Malcolm MacLachlan
Leslie Swartz
Editors

Disability & International Development

Towards Inclusive Global Health

Springer

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We dedicate this book to all those who by reason of their marginalization or social exclusion will not have an opportunity to read it.

Foreword

Until fairly recently, the fields of disability studies and international development were viewed as completely separate. Much of what we know about disability and contemporary approaches to disability was researched and written about in wealthier countries, and it remains true to say that the major debates about disability are dominated by people in such countries. In the international development world, furthermore, the issue of disability was almost completely ignored. Plans for economic development and empowerment of the poorest of the poor in lower-income settings rarely considered issues faced specifically by disabled people.

There is an enormous irony to this situation. We know that the vast majority of disabled people live in low and middle income countries. We also know that there are strong links between disability and poverty worldwide. Disabled people are less likely to be adequately skilled for the workplace, they are more likely to be denied access to work because of prejudice and stigma, and disability itself is costly. Particularly in countries where the state does not provide adequate services and care (and this is the case in most countries in the world), disabled people and their families bear an enormous burden of care and loss of opportunity to work because of care burdens. Many conditions in the majority world, including war, internal displacement, communicable diseases (including HIV/AIDS, malaria and tuberculosis), parasitic infections, famine and civil strife, and lack of access to clean water are all factors which may dispose people to disabilities. It is therefore crucial that the two fields of disability studies and development studies begin to talk to one another so that both can contribute to improving the lives of people (and not only disabled people) worldwide.

There are some encouraging signs emerging. The United Nations Declaration on the Rights of Disabled Persons had been promulgated after a long consultative process, and the Global Partnership on Disability and Development has recently been established. In order for such initiatives to succeed, however, it is crucial that we learn more about disability and development issues on global context. This book is especially welcome in that it covers disability issues in a range of low and middle income countries. It provides a refreshing mix of case studies of country level activities, descriptions of emerging disability research networks and initiatives, and theoretical papers looking at disability research more generally.

It is crucial that disability activists and researchers worldwide join hands to keep disability firmly on the international development agenda, and to infuse disability studies with knowledge about the way in which disability is experienced and dealt with by most disabled people in the world. This book is an important step to reaching these goals, and it is my pleasure to welcome its publication and the possibilities it encapsulates. This book is also a challenge to all of us to do more and to learn more about disability and international development and it is essential that we pay this book the compliment of taking the work of understanding disability and international development forward.

I congratulate the editors and authors of this landmark volume for their excellent and important work. May this be the start of a fundamental change in how we view disability and international development

Cape Town
March 2009

Kudakwashe Dube
Chair of the Global Partnership on Disability
and Development, and CEO of the Secretariat of the
African Decade for Persons with Disabilities

Acknowledgements

An edited book is a collective, but not necessarily a unified, expression of interest in a particular theme. We welcome both this collectivity and the variation within it; as it reflects a much wider community of individuals and groups who share a concern with realizing the rights of persons with disability. As researchers and practitioners we have been inspired by a range of people, especially those in civil society who have done so much to develop this area and have provided such important leadership in recent years. Especially important to shaping our own thinking have been A.K. Dube, Chair of the Global Partnership on Disability and Development, and CEO of the Secretariat of the African Decade for Persons with Disabilities, who also kindly agreed to write a forward for this book; Rachel Kachaje of Disabled People International; Alexander Phiri of the Southern African Federation on Disability; Elias Ngongondo of the Malawian Ministry of Disabled Persons and the Elderly; and Mzolisi ka Toni of Disabled People South Africa.

The production of this book has also been supported by our colleagues at Stellenbosch University's Department of Psychology and Centre for Rehabilitation Studies; and Trinity College Dublin's School of Psychology and Centre for Global Health, "especially from Michael O'Toole, Hasheem Mannan and Eilish Mc Auliffe and Marcella Maughan". Diarmuid McClean, Vincent O'Neill and David Weakliam, all in Irish Aid, encouraged the Centre's development of work in this area, as have grants from Irish Aid, the Health Research Board (Ireland), the Irish Research Council for Humanities and Social Sciences and the European Union's FP7 programme. Collaborations with Aidan Leavy of International Services (Ireland), the Dochas Disability and Development Group, and especially consortium partners on the A-PODD and EquitAble projects, have also been very important in helping to develop our work in the Centre for Global Health. Stellenbosch University generously permitted Leslie Swartz to be seconded to the South African Human Sciences Research Council (HSRC) for three years, and it was at the HSRC that he developed his interest in disability studies. Emma Sherry (of Capital Letters) provided us with speedy and professional copy editing, and Ian Marvinney and Khristine Queja at Springer have been supportive and encouraging throughout. We should also like to thank our partners and families for their patience.

Contents

List of Tables

List of Figures

List of Boxes

Author Biographies

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Mary Anne Burke has published widely in the areas of public policy, social conditions and human rights. She developed Gender-based Analysis (GBA) and social inclusion tools, including the "*BIAS FREE* Framework", a tool for examining and eliminating biases that derive from social hierarchies, with Margrit Eichler. She has extensive experience as Senior Policy Analyst and Statistician in the Canadian government for Statistics, Canada; Status of Women; Health Canada; and Human Resources and Social Development Canada, and internationally for UNICEF and the Global Forum for Health Research. She is President of the *BIAS FREE* Co-operative, Inc. and Assistant Professor at OISE/UT.

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Petra Engelbrecht is at present Executive Dean of the Faculty of Educational Sciences, North-West University, Potchefstroom campus, South Africa. She is an acknowledged researcher in the field of inclusive education as well as research capacity development in higher education. She has led and is still leading several international research projects funded by various agencies on equity in inclusive education as well as the implementation of inclusive education in school communities.

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Marianne Griffiths studied at Dublin Institute of Technology where she received a BA (first class honours) in International Business and Languages (Spanish and French). She has worked with people with intellectual disabilities in a community residential setting for several years, providing care, promoting self-advocacy and encouraging the independence of the service users. She also worked providing family support to children and teenagers with intellectual disabilities living at home. She completed the MSc in Global Health in Trinity College Dublin where she received the Kevany Prize for academic excellence. As part of her Masters qualification she lived in Bolivia and researched advocacy and empowerment for people with disabilities.

Ansie Elizabeth Kitching is an educational psychologist and lecturer in the Faculty of Educational Sciences, North West University, Potchefstroom campus, South Africa, since 2004. She has 10 years experience in research and teaching in inclusive education. She is currently enrolled for a PhD in Community Psychology. The focus of her research is on the co-construction of enabling social contexts in school communities.

Mitchell Loeb, Msc is an epidemiologist with research experience from Canada, Norway, the United States and several developing countries in sub-Saharan Africa and Southeast Asia. At SINTEF Health Research, in Norway, he collaborated in a series of surveys of living conditions among people with disabilities in the southern African region (South Africa, Namibia, Zimbabwe, Malawi, Zambia and Mozambique). In 2005 he consulted for the World Bank in Indonesia to supervise disability data collections in support of the Indonesia Poverty Analysis Program. He also acted as disability data consultant for the Medical Committee Netherlands Vietnam (MCNV) in 2006 where he facilitated workshops to formalize a common understanding of disability, and harmonize the collection and management of disability data in Vietnam. He is currently a health scientist at the National Center for Health Statistics/CDC in the USA and is involved with the work of the Washington Group on Disability Statistics.

Mac MacLachlan is with the Centre for Global Health and School of Psychology at Trinity College Dublin, where he established the Dublin Psychoprosthetics Group (www.tcd.ie/psychoprosthetics). He is also Extraordinary Professor of

Disability and Development at the Centre for Rehabilitation Studies, Stellenbosch University, and Visiting Professor at the Department of Social Medicine and Global Health, Harvard University. Mac wants to promote inclusive global health and has particular interest in disability, international aid and cultural influences on healthcare. He pursues these through interdisciplinary social science with a strong interest in promoting research utilization. Before moving to Trinity Mac worked as a clinical psychologist and management consultant in the UK, and then as a lecturer at the University of Malawi. He is a co-founder of AfriNEAD (www.afrinead.org) and Principal Investigator on EquitAble (www.medicine.tcd.ie/global_health/research/projects/equitable.php) and A-PODD (www.A-PODD.org). He has worked with local and international NGOs and WHO, OECD, Unicef, and GDN.

Hasheem Mannan, PhD is a Marie Curie Fellow at the National Institute for Intellectual Disability and a research associate at the Centre for Global Health, Trinity College Dublin, Ireland. His international research experience incorporates projects for WHO (Geneva, Switzerland), the National Center for Health Statistics (Maryland, USA), and the National Disability Authority (Dublin, Ireland). He obtained his doctorate in Special Education with emphasis on disability policy and family studies from the University of Kansas and his Masters in Community Disability Studies for Developing Countries on a British Chevening Scholarship at the Centre for International Child Health, University College London.

Natalie Melling-Williams is a physiotherapist and has completed her Masters in Medical Sciences in Rehabilitation through the Centre for Rehabilitation Studies at Stellenbosch University. She now does project work with the Centre, and is currently primarily focused on the AfriNEAD project. The African Network on Evidence-to-Action in Disability (AfriNEAD) aims to link people with disabilities, academics, business people, governments and civil society in order to ensure that research evidence addresses, informs and guides the development of new and existing policies, programmes and products in and for Africa, so as to improve the quality of lives of people with disabilities on the ground.

Gubela Mji is a physiotherapist working at the Centre for Rehabilitation Studies at Stellenbosch University, Cape Town, South Africa. Gubela has experience in working in rural areas and amongst vulnerable groups such as homeless disabled people. She is engaged in various collaborative disability research projects with some Disabled People's Organizations and academics at local, continental and international levels. Gubela is also the chairperson for the African Network on Evidence-to-Action on Disability. She is currently working on her PhD, exploring the indigenous health knowledge carried by older Xhosa women.

Willy Nel is an educational psychologist and lecturer in the Faculty of Educational Sciences, North-West University, Potchefstroom campus, South Africa, since 2007. Willy is active in organized psychology through the Psychological Society of South Africa (PsySSA) and he serves on the South African Journal of Psychology as an associate editor. He is currently enrolled for a PhD and his research focuses on the provision of education support services for the ‡Khomani San (a South African indigenous First Peoples grouping).

Tone Øderud is a Senior Research Scientist and MSc at SINTEF Health Research in Norway. She has conducted research and development projects within the field of disability issues, service delivery systems, assistive technology, accessibility and universal design for 18 years. Ms. Øderud is currently involved in the development of local rehabilitation workshops providing wheelchairs and services to people with disabilities in Namibia and Zimbabwe. The workshops also empower people with disabilities by providing employment. She has special interest in development of assistive technology and services for people with disabilities focusing on user involvement.

Cliona O'Sullivan is a Lecturer in the School of Physiotherapy and Performance Science, University College Dublin. Since graduating in 1997, she has worked as a physiotherapist in a variety of clinical areas in the UK, Ireland and Burkina Faso and as a lecturer in the School of Physiotherapy, Trinity College Dublin. Her main research interests are in disability and rehabilitation; including childhood disabilities in low income countries. She is currently pursuing a PhD developing novel and objective methods of measurement and rehabilitation of disabilities associated with the upper limb. The work reported in her chapter in this book was supported by the Health Research Board, Ireland and Irish Aid.

Claire Penn is a speech language pathologist and currently holds an endowed Chair of Speech Pathology and Audiology at the University of eth Witwatersrand. She has undertaken research in areas of language disability, sign language and has a particular interest in the impact of stroke and head injury on individuals and their families. She has established the Health Communication project at Wits, which examines the interaction between health professionals and patients in a variety of settings and develops training programmes to facilitate communication. Particular interests include paediatric HIV/Aids, genetic counselling and research ethics. She was awarded the Order of Mapungubwe (Silver) in 2007 and was category winner of Shoprite Checkers Woman of the Year in 2008.

John Philander, **Dphil**, is deputy principal at Athlone School for the Blind in Cape Town, South Africa. He is a trained educational psychologist and has 15 years of experience of working with adolescents with visual impairment. His special interest is in the area of visual impairment, HIV risk, sexuality, special needs education and disability issues. His doctoral thesis (Stellenbosch University, 2008) is the first known study to evaluate an HIV prevention intervention for youth with visual impairments.

Andrea Pupulin is an international consultant dedicated to helping the most marginalized and unfortunate peoples. Following post-graduate studies in ethics, human rights theory, political philosophy and international development, he worked with orphans and street children in Brazil and in Egypt, and with Caritas, WHO and the Global Forum for Health Research. He is working with the *BIAS FREE* Framework on a UNICEF project in the Kyrgyz Republic, assessing the situation of disabled children and developing a national strategy for an inclusive Kyrgyzstan. He is currently Database Manager for the *BIAS FREE* Co-operative, Inc., and is researching exclusion of Roma peoples.

Poul Rohleder is a Senior lecturer in psychology at Anglia Ruskin University, UK. He trained and worked as a clinical psychologist in South Africa. He completed a doctorate at Stellenbosch University looking at organizational responses to HIV/AIDS as it affects persons with disabilities. His research interests include psychosocial aspects of HIV/AIDS and critical health psychology. He is currently working on a forthcoming co-edited volume with Leslie Swartz, Seth Kalichman and Leickness Simbayi, *HIV/AIDS in South Africa 25 Years On* (to be published by Springer).

Theresa Rouger, **B.A., LL.B**., is an international human rights lawyer and lectures on international law at Université Catholique, Lyon and Centre d'études franco-américain (C.E.F.A.M.), International School of Business Management, Lyon, France and U.S.A. She also lectures on the humanitarian Masters programme at the Université of Lyon 2, France. She is interested in international human rights, disability rights, gender rights, child protection rights and international law including business and human rights. She is currently working on a legal comparative disability project involving child rights with the Law Society of England and Wales. Other projects include a legal and social comparative disability project involving child rights with Handicap International, which will span across four African countries, and human rights and mental health research. She works as a legal human rights consultant for NGOs.

Leslie Swartz is a clinical psychologist and professor in psychology at Stellenbosch University. He is interested in public mental health, disability studies, and issues of identity in higher education. He is currently working on a co-edited volume on HIV and the social sciences in South Africa (Springer). He project managed and co-edited the first comprehensive volume on disability in South Africa (*Disability and Social Change*, HSRC Press, 2006) and current projects include work on HIV and disability, access to health services for disabled people in sub-Saharan Africa, and research capacity training for the Southern African Federation on Disability (SAFOD).

Patricia Thornton has undertaken research on disability and development in Papua New Guinea and latterly in Guyana, as a volunteer with Voluntary Service Overseas. In Papua New Guinea, she piloted methods of surveying disabled people to help establish the prevalence of disability, undertook a review of the VSO Disability Programme there and also carried out a study of national volunteering in Papua New Guinea. Patricia's previous career was in university-based social research, notably as Senior Research Fellow at the Social Policy Research Unit, University of York. She specialises in international comparisons of policies to promote employment of disabled people and in evaluation of UK employment programmes for disabled people.

Chapter 1
From the Local to the Global: the Many Contexts of Disability and International Development

Leslie Swartz and Malcolm MacLachlan

1.1 Introduction

A few months ago, one of us participated in a disability workshop held in a southern African country. The workshop went well, and it was clear from the inputs from people at the workshop that there is an assertive and vibrant disability movement in some very poor countries, some of which are only tentatively emerging from decades of war and civil conflict, and some of which continue to face deepening economic, political and governance challenges. The meeting was held at a hotel that has conference facilities. The building was not fully accessible to wheelchair users but was the only venue the organization could find and afford in that African capital. While we were there, the leadership of the organization told the management about the difficulties in getting to and from the conference room, as there was a small step close to the entrance to the conference room that could not be negotiated by wheelchairs. We struggled with this environmental barrier, but were delighted to emerge from one of the later sessions of the meeting to find that the hotel management had arranged for a concrete ramp to be built there and then, so that wheelchair users could more easily access the conference room. The concrete would not be dry by the time our meeting was over, but the ramp would be there for later users.

The makeshift ramp that was built at the hotel was subject to no plans, no designs, no building regulations, and no local or national laws or policies complying buildings for public use to be accessible to disabled people. The fact that our meeting was held where it was, and the reaction on the part of some people to issues of impairment being made visible, tells us part – and an important part – of the story of disability and international development. Most countries in the world are poor and far from the rarefied world of high-income countries with substantial provisioning for disability. But daily activism of an almost routine nature, and receptivity to this activism, can and does make a difference.

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After the meeting, many of us were on the same flight to a hub from which we would go our different ways to our home countries. The airline we were using was a well-known international airline, subject to international regulations. Ground staff of the airline could not have been more rude or oppressive towards those of us with visible impairments. They talked only to people with no obvious impairments, offered no help for a number of blind people and wheelchair users to navigate their way through security checks and customs, and claimed inaccurately that the airline had not been informed that disabled people would be on board, even threatening not to allow disabled people to board. There are, for good reason, international safety regulations about having disabled people on aeroplanes – there must be adequate provision so that, especially in an emergency, there is minimal danger to all passengers. Whether this was part of the concern of the airline staff we do not know, but even if it was, there was no excuse for the rude, and indeed disablist, way in which members of our group were treated. We suspect that it would be very unlikely that employees of the same airline working in high-income countries would have behaved in the same way.

These two images of how disabled people are treated and live their lives in low and middle-income countries are to an extent emblematic of more pervasive images of disability in these countries. On the one hand, we have an image of disabled people being exceptionally badly treated, locked up, shackled, and even killed in low and middle-income countries; on the other there is a view that people living rural lives far removed from the dehumanizing reaches of the global formal economy are tolerated and given meaningful roles in a world more tolerant of impairment and diversity. These images resonate through much of the literature on disability in poorer countries in general, and in the literature on specific areas, such as the literature on psychiatric disability (Swartz, 1998).

Somewhere between these two extremes of complete oppression and complete idyll, disabled people live their lives. Part of what is confusing about thinking about disability in such contexts is that, commonly, both images hold an element of truth simultaneously. There is no longer any question, for example, that poverty and disability are reciprocally related, with poor people more likely to be or become disabled and disabled people not only more likely to be poor but also to bear a burden of high costs of care and resources in countries where these are not provided (Emmett, 2006). There are cycles of impoverishment and disablement – consider for example a parent of a child with a serious mobility impairment in a low-income country. The parent may have to take off work to care for the child, and in the absence of assistive devices and free accessible transport, the parent may have to carry a growing child (even an adolescent) on her back when the child needs to go anywhere. Because of the difficulties of getting around, the child (especially if the child is a girl) may have interrupted schooling or no schooling at all, even if the school is prepared to accept disabled children. The child then loses opportunities to learn and train in order to support him/herself and the family in years to come. The parent, meanwhile, may come to have chronic back problems as a result of the sheer physical effort of caring for the child and carrying the child around, and may also develop a serious and disabling mental disorder because of the anxiety and demands of the situation. The parent may become less able, even when opportunities are presented to earn a living and support a family.

On the other hand, and equally true, we know that there are other stories. Duncan (2007) for example carefully documents case studies of how disabled people living in extreme poverty and with what seem to be no resources can and do organize their lives such that they not only find ways of surviving but also find a dignity in the way they live their lives and spend their time. In his now classic writings, Werner (1987) demonstrated how, with considerable ingenuity and at almost no cost, very poor people made their own assistive devices from what others would regard as waste or worthless materials. Local emancipatory practices have been shown to have the potential to improve people's lives and livelihoods (Lorenzo et al., 2007).

There is a real danger that we may romanticize the difficult lives of poor people, especially by drawing on idealized and unhelpful ideas about "culture" (Daniels and Swartz, 2007; Swartz, 2007, 2008; Tomlinson and Swartz, 2002). But if we look to the empirical evidence, we can see impressive examples of the ways in which in many poor parts of the world people with disabilities have taken an active role in advocating for their rights and in putting disability at the heart of the international development agenda. In southern Africa, for example, the Southern Africa Federation on Disability (SAFOD, which represents national Disabled People's Organizations (DPOs) in ten southern African countries, is internationally known as an important player on the disability and development scene. Once again, this vibrancy and effectiveness takes place against a backdrop of almost inconceivable challenges for many readers of this book. SAFOD coordinates a network of ten national DPOs, and recently launched its groundbreaking SAFOD Research Programme (SRP), groundbreaking because it is led by a Disabled Person's Organization (DPO). This programme, with significant donor support, is situated in Bulawayo, Zimbabwe, where, at the time of writing, there is a high degree of political repression, severe hunger, a cholera epidemic superimposed on the HIV/AIDS epidemic, almost total collapse of educational and health services, and no consistent supply of any basic services – including supply of water and electricity, and removal of rubbish and sewage. To say that SAFOD leadership are not suffering at present would be inaccurate, as it would be inaccurate to say that the particular struggles faced by disabled Zimbabweans are not more challenging than those faced by non-disabled Zimbabweans (for more discussion on this issue see Loeb, Chap. 2).

Under extremely difficult circumstances though – circumstances that must not be overlooked – organizations are contributing to important and exciting developments in how disability is viewed within the international development context. Key role-players in Disabled Peoples International (DPI) include disabled people from low-income countries. The African Decade on Disabled Persons, one of the offshoots of the UN Decade on Disabled Persons (Chalklen, 2006), has now become a misnomer as it has been extended (into a second decade) and it continues to link struggles for disabled people in sub-Saharan Africa with global struggles. The UN Convention on Disabled Persons was drafted in part by disabled people from low and middle-income countries. The recently established Global Partnership for Disability and Development (http://gpdd-online.org/disability) embraces not only the vibrancy of these African DPOs, but also the parallel and equally impressive developments that have taken place in South America, Asia, the Pacific and elsewhere. The GPDD statement on disability and international development is uncompromising:

> The chronic and vicious cycle of disability and poverty is a critical threat to the eradication of poverty and the enhancement of sustainable development in several of the world's poorest regions. Many poverty reduction strategies and ambitious development projects that seek to achieve the Millennium Development Goals (MDGs) and a critical reduction in poverty around the world fail to capture the necessity of incorporating the needs of people with disabilities, and their voices, in the design and implementation of these programs.
>
> Studies have shown that a majority of existing Poverty Reduction Strategy (PRS) papers fail to address the needs of people with disabilities, and often relegate disability issues to side programs without considering them within the mainstream strategies targeted at the general population. Additionally, there is a significant lack of monitoring and evaluation of benefits and outcomes of PRS for people with disabilities.
>
> Exclusion from mainstream reforms and systems has marginalized people with disabilities for generations, and it is vital that measures aiming to improve well-being and standards of living, reducing poverty, and increasing means of economic sustenance include them at every stage of the process. Development projects centred on disability issues, such as special education schools, tend to be fragmented, and mostly relegated to select ministries or departments.
>
> (Downloaded from (http://gpdd-online.org/disability January 19th 2009)

The GPDD seeks to address the devastation of disabled people's lives in poorer countries, with oppression and exclusion of disabled people being an omnipresent feature; however, once again, the fact that there is meaningful representation by people from low and middle-income countries on such a body is a cause for great optimism.

A review of the architecture or function of international development agencies is beyond the scope of this book. There are however a few issues that are particularly pertinent to disability that are therefore worth a brief mention. While there have undoubtedly been "development successes", Black argues that "Instead of creating a more equal world, five decades of "development" have produced a socio-economic global apartheid: small archipelagos of wealth, within and between nations, surrounded by impoverished humanity" (Black, p 13, 2002). We have already noted above, in the form of the quoted GPDD statement, that people with disabilities are among those groups who have been largely excluded from the benefits of "development". One of the key challenges for people with disabilities (PWDs) is therefore their empowerment, to be able to "get on" the development agenda. Barbery (2007, p 76) suggests that "Empowerment is the expansion of poor people's abilities to participate in, negotiate with, influence, control and hold accountable institutions that affect their lives." We believe that the application of the social model of disability to the challenges that many people with disabilities in low-income countries face, has in fact prepared Disabled People's Organizations (DPOs) well for this sort of struggle (see Watermeyer et al., 2006).

Many of the difficulties with "development" actually centre around the "development" institutions that "affect peoples lives." The need to reform these institutions and how they relate to each other has been recognized in major policy documents such as the Paris Declaration and the Accra Accord. The Paris Declaration sought to harmonize the activities of donor governments, institutions and agencies; align their work with those of the national governments of low-income countries; and increase a sense of ownership among the intended beneficiaries of aid. However, the Advisory Group on Civil Society and Aid Effectiveness (2008) argue that the Paris Declaration "… fails to take into account the rich diversity of social interveners in a democratic society and fails to recognize the full range of roles played by CSOs (Civil Society Organizations) as development actors and change agents" (p. ii). The Advisory Group goes on to claim that "CSOs are often particularly effective at reaching the poor and socially excluded, mobilizing community efforts, speaking up for human rights and gender equality, and helping to empower particular constituencies" (p. ii). While we would want to support these aspirations, we would also stress the need to demonstrate what is being claimed here, to be able to point to research evidence that shows this to be the case. We would also stress that a strong civil society should be a complement to, not a substitute for, strong governmental institutions and services, particularly services that are equally accessible to all (MacLachlan et al., 2010).

The chapter by Griffiths et al., discusses the importance of Poverty Strategy Reduction Papers (PRSPs) as the primary documents that outline a country's development plans, at least in the short to medium term. PRSPs are the development agenda that disability needs to be on and so it is important that the GDPP make the sort of strong and determined statements that we have quoted above. Now that the issue of disability is at the "development" table we need to understand more about how the "development world" works and some of its inherent problems and challenges. MacLachlan et al. (2010) argue that the very term "development" is problematic, as it positions one group as being superior to another, and that development is about changes in relationships between people, rather than simply about technical or material gains, even though these are of critical importance too. MacLachlan et al. (2010) also argue that the international aid system can be understood through a triangular relationship concerning the psychological, socio-political and economic dominance of some parties over others; the injustice of such relationships, of poverty and of how organizations attempt to address poverty; and the implications of dominance, injustice and social and cultural change for the identity of the recipients of aid, as well as its givers and mediators. The themes of dominance, justice and identity also of course resonate with regard to the sort of disadvantaged relationships that people with disabilities often have with "mainstream" society.

1.2 What is this Book About?

The discerning reader will have noted that this is not the first text to address issues of disability and international development. This is both true and something to celebrate. The fact that there are now a number of materials available that address disability and international development (see, for example, Albert, 2006; MacLachlan et al., 2009; Watermeyer et al., 2006; Bhanushali, 2008; Barron and Amerena, 2007) and overarching policy-oriented documents such as the GPDD website, means that our thinking about disability and international development is coming of age. Many in the disability field and in the international development field are now thinking about disability as a cross-cutting development issue, which is an encouraging sign.

It is also true, though, that there is fragmentation in the disability field itself, with debates still raging about fundamental approaches to thinking about disability (Shakespeare, 2006). Similarly, the international development world is riven with debates and disagreements, and different points of departure (Giddens, 2001). In both the disability and development fields, furthermore, there are widely differing discursive spaces. Some materials are available as resources for people who have not accessed much formal education (Conant, 2008; Maxwell et al., 2007; Werner, 1987); other texts are accessible to those with only very rarified technical skills. These issues of differences in texts – perhaps even “textures” – are magnified by the exciting, dynamic, but often very challenging overlap between the loosely bounded fields of disability studies and development studies.

This book makes no claim to be either the first or the last word on disability and international development. What we have tried to do, though, is to put between the covers a fairly short and reasonably accessible text; a series of chapters tackling the disability and international development interface from a range of perspectives, using various methods, and with foci which range from the broad and comparative to the local and specific. Some edited texts attempt to impose on all chapters (and authors) a fairly uniform approach to the topic. Indeed, some edited books have uniform headings and subheadings across all chapters. Some books, furthermore, attempt to demonstrate the “state-of-the-art” at a particular moment in the history of a field.

This is a different sort of book, and for this we make no apology. We wanted a book (and we believe we have one) which could give readers some sense of the fluidity within the field and the vitality that comes from the multiple approaches, indeed, even to thinking about what the field is and should be. At times we disagree with our own authors, or we ourselves might have taken a different approach to the topic. But in this book we have tried to embody what we believe to be fundamental to all work on disability and international development – an openness to and inclusion of other views, other voices and other approaches. Having said that, we also recognize that this book is a very particular kind of document – an academic text written largely by academics – and as such it is only one of the range of different types of document in the suite of what needs to be said about disability and international development, and by whom.

1.3 Outline of the Book

The book is divided into three sections. The first of these focuses on broad contextual issues, using selected countries as case studies. The second section looks at disability and research development, and in the final section authors discuss some specific issues and challenges.

1.3.1 Section 1: Contextual Issues

Loeb kicks off this section in Chap. 2 by going to the heart of the disability and development field. Introducing the concept of failed states and comparing and contrasting the Zimbabwean and South African cases, he shows how inextricable disability issues are from broader questions of governance. As the disability and development fields mature and begin to talk more to each other, it should no longer be possible to discuss disability without thinking about governance. Conversely, the case of disability rights forms a useful lens through which to interrogate governance issues.

Rouger (Chap. 3), looking specifically at the Ethiopian case, but with implications which are far wider than Ethiopia, shows that there is a slew of international agreements about disability in international practice, and that governments are required through various means to implement disability policies and practices. Despite this, actual on-the-ground implementation often does not occur, for a range of reasons that Rouger discusses. If realizing the rights of disabled people in global context is to be more than lip service, much more attention needs to be given to this policy-practice divide.

Focusing on Kyrgyzstan, Burke and Pupulin in Chap. 4 pull the lens in much more narrowly to focus on the process of developing policy in a newly existing state. They demonstrate the interfaces between policy and process. The process of moving the discussion on disability from one of deficits to an engagement of what it takes for a society to be inclusive is not a process that can be taken for granted world-wide, and the *BIAS FREE* Framework proves helpful in developing this process, as is illustrated in the Kyrgyzstan context.

1.3.2 Section 2: Disability Research and Development

This section opens in Chap. 5 with a discussion by Mji, Gcaza, Melling-Williams and MacLachlan of a new research partnership with a wide range of stakeholders, including DPOs, the African Decade on Disabled Persons, and academic and research institutions. AfriNEAD (the African Network for Evidence-to-Action on Disability) is designed to stimulate and collate research on disability in Africa – but research of a particular kind. Two core principles are at work here – providing information which will have a positive impact on disabled people’s lives in a development context, and increasing the participation in and ownership of the entire research and dissemination process by disabled people. The authors show that though the logistical challenges of setting up and maintaining such a network are immense, even more important perhaps is a supportive and mutually empowering ethos in all the network does. They draw on the African concept of ubunt (human interrelatedness) and use this to envision new ways of thinking about local and virtual communities of practice.

Moving to the challenges of developing research capacity in new contexts, in Chap. 6 Swartz describes some of the exhilaration but also the challenges involved in this process. There is a need, he argues, to balance participation imperatives with the right of disabled people to develop stronger technical research skills. To claim that capacity building in research is an easy process is to ignore the real challenges involved, and Swartz argues that the fundamentals of basic knowledge management need to be in place as a foundation for sustained and versatile research capacity.

Griffiths, Mannan and MacLachlan in Chap. 7 consider the relationship between empowerment and advocacy, the inclusion of disability in PRSPs, and the reality of advocacy actions on the ground in the resource-constrained environment of La Paz, Bolivia. There is a need, even for poorly resourced locally focused DPOs, to invest in and contribute to including disability on the development agenda, as only such inclusion can ultimately address the needs of DPOs and of PWD more generally.

In Chap. 8, Thornton gives a reflexive account of the complex process of piloting disability surveys in Papua New Guinea. Nothing in this sort of work can be taken for granted, and researchers who wish to assist countries and international development agencies with collecting what on first impressions may seem the simplest and most uncontroversial data on disability ignore the cultural and process issues at their peril. Linking back to the chapter by Mji et al., that opens this section, Thornton shows that understanding processes and relationships is always important.

1.3.3 Section 3: Some Specific Challenges

In Chap. 9, Rohleder, Swartz and Philander discuss the complex and controversial issues associated with the disability/HIV interface in sub-Saharan Africa in particular. Though there is now great awareness about HIV issues in the disability sector, there is probably less awareness about disability in the HIV sector. We need to know much more about this life-and-death development issue and the authors suggest that part of why we do not know more can be traced to attitudes towards disability and sexuality.

In Chap. 10, Eide and Øderud discuss the huge gap between the need for assistive technology and availability of such technology in low-income countries. What may seem to be a narrow technical matter – getting technology to people who need it – is in fact a much broader organizational systems challenge. As we have seen in many other chapters, process issues and relationships amongst people also play a very important part. The potential for international agencies to waste vast amounts of money and resources on devices that will not be used or will not be maintained is enormous. We need to understand the local terrain in all senses of that word – physical, social, and relational, in order to allow technology to make the difference it can.

It is often the case that children's issues are not much considered in debates on disability and those on development. Focusing on work in Sierra Leone and Burkina Faso, in Chap. 11, O'Sullivan and MacLachlan redress this imbalance. Participatory methods are used to gain a better understanding of the needs of disabled children in these two countries. A core contribution of this chapter is to show that even in the context of fairly small scoping studies it is both desirable and possible to access and involve stakeholders from different levels, ranging from children with disabilities and their families to policy makers. Without considering the overarching human rights framework, we cannot realize the rights of disabled children and their families.

Continuing a theme that is central to child issues, Engelbrecht, Kitching and Nel in Chap. 12 provide a helpful overview of what is at stake in inclusive education, from the earliest years to tertiary level. In common with other chapters, these authors note the good quality of many policy documents but also the challenges in implementing these, and it is clear that the policy-implementation gap remains a crucial one for ongoing research and action.

In Chap. 13, Barratt and Penn also discuss work with children, this time focusing on cerebral palsy in rural South Africa. One of the most interesting features of this careful exposition, for purposes of this book, is that the chapter in some senses gives a practical example through a case study of what can happen when a disability focus is brought to development policies. Partly in order to increase access to health care, the South African government has instituted a policy whereby newly qualified health professionals have to complete a year of community service before they may be registered to practice. Understandably, this requirement for an extra year of work, often far away from home, has not met with unqualified support from trainees, but Barratt and Penn show how much can be achieved – to the mutual benefit of the trainee and the community.

We want to finish by briefly considering the relationship between disability and health. We are of course aware that health and disability are different, but also that everyone has the right to health, and that the most recent conceptions of health are, thankfully, much broader and more inclusive than heretofore. In November 2008, government ministers from some 60 countries met and endorsed the Bamako Call for Action on Research for Health. The Call adopted a reinterpretation of "health research," as "research for health". IJsselmuiden and Matlin (2006) have argued that in relation to health "the fields of interest span the relationships between health and, among many others, social, economic, political, legal, agricultural and environmental factors" (p.4). For example, major health gains have been made possible through civil engineering improvements in water quality, sanitation and housing conditions, in addition to medicines, assistive technologies and other forms of healthcare. Recognition of the intersectoral nature of health is an important part of the Bamako Call: "The nature of research and innovation for health improvement, especially in the context of the United Nations Millennium Development Goals, is not sufficiently interdisciplinary and inter-sectoral; there is a need to mobilise all relevant sectors (public, private, civil society) to work together in effective and equitable partnerships to find needed solutions" (Recognition Statement 5). This "inter-sectorality" invites a more joined-up way of thinking about and approaching a whole range of human challenges.

While not all of the chapters in this book explicitly address "health", they are all ultimately concerned with health, welfare, and the achievement of human rights to fully participate in society. We therefore make no apology for using the term "health", but we also accept its potential to be provocative.

Michael Marmot, the Chair of The Commission on the Social Determinants of Health (CSDH, 2008), recently stated that "social injustice is killing people on a grand scale" (Marmot, 2008). The CSDH provides an authoritative summary of research showing how social inequalities disadvantage people and diminish their health and welfare. The report does not, however, adequately address how many of the same processes result in disability, affect people with disability, or how the adoption of services that are universally accessible would be beneficial for all. Anticipating the forthcoming World Health Report on Disability and Rehabilitation, we hope this book will contribute to attempts to broaden people's thinking about disability, health and development, and to moving towards a more inclusive global health which foregrounds the situation of some of the most disadvantaged people, in some of the poorest countries in the world. The chapters in this volume range across South America, Asia, Africa and Europe; education, policy, research and practice, and adults and children with disabilities. We hope that this book, which lightly sketches such a vast life-scape will both delight and infuriate, excite and perplex, because it is in the debated and contested spaces that thinking can go on – and that collectively we can do better as thinking people to promote disability in international development.

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Chapter 2
The Effect of Failed States on the Well-Being and Lives of People with Disabilities

Mitchell Loeb

2.1 Introduction

This chapter will present documentation to describe failed states and attempt to draw a connection between state failure and the lives of people with disabilities. There is a general lack of evidence linking state failure directly with disability, either in terms of its effect on the well-being and lives of people with disabilities or as a cause of disability. However, through an examination of current literature, ancillary evidence and specific cases, the association between failed-states and disability is addressed through an assessment of the effects and ramifications of state failure on people in general; through the link between state failure and poverty; and the link between poverty and disability. Through these associations it will be shown that state failure can have significant detrimental effects on the lives of people with disabilities.

Unstable or weakened states can exist in various recognized levels or degrees of decline; they can be *fragile, crisis* or *failed states.*

- According to the Crisis States Research Centre (CSRC) at the London School of Economics "a *fragile state* is a state significantly susceptible to crisis in one or more of its subsystems. (It is a state that is particularly vulnerable to internal and external shocks and domestic and international conflicts)." (CSRC 2006). The opposite of a *fragile state* is a *stable state* – however, as will be shown, even relatively stable states may be impacted by a neighbouring fragile state in the throes of failure.
- The CSRC defines a crisis state as one under acute stress, potentially unable to manage conflict and shocks and under the impending danger of state collapse. Specific *crises* within the subsystems of the state can also exist, such as an economic crisis, a public health crisis like HIV/AIDS, a public order crisis, or a constitutional crisis.

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- A *failed state*, as defined by CSRC, is in a condition of collapse; that is, it no longer can perform its basic security and development functions and has no effective control over its territory and borders. A failed state is one that can no longer reproduce the conditions for its own existence (Crisis States Research Centre, Crisis States Workshop 2006).

A review of the current literature on the subject of failed states brings forth several examples of states that fall into the category *failed* or *fragile* – among them, those you might expect to find on such a list: Sudan (1)[1], Iraq (2), Somalia (3), Zimbabwe (4), Afghanistan (8), Pakistan (12), East Timor (20), and Liberia (27) (Milliken and Krause, 2002; Foreign Policy, 2007). These states fail on a national level; the entire population (or the majority of the population) indiscriminately suffers the effects of war, a corrupt, self-serving government, or perhaps a catastrophic natural or man-made disaster. Foreign Policy (2007) provides a set of criteria for the determination of state instability or vulnerability to collapse or conflict – these are outlined in Box 2.1. While these criteria are provided as determinants or predictors of impending state failure they also allow insight into the mechanisms of such failure and thereby an understanding of the broader impacts or consequences of failure on the underlying social fabric of the state.

The list of state failures, however, is not exclusive to low-income developing countries. High-income, developed countries can fail particular population sub-groups based on their ethnicity, gender, sexual orientation, geography or disability. History provides a disturbing record of state failure: in the 1930s and 1940s the map of Europe was being systematically redrawn and, among others, Jews, gypsies, homosexuals and the intellectually and physically impaired were targeted during WWII by their state; the plight of African Americans in the United States has been well documented throughout history and was given new focus in a recent speech by then Presidential-candidate Barack Obama (NY Times, 18th March, 2008); women in many western societies have fought disenfranchisement – and won their battle against states that would deny them the right to vote, and deprive them of their equality (and basic human rights); in fact the success of the women's liberation movement has informed many of the disability activists both in the west and in South Africa in particular. More recently, inhabitants of the State of Louisiana may feel that their local, state and federal governments have failed them in the aftermath of Hurricane Katrina. Finally, it seems that there is no statute of limitations on the laying of responsibility or acceptance of blame for the failure of a state to adequately provide for its citizens. For example, the government of Australia recently apologized to its aboriginal population for having failed them for generations (NY Times, 13th Feb, 2008), and the US Senate is currently negotiating legislation that will include an apology to Native Americans for years of government mistreatment and abuse (Library of Congress, 2008, http://thomas.loc.gov/Search on Bill number: S. J. Res. 4).

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[1] Numbers in parentheses refer to ranking on the Failed State Index (2007) that ranks 177 countries from worst, Sudan (FSI = 113.7) to best, Norway (FSI = 17.1).

Box 2.1: Indicators of State Vulnerability (derived from: Foreign Policy, 2007)

The Foreign Policy's State Failure Index ranks are based on twelve indicators of state vulnerability – four social, two economic and six political. The indicators are not designed to forecast when states may experience violence or collapse. Instead, they are meant to measure a state's vulnerability to collapse or conflict.

Social Indicators

1. *Demographic pressures*. Including the pressures deriving from high population density relative to food supply and other life-sustaining resources; the pressure from a population's settlement patterns and physical settings, including border disputes, ownership or occupancy of land, access to transportation outlets, control of religious or historical sites, and proximity to environmental hazards.
2. *Massive movement of refugees and internally displaced peoples*. Forced uprooting of large communities as a result of random or targeted violence and/or repression, causing food shortages, disease, lack of clean water, land competition, and turmoil that can spiral into larger humanitarian and security problems, both within and between countries.
3. *Legacy of vengeance-seeking group grievance*,. Based on recent or past injustices (dating back perhaps centuries), including atrocities committed with impunity against communal groups and/or specific groups singled out by state authorities, or by dominant groups, for persecution or repression; institutionalized political exclusion; public scapegoating of groups believed to have acquired wealth, status or power as evidenced in the emergence of *hate* radio, pamphleteering and stereotypical or nationalistic political rhetoric.
4. *Chronic and sustained human flight*. Both the *brain drain* of professionals, intellectuals and political dissidents and voluntary emigration of *the middle class*; growth of exile/expatriate communities are also used as part of this indicator.

Economic Indicators

5. *Uneven economic development along group lines*. Determined by group-based inequality, or perceived inequality, in education, jobs, and economic status; may also be measured by group-based poverty levels, infant mortality rates, and education levels.
6. *Sharp and/or severe economic decline*. Measured by a progressive economic decline of the society as a whole (using: per capita income, GNP, debt, child mortality rates, poverty levels, business failures); a sudden drop in commodity prices, trade revenue, foreign investment or debt payments; collapse or devaluation of the national currency and a growth of hidden economies,

(continued)

Box 2.1 (continued)

including the drug trade, smuggling, and capital flight; failure of the state to pay salaries of government employees and armed forces or to meet other financial obligations to its citizens, such as pension payments.

Political Indicators

7. *Criminalization and/or delegitimization of the state*, Endemic corruption or profiteering by ruling elite and resistance to transparency, accountability and political representation – includes any widespread loss of popular confidence in state institutions and processes.
8. *Progressive deterioration of public services*. A disappearance of basic state functions that serve the people, including failure to protect citizens from terrorism and violence and to provide essential services, such as health, education, sanitation and public transportation; also using the state apparatus for agencies that serve the ruling elite, such as the security forces, presidential staff, central bank, diplomatic service, customs and collection agencies.
9. *Widespread violation of human rights*. An emergence of authoritarian, dictatorial or military rule in which constitutional and democratic institutions and processes are suspended or manipulated; outbreaks of politically inspired (as opposed to criminal) violence against innocent civilians; a rising number of political prisoners or dissidents who are denied due process consistent with international norms and practices; any widespread abuse of legal, political and social rights, including those of individuals, groups or cultural institutions (e.g., harassment of the press, politicization of the judiciary, internal use of military for political ends, public repression of political opponents, religious or cultural persecution.)
10. *Security apparatus as "state within a state"*. An emergence of elite or praetorian guards that operate with impunity; emergence of state-sponsored or state-supported private militias that terrorize political opponents, suspected *enemies*, or civilians seen to be sympathetic to the opposition; an *army within an army* that serves the interests of the dominant military or political clique; emergence of rival militias, guerrilla forces or private armies in an armed struggle or protracted violent campaigns against state security forces.
11. *Rise of factionalized elites*. A fragmentation of ruling elites and state institutions along group lines; any use of nationalistic political rhetoric by ruling elites, often in terms of communal irredentism or of communal solidarity (e.g., *ethnic cleansing* or *defending the faith*).
12. *Intervention of other states or external factors*. Military or Para-military engagement in the internal affairs of the state at risk by outside armies, states, identity groups or entities that affect the internal balance of power or resolution of the conflict; intervention by donors, especially if there is a tendency towards over-dependence on foreign aid or peacekeeping missions.

The effects of state failure on a population or population subgroup may, furthermore, be exacerbated by historically pre-existing conditions. I would assert, for example, that the living conditions of those most affected by Hurricane Katrina were poor at the outset, and these conditions were further worsened by the natural disaster of the hurricane. Discrimination in an emergency setting in a failed state can be life-threatening (IFRC World Disaster Report, 2007). The International Federation of Red Cross Red Crescent Societies (IFRC) World Disaster Report goes on to state that "the most marginalized and vulnerable risk not surviving the crisis or, if they do, they are then overlooked in plans to recover and regain their livelihoods." Only when aid agencies and government agencies are aware of the consequences and manifestations of discrimination during the heightened tensions brought about by emergency will minority groups, older people, persons with disabilities, and women and children become a key factor in emergency planning, relief programmes and reconstruction efforts (IFRC World Disaster Report, 2007).

Several marginalized and vulnerable groups, among them women, blacks, gays & lesbians, and people with disabilities, have fought or are still fighting their battles before the portals of governments and legislatures and the benches of the judiciary in order to be heard, to be included, to be permitted to participate on an equal basis in society. Most countries are not without their underprivileged or disenfranchised groups – and several of these groups may have been subjected to long-term, generational neglect leading them to the conclusion that their state has failed them.

One common, even natural, reaction to the failure of a state may be to take flight. When one's safety is threatened for political reasons or one's survival is threatened for economic reasons – when the basic elements of existence (e.g. food, health care) become scarce or absent, the need to protect one's self or family may become the driving force that impels one to flee. Western democracies and more stable, more prosperous borderlands are continually assailed with waves of refugees (political and other) fleeing their homelands that have failed or are on the brink of collapse.

For many, allegiance to a homeland, or national pride, represents a strong bond that is not easily broken. This sense of allegiance may also have a bred-in-the-bone quality that is culturally nurtured and at times politically exploited. And while many may find the strength to break the bonds of allegiance or the equally compelling bonds of family in order to flee or migrate from the untenable consequences of state failure, still many others choose – or have no choice but – to stay.

Solomon (1996) identified eight factors that may influence one's decision to migrate (see Box 2.2). These include socio-cultural factors, communications and technology, geographical proximity, precedent, demographic factors/population growth, environmental factors, economic factors and political factors. Apart from man-made or natural environmental disasters, state failure is most frequently associated with aspects of economic and/or political mismanagement.

Any one or any combination of the extenuating factors that may lead one to a decision to migrate also offers some insight into the potential consequences of migration – on both sides of the "migration equation" – not merely what people are escaping from and leaving behind, but also what they may be escaping to. The burdens placed on an individual, a family or a society that is required to deal

Box 2.2: Determinants of Migration (Derived from: Solomon, 1996)

1. *Socio-cultural factors*. Bosnia, Rwanda and Burundi are recent examples illustrating how people may be forced out of their homeland as a result of their specific cultural and ethnic identities; the crisis in Sudan/Darfur represents an example of domestic migration. (This effect can work both ways – in terms of a socio-cultural *pull*; Israel might be an example of such an effect, where, among the Diasporas, there are socio-cultural incentives or advantages to migrate *home*).
2. *Communications and technology*. It is claimed that the communications and technology revolution has acted to encourage population movements. Recent advancements in information technology have resulted in people having more information at their disposal and being better able to make informed decisions regarding the need and feasibility of migrating.
3. *Geographical proximity*. It has been argued that foreign populations originate primarily from the same geographical area, in part because migrants retain a certain loyalty to their country of origin. Consequently, they may wish to visit their loved ones or, if they are refugees, they may wish to return to the land of their birth once circumstances stabilize. Examples include Zimbabwean and Mozambican refugees residing in South Africa, or France's experience of migration from Algeria, Morocco and Tunisia.
4. *Precedent*. Some experts suggest that precedent plays an important role in migration. A pioneer group, who smoothly migrate, acts as a magnet for further migration: for example, most foreigners in Germany are from Turkey (34%) and the former Yugoslavia (13%).
5. *Demographic factors/population growth*. Population growth in itself does not necessarily constitute a factor that urges people to cross international borders. However, when coupled with economic decline, population growth induces migrants to cross borders in search of a better life. This results simply from fewer employment opportunities, greater stress on the social and welfare services of the state and, ultimately, social and political discontent.
6. *Environmental factors*. Increasingly, policy-makers are aware that deepening ecological damage can also foster major population movements. These environmental migrants result from two categories of catastrophe:

   - Those without an anthropogenic cause, arising from volcanic eruption, earthquakes, whirlwinds, hurricanes, drought, landslides, avalanches, floods, and forest fires
   - Those with an anthropogenic cause, including the destruction of arable and grazing land, sustained heavy flooding, and increased hurricanes, whirlwinds, hailstorms, landslides, avalanches and forest fires as the direct or indirect result of human activities.

7. *Economic factors (local/global)*. Economic considerations were the primary cause of the westward movement of people from former Eastern Bloc countries, as well as the main cause of the movement of Haitians, Mexicans and El Salvadorans into the United States, and the movement of North Africans into Western Europe. This desire for an improvement in life's chances also seems to be a prime motive for migration in Africa. For instance, between 1986 and 1990, countries in central Africa lost between 2 and 5% of their populations to eastern and southern Africa. This shift coincided with differential GDP growth rates: higher in eastern and southern Africa, with an average of 3.2%, and lower in central Africa, averaging 0.5%.
8. *Political factors*. Turmoil resulting from political rivalry, ethnic strife, socio-economic inequities or regional imbalances tends to promote south-south migration. Its roots take various forms: persecution of certain groups, denial of political rights, mass expulsions, *coups* or civil war. While the link between political instability and mass movement has ancient historical roots, more recent examples include the two to three million Iraqi Kurds who escaped persecution and repression by sheltering in neighbouring Iran and Turkey, or the case of the former Yugoslavia where disintegration, civil war and the redrawing of boundaries created an internal haemorrhaging and resulted in the release of large numbers of refugees to both Hungary and Germany. A process that began with the fall of Tito in 1980 continues today with the recent declaration of independence by Kosovo in February of 2008. In southern Africa, civil strife in both Angola and Mozambique has displaced thousands of people, and most currently it has been estimated that as many as 3 million Zimbabweans (out of a population of 13 million – about 23%) have fled the political crisis in that country for better prospects in South Africa (Economist, 9th Aug 2007).

with a "stranded" sub-population of people with disabilities, left behind by a mass exodus from the consequences of state failure, describe but one side of this migration equation. Despite the promise of greener pastures, an influx of migrants may be felt as palpable stressors to a host economy or social structure that may result in consequent failure on a larger or smaller scale. For example, the influx of Mexican migrants to the USA has had repercussions on the entire US economy, and those fleeing the oppression and economic collapse of Zimbabwe for South Africa have placed added pressures on an extant fragile social system.

Some migration scenarios may also, in and of themselves, be mitigating factors or consequential in creating a population of disabled people, most notably through acts of war and violence – but also through neglect. When armed conflict is entered into the equation, the result will always be an increase in the number of victims, many of whom will become disabled as a consequence of these actions.

The failure of states and repercussions felt by their victimized citizens continue to feed the global press and are continually the subject of global concern. Nowhere in the documentation, however, is the plight of the disabled person elucidated – neither in terms of the disabling consequences of migration nor the life situation of the disabled person left behind in a failed state. A search of the literature that combines disability and failed or fragile state brings forth nothing. Independently, disability and state failure are factors that tend to marginalize people. This general lack of awareness, or oversight, in the literature is noteworthy, especially since migration (as a component of state failure) may compound marginalization for persons with disability.

I now consider two quite different cases of how persons with disabilities are affected by state failure: the case of South Africa as it emerged from the failure of apartheid and the case of Zimbabwe and the challenges facing those struggling to survive in a failing state.

2.2 Surviving a Failed State

2.2.1 The Example of South Africa: From Apartheid to Reunification – and Disability

The history of apartheid and its downfall provides an example of the power of a failed state to suppress a people on the basis of race and to compound that suppression on the basis of disability. However, in South Africa, the commitment to the disability rights movement and the inspirational leaders who spearheaded its inception and growth ensured that the emerging post-apartheid democracy of re-unification would not neglect the lives and livelihood of people with disabilities. This is perhaps best outlined in *A history of the disability rights movement in South Africa* (Howell et al., 2006).

The authors proffer a depiction of the rise of the disability movement as it dovetails with the fall of apartheid, and in the process they also offer some insight into the disparities not only between black and white but between disabled and non-disabled.

> Under apartheid, the experiences of disabled people were also the experiences of a deeply divided people living in a profoundly unequal society. The lived experiences of black and white disabled people under apartheid were very different and reflected the general inequalities between white and black people in South Africa. For the majority of black disabled people, their lives were about struggling on a daily basis to cope with the poverty, deprivation and violence of the apartheid system, a struggle compounded by their disability. However, it is important to recognize that under apartheid all disabled people, black and white, were discriminated against and marginalized because of their disability and had very limited access to fundamental socio-economic rights such as employment, education and appropriate health and welfare services. This kind of discrimination and marginalization occurred because disabled people in general were

> seen as people who were sick or in need of care, rather than equal citizens with equal rights and responsibilities (Howell et al., 2006).

The disability movement in South Africa has been pivotal in ensuring that the rights of persons with disability are included on the political agenda. At an early stage in the country's reconstruction, the National Office on the Status of Disabled Persons (OSDP) was established within the Presidency at the national level, and within the Premier's office in the nine provinces. The South African Constitution, adopted in 1996, was very clear on the issue of disability and the need to eradicate any form of discrimination on the basis of disability (Matsebula et al., 2006).

The comprehensive policy in South Africa on disability issues is founded on the Integrated National Disability Strategy (Government of South Africa, 1997). This policy document was formulated in 1997 following a participatory process in which people with disabilities were consulted throughout the country. The Integrated National Disability Strategy (White Paper) provides a blueprint for integration and inclusion of disability into every aspect of governance (Vuyiswa McClain, 2002).

Despite the long struggle for recognition and equality and these very best of intentions, disparities between disabled and non-disabled still remain. A recent research project addressed issues of poverty and disability in South Africa's Eastern and Western Cape Provinces (Loeb et al., 2008a). In this research, poverty was addressed through paradigms defined not only by income and material possessions but in terms of inclusion in the benefits that society offers to all its constituents; in particular education and employment, and these paradigms were subsequently assessed in relation to disability.

The results of this research indicated that the policies of the South African Government (ODP, 1997) in providing disability grants to members of society who have a disability have played a significant part in equalizing the living situation of these individuals. In the Eastern Cape in particular, mean monthly incomes among households with a disabled family member were not only *not* lower than households without a disabled family member, they were significantly higher, and this finding has been reiterated through the analysis of material possessions – households with a disabled family member in the Eastern Cape have more possessions than Eastern Cape households without a disabled family member.

Results in the Western Cape were less divergent and reflect, in part, the socio-economic structure particular to that area; households with a disabled family member had similar monthly incomes and similar amounts of material possessions as families without a disabled family member. However, despite the improved situation of households with a disabled family member in terms of financial resources (due primarily to the allocation of disability grants), other measures of poverty (in particular education and employment) remained divisive for those with disabilities.

Findings from this survey indicated that the improved economic status of households with a disabled family member was not the result of employment. According to the survey results, unemployment is high in the Eastern Cape, with only 6% of individuals of working age (regardless of disability status) currently employed, and in the Western Cape where similar monthly incomes between households was recorded, unemployment was significantly higher among those with a disability. Assuming equality in terms of economic status between households with and without a disabled family member, it remains alarming that access to education should remain so inequitable, with a significantly larger proportion of school aged children with a disability in both Eastern and Western Cape provinces having never attended school.

The provision of disability grants is a government initiative that clearly benefits a group of people who experience disadvantages (in terms of education and employment). This financial gain, however, has not been easily translated into social equality, and this inequality is most evident in the lower numbers of employed among those with disabilities, and the lower number of those with disability among those receiving both primary and secondary education.

Although grants do provide for an immediate solution to, at times, dire situations, the decreased access to both employment and education will exacerbate the problem and perpetuate the need for, and dependency on, these grants. A more lasting solution would be to ensure that people with disabilities are afforded access to services which would increase their self-sufficiency and make the grants themselves redundant. This is in turn dependent on the improvement of the socio-economic situation of all members of the poorest sectors of South African society.

Despite the continued challenges facing South Africa in terms of the removal of physical, legislative, social and attitudinal barriers to equitable access to basic services and rights such as education, employment and health services to people with disabilities – there are existing structures, both governmental and non-governmental, that are committed to redressing these inequities. There is a coincident obligation on the part of DPOs and will on the part of the government that, if activated in unison, would provide the impetus for progress for those who continue to fall between the gaps of state prosperity.

2.3 Failing in a Failed State

2.3.1 The Example of Zimbabwe: From Prosperity Through Deconstruction to Ruin – and Disability

Interestingly, the disability movement that began to blossom in South Africa in the late 1970s and early 1980s "was strongly influenced by the existence and success of the Zimbabwean Movement of Disabled Persons" (Howell et al., 2006). Not unlike the then current struggles in South Africa, the disability movement in Zimbabwe also sprung from a local liberation struggle in the mid to late 1970s. In 1991, the Southern Africa Federation of the Disabled (SAFOD), an umbrella organization for the national Disabled People's Organizations: in the Southern African Development Community (SADC) (SAFOD, 2008), organized a symposium on equal opportunities legislation for disabled people in Harare. The key outcome of the symposium was the ratification of the Harare Declaration on Legislation for

Equalization of Opportunities for Disabled People. Zimbabwe was especially active in taking forward the recommendations from the symposium and managed to secure the passing in 1992 of the Zimbabwe Disability Discrimination (or Disabled Persons) Act. The Act makes provisions for "the welfare and rehabilitation of disabled persons; to provide for the appointment and functions of a Director for Disabled Persons' Affairs and the establishment and functions of a National Disability Board; and to provide for matters connected with or incidental to the foregoing" (Government of Zimbabwe, 1992). The Act was last amended in 2002.

Until the late 1990s Zimbabwe was a breadbasket for southern Africa, with steady economic growth supporting strong health and education programmes. However a combination of factors has changed – and even reversed – that trend. According to a DFID report (2005), recent military involvement in neighbouring Democratic Republic of Congo, along with a combination of economic mismanagement, political instability, and poorly implemented land reforms contributed to the economy declining by 30% during the period 2000–2005. Under multiple political, economic and social burdens, including high levels of HIV/AIDS, the country has become unable to service its external debt and requires substantial humanitarian assistance, with as much as 70% of the population below the poverty line (DFID, 2005). Thus, despite a history of positive or affirmative action on behalf of people with disabilities, Zimbabwe is currently undergoing a phase of socio-economic *deconstruction* that has affected the majority of Zimbabweans, but perhaps most severely affected will be the vulnerable and marginalized – among them people with disabilities.

The media have recently described Zimbabwe's economy as *capsized* or *in free fall* and its society as *collapsed*. The result of the most current events has been a notable migration of Zimbabweans, for the most part to South Africa. Two points are worth mentioning with respect to migration and disability. *Migration* evokes *action* and thus it follows that one's *ability* to migrate is correlated to their physical (and in some cases mental or emotional) *capacity* – thus people with disabilities or functional limitations are often less able to migrate, to physically leave a failing state.

Secondly, it appears also that migration or one's ability to migrate is further dependent on one's personal socio-economic situation ('South Africa's Wealth is Luring Black Talent', UN Economic Commission for Africa as reported in NYT, February 12th, 1993) – the greater one's wealth the further they are able to go. Evidence indicates that people with disabilities are over-represented among those living in poverty and thus with the fewest means at their disposal to migrate.

Without direct empirical evidence linking state failure and disability, simple reckoning can be used to illustrate *effect by association*. For example, evidence exists to corroborate the fact that state failure may exacerbate and spread the effects of poverty – and we have evidence that disability and poverty are inextricably linked – it follows then that there must exist a link between failed states and disability. This is further evidenced by the data presented below.

While the Zimbabwean survey of living conditions among people with disabilities was carried out in 2000–2002 at the cusp of state failure, and the South African

Table 2.1 Education and literacy among persons 5–18 years of age inclusive, South Africa and Zimbabwe Living Conditions Surveys

	SA		Zimbabwe	
Disability	Yes	No	Yes	No
School attendance				
% Never attended school	13.7	1.6	25.3	8.0
Literacy				
% Unable to write	17.5	13.3	46.4	19.2

Source: Surveys of living conditions among people with disabilities in Zimbabwe and Eastern & Western Cape Provinces, SA. SINTEF Health Research, Oslo, Norway: www.sintef.no/lc

survey mentioned above was carried out in 2004/2005 during a period of national re-construction, it is of interest to contrast the two countries (Table 2.1).

There can be no doubt of the link between poverty and disability and this is illustrated in the table above that compares school attendance and literacy rates among disabled and non-disabled children between the ages of 5 and 18 years. Non-attendance rates are significantly higher among children with disabilities in both countries (SA: $\chi^2 = 62.83$ (1), $p<0.001$; Zimbabwe: $\chi^2 = 121.35$ (1), $p<0.001$). Illiteracy rates (as measured by ability to write) were also higher among children with disabilities, but the difference was only statistically significant in Zimbabwe ($\chi^2 = 151.47$ (1), $p < 0.001$).

Reasons for regional differences are not immediately evident; however, each country has experienced social development (pre-colonial, colonial and post-colonial) differently, and the results may, in part, be a reflection of that history. For example, under colonial rule Zimbabwe experienced the development of a well-functioning social infrastructure (albeit to the exclusion of the majority black population), and in particular, the development of facilities specifically designed for those with disabilities (Jairos Jiri Association). In 1995 it was noted that an extended network of institutions still served persons with disabilities (Devlieger, 1995). That the infrastructure remains intact is a tribute to those who would continue to fight for the inclusion and rights of people with disabilities. However, under the current economic situation, the fiscal constraints placed on schools serving all children – and children with disabilities in particular – reduce both the quality and quantity of education provided. South Africa on the other hand, at the time of the survey, had the benefit of several years of re-unification policy that may have improved the situation for children with disabilities somewhat.

Unemployment in sub-Saharan Africa is high, regardless of one's disability status, and this is illustrated in Table 2.2. In the surveys presented here *working* has been operationalized as *working outside the household and bringing cash into the household*. In both countries informal employment is common and often encouraged without strict enforcement of laws and regulations governing work environments. Subsistence farming and barter trade are other important factors influencing household income. Although the way in which *working* has been defined here will also cover

Table 2.2 Employment situation among persons 15–65 years of age inclusive, South Africa and Zimbabwe Living Conditions Surveys

	SA		Zimbabwe	
Disability	Yes	No	Yes	No
Are you currently working?				
% Unemployed	91.9	87.0	78.4	78.3
Do you have a skill?				
% Unskilled	75.9	88.6	64.6	71.8

Source: Surveys of living conditions among people with disabilities in Zimbabwe and Eastern & Western Cape Provinces, SA. SINTEF Health Research, Oslo, Norway: www.sintef.no/lc

the informal economy, it is limited to the cash economy and may thus underestimate the level of activity to secure a living for the household.

The results demonstrate that unemployment, as defined in these surveys, is significantly higher among individuals with a disability in South Africa ($\chi^2 = 7.56$ (1), $p = 0.006$) though not in Zimbabwe. Recall however that the survey in Zimbabwe was carried out in 2002. Due to recent developments, including the downturn in the economy, living conditions, including access to work, have deteriorated dramatically.

Survey results are different in terms of the possession of skills. While the ranks of the unskilled are substantial, the difference between those with and those without disability are reversed; there are significantly fewer unskilled individuals among the disabled in both countries (SA: $\chi^2 = 54.07$ (1), $p<0.001$; Zimbabwe: $\chi^2 = 23.32$ (1), $p < 0.001$). This again may be a reflection and a remnant of earlier programmes and initiatives that focused on the disabled, raised awareness concerning their rights and provided them with sheltered workshops and skills-training environments.

As mentioned above, the ability to migrate is dependent on one's personal socio-economic situation. Professionals or skilled labourers, who have the economic means and are internationally mobile, will be less confined to geographical space than unskilled or semi-skilled labour. This has been borne out in a study by the United Nations Economic Commission for Africa that estimated that in 1987 an astonishing 30% of the skilled manpower in Africa was living in Europe (South Africa's Wealth is Luring Black Talent, NYT, February 12, 1993). This also seems to be confirmed by the fact that the overwhelming majority of Mozambican migrants in South Africa are unskilled (Washington Post, 26 November 1990 as cited in Solomon, 1996).

This would seem to substantiate the theory that distance migrated is proportional to education and skills level. Considering the disadvantaged, the marginalized, the vulnerable, and the disabled – they would not have the means to migrate at all. They would be among those left behind.

Deconstruction, according to Alexander Phiri, Director General of SAFOD, located in Bulawayo, Zimbabwe, seems to be a very appropriate term to use in the case of Zimbabwe, not only with reference to disability but to any people-centred development that many African leaders, including Robert Mugabe, promised their citizens when they delivered them from colonial rule. During a relatively short span of time, many African countries attained independence, with South Africa being the last one to do so in 1994. State by state Africa emerged from bondage and became a continent of freedom and hope. Phiri goes on to state, however, that “if the truth were to be told, what used to be called the Dark Continent still remains dark today to a majority of its inhabitants in terms of poverty. As Africa[n] people we are poor because we have not enjoyed freedom, and many of us are living under predatory, incompetent governments which are difficult to remove from power, and yet they promised us milk and honey when they got into power at independence. Our liberation leaders are enjoying all the milk and honey and we are not.”

Many of Africa’s citizens may count themselves among the ranks of the poor, and in any given situation, people with disabilities will be located on the lowest rungs of the ladder. Ironically, the very same governments that were expected to be the liberators of their people are making these citizens poorer through corruption, bad economic policies and dictatorial practices that scare off investors (Guest, 2005; Phiri, personal communication).

In the early 1980s, Zimbabwe was a prospering country; the average annual income was ZW$950 and a Zimbabwean dollar was worth more than an American dollar. By 2003, the average income was less than ZW$400, the country’s economy was in freefall, and, by late 2003, inflation had reached 526% (Guest, 2005). In September 2007 Zimbabwe experienced the most severe economic collapse in its modern history. At that time, one American dollar was worth about 30,000 Zimbabwean dollars. Today income and savings have been devalued at an alarming rate, hyperinflation is running at not less than 10,000% and unemployment is standing at 82% (Phiri, personal communication). At the time of writing (07/21/08) the inflation rate is reported in the media (CNN.com) as 2.2 million% and the value of one American dollar is approximately 100 billion Zimbabwean dollars, the denomination of the newly introduced banknotes.

Phiri goes on to explain that the current plight of people with disabilities in Zimbabwe is critical on several fronts:

1. People with disabilities are among the most stigmatized and marginalized in the country, and as the situation becomes more desperate, people are becoming less and less tolerant towards those deemed to be a *burden* on their families; abuse and neglect of children with disabilities is widespread and women with disabilities in particular are highly vulnerable to sexual abuse and exploitation, and HIV and AIDS. This statement is borne out by Turnbull (1992) who claims that “Tolerance of people with disabilities has also tended to diminish sharply during periods of economic hardship” (Turnbull, 1992 – cited in Choruma, 2006).
2. Specialist services for people with disabilities have collapsed, and hyperinflation has totally eroded the value of the state disability allowance – currently just over ZW$800 per month; assistive devices (wheelchairs, crutches, etc.) are in short supply and completely unaffordable to most people who need them. State grants for devices have collapsed; special schools are struggling to function.
3. People with disabilities suffer disproportionately from Zimbabwe’s crisis; the collapse of health services particularly affects people with disabilities as

they typically use health services more than non-disabled people. For example, catheters for those with spinal cord injuries are in desperately short supply and prohibitively expensive; the collapse of the water supply disproportionately affects people with disabilities as they often need to use more water for sanitation and are least able to collect water from informal sources (shallow wells, rivers); and the high cost of transport has severely impacted on the mobility of people with disabilities.

4. Focus on short-term humanitarian assistance has further marginalized disability issues and funding for organizations for and of people with disabilities has declined.

Over a period of a little less than 30 years this once prosperous country has been systematically de-constructed into a failed state. Living conditions for the hardiest are dire and, all things considered, the current economic situation has made things even more difficult for people with disabilities (Choruma, 2006).

2.4 Conclusions

We may harbour some expectations that our homelands will develop over time; that they will evolve and prosper, and provide a socio-political infrastructure that allows all citizens, regardless of gender, race or disability status, to thrive. To this end, the intentions of the international community are most honourable when issues of human rights are concerned. This has been reconfirmed in 2006 through the adoption and recent ratification of the UN Convention on the Rights of Persons with Disabilities.

The purpose of this Convention is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (UN Enable, 2006).

The rights and freedoms demanded of the Conventions are dependent, however, upon a well functioning social structure that is supported by the political will and determination to ensure the equitable distribution of and accessibility to services that may benefit the lives of people with disabilities. The livelihood of people with disabilities is dependent on an open and accessible socio-political environment, free of physical, attitudinal and legislative barriers.

Several countries styled on western democracies or successful single-party states may represent examples of successful socio-political structures in which the rights of all citizens are paramount. Social structures incorporating a system of health and social services have been constructed to serve the needs of the public. With few exceptions the services provided are intended to be available and accessible to all – providing people with disabilities access to not only these services but to a life that is based on social and economic equity.

The actual situation in many low-income, developing countries presents a different picture. In many such countries authorities are dealing with opposing dilemmas: to provide services with scarce resources while at the same time trying to meet the growing demands of those who need those services. The economically sound provision of services is based on existing and, at times, forecasted need for the service in question. In terms of disability, need may be based on proportion of the population that has been enumerated or counted as disabled. Disability prevalence is widely under-reported in many low-income countries (Loeb & Eide, 2006; Mont, 2007; Loeb et al., 2008b). Prevalence rates in these countries tend to reflect that proportion of the population with, for the most part, severe impairments. The exclusion of lesser degrees of disability would then suggest that the real need for services is larger than that based solely on the proportion of the population with severe impairments (Mont, 2007, Loeb et al., 2008b). This is not to underestimate the value or need for services to those with severe impairments, but full social participation requires that the needs of those with moderate and even mild disabilities be addressed.

As mentioned earlier, Zimbabwe is currently in a period of socio-economic *deconstruction*. In this phase the vulnerable and marginalized – among them people with disabilities – will more acutely feel the effects of the disintegration of the social infrastructure. As limited services become scarcer the plight of those in need becomes more desperate and the already extant poverty-disability interdependency becomes entrenched.

Disability movements at national and international levels continue to be preoccupied with the fulfilment of human potential. The rights of persons with disability have been acknowledged in a UN Convention. One might imagine that these efforts would gain support through national legislative policies that would ensure the rights of people with disabilities. But politics make strange bedfellows … and too often, policies can have a negative effect on those they are intended to serve. Entrapped citizens of a failed state become the unwitting pawns in a game that has few, if any, victors.

One particular factor has been omitted from both sides of the *migration equation*, and that is hope. Zimbabweans who flee their homeland leave often with only hope – hope for a job and the ability to send money home to family still in Zimbabwe – hope and $50 – the cost of boat transport across the Limpopo River (IRIN, 2008). And, despite dire circumstances, Zimbabwe is not devoid of its citizenry. While some may leave a failing state because they are forced to for political reasons or for reasons of survival, some remain – the party loyal, those who would remain with their family or would not abandon their country in a time of crisis, and some remain because, for them, there is no means of escape. There are those also who remain because they continue to be hopeful – those who place their hope in imminent change and in a more stable and equitable future.

Notwithstanding the relative scarcity of compelling empirical evidence, there is an important relationship between failed states, poverty and disability. The evidence that I have provided indicates that even relatively strong states (like South Africa, as it emerges from a failed past) may continue to fail marginalized people in significant ways, and more conventionally recognized failed states (like Zimbabwe) fail people, and disabled people especially, with at times dire results.

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Chapter 3

The Impact of International Human Rights Law on the National Laws of Ethiopia from a Gender Rights and Disability Rights Perspective

Theresa Rouger

3.1 Introduction

As the importance of disability as a human rights issue is recognized more consistently internationally, the question arises as to whether this international interest transfers to practices at local country levels. To what extent do international agreements and treaties make a difference at local level? With reference to the situation on the African continent as a whole, it has been suggested that the question of disability rights and the realization of these rights can easily be separated from more general question concerns about governance at country and regional level. This chapter takes the situation of Ethiopia as a case study and after a brief introduction examines the links between policy in Ethiopia and international codes and conventions. The particular lens of the analysis will be through a gender rights and disability rights approach. As may be expected, there are some disjunctions between Ethiopian practices and international prescriptions, and some suggestions for changes in approach to the field are made.

3.2 Introduction to Ethiopia and Disability

Tirrusew Teferra (2005) wrote that the most commonly known causes of disability in Ethiopia are the presence of diversified pre and post natal disabling factors like the health of prospective mothers, difficulties relating to delivery, childhood infectious diseases, lack of proper child management, traditional and harmful practices, malnutrition, civil strife, periodic episodes of drought and famine and the absence of early primary and secondary preventative services at large.

The International Labour Organization has pointed out in a study made in 2004 that the 1994 Census is acknowledged to have underestimated the number of

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disabled persons in the country. In 2003, it was estimated that there were over 5 million children, adults and elderly persons with disabilities in Ethiopia, representing 7.6% of the population.

Teferra has further argued that persons with disabilities have neither equal participation nor equal opportunity to health and education. In Ethiopia, many women with disability serve domestically but are still not recognized as "productive" citizens. Furthermore, children with mental retardation and severe disability are often kept indoors for fear of social and community condemnation and denied rights to happiness through play, social interaction and schooling.

Other factors that increase the vulnerability of persons with disabilities were also identified at the 2007 Handicap International planning workshop:

- *Poverty*. It is widely recognized that poverty is directly related to HIV risk, and worldwide people with disability are over-represented among the poor. Ethiopia is no exception, where food, money and material goods may be exchanged for sex by disabled women who have no alternative means of generating income.
- *Physical dependency*. Visually impaired persons might be led to unsafe areas where they can suffer sexual violence. An adolescent with motor impairment cannot resist sexual advances from an aggressor, who may well be a family member. Others living in institutions are highly susceptible to aggression from caregivers or other residents without means for recourse in the event of sexual abuse.

Legal obstacles that deny persons with mental disability basic rights, such as the right to bear witness in a court of law, the right to make decisions for oneself (autonomy), and the right to information about HIV, serostatus, etc.

3.3 International Law, National Law and Local Cultural and Traditional Practices

3.3.1 The United Nations and the African Regional Human Rights Standards

The United Nations has been the primary actor engaged in efforts to promote human rights since 1945 and right up to the present day, culminating in the recent twenty-first century Convention on the Rights of Persons with Disabilities 2007. International human rights law focuses on the protection of the inherent dignity and equal and inalienable rights of all people, including women, children and persons with disabilities.

The United Nations methodology has been to promote human rights from the top down, typically done through cooperative strategies such as creating human rights norms, raising awareness about human rights and monitoring human rights performances. International states rarely use force as a means to promote international human rights.[1] Generally speaking, States, including Ethiopia, have not willingly relinquished sovereignty in order to give the United Nations and international organizations the legal right to use enforcement measures for human rights. There are other regional human rights standards, such as the African Charter's Protocol on women's human rights and disability rights that strengthen the legal framework of their human rights entitlements.

3.3.2 Does International Human Rights Legislation Have an Impact on Domestic Law?

Today, almost every area of national legislative concern is affected in one way or another by international and/or regional treaty standards. Over 20 years ago, concrete constitutional and legislative commitments to women's rights and disability rights were practically non-existent. Today, we see some countries, including Ethiopia on some level, responding to the worldwide call for protection of minority groups and adopting laws against domestic violence and female genital mutilation, strengthening social protectionist policies for disability workers and basically moving into the private sphere (harassment, battery, marital rape, incest, female genital mutilation, etc.) that traditionally affects women. As noted by many feminist activists in Ethiopia, both the formal and informal justice systems have often failed to take gender and disability rights into account. In many instances the challenge to the barriers between the public and private spheres in the formal and informal justice systems has proved and continues to prove to be an uphill struggle.

Philip Allot (1992) argues that International Human Rights legislation is important but one should not disregard the importance of national legislation, an essential and fundamental link in the fulfilment of international law-making.

Compared to previous Constitutions of Ethiopia, the Constitution of the Federal Democratic Republic of Ethiopia (FDRE) 1995 has made progress in terms of addressing the concern of persons with disabilities and gender and child rights. A national country's constitution is a country's legal "birth certificate". A constitution can provide courts with a useful tool for the elaboration of standards on gender equality and disability rights. Article 41(5) of the FDRE sets out the States responsibility for the provision of necessary rehabilitation and support services for persons with disabilities: *The state shall, within its available means, allocate resources to provide rehabilitation and assistance to the physically and mentally disabled.*

The Constitution states in Article 9.4 that all International Human Rights instruments ratified by Ethiopia are considered to be an integral part of the law of the land.

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[1] Force has been used against sovereign states but it has usually been used against weak states that do not have the power to protect its sovereign interests. Critics argue that when some states intervene in other countries on human rights grounds, it is unclear whether the state in question is genuinely concerned by human rights abuses or are only trying to further their own national/foreign policy interests.

The integration of human rights instruments to Ethiopian law means that the Ethiopian government is duty bound to respect, protect and fulfil the specific obligations as set out in the various conventions. Depending on the specific conventions, the Ethiopian government will be held responsible at the international and domestic level when violating a declared right.

The FDRE states in Article 35(4) that women have the right to be protected from practices that are harmful to them. This is in obvious contrast to previous constitutions that had no provisions protecting women from customs and traditions that are harmful to them.

The Ethiopian Penal Criminal Code 2005 further emphasizes the domestic legalistic move towards gender and child rights including persons with disabilities, thus displaying an obvious impact of International Human Rights Conventions. Many national labour laws providing rights to persons with disabilities have also been enacted in response to international labour law such as the ILO Convention concerning Vocational Rehabilitation and Employment (Disabled Persons) No. 159 (1983). But while the move is obviously a positive one, Ethiopia has a long way to go in offering the type of protection desired or aspired to by the international and national community.

Giorgis et al. (2004) point out that Article 564 in the New Criminal Code states that harmful traditional practices, which result in the death of a pregnant woman or a young child, are punishable under criminal law. Local practices such as smearing the umbilical cord of a newborn baby with animal dung or prevention of the child from having an injection will also be considered as crimes under this provision.[2]

Giorgis et al. further point out that the New Criminal Penal Code contains a provision declaring that traditions like Female Genital Mutilation (FGM) are now considered as a criminal offence. Prior to 1995, FGM was not even recognised as a criminal offence. Now, according to Article 568 circumcising a girl/woman of any age is punishable. The penalty provided is from 3 months to 3 years imprisonment or a fine not less than 500 Birr.

3.3.3 Local Customs and Traditions: Informal Justice Systems

While the justice system, both nationally and internationally, is being used more and more by women to claim their legal rights, many women or persons with disabilities will never come into contact with the formal justice system. The term "informal" or traditional justice institutions describes customary or religious norms that deal with a wide range of issues, including resolving marriage disputes,

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[2] Article 566 states that in pronouncing penalties for such acts, the court will take into consideration the age, educational level and social background of individuals who committed the act. So while the punishment may in some cases range from 6 months to 1-year imprisonment, it can sometimes result in a strong warning to the accused.

recording births and marriages, allocating land ownership and land use rights and in some instances rape cases.

While one cannot over-emphasize the importance of international or national legislation, one should not underestimate the impact of local justice, culture and traditions on the everyday lives of these vulnerable groups.

In Ethiopia, disputes are often resolved at the district or local level (woreda or kebele) by religious or customary courts, in accordance with religious or customary laws, which might have discriminatory consequences for members of some ethnic groups. In some instances, local culture and tradition is a lot more powerful than any national or international law. Are constitutional human rights' standards provided to those seeking justice at local/district level? Probably not. As Nyamu-Musembi points out, in many African countries the application of customary or religious law in matters of family is generally exempt from constitutional scrutiny. Even where such constitutional scrutiny exists, in practice it can be difficult to enforce the constitution's reach to those customary and religious forums. Many of the laws are made and enforced locally with the higher officials turning a very convenient "blind eye" to decisions that should otherwise shock. Women can of course appeal the decision but many do not, fearing reprisal from family or the community.

The World Bank points out that many women (and this would undoubtedly include persons with disabilities) opt for the traditional methods of justice because they tend to be closer, cheaper and more often more efficient than formal justice systems. The decisions may enjoy greater legitimacy among the local community. The negative aspect of the local justice system is that they are barely answerable to women. Critics say that the decisions (more often than not made by the male members of the population called elders) are often made based on entrenched traditional views of gender roles where the perpetrators (usually male) are often given reduced sentences or warnings because of lack of evidence on the part of the victim or simply lack of sympathy for the female viewpoint.

Many international and local NGOs have carried out tremendous and painstaking work on trying to educate the local population on the negative impact of certain life-threatening practices. Change has not come easily and has been met with hostility in some areas but in order to appreciate the work done by the international community and the local community, critics argue that traditions and local customs should be respected even if they appear peculiar to those of us coming from the developed world. In some instances, certain traditions have existed for centuries and are associated with marriage chances or coming of age and the removal of those create confusion for those marginalized groups such as persons with disabilities. However, I would argue that any culture or tradition that can kill/injure or maim requires action, such as was provided both by the Ethiopian community itself as well as local and international NGOs when faced with the many horror stories associated with FGM.

Gender based violence is often embedded in the traditional and cultural power relations in which men dominate women. Many Ethiopian women, through fear, embarrassment, confusion and ignorance of their legal rights, remain silent. Silence in Ethiopian society (at domestic, community and even at state level) in the face of sexual abuse or rape is the price paid for the family's reputation and honour, sometimes at the risk of the individual woman's interest.[3]

This is one of the many reasons why rape and other acts of domestic violence are highly under-reported crimes in Ethiopia. The reverence of female virginity until the consummation of marriage is still deeply felt amongst many Ethiopians (particularly in rural areas) and it puts tremendous cultural pressure on girls' societal and cultural behaviour.[4] Many children with disabilities are "hidden away" from public view as they are sometimes seen to bring shame upon the family and those that suffer physical abuse are allegedly "protected" by this shroud of silence; they simply do not know who to turn to.

3.4 International Human Rights Instruments in Relation to Global Health and Disability

3.4.1 Global Health and Disability

The human right to health has been specifically mentioned in several international human rights treaties and instruments, and in each of the major regional human rights systems. In the past decade, the right to health has seen an unprecedented level of interpretation, expanding both its normative scope and identifying specific responsibilities of governments. Ethiopia has adopted several international agreements and conventions that have great importance for the protection and promotion of special needs and human rights concerning health and persons with disabilities.

The general concept of the right to health made its first appearance in Article 25.1 of the Universal Declaration of Human Rights (UDHR) in 1948. The UDHR represents the normative basis that led to formulating the standards concerning persons with disabilities that exist today. Article 25 (1) specifically mentions the socio-economic rights of people with disabilities: the right to an adequate standard of living, including food, clothing, housing and medical care and social services, and the right to security in the event of unemployment, sickness, disability, widowhood or old age. Article 7 guarantees equality before the law and equal protection by the law for all people, including against discrimination.

The idea of the right to health was then isolated and defined somewhat more precisely in the International Covenant on Economic, Social and Cultural Rights (1966 – ICESCR Article 12). This includes steps related to the treatment and control of epidemic diseases (Article 12.2 (c)), such as access to affordable

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[3] Discussions held between writer and the Ethiopian Women's Lawyers Association. June 2007.

[4] The police make separate classification of rape of virgins and non-virgins in their investigations, although the law does not require such classifications. Information obtained from several interviews held between writer and various members of the Ethiopian police force in June 2007.

HIV-related medications, and the creation of conditions which would ensure to all medical services and medical attention in the event of sickness (Article 12.2 (d)).

While the Covenant does not explicitly refer to disability, disability can be included under "other status" in Article 2(2), which calls for non-discrimination on any grounds such as race and colour, and "other status". At its 53rd meeting in 1995, the U.N. Commission on Human Rights subsequently concluded that "discrimination on the basis of AIDS or HIV status, actual or presumed, is prohibited by existing international human rights standards" in that the term "or other status" in international human rights instruments (including the ICCPR and the Convention on the Rights of the Child) "can now be interpreted to cover health status."

The UDHR proclaims people's right to a standard of living adequate for their health and well-being that includes medical care and other basic necessities like food, clothing and housing. Thus, while the right to health is an important free-standing right, it is closely linked to many other human rights protections contained in international treaties and domestic constitutions, including rights to life, non-discrimination, privacy and freedoms of association, assembly and movement.

Other important core Human Rights Conventions ratified by Ethiopia include the International Convention on the Elimination of All Forms of Racial Discrimination (CERD) 1966, which is monitored by the Committee on the Elimination of Racial Discrimination (1966); the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) 1979[5] which is monitored by the Committee on the Elimination of Discrimination against Women; the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT) 1979,[6] CAT is monitored by the Committee against Torture; the Convention on the Rights of the Child (CRC) 1989, which is monitored by the Committee on the Rights of the Child.[7]

The Ethiopian government has acknowledged that international human rights norms give persons with disabilities the "judicial right and the human right to be treated equally, to have the same rights as everybody else." To date Ethiopia has ratified all of the above conventions with the exception of the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (MWC).

While many of the above mentioned international conventions do not refer explicitly to disability rights, except Article 23 of the Convention on the Rights of the Child, it has been understood that disability rights are certainly inherent in all of the conventions and Ethiopia, as a ratifying member state to the conventions, is expected to adhere to all rights contained in the respective international conventions. Gerard Quinn and many other renowned academic experts point out that it is by

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[5] Ethiopia ratified the Convention on the 10th October 1981.Ethiopia is not a signatory to the optional protocol.

[6] Ethiopia ratified (without signing) the CAT on the 13 April 1994.

[7] Ethiopia ratified the CRC on the 13 June 1991 without any reservations. However, it has not ratified the Optional Protocol on the sale of children (OPSC), child prostitution and child pornography nor the Optional Protocol on the involvement of children in armed conflict.

now clear that disability is covered by the term "other status" in Articles 2 and 26 of the ICCPR. The ICESCR Committee has taken this view in interpreting the comparable non-discrimination provisions of that treaty so when studying national legislation, it can also be inferred that persons with disabilities can be included under the term "other status".[8]

Recent years have witnessed the development body of international law relating specifically to HIV/AIDS related discrimination. United Nations resolutions have now clarified the term "or other status" to be interpreted to include health status, such as HIV/AIDS. In 2001 the UN Commission on Human Rights (UNCHR) adopted a landmark resolution declaring that "access to medication in the context of pandemics such as HIV/AIDS is one fundamental element for realising the right to health." Other resolutions call upon States to "pursue policies that would promote the availability and affordability of medicines". The ILO Code of Practice on HIV/AIDS and the World of Work has developed the Code of Practice containing fundamental principles for policy development and practical guidelines for prevention of HIV/AIDS, management and mitigation of the impact of HIV/AIDS on the world of work, care, support of workers affected and infected by HIV/AIDS.

3.4.2 Ethiopia with Particular Reference to HIV/AIDS

Kumsa Mekonnen has documented that in Ethiopia, women and girls are disproportionately "infected and affected by HIV/AIDS". He argues that there are many conditions that contribute to the vulnerability of Ethiopian women and girls to HIV/AIDS. For example (a) Physiological vulnerability compounded by what Human Rights Watch call "the risks borne from subordination, discrimination and inequality under the law", (b) Socio-economic disparities and limited bargaining power for women who, because of social and cultural norms (for example submission to their husband's sexual needs), have little or no control over their sexual relations.

Rape is a punishable offence under the amended criminal code Article 623. However, rape must occur outside of wedlock for any legal process to occur. Marital or spousal rape is not recognized as a crime under the amended law. Women have little or no control over their sexual lives in marital relationships. Because of socio-cultural, religious norms and attitudes, many of the women's husbands engage in extramarital high HIV-risk sexual behaviour without any legal repercussions for the husbands.[9] (d) Barriers of access to treatment – many women believe that they need their husband's permission to visit health care services and in a society where HIV-positive women may be beaten or ejected from their homes and communities, the prospect of visiting a clinic is an extremely frightening one. Added to that the poor literacy rate amongst

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[8] Ibid.

[9] Sexual violence appears to be on the increase as documented by the Ethiopian Women's Lawyers Association (EWLA) – (a local Ethiopian NGO for women's rights). EWLA are also very active in campaigning for marital rape to be criminalised.

Ethiopian women, usually the primary care providers for children with disabilities, makes any treatment practically impossible. (e) Harmful Traditional Practices (HTP)) such as FGM, early marriage and abduction makes girls susceptible to vaginal tearing and thereby makes young adults and children with disabilities vulnerable to HIV/AIDS.

Another traditional custom such as polygamy (a practice whereby both men and women can have extramarital relationships) exposes women even more to contracting HIV/AIDS. ETHARC, a local Addis Ababa organization has said that many women, for economic reasons, have been forced into high-risk sexual activities such as prostitution or commercial sex. Such high-risk sexual activity also leads to a high prevalence of HIV/AIDS amongst the commercial sex community.[10]

3.4.3 Ethiopian National Law and HIV/AIDS

Ethiopia does not have HIV/AIDS law. The FDRE Constitution and the recent Criminal Penal Code make indirect reference to HIV/AIDS but they do not address HIV/AIDS directly or the related problems encountered by HIV/AIDS victims. The amended Labour proclamation 377/2003 provides provisions pertinent to HIV/AIDS. The Articles speak specifically about HIV testing but again the proclamation seems to be very much employer versus employee biased. Apart from it being very narrow in scope one can argue that it may even lead to discrimination. In Article 12/6 of the proclamation, it is provided that the employer has a duty to keep a record of the health status of its employees. It prohibits mandatory testing, however pursuant to Article 14/2 mandatory HIV testing is justified when required by law or required by the employer by "reasonable cause," whatever that means. Almost all other labour regulations do not have any specific HIV/AIDS provisions to deal with employment relationships in both governmental and non-governmental organizations.

3.4.4 The Impact of the International Convention on the Rights of Persons with Disabilities

Despite the Convention being the most groundbreaking treaty of the twenty-first century, and the immense pressure at domestic level, Ethiopia has not yet ratified the Convention.[11] Like many other State Parties, Ethiopia tried to appease the

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[10] A study by Etharc found that the HIV prevalence rate amongst Addis Ababa prostitutes was 73% as of 1999.

[11] Many observers have attributed this to the preoccupation and intense preparations within government circles and elsewhere of the Ethiopian New Year, which was celebrated (according to the Ethiopia calendar) in September 2007.

international community and its own nationals keen on Ethiopia ratifying the convention, by signing the Convention on 30 March 2007.[12] However, Ethiopia opted not to sign the Optional protocol, much to the chagrin of local disability groups and international NGOs.

Now that the Convention has received its 20th ratification on 3 April 2008, triggering the entry into force of the Convention and the Optional protocol, it remains to be seen the impact of the Convention on a domestic level.

The United Nations state on their website devoted to the Convention that the purpose of the 50-Article Convention is “to fight discrimination in relation to a wide range of rights that are often not accorded to persons with disabilities, either deliberately or through neglect.” Pursuant to the Convention, persons with disabilities now have clear specified rights to education, health, work, adequate living conditions, freedom of movement, freedom from exploitation and equal recognition before the law. The Convention also addresses the need for persons with disabilities to have access to public transport, buildings, and other facilities and recognizes the capacity of persons with disabilities to make decisions for themselves.[13]

The Optional Protocol now gives persons with disabilities the right to petition an international expert body in case of the violation of the rights as set out above. Traditionally, persons with disabilities have had little recourse to the legal system both at domestic level and at international level. Many citing fear of the unknown and just pure lack of knowledge of the justice system, not to mention the feelings of intimidation involved, as reasons for not pursuing their respective cases. It is hoped that these issues will be addressed when the various state parties set about implementing the Convention at domestic level.

3.5 Ethiopia and its Relationship with the International Human Rights Treaty Committees

3.5.1 Ethiopia in Context

Ethiopia has a poor reporting record, hence resources are scarce and are drawn from many different committees. The poor reporting is due in no small way to the internal unrest within the country and the various conflicts with neighbouring States in the past years. This has subsequently resulted, inter alia, in very large numbers of displaced persons and refugees. Adverse climatic conditions have also contributed

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[12] Signing indicates the intention of a State to take steps to express its consent to be bound by the Convention and/or Optional Protocol at a later date. Signing also creates an obligation, in the period between signing and consent to be bound, to refrain from acts that would defeat the object and purpose of the treaty. Ratification legally binds a State to implement the Convention and/or Optional Protocol, subject to valid reservations, understandings and declarations.

[13] Further UN analysis can be found on the UN website/ http://www.un-ngls.org/site/article.php3?id_article = 469

to serious economic hardship in recent years. Ethiopia has experienced several famines and a significant part of its population has suffered and continues to suffer from extreme poverty as a result.

3.5.2 Study of the International Human Rights Committee Reports

The object of this analysis was simply to derive some sense of how Ethiopia as a state party saw themselves as discharging their obligations in the specific context of disability. Indeed, no criticism is intended of the treaty monitoring bodies either; it is well documented by Gerard Quinn and others that there is a heavy backlog of work and much discussion has been advanced on how to improve the monitoring system.

A total of 36 periodic reports ranging from 1995 to 2008 concerning all references to Ethiopia were examined.[14] However, out of all the reports studied, few made reference, if any, to persons with disabilities. I have opted to focus on those few reports that deal specifically with the issues as discussed in this chapter. The reports were selected on the basis of the availability of documentation.[15] Many of the reports deal with the observations made by the relevant committees; over the 13-year period, there were very few direct reports from the Ethiopian government despite repeated demands made by the respective committees to provide detailed, written replies.

Two of the 36 reports deal specifically with The International Convention on the Elimination of All Forms of Racial Discrimination (CERD). Nine of the 36 reports deal specifically with The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). 25 of the 36 reports dealt specifically with the Convention on the Rights of the Child (CRC). The first initial report of the State Party was submitted in 1995, 2 years after the due date of 1993, and the final concluding observations submitted on the 1st November 2006.

> This begs the question, why is there such a high concentration on the CRC? Why are there no reports or any documentary evidence on the following committees: Committee on Economic, Social and Cultural Rights, the Human Rights Committee and the Committee against Torture. There are no clear responses to these queries except to note that Ethiopia has not made international reporting a priority. Unfortunately, the various committees have no real way of "forcing" state parties to co-operate. It is really left up to the goodwill of the state party itself to decide to cooperate. Financial sanctions or international embarrassment techniques may work to a point. Resources are so limited that there is no guarantee that the state party would react, if at all. The committees have adopted a conciliatory approach and on analysis it may be the best option under the circumstances.

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[14] The number is quite low when compared to other African state parties.

[15] Unfortunately, not all of the reports were accessed online, particularly those reports dating between 1995/1996. The author will discuss only those reports that were accessed online.

3.5.3 Committee on the Elimination of Racial Discrimination (CERD)

It was noted that Ethiopia had not reported to the committee since it submitted its sixth periodic report, which was considered by the Committee at its 871st and 872nd meetings, held on 10 and 13 August 1990.[16]

> Ethiopia clearly violates the obligation under Article 9 of the convention by not submitting a report. It is clear that the non-compliance of the Ethiopian government in this regard creates serious obstacles to the effective functioning of the system set up to monitor the implementation of the Convention at the national level and highlights the difficulties of imposing international law on member states at domestic level.

The committee is obviously in a difficult position.[17] In the absence of a report or direct information from the Ethiopian government, the committee is forced to adopt concluding observations based on information received from other sources.[18]

Throughout the report, the committee expressed clear concern about the lack of application of the Convention at national/domestic level and the lack of information on adequate measures and programmes to disseminate information about the Convention to the public at large (Article 7 of the Convention). It was hoped that the Ethiopian government would provide information on human rights and information on the training of law enforcement officials in the protection of human rights. This information has not been provided to date.

The committee did not mention persons with disabilities at any stage.

> The committee noted that according to the information received, disputes are often resolved at the district or local level (woreda or kebele) by religious or customary courts, in accordance with religious or customary laws, which might have discriminatory consequences for members of some ethnic groups (Article 2 of the Convention). Again, while the Committee did not refer to persons with disabilities, one can infer that persons with disabilities were included in the minority groups.

The committee recommended that the state Party provide, in its overdue report, information on the status of religious and customary laws, including vis à vis the federal legislation, and on the measures undertaken by the State Party to ensure the public authorities and officials, including those at the level of local religious and customary courts, act in conformity with Article 2 of the Convention.

The Committee recommends that the state party provide, in its overdue report (to have been submitted no later than 31st December 2007) information on the status of the Convention in domestic law, the possibility of invoking its provisions

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[16] Ibid.

[17] Local and international NGOs provide a wealth of valuable information in these instances of non-compliance.

[18] The committee noted the establishment of the Ethiopian Human Rights commission and the Office for Ombudsman in 2000, as provided for under article 55 of the Constitution, as well as the appointment of the Human Rights Commissioner and Chief Ombudsman in 2004. However, despite exhaustive research by the writer, there does not seem to be any real evidence of change since the appointment of the ombudsman and Human Rights Commissioner.

directly before national courts and on the existence of specific legislation implementing the provision of the Convention. To date, the Ethiopian government has not submitted any report.

3.5.4 The Committee on the Elimination of Discrimination Against Women (CEDAW)

Consideration was made on the 17 February 2004 of the fourth and fifth reports to the Committee on the Elimination and Discrimination of Women submitted by Ethiopia.

> The only meagre reference made by the Ethiopian government in this report to persons with disabilities was that the Government and the active community of non-governmental organizations provided tremendous support (emphasis added by writer) for disabled groups, including war veterans. No clarification of the "tremendous support" was provided.
>
> In the concluding comments of the report, the Chairperson did point out and it may be understood within the context of women with disabilities that "there was a need for a more aggressive approach to policy-making in the area of women's human rights, and gender main streaming and gender budgeting… All Ethiopian citizens needed to be informed about their human right."
>
> The Government was urged to conduct surveys and to collate gender-disaggregated data. To date nothing has been received regarding the rights of Women in Ethiopia since this report, four years ago.

3.5.5 Committee on the Rights of the Child

The Ministry of Women's Affairs (MoWA) provided information in reply to the feedback of the CRC Country Report previously submitted to the CRC Committee in Geneva. The replies were based on the information obtained from various organizations working in different sectors.

There was a very brief uninformative mention of the programmes and services for children with disabilities. They said that these associations include services for adults as well as children with disabilities; that means there are no separate national associations for children with disabilities.

It is worth listing the programmes undertaken on persons with disabilities (which also include children) including:

- Awareness raising
- Information and education on HIVAIDS
- Production of orthopaedic appliances – including provision of new ones and maintenance of old ones, especially for children

Most of the programs and services for children with disabilities are undertaken by non- governmental organizations. The Government of Ethiopia explained that the services are limited compared with the number of beneficiaries and the demand for the service.

The Government of Ethiopia then went on to provide a very optimistic view of the Convention on the Rights of the Child saying that it has been implemented without any discrimination (author's emphasis) among all children of the country.[19] They said that it was based on the premises that the Constitution of the country considers/treats all children of the country, irrespective of their ethnic backgrounds, religion or the status of their families, equally.

In a further report, the Government of Ethiopia stated that it had adopted a number of initiatives to improve children's rights. While the report did not specifically refer to children with disabilities, one can infer that these initiatives included them.

In particular, Article 36 of the Federal Constitution of 1996 related to the protection of children's rights, and the Family Code, the Penal Code, the Civil Code and the Code of Criminal Procedure dealt with specific aspects of those rights. The Family Code had been amended to bring it into line with the Convention on the Rights of the Child.

The government also said that a lot of efforts have been made to disseminate the convention at various levels by various governmental and non-governmental organizations using various media.[20] Various training and awareness raising activities on the Convention on the Rights of the Child have been undertaken by various organizations – governmental and non-governmental organizations and the UN agencies for various target groups; namely, children, CRC clubs, teachers, social workers and professionals working for and with children. In addition to the manual prepared by the Ministry of Labour and Social Affairs, a training manual has been prepared by Save the Children Norway – Ethiopia.

However, despite the above positivism, to date there are no new bills or enacted legislation as part of CRC implementation.

3.6 Recommendations from an International Level

3.6.1 The Problems with International Law

In order for real implementation of international human rights treaties at domestic level, the United Nations needs to develop a system whereby it can guarantee at least some response at State level. Inefficiency of the convention committees has

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[19] From discussions the writer had with several commanders at police level, knowledge about the CRC proved to be very limited. In the police manual used in Addis Ababa police stations, only one half page is devoted to the CRC. There is no mention as to how children with disabilities should be treated within the justice system. This would be in direct contrast to the information the Ethiopian government provided in their report.

[20] Handicap International have held several workshops on international human rights law with a particular focus on the rights of persons with disabilities.

been well documented, but they appear to be doing the best they can under the circumstances. Change needs to come from the top down and some overhaul of the current UN committee would appear to be necessary.

3.7 Legislative Gaps in the Domestic Laws of Ethiopia

3.7.1 The Problems Within Domestic Law

As indicated earlier, all international instruments ratified by Ethiopia such as the Bill of rights are part of the law of Ethiopia and hence persons with disabilities are entitled to exercise their rights guaranteed in these instruments. Their rights can now legally be enforced by local judicial and other justice organs. The local enforcement of these rights in practice, however, is difficult. Many courts do not decide cases on the basis of international Human Rights provisions not necessarily because they have chosen not to, but sometimes out of pure lack of knowledge of the existence of these international conventions.[21]

Cases are only decided upon the basis of the laws and provisions published in the law gazette, *Negarit Gazeta.*[22] Many international instruments have not been published and translated into the local language "Amharic" and those that have been published usually only indicate that the international instrument has been ratified but do not provide detailed substantive and procedural provisions. A person with a disability for instance cannot lodge his claim to a local court alleging the violation of his rights recognized under an international instrument ratified by Ethiopia where such an instrument is not ratified because courts are required to take notice of laws published by the *Negarit Gazeta.*

Further problems relate to implementing international instruments, which fulfil conditions, ratification and publication. As indicated, Ethiopia has ratified the international bills of human rights and other important human rights instruments such as the Convention on the Elimination of All Forms of Discrimination Against Women – CEDAW and the Convention on the Rights of the Child (CRC), and these instruments are also published by the proclamation (the *Negarit Gazette*). The ratification proclamations, however, commonly contain few provisions indicating the designation of the instruments ratified and their entry into force, and lack detailed substantive and procedural provisions necessary for the enforcement

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[21] Discussions held between the writer and human rights lawyers /local NGOs in Ethiopia, June 2007.

[22] Some reject this argument saying that the publication by the 'Negarit Gazeta' is for publicity reasons and the courts can interpret international instruments as long as the legislative body, the House of people's representatives ratified them even if the laws are not published (Ethiopian Women's Lawyers Association).

by courts and other justice organs. It is difficult, for instance, for a person with disability to make claims of violation of his rights based on the ratification proclamation of one of the international instruments because such a proclamation in almost all cases doesn’t state his rights or the procedures to enforce them at local level even though the rights are outlined in the original international instrument.

Though one can argue that one can base his/her claims using the provisions of the original instruments, in such cases the situation is no better because of the problem of language and the generality of the provisions in the original instruments. All ratified and published instruments are not translated into Amharic, the working language, by the legislature and obviously unofficial translations of such instruments or their provisions may not be used by courts. Judges do not have the authority to apply the articles by translating them into Amharic.[23]

Putting aside this problem of language and assuming that the original instruments can be used again, there is a difficulty. The provisions are general and lack necessary details to apply them locally. The rights of persons with disabilities to receive special measures for instance are recognized under the United Nation Standard Rules on the Equalization of Opportunities for Persons with Disabilities. A person or group of persons may allege that they have this right since the international convention on the rights of the child is ratified and published. That the right is recognized under Ethiopian law is no question but enforcing the right poses a problem even assuming that the provisions of the CRC can be used to resolve the dispute. Deciding when a person is entitled to receive such measures, when the government is said to have violated the right and what procedures apply to resolve such a dispute at court level, etc … are difficult questions to answer under the relevant provision of the Convention on the Rights of the Child.

The Ethiopian constitution provides fundamental human rights principles that also cover the rights of persons with disabilities and rights specifically dealing with persons with disabilities such as the right to special measures. The power of interpreting the constitution in Ethiopia is given to the Federation Council and thus the provisions in the constitution cannot be enforced at court level. If for instance, a person with disability claims the violation of his rights guaranteed in the constitution (such as Article 4 Sub-Article 5 which entitles him the right to special measures), such a complaint is dealt with by the council. Putting aside problems related to impartiality and independence of the council, resolving such a case becomes very difficult because of the generality of the provisions. It is difficult for the council to interpret the provision; the problem begins with defining what disability means, and is exacerbated by further lack of clarity in the constitution. The provisions in the constitution dealing with the rights of persons are useful as guiding principles for the protection of the rights of persons with disabilities but are too general to protect persons with disabilities in practice.[24]

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[23] Ibid.

[24] Ibid.

As indicated above, constitutional provisions dealing with the rights of persons with disabilities are general guiding principles and do not provide adequate protection for persons with disabilities because of the difficulty of applying them in practice. The provisions can be useful insofar as they are implemented by a subordinate legislation. However there is no such legislation that affects the rights of persons with disabilities. Particularly the absence of an implementing legislation to enforce the rights of persons with disabilities to special measures is a serious obstacle.[25]

Another issue that arises is the recognition of sign language in the constitution as a language. In relation to persons with hearing impairments the fact that they are not allowed to apply for a driving license is another issue. There are those who advocate for persons with hearing impairments to be able to drive a car and use the employment opportunity available in the transport sector.

Some of the laws operating in Ethiopia, like the civil code, are enacted four decades ago, are not harmonized with the current notion of the rights of persons with disabilities and contain provisions that lack conformity with relevant international standards, which has a negative impact on the protection of the rights of persons with disabilities. For instance a person with visual impairment can have a permanent sign or a mark for his or her identification.[26] However, in Ethiopia, in every bank transaction a visually impaired person is obliged to bring a sighted person who has an identification card with them and to give a thumb print as their signature This is not clearly indicated as compulsory in the Civil Code but bank officials are using the provision of the civil code, which states that the signature of thumb mark of a person with visual impairment or illiterate person shall not bind him unless it is authenticated by a notary, registrar or judge acting in the discharge of his duties.[27]

The Ethiopian judiciary, in general, carries out its duties under difficult conditions and lacks basic resources to perform its functions. There is a shortage of judges both in terms of number and professional qualifications, modern management and operational systems are not practical, and court and office supplies such as furniture, equipment, buildings such as courts, offices and libraries and vehicles are inadequate.[28] With such a poor inadequate national system in place, how can one conceive of the international human rights legislation working?

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[25] Supra note 31.

[26] There is no law that forces the National Bank of Ethiopia to print Birr notes holding Braille patterns that would help persons with visual impairment to easily distinguish the notes.

[27] Supra note 31.

[28] In Ethiopia a university graduate can immediately become an assistant to a judge. After a 2-year apprenticeship he himself can become a judge. After 5 or 6 years some judges then use the experience to become practicing lawyers and earn far better salaries as a result. In Ireland and the UK it is exactly the opposite way round. (Information also confirmed in discussions held between the writer and APAP, Ethiopian NGO) in June 2007.

3.8 Conclusions and Recommendations

The domestic legal system should be subjected to a thorough reform process. Studies should be made of other African states/Western world countries with similar legal systems and changes should be implemented at domestic level even before advancing on the international sphere. Resources are clearly an obstacle; efforts should be made by the international community/NGOs, etc, to assist Ethiopia in developing a relatively up-to-date legal domestic system.[29]

I would strongly advocate the development and implementation of new laws and policies to protect the rights of persons with disabilities – policies and legislation such as affirmative action that are disability sensitive to ensure certain positions be reserved for people with disabilities.

Here particular emphasis should be given for the incorporation of detailed rules on the rights to affirmative measures in conformity with the constitution and relevant international instruments. Enactment of a comprehensive legislation is particularly important considering the length of time amendments of most, if not all, existing laws of Ethiopia might take, and the availability and efficient use of resources.

The protection of the rights of persons with disabilities does not only depend on the willingness of the government but on the resources available at its disposal. This is particularly true in resource-strapped countries like Ethiopia. The protection of the rights of persons with disabilities cannot meet the desired ends, particularly merely because the rights are stated in domestic or international legislation. The protection of the rights, particularly the protection of the right to special measures is effective mainly where sufficient financial and other resources are available for implementation. Therefore measures should be taken by the government and non-governmental actors to draw adequate resources to improve the protection of the rights for persons with disabilities.[30]

The disability community should try and ensure the participation and representation of people with disabilities in the civil service and the parliament. Persons with disabilities should be given the opportunity to participate in all areas of life and to speak on behalf of others. Persons with disabilities need to be involved in the decision-making process including being nominated to parliament.

There should be renewed pressure on the Ethiopian government to ratify the Convention. The ratification instrument should then be published in Amharic, the official working language of the country.[31] The Ethiopian government needs to respect

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[29] Many international donors like the Oak Foundation have contributed to positive change within the Ethiopian criminal legal system. They have placed cameras in the Child courts, very pertinent particularly in areas of sexual abuse, where the child does not have to be subjected to the arduous trial process and can now give evidence in front of a camera. The evidence is provided in the presence of a trained psychologist. The system has proved to be very effective to date.

[30] Supra note 31.

[31] Information obtained from discussions held with management staff at the Handicap International offices in Hune 2008 as well as local NGO's and disability organisations in Ethiopia, June 2007.

international law; it needs to respond when requested to the various human rights committees on issues of disability. It would be very advantageous for Ethiopia if Ethiopia elected a country representative to be a member of the Convention's disability committee, which should be part of the lobbying ratification process.

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Chapter 4
Building an Inclusive National Strategy for Disabled Children in Kyrgyzstan Through an Application of the *BIAS FREE* Framework

Mary Anne Burke and Andrea Pupulin

4.1 Introduction

The *BIAS FREE* Framework (Burke & Eichler, 2006) is an innovative, rights-based tool for identifying and eliminating biases deriving from social hierarchies in research, legislation, policies, programs, service delivery and practices. ***BIAS FREE*** stands for ***B***uilding an ***I***ntegrative ***A***nalytical ***F***ramework for ***R***ecognizing and ***E***liminating In***E***quities. The *BIAS FREE* Framework addresses the intersection of biases deriving from hierarchies based on gender, disability, age, class, caste, socio-economic status, religion, sexual orientation, geographical location and immigrant/refugee status, among others, and how these play out in the overall health and well-being of people. The Framework is a tool for building equitable, more inclusive societies based on respect, equality, human rights and the full participation and benefit of all people.

This chapter gives further details about the *BIAS FREE* Framework and how it can be used. Specifically, it reports on one application of the Framework and how it was used to assess the situation of disabled children in Kyrgyzstan and to build momentum for the development of a National Strategy to build a fully inclusive Kyrgyzstan.

4.2 What is the *BIAS FREE* Framework?

The *BIAS FREE* Framework is an essential tool for getting at the power structures within society that serve to reinforce and maintain hierarchies and reinforce the oppression of vulnerable populations. The Framework guides users through a rights-based approach to their work, and to the treatment of all people with dignity and respect.

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4.2.1 Addresses Multiple Biases

The Framework addresses the multiple biases that some people experience because of their position in different social hierarchies. It explores how these biases intersect and compound one another. People may be women or men, boys or girls. They can be disabled, of colour, of a particular religion, gay, poor and sometimes all these at once. The human rights abuses they experience cross many "isms", from ableism to sexism to racism and more. Understanding their situations in terms of human rights is complex.

In describing where people fit within a given hierarchy, and to facilitate the integrative approach to the various social hierarchies, the Framework uses abstract language applicable to all hierarchies. For example, the term "dominant group" is used to mean people at the top end of a hierarchy – those with the most power and ability to access and use the resources that accrue to them because of their position in a hierarchy. The term "non-dominant group" is used to refer to people whose position is further down the hierarchy and who are not as easily able to yield power and access and accrue resources. The terms *dominant* and *non-dominant* are always understood in relation to each other, within a given socio-political context.

Historically, women, disabled people, and others belonging to certain classes or ethnic, racial, linguistic or religious groups have tended to be disadvantaged relative to men, to non-disabled people, and other dominant groups in their society (Rossides, 1996; Schriner, 2001). Membership in more than one non-dominant group compounds the discrimination that people experience, and increases social, political, economic and other inequities. A disabled woman living in a low-income country in Africa or Asia, for example, would likely have access to fewer social, economic and community resources than would a white non-disabled woman living in a high-income country. Her experience, however, might not be so different from that of a disabled Aboriginal woman living on a remote "Indian" reserve in Canada.

4.2.2 Exploring Common Roots of Domination and Social Inequality

Bringing each of the hierarchies into a single framework has helped to shed light on common roots of domination and social inequality. The *BIAS FREE* Framework exposes the logic of domination faced by disabled peoples, and how it is the same for all disenfranchised communities. It thus guides the way systematically to begin to dismantle the machineries of oppression so that societies can be transformed to be fully inclusive of all people and ensure their human rights, development and overall well-being.

A common manifestation of all hierarchies is a tendency to locate "the problem" in the individual and to construct non-dominant groups as pathologically different from the dominant group (Amiot and Bouris, 2005). Rather than locating problems within the individual, the *BIAS FREE* Framework recognizes the hierarchy as problematic while, at the same time, acknowledging that personal experience is important – but without pathologizing it.

The Framework calls attention to the need at times to treat people *differently* to accommodate their differences and at other times to treat them the *same* to avoid double standards. It also helps people to identify situations of structural violence within their own cultural and historical contexts and to challenge the hierarchy in which it is rooted.

4.2.3 19 Thought-Provoking Questions

The *BIAS FREE* Frameworkconsists of a set of 19 thought-provoking questions clustered under three main problem types: *Maintaining a hierarchy*, *Failing to examine differences* and *Using double standards* (see Appendix). The questions alert the user to the presence or absence of biases deriving from social hierarchies in any given socio-historical context. The Framework points to solutions to overcome the identified problems.

4.2.4 3-Dimensional Matrix

The Framework's 3-D Matrix consists of the *type of hierarchy* examined (gender, disability, race/ethnicity, class, caste, age, religion, sexual orientation, geographical location, socio-economic status, etc.), the *type of application*, e.g. research, legislation, policy, programme, service delivery or practice, and the particular *type of bias problem* identified by the 19 questions.

4.2.5 Multiple Forms of Discrimination

The *BIAS FREE* Framework addresses multiple forms of discrimination people experience based on the intersection of biases deriving from social hierarchies and how these play out in their overall health and well-being.

The Framework helps to identify when social hierarchies are at work in a way that violates human rights and provides guidance on how to go about dismantling the power structures that serve to reinforce and maintain them. It shows the way to embed human rights and social inclusion at each step of the way, improving the health, well-being and security of all peoples.

4.2.6 Rights-Based

The *BIAS FREE* Framework is premised on the equal entitlement of all people to be treated with respect and on the inviolability of human rights. The Framework derives from the understanding of health as a human right and uses a rights-based model of health and well-being. Health (physical, mental, social and spiritual well-being) is fundamentally tied to human rights and social equality (Burke et al. 2000). The *BIAS FREE* Framework is designed to draw the users' attention to the structural and organizational determinants of health, to assist them in identifying biases in health research that derive from various social hierarchies, and in removing them, insofar as is possible.

4.3 How Does the *BIAS FREE* Framework Work?

The *BIAS FREE* Framework's set of 19 thought-provoking questions are aimed at discovering if social hierarchies are at work in research, and if so, if they are producing bias. The questions in the Framework probe the particular nature of the problem so that appropriate solutions can be applied to the identified problem. If hierarchies are not found to be at work, or if no bias is found, the researcher, policy-maker or community member can proceed to the next stage of their work. If bias is found, the Framework points to appropriate solutions that may be taken to address the particular bias problem identified.

The 19 questions stimulate discussion and soul-searching among people using the Framework. As people apply the Framework, they begin to be able to identify biases in their institutions and lives and to put a name to them. Once they identify the correct problems, they can begin to work towards resolving them. The "solutions" pointed to in the Framework help people to identify their own solutions and to address the identified problems within their particular situation and cultural settings.

In the process, people using the Framework begin to see the world through "new eyes", begin to internalize the values that underpin the Framework, and to change their attitudes and practices. This in turn leads to a more thoughtful and critical reflection on attitudes and practices, and ultimately to a process of personal and structural transformation and broad social change focused on human rights and equity.

4.4 An Application of the *BIAS FREE* Framework in Kyrgyzstan

In the Spring of 2007, UNICEF approached Mary Anne Burke to assist them in undertaking a situational analysis with regard to disabled children in Kyrgyzstan. It was to be the beginning of a process of exploring what would be needed to change the situation of disabled children to bring it in line with what was being called for by the new UN Convention on the Rights of Persons with Disabilities (UNCRPWD, 2007).

UNICEF had contracted with a local consultancy agency, EXPERT, to conduct some preliminary national research on the situation of disabled children in the Kyrgyz Republic. Mary Anne Burke followed the research from Geneva analysing research tools, legislations and results using the *BIAS FREE* Framework. Andrea Pupulin, who worked with Mary Anne in Geneva, went to the Kyrgyz Republic for four months to work directly with the researchers under the direction and supervision of Mary Anne Burke.

When Andrea Pupulin arrived in the Kyrgyz Republic the research team had already developed a set of survey questionnaires for children, parents, institution staff, etc. As well as this they had lined up a team of medical doctors to administer the surveys. So, the first task was to work with the research team applying the *BIAS FREE* Framework to both the research instruments and methodology. Working with the researchers to apply the *BIAS FREE* Framework allowed them to see for themselves the nature of the bias problems that were uncovered and consequently to find solutions to reformulate both the questionnaires and methodology to avoid the biases.

All three main problems identified by the *BIAS FREE* Framework were uncovered in the research instruments: the *H problems*: Maintaining an existing hierarchy; the *F problems*: Failing to examine differences; and the *D problems*: Using double standards. Below we describe the application of the *BIAS FREE* Framework to improving the research process, so that the products of the research can more effectively be used to promote the human rights of its intended beneficiaries. While some of the problems identified will be recognisable to researchers familiar with the area of disability, our exposition helps to link these problems to broader issues of social inclusion. Throughout the next sections we refer to problems identified, according to their characteristics as described in Table 4.1.

4.5 Questionnaire Content

H Problems: Maintaining an Existing Hierarchy

Overall, the research instruments were rooted in the "medical model" of disability, which focuses on individual deficiencies. This is an example of a *H4 problem: Pathologization*. It is opposed to the rights-based model of disability that focuses on deficiencies in the community in which the person lives and in its ability to support and provide services for disabled persons and their families. In other words, the questionnaires were designed to assess whether the disabled children could be included in society rather than trying to determine the preparedness of society for being fully inclusive, and the steps taken towards building an inclusive society where all children can enjoy equal rights and opportunities.

A number of questions were asking about the limitations of the disabled child. The nature of the questions and the way they were formulated lead to the belief that it was the child who was deficient and somewhat broken. As a result the child was

Table 4.1 The *BIAS FREE* framework for research

Type of hierarchy	Main problem type	Nature of problem	Solution	Research element
 • Gender • Disability • Race/Ethnicity • Age • Class • Caste • Socio-economic status • Religion • Sexual Orientation • Geographical Location • Health status • (among others)	*H – Maintaining an existing hierarchy* *Is dominance of one group over the other in any way justified or maintained?* *Situate the problem within a human rights framework, in which equality is an underlying value. Point out the discrepancy between this value and the inequalities among groups of people that result from the hierarchy*	*H1 Denying hierarchy*. Is the existence of a hierarchy denied in spite of widespread evidence to the contrary?	*The existence of a hierarchy is acknowledged; its validation is questioned and rejected*	• Request for proposals • Research proposal • Literature review • Ethical review • Research question & design • Research hypothesis • Description of population to be studied • Staffing • Concepts • Theoretical framework/ model • Research methods/ instruments • Recruitment of participants • Data analysis and interpretation • Conclusions • Policy recommendations • Identification of audience • Abstract/ Executive Summary • Language • Visual representations • Communication of Results
		H2 Maintaining hierarchy. Are practices or views that are based on a hierarchy presented as normal or unproblematic?	*Expressions of hierarchies are questioned and problematized*	
		H3 Dominant perspective. Is the perspective or standpoint of the dominant group adopted?	*The perspectives of non-dominant and dominant groups are respected and accepted*	
		H4 Pathologization. Is the non-dominant group pathologized when it differs from the norms derived from the dominant group?	*Challenge the norm and address the reasons given for pathologizing the group*	
		H5 Objectification. Is stripping people of their intrinsic dignity and personhood presented as normal or unproblematic?	*Recognize that every human being has intrinsic dignity and human rights that are inviolable and must be protected, and conduct the activity accordingly*	
		H6 Victim-blaming. Are victims of individual and/or structural violence blamed and held accountable?	*Victims are not blamed; individual and/or structural violence is identified and those responsible are held accountable*	
		H7 Appropriation. Is ownership claimed by the dominant group for entities that originate(d) in or belong to the non-dominant group?	*Original ownership is acknowledged and respected*	

 • Gender • Disability • Race/Ethnicity • Age • Class • Caste • Socio-economic status • Religion • Sexual Orientation • Geographical Location • Health Status • (among others)	*F – Failing to examine differences* *Is membership in a non-dominant/dominant group examined as socially relevant and accommodated?* *Establish the relevance of group membership within a given context. Once relevance is established, accommodate differences in ways that reduce the hierarchy*	F1 *Insensitivity to difference*. Has the relevance of membership in dominant/non-dominant group been ignored?	*Relevance of dominant/non-dominant group membership must always be determined; group membership must be included as an analytical variable throughout the activity and only then can its relevance be assessed*	• Request for proposals • Research proposal • Literature review • Ethical review • Research question/ hypothesis • Research design • Description of population to be studied • Staffing • Concepts • Theoretical framework/ model • Research methods/ instruments • Recruitment of participants • Data analysis and interpretation • Conclusions • Policy recommendations • Identification of audience • Abstract/ Executive Summary • Language • Visual representations • Communication of results
		F2 *Decontextualization*. Has the different social reality of dominant and non-dominant groups explicitly been considered?	*The context with respect to dominant/non-dominant group membership is explicitly examined and differences following from this are identified, analyzed and taken into account*	
		F3 *Over-generalization or universalization*. Is information derived from dominant groups generalized to non-dominant groups without examining if it is applicable to the non-dominant groups?	*Information about the dominant group is acknowledged as such, and efforts are made to obtain information about the non-dominant group or conclusions are limited to the dominant group*	
		F4 *Assumed homogeneity*. Is the dominant or non-dominant group treated as a uniform group?	*Differences within dominant and non-dominant groups are acknowledged and taken into account*	

(continued)

Table 4.1 (continued)

Type of hierarchy	Main problem type	Nature of problem	Solution	Research element
 • Gender • Disability • Race/Ethnicity • Age • Class • Caste • Socio-economic status • Religion • Sexual Orientation • Geographical Location • Health Status • (among others)	*D – Using double standards* *Are non-dominant/ dominant groups dealt with differently?* *Identify the double standard that leads to different treatment of members of dominant and non-dominant groups and how this maintains a hierarchy; then, devise means to provide the same treatment to both groups*	*D1 Overt double standard.* Are non-dominant and dominant groups treated differently?	*Provide the same treatment to members of dominant and non-dominant groups whenever this increases equity*	• Request for proposals • Research proposal • Literature review • Ethical review • Research question/ hypothesis • Research design • Description of population to be studied • Staffing • Concepts • Theoretical framework/ model • Research methods/ instruments • Recruitment of participants • Data analysis and interpretation • Conclusions • Policy recommendations • Identification of audience • Abstract/Executive Summary • Language • Visual representations • Communication of Results
		D2 Under-representation or exclusion. Are non-dominant groups under-represented or excluded?	*Non-dominant groups are included whenever relevant*	
		D3 Exceptional under-representation or exclusion. In contexts normally associated with non-dominant groups, but pertinent to all groups, is the dominant group under-represented or excluded?	*Dominant groups are appropriately represented in issues of relevance to them that have been stereotyped as being important only for a non-dominant group*	
		D4 Denying agency. Is there a failure to consider non-dominant/dominant groups as both actors and acted upon?	*Examine ways in which dominant and non-dominant groups are both acting as well as acted upon*	
		D5 Treating dominant opinions as facts. Are opinions expressed by a dominant group about a non-dominant group treated as fact?	*Opinions expressed by dominant groups about non-dominant groups are treated as opinions, not fact*	
		D6 Stereotyping. Are stereotypes of non-dominant/ dominant groups treated as essential aspects of group membership?	*Treat stereotypes as stereotypes, not as truths*	

D7 Exaggerating differences. Are overlapping traits treated as if they were characteristic of only non-dominant/dominant groups?	*Document both the differences and the similarities between members of non-dominant and dominant groups*
D8 Hidden double standard: Are different criteria used to define comparable facts with the effect of hiding their comparability?	*Ask whether there might be a hidden double standard by looking for non-obvious parallels. One way of achieving this is by asking what form the phenomenon identified within one group might take within another group*

Source: Eichler and Burke (2006)

viewed as in need of “fixing” and this explains the strong medical emphasis of the questionnaires and on the rehabilitation of the child. An entire section of the parents’ questionnaire was on medical rehabilitation services and the disabled children were referred to as “invalid”.

This is a case of pathologization of the child: the inherent condition of the child is seen as the problem rather than the community where they lived (infrastructure, public attitudes, services, etc.). If the child could not be included it was because of the way he/she was – unable to study, to move, etc.

Here are some specific examples of pathologization from the questionnaires:

Question 1: What communication skills does your child have?
One variant of the answer is possible.

Does not understand anything	1		Can read	4
Understands some words	2		Can read and write	5
Can speak and understand words	3		*Refuse to answer (do not include)*	99

A child is able to communicate but other people are not always able to understand him/her.

Question 2: What estimation can you give to the quality of the care, development and education of disabled children in specialized institutions?

The quality of care in institutions is not an issue here. The focus should be on the preparation of the outer world to include disabled children. Assessing the work of institutions is to recognize it as a legitimate living space for disabled children who are unable to live in society, thus pathologizing them.

Question 3: Does he (she) have other chronic diseases?
It is possible to indicate several variants of the answer.

Blood diseases	1		Condition appeared in perinatal period	6
Endocrine diseases	2			
Tuberculosis	3		There is no other illnesses	55
Cancer	4		Other (Indicate the kind of diseases)	
Hydatid disease	5			

These questions asked parents about the type of pathology of the children. This is problematic for two reasons:

Firstly, the parents do not always know the medical condition of their child and we observed that even the doctor’s diagnosis is often wrong, as the different commissions for disabled children frequently disagree and re-diagnose children. Consequently the results would be inaccurate.

One section of the parent’s questionnaire, to be filled by the interviewers, also included questions on the physical appearance of the mother, the state of the house, etc. (see Table 4.2). The questions aimed to find out how competent the parents were in taking care of the child and to reveal practices of neglect. If the mother appeared unhealthy, the house was not clean, or the family lived in poverty, the family was blamed, rather than trying to understand the failure of the social system to provide adequate income and other supports to the family. This is an example of a

Table 4.2 The Form completed by the interviewer after visiting the household

Question 6: Please describe the amenity of the household

		Estimate in accordance to the 5 ball scale	Notes (describe the condition)
25.1	The condition of the house on the outside (only for the private sector)	1____2___3___4___5, Where 1 is very bad condition, the house demands the complete overhaul and 5 the excellent condition	
25.2	The condition of the house/apartment inside	1____2___3___4___5, Where 1 is very bad condition, the house demands the complete overhaul and 5 the excellent condition	
25.3	The clearness in the rooms	1___2___3___4___5, Where 1 means very dirty, and 5 means very clean	
25.4	Lighting	1___2___3___4___5,Where 1 means very bad lighting, it is very dark in the rooms, and 5 means very light rooms and the lighting is very good	
25.5	Furniture	1___2___3___4___5, Where 1 means very bad furniture the lack of the furniture, and 5 the excellent condition, the presence of furniture, carpets	
25.6	The appearance of the mother	1___2___3___4___5, Where 1 means untidy, dirty cloth and 5 means accurate, clean cloth, well-groomed nails and hair	
25.7	The appearance of the child	1___2___3___4___5, Where 1 means untidy, dirty cloth and 5 means accurate, clean cloth, well-groomed nails and hair	

H5 problem: Victim-blaming. There were no follow-up questions to ask the parents what kind of difficulties they faced with their children and what support they received in overcoming them. For example, no questions were asked on whether their children were accepted in schools or whether the parents could benefit from flexible working hours to be able to look after their children. In any case a messy house is not indicative of how well children are treated. There was no recognition that having a disabled child in a community that is not inclusive adds to the expenses and work of the whole family, and can also have a negative impact on parents' ability to work and on their overall income.

F Problems: Failing to Examine Differences

Secondly, these questions are irrelevant and misleading for determining the needs of disabled children. One cannot use this data to inform policies or programmes for disabled children without assuming that children with the same pathology have the same needs. This is an example of an *F4 problem: Assumed homogeneity*. In reality children with the same condition could have completely different needs and require completely different levels of support. For instance a child with cerebral palsy may be perfectly able to walk and write on his/her own while others may need supportive equipment.

D Problems: Using Double Standards

Many of the questions were biased against disabled children because they accepted the premise that disabled children do not have the same rights as other children. This is an example of a *D1 problem: Overt Double Standards*.

Intentionally or inadvertently, the medical model advocates for disabled children to be segregated in special classrooms or institutions, and it legitimizes practices of exclusion. This is an example of a *D2 problem: Under-representation or exclusion*. The attention of the medical model is on rehabilitating the individual rather than adopting a holistic approach to improve the wider social and economic environment in which people live, which has the greatest impact on their quality of life.

The Convention on the Rights of the Child, ratified by the government of the Kyrgyz Republic, guarantees the rights of all children to full inclusion in their society and to enjoy equal rights and opportunities regardless of gender, race, or disability. The Convention clearly specifies that all children have the right to an inclusive education and to live with their families. Nonetheless, the original research questionnaires cast doubt over these rights and did not use them as their initial premises as they should have. Below are some examples from questionnaires that failed to problematize the view that all disabled children cannot be fully included in Kyrgyz society – to attend their community schools or to live with their families.

Question 4: How do you think, could your child now, or in the future, study in an ordinary school?

One variant of the answer is possible

Yes	1	
No	2	
He (she) had graduated from studies in the ordinary school	3	*These variants of the answers are suitable only for children aged 16 or older*
He (she) had been studying in the ordinary school for some years (months)	4	
He (she) has never studied in the ordinary school	5	

This question addressed to parents of disabled children inquires if in their opinion it is possible or desirable for their child to ever go to an ordinary school. There were no further questions on how their child could be included in school. Parents were not given the opportunity to explain why their child could not go to school and what needed to change in the schools and communities for him/her to be included.

A question in the questionnaires for social workers, institution staff, and members from the ministries asked:

Question 5: What do you think, how applicable is a program for deinstitutilization of disabled children in our country?
The question aimed to find out if, in the opinion of these "professionals", it is realistic, in the context of the Kyrgyz Republic, to reunite all disabled children living in institutions with their families. Living with a family is a fundamental right of every child protected by the Convention of the Rights of the Child. The research should be exploring the conditions necessary for disabled children to enjoy their right to live with their family.

Once the problems in the questionnaires were uncovered, the *BIAS FREE* Framework was used to develop new questionnaires, drawing on questionnaires that had been developed by The Roeher Institute (Burke et al., 2002a–d; Burke & Pegg 2003; Burke et al., 2003) using the *BIAS FREE* Framework, reshaping them to fit the situation and context in Kyrgyzstan. Rather than pathologizing the disabled children by trying to enumerate a long list of pathologies they have and things they can't do, the new questionnaires were refocused on trying to understand what barriers the children and their families experienced in their communities and at school. For example, instead of asking how many children could not walk, the questions were changed to ask if the child used any mobility or assistive devices to help them to move around. If they reported that they did, then the questionnaires probed to find out what was needed, whether or not the family had access to the needed devices, whether they could afford them, and if there were barriers to their child using them in their home, in the community and school, and the nature of the barrier, such as negative attitudes and behaviours by neighbours or teachers, or broken sidewalks, curbs, stairs, etc. Instead of focusing on what they could not do, the questionnaires focused on what their hopes and dreams are and what they needed to achieve them.

The questionnaires for teachers and principals were reformulated to understand what they needed in the way of training, supports, equipment and infrastructure to accommodate and fully include all children and their learning needs in their classrooms and schools. Instead of asking if disabled children could go to their local community schools, and if institutions could be shut down, the questionnaires focused on what changes were needed in the community and what additional resources parents needed so that all children could live in their families and go to their local schools with their siblings and peers.

4.6 Data Collection

The proposed methodology for administering the questionnaires was questioned. Having medical doctors administer the questionnaires was pointed out as problematic, given that their opinions would hold sway due to their elevated position in society, and because they had a vested interest in ensuring that the medical model of disability would prevail. This is an example of a *H5 problem: Dominant perspective.* Not having disabled people and their families involved in conducting the research was also an example of a *D2 problem: Under-representation or exclusion.* This is a violation of the principle of inclusion upheld by the Convention as voiced by the Disabled Peoples International (DPI) slogan: "Nothing about us without us".

Collecting data only through survey questionnaires also was cited as problematic. In a fairly authoritarian system it is unlikely that parents, who already feel disadvantaged and who are blamed for their failings as parents, would be willing to disclose more than absolutely necessary to answer the questions to people who could be seen as intimidating to them. This is an example of an *F1 problem: Insensitivity to difference*. The solution was to engage parents, disabled people and others from community-based NGOs in the data collection process, rather than to use medical doctors. In this way, the process of inclusion was modelled right from the start.

A decision was also made to hold a number of focus groups and key informant interviews so that families would feel more comfortable discussing the situations they experienced. Training sessions were held for the interviewers and guidelines were developed for focus groups with parents, teachers and disabled youth. Table 4.3 shows an excerpt from the facilitators' Discussion Guide for Parents' Focus Groups that were focused on the child's education.

Data collected through the focus groups and interviews were triangulated with data collected through surveys and secondary data. Having the information that was generated through the revised research questionnaires and focus groups rather than a list of the number of children with cerebral palsy, for example, which would have been what had been generated by the original research questionnaires, was much more useful for policy and planning purposes. Rather than identifying the number of "defective" children, the data were able to provide a picture of the degree to which there was openness in society towards inclusion of disabled children,

Table 4.3 Facilitators' discussion guide for parents' focus groups that focused on the child's education

Every child has the right to attend a community school regardless of his/her mental or physical condition. It is the duty of the schools to implement any changes needed to enable every child to access the class, follow the program and participate in every school activity. In other words, the schools need to accommodate the needs of every child and guarantee his/her full inclusion in the educational system

Objectives: to assess the degree of inclusion of disabled children in their local community schools and to identify the barriers to their inclusion

Note for facilitator. Invite the participants to think about how their child could be fully included in the community school (full inclusion means she/he can follow the lessons in class, do everything other children in the class can do)

- If the child does not go to school or goes to a specialized school ask them to think about what stops him/her from going to the local community school
- If the child goes to regular school ask them to think about what problems he/she faces in school and what he/she needs to do better and be happier. What does he/she need to be able to participate in all the activities as other children in the class (play, go on school trips, eat in the cafeteria, physical education, etc.)?
- If some parents do not want to send their child to school find out why? What prevents them from sending their child to school? Are there things of which they are afraid? If yes, what are they?
- If the child is too young to go to school ask the parents about kindergarten or if they foresee problems for their child in school. If so, why? What problems do they foresee?

Ask the parents to talk about their experiences – not to give general answers the specific support needs of disabled children and their families and teachers, and the specific barriers that existed within a child's home, community or school.

4.7 Research Findings

The research findings demonstrated that in many instances communities are not inclusive of disabled children and their families. The research identified many violations of the rights of disabled children and the physical and social barriers faced by disabled children and their families.

Some of the findings of the research:

- The medical model of disability still prevails and influences those caring for disabled children.
- Most disabled children do not go to their community schools due to the social and physical and attitudinal barriers they face.
- Stigma and discrimination towards disabled children are still widespread, especially the view that disabled children are "diseased" and need to be fixed.

4.8 Workshops

Once the preliminary research findings were available, a 2-day workshop was held in Kyrgyzstan to share the findings with a broad range of stakeholders and to explore the *BIAS FREE* Framework and its usefulness as a tool for the development of a national strategy to move towards a more inclusive Kyrgyzstan. Workshop participants consisted of representatives of parents of disabled children organizations, disabled youth organizations, NGOs, different government ministries and staff from UNICEF. Participants expressed great interest in undertaking further work to improve the situation for disabled children. Workshop participants began to constitute an informal working group and this generated a momentum for the development of a National Strategy for building an inclusive Kyrgyzstan, with a common vision and objectives shared by all the stakeholders.

As a result of the Workshop, UNICEF decided to launch a follow-up initiative in 2008 as its priority project, for which support from the Prime Minister's office has been secured. It was agreed that work would begin to create a National Steering Committee under the Prime Minister's Office. The National Steering Committee would include representatives from:

- Child Protection Department
- Ministry of Education
- Ministry of Labour and Social Welfare
- Ministry of Health
- Parents Association of Disabled Children

Table 4.4 Revised objectives

- To establish a Steering Committee to guide the process of building an inclusive Kyrgyzstan, Working Groups to develop a National Strategy and Action Plans to achieve this goal and the high level political support necessary to make the vision a reality
- To provide tools and training in equity analysis using the *BIAS FREE* Framework to those involved in the initiative
- To initiate a process of identification and elimination of all physical, social and attitudinal barriers to the full inclusion of children
- To align all legislation, policies, programmes, service delivery, social and built environments, research and practices with the vision of a truly inclusive society
- To enable families and communities to fully include and care for all children
- To end all practices involving the segregation of disabled children and close segregated residential institutions
- To serve as an incubator of ideas, methods and tools for moving towards inclusive societies that can serve as a model for other countries

- Disabled Youth Association
- Save The Children, UK
- UNICEF

It was also agreed to organize a workshop and convene a National Working group to develop the National Strategy, and that UNICEF would provide technical support to the National Working Group. A common vision, goals and objectives were also set. The overall project goal was stated to be to create a fully inclusive Kyrgyzstan that values, welcomes and treasures diversity and provides the conditions in which all people may grow, develop and contribute to society to their fullest potential, enjoy equal rights within their communities and society and achieve physical, mental, social and spiritual well-being; the associated objectives are shown in Table 4.4.

4.9 National Working Group

The National Strategy would be developed though the joint work and coordinated action of a National Working Group. The National Working Group will consist of representatives from the Ministry of Health, Ministry of Education, Ministry of Labour and Social Protection, and the Department of Child Protection. It will also be made up of representatives from Parents of Disabled Children associations, disabled youth and adults, disabled people’s organizations, community members, officials from schools, institutions, the business community, human rights lawyers and other human rights experts, the media, and local, national and international organizations and NGOs who are committed to the project goal and objectives.

The National Working Group would be subdivided into teams, each working on different aspects and issues of inclusion. Separate teams would be formed to focus on each of the following: national legislation, infrastructure, education, health, social welfare, labour, and sports and recreational activities. Teams would decide on priority areas to be addressed in each area and would take decisions jointly and democratically on specific actions and activities to be undertaken.

Each team would be responsible for identifying the specific strategies that would need to be undertaken in its area of interest, identifying an Action Plan for work over the next five to ten years, including key stakeholders, activities to be undertaken, related budget requirements, and potential funders.

Each team would be chaired by a member of the National Steering Committee. Chairs will guide the process, ensuring that each team works towards the project goal and objectives and produces an Action Plan. Chairs would be responsible for pulling all the Action Plans together into a coherent National Strategy.

4.10 Conclusion

Kyrgyzstan is a relatively young country and, like many other countries in the region, it is still shaking off the legacy of the Soviet model of care of disabled children. The medical model of disability still prevails and influences those caring for disabled children including teachers, parents and medical personnel. Using the *BIAS FREE* Framework helped to shift the emphasis and direction of the research over the course of the research. A paradigm shift occurred from the medical to the social model of disability, from focusing on “repairing” the disabled child to focusing on building inclusive communities for everyone. As such, the *BIAS FREE* Framework was a very useful tool in identifying and analyzing the problems experienced by disabled children and their parents and teachers and in finding real solutions to those problems. The Framework provided a *theoretical* understanding that promoted engagement in a research *methodology* that empowered them to participate in a *process* of challenging and transforming the social hierarchies around them. It helped participants to become profoundly aware of their *rights* and injustices around them and to take action to solve injustices that they and others experience.

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Chapter 5
Networking in Disability for Development: Introducing the African Network for Evidence-to-Action on Disability (AfriNEAD)

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5.1 Introduction

This chapter argues for the importance of networking to promote the human rights of persons with disability. The nature of relationships between people in a community can be seen as a key indicator of the well-being of that community. The global village can try and maintain the distant and sometimes difficult relationships between vulnerable groups through the imaginative use of networking, thus providing not just an opportunity, but an obligation to use such technologies to promote social capital, social inclusion and social participation. Networks offer a means of supporting and achieving these aspirations for persons with disabilities. We introduce the African Network for Evidence-to-Action on Disability (AfriNEAD) and argue for its timeliness.

Central to our approach is the concept of *ubuntu. Ubuntu* is a South African term but the concept is not uniquely South African by any means and has resonance in other African countries. In Malawi, for example, a very similar concept to *ubuntu* is that of *umunthu* (Sharra, 2005, 2006). There are various interpretations of the *ubuntu* concept, but at the heart of the concept is the idea that people are human only in relation to others[1] – the proverb "uMntu ngumntu ngabantu" (a person is a person because of other people) is commonly cited as core to the *ubuntu* concept. The concept has sparked considerable debate and difference of opinion (Bewaji and Ramose, 2003; Farland, 2007; Metz, 2007; Van Niekerk, 2007) but for the

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[1] *Ubuntu*: "The heritage of the philosophy that comes to us through our traditional African roots is *Ubuntu*: morality, compassion, care, understanding and empathy. It is one of share and hospitality, of honesty and humility. Simply put, it is the ethic and interaction that occurs in the extended family. In Africa, it draws in all people. In the "family" there is a community of shared values and equality" (Boon, 1996).

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current chapter it is sufficient to note two things: First, we hold the principle of interdependence as central to the way we should think about developing disability work in Africa (and in adhering to this interdependence, or *ubuntu*, concept, we are at some distance from a number of European approaches to disability which very strongly emphasize independence). Second, the *ubuntu* concept of interdependence or interrelatedness does not have to been seen as either archaic or as uniquely African. Indeed, contemporary possibilities for electronic communication in a global village enhance the opportunities for networking and mutual interdependence, all of which can further the possibilities for a global approach to disability work consonant with *ubuntu* principles.

In keeping with a community-based, *ubuntu* approach, persons with disabilities have raised disability as a human rights and a development issue indivisible from other human rights issues. It is within this context that they have tried to show how persons with disabilities have been marginalized by society at different levels. They have tried to work as a group and to network disability issues at local, regional and global levels. They have tried to combine their voices to reach the highest offices that handle global human rights issues. As a response to these initiatives, in some countries disability policies have been developed in an attempt to include the needs of persons with disabilities amongst the needs of all citizens of those countries. These attempts in some areas have started to give a sporadic positive impact to the lives of some persons with disabilities. However, it seems that the quality of life for most persons with disabilities may not be changing as rapidly as has political awareness (Ingstad and Whyte, 2007:5).

Despite the high priority given to the needs of persons with disabilities at an international level, when one looks at the picture, especially in countries that are struggling to see that a greater percentage of their citizens have food on their tables, there is minimal activity directed towards making an impact on the lives of persons with disabilities, especially those who live in rural environments.

This reality gives rise to a dilemma for disability activitists. Should disability networking be isolated to an agenda that deals exclusively with disability issues, or should persons with disabilities join up with other concerned advocates who are challenging those systems that marginalize vulnerable citizens, including persons with disabilities? Related to this dilemma is a further question: If disability advocates network with other concerned advocates, will this dilute the voices of these disabled advocates? What guarantees are there to ensure that the needs of persons with disabilities take the same prominence as those of other vulnerable citizens? [2]

Unfortunately, there are indications that other groups interested in development and human rights do not always offer prominence to disability issues in their struggles. It is a sad but common experience that many a time when White Papers, policies and conventions are debated, persons with disabilities are consulted only at

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[2] This dilemma is not unique to disability activism. In the history of struggles for national liberation there have been debates, for example, as to whether the advancement of equality for women or for sexual minorities should be delayed in the service of the broader national liberation agenda.

the eleventh hour of the discussions; sometimes they would have been completely forgotten had it not been for their own initiatives. As a result of this negligence, questions are being asked regarding the wisdom of mainstreaming networking for disability issues both at local, regional and international levels. Also there is the historical perspective that comes with networks in relationship to how the world has developed and been shaped, especially for vulnerable groups such as persons with disabilities.

5.2 Global and Historical Aspects of Networking

The industrialized world has moved ahead in matters of genomics, service delivery and biotechnology (Lau, 2004; De Bont et al., 2007). Different action strategies have been implemented to translate knowledge from existing theory in order to guide planning and practice innovations. Decision makers have been encouraged to consider a multifocal approach that effectively incorporates networks both at physical and technological levels as well as including a social capital approach in the planning and evaluation of programmes that hasten equity (De Bont et al., 2007; Mozunder and Marathe, 2007). These may range from information communication networks to actual physical meetings of network membership from time to time to resolve certain problems and put in place specific strategies (Lau, 2004; De Bont et al., 2007; Mozunder and Marathe, 2007; Daar et al., 2007).

For these reasons the term “network” is defined as a “compressed term” that represents a perspective of hope for forward movement and as a facilitator of conducive democratization and successful cooperation, including professional optimization to those affiliated to professional bodies or organizations. As a term used almost as universally as the term “system”, “network” has very nearly come to be mythologized (Weber, 2005). Networking also facilitates close forms of cooperation in a regional context, often initiated by support programmes and generating research interest in evidence-to-action (Weber, 2005). Gnahs (2003:100) in Weber (2005:40) maintains that networking is about dealing not only with a clear accentuation of the term “network”, but with a “school of thought, a line of orientation, “a warmth metaphor” including an accentuated demand for initiative: regions shall be guided out of their passive role, taking on an active part in dealing with their concerns”. As part of the regional networking processes, intermediary agencies for regional learning networks are created which are supposed to tie different fields together, to give creative support and to serve as bridges for the initialization of regional processes by defining needs and giving orientation of what needs to be achieved.

There has been a general perception that networks can substantially scale up the effectiveness of the existing resources and achieve equitable distribution of such resources (Lau, 2004; De Bont et al., 2007; Mozunder and Marathe, 2007; Daar et al., 2007). For example, Wilkinson and McCarthy (2007) were able to show that it was possible to reach more than three million cancer patients through cancer management network teams for the dissemination of information related to palliative management. Friedman et al., (2007) suggest that the network aspect of social capital is also useful to best understand the active, on-the-ground processes by which people of some countries, beset with poverty, racial/ethnic subordination and internal divisions (arising from inequalities at different levels), defend their own and others' safety and health. Within these discussions and innovative strategies scholars such as Boneham and Sixsmith (2005) are calling for the inclusion of the voices of older women. They perceive that these women are innovative networkers with reservoirs of prior knowledge in activities that require non-linear patterns (such as social capital) for problem-solving. These are some of the assets they have used to sustain their families during different challenges in their lives (Boneham and Sixsmith, 2005; Baum, 1997; Scott and Wenger, 1995).

The concept of networking is as old as humankind. Early on, humanity recognized the need for networking and co-opting the strengths and potential of other human beings in their day-to-day existence for survival, progress and development. The old adage "the whole is greater than the sum of its parts" also recognizes this. In the past this maxim would sometimes involve moving from one's own environment to be closer to those whom you perceive could enhance your human existence; for example, when those you were living with are no longer able to do so. The networking concept was also applied by early traders who saw the exchange of goods and human bodies as a way of enhancing their own trading vocation and skills; on the other hand, those persecuted by religious or political dogmas saw moving to other environments as a means of saving their own lives. It is interesting to note that the very oppressive approaches they were running away from in their own countries were carried at an unconscious level as the template that would at a later stage be used to subordinate and subjugate those whom they found living in their new environments (Mkhize, 1973).

It appears then that the world as we see it today has been shaped by these early networkers. From these early activities, a myriad of networking activities and exchanges started happening. People and goods migrated along with knowledge and technologies, initially slowly and later with increased pace and speed. This was influenced by industrial and technological revolutions that further facilitated and enhanced the rate and pace of networking. The result was the development of national, regional and international seaports, airports, information networks, and even scholars disseminating information; all of these constitute important potential nodes of communication and exchange.

Today we have the most extensive network of all humankind and that is the "global village". The "globalization philosophy" sees the world as one centre stage where myriads of networks, like electric wires, join individuals, organizations and systems to the global stage and to each other. As access to different commodities improves for some people, many human rights activists recognize the exclusion that continues to persist for the greater part of the world's population. For this reason they continue to lobby and network for a global village where access transgresses boundaries and is improved for all.

5.3 Perceived Culture of Global Networks

Much as there has been rapid growth and development in networking and globalization, concerns have been expressed about how the globe has become increasingly unsafe to live in, and at the widening of the gap between the poor and the rich. Health and its services has in many instances become an exclusive commodity for the rich (Rasool, 1997). Hunger, in certain parts of the world, has escalated to epidemic levels, and it is estimated that the number of undernourished in sub-Saharan Africa, for example, will treble between 1990 and 2080(von Braun, 2007). All "our children"[3] have become unsafe at all layers of our globe, irrespective of socio-economic status. They are at risk of being trafficked like goods, from south to north, from east to west, by those requiring instant gratification. The responsibility for some of these ills has been laid at the doorstep of modern technology in that it facilitates networking and makes it easy to form a family of "all sorts" depending on your interests and your networking skills.

On the other side of the coin, the interpretation of human rights and strategies to unlock equity and develop a "true global village" has taken another turn of events (Werner, 1997). The new economic order, led by those who have learnt from the architects of the old hegemony and who want to maintain the separatist exclusive gains achieved in the past, manipulates global dynamics by continually changing the goal posts for what is required to achieve global equity and to alleviate poverty and human suffering (CDRA, 2004/2005). New institutions and networks such as the G8 have been developed and accepted, depending on the extent to which you or your country is compliant with their development scale (Korten, 2003; Chossudovsky, 1997). Terms and language such as "developed" and "underdeveloped" regions, "scientific" and "non-scientific" knowledge are being loosely used in the description of some human development (Werner, 1997). We need to ask whose yardstick is being used in order to classify a whole country/ continent and its people as being "underdeveloped" and what is the impact of that term on the people of those worlds, including the new generation of those worlds? In our view, "development" should be understood to be about groups of people in a reciprocal relationship that represents improving the circumstances of all involved. It is not something that one country or group does to another country or group; it is something they help each other with. All countries should be developing countries; the process of improvement should not be claimed as an end-state by some and as a target for others (MacLachlan, Carr and Mc Auliffe, in press).

At these highly charged networking activities, you see the concerned advocates and networkers waving placards that highlight the plight of the poor (Werner, 1997; Chossudovsky, 1997). They call for a revision of laws that govern exports and subsidies to smallholding farmers (Shiva, 1997). They taunt the giants of the First World regarding the privatization of natural resources and destruction of the natural environment for profit. They ask, "Since when do shrimps and flowers fill stomachs?"

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[3] Within African culture, children belong to and are the responsibility of all adult village people.

And they end warning that even the air that we breathe will soon be sold at a price (Shiva, 1997; Davies, 1997; Bond, 1997; Werner and Sanders, 1997). Is this not already happening in life-saving institutions such as health care facilities? In the so-called developing countries, if you require critical care and you do not have money for private care, you could well land up in a public hospital where the balance between supply and demand dictates your chance of access to what may be seen as 'luxury' equipment, though this equipment is necessary to save life (Marmott, 2007; Rasool, 1997; Werner, 1997; Sambo, 1997; Sanders et al., 1997). For persons with disabilities these issues might imply a shift from not only focusing on equity concerns but to paying more attention to attaining their rights in a market place where gains achieved in equity could be translated into policy and action.

5.4 The Emergence of Voices of Concerned Advocates

On the ground, another group of concerned activists and advocates has started to emerge both at regional and international levels (Sanders et al., 1997). They have recognized the plight of the poor and the inequities that continue to exist for poor people, with devastating impacts on health and well-being (People's Health Movement, Medact and Global Equity Gauge Alliance, 2008). Much as their activism is driven by the general concern for human rights neglect, at the core of their struggle is the understanding that there is a strong link between those classified as developed and the poor, and that a truly healthy global village cannot be achieved amidst such inequity (Werner, 1997; Korten, 2003; Sambo, 1997). They infer that socio-economically disadvantaged persons more often report poor social networks and social support systems. This is either often due to the scramble for meagre resources or broken family units as a result of key family members having left to look for work elsewhere (Scott and Hofmeyer, 2007; Dragon et al., 2008).

These supporters of human rights are calling for collaboration through national, regional and international networks – survey and capacity building based on proven models through education, training and needs assessment (McGorry et al., 2007). They are calling for expanded information and communication networks that will widen the avenues for community-based "participatory development" that encourages the use of local information, knowledge and decision-making (Cololizza et al., 2007). They perceive that integrated service hubs and networks across nations, community awareness, workforce training and evidence-based resource material can reduce inequities across nations. They see as essential that there should be service cohesion and synergistic planning that includes health and social outcomes for all population groups including persons with disabilities. They are concerned about regulatory mechanisms that form frameworks for commercialization and the interface to industry and the impact of these for small and medium enterprises as well as intellectual property and land rights. Discussions have taken centre stage regarding ethical, societal and cultural issues that may hamper accessibility and the need to strengthen leadership support at the political level to develop capacity to address these issues (McGorry et al., 2007; Cololizza et al., 2007; Beasley et al., 2007).

They are calling for the globalization of human and political rights to answer the issues of social justice. They see the emergence of the new class that is created from swift exchange of the latest information and how certain countries are being left behind due to lack of access to this information.

Caution is extended to these fellow advocates regarding both resources and the yardsticks they will use as they charge forward to join hands with the poor and the disenfranchised. Writers such as Montegut (2008) are commenting on how difficult it has been for organizations like WHO to meet the expectations created by its programmes, as core issues that relate to equity and human rights have not been met as yet. They further comment that this might be due to the fact that the current promulgation of the Millennium Development Goals has again tried to improve health in developing countries through a focus on disease-orientated (vertical) programmes. Suggestions are made that as these professionals are building their careers they need to take cognisance of implementing positive steps for building cooperation in the regions they enter. They invite discussions that centre on roles that professionals can play in building "cooperation networks" for underpinning health and food security, conflict resolution and global health promotion (Skinner and Sriharan, 2007). They recognize that at the core of these challenges is the need to develop cohesive strategies that will eradicate poverty and human suffering.

Our view is that the argument needs to be stretched beyond poverty to the consequences of poverty. The South African Integrated National Disability Strategy of 1997 has recognized the strong link between poverty and disability. Hence, in countries beset by poverty, such as Africa's countries, there is a high disability prevalence (South African Integrated National Disability Strategy White Paper, 1997). Early on, persons with disabilities recognized the need to come together as a group to network strategies that will address the discrimination that is entrenched in systems and relationships and that have robbed persons with disabilities for many years of the possibility of attaining the status of equal citizenship. They have coined the expression "Nothing about us without us". Judge Albie Sachs (2008) of the Constitutional Court of South Africa, describes this expression as persons with disabilities reclaiming the space of "democracy and human rights" not only for themselves but for "the whole of humanity", especially those who have been marginalized. "Nothing about us without us" is about all of us as we are struggling to find our humanity and gain an understanding regarding how some can have so much while others are struggling to put just one meal on the table. So, returning to our previously described dilemma, the question is: Should concerned advocates not join hands with persons with disabilities in challenging those systems that marginalize vulnerable citizens including persons with disabilities, and network for a global village and the rest of humanity?

5.5 Drawing Experiences from the Disability Movement

Persons with disabilities, through their resilience and networking, have chalked up some notable achievements. These include the creation of the Union of the Physically Impaired against Segregation (UPIAS), which in 1976 gave impetus to disability issues by the publishing of *The Fundamental Principles of Disability*. One of their core statements was related to the acknowledgement of the role of society in further disabling persons with disabilities when they stated that:

> In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society (Oliver 2004:19).

Another landmark networking event was the walkout of persons with disabilities from the Rehabilitation International (RI) conference in Winnipeg, Canada, in 1980 and the subsequent formation of Disability People International (DPI). This move saw persons with disabilities challenging the dominance of health professionals in the disability agenda. The establishment of DPI led to other important world initiatives that challenged marginalization and oppression of persons with disabilities. These included a declaration by the United Nations of 1981 as the International Year of the Disabled Persons (IYPD). This was followed by the World Programme of Action Concerning Disabled Persons that outlined a universal approach to tackling and overcoming discrimination and creating equal opportunities throughout the world, and was followed by the proclamation of the Decade of Disabled Persons (1982–1992) that resulted in the formulation of the Standard Rules on Equalisation of Opportunities for People with Disabilities, and the creation of an increased number of organizations for persons with disabilities (DPOs) (Howell et al., 2006:49).

More recently, the UN Convention on the Rights of Persons with Disabilities (UNCRPD, 2007), which as of 2008 has entered into international law, is perhaps the most significant – moral and practical – step towards realizing the rights of persons with disabilities. The Convention seeks to address discrimination, to change perceptions and to combat stereotypes and prejudices. Article 32 of the Convention states that "Countries are to provide development assistance in efforts by developing countries to put into practice the Convention" (UNCRPD, 2007:62). Article 32 places an obligation on people in high-income countries not only to put the Convention into practice in their own country, but also to ensure that their country assists in it being put into action in low-income countries as well.

The above gains achieved by persons with disabilities in highlighting the plight of persons with disabilities as a human rights and a development issue illustrates the sophisticated networking skills that persons with disabilities have used to tackle the years of discrimination and oppression that they have experienced. Disabled people have used networks for consultation as a group when seeking to improve accessibility, or simply a tool to voice opinions, perceptions and concerns. For this group, networks have offered vital peer support. Disability networks are a vital method of sharing disability best practice. These best practices had become valuable not only for disabled people but also for others that experience marginalization; hence disabled people are increasingly being valued for their experience and innovation in this regard.

Networks can be used to build a disability community where connections are used to share resources; networks can be used to build the reputation of disability networks where they use the connections to communicate their key values to members and the wider world; and lastly, networks can be utilized to build resources where connections are used to gain resources and strengthen DPOs (Poland, 2008). There are wider disability networks with connections between various networks at different levels for various purposes and there are big networks at a high and strategic level. These networks span from international, regional and disability local networks.

Table 5.1 presents some examples of international and national disability networks. These networks have been built up over many decades and are to be found in Africa at national, regional and global levels.

Though the disabled people are commended for their networking efforts, disability networks based in the so-called developing countries appear to be weaker as they are impacted on by not having sufficient resources to sustain themselves. Again the notion of *ubuntu* and developing synergistic effects between weaker and stronger disability networks becomes an attractive option. It appears that many challenges still lie ahead.

Despite the many progressive statements promulgated in recent years, the extent of meaningful change in the actual quality of life of persons with disability in Africa remains limited. Even in a country with relative wealth like South Africa, with its internationally acclaimed and inclusive Constitution and its established national strategies and policies (for instance, the Integrated National Disability Strategy White Paper of 1997 and the South African Employment Equity Act 1998) the possibilities for persons with disabilities to have "equal rights and dignity" remain distressingly elusive. In South Africa the majority of persons with disabilities are not yet experiencing meaningful change in their quality of life, in access to equal rights and in levels of community integration, despite a favourable policy environment and a limited, but supportive, research evidence base. Thus, the historical exclusion of persons with disabilities from society still persists. Real change and social development are still required to realize a truly inclusive society.

Research in itself will never be enough. Furthermore, there is a danger that the research community – injected with the "cash" of international aid – may simply accumulate evidence without developing practicable solutions to address the ways in which society can become more responsive to and more inclusive of persons with disability. The challenge is clear: it is not just more research that is needed; it is "improved" research and research that can be translated into policy and practice. Translating research into evidence-based advocacy, policy, practice and products – particularly in the pan-African context – needs to be systematically addressed in a coordinated, coherent and consistent fashion. A wide range of stakeholders need to be included in the process, ranging from asking the appropriate research questions through to utilizing the research outcomes – that ultimately feed back into asking further relevant research questions.

It has become clear that different groups of people all over the globe have used networks as a form of strengthening interdependence and drawing from each other's experience and expertise. Society has tried to position persons with

Table 5.1 Examples of disability networks

Organization	Membership	Goals
Disabled Peoples International (DPI, 2008) http://www.dpi.org/	National organizations or assemblies of disabled people A majority of the members as well as the governing body are persons with disabilities. Respresentatives to include all races, sex, religion, language, geography, etc	To promote the human rights of disabled people through full participation, equalization of opportunity and development To promote the economic and social integration of disabled persons To develop and support organizations of disabled persons
Christian Blind Mission (CBM) http://www.cbmi-de/	International, 700 partner organizations in developing countries throughout the world	To improve the quality of life of the world's poorest persons with disabilities and those at risk of disability in the most disadvantaged societies To support and develop local partner organizations, rather than implement projects To transfer knowledge and skills, both professional and managerial, in order to contribute to development of these partners
Handicap International (2008) CAHD – Community Approaches to Handicap in Development http://www.handicap-international.org.uk/	International, 55 countries worldwide	Focus on the causes of impairment, disability and handicap and the link to able-bodied people To create social change and inclusion as citizens with equal opportunities and full access to participation
African Community-based Rehabilitation Network (CAN) http://www.afri-can.org/	Based in Uganda.Disabled persons in Africa and their families	To benchmark best practices and research with regard to disability To make information about disability issues accessible worldwide through conferences, writer's workshops, the formation of CBR national organizations, maintaining a website and publishing To promote the equalization of opportunities, social integration and rehabilitation of persons with disabilities in Africa

Disabled People South Africa (DPSA, 2008) http://www.dpsa.org.za/	South Africa, national movement	To advocate for a paradigm shift away from seeing disability as a health and a welfare issue. Instead to emphasize disability as a human rights and development issue To assist in policy making e.g. the National Integrated Disability Strategy (1997); Inclusive Education; Employment Equity; the Rehabilitation Policy
Global Partnership for Disability and Development (GPDD, 2008). http://www.worldbank.org/disability/gpdd	International, persons with disabilities and their families, including those born with disabilities and those disabled through wars, violence, traffic or work injuries, disease, disasters and other causes	To mobilise resources through fostering relationships between North and South disability NGOs and co-operations To accelerate the inclusion of persons with disabilities and their families into development policies and practices To increase collaboration amongst development agencies and organizations to reduce the extreme poverty and exclusion of a substantial number of children, women and men with disabilities who are living in poor countries
The Secretariat of the African Decade of Persons with Disabilities (SADPD, 2008) http://www.africandecade.org.za/	Africa, governments, Decade Steering Committees (DSCs), Disabled Persons' Organizations (DPOs), development organizations	To empower African organizations to work in partnership to include disability issues and persons with disabilities in policies and programmes in all sectors of society in Africa To strengthen DSCs in at least 20 African countries by 2009. To assist the most vulnerable disability groups, e.g. persons with mental disabilities, deaf or blind persons, persons with albinism to build strong African DPOs To accelerate the inclusion of persons with disabilities and their families into development policies and practices

disabilities as being the “others”; perhaps that was the starting point for change. Lately, ideas have been challenged regarding who is disabled and who is not disabled, including fundamental definitions of disability. Questions have also been asked regarding the impact of the activities of the previous decades including the information that has been used to inform decision-making. Further concerns have been raised about the lack of cohesion between different layers (persons with disabilities, academics, civil society, business and policy makers) from those that say they are the voice of persons with disabilities. It is this context that gave birth to the African Network on Evidence-to-Action in Disability (AfriNEAD).

5.6 Background to the African Network on Evidence-to-Action in Disability (AfriNEAD)

As has been mentioned, it is now recognized that persons with disabilities are amongst the poorest and that disability is both a cause and a consequence of poverty (South African Integrated National Disability Strategy White Paper, 1997). Society has begun to recognize that disability limits access to education and employment, and leads to economic and social exclusion. For the poor, this is exacerbated as they are caught in a vicious cycle of poverty and disability. James Wolfensohn (2002), former President of the World Bank, argued that if development is about bringing excluded people into society, then persons with disabilities belong in schools, in legislatures, at work, on buses, at the theatre and everywhere else that those who are not disabled take for granted… Unless persons with disabilities are brought into the development mainstream, it will be impossible to cut poverty in half by 2015. The extent of meaningful change in the quality of life, health, access to equal rights, decent work and full community integration for persons with disabilities throughout Africa remains limited.

The Millennium Development Goals (MDGs) and strategies such as the development of Poverty Reduction Strategy Papers (PRSPs), in conjunction with the recent ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), set the stage for the development of policy, products, advocacy and practice which can improve the quality of lives of persons with disabilities in Africa.

What these lofty and worthy initiatives will actually achieve will be influenced by many factors. Their chances of success will be strengthened if they are powered by an evidence base that reaches into policy decisions and practical actions, which engages with persons with disabilities, being for them, and through them, not only about them, and, where possible, being undertaken by them. There is a need for strong evidence to support and inform new developments and to monitor and evaluate outcomes. The African Network on Evidence-to-Action (AfriNEAD) intends to be part of this solution.

5.6.1 Why AfriNEAD Now?

It is time to capitalize on the impetus that has been created by international initiatives and to further strengthen the efforts of advocates and lobbyists as well as policy makers, programme developers and businesses who are genuinely trying to address the needs of persons with disabilities in their fields.

For this reason the Centre for Rehabilitation Studies in the Faculty of Health Sciences at Stellenbosch University in South Africa has promoted the development of AfriNEAD. In this it has been supported by its African civil society partner, the Secretariat of the African Decade for Persons with Disabilities, and its northern research partner, the Centre for Global Health, at Trinity College, Dublin, in Ireland.

The vision of the African Network on Evidence-to-Action (AfriNEAD) is to improve the quality of life of persons with disabilities in Africa and throughout the world by translating new and existing disability-related research into relevant and meaningful policy, practice, advocacy and products. It is a network that is uniquely African in nature and it is well positioned to link the issues of disability, poverty reduction and development with evidence and research. It seeks solutions to its own obstacles within an African context and as such it could be a significantly unique player in research and policy-making with the key objective of increasing the participation and inclusion of the persons with disability (PWDs) in all aspects of society.

We believe that there is an urgent need for evidence

- To accurately describe the situation of persons with disabilities in Africa
- To highlight gaps in evidence
- To support new policy development
- To give credibility to advocacy for policy changes
- To inform programme development
- To monitor and evaluate existing projects
- To inform further research

There is also a need for *quality* evidence that can be of real use to end-users. This requires a strategy for the training of potential researchers and capacity building amongst DPOs, but also for all researchers in disability-related fields to find common ground in concepts such as the human rights framework, the emancipatory research approach and to move away from charity-based thinking or only a participatory approach.

There is a need to learn from one anothers' experience in the developing world so as to speed up service provision in ways that are sustainable and that address the real needs of PWDs. There is also a need to accelerate and support policy changes to help develop an enabling environment in each African country. Mutual exchanges of experiences of failure and success can strengthen the case for advocates and lobbyists.

There is a need for the integration of programmes and products as well as policy with the real needs of persons with disabilities, including the right to decent work. AfriNEAD provides a link with business people with the intention of creating mutually beneficial relationships where persons with disabilities can access meaningful work in a way that is of value to all partners. AfriNEAD can also act on a consultancy basis to the business sector to advise on issues of access and reasonable accommodation for persons with disabilities in the workplace.

5.6.2 What is AfriNEAD?

AfriNEAD's vision is to become a significant contributor to and facilitator around the needs of persons with disabilities in Africa, by assisting in translating existing and new research in the disability arena into meaningful evidence-based advocacy, practice, products and policy.

Translating research into evidence-based outcomes – particularly in the pan-African context – needs to be systematically addressed in a coherent and consistent fashion. Ongoing dialogue with all stakeholders is needed to address barriers to this integration.

Thus, the network explicitly aims to facilitate an integrated, intersectoral, multiperspective and interdisciplinary approach to realizing the rights of persons with disabilities in South Africa and throughout the African continent. AfriNEAD is proposing a range of activities commencing with the establishment of Working Groups which are tasked with identifying action pathways and producing Best Evidence-to-Action Research Practice Guidelines. This will include working with member countries to develop a methodology for profiling their own local situation regarding persons with disabilities and the services and opportunities available to them, the existing available research, research that is currently being undertaken and research that is required. An important aspect will be to identify facilitators and barriers for turning this research evidence into action. To further the work done by AfriNEAD the plan is to run a biannual symposium – to keep planting the "seeds" – every second year.

The First Stellenbosch Symposium on Evidence-to-Action in Disability (SSEAD 07) was held in November 2007 and was attended by a range of international delegates, many of whom were persons with disabilities. Delegates came from 14 different African countries, as well as from North America and Europe representing governments, institutions of higher learning, and persons with disabilities organizations (DPOs), non-governmental organizations (NGOs), businesses and research funders. A significant proportion of the speakers were persons with disabilities. Debate was positive, constructive and vigorous and affirmed the need for just such a medium of interaction. For this first symposium, we invited papers around the general theme of "realizing the rights of persons with disabilities in Africa." Several of the papers that were presented at the conference, or inspired by it, are to be published in a special issue of *Disability & Rehabilitation* early in 2009.

5.6.3 How Will AfriNEAD Measure its Success? Some Reflections Regarding the Quest for Relevancy and Sustainability in Networks

The creation of a network centres on the perception that there is a problem at hand that requires a collective generation of knowledge to develop solutions. The development of new knowledge is a prerequisite for the success of a network. At the core of a network is the understanding that people with similar and sometimes opposing ideologies have come together to stimulate and continue the ongoing generation of knowledge that will assist in giving direction on the core concern of the network.

Weber (2005) maintains that monitoring and evaluation become of central importance for network development. In the past, evaluation designs in the context of the complex structures of decision-making often predetermined the evaluation direction. It is within this context that Weber (2005) suggests alternative approaches that might be suitable for a network to evaluate if it is reaching its goals. These are:

- *Between "technocratic feasibility" and "systemic irritation"*:

The idea is to move away from pre-planned evaluation models that are driven by intentional design and seek to influence conditions with already assumed results. It is suggested that even the most advanced and differentiated instruments of planning eventually cannot "handle" social reality. Thus, there is a need for open, dynamic approaches to planning and evaluation, approaches that can evolve to match the social context.

- *Between legitimization of the past and planning for the future*:

Here networks run the risk in conducting parallel activities at all levels which do not give feedback to each other, which are directed towards network goals and which see themselves as strategically orientated. Some of the evaluation designs are embedded in a "planning culture" where the emphasis is on diagnosis, feasibility studies and conditions for success, thus leaning more towards future orientation on numbers and cost benefits. The most effective interventions are those that harmonize with visions and strategies of the system of reference, in this case the network. The aim is not the realization of individual activities but a strategic feedback relationship of all measures that is supposed to create equality in the directedness of all activities.

- *"Expert objectivity" or subject participation*:

In the past it was held that some of the challenges facing those with subjective knowledge stem from a lack of the skills that were held by those with utilitarianistic rationalist models of action. The tendency then is to hand over decision-making and responsibility to experts who have the skills. During these moments, the participants bow their heads and allow themselves to become objects of analysis instead of systemic partners in the collective efficiency of examining whether the network's goals are being realized. During this process, democratization and the production of knowledge that is relevant for action has to work with network knowledge. If this does not happen, there are distinct risks of interest-guided dominance and colonization on the one hand, with a lack of acceptance and inner emigration by the network partners on the other (development of networks within the network). Knowledge production in networks thus has to rely on the cooperative structures of participatory research. The efficiency of the solution of material problems depends on the participation of those concerned, on openness to criticism, on horizontal structures for stability and democratic procedures for implementation as expressed in the disability movement's maxim of "Nothing about us without us".

- *Completeness of what is known or the processing of what is not known/uncertain*:

When members of a network congregate around a specific concept, they are not starting from a point of knowing, but from a cup that is not yet full, and the degrees of not being full vary from member to member. There are also other spaces of the network regarding concepts that might be completely empty. The starting point is to accept this and not be threatened by it. Through dialogue and debate, osmosis of ideas happens including the germination and sprouting of completely new ideas. This suggests that the network is suspended in its planning and development through a process-orientated ideology that is driven and facilitated by communication. For networks to function and move forward there should be minimal neutrality regarding communication of the core goal of the network. This communication approach is integral for bridging the gap between philosophy and concept to action. The strength of being able to play out this function is related to the ability of the network to allow "multiple, conflicting and evolving processes and purposes". By allowing these conflicting ideologies, lessons and learning occur. We live in a world that tends to say that you are either with us, and this implies you are our friend, or against us and implying that you are our enemy. The authors of this chapter are of the opinion that networks do not work like that. If a network is allowed to operate like this, then the opportunity for learning is completely stifled, thus leading to the network's own demise. Networks should therefore guard against a tendency towards "group thinking" (Janis, 1972).

- *The space in-between as the space of uncertainty about the future and rich with possibilities for growth and development*:

As human beings, we have the past, the in-between and the future. Our perception is that the space in-between is the most critical space for developmental work. Many plans have fallen flat on their face due to how the space in-between has been managed. Network members come together laden with stories of failure and success in the past. They are unsure and concerned about the future and they put their hopes in the space in-between. Trust is put on the communication debate model of the network to bring the fruits of the membership together and to weave them into a matrix that will lead into the future. Intended or unintended qualities of learning will find their space and through an integrative discussion possibilities for new epistemologies and transdisciplinary perspectives emerge. This learning will be happening at different levels of individual, dyads and groups of actors.

Network knowledge is always social; it is created and embedded in social practice, with its individual and collective elements. Whole network relationships are based on exchange, which is, in turn, based on stable expectations and norms of reciprocity and underpinned by the concept of *ubuntu*. Trust is also seen as a *sine qua non* (important and integral) for the successful undertaking of projects. This trust is not absolute and complete; it is floating and growing, always becoming and is as dynamic as the learning and knowledge of the network. To expect trust of network members to be absolute and solid would be naïve and would put the network under undue strain and at high risk of dissolving once this absolute trust is questioned with the unfolding of the network events. If the network is about the in-between space and learning and creating new knowledge for the future, one hopes that working through each other's contribution through the communication dialogue model will contribute to the development of trust. Also working through specific projects as a group and being challenged during these processes to reveal attributes that enhance trust will further contribute to the ongoing development of trust.

It is within this context that the authors are reminded of Tuckman's 1965 classic model of group formation:

(a) Initially noncommittal and friendly encounters – the *forming* phase.
(b) Followed by the struggle for space, social status and power within the social structure – the *storming* phase.
(c) Identification of whether the group is capable of working and performing into the future – the coming together of the group into a functional whole – the *norming* phase.
(d) A "performing group" – the *performing* phase. Networks do not, however, evolve along a linear pattern. Questions arise regarding who should be part of the membership of the network as well as the selection of the "actors". Following that, clarity should be given regarding how the network will be regulated, with knowledge being integrated as well as the constitution of borders and the prioritizing of activities, including the allocation of resources for these activities as well as outcomes. Table 5.2 represents a suggested framework for network cooperation.

Since networks represent dynamic rather than static arrangements of relations and cooperation, networking has to be read as a learning process. Networks do not produce a complete agenda; continuous creation is an integral component of the network using the group "thought of the moment" – or the "new thought". Consequently, networks escape the constraints of technocratic feasibility and embark on a journey of collective and continuous creation of knowledge that denounces fear of the unknown. The network constitutes itself in time and space via social practices, as a collective social setting. It regulates itself systematically and contextually.

In this chapter we have described the historical and contemporary aspects of networking to promote the human rights of persons with disabilities. We have also sought to highlight, rather than to resolve, some of the dilemmas that marginalized groups have to face in advocating for their rights. We conceive of an international network embodying the *ubuntu* village community philosophy;

Table 5.2 Framework for network design of cooperation[4]

Design elements	Function of design elements
Variety – unity	How can a balance be reached between the variety of participating actors and their integration to some kind of unity?
Flexibility – specificity	How flexible is the network in terms of its goals and self-image, how specific is it? There needs to be a balance between these two integrals
Autonomy – dependency	How much autonomy is possible and what does it consists of, how much dependency exists and what does it consist of?
Trust – control	How much trust and what kind of trust is there; what is regulated by control mechanisms and how?
Cooperation – competition	What roles do cooperation and competition play? What relationship is created between them?
Stability – fragility	What roles do stability and fragility play? How are they created? What regulation mechanisms are there to manage these?
Formality – informality	How is the relationship between formality and informality regulated; what relationship do they have?
Economy – power	What relationship is there between arrangements of functionality and power? How are power patterns generated?

helping people "be all they can be" through their participation in a collective effort and we invite you to join with us in AfriNEAD to promote this vision (AfriNEAD@sun.ac.za).

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Chapter 6
Building Disability Research Capacity in Low-Income Contexts: Possibilities and Challenges

Leslie Swartz

6.1 Introduction

The history of disability research is a vexed and highly politicized one. There is a long history of research conducted by able-bodied people on disabled people, some of it with the very best of intentions, but often at the exclusion of voices of disabled people themselves. With the development of the social model of disability and the "Nothing about us without us" approach, disabled people have waged (and won) struggles to take control of disability research, and it is now true to say that much of the best and most influential research is conducted by and for disabled people themselves.

Commenting on what he sees as what he terms an "impasse" (p.11) in British disability studies, and in the context of his view that the disability movement has stagnated since 2000, Tom Shakespeare wrote in 2006:

> While I value the achievements that have been won through the close alliance of disability politics and disability research, I believe that the weaknesses of the British approach now outweigh the benefits. Translation of ideas and ideologies from activism to academia has not been accompanied by a sufficient process of self-criticism, testing and empirical verification. The social model of disability that has successfully inspired generations of activists has largely failed to produce good empirical research, because it relies on an overly narrow and flawed conception of disability.
>
> (Shakespeare, 2006: 11).

Shakespeare takes issue with a totalizing view of disability and disability politics, a fragmented world in which, to put his argument somewhat crudely, there are "good guys" and "bad guys," and claims made, explicitly or implicitly, for an essentialist reading of disability. He believes that without a more nuanced approach to understanding the complexities – including the political complexities – of disability issues, our ability to generate useful knowledge which will forward the

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rights agenda for disabled people will be compromised.[1] If Shakespeare is correct about the magnitude of challenges facing disability studies in Britain, it is the case that disability studies faces even greater challenges in the context of low and middle-income countries, where there are vast gaps between the rich and poor, enormous governance challenges, and numerous threats to livelihood, health, safety and stability, and environmental sustainability.

In this chapter I focus on the impact of these larger issues on what at first blush may seem a straightforward task – building research capacity for disabled people in lower-income contexts, drawing on my own work in this field in southern Africa. I begin by locating the politics of disability within broader debates in identity politics and the politics of exclusion. I then examine the way in which criteria set for disability research may be influenced by disability politics in ways that are not always helpful. I then discuss an example of research capacity building as a way of building a case for a broader discussion of knowledge management issues in disability work in lower-income contexts. The brief conclusion makes some recommendations for further work.

6.2 Disability, Exclusion and the Politics of Knowledge

The story of disabled people being excluded from knowledge produced about them is not a unique phenomenon. We know, for example, that racism and colonialism, just like disablist research, depended on a process of "othering" – black and colonized peoples became objects of research, their voices excluded, their bodies objects of interest (Butchart, 1998; Swartz, 1998). This interest was sometimes well intentioned and paternalistic and sometimes aimed more clearly at naked oppression and control. The Nazi holocaust is probably the twentieth century genocide that made most overt claims to the authority of "science," including "medical science." It is no coincidence that amongst the objects of this "science" were people seen as racially inferior (Jews and gypsies, for example), those described as degenerate (homosexuals, for example) but also people whose bodies and minds were thought to defile the purity of the nation – people with disabilities (Lifton, 2000). All these groups were tortured in the name of "medical research"; all these groups were murdered in large numbers.

In the international development of knowledge and technology, then, it is not only disabled people who have historically been excluded from expertise in the knowledge economy or who have been objects of study. This fact is especially important when we begin to consider issues for disability research in postcolonial contexts. Not only have disabled people in these contexts, like many disabled people in higher-income countries, been excluded from active ownership of research processes, it is also the case that disabled people in lower-income countries

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[1] Shakespeare's particular engagement with the social model of disability is not a central issue for this chapter, but his frank appraisal of what he sees as both good and bad in disability politics and research certainly is.

generally share a history with their compatriots of having been colonized and having been excluded, commonly by reason of race and/or indigenous status, from having access to the best education available. Not surprisingly, there is a widespread suspicion of science as a whole in many postcolonial contexts, and certainly in Africa, as a recent review of media approaches to HIV/AIDS in Africa has shown (Bolognesi and Swartz, 2008).

In South Africa, a combination of factors including a mistrust in science has led to tragic consequences – a president and health minister vulnerable to AIDS denialism, a resultant crisis in provision of much-needed antiretrovirals, leading to approximately 330,000 deaths (Chigwedere et al., 2008; Nattrass, 2007). On the other hand, it is also true that the refusal to accept being othered by racist or colonialist or disablist science has led to enormous vitality, especially in the social sciences. There can be no question that the core recognition that knowledge production excludes people on the basis of their identities has led to interesting, exciting and innovative thinking, both in the postcolonial context (see, for example, Mbembe, 2001; Said, 1979; Spivak, 2006) and in the context of disability studies (see, for example, Felstiner, 2007; Lorenzo, 2003; Mairs, 1997; Oliver, 1995). Clearly, things have gone wrong as a consequence, or a partial consequence, of objections to racist, sexist, colonialist and disablist control of knowledge (witness the needless loss of life in South Africa) but much has also gone right (the importance of insider voices in the literature and in shaping the research agenda cannot be overemphasized).

Before we can begin to understand the specific challenges associated with capacity development in disability research in low-income contexts, it is important that we get to grips with what is at the heart of the tensions between the successes and the failures in contemporary critiques of dominant research modes. Disability studies is at the centre of a raft of critiques of dominant social and medical science, on a number of grounds including the following:

1. Scientists and researchers commonly treat oppressed or “other” groups as objects, and do not take into account the perceptions held by oppressed groups as valid data.
2. Research on the “other” often furthers the needs of the already powerful, and does not forward the needs of those who remain objects of science.
3. Information that is gained from research into oppressed groups is not used to their benefit and may in fact be used better to oppress them in the future.
4. Actual research participants (“subjects”) often hear nothing about the results of the data they have provided, and gain nothing from the process.

6.3 Disability Politics and Research Criteria

The consequences of these important insights can be seen in the criteria developed by the UK Department for International Development (DFID) Disability Knowledge and Research (KaR) Program for researchers wishing to contribute to the DisabilityKaR program. In the research prospectus provided for potential research bidders, the following were the criteria by which applications were judged:

- Does the outlined method represent meaningful and genuine consultation with disabled people in the South? (10 points)
- Does the outlined method allow for consultation/involvement with a wide range of disabled people, including, particularly, disabled people's organizations, disabled women and people with different impairments? (10 points)
- Does the research team include disabled researchers? (10 points)
- Does the applicant provide evidence of capacity/track record in work of this nature? (5 points)
- Does the applicant demonstrate understanding of the social model of disability? (5 points)
- Does the applicant have experience of mainstreaming from other sectors? (2 points)
- Does the applicant outline a range of empowering and/or emancipatory research methods and have experience of using them? (5 points)

Source: http://disabilitykar.net/docs/odg_research_pros.doc, [accessed 12th January 2009]

Almost all of these criteria address important process issues. Of the total of 47 points used in ranking proposals, in fact, all of the points, with the possible exception of the 5 point criterion "does the applicant provide evidence of capacity/track record in work of this nature?" are designed to ensure that whichever team does research on disability for DisabilityKar program will not only understand the importance of inclusion of disabled people in research but will also provide evidence of this inclusion in all aspects of the program and methods used.

For the sake of comparison, consider DFID criteria for evaluating expressions of interest from research program consortia, for work not in the disability field *per se*:

The principal selection criteria for Expressions of Interest will be:

- *Originality and importance* of the research
- Likelihood of research contributing to poverty eradication, relevance to Millennium Development Goals and potential for policy impact
- *Quality of proposed organizations*, researchers and Director
- Quality of *research approach*, including dissemination strategies
- Adequacy of *collaborative arrangements and capacity building*.

(source:http://www.dfid.gov.uk/research/eoiresearchprogconsort260504.asp [accessed 12th January 2009]).

There is an enormous difference between the DFID criteria for research consortia and for the DisabilityKar criteria, and it is not really fair to compare them directly as the purposes of the calls for work were of very different magnitudes. It is also almost certainly the case that in the DisabilityKar assessment these types of considerations were brought to bear – they must be implicit in any research procurement process. But the fact that they were not formally part of the process is instructive and important, and indicative, I believe, of a broader trend in disability research. Central to much of how we see disability research these days, including in lower-income contexts, are the two key issues of identity and participation. There is a strong belief that it matters whether the person doing the research is disabled or not, and it matters who participates in research processes and who does not.

It cannot be stressed strongly enough how important these twin issues of identity and participation are, indeed, to contemporary disability research, but where matters become fuzzy is that these issues are by no means unique to disability research. At the heart of the social model of disability as a whole is the belief that disabled people must be centre stage, defining the agenda, on all issues to do with promoting the rights of disabled people. This should apply no less to disability research, and indeed, the chapter by Mji and colleagues in this volume (Chap. 5) emphasizes very clearly the importance of process and identity issues to building credible and viable disability research networks. Solidarity, self-representation, and speaking with one voice are all crucial aspects of developing networks of any kind, especially for oppressed groups. The problem though is that research requires something else as well, and this is the ability to be sceptical about data, and to allow data to change one's mind.

6.4 An Example of Research Capacity Development Issues

The easiest way to explicate both the advantages provided by and the challenges raised by a particular form of emancipatory disability politics for research capacity development in lower-income countries is by way of example. I have been fortunate to be involved in a number of disability research capacity initiatives.

My experience with a very strong DPO network in southern Africa at first pleasantly surprised me, though in retrospect I should not have been surprised. My work was with a group of highly experienced and articulate activists who are accustomed to daily struggles of living, often in contexts of great poverty. A fairly senior person in the organization, for example, feels rather lucky to live in an apartment in an African capital city, but every day she has to be carried up and down the stairs to her apartment, as the only building in which she can find a place to live is inaccessible to wheelchair users like herself. Other struggles include those of discrimination and overt disavowal by some able-bodied compatriots. It may be difficult for disabled people (or any people) in wealthier country contexts where there is some accommodation in the physical environments and where disability rights are protected in a context of overall good governance to grasp fully what many disabled people in poorer countries still live with – a combination of lack of resources, ignorance, stigma and discrimination. There are some encouraging signs that things are changing in many contexts, but the core point I wish to make here is that as a colleague and I began research capacity training with this particular network, there was no question that we were working with people who viscerally understood what it means to be excluded and not to have one's needs met, to be viewed as an outsider and even at times to be feared and avoided.

I have considerable experience of teaching research issues to university students from relatively privileged backgrounds, and with good academic histories. In this group of activists, some had tertiary education but many had not completed high school. One might have anticipated that this group, therefore, far less academically prepared than my students, would struggle more than my students with basic research concepts. Though to some extent this was true with technical concepts, it was not so with what may be regarded as one of the fundamentals of research-mindedness. In order to be a researcher and to understand the research process, one has to be able to question things, to "make strange," as the anthropologists put it, aspects of life and the world which are commonly taken for granted. Many of my students, well schooled to give "right" answers, or the answers their teachers want, in examinations, struggle with the fundamental spirit of non-acceptance – indeed, of enquiry – that makes a good researcher. They are often authoritarian about their sources, believing that if something appears in a book, it is their job to be able to memorize this and to repeat what the author has said. This lack of research-mindedness, lack of understanding of the scepticism that is at the heart of much good research, is a common phenomenon, discussed by many commentators in the higher education field (Stanovich, 2007).

This problem of lack of research-mindedness that I experience with my students was largely absent in this group of disabled activists. Why? I believe that because the group with whom my colleague and I were working were accustomed to being unfairly forced to the periphery in society, because they dealt with having to question taken for granted assumptions about disability day after day, they already had considerable experience of what is for me at the core of being a researcher – the ability to question things. There may of course be a range of other explanations for what I observed, but it is certainly the case that a group of experienced disability activists, most of whom had no research training, were easily able to grasp some key concepts of what research is and does – and that they had been applying these long before my colleague and I were there to "teach" them.

There were many other encouraging features of this particular training group. As is suggested in the literature (and, indeed, this is one of the DisabilityKar criteria, as mentioned above, though our work was not part of DisabilityKar) we used a number of participatory techniques to build research capacity. Though this is not often discussed, many participatory techniques are heavily visually loaded, requiring people to draw, to make charts and so on.[2]

One of the exercises we wished to do with our research trainees was a community mapping exercise which would assist the participants, who came from a number of different countries and contexts, both to think systematically about researchable issues in their own communities and to communicate these in an accessible way to their fellow-participants. We planned carefully for a more accessible version of community mapping for participants who were blind or had severe visual impairments, making use of story telling. After the exercise was complete and we were discussing it in the larger group, one of the blind participants said what to us was a surprising thing: "Don't be so sure," he said, "that blind people don't know about what places look like. In fact we are the best geographers." All the blind people in the group

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[2] The very useful "TOOLS TOGETHER NOW! 100 participatory tools to mobilize communities for HIV/AIDS" put together by the Aids Alliance and downloadable for free from www.aidsalliance.org, for example, is a treasure-trove of participatory techniques useful for any training and not just in the AIDS field. Many of the wonderful techniques included in this manual depend heavily on visual materials.

immediately knew what he meant and a lively discussion developed on this topic. Blind participants pointed out that they all live in inhospitable environments, where there is poor road upkeep, where traffic is heavy and often very fast, where there are no pedestrian crossings which indicate it is safe to walk by the sounding of a bell, where people live and trade on pavements which were designed for pedestrians but no longer serve that function, or they live in rural areas where there are no tarred roads and it can be muddy, with pathways barely accessible. As a result of this, they are acutely aware of the physical environment, of how many steps it takes to go here or there, of road surfaces changing, of where it is (comparatively) safe to cross a road. The blind participants were amused to tell the rest of the group that whenever they get together, they discuss the physical environment in great detail and that they know more, therefore, about what places look like than the rest of us do!

This discussion in our workshop helped re-emphasize the important contribution of the social model to all aspects of disability work – if we create an environment in which people can draw on multiple knowledges, we will find useful and sometimes surprising positive outcomes. Any project which would have viewed these blind participants as objects of study and looked at them only from the outside would probably not have learnt what we all as a group learnt on that day. There is no question from this experience and many others that a participatory approach which draws on existing knowledge is a very helpful one – part of the job of the person involved in building research capacity is simply to help participants find out the ways in which they are already researchers.

Though this point is clearly true, another aspect of that training workshop illustrates some of the challenges we face in participatory research capacity development processes. After a few days of good, hard work on basic research principles, I was facilitating a session close to the end of this particular process on systematic collection of data. First, we just went round the room and asked for some basic demographic information by which people identified themselves. We captured these data on a grid, and we played around with organizing the material according to different categories – for example, we could divide the group by gender, by country of origin, by current home country, by impairment type, and so on. For the next stage of the work I wanted to introduce the participants to the basics of organizing material according to categories developed by the researcher – categories inferred from data. As it was important in any event to get some feedback from participants about their experience of the workshop, I asked them to fill in a feedback form and then as a group we would categorize the responses. The form was designed in such a way as to introduce participants to what can and cannot be learned from asking questions in a range of ways (e.g., open/closed questions, forced choice answers, etc.).

When I looked over the forms over the tea break prior to our session analyzing the data, I could see that I would have a problem with our data categorization session. The responses were uniformly positive and I would not have a range of responses easy to differentiate from one another. I should have anticipated this, as responses to workshops are commonly very positive at the time, but in the interests of building capacity about data categorization I slipped in a dummy feedback sheet that was very negative about the work we had done. We went through the responses and

I slipped in the "dummy" negative response approximately two-thirds down. When we reached this response the initial reaction from some group members was that there must be a mistake – the data must be wrong. A senior member of the group, clearly embarrassed at what he feared my colleague and I might experience as a slur on our good work, said, "We must find this person and we must discipline – he cannot be allowed to say this thing!"

We were able to use this response to discuss the nature of research and to make the point that whatever our data we cannot simply ignore data which do not fit in with what we would like our data to be. We were able to talk about the difference between the dictates of unity in activism and the fundamental research principle that there is no point in collecting any data at all if that data will not have the potential to change your views. What we did not discuss, I realize in retrospect, was the degree to which the reactions to the negative response – widespread disbelief, followed by a threat of "discipline" from a senior member of the organization to the participant who was out of line – could help us to think about the question of response set and validity of data. There was clearly a strong ethos in this group that the facilitators must be treated with kindness, and we were treated with kindness. Given this ethos, though, we must call into question the validity of the uniformly positive feedback. It is conceivable that all participants did in fact enjoy and value the training (we did, in fact, gain this impression) but in terms of developing a more nuanced understanding of the value of our work and its pitfalls, another method of collecting feedback would be required. Had we had time we would have discussed this more with participants, and there will be other opportunities for this discussion. The point for the current argument, though, is a more serious and far-reaching one, and I shall discuss this in the following section.[3]

6.5 Research Capacity and the Knowledge Management Challenge

What can we learn from the fact that in a relatively research-naïve group, and a very polite and supportive group, people were uncomfortable with negative feedback on a research capacity workshop that they themselves had probably experienced as positive? In one sense, very little – people are polite, they like to stand together, and they value input from researchers committed to helping them. There is another sense though in which our experience from this workshop, and especially the comment that the (bogus) dissenter needed to be "disciplined," reveals a deeper challenge for research capacity building for disability research in lower-income contexts.

One of the key achievements of the disability rights movement has been that disabled people have stood together and have convinced others, many of whom

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[3] We did in fact reveal to participants that we had constructed a bogus response and we did have a discussion about how researchers may report on data where there are outliers, but this discussion is not germane to the present argument.

have no interest in disability issues, and in fact may even hold prejudices against disabled people, that the collective voice of disabled people cannot be ignored. International agencies have responded to this collective action. The DisabilityKar initiative has been one of a host of initiatives which have correctly emphasized two key points central to international development: first, that disability issues are in fact core to the reaching of development goals (see, for example, Albert, 2004) and second, that a core value which should underlie the mainstreaming of disability is the full participation of disabled people in processes which affect their own lives.

One of the places where these two incontrovertible values become more complex, though, is precisely in the area of disability research. Critiques of mainstream approaches to research in general and disability research in particular are commonly well put (Oliver, 1995) but particularly in the context of poorer countries there is a serious danger of a basic principle of research being overlooked. Sophisticated critiques of crude empiricism, some of which come from the disability studies field itself, correctly point out that data do not exist "out there" and that there are commonly many interpretations of the same data (Denzin and Lincoln, 2007), but making this claim is not the same as claiming that data do not matter at all.

Many disabled people in lower-income contexts who have the ability to develop substantial research skills are unaccustomed to thinking about the importance of data as a source of information that can change one's views on the world. There are two obvious reasons for this. First, many of these people, though they have excellent research potential, as I have argued, have had relatively little education, and/or have been schooled in rather authoritarian education systems, where the authority of the "expert" is privileged over a robust engagement with issues. Second, many people (most people in the world, in fact) live in circumstances where governance and policy decisions are made not on the basis of data and information but on the basis of the relative power of different groups of people (see Chalklen et al., 2006, for a discussion of the implications of this for the African Decade on Disability). Data-driven policy making is in fact quite rare internationally. When we take these two factors into account, it is not surprising that a senior participant in our research capacity workshop wanted to "discipline" a view which potentially could be seen to undermine a group view. The issues at stake in our workshop were, in the grand scheme of things, trivial, but they point to much more far-reaching questions about what disability research is and does in lower-income contexts.

It is hardly surprising, nor is it inappropriate, that calls for more disability-related research in lower-income countries tend to be couched in pragmatic terms (Turmusani, 2003) – we need to change policies and practices which affect the lives of disabled people world-wide. Nor is it a problem, as we have seen with the DisabilityKar criteria mentioned earlier, that there should be such a strong emphasis on participation by disabled people in research processes. But there is something that may be obscured in the confluence of these trends towards pragmatism and participation in disability research in lower-income countries. This is simply the need for good knowledge management as a fundamental prerequisite for research endeavors, and the understanding that data, even crude data, do matter.

Once again, an example will well illustrate the issue at stake, an issue which if ignored can leave unchallenged calls for "disciplining" or ignoring information which does not immediately or obviously fit a collective or emancipatory agenda. Some time ago, a colleague and I were interested in finding out what policies DPOs in South Africa had, or did not have, regarding HIV/AIDS (see Rohleder et al., 2009). As a first step we approached the Office on the Status of Disabled Persons (OSDP), which is a government office and resides in the highest echelon of government in the land, the Presidency, to give us a list of DPOs and organizations serving disabled people. The OSDP did not have this information, but gave us a list they themselves believed to be inaccurate and outdated. We approached government departments, who were similarly unable to help. National DPOs also did not have up-to-date lists available and were often able to supply us with outdated lists provided by consultants at some time in the past.

Clearly, all these groups – government departments and national DPOs – were able to conduct their business in the absence of up-to-date information even on formal organizations with whom they are mandated to consult. At another level, I have worked with many DPOs and other organizations that are not able to give me any estimation of the number of people they serve. Records are simply not kept and are certainly not maintained. Forms that have been devised by the organizations themselves or by consultants may be filled out, but data are not collated and are not kept up to date. When I have questioned colleagues from DPOs about this issue, they are often very articulate, and correctly so, about how difficult it is to define disability, how data may change over time, and about the dangers of labeling. All these issues are valid and very important, especially for disabled people, who have for so long been the victims of oppressive and crude forms of data gathering. It is encouraging, furthermore, to hear from the sceptical answers about data how successful the disability movement has been in sensitizing its members to the politics of knowledge – a key issue for anybody concerned with realizing the rights of excluded groups who have been the objects of oppressive study and bureaucracy. But there is a world of difference between knowing that data are subject to political influence and are difficult to collect in meaningful ways, to not having systems of data collection at all. It is important that an organization that collects complex information is aware of the complexity of that information and the limits to its validity; this does not, however, lead to the conclusion that there is no point to data collection at all.

This issue links to the question of research capacity development in two ways. First, as we have seen, the success of the critical edge of the social model of disability in alerting disabled people to the politics of disability knowledge may have had, as a partial consequence, a situation in which the old authority of the able-bodied "experts" has been replaced by a new authority of the disability activists. This can be seen not only in the example I have given from our capacity-building workshop but also from numerous other experiences where research data (whether produced by able-bodied or disabled people) are simply rejected as not true in participatory meetings. In South Africa, in this regard, it is not uncommon to hear people claiming that the data we have on disability prevalence "must be wrong" because people feel there must be more disabled people than the statistics say, but without any discussion or engagement with the methods by which statistics are generated and collated. Though in terms of empowerment of disabled people it is an important victory that disabled people feel confident to question dominant knowledges (including statistics collected by governments and other agencies), this is not enough. Disabled people need to be able to engage with issues of method and to do more than to offer broad brushstroke critiques, critiques that are fundamental but once established have limited capacity to facilitate change.

This point leads to the second issue about data and research capacity development. If we are serious about capacitating disabled people's organizations in lower-income contexts to take charge of research processes, there is a danger that we have begun this process taking insufficient account of the current knowledge management context of many such organizations. On the one hand, a sophisticated critique of oppression of disabled people is in place; on the other, many DPOs do not have a tradition of collecting data (however mindful we may be of the limitations of that data) in a systematic and sustained way. Calls for disability research in lower-income countries commonly focus on big questions on issues, for example, like HIV/AIDS, inclusive education and economic empowerment. All these issues, and many more, are indeed important.

But if DPOs continue to be involved in sophisticated and large-scale research in which data are collected in exemplary ways, and these research processes (often led or driven by consultants or international funders) are at odds with the day-to-day management of the DPOs themselves, the possibilities for research capacity to be developed and sustained in a meaningful way are much reduced. If research is seen as somehow separate from being systematic about knowledge within the day-to-day running of organizations, the opportunity will be lost to develop DPOs in the South optimally as "thinking organizations." The key issue for developing research capacity for DPOs may be less whether these DPOs can work with outsiders who have considerable research experience and infrastructure in producing research outputs (and there are some examples of excellent collaborations of this type in this book), than whether DPOs can be assisted to regard everything they do in the most mundane as producing knowledge and data. If, to use another example, DPOs in Zimbabwe had for many years been in the habit of collecting routine information on their members and on their work, it would now, with the tragic collapse of much infrastructure in that country, be possible to extract data, however limited but more than anecdotal, on trends in what Zimbabwe's political and humanitarian crisis means for disabled people in particular. DPOs in Zimbabwe have indeed been involved in research endeavors, and good ones, over the past 20 years and previously, but there are gaps in basic knowledge about information that is not very difficult to collect.

Increasingly, government and other agencies are asking for data to inform policy and practice, and though anecdotes are important, these have their limits in convincing people far from where difficulties occur to change how they do things. Capacity building in the disability research field has until now been successful as regards issues to do with the politics of participation and the politics of research knowledge. It has been less successful in developing ways in which basic information can be routinely collected by DPOs and in developing disciplined (but technically not very complex) ways of collating and interrogating data. The challenge for the future, if we are serious about sustainable capacity building, therefore, may be rather unglamorous. While the performance of participatory processes remains important, we should perhaps be focusing less at this stage on engagement with large-scale research projects than on developing knowledge management systems and cultures within DPOs. It is from this basis of manipulating everyday "mundane" knowledge that sustainable capacity in research data collection, management and interpretation can be built. It is not possible, in short, to separate research capacity development from the broader field of organizational knowledge management.

6.6 Concluding Comments

It is impossible to overstate the achievements political processes around disability have had in advancing the strength and sophistication of DPOs in lower-income countries. Paradoxically, though, the crucial and necessary emphasis on performative and participative aspects of involvement of disabled people in research processes may have obscured some fundamental challenges that now need to be taken forward. Part of the problem with these challenges for systems of knowledge management is that such systems look in many ways similar to systems of control by which disabled and other oppressed and colonized people have been excluded and reduced to ciphers within a politics of domination. It is important for us to understand why it is no mistake that many colonial governments were very good at record keeping, for example. What is important for the sustainable development of disability research in postcolonial contexts, however, is to go beyond critique to using some methods that may look embarrassingly unemancipatory, that involve sheets of information routinely collected, and not always collected through participatory workshops. Lorde (1984) famously said that "The master's tools will never dismantle the master's house" and she was correct in this. But if we wish to build a new house in a new order in which we control resources, we should not fear applying a range of tools that have formerly been denied to oppressed people. Without due attention to the development of basic skills and technical competencies, there is a real danger of the stagnation of the kind Shakespeare (2006) describes.

Participation and inclusion are key to realizing rights for disabled people. In the field of disability research, though, these are not nearly enough. Disability research is both less than and more than disability activism – disability research could not be where it is today without activist and participatory agendas. In lower-income countries where technical and knowledge management skills lag behind research-mindedness and political acumen, however, we need to address these lags. There are many ***knowledges, many ways of seeing the world, many worthwhile perspectives. This fact should lead us to the conclusion not only that we deserve a critique of dominant ***knowledges but also that disabled people have a right of access to as many tools for knowledge development as possible.

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Chapter 7
Empowerment, Advocacy and National Development Policy: A Case Study of Disabled Peoples' Organizations in Bolivia

Marianne Griffiths, Hasheem Mannan, and Malcolm MacLachlan

7.1 Introduction

This chapter describes the concepts of empowerment and advocacy and considers their relevance to promoting the inclusion of people with disabilities (PWD) in development policy. We begin by considering the "big picture" of development policy instruments, focusing on Poverty Reduction Strategy Papers (PRSPs) as an ultimate target for the inclusion of disability on the development agenda. We then consider some pertinent theory concerning empowerment and advocacy. Next we look at what actually happens, on the ground, by presenting a case study of disability advocacy and empowerment activity by disabled peoples' organizations (DPOs) in La Paz, Bolivia. There are considerable challenges in moving from valuable but often opportunistic and unstructured local advocacy and empowerment initiatives to less immediately rewarding inclusion in national development policy instruments. In considering what policy rhetoric says, what theory suggests and what happens in practice, our fundamental concern is with how to link daily localized advocacy activities of DPOs to longer-term strategic interests of inclusive national development.

The issue of disability is one of great importance within the development context. People with disabilities make up 10% of the world's poorest people, about 650 million in total (WHO, 2005). If this 10% of the world's population, "including an estimated 400 million disabled people living in the developing world" (400 Million R, 2008) all lived in the same place they would make up the third-largest country on earth, a country about the same size as the European Union. Despite these statistics, people with disabilities are frequently ignored by policy makers and public health programmes. The Millennium Development Goals, agreed by world leaders in 2000, do not specifically mention disability; however this is an issue that affects each and every one of the existing goals (Lynn, 2007). In order to achieve the Millennium Development Goals it is imperative to address the issues of disability in low-income countries. Within this context it needs to be highlighted that during the launch of the

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MDGs there was not a standardized measure available on disability. In contrast, the health-related MDGs are monitored using an internationally harmonized and standardized measure, i.e. mortality rates. Most importantly, the need to address the issue of disability within the development agenda through international cooperation is now enshrined in international law, through the UN Convention on the Rights of Persons with Disabilities (UNCRPD,2007). While the Convention gives greater weight to moral and humanitarian arguments for the increased participation of persons with disabilities (PWD) in society, there is also a strong economic argument: not only are PWDs massively overrepresented amongst the poorest in developing countries, but they also constitute a valuable resource for economic growth, if their economic potential can be unlocked.

7.2 Disability on the Development Agenda and National Development Plans

The World Bank has contributed significantly to putting disability on the development radar due to its recognition of the double imperative – human rights and economic potential – in the context of the MDG(s). The MDGs prioritize poverty reduction in developing countries and are targets for galvanizing countries and communities into action but they do not set out strategies for achieving these goals or targets. Translating them into action requires an operational framework at the national level. In more than 70 low-income countries, this operational framework is increasingly being provided by a country-led process of developing "Poverty Reduction Strategy Papers" (PRSPs). The World Bank and International Monetary Fund have established various aid instruments to contribute to this. PRSPs, are one such instrument, and these enable countries to obtain debt relief and to access World Bank/IMF credits. PRSPs have become the main multi-lateral mechanisms for providing development aid to the world's poorest countries. In effect, they are national plans to reduce poverty. The idea is that a variety of stakeholders participate in the drawing up of the paper, with the paper reflecting stakeholder consensus and outlining priority actions to be taken.

PRSPs should outline the process that led to the formation of the PRSP; outline the poverty profile of the country; set targets and priorities within the proposed policy measures; and provide a plan for monitoring and evaluation. In designing PRSPs individual countries incorporate those aspects of the MDGs that fit their own situations and reflect the aspirations of a broad range of the country's citizens. After several cycles of PRSPs there is, however, scant evidence of disability being meaningfully incorporated into national plans. Where disability has been included in the PRSP processes, this inclusion has tended to revolve around the concept of charity; however where DPOs have been involved, the inclusion of disability has referred instead to education, training, employment, and to broader participation as well as access to services (Handicap International, 2006). Nonetheless, in some African countries disability has a higher profile than in others, including Ministries specifically addressed to disability issues. However, even where this is the case, disability has not necessarily permeated into PRSPs in a satisfactory way. In some situations Disabled People's Organizations (DPOs), whose participation in the PRSP consultation may have served to legitimize the process, have been frustrated by little or no subsequent inclusion of disability in the resulting PRSP (Dube, 2006). Elsewhere this consultative process has not even been undertaken or considered.

The PRSP process is meant to be country-driven and country-owned, results-orientated, comprehensive, partnership-orientated, based on a medium and long-term perspective, and have participation of a broad range of stakeholders (World Bank, 2008). The PRSP is not an isolated tool, but rather linked to other national and international strategies and policies (for instance, Sector Wide Approaches and Sector Investment Programmes – SWAPs & SIPs). The PRSP is now in use in over 70 countries (Handicap International, 2006). Unfortunately, disability issues have, on the whole, been poorly served by PRSPs (Dube, 2006). This raises the question of whether empowerment of persons with disabilities, and their representative organizations, and their role in advocacy, actually enables disability issues to be adequately and appropriately addressed.

7.3 Empowerment and Advocacy

We believe that in our efforts towards getting disability on the development agenda, two key elements should be addressed: the empowerment of persons with disabilities, and the strengthening of their role and the role of DPOs in advocacy. Empowerment is an imprecise concept; as explained by Rappaport (1985), the absence of empowerment is easy to notice but its presence is difficult to define. This is due to the fact that empowerment takes different forms in different contexts. Although many interpretations exist, the one we will adopt for the present purposes is that empowerment is: "a multi dimensional social process that helps people to gain control over their own lives" (Page and Czuba, 1999, p. 2). These authors correctly identify that in order to understand "empowerment" it is necessary to gain an insight into "power". Fasil et al. (2004) differentiate between structuralist and human agency approaches to power. The structuralist approach explains that powerlessness is a consequence of structural inequalities. Empowerment arises when the social, economic and institutional barriers that restrict individuals and communities from achieving their full potential are dismantled (ibid.). The human agency view of empowerment focuses upon the individual's capacity to act consciously and autonomously. This approach offers potential for immediate change on an individual basis. We believe that, in many instances, empowerment arises through a reciprocally reinforcing and virtuous circle between enabling structures and beliefs in personal efficacy.

As most people with disabilities in low-income countries find themselves in situations of disadvantage (DFID, 2000), empowerment has a role to play in order to reduce poverty and improve quality of life. Stressing personal agency, Stainton (2005, p. 291) defines empowerment as "enhancing, securing and/or legitimizing the power of oneself, another or of a collective", and sees the main aspect of empowerment being capacity. The first element of capacity is to support the choice-making process. It is not the choice itself that matters, he argues, but that people with disabilities have the tools to make that choice for themselves. Stainton sees the second element of empowerment as the ability to act on the choices available. Telling someone that they are free to attend a mainstream school but failing to provide them with the means to act on such a choice is not a choice at all (ibid.). Stressing structural issues, Ramcharan (2005, p. 283) argues that "empowerment in everyday life cannot happen unless the structures and institutions of civil society are themselves empowering rather that constraining". Both the personal agency and structural perspectives may be needed if we wish to advocate effectively for human rights.

The World Health Organization defines advocacy as "simply the process of influencing people to create change. Its lifeblood is good strategic communication – educating people about a need and mobilizing them to meet it" (2006, p. 17). McColl and Boyce (2003) describe disability organizations as having a purpose of service provision or advocacy. Their research found that most organizations began primarily for the purpose of providing a service to their members; others existed with a mandate to advocate for their members, while some groups provided a mixture of both service provision and advocacy. Some organizations were formed with a single mission in mind, whereas others dealt with a broad range of issues including (the five they identified as being most important) housing, education, employment, transportation and human rights. Other groups advocated more on philosophical or theoretical issues with the purpose of creating an inclusive environment for people with disabilities. McColl and Boyce also highlighted two important themes for DPOs: one concerned organizational tactics, cooperative or confrontational; the other how a group views those it represents as members of, or as recipients of, a service.

Newbigging and McKeown (2007) explain that advocacy is open to the criticism that it is poorly defined and lacks a theoretical basis. They claim that advocacy is "usually thought of as a process or intervention that ensures that vulnerable people have a voice within services characterized by power inequalities between providers and users". Atkinson (2000) identifies four key *elements* of advocacy: (1) empowerment (ideally people speak for themselves), (2) promotion of autonomy (enabling people to have control in their lives), (3) citizenship (ensuring rights and entitlements are met), and (4) social inclusion (addressing the exclusion of people who are marginalized in society).

Carlisle (2000) outlines four different *types* of advocacy:

1. *Representational advocacy* operates at the level of individual cases and may have traditionally prescriptive goals or represent the rights and needs of those unable to speak out for themselves.
2. *Community development*, with goals of participation and empowerment, tends to focus more on enablement rather than protection.

3. *Community activism* moves beyond facilitating communities to take enabling action, towards encouraging individuals and groups to challenge the causes of poor health more directly at policy-making level.
4. *Social policy reform* occurs where the advocate or advocacy organization has some degree of “expert” knowledge and seeks to redress health inequalities at the level of social structure. The goal of this type of advocacy is to influence governments and large organizations in order to change their policies and practices.

Although the aim of each strategy may not be explicitly to engage in advocacy, one or several of these practices may be engaged in by an organization while they simultaneously are providing a service or information to, or representing, people with disabilities.

It will be obvious from the above that advocacy and empowerment are related, and that both conceptualizations and practices of these often do, and perhaps should, overlap. While the intellectual distinction between these activities is not without practical importance for achieving impact and change in the real lives of PWD, we now consider in more detail how organizations concerned with disability actually engage in and understand these types of activities. We consider the specific example of disability advocacy in Bolivia, where there is a scarcity of research on such issues.

7.4 Disability Advocacy in Bolivia

In this section we present an exploration of the utilization of advocacy and empowerment strategies among a variety of organizations concerned with PWD in La Paz, Bolivia, including governmental and non-governmental organizations (see Griffiths, 2008, for a fuller account). Bolivia is one of Latin America’s poorest countries. It has a population of 9.2 million people and an infant mortality rate of 49 deaths per 1,000 live births. Life expectancy at birth is 66.53 years (CIA, 2008). In 2006 almost 40% of the population were living in extreme poverty and the average annual income per capita was 1,153.00 USD. According to the World Bank (2008), currently 65% of the Bolivian population lives in poverty. According to the Instituto Nacional de Estadística (National Institute for Statistics), the city of La Paz has a population of 839,168 inhabitants. Using semi-structured interviews with key informants, Griffiths (2008) gained some insight into the issues that affect people with disabilities in La Paz. Participants were all decision makers from a variety of civil society and government organizations working with PWDs. Table 7.1 summarizes the advocacy actions that were described by the participants as having been undertaken in Bolivia (see also Griffiths et al., 2009, for a qualitative analysis of the key informant interviews that identified these actions).

It is noteworthy that none of those interviewed explicitly mentioned “advocacy” as one of their organizations’ roles; nonetheless a wide range of advocacy-related actions were identified and are discussed below.

Table 7.1 Advocacy actions undertaken in Bolivia

Advocacy action	Example
Workshops	
(a) General skills training	Self-esteem and leadership
(b) Specific themes	Inclusive education and disability prevention
(c) Work-related skills training	To train people with disabilities in practical work-related skills to enhance their employability
Letter writing and lobbying	Contacting relevant authorities to make positive changes for and defend the rights of people with disabilities
Production of printed materials	To change the society's opinions of people with disabilities and to make people with disabilities aware of their rights
Cinema series	To show the reality of life as a person with a disability and raise awareness of the issue
Billboard campaign	Showing people with disabilities in a positive light
Meetings	To allow information exchange and give people with disabilities opportunities to self-advocate
Young leaders	Providing young people with the skills to advocate for themselves and their peers
Festivals and fund-raising activities	To raise awareness around disability and change societal attitudes

7.5 Influencing People to Create Change

The aims of these actions varied but the main ones were to sensitize Bolivian society regarding disability and to improve conditions for PWDs. The main issues that the disability movement advocated for were similar to those outlined by McColl and Boyce (2003): education, employment, human rights, transportation and housing. The achievement of improved conditions for people with disabilities regarding each of these was considered to be a source of empowerment. Advocacy actions (lobbying, education around the topic, publicity) were necessary to bring about this change. Within the Carlisle model of four different types of advocacy, it was evident that at least one of each of the groups interviewed fitted into each of the types involved. Most participants felt that a lack of resources prevented them from carrying out further advocacy actions, this is perhaps understandable given the fact that pure advocacy actions were not a major aim of any of the groups involved. It emerged during the course of the interviews that other issues, seen as more pressing, such as work and education, were much more likely to receive scarce resources. Nonetheless, most participants reported that they wished to see a change in society's attitude towards people with disabilities and acknowledged the part that advocacy actions played in this.

Each of the respondents undertook some advocacy actions but the lack of resources meant that large-scale long-term advocacy campaigns do not exist. Some groups and organizations worked together in order to change perceptions around disability, however poster campaigns and cinema seasons that operated on a city level only lasted a short time (several weeks). Only one organization incorporated "social political advocacy" into regular activities; this sought to make changes and improvements at a community level. In all, it seemed that communication between groups representing people with disabilities and government organizations was quite open. Regular meetings, the existence of the disability network and a willingness of the parties involved to take on board the opinions of their colleagues meant that information was communicated and exchanged with ease. Within the disability network, most members acknowledged that it was easier to achieve their objectives by working within a network in a collaborative manner.

7.5.1 Government as an Agent of Change

The government plays an important role in advocacy and it was usually the case that civil society groups attempted to influence the government in order to create change. Due to the fact that civil society groups have very limited resources in Bolivia, they frequently looked to the government as the only authority with the means to provide real and lasting change. The government also has a responsibility to empower it's disabled citizens by reducing the barriers that exist and enabling them to make choices and act on these choices accordingly. While participants were not directly critical of government under-funding of disability services, there was a lot of criticism regarding the fact that the most recent laws had not been enforced. The existence of the laws was viewed as a positive step. Government Decree 27477 explicitly states that 4% of the employees of public institutions should be people with disabilities. The reality seems to be far from this. Part of the reason that this law is not enforced is due to the fact that there is no authority with coercive powers to enforce it. CONALPEDIS (Comité Nacional de la Persona con Discapacidad/ National Committee for Persons with Disabilities) can demand that a public institution grant employment to a certain number of people with disabilities, but cannot fine or impose legal penalties on an organization that does not comply with the rules.

The situation within the private sector was considered to be even more difficult. There are no obligations for businesses or academic institutions to employ people with disabilities. Consequently it appears very difficult for disabled people to obtain employment in the private sector. As explained by various respondents, the attitude of business owners towards the employment of people with disabilities is extremely negative. A large part of the Bolivian economy is based on the informal market, the nature of which would make any sort of quota regarding the employment of people with disabilities impossible. While certain programmes do exist to implement the laws within the public sector, evidence from the ground suggests they are not hugely effective. The respondents who informed the authors of these successes worked for each of these authorities; none of the respondents from civil society groups referred to such successes. One positive action taken by the government, however, was to train a small number of people with disabilities in vocational skills such as plumbing and carpentry.

The government received criticism regarding the recent project of registering people with disabilities. This was considered to be a waste of time by one respondent. It was also viewed as divisive and perhaps contributing to discrimination against people with disabilities by highlighting the differences between disabled and non-disabled people. The mother of a young Bolivian man with an intellectual disability explained that he did not want to "register as disabled" as it would immediately make him more visible and thus more marginalized within society. Some channels do indeed exist to enable civil society groups representing people with disabilities to communicate their wishes, the most important of these being the Municipal Units established by CONALPEDIS (although only 30% of municipalities have these up and running at present) and the Vice Ministry for Coordination of Social Movements. Despite the existence of these authorities, anecdotal evidence would suggest that little actually changes as a result of the needs that are communicated.

There seems to be no lack of will to improve things and to listen to the needs of the people. However, it is the inability to turn requests and suggestions into actions at a government level that appears to prevent these actions from becoming a reality. Despite this, it is important to highlight the actions of the civil society groups themselves in changing attitudes, improving services and advocating on behalf of people with disabilities.

7.6 Means of Empowerment: Education and Employment

The theme of empowerment, helping people to gain control over their own lives, was presented by the participants in several ways. The principal methods of empowerment addressed were those of education and employment. The issue of education was viewed as the most important by parents of children with disabilities. Educating children with disabilities was considered to empower them to change their lives in the future, to allow them to gain an understanding of living within a society and to integrate them into the community. Inclusive education was seen as the ultimate goal. Opinions on how this should be attained were rarely expressed and respondents with experience of the education system seemed to acknowledge that a certain amount of training and resources are necessary in order to integrate children with disabilities into educational establishments. Inclusion has largely replaced the use of the word "integration" and in fact represents a different concept. While integration may be seen as the child adapting to the setting (normally a school), inclusion refers to the school or organization adapting to the needs of the students or potential members (Lindsay, 2007).

Eleweke and Rodda (2002) cite a number of authors explaining that the rationale behind inclusion is to give a child with a disability the opportunity to learn how to cope in the "real world" by learning to adapt to school at an early age. The authors echo the sentiments of one study respondent reporting that for inclusive education to work in a meaningful fashion the diverse needs of the students must be met. Programmes to make this possible must be put in place, barriers to accessing schools and universities must be removed and other students and their parents should be educated on the importance of inclusive education. These authors explain that inadequate facilities and services, a lack of teacher training programmes and few relevant materials make this difficult to achieve in any relatively poor country.

In order to become empowered, the issue of work was considered to be extremely important by all of the discussants. The fact that it was so difficult for people with disabilities to find employment was considered disempowering. The fear of not being able to cover basic living costs and the inability to support one's family fed into the desire for increased employment opportunities. Empowerment of the disability movement is difficult if people with disabilities constantly live in poverty.

In order to achieve this, integration into the workplace is of paramount importance. This issue becomes doubly important when viewed in the context of political changes. The proposed provision of social security payments to people with disabilities is much debated. All participants working for civil society organizations were against the provision of such payments stating that this would only add to the isolation of people with disabilities, preferring instead the more empowering possibility of increased employment opportunities.

7.7 Barrier Removal as Empowerment

The "social, economic and institutional barriers" (Fasil et al., 2004) that restrict individuals from achieving their full potential were addressed on various levels. At the most basic level, the attitude of Bolivian society to disability can be considered to be a social barrier. Similarly, the lack of unity and sense of mistrust that exist in the disability movement can also be considered as a social barrier. Participants reported that a huge amount of stigma exists around having a disability and being the parent of a person with a disability in Bolivia. Local myths and folklore have added to this stigma, and to a tradition of hiding people with disabilities away. Service provision in isolating institutions has meant that society has not had a chance to accept and integrate its people with disabilities. The strength of this attitude is such that it prevents many people with disabilities from reaching their full potential in the workplace, in education and in living full and happy lives. Advocacy was seen as having an important role to play in changing this culture. Improving society's attitude to disability would empower people with disabilities, reduce discrimination and allow them the same choices as people without disabilities.

The culture of the disability movement itself plays a role in the effectiveness of advocacy for and empowerment of PWDs. A culture of negative attitudes towards the disability community has contributed to feelings of suspicion of change and of "outsiders" (non-disabled people). It seems that the societal "victim" label given to people with disabilities has been internalized and that developing the confidence and the abilities to change things for the better will take work and effort; this is not something that will happen easily for many people. A lack of unity in the disability community was also evident. Bickenbach et al. (1999) outline some differences amongst PWDs, which arise as a result of a lack of commonality of experience, between people with very varied disabilities. Thus there is no unifying culture or experiences that people with disabilities share, perhaps unlike other minority groups.

A lack of resources allocated to disability can be considered to be an economic barrier, often preventing people with disabilities from reaching their full potential and the theme of money was crosscutting throughout each of the other themes. This lack of resources was cited as a reason for inadequate programmes to integrate children into schools or adults into the workplace. Resources seemed to be over-stretched in every area and a lack of continuous funding from government sources meant that activities and coverage were frequently constricted as groups relied on fundraising to pay their bills. The Bolivian government, while committed to fighting poverty, finances many worthwhile causes including that of vulnerable children and extreme rural poverty. Although a priority, it must be understood that disability is just one of many causes deserving of scarce government resources.

7.8 Advocacy and Empowerment: Practical Uses in Disability Movement

Empowerment and advocacy have an important role to play in improving the quality of life of people with disabilities. The many laws that exist indicate that people with disabilities have a level of "legal" empowerment. However, it must be acknowledged that there are still limited mechanisms in place to ensure that they are "enabled". There are very few practical means available to make choices and actualize national plans by implementing actions. Stainton (2005) would not consider people with disabilities in La Paz to be empowered. These citizens with disabilities are lacking in power as the social, economic and institutional barriers that exist prevent them from achieving their full potential.

There is much scope for advocacy actions to improve this. Each of the types of advocacy outlined by Carlisle (2000) have the potential to improve things for people with disabilities in Bolivia: individual case advocacy, improved enablement on community development, challenging health inequalities and total social policy reform would all assist in empowering PWDs in La Paz. McColl and Boyce's (2003) study of Canadian disability organizations illustrated that the issues of education, employment and human rights are of huge importance to the disability movement in Canada as well as in Bolivia. They explain that with strong leadership, adequate human and financial resources and correct tactics an organization can successfully advocate for its members and change things accordingly.

As explained by Ramcharan "It is entirely possible for a multitude of empowerment practices to be implemented without empowerment being achieved" (2005, p. 283); this seems to be the case in Bolivia. If the aspired to "National Plan" is to be put into action then it is necessary to influence the government and non-government authorities to take action. It is only by influencing those with the necessary resources to put the plan into action that real and practical empowerment can become a reality for people with disabilities in La Paz.

7.9 Recommendations

PWDs, and organizations that represent them, should address empowerment, advocacy and inclusion in national policy development instruments, as distinct but overlapping and interlocking goals. This means that DPOs should articulate which of their activities are targeted at achieving which of these kinds of goals. The further development of networks or alliances (see also Mji et al., this volume) may be one means of collectively achieving this, although such collaboration can itself of course offer challenges (Forsyth and MacLachlan, 2008). Ultimately, however, each representative organization should be cognisant of what it is purposefully contributing to empowerment, advocacy and inclusion in national development instruments. Our case study of La Paz illustrates that, despite the fact that none of the agencies identified advocacy as one of their roles *per se*, there was considerable advocacy-related activity going on. Becoming more aware of this and thinking through how such activities can influence important development processes, such as PRSPs, is a critical step towards achieving greater social inclusion and participation for PWDs.

Understanding cultural attitudes towards disability is vital in order to foster real and lasting change and facilitate genuine empowerment. We need to understand the nature of stigma, prejudice and discrimination towards PWDs if they are to be meaningfully part of the design, drafting and implementation of the PRSP. Each country and culture is unique in its approach to disability (Groce, 1999). Social networks, family, friends and the community in which a PWD lives, each have an impact on their life; similarly myths and folklore surrounding disability may affect the success or failure of a PRSP, at least from the perspectives of PWDs.

While existing legislation may provide for 4% of the employees of public institutions to be PWDs it was noted that failure to abide by this cannot be penalized, and no such requirement exists among private employers. Legal empowerment that cannot be enforced, or enabled, is ultimately undermining of the rights of PWDs. This is just one of the areas where strong leadership is required, in this case, perhaps by several DPOs coming together undertaking targeted advocacy actions and perhaps even a legal class action providing a test case for public sector employment.

A common theme throughout the interviews reported above was a lack of human and financial resources to address the immediate and pressing needs of PWD. Clearly diverting scarce resources away from such needs, to try and influence government policy regarding the much broader issue of development, is questionable. It is, however, probably the case that unless collectively DPOs can contribute something to this cause, they may continue to be caught in a “poverty of resources” trap. Ultimately the enhancement of local resources may only be achieved in a meaningful and sustainable manner if the rights of PWD impact in a real way on the drawing up of development policy documents, such as PRSPs. This may require the direction of a modest level of resources, by many different organizations, to achieve this.

We would also call for greater use of evidence-based advocacy as well as recognition that good evidence alone is not enough and that many non-evidential factors also influence decision making in PRSP processes (see for instance African Policy on Disability and Development: www.medicine.tcd.ie/globalhealth/research/projects/aPODD.php. However, these non-evidential factors may well be susceptible to the results of well-coordinated and well-targeted advocacy campaigns, as well as learning from the experience of DPOs in other countries regarding PRSP inclusion and outcomes and the avoidance of pitfalls.

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Chapter 8
Cultural Challenges in Piloting Disability Surveys in Papua New Guinea

Patricia Thornton

8.1 Introduction

This is a reflexive account by a naïve researcher from the United Kingdom (UK) of the experience of piloting disability surveys in a developing country. I arrived in Papua New Guinea in July 2005 with long experience of disability-related social research but none in a developing country. In fact, I had never lived outside the UK. My task, as a Voluntary Service Overseas (VSO) volunteer, was to pilot survey methods as a first step towards establishing the prevalence of disability in Papua New Guinea, and to report within 12 months. While concerned about the likely mismatch between local conceptions of disability and internationally recognized definitions, about researching something that Papua New Guineans might not see as a priority or even as a problem and about scope for disabled people to take an active part in research production, I arrived with worries about how survey methodology might be made to work. The main problems I anticipated were reaching people to interview, dealing with aversion to taking part, communicating the purpose of the research, managing expectations of returns to participants, achieving informed consent and other familiar aspects of ethical social research. Many of these difficulties occurred and unsuspected problems arose. But what had barely crossed my mind was the possibility of difficulties with the field research personnel. Whilst I had realized that Papua New Guinea had no cohort of professional interviewers to employ, and I expected to train inexperienced local people, I had no idea of the extent of the challenge that interviewers would present in the research process.

The advantage of pilot studies in virgin territory is to report frankly on what works well and not so well. The originator of the project, a church organization promoting community-based rehabilitation services in Papua New Guinea, genuinely wanted to learn. Unlike in the policy-related social research environment I

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was used to back home, I felt no inhibitions in exploring what might turn out to be methodological failures. This chapter expands on the report I wrote with technical support from a Papua New Guinean research assistant (Thornton and Pirpir, 2008). The report was written as a "how to" guide for Papua New Guineans carrying out further disability surveys, including a template questionnaire developed in the pilot studies. Fully exploring the body of literature on conducting social research, and specifically disability research, in developing countries was impractical while on the job due to very poor internet connections and difficulties sourcing publications, and this chapter draws on literature I accessed after my return to the UK.

While some of the difficulties discussed in this chapter may apply to social survey research in many developing countries, others are peculiar to the Papua New Guinea context and a brief description of that follows. The chapter focuses on selected issues faced in the research process: deciding on a definition of disability; limitations on involvement of disabled people in research production; and cultural influences on the process, with particular reference to expectations of benefit and consequent effects on the quality of data collected.

8.2 The Papua New Guinea Context

Papua New Guinea is a young nation in the South Pacific, one of the last places in the world to come under colonial administration and to undergo decolonization. In the 1880s a permanent European presence was first established in coastal and island areas but inland highland dwellers had no contact with Europeans until the 1930s or later. Following Australian administration from the early twentieth century, independence came in 1975. Economically and in terms of social development, the post-independence years have seen mostly disappointing results. Economic growth has barely kept pace with population growth, despite rich natural resources and considerable external financial and practical assistance from Australia and other donors.

According to the UN Human Development Index, Papua New Guinea is now one of the poorest developing countries in terms of life expectancy, adult literacy, births attended by health professionals, number of physicians and access to safe water, with growing rates of HIV and TB. Deteriorating transport routes, grossly inadequate budgets, bureaucratic corruption and mal-administration block delivery of depleted health services. Corruption has worsened since independence, with Transparency International ranking Papua New Guinea as the 16th most corrupt out of 179 countries surveyed in 2007. The great majority of the population, 87%, lives on subsistence farming sometimes supplemented by cash cropping, forestry and fisheries. The formal employment sector is very small and stagnating. Crime and disorder is an ongoing problem: youth migrate to urban areas in search of scarce employment and fall into crime, and clan-based hostility erupts into open warfare, notably in highland regions.

Papua New Guinea is a diverse country. It has 800 or more languages, associated with tight-knit clan-based social groupings that protect their territories and cultures. While English is the language of education, Melanesian pidgin (Tok Pisin) is the *lingua franca* for people who have contacts outside of their home community. Tok Pisin is not much found in a written form, with the notable exception of the pidgin Bible that is disseminated through the work of the many missionaries and faith-based organizations that have led the great majority of the population to Christianity. Proclaimed Christianity goes hand-in-hand with supernatural beliefs, including beliefs about causes of impairment and illness.

8.3 Defining Disability

The first challenge for the project was reaching a consensus on the definition of disability to be used in the pilot surveys. Well prior to my arrival, in addition to VSO and the church-based promoter of community-based rehabilitation, representatives of one disability service organization, two research institutions, two university departments and two government departments had met to map out a research strategy. In their planning they had adopted a medical model of disability. This reflects the limited engagement in Papua New Guinea with concepts of disability. The definition in the national disability strategy is an uneasy compromise between paternalism and the WHO interactionist approach (adoption of the latter encouraged by UN regional advisers).

> Disability refers to people with special needs who require special attention, care and support in their families and communities, and encouragement to determine the full potential in life and refers to the needs created by the interaction between a person with an impairment and the environmental and attitudinal barriers he/she may face.
>
> (Department for Community Development, 2005, p8)

When, as a first step, I reviewed the limited literature reporting disability surveys in Papua New Guinea, I found a fair degree of conceptual and terminological muddle, and limited justification for the selection of the definitions adopted. These surveys variously asked about a mix of health conditions and impairments; impairments alone; impairments and activity limitations separately; activity limitations generally; a selected range of activity limitations; and a very narrow range of activity limitations. Only one work had collected additional data on participation restrictions, using the WHO categories then current of impairment, disability and handicap.

Not all members of the original planning group for the research project were fully familiar with the WHO use of “disability” as an umbrella term covering impairments, activity limitations and participation restrictions linked to a health condition. The concept of disability as a continuum was unfamiliar and dichotomous disabled/non-disabled and severe/mild categorizations were taken for granted. It seemed that disability was seen as an individual deficit rather than as a product of the environment in which one lives. Understandably in a country where much impairment is preventable, there was strong interest in the group in collecting data on health conditions and impairments to support the case for preventive and remedial interventions. Ambitious plans had already been mooted for teams specializing in different types of impairment and health conditions to advise and to support fieldwork, presumably to assist with diagnosis. I soon realized the impracticality of these plans. The specialists were scarce or almost non-existent, and in any case had many more pressing demands. The alternative of asking survey respondents to name their health condition was equally impossible in a country with five physicians per 100,000 population, where conditions are rarely diagnosed and people seldom use medical labels. Translation to and from Tok Pisin and indigenous languages would be a further barrier. Relying on unskilled fieldworkers to record impairments also would result in highly unreliable data.

The project steering group, put in place on my arrival, agreed that it was my role to review the plans so far and propose a manageable and coherent research strategy. They accepted a proposal to pilot questions on activity limitations, using a screening question derived from the ongoing development work of the Washington Group on Disability Statistics and employing a four-point scale of perceived difficulty for each activity from “no difficulty” to “cannot do at all”. The key point in support of this approach was that it is important for Papua New Guinea’s international standing that its disability data can be compared with that of other countries. Although not recommended by the Washington Group at that time, we also agreed to pilot interview questions on participation restrictions, tailored to the Papua New Guinea cultural context. Isolated from much of the internet-based literature, I did not realize at the time how courageous these decisions were and that a review of data and statistics on disability in developing countries (Eide and Loeb, 2005) was finding that screening in low-income countries to a large extent continued to be impairment-based.

The project did not want to lose sight of the original aim to understand causes of disability and it was considered useful to explore respondents’ perceptions of causes, including supernatural beliefs. Further question sets were developed to ask about service use, aids and adaptations used and unmet needs.

8.4 Outline of the Pilot Survey Methods

Table 8.1 outlines the methods of a series of three pilot surveys. Survey 1 involved asking informants in the rural highlands site to identify for interview people with one or more specified activity limitations. Here it had already been decided to use local community-based rehabilitation volunteers to interview the individuals listed. As discussed in Sect. 8.6 below, in practice some deviations from the plan were forced upon this pilot: community leaders also acted as interviewers; and self-referred people were also interviewed. Survey 2 tested an activity limitation screening question and a limited range of follow-up questions put to household

Table 8.1 Survey areas and methods

Site	Interviewers	Household data	Identification method	Data on people with difficulties
Survey 1 Rural Highlands Eastern Highlands Province	Local community-based rehabilitation volunteers Community leaders	None	Listed by local informants and Self-referral	Data from interviews with 495 people with difficulties • Socio-economic • Type, extent and duration of difficulty • Perceived causes • Help sought, aids used • Unmet need • Type and extent of participation restriction
Survey 2 Rural Coastal Madang Province	University students (non-local)	1,142 households 7,309 members Data from household representative: • Number in household • Socio-economic characteristics	Screening question to household representative	Analysis of data from household respondents on 2,153 household members with difficulties • Extent of difficulties overall • Type and duration of difficulty • Type and extent of participation restriction
Survey 3 Urban Highlands Eastern Highlands Province	Local community-based rehabilitation volunteers Selected community based rehabilitation volunteers from Survey 1 Local youth	940 households 5,717 members Data from household representative: • Number in household • Ages and sex	Screening question to household representative	Data from interviews with 722 people with difficulties • Socio-economic • Type, extent and duration of difficulty • Perceived causes • Help sought, aids used • Unmet need • Type and extent of participation restriction

representatives in a rural coastal site. Here the questions were “add-ons” to a survey of household wealth conducted by the Papua New Guinea Institute of Medical Research for James Cook University, with non-local university students as fieldworkers. My involvement in Survey 2 was limited to question design, interviewer training and analysis; that is, I had no supervision responsibilities in the survey site. Survey 3, in an urban highlands site, built on the previous two surveys. It used a slightly revised household screening question, followed up by interviews with household members identified as having activity limitations. Here the interviewers were a mix of well-performing interviewers brought in from Survey 1, local community-based rehabilitation volunteers and local unemployed youth. The data collected also are listed in Table 8.1.

Under the auspices of the project, two follow-up studies were carried out with sub-samples of respondents in Surveys 1 and 3. One follow-up qualitative study, not referred to further in this chapter, explored cultural aspects of disability. The other, carried out in conjunction with a university department of physiotherapy, focused on people with moving difficulties. Here physiotherapy students conducted the interviews, which conjoined qualitative and quantitative methods.

8.5 The Missing Role of Disabled People in the Research Process

My background in disability research in the UK, reinforced by VSO's pre-departure training, made me acutely aware of critiques of the traditional top-down research and development paradigm in which groups that are intended to benefit, such as disabled people, have no control or active role. In the UK, several research funders now specify involvement of disabled people in disability research so that disabled people participate as lead (co)researchers, advisers, fieldworkers, analysts and disseminators. Some funding bodies demand that disabled people or organizations of disabled people themselves have identified the agenda and control production. The disability movement advocates emancipatory research as opposed to participatory research.

At the time of the pilot surveys no platform for emancipatory research controlled by disabled people existed in Papua New Guinea. The emancipatory research model typically presumes that organizations of disabled people exist and desire control. In Papua New Guinea, organizations of disabled people at the time of the research were nascent and fragile, some brought into being via a few disabled individuals in touch with disabled people's movements and disability-aware funding organizations outside the country. Some province-wide organizations claimed scores of members but typically only a handful of office-holders met. A limited road and boat system, prohibitively expensive air travel and poor telecommunications thwarted a well-functioning nation-wide organization. Most effort went into establishing organizations with presidents, treasurers and so on, and into obtaining accreditation and funding to support the organization *per se*. Sustainability was a major problem as groups divided or collapsed through rivalry for status, financial mismanagement and corruption. A small number of representatives raised the profile of disabled people through the press but otherwise it was unclear what the organizations of disabled people stood for. During nearly two years, I heard from them almost no mention of disabled people's rights, discrimination or environmental barriers. Against this background, it was hard to see disabled people's organizations in Papua New Guinea as ready to share the aspirations of DPOs in Zimbabwe and Zambia: that disabled people should have the leading role in determining and implementing research (Albert and Harrison, 2006; Albert, n.d.).

It is widely recognized in Papua New Guinea that the capacity of organizations of disabled people needs to be built. Latterly, there have been some encouraging developments. An Australian disability organization supported a national meeting of "women with disabilities" in 2006, attracting disabled women who had never before travelled outside their home areas. This meeting inspired at least one participant to establish back home an association of disabled women and a mixed gender association, meeting in her backyard with a total of 97 members and rising (Lombange, 2008). In 2007, a Japanese disability organization held a national event to build the capacity of organizations of disabled people, attended by disabled people from most parts of the country. The National Assembly for People with Disabilities is working with support from a VSO volunteer to strengthen its capacity. A quarterly national disability magazine, supported by VSO volunteers, aims to raise consciousness by featuring disabled people's stories and promoting aspects of national policy.

The few organizations of disabled people centre on a few urban areas and rarely reach the rural areas where the great majority of the disabled population lives. Here, engaging people whom we categorise as "disabled" is a huge challenge, as is attempting participatory disability research in which disabled people are active in the process. The major obstacle here is little mutual recognition of communality amongst people with impairments or activity limitations. Disability as an identity is not an explicit cultural concept (Whyte and Ingstad, 1995). The word "disabled" has no equivalent in indigenous languages and Tok Pisin refers to an individual's non-functioning body parts as "broken" or "no good" (such as "man with no good eyes"), with no collective term other than the recently introduced and by no means widespread "disable". Common beliefs are that impairments and illnesses stem from breaking taboos, from offending evil spirits and especially from provoking sorcery by offending social norms or arousing jealousy. The impairment itself does not necessarily affect social acceptance in all Papua New Guinea societies. Rather, in our highlands sites stigma could result from the shameful behaviour that provoked sorcery. Consequently, there was not the sense of oppression or discrimination linked to impairment that brings solidarity amongst disabled people in the North. Considerable consciousness-raising in communities is essential to enable participatory research.

Because of these factors and the short time frame for the pilot project, the role of disabled people was very limited. That said, the National Assembly of Disabled Persons had played a part in setting the agenda by calling for a disability question in the next national census, and representatives of organizations of disabled people supported the new disability policy of the Department for Community Development that involves promoting the collection of disability data. The National Board for Disabled Persons (a grant-aided association of service-providers, organizations of and for disabled people and other stakeholders in the disability field) had called for standardized disability surveys. There was a clear consensus that data is power.

However, in the communities where the research took place there was no involvement of disabled people in the production of the research.

8.6 Cultural Influences on the Research Process: Expectations of Material Benefit

An anxiety I brought to the fieldwork was about how to explain the purpose of the research to meet the threefold aim of not raising unrealistic expectations, achieving informed consent and reducing non-response rates. I knew that the results of the research project would not benefit participants or their communities. Rather, the findings were intended to inform disability policy and service planning. Yet the arrival of researchers asking questions about activity limitations, service use and unmet needs was bound to prompt unrealistic expectations of material benefit. It is of course a common tendency for top-down research by outsiders to raise local people's expectations of solutions to problems, and an elementary step in fieldwork is to make clear the purpose of research and whether or not any action might result (Bulmer and Warwick, 1983b; Pratt and Loizos, 1992).

Our attempts to forestall false expectations paralleled those set out in fieldwork for development textbooks. In sessions with community leaders and interviewers we explained that the purpose of the research was to assist the government and other agencies to improve planning in the country. The preamble to the interview spelt this out, and during training the interviewers practised using the prescribed form of words to make it as clear as possible that the interview was not a route to the solution of immediate problems. The message probably was not reinforced enough. No doubt it was hard for the majority of local people to understand what a survey is and what it is for, especially if they have never encountered a survey (Bulmer and Warwick, 1983b). Even "good practice" examples found local people hoping the research would lead to immediate benefits (Pratt and Loizos, 1992). In retrospect, it was unhelpful in introducing the research to say that it aimed to benefit other people in the future (a common appeal to boost participation in research in the UK). The idea of benefiting some unknown others was alien and culturally inappropriate because social relationships in Papua New Guinea are ruled by the *wantok* system. Literally meaning people who speak the same language, wantoks are in-groups of people from the same community or clan who observe strong obligations towards reciprocal help. For them, benefiting non-wantoks is a foreign and unacceptable notion.

There are a number of reasons why community leaders, interviewers and respondents were not persuaded that material benefits would not flow from the research project. It is already documented that foreign researchers are likely to be perceived as representatives of international donors or other similar agencies, and respondents may participate in the belief that the researcher will bring tangible benefits to the community (Devereux and Hoddinott, 1992). Top-down research by outsiders leads to assumptions that money inevitably will be spent locally (Pratt and

Loizos, 1992). In Papua New Guinea the influences of development are especially unhelpful in this respect. In the 1970s, around the time of independence, local level organizations, such as village associations, emerged as people sought local participation in development. But disillusionment set in amongst grass-roots organizations when aspiring politicians used them for personal advancement and profit. Community development projects have been supported by an array of external donors. Top-down development initiatives bringing money or "cargo" to communities have shaped expectations of material benefits and cash. So, when an outside organization appears on the local scene, especially when represented by a white-skinned person, the assumption is that material benefits will follow. This "handout mentality" obstructed the research in more ways than one.

The questions put to respondents are likely to have fuelled expectations of individual benefit. The theoretical concept of unmet need used in the questionnaire was hard for interviewers to explain and respondents to grasp. Having been asked if there was anything they needed for their difficulty and did not currently have, some respondents not surprisingly believed that their needs would be met. Some time after the fieldwork was completed, a complaint was relayed to me that the wheelchair a respondent wanted had not been forthcoming. In planning the project, we had been keen to give something back to the people who took part. Paying respondents was out of the question. Even if the budget had allowed, giving money or presents to individuals would have been culturally inappropriate and divisive as well as fuelling escalating expectations (Devereux and Hoddinott, 1992). What was decided upon in Survey 1 and Survey 3 was to offer sight and hearing tests to all participants and a referral to a clinic if a deficit was detected. This may have encouraged a misunderstanding that other health-related services would follow from the project.

Rather to my surprise, refusal to take part was minimal. It has been commented that rural people in developing countries like being interviewed far more than might be thought (Heyer, 1992) and that refusal rates are comparatively low in rural areas of developing countries (Hershfield et al., 1983). There were no issues over accessing women for interview; indeed an impulse to protect women is not in the Papua New Guinean psyche. And in the relatively classless social structure there was no holding back through beliefs of being unworthy for interview found elsewhere (Bulmer, 1983). Despite the demands of subsistence farming and cash cropping in Papua New Guinea rural societies, there was generally no financial sacrifice attached to giving time for an interview, and people appeared to welcome a novel event. Heyer (1992) also notes that people frequently asked to be interviewed if they were not on the list. This was our experience too, and it may be that people were motivated by concerns not to miss out on presumed returns to them; just being on a list raises expectations. In Survey 1, where the sample was supposed to be provided by local informants only, the strategy was wrecked by fieldworkers accepting for interview other people who put themselves forward. It was impossible to interview everyone within the time and budget available, leading to reported dissatisfaction amongst those left out.

The expectation of gains from taking part had important consequences for the reliability of the data. In sharp contrast to the North where under-reporting of disability is problematic, there are indications that our Papua New Guinean respondents exaggerated the degree of difficulty with activities. Evidence is available for seeing and hearing. As noted above, in two surveys people were offered optional sight and hearing tests, administered by the interviewers. These were simple tests involving identifying the direction of a shape on a chart and indicating hearing a sound from a noisemaker. The results were compared with responses to subjective questions about extent of seeing and hearing difficulty. While numbers are small because not everyone with a hearing or seeing difficulty accepted the test, and bearing in mind that the measures are not strictly comparable, analysis showed that considerable minorities who claimed they were unable to see or hear at all, or had a lot of difficulty, were found in the tests to have normal vision or hearing. In comparison, few people who reported no seeing or hearing difficulty were found to have one in the tests. It is hard to avoid the conclusion that people expected to gain something, presumably money, by claiming a difficulty they did not have. There are parallels here with the problem of enumerating households in Ghana, where the expectation that researchers would bring free or subsidized food aid meant that over-reporting of households was standard practice (Devereux, 1992).

8.7 Payment Issues

It had not occurred to me that the expectation of gains would be problematic in relation to community leaders. I had quickly learnt that it would be essential to engage them to gain their acceptance of the research and assistance in smoothing the path to respondents. The textbooks emphasize that establishment and maintenance of community goodwill is crucial (Christensen, 1992) and that the ethics of fieldwork insist that local customs be respected (Hoddinott, 1992). In the parts of highland Papua New Guinea where the fieldwork took place, the “bigman” commands the social scene. Each hamlet has one or more of these influential figures. Not a hereditary position, status as a bigman arrives through accumulation of wealth (such as pigs) and wives (who rear the pigs) and demonstration of leadership. Little can happen in their domain without reference to them.

In our first survey, in the rural highlands site, we invited bigmen to join the first interviewer training day, intending to ensure that both local interviewers and bigmen received the same messages about the purpose and conduct of the research. The unintended outcome was that the bigmen assumed that they too would conduct interviews. In the course of that training day it became apparent that they were motivated by the prospect of payment, not simply that they assumed their status naturally qualified them for the task in the same way that community leaders feel that they deserve to be interviewed (Mitchell, 1983). Indeed, many went on to conduct interviews, something that the field supervisors could not prevent due to the social unacceptability of challenging a bigman. The consequences were disastrous. The local interviewers were community-based rehabilitation volunteers who had been selected because they had secondary education and knowledge of English as well as experience with disabled people, attributes lacking in the community leaders who failed to master the questionnaire. Many of the community leaders' returned questionnaires were too poorly completed to be included in the analysis.

Payment of interviewers was a particularly thorny issue, eventually handled without pain in the final, urban survey. Our initial suggestion in the first rural highlands survey, that a lump sum be given to be spent on local community-based rehabilitation efforts, was received with silent hostility by community leaders and interviewers at the first training day. This reaction may be associated with the low profile of community-based rehabilitation in the locality and, as mentioned in the previous section, with the unfamiliar concept of people with impairments or activity limitations as a social group, let alone a deserving community group. It was only much later that we realized that the proposal was unacceptable because of suspicions about the financial probity of the main field supervisor, a local man, who would have access to any lump sum and power over its distribution. The planned questionnaire practice sessions were effectively derailed until a piece-rate method of payment was agreed upon. The field supervisor was charged with distributing payments along with monies to cover travel and subsistence expenses, but irregularities in the distribution caused discontent which later deterred several fieldworkers from any further association with the project during the follow-up study. Here the project undoubtedly escalated tensions in relationships and caused conflicts that may well have persisted long after the research was completed (ESRC, 2004).

Interviewers sharing recompense equally, regardless of number of interviews completed, might have made the payments more transparent and less open to manipulation. The university student interviewers in the Survey 2 chose to pool and share equally the agreed per interview fees. Fabrication of completed questionnaires was an unfortunate consequence of the piece-rate payment system in the first survey. In Survey 3 this problem was eliminated by much tighter supervision and checking of returned questionnaires prior to payment.

The overall impression gained from the first survey was that community leaders, the field supervisor and interviewers sought to exploit the project. For them it was a moneymaking opportunity. "Sucker bias" where outsiders are seen as fair game for deception (Mitchell, 1983) is not just a respondent phenomenon. The project was expected to pay highly inflated costs for use of a rural resource centre and for catering during training. Our explanation that the budget was extremely limited, and by no means a bottomless pit, was met with disbelief. Those who knew of the instigator of the research, the promoter of community-based rehabilitation, pointed to instances where money had been forthcoming when asked for. Even physiotherapy students who were to undertake field interviews in the follow-up study as part of their course, with credits attached, attempted to negotiate upwards their daily fee. Indeed, a subgroup of these students withdrew from the fieldwork because they perceived the payment to be too low. Their attitude surprised me because the purpose of the follow-up study was to reach a better fit between the content of the physiotherapy course and the needs of physically disabled people, in turn equipping qualified physiotherapists with the appropriate skills. To my chagrin, one student accused me of being motivated to do the research only to obtain a publication (having already over one hundred publications this could not have been further from my mind). There are echoes here of the comment, reported by Wilson (1992), by a member of a much researched community to the effect that it is justifiable for local people to exploit researchers because they use local people to further academic success and fame.

It would be a mistake to characterize Papua New Guineans as grasping, self-interested individuals. The role of money in Papua New Guinean societies is complex. Wealth is not accumulated for one's self and money is important less for its economic purchasing power than for its social currency value. Money is shared with the community, put towards bride price payments or funerals for example. By doing so, people "buy" status. Another factor is customary reciprocal giving, fundamental to the wantok system, in which help is given in expectation of being helped in return. We knew it was essential to give something back to the community members and were careful to lay on lavish meals during training and an end of fieldwork feast for interviewers and community leaders with a ceremony to give out certificates of participation. It may be that our gifts did not weigh equally in the scales of reciprocity. Also relevant is that in some societies, especially in the highlands regions, the notion of compensation is deeply embedded. If a community member is harmed by an out-group, the transgressors must compensate the community for that harm, in kind or, increasingly, in cash. For example, inter-clan warfare will be suspended if someone is killed or injured until appropriate compensation (pigs, cash, even women) is paid. Without satisfactory compensation, ancestral lands and garden plots are fiercely defended against encroachment by electricity or fresh water supply pipes and roads intended to benefit the community. It may be that the highland communities in Survey 1 were seeking compensation from us for some perceived harm.

8.8 Other Cultural Influences on the Data Collected

Section 8.6 shows how expectations of material benefit affected not only the production of the research but also the quality of the data collected, including its reliability and validity. This section considers some other cultural influences on the data.

8.8.1 Lexical Equivalence

A lack of lexical equivalence is often cited as a problem affecting the quality of data collected in cross-cultural research (see several chapters in Bulmer and Warwick, 1983). It was to the project's great advantage that the word "difficulty" in the English language version is equivalent to the commonly used Tok Pisin word *hevi* and to the term in the Yagaria language in the rural highlands site. Thus the questions about difficulty with specified activities were easily understood by interviewers and respondents alike. We encountered a few problems with terms to describe the activities themselves, as the vocabulary of Tok Pisin is limited. The literature on research in developing countries notes that interviewers may shorten questions or simplify the language through on-the-spot adaptations (Bulmer and Warwick, 1983a). Reports of seeing and hearing difficulties may have been exaggerated if interviewers referred to eye and ear problems rather than seeing and hearing difficulties. To reduce room for miscommunication, the follow-up study with sub-samples of people with moving difficulties deployed photographs alongside verbal descriptions of activities. Bulmer and Warwick (1983b) cite an objection to using this device on the grounds that many peoples have no experience of seeing their own image but photographs appeared to work well in the rural highlands as well as the urban highlands site.

Asking about extent of difficulty on a four-point scale from "no difficulty" to "cannot do at all" worked well, capturing mild to moderate activity limitations which seem to have gone unreported with disability prevalence measures used in English-speaking African nations (Loeb and Eide, 2006). Loeb and Eide (2006 p.115) speculate that people do not acknowledge a limitation if they are unaware of the possibility of improving the situation with relatively simple technical aids but in our Papua New Guinea pilot surveys non-acknowledgment of limitations did not appear to be associated with lack of awareness of remedial aids.

8.8.2 Conceptual Equivalence

A further concern for surveys in developing countries is that of conceptual equivalence (see several chapters in Bulmer and Warwick, 1983b). The literature observes that the idea that individuals have views of their own is a cultural value, and that in some societies there is a greater likelihood that respondents regard themselves more as part of a community or kinship group than as individuals (Bulmer, 1983). The primacy of the individual can seem alien (ESRC, 2004). While the pilot surveys seem to have been successful in eliciting self-perceptions of difficulties with activities, it appeared hard for some interviewers to understand or accept the concept of subjective, individual judgement. This stems in part from the novelty of the concept of the individual in Papua New Guinean societies. But where interviewers were community-based rehabilitation volunteers there were also external influences: it was hard for them to put aside their training which had led them to see themselves as experts in identifying difficulties their disabled clients faced. As these volunteers already knew the people they were interviewing, they saw no point in asking questions if the answers were already known to them. In considering sources of interviewers, Bulmer (1983) concludes that use of insiders is best avoided because of the difficulty of the local interviewer in achieving the necessary detachment from known respondents.

8.8.3 Status Equivalence

The last point relates to the issue of status equivalence between interviewers and respondents. The literature contains many warnings that the status gap is likely to be wider in developing countries than in the North and that the veracity of the data collected is likely to be affected if relationships between researcher and researched are asymmetrical (see several chapters in Bulmer and Warwick, 1983b; ESRC, 2004). The prevailing assumption is that well-educated interviewers are perceived by respondents as having higher status, class, power and privilege; such asymmetries may result in acquiescent response styles and give rise to spurious results (ESRC, 2004). In surveys 1 and 3 the community-based rehabilitation volunteers and unemployed youth who served as interviewers had no more than grade 10 education, in line with the suggestion in Bulmer (1983) that interviewers with only primary or secondary education are more suitable in rural surveys. It might be assumed that community-based rehabilitation volunteers have acquired a privileged status but in Papua New Guinea volunteers are not necessarily respected, because they do not bring in financial rewards that can be shared with their communities in the customary way (Millar, 2004; Thornton, 2007).

The status gap is even greater where a European is the interviewer and I was advised that respondents would simply tell me what they thought I wanted to hear. Wuelker (1983 p.165) warns that a non-Asian interviewing an Asian would be “a fiasco” because Asians are far too polite to tell a foreigner something they might not like to hear. Melanesians are not Asians, and my impression is that their interview behaviour is more influenced by notions of right and wrong answers than by politeness or deference. For this reason, as well as risk to personal safety to me and my research assistant, who was an outsider from a distant province, I was strongly advised not to be present during interviews in Survey 1, effectively devolving the local management of research to the fieldwork supervisors. As ESRC (2004) notes, this action endangers proper conduct of field research.

8.8.4 Respondents’ Frames of Reference

The literature warns survey researchers to think about whether respondents have an adequate frame of reference for answering their questions, with particular relevance to opinion questions (Bulmer and Warwick, 1983a). Bulmer (1983 p.213) notes that articulating an opinion requires sufficient self-awareness to see that custom and tradition are not the only source of ideas and beliefs. Without an appropriate frame of reference a high proportion of “don’t know” answers to opinion questions can be expected (Mitchell, 1983). Our first and third surveys asked respondents, for each reported difficulty, if there were any kinds of help they needed for that difficulty and if so what that was. Not surprisingly, quite high proportions said they did not know, up to one in three in the cases of difficulties remembering and communicating, though well under one in ten in the cases of seeing, hearing and moving difficulties.

The question followed on from two questions on use of human sources of help and practical aids in which answer options were read out by the interviewer. The aim was that prior listing of sources of help and aids would stimulate people's thinking about what might be possible, given very limited exposure to personalized services and aids and adaptations, but this device appeared to have little effect. The overall impression is of people holding a narrow, medicalised view of what would help them. For most difficulties, an expressed need for medical advice, treatment or medicine emerged very strongly. The aids people said they needed were almost exclusively spectacles, hearing aids and sticks or crutches. It did not seem to occur to people that difficulties they had cited could be eased by environmental accommodations. For example, poor light to read by was reported as a cause of seeing difficulties but nobody said large-print materials or proper lighting was what they needed. The overall project left the strong impression that improving and accommodating living conditions is a foreign concept in Papua New Guinea.

8.8.5 Non-comprehension

Bulmer and Warwick (1983a p.145) comment that data are only rarely collected and reported about the full extent of non-comprehension. It was only in Survey 3 (the urban highlands survey) and in the fieldwork for the follow-up study that I saw first-hand the degree of comprehension. Otherwise, an impression of respondent non-comprehension is derived from that of the interviewers. Interestingly, a question set that presented difficulty to the interviewers was taken from the national census, about the main work that the respondent did in the last week. This may reflect the limited primacy of the concept of work in Papua New Guinea societies or the difficulty of identifying a single main type of work. Most problematic were questions about participation restrictions. The project tried out ways of asking people about the effects of their activity limitations on taking part in aspects of life present in Papua New Guinea societies. (Note that we did not attempt to ask about the effects of impairment on participation.) Five participation areas were chosen, with verbal examples, and respondents were asked to say how far their participation was restricted on a four-point scale from "not at all" to "all of the time". Because people might not do one or more of these things if they had no difficulty, it was made possible for them to say that an area of participation did not apply to them. This answer option proved very hard to make work, even after refinements. The subtleties got lost in Tok Pisin. The questioning is quite complex: first the interviewer had to find out if the area of participation was something that the respondent did not currently do; then they had to find out if it was something they would do if they did not have a difficulty. Some interviewers found it hard to understand the concepts involved; hypothetical questions are notoriously difficult. Our recommendation was that further surveys should focus on questions about extent of restriction on participation in the community (exemplified by going to market and church and joining in village get-togethers), activities that most people do or aim for, and, with a filter question, activities at school.

8.8.6 Privacy

The necessity for private interviews is debated in the literature on survey research in developing countries. Hershfield et al. (1983 p.248), for example, comment that personal privacy is neither common nor highly valued in rural areas in most developing countries and that usually the interview takes place in the presence of family and other bystanders. Our Papua New Guinea experience was that interviewers were not invited inside dwellings (hospitality is not a noticeable feature of many Papua New Guinea societies) and that curious bystanders congregated around the outdoor interview locations. Mitchell (1983 p.233) notes reports from the field suggesting that responses are influenced by overheard answers by local opinion formers. This did not seem to be the case in our pilot surveys, in part because the people interviewed tended not to have high status. While Hershfield et al. state that privacy is preferable, they acknowledge that third party presence can be helpful in obtaining factual information. The impression in our research was that on-lookers other than close family members did not intrude but rather served as silent witnesses, helping to keep the respondent honest (Mitchell, 1983). When, in a conference on our draft findings, the perennial question was raised about possible under-representation of children and disabled children being "hidden away", it was helpful to point out that the presence of bystanders inhibited dishonest responses.

8.9 Conclusion

In Papua New Guinea there has been a real desire across a range of stakeholders to obtain well-founded data on the prevalence of disability and characteristics of disabled people, to aid planning and advocate for improved services for the disabled population. Solid data are essential to compete for the attention of politicians and international development organizations and to attract the level of investment required to meet needs. Encouragingly, organizations of disabled people recognize that numbers are strength. The purpose of this chapter has not been to report the prevalence estimates obtained through three pilot surveys in selected sites in Papua New Guinea; these estimates are tentative and vary due to differences in the survey populations and in methods tried. The intention is that the recommended method and questionnaire template be used in other carefully selected parts of this heterogeneous country to arrive at a national prevalence estimate.

The thrust of the chapter has been to draw attention to cultural constraints on gathering disability data, from the perspective of an outsider doing acknowledged top-down research. Some of the methodological problems reported here are common to efforts to undertake surveys in developing countries; indeed it is claimed that problems in survey methodology in the North are merely writ large in developing countries (Bulmer and Warwick, 1983b). Other problems met have a special Papua New Guinean flavour. Groce (2006 p.43) now argues that "unique" influential cultural practices might be organized into recognizable patterns that can be anticipated and addressed in disability research. Along with Groce, I hope that insights from research in specific cultural settings might be helpful for those collecting data about disability in any community. Yet, although well-founded disability research among Melanesian populations is as yet rare, this contribution may prove to test Groce's proposition.

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Chapter 9
Disability and HIV/AIDS: A Key Development Issue

Poul Rohleder, Leslie Swartz, and John Philander

9.1 Introduction

Despite the severity of the HIV epidemic globally, and particularly in southern Africa where the epidemic is concentrated (UNAIDS, 2007), persons with disabilities have until recently been generally overlooked with regards HIV prevention and HIV care (Groce, 2003a, 2004, 2005). This is a serious omission, as it is well established that vulnerable groups, such as young women in southern Africa, are most at risk for HIV. Persons with disabilities and particularly youth with disabilities are "among the poorest and most marginalized of all the world's young people" (Groce, 2003b; p. 3). The majority of persons with disabilities live in the "developing world" (World Bank, 2004), countries which also have some of the largest HIV epidemics in the world.

9.2 HIV/AIDS and Persons with Disabilities: What are the Risks?

Groce's (2004) seminal work, the World Bank/Yale University Global Survey on HIV/AIDS and Disability, has reported that persons with disabilities may be at increased risk for HIV infection, yet have generally been excluded from general HIV prevention campaigns, and face numerous barriers to accessing appropriate HIV prevention resources. A review of the literature in southern Africa (Rohleder et al., 2009) similarly suggests that persons with disabilities in this region are at significant risk for HIV infection. Some of the more significant risk factors include:

- *Poverty*: Persons with disabilities are more likely to earn lower incomes or be unemployed and live in conditions of poverty than the rest of the population in

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countries throughout the world (Elwan, 1999), and women with disabilities may be particularly disadvantaged (Hanna and Rogovsky, 1991; Collins et al., 2001). This may place women with disabilities at risk for HIV infection through the need to turn to prostitution or transactional sex as a means of financial and material support (McCarthy, 1993; Smith et al., 2004). Persons with disabilities in South Africa are also reported to be disproportionately unemployed and poorer than the rest of the population (Emmett, 2006; Schneider et al., 1999; Statistics South Africa, 2005). Poverty may act as a barrier to accessing health care (Saloojee et al., 2007; Smith et al., 2004).

- *Lack of education*: Persons with disabilities worldwide have lower levels of education than the rest of the population (Elwan, 1999). Literacy levels among persons with disabilities have been found to be lower than the rest of the population, in a study conducted in Malawi (Munthali et al., 2004). Part of the reason for this is that education may be seen as unnecessary or problematic for children and adolescents with disabilities as they may be perceived as being unable to learn, or a disruption to the rest of the class (Groce, 2003b, 2004). In low-income countries, the lack of financial resources may persuade parents to invest in their non-disabled child, rather than their disabled child, with few disabled children then attending schools in poor areas (Groce, 2003b; Saloojee et al., 2007). Lack of education may act as a barrier to accessing HIV prevention information.
- *Vulnerability to sexual abuse*: It is well established in the international literature that persons with disabilities are at increased risk for sexual abuse. Review studies have indicated that persons with disabilities may be up to three times more likely to be abused, including sexual abuse, than persons without disabilities (Groce, 2004; Sullivan and Knutson, 2000), with women being particularly vulnerable to sexual abuse, although men with disabilities are more likely to be sexually abused than men without disabilities (Sobsey et al., 1997; Sullivan and Knutson, 2000). In many cases, vulnerability to abuse occurs both at home and in environments that disabled people encounter as a result of their disability (Crossmaker, 1991; Hassouneh-Phillips and Curry, 2002; Furey et al., 1994; Sobsey and Doe, 1991). In a review study of sexual assault cases of persons with learning disabilities in South Africa, it was found that in the majority of cases the perpetrator was known to the victim (Dickman and Roux, 2005).

  One factor contributing to the increased vulnerability for sexual abuse of persons with disabilities is the lack of education and knowledge about abuse (see, for example, McCabe et al., 1994). Persons with disabilities (particularly learning disabilities) may also be perceived as unreliable witnesses or are simply not believed, and the perpetrator may feel he or she will not be discovered (Andrews and Veronen, 1993, cited in Nosek et al., 2001). As a result, few cases of sexual abuse of persons with disabilities reach conviction (Brown and Turk, 1994; Sobsey and Doe, 1991; Pillay and Sargent, 2000).
- *Unsafe sex*: Persons with disabilities, particularly learning disabilities, have historically been regarded as asexual (Craft, 1987; Milligan and Neufeldt, 2001), and thus sex education is seen to be unnecessary. This however is a myth and many studies have shown that persons with disabilities are sexually active (for example, Blanchett, 2000; Blum et al., 2001; Cheng and Udry, 2002; Nosek

et al., 2001; Peinkofer, 1994). As with non-disabled people, persons with disabilities may engage in unsafe sex; sex without a condom (Blanchett, 2000; Cook, 2000; Nosek et al., 2001; Mulindwa, 2002; Munthali et al., 2004). International studies have reported sexually transmitted diseases among persons with disabilities (Jackson and Wadley, 1999; Mulindwa, 2002; Nosek et al., 2001), a further indication of unsafe sex and a risk for HIV infection.

- *Lack of sex education and HIV awareness*: Despite the evidence that persons with disabilities are sexually active, and as with non-disabled persons, also may engage in unsafe sex, persons with disabilities reportedly have received little or no sex education (Berman et al., 1999; Heyman and Huckle, 1995; McCabe, 1999; Milligan and Neufeldt, 2001; Pueschel and Scola, 1988). With little or no education about sex, and as a result of barriers to accessing HIV prevention information (Groce, 2004; Rohleder, 2008), knowledge about HIV and HIV prevention, including safe sex, is low (Bat-Chava et al., 2005; Munthali et al., 2004; Yousafzai et al., 2004). In South Africa, low levels of HIV knowledge have been reported for persons with visual disabilities (Philander and Swartz, 2006) and youth with physical disabilities (Wazakili et al., 2006). Where sex education is provided, the extent to which the topic of HIV/AIDS is covered may vary among disabilities (Getch et al., 1998; Howard-Barr et al., 2005; Kelly et al., 2002), and according to the severity of the disability (Birch et al., 2002; Yousafzai et al., 2005). Furthermore, persons with disabilities may face numerous barriers to accessing general HIV prevention information, for example accessing information that is available in sign language or in Braille formats, or health care services that are inaccessible for wheelchair users, or accessing information that is in a format that persons with learning disabilities may be able to understand (Munthali et al., 2004; Yousafzai and Edwards, 2004; Yousafzai et al., 2004; Yousafzai et al., 2005).

The myth that persons with disabilities are asexual (Craft, 1987; Milligan and Neufeldt, 2001), or alternatively sexually uninhibited and inappropriate (Craft, 1987), has resulted in a reluctance on the part of carers to provide sex education, as it is either perceived as being unnecessary or potentially dangerous (Craft, 1987; Heyman and Huckle, 1995). Carers may also feel anxious about providing sex education, as they may feel inadequately trained to do this (Bratlinger, 1992; Christian et al., 2001; Howard-Barr et al., 2005; Parritt and O'Callaghan, 2000).

Other risk factors for HIV infection include substance abuse, where the use of substances during sex may increase the likelihood of the occurrence of unsafe sex. Substance abuse has been suggested as being a serious issue for persons with disabilities (Bachman et al., 2004; Blum et al., 2001; Li and Ford, 1998). Some studies have reported the use of substances by persons with disabilities during sex (Blanchett, 2000; Kelly et al., 1992). Persons with disabilities may use substances as a means to cope with their identity as a disabled person (Njoki et al., 2007).

Associated with this then is the experience of stigma and social isolation for many persons with disabilities. Stigma is reported as a significant concern for men and women with disabilities, who may perceive themselves as sexually unattractive and undesirable (Potgieter and Khan, 2005; White et al., 1992, 1993). This may lead some persons with disabilities to engage in or remain in potentially unsafe sexual relationships, out of a need for affection and attention, or as a result of low self-esteem (Becker et al., 1997; Yousafzai and Edwards, 2004). In South Africa, Wazakili et al. (2006) found that among some youth with physical disabilities, the need to be loved was reported to be more important than having to practice safe sex. Very similar findings were reported by Philander (2007) in his study on adolescents with visual impairments in South Africa, and Joseph (2006) reported that a group of South African male adolescents claimed that because their chances to have sex were much diminished by virtue of their status as disabled people, they would take every opportunity they could to have sex.

As a result of the myths around the sexuality of persons with disabilities, and common perceptions of disabled people as either asexual and sexually inappropriate or incompetent, and the stigma and isolation associated with being disabled, talking about sexuality may be difficult for persons with disabilities themselves, as it makes one have to face the emotional pain that such stigma about "disabled sexuality" carries. As Shakespeare (2000) states:

> Sexuality, for disabled people, has been an area of distress, and exclusion, and self-doubt for so long, that it was sometimes easier not to consider it, than to engage with everything from which so many were excluded. Talking about sex and love relates to acceptance on a very basic level – both acceptance of oneself, and acceptance by significant others – and forces people to confront things which are threatening, given the abuse and isolated lives of many disabled people (p. 160).

9.3 HIV Interventions and Persons with Disabilities in Lower-Income Countries

Whereas a few years ago there was very little discussion about HIV prevention in lower income countries, there is now increasing interest in the topic. For the first time in South Africa, for example, persons with disabilities have been included in the HIV and AIDS and STI Strategic Plan for South Africa 2007–2011 (Department of Health, 2007). Hendrietta Bogopane-Zulu, a South African Member of Parliament who has a visual impairment, has been central to these developments and has also networked vigorously on HIV/AIDS and disability issues in a range of other countries. The South African Strategic Plan identifies persons with disabilities as a vulnerable group, and calls for HIV preventions that are customized and focused on such vulnerable groups. In South Africa, HIV/AIDS prevention education is included as part of the national curriculum for secondary schools. However, an evaluation of this education on implementation (Visser et al., 2004), indicated that not all schools had successfully implemented the programme. Little is known about the provision of HIV/AIDS prevention education in schools for persons with disabilities in particular.

In a study exploring the response to HIV/AIDS by organizations and schools working with persons with disabilities in South Africa (Rohleder, 2008), it was found that although there was a high awareness of the risk for HIV infection for persons with disabilities, there was a general view that there was a lack of appropriate sex education and HIV prevention. Although many disabled people's organizations had some form of HIV policy on their books, close scrutiny of their reports of what was actually taking place at selected organizations suggested a range of practices, and considerable discomfort around the topic of sexuality of persons with disabilities.

A range of publications are now available on HIV and disability in low and middle income countries. There is also a vibrant African campaign on disability and HIV, which met in Kampala, Uganda, recently, for the second time. The next issue of the magazine *Exchange*, which is funded by the Royal Netherlands Embassy and is based in Zimbabwe and focuses on HIV, sexuality and gender (due in early 2009 but not yet available at the time this book went to press) was slated to focus on HIV and disability. The organization AIDS-Free World has collated on its website a wide range of available literature on HIV/AIDS and disability (see http://www.aids-freeworld.org/content/view/114/66/). The materials collated by AIDS-Free World all in different ways focus on the need for inclusion of disabled people in HIV programmes, for elimination of discrimination against disabled people, especially on the grounds of sexuality. Mgwili and Watermeyer (2006), for example, movingly describe the experiences Mgwili has had as a disabled woman in her interaction with reproductive health services. Health workers held discriminatory and stigmatizing views on sexuality for persons with disabilities, and this must have implications for an epidemic which is spread largely through sexual contact.

What is markedly lacking on the literature on HIV and disability in both lower income and wealthier nations is that though there is consensus on the importance of the issue, and there has been much innovation in the area largely through the work of NGOs and DPOs, there are few reports of evaluated interventions of any kind. Dickman and her colleagues (Dickman and Roux, 2005; Dickman et al., 2006) report on an innovative programme run by psychologists and social workers working for a Cape Town, South Africa-based NGO to prepare intellectually disabled complainants in sexual abuse cases for court appearances, alongside training and support on issues of disability for court officials and law enforcement personnel. A review of 10 years of the programme (Dickman and Roux, 2005) showed a conviction rate for perpetrators of sexual assault against disabled complainants equal to the rate of conviction for those who sexually assaulted non-disabled people. Though the authors mention a number of caveats to the interpretation of their data, it does appear that in the context of this programme, intellectually disabled people who are sexually abused are no longer discriminated against in the justice system on grounds of disability and perceived inability to provide credible evidence, if the conviction rate is taken as the key criterion of assessment.

Philander (2007) reports on the only known formally evaluated HIV prevention intervention for adolescents with visual impairment that we have been able to find, using a control group and a 6-month follow up. The outcome of this quasi-experimental study showed a rather depressing similarity to many other studies of HIV prevention in non-disabled populations – the intervention did not show an impact on behavioural measures though some of the null findings could be attributable to small sample size. Nonetheless, part of the strength of the study lies in its rich qualitative data and very careful description of the interventions implemented.

9.4 Concluding Comments

Though there has been some progress in the field of HIV/AIDS and disability, there is a long way to go, and the issue is urgent in sub-Saharan Africa in particular. It is interesting to speculate on why, given the excellent work that has been done on outlining risk factors persons with disabilities face for HIV, we have very few data on actual rates. The only two known studies from Africa – Cameroon (Touko, 2008) and Kenya (Taegtmeyer et al., 2009) compared prevalence rates after voluntary counselling and testing among Deaf persons to hearing persons testing for HIV, or national prevalence rates. Results from these studies suggest that prevalence rates, for the Deaf, may be similar to the general population. There can be no doubt that good data showing the relative risk persons with disabilities face for HIV infection compared with non-disabled people would be helpful for example. This information would provide an evidence base for further work and if it were found that persons with disabilities were at equal or increased risk for infection this would provide an important basis for lobbying for increased funding to this neglected area. In the unlikely event that the risk were lower for disabled people, this could also be helpful for rational future use of resources.

Some time ago, a group of concerned disability activists and scholars (we know from anecdotal account) did plan a case control study to begin the process of developing evidence on HIV risk on the basis of disability. There has also been vigorous lobbying with designers of a number of large-scale HIV surveys to include questions about disability. As regards the case control study, some disability activists were very concerned that a study focusing on assessing seropositivity for HIV amongst persons with disabilities would be politically explosive and the study did not go ahead. In the case of the surveys, people running these, who had no particular interest in disability, could not be convinced that disability might be an important variable to understand in the context of the epidemic. There were also concerns that able-bodied people might be upset by the questions on disability and less inclined to participate in the surveys. The questions on disability status were omitted.

Space does not permit us fully to unpack the complex politics surrounding these decisions about research into HIV/AIDS and disability; suffice to say that the two examples both show how intertwined the area remains with issues of stigma, fear and discrimination. Clearly, the discomfort around systematically researching disability and HIV issues needs to be faced and dealt with if we are to move beyond the current (very important but not sufficient) phase of a great deal of descriptive and anecdotal knowledge.

The challenge is not minor. The issue of disability, and working with persons with disabilities may cause anxiety for many, as they are required to face issues of vulnerability, “damage” and “abnormality” (Marks, 1999; Sinason, 1992; Watermeyer, 2006). Similarly, with sex and HIV/AIDS, anxieties are raised about issues of deviance and risk (Joffe, 1999), with people drawing on metaphors of HIV/AIDS as sin, punishment and evil (Sontag, 1991), to draw a distinction between “us” and “them” (Joffe, 1999; Rohleder, 2007). For those who are tasked with the provision of sex education for persons with disabilities, this may cause some tension between the recognition of the rights of persons with disabilities to lead full sexual lives, and a need to impose a sense of morality and a need to restrict the expression of sexuality in a manner that is considered moral and acceptable (Rohleder and Swartz, 2009; Rohleder, 2008). For researchers who need to provide a research base for interventions, it may be easier to avoid the issue altogether. In the meantime, disabled people are being infected with and affected by HIV in the context of the most serious epidemic the world (and the poorer parts of the world in particular) is facing. We need to do better.

Afterword At the time this book was going to press, new data were released from the Human Sciences Research Council in South Africa from their third national HIV survey (Shisana et al., 2009), which, for the first time, invited survey participants to respond to questions about disabilities including sensory, physical, intellectual, and mental disabilities. Results of the survey mention that persons with disabilities have a higher prevalence rate of HIV (14.1%) compared to the prevalence rate among the general population (10.9%), though the confidence intervals overlapped, and the confidence interval for disabled people was very wide, which suggests a difficulty in accuracy of the estimate. This confirms suspicions that persons with disabilities may be considered at least as at risk as the general population and may even be more at risk for HIV infection than the general population. These data provides us with a suggestive evidence base for further work to be done.

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Chapter 10
Assistive Technology in Low-Income Countries

Arne H. Eide and Tone Øderud

10.1 Introduction

World Health Organization (WHO) has estimated that 10% of the global population has a disability, with social educational and/or economical consequences. Although such estimates have a weak basis (Metts, 2000; Eide and Loeb, 2006a) it might be about 600 million people around the world with special needs in terms of health care, education, rehabilitation, appropriate assistive devices and social support. Furthermore it is indicated that 80% of people with disabilities live in low-income countries and also in very poor life conditions with limited access to health care services, rehabilitation and assistive devices. Case studies in developing countries show that higher disability rates are associated with higher rates of illiteracy, poor nutritional status, lower immunization coverage, lower birth weight, higher rates of unemployment and underemployment, and lower occupational mobility (Elwan, 1999). Disability can cause poverty by preventing the full participation of persons with disabilities in the economic and social life of their communities, especially if the appropriate supports and accommodations are not available. This chapter draws on results from recent studies on living conditions among people with disabilities in southern Africa (Eide et al. 2003a, b; Loeb and Eide, 2004; Eide and Loeb, 2006b) and aims at describing the situation for disabled people in low-income contexts with regards to assistive technology.

Assistive devices and technologies such as mobility aids, hearing aids, visual aids, wheelchairs, prostheses, and adapted computer software and hardware increase the possibilities for individuals with disabilities to participate in their societies and live independently.

The UN Resolution "The Standard Rules for Equalization of Opportunities for People with Disabilities" (UN, 1994) is an important document with strong impact on the future of people with disabilities. Standard Rule 4 on Support Services states: "States should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level

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of independence in their daily living and to exercise their rights". The resolution also states "States should ensure the provision of assistive devices and equipment according to the needs of persons with disabilities, as important measures to achieve the equalization of opportunities" and "States should support the development, production, distribution and servicing of assistive devices and equipment and the dissemination of knowledge about them."

The 58th World Health Assembly adopted the resolution "Disability, including prevention, management and rehabilitation" in 2005 (WHO, 2005). The resolution states that 80% of people with disabilities live in low-income countries and that poverty limits access to basic health services, including rehabilitation services. On assistive technology the resolution urges member states to "facilitate access to appropriate technology and to promote its development and other means that encourage the inclusion of persons with disabilities in society" and to "ensure provision of adequate and effective medical care to people with special needs and to facilitate their access to such care including prostheses, wheelchairs, driving aids and other devices."

The recent UN Convention on the Rights of Persons with Disabilities (UN, 2006) calls for member states to provide individuals with disabilities mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities. In spite of important high-level policy support (UN, 1994, 2006; WHO, 2005), the majority of people with disabilities living in low-income countries, however, have little or no access to assistive devices that could contribute to improving their life situation and help many to a more independent life (Øderud and Grann, 1999). Supply of assistive devices is very far from meeting the needs, and service delivery systems are either non-existent or limited.

WHO reports that rehabilitative services in the developing world reach only 1–2% of the disabled population (Frye, 1993). Production is low and often of limited quality. There is a scarcity of personnel trained to manage the provision of such devices and technologies, especially at provincial and district levels. In many settings where access might be possible, costs are prohibitive. The priorities of health care in low-income countries are largely preventive or promotive, and rehabilitation is not given priority. May-Teerink (1999) underlines the lack of knowledge and research on assistive technology and rehabilitation in low-income countries. In her study carried out in Uganda, May-Teerink found that the use of assistive devices were indicative of greater mobility, which led to better opportunities for formal education or employment. She further reported that gender-related issues may limit women's access to rehabilitative equipment due to limited financial resources of women living in low-income countries.

It has been estimated that there are around 37 million people in the world who are blind, and that an additional 135 million have a severe visual impairment (http://www.cbmicanada.org). It has further been estimated that 90% of the worlds' blind children have no opportunity to attend school, and that 80% of blind adults cannot work, because they lack training facilities and assistive devices. WHO has further estimated that there are around 250 million people worldwide with disabling hearing loss that could benefit from hearing aids (AUDINEWS July 2002). The large majority of these live in low-income countries without any type of hearing aids.

The United Nations Statistical Office estimates there are 20 million people in the world who need a wheelchair but don't have one. Recently the global Consensus Conference on Wheelchairs organized by WHO, the International Society for Prosthetics and Orthotics (ISPO) and USAID (2003) have indicated that 1% of the world's population, or about 60–65 million people, are in need of a wheelchair. According to estimates by Hotchkiss and Knezevitch (1990), 1 million wheelchairs per year are needed if the supply of wheelchairs is going to meet the demand by the year 2020. This is most likely a gross underestimation, as it does not take the expected 5-year life span of a wheelchair into account. Distribution of wheelchairs to developing countries over the past several decades has, however, cumulatively provided less than half a million units (Pearlman et al. 2006), and there is currently a staggering and growing demand.

There is limited data and knowledge on assistive technology in low-income countries. This goes for demand, supply, quality and effect of assistive technology on the welfare of disabled individuals. Critics have for instance argued that wheelchairs supplied in low-income countries in many instances are sub-standard (Pearlman, 2006). Armstrong et al. (2007) state that two of the most common methods for distribution of wheelchairs are either mass produced in high- or middle-income countries or used wheelchairs delivered with minimal service provision. Furthermore, for wheelchairs that are damaged, replacement parts are typically not available. Most donated products are originally designed for indoor use and do not perform well for active users in rugged environments (Mukherjee and Samanta, 2005). Locally adapted and small-scale production found in low-income countries has amounted to around 50,000 units during the last two decades (Pearlman et al. 2006).

Supply of assistive devices is clearly more than a question of quantity and distribution. Equally important is the quality of what is offered. Unfortunately, much of the AT in use in these countries are either technically outdated and not adapted to local circumstances or imported sophisticated technology beyond common people's reach. There are furthermore many examples indicating that supply of AT without considering the need for a service delivery system that includes individual assessment, adaptation, training in use, follow up, maintenance, proper distribution, qualified personnel, etc., is the reality in many countries (Øderud, 2000).

Assessment of user needs and prescription of appropriate devices are key issues in the process of ensuring that people with disabilities are receiving equipment that is correctly fitted and meets the individual needs that could positively influence their quality of life. A poor fit can mean the development of complications like pressure sores and infections, which may even be life-threatening (Armstrong et al. 2007). The width, height and length of a wheelchair should be adapted to fit the individual size of the person and especially for children. If the wheelchair is not fitted correctly the child is at a risk of developing postural problems (scoliosis, kyfose, etc.) and possibly digestive problems. Individual adapted postural support including a cushion is needed to prevent the increase of disability, prevent possible pressure sores and development of additional problems.

In many low-income and middle-income countries, only 5–15% of people who require assistive devices and technologies have access to them. Production is low and often of limited quality. There is a scarcity of personnel trained to manage the provision of such devices and technologies, especially at provincial and district levels. In many settings where access might be possible, costs are prohibitive (WHO).

Since the development, production and distribution of assistive devices and technologies are not an integral part of the health care system in many countries, their provision falls to nongovernmental organizations and other groups. Because there is no central coordination for these efforts, in many instances assistive devices and technologies are produced without adequately taking into account the needs of people with disabilities, their living conditions or environments. In cases were external funding is in place, related programs often collapse when the funding is no longer available (WHO).

The following citation from Zimbabwe indicates the importance of availability of appropriate assistive technology and a service delivery system. Poor fit and/or lack of relevant assistive technology may imply a question of life and death in poor countries.

"We were 19 people being rehabilitated in 2001 and discharged in 2003. I am now the only person alive. The rest have died because of pressure sores. If someone can't afford a wheelchair and is using a wheelbarrow and doesn't have a cushion, what do you expect?" (Ms. Gladys Charowa, Chair of Disabled Women's group DWSO, Zimbabwe) (Personal communication, T. Øderud).

10.2 New Knowledge About Assistive Devices in Developing Countries

In Malawi, Namibia, Zimbabwe and Zambia, studies on living conditions among people with disabilities have recently been carried out (Eide et al., 2003a, 2003b; Loeb and Eide 2004; Eide and Loeb, 2006b) by SINTEF Health Research in collaboration with national universities, central statistical offices and national affiliates of the Southern Africa Federation of the Disabled (SAFOD). The studies were all National, representative household surveys with two-stage sampling; activity-based screening was carried out in a sample of small geographical areas (enumeration areas) drawn from the national sampling frames. Households with a disabled member were later revisited for data collection. One section in the research instrument was about disability, one on general living conditions in the households, and one on activity and participation. Individuals with disabilities responded to the disability related questions, otherwise the head of the household was interviewed. In some households the main respondent also reported for the individual with a disability if this person were unable to respond for some reason. Research instrument was based on previous surveys in the region and adapted to each context through a comprehensive process involving all relevant stakeholders in each country. Although the different national studies are comparable, research instruments thus vary somewhat between the countries. All studies were carried out in close collaboration with the national federation of disabled people affiliated with Southern Africa Federation of the Disabled (SAFOD), Central Statistical Office in each country, and the National Universities. The Norwegian Federation of Organizations for Disabled People (FFO) has initiated, funded and supported all four studies. For further details on methodology (see Eide et al. 2003a, 2003b; Loeb and Eide, 2004, Eide and Loeb, 2006b).

Table 10.1 provides information about the sample in each country. The following analyses concern the sub-population of individuals with disabilities. The number of respondents in the tables below corresponds to the number of individuals with disabilities for each country given in Table 10.1 with small variations due to missing information, unless other information is given in the tables.

Some variables may differ between the countries with regards to formulations and number of answer categories. Whenever this is the case, footnotes in the tables provide explanation, and some results are referred to in the text if this is found most practical.

In all four countries assistive devices for personal mobility is by far the most frequent, followed by devices for sensory impairments (eye glasses, hearing aids, Braille). This reflects the proportion of the different impairment categories (see Table 10.2). The majority of those who reported that they had an assistive device stated that it was in good working condition (Malawi: 53.6%, Namibia 69.2%, Zimbabwe: 74.7%, Zambia: 77.2%).

Table 10.1 Sample

	Namibia		Zimbabwe		Malawi		Zambia	
Disability	With	W/out	With	W/out	With	W/out	With	W/out
No. of households	2,286	1,356	1,943	1,958	1,521	1,537	2,885	2,886
Total no. of individuals in HH	16,459	6,855	11,460	10,252	8,038	7,326	15,210	12,979
Individuals with disabilities	2,537		2,071		1,623		2,898	

Table 10.2 Source of assistive device (percentage of individuals with a device[a])

Source	Namibia	Zimbabwe	Zambia	Malawi
Private	29.1	31.2	42.8	34.4
Government Health Service	59.1	27.4	14.8	17.9
Other Government Service	0.7	3.2	3.2	1.4
NGO	2.3	8.3	8.8	9.3
Other	8.2	28.8	24.7	36.8

[a] Individuals with an assistive device. N = 304 (Malawi), 446 (Namibia), 372 (Zambia), 506 (Zimbabwe)

Different sources of the assistive devices were given.

In three countries, sources outside Government dominated, while in Namibia Government health service provided close to 60% of the devices. Private sources are here largely donations from the commercial sector. The domination of Government as a source in Namibia is also reflected in the reported information on maintenance of the assistive device (Table 10.3). In Namibia more than one third (36.3%) report that their device is maintained by Government, while this figure is between 3 and 6% for the other three countries. The combination of "self-repair" or "maintained by other family member" exceeds the figures for Government for all countries, but this is not as pronounced in Namibia as compared with the other three countries. The proportion of assistive devices that are not maintained at all is particularly high in Malawi (36%) and low in Namibia (12%).

Table 10.3 further reveals that a large proportion of assistive device users, in Malawi it is even a majority, do not get any information or guidance with regards to use. Between 22 and 42% state that the device (i.e. the main device) is not in good working condition. Combining these quality indicators may indicate that the situation is most difficult in Malawi and least in Namibia.

Respondents were asked to describe their impairment, and this was later used to categorize into some main impairment groups. Table 10.4 shows that the largest group of impairments fall into the "physical category", followed by sensory impairments, mental impairments and impairments related to communication.

The figures in Table 10.4 also indicate differentiation in needs with regards to different types of assistive devices. In the data material from Zambia for instance, the most frequent devices in use were mobility devices (wheelchairs, crutches, etc.) (78% of those with an assistive device). This was followed by sensory devices (eye glasses, hearing aids, Braille, etc.) (38% of those with a device), and communication devices (sign language, interpreter, portable writer, computer, etc.) (14% of those with a device). Other types of devices, i.e. for personal care and

Table 10.3 Quality aspects of service delivery with regards to assistive devices

Quality indicator	Namibia	Zimbabwe	Malawi	Zambia
Device maintained by owner or family	43	66	38	58
Device not maintained	12	15	36	11
No information or help given on use of device	28	23	59	37
Device not in good working condition	31	22	42	25

Table 10.4 Types of impairment (%)

Types of impairment (%)	Namibia	Zimbabwe	Malawi	Zambia
Physical	40	46	43	42
Sensory; Visual/hearing	28	32	39	44
Psychological	16	11	12	11
Communication	6	–[a]	3	3
Others	10	11	3	–[a]

[a] Answer category not included in the questionnaire

protection, for handling products and goods, and household items, were reported in use by very few individuals.

Table 10.5 first of all shows that impairments in this context are inflicted upon individuals early in life, contrary to what is the case in richer parts of the world. While demographic distribution in the populations explains some of this difference, it also reflects the vulnerability of children in poor contexts as well as problems related to health care services. This information further indicates the importance of a child perspective on service delivery in this particular context.

Table 10.6 indicates that the largest "service gaps" are found with regards to assistive devices and vocational training. Largely, the assistive device/service gap is around 50%, the vocational training gap around 30%, and the health service gap between 0 and 20%. As this is self-reported, it can be assumed that the real gap is larger as many individuals are not aware of, for instance, what kind of assistive devices could have helped them.

Zimbabwe stands out in this comparison as both the assistive device/service gap and the vocational training gap is considerably smaller than for the other three countries. The study in Zimbabwe was carried out before, or rather in the early stages of, the economic downfall of the country, and the result may reflect particularly developed services for individuals with disabilities in the country. With regards to health services, Zimbabwe and Zambia appears to have no gap, while Namibia and Malawi has reported around 20%. It is also indicated that the need for traditional healers is met and that this type of service is also given in excess of the stated need, indicating that this culturally embedded service to some extent replaces other types of services.

Table 10.5 Age of onset of impairment (%)

Age of onset	Namibia	Zimbabwe	Malawi	Zambia
From birth	31	20	23	30
1–10	21	24	36	21.4[a]
11–20	12	9	11	43.1[b]
21–60	32	32	23	
61+	4	15	7	

[a] Acquired disability between birth and age of 10

[b] Acquired disability as children or young adults (less than or equal to 20 years)

Table 10.6 Types of services that are needed and received (%)*

	Namibia	Zimbabwe	Malawi	Zambia
Services	Need/Received	Need/Received	Need/Received	Need/Received
Health services	91/73	94/92	83/61	77/80
Assistive device/service	67/17	57/37	65/18	57/18
Vocational training	47/5	41/23	45/6	35/8
Traditional healer	33/47	49/90	58/60	32/63

Need: Percent of total number of disabled.

Received: Percent of those claiming they needed the services actually receiving the services.

The proportion of individuals with disabilities having an assistive device varies from 14.9% in Zambia to 25.8% in Zimbabwe. A clear gender difference is demonstrated in Malawi and Zambia in that females have less access to assistive devices as compared with men. Also in Zimbabwe, more men have an assistive device, but the gender difference is not pronounced. In Namibia this question was phrased differently and it was asked for experience rather than ownership, and hence Namibia is not reflected in the table. Also in Namibia a clear gender difference was demonstrated, confirming the findings presented in Table 10.7; male individuals with disabilities report more experience with assistive devices than females.

A clear urban/rural difference is demonstrated, in that individuals with disabilities living in an urban setting report to a larger degree than rural dwellers state that they have an assistive device (Table 10.8).

There are marked differences with regards to type of impairment, as could be expected. Individuals with a physical disability report significantly higher access than other impairment groups, sensory comes as second, followed by age/other and lastly psychological. Controlling for gender revealed that there is a pronounced difference when it comes to physical and sensory impairments in that the proportion with an assistive device is significantly higher among men. For age/other and psychological impairments gender differences are smaller and not statistically significant due to low numbers (Table 10.9).

Table 10.7 Assistive device by gender

	Do you have any assistive device? (% Yes)		
Gender	Malawi	Zambia	Zimbabwe
Male	25.3	15.7	26.6
Female	14.1	11.9	25.0
Total	19.8	14.9	25.8

Table 10.8 Assistive device by urban/rural (%)

Yes, have an assistive device	Urban	Rural
Zimbabwe	35.1	22.2
Namibia	24.7	16.0
Zambia	17.2	11.9
Malawi	20.4	19.7

Table 10.9 Assistive device by impairment type

	Do you have any assistive device? (% Yes)			
Impairment	Malawi	Zambia	Zimbabwe	Namibia
Sensory	14.2	12.7	21.1	14.2
Physical	30.3	19.1	37.6	31.5
Psychological	3.2	2.2	2.7	1.2
Age/other	10.7	–	17.0	2.2
Total	19.6	14.2	25.8	18.4

In Table 10.10, the population of disabled is split in age groups of largely equal size. The proportion of disabled having an assistive device increases with age. Comparing the oldest age category with the youngest shows seven times higher proportion of individuals having an assistive device among the 61+ than the ones who are between 0 and 10 years of age. For all age categories women report lower figures than men. For the three oldest age categories, the gender difference is particularly high in that men report twice or more as high figures as boys. The gender differences in the younger categories are non-significant although among the 0–10 age group girls report 3.1% as compared to 6.8% among boys. The lack of significance is due to the low number having a device in this age group.

Table 10.11 demonstrates that individuals who report that they attend or have attended school are more likely to have an assistive device as compared to those who have never attended.

For the Namibian and Zimbabwean samples different answer categories were applied with regards to employment. No significant differences in use of assistive devices were found in these two samples when comparing those who were currently working with those who had been previously or never employed. For Malawi and Zambia (Table 10.12), it is demonstrated that those without any working experience

Table 10.10 Assistive device by age groups

	Do you have any assistive device? (% Yes)			
Age group (years)	Malawi	Zambia	Namibia	Zimbabwe
0–10	4.9	10.0	5.5	11.2
11–20	9.7	10.2	11.0	14.9
21–40	19.5	29.7	25.0	15.3
41–60	23.8	31.4	35.7	27.9
61+	35.4	15.1	22.9	41.7
Total	18.7	12.1	17.8	25.5

Table 10.11 Assistive device by school attendance

Have you ever attended school?	Do you have any assistive device? (% Yes)			
	Malawi	Zambia	Namibia	Zimbabwe
Never attended	17.8	11.3	12.9	15.2
Attending/finished/left	21.9	16.6	21.6	18.6

Table 10.12 Assistive device by employment

	Do you have any assistive device (% Yes)	
Are you currently working?	Malawi	Zambia
Yes, currently working	26.1	19.7
No, but have been employed previously	39.6	22.6
No, never been employed	20.1	15.0
I am a housewife	11.3	14.3

more often report that they do not have an assistive device as compared to those with work experience. Between 20 and 30% of the population of individuals with disabilities state that they are currently working, and between 15 and 25% have no working experience whatsoever.

10.3 Discussion

The need for assistive devices among the majority of individuals with disabilities living in low-income countries are far from being met. Furthermore, the quality of much of what is offered is often not up to acceptable standards, and service delivery systems are underdeveloped or non-existent. Good intentions, charity and small-scale model programs characterize this arena in many poor countries. Individuals with disabilities are thus denied assistance that clearly could have increased their independence, level of activity and social participation, and thus their living conditions.

Research on assistive technology in low-income countries is scarce. We do have a broad picture of the situation, but lack more precise knowledge that could be of importance in policymaking, resource allocation and measures to improve the situation for individuals with disabilities in low-income countries. The four studies on living conditions among people with disabilities in Zimbabwe, Namibia, Malawi and Zambia provide unique representative information about disability in the Southern African Region, including information about use of assistive devices, quality aspects and service delivery.

The studies have indicated pronounced problems in service delivery when it comes to the quality of the devices (working conditions), instructions for use and maintenance which is to a large extent left to the owner of the device and his/her family or simply not maintained at all. Clearly this situation has negative consequences for the users of devices as well as their families, with increased risk for complications and secondary conditions due to wrong use or wrongly fitted devices (Armstrong et al. 2007). The role of Government vs. private sources on the supply side varies between the countries, and there are indications in the results that the relatively strong Government involvement in Namibia puts this country in a somewhat better position than the other countries in the study. There is, however, not sufficient information to conclude that the model in Namibia necessarily is optimal, as it is also the case that the "assistive device/service gap" in fact is comparatively largest in Namibia and actual use of devices is lower than Zimbabwe and equals the figures from Malawi. The relatively positive results from Namibia may simply reflect a comparatively better economic situation and that there is more money in place to import devices. The results are rather indications of a service delivery system in the region that is fragmented and that does not deliver the services needed to the population in question.

The four data materials have shown a large "needs gap" with regards to assistive devices, and that females and rural dwellers have less access to this technology. May-Teerink's observation with regards to gender is thus confirmed. Furthermore, as the demographic profile of most low-income countries is characterized by a large proportion (often around 50%) of children and adolescents, the results indicate a pronounced need for taking a children's perspective in future service delivery systems.

With regards to school attendance and employment, the results bring support to May-Teerink's (1999) findings from Uganda and other literature on this issue (Armstrong et al. 2007). While the analyses here show that there is a positive association between having an assistive device and school attendance and having a job or work experience, this is, however, not sufficient to conclude that there is a simple cause and effect relationship. Other mechanisms may also be present, but the indication is clear and in line with previous findings and assumptions.

It is vital to promote the possibilities for people with disabilities to take part in education, employment and social activities in society using AT as a tool in order to improve their quality of life. The use of assistive devices is influenced by general knowledge, local supply, technical competence, adaptation to individual, follow up and environmental conditions, as well as local services. There is a chain of links that has to be fulfilled so that the assistive devices can be of best use in different contexts.

Although in no way sufficient, there are currently many ongoing, often small-scale, programs for production, import and distribution of assistive devices in low-income countries. There is a need for studying the many different models in order to extract the most promising experiences. In this way ongoing and new programs can learn from each other. It is further necessary to strengthen research-based knowledge about the role of assistive technology in reducing the link between disability and poverty in order to develop and improve current practice further. Assistive devices should contribute to improve the opportunities for individuals with disabilities to be active integrated members in their local community and in the society in general.

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Chapter 11
Childhood Disability in Burkina Faso and Sierra Leone: An Exploratory Analysis

Cliona O'Sullivan and Malcolm MacLachlan

11.1 Introduction

In 2006, close to 9.7 million children died before their fifth birthday worldwide and 4.8 million of these deaths occurred in sub-Saharan Africa. The main causes of global child mortality are: neonatal disorders (33%), diarrhoea (22%), pneumonia (21%), malaria (9%), AIDS (3%), measles (1%), other (9%) and unknown causes (1%). Neonatal disorders are those which occur in the first month of life and include: preterm birth, severe infections, asphyxia and congenital abnormalities (Lawn et al., 2005). The highest rates of neonatal mortality are found in sub-Saharan Africa (UNICEF, 2008a; Lawn et al., 2005).

Whilst statistics pertaining to mortality rates for various illnesses are available, little is known about the survivors of these illnesses, although many are left with significant impairments and disability. For example, in Burkina Faso, West Africa, the World Health Organization reported more than 22,000 suspected cases of meningococcal disease including 1,490 deaths between January and April 2007 (WHO, 2007a). However, there is no data available pertaining to residual disabilities experienced by survivors of this recent outbreak of meningitis.

In 2000, world leaders agreed to a set of timebound and measurable goals for tackling poverty, hunger, disease, illiteracy, environmental degradation and discrimination against women by 2015; these goals are now known as the UN Millennium Development Goals, (MDGs). While disability was not specifically targeted in these goals, issues around disability are intrinsically linked to several of them.

For instance, with regard to the first MDG, "Eradicate extreme poverty and hunger," it is acknowledged that there is a strong correlation between disability and poverty (Mont, 2007). With regard to the second MDG, "Achieve universal primary education," there is evidence that people with disability in developing countries are more likely to have lower education levels and higher illiteracy levels than people without disability (UN Enable, 2008). Disability in childhood often means that a child is unable to walk

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to school or parents may feel that it is best to 'invest' in a non-disabled child's education. Moreover, schools often report that their teachers are not trained to teach children with special needs and therefore will not give a child a place in school.

The fourth MDG, "Reduce child mortality," is benefiting from increased international attention and there is evidence that child mortality rates are reducing (UNICEF, 2008b). However it is not yet known whether child disability rates are increasing as a result. It is not known whether the major causes of childhood mortality in low-income countries are also the major causes of childhood disability. It is feasible that while more children are now surviving illnesses such as meningitis and malaria; they may be left with residual disabilities as a result; thereby concurrently increasing childhood disability rates.

Accurate information regarding childhood disability is necessary to plan intervention programmes, provide resources for services, develop and monitor policies at a national level, and to compare disability rates and experiences internationally. Currently, there is a dearth of information on a range of childhood disability issues including the prevalence of disability; severity of disability, causes of disability, impact of disability on development, function and social integration; need for services; access to services and cultural views of disability in developing countries. Without such information, the lives of disabled children in low-income countries are unlikely to improve and the key goal of poverty reduction in low-income countries is unlikely to be achieved.

11.2 Measuring Disability

Measuring disability has proven problematic mainly due to the use of differing definitions and parameters. The World Health Organization's (WHO) International Classification of Functioning Disability and Health (ICF) describes the outcome of disability at three different levels (WHO, 2001). Firstly, as an impairment of a body function or structure; secondly; in terms of limitations of activities; and, finally, in terms of participation restrictions. This framework acknowledges the complexity of defining disability and has great potential for the collection of meaningful disability data.

Collecting disability data on children is even more complex as children naturally change from being fully functionally dependent from early infancy to being fully independent in late adolescence. The first two decades of life are characterized by rapid growth and significant changes in the physical, social and psychological development of children and youth (WHO, 2007b). The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) is derived from the ICF and is designed to record the characteristics of the developing child and the influence of its surrounding environment. The ICF-CY was published by the WHO in 2007 and uses a common language and terminology for recording problems involving functions and structures of the body, activity limitations and participation restrictions, manifested in infancy, childhood and adolescence and relevant environmental factors (WHO, 2007b).

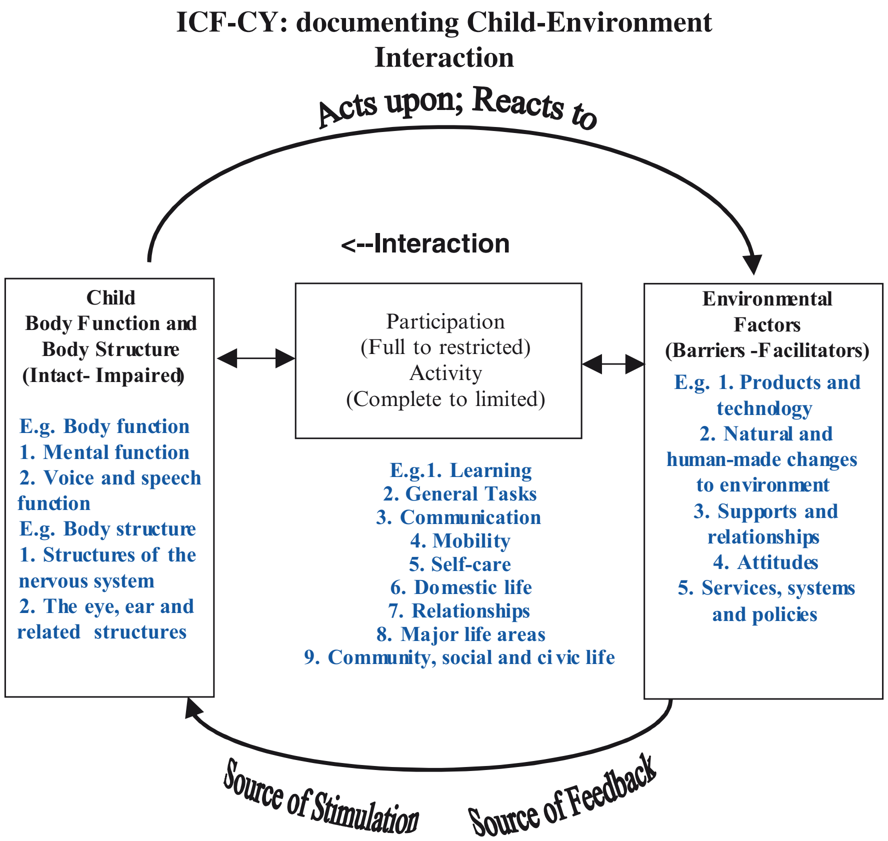

Fig. 11.1 ICF-CY Framework

The ICF-CY model (see Fig. 11.1) stresses three broad issues: body structures and function, participation, and the environment, and it explores how each of these issues is interlinked.

11.2.1 Body Structures and Function

During childhood and adolescence, there are variations in the timing of emergence of body functions and the acquisition of skills associated with individual differences in growth and development. Delays in the emergence of capacities may not be permanent but in some cases can reflect developmental delay or may indeed be a permanent manifestation of impairment at the level of body structure or function. Examples of body structures within the ICF-CY framework include structures of the nervous system and structures related to movement (Fig. 11.1). Examples of body functions include mental functions, Neuromusculoskeletal, and movement-related functions (Fig. 11.1). Generic qualifiers are used to indicate the extent or magnitude of an impairment of body structure or function (WHO, 2007b).

The qualifiers are rated according to the following scale:

0 No impairment
1 Mild impairment
2 Moderate impairment
3 Severe impairment
4 Complete impairment
8 Not specified
9 Not applicable

11.2.2 Activities and Participation

Activity is defined as "the execution of a task or action by an individual," while participation is defined as a person's "involvement in a life situation" (WHO, 2007b). Participation from the point of view of a child differs dramatically from that of an adult, and indeed also from that of an older child or adolescent. For example, in early childhood, a child's participation is dependent on family, service providers and its immediate environment. Examples of participation within the ICF-CY framework include communication, mobility, community, and social and civic life (Fig. 11.1). Two qualifiers are used to rate this component: a performance qualifier and a capacity qualifier. The performance qualifier describes what an individual can do in his/her environment and the capacity qualifier describes an individual's ability to execute a task or action. The qualifiers are rated in accordance with the following scale (WHO, 2007b):

0 No difficulty
1 Mild difficulty
2 Moderate difficulty
3 Severe difficulty
4 Complete difficulty
8 Not specified
9 Not applicable

11.2.3 Environmental Factors

Environmental factors are defined as "the physical, social and attitudinal environment in which people live and conduct their lives" (WHO, 2007b). A child's environment changes dramatically from infancy to adolescence and is related to their increasing functional capacity and independence. For example, a baby is significantly dependent on people in his/her immediate environment. Older children are closely connected to home and school life, while the environment of an adolescent includes broader aspects of society such as work or sport. Examples of environmental factors within the ICF-CY framework include products and technologies and attitudes (Fig. 11.1). The following is the negative and positive scale for the extent to which an environmental factor acts as a barrier or a facilitator (WHO, 2007b):

0 No barrier
1 Mild barrier
2 Moderate barrier
3 Severe barrier
4 Complete barrier
 +0 No facilitator
 +1 Mild facilitator
 +2 Moderate facilitator
 +3 Severe facilitator
 +4 Complete facilitator
8 Barrier (Not specified)
 +8 Facilitator (Not specified)
9 Not applicable

It must be noted that for all of these scales to be used in a uniform manner, assessment procedures have to be developed through research (WHO, 2007b).

This chapter describes an exploratory study of people's perceptions of childhood disability in Burkina Faso and Sierra Leone. Although these two countries are closely related geographically, they also have quite different profiles in relation to childhood disability, presenting the possibility of instructive comparison for understanding disability in the wider region. Sierra Leone has gone through a long period of civil war (1991–2001) and a severe humanitarian crisis. The war has created high levels of disability due to poverty and resultant ill health and also due to traumatic injuries such as amputations as a result of landmines and machete assaults. While Burkina Faso has been relatively politically stable for the past two decades, it suffers from chronic food shortages as a result of drought, desertification and falling export prices. The country also faces major challenges in health due to the spread of HIV/AIDS and outbreaks of meningitis, cholera and yellow fever. Services for children with disability in Burkina Faso are negligible; in 2006, there were 32 physiotherapists working in Burkina Faso, with most concentrated in the urban area of Ouagadougou (Handicap International Burkina Faso, Personal Communication, 2008). Table 11.1, which presents some descriptive statistics for these two countries, clearly illustrates their distinctive and contrasting profiles. Table 11.1 also contrasts these statistics with those of

Table 11.1 Health statistics of countries of interest

	Ireland	Sierra Leone	Burkina Faso
Human Development Index Ranking (of 177 countries)	5	177	176
Life expectancy at birth	78.4	41.8	51.4
Under 5 Mortality Rate (per 1,000 live births)	6	282	191
Infant Mortality Rate (per 1,000 live births)	5	165	96
Maternal Mortality Rates Adjusted (per 1,000 live births)	1	2,100	700
Physicians (per 100,000 people)	279	3	5

(*Source*: UNDP Report 2007/2008)

Ireland, as an example of a comparatively much wealthier country and the country where the authors of this chapter reside.

To eliminate poverty, the prevalence of disability must be reduced, through both interventions that prevent disability and the implementation of programmes that address issues around childhood disability like access to health care, education and acceptance and integration/participation into family and community life. While the problem of disability in this region is acknowledged by most government bodies and non-governmental organizations, the extent of the problem and its repercussions are unknown. The access to slim resources for health care is competitive and priority is often given to interventions that influence a reduction in mortality rates. For this reason, disability is often not on the agenda, and, if it is addressed, the resources are patchy, both in continuity and geographical distribution. Research that accurately reflects the issue of childhood disability is imperative if effective strategies to prevent and manage childhood disability in sub-Saharan Africa are going to be implemented. The objectives of the exploratory research to be reported here were to gain an insight into childhood disability in Burkina Faso and Sierra Leone, identify what research questions are important to examine from the point of view of a range of different stakeholders, and to determine the optimum methods of conducting such research. The proposed study objectives were explored with the relevant stakeholders and modified or expanded upon to incorporate their interests.

11.3 Methodology

Initial contacts were made via colleagues working in or who had previously worked in the sub-Saharan region: Irish NGOs including Trocaire, Concern, VSO, and Goal, and international NGOs working on disability or health issues, including Handicap International, Leonard Cheshire Foundation, International Service Ireland, Mercy Ships, and the World Health Organization. Once in-country, the following cohort were contacted: international and national NGOs working on disability and health issues, schools for children with disabilities, health and rehabilitation programmes, community programmes, universities, third level institutes, research institutes and ministries of health. The objectives of the project were explained to them and a variety of personnel were invited to participate in an interview. The interview was semi-structured and the interview template is outlined in Appendix.

Persons interviewed included parents/guardians of children with disabilities, children with disabilities, teachers, doctors, nurses, physiotherapists, occupational therapists, community leaders, development workers, programme directors, researchers and staff of health ministries. Answers to questions were given in French and English and were transcribed in English. Where local language was used, answers were translated by an interpreter into English. All interviews were conducted and transcribed by the first author, except interviews in local language. It was decided at an early stage that interviews would not be taped, as due to the nature of the project, ethical approval had not been sought prior to the visit.

Responses to questions during the interviews were transcribed by the first author. Questions were then categorized, using thematic content analysis, under headings or topics, (e.g. Causes of childhood disability). The various responses given to each question category were then themed for similar topics, (e.g. medical causes). The contents of each topic are then described in the text, (e.g. cerebral palsy).

11.4 Results and Analysis

In all, 36 interviews using purposive snowball sampling to ensure a broad range of stakeholders were included in the sample. The interviews were conducted over a 4-week period. Figure 11.2 outlines the number and the participants of interviews undertaken. Numbers are pooled for both countries to prevent identification of participants.

Seven broad topics emerged from the analysis of interviews: Disability policy; Meaning of disability; Prevalence of disability; Causes of childhood

Fig. 11.2 Number and Participants

disability; Impact of disability on the child, family, mother, community, nationally; What would most improve the lives of children with disabilities? and, finally, Challenges facing the disability movement.

11.5 Disability Policy

In Burkina Faso, while disability issues come under the realm of the Ministry of Health, there is no dedicated government post for disability issues. Issues around disability are driven by an umbrella organization of NGOs working on disability. In Sierra Leone, government responsibility for disability issues is divided between the Ministries of Health and Welfare. Similar to Burkina Faso, disability issues are highlighted by an umbrella organization of NGOs working with disability issues called SLUDI (Sierra Leone Union for Disability Issues). Respondents in Sierra Leone reported that disability issues were not a priority as efforts to improve mortality rates took precedence and therefore there was a lack of commitment to disability issues generally. Neither country has a government policy on disability.

11.6 Meaning of Disability

We use the ICF-CY conceptual framework to describe child disability through two case studies, one drawn from each country. This is one of the first published accounts of the use of the ICF-CY in a low-income country setting. These case studies are presented so as to give an impression of the meaning that people's disabilities had, both at the personal and community level. Tables 11.2 and 11.3 expand on the basic framework and illustrate how the classification system can be implemented to capture components of individual cases of childhood disability in Burkina Faso and Sierra Leone.

Table 11.2 ICF-CY classification system related to components of "J's" story

	Body function and structure	Participation and activity	Environmental factors
Level 1 classification	Mental functions	General tasks and demands	Attitudes
Level 2 classification	Emotional functions (b152)[a]	Managing one's own behaviour (d250)[a]	Individual attitudes of immediate family members (e410)[a]
Detailed classification	Regulation of emotion (b1521)[a]	Acting predictably (d2503)[a]	
Qualifier	3 – Severe impairment	3 – Severe difficulty	2 – Moderate barrier

[a] ICF-CY detailed classification codes (WHO, 2007b)

Table 11.3 ICF-CY classification system related to components of ‘P’s’ story

	Body function and structure	Participation and activity	Environmental factors
Level 1 classification	Neuromusculoskeletal and movement related function	Mobility	Products and technology
Level 2 classification	Muscle function (b730–b749)[a]	Changing and maintaining body position (d410–d429)[a]	Assets (e165)[a]
Detailed classification	Muscle tone function (b735)[a]	Sitting (d4103)[a]	Financial assets (e1650)[a]
Qualifier	3 – Severe impairment	4 – Complete difficulty	3 – Severe barrier

[a] ICF-CY detailed classification codes (WHO, 2007b)

11.7 Case Scenario 1

“J” is 11 years old and is cared for by her maternal grandmother. “J” has severe learning difficulties and behavioural problems. She is unable to speak and doesn’t understand questions or commands. Her grandmother is unsure of the cause but thinks that it may be since birth or since having meningitis as a baby. “J” has no physical disabilities – she can eat, dress and toilet independently but needs assistance to toilet and dress appropriately. However her grandmother worries about her behaviour and personal safety. “J” was rejected by parents; her parents separated soon after she was born and when her mother re-married, her new husband didn’t accept her. She then went to live with her father who didn’t care for her properly – Her grandmother used to see her running wild around the market. She worried about her safety and decided to look after her 10 months ago. In her community “J” is not well treated. Her neighbours mock her and other children laugh at her and call her “mad girl.” “J”s experience is conceptualised using the ICF-CY framework in Fig. 11.3.

11.7.1 Case Scenario 2

“P” is 1 year and 5 months old. When he was 1 month old, his parents noticed that his head was beginning to swell and he was diagnosed with hydrocephalus. A philanthropist paid for him to undergo surgery in another country. Further surgery is required in 2–3 years but his parents do not have the finances to fund this. Currently his communication is age appropriate. He has no head control, and poor muscle tone, but he can move his arms and put food in his mouth if his head is supported. He attends regular physiotherapy. He is accepted well into his family. His mother and father now both work part-time so that they can share his care. He is not well accepted in his community – he is perceived as a ‘snake’. His family have become isolated in their own community. His father worries about this isolation and they keep “P” cov-

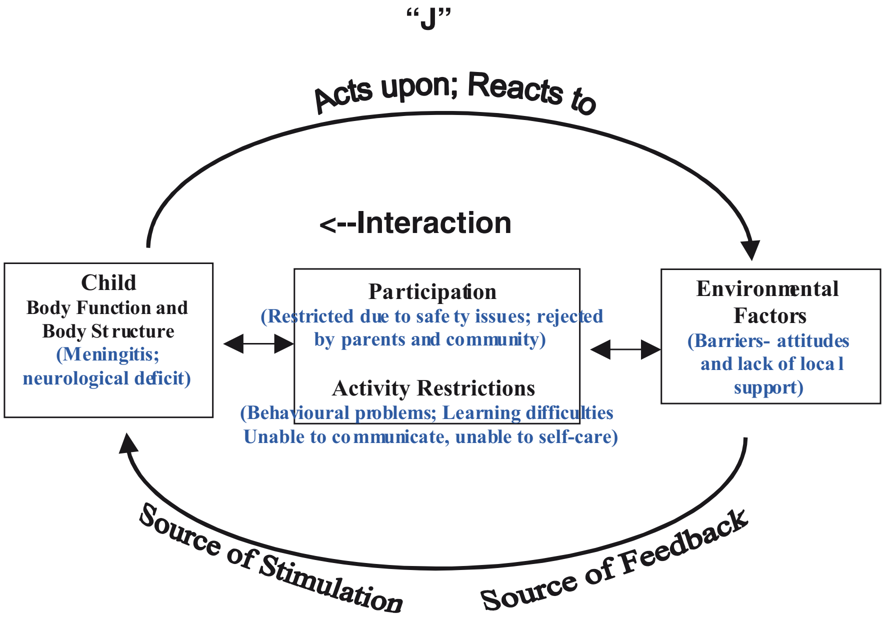

Fig. 11.3 Describing "J's" Experience using the ICF-CY

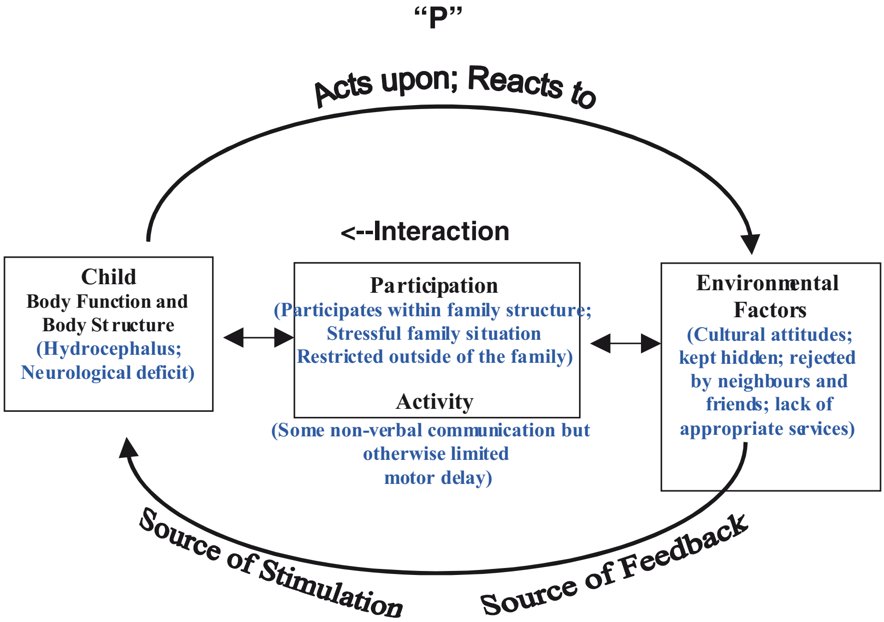

Fig. 11.4 Describing "P's" experience using the ICF-CY

ered when he is in public. His father worries that he will get too heavy to carry and that there are no services for him in their country. He hopes that they will get support from their friends and that “P” will get better in the future. “P”s experience is conceptualised using the ICF-CY framework in Fig. 11.4.

11.8 Prevalence of Disability

Respondents in both countries said that the respective prevalence of disability is unknown. In Sierra Leone, a question on disability was included in the most recent census – however the results were considered to be unreliable. The prevalence of disability in Sierra Leone is estimated to be between 7 and 10%.

11.9 Causes of Childhood Disability

The reported causes of childhood disability fell under four broad themes: medical, social, traditional/cultural beliefs and environmental causes. Medical causes include: cerebral palsy (as a result of antenatal and postnatal complications, difficult labours, meningitis or malaria), neonatal complications, meningitis, malaria, congenital deformities/club foot, accidents, amputations, fractures, malnutrition, polio, “high fever,” epilepsy, injections (polio virus), osteomylitis, measles, unknown-or sometimes “difficult to diagnose” problems, and blindness. Causes of blindness included river blindness, traditional medical practices, malnutrition, lack of Vitamin A, corneal ulcers, glaucoma, and war-associated physical trauma.

Social causes were mostly related to poverty, and included malnutrition, lack of vaccines, lack of mosquitoe nets, lack of knowledge, delay in seeking medical help, reduced access to medical services, transport issues and war. The Sierra Leoneon war resulted in more than 5,000 upper limb amputees and in Sierra Leonne upper limb amputation is regarded as a symbol of the conflict.

Most respondents reported that for some people, the causes of disability were closely linked to traditional beliefs and cultural values. Strong traditional belief systems associated with disability were evident in both countries. A disabled child was often regarded as punishment for something that parents or ancestors had done. Disability was often associated with witchcraft, as a result of a “spell” imposed on a child, their family or ancestors. One interviewee with polio since childhood reported: “I was in my twenties and a university graduate when I realized that my disability was due to a medical cause and not because of something that my ancestors had done.”

Attributions to environmental causes included the climate, for example increases in the incidence of meningitis during the Harmattan season in Burkina Faso. Other environmental causes included lack of sanitation, accessibility to medical services and poor transport due to difficult terrain.

11.10 Impact of Disability

Most respondents reported that children with disabilities were often isolated, neglected and marginalized at times both within and outside of their family. Traditional beliefs often dictated that disabled children were not considered human and were thought of as spirits or snakes. Disabled children were feared and seen as a sign of bad luck or an omen, resulting in them being hidden within their households. One interviewee reported: "When I was 6 or 7, one morning I went to buy bread at the market – however the man refused to serve me as I was his first customer and it would be bad luck for the day."

As a result, there was a huge stigma associated with disabled children and their families. Access to education or basic stimulation was therefore denied, meaning that their full potential could not be realized. Children with disabilities were often subject to abuse and in both countries it was reported that they were sometimes abandoned by one or both parents. In some instances, children with physical disabilities were used as beggars and provided income for their families. In one situation a teenage girl with severe physical impairments was fully supported by an NGO to attend school – however her mother refused this help, as she was the main breadwinner for the family.

The impact of a disabled child on the family was also negative. Traditional beliefs dictate that people believe that having a disabled child is punishment for something that a family member or their ancestors have done in the past. Families are marginalized and "mocked." Having a disabled child creates many tensions within the family. There are fears over what people think, and/or blame is apportioned. It also places an extra financial strain on families. A parent may have to stay at home from work to look after the child. Medical or rehabilitation services that may be available are costly. One respondent reported that "a disabled child is not a good investment*."*

Some interviewees highlighted how mothers were often marginalized by their spouse and the community, which placed huge stress on the mother. One interviewee reported: "I was put in residential care at the age of four and didn't meet my mother again until I was nearly 30 – my father had divorced her because she had given him a disabled child." Having a disabled child often meant that mothers had little time for other children. Mothers were often ill equipped to deal with a disabled child and it often affected the productivity and income generation of the mother.

The impact of childhood disability on the community mostly related to traditional belief systems. It resulted in gossip and fear within the community and strong community bonds could be broken as families were rejected. It was perceived that at a national level, childhood disability put a strain on public resources, imposed poverty on families and ultimately limited development.

11.11 What Would Most Improve the Lives of Children with Disabilities?

The responses to this question fell under three broad themes as follows: social inclusion, education, and rehabilitation. The most common answer to the above question was the idea of creating a "disable aware society." It was reported that there was a need to raise awareness and knowledge in the general population that “children with disability have potential to be useful in society.” It was acknowledged that negative attitudes and beliefs had to be addressed. Methods that could be employed to achieve this included: education through the media and through sport, employing more people in the area of integration, and the use of role models (e.g. involving people with disabilities who have had successful careers, etc., in the awareness campaign). Other areas included improving infrastructure, transport and general accessibility for people with disabilities. Some respondents also called for commitment from the relevant ministries including the development of policies and legislation that would ultimately protect children with disabilities.

It was widely acknowledged that children with disabilities have reduced access to adequate education in both countries. In both Burkina Faso and Sierra Leone, many NGOs are advocating inclusive education, whereby children with disabilities can attend mainstream schools and special needs schools are coordinated or amalgamated with mainstream schools. Some of the challenges to this include the lack of specialist teacher training and lack of or unreliable government funding.

A high proportion of births in both countries are attended by traditional birth attendants (TBAs). It was reported by many respondents that there is a need for more training and resources for community midwives, TBAs and traditional medicine practitioners, particularly in the area of early recognition of signs of foetal or maternal distress. The need for more comprehensive community-based rehabilitation (CBR) and primary care coverage was also highlighted. Lack of human resources and retention of well-trained local health professionals in both countries was also a challenge – it was reported that in Sierra Leone, out of a total of 30 medical graduates in 1 year, only six remained in Sierra Leone 1 year later.

Resources for all health services should be adequate so that services are provided free of charge. There is also a need for resources for adequate equipment, maintenance and infrastructure. While a few respondents advocated residential care for children with disabilities, most were in favour of supporting children and their families so that they could be cared for at home and therefore didn’t become institutionalized; “Organizations should not take children out of the outside world as it is harder to get back in later in life.”

11.12 Challenges Facing the Disability Movement

The challenges facing those in the disability movement fell under five broad themes: government commitment, cultural attitudes and beliefs, financial issues, education and mental health. Respondents in both countries reported that disability is not a priority and as a result, government funding for disability services is insufficient and unreliable. There was a need for national policy, legislation and monitoring. There was a strong feeling that the negative social and cultural beliefs associated with disability permeated all levels of society and needed to be addressed.

The lack of adequate funding or unreliable funding for disability resulted in poorer quality of services, poor training levels and staff retention problems.

There was also a lack of awareness of existing services. Corruption was also reported to be a problem. Insufficient funding means that there are poor training levels for staff working with people with disability, particularly a lack of specialist training (e.g. specialist teacher training or training for technical support). This adds to staff retention problems. Lack of access to education for children with disabilities is also currently a major challenge.

One of the biggest challenges facing the disability movement, particularly in post-war Sierra Leone, is mental health issues. During the war, traumatic incidents such as machete assaults, rape and the high level of drug-use and alcohol abuse by rebels means that a high proportion of Sierra Leoneons are suffering from psychological illnesses such as stress, depression and addiction. Current research being carried out in-country has already noted high levels of depression in Sierra Leone. A particularly vulnerable sub-group are the former child soldiers of Children Associated with Fighting Forces (CAFF). In Sierra Leone, it is estimated that there were between 1,700 and 3,000 child soldiers during the war, some of whom joined forces as young as 5 years (Medeiros, 2007). There is evidence that many of the worst atrocities committed during the war were committed by children, often under the influence of drugs and alcohol (Medeiros, 2007). These children are now teenagers or young adults and many have been marginalized and not accepted back into their communities, as they are feared. Coupled with this is the fact that many suffer from depression and drug and alcohol addictions and there is anecdotal evidence of a high suicide rate within this cohort. The lack of services for mental health in Sierra Leone is startling: There is currently one psychiatrist in Sierra Leone and one addiction centre in Freetown.

11.13 Research Needs

In addition to getting a better understanding of the circumstances of persons with disabilities in Sierra Leone and Burkina Faso, we also sought to identify at least some elements of a possible research agenda. In doing so it is clearly important to include the point of view of all stakeholders (children, parents, people working with childhood disability, NGOs, ministries, universities). As a result of the interviews, numerous topics and ideas for pertinent research were evident. It was widely agreed that the outcome of research should promote efficient and effective progress in the introduction of programs that reduce the burden of childhood disability. Interviewees felt that current research was often of poor methodological quality and that relevant findings didn't always filter down to those working on disability issues at grass roots level. It was also acknowledged that research undertaken should be communicated to the relevant Ministries so that findings can be acted upon systematically, ensuring that information was also provided at a national level.

Table 11.4 summarizes the research questions identified and the tick marks outline whether these research questions arose from interviews in-country or from gaps in the literature identified by the authors.

Table 11.4 Summary of research topics

Topic	Source: Interviews in West Africa	Source: Literature
Prevalence of childhood disability	√	√
Type		
Regional variation		
Causes		
Cultural attitudes and beliefs towards children with disabilities	√	√
Optimum methods of raising awareness of issues relating to childhood disability	√	
Existing services and programs working on childhood disability issues	√	√
Effectiveness		
Quality		
Service mapping		
Prevention strategies		√
Legislation and policy	√	√
Needs assessment	√	
Parent-related research	√	
Resources spent on disabled child		
Perceptions		
Obstacles		
Child development	√	
Europe V West Africa		

In addition to rich qualitative studies, randomized control trials and longitudinal studies are needed, along with a long-term commitment to this chronically underserved area from funding agencies and universities. Research should incorporate collaboration between universities, international and national NGOs and Ministries of health, as well as other Ministries that provide services that can promote the inclusion and participation of persons with disability in society. Such research also needs to take into account not only the relevance of local cultural practices but also the power relationships between disabled and non-disabled people, and between different institutions within and between different countries (MacLachlan et al., 2010). There are also significant barriers to research that need to be overcome and these include financial constraints, the fact that funding for disability has to be sought in a very competitive market, a lack of suitably trained personnel in-country, language differences, poor infrastructure, as well as access to children with disabilities and their families.

In conclusion, there is no doubt but that the life of a child with a disability in both Burkina Faso and Sierra Leone is a difficult one. Childhood disability can immerse vulnerable families in poverty. Cultural beliefs dictate that children may be neglected, isolated and subject to abuse. The lack of appropriate health and rehabilitation services and opportunity for education, coupled with a lack of funding and commitment from government ministries and donors, serve to confound negative perceptions associated with disability and to make the attainment of basic human rights for persons with disability frustratingly difficult.

Acknowledgements We acknowledge the Health Research Board, Ireland, and Irish Aid for funding this project.

Appendix: Interview Template

Introduction

My name is Cliona O'Sullivan and I work as a lecturer in the School of Physiotherapy and Performance Science at University College Dublin. I have worked as a clinical physiotherapist for 9 years and for that reason, I am experienced in rehabilitation of disability. I am very interested in issues around disability in developing countries since working in Ouagadougou, Burkina Faso, where I worked in a local NGO for children with disabilities.

As we know, in Sub-Saharan Africa, one in every five children dies before their 5th birthday. The main causes of global child mortality are: neonatal disorders, meningitis, malaria, diarrhoea, pneumonia, AIDS, measles and other, sometimes unknown, causes. While we have valid statistics on the causes of child mortality, little is known about the survivors of such illnesses, although many are left with gross neurological difficulties, among other things.

Because there is so little that we know about such children, I am interested in investigating/studying/researching these issues a little further here in Burkina Faso/Sierra Leone. I am interested in people's views about the most pressing area that needs research and most effective way to carry out research in this area. I am hopeful that by carrying out good research, we will gain answers to these questions. By knowing this information, it is then possible to implement interventions that will prevent disabilities, reduce disability and improve functional abilities and social participation.

The purpose of my meeting with you is to gain an insight into disability in Burkina Faso/Sierra Leone through your eyes and to gain a better understanding of the causes of disability and the problems faced by children with disabilities and their families in Burkina Faso/Sierra Leone. I am also interested in your opinions on the best way to engage children with disabilities and their parents to participate in research about disability.

The objectives of my visit to Burkina Faso and Sierra Leone are to:

1. Identify the need for research in this area, specifically what research questions are important to examine from the point of view of all stakeholders (children, parents, people working with childhood disability, NGOs, ministries, universities)
2. Identify the best way to conduct such research in the context of Burkina Faso and Sierra Leone (methodologies/difficulties/obstacles)?
3. Identify the best way to form collaborations with NGOs and local universities

Questions

Families

Do you have a child with a disability? Gender/Age?
What was the cause of the child's disability? What happened/Describe events.
How would you describe the child's disability? What can the child do?
What are they unable to do and what do they need assistance with?
Does the child interact with the family/siblings? Play?
Does your child go to school? Do you think your child will be able to go to school? If not, what are the reasons?
Do you have help with the child? Family/community/health services/local or traditional healers?
Do you think that the disability will get better?
How do you think that the child's quality of life will improve?
What are your aspirations and hopes for the child?
In your opinion, how has the disability of your child affected your life/the life of the rest of your family?
In your opinion what is the area/s that need research? What are the questions that need to be answered?
In your opinion, how would you carry out this research?
What are the solutions?
What is disability?
How are people with disability seen by other people in your community?
What would most improve the lives of people with disabilities?

Children/Adolescents:

What age are you?
How would you describe your disability?
What caused your disability? Can you remember how it happened?
What are your abilities? What can you do? What are your skills?
What do you have difficulty doing? What do you need assistance with? What kind of assistance do you need?
Do/did you go to school? If not, why not?
In your opinion, do you participate in the normal activities that a boy/girl of your age would do?
What would you like to be able to participate in? What are the barriers to this at the moment?
Do you work? What do you do?
What are your aspirations and hopes for the future?
In your opinion what is the area/s that need research? What are the questions that need to be answered?

What is disability?
How are people with disability seen by other people in your community?
What would most improve the lives of people with disabilities?
In your opinion, how would you carry out this research?
What are the solutions?

NGO/Ministries/University:

Do you work in the area of disability? Describe your work in this area?
What are the aims or the philosophy of your work in this area?
Are there statistics on the prevalence of childhood/adult disability? What are your opinions on the causes of childhood/adult disability/impact of childhood/adult disability/concerns for the future/obstacles or influencing factors to full participation?
Has childhood disability been measured in Burkina Faso/Sierra Leone? Is there a question on disability on the census?
In your opinion what is the area/s that need research? What are the questions that need to be answered?
In your opinion, how would you carry out this research? Would you be interested in collaborating/facilitating research in this area?
What are the solutions?
Are there reports/publications in this area?
Similar work carried out by other associations?
What is disability?
How are people with disability seen by other people in your community?
What would most improve the lives of people with disabilities?

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Chapter 12
Education, Disability, and International Development

Petra Engelbrecht, Ansie Kitching, and Willy Nel

12.1 Introduction

One of the biggest challenges facing education systems throughout the world is that of inclusion in education. In general, inclusion is about a philosophy of acceptance where all people in society are valued and treated with respect (Carrington and Robinson, 2004) and in education there is specific emphasis on the development of inclusive learning communities in which diversity is acknowledged and welcomed. In wealthier countries inclusion in education efforts tend to focus on the merger between well-resourced segregated forms of special schooling for learners with disabilities with equally well-resourced mainstream education facilities. In economically poorer countries, however, where a separate education system for people with disabilities has never been fully developed and where mainstream education lacks resources, efforts tend to focus on all learners who are unable to access education. Compounding the challenge to building inclusive education communities globally is the prevailing understanding of why some learners experience difficulties with learning. According to Howell (2006), this understanding is deeply rooted in a historical assumption that learners of all ages can be identified and classified through notions of what is normal and abnormal.

Against this background, this chapter will discuss the global development of inclusion in schooling as well as inclusion in higher education for persons with disabilities in more detail. In conclusion, the integration of research, policy and practice will be evaluated.

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12.2 Inclusion in Schooling and Disability

12.2.1 Background

The development of education for people with disabilities has involved specific stages during which education systems have explored a variety of ways to respond to children with disabilities. In most countries, there has been a tendency to identify and categorize school children through notions of "normality" and a strong belief that the learning needs of children with disabilities should be met with additional specialized support or intervention. A result of this distinctive categorization was the development of a dominant mainstream school system for "normal" learners and a secondary educational system for learners with "special needs" (Howell, 2006). The first 70 years of the twentieth century were characterized by the "medical model" (or deficit discourse), which conceptualized those with disabilities as "abnormal" and in need of the attention of specialists in "special" schools. Placement in special educational settings therefore excluded groups of children from the mainstream of education and of society in the genuine belief that this was in their best interests (Green and Engelbrecht, 2006).

12.2.2 Movement to Inclusive Education

Since the 1970s the appropriateness of separate systems of education has been challenged, both from a human rights and an effectiveness point of view. Opponents of the medical model argued that this way of looking at disability has contributed to the ongoing discrimination against and marginalization of people in a number of ways. For example, by focusing on the impairment and the "objective" degree to which a person cannot undertake some activities in the "normal" way, attention is drawn away from issues of discrimination and the rights of people with disabilities. People with disabilities and the organizations that they have formed also questioned the notion of disability as an individual tragic occurrence that classifies a person as incapacitated in some way and dependent on the good will of others (Howell, 2005). Segregated special education was increasingly condemned as part of an oppressive social system through which people with disabilities were excluded from participation in society (Barton, 1998). For several years, "mainstreaming" or even "integration" were recommended strategies for addressing this concern. Both involved placing specific selected learners with disabilities in mainstream schools under certain conditions, but neither approaches assumed that all learners have an unquestioned right to belong in a mainstream school and classroom or that schools should adapt to the needs of their pupils (Green and Engelbrecht, 2006).

Increasingly it was argued that perspectives that assume that the sources of difficulties in learning are *within* the learner ignore environmental influences (e.g. home and school influences) on learning and do not explain the quality of learning and educational difficulties that can arise from sources other than impairment (Ainscow and César, 2006). If environmental influences are taken into consideration, a definition of disability must describe the relationship between a person with an impairment and the society or environment of which they are part, the so-called social model of disability. A social model of disability derives from social and political understandings of disability, where the focus is on the nature and organization of society and its response to people with impairments rather than on the nature/extent of the individual's impairment (Howell, 2005).

The international development of inclusive education for people with disabilities is therefore essentially based on a social model of disability and the rights of children with disabilities to be included in mainstream schools. The rights discourse lends itself easily to international declarations of which the Salamanca Statement on Special Needs Education (UNESCO, 1994) has exerted a powerful influence on education policies across the world (Artiles and Dyson, 2005). The Salamanca Statement (UNESCO, 1994), for example, argues that mainstream schools with an inclusive orientation should be the most effective way of combating negative attitudes and can contribute to the development of an inclusive society and achieving education for all. Subsequently there have been considerable efforts globally to move educational policy and practice in a more inclusive direction. It is also more widely recognized that reorganizing mainstream schools through school improvement strategies is an effective way of ensuring that all children, and not just those with disabilities, can learn effectively (Ainscow and César, 2006).

The development of inclusive practices in schools is contextually determined by the social learning processes that influence people's actions as well as the thinking that informs these actions in specific contexts (Ainscow et al., 2006; Green and Engelbrecht, 2006). However the following key elements in the implementation of inclusive education that tend to feature strongly in all contexts have emerged internationally:

- Inclusion in education is a never-ending search to find strategies that effectively address diversity in schools.
- Globally, inclusion in schools is concerned with the identification and removal of barriers to participation in educational settings.
- Inclusion is not only about the presence of children with disabilities in mainstream schools but also about the quality of their learning experience (Green and Engelbrecht, 2006).

Even a cursory review of literature on the development of inclusive schools leaves one in no doubt that despite the high status the concept of inclusion in education has gained and the successful inclusion of children with disabilities in some schools, challenges regarding implementation remain complex. Issues of quality, efficacy and morale of teachers in implementing inclusive education policies are key, and differing notions of equity may increase complexity. Entrenched attitudes and discriminatory practices towards people with disabilities play a major role in the development of inclusive school communities in various countries (Howell, 2005, 2006; Carrington and Robinson, 2004; Green and Engelbrecht, 2006).

Applying the social model of understanding disability implies that the relationship that exists between a person and the society in which he or she lives is dependent on how that society is structured and functions. If the society is critical of differences, it is likely to be more difficult to remove the barriers that restrict access for children with disabilities to inclusive schooling.

12.2.3 Inclusion at Tertiary Level and Disability

12.2.3.1 Background

The inclusion in higher education of students with disabilities has become a matter of concern in recent years. As discussed in the previous section, the deficit discourse that stigmatized, disempowered and marginalized people with disabilities is being replaced by a discourse that focuses on the rights of people with disabilities to take up their rightful place in society. These discourses are useful when examining the participation of students in higher education.

For students with disabilities, the first barrier to higher education can be the schooling system they were exposed to and the advice they received regarding future career paths. That is, even if they do complete their schooling they would not have completed the necessary subjects at the appropriate level for entry into a higher education institution. These problems are most often informed by attitudes within schools that reinforce the notion that people with disabilities do not have a future in higher education. Other barriers arise from the way in which universities are structured and function, the role that higher education plays within a specific society as well as the attitudes that inform selection criteria (Howell, 2005; Parker, 1998; Ryan and Struhs, 2004). Furthermore, those responsible for the entry and participation of people with disabilities in higher education frequently lack sufficient knowledge to carry out their responsibilities under disability discrimination legislation (Ryan and Struhs, 2004).

In some countries, especially the wealthier countries, initiatives to promote greater inclusion have had some success in improving access to higher education and raising awareness across the sector of the need to ensure full participation by learners with disabilities once they enter the university (Parker, 1998). Legislation and government education policies, for example in the United Kingdom, United States of America and Australia, have facilitated the inclusion of learners with disabilities into higher education but negative attitudes still play a role. Evidence of what was termed “a shortfall in the attitude budget” was found in an inquiry in Australia into the effectiveness of programmes aimed at students with disabilities across the spectrum (Senate Employment, Workplace Relations and Education References Committee, 2002). Results indicate that students in higher education are frustrated by the fact that they have to invest time and energy in order to negotiate their requirements with staff and lecturers with an additional inhibiting factor, the requirement that prospective students at Australian higher education institutions have to self-identify their disability status. In less wealthy countries, for example South Africa, the failure of university management to either formulate or implement policy has been exacerbated not only by negative stereotyping but also by the lack of funding to implement effective learning support strategies in higher education (Howell, 2005; Matshedisho, 2007).

12.2.4 Higher Education, Disability and the Professions

In addition to the general barriers students with disabilities experience in entering higher education, those who choose a professional career, for example in engineering, law and medicine, experience additional barriers. Lack of clarity regarding decision-making about admission criteria as well as the position of practical placements has, for example, been problematic. Where professional or registration bodies stipulate that certain competencies need to be met before practicing rights are granted (e.g. nursing), universities are placed in the difficult situation where the needs of their students with disabilities, who may require adjustments or accommodations to facilitate the demonstration of such competencies are not met (Ryan and Struhs, 2004). Regarding admission criteria, Roberts (2004) for example found in a study on four medical schools in the United Kingdom that there was no standardization regarding admission criteria for students with disabilities. This means that an applicant with the same disability may get accepted at one medical school while rejected at another. The result has been that people with disabilities are globally underrepresented in the professions, with lower academic achievement and employment success (Foreman et al., 2001).

Without question, successful job entry, job advancement and attainment of leadership roles in the workplace are dependent on the quality of education and training individuals have received. The importance of university-wide policies and practices that ensure that students with disabilities derive maximum benefit from their educational opportunities cannot be overstressed (Foreman et al., 2001).

12.2.5 Postgraduate Training and Disability

Concurrent with the growing criticism of the medical model, a growing awareness of the rights of people with disabilities and an increasing need for in-depth knowledge on support for people with disabilities, the discipline of disability studies on postgraduate level has emerged as an independent academic field within higher education (Lorenzo et al., 2006).

The development of postgraduate training programmes in disability studies has not been limited to specific academic fields. Internationally, programmes exist in the fields of education, counselling psychology, social work as well as nursing and dental training. The programmes seem to have become more generic in nature over the years.

Sweeney and Dalton (2007) identified similarities in contemporary international perspectives that indicate a clear shift of focus from a medical-based approach to a more holistic multi-disciplinary approach in disability studies. They recommend that compartmentalization in terms of disciplines, ideas and practice should be challenged and changed if disability studies is to go forward and offer an alternative, effective perspective. In view of the above arguments it seems imperative that postgraduate training in working with people with disabilities moves towards inter-professional training since it provides the students with opportunities to learn some specific information about interacting with the other professions and gain knowledge about the roles, knowledge and contributions that can be made by professions other than their own (Cook, 2005).

In the development of postgraduate programmes it is also important to emphasize issues that are important to people with disability, rather than address the needs of academics and scholars of disability. To ensure the relevance of themes addressed in postgraduate studies on disability it is imperative therefore to have a collaborative and multi-agency approach (Parkinson, 2006), through acknowledging the input of people with disabilities and sustaining healthy links with academics, campaigners and disability organizations. Three important focus points for learning and teaching of postgraduate students include an understanding of disability, an awareness of the experience of people with disabilities and a contribution to social change (Parkinson, 2006).

Barton and Olivier (2000), warn that “Fashionable issues like postmodernism, representation and embodiment may well turn on disability studies scholars but their immediate relevance to the struggles of people with disabilities to lead a decent life are hard to justify”. The same authors suggest that courses in disability studies should critically engage with the writings, poetry and songs of disabled scholars, writers and activists from within the disability movement. This will ensure that they are in touch with important ideas, insights, understandings and questions that concern the disabled community. They also suggest the involvement of people with disabilities in the designing and teaching of such courses, but at the same time warn against tokenism. Parkinson (2006) furthermore emphasizes the importance of a client-centred approach rather than a service-driven approach to the training of postgraduate students. Recent literature (Parkinson ,2006) refers to the emerging affirmative model that embraces a positive view of disabled identities that are social rather than tragic in type, based on the belief that there are benefits of being disabled and impaired in terms of both lifestyle and life experiences. This approach appreciates that not all people with disabilities look upon themselves in the same way, and therapeutic practice needs to reflect the range and variety of perspectives of self and society when constructing a context in which to explore their own attitudes to disability and impairment.

The development of postgraduate programmes on the African continent brings the issue of the strong Eurocentric basis of current theories and literature to the fore and addresses the necessity to focus on Afrocentric approaches in development of postgraduate programmes in order to accurately reflect local and regional experiences Priestly (2005). A programme introduced at the University of Cape Town, South Africa, in March 2003 is an example of a collaborative approach to such a programme. This programme developed through dialogue between the academic community at the University, the Centre for Disability Studies at the University of Leeds and disability rights movements in South Africa. The aim of the programme is to foster a research community that will mobilize and inform disability transformation in society (Lorenzo et al., 2006). The postgraduate students enrolled in the first year of the programme included students from the fields of occupational therapy, speech therapy, nursing and human resources and art. The contents of the course are multidisciplinary in nature, involving academics from sociology, psychology, health and rehabilitation.

12.3 Conclusion

Education is recognized as crucial to the aspirations of people with disabilities to enjoy full and equal opportunities (O'Connor and Robinson, 1999). The global focus on the rights and equity of people with disabilities in education has resulted in a number of stated intentions and written policies in various countries. Throughout this chapter it was indicated that despite the magnitude of written and stated policies regarding the inclusion of people with disabilities in education on all levels, ample evidence exists which indicates the lack of successful outcomes of current policies and the implementation of research results on implementation issues (Dyer, 1999; Chafouleas and Riley-Tillman, 2005; Vlachou, 2004; Welgemoed, 1998).

One of the most critical issues in implementing inclusive education policies is the abstract and idealistic articulation of rights and equal opportunities in policy documents, which through their abstraction have been disconnected from the composition of the education contexts in which policies must be implemented. Through their abstraction, policies fail to take the implications of dominant discourses for implementation into consideration and are constrained in particular by the fact that no strategies for bringing about change are included (Vlachou, 2004). The dominant and persistent societal focus on an individual deficit approach that is detrimental and counterproductive to the successful implementation of the inclusion of people with disabilities in education systems continues to dominate education. By doing so, it totally overlooks disabling barriers of an institutional, attitudinal and ideological nature and directly affects the implementation of inclusive educational policies (Vlachou, 2004).

It is clear that enforcing implementation through policy change at a macro level cannot change human behaviour, values and attitudes (Welgemoed, 1998). Enhancing the recognition and acceptance of the basic rights of all learners with disabilities to be accommodated in inclusive education communities on all levels involves an acknowledgement of the complexity of the dynamic interactions between societal as well as contextual factors and continuous efforts to integrate policy and research results in the daily work of school and university-based practitioners. Bridging the gap between the idealism expressed in policy documents and the realities of education systems is a challenge that needs to be addressed on an ongoing basis.

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Chapter 13
Listening to the Voices of Disability: Experiences of Caring for Children with Cerebral Palsy in a Rural South African Setting

Joanne Barratt and Claire Penn

> *For some of these people it is very difficult. They do not have help and they do not have money and there is nobody to help them care for the child but what must they do? This is the child that God has given them.*[1]

13.1 Introduction

For the majority of persons living with disability in South Africa, the experience is inexorably linked with huge challenges imposed by poverty and access, together with the burden imposed by other diseases and by profoundly restricted choices. Nowhere did this lesson become clearer than in our research conducted in Tonga, a rural village in the Nkomazi municipality of the Mpumalanga province of South Africa, which has recently been defined as a "pocket of poverty" (Nkomazi Spatial Development Framework (2003)).

After a year's community service as a speech and hearing therapist in this community, the first author was granted access to this community in 2006 to gather material for a research project using ethnographic methods. These methods enabled a profoundly powerful snapshot of the link between disability and daily life; the interface between historical, social and demographic factors; and the relationship between the individual and the community, which are described elsewhere in this volume.

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[1] Comment made by the research mediator after collecting data for this study.

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In this chapter we will foreground the narratives of the participants of this research in an attempt to demonstrate the relationship between these variables and to inform intervention and training models. While the focus of our study was on the condition of cerebral palsy, it became clear that the voices of this study seemed to echo those of many other individuals and communities living with the challenge of disability and highlights the relationship between disability and contextual aspects such as poverty and social exclusion.

13.2 Service Provision in a "Uniquely South African" Setting

13.2.1 Childhood Disability in South Africa

In South Africa, between 5.2 and 6.4% of children under the age of 9 years are estimated to be affected by motor, sensory, or intellectual disabilities (Christianson et al., 2002; Couper, 2002). One of the most common childhood disabilities, particularly in rural areas, is cerebral palsy, which is estimated to affect as many as 8% of live births (Christianson et al., 2002). Significantly, 32% of the causes of cerebral palsy in rural areas are postnatal and include brain injury resulting from, among other factors, meningitis, malaria and gastroenteritis and subsequent dehydration (Potterton, 1996).

Socio-economic variables which contribute to disease exposure and healthcare access, place children at risk for disability in South Africa, and poverty plays a pivotal role in predisposing neonates to conditions which may result in cerebral palsy. Mothers, particularly in rural areas, often do not have access to prenatal care, have limited health literacy, are exposed to the spread of infectious diseases, such as HIV/AIDS and tuberculosis, and do not take in sufficient nutrition (Levin, 2005; Nutbeam, 2000). Additionally, there may be limited access to running water and high levels of stress related to poverty (Bhorat et al., 2006; Hutcherson, 1991). Thus children in poor families are more at risk for acquiring chronic health problems and disabilities, and caring for these children imposes substantial costs on their families.

13.2.1.1 Setting

The small rural village of Tonga falls within the Nkomazi municipality in the Mpumalanga province of South Africa and is situated approximately 30 km northwest of the Mananga border post into Swaziland and approximately 40 km west of the Mozambiquan border. The Nkomazi municipality forms the eastern section of the Lowveld region and is located approximately 350 km east of Gauteng, consisting of a wedge of land between the Kruger National Park in the

North, Mozambique in the East, Swaziland in the South, and the Mbombela and Umjindi Municipalities in the west. The closest towns are Malelane, which lies 45 km northwest of Tonga, and Komatipoort, which lies 60 km northeast of Tonga. The Nkomazi municipality is made up of two areas with vastly different characteristics in terms of economic and social development. Tonga falls into the Kangwane region in the south, and has approximately 350,000 people living in approximately 45 informal settlements. The majority of inhabitants are black SiSwati speaking residents (Nkomazi Integrated Development Plan, 2006–2007).

According to the Nkomazi Spatial Development Framework (2003) the last national election reflected that almost 90% of the adult population's political persuasion is to the African National Congress (ANC). There is very little land ownership as all land belongs to the State. All settlements are growing at a rapid rate and in the absence of proper planning the settlements are expanding in an uncontrolled manner. Urban sprawl is rife and places stress on existing infrastructure and has the effect of sustaining the current state of underdevelopment (Nkomazi Spatial Development Framework, 2003).

Economically, Tonga has always served a dormitory function, meaning that residents commute from the area to their place of work. There is very little investment or economic development in the area and the inhabitants have to travel long distances for consumer goods. Businesses are mostly represented by small general dealers and liquor stores. Informal industrial businesses such as car repair shops, exhaust repairs, tyre sale and fitment, and welding shops are found in all settlements (Nkomazi Spatial Development Framework, 2003).

Social and community facilities are limited. Recreation facilities are provided in the form of two libraries, a formal sport facility that is in a state of disrepair, and numerous informal soccer fields. No public parks exist. Almost all cemeteries are informal. Bus shelters are widely unavailable or are of an insufficient standard. Very little provision is made for the disabled, at both public and council buildings. There are grave concerns about the conditions that pensioners and disabled persons have to endure on pension payout days, as there is a lack of water, sanitation, and shelter. Most of the infrastructure needs upgrading and there is a general lack of equipment and furniture (Nkomazi Spatial Development Framework, 2003). Emergency services and the judicial system are insufficient and no correctional facility exists in the region (Nkomazi Integrated Development Plan, 2006–2007). The area has a high prevalence of HIV/AIDS, although since 2004 antiretroviral medications have been available at some hospitals and clinics.

Environmental degradation is taking place at an alarming rate and is attributed to a number of factors, including the under-provision of municipal services, the extent of urban sprawl and unsustainable subsistence farming methods (Nkomazi Spatial Development Framework, 2003).

Table 13.1 below provides a summary of the community profile for the Nkomazi municipality as determined by the Nkomazi Integrated Development Plan (2006–2007):

Poverty levels among people with disabilities have been documented by the Mpumalanga Province Community Based Rehabilitation (CBR) Disability Support

Table 13.1 Community profile for Tonga

Employment	40% of the economically active population are unemployed
Income level	73% of households bring in less than R2,000 per month
Dependency ratio	1:8
Household density	6 persons per household
Population distribution	50% of population under 17 years old
Population growth rate	20–30% per annum
Water provision	41% of households have water supplied in their houses 14% of households have access to an outside tap
Sanitation	55% of households make use of a chemical sanitation system 20% of households make use of pit latrines 7% of households make use of chemical toilets 5% of households have access to flush toilets 13% of households have no sanitation at all
Electricity	60% of households have access to electricity
Roads	40% tarred, with internal roads almost inaccessible
Health	2 × 24-h hospitals functioning at a primary healthcare level 1 × 24-h clinic 27 × day clinics 6 × home-based care initiatives
Education	32% of the population have no formal education 113 primary schools 40 secondary schools 3 combined schools 45 adult education centres Teacher:pupil ratio of 1:54
Literacy levels	24% of the population are illiterate
Community/social facilities	2 libraries Informal soccer fields Informal cemeteries only

Project (Nkomazi Spatial Development Framework, 2003). This research was conducted in the Lowveld district of the Mpumalanga province between August 1999 and July 2000 among 907 predominantly rural African households with disabled family members and revealed the following:

- 38% of families have no regular monthly cash income
- 49% of families rely on R530 or less income per month
- 11% of families have a regular monthly income of between R531 and R1,199
- 2% of families have a regular monthly income of between R1,200 and R1,999
- None of the 907 families had a monthly income exceeding R3,000
- 82% of disabled school-age children do not attend school

These statistics illustrate the strong relationship between disability and socio-economic status (Anderson and Phohole, 2003), and strongly justified the goals and framework of the current study.

13.2.2 Access to Setting

During a year's compulsory community service at Tonga hospital, the first author provided an in- and out-patient therapy service at the hospital, outreach services at 15 clinics in the surrounding area, and home visits to patients who were unable to access the clinics or hospital. This year enabled a first-hand experience of many of the frustrations that local people have, including poor provision of municipal services, poor conditions of the roads and limited access between the hospital and many of the homes in the community, as well as the frustration of travelling long distances in order to acquire basic products. Considerable time was spent with the community elders, in order to gain access to the community and visiting the homes of local leaders in order to obtain an understanding of the needs of the community and to deliver a basic rehabilitation service. This experience provided a degree of understanding of the way of life within the community, the beliefs and cultural practices, as well as the support structures and roles of various members of the community.

Access to both community structures and patients was achieved through collaboration with a Community-Based Rehabilitation Worker (CBRW) who is a local SiSwati-speaking woman, confined to a wheelchair. The CBRW understands the nature and experience of living with a disability in a rural area, and in this way was able to provide insight into the community, their culture and belief systems. These factors motivated us to return in order to explore in more depth the contextual aspects related to disability, so as to better inform healthcare policies, service delivery and the training of students. We chose to interview and observe caregivers of children with cerebral palsy. The CBRW was employed and trained to assist with this in terms of accessing caregivers and carrying out narrative interviews in SiSwati in the homes of the caregivers.[2] The interviews were audio-recorded and later translated and transcribed. We then derived and extracted themes which were linked to detailed ethnographic notes and to the results of interviews with the CBRW after each consultation.

Appendix A provides a paraphrased ethnography and interview to demonstrate the type of questions asked and the data collection process.

13.2.3 Caregiver Informants

The informants in this study were 27 caregivers of children with cerebral palsy. Caregivers who at the time were currently accessing services at the hospital and clinics, as well as those who were not accessing such services were included. Caregivers included 12 mothers, three fathers, seven grandmothers, one grandfather,

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[2] In line with the basic fundamentals of qualitative research and participant observation, we employed a range of methods including ethnographic field notes, interviews and personal reflections in order to triangulate results.

one aunt, one step-mother, one male cousin, and one male neighbour. The age of children with cerebral palsy ranged from 8 months to 14 years.

13.2.4 Disability Narratives

The informants' narratives revealed an intricate web of variables, which emerged as relevant and framed the experience of caring for a child with a disability in the context of poverty. The link between poverty and disability emerged clearly and illustrated how poverty renders persons vulnerable to disability and how disability impoverishes individuals' chances of breaking the poverty cycle. Most apparent was the way in which individuals are not only disabled by a physical impairment but remain disabled by their living conditions (Table 13.2).

Of the many possible ways of coalescing the data that emerged, the following seemed to have particular relevance for the purpose of this chapter. We conceptualize these themes schematically in Fig. 13.1.The core themes that emerged are discussed as follows:

- *Macro-variables* are those aspects emerging in the data that relate to broader issues such as government policies, the disease profile of the country and how these factors play out at a local level and how they affect accessibility to services.

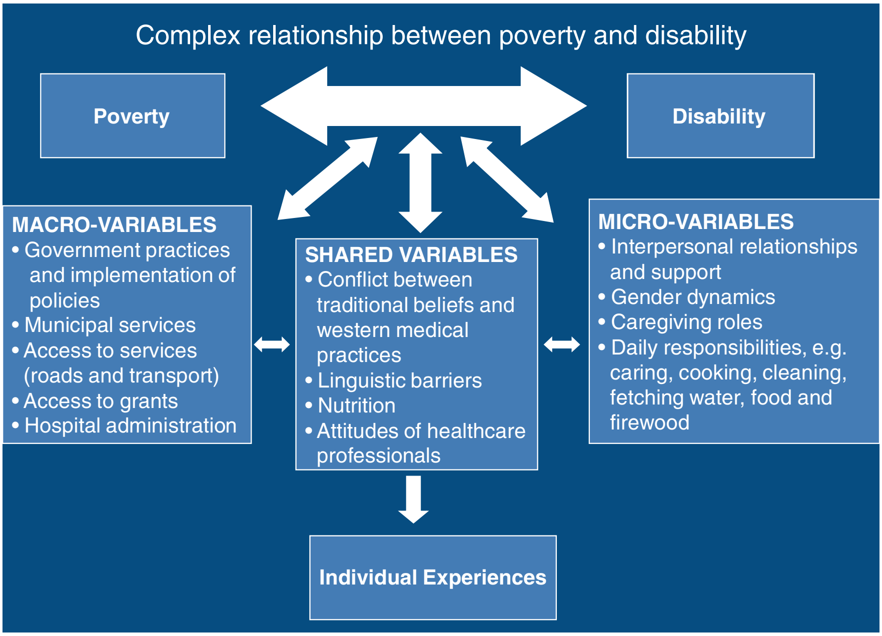

Fig. 13.1 Relationship between poverty, disability, and macro-, micro-, and shared variables. Some illustrative voices…

Table 13.2 Summary of living conditions of informants

	Distance of home from road	Electricity	Water	No. of people in house	Sanitation	Grant recipient	Other financial support	Support structure	Father involved
1	500 m	Yes	Rainwater reservoir	23	Long-drop 15 m from house	No	Father pays maintenance and grandfather's pension	Family and community	Maintenance only
2	2 km	No	No – walks 3 km	4	On neighbour's property	No	Mother's boyfriend (R300 per month)	None	No
3	4 km	No	Water point on property	3	None	Disability grant	Father pays maintenance	Boyfriend	Maintenance only
4	1.5 km	Yes	Running water in house	7	Long-drop 5 m from house	Child support grant	Mother's cousin	Both parents, family and neighbours	Yes
5	1 km	Yes	Running water in house	16	Long-drop 5 m from house	Disability grant	Father employed and grandfather's pension	Parents, family and neighbours	Yes
6	1 km	Yes	Running water in house	16	Long-drop 5 m from house	Disability grant	Grandfather's pension	Parents, family and neighbours	Yes
7	On tar road	Yes	Rainwater reservoir	8	Long-drop 5 m from house	No	Grandmother's pension	Grandmother and family	No
8	5 km	No	No	14	Long-drop 100 m from house	Child support grant	Grandmother's pension	Grandmother	No
9	10 km	Yes	Water point on property	11	Long-drop behind house	Disability grant	Father is employed	Family and community	Yes
10	45 km	No	Water point on property	5	Long-drop behind house	No	Grandmother's pension	Grandmother	No
11	50 km	Yes	No	8	Long-drop 100 m from house	No	Live off land	Father and step-mother	Yes
12	45 km	No	No	5	None	No	Father is employed	Male cousin and neighbour	Yes
13	15 km	Yes	Water point on property	17	Long-drop	Disability grant	Uncle	Aunt	Yes
14	8 km	Yes	Water point on property	13	Long-drop	Disability grant	Father is employed	Extended family and neighbour	Yes
15	8 km	Yes	Water point on property	3	Long-drop	Disability grant	Father is employed	Mother's family and neighbour	Yes

- *Micro-variables* which relate to personal, family, and community experiences, cultural practices, and roles within the family, and how these factors influence individual experiences of disability.
- *Shared variables* relate to variables which link to both macro- and micro-variables. They include the interface between traditional and western models of treatment-seeking behaviours as well as religion.

This division though somewhat overlapping and artificial seemed to capture the themes and our observations. Figure 13.1 above provides a graphic representation of the relationship between poverty and disability, and the effect that this relationship has on the individual as a consequence of the macro-, micro-, and shared variables.

13.3 Macro-variables

13.3.1 Information on and Access to Government Resources

Part of the attempt made by the South African government to ensure accessible healthcare services has been the implementation of the "free healthcare policies". Currently, free healthcare is accessible to children under the age of 6 years, pensioners, disabled persons and pregnant women. Additionally, a wide variety of grants are available, including child support grants, care-in-aid grants and disability grants. While every child with cerebral palsy in this study should have been eligible for a State financial assistance as a result of their disability, only seven children were receiving any and there was much confusion regarding the process of accessing grants. These voices illustrate this:

> I tried to apply for a disability grant but I haven't got my reply yet. They told me at the hospital that the child won't get a disability grant until she is 7 years old, so I went to the pension office and they gave me a child support grant form that I filled and sent back. I thought that the child dependent form is the same as the child disability grant.
>
> I don't have the right information on how to apply for a disability grant.

In addition to accessing grants, difficulty was reported in accessing social services in order to register the child so as to make them eligible for financial assistance. One grandmother reported:

> The child does not have a birth certificate so he does not get the government grant.

Some caregivers reported difficulty in accessing so-called "free" assistive devices, available through the government healthcare system. One mother whose child was in need of orthotic shoes reported the following:

> My child needs the special shoes. They told us to write our names on the list in 2004 as the shoes were not available at the time. So we have been waiting for three years with no reply from anyone.

Consistent with findings from other studies conducted in South Africa (Meyer and Moagi, 2000) it was found that six out of 15 children were supported by a grandparent's pension. In some instances it was found that the grandparents actually felt that it was their responsibility to use their pension money to care for their children and grandchildren. One grandmother reported,

> When he got sick I knew it was my duty to take him to all the medical professionals for help using my pension funds.

The powerful role of kinship is explained by Maverick (1966) who reports that within the Swazi culture, the grandparents are instrumental in teaching, and bring up the young. In addition, he reports that should a child fall ill he or she is often sent to live with the maternal grandparent until health returns. While this was not explicitly reported in any of the narratives, there was evidence that this practice still exists today.

13.3.2 HIV/AIDS

While the focus of the present study was on cerebral palsy, the influence of other health variables, specifically the HIV/AIDS pandemic in this community was pervasively detectable. Having the largest number of persons living with HIV/AIDS in the world residing in South Africa (Rehle and Shisana, 2003), this epidemic has profoundly affected rural areas due to, amongst other factors, lack of access to appropriate information, illiteracy, and in many cases, restricted life choices. With a few exceptions, the disease was seldom directly acknowledged in the interviews, reflecting the stigma and silence that surrounds it. However there were frequent allusions to family deaths, absent and ill family members and artefacts evident in the homes (such as medication, and t-shirts and tablecloths with HIV/AIDS logos), which fore-grounded the local presence and impact of the disease. Ironically, this disease provides family members with access to disability grants, which were acknowledged to be helpful in addressing the needs of disabled children.

13.3.3 Infrastructure and Access

The interviews confirmed that transport remains a major barrier to healthcare services for people living in rural areas (Anderson and Phohole, 2003). Common complaints among the caregivers included travelling long distances from sites barely accessible by motor vehicles, combined with expensive, unreliable transport, making regular follow-up visits difficult to achieve. One grandmother whose grandchild was not receiving any form of financial assistance reported,

> When he needs to go to the hospital it is difficult because I have to find someone with a car and loan money from people to pay them to take us to the hospital because there are no taxis from here.

Another mother who lived 45 km off the tar road in an area where there is no public transport and whose only source of income was R180 child support grant reported "I loan money from people, usually R50 to take him to the hospital or clinic".

13.3.4 Inability to Work

Five of the mothers of the children with cerebral palsy felt that they were unable to go out in search of work as their children required constant care and they felt they were unable to leave their child with anyone else while they went out to work. Reports of this included:

> I always have to take him everywhere I go because no one is able to help look after him – they complain that he cannot even say when he wants to go to the toilet and that he is just an inconvenience.
>
> When I am away for any reason I get back and find (the child) refusing to eat because I am not there. She will only eat if I am there.
>
> Neighbours take (the child) if I am here at home otherwise I don't want them to take her because (the child) needs constant care.

Such comments reflect the fact that the mothers may not trust others to take care of them as they would a non-disabled child. Whereas generally after weaning, a child in this community is frequently left in the care of older children (Kuper, 1963), at each of the 15 homes we visited, the child with cerebral palsy was always in the care of a mother or grandmother.

13.3.5 Hospital Administration

Hospital administration, particularly problematic filing systems, were reported by all of the informants and proved to be a major barrier affecting accessibility of healthcare services. As a result, informants reported that they are hesitant to make follow-up appointments at the hospital. Comments such as the one below were common:

> I often stay there for two to three hours waiting for the child's file with the nurses sending me everywhere.

13.4 Micro-variables

13.4.1 Support Within the Family and Community

The majority of informants reported that lack of support both from within the family and the community were barriers to accessing quality healthcare. This related both to the physical assistance in caring for a child with a disability, as well as emotional support. In many instances, the emergence of a disability in the family came as a shock and was regarded with much suspicion, particularly in relation to traditional and cultural beliefs. One caregiver reported fleeing from Mozambique in the middle of the night to escape the father of the child, after being given an ultimatum to choose between the child and himself. The mother reported:

> He chased me away. He said he didn't want the baby because it was so tiny. He said I must choose. I can stay or I must kill the baby.

Another caregiver reported having lost all support from persons in the community whom she had previously regarded as friends. She said:

> I have no friends. Now they just laugh at me saying my child is disabled.

Another instance where a significant lack of support was reported was in this narrative obtained from a mother in response to asking how the neighbours respond to the child with cerebral palsy:

> If it was according to them I would have taken (the child) and given him away or thrown him in the dustbin. They don't think he will ever be a normal person at all. Even his father's family doesn't like (the child).

13.4.2 Reactions to Disability: Acceptance, Guilt, Disappointment and Depression

During the interviews a range of reactions to disability were noted. Of the 27 participants interviewed 22 reported that they had accepted their child's condition, while five reported that they had not come to terms with having a disabled child. A combination of positive and negative responses was obtained in response to acceptance, illustrated by the voices below:

> It took me a while to understand. I just prayed and said he is my blessing from God. It was very painful though.
>
> (The child's) father did not have any problem with him being disabled.
>
> The neighbours like him like any other child.
>
> (The child's) father's mother doesn't want (the child). She is ashamed of her.
>
> I have not seen any of the neighbours who like (the child).
>
> I don't think (the child's) mother has accepted that he is disabled because she doesn't show care or love for (the child) at all. She doesn't want (the child) to touch her and when he cries she just leaves him there without caring.
>
> He has no relationship with his granny and I don't know why she dislikes (the child). I think she needs counselling to help her and then stop disliking the child.

Sixteen participants reported a sense of sadness related to bearing, bringing up and caring for a child with a disability. Some of the comments included:

> I was very disappointed since it was my first-born. I expected that since she was my first-born she would be everything I ever wanted from a child.

> It is difficult to see other children walk and yours cannot.
>
> It is very painful because I did not ask for a disabled child.

Guilt was an emotion that was frequently alluded to; however, only two informants overtly discussed bearing the burden of guilt for giving birth to a child with a disability. When asked what she thinks assists the child in his development, one caregiver reported:

> There is nothing I can do. I just keep telling him that I am sorry.

Some evidence of despair and desperation especially at the time of diagnosis, as well as the experience of depression was evident in the following narratives:

> At first I felt terrible. I lost weight and I used to spend time alone thinking about (the child's) disability, but after two years I accepted the situation as it is and I regained weight.
>
> We can't even resolve things like adults. She is always upset without reason. She doesn't even communicate what is wrong. She just becomes angry and upset without reason.
>
> It took me a whole year to accept. During that time I was just crying all the time.
>
> It took me nine years to accept her disability. From time to time I still become upset.
>
> I left (the child) with his father because I didn't know what to do with him because he was very sick and no one was able to help him so I came to his father for help. I always thought about him.
>
> When (the child's) granny is here she usually says bad things about the child. She even said she wishes this situation would be over. I don't know what she meant about the situation being over or maybe she wishes (the child) to die. I don't know.

13.4.3 Family Roles and Gender Dynamics

In this study, 12 of the children were cared for primarily by their mothers, two were cared for by a grandmother, and one by a father. The complexities of the rural context in regard to gender roles were reflected in some of the narratives. Like in many other rural contexts, men frequently become migrant workers, and relocate to the cities in search of work, while the roles of women include growing and harvesting crops and caring for children and the sick (Cancian and Oliker, 1998). In the community we researched we noticed a marked absence of men yet of the 15 families who participated in the study, nine of the fathers lived with the family and were actively involved in the child's upbringing, two paid maintenance regularly, and four did not have any contact with the child.

In situations where the father was not involved, this put obvious strain on the caregiver who was taking care of the child both from an emotional and a financial point of view. Some of the comments made by the female primary caregivers in instances where the father was not involved included:

> We do not have any relationship since he denied the child after he was born. It is easy for him to say that he does not love the baby because he is disabled.

> One day we had a fight and the father told me that he knows (the child) is not his son because they have never had a disabled person in their family.

Of the 15 children with cerebral palsy, seven had been abandoned by one or more family member(s). Of these seven children, five had been abandoned by their father and the father's family (indicating the role and power of the paternal family), two had been disowned by their mother, one of whom was now cared for by her grandmother, and the other child was now in the care of his father. Comments that arose from this discussion included:

> We broke up after the birth of (the child) because of bad influence from his mother.

> While I was living with his family (the child) got sick. I then decided to leave and come back home because the father's mother was saying that (the child) is not her son's boy.

Another common theme that emerged in relation to gender was the issue of kinship, and it appeared that in many instances the paternal grandmother had enormous power over her son's relationships and would make the decisions regarding her son's involvement with the child. This is explained by Kuper (1963) whose perspectives on kinship, although produced over 40 years ago, suggest that the legal authority of the father is in contrast to the more indulgent relationship with the mother, for whom Swazi men express affection and appreciation, as well as respect. This description is evident in the quotation below where a mother reveals that the father's family are denying that the child is part of their family, due to the presence of the disability:

> The father's mother says the child is not her son's boy. They have never had a disabled person in their family. They do not want the child in their house.

13.5 Shared Variables

13.5.1 Traditional Beliefs and Western Medical Practices and Religion

A wide range of responses to cultural beliefs and practices in relation to the causation and treatment of cerebral palsy were elicited. All except for two families had consulted with traditional healers regarding their child's condition and a variety of responses to traditional treatment were elicited. The narratives revealed that grandmothers and grandfathers were consulted first before any action was taken in terms of managing the child's disability. It appeared that for the most part it was the grandparents who recommended going to the traditional healers, while the parents of the child held conflicting beliefs about which approach to follow. In many instances, traditional healers and western healthcare practitioners were consulted concurrently. This conflict and family responsibility for the child's wellbeing is described in the narrative below:

> My mother said we must take him to the traditional healer. They said it is witchcraft and evil spirits. They said they can cure it and gave us herbs to chase the evil spirits away, but

> we haven't seen any improvements in the child's condition so now I have decided to stick to the hospital ways. It is much simpler.

Another explanation for disability obtained through the narratives was that of *umuthi*. Translated into English, *umuthi* can mean either "medicine" or "poison", and refers to substances fabricated with an expert hand, designed to achieve either healing or illness (Ashworth, 2005). Dangerous substances deployed as *muthi* can enter the body through the mouth in the form of food or drink, through the lungs, through the skin, or through sexual contact, so anyone who puts their body in contact with another person or substance needs to be careful (Hammond-Tooke, 1970). This narrative obtained from a father describes this concept of *umuthi*, while the final sentences expose conflict and confusion between the traditional and western explanatory models:

> I heard the elders saying that if a child is disabled it is because of cross-dressing of males and females in the house or older people wearing younger people's clothes. So they say all this cross-dressing causes confusion in the family and can lead to disability. Now I have confirmed it is not this, but something that I don't understand.

Further conflict is evident in the quotations below, both obtained from mothers:

> I think that there was a problem while I was giving birth to him. Traditionally we call it umuthi.

> I don't know. At the hospital they told me she was affected and that is what I believe now.

However, this "confusion" must be interpreted with caution since both the researchers and research mediator were affiliated with the hospital. Scheper-Hughes (1990) warns that patients may respond to the doctor's explanation of disability or illness by shifting his or her explanatory model towards that of the doctor in order to make a working alliance possible.

Consistent with the view that disability and spirituality are intertwined (Pfeiffer, 2003; Mweshi and Mpofu, 2001), seven participants spoke about disability in terms of religion and stated that they had accepted the children with cerebral palsy as a religious blessing. Exploring the experience of cerebral palsy included:

> I don't know. I just think (the child) is my gift from God and God is tempting me to see if I can rise above this challenge.

> We believe God knows what he is doing.

A main concern of one grandmother was who would care for the child should she be unable to do so. She reported, "It is something I think about everyday. I always pray that God will bring a solution to this problem because there is no one I trust to take good care of (the child) the way I do".

> There is only one woman from the church who comes near her. She comes and prays for her recovery.

> I took him to (name withheld) Church and that's where he became better through our prayers. He started crawling and walking again before I took him to physiotherapy training at the hospital.

> I cried and I prayed to God to help me and to help (the child) to be strong so that he will be able to walk again.

13.5.2 Attitudes of Healthcare Professionals

Just under half of the total number of participants reported that the negative attitudes of healthcare professionals affect their willingness to access services at the hospital or clinics. While reports of poor attitudes of staff members towards patients are grave and carry enormous implications for the success of service delivery and for the commitment of caregivers to the management techniques recommended by the healthcare professional, cognizance must be taken that for any healthcare provider working with a population with whom they do not share a common language is extremely difficult, and that working in the presence of such a language barrier is likely to give rise to miscommunications. This is particularly true in the South African context where hospitals do not employ interpreters and therapists frequently need to make use of other parents or hospital cleaners as translators, and in this way much meaningful conversation is lost. In addition to language barriers, working cross-culturally can be a major barrier to effective therapy. The western bio-medical model on which so much of the therapy is based is a foreign concept to the majority of patients (Potterton, 1996), and for this reason cognizance needs to be taken of cultural issues and the patient's worldview must be taken into account (Penn, 2000). This is highlighted in the comment below:

> I want to know why the physiotherapists don't listen to what we need.

Additionally, an instance where it became evident that the caregiver's expectations had not been met at the hospital is apparent in the following quotation obtained from a father:

> I have gained nothing. They just show me exercises but don't give me medications to help the child.

This highlights a misconception relating to the extent of the neurological impairment of cerebral palsy and the nature of the management thereof. One can understand the assumption that a condition such as cerebral palsy, which is managed at the hospital, should be treated with medication. This emphasizes the need for healthcare professionals to develop their communication skills, as well as to develop resources detailing predisposing factors and aetiologies of disability, and the treatment and management thereof.

Another alarming concern was that of the communication skills of the nurses, particularly since in most cases the nurses shared a common language with the patients. The majority of informants made claims similar to the one below obtained from a mother:

> What I have found to be a problem is the nurses' listening skills. When I try to explain about the child's condition they try to disagree with me, thinking I am lying or something.

This complaint highlights both the possible lack of counselling skills, but also a power dynamic between the caregivers and the nurses, which may well be linked to cultural beliefs surrounding disability. This is explained by Crawford (1994) who demonstrates how the societal beliefs of a community affect how the members of that community construct beliefs about who becomes ill and who remains healthy and how this serves to marginalize an already marginalized community. In turn, Crawford (1994) demonstrates how the language of health has come to signify those who are responsible from those who are irresponsible, those who are respectful from those who are disreputable, those who are safe from those who are not, and ultimately those who have the right to rule from those who need supervision, guidance or reincarnation. In this way the sick and disabled are not only made responsible for their illness, but they are also made different. This gives rise to a social distancing from the "unhealthy" – a further stereotyping of an already stigmatized group.

13.5.3 Support Narratives

A large number of participants reported that the primary reason for returning to the hospital even though accessibility was difficult was because of the emotional and peer support received at the hospital. A comment from a mother revealed this:

> It is very difficult dealing with the changes I have had to go through to accommodate my baby. Most of the time I just let it pass but I deal better with it when I go to the clinic and find other women with children with the same problems. It feels good to know that I am not alone.

References to peer support are important for us as healthcare service providers to acknowledge as they have implications for refining our role in service provision within the community. It is important to consider that with significant neurological impairment, compounded by living conditions which do not allow the patient easy or regular access to healthcare facilities, and inexperienced therapists who do not have advanced training in working with such conditions, it may not be possible to achieve full or even partial recovery. However, it is achievable to set up information centres and support groups and in this way empower members of the community to stand up for their rights and the rights of their children. Narratives relating to support obtained through healthcare provision included the following:

> It took me three years to accept. All this time I have been looking for alternatives to help (the child) to get better. However, in all my hospital visits I have seen many people there that are disabled like (the child) and that made me to accept and put things into perspective.
>
> Also to see other disabled children at the hospital helped very much because I was able to see and compare (the child's) condition, and what I have realized is that (the child) is less disabled than any other children I have seen at the hospital.

13.6 Conclusions

Over 250 years ago, Olwen Hufton (as cited by Ngwisha, 2003, p. 8), wrote "The approach to the study of poverty must be predominantly qualitative not quantitative. There is no such thing as a graph of human suffering". As the above examples demonstrate, contextual factors have a powerful influence on the experience of caring for a child with a disability in a rural area. Our findings have profoundly challenged traditional methods of intervention and the goals and outcomes of rehabilitation. The narratives of the participants provide a rich tapestry for understanding disability. Rising to the surface are glimpses of how persons make sense of their circumstances and the role of hope, acceptance, gender, family structure, and religion in this regard. The stories highlighted a universal experience of caring for a child with a disability and also culture-specific features of this experience. Listening to these stories was both remarkably inspiring and humbling. As Tonga is clearly one of the most under-serviced and poverty stricken areas of South Africa, we had expected much discussion surrounding this topic and complaints regarding the accessibility of services, the provision of water and electricity, the conditions of the roads and long distances walked each day in order to collect water, firewood and food. To our considerable surprise none of the participants complained in any way! There were reports of difficulties encountered but these were merely mentioned as part of life, not as a complaint.

Similarly, as speech-language therapists we had expected an emerging theme to be one which highlighted the frustrations of having a family member with a communication disability resulting from cerebral palsy. This type of response emerged from only one of our 27 informants, again reinforcing the powerful need for reframing our scope of practice and the role of our profession in a rural context.

The powerful experience of asking and listening highlighted the need for a deeper understanding of the important variables mediating the experience of disability and the influence of both extrinsic and intrinsic factors on individuals, their communities and cultures. We have tried as far as possible to let the narratives speak for themselves, rather than interpret them. The narratives helped to clarify even the unspoken themes of fear and stigma in the community and provide meaning, context and perspective for the caregivers. In addition, they were used to define how, why and in what way the child and the families have been affected by the disability.

Writing anthropological accounts such as this one necessarily involves a power relationship. Our account is not only a dialogue with the participants but also with a body of scholarly theory about disability and its impact. As feminists and professionals, our perceptions undoubtedly and inevitably influenced our interpretations and themes which have informed our analysis. Our account, even though effectively facilitated by our research mediator, makes no claims to be speaking directly for the people of Tonga. However, through the methods used we hope to have borne witness to their lives and we have tried to understand as far as we could *what* things look like from their perspective. In asking *why* they look like this, we are cautious of falling into an oversimplified model but hope that the framework may be useful for advising policy-makers and hopefully in bringing about positive change to this marginalized community.

The stories of our informants revealed many things about the provision of services within the disability sector of South Africa. Since April 1994, some strides have been made in the area of service provision to previously disadvantaged communities. However, as this study has shown, in many areas, these changes have had little impact on the lives of those who are truly marginalized. The narratives depict a disempowered and fragmented community, with discrepancies in the provision of basic services and healthcare practices. They also, however, represent the strength and power and capability of a marginalized community in standing together and supporting each other. The need to be heard is a basic right of any individual and is the first step towards achieving a caring nation, with recognized democratic values and a social justice system that is based on equality, non-racism, non-sexism and human dignity.

The worldview of the caregiver is pivotal in a medical context for assessment and treatment and highlights the imperatives of issues such as food security and access. Social advocacy must begin by listening to those who truly know and understand the effects of disability and the barriers to service provision. Persons with disabilities and service consumers should be the main judges of service provision within a context of informed social transformation. The transformation of healthcare service provision in the presence of enabling national strategies can similarly only take place within the framework of empowerment of individuals and communities with the realization that disability is a social construct which needs to be mediated within a human rights and development framework, rather than viewed solely as a health and welfare problem. Such an approach cannot be implemented without the use of sensitive methods and effective communication amongst disabled people, their families, professionals, and researchers and with the knowledge of community resources. The essence of this is reflected on by Father Smangaliso Mkhatshwa (as cited in Goldstein et al., 1998) who states that "The struggle for health and the struggle for social justice in South Africa are the same".

Acknowledgements We pay tribute to the informants in this study whose qualities of resilience and endurance in the context of profound marginalization will hopefully influence future policy and practice for all those living with disability in South Africa.

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Appendix

Participant M – Paraphrased Ethnography and Interview

Distance of home from tar road:	*8km*
Electricity	Yes, electricity meter
Water:	Yes, tap on property
Number of people living in house:	13
Sanitation:	Long-drop
Disability grant recipient:	Yes

Other financial support:	Father
Belief in cause of disability:	Umuthi
Child's difficulties:	Holding things and eating solid food
Perception of child's needs:	Unknown, something to support her in sitting
Support structure:	Extended family and neighbours

The interview took place in village XXX. We arrived at participant M's home only to find that another participant, X, was the next-door neighbour. These two participants live approximately 8 km off the main road, and their homes are barely accessible by car. We phoned for directions, and the mother came to meet us at a nearby primary school.

Upon arrival we were clearly expected! Plastic chairs had been set out in a circle and the mother, grandmother, aunt and two men were sitting there. The child was in her buggy that had been issued by the hospital. A little boy who was about 5 years old was chasing chickens, while a toddler of about 18 months was wandering around playing with a ping-pong ball.

Soon after we arrived the men got up and left, leaving the property and walking down the street. They did not bid farewell or say where they were going. After explaining the purpose of our visit L (CBRW) took the mother aside to the edge of the property so that she could conduct the interview. The grandmother took responsibility for the child with cerebral palsy and sat with her on a grass mat under the trees talking softly. From time to time she also spoke to and scolded the other children.

I sat under a tree, observing what was going on and taking down field notes. Two of the men that had walked down the road came back. The one man lay down on the grass and lit a cigarette, while the other man came and sat next to me. He introduced himself to me in English and told me that he had completed matric last year and was unable to find a job. We sat and chatted for a while. The aunt had gone back to cleaning the house and a young man came out of the house, filled a bucket with water and took it to the wash area at the back of the plot. The house had a water point on the property and an electricity meter in the house.

The main house was modern and made out of brick and African jive music was drifting through the open windows. There was also a second smaller house on the property and a mud shack at the side of the house. The yard consisted of grass, swept ground and trees.

I noticed the close proximity of the neighbours and the fact that one could easily see what was going on in the neighbours' gardens. I observed women doing washing, hanging washing up to dry, tending vegetable gardens and filling buckets of water. Once again the absence of male contributions to the daily chores was noticed.

One of my thoughts as I sat there was "I wonder how open these women will be able to be" given that there were three men sitting around trying to listen in on the interview. At one point the aunt stopped cleaning and sat a metre or two from where the interview was being conducted and seemed to be listening to what was being said in the interview.

The toddler wandered over to where the interview was being conducted and started disrupting the proceedings. The man who had been sitting next to me went over and picked the toddler up and brought her back to where we were sitting to play.

At one point the grandmother got tired of holding the child with cerebral palsy. The aunt went inside and fetched a walking ring, which she put the child into. In this way the child was able to navigate her way around the yard and sit with fairly good trunk control.

At around lunchtime the mother went inside and brought out a plate of soft porridge and gravy. The grandmother held the child with cerebral palsy on her knee and fed her by rubbing the porridge into her mouth then waiting for a few minutes for it to slide down her throat.

Later on in the afternoon I went and sat down on the patio near to where the research mediator was conducting the interview. The mother stood up immediately and brought me a chair.

Just after the children started arriving home from school the grandmother called for one of the young boys. She spoke to him in SiSwati and then placed some money into his hand. He ran off down the road. About half an hour later I saw the same child running back down the road in the direction of the house, carrying a 1-l bottle of Fanta Grape. He handed it to the grandmother who came over and handed it to me. L (research mediator) translated for her that she was giving this to me as a token of thanks to the white doctor who had come to visit them in their home and to thank me for all I had done to help the child.

The sense of support came through strongly in the interview. The mother reported "As soon as I knew I was pregnant my family-in-law took me into their home. I then gave birth at their home. (The child) was born one month early, so she had a breathing problem. I then took her to the hospital and had to stay for 1 week because at that time she was not even crying. She only cried after two weeks".

In general it seemed that all of the family and the neighbours were fond of the child. However, the mother said she was not sure if she would be able to leave the child with any of the neighbours.

When asked about the cause of disability, the grandmother said she believed it was *umuthi*. She reported, "Anyway, I heard elders saying that if a child is disabled it's because of cross-dressing of males and females within the house or young people dressing in older people's clothes. So they say all this cross-dressing causes confusion within the family and can lead to disability". The father took the child to traditional healers who said that the disability was the result of evil spirits and gave her herbs and liquids to drink but no improvement was noted. The mother reported "The father took her traditional healers and none of them were able to help her so he decided that we should leave (the child) as she is because he is sick and tired of all the run around". The grandfather agreed that they should stop taking the child to traditional healers.

The mother reported that the first time she visited the hospital was because she thought there was a problem with the child's tongue. The doctor found nothing wrong but referred her to the rehabilitation department. The mother said that she had noticed improvement at the hospital "…because before (the child) couldn't move her body and she couldn't roll herself but now she can". Once again the mother's main complaint was that it takes a long time to get a file at the hospital.

Both mother and grandmother reported that they found it difficult to accept the child's disability. The grandmother added, "We believe God knows what he is doing".

The mother reported that she needs something to help support the child's body in sitting. She reported that she is currently using a tire to seat the child in. She has received a buggy from the hospital but there is no space in the house to keep the buggy so it has become damaged as a result of exposure to the elements.

Once again the issue of HIV and the prevention of contractible diseases was discussed. The mother reported, "I trust that I won't contract anything that will affect (the child's) well-being. But I don't know about (the child's) father because he is not with me all the time – he is working far from here. Anyway, I trust he is not doing anything that could affect (the child)". When L asked if the mother thought that the father would agree to using condoms she replied "I don't know if he will use it, and if I ask him and he doesn't want to use it I don't know what I will do".

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Index