

Sailaja Chennat *Editor*

# Disability Inclusion and Inclusive Education

 Springer

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ISBN 978-981-15-0523-2      ISBN 978-981-15-0524-9 (eBook)  
<https://doi.org/10.1007/978-981-15-0524-9>

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The registered company address is: 152 Beach Road, #21-01/04 Gateway East, Singapore 189721, Singapore

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# Chapter 1

## Disability Studies: The Context



Sailaja Chennat

**Abstract** This introductory chapter situates the contents of the book in the discipline of Disability Studies. Disability Studies is introduced as an interdisciplinary discipline with socio-political, economic, historic, socio-cultural and psychological perspectives built into it. Also, sketching how the discipline of Disability Studies has been evolving to become more inclusive in theorizations and sociological analyses, the inclusions of feminist studies, cultural studies, gerontology and transgender studies have been presented. The social model of disability has been presented with both its strengths and criticism. Examining with the lens of social model, oppression and exclusion are described as the causes for the problems faced by the disabled people, not their impairments. Ongoing debates surrounding inclusive education, the deliberations concerning where and under what conditions students with disabilities should be educated, have been discussed as the central and one of the most contentious issues in Disability Studies. To give a complete picture, global and national initiatives for the welfare of persons with disability in terms of state policies and acts have been discussed.

**Keywords** Interdisciplinarity · Multiple perspectives · Social model · Barrier free environment · Inclusivity · Critical Disability Studies (CDS) · Transgender studies · Gerontology · Technology for disabled · Disability inclusion

### Disability Studies as an Interdisciplinary Discipline

The academic discipline of Disability Studies is a diverse interdisciplinary field that investigates the nature, meanings and consequences of disability from social, historical, cultural, educational and political perspectives. It evolved through answering questions like what is the nature of disability, what are the appropriate teaching practices for students with disabilities, what counts as research and inquiry in the field of special education, etc. In his book *Disability Studies: An Interdisciplinary*

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*Introduction*, Goodley (2011), in the preface, justifies the subtitle of his book, ... “[An] *Interdisciplinary Introduction*, conveys an attempt to span a host of disciplines, including sociology, critical psychology, cultural studies, psychoanalysis and education, to analyse three overlapping layers of everyday life: psyche, culture and society” (p. xi).

According to Barton (2000):

Disability Studies provides a framework and language through which disabled people can describe their experiences. Discrimination, exclusion and inequality can be named and challenged. It offers a means through which the question of disability can be explained and understood in terms of wider socio-economic conditions and relations. It provides a basis for support and collective engagement of disabled people. Finally, it is a means through which the non-disabled world can be provided with an alternative and positive view of disability. Thus it has a very important educative function. (p. 3)

Historical analysis reveals that the research efforts and activism in the area of disability, which we now know as Disability Studies, have been a powerful influence on policy and practice with respect to people with disabilities. In other words, Disability Studies as a discipline has evolved as a means of addressing how people with disabilities have been treated historically and how they continue to be treated. Earlier perceived through the lens of medical model as people who are sick and in need of cure, through that of sociological model where people with disabilities are labelled and stigmatized by nondisabled, or through that of a psychological model where their experiences have been individualized and pathologized, people with disabilities are now being understood through different perspectives. Although medical and psychological models are still prevalent, they are being resisted by the relatively new field of Disability Studies, its philosophy being that disability is a socially construed conception. While Disability Studies does not deny that there are differences, either physical or mental, between people, they argue that “the nature and significance of these differences depend on how we view and interpret them” (Bogdan and Taylor 1994).

Disability Studies attempts to examine the social, economic and political factors that have caused the marginalization and oppression of people with disabilities. The field has emerged over the last several years, drawing on theories and perspectives from sociology, social science, women’s studies, cultural studies and education. One of the central ideas in Disability Studies is that people with disabilities are a minority group who has been discriminated against. In this sense, the study of disability is closely linked to human rights and justice and is akin to the study of race, class and gender inequalities.

The field of Disability Studies is in an evolutionary stage. Recent additions to the field such as feminist Disability Studies and cultural studies have challenged “traditional” Disability Studies and have forced the field to be more inclusive of different perspectives and positions in society. Moreover, traditionally, Disability Studies has focused on issues around people with physical, rather than cognitive disabilities. One major challenge for the scholars in the field of Disability Studies is giving voice to people with cognitive disabilities and the inclusion of their experiences.

The overall experience of disability is diverse as it is the combination of limitations in functioning across multiple domains (e.g. seeing, walking, hearing, talking), each on a range, from little to severe disabilities, either within a particular domain or across multiple domains. For each domain, the level of functioning a person experiences depends on both the individual capacity of the body and the attributes of his or her environment that can either lower or raise the person's ability to participate in any activity. An analysis of developments in the field of Disability Studies brings us to an understanding that disability is not a thing, but a conceptualization, a conceived idea that is derived from the interactions between a person's impairment and his/her environment. It is a fact that people do vary or differ from one another in sometimes very obvious ways, but to call or label some of those differences as "disabilities" is to make a judgment, not an unbiased or neutral observation. What matters is what we make out of these differences or what attitude we develop towards them and how we treat these people with differences, rather than the differences people have in comparison to others or in what way or to what extent they vary from each other. What gives full meaning to disability are the insights regarding how macro-level processes such as societal attitudes about diversity intersect with disability issues as well as how race, class, gender, language, culture and sexual orientation shape the experience of disability.

Delineating impairment from disability, impairment refers to variations that exist in human behaviour, appearance, functioning, sensory acuity and cognitive processing. Disability, on the other hand, is the outcome of interface between impairment and social, political, economic and cultural practice. Perceiving disability as an outcome of interactions among social contexts brings us primarily to the task of designing learning environments in such ways so as to enable all sites of learning accessible and to enable all members involved at these sites to have access to curriculum and learning opportunities.

Disability Studies includes a diverse group of people: people who are blind or deaf, who use wheelchairs, who experience chronic pain, who learn at a slower pace than others, who have multiple disabilities and so on and who have immensely different experiences and perspectives. Yet they are all included within a common definition of disability, with corresponding consequences for how they are viewed and treated by the majority which is supposed to be nondisabled.

Disability Studies is not medicine, rehabilitation, special education, physical or occupational therapy and any of the professions oriented towards the cure, prevention or treatment of disabilities. Although some of the scholars in the field of Disability Studies generally subscribe to the minority group model of disability, i.e. the view that the status of people as a minority shapes their experiences in society, they have certain points in departure to this view. For example, some Disability Studies scholars view disability with respect to culture and identity, while others see disability as a social construct and a label. Some Disability Studies scholars use different language to refer to people; "person with a disability" or "people first language" conveys the idea that the person's identity as a human being is primary; person labelled as disabled (mentally retarded, mentally ill and so on) foregrounds how disability is

socially constructed and imposed on people who may or may not agree to this description. Accordingly, a deaf person and Deaf person convey very different meanings, with the latter stressing membership in a linguistically defined culture. There is yet another group of disability activists, like Petra Kupperts, who prefer to be called “disabled”, “...as she feels that this word is a political identifier which links many of them in the disability culture together” (Chennat and Lakhyani 2018, p. 6).

## Multiple Perspectives on Disability Studies

The field of DSE has a defining characteristic of commitment to open inquiry, and the spirit of pluralism on which it was founded is significant enough to be considered. Neither Disability Studies nor Disability Studies in Education supports a unitary perspective. Knowledge in these areas draws on disciplines as varied as sociology, literature, critical theory, economics, law, history, art, philosophy and more and includes social constructionist or interpretivist, materialist, postmodernist, poststructuralist, legal and structural-functionalist perspectives. Nevertheless, there are certain central themes that characterize DSE, the primary among them being the idea that disability is a social phenomenon.

*Impairment*, as described by Disability Studies scholar Simi Linton (Linton and Berube 1998), refers to variations that exist or develop in human behaviour, appearance, functioning, sensory acuity and cognitive processing. *Disability*, on the other hand, is the creation or resultant outcome of social, political, economic and cultural practice. If the definitions of mild disabilities like learning disabilities (LDs) and mild intellectual/emotional disturbance (ED) can change, as they certainly have over the years, it is proved that they are the product of judgment. If the criteria for identifying any of these disabilities involve drawing a line somewhere between what is and what is not considered to be LD, MR or ED, these judgments are essentially and at best random. When it comes to low incidence disabilities like LD, a student may become “disabled” or “cured” by crossing a state. If these disabilities were anything other than interpretation about certain context-dependent differences, crossing state boundaries would not, and could not, change a student’s disability status. Anyone who has travelled to a different country, where his or her first language is generally spoken although with a different accent, will vouch for the fact that the context determines his or her position as a member of the group. Also, it is proved that capable people can be made to appear quite incompetent in an academic scenario in which most or all of the other students have more background knowledge, life experience, personal dispositions and interest in the subject at hand.

To a great extent, the demarcations between nondisabled and mildly disabled and mildly disabled and moderately or severely disabled all in a way involve judgment. Moreover, these categorizations are premised on our beliefs about what comprises *normal*, a notion that is itself context-dependent. What is normal at one time and place may not hold good at another. Considering all of human diversity normal is definitely a more justified stand from the justice and equality perspective. Some of

the disabilities have an obvious physiological component (e.g. anatomical structure, vision and hearing). To say these as socially constructed would seem ludicrous for many because it appears to deny that some people cannot walk, see or hear. Actually, what is being questioned is *not* the fact that some people cannot walk, hear or see, but the meaning or significance the society attributes to these biological differences. This is not a minor issue; what is made out of some people's differences holds direct and deep implications for how they are educated in our schools and treated at working places and other social sites.

## Genesis of DSE

Disability Studies has its origins in the political and social anarchy of the mid-twentieth century like many of the movements slackly classified under the umbrella of cultural or identity politics. Disabled people were seen as useless or worthless traditionally and hence were understood to be fixed or wiped out as the society had little forbearance to accommodate them. Disability activists see this approach as the hallmark of a modern, normalizing society. Additionally, for many disabled people, a cure may be neither possible nor desirable.

Against the society's normalizing demand for disabled people to be adapted to their environments, usually through overcoming their disability or by coming to terms with their situation, it has been the imperative of the Disability Studies movement to improve the quality of life of disabled persons through the transformation and adaptation of social and physical environments. The cry for a distinction between impairment as a medical condition and disability as the effect of social attitudes and interactions complemented and supported this activism.

Analysing the education scenario of children with disabilities, it can be seen that schools specifically for children with disabilities were opened at a time when children with disabilities were routinely denied the access to education that their "non-disabled" peers were entitled to, by default. Legislations in each country mandating the education of all children in inclusive settings marked a turning point in the education of children with disabilities. This was a time period when the disability scholars, working from a medical perspective of disability, conceptualized disability as a deficit within the individual, a deficit to be fixed, cured or accommodated, and this perspective was prominent in the disability discourse. This understanding of disability from a medical model perspective systematically informed the legislations and reflected largely in them:

During a conference in 1999, a group of about 30 disability researchers from around the world gathered together with the purpose of forging new alternatives to traditional special education research. They explored innovative ways of envisioning, writing about, and talking about the lives and possibilities of people with disabilities, including many traditions of scholarship (in social science, humanities, arts, spiritual traditions, etc.) and the numerous voices that have something of importance to say about disability issues. The group came to a consensus that the kind of work they were discussing is best described as "Disability Studies in Education."

Near the conclusion of this discussion, Susan Gabel announced that she had taken the initiative to submit an application to form a new special interest group called Disability Studies in Education at the American Educational Research Association. This marked the founding, at least in a formal sense, of the now thriving field of DSE. (Gabel 2005; Gabel and Danforth 2006 as cited by Baglieri et al. 2011)

The deliberations and scholarly writings of academicians from the field of sociology, psychology, education and special education emphasized that the objectivist representation of disability from the medical perspective was neither precise nor sufficient and discourse in this direction progressively embarked on the social model of disability.

## **Social Model of Disability**

The social model of disability that originated in Britain opposed the traditional supposition that disability is the direct result of an individual shortfall or incapability. In disability discourse, disablism is seen to represent not only a diversity of discriminatory practices but also the way in which disability, as an impact of social oppression, is taken for granted as the “symptom” of individual attributes, that is, as the effect of impairments.

Extending further the socio-political dimensions of disability and highlighting the patterns of discrimination of disabled persons, Disability Studies conceptualized the status of disabled persons as essentially similar to the challenges encountered by persons belonging to other minority groups. Thus, parallel and concurrent to the conceptualization of the social model of disability, a strand of activism evolved that put forth claims to rights of disabled persons and resistance against bigoted practices and environments.

### ***Strengths of the Social Model***

The social model, the grand idea of the British Disability Movement, has been effective politically in building the social movement of people with disabilities. It is simple and straightforward and generates a clear agenda for social change. The social model provides means of distinguishing between supporters and enemies; “disabled people” indicates a social model approach, whereas “people with disabilities” signals a mainstream approach. By identifying the societal barriers to inclusion, the social model has been instrumental in the liberation of disabled people. Michael Oliver argues that social model is a “practical tool, not a theory, an idea or a concept” (Oliver, 2004).

Oppression and exclusion are flagged as the causes for the problems faced by the disabled people, not their impairments, according to the proponents of social model. It is from this stand that they come to the moral responsibility of the society to alleviate

the barriers to enable the inclusion of disabled people. The social model has also been effective psychologically by improving the self-esteem and self-image of disabled people and a sense of collective identity among them. In the medical model, disabled people are made to feel that they are responsible for all their miseries, leading to very low self-confidence and self-esteem and depriving them of any participation in the societal activities. On the contrary, it is not the disabled person to be blamed, but society; it is not the disabled person who has to change, but society. Hence, the disabled person can feel agitated and voice against the society rather than feel self-pity.

### *Criticism of the Social Model*

As a slogan and political ideology, the social model has many benefits; but these in turn are inadequate and drawbacks as academic explanation of disability. Another drawback is its authorship by a small group of disabled activists, majority of whom had spinal injury or other physical impairments. Had people with more diverse disabilities be included whose experiences are varied, disability would not have been so narrowly conceptualized.

The social model has been criticized for neglecting impairment as a vital aspect of many disabled people's lives:

As individuals, most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence every aspect of our lives. We must find a way to integrate them into our whole experience and identity for the sake of our physical and emotional well-being, and, subsequently, for our capacity to work against Disability. (Crow 1992, p. 7)

The experiences of disability for a congenitally blind or deaf person are entirely different from that for a person bedridden due to spinal injury. People of the latter category would depend immensely on medication and suffer pain for a long period of time. For people of the former category with static impairments, which do not degenerate or cause medical complications or lead to dependence on medicines, it may be possible to perceive disability as entirely socially constructed.

Impairment is a wide and heterogeneous spectrum encompassing conditions that are relatively benign to those that are incapacitating and even fatal at times. There can always be a medical dimension to it. To describe some forms of pain, say, as socially constructed does not mean that pain killers must therefore be useless.

According to another disability activist Carol Thomas (1999), "impairment effects" are to be included in the social model, so as to account for the limitations and difficulties of medical conditions. As a logical flow out from this position, she put forth a relational explication of the social model that allows the attribution of disabling features to both impairment and social oppression:

Once the term 'disability' is ring-fenced to mean forms of oppressive social reactions visited upon people with impairments, there is no need to deny that impairment and illness cause some restrictions of activity, or that in many situations both disability and impairment effects interact to place limits on activity. (Thomas 2004, p. 29)

Shakespeare (2006) contends that there are significant problems with the social model and it has become an obstacle to the development of the disability movement and to Disability Studies.

## **Barrier-Free Environment: A Utopia**

The utopia of a barrier-free environment is criticized by many disability activists. How much ever we struggle, many parts of the globe will remain inaccessible for many of the disabled people; for example, mountain ranges, beaches and marshlands pose challenges to wheelchair users to negotiate, while beautiful nature scenery and nature's sounds cannot be enjoyed by those with blindness or deafness. In many situations, many of the barriers can be mitigated, but the diversity among people with the same type of impairment makes it extremely challenging to meet their range of requirements, for example, books in Braille, in large print, audio tape or electronic files. A large library could not possibly provide all the books in all these forms to address the needs of all readers with visual impairment. The point in focus is that while agreeing that environment and services can and should be adapted to address the needs of disabled people wherever possible, one needs to accept the fact that disadvantages still remain associated with having impairments which no level of environmental adaptations can completely alleviate.

## **Inclusion as a Central Theme in DSE**

Social inclusion and inclusive education have been major concerns in Disability Studies. One of the most contentious issues in Disability Studies is found in the ongoing debates surrounding inclusive education, the deliberations concerning where and under what conditions students with disabilities should be educated. As per the World Bank and Global Partnership for Education (GPE) Report (2017) titled "Education: Children with Disabilities Are Left Behind", despite global efforts to improve education opportunities for all, children with disabilities are being left behind as gaps between children with and without disabilities have increased spectacularly in developing countries. The report reveals that these gaps are the result of exclusion associated with disabilities, as against other characteristics of children that could be concurrent with disabilities. The report also finds that children with physical disabilities or disabilities related to hearing, seeing or speech tend to be doing better than children with intellectual or multiple disabilities. According to the assessment of disability experts, access to school for children with disabilities is often limited by a scarcity of trained teachers, a lack of understanding about the needs of children with disabilities as well as a lack of matching facilities, classroom support and learning resource that address these needs.



## Disability Studies and the Latest Trends

### *Emergence of Critical Disability Studies (CDS)*

CDS has emerged in the last decade as a way to re-evaluate the critical underpinnings of past work in Disability Studies, most notably its focus on the social model of disability. CDS calls instead upon critical social theory, which challenges the very way that the status quo is construed and maintains a space for critical reason to achieve a more participatory and egalitarian society (Meekosha and Shuttleworth 2017, p. 175).

CDS is aimed at building an alternative body of philosophy and practice in the field of disability which is essentially subversive.

The disability movement's struggle was about more than ramps; now CDS can help to highlight how societies exclude "abnormal" bodies and reformulate who is eligible for participation in civic life. Investigating difficult problems that Disability Studies tended to shy away from will now contribute to an expanded understanding of disabled people's place in the world (Meekosha and Shuttleworth 2017, p. 175).

The highlighted dichotomy and binary way of conceptualizing disability from social or medical perspectives have undergone stringent criticism from feminists, cultural studies scholars and postmodernists resulting in disequilibrium and tension in the Disability Studies community. As departure from the preoccupations and restricted binary conceptualization of disability emerged CDS. Moreover, the permeable nature of Disability Studies as a field of inquiry and

the influx of humanities and cultural studies scholars with their post-modern leanings and decentering of subjectivity during the 1990s, especially in the US, enabled a more self-conscious focus on critical theorising to take hold in Disability Studies. Use of CDS signifies an implicit understanding that the terms of engagement in disability have changed; that the struggle for social change continues, but on another plane of development- one that is not simply social, economic, and political, but also psychological, cultural, discursive and carnal. (Meekosha and Shuttleworth 2017, p. 178)

This update in the field of Disability Studies has made it possible for it to become a more encompassing field providing a platform for critically examining oppression and exclusion of a larger group of persons, including transgender, aged and others.

### *Transgender Studies*

Disability and transgender identities and communities can be analysed through a comparative and intersectional lens. From conceptual terminology to societal oppression and discrimination within many contexts including medical systems, Disability Studies and transgender studies share common issues and struggles. Understanding the intersections between Disability Studies and transgender studies



facilitates a broader understanding of how they complement each other and enhance the potential for social change in a unified manner.

Similar to “disabled” being used as an umbrella term to cover many identities, in current discourse, “transgender” is used as an umbrella term to refer to transsexuals, gender queers, intersexuals and other people who do not fit into a traditional gender binary.

Transsexuality is conceptualized as primarily a bodily experience because of its association with changing bodies. People within disability and transgender communities share histories of medicalization and institutionalization. Medical documentation is central to the medical model of disability. Transsexual people navigate the law in order to receive medical treatment; no matter the subject of a legal case, medical certificate is considered crucial for determining the rights of the trans person because of the ways trans bodies have been medicalized. There is a significant overlap between trans and Disability Studies relating to documentation, investment in normality and the ties between disability law and transsexuality (Mog 2008).

Having disability and being transgender have umpteen social implications that result in several social barriers at each stage in the life of these persons. Disability has been traditionally seen as a deficit of the individual and a personal tragedy. Historically, this has also been the case for transgender and queer people. The common place maxim is that if one tries hard enough, one can overcome the disability or can be gender normative, with the assumption that having no disability or being gender normative is the “natural” and “right” way to be.

In the context of passing as nondisabled with regard to able-bodiedness, Linton and Berube (1998) talk about how children who use wheelchairs are often taken out of them for family photographs; children with invisible disabilities are told not to discuss them (p. 20). They say that the message in this practice is that “you are like everyone else, but only as long as you hide your disability” (p. 21). Passing as nondisabled takes an emotional toll on the person passing, because it restrains them from talking about a cardinal aspect of themselves. This can be compared to how a transsexual is required to not talk about the past and transition. The additional challenge hidden in this predicament is that there is a piece of reality in their being that could possibly be used to shame an individual – being trans or being disabled. This shame, however, comes from the fact that disabled bodies and transgender bodies are devalued and are considered as the person’s deficit. Thus, passing as being nondisabled or not transsexual is considered the best way out.

The social model of disability explains that the societal barriers that people with disabilities face are created by the society which while privileging certain able bodies fail to recognize others as legitimate. As in the case of societal ableism, barriers that trans people face, like not having a safe bathroom to use, are not a result of the trans people being deficient in some way but are barriers resulting from the apathy and ignorance of the society.

Both transgender studies and Disability Studies are becoming more widely studied within universities in the United States and the other countries of the West, with developing countries following suit. Slowly, the similarities and complementarities among these and other movements for social change will help in deeper analyses of the means of oppression and pave way for socio-political change.

## *Gerontology and Critical Disability Studies (CDS)*

Gerontology, the **study** of **old age** and of the **changes** it **causes** in the **body** and its intersections with CDS, albeit a new interdisciplinary venture among academia has been initiated right from the time of UNCRPD (2006).

The Convention on the Rights of Persons with Disabilities (UNCRPD) (2006) framework for action contains a number of articles which highlight the cross-sectionalities of ageing and disability. For instance, Article 9 [accessibility], Article 19 [living independently and being included in the community], Article 20 (personal mobility) and Article 25 (health) are just a few examples of how the Convention provides a concrete framework for action which may be of particular interest to the discussions on disability and ageing.

2030 Agenda: Leaving no one behind. Promoting and protecting the rights and dignity of older persons and facilitating their full participation in society are an integral part of the pursuit of the 2030 Agenda for Sustainable Development which pledges that no one will be left behind (UN 2019).

Human rights perspective posits that every person irrespective of age, among many other diversity dimensions, has the right to living with dignity. Thus the old people have the right to inclusion with facilities like secure living, health and medical care, etc. The examination of these rights to social inclusion by older people's groups from a critical perspective is the centrality of the gerontology-CDS nexus. Inquiries into such socially relevant questions provide an initial base for theory development in this under-researched area that has considerable significance vis-à-vis policy formulation.

Some of the main endeavours in this field of inquiry are highlighting the role of self-advocacy groups in giving greater voice to older disabled people in policy debate and challenging the truncated perspective of academic and policy implementations on the requirements of older people and disabled people, albeit the commonality of many of them.

The field of CDS in gerontology also attempts to inquire into the current issues and concerns of older people (e.g. access to housing, income, transport, health and social care), the kinds of discourses used by older people's groups to legitimize these issues as the basis for claims to social inclusion, the issues and claims that have most in common with corresponding areas of concern for disabled people's groups, how this analysis inform policy making and how could future research on disability, ageing and inclusion be designed, so as to adequately respond to the related claims of both older people and disabled people. Thus, it is the mission in this field to bridge the gap between related, but traditionally separate, fields of enquiry (Priestley and Rabiee 2001).

## ***Technology for Disabled***

The whole world is working hard to realize the target of inclusion of persons with disabilities at all levels. Needless to say, the support from the field of technology has been a great boon in these efforts. “.....[T]he global society is rapidly marching towards inclusivity and access to affordable and reliable technology for empowering the persons with disabilities” (Karna 2016, p. 7). One of the most amazing developments seen in education over the past 10 years is the way that technology has created a revolution in possibilities for learners with disabilities. For years, students have struggled with their assignments or been excluded from different classes or subjects because schools had accessibility or instructional problems, resulting in inadequate and unequal educational opportunities for children with disabilities.

But the rapid development and application of computer-based technology, however, has created a sea change in the available options for disabled students. This situation has gone a long way in improving the limited opportunities faced by disabled students. Computer programs have been designed to make it easier for disabled students to access the material, communicate their ideas and work and participate in educational experiences.

While Braille reading and writing techniques have helped blind or visually impaired students continue their education since the nineteenth century, mobility, hearing and visual aids have made revolutionary changes in the world of disabled persons.

Electronics and information technology is the pulse of this revolution in learning opportunities for disabled students because they are the basis of assistive technology. Any item, equipment or product, whether purchased, modified or customized, that is used to enhance, maintain or improve functional capabilities of individuals with disabilities is assistive technology.

Hence, whether to move a part of the body, move from one place to another, access information, communicate (in oral or written mode) and comprehend (oral or written information), assistive technology is at the service of disabled persons.

Each chapter of this book covering specific disability discusses the matching technological support whether it is for mobility or communication or accessing information, as the need be.

## **Disability Inclusion**

The following sections present a glimpse of the important initiatives taken at the global and national levels aimed at inclusive education of persons with disabilities.

## *International Initiatives*

**The Universal Declaration of Human Rights (UN) (1948)** Some of the articles such as Articles 1, 2, 22 and 25 are relevant to the need of persons with disabilities.

**The Universal Declaration on the Rights of Mentally Retarded Persons (1971)** This was the first step towards integration of persons with disabilities.

**The World Programme of Action Concerning Disabled Persons (1982)** It is an international strategy to enhance disability prevention, rehabilitation and equalization of opportunities and full participation of persons with disabilities in social life and national development.

**World Declaration on Education for All (1990)** World Commitment on Education as a Right: The right of every child to education was proclaimed in the Universal Declaration of Human Rights (1948) and was strongly reaffirmed and agreed upon at this Jomtien World Declaration.

**The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993)** It was an important resolution for improving the educational conditions of persons with disabilities.

**The World Conference on Special Needs Education – The Salamanca Statement and Framework for Action on Special Needs Education (1994)** This was the first global initiative with primary emphasis on inclusive education. The Statement reads “Regular schools with inclusive orientation are the most effective means of combating discriminatory attitudes, building on inclusive society and achieving education for all, moreover they provide effective education to the majority of children and improve the efficiency and ultimately the cost effectiveness of the entire education system”.

**World Education Forum for Action (2000)** The Dakar Forum was convened to re-assert the urgency of ensuring that marginalized groups can access education, particularly in light of the Millennium Development Goals. The Forum stated: “All children, young people and adults have the right to benefit from an education that will meet their basic learning needs in the best and fullest sense of the term, an education that includes learning to know, to do, to live together and be”.

**Education for All (Flagship): Right to Education for Persons with Disabilities (2001)** The aim of the UNESCO EFA Flagship was to reinforce the Dakar statement and to make it clear that without actively seeking to integrate children with disabilities and children from other minorities, the MDGs will never be met.

**UN Convention on the Rights of Persons with Disabilities (UNCRPD) (2006)** This is a human rights instrument that explicitly sets out the rights of disabled people and is the most important tool we have to argue for inclusive education worldwide. Signatories to the convention are required to promote, protect and ensure the full enjoyment of human rights by every person with disabilities and also ensure that they enjoy full equality under the law.

### *National-Level Policy and Legislation*

**Govt. of India Report on Blindness (1944)** Govt. of India Report on Blindness (1944) merits mention here in this context. Most of the current educational programmes for the visually impaired in this country are built on the fundamental principles of the recommendations given in this report. It was in accordance with its recommendations that the Ministry of Education established a unit for the blind in April 1947 (adapted from Kumar and Agarwal 2016, p. 80).

Since 1947, many national-level commissions, committees, acts, schemes and policies have been implemented in India for education, inclusion, employment and rehabilitation of persons with disabilities. Some of the important ones are briefly presented below in a chronological order.

**Sargent Report (1944) or CABE Report** The British chief educational advisor observed that whatever was done for disabled people in India was by voluntary organizations and that the country could profitably borrow from the experiences and achievements of countries which had been proactive in this field. The report is claimed to be a landmark in the path of efforts for integration of disabled children in regular schools, and it continued its recommendation for special schools, as required by the nature and extent of the disability.

**Education Commission (1966)** Education Commission (1966) made a first to suggest that the education of handicapped children has to be planned and implemented not merely on humanitarian grounds but also based on the principle of utility. The Commission emphasized that the education of children with disability should be “an inseparable part of the general education system” and emphasized the importance of integrated education in meeting this target as it was cost-effective and useful in developing mutual understanding between children with and without disabilities.

**National Education Policy (1968)** The National Education Policy followed the Kothari Commission’s recommendations and suggested the expansion of educational facilities for physically and mentally handicapped children and the development of an “integrated programme enabling handicapped children to study in regular schools”. Eight years later a scheme for the integrated education of disabled children (IEDC), 1974, was started by the Welfare Ministry.

**Integrated Education for Disabled Children (IEDC) (1974)**

Integrated Education for Disabled Children is a centrally sponsored scheme launched in 1974 by the Department of Social Welfare which got transferred to the Dept. of Education in 1982. Under the scheme handicapped (the term in vogue then) children were sought to be integrated in regular school system. The overall aim of the programme was to enable children with disabilities to face life courageously and develop a level of self-confidence, thus bringing them into mainstream of the society. Children with disabilities were to be provided with financial support for books, stationery, school uniforms, transportation, special equipment and aids. The state governments were provided with 50% of the financial assistance to implement this programme in regular schools. The IEDC programme was revised in 1992, and in the revised programme, 100% assistance was made available to schools involved in the “integration” of students with disabilities. Various NGOs were also fully funded to implement the programme. IEDC got implemented in almost all the states and union territories.

IEDC was revised and named “Inclusive Education of the Disabled at the Secondary Stage” (IEDSS) in 2009–2010 to provide assistance for the inclusive education of the disabled children at ninth and tenth classes. This scheme got subsumed under Rashtriya Madhyamik Shiksha Abhiyan (RMSA) in 2013.

**National Policy on Education (1986)** The National Policy on Education was adopted by the Indian Parliament in 1986. The policy emphasized the removal of disparities while ensuring equalization of educational opportunity.

**The Mental Health Act (1987)** This Act replaced the Lunacy Act of 1912. The purpose of this Act was to regulate admission to psychiatric hospitals or nursing homes of mentally ill persons who do not have sufficient understanding to seek treatment on a voluntary basis and to protect the rights of such persons while being detained.

**Programme of Action (1992) (POA) (MHRD)** The NPE/POA 1986 was redesigned and POA was chalked out in 1992. The 1992 POA made a determined commitment to universal enrolment by the end of the Ninth Plan for both categories of children: those who could be educated in general primary schools and those who required education in special schools or special classes in general schools. It also called for the reorientation of the pre-service and in-service teacher education programmes.

**Rehabilitation Council of India Act (1992)** This Act casts norms for service delivery to persons with disabilities among other responsibilities of the Council. The Council has the twin responsibility of standardizing and regulating the training of personnel and professionals in the field of Rehabilitation and Special Education.

**Persons with Disabilities Act or Equal Opportunities, Protection of Rights and Full Participation (1995)** This law is an important landmark in the path of improv-

ing the life of persons with disabilities in the Indian context and is a significant step in the direction of ensuring equal opportunities for persons with disabilities and their full participation in nation building.

**National Trust Act (1999)** This Act constituted a national body for the Welfare of Persons with Autism, Mental Retardation, Cerebral Palsy and Multiple Disabilities, and the objectives of this body were clearly spelt out.

**National Policy for Persons with Disability (2006)** The National Policy (2006) recognized persons with disabilities as a valuable human resource for the country and sought to create an environment that provided them equal opportunities, protected their rights and ensured their full participation in society. The focus of the policy was on prevention of disabilities and on rehabilitation measures.

**The Right of Children to Free and Compulsory Education (RTE) Act, 2009** The RTE Act is the law giving directions for implementing the fundamental right to free and compulsory education of children in the age group of 6 to 14. Although it has pitfalls, this Act is seen as a landmark law for transforming the education system to make it inclusive. There are many aspects of the law that support inclusion of many marginalized groups of children, those with disabilities being one among them.

#### **RTE Amendment Act (2012)**

Among other amendments was the amendment with regard to children with disabilities. The amendment not only specifically included children with disabilities under the disadvantaged groups of children but also added another clause to the Act – gave children with severe and multiple disabilities the right to opt for home-based education.

**Right of Persons with Disabilities Act (RPWD) 2016** Apart from covering 21 categories of disabilities from the previous 7 categories under the 1995 PwD Act, this new Act emphasizes rights of persons with disabilities – right to equality and opportunity, right to inherit and own property, right to home and family, right to safe and secure living and medical care and reproductive rights among others. Unlike the 1995 Act, the new Act talks about accessibility – setting a 2-year deadline for the government to ensure that persons with disabilities get barrier-free access to physical infrastructure and transport systems. Additionally, it also holds the private sector accountable. This also includes educational institutions “recognized” by the government such as privately owned universities and colleges. A game changer feature of this Act is the increase in reservation for persons with disabilities in government jobs from 3% to 4%.

The new list of recognized disabilities includes three blood disorders: thalassemia, haemophilia and sickle cell disease, and acid attack survivors have also been included in the list, so also intellectual disability, Parkinson’s disease, cerebral palsy, dwarfism and autistic spectrum disorders. With this new Act, the development in the disability arena has been catapulted onto a higher level.



## Consolidation

The field of Disability Studies covers the development of the theoretical, research, educational and advocacy models necessary to remove the legal, physical, policy and attitudinal barriers that exclude people with disabilities from society. Disability Studies, as a field of study, challenges the way in which disability is constructed in society and has the potential to benefit people with disabilities as well as society by the participation and presence of people with disabilities in our schools, neighbourhoods, workplaces, families and lives. The interdisciplinary intersections in the field and the emergence of the field of Critical Disability Studies are immense leaps in the academic discourse and social practice for equity and justice for full participation of persons with disabilities in the society. At national and global levels, efforts are on the go since more than half a century for the inclusion and participation of persons with disabilities in all the social platforms. The pace has been set and it definitely is a long steady ahead, especially for India and all other developing countries.

Silhouetted against the above background of Disability Studies is the presentation of inclusive education of children with specific disability (six categories) in the following chapters of this book.

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## Chapter 2

# Sociology of Disability



Sailaja Chennat

**Abstract** Conceptual map of sociology of disability, dwelling on the social history of disability, society's perceptions and perspectives on the disabled body, the explanations of disability by theorists, sociologists and activists etc., is critical to understanding disability which is a complex and dynamic phenomenon as also a highly debated one. Social model, as one of the central points of discussion in the discourse of sociology of disability, is presented with in-depth analysis. Disability discrimination as oppression is discussed, explaining how the history of disability discrimination chronicles a persistent infliction of segregation, dehumanization and exploitation. A brief discussion of the analysis of disability through the lens of theorizations by different sociologists like biopower of Foucault, habitus and capital of Bourdieu, capability approach of Sen and capitalism of Marx is presented. This is followed with the analysis of disability through sociological principles like normalcy and subjectivity and conceptualization of disability by sociologists and disability activists using the theorization of ableism. The chapter ends with a discussion on cultural and feminist perspectives of disability.

**Keywords** Disability as oppression · Bio power · Habitus and capital · Marxism and disability · Disability and capability approach · Normalcy · Culture · Feminist studies · Ableism

Disability is a complex and dynamic phenomenon and a highly debated one. It is the conceptual map of sociology of disability, dwelling on aspects like the social history of disability, the society's perceptions and perspectives on the disabled body and the explanations of disability by theorists, sociologists and activists that help us understand disability.

The core team of scholars whose research and writings since more than the 20 years have contributed to the development of the field of sociology of disability comprises Len Barton, Sally Tomlinson, Mike Oliver and a few others. Disability is a phenomenon that is socially defined, has all-encompassing social consequences for individuals and has significant impact on societies. The social reality of disability is characterized by considerable diversity in the experience of impairment by

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people. Also, disability has been researched about and conceptualized by people with and without impairments with a range of variations in the perspectives and perceptions, all of which contribute to the field of sociology of disability. As is clear from this statement, variations occur at two levels contributing to the richness of the knowledge in the field, i.e. diversity of personal experiences of disability by the protagonists, depending on the type of disability and the sociocultural context, and, secondly, whether the researchers themselves have a disability or not, and if they do, what the type of disability is. The diversity of disability-related research among sociologists is reflected in the field of disability studies; the field of disability studies promotes recognition of disabled academics in sociology. Discourse in disability studies has explored new possibilities of development for the field of disability studies and sociology of disability:

The field of Sociology of Disability is marked by a significant shift in the analysis of the nature and impact of disability from personal to social and material aspects. Academics with disabilities, Mike Oliver (1996), Colin Barnes (Barnes and Mercer 2002), Sally French (1993, 1994; Swain and French 2008), Shakespeare (2006); Barnes, Mercer and Shakespeare (1999), Jenny Morris (1991) and Carol Thomas (2007) have all contributed to sociological analyses which have identified disability as the product of environmental, structural and attitudinal barriers. Many of the writings turned the spotlight away from the child and illuminated the role of conceptualisations, attitudes and practices of people around, apart from the institutional structures in producing school failure. (Allan 2010, p. 1)

Barton (2001) outlined the clear function and expected role of sociology of disability:

A political analysis which is inspired by a desire for transformative change and that constitutes hope at the centre of the struggles ... At both an individual and collective level a crucial task is to develop a theory of political action which also involves the generation of tactics or strategies for its implementation. This is a difficult but essential agenda. (p. 3)

On a close scrutiny, three significant deletions within the field of sociology of disability are discernable which have had negative consequences for it. The first of these is the efforts by the proponents of social model of disability to exclude the disabled body from their conceptualizations of the model. The second is the more extensive disappearance of the disabled person or a person different in some way or the other from educational policies and practices. The third is the nonexistence of disabled scholars from political discourse and action.

Social perspective of disability views disability as caused by the way society is organized, rather than as a person's impairment or difference. It looks at ways of removing barriers that restrict life choices for disabled people by alleviating which disabled people can enjoy a life of dignity and equality in society, with choice and control over their lives. Barriers are not just physical; attitudes found in society based on prejudice or stereotype, or disablism, also disable people from having equal opportunities and participating equally in the societal activities to be part of it.

## Social Model

Social model is one of the central points of discussion in the discourse of sociology of disability. A few examples of social perspective on disability are presented below flowing into the counterarguments of this model of disability.

‘This field, however, has been a greatly critiqued and contested one, with intensive battles over identity and presence and a series of active erasures and absences – the removal of the body from the social model of disability; the disappearance of the Other from educational policies and practices; disability academics’ own absence from political discourse and action’ (Allan 2010, p. 1). Social model was developed to counteract the alarming disaster discourse that encases disabled people which also portrays disability as a shortfall, a tragedy and ‘*abnormal*, and something to be avoided at all costs’ (Oliver and Barnes 1996, 66; original emphasis). It has been developed as a powerful instrument to explain the discriminatory and oppressive structures of society. ‘.....disability according to the social model, is all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on’ (Oliver 1996, p. 33).

However these contestations and criticisms have done not much for the struggles for inclusive education, nor have these enabled to reduce the cries and protests of disabled people.

The social model of disability has not been used as a tool for altering the tangible, the everyday circumstances of disabled people nor for fostering inclusion, according to its proponents. It is their wishful thinking that the social model would be used to improve the lives of disabled people, rather than the model being continuously contested on.

### *Disability as Oppression*

The social model of disability is premised on oppression; it is defined as oppression; it assumes that disabled people are oppressed ‘...the question is not whether disabled people are oppressed in a particular situation, but only the extent to which they are oppressed’ (Shakespeare 2017, p. 200). Like other forms of oppression, the history of disability discrimination chronicles a persistent infliction of segregation, dehumanization and exploitation. However, unlike race, ethnicity, gender and sexuality, disability as a civil rights issue has received considerably less public attention because disability is often misconstrued and misunderstood as a health, economic or technical issue with the consequence that biases based on disability commonly remain unacknowledged. Moreover, this slip stems from a shared fear of disability on the premise that everyone is subject to illness, accident and the deterioration of abilities and energy levels of old age.

Charlton (1998), in his book, *Nothing About Us Without Us: Disability, Oppression and Empowerment*, presents his analysis of oppression of disabled people from the data he collected through interviewing disability rights activists from 13 countries in the USA, South Africa, Asia and Europe. An emphatic indictment of disability oppression is brought out by Charlton, which, he says, is rooted in degradation, dependency and powerlessness and is experienced in some form by 500 million persons throughout the world who have physical, sensory, cognitive or developmental disabilities. He presents a theoretical overview of disability oppression that shows its similarities to, and differences from, racism, sexism and colonialism. Charlton cries out the conviction of people with disabilities that they know what is best for them. He outlines three dimensions of disability oppression. The first is the political/economic dimension that addresses how people with disabilities are marginalized economically and politically throughout the world. The second is concerned with culture and belief systems that include mythological beliefs about people with disabilities, stereotyping of people with disabilities and the pitying of people with disabilities. The third dimension explores consciousness and alienation with particular emphasis on how people with disabilities internalize disability and oppression, respond to their oppression and remain alienated from themselves and others.

## **Sociologists and Their Perspectives on Disability**

Disability has been an evolving conceptualization and interpretation. Different disability activists and other scholars have theorized/have been theorizing disability from different perspectives. The following sections are devoted to brief discussion of the different perspectives and conceptualizations of disability by sociologists and disability activists.

### ***Disability in Relation to ‘Biopower’ of Michel Foucault***

The work of Michel Foucault has proved especially significant to the explorations of the new possibilities of development for the field of disability studies and sociology of disability.

Foucault’s post-structuralist theorization of the body as a thoroughly and inevitably politicized space makes his work relevant for contemporary disability studies. His theorization lays emphasis on the body as directly targeted and shaped by historically variable regimes of biopower like prisons, military establishments, hospitals, factories and schools; gradually the body got applied more broadly as techniques of social regulation and control. According to him, disciplinary power targets the human body as an object to be manipulated and trained.

Foucault's work challenges the traditional 'social model' of disability as far as it reifies and takes for granted impairments as the neutral foundations of disability. Through Foucault's lens, impairments themselves are not 'intrinsic defects that demand to be corrected or eliminated (as the "medical model" assumes)' but rather are 'created by social and economic arrangements and conditions that can be transformed' (Tremain 2010). Foucault's work challenges us to recognize that the 'difficult physical realities' of disability are themselves socially constructed and challenges to undertake the task of diagnosing the forces that produce them. Second, Foucault argues that any attempt to understand the claims of rights must begin by recognizing these claims as a political response to the triumph of biopower. Biopower denotes power over bodies; it is 'an explosion of numerous and diverse techniques for achieving the subjugation of bodies and the control of populations' (Foucault 1980).

Power, according to Foucault, is not something that is exchanged, given or taken back but rather is exercised and exists only in action. He disputes the assumptions of conceptions that posit that power is fundamentally oppressive. Though compliance and violence are instruments or results of power, they do not add up to its essential nature. What is significant is 'how' or by 'what means' power is exercised. One of the threads of Foucault's analysis of power is that power functions best when it enables subjects to act in order to restrict themselves.

In light of Foucault's analysis, the disability studies movement can be understood as an effect of biopower. To elaborate this position: disability is shaped as socially and politically marginalized identity by a form of power. Disability studies movement is a collective of disabled people as subjects who claim a right to life which relies on the essential promise of this biopower.

### ***Disability and Its Linkage with Bourdieu's 'Habitus' and 'Capital'***

Pierre Bourdieu has contributed much to the understanding of the social rules and structures that steer human interaction and understanding of self which are applied in the development of a theory of inclusion in multicultural schools. Bourdieu's theoretical repertoire can be applied to the area of disability studies in order to discern how society produces oppressive and exclusionary systems of classification which frame the social position and interpretation of disability.

Bourdieu's (1990) concept of habitus offers a way of analysing the body to impact an understanding of the social inequalities which are integral to the lives of disabled people. Habitus, as theorized by him, is the sum total of deep-seated habits, skills and dispositions of a person and represents the way group culture and personal history shape the body and the mind and, as a result, shape the present social actions of an individual. It is the way that individuals perceive the social world around them and react and respond to it. These dispositions are usually shared by people with similar backgrounds (such as social class, religion, nationality, ethnicity, education, profession, etc.). A *habitus* is in essence the way a person perceives

the world or the lens through which he/she views society. Our habitus is dependent on our own life experiences which affect how we view our position in society. Our experiences determine our mannerisms, desires and expectations. A celebrity will view the world differently than a noncelebrity due to their respective personal experiences. Similarly, a successful business person will have a specific perspective due to the experience of belonging to the elite class which would be very different from that of a rural shopkeeper.

The habitus is acquired through imitation and reflects the socialization of individuals, which includes their individual experience and opportunities. In this context, the life experiences of a child who has been using wheelchair from the age 5 or 6 or of a congenitally blind child who has never had the experience of playing outside with friends, or exploring his/her surroundings, would be entirely different from those of a child with no impairment. These experiences or lack of them would affect the way they see and perceive the world; thus their habitus so different from that of their peer group would impact their school experiences.

*Cultural capital as theorized by Bourdieu (1990)* refers to the nonmonetary assets which affect social mobility. This includes style of dress, vocabulary, education, mannerisms, skills and artistic ability. According to Bourdieu (1997), capital comprises long-lasting assets that individuals accumulate and exchange within fields in order to achieve success. The accumulation of capital within a field is influenced by exposure to habitus. 'Fields' according to Bourdieu denote 'dynamic, concrete, political, social and symbolic institutions such as the family, law and education' (DiGiorgio 2009, p. 183). However, forms of capital vary and these can have varying values across fields, and the habitus of individuals within and across fields can be erratic, rendering the process of determining the value of capital complicated by inconsistencies. This makes the mastery of how to succeed within fields difficult. Social practice in a specific field is determined and affected by the value of capital and the operation of habitus relative to the particular field. However, if the value of capital and operation of habitus are inconsistent across a field, the mastery of social practice becomes particularly difficult. This is especially pronounced for students with disability, who as a cohort experience high levels of social exclusion reducing their exposure to the operation of certain social practices (ACARA 2012).

### ***Marxism and Disability***

If we look back into the past, perspective of impairments was inextricably linked to religious faith and beliefs. In feudal societies impairments were seen as a mark of either good or evil, and hence people with impairments often faced persecution. Weaker, older or impaired members of ancient societies had more chances to survive with the development of established agricultural production. The rural production process and the joined family systems allowed many to make a genuine contribution to day-to-day economic needs. Such large groups of families living and working together were able to provide networks of care for children and/or the



elderly with impairments. But this way of life, typical for much of the world's population for thousands of years, was to almost disappear in the last three centuries.

### **The Creation of Disability**

The rise of capitalism forced people to move away from agriculture. The rural population was being increasingly pressed by the new capitalist market forces, and when families could no longer handle the demand, the members with impairments would have been most susceptible and liable to turn to begging and church protection in special poor homes. Market forces soon favoured machinery which was more efficient, and people with impairments would have had greater difficulty working such equipment.

The velocity of change was colossally accelerated by the industrial revolution. The blooming of machinery destroyed the cottage industries and traditional family structures. With this development, factory worker could not afford to have any impairment which would prevent him or her from operating the machine. Thus, able-bodiedness was established as the norm for productive living and production for profit by this economic necessity of producing efficient machines for large-scale production. This scenario weakened the position of impaired people within the family and the community.

As work became more mechanized and precise, impaired persons were seen as less 'fit' to do the tasks required of factory workers and were increasingly excluded from paid employment. Thus, progressively, the industrial revolution removed impaired people from social interactions and transformed them into disabled people.

All through the eighteenth and nineteenth centuries, disabled were isolated into workhouses, asylums, prisons and special schools. The inhuman and oppressive processes of isolation of disabled people in institutions triggered the focused and in-depth study on disability and disabled people and their standing in the society.

In short, capitalism chronicled a huge leap from previous societal systems in many ways. The new working class whose struggles caused the production and growth of wealth was excluded from voicing about what and how of the production while suffering from their pains, both physical and mental, on an unparalleled scale. Those people thus marginalized or excluded from production had the same experience in the wider society. In this way capitalism created disability as a particular form of social oppression.

### ***Disability and 'Capability Approach' of Amartya Sen***

Sen's capability approach (CA) was developed as a framework to analyse different concepts in welfare economics, including standard of living, personal well-being, quality of life and poverty. Standard of living is understood in terms of the ability to buy a bunch of merchandise or 'commodities', which is referred to by Sen as the

opulence view. Standard of living is also measured by one's self-worth and the choices one has at his/her access level to choose from. According to Sen, the standard of living concept encompasses more aspects than the opulence and the utility measures (Mitra 2006, p. 238). Sen focuses on the type of life that people are able to live, that is, on their capability to achieve or accomplish, what they succeed in being or doing. The possession of commodities is valuable only to the extent that it enables the person to do a range of things or be a range of things. A commodity is considered to have 'characteristics'. For instance, for a person who has had polio and is unable to walk, a wheelchair has the characteristic of aiding in mobility; but for a person with no locomotor impairment, wheelchair does not have such a characteristic.

In Sen's approach, capability means 'practical opportunity' (Mitra 2006, p. 236). Capabilities are the alternative combinations of functionings that a person can achieve. Formulations of capability have two parts: functionings and opportunity freedom – the substantive freedom to pursue different functioning combinations. Ultimately, capabilities denote a person's opportunity and ability to generate valuable outcomes, taking into account personal characteristics and external factors.

The commonly understood meaning of functioning is doing an activity, some action a person carries out. In CA, functioning has a broader sense; it includes activities as well as desirable state of being for a person, such as 'being well-nourished' or 'being free of diseases'. Sen elucidates the difference between capabilities and functioning through the illustration of two people who are starving. One is doing so as a part of religious faith and ritual and the other due to poverty. The former one has decided to starve and is doing so on his/her own volition (capability), and the latter is forced to do so due to poverty and has no option but to starve (functioning).

Anyone's interests are of more concern to Sen than their actions or behaviour. He perceives two ways of seeing a person's achievement and fulfilment, well-being and advantage:

Well being is, 'how well is his or her being', so this is related to achievement, what he or she achieves by being or doing. Advantage presents the real opportunities present before a person from which he or she will have the freedom to choose. A person's capability set is a set of functioning vectors from which the person has the freedom to choose. (Mitra 2006, p. 239) 'Freedom to choose' is an important aspect in this definition.

Sen has included 'personal characteristics' as cardinal to capability in his conceptualization. Impairment is considered an example of personal characteristics that should be taken into account in assessing poverty and well-being of a person. He has factored in the impact of personal characteristics including handicap or disability (as referred to by him) on a person's capability set. Education can be considered a 'personal characteristic' that influences work as a functioning (e.g. how education influences the employability of persons with impairments). Education can be considered as a 'functioning' directly (e.g. what is the dropout level of children with impairment as compared to other children without?). By including personal characteristics, human diversity is clearly factored in CA.

Sen's approach has the benefit of having a larger coverage as it includes all types of functioning, from basic ones like nutrition, shelter, sanitation, health, etc. to complex ones like self-respect, self-worth, happiness, sense of fulfilment, social skills, etc.

### **Understanding Disability Through Capability Approach**

Health is a major concern in CA; as compared to health, disability has not got much focus in CA. Sen has focused on the impact of personal characteristics including handicap or disability on a person's repertoire of capabilities. According to him, poverty and well-being of a person cannot be assessed without considering the personal characteristics like impairment.

Under the traditional opulence or utility approach in economics, commodities a person can command are taken to be the indicators for his/her well-being, irrespective of whether or not the person has impairment. According to Sen (1999):

A person who is disabled may have a larger basket of primary goods and have less chance to lead a normal life (or pursue her objectives) than an able bodies person with smaller basket of primary goods. Similarly an older person or a person more prone to illness can be more disadvantaged in a generally accepted sense even with a larger bundle of primary goods. (p. 74)

When we analyse CA to see if it helps to define disability at a conceptual level or if it is able to do justice to account for the experiences of people with disability in an effective way, the following interpretations are possible:

CA is indeed a useful framework for defining disability as it enables the analysis of disability at two separate levels, as a deprivation of capabilities and as a deprivation of functioning.

At personal characteristic level, it can be seen as impairment, a physiological, mental or anatomical loss rather than a disability. In terms of capabilities and functioning, deprivation results from the interaction among the resources available to the persons, the personal characteristics and the environment.

The onset of a severe physical or mental impairment will almost inevitably lead to a reduction in the range of the individual's practical opportunities and in the capability set and thus lead to disability at the capability level.

### **Disability Resulting from a Combination of Factors**

Under CA, disability may be understood to be caused due to coalescence of factors: the nature of personal characteristics including impairment, age, gender, race, etc., the resources available to the person and the environment. Deprivation can result from the very nature of the impairment, irrespective of the other personal characteristics, the amount of resources available and the environment. For instance, if a person's impairment causes constant pain, due to which access to practical opportu-

nities, like going out to do shopping for self, going out to work or for entertainment, etc., becomes difficult, it is the intrinsic nature of the impairment that deprives the person of capabilities and leads to disability.

Deprivation can be due to the barriers and other hurdles in the environment that may be with respect to any or all of political, physical, economic or cultural aspects. For instance, a lady, a victim of acid attack with disfigured face and body, may have her capability set reduced not by her body image per se but by the stigmatization or by discrimination in interpersonal relations.

Deprivation can result from the economic restriction that a person's impairment may place on the availability of and demand for resources or may cause higher expenditure to realize a given level of benefit or well-being.

### **Disability Models and CA**

Disability models like medical model, social model, Nagi model and the like have been proposed by disability scholars and activists in the field. CA as an approach to disability is discernable with noteworthy differences that distinguish it from other disability models.

CA allows disability to be differentiated at two levels, capability and functioning levels. The association between a given impairment and disability resulting from a spectrum of factors differs drastically from person to person. CA encompasses all these factors at the individual level through the resources available, the environment and the personal characteristics.

### **Promoting Capabilities of Persons with Impairments**

Capabilities, as presented earlier, are the 'state of being' and 'doing' that individuals value. In order to promote capabilities of persons with disabilities, the enabling factors that allow them to convert, modify and adapt resources and commodities into capabilities (i.e. those beings and doings that individuals value) have to be identified and nurtured, like public policies. Those conversion factors can be internal (at individual level) or external (i.e. social and environmental). The 'internal' conversion factors, such as personal characteristics (e.g. physical conditions, sex, skills and talents), convert resources (or commodities) into individual functioning. The conversion of the resources is also dependent on external conversion factors and social and/or environmental characteristics. Furthermore, as pointed out by Sen, 'While exercising, your own choices may be important enough for some types of freedoms, there are a great many other freedoms that depend on the assistance and actions of others and the nature of social arrangements' (Sen 2007, p. 9). This clause is pertinent in the context of persons with impairments and even more crucial for children or persons with severe impairment, for whom caregivers' assistance is often crucial, like a quadriplegic person who is totally dependent on a person to carry him/her around. Consequently, the capability set of such persons dependent on caregivers is

shaped not only by their conversion factors but also by those of their parents' or caregivers' capabilities. In such cases, the 'external capabilities' – i.e. capabilities that depend upon another person's capabilities who accepts to share some conversion factors with them (Foster and Handy 2008) – play an instrumental role to ensure basic capabilities, referred to by Sen as fundamental physical capabilities, like being well-nourished, adequately clothed and sheltered.

## **Disability from the Lens of Sociological Principles**

The history of theoretical debates on disability has been quite stormy with the contributions of disability activists, sociologists and other scholars. The following section discusses some of these theorizations.

### ***Disability, 'Normalcy' and Subjectivity***

A societal context may have children with different types of impairments, like visual impairments, hearing impairments, speech and/or language impairments, autism, locomotor impairment, intellectual impairment or any other. There may also be people with multiple impairments. Impairments that affect the senses, movement or physical health are fairly straightforward to identify or perceive. But viewing impairment from a contextual/social lens, the degree of disability (if any), indicated by these impairments, is related to the cultural context and the environment. For example, while that a wheelchair user has a locomotor impairment remains a fact, the experience of his/her disability depends on the context.

Mild intellectual impairment, specific learning disabilities and emotional or behavioural disorders are regarded as a soft disability, as in these cases, distinguishing impairment from disability becomes difficult. Soft disabilities are those 'for which no discernable physical markers are currently known' which makes 'the identification process subjective' (Fuchs et al. 2002). Autism is identified on the basis of social behaviour which is very much based on the sociocultural context of the assessed person; in other words, the socially accepted behaviour norm, which is very much context specific, is the benchmark for assessment of autism and hence is an example of soft disability.

Some proponents of social model of disability are of the view that all diagnoses and perceptions of impairment are ultimately subjective, as cultural beliefs about the 'normal' body inform all scientific practices. To elaborate further, what is culturally perceived as impaired or abnormal is inevitably related to what is perceived as normal and then explicated neurologically and biologically. Perceiving learning disabilities, mild mental retardation and emotional or behaviour disorders is a particularly subjective process, because they (a) are diagnosed with tools that rely largely on assessment of the individual's relationship to a particular context, often schools;

(b) are difficult to distinguish from one another and often seem to overlap in school settings; and (c) seem particularly influenced by the belief systems and demands of a given society, as expressed in changes of diagnostic criteria over time and in variations in diagnostic criteria in various places (Kane and Tangdhanakanond 2008). Autism is taken to be a soft disability, because diagnosis relies on assessment of social behaviour which is culture and context bound.

### *Ableism as the Yardstick for Disablism*

The term ‘disablism’ portrays pessimistic beliefs and discrimination based on disability, centring on the societal oppression faced by people with disabilities. Ableism is classically used in the discourse related to disability and means that certain standards of physical, cognitive, sensory or other types of abilities are preferred, and people whose abilities that don’t reach up to these standards are considered impaired; these people need to be fixed.

Wolbring (2008) defines ableism as ‘a set of beliefs, processes and practices that produce – based on abilities one exhibits or values – a particular understanding of oneself, one’s body and one’s relationship with others’ (pp. 252–253). Miller et al. (2004) define disablism as ‘discriminatory, oppressive, or abusive behaviour arising from the belief that disabled people are inferior to others’ (p. 28). It is exclusion from participating in various activities of society due to various types of barriers, pitying attitude of the society or the pressure from the society to overcome their disability that gives people with disabilities the feeling of disablism.

It can be understood that disability is interpreted through the criteria and assessment of able-bodiedness and ableism. From an ableist perspective, impairment or disability, whatever it may be, or however much severe it may be, is essentially negative which makes it imperative that it should be fixed, cured or wiped out altogether from the body and the society as well. According to Campbell (2009, p. 5), ‘disability is cast as a diminished state of being human’.

What are the behaviours and practices that are the indicators of ableism? There is no single answer to this question as there are many interpretations of the concept of ableism. Simi Linton, for example, defines ableism as ‘include[ing] the idea that a person’s abilities or characteristics are determined by disability or that people with disabilities as a group are inferior to non-disabled people’ (Linton 1998, p. 9). For example, in a class, when buddy culture is initiated for helping students with impairments, it is always children with impairment to be helped; seldom does the teacher think of what abilities the children with disabilities have and how these children can reciprocate using their strengths. This practice certainly is a reflection and reassertion of ableism.

Disablism can occur at different levels: individual and institutional levels. Personal negative beliefs individuals have about people with disabilities get covered under individual-level disability. Institutional disablism indicates the development

of societal structures or institutional practices that leads to systematic exclusion of people with disabilities which can lead to additional social and physical barriers.

In societies where certain abilities are valued more than others, the natural consequence will be the emergence of political and social structures that uphold and value these abilities and fuel them. This ableist perspective and explanation are used to validate unequal treatment of people with disabilities. In short, ableist beliefs about certain abilities lead to disablism or discrimination against people who have disabilities.

Any society throws a blind eye or ignores those categories of people, who are deemed to not fit into the framework of interpretation of what is 'normal' and are consequentially excluded and socially disempowered. This fire of social and cultural apartheid is fanned and kindled by the dearth of basic amenities in the environment to address the needs of disabled people.

### *Cultural Perspective of Disability*

In the context of identity formation of disabled, cultural context, as in the identity formation of any person, has to be considered significant although this consideration raises the question as to whether there is a culture of disability at all! As a consequence of the rise of capitalism, the exclusion of disabled from communities and from their legitimized roles, both social and economic, has had an influence on this cultural context.

Throughout the twentieth century, whether it be in the novel, newspaper stories or television and films, disabled people continued to be depicted as more than or less than human, rarely as ordinary people doing ordinary things (Oliver 1990). These portrayals show disabled people either as pathetic victims of some dreadful tragedy or as superheroes struggling to overcome an overwhelming burden. But the image of disabled people as more than human does not always focus on goodness especially in children's fiction wherein the disabled adult has often been portrayed as a resentful and threatening character who manipulates children for his own needs (like John Silver) or as a man bearing a grudge against society, who uses his distorted body or artificial limbs in a threatening and aggressive fashion (like Captain Hook) (adapted from Quicke 1985). Characters in Indian mythology (*Shakuni*, *Manthara*, etc.) are examples for how disabilities were depicted to be associated with wickedness and embittered traits. It is recognized that these dominant cultural images not only defy the actual experience of disability but also are not helpful in providing role models for disabled people and in alleviating prejudice against disabled persons among the rest of the population.

One can see how the cultural images discussed above support the ideology of individualism, in presenting the disabled individual as less than or more than human. There have seldom been attempts to present culturally the collective experience of disability, and hence the process of identity formation for disabled individuals has usually been limited by images of superheroes or pitiable victims.



Identity formation among disabled has been greatly influenced by the group of people who do things or write things about disabled people; both their theories and practice are restricted by the ideology of individualism and by cultural images of disabled people as less than humans.

### *Disability from Feminist Perspective*

Human diversity, as we understand, is limited to the traditionally accepted and discussed aspects. The fundamental goal of feminist disability studies 'is to expand the terms and confront these limits of the ways we understand human diversity, the materiality of the body, multiculturalism, and the social formations that interpret bodily differences' (Thomson 2013, p. 4). When disability is incorporated as a category of analysis and a system of representation, it enables rumination regarding conceptualizations about and interconnections between these diversity dimensions, thus challenging feminist theory.

Academic feminism as an area has been alive with contestation of theories, approaches, pedagogies and practices. One approach in feminist theory is it investigates how culturally particularities of bodies have been more than saturated with meanings and how these meanings have impacted the life experiences of women. Feminist theory involves collaborative and interdisciplinary inquiry which is reflexive in nature critiquing and cross-checking on the interpellations of various identities of subjects with reference to race, ethnicity, ability, sexuality, gender and class. The intersections of these diversity dimensions result in identities that propound claim on the subjects and which they claim for themselves. Among the identities with reference to race, ethnicity, sexuality, gender and class, it is the ability/disability theory as a category of analysis in the discourse in feminism studies that distinguishes feminist disability theory.

By considering the ability/disability system, feminist disability theory goes beyond explicit disability topics such as illness, health, beauty, genetics, eugenics, aging, reproductive technologies, prosthetics and access issues. Feminist disability theory addresses such broad feminist concerns as the unity of the category woman; the status of the lived body; the politics of appearance; the medicalization of the body; the privilege of normalcy, multiculturalism and sexuality; the social construction of identity; and the commitment to integration (Thomson 2013, p. 4). Disability like gender is a concept that pervades all aspects of culture: its structuring institutions, social identities, cultural practices, political positions, historical communities and the shared human experience of embodiment (Thomson 2013, p. 4).

Women with disability have not been getting adequate attention despite the fact that people with disability in general especially certain impairments have been under lens since decades. Like many social movements geared to social change, the disability movement has often been biased towards primarily male experiences, like male sexual concerns, body images and employment issues, which have been more researched and written about than child-bearing problems (Deegan and Brooks



1985, p. 1). This is so partly because ‘ideology of masculinity’ (Brittan and Maynard 1984) shapes the experience of disability and experience in general, and this limits the range of personal responses open to both disabled men and women.

Disabled men are obliged to fight the social stigma of disability; they have the option to aim for socially powerful roles, whereas disabled women do not have this option. Disabled women are perceived as not suited to economically productive roles and suited only for the conventional nurturing and reproductive roles. Hence disabled women find it difficult to take on male roles but, at the same time, are often denied access to their traditionally accepted roles as they are often seen as asexual and unbecoming for, or incapable of, motherhood. It is this ‘double disability’ which constitutes the experience of disabled women and develops as add-on to the oppression of disability. The lack of socially acceptable roles for disabled women derives from a constellation of confusing forces. According to Fine and Ach (1995), ‘disabled women (like racial or ethnic minority women) experience a major disadvantage in comparison to the groups of disabled men and non-disabled women. The disadvantage is ‘double’ because disabled women fare worse than both these groups, economically, socially and psychologically’ (p. 7, as cited by Oliver 1990).

This can lead to an alternative argument, although from a male perspective that the experience of disabled women may be less oppressive than that of disabled men as their traditional role expectations are different from those of men. The commonplace social perception is that impairment and dependence on assistive devices, etc. do not affect women with disability; their social grooming is such that they comply with situations. For example, the traditional view of sex roles holds that dependence and compliance are more natural for females than for males. A woman, a wheelchair user, can still manage a household, get household tasks done by instructing other members in the house, provide emotional support to a family and function sexually in a ‘relatively passive’ manner (Bonwich 1985, p. 56).

From the feminist disability perspective, the above situations are oppressive in nature which are analysed and ruminated deeply.

## Consolidation

Disability is an intensely contested phenomenon, and debates within sociology of disability include many theoretical and interpretative frameworks that have been used to scrutinize the social construction of disability. A conceptual map of the sociology of disability enables one to understand disability in depth from varied perspectives. A threadbare analysis of the nature of impairment and the corresponding adaptability of the environment for both the source of the problem and its solution is crucial to the deconstruction of disability.

This chapter on sociology of disability and the previous one on disability studies as a discipline lay the conceptual foundation for the comprehensive understanding of each disability and its implications for inclusive education presented in the following chapters.

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# Chapter 3

## Conceptualizing Disability Inclusion



Sailaja Chennat

**Abstract** Situating social inclusion in the framework of diversity, this chapter introduces the reader to the philosophy and practice of inclusion discussing the conceptualizations and the inherent disconnects in the practice of inclusion in the society. Discussing the diversity in terms of types of disabilities and the degrees and levels of disability in each disability category, the dictum ‘inclusive education for all’ is demystified and the significance of special schools for different disability categories in the continuum of educational settings for children with disabilities has been emphasized. Critique on disability and marginalization has been presented next flowing into an analysis of societal response to persons with disabilities during the past few centuries: extermination to human rights-based approach. Finally, inclusive education has been discussed, delineating between what is and what is not inclusion, teacher attributes for successful inclusion and the practice of buddy culture and reciprocity in schools. Initiatives in India to promote inclusive education have been discussed, following which the necessary adaptations required in our teacher education programmes, both pre-service and in-service segments, have been presented. The latest global trends for facilitating inclusive education have been briefly presented at the end of the chapter.

**Keywords** Philosophy of inclusion · Diversity · Exclusion · Models of disability · Buddy culture · Neurodiversity · Universal design of learning · Differentiated teaching

### Inclusion

Inclusion is a way of implementing the democratic principles of equality and justice with acceptance and conviction so that every individual of the group feels accepted, valued and safe. Inclusion is the process of improving the participation of individuals and groups in society and improving the ability, opportunity and dignity of those

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disadvantaged on the basis of their identity. An inclusive community respects differences among its members and embraces the means of enhancing the well-being of every member of the community.

### ***Inclusion as a Philosophy and Practice***

Inclusion is an outlook, a conviction and a philosophy. Unless it becomes the way of thinking about people around and socializing with them, it can't be practised. In an inclusive society, people experience a sense of belonging, they are accepted for who they are within their communities and have valued roles in the community, and they actively participate in the community, involve in activities based on their personal preferences, have an active social life and enjoy social relationships with those whom they choose. When people experience some or all of these conditions in their life, they are more likely to be happier and healthier than those without them. In fact, without feeling included, people are more likely to experience poor mental and physical health, loneliness, isolation and poor self-esteem.

Integral to most definitions of social inclusion lies the concept of full participation in all aspects of life. Participation creates a sense of responsibility towards others, a community or an institution. Central to the process of inclusion are efforts to ensure equal opportunities for all, regardless of their background, be it economic status, class, ethnicity, gender, race, abilities/disabilities or whatever, to enable their full and active participation in all aspects of life, including civic, social, economic and political. So, logically, social inclusion can be approached as a goal, an objective and a process.

The whole conceptualization and theorization on social inclusion are results of social exclusion, that is, inclusion has become imperative due to the repercussions of exclusion in our societies; in other words, it is diversity and exclusion that has given rise to inclusion as a significant discourse in today's academia.

In every country certain groups of people whether migrants, ethnic people or other minorities face barriers that prevent them from fully participating in the different forums of the society. They are excluded from the society based on one or several of their identities like gender, race, ethnicity, religion, sexual orientation and gender identity or disability status; this exclusion happens through a number of practices ranging from stereotypes, stigmas and superstitions that can deprive them of dignity, security and the means and opportunity to lead a better life.

### ***Diversity and Inclusion***

Inclusion as a philosophy and practice cannot be discussed meaningfully unless it is situated in the context of diversity.

Diversity in literary terms means differences. But when used in the context of people or communities or in social contexts, it is more specific; it indicates that a group of people comprises individuals who are different from each other in some way or the other, or it may also mean collective differences among groups of people which mark off one group from another. The term generally refers to distinctions on the basis of 'race', ethnicity, class, gender, ability and, as the latest addition to this list of attributes, sexual orientation. That 'new' aspects of difference may be covered in this broader term also indicates that the understanding of diversity is not static (Joshee 2010). It changes in accordance with the ways and means used by the marginalized groups to create societal awareness of their issues. At the same time, inbuilt in the notion of diversity is the understanding that all attributes of diversity do not make a real disparity in terms of a person's social position and life chances. For example, while a person's skin colour most certainly affects social position and life chances, hair colour or eye colour does not. Importantly, diversity is not simply a descriptive term; it implies an ideological position that values cultural pluralism and supports its preservation and development within a society. The concept of diversity encompasses acceptance and respect for members of a group; it is loaded with a political perspective positively inclined to equity and justice in society.

It is from the above string of analysis – diversity being loaded with a political perspective positively inclined to equity and justice in society – that it gets linked to inclusion. Here diversity includes value and respect for pluralism in a social group establishing positive inclination to inclusivity while fostering a feeling of oneness and a sense of dignity and belongingness in each of the members of the pluralistic society. It is diversity that brings in the advocacy for equity and justice for each of the persons in a group irrespective of their abilities, disabilities, social status, religion, class, caste and so on and so forth. In an inclusive society, people understand, accept and respect diversity; it not only recognizes diversity but also embodies it so that each and every member of the diverse society can achieve their full potential in life. Such societal conditions instil in each member a sense of belonging to the community and society at large. Exclusion conversely is a process and a state resulting in lack of access to full participation in mainstream society.

## **Disability as a Dimension of Diversity**

It is clear from the above sections that diversity in a group of people has many dimensions: language, culture, race, ethnicity, skin colour, sex, age, geographic origin, facial features, economic status, educational qualifications, sexual orientations and capabilities and disabilities. Thus, disability is definitely one of the important dimensions that makes a person different from others in the group. The important feature of disability is that it is a diversity classification that cuts across all other dimensions like class, caste, race, religion and language. It represents the only minority group that anyone can become a member, anytime in life (Slorach 2011).

Any society based on democratic principles would be aware of such diversity and committed to provision of equality of opportunity to its citizens with disabilities. One of the means of achieving this aim is making the school systems platforms of equality, equity and justice through inclusive philosophy and practice.

Inclusion is an outlook, a philosophy and an overarching practice that takes into its fold people with all possible dimensions of diversities as discussed above. When inclusion is discussed with reference to disability as the diversity dimension, we are within the framework of disability inclusion which is central to the content of this book.

## *Understanding Disability*

Disability is ingrained into human life. It is a complex, dynamic, multidimensional and contested area of discourse. Almost everyone will experience temporary or permanent impairment at some point in life, and those who survive to old age will experience escalating difficulties in functioning and dependence on others. Most extended families have a member with a disability, and they are generally supported and looked after by others in the family or friends' circle who are not disabled. The moral and political issue of how best to include and support people with disabilities has been a challenge at every period of time, exceedingly so with more people living to an old age, thanks to change in demographics of societies and advanced medical technologies.

The definition of disability as given in the UN Flagship Report on Disability and Development (2018):

In the International Classification of Functioning (ICF), Disability and Health, disability is defined as a limitation in a functional domain that arises from the interaction between a person's intrinsic capacity, and environmental and personal factors. From this perspective, functioning occurs at three levels: body function and structures, activities and participation. For example, if an individual cannot move their legs, he/she experiences a limitation in functioning at the body function level. If an individual has difficulty walking, he/she experiences a limitation at the basic activity level, in other words difficulty combining body functions to perform a particular task. If an individual cannot work, because of environmental barriers (e.g. an inaccessible work place), then that person is restricted at the participation level. Similarly, the CRPD recognizes "that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others". (point 5 in the Preamble)

The definition of disability as per the World Health Organization (WHO):

Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.

Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or

she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers (WHO 2011). (<https://www.who.int/topics/disabilities/en/>)

'Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)'. (p. 4)

Thus, disability is a complex phenomenon, resulting from the interplay between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers.

The concept of disability is complex, and its interpretation is influenced by historical, sociocultural, legal and philosophical factors. One of the perspectives on disability is that we, comprising the majority population, who think we have no disabilities, are all only temporarily able. This position points to the likelihood that most of us will experience some form of disablement for some period of time during our lifetimes and also that all of us who are apparently healthy will/would have experience/experienced dependency and disabling experience at least twice, during our infancy and old age. This incantation almost seems to imply that if only the so-called normal person would accept that he/she too will be disabled someday, then a major impediment to the social acceptance and accommodation of disability and disabled people would disappear.

The Disability Discrimination Act (DDA) (1992) defines a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.

Over the past decades, various disability movements and activism supported with numerous researchers from the social and health science have identified the role of social and physical barriers in disability. This is recognized as a transition from an individual, medical perspective to a structural, social perspective termed as the shift from a 'medical model' to a 'social model'. In this model, people with impairments are viewed as being disabled by society rather than by their bodies.

The preamble to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006) acknowledges that disability is 'an evolving concept' and stresses that 'disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others'. In this, the use of 'interaction' indicates that 'disability' is not a characteristic of the person but involves the environment of the person.

The impact of a person's environment on the experience and extent of his/her disability is enormous. It is when environments turn to be inaccessible that they disable a person by creating barriers to participation and inclusion. The experience of a signing deaf individual without a sign language interpreter in a meeting, what a wheelchair user experiences in a building without an accessible bathroom or elevator and the experience of a blind person in front of a computer without screen-reading software are all examples of the disabling impact of environment.



One perspective is that disability is a deficit in a person. This view has been immensely contested by disability activists and scholars. According to Pfeiffer (2002):

Disability does not refer to a deficit in a person. Disability refers to a value judgment that something is not being done in a certain, acceptable way. Just as race is not a viable biological term and has no “scientific” definition, disability has no “scientific” or even a commonly agreed upon definition. Disability is not based on functioning or normality or a health condition, but on value judgements concerning functioning, normality, and health. In other words, the term disability is based on ideology and social class. (p. 2)

### *Diversity in Disability Groups*

It is a commonplace knowledge that members of any social group will vary in capabilities. It is also known that all of us who have no disabilities at a particular point in time are temporarily able-bodied. This is so because anyone can be faced with a disability anytime, especially physical disabilities. Many of the people with disability might have been having the disability from birth, and others might have acquired it through their years owing to various factors like disease (polio), accident (spinal injury leading to paralysis of the body), trauma or inheritance (retinal detachment). Thus, disability is an unavoidable element of human experience. The disability experience which is a sum total of and the interaction of individual’s health conditions, personal factors and environmental factors varies greatly. A group of disabled people is more heterogeneous than those of race, gender, class, etc., while conventionally, disability discourse illuminates wheelchair users and a few other typical groups such as blind people and deaf people. Disability encompasses the congenital conditions of a child, such as cerebral palsy or fragile X syndrome, a boy with one arm lost in an accident, defence personnel who has lost his feet in war, a woman with severe arthritis, or an old person with dementia, among many others.

It can be deceptive to make generalizations ‘people with disabilities’ without taking into cognizance their diverse personal factors related to gender, age, socio-economic status, sexuality, ethnicity or cultural heritage. Moreover, the experience of disability and the disadvantage faced vary among any group of people with disabilities. In general, people with severe impairments are more disadvantaged than those with mild impairments. Women with disabilities are faced with the compounded disadvantage associated with gender along with that of disability. People who experience intellectual impairments are more disadvantaged in many settings than those who experience physical or sensory impairments.

The diversity extends to how disabilities affect one’s functioning and can affect sensory functioning or mobility. In terms of the time period of its effect on the person, it can be static or progressive; in terms of its onset, it can be congenital or acquired, it can be related to external body appearance or to one’s functioning, and it can be obvious or not obvious and may be painful or not consequential at all. These differences indicate that any population of disabled people stands out distinctly with differences that impact the identity of each of its members. For exam-

ple, people with congenital impairments, say born blind or deaf, are more likely to identify themselves as disabled and be more self-contained and reflect confidence and self-respect in their social behaviour as compared to those with acquired impairments, who struggle with their changed identity. Indeed, most people born deaf and well versed with sign language do not consider themselves disabled at all; rather they consider themselves as belonging to an ethnic minority, set off the mainstream by their language and culture. Those with acquired impairments are more likely to resist being identified as disabled and spend most part of their lifetime fighting for an identity of a 'normal person' with medical and rehabilitative support. In a way, in many cases, if not all, they can be said to succumb to the 'fixing' attitude inherent in the medical model of disability, based on the idea of 'normalizing'. In any case, the boundary between disabled and able is less eternal and more porous than those between races and religions and classes. With medical advancement and rehabilitation, it is possible that some might get shifted from the status of being disabled to that of non-disabled; on the other hand, anyone can become disabled at any time, and most people will eventually become disabled to a significant degree as one grows old unless he or she dies untimely and suddenly due to accidents, etc. It sure is a fact that we are all temporarily able-bodied in a way. So, as a form of social diversity, disability is distinct in its unpredictability and inconsistency.

### *Continuum of Educational Settings*

The above discussion of diversity in terms of types of disabilities and the degrees and levels of disability in each disability category brings us to demystifying the dictum 'inclusive education for all'. Inclusive education has its own significant positive impacts on the development of children with disabilities, and this is not contested. But when children with disability are accepted as a highly heterogeneous group, a continuum of educational settings has to be considered from where the best option of placement may be decided as per the needs of these children. International bodies have stated this conviction and practice:

There are different approaches around the world to providing education for people with disabilities. The models adopted include special schools and institutions, integrated schools, and inclusive schools. Across European countries 2.3% of pupils within compulsory schooling are educated in a segregated setting – either a special school or a separate class in a mainstream school. (WHO Report 2011)

There is variance across countries in the numbers of children with disabilities who receive education in either regular or segregated settings, and no country has a fully inclusive system. What is important is to have a flexible approach to educational placement of children with disabilities: in the developed countries, for example, the system aims to place children in the most integrated setting possible while providing for more specialized placement as required by the needs of the children. Inclusive education as a practice is definitely contextual; educational needs must be assessed from the perspective of what is best for the individual and the available

material, financial and human resources within the country context. In fact, position taken by some of the disability advocates is that it should be a matter of individual choice whether mainstream or segregated settings meet the needs of the child. Signing deaf children and advocates for children with intellectual impairments argue that inclusive education is not always the best option as it is not a positive experience. Advocates of special schools – such as schools for the blind, deaf or deaf-blind – particularly in low-income countries, often argue that these institutions provide matching and specialized learning environments suited to the needs of the children with the specific disability. The World Federation of the Deaf argues that often the best education environment for academic and social development for a deaf child is that where sign language is the medium for all communication. The thinking is that placement in a regular school without meaningful interaction with peer group, teachers and other members would exclude the deaf child from education and society at large (Source: WHO Report 2011).

Thus, in the context of education of children with disabilities, the significance of special schools and segregated settings cannot be overlooked. Special schools do have a significant position in the continuum of educational settings for children with disabilities. Children and parents should be able to make informed choice of the right educational setting for their child from a variety of settings.

### *Disability and Exclusion*

People with disabilities are among the most marginalized groups in the world. They have poorer health outcomes, lower education achievements, less economic participation and higher rates of poverty than people without disabilities (WHO Report 2011).

There is a significant correlation between poverty and social exclusion, and a major cause of poverty is the lack of employment. Needless to say, in the context of people with disabilities, the situation with regard to employment is far from what should be. In the modern times, with the proliferation of the market, the boom of services, like human, welfare, social and educational and professional, and the increasing need to be 'intellectually and physically fit' for work make people with disabilities economically vulnerable and socially excluded. Hence, additional to making our educational systems inclusive in philosophy and practice, employers and employees need to be sensitized to ensure inclusion of people with disabilities at all levels.

Exclusion of disabled persons from society is politically analysed as the result of barriers and discrimination. For example, because voting material is not produced in Braille or information on candidates is not provided in sign language or through alternative communication, a person who is deaf-blind is excluded from political participation. Because deaf-blind persons are not provided interpreters in theatre plays, cinemas and other places of cultural life, they are excluded from participation in the cultural life of society. Because deaf-blind persons are seldom accepted as actors or actresses in television, theatre or the film industry, they are almost invisible in cultural life.

‘The experience of disability is unique to each person, but there are common impacting factors. Within India as in the Western world, people who are discriminated on the basis of disability often experience other levels of marginalization such as that of class, gender, poverty and rural-urban divide’ (Ghai 2015, p. 101). It is the exclusion of people with disabilities that urges the society to think about and act for their inclusion respecting disability as any other dimension of diversity.

The philosophy, perspective and corresponding response of the society to people with disabilities have undergone major changes in the past decades, starting with the extremes of exclusive attitudes and approaches to inclusive practices, the capture of which is presented in the following section.

## **Societal Response to Disability**

History chronicles a clear progress of societal response and attitudinal change from exclusion to inclusion of people with disabilities, through phases of annihilation, exclusion, abandonment and denial, segregation and integration moving to inclusion.

### ***Integration and Inclusion***

Educating children with and without disabilities in the regular schools, the current philosophy, marks a significant milestone in the history of education of children with disabilities. The democratic principle of providing equity and equality of educational opportunities to all children while upholding the right of each child was the philosophy of the twentieth century. It was after the mid-twentieth century that this new wave of change brought in the landmark amendment in the policy of education of children with disabilities.

Integration was the initial step in this direction, making a few additional arrangements for children with disabilities in schools which were inadequate and hence brought in very little change overall. It was almost like letting these special children be, rather than adapting to their needs with a conviction about the philosophy of inclusion. This phase of integration is slowly evolving into that of inclusion wherein school systems have started endeavouring to bring in fundamental changes to embrace all children.

History tells us that efforts have been put forth to include children with disabilities in regular education settings, starting from the first institutions for children with impairments in the early nineteenth century to the segregated special classrooms in public school systems during the early twentieth century to the mainstreaming movement of the second half of the century to the influential legislative directives of the last quarter century.

## **Models of Disability**

Models of disability provide a framework for understanding the way in which people with impairments experience disability. In fact, the legislative mandates, laws, regulations and structures of a society that impact the lives of disabled people reflect the disability model of the particular society. Disability is a human reality perceived differently by cultures and historical periods. For most of the twentieth century, disability was defined according to a medical model that defines a disability as the result of a physical condition within an individual. The definition of disability formulated in 2011 by the World Health Organization (WHO) was based on human rights.

### ***Charity Model***

In the charity model, disability is seen as a personal tragedy. It was theorized and practised by non-disabled people and it is a way of relating to disability. Where the medical model sees medical professionals as experts in disability, the charity model sees non-disabled people as the saviours of disability; sympathize and take charge of disabled and give them a life. Disability is seen not only as something that should be cured but something that is tragic. It therefore projects the lives of disabled people as tragic and pitiable. The charity model is also underscored by the tenets of the eugenics model, where categories of *fit* and *unfit* were constructed to validate mounting disparity in the industrialized world. This model requires that those with resources should help those without.

### ***Deficit Model***

Persons with disabilities continued to feel that the attitudes towards them were disempowering and infantilizing in the context of the charity model, and they started voicing against these attitudes in the 1970s and 1980s. A shift in the attitudes can be seen in the deficit model.

The deficit model was the prominent framework regarding disability till very recently which says that there is something lacking in the person with a disability and must be corrected. There are two main variations of this model: medical model and rehabilitation model related to employment. Whatever the nomenclature, each model specifies a deficit (health condition and employment condition) which must be fixed in order to make the person with a disability 'normal'. Of course implicit is also the understanding that many of these conditions cannot be fixed so that the person with a disability will never be considered normal.

But there is no dearth of something or any lacking in the person with a disability that keeps her from being normal. ‘Normal’ is a culturally defined value based conceptualization. According to Amundson (2000), the concepts of normal and abnormal form the basis of the deficit model of disability. Normal and abnormal are perspectives based on social judgements of what are and what are not acceptable biological variations and functioning. By categorizing people with disabilities as abnormal, these value judgements made mostly by the able-bodied majority are used to legitimize the disadvantages which confront people with disabilities.

### ***Medical Model***

The medical model views disability as a feature of the person, directly caused by disease, trauma or health condition. It calls for medical treatment or intervention, to ‘fix’ the problem within the individual. Disability is seen as a personal tragedy with which the individual must both come to terms and with which she/he must integrate into the society whose rules are set up for the needs of individuals without disabilities. Another feature of the medical model of disability is that it is based on two assumptions that have a dangerous impact on human rights: (1) disabled persons need to have shelter and welfare and (2) impairment can foreclose legal capacity. The first assumption legitimizes segregated facilities for disabled persons, such as special schools, living institutions or sheltered workshops. The second assumption has led to the creation of mental health and guardianship laws that take an incapacity approach to disability. In other words, the focus is on impairment isolating the experience of disability from the environmental influences including the attitudes, perceptions and approaches of the society. ‘Michael Oliver, one of the founding fathers of the social model of disability, has called this the ideological construction of disability through individualism and medicalisation, the politics of disablement’ (Theresia 2016, p. 3).

### **Rehabilitation Model**

Rehabilitation model is based on the belief that disability is something that can be overcome. In this model, sufficient and appropriate effort on the part of the person is what is required to overcome disability.

[B]ecause many PWDs will never experience a cure that eliminates their disability, it is often the case that medical professionals who adhere to the medical model will regard PWDs as failures and an embarrassment (Pfeiffer 2003: 100). Persons with disabilities are often perceived as failed in life if they do not overcome their disability. Similar to the perspective in medical model, this model posits that care and support are the portfolios of professionals. This approach often fails to take into consideration the reality of permanent disability. Employment and economic independence are central to the rehabilitative process as posited in this model. This

model being based on perspectives and perceptions similar to medical model has been rejected by many disability activists and others with disabilities.

### *Social Model*

The social model of disability explains disability as socially constructed through a process of discrimination and oppression. In most discourses worldwide, the social model has overtaken the medical model, whereby cultural environment and attitudes which influence disabled people's societal participation and citizenship status are seen as the hurdle, rather than the physical impairment. The transition from the individual, medical perspective to a structural, social perspective has been seen as the shift from a medical model to a social model in which people are viewed as being disabled by society rather than by the impairments in their body and mind. In other words, disability is perceived as socially constructed and a consequence of society's lack of awareness and concern about persons who require specific modifications in their environment to live full, productive lives. Impairment is seen as an ordinary part of life and disability as the result of discrimination and exclusion; the social model has underpinned efforts to redeem disability from the medicalized, special needs ghetto and urges for the inclusion of disability concerns in all state-level development policies and practices. This perspective, referred to by some as the barriers model, views the medical diagnosis, illness or injury of a person, all at individual level, as being no reason for disability; human rights and contextual dimensions are inbuilt into this perspective. A person's environment is a tremendously impacting factor on his/her experience and level of disability. It is inaccessible environment that disables a person by creating obstacles to participation and inclusion. An example of such an impact of the environment is as follows: in the context of a participant who is a signing deaf wanting to participate in a seminar, other participants not knowing sign language and the absence of a sign language expert functioning as a mediator are seen as barriers, disabling the signing deaf participant.

In the broadest sense, the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment – whether physical, sensory or intellectual. (Oliver 2004, p. 23)

Nothing about us without us! The social model has also provided a powerful framework for bringing disabled people together in a common struggle for equality and rights. By doing this the social model has promoted the idea that disabled people should be actors in their own lives, rather than passive recipients of care. This equates almost exactly to current thinking on a rights-based approach to development, adopted by government development agencies throughout the world (Albert 2004).

## ***Human Rights Model***

According to Teresia (2014), the medical model of disability is based on two assumptions that have a hazardous impact on human rights: disabled persons need to be protected, and their welfare needs to be ensured and that impairment can exclude legal capacity (p. 2). The first assumption legitimizes segregated amenities for disabled persons, such as special schools, rehabilitative institutions or sheltered workshops. The second assumption has led to the creation of mental health and guardianship laws that take a patronizing and incapability approach to disability:

Human dignity is the anchor norm of human rights. Each individual is deemed to be of inestimable value and nobody is insignificant. People are to be valued not just because they are economically or otherwise useful, but because of their inherent self-worth. The human rights model focuses on the inherent dignity of the human being and subsequently, but only if necessary, on the person's medical characteristics. It places the individual centre stage in all decisions affecting him/her and, most importantly, locates the main 'problem' outside the person and in society. (Degener and Quinn 2002, p. 3) The social model elucidates disability, but the human rights model moves it forward drawing into its purview, values for policy formations that acknowledge the dignity of disabled persons. It is the human rights model that can explain why human rights do not require absence of impairment.

Human rights are fundamental rights which cannot be acquired as a credit or taken away from anyone. They are given from the time a person is born and are universal, i.e. is applicable to each human being, or every human being is a human rights subject. Nobody is obliging a person with impairment when his/her rights are being exercised. Neither social status nor identity category nor national origin nor any other status can prevent a person from exercising his/her rights. Therefore, human rights are unconditional rights.

## **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006)**

The rights-based model of disability can be clearly reflected in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006). The UNCRPD is an international human rights treaty of the United Nations targeted to protect the rights and dignity of persons with disabilities. The CRPD clarifies what human rights mean in the context of disability. The first human rights treaty of the twenty-first century represents a major step towards realizing the right of disabled people to be treated as full and equal citizens. The UNCRPD reflects the message in its preamble and in the language of its articles that human rights are unconditional and do not require the absence of impairment.

Disability is a human rights issue because people with disabilities are denied their rights; they experience inequalities; are subjected to violations of dignity and violence, abuse, prejudice or disrespect; and are even denied autonomy. Instances



are when they are denied equal access to education, political participation, etc., they are subjected to involuntary sterilization, they are confined in institutions against their will or they are regarded as legally incompetent because of their disability.

### ***Biopsychosocial Model***

According to WHO's World Report on Disability (2011):

The medical model and the social model are often presented as dichotomous, but disability should be viewed neither as purely medical nor as purely social: persons with disabilities can often experience problems arising from their health condition. A balanced approach is needed, giving appropriate weight to the different aspects of disability. The International Classification of Functioning (ICF), understands functioning and disability as a dynamic interaction between health conditions and contextual factors, both personal and environmental. Promoted as a "bio-psycho-social model", it represents a workable compromise between medical and social models. The bio-psychosocial perspective of disability is a more current one that situates disability as rooted in an amalgamation of factors at the physical, psychological (personal) and environmental levels. In this model, it is recognised that disabilities may be inherited, congenital or rooted in illness or injury and regards as significant, the impact of biological, emotional and environmental issues on the health, well-being and function of each individual in society. In fact this perspective in zinc with the WHO definition of Disability already quoted on pages 3–4 above.

### **Inclusive Education**

The above presentation on societal responses to people with disabilities and perspectives on disability brings us to the concept of inclusive education of children with disabilities: what is inclusive practice and what is not.

As already presented, any society based on democratic principles would have equality of opportunity and justice to its citizens as its primary aim. Doubtlessly, one of the means of achieving this aim is embedding inclusive philosophy and practice into the school systems to make them social sites of equality and justice.

The principle of inclusive education was adopted at the 'World Conference on Special Needs Education: Access and Quality' (Salamanca Statement, Spain 1994) and was restated at the World Education Forum (Dakar, Senegal 2000).

The philosophy and practice of inclusive education were adopted in the World Conference on Special Needs Education: Access and Quality (Salamanca Statement, Spain, 1994) and were restated in the World Education Forum (Dakar, Senegal 2000). The Statement sought participating governments to give the highest priority to making education systems inclusive and adopt the principle of inclusive education as a matter of policy. The idea of inclusion is further supported by the United Nation's Standard Rules on Equalization of Opportunities for Person with Disability Proclaiming Participation and Equality for All.

Inclusive Education (IE) is defined as a process of addressing the diverse needs of all learners by reducing barriers to and within the learning environment. It means attending the age-appropriate class of the child's local school with individually tailored support (UNICEF 2007).

### ***Inclusion in Education is***

- A process to bring all students together in one classroom and school, regardless of their strengths or weaknesses in any area, and it seeks to maximize the potential of all students.
- A process where diversity in a group with respect to any aspect is appreciated and in which each individual is recognized and respected for what he is worth.
- An effort to make sure that diverse learners – those with disabilities, different languages and cultures, different homes and family lives and different interests and ways of learning – are taught using teaching learning strategies adapted to individual learning needs.
- Is a process that allows every individual to feel accepted, valued and safe. An inclusive community consciously evolves to meet the changing needs of its members. Through recognition and support, an inclusive community provides meaningful involvement and equal access to the benefits of citizenship.
- Is a means of enhancing the well-being of every member of the community (Chennat 2017).

### ***What does Inclusion mean to a Student with Disabilities?***

- Students with disabilities experience school in the same way as their peers without disabilities.
- They experience a school climate wherein they develop a sense of personal belonging and achievement.
- They feel recognized and respected for their abilities.
- Students without disabilities learn to be empathetic and sensitive diversity among peers (Chennat 2017).

### ***The Following are some of the Processes in a Classroom and some of the Values and Beliefs of Teachers that result in a Noninclusive Classroom Ethos***

- Valuing some children more than others in a group.
- Maintaining barriers to some students' participation in the curricula and other activities of the school.

- Preserving school policies and practices which are nonresponsive to the diversity of learners, thus facilitating inequalities.
- Nurturing a mindset that inclusion mostly concerns disabled learners and that school changes made for disabled children will only benefit them.
- Viewing differences between students as problems to be overcome.
- Segregated schooling for disabled learners violates their basic human right to education without discrimination.
- Identifying academic achievement as the main aim of schooling, being prejudiced against the disabled children and being unable to see the abilities and capabilities in them.
- Perceiving inclusion in education as a separate phenomenon not in sync with inclusion in society (Chennat 2017).

### ***Teacher Strengths and Classroom Strategies in an Inclusive Classroom***

Teacher starts each class giving clear objectives.

Teacher knows each student's academic strengths and weaknesses closely including co-curricular interests and talents.

Teacher is always alert and observant about all classroom behaviours of students to facilitate identification of any special need of students and take steps to address these needs.

Teacher is sensitive while interacting with students.

While writing on the board, teacher avoids colour chalks, avoids cursive writing, writes in big fonts and speaks aloud what has been written and gives enough time for all students to write the matter in their books.

While explaining any content, teacher makes sure that students can see the face of the teacher clearly, talks loudly and maintains a slow pace.

Teacher ensures that students with impairments are seated in the front row.

Teacher appreciates and encourages students for completion of each step of any task.

Teacher makes use of visual aids like PPT or charts always augmented with audio support.

Teacher makes use of audio resources with visual representations.

Assessment, whether formative or summative, is modified to suit to the abilities and requirements of the students.

Any change in period allocation or substitution class or change of teacher or venue of class is notified well in advance to students.

During any co-curricular activities, teacher ensures that alternative opportunities are made available for students with different abilities so that no child feels excluded.

Teacher counsels each child to respect each other, accept and regard diversity among peer group, learn from each other and nurtures reciprocity among students.

Teacher uses simple language and gives clear instructions.

Teacher ensures that additional time is given to needy students to follow classroom transactions.

Teacher gives a capture of the class transaction at the end of each class.

While giving home tasks, teacher avoids dictating them, writes these on the board or gives as handouts to those who require it.

### ***Buddy Culture and Practice of Reciprocity***

In the context of education of children with disability, it is common to start with what they can't do or what they don't know. It is very rare that a teacher identifies the strengths of a child with disability and taps these for the child's development. As in any child, a child with disability too can or will have certain strength which has to be identified by parents and teachers and developed through consistent efforts and motivation. This can go a long way in the development of their self-concept. Buddy culture is commonly seen in our schools; a practice of engaging student pairs or groups to help each other in academic and co-scholastic activities. This practice becomes all the more pertinent in the context of a classroom with children with disabilities. While making buddies, what is practised in child with disability is helped by a buddy with no disability, making the child with disability feel dependent on his or her buddy. It is commonly a one-sided help.

In a classroom with children with disabilities, the practice of reciprocity is not generally followed. Reciprocity denotes **mutual** dependence, action or influence. It is important that the strengths of each child in the class, with or without disability, be identified by the teacher. While making buddies, the strengths of a child with disability may be identified so as to ensure that she or he is of some help to the buddy without disability. For example, a child using wheelchair (non-motorized) may need a buddy for navigation within the classroom and in the school. The child may have many other areas of strength like drawing, mathematics, vocal or instrumental music, computer work, etc. It is the role of the teacher to see that these talents are put to some use of the child without disability. This can ensure reciprocity between the two buddies so that the child on the wheelchair feels that he/she is of some use to his/her friend. This practice is instrumental in building up the self-confidence of the child with disability and developing sensitivity and compassion in his/her buddy without disability.

Having discussed the concept of inclusion, inclusive education and features of inclusive and noninclusive classes, the following section presents few of the initiatives both at national and global levels to make education inclusive.

## Initiatives in India to Implement Inclusive Education

Apart from the acts and policies and schemes aimed at inclusive education, presented in the chapter on ‘Disability Studies: The Context’ (p. 13–p. 16), the following initiatives have been taken by the government to make inclusive education effective.

### *Appointment of Special Educator made Mandatory (As per RTE Act, 2009)*

As per the Act, it was made mandatory for all State-run schools to have at least one special educator appointed for meeting the needs of children with disabilities. Following this statute, in 2015, the Central Board of Secondary Education made it mandatory all its affiliated schools to appoint a special educator. Through these statutes, a large number of schools got special educator’s services for their students with disabilities which is a positive step towards inclusive education.

### *Samagra Shiksha*

Samagra Shiksha proposed in the Union Budget, 2018–2019, the latest initiative in the direction of inclusive education in which school education is seen as a continuum from pre-nursery to Class 12 without segmentation. It is aimed at school effectiveness in terms of equal opportunities for schooling and equitable learning outcomes. The government schemes, Sarva Shiksha Abhiyan (SSA), Rashtriya Madhyamik Shiksha Abhiyan (RMSA) and Teacher Education (TE), are dovetailed into this scheme.

Samagra Shiksha Abhiyan is targeted at ensuring inclusive and equitable quality education from pre-school to senior secondary stage on a continuum without any grouping according to academic levels in tune with the **Sustainable Development Goal (SDG) for Education**.

**SDG-4.1:** By 2030, ensure that all boys and girls complete free, equitable and quality primary and secondary education leading to relevant and effective learning outcomes.

**SDG 4.5:** By 2030, eliminate gender disparities in education and ensure equal access to all levels of Education and vocational training for the vulnerable, including *persons with disabilities*, indigenous peoples and children in vulnerable situations.

Ensuring equity and inclusion at all levels of school education is one of the major objectives of the scheme, and inclusive education finds place under the major interventions across all levels of education of the scheme (Government of India 2019).

Apart from the latest scheme of Samagra Shiksha, the Acts and their amendments, teacher education programmes have been revamped to attune to successful

implementation of inclusive education in our schools both at pre-service and in-service phases. These have been briefly presented in the following section.

## ***Teacher Education***

### **Pre-service Programmes**

Pre-service programmes have been revamped across the country to enhance rigour and quality. 'The inclusive school' has been added as a compulsory paper in the second year of B.Ed. programme as against including it as an optional paper in the old 1-year programme of B.Ed. In all the other programmes like D.Ed., D. El.Ed. and B.El. Ed., inclusive education has been upgraded as a compulsory paper. B.Ed. (Sp.Ed.) courses for different categories of impairments, i.e. hearing impairment, visual impairment and intellectual impairment of course, are laudable initiatives in this direction.

### **In-service Programmes**

In all the in-service teacher education programmes, across government and non-government institutions, inclusive education is included as a central component with rigorous inputs, like concept and meaning of inclusive education, various models of inclusive education, identification of children with special needs (CWSN), nature and needs of CWSN, classroom management of CWSN, use and maintenance of aids and appliances, equipment and teaching/learning material required by CWSN, special schools as resource centres, role of teacher, state and central schemes for CWSN, development of individualized educational plan, community mobilization including role of school management committees, peer sensitization, tackling attitudinal barriers, etc.

These efforts, although keep reminding us that there are many more aspects to be taken care of, definitely depict a very promising scenario in the direction of inclusive education of children with disabilities.

Globally inclusive education discourse reflects post-structuralist, neo-liberal perspectives that support the philosophy and practice of inclusive education with corresponding adaptations in transactional strategies. Some of these are discussed below.

## **Global Initiatives to Support Inclusive Education**

Apart from the efforts by the international bodies like the UN and WHO, by way of formulating frameworks for inclusive education and making declarations to ensure inclusive education, presented in the chapter on 'Disability Studies: The Context'

(p. 11–p. 12), there have been universal practices initiated to support inclusive education, a few of which are presented briefly below.

### ***Neurodiversity: A New Perspective to See Persons with Impairments***

Neurodiversity is a viewpoint that considers brain-related differences like any other differences among any group and that such differences are not deficits. It is a perspective that can benefit kids with learning and attention issues and help reduce stigma around these issues. It can help reduce the feeling that something is ‘wrong’ with them, and this can help build confidence, [self-esteem](#), [motivation](#) and [resilience](#). It can help kids and their parents frame their challenges as differences, rather than deficits. It can also shed light on instructional approaches, like universal design. Universal design shares many of the principles of neurodiversity and helps to highlight particular [strengths kids have](#).

Neurodiversity is based on [brain imaging studies](#) that have shown that there are some differences in terms of how the brain is ‘wired’ in kids with learning and attention issues and how it functions to support thinking and learning.

These findings can explain the source of difficulty for many kids with learning and attention issues. Considering these brain differences as normal as any other dimensions of diversity among children, kids who have these brain differences are considered as mainstream as those who don’t have them. Proponents of this view have used it to fight stigma and promote [inclusion in schools](#) and in the workplace. The activists behind this paradigm shift underscore that the goal shouldn’t be to ‘cure’ people whose brain works differently but embrace them as part of the mainstream, which leads to the corollary that they should be provided the needed support to ensure their full participation as members of the community (Rosen 2019).

### ***Universal Design for Learning***

The approach of universal design for learning offers flexibility in the ways students access material, engage with it and demonstrate their learning. The word universal may cause misconceived notions about UDL. It may sound like UDL is about finding one way to teach all kids. But UDL is exactly the opposite approach. Classroom transactions based on this approach help all students in a class, but be especially helpful for kids with learning and attention issues. The goal of UDL is to use a spectrum of teaching methods to alleviate any barriers to learning and give all students equal opportunities to learn and succeed. It is the built-in flexibility that can be attuned to match every student’s [strengths](#) and needs and thus benefit all kids.

The approach of UDL doesn't exclusively target students with **learning and attention issues**. But it can be especially helpful for students with these differences, including those who have not been formally identified as having any impairment. In short, UDL as a transactional approach equips a teacher to address diversity in the class (Moren 2019).

Closed captions, automatic doors and smartphones with features to enhance accessibility are all examples of universal design. These design elements help people with disabilities. But people who don't have disabilities may also want to use them.

For example, closed captioning on TVs allows people with hearing impairment to see on screen text of what is being said. But closed captioning for sure benefits everybody. If one is very tired to watch the news or a game in a noisy restaurant, one could probably use the closed captions to follow along (The Understood Team 2019).

### **Two Main Principles of UDL**

UDL provides a framework for developing lesson plans and assessment methods and techniques based on the two main principles:

- **Multisensory presentation:** In the UDL approach, learning matter is not given in a single format. Textbooks, the conventional learning materials, are primarily visual. Text, supported with audio and video materials along with hands-on learning, makes available all students a chance to access the material in whichever way best suited to their **learning capabilities**.
- **Multiple ways of engagement with the learning material:** UDL provides more than one way to interact with the learning material available to them and also to demonstrate what they've learned. For example, students might get to choose between taking a pencil-and-paper test, giving an oral presentation and doing a group project (Moren 2019).

### **Special Benefits of UDL**

UDL helps all students. But in some ways, it may be especially helpful to students with disabilities:

- In UDL approach every student gets to know the objectives of a lesson transacted right at the outset of the lesson.
- Makes learning more accessible in inclusive educational settings, where most children with learning and attention issues spend most of the school day.
- Presents learning material in ways that adapt to the learner, instead of expecting the learner to adapt to the material.
- UDL makes available students more than one way to interact with the provided material, and its built-in flexibility makes it easier for students to use their strengths to work on their weaknesses.
- UDL doesn't exclude the few who receive formal accommodations as part of **Individual Educational Plans**. Thus it helps to develop self-worth and reduce stigmatization by giving a range of options to all students.



## ***Differentiated Teaching***

To say in a simple way, differentiation comprises teachers' efforts to respond to diversity among learners. In this approach to curricular transaction, teacher reaches out to a student or a small group of students using specific teaching strategies to suit to their needs, targeted to create the best learning experience possible for them.

Teachers differentiate important classroom elements according to mental readiness of students, their interests or their learning profile: content, what student needs to learn or how the student will access the information; process, learning experiences with which the student engages in order to learn the content; students' demonstration of their learning and the learning environment, the emotional aspect of the educational setting; and the way the students feel about the setting.

For example, content can be presented in multisensory modes, using differentiated activities through which all learners can work with the comparable previous knowledge and skills, but proceed with different levels of support, challenge or complexity; students can be given varied options for demonstrating their learning and providing corners in the classroom to facilitate learning quietly without distraction, as well as suitable places conducive for learning through collaborative activities; setting up regular class organizations that provide platforms for student help when teachers are busy with other students and are unable to attend to their needs help; and providing a positive classroom ethos to create an understanding about diversity in the classroom like some students need to be up and around in the classroom while others can learn sitting in their allotted seats (Daily 2017; Tomilson 2019).

## **Consolidation**

Diversity in any social group forms the premise for thinking and acting on inclusion of any member of the group facilitating the full participation of the member. It is the experience of exclusion that triggers one to take initiative for inclusion. Social attitudes and approaches to persons with disabilities have undergone a process of evolution over decades and have brought us to the right perspective on disability which advocates that a person with disability has the right to full participation in all the social activities like any other person. The different social approaches to disability and the different models of disability throw light on the social history of disability and inclusion. While understanding inclusion, discussion on what is *not* inclusion in educational settings reifies the philosophy and practice of inclusive education. In order to realize the objective of effective inclusive education, there have been initiatives in our country inspired by many efforts at the global level.

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# Chapter 4

## Empowering Persons with Intellectual Disability



Jayanthi Narayan

**Abstract** Intellectual disability is a condition due to limited ability in learning, leading to challenges in their independent living as adults. In recent years, a major paradigm shift from charity to rights has resulted in a positive move from segregation to inclusion. This progress is an outcome of many international and national conventions and mandates. In India, the Right to Education Act and the Rights of Persons with Disabilities Act have played a significant role in bringing about positive changes in the field. Yet, teachers in regular schools do not feel confident to teach children with disabilities, and there is a need for pre-service and in-service teacher training with a focus on inclusive education. Research and documentation on evidence-based practices is an area that needs to be addressed to achieve the SDG4.

**Keywords** Inclusive education · Intellectual disability · Inclusion in India · Teacher preparation for inclusion · Role of family in inclusive education · Community participation in inclusion

One of the major objectives of inclusive education from the social justice point of view is to promote education for all with equal opportunities. The focus here is the strengths in the students rather than their limitations. Therefore, the curriculum, pedagogy and teaching techniques should be geared towards bringing out the optimum potentials in children so that they not only develop self-esteem and self-confidence but also become contributing members of the society. In the context of education of children with intellectual disability (ID) and developmental disabilities (DD), it is essential to plan carefully the curricular content, the process of teaching and evaluation system based on the child's profile. In a regular school setting where the curriculum, the teaching method and the evaluation systems are predetermined, depending on the State or Central Board of Education in which the students are

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enrolled, including children with intellectual disability requires careful planning, taking into account all the stakeholders. This includes the relevant national policies, the child with intellectual disability, the Board of Education, the school administrators, class teachers, special educators, parents, peer group, evaluation team who certifies the child, therapists where applicable and the other support staff in the school and the community. Inclusive education is possible if all the stakeholders play their role correctly. Among persons with disabilities, those with intellectual disability have a higher demand on support. Many a time, they are misunderstood for other condition due to the invisible nature of the condition, particularly in the case of milder intellectual disability, leading to more complex issues to be addressed. It is a challenge to be met but not an impossible challenge to meet. In this chapter, we discuss the concept of inclusion of persons with intellectual disability, the historic development of their educational provisions through the years, the sociological perspectives, current status, issues and challenges in including them in the regular school without compromising on the appropriate education to which they have a right.

### **Case Study 1**

*Subhash (all names changed for anonymity) aged 10 with mild intellectual disability was enrolled in class 3 in an inclusive school. The class teacher informed all children and their parents about Subhash and that he is like any other student in the class. Anil, who is a classmate of Subhash, was told by his mother to stay away from Subhash and that Subhash can be harmful and can hurt other children. After a few days, Anil's mother came to the school and told the teacher that she wishes to confess as she feels guilty. Surprised, the teacher listened to her. Anil's mother told her, 'My son Anil came home and told me, Subhash is very helpful and friendly. Just that he needs the teacher to help him more often. At lunch time, he volunteers to get my water bottle, and in the evening before leaving, he looks around to see if anyone has dropped pencil/eraser and so on, picks it up and gives it to them. All of us like him ma. Do not talk ill of him'. The teacher consoled the mother who had tears rolling down. The teacher tells this event whenever she talks of inclusion.*

***Children are like clean slates. Write only the right content on it!***

## **Conceptual Foundation**

### ***Nomenclature***

Intellectual disability is the current legally accepted name to a condition that had been known by varied names in the past based on the social and medical perspectives. Mental subnormality, mental deficiency, oligophrenia, mental handicap and mental retardation were some of the popular terms that were used to refer to the condition. Idiot, imbecile and moron were also used to refer to a person with intel-

lectual disability of varying degrees, but were out of use early as they held derogatory implications. With the developments and trends in the area of disability rehabilitation as a whole and intellectual disability in particular, there emerged a paradigm shift from charity to rights. With increased awareness about the condition, the medical model too changed to a social model resulting in the medically oriented names changing to socially acceptable terms. For example, the word ‘disability’ was found to be more acceptable as it is descriptive of the functional aspect arising from the condition than the word ‘handicap’ that has its origin in the phrase ‘hand-in-cap’. This meant, in olden days, persons with disabilities held their cap to beg and people put ‘hand (with money) in cap’ to the beggars. With time the term changed to refer to the persons with disabilities as ‘handicapped’. With due respect to human beings and their rights, currently, the condition is referred to as intellectual disability, and the persons having the condition are called ‘persons/individuals/children with intellectual disability’, thus putting the person first. It is considered inappropriate to refer to such a person as ‘intellectually disabled’ and the right way of referring is ‘person with intellectual disability’. In fact, this ‘person-first’ reference is appropriate to refer to any person with any disability. With the Persons with Disabilities (equal opportunity, protection of rights and full participation) Act (1995) getting replaced with the Rights of Persons with Disabilities (RPwD) Act (2016), ‘intellectual disability’ is the legally accepted term in India.

With time and developments, perspectives change. With change in perspectives arises the redefining of the condition of disability. As discussed earlier, from the medical model which looks at disability as a deficit and hence focuses on treatment and cure, there is a change in perspective to look at disability from a social point of view. This reflects that the problem is not so much with the person as it is with the system, attitude and environment. You will understand this when you visualize a person in a wheelchair having to attend a programme in the first floor of a building and the building not having a ramp or lift. Where is the problem? Is it with the person or with the environment? Hence the current focus is on changing the environment so that the person with disability leads a life with dignity.

To quote Schalock et al. (2007, p. 118), on the merits of the current change from mental retardation to intellectual disability:

*The fact that the construct of intellectual disability belongs within the general construct of disability helps one understand why the term intellectual disability has emerged as a preferred term to replace mental retardation. The term intellectual disability (a) reflects the changed construct of disability proposed by AAIDD<sup>1</sup> and WHO<sup>2</sup>; (b) aligns better with current professional practices that are focused on functional behaviours and contextual factors; (c) provides a logical basis for individualized supports provision due to its basis in a social–ecological framework; (d) is less offensive to persons with disabilities; and (e) is more consistent with international terminology.*

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<sup>1</sup>American Association of Intellectual and Developmental Disabilities.

<sup>2</sup>World Health Organization.

## *The Condition*

Intellectual disability (intellectual developmental disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in *conceptual, social and practical domains* (DSM 5, 2013). Therefore, to diagnose intellectual disability, in addition to assessment of intellectual functioning, significant deficits in adaptive behaviour should be assessed in the domains of conceptual, social and practical skills. As rightly cautioned by Schalock et al. (2010) and the American Psychiatric Association (2013), best practice in clinical assessment is to consider all sources of measurement error when using and interpreting results obtained from standardized assessment tools and informing the clinical judgment.

In the latest revision of the DSM (DSM 5), use of IQ scores as the determinant of the severity levels of intellectual disability (i.e. mild, moderate, severe and profound) is abandoned. Instead, DSM 5 has proposed using the individual's adaptive functioning level across conceptual, social and practical skills to guide clinical judgment in determining the severity level of intellectual disability.

(<http://www.apa.org/pi/disability/resources/publications/newsletter/2016/09/intellectual-disability.aspx>)

Simply put, intellectual disability is a lifelong condition, associated with a wide range of sensorimotor problems, psychiatric and behavioural disorders (Salvador-Carulla and Bertelli 2008). As a result, it has lifelong consequences for the families and caregivers at each stage of the person's life. To quote an example, the demands placed on the caregiver during infancy of the person with ID/DD and during adolescence of a person with ID are very different, with each stage having challenges and demands related to the developmental tasks expected of that age. Worldwide, including in India, the condition is considered as a disability, as it is associated with long-lasting skill deficits.

To quote Edgerton's (1967) observation on intellectual disability half a century ago, which holds good even today, 'mental retardation is pre-eminently a human condition that is both, biological as well as cultural. Socio cultural understandings are those that a group of people share, which in turn, become a system that influences the services, government regulations and larger economic, political and social aspects that impact the quality of life of the person with disability – more so in less visible conditions such as mental retardation'.

Persons with intellectual disability, due to the arrested and incomplete development of their mind, face a number of performance difficulties. As seen earlier, the current definitions classify them into conceptual, social and practical domains. They can have difficulty in learning even the simple tasks involved in the daily routine that is learnt naturally by others in childhood, they are slow in performing various activities, and they tend to have poor memory and have difficulty in understanding abstractions, generalizing learnt concepts and skills, making judgments and making decisions.

## *Classification and Prevalence*

DSM 4 (2000) provides classification based on IQ and the estimated prevalence in each level. The condition has varied degrees ranging from mild to profound levels, and those with mild level tend to be the maximum (85%) in the population. It is to be noted that the more severe the condition, the less the number of people affected (Box 4.1).

### **Box 4.1: Prevalence Based on IQ Classification (The Term Mental Retardation Is Used in DSM 4)**

Diagnostic Criteria for Mental Retardation (DSM 4 TR)

*Code based on degree of severity reflecting level of intellectual impairment:*

**317 Mild Mental Retardation:** IQ levels 50–55 to approximately 70 (85%)

**318.0 Moderate Mental Retardation:** IQ levels 35–40 to 50–55 (10%)

**318.1 Severe Mental Retardation:** IQ levels 20–25 to 35–40 (3–4%)

**318.2 Profound Mental Retardation:** IQ level below 20 or 25 (1–2%)

**319 Mental Retardation, Severity Unspecified:** when there is strong presumption of mental retardation but the person's intelligence is untestable by standard tests

*Source:* American Psychiatric Association (2000). Diagnostic and Statistical Manual of Mental Disorders (4th ed., text rev.). Washington, DC

The current thinking recommends functional assessment of adaptive behaviour also as a parameter to classify a person with intellectual disability. Though DSM 5 classifies based on conceptual, social and practical domains, in India, the IQ-based classification is in use for certification of a person with intellectual disability.

In India, NSSO and Census have included disabilities in the past two surveys. However, Girimaji and Srinath (2010) after reviewing the epidemiological studies till 1999 reported a point prevalence of 2.5%, with males, rural areas and the low socio-economic status having more persons affected. They also inferred that variations in prevalence were observed as the studies differ in terms of case definition, methodology and population studied.

From the viewpoint of inclusion, the point to be noted here is that those with mild intellectual disability are the largest in number (85%) and as the severity of the condition increases, the number of persons affected reduces. This clearly indicates that a large number of person with intellectual disability can be included in the regular classes with suitable arrangements made so as not to compromise on the education that is appropriate to them.



## ***Causes and Prevention in Brief***

Knowing the causes for intellectual disability can help to a great extent in taking preventive measures. As for most disabilities, the causes can be of prenatal, natal or postnatal origin. The prenatal (during pregnancy) causes can be genetic or chromosomal factors, inborn metabolic errors, maternal drug consumption during pregnancy, infections and intoxication and so on; perinatal (during delivery) causes can be difficult labour, delayed birth cry, anoxia and infections; and postnatal (after delivery) causes can be encephalitis, meningitis, brain injury, exposure to teratogens and so on. Intellectual disability can be due to a number of known or unknown genetic causes, trauma, metabolic errors, neurophysiological or environmental causes or a combination. A finding by Srinath and Girimaji (1999) revealed that in India, acquired causes account for about 30% of mental retardation (ID). They also reported that about 25% of causes of mental retardation (ID) are preventable in India.

Recommended pre-conceptual factors for prevention of childhood disabilities include women avoiding teen or late pregnancy (over the age of 35 years), avoiding consanguineous marriages particularly if there is a history of childhood disability in the family and seeking medical advice if there are any medical conditions of concern among the prospective parents or a child with a childhood disability in the family. During pregnancy, periodic medical check-up and following medical advice, nutritious food and adequate exercise, information in advance on child birth and child rearing and the precautions to be taken and if needed where to get the immediate help are some of the important aspects. After birth, knowledge on the child's health condition, APGAR scores and the linked information and care, timely immunization and the right childrearing practices are paramount in bringing up a healthy child. With the technological advances and the women and child health care services with ASHA and Anganwadi workers in the rural areas reaching out, communication and supports have significantly increased and are faster to reach the child and family in need. Good practices, knowledge and awareness on the support systems and taking steps immediately in case of need will help in preventing many of the childhood disabilities, at least a part of the 25% noted earlier by Srinath and Girimaji (1999). Rashtriya Bal Swasthya Karyakram (RBSK), a centrally sponsored programme by the Ministry of Health and Family Welfare under the National Health Mission, has taken initiatives nationwide to reach out to children on the aspects of 4Ds, namely, *disease, defects at birth, deficiency and developmental delays including disability*. Prevention, early identification and intervention of childhood diseases and disabilities are a major focus in this programme. For more detail visit [rbsk.gov.in/](http://rbsk.gov.in/).

## **Socio-cultural Perspectives**

India has been an inclusive society. Based on the social, economic and religious beliefs and customs, persons with disabilities were treated by their families in their home or community environments. Persons with disabilities were with the families

and were not ‘institutionalized’ as seen in the history of western countries. Historically, the status of persons with intellectual disability has undergone different stages ranging from perception of ‘God men’, ‘outcome of past karma’, considered as mentally ill (‘mad’), persons with limited capacity to learn and deserving charity, to the current status of having rights. Perspectives are bound to change with the progress and developments in every field and so also in the area of intellectual disability (Narayan et al. 2013). Absence of a visible disability in most persons with intellectual disability makes it difficult to understand the condition, leading to varied interpretations in different contexts and in different times in the history.

### Case Study 2

*A young man, Vikas (name changed), aged 24, having Down’s syndrome and moderate ID was brought for assessment to The National Institute for the Mentally Handicapped (NIMH). He was observed to have a big kumkum bindi on the forehead and wore a constant smile on the face. He was nonverbal, and his response to questions was always a head nod of yes or no (vertical and horizontal nods, respectively). Talking to the mother, it was noted that Vikas is the only child and her husband, who was an electrician, fell from an electric pole a few years ago and was bedridden and paralysed since then. People in their neighbourhood considered Vikas divine and would come to him if they have to make any decision, major or minor, and ask him. If his head nod is a ‘yes’, they would go ahead with the decision. If his head nod is negative, they may drop the idea. Either way, they would leave some token money in a plate placed in front of him. The mother was asked if her son really had any divine power and she said, ‘I do not believe so, but the people believe. I think God who paralysed my husband has shown me a way through Vikas’. When asked why she had come to NIMH, she said that she had come to know that certification helps in getting benefits such as bus passes and she had come for that. Of course, the mother was counselled that her son, if trained, can do more than the head nod and was guided to vocational training. He was trained to work in a printing press as a helper, and he currently earns significantly more than before as a ‘divine man’. However, the mother informed that there were people still coming to him for his head nod for making their decisions!*

Since the Vedic period, significant changes have occurred in India leaving historic land marks. To name a few, Mauryas in ancient India, Moghul in medieval India and the British rule in the pre-independent India all had influenced the status of persons with intellectual disability. In all these times, one feature that was found common was ‘charity’ to persons with disabilities. Charity and service to ‘destitute, disabled and the weaker section of the society’ was the way of life since Vedic times of ancient India (Miles 1994). Interestingly, persons with intellectual disability were not segregated as a separate group nor mainstreamed. *Sick, disabled, aged, widows and destitute* were classified as one category and differentiated from the social construction of ‘normality’ for addressing the practical issues related to support and protection. Kings and noblemen provided shelter and livelihood to them. It was also a practice among people to give alms to persons with disabilities out of fear to avoid curses from them as it was believed that their curses would come true. Such a belief is seen in some parts of the country even today. Past sins or sins in the previous birth

and their consequences in the form of karma as a cause for the birth of children with disability are another belief existing even today. It is a common practice observed in many parts of the country since early years to present days to do special poojas spending money and resources much beyond their capacity and/or undertake pilgrimage to ward off the ill effects of such sins. It is well known that family background, gender, religion, caste, economic status and area of living such as rural, urban or tribal all influence the status of person with intellectual disability in the given context.

India has come a long way since the Vedic period to current day with Mogul and British periods contributing to the change in some of the practices. Focus on shelter for persons with intellectual disability along with persons with mental illness was seen during the British period. The number of centres and organizations for persons with intellectual disability grew rapidly in the independent India. In early years, they were established by the parents when they found that their children with intellectual disability were refused admission to regular schools. This was the beginning of the establishment of special schools in India. The teachers were untrained but had the good will and motivation. The teaching-learning was on trial-and-error methods. The families having children with intellectual disability formed a fraternity and supported each other. In many areas where such schools were not established, the parents hid the children from public, and there were family conflicts and instances of disowning the child.

The Ministry of Welfare, currently known as the Ministry of Social Justice and Empowerment (MSJ&E), has been playing a key role in ensuring a dignified life that persons with disabilities deserve as a right. With the establishment of the National Institute for the Mentally Handicapped (NIMH) in 1984 (currently renamed as the National Institute for the Empowerment of Persons with Intellectual Disability (NIEPID)), by MSJ&E, service delivery models, human resource development and research and development to reach out to persons with intellectual disability received focus. The Rehabilitation Council of India Act (RCI 1992) was enacted with the view to regulate human resource development in the field of disability rehabilitation. Persons with Disabilities (equal opportunity, protection of rights and full participation) Act 1995 (replaced in 2016 by the Rights of Persons with Disabilities (RPwD) Act) ensuring rights to persons with disability brought about a significant shift in the perspectives. A paradigm shift from charity to right was evident since the enactment of this Act. Parents started to come together to voice their opinion and demand support to their children as a right. Federation of parent organization in the name of Parivaar, came into existence with the support of NIMH. In response to the demands from the parents on 'who will look after our dependent child with ID/DD after us', the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act (1999) was enacted with the main objective of guardianship to the four disabilities considering the need for their lifelong support.

Such a transformation among parents and the response given by the government is a good example of positive changes in the social perspective. Though there is a long way to go considering the unreached areas, prevailing illiteracy, poverty and

strong cultural practices based on misconceptions in some parts of the country, the past three decades have seen significant progress in the area of addressing disabilities, particularly intellectual disability.

## **The Protagonist Views**

As seen earlier, social, cultural and religious understandings are those that a group of people share, which, in turn, become a system that influences the services at local, regional and national levels involving the political and economic aspects. In comparison to other disabilities, those with intellectual disability have difficulty to communicate their viewpoints. How to understand them and the way they see and experience the world is a less explored area to find an answer. Generally, their viewpoints get dismissed or ignored, and others decide for them rather than finding ways of understanding their subjective experiences. This is an important issue from the sociological viewpoint. Self-advocacy is a buzz word in the area of disabilities. 'Nothing about us without us' is advocated by various groups of persons with disabilities and is also being followed in many instances such as meetings where policy decisions are made where persons with sensory impairments and motor impairments participate and contribute. However, a person with intellectual disability does not participate in such occasions due to his/her limitations, and as a matter of convenience, parent/guardian is accepted as the representative of the persons with intellectual disability. Even if we accept that the guardian acts in the best interest of the person with intellectual disability, it is certainly not the same as the participation of person with intellectual disability. Given the reality, this is the arrangement. Nevertheless, in recent years, it is heartening to see the participation of person with intellectual disability in national and international conferences where time is allocated for self-advocacy and persons with intellectual disability stand up to express their views. Good initiative!

The Right to Education Act (RTE 2009) has made elementary education a fundamental right to all children which demands that children with diverse learning abilities and with varied socio-economic and cultural backgrounds be provided with the education that is appropriate to them in the regular schools. Subsequently, Indian government's flagship programmes such as Sarva Shiksha Abhiyan (SSA) for primary education and Rashtriya Madhyamik Shiksha Abhiyan (RMSA) for secondary education have been implemented to provide education for children including those with special needs. In the year 2013–2014, about 21 lakh children with disabilities were enrolled in SSA schools in the country (DISE 2014). Still students with intellectual disability struggle to receive effective and appropriate education in inclusive settings. Adolescents and young adults with intellectual disability do not receive optimum training in independent living skills. Though the number of special schools has increased in the past three decades, programmes for adolescents and adults are far and few in the country. Vocational training, employment, recreation and leisure facilities have not been focused enough to let them lead economically independent

and socially fulfilling lives. Though there are health insurance schemes like the Niramaya of National Trust, it does not meet all the needs of all individuals with intellectual disability.

In terms of parental perspective on education, it is to be noted that many parents prefer to send their children with intellectual disability to special schools as they believe that their child is safer and more secure in such a protected environment. Further, they believe that there are less number of children in each class and they have specially trained teachers to teach them as against the regular schools with large enrolment of children in each class and the likelihood of their child getting ignored is higher. These are issues that cannot be brushed away without due consideration.

## **Academic and Psychological Implications**

Developments and trends are dynamic. Most changes are aimed at progress. Status of persons with intellectual disability has come a long way in leading them towards dignified lives. Education for all has come about as a major turning point world over, working towards ensuring that all children receive education. It is indeed a challenge when children with limited intellectual capacities are to be educated, that too, in the mainstream schools without compromising on the appropriate education. Special schools in the past had a tailor-made programme for each student. With inclusive education in place, the linked issues of readiness such as accessible infrastructure, teacher preparation, curriculum content and process adaptation, evaluation and peer group preparation are all challenges to be met. Governments are geared up to meet the challenges. As rightly quoted by Tomilson (2015), in Salamanca, 300 participants representing 92 governments and 25 international organizations met ‘to consider fundamental policy shifts required to promote the approach of inclusive education, namely, enabling schools to serve all children, particularly those with special educational needs’, and inclusive education and special education were thus inevitably conjoined.

Given the situation, the students with intellectual disability are to move from the protected special school environments with a few children taught by a qualified special teacher to classrooms with a large number of children, who tend to learn faster than those with intellectual disability. Socially, there is difficulty among children with intellectual disability in being with peer group and interacting with them. Though there are occasions when they are helped by their peers, many a time they are bullied or ignored. Due to lack of awareness about their condition, they do not get appropriate education that they deserve to get. All of these can have a significant psychological impact on them – positive environment leading to a safe and secure feeling and negative environment leading to an insecure feeling and a low self-esteem among those with intellectual disability. As most of the persons with intellectual disability have difficulty expressing their feelings and emotions, they are misunderstood based on the exhibited behaviour. An understanding teacher makes a

big difference in the positive direction for the development of self-awareness, self-confidence and higher self-esteem in a student with intellectual disability which in turn results in bringing out their optimum potential.

### **Case Study 3**

*Kamala (name changed) aged 13 with mild intellectual disability was in a special school for children with intellectual disability. With the special education support, she had learned to take care of herself for her personal needs and had learned academics that matched class 4 level. Having known about inclusive education, the parents moved her to a regular school that had resource room support. After one term in the regular school, the parents preferred that she would go back to special school. The reasons for the decision included primarily the safe and secure environment with one class having not more than 10 children as against the regular class with a large number of children where their child was 'lost'. They were also concerned about the individualized education plan (IEP) that she was receiving in the special school, and the parents believed that in spite of resource room support in regular school, she was learning more in the special school.*

*Aruna (name changed) aged 12 with mild intellectual disability was in an inclusive school and was getting the additional support from the special teacher who would visit the regular class and work with the class teacher. When needed she would take Aruna for individual instruction. At class 7 Aruna was found to lag behind the class level and was not benefitting from the academics taught. The special teacher, after discussing with the parents, enrolled Aruna in the class where children were preparing for National Institute of Open Schooling (NIOS) system of education and evaluation. Aruna learned and appeared for NIOS examination on a phased manner and passed class 10 examination with a 58% aggregate marks at the age of 17. She enrolled for class 11 vocational programme of NIOS.*

*Decisions regarding the right option for educational environment for each child vary. Every child has to be considered for suitability based on evaluations and observations over a period of time. Parents have to be educated on the various avenues for education to make an informed decision that is appropriate for the child.*

## **Issues and Challenges**

### ***Nature of the Condition***

Avramidis and Norwich (2002) conducted a review of literature of a large body of research studies on attitude towards integration and inclusion and found that among many parameters, the type of disability played a major role in the teachers accepting a child with disability in the class. They found that many of the reviewed studies revealed that teachers were more willing to accept a child with sensory/motor disability rather than cognitive impairments and that the teachers' attitudes were found to be strongly influenced by the nature and severity of the disabling condition and

less by teacher-related variables. This is a major factor when it comes to including children with intellectual disability. For children with sensory or motor disabilities, the process of teaching is adapted to suit the learning style and the learning channel, while the content to be taught remains largely unaltered. In the case of children with intellectual disability, due to their limited cognitive ability that restricts understanding of abstract concepts, the content of the curriculum needs to be modified significantly. As teachers in regular schools are not prepared for this kind of adaptation, they are at a loss, and they prefer that a special teacher takes care of the educational needs of such children.

### ***Teacher Preparation***

Present status of teacher education in India is yet to meet the challenge of preparing teachers for inclusive setup. We currently have the parallel system of regular education with the Department of Education, Ministry of Human Resource Development (MHRD), while the special education is regulated by the Rehabilitation Council of India (RCI), MSJ&E. Inclusive education has the focus of education of all children with the regular teachers, while the special teachers are engaged as a support as is the practice in SSA and RMSA (currently SSA and RMSA are merged to be called as Samagrah Siksha). As the special teachers are trained to work in special schools with single disability specialization, they are not competent enough to work with children of varied disabilities included in larger classes. Though the regular and special teachers are provided with in-service training, the competence level of the teachers is yet to reach a stage when all children benefit from education in the inclusive setup.

### ***Awareness***

As seen earlier, due to the invisible nature of the condition, many a time children with intellectual disability are less or wrongly understood by the parents and community. It is also true that children who do not have intellectual disability tend to get classified as having intellectual disability. For example, those with average or above-average intelligence such as those with high-functioning autism/Asperger's syndrome, high-functioning cerebral palsy, specific learning disabilities or attention deficit hyperactivity disorders (ADHD) get wrongly classified with those with intellectual disability. The most urgent issue to address is creating awareness among all the stakeholders on the condition and the supports available to address their needs.



## Role of Family

In the past three decades, there has been considerable progress in parental awareness and involvement. Parents do not hide their child with intellectual disability anymore. The initiatives of federation of parent associations, Parivar, is a significant move in the country as it gives a platform to parents to voice their views and express needs on behalf of their child with intellectual disability (for details: [www.parivaarn-fpa.org](http://www.parivaarn-fpa.org)). While professionals *choose* to work with persons with disabilities, no parent *chooses to be a parent of a child with a disability*. Hence, when they get to know that their child has a disability, they go through a series of emotional stages ranging from denial, guilt, shame, helplessness, anger and frustration, before accepting and coming to terms with reality. During this time, they need the right guidance on the facts about the condition and where to seek help, what benefits and supports the government system provides, how to get certified and so on. An understanding family is the most significant support in the development of a person with intellectual disability. Grandparents and siblings need to be included in the support system so that the parents are not over-loaded and the person with intellectual disability gets the sense of belonging in the family.

## Role of Community

The ultimate inclusion is when person with intellectual disability and developmental disabilities form part of the community as contributing members. Over the decades, development of community-based rehabilitation (CBR) has been influenced by concerns of persons with disabilities at the community level and by disabled people's organizations (DPOs). These concerns have contributed importantly to the evolution of the CBR concept and resulted in increased recognition of discrimination and exclusion and the need to address social and political aspects of disability (Hartley et al. 2009). The implementation of RPwD Act (2016) strengthens the rights of persons with disabilities which in turn gives an opportunity to persons with disabilities to participate and contribute effectively in their community. Gone are the days when person with intellectual disability would be hidden by the family and shunned by the society. Their involvement in the community is gaining visibility through media. Yet, as mentioned earlier, persons with intellectual disability are largely dependent on their caregivers with limited capacity for self-advocacy, and therefore, parents represent them in many occasions in the community. It is essential that the community comes forward to include them, provide job opportunity and accept them as a member in the community.



## **Classroom Implications: Pedagogic Strategies**

Including children with intellectual disability in early years starting with preschool leads to smooth and spontaneous social inclusion and develops personal and social skills in the child with intellectual disability. Learning in early years is predominantly based on exploration and concrete experiences which is the way children with intellectual disability also learn. Hence modelling and imitation of typically developing children significantly helps them to acquire skills. The teacher is more of a facilitator in such environments. It should however be remembered that children with intellectual disability, because of their limited cognitive ability, tend to learn slowly and require a lot of opportunity to imitate and practise. As children advance to higher classes, concrete learning experiences gradually reduce and abstractions increase. Picture learning is replaced by words and symbols, object counting is substituted by number symbols, and reading, writing, and arithmetic are done with paper-pencil activities. As seen earlier, children with intellectual disability have difficulty understanding abstractions. Repetition and concrete experiences enhance their learning. They also have difficulty in transfer of training. What is learnt in one environment does not naturally get generalized to other situations. Hence teachers in higher classes find it difficult to teach children with intellectual disability. Children with vision, hearing or motor disabilities have adequate intellectual ability, and therefore, when arrangements are made to compensate for their sensory and motor disabilities, they learn like other students in secondary and higher secondary classes as well as higher education following the curriculum like other students with minimal adaptations. Due to the limited intellectual ability, children with intellectual disability need content adaptation and specialized instruction to learn. There are a number of studies on teacher readiness for inclusion which reveal that teachers without adequate training do not feel confident to teach children with such special needs (Rose 2001; Sharma et al. 2008). It is essential to provide in-service training to teachers so that children with intellectual disability are included in regular schools.

The role of technology is a part and parcel of our daily life. Teachers have effectively started to use technology to enhance the skills of students with and without intellectual disability. Use of iPads, calculators and laptops for the students and smart boards and computer-assisted instructions (CAI) have become a part of the teaching-learning environment. However, it is yet to spread its wings throughout the country. Universal Design for Learning (UDL) and Differentiated Instruction (DI) are strategies proven to be meeting the diverse learning needs of children, including that of children with disabilities ([www.cast.org](http://www.cast.org) 1996; Tomlinson 1999).

## **Role of Teachers, Peers and Other School Staff**

Inclusive education is not restricted to just preparation of the teachers to have all children in the classroom. It involves all the stakeholders including regular class teachers, special teachers, other administrative and support staff members and the peer group.

### ***Regular Teacher***

With the Right to Education Act (2009) in place, the responsibility of educating all children including those with special needs is that of the regular teacher. However, through SSA and RMSA, centrally sponsored programmes of the government of India for education of all children at primary and secondary levels, preparation of regular and special teachers to meet the challenge has become imperative. As a result, the pre-service and in-service teacher education programmes for general and special teachers are in the process of revision with a focus on providing competency and skills to the teachers to meet the challenge.

### ***Special Teacher***

The present system in India through SSA has special teachers in the role of itinerant teachers wherein they visit the regular schools periodically and assist regular teachers in teaching children with special needs in the inclusive class. The support can be in the form of team teaching, individual support to the child with learning needs, preparing assessment and teaching plans, evaluation and coordinating the special need support. As mentioned earlier, children with intellectual disability need adaptation in content and process of the curriculum transaction, and the special teacher ideally has to play an active role in supporting the regular teacher in the development of adaptation and suitable teaching-learning material and evaluation of the children. The special teacher has to also work closely with the parents to extend educational support at home and guide them in terms of the suitability for the various examination boards such as the National Institute of Open Schooling, private candidacy or appearing along with other children in the regular school system. This varies based on the competency of the child and various educational board support systems. There are children who may not be capable of appearing in any of the board examination in spite of the supports and allowances provided because of their limited intellectual capacity, and they need guidance for vocational training and placement. A small percentage of children with severe/profound level of intellectual disability may need lifelong support too. However, as seen earlier, 85% of those with intellectual disability have mild intellectual disability and are capable of

getting educated in the regular school if appropriate supports are provided. A special educator plays a major role as a coordinator for helping with the right option for the child with intellectual disability.

### ***Peer Group***

Success of inclusion largely depends on the spontaneous peer group acceptance of the child with ID. Acceptance can happen only if the peer group is aware of the condition and that it is alright for the child with intellectual disability in the class to learn slower than the rest of them and that the teacher will provide the needed support. It is important to inform them that the peer group also has responsibility towards them. The teacher can effectively take the help of the other students for peer tutoring and cooperative learning activities. There are numerous studies on the success of peer tutoring and cooperative learning when the peers are systematically prepared (Kagan 1994; Slavin 2011).

### ***Administrative and Support Staff Members***

Most of the administrative staff members tend to stay in their offices and do not interact with the children. Many of them do not know about the inclusion of children with special needs in the school. It is essential to prepare them with information and encourage interacting with them. There are instances where the headmaster and management of the schools resisting inclusion. Creation of awareness among them leads to development of positive attitude. The support staff play a major role in helping teachers in the class, during break times or during lunch time and wash areas, escorting in the school bus and guarding the gate so that children are safe in the school. All of them should essentially be prepared so that they understand intellectual disability and suitably interact with them.

### ***Role of Professional Support Team***

The professional team is essential for supporting the school system for successful inclusion of children with intellectual disability. A psychologist is the key person in assessment for certification of a person. She/he plans a key role in the management of emotional and behaviour problems that are found in some children with intellectual disability. A school social worker is the link between the home and school providing guidance and counselling to parents. Coordinating the professional team meetings and maintenance of records related to the students is a major part of the social worker's tasks. The school social worker also supports in the smooth transi-

tion from home to school in early years and from school to vocation in the later years. Preparation of the various stakeholders within the school and the community is another important role of the social worker. Many children with intellectual disability can be on medication for epilepsy and other conditions requiring a physician/psychiatrist/paediatrician's attention. In addition, some of the children with intellectual disability have other conditions such as cerebral palsy, autism and/or sensory impairments and deafblindness that need the attention of physio-occupational therapist and/or speech language pathologists. SSA team generally includes these professionals so as to provide a comprehensive support to children who are included in the regular school. As mentioned earlier, there are children with severe/profound intellectual disability who may have significant intellectual limitations and may need support all through their lives for even activities such as feeding and toileting. Some may be enrolled in special schools, while some may be at home. SSA has home-based training programmes for such children so that the caregivers are trained by the special educators to maintain the learnt skills and the children get maximum possible benefit.

## **Misconceptions**

### ***Condition***

Due to the invisible nature of the condition, many a time intellectual disability is misunderstood and misinterpreted. As there is no visible disability such as blindness or motor disability, parents when confronted with such a child get puzzled. In the process of 'doctor shopping' to find a cure, they come across people offering support ranging from black magicians to megavitamin prescriptions, all promising 'cure'. As rightly noted in a review of literature by Preece and Trajkovski (2017) in the context of autism, studies on parent education are very few, and there is an urgent need to educate the parents. Influence of religion and belief in past karma has also influenced perception of the condition by the family and community.

### ***Education***

There exists a professional belief that children with intellectual disability cannot benefit from inclusive schools as they are not capable of studying in high schools. In recent years, the Central Board of Secondary Education (CBSE) and the state boards have shown that children with intellectual disability have completed class X examinations with the adapted curriculum and evaluation systems with the support of scribe and additional time. A large number have also completed secondary education through the National Institute of Open Schooling (NIOS).

## ***Independent Living***

Vocational training, employment and independent living are considered to be challenges for persons with intellectual disability. When compared to the situation 30 years back, certainly there is a positive change in considering persons with intellectual disability for vocational training and job placement. However, such support systems are still emerging, and we have a long way to go. As noted by Baine (2017), employability skills refer to those skills, knowledge and competencies that enhance a worker's ability to secure and retain a job, progress at work, cope with change and so on. To have persons with intellectual disability employable, in addition to the work skills, the required social competencies in the work situation and the job market have to be inculcated. Considering these points, and the competitive job market situation, we have to plan effective curriculum for post-school training. Prime minister's skill development scheme which also includes skill enhancement of persons with disabilities is one such effort initiated in the recent past in India.

## **Way Ahead**

Since independence, we in India have come a long way in establishing the rights of persons with disability, providing guardianship to them and regulating the human resource development in the field of disabilities. Families of children with intellectual disability who used to hide their children with intellectual disability have formed federation of parent associations and demand their rights. Historically, special schools were established by the parents because the regular schools would not admit the children with intellectual disability. Today we have brought them into the mainstream schools aiming at equality, equity and quality. Certainly we have come a long way, yet there is a lot more to be done.

## ***Adults with Intellectual Disability***

Early intervention and school aged programmes have gained focus, but post-school programmes and care of the adults and senior citizens with intellectual disabilities continue to be ignored areas. Health and fitness of adults with intellectual disability, living arrangements in the absence of parents and dignified lifestyle need focus and attention from the government and professionals. The parents' anxious question of 'who cares for them after us?' remains unanswered and needs urgent attention.

## ***Information Technology (IT)***

Developments in IT are rapid, and it has become almost impossible to lead a life without IT support. It needs to be brought in the lifestyle of persons with intellectual disability to compensate for their cognitive deficits. Use of a calculator and digital watches and limited use of iPad/tablet are seen in some instances with regard to IT. Much more is a possibility through teaching-learning aids and functional aids to be of use throughout their lives.

## ***Research***

Research in India in the area of intellectual disability is far and few. As it is a condition requiring attention of various disciplines, it is essential that research and development get focus. Advances in science and technology are rapid. Studies using fMRI indicate that intensive research-based interventions can change the brain processing of struggling readers to more closely match that of typical readers (Sousa 2007). Research in education for Indian conditions, keeping in view the socio-economic and cultural perspectives, is a need of the hour. Indigenous practices in childrearing and their impact on children with developmental delays, ecologically based curriculum and instructional methods, teacher preparation for their changing roles in inclusive classrooms, promotion of health services for persons with intellectual disability and analysis of support systems or the lack of it in rural, tribal, coastal and other such specific communities are some of the unexplored areas and need to be studied if we have to realize the goal of equality and education for all in its true sense.

The Sustainable Development Goal on Education (SDG 4) aims to ensure inclusive and equitable **quality education** and promote lifelong learning opportunities for all, and persons with intellectual disability too have to be taken along with quality education and learning opportunities all through their lives.

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# Chapter 5

## Inclusive Education for Children with Autism: Issues and Strategies



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**Abstract** Educational inclusion for children with autism has to go beyond the usual understanding of inclusion which is about placing all students in the general education classroom and believing that children will benefit by merely being around other children. Rather it has to be based on an understanding of autism and viewed from the perspective of the student with autism. The latter must be taught using methods that enable them to learn. They must have access to assistive strategies and aids specific to their needs just as students with other conditions do. Most importantly, those tasked with teaching them have to own their roles as cross-cultural interpreters, between their autistic students, their non-autistic peers, the school and the wider community.

**Keywords** Spectrum · Rights · Social understanding · Communication · Sensory · Advocacy · Detail thinkers · Structure and visual strategies · Experiential learning · Bullying · Positive environment

### Overview

Autism spectrum disorder is one of the newly included disabilities in India's new rights-based disability law, the Rights of Persons with Disabilities Act (2016). The Act, which upholds the principles enshrined in the United Nations Convention on the

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Rights of Persons with Disabilities (UNCRPD), to which India is a signatory, mandates the State to take necessary steps to ensure reasonable accommodation for persons with disabilities. It enjoins upon the appropriate government and local authorities to ensure that ‘all children with disabilities shall have right on an equal basis to freely express their views on all matters affecting them and provide them appropriate support keeping in view their age and disability’ (RPDA, 4.2). The inclusion of a relatively lesser known and highly marginalized disability like autism within rights-based legal frameworks is a major step forward in securing recognition and acceptance for the needs and challenges faced by persons diagnosed with the condition. It poses challenges and opportunities to the educational system to open their doors to students with diverse abilities, capabilities and learning styles and tailor their pedagogic practices and strategies to include persons on the autism spectrum within their classrooms. This chapter provides an introduction to the experiential realities of persons with autism and their families with a view to sensitizing teachers about the nature of the condition and its implications for stakeholders and the wider community. The chapter introduces the reader to the evolution of autism as a diagnostic category and the cluster of symptoms that define it. It discusses the role of critical stakeholders like the family, community and teachers in fostering a climate of acceptance and inclusion. Strategies for inclusion of the child with autism into the classroom are explained, with special emphasis on pedagogic strategies that capitalize on the strengths of the child and work around the core difficulties associated with the condition. We thus emphasize inclusive practices that respect ‘neurodiversity’ rather than denigrate individual differences. To begin with, we place autism spectrum disorder within a historical context both globally and within the Indian context.

## Conceptual Foundations

The term ‘autism spectrum disorders’ (or autism spectrum conditions or ASC) refers to a neuro-developmental difference which impacts an individual’s functioning in the core areas of language, social communication and imagination. The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) published by the American Psychiatric Association in 2013, which outlines diagnostic criteria for autism spectrum disorders, indicates symptoms like persistent deficits in social communication and social interaction across multiple contexts and restricted, repetitive patterns of behaviour, interests or activities, which must be present in the early developmental period. To meet a diagnosis for autism, these symptoms must cause clinically significant impairment in social, occupational or other important areas of current functioning and are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay.<sup>1</sup>

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<sup>1</sup> See <https://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria> accessed on 25 May 2018.

Autism is a 'spectrum' condition, as individuals diagnosed with it may present with varying levels of functioning and (dis)ability, ranging from persons who may be completely nonverbal to those with advanced language ability, from those with difficulties in social functioning and acute sensory issues to those who may merely appear odd, eccentric and socially awkward. Underlying this apparent variety is a fundamental difficulty in making sense of the world in the same manner as a so-called 'normal' person, or, as autism self-advocates would have it, 'neuro-typical'.

Even though autism has probably always been a part of human experience and the great variety of the human family, it received a formal 'name' and identity as a distinct condition only in the last century. The term 'autism' was thought to be first used by the Swiss psychiatrist Eugen Bleuler in 1910, while defining the symptoms of schizophrenia. He derived it from the Greek word 'autos' meaning self, same, directed from within. In 1943, the US-based Austrian psychiatrist Leo Kanner published his study of 11 children who symptoms of what Kanner termed 'infantile autism'; however, unlike Bleuler who used the term as an adjective to describe the behaviour of patients with schizophrenia, Kanner used it as a noun, a name to describe a set of symptoms in his 11 young patients, who displayed fundamental difficulties in relating to other persons and appeared to be extremely aloof and disconnected from 'normal' social interaction. Even though Kanner believed the condition to be an innate one, he also was responsible for blaming cold, unresponsive parenting and the term 'refrigerator mother' which came to dominate the psychoanalytical discourse around autism particularly in the 1950s and 1960s in the USA and other western countries. The child psychologist Bruno Bettelheim in fact popularized this notion leading to a great deal of guilt and blame being experienced by a whole generation of mothers. The reverberations of this view are still experienced by parents; it has been reported by several mothers that they are blamed for the child's condition not just by family members and lay persons, but also by doctors and other medical professionals. It was the sustained work of clinicians such as Dr. Bernard Rimland and Dr. Eric Schopler in the USA and Lorna Wing in the UK that debunked the myth of parents being responsible for their children's condition and established autism as a developmental condition. Both Dr. Rimland and Dr. Wing were parents of persons with autism themselves; parental activism and advocacy has in fact played a crucial role in creating awareness and improving public understanding about the condition. Sustained research efforts in the fields of neuroscience, psychiatry, developmental psychology and education over the past few decades have substantially contributed to the fund of knowledge about autism.

The understanding of autism as a 'spectrum' condition was also an important development. Earlier, in 1944, a Viennese paediatrician Hans Asperger made a study of four boys exhibiting what he termed 'autistic psychopathy'; their symptoms were not as severe as Kanner's cases; in fact, they displayed a high degree of linguistic ability and a high degree of intelligence. Asperger's work became known to the English-speaking world many decades later, when the UK-based developmental psychologist Uta Frith translated it into English. The British autism expert Lorna Wing earlier popularized the term 'Asperger syndrome'; and the notion of autism as

a spectrum condition, spanning a range of abilities, yet marked by a fundamental difficulty in social functioning, came to be accepted (see Feinstein 2010).

Autism was first included in the third edition of the DSM in 1980, under the category 'infantile autism' and in the fourth edition as 'autistic disorder'.

The above brief description about the early understandings of autism is intended to convey to the reader that no diagnostic label is static across time and, in fact, keeps developing and changing. Autism is no exception. From being regarded once upon a time as an extremely rare psychiatric disorder, akin to schizophrenia, it is today commonly accepted as a neuro-developmental condition which affects approximately 1 in 68 persons, as per the Centers for Disease Control, USA.<sup>2</sup> In the following section, we will discuss autism in the Indian context, with special reference to the difficulties resulting from lack of awareness, paucity of facilities for diagnosis, rehabilitation and education and the social stigma surrounding the condition.

## Indian Context

While there are no reliable inclusion figures available about the prevalence of autism in India, experts believe that the figure could be as high as 10 to 18 million. Data on disability in India is generally sparse and unreliable, due to issues of identification, stigma and lack of awareness. According to the Census of India (2011), 2.68 crore (i.e. 26.8 million) persons in India have disability. It is hoped that the next Census will incorporate categories like autism, which has found a mention in the list of 21 disabilities named in the new Rights of Persons with Disability Act (2016). In this section, we will discuss autism in the Indian context, with special reference to the difficulties resulting from lack of awareness, paucity of facilities for diagnosis, rehabilitation and education and the social stigma surrounding the condition.

It is widely believed that autism is a 'western' disorder that is associated with the cultures of industrially developed societies and the preponderance of nuclear families. However, this is a myth. Autism is found across societies and cultures, and while the diagnostic term may be unfamiliar, the cluster of symptoms it denotes are not new. In the Indian medical literature, for instance, descriptions of autism or autism-like conditions have a long history, and the earliest case studies date back to the 1950s and 1960s. However, it was regarded as an extremely rare and severe condition, and awareness amongst paediatricians and general physicians was very limited. Obtaining a diagnosis of autism was not an easy task, due to the lack of awareness and the stigma surrounding disability in general and mental disability in particular. The term 'paagal' (mad, crazy) is frequently used to describe persons with any kind of cognitive or behavioural issue, and it is a highly stigmatizing one.

While autism is still not very well understood in the disability sector in India, there has undoubtedly been a great deal of awareness generated over the past two

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<sup>2</sup><https://www.cdc.gov/media/releases/2016/p0331-children-autism.html> accessed on 25 May 2018

decades, primarily due to the efforts of civil society activists and parents' groups. Awareness amongst the medical, psychiatric and service-provision communities has also grown, and a diagnosis of autism is no longer as difficult to come by as it was a couple of decades ago. The expansion of awareness and information through the Internet and social media has also had a major impact on awareness and help-seeking.

However, the flip side is that there is a great deal of information which is not backed by robust research available in the public domain which leads families to experiment with various therapies and procedures which may not help and in fact sometimes even harm the child with autism.

The Indian scenario presents a highly skewed picture. While there are islands of awareness, expertise and research in urban, metropolitan centres, the majority of the population in the rural hinterland and small towns lacks even the most basic facilities for identification, management and rehabilitation of persons with autism. Thus, many individuals fall through the cracks and are either never diagnosed or misdiagnosed. Some of them may receive the label of 'intellectual disability' or 'mental retardation'; others may be considered mentally ill or unstable. This gap in identification has serious consequences for education and inclusion, as the core difficulties that underlie the condition cannot be adequately addressed. Teaching strategies are successful if they are tuned towards understanding and remediating difficulties and rewarding and strengthening success. Many children with autism find themselves out of school. The scant number of specialized schools equipped to teach appropriately and the crisis of an overstretched and under-resourced public education system hardly needs emphasis. The family is usually the sole agency which must devise its own strategies to cope with the demands of raising a child with autism. It is against this backdrop that policies and strategies for inclusion of children with disability must be contextualized, in order to make our practices meaningful.

The unique challenges that autism presents, as mentioned earlier, include difficulties in social language and communication, sensory difficulties and seemingly-odd and stereotypical behaviours like rocking, spinning and hand flapping, extreme responses to stimuli and, in lay terms, behaviour that appears 'bizarre' and 'crazy' to the untrained or unempathetic eye. This makes it a socially highly stigmatizing condition for both the individual and the family. The child's behaviour is blamed on poor parenting and training; families often become social recluses, unwilling to expose the child to wider social circles for fear of rejection or social disapproval (Vaidya 2016). This reduces avenues for social learning and acceptance and further heightens the stigma and isolation. Schools are unwilling to accept children with disabilities like autism because they are considered 'unruly', 'violent' and 'unteachable' and find it difficult to understand or cope with traditional teaching methodologies that presuppose a learning style based upon the 'norm'.

A, presently a young man in his 30s, was diagnosed with autism in the 1980s by a foreign-trained clinician who had a knowledge of the condition. The autism diagnosis in the early 1980s was a particularly daunting one as the term was practically unknown in India and there were hardly any facilities or services available. The first child of well-educated, professional parents, A, was a healthy and active baby. As a

toddler, he was hyperactive, seemed to listen to nobody and was not receptive to instructions from his mother. The mother was blamed for being a bad parent and advised to discipline her child and teach him to behave appropriately. When she sent him to nursery school, he would tap and twirl the toys rather than play with them, wander around the classroom and seemed unable to do the things his peers did. His mother hoped that he would mature with age, but that was not to be. As he grew older, his difficulties intensified and the social stigma and isolation of the family grew. Over the years, his mother learnt to understand his difficulties with social and imaginative behaviours and trained as a special educator to help her son and other children like him. She then tried putting him in a school alongside other children. Within a few months, she was asked to take him out as the school felt threatened by his twirling and flapping of his hands. Over the years, with patient training at an autism special needs school run by a non-governmental organisation (NGO), A's most difficult behaviours have reduced, and he is able to participate in the social life and activities of his family and peers and spends his day working at the vocational centre of the NGO.

Children who are 'high functioning' or 'verbal' are able to secure admission in schools and even do well academically, at least in the lower grades. But they also encounter difficulties particularly after the primary grades when the social skills of their peers develop in qualitatively different ways.

B was admitted to the kindergarten and then the primary section of an upper crust school. By the time he approached middle school, his social and other difficulties kept getting him repeatedly punished. The school decided that they did not want to keep a child who was clearly intelligent but to their understanding 'unwilling to apply himself'. That is when a new school counsellor suspected that he might have autism. Once the diagnosis was confirmed, the school made it clear that he had to leave. In his teens B dropped out of school with a battered self-esteem, deep confusion and frustration at not understanding why he failed repeatedly at understanding what was expected of him and a feeling that he was 'useless'.

Adolescence, in particular, can be a very challenging time for many young people on the autism spectrum, as academic demands, peer pressures and dawning sexuality have to be dealt with and negotiated and for which appropriate counselling and support are essential. In later sections in this chapter, we will highlight the specific issues and challenges of including persons with autism into the classroom.

C, presently in his early 20s, received a diagnosis of autism at the age of 3. He achieved his motor milestones at the appropriate age, but his speech was delayed and idiosyncratic. He displayed a fascination with brand names of various products and would copy their names all over the walls of his home. He was hyperactive and would run away without the slightest inkling of danger. Intelligent and with the kind of keen curiosity that fuels learning, he was enrolled in various nursery schools, but each time his family was asked to withdraw him because he was unable to comply with instructions and interact with other children and was labelled a 'security risk' because of his propensity to tinker with machinery and run away. He received a placement in a special school for children with autism and, thereafter, never attended a mainstream school. With appropriate autism-friendly teaching

strategies, he was imparted literacy, numeracy and vocational skills. He is presently pursuing his education through open schooling. C's family received support and counselling through a parent-run autism NGO and thus learnt to accept and cope with their son's difficulties.

D, along with her parents, attended an intensive and empowering training at an autism NGO when she was 4 years old. At the close of the training, encouraged by the NGO, her parents admitted her in a regular school. Initially her parents closely monitored her progress, ensuring that her learning was rock solid, that she was indeed learning and not merely using her strong memory to scrape by, and referring back to the NGO whenever there was any learning, social or other challenges at her school. In time she learnt to not just learn but to effectively negotiate the social space at school. Now at 12 she is a student who looks forward to going to school each day. There still are little social glitches that she needs help to address. Her parents are aware that this is just a start and refuse to become complacent merely because she is settled well at school.

The preceding presentations reveal how the symptoms of autism can confuse and confound families and go against the grain of socially acceptable behaviour. Parents are blamed for not disciplining or training their child, and therefore they withdraw into a shell and do not engage with the extended family or wider community. There is an acute need to make the community aware of conditions like autism, so that children and their families are able to access social spaces and support. The aim of the chapter, as discussed earlier, is to equip teachers and educators to engage effectively and empathetically with children who are unfairly dubbed as 'unteachable' because of their neurological differences.

In the following section, we shall examine some sociological perspectives on disability and difference that will enable us to contextualize the issues and challenges of autism better.

## Sociological Perspectives

Disability has been regarded as a deviation or departure from the 'norm' and has by and large been a concern of the medical profession, psychology, special education and rehabilitation science. However, contemporary social science research is increasingly focusing upon its sociocultural and political dimensions, viewing persons with disabilities as a minority group that has been subjected to prejudice, discrimination and social oppression, on similar lines as other marginalized groups in society. Sociologists and anthropologists have addressed it in terms of stigma and social deviance. For instance, the symbolic interactionist theorist Erving Goffman (1963) in his well-known book *Stigma* (1963) highlighted the constant struggle against devaluation of one's identity as a person who is not quite regarded as a legitimate member of human society on account of the stigma of disability. The stigmatized individual may 'pass' as socially acceptable; in case she/he fails to do so, the 'spoiled', stigmatized identity may be internalized by the person and

lead to social rejection. Sociological and anthropological writings on the subject of intellectual disability or ‘mental retardation’ draw attention to the constructed nature of the category and how it is dependent upon social and cultural contexts at various points in history. From a sociological perspective, we see the role of social institutions, cultural practices and politico-economic processes in ‘naming’ and ostracizing persons whose minds and bodies work differently from the ‘norm’. The idea of ‘normalcy’ itself is socially constructed, and a product of a particular way of thinking about the world, that emerged at a specific moment in history. Cross-cultural studies of ‘normalcy’, ‘competence’ and ‘disability’ give us rich insights into how difference is understood and accommodated in diverse cultural contexts. For instance, Mehrotra and Vaidya (2008) in their comparative study of intellectual/developmental disabilities and gender in Haryana and Delhi highlight the role of urbanization and universal education in creating a new category of ‘learning disabled’ children whose mental limitations become sources of stigma in a competitive urban milieu. However, as Mehrotra’s work in rural Haryana indicates, physical disabilities that affect an individual’s ability to work in the field and farm are greater causes of concern than intellectual disabilities.

Traditional religious and cultural understandings of disability play a crucial role in determining familial and societal responses to disability. The notion of disability as a consequence of ‘karma’ and the rich body of mythological and literary narratives around disability are very much a part and parcel of our cultural repertoires. Characters from the epics Mahabharata and Ramayana like Manthara, Shakuni and Dhritarashtra are depicted as disabled to connote moral flaws or defects in character (Ghai 2015). Thus, the stigma surrounding disability has a strong cultural resonance as well.

The following section will address the protagonists’ views with regard to autism. This is crucial in order to gain an insight into the lived experience of disability.

## The Protagonist View

Society is by and large rigid when it comes to acceptance of anything that does not fit the norm. The need to stick to things that are predefined and specific perhaps stems from the comfort of the familiar and fear and of the unknown and contempt of the unfamiliar. People with disabilities have traditionally been viewed at best as flawed and less than others and at worst as evil, tragic and a blot on society.

Not surprisingly, society’s perceptions shape parents’ initial reaction towards their child with autism, or any disability. It often takes years for parents to themselves accept their child with disability in a positive light and without judgements. All efforts are directed towards ‘normalization’ and making the child fit into society’s judgmental norms.

Living in an environment that sees them as flawed, as individuals who have blighted their parents lives, as ‘less’, as ‘incapable’ and as tragic mistakes, individuals with autism begin to internalize these judgements about themselves.



Parent advocacy is mostly directed to support the 'poor' parents whose lives are so difficult because of their child. Glorification of parental struggles, not as a part of a joint effort by them and their children, but as despite their terribly 'difficult' children, perpetuates this perception. The person with autism ceases to be a person and becomes an extension of parental aspirations, and an object that must be 'fixed' using any method that is proffered, leading to a proliferation of 'treatments' that normalizes the violation of the personhood, dignity and rights of the person with autism.

Starting with Temple Grandin's 'Emergence: Labelled Autistic' published in 1986 which provided the spark, the autism self-advocacy movement has taken small steps in asserting itself though still confined to the western world. Persons with autism have begun to speak out in demanding their rights. They do not see themselves as 'afflicted by autism' but as persons who have autism. They have no patience with so-called politically correct language that insists on terms like 'persons with autism'. They call themselves 'autistic' people with pride in their personhood and have no desire to be 'normal'. Autistic self-advocates like Professor Stephen Shore, Dr. Wenn Lawson and John Elder Robison amongst others have through their writings opened up the world to an understanding of the autistic experience that was earlier denied to those who consider ourselves as the norm. They are striving to create a world in which autistic people enjoy the same access, rights and opportunities as all other people and one where autistic voices are included in any public discourse on autism, whether in public policy, mass media or other venues.

In India, this continues to be a struggle. In a milieu where anything that goes by the term 'mental', disability or otherwise, is denigrated, sneered at and looked down upon, persons with autism who lead regular included lives prefer not to reveal their condition for fear of repercussions, and worse reprisal, due to the stigma attached to a mental condition. While persons with physical disabilities have moved forward with the demand of 'Nothing for us, without us' and are vocal self-advocates, it will be many more years before persons with autism can do the same.

In the meantime, the movement to change society to accept diversity and in particular mental diversity will have to continue through inclusive education, inclusive leisure, inclusive travel opportunities and so on, so that persons with autism too can stand up and stand out and demand 'Nothing for us, without us'.

## **Academic and Socio-psychological Implications**

Autism has a varied continuum of behavioural manifestations that is unique for every child. Knowing a child with autism means you know only that one child with autism. This is the reason it is often hard for the uninitiated to address the academic or other needs of children with autism. The contemporary school system and institutes of higher education focus on providing education en masse. This approach has an exclusionary effect on those children with autism who need environmental and instructional adaptations.



Teaching children with autism has to be based on a firm understanding of autism spectrum conditions, an understanding of how autism may affect learning and an understanding of how autism affects a particular individual. Programmes have to be highly individualized and take into account the individual strengths as well as challenges so that they harness the strengths and develop skills and potentials to the maximum possible level. This understanding of their unique learning styles has been changing and evolving, and as our understanding of autism and the diverse ways it affects children grows and deepens, the methods too change and evolve to incorporate this understanding.

Children with autism may have cognitive abilities ranging from the functionally high to those who require high levels of support even for their daily routines. In addition, they may have exceptional talents regardless of their level of functionality. So, someone requiring a high level of support may have a photographic memory, while another who is independent in daily routines may have difficulties in remembering contextual facts and information. Some will have fluent speech, whereas another will be nonverbal. However, the acquisition of language does not automatically equate communication. There must therefore be awareness that the root of many behavioural challenges stems from frustration from a difficulty in communication.

Some children may be passionate about a subject and talk endlessly about it. They may not realize that the listener does not share their passion and are feeling bored of the conversation. This difficulty in recognizing other's perspective also leads to difficulties in inferring meaning from idioms and metaphors. They may not perceive jokes or sarcasm and instead understand them literally, without reading between the lines. Though they may want to strike up conversations or be included in discussions, they may find it challenging to initiate or hold a conversation beyond the initial greetings. If frustrated in monopolizing a conversation with their favourite topic, they may indulge in undesired behaviours like crying, pushing or hitting. The vast majority of them need help in learning how to initiate and sustain a conversation without giving in to the desire to force the conversation to their favourite subject. Social stories often help them in understanding the behaviour desired of them.

A greater challenge is social understanding. Children with autism have a very different understanding of social norms, the fine give and take of social rules which are ever-changing. This is of greater relevance to the more able learner with autism who will tend to rely on social scripts they learn by rote to help them navigate the social world of the mainstream classroom. Rewards like praise or other forms of social approval are usually not effective at first in the learning process; and neither is punishment, as understood in everyday terms.

Individuals with ASC are mostly concrete, literal thinkers. In addition, unlike most typically developing children, many do not learn through imitation and observation. So, they may not have those skills in place that the non-autistic learns incidentally, unless those have been explicitly and systematically taught.

The learner with autism may often be easily distracted by extraneous factors in the environment. They may focus excessively on irrelevant details and, in the

process, miss the big picture. This can affect their ability to prioritize the relevance of details. Their focus on individual details prevents them from focusing on the task in hand as well as the desired outcome. This can affect their organizational and sequencing skills. For example, a child may master each individual skill of shutting the washroom door, unzipping his pants, urinating, zipping up, washing his hands and unlocking the door. But difficulties in putting activities in sequential order may lead the child to miss a step. He may come out of the bathroom without zipping up, or not washing his hands before coming out or forgetting to close the door when using the washroom. When faced with more complex sequence of tasks such as writing for an exam, they may feel overwhelmed in their attempt to plan and work through the different steps and get stuck half way through the task, or not be able to get started at all.

They also face difficulties with generalizing. So, they may learn skills or behaviours in one situation, but not be able to apply those same skills in a different situation. A child may learn to recognize and label as a 'car' the picture of say a red Maruti Alto. But he may not do the same with a picture of a different car say a white Toyota Corolla, or even with a real Maruti Alto on the road. A child may be able to add two three-digit numbers with ease, when the numbers are presented one under the other with a 'plus' sign. But when that same sum is written in a single line ( $239 + 476 =$ ), the child may not know what to do. Or be lost when given the sum: Arpita has 239 stickers. Her brother gives her another 476. How many stickers does Arpita have now?

Many may have sensory processing difficulties leading often to unusual behaviours that may interfere with learning. Despite these difficulties children with an ASC can learn, develop adaptive behaviours and show significant progress.

Individuals with autism exhibit a splintered developmental profile, being able to function in some areas at levels higher than their overall level of functioning, at par in some areas and far below in others. For example, a 3-year-old with autism may be reading at a second-grade level, while his social skills are nearly nonexistent. Another may perform much above the grade level in mathematics and two classes below in languages and have minimal interaction with peers.

An effective educational practice has to be flexible enough to address the individual concerns of the entire spectrum of students with autism. A practice that identifies and considers the unique characteristics of each child takes cognisance of the individual areas of strength and weakness and also individual interests and preferences and ensures that students have a positive learning environment.

## Issues and Challenges

Students with autism benefit greatly from learning and growing alongside non-autistic students. However, the learning environment has to be inclusive in the real sense of the term. Inclusive education is often interpreted as 'teaching' all children in the same classroom. However, what it really means is diverse children all 'learning'

together. Merely placing all children together in the same classroom does not lead to learning. Mere 'teaching' is not enough. If learning does not happen, then there is no education happening either.

When students in an inclusive classroom do not learn, it is viewed as the child's fault. Yet it is no one's fault. However, those in a position of power in this equation, namely, teachers, can introspect on what they want to change in order to help the child learn. Even in situations where a teacher does not understand autism too well, introspecting on how to bring about positive change can show the way and enable learning to take place.

The diagnostic features of autism – difficulties in social interaction and communication and restricted, repetitive and stereotyped patterns of behaviour, interests and activities – are broadly well known by educators (Bishop 1989). However, the experiences that those features mask, which strongly impact the functioning of students with ASC in inclusion settings, are little understood. For instance, in addition to the preceding, individuals with autism often face challenges in processing sensory input leading to hypersensitivity or hyposensitivity to stimuli such as light, sound, vision, hearing or touch and dealing with proprioceptive and vestibular input. This can affect the way they respond to the environment resulting sometimes in rocking, finger flicking, looking through the sides of their eyes or sniffing objects. While such behaviours are often odd seeming, they are a reflection of a physical need within the person and often enable them to process the world better.

Autism has no physical markers. There is nothing that visibly informs the observer of the challenges that the student with autism faces, unlike with the student with blindness or mobility impairment or intellectual impairment where the observer has an 'in' into what it might feel like to not be able to see, to control one's movement and mobility or to not be able to think as quickly and sharply as others and feels pseudo-experiential empathy for the individual. With the student with autism, the average observer cannot comprehend what the autistic experience could be like and feels little empathy for a child who 'looks like any other' but behaves in a manner different from the norm, a manner that is seen as 'odd'. Even those with Asperger syndrome or high-functioning autism who have fluent speech and appear so 'normal' that they often go undiagnosed can be socially naive and face the same challenges in social understanding as others with autism.

Awareness and an understanding of the strengths and challenges of the students in the classroom is essential in supporting their learning.

The world expects us to observe others, intuit what is there in their minds and act accordingly. Individuals with autism have difficulty in inferring mental states of others (Baron-Cohen 1995). When a teacher asks all the students who were talking in class to stand up, non-autistic students will not stand up, knowing that the teacher has not seen them and so would not know they were being disruptive in class. However, the student with autism will own up if he was one of those talking. The non-autistic child will know to tease the student with autism when the teacher is not looking, knowing that if the teacher has not seen, then the teacher does not know and they will not get punished. The latter however will retaliate in full view of the teacher without any attempt at hiding the action from the teacher, and get into trouble. If the

teacher wants to know who had written the swear word on the board, students would all keep quiet. The student with autism however will volunteer the name of the writer. Because that is the fact and facts make sense to him. It would not occur to him that divulging the name of the offender would make him unpopular in class. Not understanding mental states is also the reason why the student with autism finds it difficult to lie; when they do, their lie is obvious. Other students quickly get to know that the student with autism will not be able to complain to the teacher and present his side of the story. This sets the latter up for merciless bullying throughout their school years.

They are also detailed thinkers. This is a great strength leading to their facility in noticing details most of us miss and fascination with large bodies of facts (Frith 1989). It is easier for people with autism to understand individual facts or concepts, but they have difficulty in integrating them with related information. They can have extensive theoretical knowledge of things but may find it difficult to apply them to everyday life. Knowing the statistics of every cricket match played in the last 50 years does not mean they would be able to actually play a match on the field. This can also lead to literal interpretation of situations. When teacher walks into a noisy rumbustious class and says: 'Are you done?', it is a directive to stop and settle down so teaching can start. The student with autism on the other hand might hear the words 'are you done', miss the context, perceive a choice and answer 'No Sir'.

Sunil whose pen has rolled away asks, 'Can you pass me the pen'. Vishesh, who has autism answers, 'Yes', and he continues writing without handing the pen to Sunil. Vishesh is not being rude. He simply focused on the words 'can you pass me the pen' without integrating the context, viz. that Sunil did not have anything to write with. For him it was a question on his ability to pass the pen to which the answer naturally was 'yes'. Situations like this lead to Vishesh being labelled as rude, arrogant and uncooperative.

When one is focused on details and facts, and not on coherence, then it is difficult to be flexible. Mr. Das the English teacher starts class by asking Swati who is tall and has autism, to write the name of the lesson on the top of the board. One morning Ms. Tiwari walks in to substitute for Mr. Das (who is on leave). Ms. Tiwari reads out the topic of the day's lesson and starts distributing worksheets. Much to Ms. Tiwari's chagrin suddenly, unasked, Swati marches up, grabs the chalk from under Ms. Tiwari's nose, goes to the board, writes the title of the day on top and goes back to her seat.

Detail thinking can affect learning in diverse ways. Children with autism often learn to read in a discrete manner. They may read words, read sentences, as a mechanical exercise, focusing on the letters, the words and their sounds. Reading is not part of a coherent whole where the meaning plays an important part. They may read complex passages fluently, be able to mechanically reproduce entire pages of what they have read, but not derive any meaning from the exercise. Saima is eight and a fluent reader of texts beyond her age. She is hyperlexic and started reading from before age 2. When she was in grades one and two, she excelled at producing answers to questions on the small passages that they read in the classroom. Now in grade four, her answers are often incomplete or not connected to the question asked.

She picks up entire irrelevant chunks of the lesson from her memory and writes that for an answer. When the teacher asks her to briefly tell the class about a passage that they have read, she repeats the entire passage word for word. She is often punished for not paying attention and slacking in her work.

When writing examinations, typically students skip difficult questions and move on to the ones they are certain of scoring well on and come back to tackle the difficult questions last. Students with autism will follow the sequence in the question paper and, if stuck at a question they are not certain of, may not be able to proceed with the ones they know the answers to and leave the test incomplete. Even after an explanation of how they can skip questions and move on, they may not be able to do so at the next test. Planning and achieving a goal by flexible means can be a challenge. So is inhibiting impulsive responses, self-monitoring and self-correction. This makes it difficult to learn from past mistakes and developing strategies to overcome difficulties. Molly is a very intelligent, well-read student. When teacher asks the class a question, generally we see that students put up their hands to answer. Molly shouts out the answer without putting her hand up and without waiting to be asked to answer. Teacher reprimands her for speaking out of turn and punishes her for doing so, but Molly persists in blurting out the answers to questions put to the class. Many students with autism have difficulty in modifying behaviour in relation to feedback and therefore persist in actions that 'fail' or are punished in some way and are then labelled disobedient, willful and provocative.

Taking instructions in a group can be confusing for some students. When teacher says: 'Take out your books', the student might not realize that the instruction was also meant for him and not take his book out. In addition, the student with autism typically needs time to process information and also finds it difficult to engage other sensory modalities when processing a verbal instruction or command. When the teacher is speaking to her, Saima looks away from the teacher. Even when the teacher scolds her and tells her to 'pay attention' to what she is saying, Saima continues to look in another direction or looks out of the corner of her eyes. Saima has difficulty in listening and processing information, as well as looking a person in the eye, while doing so. Looking away helps her to deconstruct and follow the teacher's instructions. However, her teacher interprets this as indiscipline.

There are many challenges that the environment throws up that make negotiating the classroom challenging for the autistic learner. Classrooms are unpredictable and changeable. As children move up to more senior classes, teachers change through the day: with different subject teachers, proxy teachers and so on. When a teacher is absent, sections might be combined. In addition, different teachers bring different expectations. Rules, too, keep changing. There are different rules in the classroom, playground, library, at tiffin time, in the computer lab. You can ask a question aloud in the classroom, but you may not in the library. You can pace in the playground but not in the classroom. At the computer lab, you put your hand up before answering a question, but not during tiffin time. Schools can be social minefields for autistic learners, further compounded by the varying levels of demands from peers.

Students with autism have a strong need for sameness and predictability. They want things to remain the same way and have resistance to change and difficulty

when encountering unexpected situations. As mentioned earlier, they may have difficulties in processing information as well as understanding social expectations, in addition to sensory overload. As a result, teachers may experience students who do not carry out a task, students who insist on doing a task in a particular way, students who are abrupt, students who do not keep an appropriate physical distance from other students or students who appear 'restless' and overactive. Such behaviours can often be a manifestation of underlying confusion and anxiety. They may also be indicative of a need for attention and help, or a means of escaping from a stressful situation, of protesting against bullying or teasing.

In some instances, alongside behaviours that are mistakenly viewed as 'disruptive', the student may have an islet of ability: an exhaustive knowledge of the solar system, an astonishing facility in numerical calculations, hyperlexia or exceptional skills in information technology. The interpretation then is of an intelligent student who is noncompliant, deliberately contrary and undisciplined.

Currently teachers do not have an understanding of autism that extends beyond the theoretical, making the classroom a challenging exercise both for themselves and the students. Effective inclusion of students with autism in the regular classroom has to incorporate an understanding of inclusion, an understanding of autism spectrum conditions and, more critically, an understanding of the experiences of students with autism in mainstream classrooms.

## **Role of Family Members and Relatives**

Akin to the case of children without disabilities, parents of children with autism are partners in the educational process that requires close collaboration between home and school. Parents can provide appropriate support by keeping themselves updated on specialized knowledge, skills and research-based treatment. Parents often need to negotiate with authorities, and for that they should be aware of the specific provisions in the rules, acts and policies. In addition to parenting, they may need to take on many other roles such as teacher, advocate, negotiator and mentor. This at times can be challenging. A common occurrence is that the onus of this is usually on the mothers, while most fathers prefer to stay on the outskirts.

There is much that the family can do, and often does do, when there is a child with autism in the family. These include:

- Accept the child and the associated challenges.
- Understand that the child will certainly learn and progress, but she/he will not become 'non-autistic' with age.
- Not chase the chimera of a magic cure.
- Educate oneself about autism, understand autism and understand one's own child.
- Educate oneself about the best ways to help the child learn.
- Work to create open communication between the efforts at school and home.

- Be an advocate for the child's rights. Be aware of laws, policies and entitlements.
- Create support systems to share responsibilities and duties within the family.
- Involve siblings so they feel deserving of as much attention as the autistic sibling.
- Do not demand the involvement of siblings as a 'duty'.
- Having a child with autism in the family affects different members of the family differently. Make space for discussing and resolving issues.
- Build on the strengths of the family members and extended family members.
- Identify activities that can be done together and that can be enjoyed by all. These can be as simple as a walk in the park.
- Not compare the child (or the siblings) with any other child to their detriment. Each child has their own strengths and weaknesses.

## **Role of Community**

As discussed earlier, children with autism have different ways of learning, attending or responding in what is a lifelong condition that presents varied and shifting manifestations at each stage of the life. There is no doubt that the community plays a vital role as a support to the individual and the family and to bring together all the actors who work within the community.

K's family has lived in the same locality in Mumbai for several decades. When K was younger, like a lot of other children with autism, he would sometimes wander off. On every occasion, someone in the community would spot him on the streets, recognize him and ensure he was brought back safe to his home. K and his family were so integrated in their community that his parents never doubted that K would be safe no matter when he wandered off.

Rare is the family that lives in isolation. The vast majority live within communities that spiral out to a larger whole: a home, a school, a lane, a street, an area, village, district, town, city, state and country. It is the community that can ensure access and inclusion across all areas so that persons with autism have a full rich life, participating in leisure, recreational, civic, economic and political life of the community. A lot can be achieved when people from different sections of the community share a common goal of inclusion and participation of persons with autism and others who are 'different'.

Without community support the inclusion of persons with autism will be painfully slow. All stakeholders, namely, people with disabilities, family members, self-help groups, disabled people's organizations, community members, local authorities, local leaders, decision- and policy-makers, have to work together to address barriers within the community and ensure the successful inclusion of people with autism in their communities with equal rights and opportunities.



Inclusive education alone will not lead to inclusive lives. If anything, the opposite is true; an inclusive society that offers inclusive life opportunities to persons with autism will more naturally welcome students with autism into their schools and classrooms.

## **Classroom Implications: Pedagogic Strategies**

Persons with autism have a chaotic inner world. Imagine a world where you have difficulty in expressing yourself, in processing words that are thrown at you and in understanding that other people have other thoughts, other emotions, other intentions and other desires and difficulty in navigating the social world. Add to this hypo- or hyper-sensitivity to the sensory environment. It is easy to see that they have a far tougher time in the classroom than the person who teaches them!

The population of those with autism just as those in the wider population include the exceptionally intelligent to those with learning difficulties. However, they all perceive the world differently from the non-autistic. Just as many who are blind often compensate with strong tactile skills, and those who are deaf with strong visual memory, persons with autism compensate by being strong visual learners and with excellent rote memory (Grandin 2006). For most, including those who are high functioning (the population that currently largely comprise those in mainstream classrooms), early intervention that focusses on helping them ‘learn how to learn’ ensures successful inclusion in later years.

An inclusive classroom is one that employs strategies that enable learning for all students. Increasingly, centres of education are trying to provide accessibility and promoting the use of assistive measures to aid learning. Yet a common riposte to suggestions on using assistive modalities such as visuals or structuring the classroom for a student with autism is met with ‘Why should we do this for her? She must learn like others do’. The concept of enabling accessibility is somehow conjoined to visible disabilities (braille, sign language, JAWS software, etc.), coupled with resistance to accommodations to learners with an invisible condition such as autism.

With autistic learners in the inclusive classroom, teachers have to look beyond the invisibility of the condition and remind themselves that the student indeed *has* autism with its concomitant needs, despite appearing typical and not showing any ‘visible signs’ of their condition. Teachers will have to dig deep into their understanding of autism to implement classroom strategies to interpret the student’s behaviours and needs so as to accommodate the *learning styles* of the learner and facilitate effective learning (see Vaidya and Barua (2017) for a discussion on language teaching and learning for children with autism).

A critical strategy to promote learning is to actively plan for provoking positive learning behaviours! That could relate to almost any and everything the teacher does in the classroom!



Persons with autism benefit from an environment where abstract rules and symbols are concretized and made visible. This can apply to the physical environment, to time and to activities. They benefit from an environment that is physically structured for learning, when the passage of time is made concrete and when activities to be carried out are structured as well. Concretizing and structuring are not unique to autism; they are used widely by all: in our class timetables, diaries, planners, shopping lists and so on. We structure the physical environment to speak for itself. The stove is in the room where we cook, and the bed tells us that this is the room where we sleep. We don't eat in the room where the shower is. The meaning of the physical space does not have to be deduced. The only difference is that people with autism need these external reminders and supports at a higher level.

Structure and visual strategies are effective means of providing clarity through which the child understands clearly what is expected of him, keeping anxiety and confusion at bay. They provide predictability by telling them what to expect and what will happen next. They help them pay attention to the details that are important and develop flexibility by helping the learner deal with change. They elicit positive learning behaviours, naturally. They also enable the student to function independently by telling the student how to move through the physical space purposefully and not be dependent on supervision. And for a population that is not as socially motivated as others, it increases the student's motivation to complete assigned activities (Mesibov et al. 2004).

Some specific actions that can be taken to facilitate learning are:

- Seat students who are hypersensitive – to movement, excessive visual information, sounds, etc. – and therefore distractible, in the front of the class, away from open windows, doors and colourful walls that are chock-a-block with posters, notices, etc.
- Students with autism can feel overwhelmed by having to refer to the entire week's timetable when trying to check 'what next'. Many benefit from having only that day's timetable visually available on their table, serving as a ready reckoner of the day's activities.
- Make the abstract concept of time concrete and visible by using calendars, timetables, visual and audio timers to inform and remind students of the 'when' and the 'how long'.
- Give visual reminders to help them stay on task. A student who has to go to the library and fetch a book to be used in class can carry a slip that ensures that he does exactly what he has been asked to do.

*Go to the Library.*

*Ask Mr Singh to issue 'An Early History of Man'.*

*Take the book.*

*Come back to class.*

- A student who gets stuck at a task and is unable to ask for help can have a 'Help' card accessible on his table. The first few times when the teacher observes that he needs help, she can direct him to hold up the card and say, 'Help'. After a first few times, the student will start doing this on his own and in time will just need to see the 'Help' card to be able to ask for help and eventually be able to ask for help spontaneously. The visual will act as a prompt for the verbal. A much better situation than getting anxious and stressed at not being able to ask for help and complete the task.
- Teachers often believe that a verbal explanation will suffice given how intelligent the student is. It mostly does not. Later, when in trying to deal with the anxiety the student exhibits disruptive behaviours, instead of their anxiety being addressed, they are taken to task and things take a turn for the worse. The student with autism is always the loser.

In the early stages, students require detailed schedules. As students get more sophisticated in their understanding, schedules and visuals require less detailing. The following section carries a few more examples of the use of visuals and structure:

- It is hard to find a person who does not respond to praise and recognition. Students with autism however get a lot more negative feedback than positive. Given their difficulty in understanding social rules and in interpreting and participating in conversation and social give and take, they often do things deemed 'inappropriate' from a non-autistic point of view. As a result, they experience far more 'Don't do this', 'Why are you doing that', than praise. Such responses do not help them learn what is expected of them. Instead, catch the student being 'good'. Ayesha completes her math exercise much ahead of other students. On many days, in the remaining 10 or 12 min of class time, Ayesha tends to get up and walk restlessly around the class which the teacher disapproves of. A common approach to enforcing discipline and extracting obedience is to give a negative reaction when the student does anything we don't want. A far more effective strategy would be to praise, reward and acknowledge when the learner does something we are happy about. Usually, teacher scolds Ayesha for walking around. But the scolding has not stopped Ayesha from repeating her pacing. Instead on the occasions when Ayesha keeps to her seat after finishing her class-work if her teacher were to say: 'Well done Ayesha! Good that you are sitting and waiting for others to finish', the chances of her trying to stay in her place would be higher.
- Unexpected unscheduled changes lead to anxiety. Inform in advance of any impending changes, including change in timetable, change in teacher, change in subject to be taught, change in activity, a change in routine, in short, any change. Use visuals to give clarity. If a history lesson is cancelled to accommodate a visit by Kalaripayattu (martial arts) performers from Kerala, while other students without autism might exult at the cancellation, the student with autism will be extremely distressed at this change. A verbal explanation may not be enough. But a change in the visual schedule, or timetable, will ensure:

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 Tuesday
 

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 English
 

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 Math
 

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~~History~~ *Kalaripayattu*


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 Music
 

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- Tell the student what you want, not what you don't want. Teacher tells Ayesha: 'Why are you walking around?' Ayesha knows she is walking around. It does not help to label her action. Instead it would help her to know what she should do instead of walking around. It would be more effective to say: 'Ayesha, go sit in your place'. That tells Ayesha what exactly her teacher wants her to do.
- Encourage alternative behaviours. When Ayesha paces after finishing her class-work, chances are that she does so because she does not know what she should do now that the work assigned to her is done. Despite having fluent speech, she will not be able to ask the teacher: 'Mam, I have finished. What shall I do?' In such situations students with autism may try to engage (and thereby 'disturb') classmates who are trying to finish their work, talk loudly or do things that would be seen as disruptive. A sensitive teacher will intuit that they need help to stay engaged while waiting for the period to get over. A note on the table that tells Ayesha and students like her what to do while waiting for class to get over would act as an effective visual reminder. The activity ideally has to be something that the student enjoys. It could be a favourite book to read, a puzzle to do, Sudoku to solve, a car magazine to flip through, railway timetables to explore or anything that is of interest to that particular student.
- Give clear and precise instructions.
- Eschew idioms, sarcasm, irony and other forms of indirect speech when addressing the student. It would not have the stinging effect that the teacher intends and would instead confuse the student. Telling Ayesha 'Why just walk in the class your majesty, go take a stroll around the school' or 'Do you think this is your local park?' would in the first instance make Ayesha think she had permission to take an extensive walk and in the second have her answer, 'No', and keep walking.
- Address the student by name when giving a general instruction. But try and include a few other students too so that the student with autism is not obviously marked out. 'Romit, Ayesha, Sunil, Norma, everyone, take out your History books. Open to page 67'.
- Link work to the pupil's particular interests.
- Many students with autism have difficulty in writing longhand. Let them use computers instead.
- Students with autism can find it difficult to write passages or explanations. Since the purpose is to evaluate their understanding of lessons taught, allow them to do so through alternative means such as giving bulleted answers, drawing a map of the material or answering multiple choice questions.

- Be high on the awareness that a change in behaviour that appears as disruptive or challenging may be an outward manifestation of stress; identify the cause – anxiety, bullying, sensory overload, etc. – and act accordingly.
- Make learning experiential. Experiential teaching is critical for all early learners. Placing six pencils in the box, taking one pencil out to give to the teacher and counting the leaves collected during a nature walk, all of these teach numeracy better than merely circling flowers in an exercise book. Filling containers with sand, emptying them and half-filling containers can teach empty, full, etc. far better than pictures in a math book. Making a pinhole camera teaches students a lot more about light than a lecture read out from a book. Having students do group ‘projects’ is a great way of enhancing learning. However, it’s equally important to ensure that students actually do the projects and not submit something from an online project mart! Tracking birds spotted in the neighbourhood over a year and then making a presentation to the class can give a better understanding of pollution. For students with autism, learning through seeing, touching, doing and experiencing, especially in the early years, often makes the difference between understanding and internalizing concepts, or merely learning things by rote. The latter enables them to appear to do well as they flounder through the early years and then have to drop out in middle school when rote learning alone does not suffice.
- Incorporate peer mediation. Try to pair the student with autism with a buddy who is good at their work. Don’t make it a chore for the other child. Introduce it as a fun request. The buddy has to ‘want’ to do this. Students are far more willing to listen to a peer than to a teacher. The buddy too benefits, because in trying to help they have to think through whatever they do in providing support. They also learn patience and sensitivity and the realization that they have more in common with the person with autism than they had imagined. Sometimes buddies can lead to lifelong friendships, an experience that most students with autism do not have.

## **Role of Teachers, Peers and Other Support Staff**

Inclusion also means non-exclusion (NCF-2005) and inclusive education is about embracing all. An inclusive education system accommodates all children including children with different abilities; street or working children; children from remote or nomadic populations; children belonging to ethnic, linguistic or cultural minorities; or children from other disadvantaged or marginalized groups. With reference to disability in particular, the Scheme of Inclusive Education for Disabled of the MHRD states ‘Inclusive Education means all learners, young people with or without disabilities being able to learn together in ordinary preschool provisions, schools, and community educational settings with appropriate network of support service’. And as the IDESS stipulates, this goes beyond primary education.

Teachers play a critical role in making this a reality. The success of inclusive education derives from multiple factors. But no matter how well articulated an educational policy, however excellent the educational infrastructure or how well resourced a program might be, effective inclusion does not take place until regular classroom teachers deliver relevant and meaningful instruction to students with disabilities (Mastropieri and Scruggs 2010). Beyond that, teachers serve many roles in the classroom. They set the tone of their classrooms, build a warm environment, mentor and nurture students, become role models, listen and look for signs of trouble and diffuse and resolve challenges. Teachers can do this when they are excited about the work they do and excited about seeing all children learn. If teaching is merely a 'chore' for a teacher, inclusion will remain a distant dream. It is critical that the teacher is invested in inclusion.

As already stated society stigmatizes disability. When it is a mental disability like autism with its somewhat unusual behaviours, the stigma is pronounced and compounded further by related myths. Myths such as that bad parenting causes autism, the result of karma, a flaw in the family, that having a child with autism is a deserved curse, etc. Teachers are the most important piece in changing these misconceptions and knitting together the school management, support staff, students and parents in deconstructing myths and creating a conducive environment for autistic learners.

Children pick up cues from adults, and teachers are one of the most important adults in students' lives. Their influence can be far greater than parents. Teachers often have to contend with parents of other children who have discriminatory beliefs and do not want the student with autism in the class. The teacher who is strongly invested in inclusion and therefore able to stand up to such parents and convince them of the right of the student with autism to be in the classroom will set an example of attitude to differences and generate support of other students. Teachers' immense power over students has been illustrated by campaigns like 'No crackers for Diwali' that was promoted through teachers in schools. Many parents reported being prevented by their children from buying crackers. Examples that teachers set have lifelong implications.

Because children with autism 'look' so typical and because their special needs often manifest as unusual and socially inapt behaviours that can sometimes appear 'rude' or 'aggressive' or 'defiant', it is easy for teachers to allow their prejudices to colour their dealings with the student. An effective teacher has to be aware of and avoid this pitfall and know not to take the student's behaviours personally. For this it is also important for the teacher to understand autism. When the teacher does not understand autism and hence does not understand why a child behaves in a particular manner and does not understand the best way to help the child learn, they cannot be an effective teacher. It is in this context that the much-debated concept 'do not label' has to be understood. 'Do not label' means to not make assumptions of the child's ability based on their condition. To not postulate, 'This child is blind; he cannot learn science'. 'This child is deaf, he can never speak'. 'Or this child has autism, he will be aggressive'. It is important for the teacher to know the diagnostic 'label'. When the student is blind or on a wheelchair or cannot hear, the class knows

the diagnosis whether it is conveyed to the teacher or not. But when the child has autism, without the diagnosis the teacher might label the student as deviant and disruptive and make assumptions on ability. The label helps the teacher understand the child and provide supports and help the child learn accordingly. It is not the label on its own that is damaging, but the prejudices and assumptions that the teacher brings to the job (Barua 2013).

If the teacher is impatient or critical of the behaviours of the student with ASC, other students sense it and that sets an example for the rest of the class. Student behaviour is a reflection of the teacher's. The teacher's attitude to the student with autism will determine the attitude of the class. Whether the teacher is understanding and respectful of the student with ASC, or dismissive and judgmental, makes all the difference between a class that is inclusive and accepting, or rife with teasing and bullying.

Teachers have to ensure that all students get the support they need, including students with autism. Different students with disabilities require different assistive devices. Some require prostheses; others require aids such as ramps, braille, wheelchairs and special lenses; as mentioned earlier, people with autism require visual supports, visual communication systems or other forms of assistive and augmentative modes of communication, structure and routine.

In the everyday classroom transaction, the teacher will have to ensure that all students have the opportunity to learn by moving beyond book and chalkboard teaching and incorporate exploratory hands-on learning. Making learning experiential will not merely benefit the student with autism but students of all learning abilities. Numeracy is better learnt by collecting and counting-sorting-grouping-classifying leaves or seeds on a nature walk than merely circling cars or bunnies on a textbook. Photosynthesis is better understood by masking leaves in the garden or in potted plants in the classroom than by just reading out a passage in the book.

Many students with autism have difficulty in understanding the rules of group games or participating due to challenges in proprioception. The sensitized teacher will allow such students with autism to do other activities during sports or games time.

Studies show that students with autism are the most bullied population in schools. They are not only the most bullied, but the most censured for misbehaviour when they react to bullies! Typically, most bullying happens during unstructured times such as free time and recess (Johansson 2014). Teachers have to be aware of this and take steps to ensure bullying is kept at bay. They can provide peers with some awareness of the different abilities of their classmates, not as a lack of ability, but as differences. Pairing the students with special needs with a sensitive and helpful 'buddy' is often a great strategy. So is ensuring that the student with autism is engaged in some alternative activity during recess, such as library time or helping the teacher with small chores. Many students with autism have certain strengths and skills that could be highlighted. Knowing that their classmate with autism has a stunning store of cricket scores in his head, or that she can calculate at lightning speed, or knows every historical detail of the reign of Akbar, creates an 'awe factor'

that can prevent bullying. The teacher has to be vigilant to spot signs of bullying. If there are reports of a change in behaviour of the student with autism including what appears to be disruptive behaviour, the teacher has to consider the possibility that the student with autism is being picked on and is unable to report being bullied, despite otherwise good skills in communication. As already stated, the student with autism is not only the most bullied, but likely to be the most disciplined for misbehaviour when they react to bullies.

The teacher also has to be conscious to include the child who is being left out or is falling behind socially, cognitively or in any other way. It is easy to focus on the student who is always in the present, whose hand is often up, who asks questions and who is socially engaged. Many students with autism as well as other disabilities or social challenges will tend to not draw attention to themselves. It is the mark of the good teacher who knows to include the child who does not do these things. It is rightly said that 'the crying child gets the milk'; but the child who is quiet also gets hungry but may not have the voice or the temperament to cry.

The teacher has to create a warm inclusive environment in which inclusive communication plays a determining role. The teacher has to use mindful language. This could be a simple shift from viewing and labelling disability as a 'problem' to a 'difference'. Not seeing the child with autism as having a 'problem' with communication but rather having a 'different' understanding of communication. The teacher has to not use pejorative phrases that can be derogatory to disability such as 'Why are you being stupid?' 'Are you blind?' 'Stop acting like you are deaf', all of which are in common use. The teacher will have to be thoughtful in tone and syntax. The debate on politically correct terminology suggests the use of person-first language. However, one has to be aware that many self-advocacy movements suggest a preference for 'autistic' versus 'person with autism'. What determines whether disability identity is being undermined or not lies more in the intent rather than the words, and here the teacher will be the role model, as the person in authority with whom students spend a great deal of their lives in close interaction.

All children flourish in a warm, nourishing and positive environment. Attitude and understanding is critical. For students with autism, this is doubly important because of the invisibility, and the sometimes unusual manifestations, of the condition. While autism-specific strategies are indeed important when including children with autism, the person delivering those strategies even more so.

School management will of course ensure that teachers get the required training and resources required and that they have the opportunity to upgrade their skills through in-service training and professional development. Teachers on their part have to remind themselves that students with autism live in a world that they have difficulty in making sense of and have difficulty communicating with and that that world often has difficulty in understanding the communication of persons with autism. This along with their sensory defensiveness can make life and learning challenging even for very intelligent individuals. Teachers have to appreciate the experiences of their students with autism. They have to take time to listen to their students. The most effective role that teachers can play is that of being cross-cultural interpreters, between their students with autism and the world of the neurotypical.



## The Way Forward

Including the student with autism in the classroom is not merely about the child with autism. It is about every form of diversity. Inclusion stems from openness to and willingness to include every form of difference: of ability, religion, caste community, socioeconomic conditions, skin colour, physical appearance, gender and sexuality, amongst others. Openness leads to a desire to understand and learn about.

It is not inclusion if the environment remains inflexible, leaving all the effort to the child (Jordan 2004). Thus far, the provision of education in our schools presumed that the job of the teacher was to ‘teach’. The student was expected to learn. If the student did not learn, then it was presumed to be due to incapacity or lack of application. The student was viewed as the problem. There is now the beginning of a shift in this view with the acknowledgement that mere ‘teaching’ is not enough if the student is not learning. However, this is yet to percolate down into practice. There has to be a concerted and mindful effort to make this a systemic change in educational practice.

Autism is a condition that turns perceptions of normality, functionality, intelligence and disability on its head. It challenges a mindset that is attuned to normalization and viewing the individual as faulty and needing to be ‘fixed’ in order to hold a place in society. A school that successfully includes students with autism can include students with any form of diversity! The goal has to be to bring about a shift to ‘fixing’ the systems of education and the environment, so that they provide the most appropriate supports to enable the child to succeed, rather than try to ‘fix’ the student.

Finally, schools’ philosophy, attitude and culture of inclusion is critical for schools to successfully include all students. This must flow from the top and ‘infect’ staff right down to the outermost circle, students, parents and the community. The school philosophy has to be the driver for real change and inclusion to take place.

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# Chapter 6

## Children with Locomotor Impairment: Enabling Environment for Inclusion, Education and Participation



Sailaja Chennat

**Abstract** Locomotor impairment affects mobility of a part of body or the whole body and is too obvious in most cases. Hence, this impairment negatively affects body image and self-confidence of such persons. Due to restricted mobility and resultant lack of opportunities for free play and exploration of environment, these children are deprived of commonplace experience and knowledge. Assistive technology is of great help to persons with locomotor impairment in overcoming the challenges faced by them. Children with locomotor impairment require psychosocial inclusion much more than academic inclusion that helps build a positive self-image and self-worth and encourage participation in both academic and co-scholastic activities.

**Keywords** Mobility · Body image · Self-worth · Prosthetic devices · Orthotic devices · Psychosocial inclusion

### Overview

A person with disability is perceived as different or at extreme level, inferior, to able-bodied peers. Such negative perception and stigma infect almost every aspect of our cultural values from the highly rated traits we associate with masculinity and femininity to beliefs about what is beautiful. The specific challenges people with disabilities face with regard to self-esteem and body image are agreed upon across the globe and are supported with adequate research evidence. At the broadest level, studies have found that impairment related to limbs and body, affecting mobility in particular, has a negative influence on a person's psychological experience, attitudes and feelings about his/her own body. Therefore, it is easily understood how locomotor impairment basically scars the minds of children. Of course this preamble is not

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meant to present a tragedy image of persons with such impairment. We have many talented persons to be proud of. Some of them are the legendary dancer Ms. Sudha Chandran with a Jaipur foot; Ms. Malathy K. Holla, International para-athlete from Bangalore, the proud recipient of the Arjuna Award and Padma Shri, who is paralysed completely from age 1; Ms. Arunima Sinha, the first woman amputee to climb Mount Everest with prosthetic leg; and many others with locomotor impairment who have proved that success in life is within their reach and capabilities despite having an impairment (Pareek 2014).

Children struggle with their sense of identity during their early years, especially in their adolescence, and tend to feel awkward about their bodies and worry about being normal. Many of the critical aspects such as body image, self-confidence and identity development are linked to each other. Body image is the perception of one's body: how it looks, feels and moves. It is shaped by perception, emotions, physical sensations and changes in relation to mood, physical experience and environment. Growing children experience highly dynamic perceptions of the body image which is influenced strongly by self-esteem and self-evaluation, more so than by external evaluation by others. It can, however, be powerfully influenced and affected by cultural messages and societal standards of appearance and attractiveness.

It is in the above context that the case of children with locomotor impairment (LI) becomes significant. Children with LI may have different types and degrees of difficulty in physical movement of either a part of the body or whole body. These could be due to anomalies from birth or ones that developed later in life as a result of accidents or diseases, etc. Most types of locomotor impairment affect the external appearance of a person especially because most of them are dependent on some sort of assistive device for their mobility or body movements. Needless to say, unlike other impairments, for example, those related to hearing, information processing, etc., this impairment cannot be hidden from view and is too obvious. Being an obvious and hard impairment, this disability severely impacts a person's body image.

This chapter attempts to present the characteristics of children with locomotor impairment, to enable readers to develop a deep understanding about the nature and needs of these children that practically are linked to their psychosocial and educational concerns. Issues of accessibility and socialization emerging from their characteristics, the implications of these aspects for classroom transactions and the consequent role of teachers to support and help these children, academically and psychosocially, have been covered in the chapter.

## **Indian Context**

Case narrations presented in the following section give a glimpse of the status of persons with LI in the Indian context. Both the cases narrated are of people who have been associated with this author and their names have been changed for maintaining anonymity.

## Case Narrations

### *Shailesh*

Shailesh, one of the boys in her class, did not specifically catch the attention of Ms. Sheela, the English teacher of Std. X, who had newly joined the school except that he used his left hand for writing and was seen uncomfortable while writing due to space issues which made him a bit slower than the others in competing written work. In her initial few interactions with Shailesh, Shailesh seemed a bit sober and low at self-confidence, although he was involved in the class processes and was seen attempting to answer questions when motivated by Sheela.

It was much later, after many personal interactions with Shailesh, that Sheela came close to his realities: he didn't have right fingers or palm. The sight of his right forearm was distinctly different which, perhaps, made him hide his hand all the time from view of others. The immediate thought that came to the teacher's mind was, 'Oh, this is a very minor impairment, after all he is able to write almost as quickly and legibly as anyone else. Compared to those with visual impairment and hearing impairment, this impairment is much less disabling'. This conception was proved to be totally unsubstantiated when she came to know his predicament later in close personal interactions. His childhood and early schooling were very difficult, tarnished by ridiculing comments and remarks from family members, friends, etc. which demoralized him and drained him off his self-confidence to face people.

As a child, he was scorned and mocked at for his impairment which made him mentally and physically weak and diffident in studies. The epithets were many, with their meanings ranging from one armed, armless, looking like filmy villain, frightening, gory, etc. The incising taunts left deep scars in the small child's mind that were to stay for lifetime. He shirked from going to school and was forced to continue due to pressure from his father who was a very positive and caring parent. But after his fourth standard, he refused to attend school and was homebound for a year. It was his father who counselled him continuously and made him come to terms with his physical impairment and to be strong to face the world come what may. As a result, he resumed his classes in sixth standard. He was slowly picking up himself from the lowest level of self-confidence and body image to a manageably okay level of academic and social well-being.

It was a learning for Ms. Sheela as to how societal attitudes and outlook can harm a child eternally and drain him off his/her self-confidence and feeling of self-worth.

### *Ms. Kamla*

Ms. Kamla is 26 years old and has an M.Phil degree. She uses crutches to walk.

She was affected with polio when she was a child and this put an end to her independent walking. Being a little child, the plight of not being able to walk and play

around had a severe emotional impact on her and made her very quiet, inactive and gloomy. She was feeling isolated from her peer group and gradually started loving solitude. She hardly talked to anyone, smile was stolen from her and she remained aloof and cut off family members.

Her gloominess and noncommunicative nature were misunderstood as symptoms of intellectual impairment, and she was admitted in a special school for children with intellectual impairment. In the fourth year, in class IV, teachers recognized her intelligence, especially in mathematics, and advised the parents to get her admitted in a regular school. From then on, academically she didn't look back, although her social skills remained poor for long owing to the attitude of peers and community at large. From school to her M.Phil degree today, she has had a steady academic growth with a spectrum of challenges to face vis-à-vis 'societal attitudes' and 'insensibilities'.

## Data on Persons with LI

As per the Census 2011, in India, 20% of the disabled persons are having disability in movement (Disabled Persons in India 2016).

As per the Rehabilitation Council of India Act, 1992, locomotor disability means a person's inability to execute distinctive activities associated with moving, both himself/herself and objects, from place to place, and such inability resulting from affliction of either bones, joints, muscles or nerves (RCI 2000) (Table 6.1).

The above study clearly revealed that locomotor disability is the most prevalent type of disability affecting the population of all ages in India.

The results from the study also indicated that polio, injury other than burns, other illnesses, stroke, arthritis and cerebral palsy are the main causes of locomotor disability and that injury other than burns is a vital cause of having disability in India. Home accidents, transport accidents, agricultural field accidents and other work site accidents are the main reasons behind causing injury which lead to disability afterwards.

Disabled Persons in India Report (2016) has also revealed the following:

- Among the disabled in the age group 20–39 years, 22% are having disability in movement and 18% has disability in hearing and 6% has multiple disabilities.
- Among the disabled in the age group 40–59 years, 23% are having disability in movement and 19% has disability in seeing and 5% has multiple disabilities.
- Among the elderly disabled persons, the disabilities in movement (25%), in seeing (25%) and hearing (12%) are prominent and 12% has multiple disabilities.

**Table 6.1** Percentage distribution of causes of locomotor disability by age, India, 2002

Causes of locomotor disability**	Age			Total
	<15	15–59	60+	
Cerebral palsy	1.5	2.2	3.8	2.5
Polio	62.4	31.9	3.4	28.9
Leprosy cured	–	0.9	1.1	0.8
Leprosy not cured	–	1.2	1.7	1.2
Heart stroke	1.3	5.6	15.3	7.5
Arthritis	–	2.3	6.5	3.1
Cardio-respiratory disease	–	0.3	0.7	0.4
Cancer	–	0.3	0.3	0.3
Tuberculosis	–	0.4	–	0.3
Other illness	11.0	12.4	12.6	12.3
Burns	2.7	2.4	0.7	2.0
Injury other than burns	9.8	27.9	29.9	25.7
Medical/surgical intervention	2.4	2.5	1.4	2.2
Old age	–	0.2	12.2	3.3
Not known	4.3	4.7	4.7	4.6
Other reasons	3.2	4.8	5.5	4.7
<b>N</b>	<b>100 (4410)</b>	<b>100 (17,865)</b>	<b>100 (7847)</b>	<b>100 (30,122)</b>

Note: ( ) Indicates number of cases; – Indicates number of cases <20; Chi-square test (\*\*5% level of significance)

Source Patel (2008)

## Locomotor Impairment in RPWD Act, 2016

The Schedule in the Rights of Persons with Disability Act (2016) defines locomotor disability as ‘a person’s inability to execute distinctive activities associated with movement of self and objects, resulting from affliction of musculoskeletal or nervous system or both’. What is implied is that impairment of mobility can be related to either muscles and bones (orthopaedic) or muscles and nerves (neuromuscular) or both orthopaedic and neuromuscular. Some common conditions giving rise to locomotor disability could be poliomyelitis; cerebral palsy; amputation; injuries of the spine, head and soft tissues; fractures; and muscular dystrophies.

It includes the following: (a) leprosy-cured person, a person who has been cured of leprosy; (b) persons with cerebral palsy which is a nonprogressive neurological condition affecting body movements and muscle coordination, caused by damage to one or more specific areas of the brain, usually occurring before, during or shortly after birth; (c) persons with dwarfism, a medical or genetic condition resulting in an adult height of 4 feet 10 inches (147 centimetres) or less; (d) persons with muscular dystrophy, which is a group of hereditary genetic muscle disease that weakens the muscles that move the human body; and (e) acid attack victims, those disfigured due to violent assaults by throwing of acid or similar corrosive substance.

Persons with LI may need medical care at some point or the other and in certain cases specialized ones which may also be for lifetime. But, the social realities including the social stigma associated with body and appearance are the severe challenges that people with locomotor impairment are faced with. What is required is an amicable environment with an integrated approach to make the person feel psychosocially included in the society. Integrated approach is possible only with the coordinated efforts of many professionals like doctors, social scientists, engineers, psychologists and others.

## Conceptual Foundation of Locomotor Impairment

Locomotor impairment (LI) denotes impairment in mobility; it can be movement of any part of the body or mobility of the person from a point to another due to either one or two or all of the three – nerve, muscle and bone – related issues. The term LI includes impairments caused by congenital anomaly (e.g. clubfoot, absence of some body part, etc.), impairments caused by disease (e.g. poliomyelitis, bone tuberculosis, etc.) and impairments from other causes (e.g. cerebral palsy, amputations and fractures or burns that cause contractures). These can be divided into three main areas: neuromotor impairments, degenerative diseases and musculoskeletal disorders. The characteristics of an individual who has LI will depend on the specific disease and its severity, as well as additional individual factors:

1. A neuromotor impairment is an abnormality of, or damage to, the brain, spinal cord or nervous system that sends impulses to the muscles of the body. These impairments are acquired at or before birth and often result in complex motor problems that can affect several body systems. These motor problems can include limited limb movement, loss of urinary control and loss of proper alignment of the spine. The two most common types of neuromotor impairments are cerebral palsy – nonprogressive disorders of voluntary movement or posture that are caused by malfunction of or damage to the developing brain – and spina bifida, a developmental defect of the spinal column which may or may not affect intellectual functioning.
2. Degenerative diseases are composed of various diseases that affect motor development. The most common degenerative disease found in the school population is muscular dystrophy which is a group of inherited diseases characterized by progressive muscle weakness from degeneration of muscle fibres.
3. Musculoskeletal disorders are composed of various conditions that can result in various levels of physical limitations. Two examples of musculoskeletal disorders include juvenile rheumatoid arthritis and limb deficiency (Project IDEAL In Action 2013).

## **Impact of Locomotor Impairment**

When we see children or adults using crutches or wheelchair, their appearance as a disabled is very obvious to us. Do we think of their capabilities in academics and cocurricular activities? What do they feel about body image? What is the level of their self-confidence? Most of the children with locomotor impairment do not have any cognitive inabilities; in other words, the range of cognitive abilities is as spread out in this group of children as in any other group. What hits them emotionally is the way they look, the image of their body while being supported on crutches or while moving in a wheelchair or while moving with the support of a walker, the feeling of dependence while being carried by someone, etc.

LI affects a child's educational performance, social life and identity development in varying degrees. Our concern in this chapter is about inclusion in the school system of children with LI, keeping at the centre all these impacts of LI.

## **Sociological Perspective on Persons with LI**

A person with LI may be perceived differently from the perspective situated within medical model of disability and from that within the social model. Some examples of social perspective are as follows: A wheelchair user wants to get into a building with a step at the entrance. Under a social model solution, a ramp would be built at the entrance so that the wheelchair user can freely enter the building. Using the medical model, there are very few solutions to help wheelchair users to negotiate stairs which excludes them from many essential and leisure activities; additionally, the wheelchair may be pointed at as the barrier for the person's entry into the building. A wheelchair user wants to study in her neighbourhood school within 3 km of her home, but is unable to do so because the school doesn't have a wheelchair-friendly toilet. From a social perspective, the school would adapt to the child building a toilet especially suited to her requirement, whereas from a medical perspective, she would be asked to seek admission elsewhere. A child using crutches finds it difficult to negotiate stairs. From a social perspective, the school would have her classes on the ground floor when she passes to the higher standard each year so as to give the possible comfort to her.

The historical or conventional conceptions of what is a perfect body impact the sociological perspective on persons with locomotor impairment to a considerably large extent. Needless to say, these conceptions are socioculturally situated. So the yardstick of ableism and normalcy decide the way persons with LI are perceived and assessed by the majority of non-disabled people of the society at large. According to some of the advocates of social model of disability, all identification and assessment of impairments are ultimately subjective, as traditionally carried



over beliefs about the 'normal' body form the base for all scientific practices. To be more specific, what is historically and culturally understood as impaired or abnormal is inevitably built on what is perceived as normal and then explicated neurologically and biologically. Autism is considered to be a soft disability, because a child is identified to have autism on criteria of acceptable social behaviour which is culture and context bound.

## **Understanding the Nature of Children with Locomotor Impairment (CwLI)**

Social integration, positive self-concept and behavioural adjustment are important dimensions of a child's development. For CwLI the behavioural, emotional and psychosocial aspects of personality may get affected due to considerable limitation of movements and consequently access to basic needs. These aspects of development are discussed below.

### **Intellectual Ability**

Children with LI generally do not need any modification in curriculum as they do not have any difficulties related to learning, like perceptual or sensory problems or related to information processing. Any group of children with LI has the same variations in intelligence as any group of children. Most students with LI with assistive devices and restricted mobility will require some infrastructural modifications and accommodations in the classroom, be it regular transactional space, a lab or toilets. In order to enable their independent functioning, many of them will require assistive technology as well. Much more than all these, what they need in abundance are acceptance and regard: in other words, affable and conducive environment. They can be enabled to contribute more to the classroom processes than what a teacher could do for them if they are allowed to bloom in such a classroom climate.

### **Restricted Mobility**

Students with LI have varying difficulty in motor movements corresponding to the part or parts of body which are affected. When motor problems affect fingers, palms and/or hands, they may have difficulty in manipulating standard classroom equipment such as writing tools, keyboard, books, geometry equipment, microscope and dissection equipment or have difficulty in managing daily tasks such as having lunch, using toilet, taking off shoes and socks, tying shoelace, moving from one class or venue to another, etc. Even with the help of assistive devices, they may take

longer time in accomplishing these tasks. For example, a student using an alternate input device for computer may be able to type only three words in a minute. Such issues will make it difficult for these children to keep pace with the ongoing school-work along with writing and revising lessons, and this paced back experience can have negative psychological impacts.

## Lack of Free Play in Childhood

Many children with LI are likely not to have had much free play, alone and/or with friends; this deprivation in childhood impacts them in the adolescent phase and adulthood too. Play is considered to be the primary activity of a child, a prerequisite to competence in many roles, including vocational, later in life. During play, a child explores the environment purely randomly. Play has an exploratory component that is engaged in for its own sake and a competency component that results from an inner drive to master the environment (Reilly 1974). Environment generally amuses and gives internal motivation to a child; children in general are enthused to master it which gives rise to a skill component. When one sees work and play on a developmental continuum, play is seen in a continuum to serve an adaptive function in adulthood.

Child's free play has high significance for future life. It is through free play that children explore their own environment and their capacities; they get to experiment with objects, thus getting opportunities to make decisions, to understand cause-and-effect relationships, to learn, to develop perseverance and to understand consequences of decisions and actions. In fact, free play also paves way to development of creativity; when free play is in groups of children, it aides in social skill development too. According to Cotton (1984), in addition to developing competence through play, the child also learns to cope with anxiety, frustration and failure.

As found by Mogford (1977) and Clarke, Riach and Cheyne (1977/1982), children with locomotor impairment, when deprived of opportunity for free play, are likely to lead to end up with certain types of secondary disabilities such as increased dependence on others, low levels of motivation, inability to be forceful in expressing themselves in any groups, lowered self-esteem, etc.

'These secondary disabilities have an impact, not only on the child's play and development, but also on later functioning in school, community and society, and the workplace' (Missiuna and Pollock 1991, p. 883).

'Vygotsky, in his times had theorised about secondary disabilities rooted in the environment. According to Vygotsky's (1993) key insight was that a primary disability—the condition that is diagnosed, of people, such as blindness (to him) or mental health difference (to me) becomes problematic only when secondary disability is imposed by other people. This secondary disability emerges from the negative social consequences of the primary disability, that is, the stigmas that people associate with difference in turn apply such that the person of difference feels rejected and of lesser value. Vygotsky's solution was not to fix the child, but to

change the context of the child's development so that the point of difference did not produce secondary disabilities and the accompanying feelings of inadequacy that follow from social judgment such as pity or scorn' (Smagorinsky 2014, p. 19).

## **Lack of Common Experiences from Random Explorations**

Students with LI may lack knowledge of common places due to the difficulty in randomly moving around and exploring items or activities that interest them. This dearth of experience may be evident in the lack of comprehension of material in areas of study which are based on such experiences. For example, some students who may have difficulty in squatting on the ground may have never seen an ant; some of them may not have had an opportunity to be close to the ground and explore the diverse animal world there. Due to this dearth of experience, comprehension of related readings in content areas would be affected.

Lack of common experiences may not only impact the comprehension of learning materials negatively, but it may also result in lower achievement and IQ scores when questions are based on experiences that they have been deprived of. 'For example, one item on a standardized IQ test asks how to remove a ring stuck on a finger and a student who has no palm selected the picture showing pliers instead of the one showing soap and water. In another test, the student was asked to select a picture illustrating one way we all talk to each other; a student with cerebral palsy picked a calculator instead of a telephone because it looked like the augmentative communication device she had been using' (Heller and Jones 2003, p. 9).

## **Difficulties Related to Communication**

Locomotor impairment can be related to either muscles and bones (orthopaedic) or muscles and nerves (neuromuscular) or both of these. Communication-related issues are seen with some of the types of locomotor impairments. Children with CP (cerebral palsy), for example, often have communication difficulties. In others, speech delays, articulation disorders, fluency disorders and voice disorders are common; some may also have difficulty producing sounds due to poor muscle control. Many youngsters with CP have dysarthria, a motor speech disorder. Such students with speech impairment can be affected academically by being unable to articulate their questions and ideas, ask for clarification of the teacher's lecture or fully participate in the learning process. This can affect their participation in academic and social activities and many times make them isolated even when surrounded by people.

## **Fatigue and Endurance**

The variations of locomotor impairment make up such a wide spectrum that it is intensely challenging to understand the experience of different children. The individual factors, occurring as a part of LI, may be anything between very slow movement of a part of body, to whole body, and difficulty in speech; all these affect education performance in varied manner. Many of them experience fatigue and endurance problems due to the effort it takes to move. Also fatigue and endurance may occur as a side effect of medications taken for some issues like seizures. These problems can minimize attention to school tasks and can interfere with learning (Heller and Jones 2003, p. 8).

### ***Impacts of LI***

The following are some of the probable impacts of LI although not all may have these impacts, personality attributes or peculiarities.

### ***Adjustment***

Some persons with LI may have personality maladjustment. In the face of continued demands that exceed their available resources, there may be increasingly disorganized and disintegrative behaviour. Responses to the physical, social and cultural environment may become more exaggerative. Very common responses made are depression, anxiety, escapism, identification, rationalization and sublimation. The more complex reactions are as follows.

### ***Projection***

Insecurity felt by persons with LI may compel some of them to resort to projection, i.e. transferring the blame of disability to others and attributing unacceptable impulses, thoughts and desires of self to others. They tend to believe that their disability is the result of others' actions.

## ***Psycho-neurotic Reactions***

Conversion is a neurotic defence mechanism in which person with LI may show symptoms of some physical illness without any underlying organic pathology. The person avoids the problem related to his/her disability by falling sick. A hysterical response is manifested in panic reactions involving emotional outbursts and some motor activities. A phobic reaction is a persistent fear of some object or situation which presents no actual danger to the patient or in which the danger is magnified out of all proportions to its actual seriousness.

In hypochondriasis situation, a person having lost a limb in an air crash may refuse to travel by air. Perfectionism is the response where a person, for example, an amputee, may refuse to leave the institution where he/she is undergoing treatment on the plea that he/she is not yet cured and may refuse to accept substitutes like an artificial limb.

Due to limitations in their activities, they may develop morbid anxiety about their health with numerous and varying symptoms that cannot be attributed to any organic disease, reason being disablement attracts their attention constantly.

## ***Impact on Learning***

The specific impact on learning of an individual is contingent upon the environmental adaptations, the cause of impairment, the part of the body impacted, its level of severity and individual factors. Bearing of LI on learning is generally seen as a secondary impact, not direct. For example, if the class of the child using crutches is on first floor, even a bright child may be demotivated in attending the class regularly. Or a wheelchair user who is interested in outdoor games and activities, if deprived of these opportunities because of the fact that he/she is a wheelchair user, may gradually lose interest in attending school. Two individuals with identical diagnoses may be quite different in terms of their capabilities. Many CwLI have no cognitive, learning, perceptual, language or sensory difficulties. However, individuals with neuromotor impairments have a higher incidence of additional impairments, especially when the brain is involved. For most students with LI, learning is contingent on the accommodations made in the classroom and school for their access to academic transactions and resource materials.

## ***Impact on Body Image***

Body image and confidence are closely related in the case of any person. If you're content with and can accept your body, then you will beam with confidence, leading others around you to do the same. Importance of confidence is applicable to anyone,

with or without disabilities. But the dilemma that many disabled people eternally bear calls for serious attention. It is a natural human instinct to love oneself, but when one's body image fails to meet the attributes of at least a 'likable body' if not 'lovable', then the emotional well-being of such a person is at stake, though this is a very subjective aspect. When one gets trapped in such a dilemma of dislike and love, the internal conflict thus developed kills one's self-confidence. This can lead to isolation even when one is surrounded by many people.

The link between body image and disability has been proved through number of research studies. 'More and more research has confirmed the unique challenges people with disabilities face with regards to self-esteem and body image. At the broadest level, studies have found that physical disability in particular has a negative influence on people's psychological experience, attitudes and feelings about their own bodies' (Gerber 2016, p. 1).

Independence, dominance, strength, athletic appearance with a six-pack body, etc. are just some 20 of the attributes and body images associated with masculinity in our society. For young adults and men with physical disabilities, especially where the impairment is obvious and it makes them dependent on devices such as wheelchairs, crutches, canes and artificial limbs for mobility, it may get difficult to live up to such masculine ideals. This often may damage the self-esteem of disabled men, leading them to question their masculinity, their desirability and their very place in society. The same applies to disabled young girls and women. The idea of feminineness and beauty associated with body image may affect severely girls and women with locomotor impairment, dependent on assistive devices for mobility.

'The point of departure for the disabled identity is an impaired body (or mind). Revulsion is programmed into the non-disabled social order against impaired bodies. Abnormality defect, deficit and deficiency are the epithets used to describe such bodies, since they appear to depart from both a 'natural' normal sexed body and a socially mediated and acceptable body' (Addlakha 2013, p. 220).

Following are quotes of persons with LI which are evidences of their life experiences:

I never realised that I was different to others until it reached an advanced stage. And it wasn't the actual curve that made me dislike myself, but instead the brace I had to wear. That's when I felt most different and isolated, which made me hate wearing the brace. (Narration of a person with cerebral palsy. Brace is a supportive aid worn by a person with cerebral palsy)

After I had a spinal fusion operation I thought things would change, but the operation was not a success and my back got worse. And this happened just as I started at a mainstream secondary school after being a student in a special needs school. To a certain extent, people living with disability at the special needs school were better. But they too can be as judgmental and cruel as anyone else, so having a disability does not provide immunity from such nasty characteristics. (Narration of a person who uses wheelchair and gets carried by someone as and when required)

Throughout my time at school I struggled, but I did not allow anyone to notice it or pick up on it. I knew that to survive such environment you must never show your weakness or vulnerability. I often heard other students laugh or mock me, saying in a derogatory tone to each other: "Is that your friend or your baby?" They always spoke in a low volume, but I always sensed it, even without hearing them. I pretended not to notice because I knew I

could not confront them. (Narration of a child with cerebral palsy who looked very small, using a wheelchair)

I did not dislike these students, in fact, I laughed in secret at their jokes. I could not blame them entirely as we live in such a 'perfect body' obsessed culture. Everywhere I turned, the idea that your body has to conform to a set standard deemed as the norm. It was everywhere: in all the media and among people.

All I ever saw on TV were able bodied people that were regarded as 'normal'. They were loved and desired. But I don't once recall seeing a single disabled person that received similar attention and desire.

I had no remedy or a plan to deal with these daily taunts so, as the days passed, I developed a dislike for mirrors. I escaped looking in them and soon discovered that what I couldn't 'see', couldn't weaken me. I ignored the bullies and strived to be stronger than their superficial attitude. I studied hard, excelled at most subjects and my confidence grew slowly. (Aljadir 2015)

### ***Impact on Self-Perception and Social Skills***

Students with LI realize as early as preschool that they are different from others, and many know the name of their conditions with at least one of its effects by age 3 or 4 years (Dunn et al. 1988). The perception of self by a child with LI, like any other child and maybe to a higher degree, impacts their performance in school. Students' reactions to their disability may result in feelings of isolation or unhappiness (Rydstrom et al. 1999). Restricted free play and opportunities to explore the environment may negatively impact their social competence and social support which are two of the major coping strategies to handle problematic situations.

But there is enough research support to prove that many of these children with LI can bloom and come up in life if they are given matching opportunities and facilities to optimally utilize their strengths. There are renowned orators, singers, visual artists, dancers and swimmers and many others with LI who have won over disabilities and realized their dreams. The collaborative team of teachers, parents and professionals should be with these children with LI and identify the talents untapped in them and kindle them with love and motivation, thus facilitating their blooming as a successful person (the impacts of locomotor impairment presented above are adapted from Disabled Persons in India: A Statistical Profile (2016)).

Some case narrations are presented below:

(Reported in 2017) Javed Shaikh has cerebral palsy with little control over his lower limbs. He also had mild hearing impairment. He first stepped into a classroom at age 14, after a special educator from a state run school found Javed and counselled his family.

For the first 14 years of his life, Javed Shaikh's world was confined to the four walls of his house. He spent his days either in bed or watching TV. He could not speak and insisted on eating only Kurkure, a packaged snack.

Today, after therapy and 4 years in a regular school, Javed is a new person. He doesn't like missing school, happily on his notebooks, and has friends. He can eat and dress on his own, can operate his mobile phone, can lip-read, and can

even say a few words. He points at his school bag and prods his mother if they are getting late. “I had never imagined that Javed would one day go to school,” says his Mother.

At a camp organised for children with special needs at a School, an orthopaedic specialist examined Javed and recommended a hearing aid and leg braces. A few days later, a special educator visited Javed’s home again and convinced his grandmother to send him to the “school readiness” classes held at the same school premises.

That was the first time Javed stepped inside a classroom. This was a class to prepare children with special needs for school. It was here with the special educator that Javed learned to first sit erect, to eat food other than Kurkure, and to use the toilet by himself. He was given a hearing aid, sets of school uniform and a school bag, and was formally admitted in a School.

‘He has improved so much over the years, whenever you call him, he has a smile on his face’, says his teacher. ‘We don’t expect these children to excel academically as much as we want them to enjoy the school experience and come to school daily’, says the special educator who helped him start his school life. (Adapted from Yadavar 2017)

Mr. Abeer (pseudo name), a friend of mine, is a professional working hard to earn and fend for his family with two young adult children. It took long for me to understand why his gait had a limp and his walking was so laboured. He had one prosthetic Jaipur leg, attached at knee level. I was full of appreciation for him that he had waded through successfully and accomplished so far. Later, on getting closer to him, I realized that his life journey was quite bumpy and stormy. Having lived till early adolescent phase with no impairment and suddenly to see life turn upside down due to an accident in which one of his legs had to be amputated was immensely painful and challenging for him. This was followed with those months of medical care at hospitals with subsequent trials for prosthetic leg with many companies. During this time he was fighting with his body image, drained self-confidence and new identity of a disabled boy, which was extremely challenging. Finally he settled with Jaipur leg. The first few months of getting used to the prosthetic foot were very painful. Having got used to walking with it, he slowly started feeling more self-confident and mobile. But the pain doesn’t leave him. Endurance of pain has become a constant in his daily experience. But the spirit of achievement that he has become independent and mobile compensates for all the pain he endures.

Much more than the physical pain, he says, is the agony he suffered from the ridicule and the exclusion he suffered as an adolescent at school. After the long gap of medical care and rehabilitation, when he rejoined his school, he did not get a very warm welcome. He had paced down in all his movements and he realized that most of his friends no more waited for him for any activity. All of a sudden he felt alone which according to him was worse than all the pain he had gone through and was going through.

His class teacher was the catalyst for a major turning point in his life. She helped him draw out his talent at singing which helped him to rebuild his self-confidence



and earn new friends. With this new found arena of accomplishment, he was motivated to do better in academics, and he slowly regained all his lost vigour and self-esteem. Since then he has not looked back (from the experiences of the author).

## **Challenges Faced by CwLI**

Considering the diversity in conditions that result from locomotor impairment category, challenges will differ from individual to next; correspondingly, the ways and means of addressing their needs should be decided by each student's unique needs. The nature of LI and its impact on children presented in the above section will logically flow into the challenges arising from these impacts. The following section presents the challenges that children with LI may face in different degrees.

### ***In Accessible Modes of Transportation***

As per the government policy, most of our state-run schools and colleges and departments have ramps and wheelchair-friendly toilets which are for sure basic needs of children using wheelchair. But this facility is of use only when our students using wheelchair reach the institutions. But sadly our public transport system is not congenial for wheelchair users. Some of the modern buses have ramps for wheelchairs to be pushed in, which account for less than 2% of the overall number of buses that ply on our roads. Thus, students who use wheelchair find it difficult to reach schools.

### ***Inaccessible School Building***

Most of school buildings have two or more floors, but have no lifts. Students using wheelchair may enter the ground floor, if there are ramps, but are deprived access to the upper floors. Many times, classes get accommodated on the ground floor for helping children with LI. But, all venues of learning, like science and computer labs, library, etc., cannot be accommodated on the ground floor, and this can lead to deprivation and dejection among children with LI.

### ***Steering Around Classroom***

It is a fact that most of our classrooms are cluttered with more number of students than what is manageable, stacked in them. Such a situation results in grave distress for children on wheelchair. It is understandable that they require more space to

navigate through the classroom space. Also, any altered seating arrangement to facilitate group activity poses additional challenge for these children.

### ***Difficulty in Manoeuvring Through School Spaces***

Most of our schools have paucity of space which causes corridors and hallways in our schools congested and jammed which makes it difficult for students to manoeuvre through using wheelchair, crutches, walkers, canes, etc., especially those using wheelchair.

### ***Sports and Cultural Activities***

Children with LI are mostly seen to be left behind in their classes during sports, literary and cultural activities that their friends enjoy participating in. Generally, the sense of isolation and exclusion they go through is not properly conceived by either peer group or teachers. In fact, sensitive teachers with conviction in inclusion can think of alternative games and other activities for children with LI.

### ***Communicating Effectively***

Some of the CwLI with neurologic issues may have difficulty in communication effectively. Dysarthria is a motor speech disorder caused by a neurological injury or disease, and it can affect one or more of the speech subsystems – respiration, phonation, resonance, prosody or articulation. If the damage is in the nervous system, the severity of the signs and symptoms of childhood dysarthria is severe. As a child grows and begins to talk, dysarthria may become more noticeable as child's speech becomes slurred with an abnormal speaking pattern. Their speech can range from talking too fast or talking extremely slow.

### ***Low Self-Image***

There is enough literature that proves the link between body image and disability (see second para under Impact on Body Image on page 12). CwLI, using wheelchair, crutches, cane or walker may have a low self-image due to their appearance that is too obviously different from others, their dependence on a support (often, although not in all cases) and the experience of lagging behind in a group due to their laboured movement. Of course there may be exceptions to these impacts of

LI. In fact most of such impacts get evened out with love and care of parents and facilitative school ethos with empathetic and cooperative teachers and peer group.

### ***Exclusion from Social Activities***

CwLI are more likely to have difficulty in participating in activities because of their limited mobility. Due to slow and limited movement, they experience greater constraint in participation than their non-disabled peers with this restriction much more in the case of children with cerebral palsy. 'Children with orthopaedic impairments struggle to participate in many of the socially accepted activities that bond children together, such as contact sports or musical and art programs, as these activities are not conducive to their specific disability' (Lindsay and McPherson 2011). Additionally, children with orthopaedic impairments are often dependent on family members for self-care and transportation, which may limit the child's ability to participate in extracurricular activities (Kang et al. 2011).

Faced with restrictive experiences related to physical aspects in their lives, many also face emotional issues, especially if they feel excluded from their peers. Many quality of life (QOL) surveys have shown that children, especially adolescents with orthopaedic impairments, who are more involved with activities have more quality friendships and are more satisfied with their lives overall (Biastro et al. 2015). Due to lack of mobility, children with orthopaedic impairments suffer from the frustration of not being socially accepted by their peers. Social exclusion can cause many ill effects such as poor academic performance, disruptive behaviour and the inability to show social competence (Lindsay and McPherson (2011). In addition to being socially excluded, children with locomotor impairments, especially adolescents, run the risk of being bullied, which may lead to anxiety, depression and a general reluctance to attend school.

Children with orthopaedic impairment who participate in social activities with their peers report being as happy as their peers. The more often a child participate in a social activity, the higher the reported level of happiness (Biastro et al. 2015).

## **Role of Teachers**

### ***Teaching Strategies***

As with most students with disabilities, the classroom accommodations for students with LI will vary depending on the individual needs of the student. Since many students with LI have no cognitive impairments, the student's inclusion in the general class is much more possible than that of children with most other disabilities.

In order to help the student to access general curriculum, the student may require the following accommodations.

### ***Classroom Accommodations***

General: Do not assume that students with LI cannot participate in an activity. Always consult with the student regarding limitations. Do not assume that assistance is required. It is important that assistance is given only if the student asks for it. Make necessary spatial modifications to ensure that the student can participate in group activities. This may include adapting equipment or pairing the student with another student, etc. as the case may be. Make sure that the child can make use of emergency exits and routes and provide assistance as necessary.

Children with LI may need special seating arrangements to help them with posture and mobility, as navigating the classroom or moving around school hallways may be difficult. Schools may also need to arrange the schedules of these students in a way that saves them from having to move from one class to another. Providing lifts in case of multi-floored buildings is a must. Some of them may need instruction focused on development of gross and fine motor skills.

In the case of children using wheelchair, the following points have to be taken care of.

Make sure that children with LI have their classes on the ground floor room. Check for accessibility in and out of the classroom. Arrange for classroom furniture such as wheelchair-height work stations, aisle widths, etc., as per the student's needs. Treat wheelchairs with respect; it is often considered to be part of the person's body space; do not hang onto or lean on it. Counsel the peer group to ensure compliance. Push the wheelchair only if asked or if you have offered and it has been accepted.

In the case of children with hand-function limitations, the following points have to be kept in mind:

If student wants to use a note taker, this should be allowed. Accept alternate modes of submission of assignments, like tape recording of written assignments and/or exams. Allow to give exams orally when necessary or allow extra time for students who are able to write but with slower pace than others. Allow students to use a scribe or computer for exams. Utilize competencies learned rather than speed as a grading criterion. Allow the use of tape recorder for recording lectures and discussions.

Children with chronic back problems may need the following accommodations:

Allow students to alternate activities in sitting, standing and walking as required as some of them may have difficulty to keep sitting throughout the class time.

Teachers in all subject areas and peer group should be aware of the impact of LI

on a student's behaviour in class. Students with LI, for example, might get tired more quickly than their peers without these impairments. Be empathetic and sensitive to emotional discomfort that often accompanies chronic pain that some of them endure. Peer counselling becomes crucial in this regard.

Classroom accommodations source: *Cross the Hurdles: For Students With Locomotor Disabilities* 2014.

Children with LI may also need assistive technology devices to help them communicate.

## Assistive Technology

For most people, technology makes things easier. For people with disabilities, technology makes things possible (Radabaugh 2014).

The following case narration gives a good picture of the above statement.

Sarah has difficulty walking and was left indoors with little chance to attend school, to play with other children and to accompany her family outside home. When she got her wheelchair, she began moving around by herself, interacting with others, attending school and participating in family activities. Her physical and mental health improved as a result of better posture, physical activity and new opportunities. This reduced her family members' stress and worries related to her current and future situation. They no longer had to carry her – a task that had become more difficult as she grew. This freed up time for them to work, rest and otherwise improve the family's living conditions and quality of life. One of the main reasons for Sarah to get a wheelchair was to be able to attend school. But Sarah and her family soon realized that a wheelchair alone would not be sufficient. First they got help to repair the holes in the road to the school. Still Sarah finds it hard to get to school during the rainy season, as the road gets muddy where it is not paved. Her friends usually push her across those parts. There is an option to go by bus, but it is impossible for her to enter the bus. Sarah's parents talked to the principal of the school about the needs for making the school accessible. Although a bit reluctant in the beginning, the principal is now cooperative and has ensured that a ramp has been built at the entrance, narrow doorways have been replaced and a bathroom has been extended. As there is no elevator in the school building, Sarah's classes are all on the ground floor. A specific place has been allocated for her in the classrooms with a desk under which she can enter with her wheelchair. She would like to move around more in the classrooms, but there is currently no space between the desks and seats used by her classmates. Although Sarah still encounters accessibility problems in certain areas, she continues using the wheelchair as the benefits outweigh the remaining problems.

Due to the various levels of severity of LI, multiple types of assistive technology may be used. As with any student with a disability, assistive technology is helpful to address need of the student to be able to access the educational curriculum. For students with LI, these fall into three categories.

## Keyboards

Several types of **alternative keyboards** are available for the use of children with LI. Keyboards can be expanded for students who have difficulties with fine motor skills or contracted for students with limited mobility who may rely on one or a few fingers, or a device such as a pointer, to operate the keyboard. The keys on some keyboards are rearranged so that the most common keys are clustered together, while others, such as a chording keyboard, have a small number of keys that are pressed at the same time in combination. Programmable and virtual keyboards can be operated by a touch-screen monitor or overlay or a variety of input devices. Keyboards can also be paired with keyguards and moisture guards or overlays. Keyguards and moisture guards protect the keyboard from dirt and fluids, while an overlay can be used to identify common keys, hotkeys or shortcut keys or alternative responses programmed into a keyboard.

## Adapted Computer Mouse

Computer mouse sticks and joysticks and trackballs are just a few examples of a variety of input devices that are readily available to help students overcome limited mobility or problems with fine motor coordination. Mouse sticks are small levers built into a keyboard that require very little motion to be fully operational. If students do not have the ability to operate an input device with their hands or arms, they may be able to use a foot mouse or a hands-free mouse that is controlled by a device worn on the student's head that tracks changes in motion via infrared that interacts with a monitor. Eye-tracking technology is also an option that interacts with an emulated keyboard similarly to the hands-free mouse device. Head devices require control and coordination of the head and may need to be introduced gradually and monitored as students may become fatigued quickly. There are also low-tech pointers, such as mouth sticks and head wands that can be used to interact with a variety of alternative keyboards – both physical and emulated.

## Switches

Switches can help students operate a variety of technologies, including wheelchairs, computers and other technologies. A switch can operate as a single-input device, basically either turning something on or off or a multiple-input interface depending on the student's access to and ability to control the switch. Switches can be activated by almost any part of the body, such as an arm, hand, finger, leg, foot, head or chin (Hasselbring and Glaser 2000), and come in a variety of types, such as paddles, lever, light beam, pillow and 'sip and puff'. Sip-and-puff switches operate in

reaction to a student's breath. Students must be able to control their responses to any type of switch device, and training is required for the student to become proficient in their operation.

**Voice recognition technology (VRT)** allows students with extremely limited or no mobility to interact with a computer or computer-controlled device. Voice recognition software can either require continuous speech or discrete speech, which requires a pause between words. Microphones can be used in order to block out unwanted ambient noise during operation. A student who uses voice recognition software must be able to control their verbalizations, and voice recognition software often has to be 'trained' to recognize an individual's speech patterns.

**Devices to Access Information:** These assistive technology devices focus on aiding the student to access the educational material. These devices include speech recognition software, screen reading software, augmentative and alternative communication devices (such as communication boards), academic software packages for students with disabilities, etc.

**Devices for Positioning and Mobility:** These assistive technology devices focus on helping the student participate in educational activities. These devices include canes, walkers, crutches, wheelchairs, specialized exercise equipment, specialized chairs, desks and tables for proper posture development (Source UNICEF 2015).

### **Prosthetic and Orthotic Devices**

Children with LI especially those with cerebral palsy have limitations with regard to the strength and stability of body, and hence these become their primary concern. Stability of body is vital for moving around completing tasks at hand, and orthotic devices worn on the body help build stability and strength, comfort and independence.

Sometimes, orthotic devices may be required as a temporary support; or some may need these for lifetime. But in all scenarios, orthotic devices have the potential to bring the stability and alignment to young people that is required to grow, move and be active participants in their lives.

A simple way to describe an orthotic device is that they are braces that are worn externally by a child or adult. In actuality, the braces are complex tools that address a person's specific body condition. What materials a device is comprised of, how it fits and the role it's expected to play in a child's development will correspond to the child's structural and functional needs.

In many cases, devices are prefabricated to the child's physical characteristics. Others are manufactured in specific sizes. As a child grows and his or her body changes, orthotic devices will need to be modified and replaced.

Orthotic devices are designed to relieve and correct several conditions, like misalignment or dislocation of the knee or hip, spastic movement, deformities, low-tone pronation (fallen arches, outward-turned foot due to muscle weakness), high-tone pronation (high arch, outward-turned foot due to increased muscle tone), swing-phase inconsistency (erratic movements in the foot), drop foot (drop of the front of the foot due to weakness), eversion (outward turn), inversion (inward turn), etc.

From a practical standpoint, the goal of orthotics is to enhance the quality of life for children with cerebral palsy. Some ways orthotics can help children with disabilities include the following: improve independence by enhancing mobility, reduce stress and fatigue, reduce the likelihood of a fall or an injury and take the focus off of required mobilization and onto family time, play time, building relationships and pursuing interests (Source: Stern 2019).

There are several types of orthotics, including:

1. Foot Orthotics – These are more commonly referred to as inserts that are placed in shoes to shift the weight of the feet and legs and bring balance, relieve shock and minimize stress. They can be rigid or soft, and they can be custom-made or fitted. Also, the orthotic device can come in the form of an actual shoe.
2. Ankle-Foot Orthotics – Sometimes referred to as AFOs or foot drop braces, these semirigid L-shaped braces stabilize both the foot and ankle to bring muscles and joints into alignment.
3. Hip-Knee-Ankle-Foot Orthotics – Called HKAFOs, these devices use bands, belts, pelvic girdles and knee-ankle orthotics to help position a person upright while centring the knee joint.
4. Knee-Ankle-Foot Orthotics – Called KAFOs, these devices stabilize the knee, ankle and foot, allowing for proper function and movement. KAFOs are equipped with mechanically or electrically controlled hinges. They are useful when a child has limited movement in his or her legs so they can help when learning to walk.
5. Knee Orthotics – A brace that is worn to support and align the knee; it extends from above the knee to below it.
6. Spinal Orthotics – If a child needs additional support or alignment in his or her upper torso, a spinal orthotic device can help a child sit up or stand; it is particularly useful if a child has limited trunk control.
7. Trunk-Hip-Knee-Ankle-Foot Orthotics – Sometimes called THKAFOs, are HKAFOs with spinal orthosis for control over trunk motion and spine alignment, most often used by individuals with paraplegia.
8. Prophylactic Braces – This brace is rigid and has knee hinges; it is used mostly for people who have knee injuries.

In addition, some shoes and supports are designed for orthotic support. These include:

Orthopaedic shoes  
Shoe modifications  
Arch supports  
Heel modifications

For children with cerebral palsy, wearing a brace can be a difficult experience if they have deformities or other issues that can cause pain. If a child's muscles are already under pressure, he or she may have tolerance issues (Source: Stern 2019) (Fig. 6.1).





Fig. 6.1 Prosthetic devices (Source: Cheprasov 2019)

## Psychosocial Inclusion

As presented earlier (p. 8), children with LI do not have cognitive, learning, perceptual, language or sensory issues, and hence what these children require is more of psychosocially conducive ethos rather than academic modifications and adaptations.

Body image and self-worth of children with LI, especially from their preadolescent stage onwards, are commonly seen to be impacted by locomotor impairment. These in turn are related to how these children are perceived and treated by teachers and peer group in class and school sites. In fact these are the secondary disabilities built up on the primary impairment of body part or parts.

Sense of belonging, like sense of body image and self-worth, is a psychological construct. In order to help children with LI develop sense of belonging to the class, teacher has a crucial role of being a counsellor to these children and more importantly the peer group. In fact, the onus of the sense of belongingness of the child with LI rests with the cooperation and understanding of the peer group. Ridicule by peer group connected to the physical appearance of the child with LI is very commonly seen in schools which impacts the child's self-image and self-worth; labelling and nicknames are common experience of these children. Such ridicule and labels on a longer run can make the child withdraw from others and progressively become introvert and feel isolated. Peer counselling is critical to prevent such a situation and to ensure more amicable classroom ethos and help the child with LI feel included in the class group.

Students with LI tend to have low social skills. It is very important for teachers to help such students improve their social skills and help them feel included in class and school and help in integrating them into the society in general. Firstly, the

teacher should help children to be self-confident. Self-confidence which is related to body image along with other attributes is seen to be low in many children with LI. Teachers should use strategies that kindle friendships such as role-playing, teamwork or other structured activities. In such situations, students with LI might have richer social interactions and thus might notably improve their social skills.

It is important to recognize and appreciate each of the smallest achievements of children with LI, like those with any disability, to motivate them to perform in the class, both in academic and co-scholastic activities.

During co-scholastic activities, especially performance and games, etc. where some children with LI might find it difficult to participate, it is important to find alternative activities for them according to their interests and the available resources so that they don't feel left out. In some cases, even if they are allowed to be at the site of such games and shows with an opportunity to see these activities, they might feel included. Teachers and peer group have to be sensitive and conscious to make them feel included in all the ways possible during such activities, rather than letting them be in the classroom all to themselves which is the experience of many children with LI in our schools. These attempts go a long way in maintaining the psychosocial well-being of children with LI.

Encouraging interrelationship between students is effective in fostering a conducive psychosocial environment for students with LI. This has been elaborated on page 16 of the chapter on Conceptualizing Disability Inclusion. It is an important role of the teacher and the counsellor to understand the varied potentials of a child with LI so that these potentials can be used when students are paired or grouped for various activities, academic or co-scholastic, for example, drawing and painting skills, singing ability, mimicry skill, oratory ability and the like. Exploring and drawing out these potentials of these children depend on the sensitivity and perseverance of the teachers who interact with them. It is through these interrelationship and reciprocity between children with LI or any other impairment for that matter that the sense of their self-worth be maintained.

### ***Role of School Staff and Peer Group***

Above presentations on the nature of children with LI and their needs clearly tell us about the role of other school staff and peer group in the class and in the school. Unless the child with LI feels socially included in the school experiences in totality, any effort by the teachers of the child will not bear fruits. The emotional needs of the child arising from body image and lack of self-confidence need to be empathetically understood by all the school personnel, other teachers and students. Only with their support and care can the child with LI do his/her best in an enabling environment.

In the context of students, calling names like 'langda' and 'pangu' (words in Hindi meaning lame, crippled respectively), for a child whose gait is different due to impairment in the leg, or commenting sarcastically on the slow pace of a child

using crutches, like 'kitna tez hai' (Hindi expression, meaning how fast!), etc., can demoralize children with LI. These are what students should refrain from. For this, teachers and principal have to regularly counsel students and ingrain in them respect for differences among children and help in maintaining an enabling environment.

### ***Role of Community***

Persons with LI are faced with stigma and exclusion in their immediate community and the society at large. Most people tend to look down on them and treat them as special and discriminate them. They may find it hard to socialize with members of the society. This can lead to depression as well as self-pity, if not checked. It is commonplace occurrence that even family members do not take the child using wheelchair along, for all family gatherings or other social functions, the reason being embarrassment caused due to the looks, expressions and inquiries by relatives and acquaintances at these gatherings about the child, sometimes culminating at ridicule and scorn. These scenarios have to change totally. Community and extended family have to be open to differences among members, young or old; accept and respect them with their abilities and limitations; and provide an enabling environment to ensure their inclusion.

### ***Professional Support Team***

Because of the multifaceted nature of LI, other specialists may be of immense help in developing and implementing an appropriate educational program for the student in a psychosocially conducive ethos. These specialists can include:

Physical therapists (PT) who work on gross motor skills (focusing on the legs, back, neck and torso). According to the needs of a child, these services may be required to provide support.

Occupational therapists (OT) who work on fine motor skills (focusing on the arms and hands as well as daily living activities such as dressing and bathing).

Speech-language pathologists who work with the student on problems with speech and language. For example, students with cerebral palsy.

Physical education classes, in particular, may pose difficulties for some or all children with LI. Some students with LI will need to be excused from gym/yoga classes. Other students with mild LI may be able to participate. Adapted physical education teachers, who are especially trained to work along with the OT and PT to develop exercise programs to help students with disabilities, may be needed.

Art (visual and performing) professional: Music, theatre, painting, dance, sculpture and other art forms both visual and performing art forms are channels successfully used for the creative expression and well-being of children with impair-

ments. Proper assessment of the capabilities of children with LI has to be carried out in a systematic and reliable way to design cocurricular activities for them, be it cultural, literary or sports. Shutting them off all these activities and labelling them as locomotor disabled is the most damaging treatment that can be given to them. According to the aptitude and capabilities of each child, he/she should have exposure to the art form that can draw out the best in him/her. The case narrations presented earlier and the one to follow are evidences enough to support this possibility of interface between art and disability.

There are many persons using wheelchair or crutches or walkers who are able to participate in dance performances. There is a dance troupe named Ability Unlimited in Bangalore in which many dancers are wheelchair users. In their performances, the crutches and the wheelchairs are used as props, like wheelchair used as the chariot of Rama and crutches and bow, in 'Ramayana on Wheels'. 'We are One', in Delhi, is yet another dance troupe comprising many dancers using wheelchair and crutches (Ability Unlimited 2018).

Video link for performances of 'We Are One' – <https://youtu.be/00-C5oXN8os>

### Case Narration

**Mr. Rajkumar**, around 23, a Delhi-based dancer is the founder of a dance troupe.

Mr. Rajkumar's dance troupe is inclusive in terms of having dancers with and without impairments. He uses crutches; some of his colleagues use wheelchair, some use crutches, some are hearing impaired and others are visually impaired. He didn't have an easy childhood. His journey as a little boy affected with polio was rather tough and painful. He started using calipers when he was in class 2. His teachers played a significant role in motivating him and move beyond his limitations. As a child, he wanted to play cricket as others but he knew that he couldn't do so due to his impairment. Many doubted his ability to manage an independent life. In his words, 'My disability was a challenge more for others than me'.

Slowly he started getting interested in dance by watching TV and films. His teachers supported him and encouraged him. That's when his life took a different turn. He started enjoying moving rhythmically sitting on wheelchair and gradually participating in dance performances. Joining Amar Jyoti School was a major turning point in his life when he got exposed to dance classes and performances. Since then he has not looked back. Performing on wheelchair for the past 15 years made him realize that the view of the world was beautiful even from a wheelchair.

### Consolidation

Locomotor impairment is a large umbrella term that encompasses a wide spectrum of impairments from that of the smallest body part to the whole body, thus impacting movement of any part of the body or the moving of the person from a point to another. It is an impairment most of the types of which are too obvious and cannot be hidden from view of others; most of the children with this impairment have obvi-

ously different appearance. More often than not, this leads to low body image and hence low sense of self-worth and confidence. Logically flowing out from such a situation is the reality that they need more of psychosocial accommodation rather than academic inclusion. Their additional requirement is related to accessibility. As it is mobility that is affected in these cases, most of them have accessibility issues: accessibility of buildings, transportation, information, learning sites, learning resources, etc. Hence, making school, all classrooms and other sites of learning and activities and information and resources accessible for these children is the responsibility of the society. However accessible these spaces and resources, etc. be made, unless these children feel emotionally and socially included in an environment devoid of bullying and ridicule, where they are respected for what they are, where they are valued, their education cannot be inclusive.

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# Chapter 7

## Revisiting Visual Impairment



Gagandeep Bajaj

**Abstract** This chapter looks at the possibilities for the academic and social inclusion of learners from the vantage point of visual impairment. Another focal area is listening to narratives from the field and understanding their theoretical, as well as practical, implications in the Indian context. The chapter begins with case narrations from the Indian classroom, wherein certain issues to reflect upon have been highlighted. Subsequently, the nature of visual impairment and the educational and psychosocial concerns of learners with visual impairment are delved into so that one can get a glimpse of the protagonist's viewpoint. The role that stakeholders, such as family members, teachers and other members of the community, play in their lives is equally relevant and worthy of attention. The chapter will attempt to address these issues and also look at the pedagogic strategies that can help in fostering the academic and psychosocial well-being of learners with visual impairment in an inclusive school.

**Keywords** Inclusive education · Learners with visual impairment · Academic and social inclusion · Blindness · Low vision · Educational and psychosocial concerns · Independent living skill training · Braille · Pedagogic strategies · The Rights of Persons with Disabilities Act, 2016

### Overview

Inclusion has been adopted as the stated policy in our educational system for many years now.

You have read about the basic premise of inclusion in the first chapter. It is evident that inclusion is an integral part of educational discourse in various countries of the world. However, there is a disconnect between theory and practice. The fervour with which inclusive education is talked about from podiums of seminars is inadequately reflected in the school scenario. There are many challenges to be

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addressed by a school trying to implement a system of inclusive education in order to arrive at an answer to the question, 'How do we successfully include all students?'

With the above background in mind, let us look at a few situations which have been taken from actual classrooms:

- Siddharth is a student of Class 7. He is a learner with visual impairment, studying in an inclusive school. He uses Braille books which are provided by the school every year. However, this time, it is the month of August and the books are yet to arrive. When he asks his teachers about them, they express their helplessness. They have also asked Siddharth to arrange for his own books, but he is not aware of the places where Braille books are available.

Issues to reflect upon:

If you were Siddharth's teacher, what would you have done in the above situation?

What are your suggestions to ensure that Siddharth is provided a conducive learning environment?

- Ragini is a learner with visual impairment, who studies in Class 6. She is a budding scientist and has been performing simple experiments at home ever since she was a little girl. Her school offers students many options in the form of clubs, where they can choose a cocurricular area of their interest. The 'science club' was a natural choice in her case. However, when she conveyed this to her teacher, she was told that the school had already allotted her the 'music club'. On being asked the reason for this, the teacher explained that blind children are always good in music and Ragini will do very well in this activity.

Issues to reflect upon:

What are the assumptions that underlie this situation?

What impact would such events have on Ragini's experience of inclusive schooling?

- Vivaan studies in Class 9 of a public school. He is really excited nowadays because the entire class is going for an educational trip to Shimla. He spends a major part of his day planning the trip with his classmates. Vivaan has already made a list of things to pack and activities that he wants to do in Shimla. On the day that the teacher was collecting money for the trip, she opined that it will be difficult for him to manage there on account of his visual impairment. As a result, the Principal has decided not to allow him to go for the trip.

Issues to reflect upon:

What are your views about this situation?

What kind of support can be offered to Vivaan by the teacher and/or the school administration?

Envision alternative scenarios for Vivaan.

Reflecting on the above situations might have directed your attention towards the varied challenges that learners with visual impairment (VI) have to face in their life



at school. How the individual student copes with these, as well as how the system responds to such situations, decides the successful engagement with inclusive schooling. Let us now understand the concepts underlying visual impairment.

## Conceptual Foundations

The educational discourse related to the persons with disabilities has traversed a path from segregation and integration towards inclusion. In terms of the theoretical orientation, charity and medical models have made way for an understanding based on the social and human rights models. Since inclusion is being viewed as a viable alternative across disabilities, stakeholders in the educational scenario need to understand disability as one of the dimensions of diversity in the general classroom. All teachers need to be prepared for modifying the teaching-learning process to address the needs of every child in the classroom. This section deals with the conceptual foundations of visual impairment.

According to The Rights of Persons with Disabilities Act, 2016, visual impairment is subdivided into the following categories: blindness and low vision. We need to understand the meaning of both these categories because of the differing implications in terms of educational and psychosocial aspects. Technically, these terms, as described by the Act, are as follows:

- (a) ‘Blindness’ means a condition where a person has any of the following conditions, after best correction: (i) total absence of sight, (ii) visual acuity less than 3/60 or less than 10/200 (Snellen) in the better eye with best possible correction or (iii) limitation of the field of vision subtending an angle of less than 10 degree.
- (b) ‘Low vision’ means a condition where a person has any of the following conditions, namely, (i) visual acuity not exceeding 6/18 or less than 20/60 up to 3/60 or up to 10/200 (Snellen) in the better eye with best possible corrections or (ii) limitation of the field of vision subtending an angle of less than 40 degree up to 10 degree.

Interpreting these terms in functional equivalents is crucial for determining the learner’s visual efficiency. A functional assessment helps to make accurate decisions about assistive technology required, seating arrangements in the classroom and pedagogic strategies to be used, amongst others:

Another aspect of visual impairment that has implications for the learner is whether it is congenital or adventitious in nature. Congenital visual impairment refers to the condition when the loss of vision is present at birth or occurs in early infancy. Adventitious visual impairment refers to the loss of vision at a later stage in life, due to an illness or accident. It is generally observed that, adolescents with adventitious visual impairment have greater issues with acceptance of their condition and episodes of denial, maladjustment etc. are more common. As a result, the kind of psychological and material support required by both groups, differs considerably.

Vision is our primary source of information about the environment, and any loss in acuity affects all aspects of the child's life including the teaching-learning process. Seeing things gives us impetus to explore what they are and stimulates our curiosity. In the case of congenital blindness, starting from infancy, absence of vision limits her understanding of the world. Developmental delays, like in motor development, conceptual development and language development, are possible. However, it is important to remember that learners with visual impairment possess the same intellectual capabilities as their peers. Timely interventions, which are coordinated by an educational team, consisting of parents, professionals, paraprofessionals and, most importantly, the child herself, can ensure an appropriate development in all spheres.

Visual impairment might affect learners in a variety of ways. There is a reduction in the range and variety of experiences that they are able to obtain along with the lack of integration amongst those experiences, their ability to move about is restricted; they experience a diminished sense of control over their environment; communication is limited, particularly that of a non-verbal nature; concepts are inadequately formed and frequently based on incomplete information. The popular doctrine of sensory compensation, which says that if one sense is deficient, the other senses get enhanced, has not been supported by research. However, learners with VI, with relevant instruction, can learn to use their other senses for daily tasks. In fact, the need for getting oriented to one's environment and the capability to move confidently is one of the biggest challenges that learners with VI face, but it can be dealt successfully by starting orientation and mobility training at an early age. There are innumerable examples of individuals with visual impairment who confidently negotiate their environment.

Social competence is another area that deserves consideration. It is required to interact successfully with others and develop lasting interpersonal relationships. Learning how to communicate effectively is an important component of social competence. Lacunae in this area frequently lead learners with VI towards social isolation in schools. Victimization by peers or others can lead to various mental and physical issues.

We will now delve into the educational and psychosocial implications of visual impairment and try to understand the role that the school and teacher, amongst others, can play in empowering the learner with VI.

## **Educational and Psychosocial Implications**

The situation of having learners with special needs in the classroom has far reaching educational and psychosocial implications for the general education teacher. Teachers today have to teach in classrooms which house a diverse population of learners, of which learners with VI is an important component. They are required to understand their needs and collaborate with special education teachers, amongst others, to adapt the learning environment, curriculum and teaching-learning

strategies accordingly. This puts teachers in a situation for which they need adequate preparation. Conceptual development, effective communication, personal independence, social adjustment, etc. are educational goals for all learners, including those with visual impairment. The only difference is the methods adopted to reach these goals.

Chapter III, Section 16 of the Rights of Persons with Disabilities Act, 2016, mandates that the appropriate government and the local authorities shall endeavour that all educational institutions funded or recognized by them provide inclusive education to the children with disabilities and towards that end shall (i) admit them without discrimination and provide education and opportunities for sports and recreation activities equally with others; (ii) make building, campus and various facilities accessible; (iii) provide reasonable accommodation according to the individual's requirements; (iv) provide necessary support individualized or otherwise in environments that maximize academic and social development consistent with the goal of full inclusion; and (v) ensure that the education to persons who are blind or deaf or both is imparted in the most appropriate languages and modes and means of communication.

The above clearly situates the education of learners with special needs in the inclusive framework. The philosophy of inclusion needs to permeate every decision related to schooling, whether it is admission, access or pedagogy. At a physical level, providing an accessible environment is an important step for inclusion. Designing school infrastructure keeping in mind the principles of universal design is required. Free access to all areas of the school should be there. This means enough space for free movement, availability of ramps, tactile markings at the top and bottom of all stairs with railings and at the entrance of every room, all signs, name plates, etc. need to be large in size, marked with contrasting colours and raised letters. The library should be equipped with computers, scanners and screen reading software. Use of contrasting colours on the stairs is required for learners with low vision. In general, all parts of the school building should have bright and uniform lighting and good acoustics with a minimum of background noise.

At the level of the classroom, design and arrangement of furniture should be disabled friendly, free of clutter, with appropriate height of desks and chairs which provide for a diversity of seating arrangements. However, it is important to maintain consistent arrangement of objects in the classroom and inform the student of any change in advance. Material can be provided in the classroom itself, or a separate resource room can be used for equipment and other teaching-learning materials. Appropriate lighting in the class is essential for learners with VI. Factors to be considered are controlling the glare, for example, some learners can see better in bright light, while others may need subdued lighting. Distance of the child from the board is also important. In the case of learners with low vision, the light should fall on the work area from over shoulder of the preferred hand.

We have discussed earlier that concept development might be affected due to visual impairment. Thus, appropriate conceptual clarity needs to be achieved through tactile support and extensive use of teaching-learning material and appliances. The use of screen reading computer software is helpful in fostering a sense

of independence in academic work. However, not many schools have this facility, forcing learners to rely on recorders and scribes. Other issues related to pedagogy and teachers have been dealt with in the relevant sections.

To what extent a learner benefits from an inclusive educational setup also depends on the level of independence she possesses while performing day-to-day tasks. Training in independent living skills thus assumes importance. These include orientation and mobility training, training in activities of daily living and use of assistive technology. With the help of independent living skills, learners with visual impairment can participate meaningfully in a variety of social and school-related activities. Thus, learners develop a greater sense of agency, self-esteem and motivation. Research also shows that learners with VI who are equipped with these skills have a richer quality of life (Sapp and Hatlen 2010). Separate time and resources have to be allocated in the daily school routine of the learner with VI for these activities in order to gain competence.

Having positive feelings about oneself and a sense of confidence in one's abilities are essential components of personal adjustment. Most people learn by observing visual signs like body language and facial expressions and using these images to develop appropriate ways of personal and social behaviour. In the case of learners with VI, there is a loss of incidental learning, and learners are unable to imitate their peer's physical mannerisms and have difficulty developing body language that is socially appropriate (Batshaw 1997). Also, the restrictions in mobility and limitations in the variety of experiences sometimes result in passivity and dependence. In addition, people with visual impairment face negative attitudes and bias from society at large which leads to discrimination and diminished opportunities for participation in the community. It is worthwhile to ponder about the issue of whether the characteristics attributed to people with visual impairment, like being isolated, socially immature, self-conscious and dependent, are wholly due to the disability or caused by the way people treat people with visual impairment (Hudson 1994; Kirk et al. 2006). The school has an important role in nurturing feelings of self-esteem and self-acceptance in learners with VI. This can be done by focusing on her abilities and achievements, providing the necessary infrastructural and resource support for the learner to perform well in academic and nonacademic tasks, creating opportunities for positive interactions with persons with sight, etc. The school psychologist and counselor, along with the regular teacher, can be helpful in this regard.

Establishing social relationships is an integral part of life at school for all children. Inclusive education cherishes the goal of social integration of learners with disabilities into the adult world. The school environment thus needs to be a learning ground for friendly interaction between learners with and without disabilities. Supportive peers are the one of the best resource that a learner with VI can have in the school. However, simply being in the same class does not guarantee friendship. The teacher needs to take initiative in this direction. One example of this is the circle of friends where the teacher guides other learners to spend time with the learner with VI at an informal level in order to understand each other beyond studies. Because of the low incidence of visual impairment in the population, many people

have never interacted with a person with visual impairment before. Although many times, their peers want to help but either hesitate or do so in ways that are inappropriate, creating an unnecessary dependence. Still others harbour stereotypical attitudes borne out of ignorance. Sensitization at the level of the institution and teachers can go a long way in helping sighted peers to have a realistic picture of the abilities of the learner with visual impairment. This will put them in a position to help when it is really required and in ways that are effective.

## Issues and Challenges

Including learners with VI in mainstream schools brings to the fore many issues and challenges which need to be addressed. We have been discussing some of these issues and now we will examine them in greater detail. Equitable access to the physical environment is an essential prerequisite for inclusion. According to the RPWD Act, 2016, some of the provisions for universal design are as follows.

The central government shall, in consultation with the Chief Commissioner, formulate rules for persons with disabilities laying down the standards of accessibility for the physical environment, transportation, information and communications, including appropriate technologies and systems, and other facilities and services provided to the public in urban and rural areas, 41 (1). The appropriate government shall take suitable measures to provide (a) facilities for persons with disabilities at bus stops, railway stations and airports conforming to the accessibility standards relating to parking spaces, toilets, ticketing counters and ticketing machines; (b) access to all modes of transport that conform the design standards, including retrofitting old modes of transport, wherever technically feasible and safe for persons with disabilities, economically viable and without entailing major structural changes in design, 42. The appropriate government shall take measures to ensure that (i) all contents available in audio, print and electronic media are in accessible format; (ii) persons with disabilities have access to electronic media by providing audio description, sign language interpretation and close captioning; and (iii) electronic goods and equipment which are meant for everyday use are available in universal design.

As is evident from the above, the standards have been elaborately spelt out and deal with various aspects. However, in reality very few schools have unhindered access to classrooms and other parts of the school, such as, library and playground. Ramps are available in many government schools but usually only at the entrance. Tactile tiles and other basic requirements are also missing. Universal design is not simply about infrastructure, although that is an important part. Rather, it is about providing equal access to the learner with VI in terms of core and specialized curriculum, books and other learning materials and equipment. Flexibility is the key to address the diversity of an inclusive classroom. Textbooks which are available in the class as print, tactile and talking book versions are an example of universal design for learning.

Another area of concern is the availability of resources and material which have been adapted for the learner with visual impairment. While many organizations are working to develop such material, schools have limited awareness and access to them, resulting in a dearth of resources in the classroom.

An issue which is of utmost importance is the lack of preparedness which general education teachers experience on finding a learner with special needs in their classroom. This issue has been elaborated in the section on teachers.

Due to these issues, the learner with VI might perceive the learning environment as hostile and find herself unable to negotiate the complexity of the content. Research studies based on the voiced experiences of learners with VI report the presence of exclusionary practices in inclusive schooling (Whitburn 2014; Opie Deppeler and Southcott 2017).

Understanding issues related to self and developing a healthy sense of identity constitute major challenges for any individual but take on different dimensions for learners with VI. Interaction with peers and having meaningful relationships is an important part of the school experience. Inability to gauge visual cues and body language, as well as exhibiting mannerisms, such as constant head movement and eye poking, results in rejection by peers and feelings of alienation (Punia and Berwal 2017). The urge to be a part of the group can sometimes lead the learner with VI to succumb to peer pressure in the form of drug addiction or sexual exploitation. Guidance and counseling at the school level to cater to their specific concerns is required.

Choosing and pursuing a career pose a challenge to learners with VI because of the limited career options available to them. They face many attitudinal barriers at the societal level regarding their abilities and have to battle this prejudice to prove their worth.

## **Role of Family and Community**

The role of the family, particularly the parents, is indispensable in the education of learners with VI. Parental reactions to having a child with visual impairment in the family range from overprotection to neglect. The family's attitude towards the disability determines, to a large extent, the child's perception of her potential. Along with material support, the psychological support provided by parents is like a bedrock for the child with VI. It decides whether the child will develop resilience towards adversity and take up the challenge or succumb to insurmountable odds. Influences that hinder the development of a child with VI include overprotection, negligence, parental bias and unrealistic expectations. These might result in confusion and low self-esteem. Often, parents have low expectations from their child, with regard to independently managing her personal life and career. This leads to a state of dependence on parents for fulfilling their needs and a lack of self-belief and

will to accomplish tasks. Community members, also, are often ignorant about the needs of individuals with VI and tend to avoid them. They are perceived as a burden on society, with nothing of value to offer. This perception is strengthened due to limited opportunities for social interaction. Thus, children with VI do not get a chance to familiarize themselves with social situations and learn the skills required for healthy interaction. Parents need to actively seek out opportunities where children with VI can participate in community life. Parents and other family members should cultivate acceptance of the situation and become aware of the needs of their child so that they are in a position to address them. They can partner with teachers and counselors in order to bring out the true potential of their child. At the same time, the community needs to be sensitized about children with VI. Community members can play a constructive role in integrating them in day-to-day activities. Individuals with VI can positively contribute to the society, provided they are given an opportunity to do so. For this goal to be achieved, a conducive environment needs to be consciously created by all stakeholders.

## **Role of Teachers and Other Members of the School System**

In the present section, we turn our attention to the various members of the school system and their involvement in the process of inclusive education.

### **Administrators**

The attitude of the head of any institution sets the tone for its functioning. Awareness of and sensitivity towards the needs of learners with disabilities on the part of the administration is a prerequisite for an effective inclusive school. Administrators are responsible for providing specialized services, facilities and technological assistance required by the learners with VI. This includes conducting orientation programs to sensitize teachers and other personnel about inclusive practices and create spaces for discussion in order to resolve the issues which crop up during transaction. Arranging personnel preparation programs, case conferences and parent orientation programs on a regular basis and locating resources for learners and teachers helps in promoting an inclusive school climate. As far as mobilization of resources is concerned, good administrators liaison with agencies working in the respective disability area, in order to organize material and human support. Creating a barrier-free environment in the school based on the principle of universal design is another key task. Thus, the disposition towards inclusion needs to be reflected in all aspects of planning and implementation.



## Special Teachers

Special teachers in inclusive schools work in tandem with regular teachers to address the needs of learners with special needs. The responsibilities of the special teacher largely consist of teaching the expanded curriculum. These include orientation and mobility, activities of daily living, provision and use of assistive devices, sensory training, independent living skills and communication skills. She needs to coordinate with the regular teacher to chalk out a timeline for these components in the timetable of the school. Guidance about curricular adaptations and modification of cocurricular activities helps regular teachers feel better equipped to teach learners with VI. Preparation of individualized education plans, development and adaptation of relevant teaching-learning material, functional assessment and transcription of assignments and scripts are some of the other tasks that the special teacher assists with. Many learners report that finding readers and writers is a major concern and seek help from the special teacher in this respect. Creating awareness about visual impairment amongst members of the school and community is another way in which special teachers benefit the cause of inclusive education.

## Regular Teachers

Suman is a teacher for Class 5 in a government school. She has a learner with VI in her class, whom she has requested the Principal to shift to another section. On being asked the reasons for this request, she says, 'I feel that I cannot do justice to this child. She just sits in the class. Neither does she take notes, nor does she answer when I ask her questions. I don't know whether she understands what I teach and I think I am not in a position to help her learn. Maybe she should go to a special school where teachers know how to teach students like her'.

The above response typifies the helplessness that many regular teachers feel while dealing with learners with special needs. Most teachers are inadequately prepared with regard to the needs of these learners and the specific pedagogic strategies required in the classroom. Also, teachers in Indian classrooms usually have to handle large classes. The standard argument in such a scenario is that learners with disabilities exert an additional strain on the system, which is already overburdened. However, we need to realize that learners with disabilities have an equal right to be part of the mainstream classroom. Also, inclusion does not only concern the learner with disabilities, but rather it is a question of having an attitude on the part of the teacher, which focuses on the uniqueness of each child, understands their needs and learning styles and adapts experiences accordingly. In the context of the present section, along with the requisite expertise in teaching methodology, the teacher should know the ways of adapting the curriculum and assessment for learners with VI, in a manner that the concepts taught remain the same. For this, appropriate pro-



professional development and support is required. While the regular teacher is responsible for the transaction of the curriculum for all learners, she might need assistance in providing guidance to learners with visual impairment, regarding Braille, screen reading software, Taylor frame, etc. This assistance can be given by the special teacher as discussed above. For instance, the assignments and evaluation sheets of the learners with VI who use Braille can be transcribed by the special teacher. Alternately, oral or computer-based tests can be conducted instead of handwritten ones. It is recommended that in the early years, examination should be conducted in Braille with transcription, after which a scribe or computers can be used. However, many schools in the country face a severe shortage of special teachers and itinerant teachers are common, even in a relatively better placed city like Delhi. As a result, if one special teacher is deputed for four to five schools, she will be able to visit each school only once a week. It is said that the success of inclusive education depends on the strength of the collaborative partnership between the regular and special teacher. How meaningfully can this take place in the situation described above is a question that all of us need to think about.

Teachers, sometimes, have lower expectations of learners with VI as compared to other learners in the class. It is important for the teacher to realize that the learner with VI must accomplish the same tasks as her sighted peers, with the help of specialized aids and material. Given the fact that we are focusing on the positioning of mainstream and special schools on a continuum of educational settings which are available for learners, it becomes imperative to think of teacher preparation. The policy initiatives in this area have mandated that all schools, whether government or private, are inclusive schools. For instance, Article 23L(2) of the amended PWD Act emphasizes that all teachers should have the requisite training for teaching learners with special needs in a regular classroom. Hence, the traditional division between special schools and mainstream schools has become blurred. All learners deserve to be in a mainstream school as a matter of right. Special schools are witnessing a change in their previously assigned role of being solely responsible for the learner with special needs. They are now increasingly in a position to serve as centres for providing resources and services required by the learner with visual impairment, to function effectively in an inclusive setup. There is a broad spectrum of conditions under visual impairment, and this diversity has to be kept in mind while making space for the differing needs of learners with visual impairment. Thus, educating learners with VI is no longer the sole prerogative of special school teachers. Mainstream teachers need to be equipped to handle the diverse classroom and work in close collaboration with resource teachers.

Roles of in-service teachers are changing as a result of the factors outlined above, but teacher education programs have not kept pace with preparing graduates for their new roles. A study by Das, Kuyini and Desai (2013) examined the perceived skill levels of regular primary and secondary school teachers in Delhi, required for teaching students with special needs in inclusive education settings. It found that nearly 70% of the teachers had not received training in special education and 87%

of them did not have access to support services in their classrooms. These findings are also corroborated by other studies (Kuyini and Desai 2008; Bindal and Sharma 2010) which indicate that regular education teachers resist the implementation of inclusive education when they are inadequately trained to work with learners with special needs.

Attitudinal change is at the heart of the inclusive education debate. There has been a gradual change at the theoretical level, about the recognition of disability as a human rights issue rather than a medical one. However, this has not been followed by a concomitant change at the practical level. It is important to recognize people with special needs as equal and empowered partners, capable of contributing to the growth of society. This change needs to permeate to the very foundation of the school system. Although attitudes of all stakeholders are significant in this process, teachers play a pivotal role in shaping attitudes in inclusive classrooms. Thus, focusing on knowledge regarding various disabilities, educational and psychosocial implications of having learners with special needs in the class, curricular adaptations, etc. during teacher preparation would enable teachers to have positive attitudes towards learners with special needs and feel confident while teaching in an inclusive classroom.

In the context of visual impairment, teachers need to have an understanding of vision loss, development patterns and characteristics of learners, diversity across the spectrum of visual impairment, planning and managing the teaching-learning environment according to specific needs, ability to modify the core curriculum, ability to implement special classroom strategies, awareness of and ability to access specialized services, resource material, equipment and assistive technology required by the learner with visual impairment, ability to modify assessment procedures, knowledge of policies and laws related to disability and establishing collaborative partnerships with other professionals and families of learners with visual impairment.

Preservice and in-service programs need to take cognizance of this emerging reality and tailor their coursework and internship modules accordingly. Many preservice courses have been revised following the recent NCTE guidelines. For instance, the B.Ed. program at the University of Delhi now has a compulsory paper on 'The Inclusive School' as compared to an optional paper in the earlier program. More such efforts are required to ensure readiness of all schools to implement inclusion.

Professional development programs should be planned in an ongoing mode rather than as one time workshops, so that they can also serve as a platform to discuss issues that teachers face on a regular basis while teaching learners with special needs. The relevance of the programs can be increased if the content is decided after consultations with the participants, instead of using the 'top-down' approach which is usually followed. There is an urgent need to take into account ground realities in order to prepare the teacher for the diverse classroom.

## Classroom Implications: Pedagogic Strategies

The curriculum is divided into two areas, one of which is the core curriculum. It consists of themes which are considered essential for all learners. Thus, while the content remains the same, the curriculum can be adapted or modified, as has been exemplified at various points in this chapter. The other vitally important area is the expanded curriculum. In this case, it consists of training in skills that can enable learners with VI to participate as equal and empowered members of the school and society. For instance, orientation and mobility teaches the learner with VI to understand spatial concepts relative to herself so that she can travel independently. Other areas include leisure skills, assistive technology and career education. As explained earlier, independent living skill training enables learners with VI to handle day-to-day tasks on their own. Examples of this include learning to find and wear clothes, eating, recognizing coins and notes in order to make payments while shopping. According to Lewis and Bagree (2013), both the expanded and the core curriculum must be addressed in an integrated manner by teachers for successful inclusion to occur. Guidance and counseling, life skill education, teaching of cocurricular activities, independent living skill training, etc. need to be integral parts of the teaching-learning program for learners with visual impairment.

**Task** Have you ever wondered how individuals with visual impairment are able to find out where different food items are placed on their plate? You can try out a small exercise to understand this. Imagine the plate is a clock. You can close your eyes and ask a person to place food on the plate according to the time. Subsequently, you will be able to locate the food without looking, provided the server tells you that salad is at 3 o'clock and dal is at 6 o'clock.

Cocurricular activities are an area which is sometimes neglected in the case of learners with VI, because the physical education or the art periods are often used for completion of academic work. Another reason for this is the assumption that neither are these activities important for learners with VI nor will they be able to participate in them. In fact, being excluded affects learners with VI at physical and psychological levels. The reality is that learners with VI can play games and take part in dance, music and art-based activities, provided appropriate modifications are made. Special teachers can provide guidance in this regard. Can you think of the modifications that would be required for the game of cricket in order to enable them to participate?

### Reflection

Imagine a situation where you are a Grade VI teacher in a government school. There are 35 learners in your class, one of whom is visually impaired. Over the course of a few months, you notice that the child usually sits alone on a bench meant for two students and does not participate in most of the activities outside class, like the assembly, physical education and S.U.P.W.

How would you try to understand the various aspects of the situation? What strategies would you employ in order to enhance the participation of the learner with VI?

The above exercise emphasizes that in order to understand whether a learner feels included or not, it is essential to focus on the quality of her participation in the day-to-day experience of the classroom. In an inclusive setup, it is especially important to create situations for active learning by shifting the focus from teaching to learning, in a classroom environment which emphasizes flexibility and multidisciplinary orientation. Every learner should feel valued as an equal member of the class. This brings our attention to classroom strategies because the promotion of inclusion will depend upon the strategies which teachers adopt to ensure that learners participate fully. There are many institutions which are making concerted efforts towards inclusive classrooms, for instance Amar Jyoti and schools like Tagore International School, Shri Ram School and St. Mary's School.

Many of the strategies outlined below would benefit all learners in the class. Using the multisensory approach, where the visual, auditory and tactile senses are used while teaching any concept, would be of use to all. However, learners with VI rely predominantly on their auditory and tactile senses for learning and hence require certain specialized strategies. Puri and Abraham (2004) has given some relevant points which a general education teacher can keep in mind. Some of these are as follows: The learner with VI should be familiarized with all areas of the school, and concerned teachers should be made aware about the learner's background, eye condition and its prognosis. She should be assigned a front seat, and verbal communication should be consciously used, for example, speaking out whatever is written on the board. Classmates should be encouraged to read out whatever is written on the board, and the teacher should ensure that the learner has the reading material and other worksheets, etc. in an appropriate format and follows all classroom norms.

SCERT has given certain additional tips for teachers teaching learners with VI. Visual information should be kept simple and uncluttered. Extra space should be left between words and lines, while writing on the board or preparing worksheets. Learners should be encouraged to ask for clarification of visual inputs and assisted through steps while solving problems.

Other areas that need to be taken into consideration while formulating strategies for learners with VI include allowing learners to work with concrete objects. Hence, provision of supplementary materials for enhancing conceptual development through tactile experience is imperative. Learners with VI tend to have atomistic experiences because they are unable to 'unify' their experiences. The teacher should take this into account and allow them to understand the relationships between objects in order to get a holistic perspective. She needs to encourage them to explore their environment without fear, in an adequately supported manner. There are certain assistive tools and modified learning materials which are essential for any classroom strategy to succeed. The general teacher should have an awareness of these materials and how to procure them for the learner. These are useful for blind, as well as learners with low vision. Constant effort has to be made to encourage the learner with low vision to use her remaining sight.

Some examples of these devices and materials are Braille slate, Braille, Taylor frame, geometry kit and abacus for mathematics, large print, tactile and talking books, notebooks with high-contrast lines and bold squares, table lamps, optical aids like magnifiers, talking calculators, three-dimensional models, tactile maps, high-contrast charts, magnification screen readers, talking phones and screen reading software like JAWS and Windows-Eyes. Learning how to use these devices comes under the purview of the expanded curriculum. Training for these should start at the primary level so that the learner with VI can effectively participate in the regular classroom. Some of the strategies which can be used for learners with VI in an inclusive classroom have been discussed below.

**Collaborative Teaching** Inclusive education, in a sense, is an exercise in collaboration. The general teacher, special teacher, ophthalmologist, guidance counselor, psychologist and parents need to work as a team so that the learner with VI can achieve her educational goals. Collaborative teaching may take the form of co-teaching, where a general and special education teacher become equal collaborators in class and lend the benefit of their expertise to all learners. It could also be in the form of consultation. In this case, the general teacher is largely responsible for the whole class, and the special teacher offers consultation about teaching and assessment adaptations, as well as learning materials. The success of this strategy depends on the effectiveness of interpersonal communication skills, mutual trust and respect for each other and a shared vision of the learner's future.

**Peer Tutoring** We are all familiar with the idea that students learn from each other. In fact, many of us would have had the experience where we hesitated to ask our doubts from the teacher and turned to a classmate for clarification instead. The focus here is on how to turn this random interaction into a systematic strategy for learning. In peer tutoring, the 'tutor' provides a learning experience for another learner, who is called the 'tutee' with the guidance and support of the teacher. The learner with VI gains due to greater individual attention and concept clarification in an informal environment, and the sighted peer gets to revisit her concepts. Both benefit from the increased level of cooperation and self-confidence. They also get a chance to closely interact and, hence, develop sensitivity for the others' point of view. Although usually we assume that the tutor would be the sighted peer and the tutee would be the learner with VI, the roles might be reversed as well. The teacher needs to prepare both parties for their respective roles and facilitate the session. A similar strategy can be tried out for small learning groups in the class. This approach was taken up in a research study wherein both groups of learners showed a significant improvement in academic output, social skills, self-esteem and self-confidence.

**Social Learning** As explained elsewhere, learners with VI sometimes exhibit socially inappropriate behaviours due to missing out on the subtle signs that people with sight naturally use to develop social competence. Thus, direct instruction in social skills can help them maintain healthy interactions with others, understand and

respond to their social environment in a socially adaptive manner. For a positive social interaction, learners with VI need to be able to initiate and continue conversations; have appropriate posture and facial expressions; not exhibit mannerisms like eye poking, shaking the head, constant blinking, etc.; be able to decode and solve problems; establish friendships; and ask for help when needed. Many of these skills can be taught during the course of the lesson through role modeling and giving direct instruction and feedback according to the situation. Sometimes, individual time outside the class might be required. During this time, the teacher can encourage the learner with VI to analyse her level of social competence, identify stumbling blocks and collectively formulate a stepwise plan to overcome it. The teacher can provide specific opportunities to practice the skills and give constructive feedback to facilitate the process.

**Buddy System** It has proven to be especially effective in the case of learners with VI, with many schools trying it out successfully. The learner with VI is assigned a ‘buddy’ or many ‘buddies’ who are with her for different tasks. For instance, a buddy can sit with her in the class and help out with assignments, board work, etc., while another buddy can accompany her to the playground and yet another goes with her to the school bus at dispersal time. If implemented sensitively, it gives a chance to the learners to bond with and learn from each other. Peers can be encouraged to record books, help in preparing e-books, take printouts in large fonts, read aloud and study together.

## Misconceptions

There are many misconceptions associated with the visually impaired. We have understood the doctrine of sensory compensation in an earlier section, wherein other senses are thought to be heightened. However, this is not corroborated by research. People with visual impairment are also commonly believed to have an inherent talent for music. This belief leads to music being offered as a vocational option to learners with visual impairment, but there is no evidence of a direct connection between visual impairment and music. The misconception results in a denial of opportunities to explore other fields, such as dance and fine art. Many times, teachers are apprehensive about including learners with visual impairment in physical education and Yoga classes. However, such apprehensions are misplaced, since learners can adequately perform these activities with physical and verbal prompts. Science and Mathematics are believed to be areas which are difficult for learners with visual impairment, particularly at the secondary level. As a result, teachers actively discourage students from pursuing these subjects after eighth standard. Actually, the knowledge provided by these subjects is as relevant for them, as it is for other learners. This has far reaching consequences for their personal and professional lives. For instance, they are denied scientific knowledge necessary in order to understand the world around them. Moreover, concepts of Science and Math are essential for career deciding competitive exams. So, it has implications for the career avenues available to them as well.

We also find a belief amongst some stakeholders that the system of special schools is better suited for these learners. While there are many hurdles in the path

of inclusive education, the answer does not lie in reverting to the exclusionary practices of the past. Research has amply demonstrated the benefits that accrue from including all learners in mainstream schools.

## The Way Forward

Despite the many challenges present in the path of including learners with visual impairment in mainstream classrooms, the journey is worth embarking upon. There is a need for individuals involved in the education of learners with visual impairment to understand the issues that concern them and reflect upon the possible ways of negotiating these challenges. In this regard, the teacher needs to collaborate with various other functionaries, in order to enable the learner with visual impairment to effectively engage with the school and also to provide guidance to the learner, for the path after school. It is imperative that the whole process is imbued with a sense of dignity and self-respect, rather than an attitude of charity. Furthermore, the school should be designed in such a manner that it supports the learning of every student in an environment that welcomes diversity. The way forward needs to take into consideration the voices from the field, so that policy and practice reflect the views of both practitioners and learners with visual impairment.

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# Chapter 8

## Revisiting Inclusion of Children with Hearing Impairment: Issues and Possibilities



Sangeeta Singh

**Abstract** Children with hearing impairment are seen as a homogenous group having common educational and communication needs. Therefore, common intervention programmes and teaching strategies are considered for their inclusion in the classrooms. It reflects the limited understanding of the nature of hearing impairment where ‘one size fits all’ approach is used to educate children with hearing impairment. This approach can drastically impact the academic, emotional and psychosocial development of the child with hearing impairment. The chapter discusses the range of diversity among children with hearing impairment, their needs and related challenges faced by these children in inclusive settings. Role of various stakeholders in the inclusion of these children in classroom is also discussed.

**Keywords** Sign language · Communication · Diversity · Deaf · Hard of hearing · Social integration

### Overview

The present chapter focuses on understanding and addressing the issues, challenges and various perspectives of children with hearing impairment. According to the Rights of Persons with Disabilities Act, 2016 (RPWD 2016), persons with hearing impairment refer to (a) ‘deaf’ which means persons having 70 DB hearing loss in speech frequencies in both ears and (b) ‘hard of hearing’ which means persons having 60–70 DB hearing loss in speech frequencies in both ears. The RPWD Act, 2016, defines the hearing impairment in terms of hearing loss which is quantified in decibels. However, apart from degree of hearing loss, there is a range of variations among the persons with hearing impairment in terms of age of onset of hearing impairment, cause of hearing loss, type of hearing loss and the time of onset of hear-

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ing loss, i.e, whether the hearing loss is by birth or acquired in the later years of life. Communication, language, educational needs and intervention programmes vary depending on the nature of hearing impairment. Besides physiological variations, there are differences in how the people with hearing impairment are perceived in the society. It is very crucial for the people who are associated with the persons with hearing impairment directly or indirectly to understand the nuances of these variations. Hearing loss is not only the malfunctioning of hearing apparatus, but it also affects the child's cognitive, social and emotional development. Inclusion is a philosophy which urges to offer education to every child while considering their individual differences and needs. The act ensures that every individual must be included in regular school for getting education. For that, it incorporates various suggestions that ensure the accessibility to information, communication and educational institutes of children with special needs. After the Right to Education (RTE) Act, 2009, and RPWD Act, 2016, it has become mandatory to admit children with special needs in regular schools. The recommendations and suggestions given are on the basic assumption that children with special needs (CWSN) will be benefitted in regular schools in terms of education. However, there is a continuum in the nature of hearing impairment because of various factors that influence the communication and educational needs of children with hearing impairment (CwHI).<sup>1</sup> Before discussing the issues and challenges with respect to inclusion of CwHI, it is essential to understand the nature of hearing impairment and the perspectives about hearing impairment which is the base for their communication and educational needs.

*Alok is 16 years old studying in Class VIII. He has bilateral and moderate hearing loss. When he was 8–9 years old, he realized that he had a hearing problem. He used to mispronounce the words most of the time. During attendance call he says 'pasent' instead of 'present'. Other class fellows make fun of him and laugh on him whenever he pronounces the words incorrect. The teacher never stop them and understands why he is mispronouncing the words. His parents were not aware about the assistive devices and thus he did not use hearing aids. At Class VIII, few of his teachers could identify that he had problem in speaking. Many of his classmates don't like to interact with him since he doesn't understand what they are speaking. They found him dumb and give less importance to his views in classroom as well as informal discussions. When students were asked by the teacher to recite the chapter one by one, he realized he was not able to speak well. The teacher quit him and*

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<sup>1</sup>The term children with hearing impairment (CwHI) refers to both deaf and hard of hearing children. Considering their special needs and learning styles, the term deaf and hard of hearing will be used separately throughout the chapter. Here the term 'deaf' refers to those people who rely on sign language for communication purpose and who cannot be benefitted through assistive devices. Hard of hearing refers to those who have certain level of residual hearing and can be benefitted by the use of assistive devices.

*asked the next student to recite the chapter. On the occasion of ‘World Environment day’, he made a model like all of his peers in his class, but he was neglected because he couldn’t present his work. Realizing his performance he gave up participating in the upcoming competition held in the school. He keeps quiet in the class and does not try to engage in classroom activities.*

The case of Alok reflects the various challenges faced by children with hearing impairment in the regular classrooms. It is because of the lack of sensitization about hearing impairment among hearing peers, teachers and other school staff members. One can imagine how a curious child like Alok is demoralized for his unintelligible speech and special needs that are not fulfilled in the classroom. Here the question is whether it is Alok who is responsible for facing this situation because he is not among the so-called normal ‘hearing children’ or is it the classroom situation, environment and teacher’s and hearing peers’ attitude which are restricting him to be a part of the classroom like other hearing peers. Before we answer this question, we need to understand the various issues and concerns about hearing impairment. The next section discusses about nature of hearing impairment which is very crucial for everyone who is working with children with hearing impairment to understand and have knowledge about the range of variations among children with hearing impairment.

## **Nature of Hearing Impairment**

Generally CwHI are considered as children who cannot hear. However, the challenge is not only restricted to their ability to hear. Hearing loss impacts the child’s language, educational and social development which is significant for child’s holistic development. Hearing impairment entails wide range of variations which are because of numerous factors including cause of hearing loss, age of onset, types of hearing loss, degree of hearing loss and whether the hearing loss is by birth or acquired in later ages.

### **Alerting Signs Generally Shown by Children with Hearing Impairment**

- Child appears to have physical problems associated with ears. For example, she/he may complain about ear aches, discomfort in ear or strange ringing or buzzing sounds.
- Poor articulation of sounds by the child. She/he may particularly omit consonant sounds. Omitting consonant sounds from speech is often an indication of a high-frequency hearing loss.

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- While listening to radio, television or sound recordings, children with hearing impairment turn the volume up so high that others complain.
- Child turns her/his head towards the speaker in an apparent effort to hear better.
- Child frequently requests for repeated instructions.
- Child does not follow instructions or does not pay attention in the class.
- Child feels reluctant to participate in oral activities.

Adapted from T. Stephens, A. Blackhurst, & L. Magliocca (1982). *Teaching mainstreamed students* (New York: Wiley)

On the basis of degree of hearing loss, CwHI are classified into various categories. Decibel (dB) is used to refer the quantified description of hearing loss in a person. People with hearing losses up to 25 dB are still considered to have normal hearing. Many a times definition of hearing impairment varies slightly; however, hearing losses from 26 to 40 dB are more often categorized as *mild*, those from 41 to 55 dB as *moderate*, from 56 to 70 dB as *moderately severe*, from 71 to 90 dB as *severe*, and losses greater than 90 dB in the better ear are categorized as *profound* (Marschark et al. 2002). Hearing loss of any level can impact the social as well as emotional aspect of a person's life. Generally, people with relatively mild hearing loss are believed to have neurological problem rather than auditory as they can hear others talking but cannot understand them (Burkey 2006). However, it is not true. It is important to mention here that even a slight hearing loss is enough to prevent a person from hearing some of the softer consonant sounds.

Someone may have a different degree of hearing loss at different pitches. For example, someone might have a mild hearing loss in the low frequencies but a profound hearing loss in the high frequencies, which means that they could hear a dog barking but not the ringing of a doorbell.<sup>2</sup> Hearing losses can also be conductive which occurs as a result of interference with the transmission of sound from external ear to inner ear. Conductive hearing loss can be treated medically using antibiotics and decongestants and surgically by the insertion of PE tubes. Some conductive losses can be resolved spontaneously, while 'some residual of pathologic condition may remain for long periods of time' (Northern and Downs, 1974 as cited in Vinson 2001). Sensorineural hearing losses are due to the damage in cochlear hair cells. Unlike conductive hearing losses, sensorineural hearing losses are irreversible. There are various causes which are responsible for sensorineural hearing losses including ototoxicity caused by drugs (including certain antibiotics and drugs containing high levels of aspirin), infections (such as meningitis or maternal rubella) and genetic factors. When there is both conductive and sensorineural hearing loss in the same ear, it is categorized as mixed hearing loss. The level of hearing in a person having mixed hearing loss can usually be improved but not treated completely.

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<sup>2</sup>Source: <http://www.medel.com/blog/degree-of-hearing-loss>

A person may be post-lingual deaf or pre-lingual deaf based on the age at which she/he has lost her/his hearing. Pre-lingual deaf people are those who lose their hearing before they acquired speech, while post-lingual deafness develops after the acquisition of speech. Hearing loss which occurred before or at birth is called congenital hearing loss and that acquired after birth is adventitious. Most often it is believed that all pre-lingual hearing losses are congenital; however, it is not true. It is important to mention here that all congenital hearing loss is pre-lingual but not all pre-lingual hearing loss is congenital.

## Needs of Children with Hearing Impairments

Generally the attitude of the teachers and the stakeholders involved in the education and early intervention programmes for CwHI entails the notion of deficit model which is reflected in the programmes defined for them. There is more focus on use of hearing aids and other assistive devices so that CwHI could be taught by using speech. The idea here is not to demean the particular philosophy or approach for teaching CwHI. The point is to emphasize the fact that there is limited knowledge and awareness about the needs of CwHI. Generally, it is believed that there is a solitary way for teaching CwHI without considering the range of variations in the nature of hearing impairment.

Various needs of children with hearing impairment which impact their overall development are discussed below:

### **What Is Total Communication?**

*Total communication (TC) is the philosophy of educating children with hearing loss that incorporates all means of communication: formal signs, natural gestures, fingerspelling, body language, listening, lip-reading and speech. The goal is to optimize language development in whatever way is most effective for individual child. Total communication is truly a philosophy rather than a methodology.*

*Source: Communication considerations A-Z (<http://www.handsand-voices.org>)*

- **Language and Communication**

Acquisition of language is a critical aspect of child's development. It is pertinent to both the children with hearing impairment and hearing children. Language fluency at early period of child's life supports his/her social, cognitive and language development. It seems that children achieve language quite naturally; however, it needs explicit instructions at home and school as well. For vast majority of children with hearing impairment, language acquisition is a considerable challenge especially for those who have hearing parents. Deaf children especially do not get the

opportunity to communicate with the hearing people around them, thus restricting *incidental learning*. Delay in language development further impacts learning, cognitive and social development of children with hearing impairment. There is no solitary method through which children with hearing impairment can communicate. And we cannot say that a particular child with hearing impairment can use a specific way to communicate. It is very much depending on the nature of his/her hearing impairment, hearing status of their parents and immersion of child in the deaf community. There are various methods for communicating with children with hearing impairment which are as follows:

1. **Natural Sign Language:** For those children with hearing impairment who cannot master a spoken language, sign language provides an excellent alternative, for example, children with severe hearing loss and those who have pre-lingual hearing loss. Like spoken languages, natural sign languages are real languages comprising of large vocabulary in signs and grammar that determine the construction and combination of sentences. It is developed by deaf community for communication purposes (Jepsen et al. 2015). It is not universal. Every country has its own sign language developed by the deaf people of their country, for example, Indian Sign Language (ISL) in India, American Sign Language (ASL), Chinese Sign Language, Danish Sign Language, etc. Various parameters of Indian Sign Language include hand shapes, hand movements, orientation, location and facial expression (Zeshan 2000). When any of the parameters changes, meaning of the signs change.

Sign languages also make use of manual alphabets which is known as *fingerspelling*. Fingerspelling is used to spell out words. Different sign languages use different manual alphabets. For example, in British Sign Language and Indian Sign Language, two hands are used to represent the letters of the alphabet, whereas in American Sign Language, one hand is used.

2. **Signed Systems:** Signed systems are artificial manual coded English. It is a representation of English in a manual manner. It combines natural sign languages, English word order and grammatical markers (plurals, -ing, etc.).
3. **Simultaneous Communication (SimCom):** For children who have some hearing, the teacher might speak and sign at the same time, what is referred to in the United States as simultaneous communication or SimCom and in other countries as sign-supported speech. Simultaneous communication potentially could have advantages for children with cochlear implants or hearing aids, helping them to catch words or signs that they missed or did not understand. However it has a bad reputation from both linguistic and cultural perspectives.
4. **Spoken Communication:** Some deaf people especially those who are educated in mainstream schools and those who are post linguually deaf can speak. Even the hard of hearing people supported with assistive devices use speech for communication purposes.
5. **Speech-Reading/Lip-Reading:** Speech-reading is often used synonymously with the term lip-reading. Speech-reading is using what you see on the speaker's lips as well as facial expressions and gestures to understand conversation.

6. **Cued Speech:** Cued speech is another form of visual communication which is a supplement to spoken language intended to make it visible. It uses hand shapes and placements in addition to mouth movements to represent English phonemes or speech sounds. It is estimated that only about 20–30% of spoken English is visible on the lips. For example, if we pronounce the letters ‘m’, ‘p’ and ‘b’, they look the same; therefore, it is impossible to speech-read the words ‘mat’, ‘pat’ and ‘bat’. The words ‘mat’, ‘pat’ and ‘bat’ are distinguished through cueing the initial consonants by using different hand shapes, helping deaf child recognize which sounds are being used.

- **Social Integration**

### **An Experience of Hard of Hearing Student**

Tanvi is a hard of hearing student studying in a regular school with her hearing peers. She is the only hard of hearing student of her class. She wears BTE hearing aids on both ears. During group discussions, she asks her hearing peers frequently to repeat the sentences. Sometimes they repeat the content calmly and sometimes get frustrated while answering the same thing repeatedly. She is unable to understand the sentences spoken too fast during group discussion. Many times, she gave up participating in the discussion. According to her hearing peers, she just pretends to understand the content, and in reality she does not have that IQ to understand the things. Tanvi feels she cannot become like her hearing peers and does not fit into her class. As a result, she spends most of her time alone in the classroom.

As presented above, the case of Tanvi reflects the importance of social interaction with peers in the school for her social development. Usually, children with hearing impairment develop feeling of isolation in a regular school. It is because they are not accepted wholeheartedly by their peers and teachers which can lower their self-esteem. Now the question for teachers is what can be done to sort out such situation. It will be discussed in the later part of this chapter.

Learning of the roles, rules, attitudes and values of the community is an important part of a child’s development. It begins with the parent-child interaction which provides a foundation for social interactions with others. As compared to hearing peers, children with hearing impairment are socially immature (Marschark 1993). It is because of the absence of interaction and appropriate mode of communication used by the hearing parents and peers with them. They also face difficulties in acquiring and understanding moral and behavioural codes. This is so because these codes are transferred to one member of the society to others through verbal mode of communication which is not understandable to learners with hearing impairments.

In the classroom where hearing peers enjoy chatting and sharing jokes following typical auditory-oral mode of communication, it seems difficult for children with hearing impairment to participate in it. It happens with children with hearing impair-

ment when hearing peers do not know how to make his/her participation possible in the discussion.

As a result, child with hearing impairment feels isolated in a class which is considered as an important institution for making and maintaining social relationships. Moreover, learners with hearing impairment experience dearth of good friendships with hearing peers and constant lack of everyday conversations and discussions that take place between hearing peers.

## Perspectives of Deafness

The term hearing impairment comprises two categories which are deaf and hard of hearing. According to RPWD 2016 Act, the two categories refer to the classification of people with hearing loss based on the degree of their hearing loss. However, people from deaf community visualize the difference based on the use of language and cultural norms associated with it. Sign language is not only the medium for communication purpose, but it is part of their identity. Based on the view how deafness is perceived and by whom, the educational settings, communication choices, teaching styles and learning environment are determined for educating CwHI. Like models of disability, deafness is perceived under medical, social and cultural model of deafness. These models are the reflection of understanding of deafness from the insiders' and outsiders' perspective. First is the medical model which represents the view of *hearing world* about congenital deafness (Power 2005). Here the focus is on the inability of a deaf person to hear and communicate through speech. It is based on the deficit theory and holds that deafness is a pathological condition or inability to hear and thus a person is disabled because of her/his faulty hearing ability. Contrary to this is the sociocultural model which is also called constructionist model. The proponents of this model believe that people construct their lives through the interaction with other individuals and agencies of the culture in which they live (Powers 2002). These agencies may include education, religion, peer group, social class, vocational institutes and families which play an important role in the formation of their selves. According to Senghas and Monaghan (2002), deafness under sociocultural view is 'identified as one range within the larger spectrum of human variations, and this view assumes that deafness allows for an alternate constellation of very human adaptations, among the most central being sign language'. Here we can say, sign language plays a central part in forming an identity of a deaf person. It is something like what most of the people from deaf community say 'We are not disabled but are Deaf' since they can communicate using their own language which is sign language.



## **Inclusion of Children with Hearing Impairment**

Defining inclusion or inclusive education is an arduous task especially when it has various meanings associated with it. There is confusion over whether inclusion is a 'goal' or a 'state' or a 'process' (Powers 2002). Without getting caught into the confusion of elucidating inclusion, I will use the definition of 'inclusive education' provided in the RPWD Act, 2016. According to the act, 'inclusive education' means a system of education wherein students with and without disability learn together and the system of teaching and learning is suitably adapted to meet the learning needs of different types of students with disabilities. The definition recognizes the individual differences of a child in terms of her/his learning needs and emphasizes on 'learning together' irrespective of whether the child is with disability or without disability. The act has recommended various provisions aimed at successful inclusion of children with disabilities. In particular for children with hearing impairment, it is for the first time the act recognizes the importance of sign language for communication and accessibility to educational institutes, public offices, television programmes, hospitals and recreational centres.

### **A Regular School Teacher's Reflection on Inclusion of Children with Hearing Impairment**

Inclusion for children with hearing impairment is an opportunity for them to study with the hearing children. They will learn to adapt in the society better if they are educated in a regular school. However, as of now, I do not feel prepared to deal a deaf student in my classroom. It is because I am not a trained teacher as special teachers are to teach deaf students. Secondly, how will I communicate with deaf child is a big question for me. Yes, I feel I could handle a hard of hearing (HOH) child. I think there would not be that much problem with HOH child since she/he can be benefitted from assistive devices. They have fewer challenges related to communication as compared to deaf children who cannot hear and speak. One can manage to include HOH in a classroom by incorporating few classroom modifications like seating arrangement and use of more visual aids.

The reflection of a teacher teaching in a regular school clearly indicates various misconceptions and apprehensions related to teaching a child with hearing impairment. The teacher distinguishes deaf child and hard of hearing child on the basis of their needs especially related to communication. Most of the teachers in Indian context feel impractical to include deaf child in a regular school because of their unique language and communication needs. Most of the times, HOH are considered as children with impairment who can become like a hearing child with the use of

assistive devices. However, it is a big mistake because they have special learning styles and needs that are required for their academic and social development. Recall the challenges faced by Tanvi who is only the hard of hearing student in her class. During the fieldwork for my doctoral study, I found various challenges as seen by the educational stakeholders for inclusion of deaf children in regular school which I would like to reflect upon here:

1. **Lack of proper infrastructure:** The schools do not have proper infrastructure in terms of acoustic environment, furniture and space to arrange the seating arrangement especially for group discussions. Secondly, there is unavailability of assistive and support devices needed for the children with hearing impairment. One can say there is long way to go for achieving universal design for learning.
2. **Lack of appropriate training:** Most of the teachers in regular school feel that they need in-service training programmes in the form of workshops, conferences and seminars for understanding and addressing the needs of children with hearing impairment. Most of the times, training programmes are organized in accordance with the presence of children with the kind of disabilities they have in their school.
3. **No training in sign language:** Teachers in regular schools found communication as one of the big challenges for teaching deaf child. According to them, they are not trained sign language professionals who can address the language and communication needs of a deaf child. Some of them feel that depending on other professionals who know sign language will prevent them from building a positive teacher-student relationship with children with hearing impairment.
4. **Lack of awareness about children with hearing impairment:** Teachers in regular school have limited understanding of children with hearing impairment. It reflects the need to update the curriculum for teacher education that entails the content related to children with special needs and appropriate programmes for successful inclusion.

Inclusion of children with hearing impairment cannot be possible without the collaboration of teachers, family and community. Besides teachers and family, peers play an important role in the life of every child, and children with hearing impairment are not exception. In this section, I would like to throw light on the role of people who are directly or indirectly responsible for the language, social, emotional and cognitive development of a child with hearing impairment.

## Role of Family

Hearing status of parents plays a crucial role in the acquisition of language in deaf children. For many hearing parents, having a deaf child is their first experience. They encounter with the challenges in taking decision related to communication choices and kind of schools for their deaf child. Deaf children of deaf parents are

privileged to have a home environment providing full access to a natural visual language, i.e. sign language from birth. Contrary to it, hearing parents are in the vulnerable condition since they do not have understanding about various communication strategies that can be used for communicating with their deaf child. They get trapped into the medical-driven advices from medical professionals once they realize about the hearing impairment of their child. It is drawn towards speech therapy and use of assistive devices so that a child with hearing impairment will be able to hear and speak. The irony is parents focus on intervention programmes to develop the speech of their child with hearing impairment without the knowledge of the nature of hearing impairment their child has. They do not realize the significance of critical period of language development which is missed in the hope that their child with hearing impairment would speak like a hearing child.

We can say modality of language is not important. It is crucial to develop a language in any form so that child with hearing impairment can communicate with the people around her/him. The parents-child bond gives a child with hearing impairment a secure base for exploration, from which she/he can learn about the world on her/his own – eventually leading to positive self-esteem and self-confidence.

### **Hasina's Story**

*'Hasina, an 18-year-old girl from Muslim family, studies in eighth standard in a Hindi medium school for the deaf. According to her mother, Hasina was born with normal hearing. When she was 7 years old, she had typhoid and tuberculosis, and "126 injections of streptomycin" were given to her. As a result, she gradually developed hearing loss and her speech was also affected. After consultations at hospital, she was diagnosed as having bilateral severe sensorineural hearing loss. At the age of 8, she was admitted to a school for the deaf. She wears body-level hearing aids, which she finds beneficial. She communicates through mix of verbal speech (incomplete sentences) and sign language. She takes a little time to understand what is said to her, but she loves to respond. It is not difficult to understand her speech provided one makes little extra effort. Hasina feels frustrated when her family fails to understand her – she is convinced that they do not pay enough attention to her'.*

### **Radha's Story**

*'Radha is 15 years old and is the only child of educated parents from upper socio-economic strata. She studies in Class X in an English medium school for the deaf. Radha's parents had noticed her deafness before she was a year old. Radha was diagnosed with bilateral profound sensorineural hearing loss, and she has used BTE (behind the ear) hearing aids regularly at home and at school. She and her parents communicate orally, which is quite stressful for all of them.*

*Radha does not have any friends in the neighbourhood. She hates the school holidays as she feels lonely at home. Her mother does not allow her to visit her school friends since they stay far from her house. Radha reveals that her mother begins vomiting and has dizzy spells, if she comes home late from school or visits her friends on her own. She is tired of her mother's overprotective attitude. She realizes that she needs her mother's emotional support but at the same time fears her.*

*She maintains little communication or interaction with her father, who stays in Cochin for long spells, and she gets very tense when interacting with him'.*

Adapted from Limaye (2013).

Hasina's story highlights the role of parents in creating home environment which is suitable for healthy communication with their child with hearing impairment. Communication gap often leads to develop feeling of isolation among children with hearing impairment in their home. Parents often guess and comprehend their child's unintelligible speech at their own level which sometimes is not correct. It leads to frustration and negative attitude towards parents by the children with hearing impairment. Radha's story reflects her frustration because of overprotective nature of her mother. It has been found by research study that overprotection and poor sociability make children less independent that precludes their development and is one of the reasons for low self-esteem among children with hearing impairment (Gomez et al. 2014). Therefore, one can say that parenting of a child with hearing impairment plays a vital role in developing an overall development of a child with hearing impairment.

## Role of Peers

Adolescents need to feel accepted and to participate in the school activities in order to develop positive self-image (Israelite et al. 2002). If adolescents with hearing impairments perceive themselves to be accepted and liked by their peers in classroom, they will develop positive feelings which will also enhance their self-esteem. Positive self-image is very important to any adolescent as it affects socio-affective domain of his/her development. Therefore, it is required for teachers to organize learning experiences that include participation of learners with hearing impairments to foster positive sense of self.

I would like to mention here again the experience of Tanvi discussed earlier in the chapter. We would discuss here, implications for teachers to involve children with hearing impairment and hearing peers so that every child would feel as part of a class:

1. A teacher can conduct activities where children have the opportunity to know about the strengths and weaknesses of their peers. It will help them to respect and value the individual differences. It is always good to encourage group activities as it helps to develop social skills and team spirit. For example:

*Divide the students into three or four groups. Ask the students of a group to write at least three positive qualities of each member of other group on a chit. For example, students of Group A will write positive qualities for the members of Group B and Group B for Group C and so on. Now mix all the chits and ask each student to take one chit and tell the name of the student and his/her positive qualities written on it. Once the activity is done, ask every student:*

- *How do you feel about the words that were written to describe you?*
- *Were you surprised by any of the words that were chosen to describe you? If so, why?*

2. Encouraging social support: The educational planning must incorporate the opportunities for social support and interaction for children with hearing impairment. There is a need of giving minimal attention to the social needs of learners with hearing impairments so that they could be included in mainstream settings. Teacher can play an important role to make meaningful social connections between all children.

Following are the strategies that a teacher can use to provide social support and develop social skills:

1. **Games:** Competitions in games like cricket, chess, football and other recreational activities can promote interaction between hearing peers and learners with hearing impairments.
2. **Activities:** Promote activities where hearing peers could understand the communication needs of learners with hearing impairment. Learners with hearing impairment can be designated as ‘signing specialist’ in the classroom. Assign them the task of teaching sign language to their hearing peers and teachers for approximately 30 min once in a week. This will promote the interaction between them and help them get away from the feeling of isolation.

## Role Model

Bringing adults with hearing impairment into the classroom whenever possible will enhance role model opportunities. Above all the voices of those hearing impaired adults who have gone through inclusive educational settings must be recognized. These individuals should be viewed as desirable consultants in formulating school programs.

## Classroom Implications

This section is divided into three parts. First part highlights the modifications one can adopt in the classroom environment to make it conducive for teaching-learning process. Second part discusses the general teaching adaptations that could enhance learning skills among children with hearing impairment. Finally, the last part covers the various strategies to involve students in classroom participation.

## 1. Classroom environment

- Reduce noise and reverberation by using carpets, draperies, acoustic ceiling tiles and other acoustic wall treatments.
- Set up semicircular seating arrangements so that children with hearing impairment can see other students during classroom discussions.
- Seat child with hearing impairment in the place from where she/he can comfortably attend and participate during teaching-learning process.
- Do not let the child with hearing impairment to sit near door and windows. Such locations are sources for distraction while learning in the classroom.
- Avoid activities that can create noise in the classroom (dragging furniture, turning on air conditioners, fans, exhaust fans, etc.). It can disturb learners using hearing aids and those having cochlear implants.
- Always ensure that there is adequate light to see the teacher's face. It helps the lip-readers to visualize the instructions clearly.
- Avoid standing in front of a light source like a window – the glare from behind makes it difficult to read lips.

## 2. General teaching adaptations

- Use visual media (e.g. overhead projectors, charts, models, handouts, flash cards and videos) as much as possible while teaching. Try to arrange videos having captions or subtitles.
- Avoid covering your face with scarves or hands while teaching. Male teachers must trim their moustache and beard to avoid covering of their lips. Otherwise, lip-/speech-readers find it difficult to get the verbal instructions in the classroom.
- Avoid shouting while teaching as the messages become distorted through hearing aids and cochlear implants.
- Team teach with sign language interpreter and/or special educator of students who are deaf or hard of hearing when needed.
- Always maintain eye contact with children with hearing impairment. It conveys direct communication. Even in the presence of sign language interpreter, communicate directly to child with hearing impairment. She/he will turn to the interpreter as needed.
- Provide regular breaks to children with hearing impairment. The effort to listen the classroom instructions and other conversations taking place in the classroom often increase their fatigue level.
- Keep instructions brief and as simple as possible. Avoid paraphrasing, when repeating instructions. Repeat exactly the same sentence.
- While teaching stick to one topic and complete it. Then go for another topic. Otherwise learners with hearing impairment get confused. Context is important for lip-readers.
- Ensure that lecture notes and copies of OHTs or PowerPoint slides are available (as a handout or on a website) in advance of the lecture if possible, so the student can become aware of the material and its vocabulary.

- **Direct Instructions:** Unlike hearing peers, learners with hearing impairment do not absorb information from the environment passively and thus miss out information related to day-to-day life activities. As a result, learners with hearing impairment need to be taught by giving direct instructions, the skills which hearing learner can easily take in incidentally.

### 3. Classroom participation

- Cue student visually to indicate them that someone is talking during classroom discussions. Repeat the information when needed. It will help the students to feel involved in the classroom discussions.
- Group discussions should be controlled in such a way that every student gets chance to participate. One student speaking at a time works well for hard of hearing student. Otherwise it becomes difficult for them to focus on so many speakers at a time.
- Peer-tutors, note-takers and cooperative learning methods can be used to encourage their participation in classroom activities. Teacher can involve one of the peers to make notes of classroom instructions.
- Provide extended time to learners with hearing impairment during tests.
- In small group discussions, allow for participation by children with hearing impairment. Ask for a hearing peer to team up with the learner with hearing impairment for group activities.
- Allow children with hearing impairment to make models, role-play, and develop skits and projects to demonstrate their understanding of the information.

## Misconceptions and Myths About Hearing Impairment

There are various misconceptions related to hearing impairment which sometimes have cumulative impact on the challenges faced by CwHI. Prevalence of misconceptions creates obstructions in reaching out to the proper resources and educational needs required for the intervention and holistic development of a CwHI. Some of the misconceptions are discussed below:

- People with hearing impairment are totally deaf and they cannot perceive any sound. In reality, few are without residual hearing. Residual hearing is the hearing that remains after the onset of hearing loss.
- Hearing aids and cochlear implants will restore hearing and/or cure hearing loss. These devices can only offer a child with benefits such as hearing speech and environmental cues including sound and music. The benefits derived by the person with HI via the devices mentioned above are dependent on various factors including age, duration and degree of hearing loss.
- It is a big misconception that all people with hearing impairment are excellent speech-readers. All deaf people are not comfortable with lip-reading. Regardless

of their ability and comfort level, ‘deaf people are able to get only 20 to 30 percent of conversational content when lip reading and can identify perhaps three to four words out of every ten’ (Chambers et al. 1998).

- All people with hearing impairment use sign language for communication purposes. There are different kinds of communication needs of a person with HI depending on her/his severity of hearing loss, age of onset, immersion in the deaf community and cause of hearing loss. Many people with hearing loss do not use sign language. Those who have enough residual hearing function successfully through a combination of hearing and lip-reading.
- All people with hearing loss are the same. It is incorrect to say that as there is no diversity among people with hearing impairment. Their interest, abilities, dreams, tastes, talents and viewpoints are as diverse as so-called hearing people have (Chambers et al. 1998).
- All people with hearing impairment have same special needs. It is a big mistake to view people with hearing impairment through same lens which can have devastating impact on their academic and social development.

### **Common Myths About Deaf Children’s Language**

- *Sign languages are an inferior form of communication primarily useful for ‘oral failures’.*

Natural sign languages fully support child development and education. American Sign Language, spoken English, French Sign Language and spoken French, for example, are all true languages, and none is inferior to another.

- *Learning to sign interferes with learning to speak.*

This myth has long been passed from profession to profession, but there is no evidence to support it. Sometimes learning to sign actually facilitates acquisition of spoken language by deaf children, and other times it is independent of it.

- *Any deaf child can learn to speak.*

Perhaps, but she/he may cannot speak necessarily with sufficient intelligibility for people outside of the family to understand him/her. Programs that advertise this claim do not accept (or eventually transfer out) deaf children who do not have or do not acquire sufficient spoken language skills

- *Identification and intervention within the first 6 months enables deaf children to develop language normally.*

Even with early identification and intervention, deaf children typically fall in the bottom 25% of the range of ‘normal’ language development compared to hearing peers.

(continued)



- *Deaf children with cochlear implants develop normal speech and language.*

Many of them develop better speech and language, but rarely as good as hearing children. These children receive extensive speech training, which also contributes to the speech intelligibility; it is not implant alone.

- *Children with cochlear implants should not be allowed to learn sign language.*

There is no evidence that this is harmful, and there is even some evidence that it leads to better academic and social outcomes.

- *Hard of hearing children develop language and academic skills similar to hearing children.*

Those children often have good speech, leading to the assumption that they hear better than they really do. In fact, even children with minimal hearing losses frequently demonstrate language and academic delays.

Source: Marschark, M. & Hauser, P.C. (2012). *How Deaf Children Learn: What parents and teachers need to know*. NY: Oxford University Press

## Way Ahead

In conclusion, it can be said that there is no ‘right’ way or perfect solution to teach children with hearing impairment. The range of variation among children with hearing impairment is so vast that one cannot rely on solitary approach for their communication choices and educating them. There is utmost need of collaboration of direct educational stakeholders including teachers, Principal, school administration staff, parents, medical professionals working in the field of hearing impairment, special educators, deaf role models, deaf educators, peers and community. Understanding of different perspectives of deafness is crucial for all the people involved in the intervention programmes and communication choice for deaf and hard of hearing children and for taking academic decisions for them. The new RPWD act focuses on the endeavours such as incorporation of sign language in educating children with hearing impairment and use of appropriate technology to support access to communication and education for such children. There is lot to do in terms of creating sensitization among teachers, parents and people who are directly or indirectly involved with children with hearing impairment, providing training programmes for addressing the language needs and social needs of these children. For that collaboration of teachers, parents and community is required to work together to remove all the barriers faced by children with hearing impairment including attitudinal barriers.

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# Chapter 9

## Specific Learning Disability: A Hidden Disability



Apoorva Panshikar

**Abstract** The chapter ‘Specific Learning Disability: A Hidden Disability’ purports to educate the reader about one of the high incidence disabilities, i.e. specific learning disability (SLD). In the chapter, attempts are made to bring about understanding of the concept of SLD, its characteristics and types. The causative factors are discussed not so much from a medical perspective as social perspective. Efforts are made to clarify the misconceptions surrounding the condition. The numerous ways to support a child with SLD in schools (to meet the academic and nonacademic needs) and in community are included. Discussions on the issues, challenges and future paths in the field of SLD attempt to give a near holistic understanding.

**Keywords** Specific learning disability · Disabilities · Hidden disability · Academic problems · Strategy training

### Overview

In this chapter, we will attempt to comprehend the concept of specific learning disabilities, commonly represented as SLD, the context that guides the attachment of the label of SLD to an individual, the misconceptions around the condition, the academic and psychosocial needs of individuals with SLD and ways to help children with SLD in classrooms. The discussions cannot be complete without dwelling on the role of parents and important people in the child’s life in helping the child deal with SLD. There are challenges in any walk of life. This is true of the field of SLD as well. The future trends guide the way ahead for the field and individuals living with the condition.

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## Conceptual Foundations

In a mainstream or inclusive education classroom, the most commonly found disability is SLD. In India, various studies done have documented the prevalence of SLD between 3% and 14% of school-going population (Bandla et al. 2017; Padhy et al. 2016; Mogasale and Mogasale 2012). The term ‘learning disabilities’ was first coined in the year 1963 by Samuel Kirk, and even today it is a general term that is used to describe learning problems of a specific kind.

National Joint Committee on Learning Disabilities (NJCLD 2016), a coalition of parent and professional organizations in the USA, updated the following definition of learning disabilities in 2016 (which was adopted in 1990):

Learning disabilities is a general term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning, or mathematical abilities. These disorders are intrinsic to the individual, presumed to be due to central nervous system dysfunction, and may occur across the life span. Problems in self-regulatory behaviors, social perception, and social interaction may exist with learning disabilities but do not by themselves constitute a learning disability. Although learning disabilities may occur concomitantly with other disabilities (for example, sensory impairment, intellectual disabilities, emotional disturbance), or with extrinsic influences (such as cultural or linguistic differences, insufficient or inappropriate instruction), they are not the result of those conditions or influences.

An analysis of the definition of LD given by NJCLD indicates the following:

- (i) Specific learning disabilities (not learning disability) is a group of disorders. It is characterized by a group of difficulties (not just one problem) in a person that manifests differently in different individuals. To illustrate, a child may not show only reading problems; it may be accompanied by oral language issues and problems in doing math word problems as well.
- (ii) There exist a wide range of problems in the skills that individuals acquire and use across their life span. These include listening, speaking, reading, writing, reasoning and mathematical abilities.
- (iii) Different children with LD have different combinations of problems. The severity of the problems also differs. For example, one child with LD has problems in reading and maths, while another exhibits issue in reading and spelling, and a third child has difficulties in understanding and using oral language. Similarly, two children with reading difficulties manifest the problems differently. One student can read fluently but cannot understand what is read, while another child cannot read at all.
- (iv) The above listed problems are not just difficulties but are ‘significant’ difficulties. This implies that when standardized tests (educational or tests of psychological processing) are administered to the person, she/he shows a lag of at least 1.5 to 2 years in academic achievement or cognitive processing on the tests.

- (v) LD is due to dysfunction in the central nervous system. There may be hereditary, genetic or even environmental factors responsible for causing the central nervous system dysfunction.
- (vi) Along with the problems in reading, spelling, writing, mathematics, etc., the child may show problems in social skills and self-regulation. A child may thus have problems in making friends, difficulty understanding nuances of nonverbal behaviour, deficits in making decisions in social situations, etc.
- (vii) A person with other disabilities as intellectual disability (formerly called mental retardation), visual impairment, hearing impairment and emotional disturbance may have an LD; however, intellectual disability (or any of the other disabling conditions) cannot lead to a LD. These conditions do not cause an LD; they can coexist.
- (viii) LD exists irrespective of cultural background, social strata, economic strata, impoverished familial background, opportunities for educational access and school environment.

LD is neither a disability in the Western countries nor an English-language-based condition. It is therefore reassuring to review the definition of LD used in India and defined in the Rights of Persons with Disabilities Act (RPWD) of 2016. It was only in the year 2016 that India acknowledged ‘specific learning disabilities’ as a disabling condition and defined ‘specific learning disabilities’ as:

a heterogeneous group of conditions wherein there is a deficit in processing language, spoken or written, that may manifest itself as a difficulty to comprehend, speak, read, write, spell, or to do mathematical calculations and includes such conditions as perceptual disabilities, dyslexia, dysgraphia, dyscalculia, dyspraxia, and developmental aphasia. (Rights of Persons with Disabilities Act 2016)

The major difference that exists in the RPWD as compared to the NJCLD is that it does not refer to the aetiology of LD which is clearly listed in the NJCLD definition. Similarly, it does not mention the secondary manifestations of LD, the comorbid conditions or the deficits in acknowledging that problems in reasoning may be present.

## Characteristics of Children with Specific Learning Disabilities

The case of a 12-year-old student may illustrate some of the classic problems experienced by a child with LD:

*The class teacher of this grade 7 student had observed these behaviours: The student required constant reminders from the teachers to pay attention to any activity done in class – be it an academic activity or non-academic activities like art/craft. Incomplete notebooks, spelling errors, answers that made minimal sense characterised his written work. He read like a grade 3 student – slowly, with a lot of effort and he could barely retell what he read. He was a loner, his classmates found him stupid, and he was bullied by many in his class. He ‘seems lost’, his teacher would say.*

Though the described case is a rather illustrative one, a single case description cannot highlight the wide spectrum of difficulties experienced by persons with SLD. Beyond doubt, the most common characteristics of SLD are difficulties in reading, writing and doing mathematical calculations. However, a person with SLD may not possess only just these characteristics. Janet Lerner (2000) has listed nine defining learning and behavioural characteristics of persons with SLD (some characteristics seen in the cases described above will be found here):

1. **Attention related:** Those students with attention disorders may not be able to focus their attention or sustain their attention to complete tasks. They are highly distractible. These children are the ones who may have attention deficit hyperactivity disorder along with SLD.
2. **Poor motor abilities:** Gross and fine motor movement problems may be exhibited by some students with SLD. Difficulties in coordination of motor skills may be observed as well.
3. **Psychological processing and information processing problems:** Issues in processing visual and auditory information to make sense of it may be present. Discriminating visual and auditory stimuli, blending sounds to make words, etc. is a difficulty faced.
4. **Oral language difficulties:** Several persons with SLD show problems in understanding oral language. Poor vocabulary, poor communication and listening and speaking skills are likely to be seen.
5. **Reading difficulties:** Problems in decoding words and reading sight words and problems in comprehending read information are seen in majority of students with SLD.
6. **Written language difficulties:** Many students may exhibit problems in writing. Communication of ideas through written mode is a concern, and it may be characterized by grammatical errors, poor ideas and vocabulary inappropriate for the level.
7. **Mathematics difficulties:** Understanding mathematical concepts, doing arithmetic computations, solving quantitative problems and understanding time and measurement seem to be problem areas for some students with SLD.
8. **Social skills deficits:** SLD for a few is manifested in learning to use appropriate social behaviours as well. Difficulty in learning how to act in social situations leads to poor social relationships and difficulty in making friends and maintaining friendships.
9. **Executive functioning deficits:** Some witness a major difficulty in regulating their thinking to organize information for effective use. Higher-order thinking, problem-solving and adaptability require use of executive functioning.

Prior to Lerner, Clements (1966) enumerated ten characteristics of SLD, viz. hyperactivity, impulsivity, perceptual-motor impairments, disorders of memory and thinking, emotional lability, academic difficulties, coordination problems, language deficits, disorders of attention and equivocal neurological signs. In addition to the list of characteristics mentioned by Lerner, Clements mentions emotional lability as an important characteristic. In many individuals with SLD, we observe

sudden mood changes, a characteristic that increases the chances of poor social relations for them.

It may appear that the major concerns for a person with SLD are meeting the academic demands and fulfilling the expectations of structured and formal learning conditions. This primarily may be true; nonetheless it is seen that the experience of failure at academic tasks, inability to satisfy parental and teacher expectations, etc. lead to secondary problems. The emotional scars of repeated failure and the inability to achieve and develop a sense of competence and self-worth are often indelible. Consequently, students with SLD sometimes develop secondary emotional disturbances. About 30% of children with SLD have been found to show behavioural and emotional problems, viz. attention deficit hyperactivity disorder, depression, anxiety, suicidal ideation, substance abuse, etc. (Sahoo et al. 2015). The student whose failure to learn is accompanied by emotional problems may be the victim of a continuous cycle of failure to learn, and thus it can lead to adverse emotional responses – feelings of self-derision, poor ego perception and anxiety which augment the failure to learn syndrome. Low motivation, anxiety, poor self-esteem, behavioural concerns, psychosomatic effects and being self-critical and critical of others are some of the psychological effects of having SLD.

## Types of Learning Disabilities

The fifth edition of *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* revised in 2013 lists specific learning disorder as a diagnostic condition and states that ‘it is a neuro-developmental disorder of biological origin manifested in learning difficulties and problems in acquiring academic skills markedly below age level and manifested in the early school years, lasting for at least 6 months; not attributed to intellectual disabilities, developmental disabilities, developmental disorders, or neurological or motor disorders’. The diagnosis requires the clinician to specify whether there is an impairment in reading, written expression or mathematics and specify the level of severity of the condition and requires that the diagnosis mention it.

Based on the identification criteria, at least three types of specific learning disabilities can be delineated: specific learning disability in reading, specific learning disability in writing and specific learning disability in mathematics:

1. SLD in reading includes possible deficits in word reading accuracy, reading rate or fluency and/or reading comprehension. This condition is also known as dyslexia. It is the most common type of SLD.
2. SLD in written expression includes possible deficits in spelling accuracy, grammar and punctuation accuracy and/or clarity or organization of written expression. Dysgraphia is another term used to communicate problems of this kind.

3. SLD in mathematics includes possible deficits in number sense, memorization of arithmetic facts, accurate or fluent calculation and/or accurate math reasoning. The given condition is called dyscalculia at times.

The RPWD Act (2016) mentions that conditions like dyslexia, dysgraphia, dyscalculia, perceptual disorders, developmental aphasia and dyspraxia are included in the term SLD. The terms dyslexia, dysgraphia and dyscalculia are synonymous with three SLDs – SLD in reading, SLD in written expression and SLD in mathematics, respectively. Developmental aphasia is an impairment of language, affecting the production or comprehension of speech and the ability to read or write (National Aphasia Association, n.d.). Dyspraxia on the other hand as defined by Dyspraxia Foundation refers to a disability affecting fine and/or gross motor coordination in children and adults.

## Sociological Perspective of SLD

That the cause of SLD is the dysfunction of the central nervous system is a known fact. The medical model of disability views disability as entrenched in the person (the brain, in case of SLD), and thus the locus of the problem is the person. The aetiology of SLD can be traced to heredity, genetic make-up, exposure to teratogenic influences in prenatal or postnatal developmental stages, trauma during birth or in the developmental period or metabolic conditions. It is a well-accepted fact that these conditions will cause SLD; yet, the severity of the manifestation of the condition is variant and dependent on many factors extant in the context the person lives in. Conceptually, the socio-environmental factors do not cause SLD. Nonetheless, the difficulties experienced by the person can be aggravated or abated due to conditions prevalent in the person's social milieu.

The sociological aspects prompt not only the identification of the disabling condition but also the possibility and nature of service provision for a child with SLD. The identification of SLD appears to be guided by factors like exposure to educational opportunities, facilities for availing appropriate education, multilingualism (Ahmad 2015), multiculturalism, qualifications of school teachers, quality of teachers, stability of teachers in schools, impoverished family backgrounds, urban-rural differences, availability of cultural-fair assessment tools (Ahmad 2015), trained professionals to conduct assessments with expertise, media exposure to the disability, the government schemes and policies, teacher expectation of students learning vis-à-vis curricular demands, ability-based grouping of classes, social stigma/social acceptance (Ahmad 2015), etc. The situation in India is thus teeming with numerous instances affirming the same.

The case of Ajay, a 9-year-old studying in grade 4, may shed light on some socially driven factors that augment the likelihood of the identification of SLD and his not being able to get the services he needs. The child's personal, medical and



academic history as reported by his mother help understand it better (M. Raut, Personal Communication, September 11, 2017):

*Ajay has a perinatal medical history of neonatal jaundice (that required hospitalization), and high fever accompanied by febrile convulsions at age of one and half year. Neonatal jaundice, high fever and febrile convulsions are documented causes of SLD. Hence, a neurobiological basis of SLD exists. Ajay's parents are separated, and the mother is trying to make ends meet. She is unable to spend time with him. Ajay attends a government run vernacular school. The mother said that his teachers change very often and there is no consistency in the education the students receive. She feels that the problems started when Ajay was in grade 2 and his class did not have a teacher for 2-3 months. The school head is very particular about implementing government policies and so he refers underachieving students for SLD assessment. The school, however, has no special education teachers. When Ajay was referred for a clinical psycho-educational assessment, the professionals who were to assess him did not have standardized assessment tests in his language. He was assessed to have SLD using informal measures. Ajay's mother has no cognizance of what the implications are of having SLD or what line of action is to be charted.*

The case prompts us to dwell on the inherent sociological aspects that may be enumerated as the child's family situation, the socio-economic stratum he belongs to, inconsistent teaching-learning opportunities, inconsistent quality of education, proactive school head, presence of mechanism to assess the student, nonavailability of appropriate assessment tools, absence of special educator in the school to provide remedial intervention, etc. Given this combination of factors, the child is bound to experience academic as well as psychosocial difficulties. Unlike in the case of Ajay, some children who have SLD may not be identified because the parents and the family fear social rejection and ridicule. Hence, they may deny the existence of the problem. In such a situation, the child will suffer academic failure and experience some psychosocial issues but may not get formal help.

## Issues and Challenges

The field of SLD is rather fluid, and the discord far outweighs consensus. The NJCLD, (elaborate) in 1994 listed the following issues:

- Lack of understanding, acceptance and willingness to accommodate normal variations in learning and behaviour
- Lack of sufficient competent personnel and appropriate programmes to support the efforts of teachers to accommodate the needs of children who do not have learning disabilities but who require alternative instructional methods
- Insufficient supply of competently prepared professionals to diagnose and manage exceptional individuals
- The false belief that underachievement is synonymous with specific learning disability
- Failure of multidisciplinary teams to consider and integrate findings related to the presenting problem(s)

- General preference for the label ‘learning disability’ over ‘mental retardation’ or ‘emotional disturbance’, which leads to the misclassification of some individuals

Given the Indian scenario, there are plenty of issues that affect the well-being of persons with SLD, and many of them arise from the conceptual understanding of the disability to operationalizing the definition and to the nature and scope of research undertaken in the area. Lack of clear definition and understanding about SLD (Ahmad 2015), lack of awareness about SLD (Ahmad 2015; Karande 2008), non-availability of standardized tests for the Indian population and in vernacular languages and high cost of remedial services (Karande 2008) are burning issues even today. Many a time, the fear of stigma and low awareness levels leads to poor referrals for assessment (Shah and Trivedi 2017).

The situation in our country is more than alarming because there is documentation of certification of SLD practices in just a handful of places, viz. Maharashtra, Karnataka, Kerala and Delhi (Sandhu 2015). In addition to this, lack of clarity about how to quantify SLD to meet the benchmark requirement of 40% disability as required by RPWD Act makes it difficult to diagnose an SLD (Sandhu 2015) that warrants legal provisions for educational supports.

It is observed that teachers are often unable to differentiate children with SLD from children who are underachieving for reasons other than the child’s distinctive characteristics. This leads to a skewed misrepresentation and teachers often resorting to grouping all underachieving children as ‘learning disabled’. In the USA in the late 1970s, the Response to Intervention (RTI) model was proposed. It aimed at systematically identifying children with LD than labelling them primarily based on ability-achievement discrepancy. The model is a three-tiered model, wherein at tier one all students receive systematic evidence-based teaching. Those who do not achieve set objectives are placed in small group instruction environment. Despite this if some student fails, then thorough assessment is conducted to ascertain the presence of a specific disability. This model is nearly non-existent in Indian schools (Venkatesan 2016), and therefore, any underachiever is referred for in-depth psycho-educational assessment. Though the RTI model is a widely employed model in the West, it is not without problems; for example, the underachievement criterion may exclude some high-ability students with LD as they often manage to achieve within the normal range and, therefore, are unlikely to receive the early individualized instruction that would enable them to make academic progress consistent with their abilities. Another situation may arise as well, for example, there are students who are underachievers and do not respond to intervention who may be inappropriately identified as having a learning disability. This includes environmentally disadvantaged, minority and English language learners who are overrepresented within the population of underachieving students and students who are at risk and in need of specialized supports and instruction for other reasons (e.g. lack of motivation, emotional stress).

The need of the hour is that schools employ universal screening policies to identify all those students who may exhibit learning problems. In-service training of

mainstream classroom teachers will go long way in early identification and providing classroom-based supports for these students. Greater number of special education teachers certified by Rehabilitation Council of India is essential. The dearth of qualified personnel is a matter of concern as well (Karande 2008).

## Classroom Implications and Pedagogies for Children with SLD

Students with SLD require lot of support to manage not only their learning issues but also the psychosocial needs. Considering that most children with SLD attend inclusive schools, the supports that may be made available to them can be classified into two categories – academic supports and supports for socio-emotional needs or nonacademic supports:

Consider the case of two students in grade 8.

*Sahil who is assessed with SLD in Math/dyscalculia manifests major difficulties in reading the various mathematical signs and symbols. Difficulties in understanding the mathematical concepts and relationships are also observed. He now experiences anxiety whenever he is required to do Math. Solving equations in Chemistry is a huge stressor for him as well. Mala, his peer, has SLD in reading/dyslexia. She cannot comprehend what she reads unlike her peers. This also affects her Math performance. However, she has learnt to cope with her problems as she uses some strategy-based techniques to understand what she reads.*

Both the above-mentioned students need different kinds of supports in the classroom. Sahil needs support to deal with his emotional concerns along with academic supports or dealing with math-related issues. Mala, on the other hand, requires academic support majorly.

**Academic Support** Student with SLD will benefit immensely from certain changes in the classroom instructions and interactions. It is understood that the child will be expected to study the grade-level prescribed syllabus. For the child to truly access the prescribed curriculum at that grade level, it will be necessary to adapt the curriculum to meet the requirements of the child with SLD. Therefore, changes will have to be made in respect of what is taught (content), how it is taught (use of instructional methods) and how learning is demonstrated (methods of evidencing the learning so that it can be assessed) and when, where and with whom the teaching-learning happens (the teaching-learning environment). A few general guidelines may be specified for facilitating the teaching-learning process as well as student engagement in the class (Heward and Orlansky 1992):

- Provide brief and simple instructions.
- Be clear in giving instructions about homework, the dates of exams, etc.
- Provide advance notice of any changes.
- Provide handouts and visual aids, review sheets, study guides (where possible).
- Use buddy system, peer tutoring in the classroom.

- Use more than one way to demonstrate or explain information.
- Break information into small steps when teaching many new ideas/tasks in one lesson.
- Allow the student to use technological devices in the class, e.g. tape-recording lectures, spell-check, grammar-check, voice to text and text to voice readers, calculators, etc.
- Provide alternative ways for the students to do tasks, such as dictations or oral presentations.
- Reinforce, encourage and motivate the child.
- When in doubt about how to assist the student, ask him or her.

Many a time this may not suffice, and the child may require individualized instruction (planned by developing an Individualised Education Programme/Plan, i.e. IEP). This helps to work on the key deficit areas that impede learning and develop the required skills in the student. When employing this ‘skill training approach’, the special educators/skill trainers:

1. Specifically identify the skills to be taught to the student.
2. Analyse the task into smaller tasks (or subskills) so that the student can master just one single skill at a time.
3. Use direct teaching methods that will help the student acquire and master the skill(s).
4. Monitor the student’s learning continuously so as to modify the instructional method, if the need be.
5. Evaluate the learning and instruction (Heward and Orlansky 1992).

Most often these skills may be reading skills, language skills, math skills or even executive functioning skills. Systematic, explicit and direct teaching is essential for the students to acquire and use these skills. Some of the major intervention areas for developing reading skills are vocabulary skills, phonemic awareness skills, phonic skills and reading comprehension skills. These four skills are extremely important to make the student a fluent reader who can then read and learn with minimal help. The Orton-Gillingham approach, Sounds in Symbols programme, Alpha to Omega programme, Slingerland method, Sonday system, Jolly Phonics, etc. are some of the well-known and widely used programmes to teach reading skills. In an attempt to use a combination of Multisensory Strategy Training based on Orton-Gillingham approach coupled with repeated reading, collaborative reading and multisensory reading, Thomas (2015) indicated that it produced better academic achievement in students with LD. Nag (2017) observed that in India most schools teaching akshara-based languages follow the synthetic phonics method. According to her following some simple guidelines will make reading acquisition of alpha-syllabaries more efficient:

- (i) In the beginning teach the high-frequency aksharas that will help read and spell early words.
- (ii) Use explicit methods of teaching of phonemic markers to the students.
- (iii) It is not essential to teach consonant blends at very early grades.

- (iv) There is a need of a robust oral language programme to accompany the early reading programme.

Apart from use of synthetic phonics, use of phonologically based programmes along with non-phonologically based remedial intervention programmes (Sarkar 2012) improves reading. The use of neurolinguistic programming in the form of multisensory intervention shows improved phonemic awareness, phonological awareness, vocabulary, reading fluency and reading comprehension (Prabavathy 2014) in primary school children with dyslexia. It is not unheard of to use computer-assisted instruction (CAI) in process of remediation. The use of games and simulations modes in CAI help remediate deficits seen in children with LD (Kumar 2015). Similarly, attempts at using multimedia packages also benefit children with dysgraphia in primary schools (Anilakumari 2012).

At Samveda Research and Training Center, a Samveda Remedial Teaching – Math programme is run. After being exposed to this programme, students show gains in their math learning with respect to reduced errors in preoperational- and operational-level arithmetic (Karibasappa et al. 2008). In the programme, after doing an error analysis, the conceptual base is developed. This is followed by developing the language for math. The principle of mastery learning and use of instructional techniques helps in teaching fundamental arithmetic.

Explicit teaching of strategy takes precedence for children with SLD. Learning strategies instruction is vital for children with SLD as many may fail to use the acquired knowledge and skills in environments beyond the structured classroom or new situations. Learning strategies instruction entails teaching the students directly and explicitly the task-specific strategies that they master and then guide them to complete the tasks of similar nature. Many studies use cognitive behaviour intervention strategy approach to teach strategies for learning, and this can be done with the use of other methods like CAI (Jena 2013). Employing cognitive behaviour intervention involved a 6-step procedure (Jena 2013) reading errors reduced, word fluency increased and reaction time to task improved. The 6-step procedure involved the following:

- (i) Task description, i.e. knowing what to do
- (ii) Formulation of strategy to solve the problem and plan the action to be taken
- (iii) Modelling of the target skill by the teacher for the student
- (iv) Guided practice to the student to complete the task
- (v) Verbalization by the student (overtly and covertly) to develop mediation behaviour
- (vi) Self-monitoring and self-reinforcement of the behaviour and strategy by the student

There are numerous learning strategies which employ a similar training protocol, and over a period of time, the students internalize the well-structured strategies. Some such strategies are described here:

- SQ3R – This is a learning strategy to develop comprehension skills. Herein the acronym is expanded as:

- Survey the text.
  - Question yourself about each section of the text.
  - Read the whole text quickly.
  - Recite the question and identify the parts of the text that will help answer your questions.
  - Lastly, review the text slowly and find your answers.
- COPS – COPS is a strategy that helps the students to become aware of and monitor their written composition skills. In this strategy COPS stands for:
    - Capitalization
    - Organization of ideas in the written composition
    - Punctuation
    - Spellings
  - SQRQCR – Learning strategies are used in math learning too. SQRQCR is a strategy to solve word problems:
    - Survey the word problem.
    - Question yourself what answer the problem wants you to get.
    - Read the problem to get information you need to solve the problem.
    - Question what operations are needed to solve the problem and in what order you should perform them.
    - Compute the answer.
    - Question yourself to whether the obtained answer is reasonable and correct.

Mehta (1994) developed and validated metacognitive strategies to develop reading comprehension skills, memory skills, concept development, reasoning skills and problem-solving skills. Some of these acronym-based learning strategies are described below. RUHAARS, a strategy for developing reading comprehension, stands for:

- R – Read (to aid comprehension).
  - U – Understand.
  - H – Highlight what is to be understood.
  - A – Ask questions to self.
  - A – Answer them.
  - R – Recheck.
  - S – Seek help, if required.
- UNIMOW is a strategy to develop memory skills. It is elaborated as:
    - U – Understand what is to be remembered.
    - N – Name the symbols.
    - I – Imagine the association.
    - M – Make words or sentences.
    - O – Overtly restate.
    - W – Write them own.

- To develop reasoning skills, R-SERL strategy was developed. It stands for:
  - Read.
  - State what is asked.
  - Explore relationships.
  - Restate the relationship.
  - In your own words
  - Link it with what is asked.

**Nonacademic Support** The support in the nonacademic areas would focus on reaching out to the students for their socio-emotional needs. Hence, a few guidelines mentioned below may help in the classroom:

- Positive classroom environment – providing the student with a nonthreatening classroom environment that is open to individual differences and not averse to failures aids the student.
- Acceptance of the child and his/her limitations – the acceptance of diversity in the class vis-à-vis the learning styles, learning rates and learning supports makes the classroom less threatening for the student.
- Openness to child’s needs – this point also draws from acceptance of individual differences. Acknowledging that the student with LD has learning needs that cannot be met through regular classroom teaching and he/she will require specialized intervention and adaptations that will help the student develop interest in learning is essential.
- Peer support – the use of peer and buddy support to encourage and motivate the student in completing and mastering different learning tasks can be used.
- Counselling – many a time, despite making positive changes to the classroom, the student may need to unburden the pent-up emotions. Counselling from a teacher or professional counsellor will help the student articulate his/her concerns and gradually overcome emotional and social issues.
- Probing questioning – students with SLD tend to take longer time to comprehend questions and process their thoughts to answer questions posed to them. Needless to say there may be exceptions. Therefore, it is imperative that the teachers have to be patient while posing questions to them to give them adequate time, also rephrase questions and use probing skills to help them answer.
- As in cases of children with any type of disabilities, teachers have to assess the child with SLD holistically to identify the talents and other good qualities in them so as to provide opportunities to develop these dimensions of their personality and nurture reciprocity among peer group. This helps to develop a feeling of interdependence among peer group and boost the self-confidence and self-worth of children with SLD like any other child with any disability.

## Supporting Children with SLD: Role of Various Stakeholders

Specific learning disabilities comprise much more than academic difficulties; there is a close relationship between a student's academic learning and his/her socio-emotional domain. Thus, the manifestations of specific learning disabilities do not stop at academics, but extend themselves to encompass all the aspects of the person's life, including social relationships, social involvement, life choices, etc. Hence, intervention for a person with SLD will never be restricted to an academic programme in the school. Any individual lesson plan made for the intervention for a student with SLD will have to involve a multidisciplinary aspect, thereby getting the family members, the immediate community as well as the professional support, all into the programme. Here, what will help the child are interventions which can enable the child to overcome his/her deficits in perception, motor skills and socio-emotional behaviour, thereby overcoming the impediments to his/her learning. It is thus important to examine the role of the key supports and support systems:

*Raima is known to be a good dancer; what is also known is that she has Specific Learning Disability. When she was assessed to have SLD, she was depressed and felt very let down by God. She was angry and aloof, and refused to go to school. However, today she is a different person. A lot of credit goes to her family, teachers, school, and friends and peers for what she is today. Raima's parents confided in the school authorities and the teachers and sought their cooperation in helping Raima deal with her issues. Her parents and teachers worked out an Individualised Education Plan so that Raima's learning outcomes were specifically planned, monitored and evaluated. Since Raima was learning Kathak, her parents encouraged her to invest more time and effort in the same. With her teachers changing their teaching methods for Raima, her peers helping her in completing classwork and learn the taught content, Raima gained confidence. The school also encouraged Raima to participate in dance competitions. Her self-esteem was high as she saw that she was appreciated for her dancing skills. Raima, today is a happy person – thanks to the people around her. (J. Sengupta, Personal Communication, November 2016)*

**Role of Family Members** Remediation is a team effort where parents have to be active participants. The methods of engagement used by the educators in the school can be extended in smaller measures during home learning as well. Family members should act as facilitators of the child's learning at home as this helps the child internalize the learning better. Parents should partner with the school and share relevant information about the child's education and development. Parents should monitor the child's progress and periodically ask for a report from the school, as well as provide their observations about how the programme is working (or not) for the child; this will help to modify the programme better.

Specialists like the occupational therapist, the speech therapist, the psychologist, etc. will include therapy activities in the IEP. These need to be followed up by activities in the daily life and play of the child. The parents play a role of facilitators of these activities in the home environment.

The most important thing needed for any child to blossom is acceptance. And acceptance by the immediate family, especially one's siblings, cousins and extended



family, goes a long way in helping the child fight all odds and reach his optimum potential. The child with SLD should be included in all family gatherings and festivities, as a neurotypical child would be. They sometimes have difficulties in self-regulation and may not understand social etiquette. However, regular exposure to these environments, with right encouragement and instruction, will gradually help the child to overcome these issues.

**Role of Teachers** In terms of academic intervention, the greater onus lies on special educators. A special educator assesses the child's strengths and weaknesses using various tools of assessment and collaborates with professionals from the multidisciplinary team as well. Following the data analysis, an IEP is drawn and implemented. As much as it is important to implement the IEP, it is crucial to follow the IEP and update and modify the IEP goals as per the changes seen in the child during the duration of the plan. Most students with SLD benefit greatly from experiential learning/learning by doing. The teachers may need to scaffold the learning process as well as provide different modes to express the learning and assess the child's learning. The teachers employ a versatile approach towards the whole teaching-learning process.

**Role of Peers** The peer group is particularly important for students with SLD as for any child. The involvement of the peers in the educational and social life of students with LD is seen to improve academic and cocurricular outcomes. Peer support or peer-mediated structures are strategies that involve placing students in pairs or in small groups to participate in learning activities that support academic instruction and social skills. The benefit of such placements is beneficial to students with and without disabilities alike. Using peer-mediated learning environments like peer tutoring, cooperative learning and buddy systems have proved to be particularly useful in teaching math skills (Calhoun and Fuchs 2003), world history (Mastropiere et al. 2003), vocabulary development (Hughes 2006) and improving prosocial behaviour and decreasing negative behaviours (Harris 2010).

**Role of Community** A parent-community-school network can interlink resources from all three areas to create early literacy awareness, health care and mental health awareness and invite past students to participate in school programmes and partnerships with local businesses and indigenous organizations to provide work experience and structured work placements for students. At least some children with SLD may have skills like drawing, painting, athletics and sports. As a community, it is crucial we acknowledge that the child is good at a task that may not be conventionally considered valuable. Being forthright in supporting the children in the pursuit of their artistic abilities will make them happier individuals.

**Role of Professional Support Team** An interdisciplinary team is most crucial for the benefit of the child. When an Individualised Education Plan (IEP) for a student with LD is designed in consultation with the different therapists (occupational

therapist/physiotherapist/speech therapist), etc., along with the educators, the plan will incorporate all the disciplines.

Occupational therapists help children by working on the underlying motor problems, attention and self-regulation challenges or perceptual deficits that may be contributing to the academic difficulties of the child. This helps to provide any necessary accommodation and develop effective strategies to improve the child's engagement in the classroom environment. When communication is clearly impaired due to language difficulties (receptive or expressive), speech and language therapy becomes a part of the remediation plan. Collaborative efforts not only save resources but also enable the child to achieve his/her best potential.

We can easily say that when schools, parents as well as communities appropriately and effectively attend to the intervention and remediation of students with learning disabilities, life outcomes for these students improve.

## Misconceptions About Specific Learning Disabilities

It appears that though there is ample of literature available to increase awareness about SLD, the common man and some professionals as well have certain misconceptions about the condition. Many organizations in their literature on SLD and researchers (Dunne 2016; Sopczyk 2014) have tried to bust the myths and misconceptions about SLD. Below are some misconceptions and facts about SLD drawn from above literature.

Misconceptions	Facts
People with SLD cannot learn at all	People with SLD can learn with teaching methods suited to their needs
People with SLD are just lazy and so cannot carry out expected tasks	People with SLD work as hard as others or even harder but may not succeed. However, due to repeated failure, they may later give up and so appear lazy
SLD disappears with age	SLD neither can disappear nor be cured. As one becomes older, the person learns ways to deal with the condition, and so it may seem that SLD has been cured or has disappeared
SLD can be easily be identified at a young age	It is not very easy to identify SLD because the signs and symptoms may go unnoticed for a long time and may be attributed to maturational delay, laziness, lack of interest, dislike, etc.
SLD is only a problem in school settings	While SLD can cause accomplishing academic tasks more difficult, their influence can extend well in nonacademic areas (art, craft, music, dance, etc.) and social life as well
All people with SLD are just the same	SLD is a very heterogeneous condition. There will hardly be any similarity between two persons with SLD
Giving matching provisions to those with SLD is enough	Individuals with SLD do benefit from provisions and supports. This however is not enough. They need specialized teaching-learning opportunities

## Way Ahead

Learning disabilities is such a high incidence condition that the discussions about SLD and the individuals with SLD are bound to continue. Even after 55 years of the term being coined, there are discussions about what conditions or what learning difficulties profiles can be included under the umbrella term of SLD – Dyslexia? Dyspraxia? Perceptual processing disorders? Nonverbal SLD? The issues about where should children with SLD be educated will continue to be of interest. Whether inclusive education, special education or resource room model of teaching is best will yet intrigue parents and professionals alike.

The field of SLD is also taking gradual strides for bettering the services provided to those with SLD. We can see an increase in the number of students with SLD not only enrolled in schools but also completing their school education satisfactorily. Many schools are becoming more and more inclusive by providing the students with an adapted curriculum – teaching as well as evaluation. The use of assistive technology is empowering the students by making the curriculum accessible. Preservice and in-service teacher training programmes are focusing on inclusive education pedagogies, and thus we will witness the use of Universal Designs for Learning employed widely. Differentiated instruction will focus on the needs of children with SLD giving them opportunities to benefit from educational experiences maximally. Individuals with SLD may prefer open learning and home-schooling for their education. Although SLD is a lifelong condition, the major thrust has been on school-going children. In the future, the life span coverage will start gaining prominence as services and provisions will be necessary for the children of today who will be the youth of tomorrow. We are already seeing this marginal shift as Government of India's flagship programme Sarva Shiksha Abhiyan (for elementary school) has made way for Rashtriya Madhyamik Shiksha Abhiyan. Thus, we expect to find a substantial increase in the direct and indirect services for the adolescents and adults with SLD.

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