intellectual disabilities experience difficulties with memory, encoding, retrieval, and strategy employment, which affect word-problem solving, and therefore mathematics for this population often focusses on elementary mathematical skills such as counting.

Aim of the Study

The specific purpose of Study 4.5 (Naudé et al., 2020) was to determine the effect of an aided language stimulation program on subtraction word-problem solving for children with intellectual disabilities.

Research Methodology

A multiple baseline across behaviors design was used and replicated across the seven participants. Intervention was withdrawn for a 3-week period and followed by a maintenance phase of the study. All seven of the children included in this study were between 8;0 and 12;11 years old, had been attending a school with English as the medium of instruction for at least 2 years, and had an IQ score of between 40 and 69 as measured by the "Kaufman Brief Intelligence Test, Second Edition" (KBIT-2, Kaufman & Kaufman, 2004). They also had receptive language skill scores of between 4.00 and 8.00 on the "Peabody Picture Vocabulary Test, Fourth Edition" (PPVT-IV, Dunn & Dunn, 2007) and mathematical knowledge scores of between 4.0 and 8.0 on the "Wechsler Individual Achievement Test, Second Edition" Mathematical Reasoning subtest (WIAT-II, Wechsler, 2005). A multiple baseline design across behaviors (three different types of subtraction word problems) was used and replicated across the seven children who participated. The first type of word problem was a "change" type of problem, where the change is unknown, e.g., "*Zinzi has seven sweets. She gives some to Joe. Now Zinzi has five sweets. How many sweets did Zinzi give to Joe?*" The second type of problem was a "combine" type of problem, where the subset is unknown, e.g., "*Zinzi and Joe have nine sweets together. Zinzi has four sweets. How many sweets does Joe have?*" The third type of word problem was the "compare" type, where the dif-

ference is unknown, e.g., "*Zinzi has six sweets. Joe has two sweets. How many sweets does Joe have less than Zinzi?*" Once a stable baseline was obtained for all three word-problem types, intervention started. This was done in a small group setting with the first type of word problem type, while the other two types remained in baseline. Intervention included a custom-designed aided language stimulation board that contained 36 graphic symbols depicting the language skills needed to decipher the mathematical problems, as well as 11 numerals and calculation mats (Naudé, 2014). When the 5-day long intervention for the first word-problem type ceased, intervention for the second word-problem type began. This again lasted 5 days, and after the intervention was concluded, the final intervention for the third type of word-problem solving started. After a withdrawal period of 4 weeks, three maintenance probes were conducted for all three word-problem types. Intervention was again withdrawn for three weeks and followed by the maintenance phase of the study.

Results

Results from this study demonstrate the complex interplay between child and pedagogical factors in subtraction word-problem solving tasks. The results indicated a positive effect of the aided language stimulation program on the subtraction word-problem-solving skills of four of the seven children with intellectual disability. The remaining three children showed a negligible effect.

Limitations and Future Research

Predetermined time periods informed the intervention rather than the participants' data points. Furthermore, the effect of the aided language stimulation program used in Study 4.5 has limited generalizability to other mathematical operations such as addition. Therefore, future studies to investigate the effectiveness of using this method with other mathematical operations are recommended. An investigation into the effect of training on the implementation of this program with teachers is also highly recommended.

Implications for Implementation

Subtraction word-problem solving may be facilitated in children with intellectual disabilities by using aided language stimulation. The study used a small group approach in intervention, similar to the actual classroom context, and successfully demonstrated that small group interventions may be a feasible alternative to one-on-one instruction. Moreover, the materials developed for this study (Naudé, 2014) are paper-based, making them relatively inexpensive and easily reproducible in schools in low- and middle-income countries where resources are limited.

Comparing Two Response Modes in a Mathematics Test for Learners in Foundation Phase with Severe Physical Disabilities: A South African Example (Bornman et al., 2016)

Introduction

Study 4.6 deals with the final research study discussed in the context of inclusive and quality education for all. An oral and a visual response mode (eye gaze with an eye transfer [E-Tran]) were compared to determine the best possible technique for accommodating children with severe physical disabilities when answering mathematics tests (Bornman et al., 2016). Test accommodations refer to those adjustments that are made either to tests (e.g., by enlarging the print) or to the way in which children should respond to tests (e.g., by using eye gaze rather than the traditional written mode). Research suggests that tests without modified response mode options may be biased against children with severe physical disabilities, and that test scores reflect the extent of children's disabilities rather than their actual potential.

Aim of the Study

This study aimed to compare the performance of children with severe physical impairments on their mathematics scores using two different response modes. It was hypothesized that children with physical disability would obtain higher test scores in the eye-gaze response mode. Fourty-two Grade 3 chil-

dren aged between 8;2 and 11;9 years, with severe physical disabilities and attending schools in the Gauteng province of South Africa, participated in the study. All the children functioned at Level V on the Gross Motor Classification System, Expanded and Revised scale, which indicated that they needed wheelchair transport (Rosenbaum et al., 2008).

Research Methodology

A crossover within-groups design was used, and the children were randomly assigned to two groups. Each child had to complete both mathematics tests, one in the eye-gaze mode and one in the oral response mode, 1 week apart.

Results

Results showed that their scores for the eye-gaze response mode were significantly higher than for the oral response mode. Hence, teachers should be trained with regard to possible test accommodations that will allow all children to demonstrate their knowledge of a given subject, irrespective of the subject (in this case, it was mathematics) and irrespective of their specific disability (in this case, it was severe physical disability). Low-cost options such as eye gaze might be an underused and much-needed test accommodation in low- and middle-income countries.

Limitations and Future Research

The limitations of the study mostly revolved around the eye-gaze response mode. For the purpose of this research, only one response set was used. Future studies can thus explore the use of providing a different set of possible answers to each question or providing the same set of possible answers for both the oral response and eye-gaze response mode. However, this change may affect the test validity, making a within-groups design not possible. An alternative that could be explored in a further study would be to find two different groups to participate in the study, to allow each group only one condition, and then to compare their scores. This type of independent-group design, would, however, require a much larger sample, which could be difficult to find for atypical populations (for example, learners with severe physical disabilities).

Implications for Implementation

The results of the study have implications for the curricula and pedagogy to be used when new teachers are trained in how to adapt tests to allow fair and equal opportunities for all children to participate and benefit from inclusion. By providing support and flexibility in terms of test accommodations, more effective learning can take place in the classroom.

Impact of the Presented Studies on SDG 4: Quality Education and Lifelong Learning

Education, as articulated in the SDGs and CRPD, explicitly mentions persons with disability and encompasses empowerment and full participation in society, taking a lifelong perspective. It focuses on guaranteeing equal and accessible education for all persons with disability by building inclusive learning environments and providing the needed assistance for persons with disabilities. Utilizing the CRPD to implement and monitor the implementation of the SDGs will ensure that barriers such as policy, practice, knowledge skill, and attitudinal barriers, which maintain the exclusion and inequality of persons with disability, are not created or perpetuated.

In Study 4.1, an argument was made that while policies may be in place, they are not necessarily implemented, which thereby creates significant practice barriers for persons with disability. Studies 4.2 and 4.3 highlighted another practice barrier by focusing on teachers' attitudinal barriers toward the inclusion of children with disability alongside other learners, which often stems from limited knowledge and skills in how to handle children with disability in the classroom. Studies 4.5 and 4.6 attempted to address these knowledge and skill barriers by highlighting specific strategies that teachers could employ in the classroom to accommodate children with disability. Study 4.5 explained how an aided language stimulation program could be used to teach mathematical skills to children with intellectual disabilities (with a specific emphasis on word-problem solving subtraction). Study 4.6, in contrast, focused

on how teachers could implement an easy-to-use low-cost strategy to assess mathematical skills that is applicable in low- and middle-income countries. Finally, Study 4.4 emphasized the high stakes that parents (both in rural and urban areas) place on the education of their children with intellectual disabilities.

When inclusive, accessible, and quality education for individuals with disabilities is realized at all levels (primary, secondary, and tertiary, as well as vocational training), the vicious cycle of poverty will slowly start to break.

Conclusion

Inclusion is not only a fundamental human rights issue, it is also in everybody's best interest. This chapter aimed to illuminate access to health and quality education using the SDGs and CRPD as guiding frameworks and reviewed and discussed different studies that speak to them. In addition to reviewing the aims, methods, and results of the studies, more importantly, the practical implications for implementation were explained and suggestions for future research were made.

Folklore has it that in explaining the principles of the lever, Archimedes declared to his friends: "*Give me a place where I can stand – and I shall move the world*." It is now the turn of our generation and our continent to move the world toward good health and well-being, as well as quality education for all – including the most vulnerable members of society, namely, those individuals with severe communication disabilities.

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Access to Early Childhood Development and Inclusive Education Services for Refugee Children with Communication Disability in Rwanda

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Introduction

Note: All data and organization names/acronyms quoted in the chapter were correct at the time of authorship (2016). Authors acknowledge that policies and practices, research outputs, and data may have changed or emerged since the time of authorship, and may not be included here.

Access to appropriate education is every child's right (United Nations (UN), 1989) and is critical to the success of contemporary global poverty reduction strategies (UN, 2016a). Since school curricula depend upon the ability to understand the spoken and written word and communicate thoughts effectively to demonstrate understanding, communication delays and disabilities can negatively impact upon a child's access to the school curriculum and future employment (Hore, 2017). However, little is known about communication development and disability in Majority World countries, a lack of which affects the identification of children who struggle to learn language, and leaves children with communication disability vulnerable to exclusion from education and social support services. If a communication disability is identified early, communication development can be encouraged through community- and home-based interventions and the negative effects of delays and disabilities minimized.

Refugee children with disabilities are at particular risk of not being identified for inclusion in early intervention programs and education services, especially in emergency contexts. The "invisible" nature of communication disability and a lack of understanding by communities and service providers are compounded by a high degree of stigma attached to disability, which may hamper the identification of children with communication challenges in forced migration situations and, consequently, impact upon their access to essential protection and support services.

In this chapter, we describe the refugee context in Rwanda, East Africa, outlining the current situation of refugees with disabilities and the early childhood development (ECD) and education service provision available to them. We go on to describe an ongoing research project investigating the tools and processes used to identify refugee children with communication disabilities, and the opportunities and barriers they face when seeking ECD and education services in the refugee camps of Rwanda. Finally, we discuss the potential impact of such research on refugee communities in Rwanda and its prospective applicability to other refugee-receiving nations in the Majority World.[1]

Background

Forced migration is currently one of the world's most pressing issues. It is estimated that, at the time of writing, there were 65.3 million forcibly displaced people globally, 21.3 million of those being refugees who fled across their state border seeking protection in another country (United Nations High Commissioner for Refugees (UNHCR), 2015d). A refugee is a person who has fled their home state due to a well-founded fear of persecution for reasons of race, religion, nationality, membership of a particular social group, or political opinion (Art. 1A (2) of the Convention Relating to the Status of Refugees, UN 1951) and who has been granted refugee status by their host state,[2] which affords protection under international humanitarian law and refugee law,

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[1] Shallwani (2015) states: "The term 'Majority world' highlights the fact that the majority of the world's population lives in these parts of the world traditionally referred to 'developing.' The term 'Minority world' is similarly used to refer to those countries traditionally referred to as 'developed', where a minority of the world's population resides" (unpaginated). The authors recognize the controversy in using a "two-worlds approach" (Young, 2010), but have opted to use the terms for clarity.

[2] Before refugee status is granted, those who have crossed a border and are awaiting refugee status determination are considered asylum seekers.

including the guarantee of non-refoulement.[3] 51% of refugees globally are children, often unaccompanied by an adult responsible for their care (UNHCR, 2015d).

Despite current media attention focusing on the refugee crisis in Europe, 86% of the world's refugees reside in Majority World countries, many of which themselves struggle with poverty and economic, political, geological, or meteorological instability and also have to cope with high numbers of cross-border economic migrants. The world's least developed countries host 26% of the global total of refugees (UNHCR, 2015d). Many refugee-producing nations are also refugee-receiving nations (e.g., the Democratic Republic of the Congo during the 1994 Rwandan Genocide against the Tutsi[4]), which creates a complex situation for humanitarian actors and host-state governments to address.

The United Nations High Commissioner for Refugees (UNHCR) is the UN agency responsible for the protection of refugees and asylum seekers, returnees, stateless persons, and, under certain conditions, internally displaced persons, and it has under its protection approximately 63.1 million refugees—over four million in sub-Saharan Africa and over 2,739,000 in East Africa alone (UNHCR, 2015d). It works in collaboration with state and non-state partners to ensure the protection of refugees and other persons of concern through a wide range of activities, including humanitarian assistance and advocacy, mainly funded by donor states in the Minority World. Furthermore, UNHCR's role is that of coordinator for crisis response, managing various humanitarian actors who are responsible for the provision of different services in refugee communities, for example, water and sanitation, education, food, and shelter. The management of large-scale displacement situations is therefore a fluctuating, highly complex task—none more so than in states such as Rwanda receiving refugees from more than one refugee-producing state.

What is a Refugee?

As a result of events occurring before 1 January 1951 and owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it.

– (Article 1A (2), UN 1951, unpaginated)

Refugees in Rwanda

Rwanda is a small, landlocked East African nation of 11 million people and has borders with Tanzania, the Democratic Republic of the Congo, Uganda, and Burundi. The country ranks 163rd out of 188 on the Human Development Index with a gross domestic product per capita of less than 639 USD; 63% of the population live below the international poverty line of 1.25 USD per day. Life expectancy is an average of 65 years and, although access to healthcare is improving through government health insurance schemes, there is currently only one doctor per 15,428 people. The land in Rwanda is mountainous, and the country is prone to recurring natural disasters such as landslides in the rainy season, and chronic food insecurity in some regions caused by drought and flooding. 80% of the population live in rural, remote areas and struggle to access basic services. Emerging from the 1994 genocide against the Tutsi, Rwanda has an ambitious development agenda—literacy rates are increasing and now stand at 65.9%, and 98% of children attend primary school.

Rwanda is host to over 154,000 registered refugees,[5] mainly from the Democratic Republic

[3] "No Contracting State shall expel or return ("refouler") a refugee in any manner whatsoever to the frontiers of territories where his [or her] life or freedom would be threatened on account of his [or her] race, religion, nationality, membership of a particular social group or political opinion." (Art. 33 of the 1951 Convention Relating to the Status of Refugees).

[4] "Genocide against the Tutsi" is the preferred term of the government to refer to the ethnic conflict of 1994.

[5] The number is changing rapidly with the influx of Burundians fleeing political persecution and civil unrest.

of the Congo (DRC) and, more recently, Burundi, who have fled civil unrest and political instability (see Fig. 28.1). The protracted refugee status (PRS)[6] of many people from the DRC, the mass influx of Burundians and the return of Rwandan refugees who fled ethnic persecution between 1959 and 1998, has created a growing forced migration situation of ever-increasing complexity for the small, landlocked, and resource-poor country. The Ministry of Disaster Management and Refugee Affaires (MIDIMAR)[7] is the main governmental body responsible for refugees in Rwanda and is supported by UNHCR, which has been a constant presence for decades, most prominently in the years following the genocide against the Tutsi in 1994, during which 3.5 million Rwandans became refugees (UNHCR, 2015b). All but 48,000 registered Rwandan refugees have now found closure on their refugee status and have either returned or integrated into their country of asylum (UNHCR, 2015b). Many Rwandans fled to the DRC and Burundi—countries themselves now experiencing outflows of refugees into Rwanda, creating a complex mixed migration situation.

Violence in Eastern DRC began to force civilians across the border during the early 1990s. Major rebel offensives continue to this day from a number of local militias. Although many thousands of people from Kivu Province in Eastern DRC are internally displaced, thousands of refugees have crossed into Rwanda and the Rwandan government, in accordance with international and regional conventions, has provided land for camps and access to services with the support of UNHCR, other UN agencies, and international and national non-governmental organizations. To date, MIDIMAR manages five camps for Congolese refugees.

In addition to the refugees from DRC, Rwanda has seen a mass influx of, at the time of writing, over 80,000 Burundian refugees since civil unrest began in April 2015. MIDIMAR, therefore, also manages one large Burundian refugee camp, housing over 50,000 people. Furthermore, the number of urban refugees[8] has swelled from 2000 to over 30,000. This complex situation puts pressure on the Rwandan government and the country's infrastructure. Hosting so many refugees and integrating returnees has had an impact on the provision of social services, which already struggle to meet the needs of Rwandan citizens. A persistent lack of funding[9] limits the types and extent of services provided, such as health, water and sanitation, social care, and education, to the most basic in many circumstances.

UNHCR functions on the premise that one of three "durable solutions" should be sought for refugees: (a) voluntary repatriation, (b) local integration, or (c) resettlement in a third state. For refugees from DRC with PRS, voluntary repatriation is currently not an option as civilian-targeted violence persists in their home country. Two options, therefore, remain: local integration or resettlement in a third state. Rwanda is already one of the most densely populated countries in Africa and is reaching a saturation point for local integration. Resettlement has therefore been employed as a strategy to end the protracted state of the most vulnerable. Between 2012 and 2015, 7324[10] Congolese refugees were resettled in third states. However, this option remains limited for the vast majority.

Disability and Humanitarian Response

Refugees with disabilities are widely considered to be some of the most vulnerable members of society (UNHCR, 2010, 2011, 2015c; Women's Refugee Commission (WRC), 2014, 2015). As UNHCR stated in 2009, refugees with disabilities are "too often invisible, too often overlooked, …. [and] among the most isolated, socially excluded and marginalized of all displaced populations" (Costa, 2012, unpaginated). Although the World

[6] 25,000 people or more from one refugee producing source being refugees for more than five years (UNHCR, 2015d).

[7] Now (2020), it is called Ministry for Emergency Management (MINEMA).

[8] Refugees (mainly from DRC and Burundi) choose to reside in the cities of Kigali and Huye, rather than in the designated camps.

[9] Only 25% of the requested funding for Rwanda by UNHCR was received in 2015 (UNHCR, 2015e).

[10] Personal communication with UNHCR Rwanda.

Fig. 28.1 Refugees from DRC and Burundi Cross the Rwandan Border Seeking Asylum (2016)

Health Organization (WHO) estimates that approximately 15% of any given population has a disability (WHO and World Bank, 2011), data relating to persons with disabilities in refugee populations report a figure as low as 1.65% (Tanabe et al., 2015). Such differences in prevalence may include underreporting and may be for multiple reasons but can be attributed, in part, to the fact that refugees with disabilities often fail to come into contact with humanitarian support (UNHCR, 2011; WRC, 2014).

There has recently been a more concerted effort by humanitarian actors to include persons with disabilities in service provision and programming, under a human rights agenda. Those with disabilities who are identified in humanitarian contexts are, however, often those with "visible" physical difficulties. Those with less visible challenges, such as communication disability, often go unidentified, fail to access the humanitarian and protection services they need, and find themselves at increased protection risk (Battle, 2015; WRC, 2014). This is particularly the case for displaced disabled women and girl-children (Battle, 2015; Brownlie et al., 2007; UNHCR, 2003; WRC, 2015) who are considered to be doubly disadvantaged due to their dual status as women/girls and as persons with a disability (Costa, 2012).

ECD and Education for Children with Disabilities in Sub-Saharan Africa

Education Services

Children in sub-Saharan Africa are disproportionately affected by disability. Indeed, sub-Saharan Africa is home to more children with disabilities than any other continent (United Nations Children's Fund (UNICEF), 2008). Prevalence is particularly high in conflict or post-conflict states with reduced medical care facilities (UNICEF, 2008). Internationally, children with disabilities are less likely to attend, stay in, or progress through school, and the gap between them and their non-disabled peers is more pronounced in Majority World countries (WHO and World Bank, 2011). Given that Africa is the world's poorest continent and approximately 57 million primary-school age children in Majority World countries do not attend school at all (UN, 2016a), the proportion of children with disabilities who do not attend school is

estimated to be over 90% (United Nations Educational, Scientific and Cultural Organization (UNESCO), 2006, 2010; World Vision, 2007). It is, however, extremely difficult to estimate exactly how many children this equates to when accurate data on the prevalence of disability in sub-Saharan Africa is scarce, and data collection is hampered by a lack of a universal definition and understanding of disability, political instability, conflict, and challenging terrain (Chataika et al., 2012; WHO and World Bank, 2011).

The right to education for children with disabilities is acknowledged in international human rights frameworks. The WHO and the World Bank (2011) consider it key to global poverty reduction and economic independence and critical in the quest for social equity (UN, 2016b). The United Nations Convention on the Rights of the Child (UNCRC), for example, states that "Children who have any kind of disability have the right to .... all the rights in the Convention, so that they can live full and independent lives" (UNCRC: UN 1989, Article 23). Furthermore, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD: UN 2006), states that countries should ensure that "…children with disabilities are not excluded from free and compulsory primary education…on the basis of disability" (Article 24, 2a) and that governments should, as far as possible, provide individual support services within their education system to persons with disabilities.

A "Framework for Action" developed at the 1994 Salamanca World Conference on Special Needs Education stated that all schools should accommodate all children and that educational policies should specify that disabled children attend the local mainstream school. Further to this framework, delegates also developed the "Salamanca Statement," which stated that "those with special educational needs must have access to regular schools which should accommodate them within a child-centered pedagogy capable of meeting these needs" (UNESCO, 2013, unpaginated). This conference was considered seminal in promoting inclusion in education, and its published framework and statement continue to form the backbone of global inclusive education (IE) policy.

Early Childhood Development

Facts and Figures

- 57 million primary-school age children remain out of school in Majority World countries.
- More than half of those children who have not enrolled in school live in sub-Saharan Africa.
- An estimated 50% of out-of-school children of primary-school age live in conflict-affected areas.

(UN, 2016a)

Services

Early childhood development (ECD) services in refugee camps in Rwanda provide support for parents and children aged 0–6 years with the aim of ensuring children get the best start in life and are prepared for a lifetime of learning. They provide support on issues such as health, nutrition, early stimulation, and play to ensure psychological, physical, social, and cognitive development and preparation for the transfer to school with the best opportunities for success. Sub-Saharan Africa has some of the highest birth rates in the world, with high proportions of children under 6 years old.[11] However, data on how many children access services and support to encourage development in the early years are scarce, partly due to different approaches used in different countries and partly due to the limited number of countries with official ECD policies and programs (UNICEF, 2016). Data on the proportion of children with disabilities who access the ECD services that are available are startlingly absent.

The most recent international policy statement regarding ECD inclusion for children with disabilities was made in September 2016 by the United Nations Committee on Inclusive Education for the UNCRPD (UN, 2016b). Their document supplements the UNCRPD and sets out the benefits of inclusive ECD services and education for all children, including peers without disabilities, within a human rights framework, and therefore redoubles efforts to ensure the needs of children

[11] 24% of the Rwandan population are 0–6 years old (MIGEPROF, 2015).

with disabilities are catered for as an integral part of education service planning (see the shaded text below). When combined with the recently developed Sustainable Development Goals (SDGs: UN, 2016a), the message to the world is clear: no one is to be left behind when it comes to education and ECD.

The Value of Early Childhood Interventions for Children with Disabilities

> Early childhood interventions can be particularly valuable for children with disabilities, serving to strengthen their capacity to benefit from education and promoting their enrolment and attendance. All such interventions must guarantee respect for the dignity and autonomy of the child. In line with SDG 4, and the 2030 Agenda for Sustainable Development, States parties are urged to ensure access to quality ECD, care and pre-primary education, together with the provision of support and training to parents and caregivers of young children with disabilities. If identified and supported early, young children with disabilities are more likely to transit smoothly into pre-primary and primary inclusive education settings.
>
> (Comment 65, UN, 2016b, p. 21)

Services for Children with Disabilities

Despite the international pressure to design and implement inclusive early-years and education services, the inclusion agenda is not without controversy. This is particularly the case in the Majority World, where capacity and resources to provide services are often scarce, and explanatory models of disability do not necessarily reflect the understanding of disability using the biopsychosocial model conceptualized in the International Classification of Functioning, Disability and Health (ICF, WHO 2001), but remain heavily medicalized (Barrett, 2013; Marshall, 2016). In response to this, the World Report on Disability (WHO and World Bank, 2011) highlights the potential barriers to implementing inclusive practice, including system-wide, school-wide, and community-wide barriers, and makes suggestions to improve access to education for children with disabilities across the globe. A wider literature review and synthesis suggests that a gaping divide between inclusive policy and capacity to deliver, combined with continued discrimination and negative attitudes toward persons with disabilities within communities and the teaching profession, is a substantial obstacle to providing appropriate IE services for children with disabilities in Majority World contexts (Barrett, 2013; Handicap International and VSO, 2015). As Anthony (2011) states, "Culture, though dynamic, is well-anchored in tradition" (p. 1076). This comment highlights the importance of adapting practice to local contexts, coupled with awareness-raising and sensitization on disability rights, in order to effect change. Despite the challenges, headway is being made with the inclusion agenda in Rwanda from both top-down (government-led) and bottom-up (grass-roots initiated) approaches to inclusive ECD and education in response to SDG 4 and the 2030 Agenda for Sustainable Development (see Fig. 28.2).

Inclusion in ECD and Education for Refugee Children

Traditional single-mandate humanitarianism dictates that actors respond in a way that protects life and protects people from risk (Shivji, 2012).

SDG 4: Ensure Inclusive and Quality Education for All

Targets include:

- By 2030, ensure that all girls and boys complete free, equitable, and quality primary and secondary education leading to relevant and Goal-4 effective learning outcomes.
- By 2030, ensure that all girls and boys have access to quality ECD, care, and pre-primary education so that they are ready for primary education.
- By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples, and children in vulnerable situations.

Fig. 28.2 Children with hearing impairment access education in their local mainstream schools in Northern Rwanda with Support from British NGO. (©Chance for Childhood, Used with Permission)

- Build and upgrade education facilities that are child-, disability- and gender-sensitive and provide safe, nonviolent, inclusive, and effective learning environments for all.
  (UN, 2016a)

However, following the humanitarian "failures" of the 1990s,[12] and as more refugees now find themselves with PRS,[13] modern humanitarianism calls for agents to go beyond this mandate, looking more toward longer-term development agendas to enable people to rebuild their lives (Chandler, 2001; Goodhand & Atkinson, 2001; Mills, 2005; Milner & Loescher, 2011; Shivji, 2012). Provision of services to children, including early-years support and education, is a priority in these instances and is considered key to improving the life chances of vulnerable children (e.g., Plan International, 2013a, b).

Inclusion in education is clearly not without its challenges in refugee contexts, particularly within Majority World states which themselves face difficulties with resourcing and implementing inclusive policies. The Inter-Agency Network for Education in Emergencies (INEE) has, however, published minimum standards for education in emergencies (INEE, 2010), based upon the Sphere Project core principle that people affected by disasters have a right to life with dignity (Sphere Project, 2011). An accompanying guide to IE (INEE, 2009), setting out basic guidelines for inclusion achievable in all emergency and recovery contexts, advises humanitarian actors to focus on identifying who is excluded from education (asking children as well as adults in the community, as they often give very different and very valuable information) and identifying what can be done to improve learning for all with available resources. The guide emphasizes the need not only for adapted school environments and teaching pedagogy to make learning accessible for children with a variety of learning needs but also for widespread community awareness campaigns to be implemented to ensure the message that all children have a right to education, regardless of ability, is absorbed by carers and communities. Widespread misunderstanding and fear surrounding disability among teaching staff have also been identified as a key barrier to inclusive early-years and education provision, both in non-emergency and emergency contexts (Arbeiter & Hartley,

[12] Bosnia, Rwanda, Somalia.

[13] 41% of refugees under UNHCR's mandate have protracted refugee status (UNHCR, 2015a).

2002; Greyling, 2009; INEE, 2009; Johnstone & Chapman, 2009; Mukhopadhyay et al., 2012; Ntombela, 2011) and humanitarian actors are recognizing the value and importance of supporting and training teaching staff on disability and inclusion, to dispel myths, allay fears, and build confidence in their ability to teach a diverse range of students (Save the Children, 2008a, b).

ECD and Education Services for Refugee Children with Disabilities in Rwanda

The Government of Rwanda, along with the UN, has a commitment to provide ECD and IE services for all children, including those with disabilities, in order to promote better life chances for all. Service provision for refugees in Rwanda is required to be commensurate with Rwandan national policy and clear inclusive policies and guidelines are in place stipulating that children with disabilities should be provided for in their local schools and ECD centers (Karangwa, 2014; MIGEPROF, 2016; MINEDUC, 2013). There is, however, an overwhelming belief among carers, communities, and service providers that children with disabilities need specialist, segregated care. This is reinforced by caveats in Rwandan inclusion policy, such as the creation of a curriculum for children with intellectual impairments, designed to standardize practice in special "centers," which are often residential. Despite these loopholes, UNHCR Rwanda is keen to avoid further family separation following forced displacement, both on moral and protection grounds, and is therefore committed to implementing effective inclusive services within refugee camps, within local communities into which refugees integrate, and in urban settings.[14]

It is thus crucial to understand how children with disabilities in refugee communities are identified and what support they should, and do, receive. UNHCR Rwanda has an established disability action plan to improve the identification and registration of persons with disabilities, and to ensure their inclusion across services including ECD and education. This action plan includes a monitoring, evaluation, and learning plan to enable critical reflection on, and evaluation of, any interventions and learning from both successes and challenges to enhance future programming.

Refugees with Communication Disability: Access to Services

In line with the ICF (WHO, 2001), people who have difficulties with receptive and/or expressive language, speech, voice, or fluency that affect the way in which they participate and function in society are considered to have a communication disability (Wylie et al. 2016a, b). Communication disability is both misunderstood and chronically stigmatized across East Africa, and persons with communication disability are under-identified and underserved across the region (e.g., Barrett & Marshall, 2013). Its "invisible" nature, often as a secondary difficulty to a primary impairment such as an intellectual, physical, or sensory impairment, makes identifying persons with communication difficulties challenging for nonspecialists. This is particularly the case for children, for whom proxy reporting by carers is commonplace. Estimates of the proportion of persons with disabilities who may have a communication disability are as high as 49% in the East African region (Hartley, 1995, 1998). Census and household survey data, even those disaggregated for disability, are likely to grossly underestimate numbers of persons with communication disability due to its hidden nature (that it is secondary to other impairments/disabilities), lack of understanding among data collectors, and the fact that data for under-fives are commonly excluded.

Although inclusive ECD and education policies are being put into place in some countries such as Rwanda, reference to supporting children with communication disability, beyond hearing impairment, is uncommon. It is also recognized that there is a gap between inclusive policy and practice in the humanitarian sector (Pearce & Buscher, 2014) due to a lack of data, limitations in physical and human resources, and awareness, knowledge, and

[14] Personal communication with UNHCR senior disability advisor, Geneva, June 2015.

skills (particularly relating to communication disability) among humanitarian actors and local service providers (e.g., UNHCR, 2015c; Barrett et al., 2016). The lack of awareness of communication disability can be found among those charged with identifying children with disabilities, placing children in appropriate inclusive ECD and education settings, and providing accessible learning opportunities.

Despite a call by the UN to include persons with communication disability in humanitarian programming, there is a distinct paucity of research into the prevalence and identification of communication disability and service provision for children with communication disability in refugee populations (Battle, 2015). Some humanitarian actors are beginning to recognize that communication disability is a contributing factor to exclusion from a wide range of services in refugee populations, but lament a lack of expertise and in-house capacity to comprehensively address the issues (e.g., WRC, 2014).

Listening to the People

There are few more marginalized and vulnerable groups in the world than refugees with disabilities. However, persons with communication disability are frequently neglected in research, often because researchers and project implementers lack the knowledge and skills to engage persons with communication disability using appropriate means (Plan International, 2016; WRC, 2015). Some research evidence from Rwanda suggests that the current response if a person with communication disability is identified, is to provide sign-language interpreters to help "translate" messages between the person with communication disability and service providers (Barrett & Marshall, 2016). However, the use of formal sign language is almost exclusively limited to the small proportion of deaf people who have been educated in a school for the deaf or have been taught sign language as adults, and in any case, the sign language may be different from the sign language used in their host state. Moreover, persons with communication disability in the Majority World are more likely to use idiosyncratic gestures, best understood by their carers or family, for which a formal sign interpreter would be ineffective. (Barrett et al., 2016; Save the Children and Handicap International, 2011; WRC and ChildFund International, 2016). The use of formal sign language would also be inappropriate to use with many people with diverse communication challenges, such as people with poorly developed symbolic understanding or those with communication difficulties such as speech-sound, or fluency challenges, who require different approaches to communication facilitation.

These misunderstandings most likely stem from a desire to help persons with communication disabilities with the perceived available resources, but illustrate the grave lack of awareness and knowledge about communication disability and the absence of skills to respond to the needs of this diverse and vulnerable group in humanitarian contexts. The Women's Refugee Commission (2015) recognizes that the use of *inappropriate* communication methods is as much of a barrier to assisting persons with communication disability as using no communication support at all. It is therefore crucial that information regarding people's understanding of the nature and causes of communication disability, their attitudes and beliefs surrounding communication disability, their help-seeking behaviors, and their perceived solutions to communication disability are investigated more thoroughly before services can be developed that are sensitive to the circumstances, needs, and aspirations of persons with communication disabilities and their families (Barrett, 2016; Marshall, 2016; Wylie et al. 2016a, b). Providing appropriate and accessible ECD and education for children with communication disability in refugee communities requires listening to families caring for children with communication disability—to their experience, to the opportunities and challenges they face, and to their understanding of what can be improved to enhance their experiences. It also means listening to those who come into contact with families of children with communication disability—community leaders, disability committees, humanitarian actors, educationalists—about their experiences, their concerns, their ideas for improvement. These voices must then be synthesized with policies, procedures, and guidelines,

to identify the most pressing concerns for families and educationalists and to identify opportunities to improve service provision to respond to their most significant concerns with available resources. As discussed by Mukhopadhyay et al. (2012) and Anthony (2011), international policy and procedure that fails to adapt to the context and needs of local service users is no more than a fruitless endeavor. Chataika et al. (2012), reporting on the 2009 African Network for Evidence-to-Action in Disability (AfriNEAD) symposium, assert that local beliefs and attitudes about disability across Africa conflict with international policy and recommendations. They, therefore, call for African voices to spearhead policy change and implementation that responds to local challenges. If those voices are not listened to, the gap between inclusive policy and the ability to implement it will continue to widen—ideals stagnating at the political level, failing to reach those in need (Barrett, 2013).

Motive

In 2015, a study was undertaken by UNHCR Rwanda to identify the challenges to inclusion and service access for refugees with disabilities in refugee camps and urban refugee communities in Rwanda (UNHCR, 2015c). This study identified that refugees with disabilities, including persons with communication disability, have specific difficulties accessing the services that should be available to them, and in realizing their human rights. A desire to find out more about the barriers to identifying refugees with communication disabilities (including stigmatization within the community and the lack of awareness, knowledge, and skills of humanitarian staff and service providers) and about their subsequent access to services, including ECD and education, was expressed by various stakeholders working with refugees.

Accordingly, it was relevant to find out more about communication disability and to increase awareness and understanding among staff of the challenges facing children with communication disabilities living in camps and urban refugee communities. It appeared to be particularly crucial to understand more about the experiences of children with communication disabilities and their families and how best to provide inclusive ECD and IE services in accordance with international and national policies and guidelines.

Aims, Objectives, and Research Methods

The aims of the study are as follows:

- To describe and critically interrogate the current tools and processes used to identify refugee children with communication disability in Rwanda
- To map the opportunities and barriers to accessing appropriate ECD/IE services for refugee children with communication disability in Rwanda

The research is in two stages, using a mixed methods design. It is primarily qualitative in Stages 1 and 2, with some quantitative analysis of existing UNHCR disability statistics in Stage 1, to facilitate the identification of participants for Stage 2 (Tashakkori & Teddlie, 1998). These quantitative data are being collected and analyzed before the qualitative data, thereby constituting a sequential transformative methods approach (Creswell, 2009).

The pronounced focus on a qualitative methodology, within the mixed methods approach, was chosen to enable the researcher to explore the experiences, thoughts, and opinions of a range of individuals either caring for or providing services for children with communication disability and of the children themselves. These data are being analyzed to identify emerging themes important to the people at the heart of the research and therefore central to considerations to future service development. The iterative nature of qualitative investigation facilitates open discussion and flexibility, giving voice to the concerns of the participants.

Outcomes of the research are not anticipated in advance, and the direction of the focus groups and interviews conducted may adapt as the research progresses, responding to important topics or themes identified along the way. A process of "mapping" opportunities and barriers to accessing ECD and IE services (see Stage 2 aim, in Table 28.1) will allow

for fluid and detailed descriptions of the experience of families to be combined with the opinions and experiences of service providers, thereby producing data that can be compared, contrasted, and connected through thematic analysis. The end result will be a set of data that describes the barriers and opportunities for accessing ECD and IE services for refugee children with communication disability in Rwanda. The outcomes will be of interest and use to humanitarian organizations, ECD and education service providers, donors, and government departments within Rwanda and, potentially, regionally, or globally in the humanitarian sector. Data collection will take place with communities of refugees from DRC due to their PRS and need for longer-term development opportunities, and from Burundi, for a contrasting experience of emerging from emergency status. Participants will include humanitarian staff and service providers involved in the identification and registration of children with disabilities, teachers, ECD staff, community mobilizers, community leaders, carers of children identified as having communication disability (ages 2–12), and children with communication disabilities themselves (ages 8–12).

Carers of children under 2 years of age during the recruitment phase will be excluded from the study as communication disability may be difficult to identify during the 0–2 years' stage of development, particularly by nonspecialist staff. Carers of children over 12 years old at the time of recruitment will also be excluded, as this study will focus on service provision in the early years and primary-school years only.[15] Carers of children identified as having communication disability must themselves be over 16 years of age, and service providers (humanitarian staff, teachers, ECD staff) must be over 18, with the capacity to consent to participate. Children aged 8–12 years who have the capacity to assent/consent and can participate verbally or using formal Rwanda sign language may participate, under strict ethical guidelines.

Given that a mixed methods approach will be employed to generate data, methods of data analysis will include quantitative statistical analysis of disability data, analysis of key documents, and thematic analysis of qualitative data using thematic network analysis (Attride-Stirling, 2001). Challenges to collecting data may arise due to the nature of cross-cultural, cross-lingual research and other practical and ethical considerations discussed below. For this reason, a generous lead-in time has been factored into the research timetable to allow flexibility and responsiveness to any challenges that may be encountered.

Ethical Considerations

Aside from the ethical considerations of working with highly vulnerable groups (displaced persons, children, persons with disabilities), there are other significant, ethical challenges to be considered when conducting cross-cultural research. First, although the study has been scrutinized by the ethics committee of a UK university, the guidelines for such ethical approval originate from, and are bound by, Minority World cultural norms. For example, the consent forms and participant information sheets required for the British ethical review system may not be appropriate for use with people from cultures vastly different from that of the British academic community, due to differences between the dominant and researched cultures' self-identities and understanding of research (Darou et al., 1993). The lengthy explanations of the research process required by Minority World academia may not directly or easily translate into local languages or match cultural understandings, and access to such information may be impeded by literacy levels, issues of multilingualism, and differing cultural beliefs. Scrutiny by a Rwandan ethics committee goes some way toward identifying and addressing challenges within the local context. Nonetheless, researchers must be mindful that global academic institutions may follow similar protocols, particularly in former colonial states, due to post-colonial influence and globally accepted, although Minority World-conceived, standards of "best practice."

Second, ethical issues surrounding perceived obligation to take part may influence participation if the researcher is deemed to be in a position of power on one or more levels: an "outsider," a "Westerner," a "white person," an "academic," and a potential

[15] Only 9 years of basic education are currently compulsory in Rwanda, from pre-primary (age 3+) to primary 6.

Table 28.1 Aims, objectives, and research methods

Aims	Objectives	Methods
Stage 1: • To describe and critically interrogate the current tools and processes used to identify refugee children with communication disability in Rwanda	• Describe the tools and processes used to identify refugee children with communication disability in Rwanda • Document the self-reported understanding, behaviors, and experience of staff responsible for determining if children experience communication disability	• Documentary analysis of UNHCR/ partner policies, procedures, forms, and statistics on identification and categorization of persons with disabilities • Focus-group discussions and interviews with UNHCR partner staff and community mobilizers.
Stage 2: • To map the opportunities and barriers to accessing appropriate ECD/IE services for refugee children with communication disability in Rwanda	• Describe and document the ECD and IE services that are provided to refugee children in Rwanda • Describe ECD/education service providers' views of opportunities and barriers to including refugee children with communication disability in ECD/education services • Describe the opportunities and barriers to the inclusion of refugee children with communication disability in ECD/education settings in Rwanda • Describe current and potential ECD/ IE service users' views of opportunities and barriers to including refugee children with communication disability in ECD/education services • Carry out a literature review of global evidence of inclusion of refugee children with communication disability in ECD/education. • Apply the global literature to the Rwandan context, in order to document opportunities for improved access to ECD/education services for refugee children with communication disability	• Documentary analysis of official policies and non-official documents • Focus-group discussions and interviews with ECD/IE service providers. • Class/ECD session observations • Focus-group discussions and interviews with children with communication disability and their families/carers and community groups (e.g., disability committees. • Literature review

"provider" of money, goods, or services—particularly in post-colonial contexts (Marshall & Batten, 2004). Researchers must take great care not to impose or perpetuate neo-colonialist practice in cross-cultural, Majority World research, thus ironically disempowering the very people the research is often directly claiming to empower. If the research is associated with the organizations providing services, people approached to participate may believe that their access to services may be affected, positively or negatively, by their participation. It is thus critical that participants receive clear, accessible information about the purpose of the study, including child-friendly information, and including information about any direct or indirect benefits to them as participants. UNHCR is particularly keen on not involving refugees in research from which there will be no immediate or future benefit to the participants or their wider communities. For these reasons it is important to have a local partner who understands both the research and the local community well, so that concepts and ideas, not just words, can be translated and transmitted effectively (Barrett, 2016; Barrett et al., 2016; Hickey et al., 2014). It is also vital that research be conceived in such a way that the aims, objectives, and purpose are clear, and

that the appropriate organizations and service providers are involved from the start.

Third, a gender dimension to the research may also affect the participation of certain groups. As the primary researcher is female, participation by some men from traditionally gendered societies may be affected—refusal to participate, withholding of information during participation, or styles of interaction may be different to that experienced by a female researcher interacting with other women.

Fourth, perceived control of research led by an "outsider" could affect participation and the level of information divulged, particularly during qualitative research. Traditionally, researchers are in control of the information gathered, and later methods of dissemination. However, if participants do not feel some control over the information about themselves and their communities and how that information is used, their level of engagement may be affected. This is also an issue of considering what is morally right, not just ethically sound. Researchers must avoid being "takers of information," instead sharing in the knowledge the research generates and sharing that knowledge in the most appropriate forms to benefit the communities to which it refers (Sommer, 1998).

Although the benefits of employing a participatory action research methodology to ameliorate some of the ethical dilemmas discussed are advised by many cross-cultural researchers (e.g., Marshall & Batten, 2004), studies that are not conducted in this manner *can* employ flexibility of design and encourage a more equitable relationship between the researcher and the participants (Darou et al., 1993) in which power relationships are broken down and participants share in the benefits that the results of the research may bring to them. Interpretive Description (Thorne, 2016) is a methodology that embraces such practices and has been used to guide this research. The researcher must also understand and apply the principles of cultural humility in their research practice (Walters, 2015), acknowledging that they can never fully understand a culture they were not born into and reflecting upon the power relationships at play, particularly as a Minority World researcher in an ex-colonial Majority World context.

Potential Impact of this Research

This research project is investigating the pressing issues facing refugee children with communication disability in Rwanda, allowing their voices and those of their carers and communities to be heard. Their experiences, views, and suggestions for change have the potential to influence service planning and development for ECD and education in refugee communities in Rwanda and the East African region more broadly, ensuring that the most vulnerable and most excluded members of society begin to be recognized. In the spirit of the "nothing about us without us" movement (Charlton, 2000), the research will give persons with communication disabilities and their carers the opportunity to influence decision-making about the services they receive. This will go some way toward them gaining not only physical access to ECD and education but also meaningful inclusion and opportunities for learning, as per SDG 4 and the 2030 Agenda for Sustainable Development.

The researchers aim to raise awareness of communication disability among communities, humanitarian actors, and ECD/education planners and service providers; to highlight the importance of recognizing the diversity of persons with communication disabilities, avoiding the "one size fits all" approach to disability mainstreaming currently in operation; and to demonstrate the importance of listening to the voices of service users with communication disability to inform future planning.

Considerations for Future Developments

The global refugee situation is at an all-time crisis point and the majority of refugees and internally displaced persons are hosted in resource-limited, Majority World countries which potentially face similar barriers to the inclusion of *all* persons with *all* disabilities in *all* services. Although focused on one small aspect of inclusion in ECD and education, access to both services is considered a fundamental human right under international law and is considered transformative in the lives of children,

both economically and socially. As discussed in the UN (2016b) general comments on the UNCRPD article 24 (inclusive education), IE is fundamental to developing inclusive societies. If not *all* children are visible, included, and provided for in education, where peer relationships flourish and young minds develop, will society ever include them?

The study has the potential to be both scaled up within Rwanda and/or replicated beyond Rwanda, to gather more regionally or globally relevant data on the challenges facing refugee children with communication disability in accessing inclusive ECD and education services. Findings may then be considered more widely and may have the potential to influence the types of inclusive services developed for refugee communities in similar contexts across the world. Furthermore, the data from Rwanda have the potential to be used to illustrate the importance of further research into communication disability and its impact on the lives of refugees across the globe.

Summary of Key Considerations for the Research Project

- Forced displacement is one of the most pressing issues of our time.
- Protracted refugee situations (an average of 26 years) are commonplace.
- 86% of refugees are displaced within the resource-limited Majority World.
- Persons with communication disability are under-identified and misunderstood in many Majority World contexts.
- 15% of any population is estimated to have a disability, and up to 49% of these may have a communication disability.
- Inclusive ECD and education are major foci of the Sustainable Development Goals (UN, 2015) and the 2030 Agenda for Sustainable Development, considered key to global poverty reduction efforts.

Summary and Conclusion

Communication is a fundamental human right (International Communication Project, 2014; UN, 1948). Research into the opportunities and challenges of accessing basic support services for refugees with communication disability is a new endeavor. Although communication disability has been recognized as a barrier to service access for refugees across the globe (WRC, 2014, 2015), the lack of understanding about the causes and nature of communication disability, the paucity of data on its prevalence, and the underdeveloped awareness, knowledge, and skills of service providers, has resulted in frustratingly little research into the challenges facing refugees with communication disabilities in accessing basic services that should be afforded to them under human rights and refugee law.

In this light, research into access to ECD and IE for refugee children with communication disabilities is crucial to ensure one of the world's most vulnerable groups of people are not systematically excluded from the very things that could offer them more successful inclusion in society and a more independent future. The huge number of long-term refugees in Rwanda, the relative stability of the Rwandan context, and the forward-thinking inclusion policies in the country afford the opportunity to conduct high-quality research into the experiences, needs, and future aspirations of these vulnerable children and their families.

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Inclusion of Children with Social Communication Disorder in Kenya

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Introduction

Undiagnosed language disorders are common in both community and psychiatric settings. However, the identification of these disorders is helpful in preventing long-term behavioral challenges in these children (Toppelberg & Shapiro, 2000). Little information is available regarding the diagnosis of children with social communication disorder (SCD) in Kenya and sub-Saharan Africa (SSA), despite the fact that these children will require additional educational support (Mandy et al., 2017). A study by Mutai et al. (2016) investigated the effects of communication disorders on the academic performance of learners in mainstream primary schools in Kericho County, Kenya. Findings indicated that teachers use different strategies to support pupils' learning and there was no single strategy that worked for all learners with communication disorders. There were few differences between the typically developing learners and learners with communication disorders in the use of these strategies, although pupils with communication disorders were more likely to receive additional support. These strategies may thus benefit learners who have SCD.

Traditionally, education in Kenya has been organized on a two-tier basis: one tier is the mainstream school system, while the second tier is the special school system, which caters for children with disabilities such as deafness, blindness, and intellectual disabilities (Mutai et al., 2016). This organization ignores children with communication disorders as they have instead been included together with regular children in inclusive settings. Children who are misdiagnosed, or receive no diagnosis, will not have the opportunity to receive the needed support for SCD (Norbury, 2014). This calls for an urgent need to identify the characteristics of SCD, its causes, and its implications on learners.

Motive and Research Question

As stated in the introduction, there is little literature currently available regarding SCD in SSA. Therefore, the aim of this study was to investigate the inclusion of children with SCD in mainstream schools in Kenya with the following objectives:

1. Describe the characteristics of SCD.
2. Establish the causes of SCD.
3. Investigate the current inclusion of children with SCD in schools in Kenya.
4. Determine the intervention measures for educational accommodations which may benefit children with SCD in the SSA context.

In particular, the latter objective sought to assist African therapists and teachers by determining the intervention measures for educational accommodations in this population.

Theoretical Background

Global Overview of Social Communication Disorder

SCD is a new diagnostic category under Communication Disorders in the section on Neurodevelopmental Disorders in the DSM-V (American Psychiatric Association (APA), 2013). SCD is characterized by difficulty with the social use of both nonverbal and verbal communication such as challenges using language for social purposes, being unable to match the social context with appropriate communication, having difficulty following the rules of the communication context (e.g., back and forth of conversation), understanding nonliteral language (e.g., jokes, idioms, metaphors), and integrating language with nonverbal communicative behaviors (Swineford et al., 2014). These deficits may result in functional limitations, ineffective communication, a dearth in social participation, and low academic achievement. As sufficient language skills ought to be established before higher-order social communication deficits can be detected, diagnosis of SCD can only be made at 4–5 years of age (Swineford et al., 2014). The boundaries for SCD have not yet been consistently defined in the literature, and there is considerable overlap with the social and communication impairments of other disorders, particularly autism spectrum disorder (ASD) (Topal et al., 2018). Differential diagno-

sis is based on the fact that children with ASD will present with restrictive/repetitive behaviors, while SCD excludes these (Topal et al., 2018). Individuals diagnosed with SCD according to the DSM-V may have previously been diagnosed with pervasive developmental disorder – not otherwise specified or with Asperger's disorder/ASD according to the previous DSM-IV criteria (Mandy et al., 2017). Children with SCD also have a higher chance of co-occurring attention deficit hyperactivity disorder (ADHD), language disorder (LD), and behavioral problems (APA, 2013).

Despite the challenges faced by children with SCD in acquiring, enjoying, and sustaining social relationships, social skills remain a significant part of a child. It is, therefore, safe to assume that a lack of social skills may hinder long-term development, social interaction, and communicative behavior of children with SCD (Norbury, 2014). Individuals with SCD have academic, interpersonal, and vocational dysfunction as a result of their core symptoms, while the secondary symptoms of the disorder include problems in developing a sense of agency, emotional regulation, and the development of self (Topal et al., 2018). Consequently, there exists a significant developmental gap between a child with SCD and their typically developing peers.

Social Communication Disorder and Education

Formal education is characterized by a rigid curriculum regarding methodology, content, and objectives that are presented in a continuous process of learning. It corresponds to the process of learning that is adopted in schools from primary to university level. Formal education is offered in institutions that are administrative in nature and require classroom attendance with other children. Due to the social communication difficulties experienced by children with SCD, social interaction and friendship formation in such an environment may be challenging (Norbury, 2014). Children with SCD will require individualized clinical and educational support (Norbury, 2014), particularly as there is a relatively high comorbidity with other disorders such as ADHD and LD (Topal et al., 2018). In most advanced countries, formal education is considered a basic right by the constitution and by the state policies of the ruling party. Access to education and how well the education sector is performing can be used as a gauge as to how the current government is performing (Mandy & Skuse, 2013). The United Nations Educational, Scientific, and Cultural Organization (UNESCO) advocates for the equal opportunity to access education for every child, irrespective of their ability, gender, or social status (UNESCO, 2014).

Primary Education in Africa

Over the past decade, a new trend of abolishing tuition fees in SSA countries has been witnessed. The initiative of Free Primary Education was geared toward revamping the education sector, which has been facing heavy financial burden since post-independence, especially for parents whose children have disabilities (Tooley et al., 2008).

Some of the countries that have adopted inclusion and have been studied widely in the past include Malawi, Uganda, Kenya, Tanzania, South Africa, and Zambia (Lincove, 2012). However, the questions that remain unanswered to date are: did the introduction of inclusive education improve the education of children with special needs, and what is the quality of that education?

Primary Education in Kenya

Primary school admission begins at ages 5–7, after the child has attended kindergarten for a year or two; hence this would be the correct stage to identify and assess learners with SCD. The primary school entry level is Grade One and progresses to Grade Eight where a candidate completes the exam for the Kenya Certificate of Primary Education (Nishimura & Yamano, 2008). Upon successful completion of the syllabus within one academic year, the student progresses to the next class, while those who do not manage to meet the threshold repeat the class for another year. As children with

SCD may encounter educational barriers, they may be forced to repeat a class.

The introduction of Free Primary Education (FPE) was implemented with the aim of providing a platform for disadvantaged children to access education (Adoyo & Odeny, 2015). The FPE program received an overwhelming response from the public who embraced the initiative and enrolled their children in public schools. This was the beginning of unplanned inclusion, thereby recording a significant increase in enrollment in most schools (Tooley et al., 2008). However, the program was not without serious challenges. The high enrollment meant overstretching the available resources, which compromises the quality of education for learners with disabilities (Urwick, 2011). There also exist negative parental attitudes regarding the quality of public schools in Kenya, despite the FPE program, such as perceptions that the system is characterized by congestion, lack of specialized personnel, and inadequate facilities (Tooley et al., 2008). The Kenya Institute of Curriculum Development as well as the Kenyan National Examination Council has differentiated the curriculum and adapted the national examinations to cater for the needs of individual learners (Adoyo & Odeny, 2015).

Methods

An exploratory design (using secondary sources) was adopted in this research. Secondary data were derived from existing published articles, journals, books, and other relevant documents pertaining to the research questions (Johnson & Christensen, 2010).

A literature review was first conducted to determine if there is any literature available on SCD specifically linked to Africa. The broad search terms "social communication disorder" and "Africa" were entered into the following databases: African Journals Online (AJOL), Google Scholar, TRIP (Turning Research Into Practice), Cochrane Library, PubMed, Africa-wide Information, Sabinet (African Journals), CINAHL, and EBSCOHost. The reference sections for articles used in the theoretical background section of the paper were then searched to ascertain if any literature regarding SCD in Africa was available. Thereafter, a search of the terms "neurodevelopment" or "language impairment" or "communication" and "education," and "Africa" were used, with the further restriction of only searching for results from academic journals, books, and dissertations from 2010 to present. This search was conducted on the following databases: AJOL, EBSCOHost, Eric, CINAHL, Africa-Wide Information, and Google Scholar. The bibliographies were searched for relevant African literature, and forward citations were checked to find any further information. Title reviews were conducted first, followed by abstract reviews. Thereafter, a full text review was conducted to determine inclusion or exclusion.

Results

Literature Related to Social Communication Disorder in Sub-Saharan Africa

The initial literature search revealed a lack of published information regarding SCD in SSA. Furthermore, the search for literature regarding classroom accommodations for children with SCD/communication difficulties/neurodevelopmental disorders also yielded few results. In a scoping review conducted regarding ASD in SSA, Franz et al. (2017) remarked, "We were struck by the absence of peer-reviewed data on early intervention and education-related aspects of ASD" (p. 744). Several peer-reviewed articles were available regarding ASD in Africa, inclusive education, and communication difficulties. However, no literature clearly linking the abovementioned concepts could be found.

Characteristics of Social Communication Disorder in Sub-Saharan Africa

As the current search yielded no literature from SSA regarding SCD, the global characteristics of

SCD are now described. However, the diagnostic criteria for SCD as described in the DSM-V (APA, 2013) include context and cultural standards in communication in every part of the symptom description. In summary, the DSM-V indicates the following criteria for SCD: children with SCD manifest problems in the use of communication in an appropriate manner for the *social context*, the match-making to *listener or context*, the observation of *rules* in conversation or story-telling, and the understanding of *nonliteral or ambiguous* language (APA, 2013). Therefore, the diagnostic process based on DSM-V is not detached from the SSA context given the need for inclusion of context as a concept. Nevertheless, the current study shows a need to investigate the epidemiology of SCD and the specifics of the SSA context relating to, for example, onset, participation, and comorbidities. The DSM-V diagnostic criteria still need the reflection of professional personnel relating to the SSA context: where are the problems of the student in following which rules of conversation? In which situation does he/she struggle? How is the participation impeded?

Perception of Causes of Social Communication Disorder in Sub-Saharan Africa

There is a uniquely African concept of disability which acknowledges multiple causes of disability. Gona et al. (2015) studied the perceived causes of ASD and neurodevelopmental disorders on the Kenyan Coast (Kilifi and Mombasa), while Sharkawy et al. (2006) studied the perceived causes of epilepsy in Kilifi, Kenya. These two studies had strikingly similar results in terms of what parents and community members perceived as causing these neurological disabilities. As there are overlapping symptoms and similarities between SCD, ASD, and other neurodevelopmental disorders, the causes listed in this research may provide insight into how hidden disabilities such as these may be perceived within the African culture.

Supernatural Causes

These are perceived causes that involve external forces such as evil spirits, witchcraft, or curses. The majority of the participants interviewed by Gona et al. (2015) believed that evil spirits could invade the mind of a child and effectively take over the control of their whole being, which could happen before birth or during early childhood. Evil spirits locally called "Jinnies" were cited as causing ASD in the coastal region of Kenya (Gona et al., 2015), while "Nyago" was an evil spirit cited as causing epilepsy in Kilifi, Kenya (Sharkawy et al., 2006). Witchcraft was another external force perceived as a possible cause of disabilities. Both ASD and epilepsy have been considered to be a direct manifestation of sorcery or witchcraft (Gona et al., 2015; Sharkawy et al., 2006). Perceptions further include punishment by God or by the ancestors as a supernatural cause of disability, with both studies citing extramarital affairs as a transgression that may have caused this (Gona et al., 2015; Sharkawy et al., 2006).

Biomedical Causes

In terms of biomedical causes, exposure to harmful substances or environments and hereditary causes have been mentioned by participants in the studies. Exposure to infections and drugs were perceived as causing ASD. According to participants in the study by Gona et al. (2015), using malaria drugs or family planning pills during pregnancy was perceived as a possible danger to the developing fetus. Professionals believed that habits such as alcohol use or smoking during pregnancy may cause ASD.

Birth complications were perceived to cause both ASD and epilepsy (Gona et al., 2015; Sharkawy et al., 2006), while parents of children with ASD, clinicians, and teachers regarded malnutrition as a possible cause of ASD. Both cited studies also indicated a perception that these difficulties could be hereditary, where they are passed from parents to the unborn child, such as where "the mother is sick and it transmits to the child" (Sharkawy et al., 2006, p. 204) or where "it can be passed from my blood to the child's blood. It can be passed in families" (Gona et al., 2015, p. 8).

In a study on epilepsy, participants also mentioned neurological causes, stating "the brain having abnormal electricity," "the veins do not allow blood to the brain," and "a growth somewhere, something that can be operated on and we remove" (Sharkawy et al., 2006, p. 205).

These biomedical views partly reflect the Western concept of genetic and neuroanatomical links suspected to be part of the cause of SCD (Topal et al., 2018). According to the authors, genetic etiology for SCD partially overlaps with that of ASD, while changes in neuroanatomy have been attributed to social communication difficulties. Studies are starting to report associations of social communication difficulties with common variants of specific genes (Steer et al., 2010). However, in a recent study, St. Pourcain et al. (2014) discovered that there were developmental changes in the strength of genetic effects on social communication skills, indicating the need to also investigate how environmental effects may influence these skills. They further determined that genes associated with social communication difficulties were nonspecific and may occur in other neurocognitive disorders.

Social communication difficulties have been further described as co-occurring with a variety of psychiatric and neurodevelopmental disorders. With respect to ADHD, it has been hypothesized that impulsivity, inattention, and hyperactivity may result in impairments in social communication, which may further cause limitations in terms of communication, social participation, and academic achievement (Bellani et al., 2011). Social communication difficulties have also been found frequently among children with neurological conditions, such as epilepsy (Broeders et al., 2010).

Inclusion of Children with Social Communication Disorder in Schools in Kenya

As literature regarding SCD was scarce, the information based on the inclusion of children with ASD, communication disorders, and other neurodevelopmental disorders was integrated to provide more information on the inclusion of children who may have SCD in Kenya.

According to Mutai et al. (2016), the Kenyan two-tier education system does not make provision for children with communication disorders to be placed in special schools. Rather, these children attend mainstream schools in an inclusive fashion. Findings of this study indicated that teachers feel that the inclusion of children with communication disorders who have difficulty with social communication in mainstream classes may result in them being teased by others and difficulty making friends. Teachers felt that more support was needed and that the government should provide guidelines on how to assist learners with communication needs.

A study by Mwendo (2012) interrogated inclusive education for children with ASD with a special focus on the challenges facing teachers at City Primary School in Nairobi County. The school was selected to participate in the study because it was the first school that rolled out inclusive education for children with ASD in Kenya. The study findings revealed that there were specific policy guidelines on inclusive education in Kenya. However, there was a lack of curriculum adaptation in the special unit that hindered the teaching of children with ASD. The study recommended that the Ministry of Education put more effort to develop a curriculum for children with ASD, especially in integrated schools.

Another study by Njenga (2011) investigated curriculum barriers to the implementation of the inclusion of learners with ASD through a case study of a city primary school in Nairobi County. The purpose of the study was to understand curriculum barriers in the enforcement of learning for children with special needs. Specifically, the study sought to document the adaptations made to the curriculum to suit children with special needs. The study findings revealed that 92% of the teachers interviewed indicated that they needed to be trained on special needs education while 70% of the teachers felt that the curriculum needed to be amended to accommodate children with ASD. The school under study had adopted the individualized educational program (IEP, e.g., Sandt & Karriker, 2010; US Department of Education,

2000) to assist in learning for the children with special needs. Njenga (2011) therefore recommended that changes be made to the curriculum to accommodate children with ASD through a concerted effort from stakeholders such as the Kenya Institute of Special Education and the Ministry of Education.

Finally, Mbugua et al. (2016) found that despite the fact that children with an intellectual impairment are allowed to attend mainstream public schools in Kenya, inclusion remains elusive as there are no individualized educational plans or programmes (I.E.P) and adjustment of lessons to fit individual needs.

In Kenya, the inclusion of learners with individual needs in mainstream schools has not been achieved satisfactorily. Most studies are not published and hence is not evidence-based.

Intervention Measures

According to Adams et al. (2015), children with SCD may benefit from individualized therapy programs such as the Social Communication Intervention Project (Adams et al., 2012). This intervention is aimed at improving social understanding, social interaction, and language processing (Norbury, 2014). Outcomes revealed improvement in total and receptive language scores but not expressive language scores. Improvement in responsiveness, appreciation of listener knowledge, taking turns, and adaptation of discourse style were noted during conversation, while improved classroom behavior and enhanced literacy skills were reported by teachers (Adams et al., 2015).

Within the classroom, certain accommodations or strategies have also been reported to be used by Kenyan teachers who have children with communication disorders in their classrooms. These include having the children share notes or study together, teachers adapting their own oral communication, arranging classroom activities that scaffold communication development, using naturalistic approaches, and focusing skill development in short blocks of time (Mutai et al., 2016). Furthermore, Simms and Jin (2015) stress the importance of teachers providing opportunities for the child to practice social communication skills in real-life situations.

The paucity of longitudinal research limits our attempts to infer from the previous literature on SCD. The only study examining longer-term stability suggests that pragmatic language impairments may be somewhat stable into adulthood but the sample size was insufficient to generalize the findings (Whitehouse et al., 2010). The social communication difficulties seen in adulthood appeared to most negatively impact the ability to have close friendships or romantic relationships. This group of individuals had relatively intact literacy and language skills, although their social use of communication remained affected.

According to Gona et al. (2015), treatment for ASD and other neurodevelopmental disorders in Kenya varied from traditional and spiritual healing to modern treatment in health facilities and included consultations with traditional healers, offering prayers to God, and visits to hospitals. Sharkawy et al. (2006) further describe a combination of traditional, medical, educational, and religious practices which are used to treat epilepsy. These may include pouring water or other liquids on children, making cuts to the skin, wearing charms, or drinking herbal mixtures. Studies conducted in Kenya have shown that preferences are given to traditional healers in the treatment of epilepsy and neurological disabilities because these conditions are believed to be caused by evil powers (Gona et al., 2011).

Discussion

Characteristics of Social Communication Disorder

There is a serious paucity of literature related to SCD in Africa. Information regarding the number of children diagnosed with SCD in Kenya is lacking, and future research is required to ascertain whether SCD presents similarly in the African context as is described in the DSM-V. There is a further need for increased awareness of the disorder in Kenya and SSA.

Causes of Social Communication Disorder

In Africa, disability is perceived as existing as a result of both supernatural and biomedical causes. The mention of biomedical causes by participants in the studies by Gona et al. (2015) and Sharkawy et al. (2006) demonstrates that cultural and biomedical beliefs need not be mutually exclusive. The perceived relevance of biomedical aspects could indicate cultural change in this part of Kenya, which mostly consists of urban settings. Contemporary African culture combines the old and new, combining traditional beliefs with diverse stages of globalization. The diversity of opinions of the participants in these two studies suggests that the community may be in the process of viewing ASD and epilepsy as disorders that could have both cultural and medical implications.

Pitten (2008) mentioned that cultural values influence the diagnosis, treatment, and welfare of families with children who have ASD. The pluralistic beliefs about the cause of disability have significant influence on the planning of intervention services for children with SCD in the Kenyan context. A successful program must be sensitive to cultural nuances, in terms of familial beliefs on causation of the SCD, as well as parental treatment-seeking patterns. Professionals should explore individual families' beliefs and the impact of their beliefs on their treatment-seeking behavior (Gona et al., 2015). Health information that is aligned with parents' beliefs is more likely to be accepted and lead to changes in behavior, as opposed to information contradicting these beliefs. Attempts to challenge a parent's systems of understanding may result in confusion and a breakdown in communication (Gona et al., 2015).

Inclusion of Learners with Social Communication Disorder in Kenyan Schools

Children with SCD are being included in the mainstream classes in Kenya, as no provision has been made for them in the special school tier of the education system. However, curriculum adaptations and IEP are not currently being implemented. This may result in children needing to repeat grades and being unable to cope with academic demands. Inclusive education must exist with support, yet teachers feel there is inadequate training, funding, government support, and curriculum differentiation needed for inclusive education (Mbugua et al., 2016).

Intervention Measures and Educational Accommodations

Interventions must be cognizant of the medical, educational, traditional, and religious spheres of SCD. According to Gona et al. (2015), parents from various cultural backgrounds attend to both traditional and medical treatment for their children with ASD and neurodevelopmental disorders in Kenya. In the case of ASD, parents sometimes consulted traditional/spiritual healers in pursuit of a "cure," instead of seeking medical attention. Although these consultations were often conducted simultaneously with medical consultations, sometimes they were carried out after visiting a number of health facilities without perceived success. Parents who attribute their child's disability to supernatural causes experience negative attitudes toward the disability, hence the need to seek a cure. Due to the stigma associated with disabilities such as ASD and SCD within the African context, parents may feel greatly relieved if their child could be cured of the disorder through traditional treatments (Gona et al., 2015). However, there is some evidence that there may be positive effects of interventions such as the Social Communication Intervention Program (SCIP, Norbury, 2014) to enable children with SCD to cope in inclusive settings in Kenya.

The effect of lesson duration, written examination, classroom management, and classroom size is all dependent on the learning curriculum in an inclusive setting. The learning curriculum regarding teaching children with SCD may have an effect on their academic achievement. The learning curriculum can be broadly designed to deliver instructions, general social knowledge, and skills (Cullen et al., 2008). In inclusive classes, a well-

designed curriculum should enable a teacher to apply the learning material, plan instructions, manage the instruction, measure and evaluate the academic achievement of the learners, and most importantly know the ability of children, preferably at an individual level. A well-designed curriculum should give the children the best chance for optimal development by learning (Oosterling et al., 2010). A trained teacher should be able to determine and advise on the objectives and goals for the learner, parents, or guardians. In this way, the teacher will help the learner to grow and attain academic achievement (Drew et al., 2007).

Grenier et al. (2005) conducted a study on cooperative learning as an instructional strategy that aims to improve the academic achievement of learners with cerebral palsy. The study findings revealed that through cooperative learning, the child with cerebral palsy was able to enhance his self-advocacy skills. The study, therefore, concluded that cooperative learning coupled with an appropriate learning curriculum had fulfilled the child's social and psychomotor goals. Although this study was not specifically aimed at children with SCD, this instructional strategy may prove useful for working toward social goals in this population.

A study conducted in the United Kingdom by Watson and Pennington (2015) investigated the communication difficulties of children with special needs and the role of teachers as guided by the curriculum in assisting learning. The study findings revealed that the assessment and management of communication difficulties were widely experienced in schools and that the teacher plays a vital role in assisting the children to learn. However, they lacked standard assessment practices, thus preventing comparison of the influence of interventions in schools and the role of the curriculum in helping with inclusion. The study recommended the adoption of a standard set of agreed clinical measures that would enable benchmarking support provision in schools to improve the curriculum so as to enable attainment of academic achievement of children with communication disorders.

Children with communication disorders and weak social communication skills are at a disadvantage when sharing and communicating educational information, such as in the "group studying" strategy currently used by teachers in Kenya. Not only are group situations difficult, but also children with communication disorders may face difficulties succeeding academically due to the fact that they may experience low self-concept and reduced motivation to achieve, because of past experiences of failure (Mutai et al., 2016). Therefore, it may be suggested that these group study sessions, or group-work during the school day, should be facilitated by a knowledgeable adult who can use the opportunity to scaffold social communication for the child with SCD, as needed.

Currently, IEP are not being developed in a systematic manner in Kenya. Team collaboration between the parents, teachers, and speech-language therapists is recommended to determine joint goals for each individual child, as well as the brainstorming of strategies that can be used in various environments to aid social communication and language acquisition.

Impacts of the Study on Persons with Communicative Disabilities in Sub-Saharan Africa

Social communication and interaction problems are noted as one of the two core features in SCD, but they are also present in children with other neurodevelopmental conditions (Norbury, 2014). These social communication disorders are often missed in conventional language assessments. Reliable assessment of social communication language abilities is difficult because it is both contextually and culturally dependent and few assessment tools are available (Adams and Hwa-Froelich, 2015; Norbury, 2014). Results of the literature review indicated that (a) Africa-specific research is needed with regard to SCD, (b) cultural considerations regarding the cause and preferred treatment options must be taken into account when assessing and intervening in this disorder, and (c) as these children are in mainstream classes in Kenya, the necessary supports should be provided to teachers to assist with curriculum differentiation and development of IEP.

Considerations for Future Work, Research, and Politics

First, there is an urgent need for research to be conducted on SCD in the African context. As the condition is relatively new, efforts must be made to sensitize professionals in Kenya and Africa as a whole toward the condition. Additionally, there is a need to establish parent support groups and initiate parent-based interventions, taking into account the challenges they face with their children with SCD. Assessments and interventions which are culturally appropriate for the Kenyan context should be developed.

Given the learning difficulties of children with SCD in mainstream schools in Kenya, there should be provision of appropriate support to facilitate their learning. In conclusion, IEP should be developed for these learners, through collaboration with teachers, professionals, and parents. The Kenyan educational system does not effectively accommodate children with SCD, hence the need to adapt the curriculum to suit the learners with SCD.

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Promoting Social Communication: Teaching Strategies for Students with Autism Spectrum Disorder in East Africa

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Introduction

This chapter is intended to serve as a resource for educators of learners with ASD working in East Africa.

The term "autism" refers to a set of descriptions that profile a wide range of children who have impairments in their abilities to initiate and sustain healthy, normal social relationships (Roseberry-McKibbin, 2007). There are many sociocultural and language implications arising from autism spectrum disorder (ASD) due to symptoms that include difficulties engaging in social interactions and problems in language development and understanding (Odom et al., 2010). However, understanding the dynamics between language and the related sociocultural aspects of students with ASD continues to be a challenge (Rodríguez, 2009). Teachers and other professionals working with students with disabilities in schools have a responsibility to examine what we know from research about students with ASD. Those working with students with ASD need to focus, in particular, on the variables affecting the child's communication. It is important to work on primary language development within each child's dominant culture and community because that is where he or she will most likely continue to learn, live, and work (Wilder et al., 2004). We also must teach families how to help their children communicate, acquire basic life skills, distinguish between safety and danger, and otherwise prepare for adult life.

As in all parts of the world, the importance of educating all children regardless of their background or circumstances is also recognized in East Africa. Tanzania, for example, has long sought to ensure that all school-aged children enroll in schools. Act No. 15 of 1984 Art. 6 of the Constitution of the United Republic of Tanzania has decreed that "every person has the right to access education, and every citizen shall be free to pursue education in a field of his choice up to pursue education of his choice to his merit and ability, the highest level according to his merits and ability." The Swahili term "*toa nafasi*" refers to providing the opportunity for children with disabilities to pursue an education.

Additional research is needed to support the extension of ASD assessment and treatment in Africa, where, potentially, clinicians, parents, educators, and caregivers could use existing tools and resources to enhance assessment and intervention. Educators in East Africa and other stakeholders in countries such as Kenya and Tanzania seek to provide an education for all students with ASD (Hippensteel, 2008). As Hippensteel (2008, p. 19) further indicated, "inclusive practices are more readily accepted by the general public in Tanzania than in other parts of the world." However, this has been difficult for schools and educators to achieve because as Hippensteel discussed, "Although the Universal Primary Education Act in 1977 and the Education Act of 1978 were authorized in an attempt to promote education for all students regardless of their abilities, the lack of resources and support from the government have made the implementation of these acts extremely challenging" (Mmbaga, 2002, cited in Hippensteel, 2008, p. 19). Given the importance of teaching all children, it is critical to use effective resources to help students with ASD improve their communication skills. Effective teaching of children with ASD will help enable them to participate more fully in their communities, which will also contribute to their self-esteem.

To ensure effective teaching, teachers must understand the different characteristics of ASD and how this affects students' communication skills both within the classroom and in other settings. It takes time for teachers to acquire the necessary knowledge about ASD due to the wide-ranging difficulties which lead to sociocultural and language implications (Rodríguez, 2009). Although the challenges in teaching children with ASD are significant, the teaching strategies discussed in this chapter will help professionals meet these challenges and contribute to continual educational progress.

Teaching Students with Autism Spectrum Disorder in Tanzania

Stone-MacDonald (2012, p. 257) commented that "Each year progress has been made to understand the issues faced by persons with disabilities

in Tanzanian society and to address those needs, starting by educating more children with disabilities and training teachers to be special educators." It is important to recognize the challenges that the country faces in implementing practical remedies when educating persons with ASD. As Stone-MacDonald (2012, p. 257) also stated, "There are educational opportunities and schools for Tanzanian children with disabilities, but those options are limited and may not be preparing them for the transition to adult life and participation in their communities." Mnyanyi (n.d. p. 1), professor at the Open University of Tanzania, describes other challenges for educators in Tanzania and further explains that "The challenges faced by teachers include and are not limited to the classroom management skills; planning for resources use; planning for teaching diverse classes; selection of teaching methods and ensuring that all pupils in the class learn and achieve the intended goals both personal and public." Presently, Tanzania faces many challenges, including providing people with the proper services needed to assess for an ASD (Harrison et al., 2014).

Theoretical Background

Challenges in Assessing Children for Autism in Eastern Africa

One of the challenges faced by East Africa with respect to providing services to persons with ASD is that the resources for appropriate assessment are limited. Due to the lack of large-scale studies on ASD, its characteristics are to a large extent little known. Often, children are not diagnosed with ASD until they are approximately 8 years or even older (Bakare & Munir, 2011). Further, as Harrison et al. (2014, p. 330) described, "In many lower-income countries, there is a paucity of assessment services for autism spectrum disorders." In their research, they provide suggestions for conducting cross-cultural assessments using the existing resources in Tanzania. Many people in the country are not correctly diagnosed or remain undiagnosed because of the lack of proper resources and the very limited or nonexistent recommendations on how to assess ASD. Harrison et al. (2014, p. 331) further argue that currently another challenge in assessing ASD is that there are no ASD diagnostic instruments validated for use in Swahili, a language that is spoken by millions of people in Kenya, Tanzania, and Uganda. The diversity of languages poses an additional challenge to the accurate assessment of ASD in Eastern Africa.

Even though the assessment of ASD is challenging, it is feasible to use evaluation techniques. Since ASD diagnostic measures in Swahili are limited, evaluators can use assessments that require little translation. Indeed, Schopler et al. (2010) created such a measure, the "CAR Autism Roadmap" (CARS2), which involves an element of play but with minimal language. The CAR Autism Roadmap website defines CARS2 as "a clinical rating scale for the trained clinician to rate items indicative of Autism Spectrum Disorder … after direct observation of the child." It is noted that the CARS2 can be used effectively through being applied flexibly with little use of language. Harrison et al. (2014) used this as a guide for the play interaction part of ASD assessment. When using this method, it is important to consider how it should be culturally relevant to the population. As such, their results indicated that the method did not create a language barrier and provided accurate results. In their research, toys and visuals associated with those familiar to the child's home culture were used as part of the assessment process while observing the child during play interaction. For the adaptive functioning component of the observation, Harrison et al. (2014, p. 334) used an interview version of the "Malawi Developmental Assessment Tool" (MDAT), which they described as "an instrument created to assess adaptive behavior in rural Africa." MDAT assesses different developmental domains which include gross motor and fine motor skills, as well as language and social interaction (Gladstone et al., 2010).

Gladstone et al. (2010, p. 14) indicate that "MDAT is a culturally relevant assessment tool that reliably identifies children with neurodisabilities and delayed development in rural Malawi." However, the researchers also note that although this may potentially be used in similar settings, more research is needed to confirm this and whether it can "work in children with more

subtle developmental problems." Administering the MDAT requires interaction with the child as well as parental interviews and can be used effectively in East Africa. In support of this, Harrison et al. (2014, p. 334) concluded that "Tanzanian caregivers were able to provide answers for their children on all of the items on the MDAT providing initial qualitative evidence that this measure is a feasible method for collecting data on adaptive functioning in Tanzania."

In addition, Harrison et al. (2014) used a checklist based on the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV-TR), and the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). The diagnosis of ASD was determined by analyzing multiple data sources, specifically, parental interviews, child observations, and the DSM checklist. According to Klin et al. (2000, p. 163), "One of the most important goals of diagnostic classification systems, such as the Diagnostic and Statistical Manual of Mental Disorders 4th Ed (American Psychiatric Association, 1994), is to enhance the agreement on a specific diagnosis among clinicians with diverse backgrounds and levels of experience." Harrison et al. (2014) used this method combined with information collected about the child through parent interviews and direct child observation. Furthermore, they suggested that, despite the cultural differences between different regions of the world, ASD characteristics are the same. They emphasized the importance of being culturally aware when using assessment measures for ASD, noting, "By collaborating with people indigenous to a region and making as many cultural alterations as possible to existing measures, particularly observational measures, we can achieve a compromise between the best practice outlined for cross-cultural assessment and helping people with ASD in need" (2004, p. 341). Clearly, in Tanzania and other regions of Eastern Africa, we can use the available resources for the diagnosis of ASD when considering the influence of local culture to ensure greater reliability of diagnosis. Before starting a process of ASD diagnosis, the professional must research the local community and apply it to the assessment procedure. In summary, it is important to consider what is culturally relevant to the child when making assessments. Table 30.1 summarizes the assessment measures discussed above.

Questions for Reflection

- Why is culture important in the assessment and diagnosis of ASD?
- Why are parental interviews such a valuable resource in ASD assessment?

The Role of the Community in Teaching Students with Autism Spectrum Disorder

In a classroom of children with diverse abilities and needs, teachers must make every effort to meet the needs of all children by promoting an inclusive and supportive environment. According to Mnyanyi (n.d. p. 3), "For teachers to include all pupils in their classroom practices there is a need to have knowledge on how to handle different types of disabilities." Educators should be aware that every person with ASD has individual strengths and needs. Consequently, teachers need to learn about each student, as well as discuss goals and concerns with the child's family or guardian to achieve student success. It is also necessary to learn about the different strategies that can be used in a classroom of students with ASD using available resources.

This chapter provides examples of how evidence-based methods can be used in a classroom with children with ASD. However, it is important to consider that strategies may not be consistently effective given that different factors need to be taken into account. As Stone-MacDonald (2012, p. 256) indicated, "Evidence-based practice is a wonderful starting point for curriculum development, but in unique locations, like rural Tanzania, it is also essential to focus on the needs of the local community." For this reason, the author argues that the teacher needs to learn about the community, as it will contribute to the overall development of the child's communication skills and

Table 30.1 Assessment measures for children with autism spectrum disorder in Eastern Africa

Assessment measure and author	Researcher (year)	Advantages	Disadvantages	Cultural considerations	Areas of the autism spectrum covered
Childhood Autism Rating Scale Second Edition (CARS2) Schopler et al. (2010)	Harrison et al. (2014)	Can be applied with minimal use of language and provides accurate and consistent results Consider IQ when the child is under or over 6 years of age and has an IQ score lower than 79. (CAR Autism Roadmap.org)	Can only be used by professionals with training in ASD	Consider the population and what is culturally relevant (Harrison et al., 2014)	Does not cover all functional levels of ASD Not very accurate in identifying individuals with higher functioning levels of ASD (CAR Autism Roadmap.org)
Malawi Developmental Assessment Tool (MDAT) Gladstone et al. (2010)	Harrison et al. (2014)	Can be used consistently in Eastern Africa Culturally relevant (Harrison et al., 2014)	It has many limitations and does not cover the entire autism spectrum reliably (Harrison et al., 2014)	Make connections to family. Parental interviews are required (Harrison et al., 2014)	It is limited. It is questioned whether it can accurately assess children with subtle developmental problems. Assesses gross motor and fine motor developmental domains, language and social interactions (Harrison et al., 2014)
Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV-TR), and the Diagnostic and Statistical Manual Fifth Edition (DSM-5) American Psychiatric Association	Harrison et al. (2014)	May be used by professionals with no experience	A clinician with more experience may be more accurate than the checklist because they consider factors that do not appear on it Not very culturally relevant. If the assessor does not learn about the child's culture, there may be inaccuracies in diagnosis (Harrison et al., 2014)	Interview families. Need to learn about the community, the child's family, and the child's past experiences (Harrison et al., 2014)	Does not accurately assess higher functioning levels in ASD

promote his or her participation in the community outside the school. As Nieto (2000) stated, affirming the diversity that the children bring into the classrooms is important to student success. Stone-MacDonald (2012, p. 255) also recognized this: "knowledge of local context is critical to give children with disabilities the best opportunities for an education and meaningful participation in their community." In the case study discussed below, Stone-MacDonald (2012) describes how establishing relationships within the community can be beneficial for students with a wide range of developmental disabilities. However, for purposes of this chapter, we specifically consider how school

and community involvement can improve the communication skills of students with ASD.

Stone-MacDonald (2012) conducted a case study in Irente Rainbow School (IRS) in Lushoto, Tanzania, which he noted was the first school in the area for children with developmental disabilities. His work provides an example of how the teacher can use local resources and what Moll et al. (1992, p. 133) describe as "funds of knowledge," which they defined as "historically accumulated and culturally developed bodies of knowledge and skills essential for household and individual functioning and well-being," to discern best strategies for improving their students' communication skills. The case study took place in the school and the local community and was conducted over 13 months. During this time, interviews were conducted with parents, teachers, and people from the community. By communicating with parents, the teacher can learn about the families' concerns, what each family does, and the family's role in the community. IRS is an exemplary institution in this regard because, as Stone-MacDonald (2012, p. 259) noted, "Within the local context, the content of the curriculum at IRS is based on local funds of knowledge important to family life and local culture." As teachers of students with ASD, it is imperative to be knowledgeable about the local community because the community's funds of knowledge inform the preparation of students with disabilities for integration into their communities after schooling. The IRS uses a model called the instructional model of intent community participation. In this program, children work with adults in the community, which engages the learners while providing immediate feedback and modeling. By supporting students in this way, they can acquire the skills necessary to become productive members of the community. In the IRS, teachers provide students with opportunities to participate in the daily activities of the community, fostering learning through modeling.

Modeling for students with ASD provides visual cues and encouragement for learning. For example, a teacher could model to students how to harvest vegetables, a community activity in East Africa. This form of instruction is not only beneficial for students but also to the community because the presence of the students as community members increases the likelihood that the community as a whole will accept persons with disabilities. When designing classroom activities and planning what strategies will be implemented to improve students' communication goals, teachers must consider how the attainment of curricular goals will assist students in their daily lives, outside of school. There are different strategies that educators can use to help children with ASD improve their communication skills and our goal is to describe some of these strategies in the following section of this chapter.

Questions for Reflection

- Why should teachers provide opportunities for students with disabilities to participate in the?
- What is the importance of learning about the where you teach?

Didactic Methods

Individuals with ASD vary in the communication challenges that affect their social interactions. Vicker (2009) pointed out some of the social challenges presenting in persons with ASD may include difficulties initiating and maintaining conversations, frequently talking about unusual topics of interest, exclaiming something inappropriate, constantly repeating specific words and phrases that were heard before, difficulties initiating and maintaining friendships, difficulty acknowledging the points of view of other people, and feeling overwhelmed if required to do an additional task while speaking. Another characteristic of ASD in children may be a lack of response when spoken to. As educators, we are responsible for reflecting on which strategy is the most appropriate to use in our classroom to help our students develop and refine the skills needed to be able to build relationships with peers and use these acquired skills outside of school.

In the following four sections, we describe the challenges in communication that children with ASD face. In each section, we discuss multiple studies of evidence-based practice that researchers have conducted with students with ASD. Following each description of the studies, there is a vignette. The authors have implemented the lessons learned from previous research and their own experience working with students with ASD to create short stories to illustrate how teachers in different regions throughout East Africa could draw on resources in their communities to implement effective strategies in their classrooms. Classroom activities to provide the child with ASD opportunities to socialize while completing academic tasks will also be suggested. Each research description and short story will be followed by a question for you, as a teacher, to reflect on what you have learned and how you could implement these strategies in your own classroom. Finally, we have included consideration of issues relating to cultural adaptation and transfer at the end of each section.

Collaborative Strategic Reading to Provide Opportunities for Communication in the Classroom

Since one of the biggest challenges for children with ASD is communicating and building relationships with other people, educators must consider how to provide the child with many opportunities to socialize and practice the skills being taught in the classroom and other settings. It is important to consider how you can build on the social skills of your students while they also learn important academic skills. An example of how to incorporate group work in class is through Collaborative Strategic Reading (CSR) (Klingner et al., 2001). Using CSR requires students to work in small groups, each with a specific role. Teachers use different reading strategies based on the genre and complexity of the text. Teachers typically select the text but students can be afforded the opportunity to choose the text they would like to read. In CSR, groups are usually comprised of four students who have the opportunity to scaffold each other in the reading process while each fulfilling a designated role. In this manner, students collaborate to complete the reading task. Alqarni (2015) described this process as students interacting with the text and other readers, as well as with the teacher. Teachers serve students well when they provide students with ASD different opportunities to socialize in the classroom as they complete academic tasks. Teachers must take into consideration the need for specific accommodations for students with ASD in this class activity, which may include the provision of sentence starters or verbal prompts to help students focus on the required topic and assist in communication. Sentence starters must be relevant to the community and region.

Odom et al. (2010) researched the benefits of CSR in three adolescents (aged 16–17 years) from Latino-Caucasian backgrounds with ASD in a rural school district in Texas, United States of America. Although their research focused on the behavioral, reading, and social outcomes of using CSR-HS (Collaborative Strategic Reading-High School), for the purposes of this chapter, we focus on the social benefits. Hume and Odom (2007) paired students with ASD with typically developing peers to complete the CSR-HS (Reutebuch & El Zein, 2013). All three students who participated in the CSR-HS had increased social interaction, and one of the students had increased social interactions from participating in the CSR-HS until independence, indicating long-term benefits. Clearly, using CSR in the classroom was effective in increasing student social interaction. When implementing CSR in your own classroom, it is important to consider the adaptations that are necessary for students with ASD. The cited researchers used task analysis, checklists for students, prompting, and visuals.

Amali's Story

Nadiya, a secondary school teacher from the city of Mwanza, used CSR in her classroom to help her student Amali socialize with other classmates during group work. Amali is a bright girl who hopes to become a nurse 1 day. She is very talented in school but has difficulties with reading comprehension, which is important because she is also learning a new language, English. Amali has trouble

speaking to classmates and her teacher because she frequently speaks about the same topic, and when her classmates try to engage in conversation with her, she goes back to her preferred activity. Consequently, many classmates avoid her. Nadiya wants Amali to have opportunities to socialize with her peers and build friendships. CSR provides students opportunities to play different roles, which can help Amali understand how to participate in conversation for different purposes. Further, as the name of the reading strategy suggests, students collaborate with other people. Before implementing CSR in her classroom, Nadiya considered which adaptations were necessary for Amali. Nadiya gave a preview of the story to Amali so that she had some background knowledge about it and could stay on the topic of conversation. Additionally, Nadiya created sentence starters and prompts related to her role in CSR and the story to help Amali focus on the classroom discussion. A sentence starter provides a prompt to begin a sentence and can help students to express themselves. Nadiya also provided Amali with a list of keywords related to her role so that when she speaks, she adheres to the topic. A few days before Nadiya used CSR in her classroom, she explained to the class what each role meant and advised all the students to stay in their role. Students were given opportunities to practice their roles before participating in the group work. Roles in CSR include that of leader, clunk expert, gist expert, and announcer. The leader ensures all group members stay on task and helps all students in the group with their role. The clunk expert helps group members figure out the meaning of a particular word. The gist expert assists other group members by informing them of the steps needed to figure out a main idea in a text. The announcer is in charge of calling other members of the group to share their ideas. Since Amali is great with vocabulary, she was given the clunk expert role, and her classmate would help her with understanding main ideas from the text. The materials used included a learning log in which Nadiya provided students with paper to write what they were learning. In addition, students used cue cards, which provided the steps necessary for each role. These can be created by cutting pieces of paper into four and writing information relevant to each role. Finally, clunk cards are provided to give strategies on how to find the meaning of a word.

There are four stages involved in implementing CSR. In the first stage, the teacher introduces CSR to the class and explains its purpose. In the second stage, the teacher models each role and different strategies and explains why each role is necessary. In this stage, Nadiya modeled using an English version she wrote of "*A Man Bird and Ogres*," which is an oral story of the Sukuma Tribe (Mirambo, 2004). In the third stage, students had the opportunity to practice their role independently with the teacher as a guide. When Amali wanted to express her ideas but could not express them in English, her teacher allowed her to write them in Kiswahili. This is because her first language can facilitate the development of the second language (De Jong, 2011). In the fourth stage, students practiced their roles independently. After using this strategy, Nadiya considered that another way for Amali to socialize was by having all students write a paragraph about the story and discussing it with partners. Nadiya provided Amali with sentence starters and a list of what she could ask her partner so that she could use it when discussing her paragraph to guide her. The final draft of the paragraph was written in English, but to help in their writing, students were allowed to write in Kiswahili because that helped them deepen their thinking of what they were learning (Fu, 2009). Given the writing and speaking prompts, Amali was able to discuss her writing and engage in an editing process with a classmate, staying on the assigned topic.

Questions for Reflection

- Why should teachers provide students with opportunities to engage in group work?
- What modifications helped enable Amali to participate in the group's activities?
- Why should a teacher allow the student to use their first language as a resource when learning a new language?

Cultural Adaptation and Transfer

To implement CSR, teachers have to know what is important to the communities that they teach. In addition, teachers need to provide texts that are relevant to the community. Doing so enables their students to build on the background knowledge that they possess. If students are using CSR for an informational text, the teacher's role is to investigate what is of importance and applicable to the community. To learn about the community, the teacher may interview parents and community members. The teacher may also ask community members about writers and topics that are meaningful to them.

In CSR, each student is assigned a role, and every member is held accountable for their task. Teachers should make connections between team members and roles in the local community to help students understand the importance of each person and each person's role in the team. For example, the teacher may lead a discussion about how a local vegetable market has different people working in it (e.g., managers, sellers) and the people they depend on (e.g., farmers). Through such role-playing, students learn how the market would not survive without each person that forms an important part of it. Similarly, CSR will not be effective if students do not carry through in their roles. Thus, the teacher needs to build a sense of community in the small groups.

Communication Strategies for Children with ASD Who Are Minimally Verbal or Nonverbal

Multiple studies have been conducted on the use of the Picture Exchange Communication System (PECS; Bondy & Frost, 1994). These demonstrate the effectiveness of PECS when compared to other methods, such as Pivotal Response Training (PRT; Lei & Ventola, 2017). The critical difference between PRT and PECS is that in PRT, communication is taught using verbal strategies (e.g., asking a child with what toy he or she would like to play and when the child chooses the toy, the teacher states the question and has the child repeat it). In contrast, PECS utilizes images (Schreibman & Stahmer, 2014). An example of PECS would be a child using an illustration of a sandwich to communicate that he or she would like to eat a sandwich. Schreibman and Stahmer (2014) assigned 39 students to either a PECS (n = 19) or PRT (n = 20) intervention. Both methods provide the child with natural opportunities for communication. The majority of students in the PECS condition experienced an increase in communication, such as requesting, commenting, using pictures, responding, and attributes. Furthermore, the children's parents were satisfied with the outcomes of their children using PECS. However, they indicated that they experienced challenges using PECS in their homes relating to the preparation of materials, such as PECS books. The researchers noted that some parents might hesitate using PECS because they are "fearful that these systems may interfere with the development of spoken language" (Schreibman & Stahmer, 2014, p. 1249). They further suggested that "given the randomized comparison design, these findings suggest that PECS may be as effective as naturalistic verbal language programs such as PRT for facilitating language" (2014, p. 1249). Finally, they mention that the use of PECS does not interfere with the development of spoken language.

As previously noted, many children in East Africa are not diagnosed with ASD until at least 8 years old, and ASD is one of the primary causes of nonverbal communication. Thus, early intervention is needed to promote language development in children with ASD (Bakare & Munir, 2011). To help develop the communication skills of nonverbal children, PECS allows communication with the use of pictures (Schreibman & Stahmer, 2011). This strategy, however, requires different modifications to serve the goals and needs of a student and his or her family while also considering the sociocultural aspects of the community using the available resources.

When implementing the PECS in the classroom, there are additional steps to implement (Collet-Klingenberg, 2008). Adaptations may also be necessary according to the availability of resources and materials. The required steps are detailed in the PECS Shorthand Notes from the BBB Autism Support Network and the PECS.

The short vignette below discusses how a teacher in the Sukuma tribe implemented the six phases of the PECS.

Lemanyian's Story

Bahiya, a primary school teacher in the Sukuma tribe, recently learned about PECS and wants to implement it in her classroom to help one of the students, Lemanyian, communicate with his family and classmates. Lemanyian is an 8-year-old boy who is minimally verbal and sometimes repeats phrases that he hears in the environment around him. He avoids eye contact when spoken to and can sometimes be unresponsive.

Before Phase I

Before implementing the first phase, the teacher must conduct reinforcement sampling, which Collet-Klingenberg (2008, p. 1) defined as, "an informal inventory of items that are of particular interest to the learner."

Lemanyian's teacher met with his mother to learn more about him. The teacher learned that Lemanyian's father grows potatoes, corn, and rice to help sustain the family and his mother provides the family with water and cooked meals. When speaking with Lemanyian's mother, she described him as a sweet boy who observes how she prepares meals every day. However, when she invites him to join, he looks away. Lemanyian likes to play outside with a ball his father gave to him years ago but avoids playing with his younger brother. Lemanyian likes to collect things he finds outside, such as leaves and pebbles, when he goes with his mother to get water. When he wants to communicate and has trouble doing so, he begins to cry. One goal of Lemanyian's mother for her son is for him to help in the family business, which is the production of crops.

After learning about Lemanyian's interests and the family's goals for him, Bahiya found objects that she thought would interest Lemanyian. She collected leaves from outside and a soccer ball. She also found pencils, cups, cornmeal, mango, oranges, a bell, and a set of drums. These additional items were collected to learn more about his preferences. She presented these items to Lemanyian, and from the items he selected, she documented what he preferred most and least. From this assessment, Bahiya learned that Lemanyian also likes oranges, so she planned to add them when training Lemanyian with PECS.

Phase I: Teaching the Physically Assisted Exchange

The goal of this first phase is to enable the student to select a picture of a preferred item. In this phase, Bahiya presented pictures of items of interest to Lemanyian so he could communicate his item of preference to Bahiya and hand the picture to her. During this phase, Bahiya did not use any verbal prompts. Before moving to Phase II, Bahiya made sure that Lemanyian was independently exchanging a picture to receive the item he wanted. She slowly stopped opening her hand and waited for Lemanyian to hand her the picture. When he was able to do it independently, Bahiya knew Lemanyian was ready for the next phase.

Phase II: Expanding Spontaneity

The desired outcome of the second phase is for the student to use his communication book by removing the picture of the desired item and handing it to his teacher. Bahiya collected different images and placed them in a notepad, having divided them into categories (such as food and sports). She gave the notepad to Lemanyian, which became his communication book. She also found a piece of cardboard, which was used as Lemanyian's communication board. In this second phase, Bahiya thought it would be a good idea to include Lemanyian's mother since it is necessary that the student also practices PECS with other people. Bahiya reports an example of when Lemanyian's mother was peeling oranges near him. When his mother noticed that he was looking at the fruit, she moved further from Lemanyian and he moved closer to give her the picture of the orange from his notepad. As he gave her the picture of the orange, his mother handed him an orange while saying the word. His mother then added the picture of the orange to the piece of cardboard. It is important to praise the child each time he hands an image properly.

Phase III: Picture Discrimination

The goal of the third phase is for the child to select the appropriate image from a set of pictures and hand it to the teacher. Before this phase, the teacher collects different images that the student does not like. In order to know what the student does not like, Bahiya observed him in school and discussed this matter with his mother. In this phase, the teacher presented Lemanyian two objects, an orange (the preferred item) and a banana (a fruit his mother said he does not eat). She presented both objects with pictures but removed them immediately so that Lemanyian could visually associate the fruit with the images. Lemanyian showed the image of the preferred item to Bahiya and she said, "You want the orange?" and praised him as she handed him an orange. It is important to ask the child if he wants the object he represents with the picture to make sure that it is what he really wants.

Phase IV: Sentence Structure

The aim of this phase is for the student to present phrases to the teacher (or another person) to communicate what he wants. The student has to take a picture that says, "I want," and a picture of what he wants and move toward the teacher. For this phase, Bahiya wrote "I want" on a small piece of paper and added it to the sentence strip (for the sentence strip Bahiya used a longer piece of paper). She assisted Lemanyian in placing the image of what he wanted (mango) next to the phrase "I want." Bahiya waited for him to give her the sentence strip. After giving her the sentence strip, the teacher said out loud "I want" and waited for Lemanyian to say "mango." After Lemanyian learned to do this, Bahiya moved the "I want" picture to the left side of the cardboard. When Lemanyian wanted something, Bahiya helped him place the "I want" sentence strip along with the image of the desired item.

Phase V: Responding to What Do You Want?

In this phase, the student becomes able to answer the question "What do you want?" The learner can already make requests using the phrase "I want" sentence strip.

Returning to the current example, we have the scenario in which students were playing instruments outside. Bahiya considered it a good opportunity to ask, "What do you want?" When asked, Lemanyian was able to combine the phrase "I want" and an image of a drum, which he handed to her. Bahiya repeated, "I want the drums" and handed them to Lemanyian who started banging the drums with his classmates.

Phase VI: Responsive and Spontaneous Commenting

In this phase, the goal is for the student to be able to make comments and express likes and dislike. In this phase, it is intended that the student will make comments on what he sees in the environment and activities he likes. It is also a goal that the child expresses his feelings in the moment. Bahiya added more sentence strips, including "I like" and "I feel" and gave them to Lemanyian. He was able to put together "I like" and an image of corn.

Question for Reflection

Why is it important to use pictures of what the child likes when implementing?

Cultural Adaptation and Transfer

When utilizing the PECS to teach communication skills to children with ASD, one of the teacher's roles is to learn about the child and what is important to her or him. The teacher must also explore where the child lives and the customs and routines of the child's family. We suggest going on a community walk with the child and his or her family to become familiar with what they see every day. In addition, we recommend having an open discussion with family members about the goals you seek to achieve by implementing PECS. Furthermore, since PECS requires the utilization of pictures to facilitate communication, the teacher may involve the family in this process by taking photographs or drawing the pictures together.

Using Social Stories, Modeling, and Meaningful Activities to Improve Social Communication in Children with ASD

Social Stories have been used as a behavioral intervention for children with ASD, and there have been numerous studies demonstrating the effectiveness of this method (Scattone et al., 2006). There has also been research on the use of Social Stories to improve social interactions in children with ASD. According to Scattone et al. (2006, p. 211), one of the functions of Social Stories is to explain and describe hints and cues in the scenario as well as teaching appropriate responses.

Scattone et al. (2006) conducted a study in which the purpose was to determine the effectiveness of using Social Stories to increase social interaction. The participants of this case study were three boys with ASD (two aged 8 years and one aged 13 years). All three students had ASD and were taught in self-contained special education classrooms or general education classrooms in elementary and middle schools in the southern part of the United States. It is not specified whether it was in a rural, suburban, or urban area. Results showed that in two of the three participants, there was an increase in appropriate social interactions. However, of the two who demonstrated increased social interactions, only one had a significant increase while the other had only a moderate increase. Scattone et al. (2006, p. 217) noted that the third participant demonstrated no meaningful improvement. According to the researchers, the participant who had the largest increase in social interaction started improving after Social Stories were introduced. For the participant who had a moderate increase in appropriate social interactions, the researchers noted that the child spoke with peers about topics the Social Stories described (i.e., Disney Movies), but not in the way that the stories were presented to them. This participant was not observed asking classmates about their favorite movies. However, it was noted that this participant's social interactions increased more toward the end of the study and also that he was the last to participate. Based on this work, the researchers recommended that students participate in the writing and editing process of their social narrative since one of the students reported that one of the phrases in his social narrative was one he does not use. Finally, Scattone et al. (2006, p. 219) concluded that "social stories, when used as a sole intervention to increase appropriate social interactions, are limited in their effectiveness." This suggests that more research is needed to determine the degree of effectiveness of this intervention.

According to the Vanderbilt Kennedy Center, Social Stories™ are written for a variety of purposes based on a student's experiences or responses to events and situations in his/her world. Unfortunately, there are many social injustices that persons with disabilities go through. As Kisanji (n.d. p. 2) indicates, "In a world guided by economics, with its concern for investment and maximum rate of return, inequalities of opportunities are created for persons with disabilities." As educators of children with disabilities, one of our biggest responsibilities is teaching our students important skills so that they can participate in their communities.

The following short story provides an example of the use of Social Stories.

Ushindi's Story

Ushindi is a 9-year-old boy with ASD in primary school. He is in Zuwena's classroom. Ushindi is very good at mathematics. His father runs a business where he trades and sells goats in a rural area of Eastern Africa. Ushindi's father wishes that his son could participate in his business. However, this is challenging because Ushindi needs to learn the appropriate social communicative skills to engage in this. Ushindi can sometimes be unresponsive when spoken to, and when he initiates conversations, it is often unrelated to the current context. Zuwena will use Social Stories and classroom activities to help Ushindi learn the proper skills needed to take part in his father's business. This example is based on recommendations from the Vanderbilt Kennedy Center and research by Scattone et al. (2006).

As Ushindi's teacher, Zuwena knew that the best way to help him was establishing a relationship with his family and learning about the com-

munity he lives in. Zuwena interviewed Ushindi's father to learn about his business and what topics of conversation are expected when trading or selling goats. After learning about Ushindi's family and community, Zuwena sat with Ushindi in the classroom and wrote the Social Story with him. She made sure to write it in the first person, from Ushindi's perspective, and to include descriptive and directive sentences in the story. Two ways descriptive sentences are used in Social Stories are to state facts and to identify what others can do to help the student. Directive sentences are used to help the student determine possible responses in a situation. Zuwena and Ushindi created a Social Story about how he can use mathematics to participate in his father's business.

Example from Ushindi's Social Story
Directive sentence: *"When a herdsman approaches us, I have to say hello."*
Descriptive sentence: *"My father wants me to give him the shillings I collect if I sell a goat."*

Zuwena made sure to include many drawings (visual supports) in the story to help Ushindi comprehend it. After Zuwena finished writing the story, she read it to Ushindi. On other occasions, Ushindi read the story to her. In addition, Ushindi's father also read the story to him on days that they would sell goats. After 1 week, Zuwena asked Ushindi's father if the Social Stories were effective according to the standard procedure.

Questions for Reflection

- Why should teachers learn about the family's needs and their participation in the community when implementing Social Stories?
- Why is it important to apply community activities to the content, as Zuwena did in her mathematics classes?
- Why should teachers provide opportunities for students with ASD to practice the communication skills they are learning in the classroom?

Many of the boys in Zuwena's classroom are sons of herdsmen that sell and trade different livestock. To support Ushindi's Social Story, she considered incorporating buying and selling livestock into her mathematics teaching. She modeled ways to greet herdsmen and sell livestock and had her students role-play how it is done. In addition, she taught her students mathematics exercises related to buying and selling, which helped strengthen not only Ushindi's skills in this regard but also those of the rest of the students.

Cultural Adaptation and Transfer

When using Social Stories and determining the goals of the intervention with the child and his family, the teacher has to take into account their roles in the community. In Ushindi's case, the goal was for the child to participate in his father's business. The teacher's role was to be an investigator and learn about the community's economy, the family's business, and how it works and interview the father to explore expected conversations in that setting. When using Social Stories and setting goals for its use, the teacher has to build on the child's strengths and consider how these could help him participate in the community. The teacher gathers material for the Social Stories through parental interviews and community walks, as well as by interviewing community members. During this time, the teacher should observe the relationships and context in the family and community to determine how to implement Social Stories.

Music Combined with Social Narratives to Address Communication Skills

Kern et al. (2006) investigated how unique songs composed for children with ASD affected their morning routines in their classrooms. The two boys who participated in the study (both 3-year-olds) showed limited social interaction with classmates. The researchers note that the boys showed interest and participated in classroom activities

that involved music. They describe that part of the school's morning routine involved greetings, being greeted by teachers and other classmates, and saying goodbye to their parents.

Materials in the study included an image that had a greeting symbol that students were able to understand despite their language or communication skills. Unique songs were composed for each student who participated in the study to suit their personalities and the requirements of their morning greetings routine. After the songs were included in the morning routine, increased independence after the morning routine was observed, and for one of the participants, the number of classmates who greeted him increased when the song was used in his morning routine. One challenge for the teachers was to change the music to the part of the song intended for when the child said goodbye to his parents as this caused anxiety in participants. They thus suggest that teacher development and collaboration are imperative for teachers to implement interventions that use music therapy. Teachers, participants' parents, and other classmates' parents were very satisfied with the effectiveness of the intervention.

In evaluating this work, the researchers suggest that additional studies be conducted with more participants since only two children took part. In addition, the songs were written by music therapists and it was not specified whether a teacher can adapt a pre-written song without the assistance of a music therapist and still achieve positive results. The researchers suggest that more studies of how songs can be used to increase social and communicative skills in children with ASD should be conducted. Clearly, music can have benefits for children with ASD and we should consider how we can use this to best help them. The following illustrative story includes strategies based on some suggestions from Kern et al. (2006).

Mogoma's Story

Mogoma is a 7-year-old boy in Malenga's classroom in a primary school in Dodoma, the capital of Tanzania. He is a very sweet boy who brings joy to his parents. He does not respond when spoken to and sometimes responds with inappropriate words. Consequently, Mogoma has had trouble making friends. His parents hope that he can have many friends 1 day. They also hope that he will be able to greet other people because it is very important in his family. Greetings are very important in Tanzanian culture and young children must show respect to elders. For these reasons, a child must learn to greet adults when he sees them.

One of the most beautiful features of the African culture is its music and how much joy it brings to its people. Music can be a very valuable way to help a child with ASD (Kern et al., 2006). Malenga plans to help Mogoma be able to greet adults and his classmates through the use of music and Social Stories. Malenga uses Social Stories and a song she has written. Malenga learned about Mogoma's family and learned the names of the adults that Mogoma interacts with before she wrote the story. Malenga uses musical instruments special to the Tanzanian culture, such as the illimba, which The Baba Project (2013) describes as "a traditional thumb-piano with an otherworldly sound." Before playing the instrument, she places spider egg sacks on the illimba to act as a resonator and to increase the volume of the illimba. In the story, she drew Mogoma greeting his teacher, his parents, his grandfather, and his peers. Malenga reads the story with Mogoma every afternoon. In addition, every morning she sings to Mogoma when he arrives at school to reinforce the social narratives. She and other teachers take turns playing the illimba as the story is read to Mogoma. She sings to Mogoma, "When I see my teacher I say, shikamoo" and she models in front of Mogoma how to greet with another teacher. The song is accompanied by the contagious rhythm of the drums that Mogoma likes. When Mogoma says "Shikamoo," his teacher responds "marahaba," which means thank you and is the proper response to "shikamoo."

Cultural Adaptation and Transfer

In the research by Kern et al. (2006) the songs were written by music therapists. Considering the availability of resources needed to implement this strategy and the desired results, the teacher should

learn about both music therapy and ASD. The teacher should explore what well-known songs and musical instruments are an important part of the community and discover, with local artists (or people who know how to play the instrument well), ways to write a song for the child. The teacher should also consider if the child has a sensitivity to certain sounds and modify the song accordingly.

Conclusions

We have provided multiple examples of instructional methods pertinent to Eastern Africa. These examples demonstrate the importance of attaining information from the community and the child's family to help students with ASD learn important communication skills that go beyond the classroom and into their daily lives.

Persons with disabilities deserve to participate in society. As teachers, it is our responsibility to give them the tools they need. To implement the instructional methods discussed above, the teacher needs to become a researcher, for when we want to help a student, we need to learn about their family, the community, their daily routines, and the world in which they live. Consider how you can use existing resources to most effectively help your students and modify these strategies to best meet the unique strengths, goals, and needs of your students. Every student is valuable and unique, and we must learn as much as possible about each one to maximize strategies to help them.

Educators in East Africa face a critical need to document and to address issues related to family involvement, as well as personnel preparation to ensure that all children and young persons with ASD may gain an education and improve the quality of their lives. Educators and families need to have access to the resources necessary to provide social and language development opportunities. In summary, when teachers involved in the education of children and young persons with ASD comprehend and embrace the diverse language and sociocultural needs of this population and practice adapting instructional methods for their students, the better equipped the students will be to enjoy life.

Final Thoughts

Music is a beautiful resource that is available everywhere and brings joy to everyone. Consider other ways that music and singing can help your student with ASD in other daily activities.

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31

Navigating Communication Difficulties Faced by Children with Autism Spectrum Disorder: Evidence From Kenya

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Introduction

Autism spectrum disorder (ASD) is a class of neurodevelopmental disorders characterized by impairments in social reciprocity, atypical communication, and repetitive behaviors (Hyman & Levy, 2013). Children with ASD tend to have slow personal, social, and emotional development. Their development tends to be slower than their peers, with delayed speech development, disturbed sleep patterns, and lack of direct eye contact. They are also more silent than their peers. The signs usually begin before a child is 3 years old. Many of the symptoms are often ignored due to the fact that only a small amount of knowledge is available about the disorder.

Children with ASD experience several communication difficulties. According to Rapin and Dunn (2003), communication difficulty is present to varying degrees in most individuals with ASD. The same authors observe that language delay is usually the first area of concern identified by most families whose children are later diagnosed with ASD. Hyman and Levy (2013) state that the early language of children with ASD is often characterized by imperative labeling (using words for naming instead of communicating), echolalia (echoing speech), atypical prosody (inflection), and improper use of pronouns (referring to self in the third person).

Children with ASD may have basic impairment in many nonverbal behaviors such as the ability to both perceive and imitate facial expression (Weigelt et al., 2013). These children, however, may be trained and supported to overcome communication difficulties, for example, by trained speech-language therapists (SLTs). As Riccio (2011) observes, some children with ASD may also be more receptive to behavioral and language therapies and thus more easily able to adapt and to understand societal conventions. These children, most probably after therapeutic interventions, can become well able to lead independent lives and begin families of their own.

Unfortunately, there is a shortage of SLTs in sub-Saharan Africa (SSA), with only one SLT per 2–4 million people (Wylie et al., 2012). The situation is worse in rural SSA settings because, as Jochmann (2006) notes, speech-language therapy (SLT) in East Africa is mainly confined to urban areas and even then is often restricted to private health care. Individuals who reside in rural and remote areas, therefore, have difficulties in accessing support (Wylie et al., 2013). Moreover, there are many barriers that make access to SLT a daunting task. Such barriers may be physical (e.g., poor transport system, Moïsi et al., 2011), informational (e.g., ignorance of available support, WHO, 2013), or financial (e.g., insufficient funds for travel, Makinen et al., 2000).

Problem Background

Globally, children with ASD may not lead meaningful and functional lives and enjoy social relationships because of the diverse communication difficulties they face. The situation is worse in SSA where such children are seen as taboo and are hidden far from public view because of the social stigma associated with disability in the African culture. In Kenya, for example, children with ASD are seen as an embarrassment and parents lock them up in their rooms (Mwangi, 2015).

The stigma associated with disability may explain the low research output on ASD in SSA. Reviewing the literature on autistic studies indicates that prevalence estimates for ASD in African countries are hardly available and there is limited research on ASD in SSA (Bakare & Munir, 2011; Bakare et al., 2012). This situation makes it difficult to establish with accuracy the number of children with ASD. Wanjohi (2010), however, notes that ASD is affecting approximately 4% of the Kenyan population. In 2017, the Autism Society of Kenya states that the prevalence of ASD in sub-Saharan African countries, including Kenya, is not clear, because of a lack of

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valid diagnostics, on the one side, and low awareness in public and governmental systems on the other (Autism Society of Kenya, 2017).

One of the avenues of rehabilitating children with ASD is through schools. However, children with ASD can access education mainly when they overcome the communication difficulties they face. Without the ability to communicate, these children cannot easily and quickly express their needs. Therefore, they may lack essential help when they need it, or worse, get the wrong help altogether because the other person may misinterpret what the child needs. A child with ASD may be locked out of opportunities to attain education, a fundamental human right, because of communication difficulties. There is, then, a need for these children to be trained in how to navigate the communication difficulties they face so that they have the ability to express their needs. Once they overcome these communication difficulties, they can easily integrate with other children in regular schools and attain education, which is a human right.

Teachers of children with ASD play a key role in helping them acquire communicative ability. It is assumed that for such teachers to be effective, they will have received adequate training in special needs education to be able to work with the children as they navigate communication difficulties. The research on which this chapter is based, therefore, sought to establish the kind of communication difficulties children with ASD in Kenya face and the interventions that their teachers put in place to enable them to navigate these difficulties. This chapter also discusses the effectiveness of these interventions in increasing the ability of children with ASD to overcome communication difficulties and, as a result, be able to lead meaningful lives.

Theoretical Background

The effectiveness of an intervention has an immediate link with evidence-based practice. Mirenda (2017) extensively elaborates evidence-based practices with regard to interventions for children with communication difficulties and describes two different routes: the research-to-practice route is more conventional though the practice-to-research route is usually used more often. In the latter, innovative techniques are driven by clinicians and their practical experience. Due to a lack of external evidence gained by conducting experimental studies, this often occurs in the field of augmentative and alternative communication (AAC) interventions where the target population is a very heterogeneous group or when the clinical setting is so unique that it is difficult to compare it to the experimental settings used in a study and expect similar results. This is especially true for the African context.

The present study aims to provide a current picture of practice-based evidence regarding AAC classroom-based interventions for children with ASD in the special context of Kenya. Mirenda (2017) discusses the potential advantages and disadvantages of taking the practice-to-research route, which will be discussed at the end of this chapter.

Among the AAC practices first developed before their effectiveness was established was the Picture Exchange Communication System (PECS). It was developed by Lori Frost and Andrew Bondy in 1985 (Frost & Bondy, 2002). The first experimental studies to establish the effectiveness of AAC were done many years later (Adkins & Axelrod, 2001; Frea et al., 2001). An evidence-based AAC practice, PECS, is now used worldwide (Tincani & Davis, 2011).

In AAC innovations, a clinician is motivated by a set of beliefs and values, identifies an unmet communication need, hypothesizes a solution, and develops a related prototype or strategy. The clinician then implements the solution with the individual(s) for whom it was designed and informally evaluates its effectiveness. The clinician begins to use this practice with more individuals once it has appeared to be effective for a few clients. The clinician also shares it with colleagues, who after having tried it out then share it with their colleagues. Eventually, in most cases, one or more researchers learn about the practice or strategy and begin to conduct carefully controlled research studies to measure its efficacy or effectiveness.

However, practice-to-research has attracted several criticisms. First, the underlying beliefs and/or

values that drove the development of the novel practice or strategy might be questionable. Second, the research response might occur several months or even several years after the practice or strategy is introduced. Finally, clinicians may not be willing to attend to and learn from after-the-fact research examining a practice or strategy that they already use and favor. These three criticisms pose genuine concerns, especially when research has failed to confirm the efficacy or effectiveness of an intervention already firmly entrenched in clinical practice.

Motive

Besides receiving assistance from SLTs, children with ASD can also be adequately supported by teachers and caregivers in the acquisition of social and communication skills (Bunning et al., 2014). In other words, children with ASD can benefit from training and support in school. Perhaps this is why the Kenyan government has recently integrated units for children with ASD in a number of public schools to teach and care for children with ASD. Furthermore, the government, through the Teachers Service Commission, recruits teachers trained in special needs education and posts them to these autistic units. The teachers are expected to instruct and support children with ASD, with the view of assisting them to acquire the social and language skills needed for them to fit into the wider society.

But what is the reality on the ground? Are teachers trained in special needs education? What communication difficulties do children with ASD face? What strategies do teachers put in place to support children with ASD to navigate these communication difficulties? Do they succeed? Such questions motivated the research reported in this chapter.

Methods

Participant Selection

The study adopted a descriptive research design within the broad qualitative approach to collect, analyze, and interpret the data. Data were collected from three units attached to three elementary schools: two in Kiambu County and the third in Nairobi County, Kenya. The schools were purposively sampled because they had units for children with ASD. The rationale of the choice of public schools rests on the premise that children with ASD, irrespective of their socioeconomic background, can access public schools in Kenya.

Data Collection

Teachers were interviewed using an interview schedule with the following sections: teacher's qualifications and experience, communication difficulties faced by children with ASD, and pedagogical preparations (see Table 31.1).

The children were observed as the teachers took them through various activities, all geared towards making them acquire communicative ability. The researchers observed the verbal and nonverbal communication behaviors of the children with ASD to identify the communicative difficulties they experienced and the impact of the interventions employed to help these children navigate through the communicative difficulties. The communicative difficulties were clearly defined to enable the researchers to determine whether a particular difficulty had occurred or not.

Three visits were made in each school to interview the teachers and to observe the teaching as it progressed. The researchers would report at 8 am and leave at 12:30 pm.

Data Analysis

All the observations were noted, and these together with the feedback from the interviews with each of the six teachers formed the data that were qualitatively analyzed. The data collected were coded and grouped into themes and subthemes. Connections between concepts or how they varied were examined and a narrative was provided (Bryman, 2016).

Table 31.1 Interview schedule for teachers

Section 1: Teacher's qualifications and experience
1. What is your highest academic level?
2. What is your professional qualification?
3. Before you were deployed to this unit, had you interacted with learners with autism spectrum disorder (ASD)? (i) If yes, specify how long.
4. For how long have you taught at the unit?
5. Have you attended any in-service course for learners with ASD since you joined the unit? (i) How many times have you attended the in-service course? (ii) How regularly do you attend the in-service course? (iii) Has the in-service course improved your ability to teach children with ASD?
Section 2: Communication difficulties faced by children with ASD
1. Which common communication difficulties do children with ASD in your class face?
2. What are some of the patterns of language use and behavior that are often found in children with ASD in your class?
3. Do all the communication difficulties mentioned above affect the ability of children with ASD to learn and socially interact?
4. Which of the communication difficulties facing children with ASD in your class can you rate as: (i) Mildly severe (ii) Not severe
5. Are there children with ASD who do not experience communication difficulties?
6. What are some of the factors that influence the nature of communication difficulties that children with ASD face?
7. How can you rate children with ASD in your class on difficulties in pronouncing words?
8. Which among the following subjects do children with ASD in your class express themselves clearly?
9. Based on your experience, at what age do children with ASD respond fast to interventions in navigating communication difficulties?
10. What are some of the challenges you face when teaching children with ASD to navigate communication difficulties?
Section 3: Pedagogical preparations
1. What is the number of learners in your class?
2. Do you employ team teaching in your class?
3. Do you have teacher aides in your class?
4. What role do teacher aides play in your class?
5. Who develops the IEP for learners with autism in your class?
6. Do you use augmentative and alternative communication (AAC) supports in teaching learners with ASD?
7. Which of the following augmentative and alternative communication devices do you use? [ ] Picture Exchange Communication System (PECS) [ ] Sign language [ ] Communication boards and communication books [ ] Communication cue cards [ ] Conversation books [ ] Voice output communication aids [ ] None
8. Which among the following do you use to communicate with children with ASD? [ ] Using simple language [ ] Using symbols or pictures [ ] Literal understanding [ ] Repeating instructions [ ] Always addressing the child by their first name
9. Are there strategies, other than the ones mentioned above, that you use to teach children with ASD in your class to overcome communication difficulties? (i) If your answer is yes, name these strategies.
10. Are there teaching resources, apart from those mentioned above, that you use when teaching learners with ASD in your class? (i) If yes, list these teaching resources.
11. What are the factors that influence your choice of strategy in teaching children with ASD to overcome the communication difficulties they are facing? [ ] Age [ ] Interests [ ] Severity of communication difficulty [ ] The availability of resources needed in using the approach [ ] The length of time it will take for the child to start showing signs of improvement
12. Do the strategies you use help children with ASD to overcome the communication difficulties they face?
13. How can the teaching of children with ASD be improved to help them overcome communication difficulties?

Ethical Clearance

Permissions were sought from the relevant offices to visit and conduct research in the three autistic units.

Results

The Number of Children with Autism Spectrum Disorder in the Sampled Schools

The study population comprised 72 children and six teachers in the three sampled schools. The ages of these children ranged between 5 and 16 years. The number of children with ASD in the schools sampled is presented in Table 31.2.

The Number, Qualifications, and Experience of Teachers of Children with Autism Spectrum Disorder in the Schools

There were two teachers in each of the three schools and these teachers were wholly responsible for the teaching and management of the units. They were assisted by six caregivers, again two in each school.

Regarding qualifications, all the six teachers in the sampled autistic units had studied special needs education at university, all having attained a Bachelor of Education degree and one was even pursuing a Master's degree. ASD was one of the courses they were taught at university. They had also taken courses on teaching intellectually disabled children and children with learning disabilities during their undergraduate programs. Thus, the six teachers possessed sufficient training and knowledge to teach children with ASD. All the six teachers had taught at their school for between 1 and 6 years.

Table 31.2 The number of children with autism spectrum disorder

School	Number of children with ASD		Total number of children
	Boys	Girls	
A	18	6	24
B	16	12	28
C	13	7	20
Total			**72**

Support Given to Teachers of Children with Autism Spectrum Disorder

The teachers interviewed reported that the school, parents, donors, and individuals supported the autistic units in various ways. Each of the three schools, for example, provided opportunities for the teachers to benchmark for best practices. The school administration organized visits to other autistic units. Such visits assisted the teachers in learning new strategies for improving their teaching. Parents, on their part, worked closely with the schools to make the work of the teacher less strenuous by offering support. In addition, different individuals, donors, and well-wishers provided equipment and learning materials that facilitated acquisition of language and social skills by the children with ASD in their specific units. These statements from Teacher 1 illustrate:

> Our school takes us to City Primary in Nairobi County for benchmarking. City Primary has a unit for teaching children with autism. The school has also employed two caregivers for these children. The caregivers help us by assisting the children in toilet training and feeding. Some children come with their caregivers. The caregivers are trained by Kenya Institute of Special Education.
>
> The parents are cooperative as they bring the children to school and follow the instructions we give them in training their children with autism. They also support us by appreciating our work and by buying some of the things their children need. They also provide caregivers.
>
> Donors such as Safaricom Foundation and Rotary Club of Thika have been very supportive. They have given us computers, television sets and videos. Some individuals also give us food and other items.

Despite these efforts, however, the resources needed were more than what the teachers, the children, and the school ever received. The most important of these was food to enable the teachers to keep the

children in school until the end of term. The teachers also lacked enough computers to be able to more effectively teach the high number of children using the most recent computer-assisted programs. The other very important resources they needed were special furniture and better rooms for these children, as the existing rooms and furniture were not conducive to these children's learning.

Challenges of Teaching Children with Autism Spectrum Disorder

The teachers in the sampled autistic units reported that they faced several challenges in their work. First, there were many children with ASD in the schools yet the teaching and learning resources were inadequate. For example, although each teacher is supposed to have five to eight children, they had over 20 in each unit. This negatively affected the length of time and quality of attention they gave to each child.

Second, there was no curriculum from the Kenya Institute of Curriculum Development for teaching children with ASD. The teachers had to prepare what to teach based on individual children's needs and the resources available.

Third, there was a lack of refresher courses, seminars, and workshops for the teachers. The teachers explained that these courses, seminars, and workshops could have helped them to share experiences on the most effective instructional methodology and skills to help children with ASD to overcome the communication difficulties they faced. However, these courses, seminars, and workshops were not organized by any government agency, thus denying the teachers an important opportunity to learn and enhance their knowledge and skills.

The fourth challenge was that though the teachers needed to share experiences, strategies, and ideas with teachers from other schools, such meetings were too few in number. Other challenges included the following: the caregivers not being helpful, the teachers not being able to know when a child with ASD was sick, some parents of children with ASD being very poor and not able to afford the things needed to support their children with ASD, and children with ASD being very emotional and sometimes producing sounds one may not understand.

Communication Difficulties Faced by Children with Autism Spectrum Disorder

The teachers reported that the children with ASD in their schools faced a number of communication difficulties. The main one was that these children were not able to speak and express what they needed and, second, a number of them stuttered. What emerged from the research was that the most severe cases of communicative difficulties in the schools involved children with ASD who were unable to use nonverbal communication.

The teachers reported that there was one child in one school who was hard of hearing. They said that this problem increased the communication difficulties that the child had to overcome to be able to interact meaningfully. It also increased the challenges that the teachers faced in teaching the child. To be able to navigate the communication difficulties such a child is facing, the teachers needed to design unique individual education programs for the child and dedicate more time to understanding the child and training him effectively.

Countering Communicative Difficulties

The teachers reported that children with ASD were taught using various activities focusing mainly on motor skills. While some of the activities were physical, others included the use of therapy balls. The children were also trained in daily life activities such as eating, dressing, and brushing their teeth. In addition, they were taught basic numeracy skills. In the morning, for instance, the children were given cards with numbers on them. The main function of these cards was to teach the children how to count. The teachers taught them how to count repeatedly. To enable them to fit well in society, the children were taught virtues. One of these

virtues was responsibility. They were trained to collect materials for use from the store and return them once they were through.

The teachers used songs to teach children and soothe their senses, especially before lunch. Children enjoyed music and would dance as the music played. The teachers encouraged the children to repeat some simple words in the songs. The songs were both in Kiswahili and English, Kenya's official languages. This extract from Teacher 5 gives more information:

> There are therapeutic breaks on a daily basis. Some of the activities these children engage in are meant to soothe them and relax their senses before lunch. Such activities include dancing to music in a circle. The children are exposed to simulation songs. Children with autism like listening to music. English gospel music is played for them. Some of the simulation songs are in Kiswahili. Some of these children can sing though they are not able to speak. By listening to songs, children suffering from autism may be learning communication skills by imitating what the singers say. If played repeatedly, the children may pick some words and be able to pronounce them. This is another important area where the theory of imitation could be useful in explaining the teaching of language to children with ASD. Imitation is significant in the acquisition of language by children with ASDs.

The teachers told the researchers that the children were given books and pencils and thereafter assisted to write. Because ASD affects the motor activity of these children, they require more attention and patience from their teachers as they are assisted to write. With effective assistance in writing and drawing and with much patience, the children do reach a point where they can write on their own. The teachers explained that this is mainly dependent on the severity of the communication difficulties that an individual child had and for how long they had been in the program.

All six teachers made use of the following teaching resources:

1. Pegboards
2. Number value task
3. Alphabet puzzles
4. Crayons
5. Picture books
6. Toy cars
7. Bicycles
8. Assorted blocks
9. Communication board
10. Knitting needles
11. Toothbrushes
12. Picture charts
13. Televisions
14. Computers
15. Videos

However, the teachers lacked useful resources such as talking books. All the teachers interviewed observed that talking books could have helped to make learning very easy and more enjoyable for the children with ASD.

Data collected indicated that teachers of children with ASD used a variety of activities to help these children navigate the communication difficulties they were facing. The teachers made use of songs and repetition of words until the children mastered them. The children also watched videos and after watching would imitate some of the actions or sounds they heard.

The teachers organized environmental walks around the school compound with the aim of exposing the children with ASD to their environment and teaching them more about it. During such walks, the children were shown and told to repeat names of structures such as classes and names of plants and animals.

Another strategy used to teach these children was computer applications. For example, the teachers used computers that had software with computer games to teach mathematics. In the process of learning mathematics, these children also learned basic communication skills. This enabled them to improve their communication abilities. The teachers from the three schools observed that most children with ASD were very good at mathematics.

To counter the challenge of reading, the teachers used repetition. This, the study established,

required a lot of patience from the teacher as she or he had to first ensure that the children could acquire speech before they could read. Other strategies used by the teachers to train these children included the use of pictures and picture charts, playing with therapeutic balls, swinging, and praying for spiritual development. The teachers used simple language, symbols, cards, and peer teaching. Those children who had acquired speech and understood a concept were encouraged to show others. The children also engaged in group activity. They had talking boards. The teachers considered the individual needs of the children when deciding the activities that each child would be engaged in. Teacher 4 noted:

> Children with autism have different needs. Teachers, therefore, come up with IEPs (Individual Education Programs) for every child. The teachers work together to develop the IEPs. We consider age, abilities and interests, severity, length of time and availability of resources when designing IEPs. IEP is aimed at improving communication skills, self-help and to be independent or social skills.

We observed one boy with ASD in one of the sampled units who was very good at information and communications technology (ICT) though he could not speak. He could understand all the instructions, which were normally given by the teacher in Kiswahili. The teachers would also communicate nonverbally and the children too would do the same. Nonverbally, the children communicated through smiling, pointing at what they wanted, using gestures, and even by crying. The teachers and caregivers trained these children in nonverbal communication skills.

The teachers and the administration in each of the schools encouraged other children to interact with children who have ASD. This was practical for the schools enrolled in this study because the autistic unit is located within the compound that caters to nonautistic children. The teachers observed that such interaction was useful in helping the children learn through imitation.

The Effectiveness of These Strategies

The teachers reported that after these children had been in the program for some time, for instance, 3 years, some of them could write their names and some could write numbers from 1 to 10. Within 3 years, about 20% of the children with ASD had developed language skills. Six of the 72 children (about 8%) had developed very good speech. These six children could clearly and effectively describe their homes and families. Ten percent of the children with ASD who had been in the program for 3 years could pronounce words clearly. All the children could respond to the speech of others and could also respond to their names. All of them could point or touch body parts once asked to do so, and they could also recognize their caregivers and parents. Moreover, they could distinguish between different types of food.

The teachers focused on teaching them reading and the children comprehended simple passages written in Kiswahili. The children also repeatedly listened to songs sung in Kiswahili.

After being in the program for 1 year, all of the children were able to use and understand nonverbal communication. They could use gestures and facial expressions, which they were not able to use before joining the program. The children could indicate the direction of their home and even say goodbye to others nonverbally. Similarly, the children, with time, could understand messages communicated through gestures and facial expressions and even interpret the tone of one's voice. They could perceive people's feelings through body language and tone of voice.

Discussion

Communicative Difficulties That Children with Autism Spectrum Disorder Face

The findings that emerged from the analysis of the data collected show that children with ASD face various communicative difficulties. The education of these children plays a significant role in facilitating the acquisition of communi-

cative abilities and social skills that the children need for them to lead functional lives.

The findings of the study show that the children in the three autistic units displayed nonverbal communication difficulties. As Weigelt et al. (2013) point out, children with ASD may have a basic impairment in much nonverbal behavior such as the ability to both perceive and imitate facial expressions. Studies have shown that the brains of children with ASD process faces as if they are objects. As a result, every time the facial expression of the communication partner is changed, the person with ASD must reidentify the person's face (Schultz, 2005).

Persons with ASD may also have a decreased ability to simultaneously process speech and gesture, which influences both social processing and pragmatic language (Silverman et al., 2010). Without specific interventions, nonverbal communication impairments may be problematic even with the development of conversational language (Hyman & Levy, 2013). The other difficulties that children with ASD in the schools sampled faced were lack of speech and repetitive speech.

Strategies Used to Help Children with Autism Spectrum Disorder Navigate Communication Difficulties

Strategies that teachers of children with ASD use to help the children navigate communication difficulties have also been discussed. For interventions to be effective in helping children with ASD to overcome communication difficulties, early and accurate diagnosis needs to be done so that these interventions can be started early. Studies have indicated that young autistic toddlers benefit more from such interventions than older children (Rogers & Vismara, 2008).

Early educational programs focus on teaching social language and enhancing appropriate behaviors (Hyman & Levy, 2013). However, from the data collected, it was clear that some parents were unable to put their children with ASD in early educational programs because of poverty or a lack of awareness. High rates of poverty and lack of awareness are common in SSA. This could, therefore, mean that many children with ASD miss the opportunity to attain critical communication abilities that could enable them to overcome communication difficulties and lead meaningful lives.

Individualized Educational Program

The study found that teachers in the autistic units made use of an individualized educational program (IEP). A comprehensive approach usually requires a combination of an IEP, behavioral intervention and supports, social and pragmatic language skills development, and family support. The interventions employed in the three units made use of each of these approaches. However, with the high number of children with ASD being taught by only two teachers per autistic unit, these interventions may not achieve the effectiveness they are supposed to.

The National Research Council (2001) observes that education is a critical component of ASD. Successful programs share the characteristics of early entry, active participation in an intensive program offered daily throughout the year, planned teaching opportunities organized with the attention span of the child in mind, and sufficient adult staffing to meet the needs of an individual child and his or her program (Hyman & Levy, 2013). The programs in the three autistic units start early at day and run parallel to mainstream programs in school. Teaching is based on the attention span of the child and the needs of an individual child. This shows that if countries in SSA are able to put in place the appropriate interventions to help children with ASD access education, even with meager resources, most of these children will acquire the communicative ability to be able to lead meaningful lives.

Peer Learning

Teaching children with ASD in an integrated school such as in the sampled schools is beneficial since the children learn not just what they are taught by their teachers but also imitate what the

other children who do not have ASD are doing. This view concurs with Hyman and Levy's (2013) observation that inclusive education allows for the child to model appropriate behavior and, in the process, the child learns how to participate in the community.

Another crucial finding was the fact that children with ASD in the three units developed an ability to comprehend what they read in Kiswahili. This is evidence that children with ASD could even achieve bilingualism if appropriate strategies are used to teach them. It could also be evidence that reading and comprehension skills could be taught much faster if the language of instruction is also commonly used in other contexts besides the school. The study assumes that most of these children come from low-income families whose main language of interaction at home is Kiswahili.

Information and Communications Technology

Another finding that emerged from the study is the importance of ICT in navigating communication difficulties. The children in the three units were familiar with the use of ICT devices and could operate the equipment very well. According to Ennis-Cole et al. (2013), technology can be used to help children with ASD communicate. One of the applications of technology currently in use is AAC devices. There are different kinds of AAC tools which can be used: nonelectronic books, boards, or other high-tech devices. All of these should offer eye-gaze or head or mouth pointers to support users who have limited physical abilities. (Ennis-Cole et al., 2013). Further, Ennis-Cole and colleagues state that AAC devices are a suitable support system for the language development of adults and children with ASD for they are nonverbal or have limited verbal skills in general and echolalia (repetitive responses). According to Millar et al. (2006), the use of AAC increased speech production in individuals with developmental disabilities and ASD who had inadequate speech to meet their communication needs. Using communication boards and computers, it is therefore clear that the teachers in the three autistic units where data were collected used technology to help children with ASD navigate the communication difficulties they faced.

Multimedia Approach

The teachers used a multimedia approach in the teaching of language and social skills to the children in the three autistic schools. It also emerged that teachers made use of more visual than audio resources in the classroom. Because of the communication difficulties that children with ASD face, the choice of teaching resources in the three units was in line with the argument by Hyman and Levy (2013) that learning may be more efficient with visual rather than auditory cues. This is supported by Stevenson et al. (2016) who emphasize the differences in audio-temporal processing between persons with and without ASD (e.g., processing verbal stimuli).

Challenges Faced in the Teaching of Children with Autism Spectrum Disorder

The study found that the number of teachers and caregivers of children with ASD was very low. This severely hindered the quality of interaction and the effectiveness of the interventions the children received, given that they need individualized attention. For sufficient attention to be given to each child with ASD and therefore ensure more effective teaching and better results, the teachers interviewed reported that one teacher should not have more than five children with ASD in their class.

These teachers may not be able to give each child the attention they deserve to achieve good results. Many other countries in SSA may also have a high number of children with ASD and a shortage of specially trained teachers. This impacts the effectiveness of the interventions employed to help children with ASD navigate communication difficulties.

In addition, the study found that there is no standardized curriculum for teaching children with ASD. Teachers develop their own curriculum. On the one hand, this can be advantageous

for the child as the teacher has to closely interact with the child to know his or her needs. On the other hand, this can have several disadvantages. The teacher can be overwhelmed by working with many children with ASD and so not know each child's individual needs. In addition, the teacher may not be well trained and experienced in designing an effective curriculum. Furthermore, if the teacher is not provided with official guidelines on how to design curricula or if there is no evaluation of such curricula, the quality of the curriculum will be highly compromised.

The study also found that teachers of children with ASD lacked many highly useful resources. Such resources could have enabled them to use more recent and effective interventions to help children with ASD navigate the communication difficulties they faced.

Suggestions on Areas of Improvement

The teachers in the three autistic units suggested that children should be enrolled in school at an early age, for example, at the age of 3 years. This will make interventions more effective. The teachers further observed that because of poverty and a lack of awareness, some parents enrolled their children with ASD in school when they were more than 6 years old. Late entry of children with ASD to school meant that it took a longer period of time for interventions to be effective. Late introduction of interventions makes very little impact in helping the child to navigate communication difficulties associated with ASD. This scenario calls for governments and other stakeholders in SSA to educate people on the importance of enrolling their children with ASD in school at an early age. To address the problem of poverty being responsible for these children being enrolled in school late, governments and other stakeholders need to heavily support the schools that have programs for children with ASD so that these children can be offered free education.

The Impact of Interventions Used to Help Children with Autism Spectrum Disorder Navigate Communication Difficulties

The study found that children with ASD face many communication difficulties, including lack of speech, repetitive speech, and lack of nonverbal communication abilities. In teaching these children, the study found that the teachers faced many challenges. These challenges included dealing with children who are not easy to understand because they lack both verbal and nonverbal communicative abilities, having children who are very emotional, having a high number of children with ASD in their classes, lacking sufficient support in terms of resources to teach these children, and a lack of regular interactions with other teachers of children with ASD to share ideas and experiences.

Despite the challenges these teachers faced, the study found that the interventions they used to teach these children to navigate communication difficulties were effective. The interventions were varied, ranging from IEP, repetition of instructions, peer teaching/learning and modeling (use of songs and interactions with pupils who do not have disabilities), and multimedia approaches (use of videos, computer and television programs), among others. These varieties of interventions have different strengths, enabling children with ASD to effectively learn a variety of communication and interaction skills.

The research found that these teachers did not have a standard curriculum for teaching children with ASD to overcome communication difficulties. They designed their own curricula and activities based on their knowledge of the challenges these children were facing. In line with the practice-to-research route, some of the interventions implemented by these teachers based on their experiences with the children they were teaching could possibly be suitable for teaching children with ASD in similar contexts. Therefore, such interventions need to be studied with the aim of improving and embracing them in similar circumstances.

The study found that the children who join autistic units early enough and stay in the program with-

out any disruption were able to develop effective and meaningful speech. They were able to overcome the communication difficulties they faced such as echolalia, imperative labeling, improper use of pronouns, and inability to use nonverbal behaviors. They could, therefore, communicate using verbal and nonverbal messages. These children could pronounce words correctly; identify and name people, places, animals, and other features in their environment; read clearly and comprehend what they read; write legibly; and hold meaningful conversations with teachers and other pupils. It was also established that upon successfully acquiring speech and being able to read and write, these children were integrated into the regular school system and learned like other children without ASD.

Considerations for Future Work, Research, and Politics

To improve the quality of interventions for children with ASD to navigate communication difficulties, we suggest a number of recommendations. There is a need, for example, for an analysis of the quality of curricula used to teach children with ASD. Since there is no agency in the Ministry of Education in Kenya that develops the curriculum for learners with ASD and teachers of these children are left to develop curricula based on the needs of individual children, it is important to establish the features of these curricula to find out whether the interventions they adopt actually help children with ASD overcome the communication difficulties they face, whether these curricula meet international standards, and whether they are effective for purposes of quality teaching. Where these interventions may be found to be inadequate, appropriate measures need to be identified that can be used to strengthen them. Research should also be done in other countries in SSA to establish whether they have curricula for children with ASD and the quality of such curricula, whether they meet international standards, and whether they are effective for purposes of quality teaching in those contexts.

The study suggests that more modern teaching resources should be made available in schools offering programs for children with ASD so that instruction may be made easier. Such resources include the use of a variety of AAC devices. This will also make interventions to navigate communication difficulties more effective.

Another recommendation is that teachers of children with ASD should be patient. For instance, teachers of children with ASD should repeat instructions over and over again for the children to understand. This is the only way these children can learn to speak, read, and write. The teachers should not compare children with ASD with those that do not have ASD. This can be achieved when there are enough well-trained teachers who can handle children with ASD. The teachers should also be taken for regular refresher courses and be given enough support and quality resources to support them as they work.

Since distance from schools for children with ASD could also be a hindrance to taking these children to school, more schools need to be spread across all parts of SSA countries that have educational programs for children with ASD. This will enable parents of these children and the children themselves to have easy access to such schools.

Our suggestion for future research is on the effectiveness of music in teaching communication skills to children with ASD. This research should focus on aspects such as the quality and complexity of the songs used in teaching communication skills.

In conclusion, we note that more awareness and sensitization are needed to counter the cultural politics surrounding acceptance of persons with disability in SSA. Everybody should know that a person with ASD, for example, is as human as any other. He or she has feelings, dreams, and hopes for tomorrow. Children with ASD need understanding, care, and support to be able to develop the communicative ability and social skills needed for them to lead functional lives in society. They should be brought into the open instead of being locked out of society in their rooms or being seen as a curse or a burden in the community.

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Using Augmentative and Alternative Communication Strategies in Schools in Namibia

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Introduction

Globally, the school environment provides children with a daily mix of social and educational encounters spread over up to 13 years. This means that for most children, a large part of their childhood is spent at school, as is mandated by national and international law. The school is the place where children form friendships and learn what it takes to be a friend, but this is also where they are prepared for life in the workplace and specifically for the career path that they wish to pursue.

However, the same is not always true for children with disability, who often face significant barriers restricting their opportunity to attend school. For these children, the social and educational opportunities so readily available to their typically developing peers are different, as is the length of education, and often it is not mandatory for children with disability to attend school, even if they are of school-going age. For these children, it might be far more difficult to learn how to make friends, especially if they have a communication disability, as social skills are heavily reliant on communication skills (Rossetti & Keenan, 2018). The unemployment of persons with disability is also a grave concern, as many of these individuals do not have the work skills to be successfully employed.

In the Participation Model, Beukelman and Light (2020) describe five prominent opportunity barriers that have a negative impact on school attendance of children with disabilities. They describe opportunity barriers as those barriers that lie outside of the individual and identify:

(i) *Policy Barriers:* In many African countries, including Namibia, inclusive education policies are relatively new (Eleweke & Rodda, 2010). Despite the fact that many of these policies are regarded as progressive and relevant, their implementation is not monitored and enforced (Donohue & Bornman, 2014).

(ii) *Practice Barriers:* These often encapsulate physical barriers such as the fact that schools may be far away, especially in rural areas, making the journey to school practically impossible. Specialized transport for children with mobility aids such as wheelchairs is not provided, and parents are often not able to finance such transport themselves (Human Rights Watch, 2015). In cases where schools might be closer to home, their facilities (such as the toilets) might not be accessible. If electricity is not available, classrooms might be quite dark, making it difficult for children with visual impairments (such as albinism) to see the blackboard, thus excluding these children from education (Baker et al., 2010). Schools might not have ramps, making it impossible for children in wheelchairs to gain access. Learning materials and assistive devices, such as braille readers or hearing aids, may not be available. Schools may have their own admission policies that are not in line with national inclusive education policies, and children with disabilities may be turned away from both their neighborhood schools and various special schools (Human Rights Watch, 2015). Large classes with high learner-to-teacher ratios and no additional therapeutic or other support (e.g., personal assistants to assist with mobility and basic care activities) may make it untenable for children with disabilities to attend their regular neighborhood schools or even some of the special schools (Van Niekerk & Tönsing, 2015).

(iii) *Attitudinal Barriers:* Some families may believe that their child with disability is not able to benefit from education, as they have not seen evidence of positive educational outcomes. Therefore, families may send their children without disability to school to learn, while in the case of their children with disability, the focus falls on care. Sometimes, children with disability themselves falsely think

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that they cannot learn, as they grow up with low self-esteem and are told that they cannot do things. Their self-perception then reflects their disability, rather than focusing on the things that they can do (i.e., their abilities) (Basil, 1992). Bullying and negative attitudes of other children, parents, teachers, and other professionals make the educational experience and going to school difficult for children with disability (Engelbrecht et al., 2005; Ngcobo & Muthukrishna, 2011). Moreover, other parents might not want children with disability in their school, as they fear that this will lower the expected teaching standard and divert the teacher's focus away from the learners without disabilities, believing that the child with disabilities will demand all the attention. Teachers in both mainstream and special schools have been reported to have low expectations of children with disabilities (Human Rights Watch, 2015).

(iv) *Knowledge Barriers:* In some cases, a lack of information about the right to education or a lack of knowledge regarding the support that is available for children with disability results in families not pursuing educational placements for children with disabilities. In addition, teachers themselves may not be knowledgeable about strategies to successfully include and educate learners with disabilities, as they may be unaware of curriculum adaptations and alternative methods of assessment (Bornman & Donohue, 2013; Bornman et al., 2016).

(v) *Skills Barriers:* Many teachers lack appropriate information and training regarding the teaching of children with disability (Engelbrecht et al., 2015). The result is that they fear that they will not know what to do with a child with a disability in their classroom and thus often oppose having such a child in their classroom (Donohue & Bornman, 2015). Teachers may furthermore lack the skill to use assistive devices to facilitate learning in the classroom (Tönsing & Dada, 2016) and, in general, struggle to facilitate the active participation of learners in the classroom (Kathard & Pillay, 2015).

Understanding the Namibian School Context

Educational Opportunities in Namibia

Most countries try to provide their children with educational opportunities in order to prepare them to be part of a community, seek out a living, study for a career, and find employment. The same opportunities are envisioned for children with disabilities in Namibia. The United Nations Children's Fund (UNICEF, 2015) has reported that as many as 16.9% of children under 10 years of age in Namibia have a disability. Article 20 of the Constitution of the Republic of Namibia (1990) states that all persons shall have the right to education and that primary education shall be obligatory for all children until they complete such schooling or attain the age of 16. In 2013, free Universal Primary Education was implemented through the Sector Policy on Education (Ministry of Education 2013), and in 2016, free Universal Secondary Education was initiated by the Namibian Government to address socioeconomic barriers to education (UNICEF, 2016). Namibia thus has a progressive, inclusive education policy (Ministry of Education 2013; UNICEF, 2016).

The Namibia Fifteenth School Day Report (Ministry of Education, Arts and Culture, 2016) states that Namibia had around 1796 government and private schools across the country at the beginning of 2017. Most of these schools are situated in rural areas spread across the vast country. The enrolment rate across the board for primary and secondary education has increased since the turn of the twenty-first century (Ministry of Education 2013; Ministry of Education, Arts and Culture, 2016). Namibia does not have the capacity yet to provide preprimary education for all children, as is evident from the difference in enrolment statistics of preprimary and primary schools (see UNICEF, 2016 and Ministry of Education, Arts and Culture, 2016). Although one year of preprimary education is recommended, no child may be refused school placement in Grade 1 if they lack such prior schooling.

According to the new Basic Education Act (Republic of Namibia, 2020), it is expected of all children to start Grade 1 in the year that they turn 6 years old and to attend school until the last school day of the year in which they reach the age of 18 years old (or older for children with disabilities) (UNICEF, 2016). It was, however, observed that children with and without disabilities also tend to start school later (Ministry of Education, Arts and Culture, 2015; UNICEF, 2016). However, the proportion of children with disabilities who never attend school in Namibia is high (16%) compared to 6% of peers without disability (UNICEF, 2015). This inequality is more marked in the most disadvantaged communities and minority groups such as the Himba and the San.

Challenges Within the Namibian Educational Context

In this section, six different challenges related to the educational context in Namibia will be described.

Classroom Size and Composition

In Namibia, factors such as classroom size (in mainstream classes as well as special learning support units) and the composition of such classes constitute a primary concern about the teaching of children with disabilities. In practice, class sizes in Namibia range between 30 to 40 for children in the larger mainstream government schools and 25 to 30 for children in private schools. The ratios reflected in the Fifteenth School Day Report differ from those seen in practice, and the report states that there are even fewer children in a classroom (Ministry of Education, Arts and Culture, 2016; UNICEF, 2016). In a learning support unit, suggestions of 15 children in a class are often followed (or at least recommended). Children with disability require more individual attention and a high ratio in such classes between teacher and children can have a negative impact on both the group and on the individual child/children with disability.

Certain mainstream schools have special classes or learning support units. The composition of these units differs from school to school. What is of concern about the composition of such classes in mainstream and special needs schools is that different types of disabilities are accommodated in these units. This requires the teachers to possess various specialized skills to effectively teach these children. Children with severe intellectual disability will be referred to special schools where possible or special institutions if available, but often they are mixed into the same classes/units. It should be noted that Namibia has only one school for hearing and visually impaired children but several units for children with hearing impairment in rural areas. There are two schools for children with intellectual disability and also a school with different classes for children with visual, hearing, and intellectual disability. In order to be placed in a special school, the parents or guardian(s) of the child concerned need to submit an application form issued by the government for public schools or by the private schools themselves. This form needs to be completed by various health professionals, for instance, an optometrist, medical doctor, audiologist, occupational therapist, or speech therapist.

Lack of Teaching Assistants

The Sector Policy on Inclusive Education (Ministry of Education 2013) recommends desired outcomes based on the envisioned policies, yet monitoring and enforcing these envisioned policies can prove to be difficult, as previously stated by Donohue and Bornman (2014). Currently, there is no law that instructs a school to assign a teacher's assistant. However, the inclusive policy states that one of its desired outcomes is the training and appointing of teacher's assistants or support professionals in general and progressively in each school (Ministry of Education 2013). At the moment, only a selected few special schools retain teacher/class assistants who are employed by the school. In general, if a child requires extra support in the classroom, the parents are advised to appoint an assistant for that child. An example in case is the Christian Academy School in Windhoek, which allows for the child's

personal assistant to accompany him/her to school. In some instances, the schools do not support the appointment of a teacher's assistant. The reasons for this may be attributed to social, financial, educational, and logistical factors and opportunity barriers (Beukelman & Light, 2020), as well as to a lack of human resources and professionals with scarce skills (a situation that presents itself widely in Namibia).

Lack of Trained Teachers in Special Education

Not all teachers have training in special/inclusive education, although the University of Namibia offers it as a selection subject as part of an undergraduate degree after which a master's degree in this field can also be undertaken. Funds for such training as part of continuing professional development are limited. Schools neither have the skilled teachers to assist children with disabilities nor the necessary equipment. This situation proves to be one of the largest skill barriers in this country. Furthermore, the scarcity of resources and the rural/urban context exacerbate the execution of the stated desired outcomes. Opportunities for vocational training are very scarce in Namibia. One resource school in the south of Namibia caters for most secondary school children with special needs in respect of vocational training such as welding or hairdressing courses. In Windhoek, there are only two secondary schools that offer a vocational stream for children with learning disabilities who struggle with the academic workload.

Limited Special Schools/Lack of Special Schools in Rural Areas

A further barrier to children with disability is the fact that, in Namibia, most special schools are situated in the capital, Windhoek. Distances in rural settings (between the homestead and school) or between the rural and urban contexts (children moving from their rural setting to live in the hostel) pose a complex problem due to the lack of resources. It is a huge problem to reach educationally marginalized children, such as those with learning difficulties, orphans, vulnerable children, and child-headed households.

Language Barriers/Suitability of the Educational Program

Furthermore, as Namibia is a vast country, children with disability often come from rural areas where they speak their home language, which is seldom English. If they get placed in a hostel in the special school, the language barrier is maintained, due to the fact that the medium of instruction in special schools is mostly English. As a consequence, many children from rural areas will go to a mainstream school in their area or will be kept at home because they are not proficient in English. Another problem related to language arises with children with hearing impairment and sign language. Namibian Sign Language is taught at schools for children with hearing impairments, but in mainstream schools, teachers often do not have any sign language training. Moreover, teachers in special schools or learning support units do not necessarily have or need an advanced diploma or degree in disability studies, inclusive education, or special needs. Therefore, children with special needs do not always obtain the necessary support in terms of referral to professionals, learning support, or assistive devices in general. Certain private schools choose their own curriculum, and this is not always suitable for the needs of children with disabilities. The schools that use a more inquiry-based program find that they can implement the inclusive policy better. Unfortunately, serious financial constraints generally limit access to such programs.

Opportunity Barriers

Further limitations placed on children in gaining access to adequate educational programs arise from parents and teachers themselves. In certain communities, attitudinal barriers become apparent when the parents still see the child with a disability as a reflection of who they are and their standing in their community. They often seem to exclude the child from the community and do not consider educating the child at all (Ministry of Education, Arts and Culture, 2015). These parents need education in terms of awareness of their child's needs and education possibilities. What is more, not only is the education of parents about their child's posi-

tion paramount yet often lacking, but also teachers lack the necessary skills and education in their approach toward children with disability and their parents. The lack of training with regard to special needs leaves teachers feeling inadequate to deal with these children. Some teachers believe that children with a disability do not belong in a mainstream school. Other teachers in mainstream schools might tolerate a child with a disability in their class but would not be able to accommodate the child's special needs in the classroom environment. Some mainstream schools do not want to be labeled as a school for children with disability and even have a strict regimen on which children (including those with disability) will be admitted to their school. Knowledge barriers contribute to parents not knowing about education possibilities for their children and to teachers and schools not realizing the need for inclusive education.

An Introduction to Augmentative and Alternative Communication

What Is Augmentative and Alternative Communication?

Augmentative and alternative communication (AAC) includes all the forms of communication (other than oral speech) that human beings use to express their thoughts, needs, wants, and ideas (American Speech–Language Hearing Association, 2017). We all use these communication strategies when we use facial expressions to show emotions such as delight or disgust, when we nod or shake our heads to indicate "yes" or "no", when we use natural gestures such as waving to say goodbye, or when we put a finger over our lips to indicate silence. We may also point to pictures to show that we like something or want something, or, if we are literate, we may even write or type a message on a cell phone. Persons with severe communication disabilities may also use AAC strategies (for a temporary or permanent period) to supplement existing speech. For example, they use AAC when their speech is not understandable, or in some cases, AAC acts as an alternative if they have no speech. The fact that a person communicates (using any form of AAC) is far more important than how he/she communicates because communication is a basic human right. Ultimately, these individuals use AAC to compensate for the lack of spoken language (speech), to facilitate their participation in society, and to increase their independence. Using AAC may increase social interaction, facilitate learning (and thus enhance school performance), aid with behavior regulation, reduce challenging behavior, and foster feelings of self-worth.

It is important to highlight that implementing AAC strategies does not mean that one has "given up" on speech, or that it would stop a person from learning to speak. Research suggests the opposite – in many cases, AAC can boost speech and language development (Millar et al., 2006; Schlosser & Wendt, 2008). AAC strategies are used to enhance the communication of children with severe communication disabilities, not to replace or inhibit their existing skills.

Benefits of Augmentative and Alternative Communication Within the School Context

In the school context, using AAC strategies holds many benefits:

- It increases participation in the classroom and on the playground.
- It promotes comprehension (receptive language skills), particularly in children with poor receptive language skills (Dada & Alant, 2009) and in children who need to learn in a language that is different from their home language (e.g., they speak Damara, Oshivambo, Nama, or Oshiherero at home, while teaching and learning in school takes place in English).
- It provides an alternative form of expressive language (output) for children who cannot rely on speech to meet all their communication needs.

- It supports language development (receptive and expressive) in children – and language is a prerequisite to learning and acquisition of literacy.
- It supports timely and interactive communication with other children and with the teacher (e.g., the child can respond when the teacher asks a question).
- It supports literacy skills.
- It can assist children to understand classroom rules and instructions.
- It can decrease the depression, frustration, and isolation often experienced by these children when they are consistently not understood and/or ignored.
- It provides positive behavioral support, for example, visual schedules help children to predict activities, which makes transitional planning easier.
- It addresses individual educational plans and personal goals (although this is not the focus of this chapter).

AAC is based on the principle that every single person can and does communicate – sometimes not in a way that is understood by everybody, sometimes not at the same speed as others, and sometimes using other forms of communication (e.g., with a specific type of body movement). It is imperative that we observe the child closely so that we can discover and recognize these forms of communication. Another principle is that we aim to implement a "try-and-see" approach, in which different AAC strategies are implemented, rather than a "wait-and-see" approach because the implementation of AAC holds so many benefits for all children. For a person who has a severe communication disability, an AAC system has the same power that a hearing aid has for a person with a hearing disability or a wheelchair has for a person with a physical disability. It is the means through which these individuals participate in activities and experience a sense of belonging.

Augmentative and Alternative Communication Systems and Strategies

As shown in Fig. 32.1, AAC systems can broadly be divided into two groups: unaided and aided systems. Unaided AAC systems rely on the person's body to convey messages, for example, natural gestures, body language, sign language, finger spelling, and facial expressions. Aided sys-

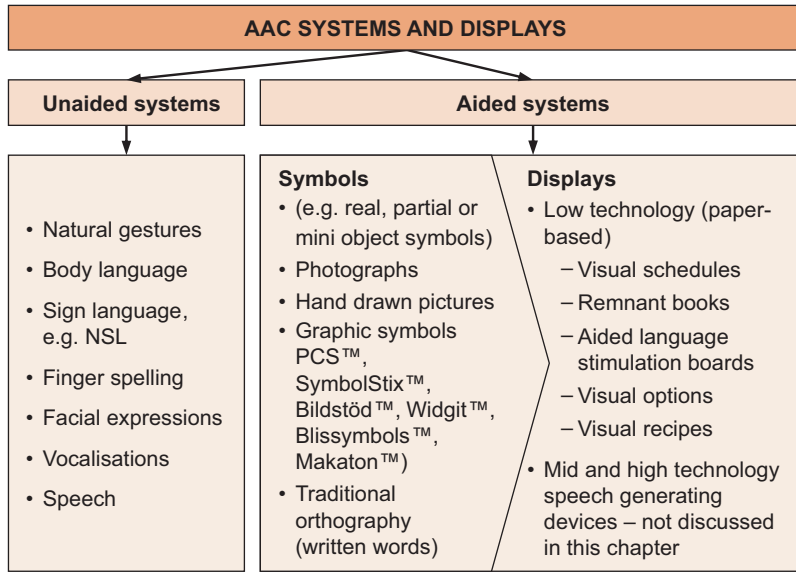
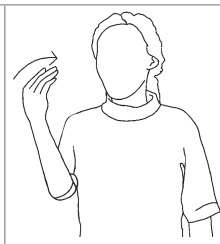
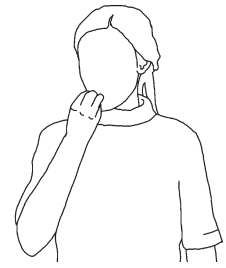
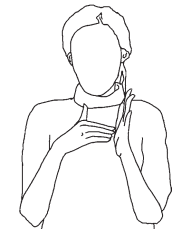


Fig. 32.1 An outline of different AAC systems and displays

Table 32.1 Examples of natural gestures

			
Sleep	**Come here**	**Eat**	**Stop**

tems, on the other hand, involve something in addition to the person's body, such as objects, photographs, graphic symbols, hand-drawn pictures, or traditional orthography (alphabet letters). These symbols can be viewed along a continuum, ranging from low technology (paper-based systems such as communication boards and books) to easy-to-use mid-technology devices such as sequential message communicators and simple speech-generating devices) to high-technology devices using specific applications and software, such as an iPad with Proloquo2Go. A few examples of unaided and aided systems will now be described in more detail, with application to the classroom context. Please note that high-technology devices will not be discussed in this chapter.

Unaided Systems

What Are Unaided Systems?

Unaided AAC systems include the whole range of communication options that involve only the person's body. At the simplest level, it involves systems that are intuitive for everybody and easily understood. Examples are head nodding and head shaking (to indicate "yes/no"), pointing with the eyes, showing with an outstretched arm or pointing with a finger (to request that you want/need something), body posture and movements, facial expressions (typically used to show emotion, e.g., smiling to show happiness), natural gestures (gestures generally understood by people within a specific culture or society that require no additional training such as *sleep*, *come*, *eat*, and *stop*), finger spelling (one-handed finger spelling is typically used – remember that this can only be used if a person is literate), and sign language. Sign language is country-specific and British Sign Language is used in the UK, American Sign Language in the USA, Kenyan Sign Language in Kenya, and Namibian Sign Language (NSL) in Namibia and Angola. Four examples of natural gestures are shown in Table 32.1.

However, it is important to distinguish between sign language (which is used by deaf individuals) and keyword signing, which is typically used as an AAC strategy. Sign language has its own grammar and own linguistic rules, whereas keyword signing uses the spoken language (which is English in Namibian classrooms) while simultaneously signing the key words. The sentence "The teacher reads a book to the children" would be signed by using the signs: *the* + *teacher* + *reads* + *a* + *book* + *to* + *the* + *children*, but in keyword signing only three concepts will be signed: *teacher* + *reads* + *children*. Keyword signing is therefore preferable, as the majority of children who have severe communication disabilities and who use AAC can hear. These children need a different way of getting their message across, other than speech. Through keyword signing, the children might learn signs (from sign language) and use them to convey their own messages. They are still exposed to the spoken input, which they can hear and which is important to build their receptive language skills. They may also understand the message better because of the extra visual input that is provided by the signs (McDowell & Bornman, 2022).

So, how does a teacher go about teaching unaided strategies in a keyword signing format? The answer is by using five easy steps that will now be described in more detail.

Five Steps to Teaching Keyword Signing

Step 1: Decide on the vocabulary you want to include The teacher should consider the aims of the lesson and decide what the most important concepts are that she would like to teach. It is always a good strategy to ensure that generic words (e.g., *please*, *help*, *more*, *finished*) are combined with the verbs, nouns, prepositions, and question words. Using these signs can enable the child to fulfill different communication functions, such as requesting *help*, requesting *more*, indicating *finished*, and displaying social etiquette (e.g., by saying *please* and *thank you*). Please refer to Table 32.2 for examples of generic signs from NSL.

Step 2: Take into consideration which signs are easier to learn First, the movement aspects are important: signs that make contact, where two hands come together, are easier to make, as are signs that require symmetrical movement (where both hands perform the same action). Signs produced within view and those that require single movements are also easier to make. Second, attention should also be given to the level of representation, as more abstract vocabulary (e.g., the word *beautiful*) is more difficult to sign than more concrete words (e.g., *car* or *eat*). Transparent signs that have a visual similarity to the concept are also easier, such as the sign for *drink*.

Step 3: Locate resources This step is country-specific as the teacher will need to obtain a copy of the country's sign language dictionary (the website na.signwiki.org contains a dictionary of NSL). In many countries, there are also associations for persons who are deaf (e.g., CLaSH in Namibia) and they might have training material such as books and/or videos and trainers available. The Internet can be a useful resource, as can competent signers who live or work in the area where the school is located.

Step 4: Start using the signs in the classroom and provide a model for use The teacher should feel comfortable in making the signs (practice using the signs in front of an imaginary class) and model the use of the signs. The teacher can also support the children to make the signs through different teaching methods, for example, shaping (the teacher places her hands over the child's hands and molds them into the appropriate handshape), or through imitation (the teacher makes the signs and asks the children to copy her).

Table 32.2 Generic signs from Namibian Sign Language (NSL)

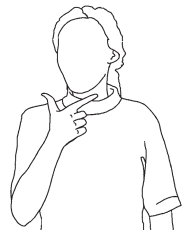
		
Please	**Thank you**	**Help**
		
More	**Give**	**Finished**

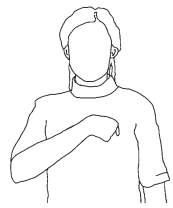
Table 32.3 "He's got the whole world in His hands"

God

Amount
Whole

He's got the

World **In** **His hands**

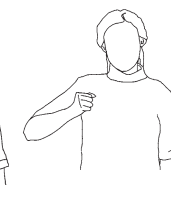


God **I** **You** **Sister** **In** **His hand**

He's got me

He's got the whole world in His hands (repeat 1st line)

Other



Baby **Brother** **Teacher** **Mother** **Father** **Grandmother**

Step 5: Sign all the time Incorporate the use of keyword signs in all lessons: tell stories with signs, sing songs with signs, use signs while teaching rhymes, and explain the key concepts of the academic lesson by incorporating signs. For example, the key words of the song "*He's got the whole world in His hands*" can be signed while the children in the class sing along (Table 32.3). If possible, try to also teach these keyword signs to siblings, parents (e.g., during parent events at

schools), and others in the community – even if they only learn the six generic manual signs.

Advantages and Disadvantages of Unaided Systems

Unaided systems have proven successful for children with various disabilities, such as children with Down syndrome (Launonen, 1996) and children with autism spectrum disorder (ASD) (Tincani, 2004). They are also quick and readily available (the child cannot forget to take the system along), the child can use them wherever he/she is, no expensive equipment is needed, and the system cannot break down. Gestures can be effective for meeting basic needs (e.g., asking for something to eat or drink), but are not always effective in telling a story about a specific event. Try to imagine using gestures to talk about a cousin's wedding two weeks ago, with somebody who does not understand the gestures!

The biggest disadvantage of unaided systems, particularly when using sign language, is that they require training. Some signs are not easily guessable and are therefore more difficult to learn. Keep in mind that unaided communication strategies must be understood by others in order to be effective. The motor demands of some signs make them unsuitable for some children, for example, those with physical disabilities such as cerebral palsy.

Aided Systems

Symbols That Can Be Used in Aided Systems

Aided communication systems require the use of tools and/or equipment in addition to the person's body, for example, a communication board, book, or speech-generating device. Various symbols can be used on these boards, books, or devices. These symbols can include object symbols (e.g., real objects that are similar to the object that will be used in the activity, such as a toothbrush; partial objects, such as a piece of chain to represent "swinging"; or miniature objects such as doll utensils) photographs, hand-drawn pictures, line drawings (graphic symbols such as Picture Communication Symbols or PCS™, SymbolStix™, Bildstöd™ [a free tool for pictorial support made in Sweden. For information go to www.bildstod.se], Widgit™, Blissymbols™, Makaton™) or traditional orthography (written words) (see Table 32.4).

The level of representation of aided symbols typically develops along a complexity continuum starting with the following:

- Real objects
- Photographs
- Line drawings (some symbols are more concrete and easier to learn, while others are abstract and more difficult to learn)
- Print awareness (e.g., awareness of printed words versus pictures in storybooks)

However, this continuum should simply be used as a guideline for typical development to decide what type of symbol should be used. The aim is therefore not to do a complete diagnostic assessment of cognitive age, but rather to select the most appropriate symbol. Children with sensory disabilities (e.g., children who are blind or who have cortical visual impairments) or with irregular symbolic development (e.g., children with ASD) do not necessarily follow this hierarchy.

The most important aspect to remember is that the symbol, irrespective of whether it is an object symbol or a graphic symbol, is a representation of the real object or activity. So, for example, if a glue stick is used to represent a gluing activity, the glue stick that is the object symbol should not be used in the activity, but rather one that looks similar to it. In order to emphasize the distinction, object symbols are often mounted on a piece of thick cardboard or pressed wood. These aided symbols can then be presented in a variety of ways, ranging from pen-and-paper options to communication books or boards to devices that produce voice output and/or written output. These devices are also known as high-technology speech-generating devices, but they fall outside the scope of this chapter.

Visual Schedules for Classrooms

A visual schedule is a valuable teaching tool that can be used by teachers, parents, and therapists to provide the child with information about the day's program. The activities that the child will partici-

Table 32.4 Examples of aided symbols

		
Real objects	**Partial objects**	**Miniature objects**
		
Using a photograph to request and receive an item	**Line drawing**	**Traditional orthography**

The line drawings are made on www.bildstod.se, a free tool for pictorial support made in Sweden

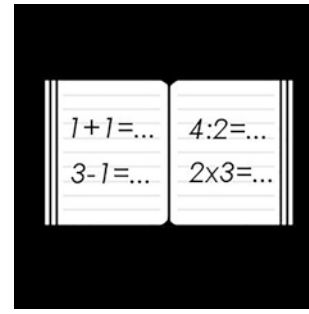
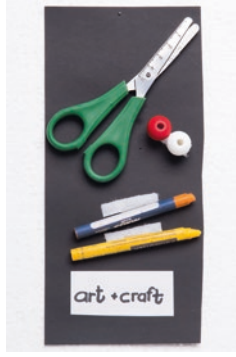
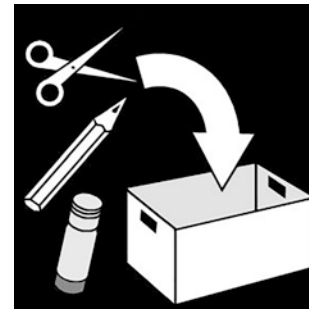
pate in during the day can therefore be depicted through symbols (e.g., objects, line drawings, or written words) in chronological order (see Table 32.5). Using visual schedules in a classroom holds many advantages for teachers:

- It ensures that classroom time is used optimally and that children can stay on task.
- It assists children in anticipating what the next activity will be, thereby also reducing anxiety between transitions (in a similar way that adults use their diaries).
- It helps to redirect children to the activity as it acts as a visual reminder of the activity.
- It serves to reduce challenging behavior because the visual overview of the sequence of activities gives the children control over the environment by showing them what will happen next.
- It helps the children to understand that unexpected events or change are inevitable, for example, they might plan to play outside, but an unexpected thunderstorm could prevent that activity.

When designing a schedule, the teacher should be encouraged to write down the activities in chronological order, for example, morning welcome, the weather activity, a mathematics activity, and story time. Next, appropriate visual symbols should be selected, and in order to accommodate all the children, more than one type of symbol (objects, photographs, line drawings) is needed. Thereafter, suitable symbols that most of the children will understand should be selected for each activity as shown in Table 32.5.

After deciding on the content of the visual schedule and planning whether object symbols, photographs, or line drawings will be used, the teacher should decide on the preferred format. Visual schedules can take on many different formats, as shown in Table 32.6.

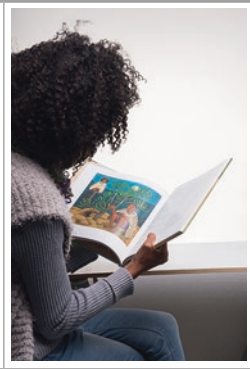
Table 32.5 Object symbols, photographs, and line drawings for a visual schedule

Activity	Object symbol	Photograph	Line drawing
Wash hands			
	Soap wrapper	**Person washing hands**	**Line drawing for "washing hands"**
Mathematics			
	Calculator	**Person pointing to calculator**	**Line drawing for "mathematics"**
Arts and crafts			
	Beads/crayons	**Person stringing beads**	**Line drawing for "arts and crafts"**

(continued)

How is a visual schedule implemented in the classroom? First, the teacher should display the visual schedule somewhere in the classroom where it is easily accessible to all the children and where they can clearly see it. Before each activity, the teacher should go to the visual schedule and highlight the symbol that represents the activity (e.g., by moving a big red arrow to indicate the specific activity). She then discusses the activity "*Can you see that we will now talk about the weather? It is time for the weather activity*." When the activity is complete, the

Table 32.5 (continued)

Activity	Object symbol	Photograph	Line drawing
Story time			
	Book	**Person reading**	**Line drawing for "story time"**

The line drawings are made on www.bildstod.se, a free tool for pictorial support made in Sweden

Table 32.6 Different visual schedule formats

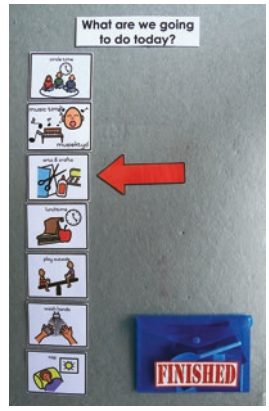
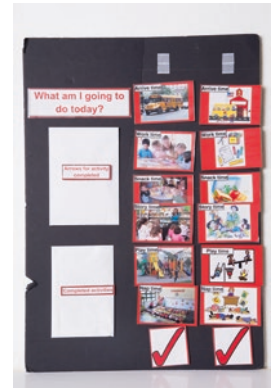
		
Visual schedule with objects	**Washing line format**	**A visual schedule using a clockwise display**
		
A visual schedule with line drawings going from left to right and an arrow that indicates the specific activity	**A Velcro strip-based schedule going from top to bottom**	**A visual schedule with photographs on the left and line drawings on the right. Envelopes for finished activities are on the far left**

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Table 32.7 Using the "*finished*" symbol

Teacher taking symbol off and turning it over.

Teacher taking the lid off the next container.

Teacher putting symbol in "*finished*" basket.

teacher highlights the symbol for the next activity and indicates that the previous activity is over. She might take the symbol off the visual schedule and turn it over; she might cover it (with a lid or fabric) or take the lid off the next container, or she might put it in the "*finished*" basket as shown in Table 32.7. Teachers should also be encouraged to use the manual sign for "*finished*" on completion of the activity while turning the symbol over or placing it in the "*finished*" basket. Children will have made the connection between a symbol and the activity as demonstrated when they smile when they see the symbol for a preferred activity, or when they see the symbol and proceed to the next activity, or when they frown or try and avoid an activity that they do not like.

Remnant Books

Teachers often have a "news" activity in which children are required to share something that happened at home (e.g., relatives came to visit) and sometimes teachers also want to share what happened at school (e.g., the school nurse came to visit). Sharing news or stories might be difficult for children who have very limited speech, but the fact that they are not able to talk does not mean that these children have nothing to say! By using a remnant book, these children can be guided to talk about past events and share stories.

Remnant books are inexpensive to make and they hold visual and tactile cues to help a child remember a specific activity. Remnants or scraps (souvenirs) are saved and displayed in a photo album or pasted into a book, as a way to document the child's story. There are no rules when it comes to selecting the remnant except that it should be meaningful for the child and that the child should associate it with the place it came from. Therefore, it is always more effective if the child helps to select it. For example, if the school nurse visited the school to give all the children injections, the empty syringe can be used as a remnant, or if the child helped with washing clothes, the soap wrapper can be used. Collecting remnants can also be a fun activity for siblings to participate in.

How does one make a remnant book? First, the book should be sourced – flip files or regular exercise books are typically used. The child's photograph can be placed on the outside cover of the book with a label such as "*Christa's Talk Book*." Each page of the book is dedicated to a specific day, the remnants are collected and laid out on the correct day, and a short sentence is added to describe it, for example, "*I went to the shop with my mother. We bought eggs*." These sentences should always focus on the child, and

what the child's role was in the activity. The remnant book allows the child to answer questions such as "*What did you do over the weekend?*" or "*What did you do at school today?*" However, the purpose is not to ask accuracy questions, for example, "*Where are the eggs?*" or The questions that are asked should not have a right/wrong answer – they must be fun! The teacher should just open the book and go through it with the child to talk about what has happened lately – it is like reading a story together, but it is the specific child's story. She should talk about the places and activities in the remnant book: "*Oh, I see you went to a party! Did you have a good time?*" The teacher can make the interaction fun and casual and have a conversation about the place or activity in the book when the child indicates that he/she is interested. She can also encourage the child to say the word of the place or activity the remnant represents. Table 32.8 shows examples of different remnant books.

Aided Language Stimulation (AiLgS)

Aided language stimulation (AiLgS) is a strategy that aims to provide children with a strong foundation for receptive language (understanding), based on the principle that receptive language precedes expressive language (Dada & Alant, 2009; Goossens, 1989). One can also visualize receptive language as filling an empty glass with water – the water represents the receptive language, and when the glass is full, it starts to spill over – with the overflow representing the expressive language. In AiLgS, the teacher points to graphic symbols on a communication display as she speaks, as shown in Table 32.9. Thus, pointing to these symbols serves as a supplementary visual input to the auditory input (the teacher's voice) that the child receives.

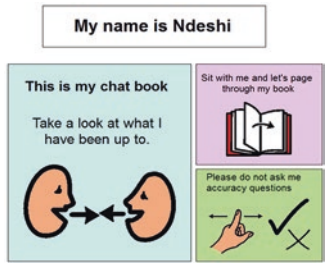
Why is AiLgS such an effective classroom strategy? First, it challenges earlier classroom practices where the emphasis was primarily on output/production/expressive abilities. Teachers commonly use it to interact with children by asking them questions, by giving them commands, or by asking them to demonstrate actions, for example, "*show me*." AiLgS challenges the perception that the emphasis should only be on output, and therefore, the most important principle of AiLgS is that one should provide input before expecting output (expression). It is an accepted principle that typically developing children hear language for 1 year before they start talking; children with communication disabilities should therefore in the same way first be provided with a model (AiLgS) before they can be expected to use language expressively. Implementing AiLgS in the classroom can be divided into five easy steps, and each of these steps will now be described in more detail.

Step 1: Adapt the physical layout of the classroom to ensure optimal learning Teachers should be aware of interruptions or disruptions during the AiLgS lesson, as children lose their focus and concentration when a teacher is distracted. Teachers should consider rearranging the classroom for different activities, for example, for arts and crafts the classroom layout might be different than for the circle time activity early in the morning. The traditional classroom layout of children's desks placed in neat rows can also be adapted so that the desks are arranged in a U-shape with the teacher in the middle as shown in Fig. 32.2.

Figure 32.2 shows that a U-shaped classroom arrangement will allow all children to see the teacher clearly. Teachers should also carefully consider who sits where, for example, children who use AAC should sit centrally, children who are blind should sit close to the teacher, children with challenging behavior should not sit next to each other, and children who give the most feedback should be evenly dispersed among children who give minimal or no feedback.

Teachers should also ensure a clear visual focus for the AiLgS board. It can either be placed on a floor easel or an area against the

Table 32.8 Examples of remnant books

		
An example of a front page for a remnant book	**An example of a page in the remnant book that tells about the child's visit to the doctor**	**Another example of remnants that were collected while having a birthday party at McDonald's**
		
Two more examples of pages in the remnant book: one is about a visit to the restaurant "Spur" and the other about a school concert	**This is another example of remnants from a school concert in which the child participated**	**An example of remnants that were collected while on an outing to a restaurant ("Spur")**

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wall, with a background that is not distracting. The teacher should also make certain that the board is at the eye level of the children, and she should make regular eye contact with each child during the group activity. If she notices that the child is not looking at her, she can gently touch the child to draw his/her attention back to the activity.

Step 2: Select a fun and suitable activity (content) The teacher should select an activity based on the content (theme) of the lesson that she wants to teach the children (e.g., insects). Next, she needs to consider how to present the activity in an age-appropriate format. For young children, she might simply divide insects into ones that fly (e.g., butterflies and bees) and those that crawl (e.g., ants and cockroaches), while older children can be taught about specific characteristics (e.g., number of legs, type of wings, functions, and habitats). Please see Table 32.10 for a display of eight different examples of AiLgS boards.

The teacher may also plan to incorporate an element of surprise into her lesson to hold the children's attention. Rather than asking them to answer questions in a predetermined order, she can pull the children's names or even a photo-

Table 32.9 Pointing to an AiLgS communication display

	
Teacher pointing to symbols on a song board	**Teacher pointing to symbols on a story board**

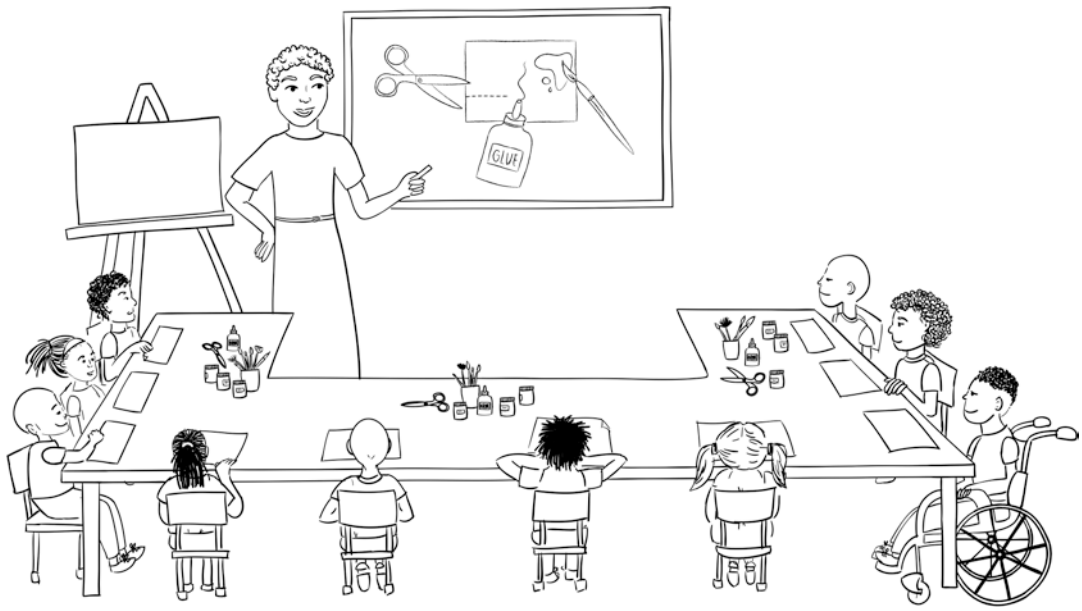
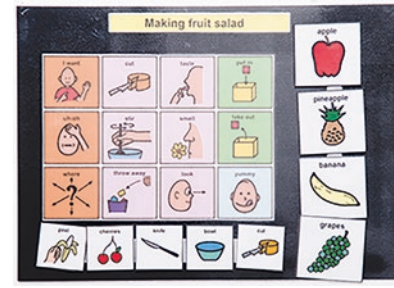


Fig. 32.2 U-shaped classroom arrangement

graph of the child out of a hat or use a spinner that randomly selects a name. Children could also be encouraged to select the next child by using the "pick-a-friend" strategy. Teachers could furthermore be encouraged to wear a funny hat or oversized glasses for a specific activity, as this will persuade all the children to keep on looking at her.

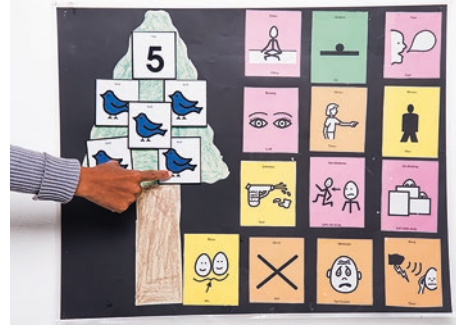
Step 3: Decide on the type and number of graphic symbols that will be used When implementing AiLgS, teachers should always remember

Table 32.10 Examples of AiLgS boards

	
A story board with general vocabulary for reading any story, as well as vocabulary specific to the story: The Three Little Pigs	**A board for a general "cooking" activity. Note the Velcro strips that can be used to custom-make the board for a specific activity: making fruit salad**
	
A board for a specific children's rhyme: Five Little Monkeys Jumping on a Bed	**A song board for the children's song: Twinkle, Twinkle Little Star**
	
A board for the church song: Jesus Loves Me	**A board for the children's rhyme: Mary Had a Little Lamb**

(continued)

Table 32.10 (continued)

	
A board for the children's song/rhyme: Baa Baa Black Sheep	**A board for the children's rhyme: Five Little Birds**

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to include the use of manual signs and gestures to retain a multimodal focus. For children who are blind, teachers can use braille letters or cut out the first letter of their names in sandpaper or carpet fabric, so that they can feel the letters and know when it is their turn to participate. The type of symbols that are used should have an immediate effect and therefore the ease of learning should be considered, bearing in mind that objects are the easiest to understand, followed by photographs, graphic symbols, and finally letters of the alphabet. Symbol reproduction should also be considered. For example, the teacher may draw the symbols, photocopy them, print them from the Internet, or cut them out from magazine advertisements.

Step 4: Prepare the necessary material and practice on your own Careful consideration should also be given to the number of graphic symbols that will be placed on the board. For example, for young children, a board with eight symbols might be sufficient, while older children might need as many as 36 symbols. Furthermore, all of the symbols included on the board should not be from the same word class. The selection should contain nouns (*book*, *butterfly*, *flower*), descriptive words such as adverbs (*fast*, *slowly*, *often*) and adjectives (*big*, *friendly*, *naughty*), verbs (*fly*, *sit*, *make*), prepositions or position words (*up*, *under*, *next to*), and miscellaneous words that include wh-question words (*who*, *what*, *where*), exclamations (*oh no! oops!*), pronouns (*I*, *you*, *he*), and negative words (*No! Stop! Don't!*).

How Can Aprons Be Implemented in the Classroom?

- Using the same strategies as those described earlier under AiLgS, an apron can act as an alternative AiLgS surface/board/display.
- Including different choices on the apron for the specific activity to encourage choice making. For example, during a creative art activity, each child can select the color of the crayon they want to use from the number of options displayed on the apron. This is an effective strategy for teaching the names of colors.
- Tapping on the symbol is also effective for drawing or redirecting a child's attention and therefore increases opportunities for joint attention.
- Showing keywords that are relevant to the specific lesson on the apron – this helps children who have difficulty in summarizing large amounts of text and who get lost in the detail.
- Including more than one language with the graphic symbol, for example, the

English word above the symbol and the home language word below the symbol, as that helps the child to get incidental exposure to the written form of both. It can also help the teacher to use both the English and the home language word to strengthen understanding.

- Including behavior control words, for example, *Stop! Wait! No!* Using these symbols, rather than having to consistently speak these words, creates a more positive classroom atmosphere and also allows the children to manage their behavior. A *wait* symbol can be handed to children who have challenging behavior and consistently seek the teacher's attention. The child can be taught that when the teacher is seated at her desk, he/she can trade the *wait* symbol with the teacher, and that will ensure that the teacher gives undivided attention for a period.
- Providing an alternative form of communication for quick messages, for example, a request to go to the toilet.

Peanut Butter Balls (24 Balls)

Ingredients

½ cup (120 g) honey
½ cup (120 g) peanut butter
1 cup (250 g) milk powder
1 cup (250 g) instant oats
2 teaspoons (10 mL) vanilla essence
Wax paper

Method

Mix all ingredients and then roll the mixture into 2.5-cm balls (size of a coin).
Lay the balls on waxed paper. Refrigerate or leave in a cool place until set.

When making the board, a hard black board is preferred as it avoids possible distractions and provides an effective contrast color. The teacher then needs to collect the material that will be needed, depending on the children's level of representation (e.g., objects, pictures, graphic symbols). She should also look up the different manual signs that would be needed in the relevant sign language dictionary.

In order to effectively use AiLgS, a teacher should be encouraged to practice using it (pointing while speaking) with an imaginary class until she feels comfortable using this strategy. The teacher should point at the symbol at least seven out of ten times while speaking the particular word. So, if the teacher uses the word *fly* ten times, she should simultaneously point to the symbol representing *fly* at least seven times (Goossens et al., 1992). Seeing that the focus is on developing receptive language skills, a ratio of 80:20 (statements vs. questions/commands) should be used. Teachers should also provide expectant pauses (count silently for 5 seconds) in conjunction with cueing, as this will help the child to respond more effectively. Cueing involves giving the child additional information, or a clue, to help him know what is expected. This can be done by providing a visual clue, for example, the teacher can point to the symbol, or an auditory clue, when the teacher provides the initial sound for the target word, for example, "*l*" for *lamb*.

Step 5: Implement the AiLgS in your classroom and measure progress Teachers should avoid focusing on each child individually in a group activity, as that means that children often have to wait too long before they have a turn. This results in them losing interest, becoming restless, and disrupting the group. Incorporating songs and rhymes into activities allow more than one child to participate in an activity. Providing equal turns (not focusing only on the verbal children), engaging children equally, calling their names, and making eye contact with all the children foster optimal participation and learning.

Measuring progress using AiLgS is easy, as a teacher can count the number of symbols that the children understand receptively and expressively, and this measuring can be done at various points in time.

Visual Aprons

The visual apron makes the language more concrete and less fleeting for children who require

specific objects or graphic symbols to aid with their receptive language (understanding). It is a teaching aid that assists with enhancing receptive vocabulary as it makes the vocabulary visible as the symbols (object symbols, photographs, or line drawings) are displayed on the apron. It is a very appealing strategy for teachers to use when working with large groups of children, as all children would benefit from additional receptive language input.

The apron is usually made from a durable, firm fabric (such as denim) with a number of receiving (soft) Velcro strips stitched to it in rows, as shown in Table 32.11. The different symbol options are then attached to the apron by using the hard (male) Velcro. This means that the teacher can point to the various symbol options while still having her hands free for keyword signing, pointing, or visually directing the child's gaze while talking about the symbols. All aprons

Table 32.11 Examples of aprons

	
Empty apron	**Apron with photographs and object symbols that can be used in a fruit salad activity**
	
Apron with photographs and line drawings for a story time activity: Three Little Pigs	**Apron for choice making in a music activity: choosing a musical instrument**

should have large bottom pockets so that the needed symbols (including object symbols) can be kept there. Table 32.11 shows the empty apron as well as three different examples of aprons. This not only allows the teacher to access extra symbols but also ensures that the symbols are readily available. If the teacher has to break contact with the group in order to find the symbols she needs, it might be difficult to capture the children's attention again.

Visual Recipes

Participating in a functional activity such as preparing food is a favorite activity for many children. Teachers also sometimes include a cooking activity in the classroom when they teach the activities of daily living. Children develop specific skills during these activities and are exposed to a whole new set of vocabulary. Using a visual recipe is an excellent way in which the teacher can guide the children to receptively understand an activity, and it can also be used to teach certain mathematical skills. In the example below, a Grade 5 math teacher wants to teach the class about halving and doubling and metric volumes (milliliters and liters, as well as grams and kilograms). She can teach these concepts as part of a fun activity and encourage optimal classroom participation because she knows that this is the best possible teaching strategy to ensure that the children remember the new concepts. She decides to give them all a visual recipe for making peanut butter balls and provides the whole class with the same recipe:

She then divides her class into three groups. Groups 1 and 3 are essentially the same in terms of their learning potential and cognitive skills, and they need no modifications to their worksheets, except for the fact that the children in Group 3 have significant sensory or motor impairments (Bornman, 2021). For example, these children will all be asked to rewrite the recipe for four times the quantity – first by doubling the ingredients (e.g., 250 g of oats × 2 = 500 g) and then by doubling them again (2 × 500 g = 1000 g = 1 kg). Please see an example of the worksheet for Group 1 in Table 32.12. Although the content on the worksheets is the same for these two groups, the children in Group 3 may require braille or sign language, or they may need a scribe to adapt the recipe.

The children in Group 2 may have a cognitive disability or learning problems, which may range from mild to severe. These children may take longer to learn or require more concrete forms of input, and although the teacher will also teach them about double and halve, they will not do so with grams and kilograms, but they will be expected to double the nonstandard units, for example, the tins or packets (e.g., 2 × 1 cup = 2 cups or 2 × 2 teaspoons = 4 teaspoons). By participating in the activity in this way, all the children will experience true inclusion and a sense of belonging. Please see an example of the worksheet for Group 2 in Table 32.13.

A visual recipe can also be used to assist children to increase their receptive language skills and learn how to follow step-by-step instructions. It is important to break down the activity into the different steps and to have clear guidelines (either through photographs or line drawings) for each of the different steps. As with the mathematics exercise, the difficulty level of the recipes may also be increased and can assist in teaching children to become more independent, for example, teaching them how to use a stove. Please see Table 32.14 for examples of visual recipes.

Place Mats

Mealtimes provide valuable communication opportunities due to their social nature, as well as valuable opportunities for language learning and development (Harding et al., 2013). However, since traditional communication boards might be considered as "being in the way" during this activity, displaying the graphic symbols that the individual needs on a placemat (as opposed to a communication board) is simply more functional. Teachers need to ensure access to communication during mealtime activities, and thus, they can take advantage of the predictability of mealtime routines by building interaction opportunities around this routine activity. Routines are effective for communication training as their predictability helps children understand what is expected of them, thereby creating a foundation for active participation. Mealtimes also happen regularly; hence, they give children lots of

Table 32.12 Example of a worksheet for Group 1

Subject: Mathematics **Worksheet for Group 1**			
Aim of the lesson:	To teach the learners about halving, doubling, and metric volumes		
Group 1: Recipe for peanut butter balls			
		Column A	**Column B**
Ingredients	**Line drawings of the ingredients**	Double the measurements for each of the following ingredients (e.g., 250 g × 2 = 500 g)	Double the measurements once more for each of your answers from column A (e.g., 500 g × 2 = 1000 g/1 kg)
120 g honey			
120 g peanut butter			
250 g milk powder			
250 g instant oats			
10 mL vanilla essence			

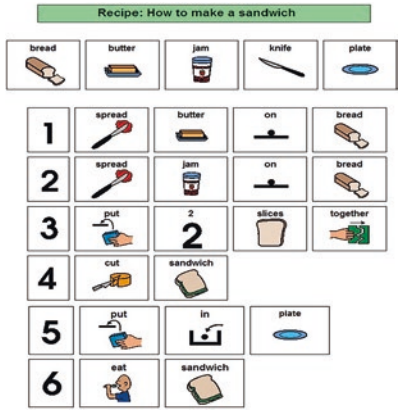
opportunities to practice their new skills. A placemat usually contains a small array of words that are relevant for conversation that takes place during this activity (see Table 32.15).

Contrary to popular belief, much of the conversation during mealtimes does not revolve around the food, but rather around socialization, for both the children with and without disability (Harding et al., 2013). Therefore, the words included on the place mat (around the periphery of the mat, so that the plate does not cover the symbols) should contain generic words to allow

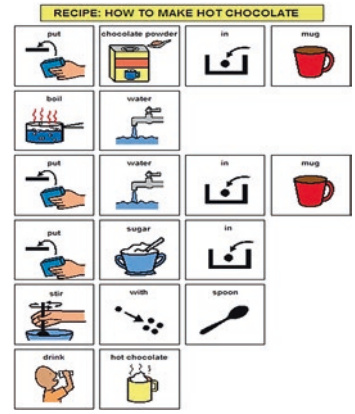
Table 32.13 Example of a worksheet for Group 2

Subject: Mathematics **Worksheet for Group 2**			
Aim of the lesson:	To teach the learners about halving, doubling and metric volumes		
Group 2: Recipe for peanut butter balls			
		Column A	**Column B**
Ingredients	**Photographs of the ingredients**	Double the measurements for each of the following ingredients (e.g., 1 cup × 2 = 2 cups)	Double the measurements once more for each of your answers from column A (e.g., 2 cups × 2 = 4 cups)
½ cup honey			
½ cup peanut butter			
1 cup milk powder			
1 cup instant oats			
2 teaspoons vanilla essence			

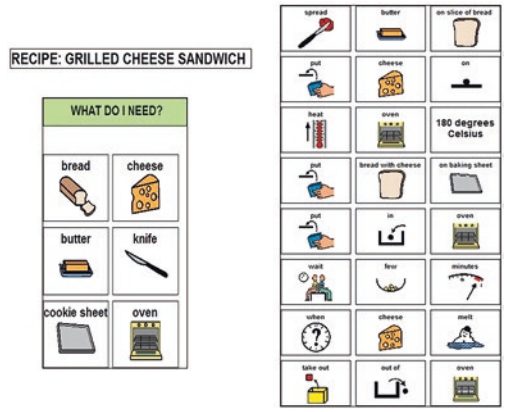
Table 32.14 Examples of visual recipes



How to make a sandwich



How to make hot chocolate



How to make a grilled cheese sandwich

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Table 32.15 Examples of place mats

Place mat using a tray as the receiving surface on which the communication board is mounted

A place mat with core vocabulary along the edges and a few loose food symbols (fringe vocabulary) on the Velcro strip that can be changed on a daily basis

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for communication. For example, include phrases with which the child can direct the conversation, for example, "*my turn*" and "*your turn*." The words should also allow them the opportunity to give feedback to others (*"I like it"*; "*No, stop*").

Conclusions

The challenges that children with disabilities, and specifically those with communication disabilities, face in the Namibian education context are by no means unique. Similar barriers have been noted in, for example, the United Nations country reports on the right to education following visits to other African counties such as Uganda (Tomasevski, 1999), Botswana (Muñoz, 2005), and Algeria (Singh, 2015), and in the Human Rights Watch report on South Africa (2015). Low resources and multilingualism characterize many education settings of children with communication disabilities on the African continent. What should become clear from this chapter, though, is that solutions are available and that they need not be particularly costly. In the hands of motivated and dedicated teachers, everyday objects, photographs from advertisements, and hand-drawn pictures can become effective tools to bridge communication gaps and assist children to understand as well as to express themselves.

Every barrier that teachers break down today is one less barrier that children with disabilities will have to face tomorrow. Teachers should thus embrace the challenge of creating change and fostering inclusive classrooms in which all children experience not only a sense of belonging but also the opportunity to grow and develop new skills.

Children are as impressionable as wet cement – whatever falls on them leaves an impression. Hence, it is up to the teacher to decide whether that impression will:

- Continue to feed the *vicious circle* of prejudice and stigma, which results in low expectations from children with limited learning opportunities and poor skills that magnify the disability, or
- Create a *virtuous circle* based on the teacher's knowledge and skills, which results in realistic expectations from the children, with children striving to meet those expectations (the so-called Rosenthal effect), ultimately strengthening and expanding the child's skills

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Critical Components in the Inclusion of Learners with Cerebral Palsy and Associated Communication Disorders

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Introduction: Cerebral Palsy

Cerebral palsy (CP) is often perceived as a group of disorders affecting the brain and the functionality of the nervous system including impaired movement, learning, thinking, and seeing; it is nonprogressive. It may occur during early infancy as a result of several conditions including head injuries, infections in the mother during pregnancy, and prolonged labor (United Cerebral Palsy Association, 2015). The severity may range from mild to severe. Mild CP might only be detectable in cases where the person runs and moves in an uncoordinated fashion, while for people with severe cases, it is impossible to walk, sit with support and feed themselves, chew their food, pick up an item, or articulate words. It is a lifelong disorder, meaning long-term care may be required, because the disorder does not affect the expected life expectancy. According to the 2015 report by the United Cerebral Palsy Association, early intervention of CP can lessen developmental problems and lead to appropriate intervention where it helps the most. Early intervention programs are family-centered, with professionals and families working together with the child in specific activities (Burton, 2015).

CP is more prevalent in low- and middle-income countries than in high-income countries (Burton, 2015). Characteristics of CP may include difficulties in speech and language, or difficulties in communication (Pennington et al., 2009). Speech problems associated with CP may include articulation errors, oral motor difficulties, and dysarthria. These speech disorders result from disturbances in musculature control over the speech mechanism due to damage to the central or peripheral nervous system (Pennington et al., 2009). It causes oral communication difficulties due to paralysis, weakness, or problems in coordination of the speech muscles (Duffy, 2012). Dysarthria usually reduces the intelligibility of speech and makes it difficult for those with dysarthria to communicate with others. Children with CP may also experience negative impacts on their educational, social, and familial relationships due to their decreased intelligibility of speech. They commonly exhibit dysarthria of varying severity. Articulatory disorders are among the primary characteristics of this dysarthria and for children with severe speech disorders. These children are at high risk for an increased disability, suffering from social isolation, impaired social development, and prejudice (Duffy, 2012). The outcomes of speech articulation intervention in inclusive education settings for children with CP combined with associated articulation disorders have not been analyzed or documented in an extensive manner.

Background: Inclusion of Learners with Cerebral Palsy in Sub-Saharan Africa

The high prevalence of children with CP in sub-Saharan Africa (SSA) is often associated with poor maternity services and diseases such as meningitis or cerebral malaria. These conditions are very common in the countries within the continent (Burton, 2015). Findings by Donald et al. (2015) indicate that the prevalence of CP is higher in African countries compared to those in Europe and North America. They further indicate that in Africa and other resource-constrained countries, there is a higher proportion of severely disabled children with CP with more comorbidities. The situation is often caused by poor care during delivery, delayed or lack of access to health care services, and poor early intervention. However, there is insufficient information on access to early intervention and other medical services for these children in most SSA countries (Donald et al., 2015).

Inclusive education in SSA continues to face several challenges due to overcrowded classrooms, with some having as many as over 60 pupils, a very high pupil-teacher ratio compared to high-income countries. Overcrowding is prevalent in countries such as Rwanda, Malawi, Kenya, and the Central African Republic where the average number of learners per classroom exceeds 70. In Malawi, for example, there are 130 children per classroom in lower grades on average. In Uganda where free primary education was introduced, more than 100 students are squeezed into one classroom (Grogan, 2009). In Kenya, public schools have an average of 50 students for every

teacher. This is despite some classes having only one teacher to every 100 pupils due to the immediate increase in school enrollment following the introduction of the free primary school initiative in 2003 (UNESCO, 2012). The overall pupil-teacher ratio in Tanzania, Burundi, Cameroun, Chad, Congo, Mozambique, and Zambia is between 50 and 70 pupils to one teacher. Countries with a more manageable pupil-teacher ratio in SSA include the Seychelles, Mauritius, Gabon, Equatorial Guinea, S. Tomé and Principe, Botswana, Cabo Verde, Comoros, and Liberia (UNESCO, 2014). The high pupil-teacher ratio means that students who may need special education services such as those with CP are likely to receive little or no attention from the teachers, which may lead to them dropping out of education. These countries will, therefore, have to consider inclusive education strategies as an effective and innovative alternative to properly educate these students. Furthermore, nongovernment organizations and human rights organizations have increased pressure on school systems in SSA countries to make inclusive education happen (Boer et al., 2012). Therefore, it is reasonable to say that inclusive education will be an increasingly more prominent issue in the education systems of low- and middle-income countries. Teachers in these countries will see increasing numbers of special needs students, including those with CP, included in their classrooms.

In Uganda, for example, learners with CP have experienced great challenges in accessing education, as shown in a 2010 UNESCO report. These challenges are attributed to the lack of modifications, adaptation, and individualized instruction required for effectively teaching learners with CP in low- and middle-income countries. In Kenya, teachers find it difficult to provide adequate instruction to learners with CP. The multidisciplinary approach involving the services of physiotherapists and occupational therapists is often too costly to implement, leading to a lack of individualization of instruction. The learners subsequently perform poorly in academics. In addition, they perform poorly in independent skills which include activities of daily living (ADLs), leading to poor academic progress and subsequent school dropout (UNESCO, 2010).

Inclusive education cannot however be achieved simply by incorporating children with disabilities into primary-school classes. Rather, schools need to change so that they can better accommodate the needs of diverse pupils and ensure that children with disabilities are included in all aspects of school life. It also means identifying the physical and social barriers within and around the school that hinder learning and actively seeking to reduce or remove all barriers. Thus, inclusive education means transforming how schools presently function. These changes stand to benefit all learners and make the whole education system more cost-effective (Boer et al., 2012).

Research Questions

1. What are the critical components in the academic inclusion of learners with CP with associated communication disorders in high-income countries?
2. What conclusions can be drawn for SSA countries?

Method

Desk Review Strategy

This study undertook a desk review of related literature. A desk review is an objective, thorough summary and critical analysis of the relevant available research and non-research literature on the topic being studied (Gough et al., 2012). Its goal is to bring the researcher up to date with the current literature on a topic, which forms the basis and justification for future research in the area. A good desk review gathers information about a particular subject from many sources. It should include a clear search and selection strategy (Gough et al., 2012). This research method enabled the researcher to retrieve, critically appraise, summarize, and reconcile the available

studies on a specific research problem in order to inform policy and practice. The aim was to comprehensively identify all relevant studies that would help the study answer the research questions.

Selection of Studies

In total, 213 targeted articles were relevant to the study; however, the main study sample comprised of 112 articles. Searches were carried out using the following key words in English: CP inclusion, CP mainstreaming, CP intervention, and Instruction strategies. The source of information was various databases, including ERIC, Education Journals, Kenyatta University Library Databases for Dissertations & Theses, Google Scholar, and Google.

From the identified studies, the second step was to select papers that met the following criteria:

- Papers published in peer-reviewed journals
- Those published during the last 10 years, as up-to-date knowledge was considered vital
- Papers that employed mixed methods and experimental designs
- Those that focused on inclusive education
- Studies that evaluated educational intervention for children with CP

The researcher also focused on studies that included school-going children with CP aged between 1 and 18 years. During this second phase, 112 studies were selected from which 36 were further excluded after reviewing their abstracts to identify the study focus. From the remaining 76 papers that were subjected to further assessment to determine their relevance, 47 were further excluded because either they were not focused on inclusive or mainstream education environments or they did not focus on the CP population or CP intervention strategies. At the end of the second step, 29 articles were found directly relevant to this study. They consisted of studies that incorporated designs whose main area of thematic overlap was inclusive education for students with CP.

After the identification of relevant studies, the third step involved grouping the 29 studies into emerging thematic areas. These themes were as follows:

1. The school learning environment (8 studies)
2. Attitude toward learners with CP (5 studies)
3. Therapy (12 studies)
4. Assistive technology: augmentative and alternative communication (AAC) (4 studies)

The researcher then embarked on a narrative description of the identified themes under each thematic heading.

Exclusion Criteria

From these searches, the researcher excluded articles that did not focus on inclusive education, those that did not include children with CP, and those that did not evaluate mainstream interventions. Mainstream interventions were regarded as those that were common interventions within regular schools or similar settings. Studies focusing on interventions outside the school setting were excluded. In the following section, the thematic areas are presented in a narrative synthesis.

Results

The Learning Environment

In this review, the learning environment adopted a broader meaning to include all the environments within the school where the learner with CP received an intervention. It also included aspects such as equipment and facilities as well as organizational factors. Among the reviewed studies, eight studies (Anaby et al., 2012; Anderson, 2007; Broderick et al., 2012; Bojuwoye et al., 2014; Carpenter & Dyal, 2007; Crombie, 2010; Mihaylov et al., 2004; Tshabalala, 2014) focused on the learning environment in regular schools in relation to provisions for learners with CP. The studies reveal various environmental barriers in the learn-

ing environment. Findings indicate that both personal and environmental factors play a significant role in determining the extent to which learners with CP participate in inclusive education environments. In these studies, the relationship between environmental modifications and participation by learners with CP is clearly illustrated.

Eight of the reviewed studies identified learning environmental factors as the main barriers facing the inclusion of students with CP. These were mostly related to service provision, assistance, and institutional policies. According to Mihaylov et al. (2004), barriers included those associated with social inclusion, with children with CP being restricted from participating in learning activities. Barrier-free environments and adaptive equipment were found to have direct impact on levels of child participation in students with CP. As noted by Mihaylov et al. (2004), children with CP have lower function in gross motor, manual ability, and cognition; they faced far more environmental barriers compared to their counterparts without disabilities. Therefore, learners with CP require further support within the school environment to enable them to participate in inclusive education.

The findings also agree with a report by the Leonard Cheshire Foundation (2008) citing environmental barriers as the major source of exclusion of children with disabilities in SSA. The report indicates that children with CP are far less likely to attend or stay in school in Africa for a variety of reasons including poverty, inaccessible schools, and public transport facilities. The report shows that in Malawi, Tanzania and Burkina Faso, these children were usually absent from school at a rate two or three times higher than that of their able-bodied counterparts. Their school absenteeism is linked to physical and social environmental barriers. This clearly indicates that any efforts toward the inclusion of students with CP must target specific environmental barriers that are likely to hinder them from accessing schools. In relation to communication challenges, speech–language therapy (SLT) services should be provided. In addition, teachers should develop their lesson plans, bearing in mind that individual learners require different language learning strategies in the case of inclusion.

Attitude Toward Learners with Cerebral Palsy

Another theme that emerged from the review was teachers' and students' attitudes toward students with disabilities. The success of inclusion of students with disabilities has often been associated with the attitude of the people involved in implementation at the school level. Among the reviewed studies, five studies (Anderson, 2007; Golmic & Hansen, 2009; Hilderley & Rhind, 2012; Phtiaka, 2011; Tshabalala, 2014) focused on the attitudes of students, teachers, and principals in regular schools toward learners with CP. Findings indicate that teachers tended to agree more on a theoretical aspect of inclusion. However, they seemed to have a negative attitude as far as its implementation was concerned. Specifically, the studies reveal that teachers play a crucial role in modeling their students to appreciate multiplicity in humans and to recognize that all children have potential. Hilderley and Rhind (2012) observe that, most often, teachers' and head teachers' attitudes are linked to successful inclusion of students with disabilities in mainstream schools. This is supported by Anderson (2007), who found that teachers are significant in ensuring that inclusion programs are being implemented successfully with the presence of equal opportunities that will promote the success of all students. This is because general education teachers work with a diverse student population and find it very difficult to work with the specific learning styles of students with disabilities, mainly because of the lack of knowledge, training, and preparation (Sze, 2009). These findings are in line with Golmic and Hansen (2009), who found that teachers' negative attitudes toward students with disabilities led to low expectations from them, which resulted in decreased learning opportunities and low academic performance.

Students without disabilities were also found to show less acceptance of their disabled peers if the disorder was more visible or severe

(Tshabalala, 2014). Some peers even expressed feelings of pity or fear toward their fellow students with disabilities. In African societies, disability is sometimes associated with negative perceptions, resulting in stigma, discrimination, exclusion, and violence, as well as other forms of abuse against persons with disabilities. In South Africa, for example, a study by Tshabalala (2014) observes that students without disabilities have negative attitudes toward students with disabilities because they perceive them as uneducable or a problem for the special education teacher to deal with. In Nigeria, the government's attempt to integrate special needs pupils into regular schools in the 1990s was received with skepticism on the part of the teachers and head teachers. They saw it as a difficult task that would hinder the progress of other pupils in the class because pupils with special needs would not cope in normal classes.

It is evident from the reviewed studies that positive attitudes play an important role in effective inclusive education. Studies have shown that the positive attitude of teachers and students without disabilities in inclusive schools is the greatest source of successful inclusive education. Research also suggests that there is a need for fundamental attitudinal changes to achieve successful inclusive educational practices. Therefore, there is a need to link inclusion research and attitudinal research. To support the development of inclusive education and practices for students with disabilities, it is imperative to have insights into the nature of the attitudes of students and teachers without disabilities toward the inclusion of their peers with disabilities.

Teachers can also encourage the positive attitudes of students without disabilities by creating opportunities for cooperative relationships. Research examining student attitudes toward their peers with disabilities found that contact with students with disabilities might lead to positive attitudes. In fact, Lieberman et al. (2017) noted that positive contact with students with disabilities is the only effective way to help them gain an understanding of and knowledge about students with disabilities. Therefore, schools can promote the interaction of students with and without disabilities in inclusive environments by structuring activities and organizing sensitization seminars to promote positive attitudes required for successful inclusion.

Therapy

Therapy generally plays a significant role in the education of students with CP as it improves their overall functioning capabilities. Occupational therapists, for example, use different techniques such as sensory integration to provide the best services to these learners. The main aim of different types of therapy is to enable full participation of learners with CP in inclusive education, including social acceptance, access to facilities, access to education, and access to medical and rehabilitative services.

A review of 12 studies (Deluca et al., 2015; Duffy, 2012; Hadley et al., 2000; Levine & Page, 2004; Pennington et al., 2009; Roostaei et al., 2016; Sharifi et al., 2014; Stiller et al., 2003; Throneburg, 2000; Trabacca et al., 2016; Wright & Kersner, 1999; Yadav et al., 2016) on SLT services for children with primary speech or language delay or disorder found that communication problems lead to negative effects on school achievement. This may also be associated with social, emotional, and behavioral problems negatively affecting the educational inclusion of these learners (Bauer et al., 2010).

The study by Bauer et al. (2010) found that a collaborative service delivery model consisting of SLTs and teachers involved joint curriculum planning, vocabulary, and phonological awareness instruction; it led to significantly higher achievement in the area of receptive and expressive vocabulary (Bauer et al., 2010). The study found significant improvement in phonological-awareness-related activities such as beginning sound awareness and letter-sound associations although no differences were noted for rhyme tasks. Meline and Kauffman (2010) examined the effect of a variety of service delivery models on students with communication deficits. They found that collaborative classroom models of service delivery sometimes hold an advantage over

the pullout programs. This is because the success of collaborative classroom models may be determined by the target of treatment as well as the student's unique attributes. Further, the study observed that one model does not hold a significant advantage over another model.

In most SSA countries, classroom-based service delivery models are usually unavailable due to a serious shortage of therapists employed in the public sector (Morgan, 2011). In South Africa, for example, by 2012 from a total of 2170 rehabilitation therapists, an overall ratio of 2.4 occupational therapists and 2.66 physiotherapists are available per 100,000 sector population (Morgan, 2011). Therapy for children with CP in most of SSA is mostly conducted in hospitals with little or no standardization and focusing only on the available medical and rehabilitation services and skills in a particular area. Usually, rural communities do not have experienced medical and therapeutic staff trained in the assessment and management of CP (Morgan, 2011). Thus, delivering an effective service that addresses all the child's needs poses a real challenge to rehabilitation departments.

A multisite country study conducted by the African Child Policy Forum on children with disabilities in Africa (2012) found that financial costs attached to medical care, therapy, rehabilitation, assistive devices, and transportation of children with CP was the most significant barrier to access to therapy for children with CP in SSA. Community-based rehabilitation programs were consequently found to be effective in increasing access to education, therapy, and assistive devices that can aid the educational inclusion of these children. A review of institutional service delivery provisions in special needs education and rehabilitation in Nigeria in 2008, for example, found that inadequate facilities, funding, low government commitment, and lack of proper policy and legislation on disabilities were the key hindrances to full implementation of inclusive programs on special needs provision in schools. Furthermore, a report by SIDA on disability rights in Ethiopia (2014) regarding the situation of persons with disabilities in Ethiopia states that while the Ministry of Health is responsible for providing general health services to persons with disabilities along with the rest of the population, there appears to be little specific focus on disability within health policies. The study further found that despite all the legal provisions and institutional arrangements in place, the attainment of the rights of persons with disabilities remained a major concern, thus creating a barrier to their successful educational inclusion.

Augmentative and Alternative Communication

AAC approaches include the use of manual signs and symbol systems. It is also referred to as a total communication approach, whereby all possible communicative modes are considered as potentially useful for communication (Clarke et al., 2016). The study by Clarke et al. observes that developmental conditions, such as CP, are usually associated with a wide range of communication impairments that affect individuals of all ages. The communication impairments are frequently associated with motor, intellectual, and sensory impairments. Research has shown that a student who is unable to meet the communication demands within the regular classroom, whether or not they are modified, will likely adopt a spectator role in his or her education (Calculator, 2009).

Four reviewed studies (Calculator, 2009; Clarke et al., 2012; Karlsson, 2014; Sze, 2009) highlighted the benefit of AAC systems within the classroom environment. The most frequently reported advantage of using AACs was that they enabled students with communication difficulties, including CP, to have more access to the general education curriculum, especially in inclusive classrooms (Karlsson, 2014). To achieve adequate inclusion of learners with CP, connections must, therefore, be made between SLTs and other professionals who support student learning (Calculator, 2009). The reviewed studies indicate that when students and the multidisciplinary team work together alongside related health professionals in selecting and implementing assistive technology in the classroom, successful outcomes in the learners' academic participation are more

likely to occur (Karlsson, 2014). Teachers, on the other hand, play a pivotal role in supporting students who use aided AAC in inclusive classrooms, as confirmed by studies and reports from both low- and middle-income and high-income countries (Clarke et al., 2016). A study by De Bortoli et al. (2012) found that teachers reported complex factors that could contribute to or hinder successful communication, participation, and inclusion of students in need of using AAC within a classroom environment. These factors included student ability, availability and integrity of aided AAC, teacher skill, knowledge, expectations, self-efficacy, peer abilities, and attitudes. In most SSA countries, however, teachers experience challenges in relation to the use of assistive technology (AT) including AAC in schools. These challenges are observed in the form of inadequate provision, limited human resources to support implementation, and limited training of relevant personnel (Borg et al., 2011; Mukhopadhyay & Nwaogu, 2009). AT in SSA is mostly not used at all in schools for children with disabilities because the main focus is on identifying these children and making them go to school. Second, technologies, in general, are seldom used in the schools. The available AT technology (ICT-based) and AAC devices are mainly located in urban areas, such as at Kilimani Primary School in Kenya and Mwereni School in Tanzania (Cullen, 2009). Projects including AT for education most often rely on external donors and rarely receive government funding in many SSA countries.

In South Africa, education policy mandates appropriate aided AAC provision, implementation, effectiveness monitoring, and teacher training, yet specific implementation plans are not indicated in national policies. While available assistive devices have made a considerable impact on the inclusion of learners with disabilities in the school curriculum, many problems relating to the use of these devices in SSA contexts have continued to persist. A study on assistive devices by Disabled People South Africa observed that teachers in some special schools lacked understanding and knowledge regarding the relevance, availability, cost, and maintenance of AT and AAC devices (Gcaza & Lorenzo, 2008). The study also established that the devices that were available in schools were often not suitable for their learning contexts in SSA, hampering rather than enabling them. Another major problem identified by some learners was that they were often not allowed to keep their assistive devices, as these remained the property of the school. The abilities they acquired through the use of the devices were therefore of little use once they left school.

While the specific environmental barriers may differ from context to context in schools within SSA, technology in all its forms remains one of the most critical components in the educational inclusion of students with disabilities and specifically CP. Therefore, schools must explore ways to make AAC available across classroom inclusive contexts. Studies show the crucial role of AT in increasing access to the curriculum and the overall academic inclusion of students with CP. It is therefore imperative that teachers and related services personnel work in conjunction to ensure the best possible AT service implementation for these learners.

Discussion

The aim of this study was to review the articles on the critical components of the inclusion of learners with CP as practiced in various countries and to consequently draw conclusions for SSA. In this review, personal and environmental factors were found to play a key role in determining the extent to which learners with CP participate in inclusive education environments. Any efforts toward their successful inclusion in SSA should establish specific strategies to address such issues.

Learning Environment

The commonly mentioned learning environment factors were associated with service provision, institutional policies, attitudes of teachers and students, insufficient or lack of therapy, and AT.

Schools in SSA can, therefore, adopt similar strategies to facilitate barrier-free facilities and ensure availability of relevant equipment that have a direct influence on the inclusive education of learners with CP. To achieve inclusive education, appropriate school amenities such as toilets, seats or chairs, playground, doors, and classrooms should be designed in a way that also considers children with disabilities. With respect to the physical environment, the study *Schools for All: Including Disabled Children in Education* (Miles, 2002) examines the significance of the areas of transport and school buildings. The analysis of the situation in Zimbabwe, provided by the Leonard Cheshire Disability and Inclusive Development Centre in cooperation with University College London, highlights a lack of assistive devices and teaching aids along with insufficiently trained teaching staff and long distances to school as major barriers to school attendance (Deluca et al., 2015).

This chapter, therefore, recommends that schools in SSA should design an environmental assessment tool that describes the environments of children with CP. In addition, we recommend that schools adopt the Universal Design of Learning (UDL) framework in designing methods, materials, and the learning environment to make learning more accessible for all students, including those with CP (National Centre for Universal Design Learning, 2012). When UDL is implemented through a planned curriculum design and the use of supports, strategies, and tools for teaching and learning, it holds great potential to establish truly accessible learning environments for all students, including those with CP. This enables them to successfully meet their diverse academic needs. Furthermore, strategies for offering rehabilitative services such as occupation and SLT should be enhanced.

Attitudes Toward Learners with Cerebral Palsy

With regard to attitudes toward students with disabilities, the primary condition for successful inclusion of students with special needs in regular schools is to foster a change in the attitudes of teachers and students toward learners with CP. Negative attitudes toward inclusion of students with disabilities are often based on practical concerns about how education can be provided to these learners given their diverse needs. Common practical concerns raised by teachers include the following: accommodating the individualized needs of students with disabilities without disadvantaging other students in the classroom, lack of adequate support services, and limited training and competence in supporting inclusive educational practice. The severity of the disorder that teachers are required to accommodate within their classroom was also mentioned as associated with their attitude toward inclusion. That is, the more severe the child's disorder, the less positive teachers' attitude is toward inclusion. The type of disorder also appears to influence teachers' attitudes. The more complex the disorder such as CP, the less favorable the attitude.

This chapter, therefore, suggests that teacher training within SSA countries should play a pivotal role in developing affirmative attitudes and acquiring relevant skills in teaching these students to enable their successful inclusion. Teacher training has been identified as one of the main factors that promote an inclusive attitude within the school system. Pedagogies that combine formal training and planned hands-on experience with students with disabilities have been shown to improve preparedness and positive attitudes toward inclusion. Therefore, we recommend this for SSA countries. Moreover, irrespective of degree type, findings from a study by Vaz et al. (2015) show that trained teachers had a better understanding of the potential of children with disabilities after completing a unit of study with a strong focus on inclusive education.

Therapy

Regarding therapeutic services for learners with CP, the reviewed studies show that teachers believe that students benefit from SLT services in ways that could eventually benefit their classroom performance through enhanced literacy, written language skills, and socialization. School-based

service therapy for these learners can be enhanced through collaboration between the SLTs, classroom teachers, occupational therapists, physiotherapists, and the class teacher. The implications for the SSA school context is that therapists should be engaged more in the classroom in order to identify barriers to learning and offer intervention strategies and, if necessary, to assist the teacher in adapting the curriculum. They could assist teachers to assess and work with learners whose disorders affect the way they move and communicate. Mitchell (2015) notes that the curriculum is the bridge through which support in inclusive education settings needs to be given. The study observes that therapists can facilitate this by designing learning programs, sharing ideas for classroom activities, using alternate teaching methodology or ways of presenting information, and identifying the most appropriate assessment or evaluation tool for use in class. Through this type of collaboration, significant improvement in physical and communication skills among these learners can be achieved to benefit their academic inclusion. This review showed evidence for the effectiveness of classroom-based intervention that involved SLT-teacher collaboration in improving language abilities and some phonological skills among learners with communication disorder such as CP and can, therefore, be adopted in the SSA context.

Augmentative and Alternative Communication

The reviewed studies maintained that learners with little or no intelligible speech such as those with CP could benefit from the provision of AAC systems in the classroom. It is worth noting that mere access to AAC and other forms of technology in the general education classroom may not contribute to increases in learners' active participation in the curriculum. However, to achieve adequate inclusion of these learners, connections must be forged carefully and deliberately by SLTs and other relevant professionals who support these students' learning. The findings of this study have clear implications for education and training regarding the different roles and various forms of AAC that are available for children with significant multiple disorders such as CP, especially within the SSA context. It is true that the presence of CP involves significant motor and language impairments, thus making the use of AAC-related intervention more challenging for teachers and therapists. Furthermore, a significant number of therapists working with these children do not have expertise regarding the ways that AAC can be effectively used with this population of learners. Therefore, teacher training programs and continuing education programs must focus more intentionally on AAC for learners with CP. Additionally, schools must ensure that students with the most significant communication disorders are not overlooked in terms of providing them with a means to learn language and effectively communicate. Therefore, access to relevant AAC for learners with CP in inclusive African school settings calls for a multidisciplinary professional approach where schools establish systems involving parents and therapists (such as physical therapists and occupational therapists) in the learners' school environment who collaborate with teachers to facilitate successful school inclusion of learners with CP.

Considerations for Future Work, Research, and Politics

The present research could be replicated with children with other types of disorders such as autism spectrum disorder or hearing impairment currently attending special schools. It would be interesting to establish the critical components in the inclusion of all disorder types in regular schools. Such information would be vital in planning for inclusion while ensuring that learning environments have provisions for each specific disorder to make inclusion more practical and successful. Other designs such as a descriptive survey could also be used for similar studies. The present research also focused on the inclusion context. It would be interesting to investigate different academic issues such as instruction or academic achievement of students with disabilities and to consider the critical components that would ensure either their successful participation or their academic achievement.

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Stuttering's Hidden Side: The Need for an Empathetic School Climate for Disfluent School-Age Children in Public Primary Schools in Kakamega, Kenya

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Introduction

Having a stutter can be a disorienting and distressing problem for anyone, but it is perhaps even more overwhelming for young children of school-going age as they gain awareness of their speech difficulties and become cognizant of the reactions of others toward their speech. In a study by Okutoyi et al. (2016), a number of children who stutter in Kakamega County reported reduced classroom participation due to a fear of speaking in class, particularly when answering questions. Reading fluency may also be negatively affected by stuttering, impacting on academic performance (Yairi & Seery, 2011).

Beyond academic demand, there is a concern for social acceptance and identity. This emerges at a time when the social world is expanding for children and there are natural developmental demands for peer social acceptance. Disfluency becomes a significant problem at this point due to the participation restrictions which prevent children from achieving their social objectives (Guitar & McCauley, 2010). Learners who perceive their stuttering as more severe may score lower on specific domains of self-esteem, such as social acceptance and the ability to make close friends (Adriaensens et al., 2017). Stuttering can impact the quality of life of children by inhibiting their participation and affecting their acceptance of self (Guitar & McCauley, 2010).

According to Okutoyi et al. (2016), there were approximately 12,000 persons who stutter in Kakamega County in 2013, of which 4400 were children of school-going age. Additionally, between 2010 and 2013, 138 learners who stutter were assessed and placed in primary schools in Kakamega County. A baseline survey conducted in 2014/2015 indicated that learners who stuttered were placed in the lowest quarter of the class in examinations across primary schools in Kakamega County (Okutoyi et al., 2016). Despite this, there is only limited literature on the impact of stuttering on the quality of life of children and adolescents in African schools. Very little is known about the psychosocial effects and possible academic challenges resulting from disfluency in the African context. Thus, this chapter seeks to expand our understanding of the effects of stuttering among school-aged children in Kenya. It provides a detailed account of the classroom and school experiences of children who stutter and the impact this has on their quality of life (academic and psychosocial) at school.

Problem Background: Childhood Stuttering

Children who stutter are a group of children with a particular disability commonly referred to as "disfluency" or "stammering." This condition has no standard definition, and different perspectives exist regarding the definition. One simple definition is "a speech disorder (also known as 'developmental stuttering' because of its childhood onset) in those who are prone to experience, at least for a period of time, intermittent disruptions in the form of one or all of the following: sound/syllable repetitions, sound/postural prolongations and complete blockages of the vocal tract" (Yairi & Seery, 2011, p. 17–18). "Developmental stuttering" has its onset in childhood, while "acquired stuttering" is caused by trauma to the brain (Craig & Tran, 2006).

Characteristics

According to Yairi and Seery (2011), stuttered speech is characterized by frequent sound prolongations, recurrent word and syllable repetitions, broken speech, and substitutions or omissions of problematic words. As mentioned in Okutoyi et al. (2016), certain disfluencies are considered more characteristic of stuttering than normal disfluency. The aforementioned authors refer to three classic core stuttering behaviors, namely, part word repetitions (repeating a syllable or small part of a word rather than repeating the entire word), prolongations (holding on to audible sounds), and blocks (inaudible moments). These three core behaviors disrupt the integrity of a word, and thus, they are considered "intra-morphic," meaning "within the word" (Okutoyi et al., 2016). Stuttering can mani-

fest into part and whole word repetitions, prolongations of sounds or hesitations, and also at times only at the beginning of a word (Blumgart et al., 2012).

Physical movements and postures in the head and neck (and other parts of the body) may accompany stuttering; these are referred to as concomitant, secondary, or accessory characteristics (Yairi & Seery, 2011). These physical manifestations contribute to the overall impression of the severity of the stutter and vary from individual to individual. Commonly recorded secondary behaviors include head jerks, lip tremor, eyes closing, nostril flaring, irregular breathing, or jaw movements, to name but a few (Yairi & Seery, 2011).

The severity of the symptoms may vary depending on the speaking context, such as whether conversing in a large group of people or when speaking on the telephone (Blumgart et al., 2012). Murphy et al. (2007) assert that singing or speaking alone may improve fluency, but this also fluctuates as stuttering may vary from day to day.

For the reasons stated above, Reardon-Reeves and Yaruss (2013) posit that stuttering involves more than just a disruption of speech, but, rather, has connections with context and impacts heavily on a person's quality of life. Context in this discussion refers to various personal reactions an individual might project as a result of the impairment in terms of affect (a person's feelings, attitudes, and emotions), behavior (such as avoidance, tension, or struggle), and cognition (the thought processes related to disfluency as well as self-evaluation).

The reactions of those in the environment are equally included in this discussion as having a critical role as they influence the personal reactions explained above (Reardon-Reeves & Yaruss, 2013). As a consequence, therapists must consider a combination of factors while seeking to improve the quality of life of children who stutter. As such, interventions aimed at improving quality of life should be aligned with the International Classification of Functioning, Disability and Health (ICF), which includes the consideration of body functions and structures, activity limitations, participation restrictions, and barriers created by contextual factors (World Health Organization, 2001). Stuttering frequency, duration, type, and severity vary greatly for each individual (Yairi & Seery, 2011), and thus, stuttering should be examined on a case-by-case basis (Murphy et al., 2007).

Psychosocial Challenges

Psychosocial challenges associated with stuttered speech largely emanate from factors internal to an individual (symptoms of stuttering) that are exacerbated by factors outside the person (such as societal attitudes toward stuttering and other external barriers) (Blood & Blood, 2004). These two factors interact, causing difficulties in adjustment within social settings (Alm, 2005). Persons who stutter can then develop negative attitudes and beliefs regarding themselves and the way they speak, as a result of their stuttering (Craig et al., 2009). Eventually, this evolves into serious physiological (e.g., tension of the muscles involved in speech), emotional (embarrassment, guilt, and frustration), and attitudinal (cognitive) reactions to stuttering in adults (Craig et al., 2009). Such behaviors are not only disruptive to the communication process of adults who stutter but also impact on their quality of life, with negative perceived effects such as emotional instability and reduced mental health status (Craig et al., 2009).

As with any other disability, stuttering impairs an individual's ability to reach his or her life goals due to its negative cognitive and affective impact (World Health Organization, 2001). Murphy et al. (2007) provide an analogy of stuttering as "an iceberg": above the waterline lies the immediately visible and audible symptoms of stuttering, but below the waterline lies a wider set of symptoms such as negative self-perceptions and emotions. These feelings may include shame, embarrassment, frustration, anger, and guilt. Negative feelings such as these may cause an increase in the amount of tension and effort associated with speaking, which may in turn lead to increased stuttering. Over time, being continually exposed to negative speaking experiences may lead individuals to form a negative self-concept and self-image (Yaruss & Quesal, 2006; Yaruss & Quesal, 2010).

More evidence is shared by therapists who have been quick to use words such as "nervous," "fearful," "shy," "insecure," "suffers increased social distance," "lower evaluation by peers," and "not readily acceptable by peers," with only a few clinicians mentioning that individuals who stutter are able to adjust to interpersonal situations (Haynie et al., 2001). A study conducted in South Africa indicated that persons who stutter also report a high emotional cost, including jobs or promotions not received, as well as relationships broken or not pursued (Klompas & Ross, 2004).

Boyle (2013) identified that stereotypical claims and popular misconceptions exist relating to beliefs that an individual who stutters is less intelligent than a typical fluent speaker. Children who stutter typically experience bullying as well as negative reactions by peers (Murphy et al., 2007), which contribute to these psychosocial challenges.

Based on these findings, we can conclude that there is some degree of stigma and discrimination and stereotypical misconceptions that can lead persons who stutter to harbor negative feelings and attitudes about their communication abilities, avoidance behaviors, and limited interactions with others (Guitar, 2006). It can then be reasonable to suggest that the disorder is not only felt in communication but in various parts of an individual's life, for instance, in maintaining relationships.

Causes of Disfluent Speech

Scholars argue that there is no single exclusive cause of developmental stuttering (Guitar, 2006). This has led to various hypotheses being tested and a belief that a combination of factors contributes to stuttering. Generally, stuttering is determined by the factors and interactions between the factors discussed below.

Genetics

Research suggests that stuttering may have a genetic component. However, genetic links cannot account for all the incidences of stuttering. Studies of twins and adoptees are among the current studies supporting the genetic basis for developmental stuttering, although findings from these studies underscored that genes interact with the environment for stuttering to occur (Guitar, 2006; Kang et al., 2010). There are two possible models for genetic transmission: single-gene/major gene transmission and multigene/polygenic transmission, with polygenic transmission being more environmentally dependent than single-gene transmission (Richels et al., 2010). While previous studies in the 1990s proposed single-gene transmission to be the most likely transmission avenue for stuttering, more recently a large group of genes on chromosome 18 were identified as being linked to stuttering (Richels et al., 2010). These findings support the theory that stuttering may occur as a result of polygenic transmission, which requires multiple genes to be present.

A study by Kang et al. (2010) reported a genetic predisposition for disfluency even though the mutations accounted for only a small fraction of the total number of persons who stuttered in the general population. Ward (2006) published results indicating that children who had first-degree relatives, at least one family member who stuttered or who had stuttered as a child, were three times more likely to develop a stutter as children who did not.

These differences may lead to a breakdown in speech production and the development of disfluent speech. This is closely supported by the argument regarding the role of speech and language development in explaining the development of stuttering (Dale et al., 2012). According to studies, children who stutter not only show some stuttering types of behavior but also exhibit some other difficulties. More specifically, speech and language delays in children have often been associated with stuttering-type behavior in childhood.

Developmental Factors

According to the communication-emotional model, stuttering develops as a result of an interplay between communicative, linguistic, emotional, and motor variables (Richels et al., 2010). The majority of children aged 2–4 years display relatively effort-

less disfluencies, which are part of the normal developmental course of language acquisition (Roth & Worthington, 2005). However, children who stutter may be significantly more emotionally reactive, with poorer abilities to regulate their emotions and their attention compared to their non-stuttering peers (Conture et al., 2006). These emotional processes impact speech and language planning, which influence the quantity and quality of disfluencies (Conture et al., 2006).

Environmental Factors

It is believed that environmental variables can influence childhood stuttering (Richels et al., 2010). These variables can be subtle and do not have to reach an extreme level (such as child abuse). The aforementioned authors use the example of a perfectionistic father who routinely makes comments about his child's mistakes. As noted by Guitar (2006), parents' reactions to their child's normal disfluencies, parental demands for increased complexity during language and speech development, and low socioeconomic status have been linked to stuttering. Richels et al. (2010) postulate that children who stutter may be more reactive to influences in their environment. It is worth noting that the environment (in particular, parental behavior) does not alone cause stuttering. Rather, environment is an important factor that might aggravate stuttering in a child that has a predisposition to stuttering.

Prevalence and Incidence

Prevalence refers to the estimate of the number of cases of stuttering at a given time, while *incidence* refers to the probability that new cases of stuttering will develop over time, and *lifetime incidence* refers to the possibility that individuals will develop stuttering at any time in their lives (Yairi & Seery, 2011).

Stuttering affects individuals of all ages. However, stuttering occurs most frequently in young children who are developing language, particularly during the development of the use of two to three word phrases, with an estimated spontaneous recovery rate of 65–80% up to the teenage years (Abou et al., 2016).

Stuttering is a relatively low-prevalence disorder among adults (less than 1% of adults stutter). However, estimates of the *lifetime incidence* of stuttering range from 4% to 8.5% (Rees & Sabia, 2011). As cases of stuttering may subside after a certain period of time, these figures are difficult to determine, and estimates may be influenced by the amount of time that the disorder has been present (Yairi & Seery, 2011).

Even though stuttering has not been extensively studied in Africa, a few scholars have pinpointed that it occurs among school-age children in Africa just as in other parts of the world. A study by Abou et al. (2016) on the prevalence of stuttering among 8765 primary school children in Cairo (Egypt) placed the prevalence rate at 1.03%. Results of this study indicated that stuttering was sevenfold more prevalent among left-handed students and higher among male students but showed a declining trend in the older age group within primary school children.

A study by Nsabimana (2010), which was conducted in 11 African countries, revealed that there were approximately 232,088,330 persons who stutter in these 11 countries, based on the universally accepted incidence of 1%. However, in 2010, there were only 67 speech therapists treating stuttering in these countries with only 728 individuals receiving intervention for stuttering. Knowledge about stuttering prevalence and incidence is thus vitally important for professional training and the planning of public healthcare services (Yairi & Seery, 2011).

School-Age Children Who Stutter: Psychosocial and Academic Challenges

Psychosocial Effects

Psychological challenges resulting from frustration, anxiety, and embarrassment may be linked to stuttering (Guitar, 2006). Some children who stutter do not have any negative feelings associated with talking, while others do. It is important to

know that a child's feelings about talking may not be related at all to how much he or she stutters. That is, a child whose stuttering appears to be mild may have more negative feelings related to talking in class than a child whose stuttering appears to be severe. If a child has negative feelings about speaking, he or she may withdraw from social situations such as sitting with others when eating or playing with a group of peers on the playground. Results of the study by Abou et al. (2016) indicate that 25% of families of affected children who stutter in Cairo expressed anxiety regarding their child's stuttering. Furthermore, the most frequently reported reactions of families include worry/anxiety/concern, uncertainty, and frustration (Langevin et al., 2010).

Nonetheless, children who stutter often experience stigmatization. This can internalize as self-stigmatization. The majority of Kenyan learners who stutter who participated in the study by Okutoyi et al. (2016) reported self-stigmatization and a negative perception of themselves.

Describe social anxiety, emotional tension, and discomfort in social situations as well as significantly fewer social responses among children who stutter as compared to their non-stuttering peers. Similarly, Aslam (2013) observed that stuttering leads to frustration after blockages or repetitions, as well as negative feelings of embarrassment, self-stigma, and, eventually, social withdrawal as a result of negative attitudes from other people. Furthermore, a study on children who stutter in Kenya also indicated that children who stutter show a number of secondary stuttering behaviors like accompanied pronunciation with unusual facial expressions needed more time to pronounce a word and tended to stutter more when they were feeling angry, excited, speaking to a person with authority, or under pressure (Ogutu, 2005).

Stuttering that persists into adolescence or adulthood has been shown to affect psychological health through social phobias, educational underachievement, and reduced social well-being. However, young preschoolers who stutter do not present with the same negative psychosocial symptoms (Howell, 2004; Reardon-Reeves & Yaruss, 2013). In fact, their language and nonverbal cognitive skills were found to be better than their non-stuttering peers, and they did not exhibit shyness or withdrawal. By the end of preschool, however, negative attitudes toward speaking begin to emerge (O'Brian et al., 2011). This suggests that negative experiences have a cumulative effect on psychosocial well-being over time.

Bullying and Teasing

Bullying refers to coercion through force and emotional/physical/verbal abuse, while *teasing* refers to mocking or provocation in a playful yet still hurtful manner (Kathard et al., 2014). Children who stutter are more susceptible to bullying and teasing than their non-stuttering peers. While exact figures for children who stutter in Africa have not yet been established, it is estimated that 81% of children who stutter in America experience bullying or teasing (Murphy et al., 2007). Bullying and teasing of children who stutter have also been cited as problematic in South African primary schools and among adolescents who stutter in Kenya (Okutoyi et al., 2016).

The short-term consequences of bullying and teasing include low self-esteem and reduced self-confidence, while children who are bullied may experience long-term social, psychological, emotional, and physical consequences (Kathard et al., 2014).

Children who stutter could be perceived by their peers as being shy or withdrawn, which could lead to reduced acceptance. Overt characteristics of stuttering could also trigger mimicking or name-calling, increasing exclusion, and increasing teasing. These factors, together with the fact that children who stutter are usually less popular than their more fluent peers, increase the risk of being bullied and teased by their peers (Adriaensens et al., 2017). Due to the negative impact that bullying can have on a child's self-confidence, it can further exacerbate stuttering behavior, promote the use of avoidance strategies, and increase negative emotions and thoughts (Murphy et al., 2007).

Academic Impact of Stuttering

Major emphasis is placed on verbal skills at educational institutions, which can cause anxiety in children who stutter, even during routine educational activities (O'Brian et al., 2011). When a child stutters, their academic performance and social life may be affected. The child may hesitate to raise their hand in class, read aloud, or talk with other children in the class (Davis et al., 2002; Guitar, 2006).

Recently, a study investigating children who stutter in primary schools in Kakamega County, Kenya, could show that children who stutter performed poorly and were found in the lowest quarter of the class based on examinations (Okutoyi et al., 2016).

A study on adults who stutter conducted in the United States found an inverse relationship between stuttering severity and educational attainment as assessed through self-rating scales. Thus, the adults who reported having the worst severity of stuttering also reported lower educational achievement than those who reported milder symptoms (O'Brian et al., 2011). Although the study could not provide conclusive evidence about the specific factors contributing to lower academic achievement, it does suggest that stuttering has an influence on this.

Research Questions

Despite the pain that children who stutter go through and the fact that these children are found in every culture, race, community, and classroom, little research attention has been devoted to this communication disability in the African context. The psychosocial effects and possible academic challenges resulting from stuttering have not been documented in African school setups. This chapter aims to expand our understanding of the effects of stuttering by providing an account of the classroom and school experiences of children in Kenya who stutter and the impact of this on their quality of life (academic and psychosocial) in school.

The following research questions were considered:

1. What are the perceptions of children who stutter in a public primary school in Kakamega Municipality regarding the cause of their disfluency?
2. What are the perceptions of teachers in a public primary school in Kakamega Municipality regarding this disfluency?
3. What are the psychosocial experiences of children who stutter in a public primary school in Kakamega Municipality?
4. What effects do psychosocial experiences have on the psychosocial and academic well-being of children who stutter?
5. What coping mechanisms are employed by children who stutter and their teachers in a public primary school in Kakamega Municipality?

Methods

Research Design

A cross-sectional mixed method design was chosen as it provides the opportunity to examine different perspectives on the same issue, using both qualitative and quantitative information (Zheng, 2015). Focus group research was used to investigate the experiences of the children, as it attempts to build a holistic understanding of a specific problem situation based on the comments and experiences of the participants (Bhattacherjee, 2012). The groups facilitated capturing the feelings and emotions of participants, but also facilitated obtaining information regarding personal life accounts, school and classroom experiences, the effects of the disorder on psychosocial well-being and school participation, and children's coping strategies. It also enabled children who stutter to enjoy support from their non-stuttering peers. Further, the involvement of friends and peers in the informal group conversations facilitated acceptance, openness, and genuine support for children who stutter. A structured survey questionnaire was used to obtain data from teach-

ers, as it could be easily tailored to obtain the needed information (Mrug, 2010).

Participants

Participants were sampled at one primary school in the Kakamega Municipality, Kenya. There were 48 participants in total, consisting of 15 teachers, 11 children who stutter, and 22 non-stuttering peers. The children ranged from 8 to 14 years old, with a mean age of 10 years. Purposive sampling was used. The teacher referral method (Keating et al., 2001) was used initially, whereby the teacher referred children who potentially stutter from his/her class.

Instruments

The informal conversation guides as well as a teacher questionnaire were originally designed by the current author since an extended literature search did not yield any suitable existing instruments which met the specific needs of the study.

The informal conversation guide comprised 15 items, including both closed- and open-ended questions, with structured items supplemented with additional follow-up questions. The questionnaire comprised 18 items to which responses were made on a five-point Likert scale to assess teachers' views on the prevalence of disfluency and psychosocial challenges related to stuttering among school-age children. A four-point Likert scale assessed the effect that stuttering was viewed to have on five life components (children's relationships, academic achievement, personal development, emotional stability, and school adjustment). Through informal conversation and interview guides, teachers' views and experiences with learners who stutter, specifically on academic outcomes and interaction behavior, were sought. Internal consistency of the questionnaire was established using Cronbach's alpha, where a score of 0.74 was obtained. According to Field (2013), a coefficient alpha equal to 0.70–0.80 or greater indicates adequate reliability. The questionnaire was piloted on five teachers before commencing with the data collection.

Data Collection

During the personal interview, a 30- to 45-min conversation with each student was carried out; this was partly spontaneous and partly elicited by pictures. Three informal group conversations were conducted.

Authority was sought from gatekeepers before data collection commenced, whereby the objectives of the research as well as ethical considerations were explained. Study participants were informed that participation was voluntary and were assured of the anonymity of their responses and confidentiality of the information shared before taking part.

Data Analysis

Qualitative and quantitative data were coded, thematically categorized, and analyzed using descriptive statistics and presented in the form of frequencies, means, percentages, and thematic narratives. These results were supported by the inclusion of verbatim excerpts, discussed in line with the previous literature.

Results

Causes of Stuttering Disorder as Perceived by Children Who Stutter

With regard to perceptions on the causes of stuttering, all 11 children who stutter (100%) believed that they were born with the condition, although it was reported that many people in the community and also their peers would try to persuade them to moderate their intake of sugar, believing that consuming too much sugar in drinks and sweets and chewing too much sugarcane leads to stuttering.

Stuttering Disorder as Perceived by Teachers

Nine teachers (60%) described stuttering as a communication difficulty. Another six (40%) described it as a learning disability. None of the respondents described it as a behavioral or emotional disability. Teachers reported further on the prevalence of the disorder and its effects on the psychosocial well-being and academic participation of children who stutter as detailed below.

Stuttering Prevalence as Reported by Teachers

Two teachers (13.3%) had encountered a majority of girls being affected by the disorder. The 13 remaining respondents (86.7%) identified boys to be the majority of learners for whom stuttering occurs most often. With regard to the level of severity, six (40%) of the class teachers indicated that they had encountered mild disfluency during their teaching careers. The nine remaining teachers (60%) considered most of their encountered incidences to be at moderate levels.

Effect of the Disorder as Reported by Teachers

Perceptions of teachers with regard to the effect that stuttering has on children's relationships, academic achievement, personal development, emotional stability, and school adjustment were obtained. The results are presented in Table 34.1.

All teachers (100%) reported that stuttering has a small effect on forming and maintaining relationships among pupils. Its effect on learning was believed to be moderate as indicated by three (20%) of the respondents, while 12 (80%) perceived the effect of stuttering on learning to be small. The personal development of pupils was identified to be either moderately or to a great extent affected by stuttering, as indicated by four (26.7%) and 11 (73.3%) of the respondents, respectively. The extent of effect on emotional stability was reported to be great by six (40%) of the teachers, while three (20%) and six (40%) classified stuttering to have moderate and small effects, respectively. Pupils' school adjustment was considered to be moderately affected by stuttering according to six (40%) of the respondents, while nine (60%) believed that stuttering has a small effect. In summary, disfluency was reported by all teachers to have some effect on all the facets investigated.

Table 34.1 Teachers' perceptions of the academic and psychosocial effects of stuttering on life components ($n = 15$)

Life components	Great extent	Moderate extent	Small extent	Not at all
Forming and maintaining relationships	0	0	15	0
Learning and academic achievement	0	3	12	0
Personal development	0	4	11	0
Emotional stability	6	3	6	0
School adjustment	0	6	9	0

The prevalence of antisocial behavior toward and negative experiences of children who stutter was also investigated. Teachers recorded the cases and encounters of children who stutter based on the psychosocial issues indicated in Table 34.2.

Cases of bullying, teasing, and name-calling reported by pupils who stutter was occasionally observed by six (40%) of the respondents. The same number of respondents also made the observation that cases of bullying, teasing, and name-calling were rarely reported by pupils, while three (20%) of the respondents had never made such observations.

Pupils suffering from physical bullying on playgrounds and during class tasks were reported rarely by 12 (80%) of the respondents, while three (20%) of the respondents had never had such an experience. "This pupil feels anxious, shy, nervous, and wary of mistakes made during conversations" was reported as happening very often by six (40%) teachers and occasionally by nine (60%) teachers.

Nine (60%) respondents indicated that children occasionally become withdrawn or depressed, while six (40%) responded that this happens rarely. Pupils who stutter were occasionally bullied and teased by classmates and friends according to six (40%) of the teachers, while the same number of

Table 34.2 Teachers' self-reports on cases and prevalence of psychosocial challenges with the presence of a stutter

	Very often		Occasionally		Rarely		Never		Total	
Statement	N	%	N	%	N	%	N	%	N	%
Cases of bullying, teasing, and name-calling are reported by the child.	0	0	6	40	6	40	3	20	15	100
The pupil suffers physical bullying in playgrounds and during class tasks.	0	0	0	0	12	80	3	20	15	100
The pupil feels anxious, shy, nervous, and wary of making mistakes during conversations.	6	40	9	60	0	0	0	0	15	100
He/she is withdrawn and depressed.	0	0	9	60	6	40	0	0	15	100
The pupil is bullied and teased by classmates and friends.	0	0	6	40	6	40	3	20	15	100
He/she is reluctant to participate in many activities involving verbal exchange.	9	60	6	40	0	0	0	0	15	100
He/she reports items stolen and/or themselves labeled/teased by peers.	0	0	6	40	6	40	3	20	15	100
People in school, including teachers, label this child as having special education needs.	0	0	0	0	6	40	9	60	15	100
He/she experiences ridicule, rejection, dislike by peers, and/or exclusion from group activities at school.	0	0	0	0	15	100	0	0	15	100
He/she is dismissed, stigmatized, and laughed at by both teachers and pupils.	0	0	0	0	0	0	15	100	15	100
He/she experiences low self-esteem and poor self-concept.	0	0	15	100	0	0	0	0	15	100
He/she exhibits attention-seeking behavior.	0	0	0	0	15	100	0	0	15	100
He/she displays truancy and dislikes school.	0	0	0	0	15	100	0	0	15	100
He/she exhibits academic difficulties and low achievement.	0	0	9	60	6	40	0	0	15	100
He/she is a bully and aggressive and loves fighting peers.	0	0	0	0	9	60	6	40	15	100
He/she is competent in academic work.	0	0	6	40	6	40	3	20	15	100
He/she takes responsibility in class and school.	6	40	6	40	0	0	3	20	15	100
He/she experiences tension and feels rushed as he/she struggles with conversations with both pupils and teachers.	0	0	15	100	0	0	0	0	15	100

teachers (40%) perceived this as happening rarely and three of the teachers (20%) never had received such complaints.

"Children who stutter are often reluctant to participate in many activities involving verbal exchange" was believed by nine (60%) teachers to occur very often, while six (40%) occasionally identified students to be reluctant to participate in many activities involving verbal exchange. Children who stutter were observed to occasionally report stolen items and themselves be labeled or teased by peers according to six (40%) teachers, while this occurred rarely according to another six (40%) teachers. The three remaining teachers (20%) believed that pupils who stutter had never reported stolen items and themselves being labeled or teased by peers.

People at school, including teachers, rarely label children who stutter as having special education needs. This was reported by six (40%) teachers, while nine (60%) had never experienced people at school labeling a child as having special education needs. According to all the respondents (100%), affected pupils rarely experience ridicule, rejection, dislike by peers, and exclusion from group activities in school, while all of the respondents believed that the affected pupils had never been dismissed, stigmatized, and laughed at by both teachers and pupils. All respondents (100%) indicated that the pupils would occasionally experience low self-esteem and poor self-concept.

Pupils who stutter were reported to rarely exhibit attention-seeking behavior, truancy, or dislike for school. This was a unanimous sentiment from all the respondents (100%). Occasionally, the pupils exhibited academic difficulties and low achievement as indicated by nine (60%) teachers compared to six (40%) who rarely experienced these difficulties. According to nine (60%) teachers, children who stutter were rarely found to be bullies or aggressive toward peers. The other six (40%) teachers found this statement never to be true.

The presence of academic competence in children who stutter was occasionally present according to six (40%) teachers. The same number of teachers (40%) agreed that academic competence is rare among children who stutter. The three remaining teachers (20%) believed that these pupils are never competent in academic work. Pupils who stutter being in a position of responsibility in class and school was endorsed by six (40%) of the teachers, while another six (40%) indicated that the pupils could occasionally have responsibility in class and school and three (20%) reported that this was never the case. All teachers (100%) ascertained that these pupils could occasionally experience tensions and feel rushed in conversation, leading them to struggle with words.

Results from the interview accounts seemed to suggest that more girls than boys experience sudden pauses, hesitations, lack of smooth speech, lack of fluency, and display poor coordination. Children who stutter were also found to have problems with answering questions, reading, talking in class, and sustaining conversations even when out of class.

Teachers classified children who stutter as either average, above average in academic merit, or perhaps even better than their non-stuttering peers. The major downside of stuttering mentioned by all the teachers related to social interaction. Children who stutter were suggested to have only a few friends which seemed to limit their possibilities and experiences in collaborative classroom settings, but generally, stuttering was believed by teachers not to affect their relationships.

Nature of Psychological Experiences Related to Stuttering as Perceived by Children

Concerning psychological experiences related to the disorder, children were asked to state the nature of their psychosocial experiences and the instances when these mostly occurred. This took various forms such as name-calling, imitating the speech of children who stutter, and bullying. A grade seven girl summarized it this way:

> Most pupils call us names, tease, laugh at me, imitate my speech while others like commanding me to repeat my utterances however much I try to be clear.

> They usually pretend that I am not clear. They know obviously that with intense pressure we get stuck. When this happens my classmates start giggling and laughing, staring at me. I become more anxious of making mistakes and totally become sullen and unable to read or answer any question. My friends usually encourages me and when she does, I am usually able to read well without stoppages and hesitations. For some pupils, we are pretenders who do not want to take up classrooms tasks and are seeking for sympathy from the teachers. Sometimes they create conversations by borrowing things from me and fail deliberately to return [them], just to see how I respond or whether [I] can gather confidence to report. They are very happy or eager to listen to [me] presenting his case to the teacher.

She pulled back her chair and continued:

> A lot of bullying and teasing happens in the playground when I talk so fast and during language lessons which require individual reading. Most times my classmates look forward for my reading turn or to answer a question in class. On many occasions, when I am identified by the teacher this thought of making mistakes makes me sweat, shake, and sweat. I only wish they could stop laughing at me so that I can feel relaxed. I know when I am not tensed I can read so well without tension.

School-Age Children Who Stutter: Psychosocial Effects and Academic Challenges

With regard to affective or emotional reactions to their stuttering, children who stutter were asked to state how it affected their sense of self-esteem, positive self-concept, and self-identity. One grade five boy reflected on this as follows:

> I was once sent by my mother to buy body oil from a shop. I set out to the shop but on reaching the shop, I could not be served by the shopkeeper because I could not say what I wanted to buy. I returned home (which was quite a distance) quite embarrassed with myself knowing that my mother [was] equally going to feel really upset (she was to rush to take our small sibling to the hospital). On reaching home, my younger sister (follower) asked me to show what I bought. I showed her the money, not able to explain myself still (stuck again). My mother approached me and ordered me to go back to the shop (this time in the company of my younger sibling sister and our neighbor's son (5 years old). She instructed them about what to tell the shopkeeper in case I was not able to express myself again. We successfully went and before I handed the money to the lady (shopkeeper) my younger sister ably expressed our desires and we were served immediately and returned home. I felt ashamed, guilty, and helpless. I live with self-doubt always. I am not sure of myself all the time. I fear speaking in front of even younger siblings and peers both at home and in school because I know I will make mistakes. I cannot do simple things that very young children are capable of doing. This makes me feel so bad.

The children who stutter were further asked to state how the disorder affected their academic participation and performance in school. A grade eight boy explained his experiences as follows:

> I love school so much and attend regularly. I do my homework regularly. I feel this communication disability does not really affect my performance because not all schoolwork demands oral presentations. I can always read silently and do all my assignments. I usually do well. Apart from English and Kiswahili lessons where we usually read one by one and then the teacher follows with oral questions, other subjects are just fine. However, at times others teachers also ask questions which most of the times I may know their answers but communication is usually my greatest problem. Many times this lands me in punishment, just as the rest of my classmates who may not be having answers for the questions. Teachers treat me differently. Here, ones who are aware of my problem are usually patient with me, giving me more time and at times skip or avoid giving me verbal assignments while others shout at me and send me out of class sometimes.

This was also exemplified in the sentiments of another respondent (grade seven boy):

> In most of the classroom tasks and subjects, I normally do have answers to teachers' questions but because some teachers rush too much and scare me, I sometimes suddenly feel my heart beating quite fast and start trembling especially when the teacher approaches me. I never utter a word anymore, get stuck completely, and cannot just express myself even when I know the answers to questions asked. As a result, I am frequently beaten and thrown out of class, as many times as my classmates who don't provide answers to teachers' questions.

On the issue of preferred subjects in school, the boy added:

> I like subjects like mathematics and science. I dislike social studies because the teachers ask many questions very quickly and requires also quick

> answers yet I cannot talk fluently when rushed. I have dropped in this subject in the last term. This teacher beats me so often and believes I know nothing. I believe she does not know my problem.

Information regarding teasing and bullying was also explored and is reflected in the sentiments of a grade seven boy:

> On the playground, I find it so hard with my problem. One day a class six boy started teasing (telling me to say my name) and went further to hit me with a stone. I decided to report the matter to the teacher. I set out to my classroom and found the teacher on her desk. I struggled with words but I was stuck, I was not able to narrate my ordeal. The teacher starred at me helplessly but I was blocked completely. She felt sorry for me because at that time I was in tears. I left the teacher's desk and went to my desk, feeling furious, angry, bitter, and ready to revenge. After an afterthought, I walked hurriedly out of class and decided to search for the boy and possibly hit him back but I could not find him. He was long gone. I strongly believe that is why some stammerers just hit those who tease and bully them rather than waiting to report [it].

Coping Strategies

With regard to coping strategies that work, for most children, this was having their friends around them and also the fact that most of the teachers in the school are warm and considerate. This was exemplified in the words of a grade five boy:

> I usually ensure that I am surrounded with my friends. With them they help when I am stuck or when mischievous children snatch my items, intimidate or abuse me, they defend and explain my case. Sometimes because they hate seeing other children tease me, they report to the teachers or just scare away those who tease me and at times they are ready to fight back by either abusing or even fighting them physically. Most times when I struggle to speak well and [am] unable, they tell the teacher what I meant to say.

He went on to add:

> Most teachers are loving and they treat us with respect. They also punish those classmates who bully us in school. They encourage everyone to read, hold conversation in class to take part in curricular activities of our choice. However, even when teachers punish and rebuke those who tease or bully me this does not end. It is only successful in class but in the playground, on the way home, around the toilets this bullying still continues.

Discussion

The objective of this chapter was to expand our understanding of the effects of disfluency on the psychosocial well-being and academic participation of children who stutter in Kenya. It provides an account of the classroom and school experiences of children who stutter and the impact of this on the quality of their school life (academic and psychosocial). The following section highlights the key results of this study and discusses the potential implications of this work.

Causes of Stuttering as Perceived by Children Who Stutter

As noted in the results section, all the children cited that they were born with stuttering, despite the fact that others in their community cited sugar as the cause. This reflects the fact that there are different cultural interpretations of the causes of disability in African countries (Legg & Penn, 2013). Further investigation into the perceived causes by community members may be warranted.

Stuttering Disorder as Perceived by Teachers

It appears from the results that teachers rarely classify children who stutter as ill-disciplined. One hypothesis may be that the social withdrawal and negative self-perceptions that develop as a result of long-term stigmatization and bullying (Aslam, 2013) may influence the behavior of children who stutter at school.

In the interview accounts, teachers opined that the major difficulty associated with stuttering is the inability to form social ties or gain social acceptance

from peers, which is an important element in students' academic progress. However, they were quick to mention that children who stutter have almost equal academic competence and at times are superior in intelligence compared to their compatriots.

The teachers' perceptions centered very much around peer interactions, with only half of the respondents citing that children occasionally feel rushed by teachers and pupils, and the stated perceptions were that children are never stigmatized by teachers or pupils. However, this is in direct conflict with comments made by some of the children during the focus groups.

Teachers indicated that children in their school who stutter occasionally had to contend with feelings of anxiety, shyness, social withdrawal, and depression, similar to findings from studies conducted in other countries (e.g., Manning, 2001; Shapiro, 2011) as well as the study conducted in Kenya by Okutoyi et al. (2016). In addition, teachers perceived that children who stutter occasionally have cognitive responses such as poor self-concept, which has also been identified by scholars the world over (e.g., Manning, 2001; Reardon-Reeves & Yaruss, 2013).

Results indicated that more girls than boys are noted to experience sudden pauses, hesitations, lack of smooth speech, lack of fluency, and poor coordination. Children who stutter are found to have problems in answering questions, reading, talking in class, and sustaining conversations even when out of class, although they are found to be average and above average in academic merit, perhaps even better than their non-stuttering peers. They also have few friends, but generally the condition is believed by teachers not to affect their relationships.

Nature of Psychological Experiences Related to Stuttering as Perceived by Children

In contrast to the perceptions of the teachers, the focus groups with the children identified stigmatization and bullying, as well as strong feelings of shame. As was identified by a grade five boy, stuttering evokes particular feelings of withdrawal, shame, guilt, and inferiority among younger and older non-stuttering siblings and peers.

School-Age Children Who Stutter: Perceptions Related to Psychosocial Effects and Academic Challenges

Although teachers reported that children who stutter do not have particular academic difficulties as a result of their disfluency, children indicated a different perspective. As one grade seven boy indicated, his marks dropped in one subject due to the immense pressure placed on him to speak in that context. He also cited that the "teacher beats me so often and thinks I know nothing." This type of response was reflected by another participant who also stated that he is shouted at and sent out of class. Based on the interview results, children who stutter seemed to like teachers who were warm, emotionally sensitive, and accommodative, but not those who were cruel, loud, impatient, inconsiderate, and rough. The focus groups indicated that a fear of speaking may contribute to negative academic repercussions, in line with the findings by Okutoyi et al. (2016). As the environment plays such an important role in the development of stuttering (Richels et al., 2010), comments related to negative responses toward stuttering by the teachers are concerning. Overall impressions of fear and anxiety (such as "some teachers scare me") characterize the relationships between many of the children who stutter and some of their teachers.

Teasing and bullying by non-stuttering peers also emerged as being a common occurrence across the school premises, from classroom to playground. The teachers mentioned low to medium rates of children who stutter reporting bullying. However, as mentioned by a grade seven participant, he found it difficult to relate his bullying ordeal to his teacher as, at that moment, his stuttering was very severe.

Another psychosocial effect that emerged during the focus groups was the development of a negative self-concept and self-stigma. As mentioned by a grade seven girl, "my classmates look forward to my reading turn." This reflects the

internalization of negative self-perceptions, as described by Aslam (2013).

This study highlights the prominence of negative reactions to stuttering in young children and also that children who stutter are aware of their stuttering at school age (Packman et al., 2003). Such findings underpin the negative impact that stuttering can have on a child's social interaction, especially in a non-empathetic school environment.

Coping Strategies

It appears as though children who stutter rely mostly on their friends as sources of support, rather than on their teachers. Teacher intervention with regard to reprimanding peers who bully only seems to have an effect in the classroom, without generalization to other contexts. The feasibility of a classroom-based intervention should be considered in these contexts, such as the successful implementation of the Teasing and Bullying: unacceptable behavior (TAB) program in Cape Town primary schools by Kathard et al. (2014).

Impact

This study has highlighted the need for interventions targeted at teachers' understanding of stuttering, as well as the development of empathetic school environments in Kakamega, Kenya. The extant literature (Bloodstein & Ratner, 2008; Blumgart et al., 2012) emphasizes the value of openness regarding stuttering and sensitization, fluency facilitation techniques, and knowledge on how to deal with children's moments of stuttering. Whether directly or indirectly, these techniques have the potential to increase children's self-esteem, enable children who stutter to understand and express their feelings, including embarrassment, pain, and/or frustration with understanding and support. They also provide the disfluent school-age child with an increased feeling of a genuine sense of power. Teachers who are aware of these techniques can modify their own interactions and those of others (peers, siblings, and classmates) who come into contact with children who stutter. Ideally, such positive approaches to disfluency have the potential to create more positive emotional climates for children who stutter, allowing their uniqueness to be tolerated and not punished. Increased acceptance of children who stutter is likely to boost their psychosocial well-being, their participation in classroom tasks, and perhaps even their levels of academic achievement. Clearly, any therapy or intervention targeting this group of children that does not include all those who are part of the lives of the children who stutter (including parents, peers, and teachers) as part of the assessment and therapeutic process may well undermine the efforts to help the child.

Study Limitations and Considerations for Future Work, Research, and Politics

This study used self-report measures (completed by children who stutter and their peers, as well as teachers) to assess the psychosocial experiences and effects of stuttered speech in young people. The sample for this study was rather unrepresentative and findings may have been impacted by sampling bias (Holmes, 2018), making it impossible to generalize this data to the general population of children who stutter, even though the disorder is quite rare. Subsequent research might consider involving larger samples and a range of research designs such as comparative and longitudinal investigations to further evaluate the impact of stuttering in adolescents and adults in Kenya. Further investigation into the perceived causes and influence of culture on the stuttering phenomenon is also warranted.

In summary, the present study elucidates the adverse psychosocial impacts and negative consequences associated with living with a stutter from a young person's perspective in Kenya. The results indicated that these consequences stem from both peer and teacher interactions. This urges the need for a refocus on teasing and bullying, as well as the need for teachers to create empathetic environments in their classrooms.

From these findings, it follows that there is a need for clear awareness programs that aim to cre-

ate friendly atmospheres in schools, where diversity is tolerated and not assaulted. This has the potential to enable learners to actualize their academic dreams. Research studies of uncommon disorders such as stuttering should make use of qualitative interpretive techniques to allow in-depth analyses. This would go a long way toward informing the design of comprehensive, individually tailored approaches for assessments, therapies, and means of managing the impact of stuttering within school setups and communities in Kenya.

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Ugandan Sign Language Interpretation Services for Learners with Hearing Impairment in Inclusive Secondary Schools in Uganda: Challenges and Successes

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Introduction

The introduction of the universal secondary education (USE; Ministry of Education and Sport, 2015) training of sign language interpreters and education of learners with hearing impairment at the high school level has not yet attracted enough attention at different educational levels such that learners with hearing impairment have a right to benefit. Article 35 (1) of the Constitution of the Republic of Uganda recognizes the promotion of the education of learners with a hearing impairment (Government of Uganda, 2015). Principle XVI (p. 26) of the amended Uganda Constitution, 2015, states that:

> Persons with disabilities have a right to respect and human dignity and the state and society should take appropriate measures to ensure that they realize their full mental and physical potential.

The Constitution of the Republic of Uganda, principle XXIV (c), under the cultural objective, further states that "the state shall promote the development of Ugandan sign language for the deaf" (p. 27). These legal provisions, therefore, permit persons with hearing impairment to have equal access to education in the best way possible, in this case, through the services of professionally trained sign language interpreters.

Uganda has embraced inclusive education through the establishment of district-based support services which are available to teachers in all 56 districts in Uganda (Lynch et al., 2011). This is in agreement with the ratified United Nations Convention on the Rights of Persons with Disabilities (United Nations General Assembly, 2008) and declarations for the rights and equalization of opportunities for all persons with disabilities, including those with hearing impairment, as stipulated in the National Policy on Disability (Ministry of Education, Science, Sports and Technology [MoESST], 2015). This consideration is applicable irrespective of the social status or level of disability experienced by those living with a disability. This commitment is evident from the existing legal frameworks surrounding education and the establishment of an infrastructure that enables the inclusion of learners with various disabilities, such as the policy of affirmative action in educational institutions. Notable among others is the establishment of a fully fledged Faculty of Special Needs and Rehabilitation at Kyambogo University, a functioning department in charge of special needs curriculum adaptations at the National Curriculum Development Centre, a department at the Uganda National Examinations Board, and a Special Needs and Inclusive Education Department in the Ministry of Education and Sports. In addition, Kyambogo Public University mandated to train special needs education teachers, among others.

Sign language was officially enshrined in the national constitution in 1995 (Government of Uganda, 2015). These legal provisions are in line with the provisions of the Uganda National Association of the Deaf (UNAD), a civil society organization that has worked closely with Kyambogo University to advance the educational outcomes of persons with hearing impairment. Kyambogo University and UNAD advocate for the official recognition of Ugandan Sign Language as the language of the deaf people in Uganda. They also aim to further their education and equal rights through the Equal Opportunities Commission, which is a constitutional body created to combat discrimination and inequalities against any groups or individuals in Uganda (Government of Uganda, 2007).

These milestones recognized the need to train sign language interpreters to support the education of learners with hearing impairment in all schools, including inclusive secondary schools.

Background

Sign Language Interpreting

Communication is important in our everyday social lives as well as the lives of those viewed differently within communities. It is also important for one to

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understand and to be understood by everybody during all dialogues in educational settings. However, research in the area of sign language interpreting has discussed gaps in teaching approaches related to the service provision for learners with hearing impairment in secondary schools (Watermeyer et al., 2006). Secondary School students with hearing loss in America have requested sign language interpretation as the primary accommodation in the classroom, followed by note-taking and technological aids (Cawthon et al., 2015). However, there is limited research regarding the accommodations chosen by deaf secondary school learners in Africa. Currently, sign language interpretation is used in Uganda as an accommodation for these children (Uganda Ministry of Gender, Labour and Social Development, 2006). This means that all learners need to acquire an education in inclusive settings through interpretation, to enable them to transition to the communities where they can live and work. Learners with hearing impairment seem not to benefit much from such provisions in the schools identified for this particular study. Sign language interpretation services in educational institutions often face a multitude of challenges. Sign language interpretation is challenging in terms of physical and cognitive demands placed on the interpreters (Qin et al., 2008) and could be worsened by poor working conditions (Ademokoya, 2011). According to Opondo and Ajawi (2015), support staff in Kenyan secondary schools reported a high level of job dissatisfaction due to their working conditions, including comparatively low wages, a lack of recognition, delay in payment of their salaries, unclear job descriptions, and working past the agreed upon official working hours. Similarly, Ademokoya (2011) found that inadequate working conditions had a significant effect on the performance of sign language interpreters in Nigeria. Interpreters are furthermore mandated to offer interpretation services for learners and teachers with varying backgrounds and cultural diversities. In addition to this, learners with deafness may or may not identify with a specific deaf culture, which is unique to each region (Reagan, 2008). This cultural identification interacts with an individual's racial and ethnic culture (Quach, 2016). Despite these listed challenges, little empirical evidence has been based on sign language interpreters in inclusive secondary schools in Uganda. There is limited literature documented in Uganda in terms of the work of sign language interpreters in inclusive private secondary schools and those that are government-aided.

Universal Secondary Education

In 2007, Uganda became one of the countries in sub-Saharan Africa to introduce free USE (Ministry of Education and Sports, 2013). USE is currently implemented nationwide and was created to provide the necessary support, materials, and facilities to effectively educate children in secondary schools. According to this model of education, government is to employ and remunerate teachers, while parents are responsible for providing their children with accommodation, lunch, uniforms, necessary medical care, and scholastic materials such as textbooks, while the government takes responsibility for paying the school fees (Huylebroeck & Kristof, 2015).

However, there is no clear mention of the benefits of USE for students with hearing impairment in Uganda, instead it's a generalised policy for all school going learners, irrespective of the nature of their disabilities. The National Assessment of Progress in Education (NAPE) provides a general overview of generalized performance indicators of learners with disabilities with no specific mention of those with hearing IMPAIRMENT (NAPE, 2013). However, according to a research study guidelines based on the 2006 Uganda Demographic and Health Survey, only 10.48% of learners with significant hearing impairments aged 13–17 years completed Grade 5, despite inclusive education policies (Moyi, 2012). Successful completion of Grade 5 is considered to be the benchmark for acquiring literacy and numeracy (United Nations Educational, Scientific and Cultural Organization [UNESCO], 2005). According to MoE (2015), the numbers of learners with hearing impairment are evenly distributed between girls and boys.

Despite the policy on free secondary school education, not all learners with hearing impair-

ment can join a secondary school of their choice and nearness. Factors underlying this range from poverty, sociocultural perception of deafness, and negative community attitudes towards educating learners with hearing impairment, with the view that they may not be contributing to the community as a social benefit (MoESST, 2015). At the time this research was conducted, there were only two government-aided secondary schools specifically designated for deaf learners in two regions in the country (one in Mbale District in the eastern region of Uganda and one in Wakiso District, central Uganda). Both of these schools have employed sign language interpreters to support teachers. Some of these teachers do not have any background in sign language. Despite Uganda's inclusive education policies, only a few mainstream schools have enrolled learners with hearing impairments. This may be influenced by the fact that stakeholders at the level of the schools and national government are having difficulty coping with the increased workload that came with the implementation of USE and subsequently fail to provide high-quality service delivery, even for mainstream learners (Huylebroeck & Kristof, 2015).

Teacher and Sign Language Interpreter Training

The number of sign language interpreters trained at university is still low and does not correlate with the number of students with hearing impairment in need of support. In 2013, it was reported that only ten students per year took the Professional ugandan sign language course at Kyambogo University, which is the only university offering the course in Uganda (Radoli, 2013).

Despite the development of a few regular schools that have enrolled learners with hearing impairment, teachers who are posted to work in the school involved in this study were professionals trained at national teacher training colleges (NTCs). These teachers may not have any background in the area of special needs education. This is because there are no national teachers' colleges that train teachers working with deaf children at the secondary level in the country. At the time of conducting this research, there was no evidence of an adapted curriculum for special needs education at national teachers' colleges. Teachers, therefore, needed to be trained in specialized skills to help them teach the different subject areas using Ugandan sign language (MoETSS, 2015).

In an attempt to promote teacher training in the area of special needs education, the Uganda National Institute of Special Education (UNISE) was established in 1991, which trains teachers and community workers to support and work with children with disabilities (Abimanyi-Ochom & Hasheem, 2014). However, the trend does not include training teachers to support learners at national teachers' colleges, nor secondary school level. This is indicative of the large gap to be filled at the secondary school level.

Attempts were made to establish Kyambogo University and later a Faculty of Special Needs and Rehabilitation by merging the three educational institutions, namely, UNISE, Uganda Polytechnic Kyambogo, and the Institute of Teacher Education Kyambogo. The faculty houses four departments: the Department of Special Needs Studies, the Department of Community Disability Studies, and the Department of Adult and Community Education. Department of Visual impairment Studies. The Department of Hearing Impaiment and Sign Language Interpretation Studies has a section that Specifically trains sign language interpreters. The objectives of this department include undertaking research and teaching in the area of disability, such as the publication of the first Ugandan Sign Language Dictionary in 2006 (De Clerck, 2013). Sign language interpreters later get placed to support teachers with inadequate or no signing skills in secondary schools which accommodate deaf children. A few sign language interpreters work in a handful of mainstream schools that are practicing inclusive education.

Bilingualism and Language Structure

Bloom and Lahey were the first researchers to divide language into "content," "form," and "use" components in 1978, and this classification system is still meaningful to this day in terms of understanding sign language (Friedman Narr, 2011). From the foreseen, the "content" represents the words in the language and their meanings. In terms of content, one sign can be used for a number of words. The "form" of language represents elements such as grammar which include syntax or inflection. Sign language possesses its own syntax and grammar; sign language interpreters typically do not sign word for word what is said in English (Friedman Narr, 2011). Grammar is further expressed spatially in signed languages (Reagan, 2008). For example, where verbal languages may use a pronoun to refer back to a name previously mentioned, an individual using sign language may use a pronoun sign in a particular space where that name was first mentioned (Huenerfauth & Pengfei, 2012). The implication of language "use" refers to the rules governing the use of a language in different contexts, target populations, and communication environments, as can be seen in the changes in signing depending on who a communicator is signing with. Differences have been noted when two deaf individuals sign together, compared to when a deaf individual signs with a hearing individual. For example, they may use more mouthing or code switching, as well as finger spelling, to assist their hearing communication partner (Jefwa, 2009).

Children who attend mainstream classes with the accommodation of a sign language interpreter are effectively bilingual, as they must be able to communicate in both sign language and written English (Friedman Narr, 2011). The learner must thus switch between the content, form, and use of these two languages. For any meaningful exchange of information to occur between two or more individuals, the parties involved have codes that should be understood and used effectively during conversations in different settings. Unfortunately, deaf learners who rely on sign language "codes" for communication often have difficulty integrating into social contexts with their hearing peers, if these peers are not proficient in sign language as well (Blose & Joseph, 2017).

As the teachers in the mainstream schools in Uganda typically are not proficient in sign language, the learners require sign language interpreters to act as bridges to communication gaps between the hearing teachers in this context and the non-hearing learners. These interpreters are thus also required to be bilingual.

Motive and Objectives of the Study

This chapter aims to explore the challenges and successes encountered by sign language interpreters working with teachers teaching learners with hearing impairment in Ugandan mainstream schools that practice the principle of inclusive education.

This study followed a period of "Segregated Special Education" in Uganda between the early years of 1980 and the late 2000s (MoESST, 2015). This is a period where learners with hearing impairment were being isolated in schools/Or units for the deaf, excluded from mainstream schools. There are very few trained teachers in the area of special needs education, and sign language interpreters are expected to understand the teaching content in class as well as nuances outside of the classroom teaching and learning. Findings will benefit stakeholders in the education sector such as speech–language therapists working in the area of deaf education and with hearing-impaired learners. It is further aimed to sensitize communities, including the parents of learners with hearing impairment, on the significance and various ways of educating deaf learners using Ugandan sign language communication in education. It is hoped that research findings will influence policymakers to redirect their priorities in policy formulation issues. The implication is that policies will take care of the rights of persons with disabilities, in line with the internationally agreed conventions and Sustainable Millennium Development Goals (United Nations, 2015). Findings can help highlight the social and professional relationship between sign language

interpreters, teachers, and educational administrators. This may stimulate further research in the area of sign language interpreting in different settings like judicial and medical settings.

The following research questions guided the study:

1. What are the challenges faced by sign language interpreters during their work in an inclusive secondary school in Uganda?
2. How do the challenges faced by sign language interpreters influence their work in an inclusive secondary school setting?
3. Which possible coping strategies can be adopted to minimize the challenges encountered by the interpreters in an inclusive setting?

Methodology

Design and Setting

The research was undertaken in 2016, and it covered a period of 6 months. The design was largely a descriptive qualitative case study approach. This design was preferred because it "explores a real-life, contemporary bounded system (a case) or multiple bounded systems (cases) over time, through detailed, in-depth data collection involving multiple sources of information" (Creswell, 2013, p. 97). The qualitative case study design is further flexible and allowed the use of a variety of data collection methods and instruments (Hyett et al., 2014), such as informal and formal interviews and observations.

The study was conducted at a school in the eastern region of Uganda. The school is located approximately 350 kilometers from Kampala, the capital city. The school chosen for the study was government aided, as this ensured that the school was implementing inclusive secondary education as required by the Uganda education policy guide lines.

Sampling Procedures

Study participants were identified using purposive sampling. This is a nonrandom technique which allows the researcher to identify participants who are able to willingly provide the required information through knowledge or experience while identifying and selecting the information-rich cases (Etikan et al., 2016).

The criteria for identifying the school where the research would be conducted was based on enrollment of learners with hearing impairment, being a government-aided secondary school working towards the principle of inclusive education, employing full-time sign language interpreters, accessibility, and willingness to participate.

The procedure used to sample sign language interpreters was by screening the accessible population of all sign language interpreters employed in the school. The purpose of screening sign language interpreters was ideally to identify sign language interpreters who had professional training in interpreting at the level of a diploma certification from a recognized university or institution of learning. The nomination procedures were completed after the head teacher had provided a list of interpreters with their individual qualifications.

Participants

A total of 11 participants participated in the study: 5 teachers and 6 sign language interpreters selected from the school identified. The interpreters and teachers identified taught and interpreted for deaf and/or hard of hearing learners from Grade 6 up to Grade 11.

In order to achieve the stated objectives, six sign language interpreters were purposefully identified from the target group. According to Creswell (2012), key informants give information that would otherwise not be available to the

researcher. Sign language interpreters are the key informants in this study because they worked closely with the teachers and learners with hearing impairment on a daily basis. Gender balance was considered in the identification process.

The identification was further based on the interpreters' proficiency in Ugandan sign language, their educational backgrounds (not limited to the area of interpreting), and working experiences as an interpreter for the deaf and/or hard of hearing persons. The ability to communicate in Ugandan sign language was important as a basis of assessing the support the interpreters rendered to learners with hearing impairment during indoor and outdoor activities in the school.

One of the interpreters identified doubled as Grade 5 teacher and had a teaching background. This was advantageous since it was in line with the study research area involving educational interpreting.

Instruments

As mentioned, the study adopted a case study design with an orientation of qualitative data collection procedures. In order to achieve this, the tools used include formal interview guides, participant observation guide, and focus group interviews (Olsen, 2012). These were developed by the researcher. Interview guides were developed and pretested according to each category of informants. The pretest was conducted in one secondary school in the central region, Wakiso Secondary School for the Deaf. This school was not involved in the final study. In addition, secondary data was obtained by analyzing the roles of the teacher's vis-a-vis the interpreters' roles in the selected school. The analysis was conducted based on the interviews completed with the teachers and sign language interpreters during and after classroom work. This identification was done by understanding the specific responsibilities that the teachers carried out inside and outside the classroom environment, where they worked alongside sign language interpreters. For example, how often the interpreters had accessed the teachers teaching notes to help them in preparation before, during, and after an interpreting assignment was investigated. The interpreters were interviewed after interviewing the teachers in order to validate the data. The interviews contained guiding questions on thematic areas for both the teachers and sign language interpreters. The following are some of the underlying questions that guided the interview procedures.

Background information for the sign language interpreters

- How long have you worked as a sign language interpreter in this school?
- Can you tell me how you came to learn sign language?
- What level of education have you attained?
- Which classes do you interpret in the school?
- Have you ever worked as a sign language interpreter before?
- How do you value your work with children who are deaf and/or hard of hearing in this school?

Information about sign language interpreters' work in the school

- How do you relate to the teaching and non-teaching staff in the school?
- What preparations do you undertake for your interpreting assignments at school?
- Which subject areas do you interpret most in class?
- What support do you get from the teaching staff to facilitate your work inside and outside the classroom?
- Which challenges do you face during indoor and outdoor interpreting assignments at school?
- How do you feel working in an inclusive learning environment like this one?
- Which other responsibilities do you have apart from sign language interpreting in the school?
- How do the children with hearing impairment treat you and other peers in the school?

Information about communication strategies

- Can you please comment on the kind of communication between you and the children with hearing impairment in the school?
- What kind of communication strategy do the teachers you work with use?

- What is the mode of communication used by the children with hearing impairment and their peers in the school?
- Can you comment on your skills in voicing and signing during your work in the school?
- Can you tell me more about co-interpreting with your colleagues in the school activities and how it has benefitted you?

Information about the coping strategies

- How do you cope with the challenges you face in your work at school?
- What support do you get from the school administration to facilitate your work?
- What additional support do you get from the government Ministry of Education to facilitate your work in the school?

Background information about the teachers of learners who are deaf and/or hard of hearing

- How long have you taught in this school?
- Are you a trained special needs education teacher?
- How many sign language interpreters do you work with in the school during your teaching lessons?
- Do you have children with hearing impairment in your class?
- How do you communicate with the children who are deaf in the school generally?
- In your own view, do you feel the school takes adequate care of all the services of sign language interpreters in the school?

Information about working with the sign language interpreters

- How do you relate with the sign language interpreters in the school?
- Can you comment on the relationship existing between the sign language interpreters and the children with hearing impairment at school?
- What kind of indoor and outdoor support do you give to sign language interpreters in their work?
- Do the children understand the information you teach through the sign language interpreters well?
- Can you comment on the relationship existing between the other teaching staff and the sign language interpreters in the school?
- What other responsibilities do the sign language interpreters have apart from interpreting in the school?
- What kind of support does the school give to facilitate the work of sign language interpreters in the school?
- In your view, what are the interpreters' feelings about working with you in an inclusive learning environment?
- Which areas do you consider to be great challenges to the work of sign language interpreters during indoor and outdoor assignments in the school?
- How have these challenges affected the work of sign language interpreters in the school?
- In which ways have the school and government tried to cope with the challenges faced by sign language interpreters?
- What do you think the school management and government should do to facilitate the effective work of sign language interpreters in the school?
- Can you comment on the contribution of sign language interpreters to the education of children with hearing impairment in the school?
- Do you have anything you would like to add to what we have discussed today?

Data Collection

Informal and formal interviews were conducted with the interpreters and the teachers on the school compound in a private place. This was to avoid detractions during the process. This was done by first seeking informed consent both verbally and in writing. For purposes of capturing the information on the challenges and coping strategies, their voices were tape-recorded for later

transcription and final analysis. The teachers were interviewed first before observations in their respective classes were conducted. The interviews were completed over 2 weeks.

Formal Interviews

The interview method was used as the primary data collection method and observations as the secondary approach. I conducted the interviews in settings away from possible detractions in the school compound. Interviews helped to obtain firsthand information from all informants on the phenomena under investigation (Creswell, 2012). Compared to questionnaires, the interview method enabled the researcher to recognize the behavioral characteristics of informants involved in the study, such as their facial expressions and attitudes. This allowed further indication of their feelings about the topic of discussion. Similarly, interviews permitted a face-to-face interaction with the informants in their natural setting in the school that was appropriate. The interview method was flexible because it could be used under almost every condition during data collection. It is capable of eliciting data in great depth. This methodology is also supported by Creswell (2012), who described the semistructured interview method. This was adopted and involved first asking teachers a series of semistructured questions and then probing more deeply using open-form questions in order to obtain additional information.

Participant Observation

In addition to interviews, formal observations were conducted by narrowing down observable sites for all selected interpreting activities taking place within the school that were relevant to the study. Apart from informal observations, informal talks with the other teachers and hearing students who did not constitute the accessible population were helpful in obtaining additional information that helped to validate the data. Ethical consideration was sought from the head teacher and the teachers in advance prior to the informal interactions and informal interviews during the students' free time, such as during break times. I conducted the observations by accompanying the interpreters and the teachers in the classrooms during teaching. The purpose of the observations was to ascertain whether the information provided by the teachers and interpreters were aligned with their utterances related to the research objectives. For example, participants were observed during simultaneous and consecutive interpreting processes in class.

Focus Group Discussions

The focus group interviews were completed for each group of informants identified for the study. The interviews were done purposively to give participants an opportunity to express views that they may have omitted during the formal interviews. Focus group discussions were completed with independent target groups with the view of validating collected data from different settings. The focus groups were completed separately for sign language interpreters and teachers, in that order. The focus discussions were led by the researcher.

Data Analysis

The constant comparative analysis approach was used. This aims to ensure that all data are systematically compared and analyzed, rather than certain data being thematically excluded (Fram, 2013). Data obtained from interviews, observations from all participants, and focus group discussions were compared. This was to address the research questions linked to the components of the research topic of challenges and successes. Data analysis also involved corroborating a chain of evidence from indoor and outdoor observations during the interpreters' work in the classroom and outdoor interactions with the learners who were deaf and/or hard of hearing.

Ethical Considerations, Validity, and Reliability

Ethical, validity, and reliability considerations are important for any successful research to be realized (Mugenda & Mugenda, 2013). While the names of the regions have been given here, there has been a degree of anonymity to conceal the

identity of the school and the names of participants for confidentiality. The background of all participants was cross-checked repeatedly to ascertain that their participation in the study is correct. As mentioned earlier, Uganda has both private and government-aided secondary schools in all five regions. As a result, access was gained to research sites by obtaining permission from the school administrators. Permission to carry out the research in the school was granted. Informed consent was obtained verbally and in writing. Face validity and reliability of the instruments was secured by peer review with colleagues at the Department of Special Needs Studies of Kyambogo University. This helped to obtain a chain of evidence and linkages drawn from data obtained from interview guides, raw data, and findings. Pretesting the instruments allowed the necessary adjustments to be made for the main study (Creswell, 2012). Ethical approval was sought from the head teachers to allow the researcher to carry out informal discussions with the learners during their free time on the school compound.

Results

Challenges Faced by Sign Language Interpreters During Their Work in an Inclusive School in Uganda

The challenges encountered by sign language interpreters emanated from the sign language interpreters themselves, learners with hearing impairment, and the teaching and nonteaching staff. Others were related to the environment in which the interpreters worked and lived.

Challenges Arising from Internal Factors

Of the six sign language interpreters who participated in the study, one had Grade 5 training (professional background as a secondary school teacher), while four had Grade 3 training (primary school) with sign language knowledge and two had university diploma qualifications in sign language interpreting. The challenges arising from their educational backgrounds were evident during the indoor and outdoor assignments. For example, interpreting some technical terms from the various subject areas taught was reported as challenging by interpreters with lesser qualifications. It was reported that working with the Grade 5 trained teachers who doubled as interpreters was challenging to sign language interpreters who had not attained that level of qualification.

In addition, sign language interpreters found it challenging to cope with fast-speaking teachers in class. The sign language interpreters reported that they were challenged in terms of matching verbal messages from fast-speaking teachers in different class lessons, especially during lessons that necessitated further explanations and emphasis. Their ability to cope with simultaneous and consecutive interpreting was checked. Another observation was that sign language interpreters found it challenging to understand some scientific terminology. The two signing skills involving simultaneous and consecutive interpreting posed a further challenge to the interpreters. Finally, skill was influenced by qualification level.

Challenges Arising from Learners

The teachers reported that some learners were "slow learners" and required a lot of time to understand the simple concepts explained. In most cases, evidence of misinterpreted information was perceived by the interpreters. This often caused misunderstanding on the part of the deaf learners when it came to giving feedback during lessons.

Simplifying difficult terminologies for students was challenging since most of the students came from different backgrounds and neighboring countries like Kenya and Rwanda. For example, one of the interpreters stated that:

> …and when they come together, a student from Kenya might understand things in a different way and they give me the signs they use in Kenya but if I use that sign the Ugandan deaf student will say NO! That it is not the correct sign to use and this brings a lot of debate and wastes a lot of time.

The interpreters further reported that deaf students would turn to do other things in class or ignore the incoming messages from the inter-

preter, which they perceived to be due to the attitudinal influences from the hearing students.

Challenges Arising from Teachers and School Administration

A "social gap" was noted among the interpreters and teachers. For example, during break times, sign language interpreters are supposed to share the same board room with the teachers. This was reported as sometimes creating a sense of social misfit among them.

In addition, sign language interpreters reported that it was the responsibility of the teachers to answer the learners' concerns through the interpreter but not the other way around.

Interpreters reported that they had received little support from most teachers because the teachers were not trained in sign language. All the teachers involved in this particular study relied on the support service of sign language interpreters for the entire curriculum. This was evident when one teacher stated that:

> …at the end of the lesson, when the teacher pauses questions to the learners, I receive the question and tell the students but sometimes the students complained that I give them hard questions…I try to explain to them that those are the very questions that were given to the hearing students since they share the same lesson so that brings misunderstanding between us and the interpreters and the deaf.

During the study, it was revealed that interpreters sometimes were requested to give support to help teachers mark the students' homework, even when they were not in a position to do it to their best. Interpreters revealed that they were further seen as disciplinarians in the class by being requested to keep students quiet whenever they caused uneasiness.

In addition, a lack of proper preparation on the side of the interpreters was a reported challenge. Sign language interpreters reported that most teachers were reluctant to offer them their teaching notes to read through in preparation before lessons begin. They added that most teachers considered them as alternative teachers yet most of the sign language interpreters were not trained as teachers.

Most sign language interpreters noted that the school administration treated them Positively like any other teachers. For example, they reported being delegated to maintain order in the dining hall, silence naughty students in class, and mark exercise books. However, my observation pointed to the fact that such delegation was beyond the ethical code of conduct of sign language interpreters during their assignment in the area of study.

Challenges Arising from the Environment and Context

The school studied consisted of large classes. In most cases, it was a first come, first served basis in terms of securing seats in class. Sign language interpreters indicated that it was challenging to direct hearing students to give room for their fellow friends who were deaf peers to allow them sit in positions where they would be able to view the teacher and interpreter. This was not easily accepted by the hearing peers. Students who were Deaf in most cases were forced to sit in positions that would not allow them to clearly perceive the signed information from the interpreters during class lessons. In the same vein, sign language interpreters were, in most cases, forced to be seated in positions affecting their performance in terms of message delivery.

The interpreter–pupil ratio was identified as one of the challenges to the performance of sign language interpreters. Sign language interpreters posted to the school were too small in numbers to sufficiently support students in interpreting subject areas in all the classes, ranging from Grade One up to Grade Six. Two interpreters per class were perceived as being inadequate to cover all the classes divided into streams leveled as stream A, B, C, and D. It was also reported that a lack of reasonable numbers of sign language interpreters in the school to Support do co-interpreting affected the work of sign language interpreters, considering the fact that teachers had little or no knowledge of sign language. Furthermore, one interpreter said that:

> …because interpreter was occupied in class and there was no interpreter who was free at that time I was called from a class I was interpreting to go and interpret for a student who was going for an examination and my deaf students quarreled.

Participants reported challenges when supporting students outside the classroom, such as interpreting in the bursar's office or attending to visiting parents among others.

Remuneration issues were also mentioned by the interpreters as having an impact on their job performance. In addition to remuneration issues, interpreters felt that they were overworked since they had to work during some weekends and public holidays, Supporting children with hearing impairment understand what they had missed in class from fast-speaking teachers.

Influence of These Challenges on the Work of the Sign Language Interpreters in an Inclusive Secondary School in Uganda

Negative reactions from teachers often led to low self-esteem among the interpreters when their abilities to interpret correct information were put to question by some teachers and students. One interpreter confided that most teachers did not understand their limits:

> When learners who are hard of hearing put up their hands to try and ask a teacher to clarify something, a teacher can answer the deaf learners that later your interpreter will explain to you.

This kind of negative feedback, as above, was indicative of negative attitudes exhibited by the teachers during their work in classes of learners with competing voices.

Once the learners realized that the interpreters were doing the marking of their exercises in class, it was reported as proof to the sign language interpreters that they had overstepped their boundaries and it was viewed as a role conflict. Some learners had developed negative attitudes towards some interpreters whenever such assignments were delegated to them. This observation was perceived as contributing negative relations among some learners, sign language interpreters, and the teachers.

Questions were asked which needed interpreters to express their feelings about working in an inclusive environment and how this influenced their performance. Although informants expressed both negative and positive feelings about motivation, the six informants expressed willingness to do their work with enthusiasm. They supported this argument basing it on the fact that children with hearing impairment in the school always passed Well during their final year examinations and later joined university. One informant expressed that:

> ...teachers encourage us and we feel proud the work we deliver to the deaf students. For example, when I interpreted in senior five in 2005 they all passed and no one failed.

Coping Strategies to Minimize the Challenges Encountered by the Interpreters in Inclusive Settings

The reported coping strategy came in the form of refresher get-together meetings where sign language interpreters went through refresher training by stakeholders such as the National Examinations Board. During these meetings, the interpreters go through challenging aspects and share individual experiences with colleagues. Furthermore, intrinsic motivation through self-motivation was also noted as a kind of coping strategy used by the interpreters to overcome challenging situations during their work in such a complex learning environment. Watching televised teaching by those interpreters employed on private and government owned television stations on educational programmes helped them develop the zeal and enthusiasm to do their work better In the school.

Discussion

Challenges Faced by Sign Language Interpreters During Their Work in an Inclusive School in Uganda

Challenges Arising from Internal Factors

Most interpreters did not have a professional background as trained secondary school teachers. In this case, the understanding in terms of the

work content and technical terms did not match their demands for employment. The assumption is that the sign language interpretation course is completed in only one public university, where consideration for course entry requires individuals to have passed Grade 11 and above. Grade 11, called senior year six in the Ugandan context, is an advanced level of education. This research showed that interpreters from lower qualification levels experienced perceived compromised competence in comparison to those who had higher qualification levels. Emphasis was placed on the fact that not all sign language interpreters were necessarily trained teachers competent in sign language.

Challenges Arising from Learners

Interpreters work in multicultural communities where language competences bring negative criticism and embarrassing situations during the assignments in an inclusive setting. This compromises their professional ethics, and as a result, their performance becomes jeopardized.

It appears as though there was a mismatch between the interpreted information from the teachers during the lessons and the learners' feedback. This observation was supported through informal discussions with the learners with hearing impairment. This may indicate problems on the part of the learners or the teachers in understanding the language content, form, and use during the lessons (Friedman Narr, 2011). The competences of not only the students but also the sign language interpreters are unclear here since some of the interpreters were not necessarily trained secondary school teachers.

Cultural differences, especially between different deaf communities, were a notable challenge that arose during the interviews. Further research regarding the complex cultural identities of deaf learners in sub-Saharan Africa is warranted (Quach, 2016), as well as the effect that this has on sign language interpretation services.

Challenges Arising from Teachers and School Administration

The responses regarding unclear roles and responsibilities of the sign language interpreters imply that the code of ethics for both teachers and the sign language interpreters had been misunderstood. This echoes findings by Opondo and Ajawi (2015) who found that unclear job descriptions led to poor job satisfaction among support staff in Kenya.

Preparation is a prerequisite for good interpretation assignments during both consecutive and simultaneous interpreting. However, results indicated that interpreters were not able to adequately prepare due to a lack of access to materials. This further contributes to the cognitive demands of sign language interpreting (Qin et al., 2008).

Challenges Arising from the Environment and Context

The interpreter–pupil ratio was identified as a significant challenge in this research study. This reflects the recommendations made by Opondo and Ajawi (2015) for schools to recruit a higher number of support staff for a more effective worker–child ratio in Kenya.

Currently, by the time of doing this research, there is no approved policy yet on special needs education in Uganda (MoESST, 2015). This implies that the remuneration of public servants in Uganda is based on agreed policies. Payments of salaries for sign language interpreters were therefore not regularized as it should have been the case with all public servants in the government-aided secondary schools. The absence of such a policy hinders sign language interpreters from accessing good remuneration from government. They were paid from project money that had irregularities in its implementation. This is similar to the findings by Ademokoya (2011) who found similar salary payment issues for sign language interpreters in Kenya.

Challenges Faced by Sign Language Interpreters and the Influence on Their Work in an Inclusive Secondary School in Uganda

A perception of negative attitudes towards sign language interpreters emerged during the study, which impacts their self-esteem as well as perceived self-competency. However, despite this,

positive motivational factors were also noted. Educational/qualification levels of the interpreters had a direct impact on their confidence and self-perceived competence, as well as their skills in terms of interpreting technical language and complex concepts. This indicates the need for continued professional development for sign language interpreters.

Coping Strategies to Minimize the Challenges Encountered by the Interpreters in Inclusive Settings

The research findings point to the fact that there were not enough monitoring and evaluation mechanisms put in place to evaluate the work of the sign language interpreters in this specific school. The lack of monitoring recommendations and capacity building would be a platform to offer refresher training for teachers and sign language interpreters on the new signs to use to deliver the curriculum. Besides there is no well established unifying and functioning Uganda National Association for Sign Language Interpreters. A professional body tasked to regulate the work of professional interpreters in the country. A non formal interaction with the association members indicated that the it had irregularities in their leadership structure.

When investigating the kind of encouragement that drove interpreters to perform their indoor and outdoor interpreting tasks, motivation was viewed in two ways, i.e., intrinsic or internal motivation and extrinsic or external motivation. The findings of this study indicated high levels of intrinsic motivation despite low levels of extrinsic motivation.

Conclusions, Impact, and Considerations for Future Work

The findings in this chapter may not be conclusive enough to generalize but are expected to give an understanding of the complex functionalities of sign language interpreters. This can be realized if educational interpreting and interpreted education are to be respected and developed in inclusive secondary schools. The voices reflected here uncover convincing evidence that learners with hearing impairment may not necessarily comprehend content as well as their hearing peers do in the same teaching and learning environments. Even if learners with hearing impairment are provided with highly qualified interpreters in a setting like this, a multiplicity of socioeconomic and cultural issues should not be ignored but looked at as opportunities for change for the better. Research into the cultural identity of those who are deaf in Uganda is currently lacking and necessitates further investigation. Cognizant that there is support accorded to learners with hearing impairment, it implies that there is some level of awareness among the teachers and other support staff.

This chapter presents findings from research on sign language interpreters working in an educational setting. This work needs to be extended to other settings, like the judiciary. The participants involved in this research represent a relatively limited range of the population, and thus, further research is needed to corroborate the findings of this study.

During the study, there was no notice of persons with deaf-blindness. Perhaps there is limited identification of and research conducted in that area in school settings. This could be another area for further research with regard to tactile signing in Uganda.

If the observed challenges are specific to sign language interpreters in Ugandan Context. educationists should work closely with them and make alterations in their teaching and pedagogical approaches and try to compensate in the documented areas of difficulty, as evidenced in the earlier sections of this chapter (such as inadequate interpreter preparation).

In the findings discussed, many factors were identified that influenced the services provided by sign language interpreters working in the inclusive setting studied. However, it may not be possible to address all of them in only one spe-

cific study. Therefore, the following suggestions are made for future reference:

- The Uganda National Association of Sign Language Interpreters (UNASLI) should establish a framework in which sensitization and raising awareness are adopted by all stakeholders in the educational sector. This will go a long way to create awareness among the teachers and hearing peers of the need to treat all classroom attendees equally.
- Interpreters should be allowed to express issues concerning their work objectively in order to maintain progressive communication and dialogue. Stakeholders should be congregated to discuss and consider ethical issues and any other challenges affecting sign language interpreters, in order to come up with workable solutions as a matter of urgency. This is feasible since interpreting and teaching are two different professions altogether.
- As a sustainable strategy for interpretation services at the postprimary level, schools and institutions of higher learning should run a refresher training in sign language and in the area of deaf culture. This will equip teachers and interpreters with new sign language vocabulary and teaching approaches. Interpreters should be encouraged to advance in their levels of education to help them widen their signing skills in educational settings
- It is also recommended that clear job descriptions and working hours be decided upon for sign language interpreters.

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Epilogue: Speech-Language Therapy in Sub-Saharan Africa Revisited: Visions for Theory, Training, and Practice

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It is always a pleasure to be asked to prepare an epilogue for any good book, but it is a particular pleasure to do so as the head of a special needs education department that has pioneered the provision of speech–language therapy (SLT) programs in Kenya. As a significant stakeholder, I am familiar with some of the authors' work as well as the processes that went into so thoughtfully preparing this handbook.

This landmark text is both timely and excellent. It is the first endeavor of its kind within sub-Saharan Africa (SSA) to present a comprehensive collection of research on communication and SLT. I am pleased to see contributions from such a wide range of cultural contexts, including perspectives from different countries across West, East, Central, and South Africa, and a diverse pool of authors, ranging from educators, researchers, and clinicians to practicing teachers and students, all bringing together different academic and clinical insights. The chapters consider specific issues relevant to persons with communication disability in the region, representing the experiences of persons with communication disability in childhood, adulthood, and older adulthood. These voices provide important insights into the nature and processes of communication disability in a changing world specifically within the SSA context.

I am not aware of any book produced in any SSA country comparable to this work. In particular, nothing approaching the scope undertaken here has even been attempted. This handbook constitutes an important scientific contribution to the fields of communication disability, hearing impairment, and SLT both in SSA and globally. It presents a broad array of theories, data, and concepts relevant to SLT and of interest to scholars, researchers, clinicians, and students in these fields. This is the first text to cover cutting-edge research on communication disability in SSA, introducing the principles and processes of evidence-based practice from systematic research and internal evidence from clinical practice.

This handbook was edited by Professor Dr. Ulrike Lüdtke, one of the most highly respected international researchers in SLT, and head of the Department of communication disorders at Leibniz University Hannover (Germany), in close collaboration with her co-editors Dr. Mathew Kinyua Karia, Kenyatta University, Kenya, representing linguistic expertise, and Dr. Edward Kija, Muhimbili University of Health and Allied Sciences, Tanzania, representing medical expertise.

I highly commend the high standards of editing. The topics across the individual chapters have continuity, and the style of witting and presentation is uniform. The editors have brought together original contributions focusing on SLT development, training, and intervention. The main chapters in the handbook highlight the history and development of SLT as a profession, some of the challenges experienced in this development, the earliest practices in training professionals in the field, and the latest trends. The strategies adopted by institutions within the SSA region to ensure the sustainability of the workforce and prevent overdependence on foreign expertise are discussed. Other chapters focus on the capacity of local SLTs to assess and treat communication disorders and the implications of this for the provision of services in both urban and rural areas.

The chapters are presented in a concise manner such that complex concepts are made understandable with clear, reader-friendly language and illuminating figures and tables. Each chapter provides a state-of-the-art literature review, consideration of the practical applications of the material, and critical discussion questions. The authors have drawn on clinical case studies, fieldwork, and comparisons of the procedures used in various settings to support their contributions. The level of language used, the concepts and their explanations, and the detailed presentation of arguments place the book clearly within the reach of the various stakeholders who will benefit from this work.

Readers, especially clinicians, will come away with a solid, practical understanding of evidence-based practice and knowledge that they will use throughout their careers to provide sound clinical decisions on the screening, diagnosis, and treatment of communication disorders. By involving authors from various fields within SLT and com-

munication disorders, the editors have succeeded in guiding the reader to an appreciation of the many aspects of the SLT profession and communication disability, and how different aspects have evolved on the continent over the years. The authors allude to theories and methods presently being researched which are likely to become important in future practice. In providing a review of the current research on communication and disability issues, this unique book will contribute immensely to the lives of persons with and without communication disorders in the region.

SSA is confronting the world's most dramatic communication disability needs, and this timely handbook coincides with the establishment and growth of the SLT profession in the region. It shows how, in the years to come, the region can utilize empirical evidence to address the SLT professional issues currently being faced. SSA has continued to uphold the oral tradition, and writing about SLT practice and experiences, as witnessed in Minority World countries, is still a challenging step that needs to be overcome toward the professionalization of SLT in Africa. This book is a first stepping-stone to build up interdisciplinary expertise with pathology, neurology, and otorhinolaryngology, and may lead to a networking forum for SLTs and other experts.

This book offers a candid appraisal of the major hurdles facing speech and language professionals in SSA. SLT training programs have commenced in a number of SSA countries in recent years, frequently supported by institutions from Minority World countries. The profession of SLT in Africa is thus historically and conceptually euro-centric.

In many SSA countries, there are documented shortages of books reflecting an African perspective. This handbook addresses this shortage in SLT and provides the foundation for similar books to be developed within special needs education in the areas of autism spectrum disorder, augmentative and alternative communication, and emotional and behavioral disorders, among others. As the field continues to grow and the demands for literature increase, it is essential to include research in special needs education to address the gaps in the literature. Such books will inform scholars, researchers, and decision-makers alike on important trends and impacts on the future development of special needs education with a specific focus on SSA.

While little is known about the SLT profession in SSA, the authors in the handbook have undertaken a significant effort to support the development of the profession in specific countries in the region and have highlighted some of the key challenges in the field. They have shown clearly that providing SLT services in SSA is challenging and complex but have also provided a firm basis for addressing these issues. The information shared in the handbook will, therefore, go a long way toward guiding the profession in its future growth. It is evident from the chapters that the issues affecting persons with communication disability in Africa as well as those faced by SLT professionals and trainers in SSA are relatively similar. Most countries experience a dire lack of unified and reliable data, standardized assessment tools, and intervention materials. The documented factors causing communication disorders in SSA have been largely linked to poverty, lack of information, and health and educational conditions. The situation calls for a critical reflection among the key stakeholders in health, education, and government to develop joint strategies that will ensure adequate sensitization regarding the cause and effects of communication disability on the lives of affected persons and their families.

I observed, however, that the handbook does not focus to a large extent on reflection and reflective practice in SLT. These two predominant approaches, identified as written reflection and reflective discussion, would have highlighted the personal experiences of practitioners in the field including lessons learned. Such information would have been significant and would have guided future practitioners in the field. Future publications should place more emphasis on these reflective aspects, particularly since there is a considerable need for conceptual and empirical work with the goal to support university- and work-based educational initiatives involving reflection and reflective practice.

In conclusion, this handbook prompts further debate about the relevance and future of the SLT field. If SLT is to be part of an African response to communication disability rehabilitation, it is clear from the handbook that the growth of SLT training in SSA is critical. Apart from the obvious advantages of professionals sharing the same language as clients in direct service provision, SLTs originating from and embedded within a culture will be ultimately best placed to re-conceptualize communication rehabilitation appropriately within the region. I believe this handbook has met the goals it set out to meet.

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