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Review of Evidence on Disability Programmes in South Asia

Amaltas

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Terms such as 'mental retardation', 'mentally challenged', 'mentally disabled', 'insane' etc. appear in this document. These terms have been only been included when they appear as such in the source documents consulted for the review.

Amaltas and the Institute for Human Development do not support the use of these terms in their own reporting. These organisations subscribe to the approach taken by the International Classification of Functioning, Disability and Health which recognises that disability is the result of the interaction between a person and her/ his environment rather than being an attribute of a person.

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ACRONYMS

DFID	Department of International Development
HDI	Human Development Index
ICF	International Classification of Functioning, Disability and Health
ID	Identity
NGO	Non Government Organisation
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SEARO	WHO South East Asia Region Office
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
UNOPS	United Nations Office for Project Services
USD	United States Dollar
WHO	World Health Organisation

EXECUTIVE SUMMARY

Disability is beginning to catch the world's attention. Occurring as a result of non communicable disease, injury, old age or congenital condition, disability is a growing problem that is now demanding concerted action by humankind. It is estimated that over a billion people live with some form of disability – that represents a seventh of the world's population. The United Kingdom has taken the lead in building a response to the issue, by hosting the first Global Disability Summit in London in July 2018 that saw several international commitments being made to disability.

This report concerns itself with the disability experienced by those with intellectual and developmental disability, in particular those with autism, cerebral palsy, Down syndrome and intellectual disability. The report was developed through a literature review of materials published between 2008 and 2018 about six South Asian countries namely, Afghanistan, Bangladesh, India, Nepal, Myanmar and Pakistan. In all, 739 published documents were reviewed and 208 included in the qualitative synthesis. Further, country experts in each of these countries contributed relevant grey literature and case studies of good practices.

Of all the people with disability, 80% are projected to live in developing countries. Several international frameworks have been put in place beginning with United Nations Convention on the Rights of Persons with Disabilities 2008, so that those with disability can participate fully in the life of the community. Nevertheless, they continue to face discrimination and stigma.

South Asia struggles with the data on prevalence; it is widely believed that the region under-reports disability. Social ostracisation remains rampant leading to poverty, and is itself fuelled by poverty. Although countries have enacted several policies and laws, these remain mainly on paper. Response to one particular type of disability is often more pronounced in some countries.

Afghanistan is preoccupied with the remnants of a decades long conflict situation. The focus is mainly on sensorimotor disability. This also means that the prevalence rate in Afghanistan is much higher than anywhere else in the region. Stigma is deeply rooted with a differential response to disability caused by war and that due to other reasons.

Persons with intellectual and developmental disability report experiencing isolation and depression due to the stigma associated with their condition. Intersectionality of this is seen with poverty as well as with the female sex. A response to disability finds a place in the Basic Package of Health Services and Essential Package of Hospital Services, but is not prioritised. Discrimination means that children with intellectual and developmental disability do not have easy access to schooling. Persons with disability from birth are disadvantaged in their search for livelihood.

Bangladesh enacted a law on disability as early as in 2001 and was one of the first to ratify the UN Convention on the Rights of Persons with Disabilities. Yet available data is faulty and the country is still to carry out a survey on disability prevalence. A Cerebral Palsy Register was established in 2015.

Persons with intellectual and developmental disability are vulnerable, especially girls. Parents are reported to keep from sending their young girls to school due to fear of emotional, physical and sexual abuse. The government response has not found much uptake, with only 8000 children with disability reportedly attending government run special schools.

Poverty and disability are closely associated in studies in the country. Educational attainments are worse in the presence of poverty and this leads further to their exclusion from a fair wage. Evidence also points out the cost of disability and vulnerability of caregivers of persons with intellectual and developmental disability.

India has the largest population of the countries being studied. Official estimates put the number of those with disability at ~27 million or 2.1% of the population. This figure is widely believed to be an underestimation. There is a shortage of services, community organisations and peer groups for those with disability; much of what is available, is in the urban areas of the country.

Neglect, violence and involuntary medical treatment have been recorded. Girls and women are particularly disadvantaged and suffer sexual abuse and physical exploitation in addition. Caregivers suffer stress and anxiety; the situation often leads to delays in seeking diagnosis and treatment.

Although the country’s flagship secondary education programme supports inclusive education, its operationalization remains a significant challenge. Other service providers are also poorly trained to take care of those with disability, making care difficult to access. The poorest children have the least chance of support. Fewer than 20% of those with disability get jobs and among them, the greatest proportion are those with sensorimotor disability. Assistive devices are beginning to become available.

Myanmar does not have much published literature on disability. The first disability survey was conducted in 2008-09 in which the prevalence of disability was reported to be 2.3%. The survey also uncovered antagonistic attitude to people with intellectual and developmental disability. The Rights of Persons with Disabilities Law 2015 has provisions for education, health and job opportunities, with a focus on women and children with disability.

What data there is, suggests that children with disability often never attend school. Girls and women experience greater public disapprobation than others, although specific data on those with disability is not available. Institutionalisation is often resorted to in cases of intellectual and developmental disability. A health response is limited and training for service providers is lacking. Data on economic participation and stigma and marginalisation is not available.

Nepal is the first country in the region to have formally legislated for disability – the first law was enacted in 1982. The rate of intellectual and developmental disability is about a tenth that of sensorimotor disability, and rates are higher in the higher mountainous region. Progressive policies and programmes have been put into play, but benefits to persons with intellectual and developmental disability are slow to come.

As with some other parts of South Asia, the concept of karma is used to explain the occurrence of disability. Stigma and discrimination is commonplace. Caregivers in Nepal are also reported to suffer high levels of stress and anxiety. Girls and women are at a disadvantage due to perceptions of greater sexual vulnerability and few girls make it to government run schools and resource centres. In post disaster settings, they lag behind others in getting their entitlements due to difficulty in accessing centres of aid distribution.

Those with disability have several health issues that affect their quality of life, but health systems are not yet well geared to providing medical support to those with disability. The government has put a system of disability cards in place as also reserved beds in medical facilities. Education of children with intellectual and developmental disability is focused to providing practical life skills up to age 10 years with no government support for formal academic education. Economic participation is particularly poorly developed with much of the effort coming from non government organisations in towns and cities.

Pakistan was ahead of Nepal in addressing disability formally, albeit through and Ordinance in 1981. But a National Policy on Disability only followed 21 years later in 2002. The last survey was in 1998 when the disability rate recorded was ~2.5%.

There is a high level of stigma and discrimination against those with disability; this information can be extrapolated to those with intellectual and developmental disability. Disability is seen as bringing 'shame' to the family making care of those with disability extremely difficult. Stigma and negative attitudes towards persons with disability prevents those with intellectual and developmental disability with gaining employment.

The education policy does not specifically make room for mainstreaming of those with disability albeit that primary education is a fundamental right of all children in Pakistan. The Education department has set up 12 special centres for children specifically with intellectual disability; most would agree that the response is quite inadequate. There is limited information on the health outcomes of those with disability.

It may be noted that each country has standalone legislation on disability. But the literature is equally aware that legislation is a long way from effective implementation in every country that is part of this review. Literature on intellectual and developmental disability is scant. In all six countries, a major challenge is estimating the prevalence and incidence of intellectual and developmental disability. A key issue is the lack of a common definition of intellectual and developmental disability, leading to difficulty in being able to collate or compare data. A second is the lack of information on the barriers and facilitators to access and utilisation of care services.

Evidence on stigma and discrimination faced by persons with intellectual and developmental disability is not available in all six countries. Stigma and discrimination results in persons not utilising public spaces and events to the same degree as their peers. In all the countries, intellectual and developmental disabilities are attributed to God. Not only does this influence treatment seeking behaviour, but also 'invisibilises' those with disability in society.

An important intersectionality highlighted is that with gender. Being a girl/ woman with intellectual and developmental disability makes them more vulnerable as compared to their male counterparts.

Anecdotal reports of forced hysterectomies were reviewed in Bangladesh, India and Nepal. Evidence pointing towards abuse and mental torture experienced by boys/ men is also available. Thus the gender matters, but it appears that both male and female with intellectual and developmental disabilities are vulnerable and at risk.

Access to health services is limited and almost negligible. There is a huge gap in number of specialists needed and the numbers that are available. Poor awareness of intellectual and developmental disabilities among healthcare providers at all levels of services as well as government bureaucrats there appears to be an overall apathy to the situation of people in this cohort. Very often, distance and high transport costs prevent parents in rural areas from taking their children for any diagnostic and treatment services which are often located in urban centres.

Education opportunities are limited for children with intellectual and developmental disabilities. To begin with, since early diagnosis is a challenge, children are often sent to a mainstream school. Special schools remain out of reach for a large majority of the population in the six countries under review. Most of these facilities are located in urban areas and are unaffordable because of the high fees, transport costs and time cost to bring the child to the special school.

The direct link between education and poverty is well established. Even though all countries have stipulated reservation in jobs for persons with disability, this largely remains on paper. It is clear that even though all six countries under review are signatories to various international treaties, including the 2030 Development Agenda that ensures non-discrimination and inclusion of persons with disability in development programmes, the reality is far from this.

Social security remains a cause of concern among persons with intellectual and developmental disability. Those who are either not able to verbalise their needs and desires because of their disability are especially at risk of being excluded or worse, penalised. This is worsened because of poor awareness of intellectual and developmental disability among government officials, and their overall apathy to the situation of those with these conditions.

The notion of rehabilitation, particularly in respect of community approaches to rehabilitation, has remained squarely on sensorimotor aspects of disability. Much of this relates to use of assistive devices that can extend the range of abilities that a person with disability has. While many persons with intellectual and developmental disability could benefit from this, training to use assistive devices successfully would need to be tailored to their learning style and pace.

Recommendations

1. *Address discrimination and stigma:* Two actions can be considered to uphold the dignity of persons with such challenges: (i) building support for an Anti-Discrimination Law; and (ii) encouraging a ‘watchdog’ function by every member of society so that all incidents of discrimination are identified and reported.
2. *Provide social security and safety net:* The onus of providing social security for persons with disability is on the government. There is a need for greater attention to inadequate and almost non-existent social protection of those with disability.
3. *Educate persons with intellectual and developmental disabilities about sexual abuse:* A critical need is to ensure that persons with intellectual and developmental disability are aware of

what they should do if they face sexual and physical abuse or violence. Men and boys are as much at risk and hence must also be made aware.

4. *Provide safe public spaces:* Creating friendly physical infrastructure will go a long way in ensuring equal participation of persons with intellectual and developmental disabilities. It is equally important to ensure that the right to entry and right to use of public facilities of persons with intellectual and developmental disability is safeguarded.
5. *Provide identity cards to all to make access to specialised care possible:* Most countries in the study report that while available, most persons with intellectual and developmental disability have difficulty in obtaining an identity document that is the gateway to government entitlements for which they are eligible.
6. *Ensure appropriate healthcare services for those with intellectual and developmental disability:* Information materials on local services would help to ensure that health professionals and community workers have information on screening and early intervention programmes. There is a need to ensure that the poorest and most marginalised who live in rural and difficult to access areas receive services close to their homes.
7. *Provide inclusive education:* There is a need to train teachers at school to identify children with intellectual and developmental disabilities as well as train them in behaviour and classroom management techniques.
8. *Provide incentives to employers that employ persons with disability:* This is found in the law of several of the six countries that are reviewed in this report. However, while this is available in the law, in fact few persons with intellectual and developmental disability find work and are often seen as being a burden on families.
9. *Include persons with intellectual and developmental disabilities in committees*: If the needs of this population are to be represented in national and state level policies and programmes, it is imperative that their views are taken on board. Persons with disability should not be viewed as passive receivers of 'charity'; rather they must be seen to be active participants in their own progress.
10. *Create support groups for parents/caregivers:* Support groups play a crucial role in helping parents/ caregivers deal with anxiety, depression and physical and emotional stress of taking care of persons with intellectual and developmental disability.
11. *Support civil society organisations:* Civil society organisations play a key role in providing care and opportunities to enable persons with intellectual and developmental disabilities to play a role in the society.
12. *Build awareness at community level:* Stigma and discrimination is reduced when more people become aware of intellectual and developmental disabilities.
13. *Build the support of society at large:* By drawing upon well-wishers in secondary groups of the parents/ caregivers, a wider community of those well-disposed to persons with intellectual and developmental disability can be created.
14. *Increase the availability of quality data:* There is a need to standardize the definition of intellectual and developmental disabilities - the Washington Group on Disability Statistics provides one option. There is likewise a need to undertake research on the exclusion of persons with disability in order to inform policy and programming.

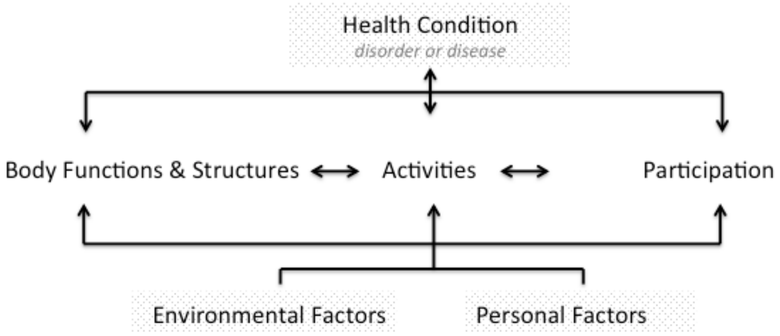
15. *Ensure inter-departmental and inter-ministerial collaboration:* There is a need to have on-going dialogue between different ministries and departments that deal with persons with intellectual and developmental disability. There needs to be a formal and continuous ways of talking, coordination and working in partnership if the programmes are to be implemented successfully.

BACKGROUND

The world is waking up to the needs of persons with disability. The World Report on Disability is prefaced with the observation that over a billion people in the world live with some form of disability. Today, about 200 million people experience considerable difficulties in functioning in their social surroundings. As the population of persons living with disability grows due to the rising tide of chronic disease and greater survivorship from injury and ill health, disability must seize the attention of policy makers.

A crucial moment in the recent history of disability has been the articulation of the International Classification of Functioning, Disability and Health (ICF) by the World Health Organisation (WHO). The ICF defines disability in terms of challenges that a person faces as a result of the interaction between the state of their bodily functions and structures, activities and participation in social situations, and their personal and external environment. The interactions between the various components of the ICF have been expressed thus:[1]

Figure 1: Interaction between the Components of ICF



Source: World Health Organisation. (2001). International Classification of Functioning, Disability and Health: ICF. Geneva, WHO

Departing from an approach that applies a medical model to disability, ICF considers the way in which a person is able to function in the personal and external environment that s/he occupies. Thus it describes functioning as the (positive) interaction between a person's abilities and the environmental context, while viewing disability as the (negative) interaction between a person's impairments, activity limitations and participation restrictions and the environmental context.[2] Since it was outlined in 2001, the ICF framework has been further refined and taken forward in terms of its operationalization, with WHO putting out a series of useful supplementary material to realise the framework.

Another important piece in the disability puzzle is the way in which disability is measured. The understanding of disability, its definition, and how it is to be measured in a way that is replicable across circumstances has been a longstanding vexed problem. A solution has been proposed by the

Washington Group on Disability Statistics, set up under the United Nations Statistical Commission. The Washington Group seeks to collect data that is comparable cross-nationally and can identify persons with disability to (i) provide services, including the development of programs and policies for service provision and the evaluation of these programs and services; (ii) monitor the level of functioning in the population; and (iii) assess equalization of opportunities.[3]

The United Kingdom has taken a leadership position in taking the discourse forward, as well as putting in place positive policies and practices that include persons living with disability. The Global Disability Summit held in London in July 2018 under the leadership of the United Kingdom, Kenya and International Disability Alliance acknowledged the long-standing neglect of the issue. It focused attention on the paucity of useable data for action, calling for broad-based support for the Inclusive Data Charter and inclusion of disability in all household surveys using a common measurement protocol.[4] The Summit, as well as the earlier World Disability Report produced by the WHO and World Bank captured the effects of disability on the human condition, citing a range of poorer outcomes for those with disability as compared to those without. It notes the disadvantages that people with disability experience, namely poorer health outcomes; lower educational achievements; less economic participation; higher rates of poverty; and increased dependency and restricted participation.[5] Yet the task to redress the historical neglect of persons with challenges has just begun.

The situation of those living with intellectual and developmental disability is even worse. The term 'intellectual and developmental disability' describes a set of conditions that begin at birth or in childhood, are chronic and adversely affect an individual's daily living and functioning. The impairment may be in the functioning of the body or of the mind. This could result in difficulties in any or a combination of the following: caring for oneself; communication; learning; mobility or moving around; decisions for oneself; living independently; and being financially self-sufficient.[6,7]

Intellectual and developmental disability includes conditions such as autism characterised by difficulty in social communication; cerebral palsy with a characteristic difficulty in muscle control; Down syndrome due to overrepresentation of genetic material from chromosome 21; and intellectual disability with typical difficulty in adaptive behaviour and cognitive functioning.[8]

Little rigorous evidence is available about the lives of persons who live with intellectual and developmental disability. Much of the research around disabilities in the world, and the South Asia region, is carried out on the wider ambit of sensorimotor challenges, rather than on condition related to an alternative way of brain functioning. Traditional approaches to persons born with intellectual and developmental disabilities have gone so far as to understand the core problems that they face, but the operational approaches to addressing their needs have been somewhat narrow. Much of the effort is limited to educational responses that attempt to teach children with challenges to adapt to the world, rather than attempt to look through their lens to consider changes in systems to respond to their life cycle needs.[9]

A better understanding of the situation and discourse on intellectual and development disorders in the South Asia region is needed to increase priority, and to design and implement appropriate programmes and policies for disability. These countries have a common cultural milieu and shared history. The purpose of the study is thus to build a better understanding of the evidence that supports a suitable and effective response in the region, and identify data gaps specifically in the countries of Afghanistan, Bangladesh, India, Myanmar, Nepal and Pakistan.

A three-phase approach was adopted for the study: the first phase involved a detailed review of the published literature; the second phase drew upon local expert knowledge in each country to access grey literature; and the third and final phase involved collating both published and grey literature to develop a comprehensive review of the material on the subject.

Studies included are those that:

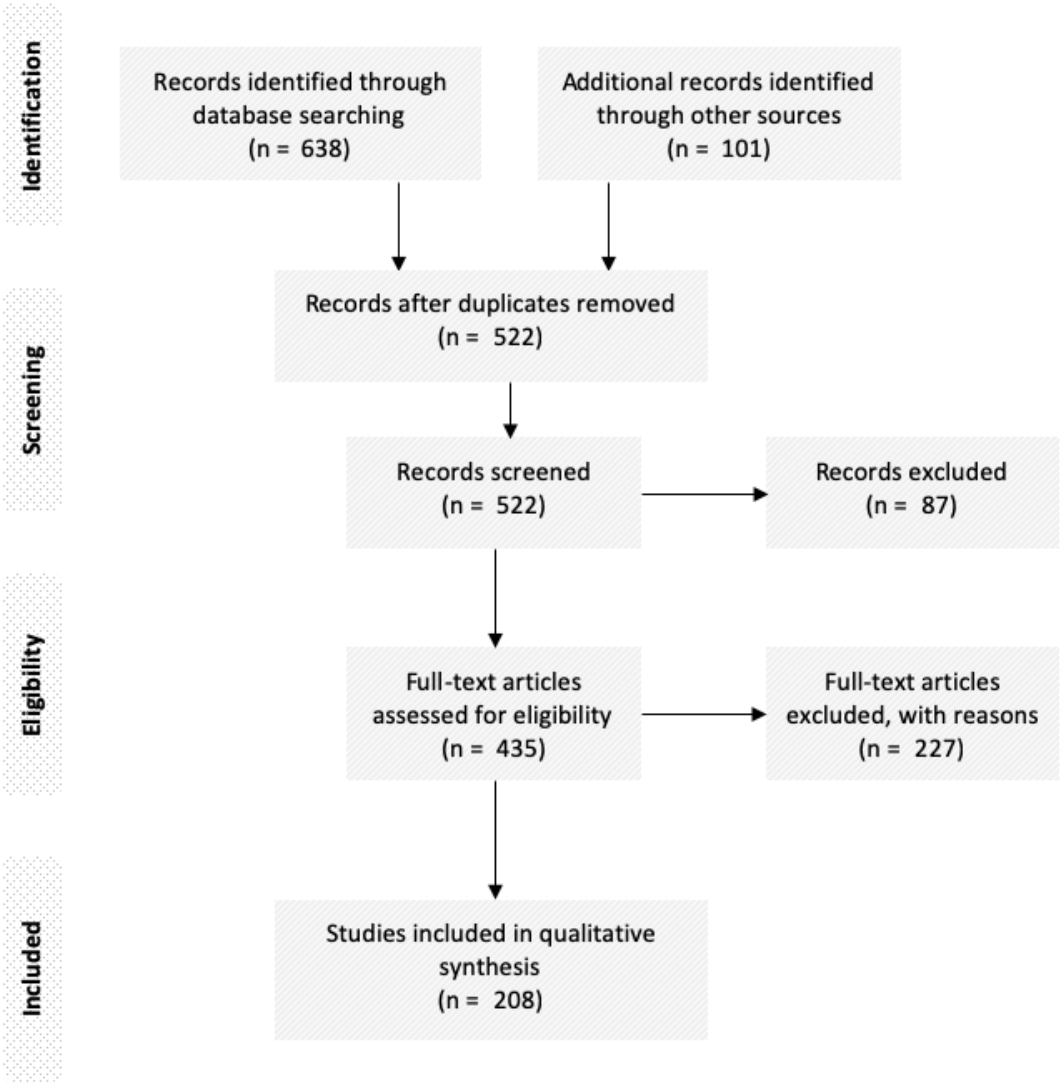
1. Were published between 2008 and 2018 *(a few seminal studies outside this range have been included)*
2. Discuss six South Asian countries, specifically, Afghanistan, Bangladesh, India, Myanmar, Nepal and Pakistan or provide regional data.
3. Have as the subject of study, intellectual and developmental disability, in particular autism, cerebral palsy, Down syndrome and intellectual disability

Three databases i.e., Web of Science, PubMed and Google Scholar were searched. Reports and policies were accessed through official websites of relevant ministries of each country's government Data from national statistical offices, national demographic/ subject surveys etc. were used to provide context. The main themes under which material has been excavated include: health outcomes; educational attainments; economic participation; poverty; stigma and discrimination; intersectionality with gender and other reasons for marginalisation; and dependency and restricted participation including access to assistive devices and enabling infrastructure. Keywords used to interrogate these databases are provided in Annexure I. Qualitative and ethnographic studies were sought in order to capture stories about how people's lives are affected by these disabilities. These have been organized along the main themes identified for the review. The PRISMA Flow diagram for the documents accessed for the literature review is presented in Figure 2.

Limitations of the study must be mentioned at the outset. One, available data and reports/papers focus largely on the broad scope of disability, with an emphasis on motor, visual and auditory impairments. Data on intellectual and developmental disabilities is scant and not really the focus of either surveys or programmes. Two, the definition of intellectual and developmental disability varies from one country to the other. Lack of uniformity of definition makes it difficult to arrive at a common understanding of the situation and context of this cohort of people. Third, the preponderance of information is available from small studies on a particular type of disability rather than those which look at the entire cohort of intellectual and developmental disability. It appears that this cohort is divided into silos of people with autism, cerebral palsy, Down syndrome or intellectual disability.

In the chapter that follow, the context and key moments in the global awakening and response to disability is described.

Figure 2: PRISMA Flow Diagram



Source: Moher, D., Liberati, A., Tetzlaff, J., Altman, D., The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med

End Notes

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[1] WHO. (2001). International Classification of Functioning, Disability and Health: ICF. Geneva, WHO Retrieved, 10 March 2019, from https://apps.who.int/iris/bitstream/handle/10665/42407/9241545429.pdf;jsessionid=04A11665500DC9A983E067BE746143A0?sequence=1

[2] The ICF: An Overview. (n.d.). https://www.cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf Retrieved, 10 March 2019, from https://www.cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf

[3] Washington Group on Disability Statistics. (n.d.). Retrieved, 11 May 2109, from http://www.washingtongroup-disability.com/

[4] Global Disability Summit: Official Readout. (2018). Retrieved, 8 December 2018, from https://drive.google.com/file/d/15PZ3CJf841KxpaTLvp3ARE_hilACPro6/view

[5] WHO. (2011). Summary The World Disability Report. WHO and The World Bank.

[6] Government of USA. (n.d.) Intellectual and Developmental Disabilities. Retrieved, 4 July 2019, from https://www.ncdhhs.gov/assistance/disability-services/intellectual-developmental-disabilities

[7] Government of USA. (2010). Intellectual and Developmental Disabilities, Fact sheet. Retrieved, 4 July 2019, from https://report.nih.gov/NIHfactsheets/ViewFactsheet.aspx?csid=100

[8] Amrit Foundation of India. (2017). The Patang project. Delhi, Amrit Foundation

[9] Amrit Foundation of India. (2017). The Patang project. Delhi, Amrit Foundation

THE GLOBAL AND SOUTH ASIAN CONTEXT

People with disability are an invisible segment of the population, made more so by the challenges they face in participating fully in society. Persons with disability comprise an estimated 15% of the world's population of whom 80% live in developing countries, and are overrepresented among those living in poverty. People with disability have historically been stigmatised and marginalised. They face barriers at multiple levels: at a systemic and institutional level (lack of inclusive policies and laws); at a physical level (inaccessible buildings and transport); and at an information level (lack of sign language, posters or interpreters at meetings). At a societal level they face stigma, negative attitudes and discriminatory practices and behaviour. Discrimination results in opportunities being denied to persons with disability including in forming relationships, expressing sexuality, marrying and having a family.[10, 11]

Because they are often viewed as being less valuable, they suffer neglect and abuse from their families and the community at large. A direct outcome of not being given support in their development is their sense of low esteem and self-worth. This heightens the exclusion, violence and abuse that people with disability experience, as well as the denial to them, of opportunities available to other citizens of their countries. Stigma and discrimination results in limited participation in decision making.[12]

The degree to which people with disability are made to feel worthless and isolated depends on the type of disability and severity of impairment. People with intellectual or developmental disability are at a greater disadvantage as compared to those with physical disability. This group of people are often segregated, not permitted to go out of their homes or are institutionalised, and are at a high risk of facing violence both physical and sexual.[13] Women and girls are most affected by stigma and have lesser access to education, health services or employment opportunities.

Available evidence shows a direct correlation between disability and poverty through numerous pathways. For one, there is an adverse impact on education, employment opportunities and earnings. Second, poverty may increase the risk of disability through poor health outcomes and its determinants. Third, stigma associated with disability may result in limited activities and participation depending on the social and cultural context. Fourth, limited resources in a community may make it difficult for a person with disability to participate in activities at the community level.[14] Their situation continues to be a cause of concern despite the progress made in recent years through the enactment of a number of global frameworks and acts.

THE WORLD

Global frameworks that are in place provide guidance for ensuring non-discrimination and inclusion in development programmes. In particular, attention must be drawn to six global frameworks that have changed the definition of how people with disability are viewed and what the countries can aim to do to encourage non-discriminatory practices and attitudes towards this group of people.

The United Nations Convention on the Rights of Persons with Disabilities 2008 (drafted 2006) aims to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disability, and to promote respect for their inherent dignity".[15] This definition changed the global understanding of and response to disability and led to legislative reforms that align to the principles of non-discrimination in many countries.[16]

The **World Disability Report** 2011 highlights the need to empower people with disability and "remove the barriers which prevent them participating in their communities; getting quality education finding decent work, and having their voices heard". The report provides evidence for innovative policies and programmes that have the potential to improve the lives of people with disability. It further states the need to create a supportive and inclusive environment and ensuring that people with disability are at the centre of these programmes.[17]

The Rio+ 20 Conference 2012 report entitled 'The Future We Want' reiterates the importance of accessibility and disability inclusion for sustainable development.[18]

The Sendai Framework for Disaster Risk Reduction passed in 2015, recognises the condition of people with disability in disaster risk reduction and adheres to the principles of non-discrimination, accessibility and universal design to strengthen resilience.[19]

The Addis Ababa Action Agenda launched in 2015 focuses on the needs of persons with disability in social protection, employment, education, infrastructure, financial inclusion, technology and data.[20]

The World Humanitarian Summit in 2016 launched the pioneer 'Charter on Inclusion of Persons with Disabilities in Humanitarian Action'.[21]

Further, the Global Disability Summit held in July 2018 drew attention to the unequal situation of persons with disability.[22] It noted that the measurement of disability varies depending on the country specific definition of disability, the kind of information collected and the objectives of the research.[23] Available evidence is scant and wrought with discrepancies because disability is not a priority issue and there is underreporting. In preparation for the Global Disability Summit 2018, Rapid Evidence Assessments were undertaken to provide an overview of interventions to improve social inclusion and empowerment among people with disability in low- and middle-income countries. Findings repeated the need for rigorous research and documentation of interventions, as there was limited available evidence. Most of the interventions aimed to improve the social skills of the person with disability rather than social integration, and did not address system level or community level changes.[24]

The Sustainable Development Goals Summit (SDG) in 2019 set the agenda for Sustainable Development Goals 2030. Under its overarching goal of "leave no one behind" it includes persons with disability in seven out of 17 goals with 169 targets.[25] It has generated momentum around the importance of involving persons with disability in playing a crucial role at all levels, including national, regional and international.[26] It makes explicit reference to persons with disability, covering access to education and employment, availability of schools sensitive to students with disability, inclusion and empowerment of persons with disability, accessible transport, accessible public and green spaces, and building capacity of countries to disaggregate data by disability.[27]

Although these global frameworks and summits brought attention to the obstacles and discrimination faced by all persons with disability, the focus of programmes and policies has not been evenly distributed. Much of the attention has been on those that have sensorimotor disability for which responses have been in the making for several decades, primarily people with locomotor issues, or those with visual or auditory impairments. Although evidence has been accumulated on programmes for people with physical disability, the prevalence of disability and the lives of persons with intellectual and developmental disability remain unexplored. People with these challenges remain overlooked, and they are at a severe disadvantage especially in education, employment and access to health services.[28]

Figure 3: SDG Goals relating to Disability

The following SDG goals mention disabilities specifically:

SDG 1: End poverty in all its forms everywhere

SDG 4: Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all

SDG 8: Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all

SDG 10: Reduce inequality within and among countries

SDG 11: Make cities and human settlements inclusive, safe, resilient and sustainable

SDG 16: Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels

SDG 17: Increase the availability of high-quality, timely and reliable data that is also disaggregated by disability in terms of the collection of data and monitoring and accountability

The global response has generated some attention among leaders and policymakers in the South Asia region. A central difficulty is that the actual number of persons with disability is undercounted. Added to this, is the sheer lack of access to many parts of the countries in the region and the lack of sensitivity among government officials to the issues faced by those with disability. The next chapter discusses these and other key aspects of the disability response of the region.

SOUTH ASIA

A key challenge to designing programmes for disability is getting robust estimates of the prevalence of disability in a country. The definition, quality and methods of data collection, rigour of sources and disclosure rates affect the calculation of prevalence of disability.[29] Many forms of disability are difficult to capture in statistics, often due to underreporting.[30] The United Nations Economic and Social Commission for Asia and the Pacific disability survey indicates that "disability prevalence in the Asia-Pacific region varies dramatically, ranging from 1.0% in the Lao People's Democratic Republic to 24.0% in New Zealand. These figures are heavily shaped by the contrasting ways that governments define disability and collect data. Comparability of data can be improved when data collection meets internationally recognized standards …".[31] Data on prevalence of disabilities are also skewed due to inadequate service provision, stigma and underreporting.[32] Little or no data is available – disability issues are given low priority or are excluded from official statistics.

However, data that does exist indicates that countries in low and middle income group have a higher disability prevalence as compared to higher income countries.[33] WHO estimates that about 800 million of the over 1 billion persons with disability in the world live in developing countries.[34] There is a growing stack of evidence that indicates a direct correlation between disability and poverty, and people with disability are among the poorest and most vulnerable.[35] The World Disability Report 2011 captures the effects of disability on the human condition, citing a range of poorer outcomes for those with disability as compared to those without. It notes the disadvantages that people with disability experience, often worsened by intersectionality with other causes of marginalization.[36]

In the South Asia Region, the situation is not very different. There is limited information and evidence on the lives of persons living with disability. In particular, there is a paucity of information that could be used to understand and respond to the situation of persons living with intellectual and developmental disorders.[37] It is observed that stigma and discrimination against persons with such challenges is pervasive across the region.[38] Some argue that while impairment is a biological phenomenon, interpretations of disability vary across time and cultural geographies.[39] Yet others underscore the relevance of foregrounding impairment as a main context of discussion of the disability situation.[40] It appears that a proper response to disability lies in examining both impairment as well as its expression in society, i.e., how people with intellectual and developmental disorders process the information they receive and interact with the world.

The WHO records that the South East Asia region has the second highest prevalence of moderate disability (16.0%) and the third highest of severe disability (2.9%). But even these "percentages are assumed to be underestimated as most South-East Asia Region countries used an impairment-based definition rather than the ICF6 definition, except Indonesia and Thailand".[41] Intellectual disability commonly comes in at rank #4 in the countries of the region while physical disabilities (mobility, visual, speech and hearing) rank between #1 to #3.[42] Independent statistics for intellectual and developmental conditions are generally not available; however, most researchers expect the prevalence to be about 1 - 1.5% of the total.[43] (Table 1)

Table 1: Prevalence of disability and rank of intellectual impairment among disability 'types'

Country	Population with Disability (%)	Year of Estimation	Rank of intellectual impairments
Afghanistan[i]	2.7	2005	NA
Bangladesh[ii]	1.4	2011	NA
India[iii]	2.2	2011	4
Myanmar[iv]	2.4	2009	4
Nepal[v]	1.9	2011	4
Pakistan[vi]	1.5	2017	NA

i Government of Afghanistan. (2006). National Disability Survey of Afghanistan 2006
ii Government of Bangladesh. (2011). Census of Bangladesh 2011
iii Government of India. (2011). Census of India 2011
iv Government of Myanmar. (2009). Union of Myanmar 2009
v Government of Nepal. (2011). Census of Nepal 2011
vi Government of Pakistan. (2017). Census of Pakistan 2017
Adapted from SEARO. (2013). For Pakistan, calculations are the author's own.

National action plans and regulatory mechanisms are in place in the six countries under review. However, evidence on the implementation and effectiveness of the policies varies and there is a need to undertake rigorous evaluation of policies, services and regulatory mechanisms as well as identify gaps and priorities to improve access and provision.[44] While policies on disability are in place in the South Asian countries included in this review, the focus of these policies is largely on physical disabilities. Specific policies on intellectual and developmental disabilities are a neglected area nor are they clearly articulated in existing policies (Table 2).

Table 2: Policies and Laws in the six South Asian countries

Country	Policy
Afghanistan[i]	The Comprehensive National Disability Policy in Afghanistan, submitted to Ministry of Martyrs and Disabled in 2003
	The Law on Rights and Privileges of People with Disabilities, *n.d.*
Bangladesh[ii]	National Policy of Disability, 1995
	Disability Welfare Act, 2001
	National Action Plan on Disability, 2006
	Bangladesh Labour Law, 2006
	National Education policy 2010
	National Women Development Policy, 2011
	National Health Policy, 2011
	Child Act, 2013
	Revised Persons with Disabilities' Rights & Protection Act 2013
	Revised Persons with Disabilities' Rights & Protection Rules 2015
	National Plan of Action, 2018 (following above Act and Rules)
	Neuro-Developmental Disability Protection Trust Act 2013
	Neuro-developmental Disability Protection Trust Rules, 2015
	National Strategic Plan for Neurodevelopmental Disorders, 2016-21
	National Plan of Action, 2019 (following above Act and Rules)
India[ii]	Mental Health Act, 1987
	The Rehabilitation Council of India Act, 1992
	Persons with Disabilities Act, 1995
	National Trust Act for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities, 1999
	National Policy on Disability, 2006
	Department of Empowerment of Persons with Disabilities (Divyangjan), 2012
	The Rights of Persons with Disabilities Act, 2016
	National Mental Health Program, 2017
Myanmar[iii]	Act on Job Opportunity for Handicapped People (1958) (Only paper, not enacted)
	Myanmar National Strategy for Development of Persons with Disabilities (2011-2012)
	The Rights of Persons with Disabilities Law, 2015
	Bye-Laws of The Rights of Persons with Disability (2017-2027)
	Myanmar National Strategy for Development of Persons with Disabilities (2016-2025)
Nepal[iv]	Disabled Persons Protection and Welfare Act, 1982
	Disabled Protection and Welfare Regulation, 1994
	National Policy Plan of Action, 1996
	Disabled Persons Service National Policy, 1996
	Special Education Policy, 1996 (2053 BS)
	Childhood Disability Management Strategy, 2008 (2064 BS)
	Guideline for Disability ID Card distribution, 2006
	National Plan & Policy of Action on Disability, 2006
	Rights of Person with Disability Act, 2017
	First amendment on Guideline for Disability ID Card distribution, 2017
	10 year National Policy and Plan of Action, 2017 (2073-2082 BS)
	Regulation on Rights of Persons with Disability, 2018
Pakistan[v]	Employment and Rehabilitation Ordinance, 1981
	Mental Health Ordinance, 2001
	National Policy for Persons with Disabilities, 2002
	National Plan of Action for Persons with Disabilities, 2006
	Special Citizens Act, 2008

Sources: [I] World Health Organization. (2003) The Comprehensive National Disability Policy In Afghanistan. Kabul, WHO Retrieved, 8 March 2019, from https://www.who.int/disabilities/policies/documents/Afghanistan.pdf
[iii] International Labour Organization. (2017). Employment policy, promotion of employment and employment services. Myanmar, ILO. Retrieved, 8 May 2019, from
http://www.ilo.org/dyn/natlex/natlex4.detail?p_lang=en&p_isn=100494&p_count=8&p_classification=08
[iv] The World Bank, Disability in South Asia. (2003). A portfolio review. World Bank
[v] Ahmed, M., Khan, A.B., Naseem, F. (2014). Policies for Special Persons in Pakistan Analysis of Policy Implementation. Berkeley Journal of Social Sciences. Retrieved, 13 May 2019, from
https://www.humanitarianlibrary.org/sites/default/files/2014/02/Feb%201.pdf

Few studies focus on specific intellectual and developmental disabilities. Additionally, those available focus mainly on children with disability and for the main part, capture the prevalence of conditions rather than the challenges that they face in their life context.

For example, a literature review on Autism Spectrum Disorders (autism) in eight South Asian countries could find only six articles from Bangladesh, India and Sri Lanka and none from Pakistan, Nepal, Bhutan, Maldives and Afghanistan. Based on the articles, the study reported that one in 93 children has autism in this region. The reported prevalence ranged from 0.09% in India to 1.07% in Sri Lanka. The study highlights the insufficient information and methodological issues around case definition, screening instruments used and diagnostic criterion in the three countries.[45]

Another review that included 80 articles of which 41 were from low income countries, aimed to review the research on childhood disability in low- and middle-income countries. Disability-causing conditions examined in this study included neurological, intellectual, hearing, visual, speech, and motor impairments. The review reports that the prevalence of intellectual disability ranges from 0.09% to 18.3%. The review found that the most common cause for severe mental retardation were congenital problems such as Down syndrome, consanguineous marriage and trauma at birth.[46]

It needs to be understood that disability is not an isolated variable, but is modified by biological, psycho-social, cultural and environmental factors. Thus, it is challenging to measure incidence, especially through population-based census. In the following chapters, we examine available evidence country by country, from each of the six countries of interest. The evidence is reviewed along the themes of stigma and discrimination; intersectionality with gender and other reasons for marginalisation; health outcomes; educational attainments; economic participation; poverty; and dependency and restricted participation including access to assistive devices and enabling infrastructure. The countries of interest are covered alphabetically, beginning with Afghanistan, going on to Bangladesh, India, Myanmar, Nepal and finally, Pakistan.

End Notes

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[10] Government of UK. (n.d.). Rapid Evidence Assessment of 'What Works' to Improve Social Inclusion and Empowerment for People with Disabilities in Low- and Middle Income Countries. International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine

[11] United Nations. (2018). Realization of the Sustainable Development Goals by, for and with persons with disabilities UN flagship report on Disability and Development

[12] WHO and The World Bank. (2011). World Report on Disability. Geneva, WHO

[13] International Disability Alliance and DFID. (2018). Dignity and Respect for All: creating new norms, tackling stigma and ensuring non-discrimination. Global Disability Summit

[14] Porasac, A. & Vick, B. (2011). Disability and Poverty in Developing Countries: A Snapshot from the World Health Survey; Mitra. World Bank

[15] Bond Disability & Development Group, UK. (2017). Stigma, disability and development. (n.p.) Retrieved, April 5 2019, from https://www.bond.org.uk/resources/stigma-disability-and-development

[16] International Disability Alliance & DFID. (2018). Dignity and Respect for All: creating new norms, tackling stigma and ensuring non-discrimination. Global Disability Summit

[17] WHO, The World Bank. (2011). World Report on Disability. Geneva, WHO

[18] United Nations. (2018). Realization of the Sustainable Development Goals by, for and with persons with disabilities UN flagship report on Disability and Development

[19] International Disability Alliance & DFID. (2018). Dignity and Respect for All: creating new norms, tackling stigma and ensuring non-discrimination. Global Disability Summit

[20] United Nations. (2018). Realization of the Sustainable Development Goals by, for and with persons with disabilities UN flagship report on Disability and Development

[21] United Nations. (2018). Realization of the Sustainable Development Goals by, for and with persons with disabilities UN flagship report on Disability and Development

[22] Global Disability Summit. (2018). Official Readout Retrieved, 10 May 2019, from https://drive.google.com/file/d/15PZ3CJf841KxpaTLvp3ARE_hilACPro6/view

[23] Porasac, A., Vick, B. (2011). Disability and Poverty in Developing Countries: A Snapshot from the World Health Survey; Mitra. World Bank

[24] Government of UK. (n.d.). Rapid Evidence Assessment of 'What Works' to Improve Social Inclusion and Empowerment for People with Disabilities in Low- and Middle Income Countries. International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine

[25] International Disabilities Alliance. (n.d.) The 2030 Agenda for Sustainable Development. Retrieved, 1 March 2019, from http://www.internationaldisabilityalliance.org/content/2030-agenda-sustainable-development-0.

[26] International Disability Alliance & DFID. (2018). Dignity and Respect for All: creating new norms, tackling stigma and ensuring non-discrimination. Global Disability Summit

[27] 2018. Realization of the Sustainable Development Goals by, for and with persons with disabilities UN flagship report on Disability and Development. Department of Economic and Social Affairs

[28] WHO, The World Bank. (2011). World Report on Disability. Geneva, WHO

[29] Stephen Thompson Institute of Development Studies. (2017). Disability prevalence and trends. K4D

[30] World Bank. (2003). The World Bank and Disability in South Asia: A portfolio review. World Bank

[31] ESCAP. (2015). Disability at a Glance: Strengthening employment prospects for persons with disability in Asia and the Pacific. Retrieved, 3 March 2019, from https://www.unescap.org/sites/default/files/SDD%20Disability%20Glance%202015_Final.pdf

[32] WHO, The World Bank. (2011). World Report on Disability. Geneva, WHO

[33] Mitra, S., Sambamoorthi, U. (2014). Disability prevalence among adults: Estimates for 54 countries and progress toward a global estimate. Disability and Rehabilitation; 36 (11) Retrieved, April 25 2019, from http://www.tandfonline.com/doi/full/10.3109/09638288.2013.825333

[34] Stephen Thompson Institute of Development Studies. (2017). Disability prevalence and trends. K4D

[35] World Bank. (2003). The World Bank and Disability in South Asia: A portfolio review. World Bank

[36] WHO, The World Bank. (2011). World Report on Disability. Geneva, WHO.

[37] McKenzie, K., Milton, M., Smith, G. et al. (2016). Current Development Disorders Report. Springer International Publishing

[38] Development Enabled. (2018). Retrieved, 6 April 2019, from https://pages.devex.com/devenabled.html

[39] Addlakha, R. (2018) South Asia and disability studies: redefining boundaries and extending horizons. Asia Pacific Journal of Education, 38:1, 147-149

[40] Hari, K. (2016). Disability Discourse in South Asia and Global Disability Governance. Canadian Journal of Disability Studies.

[41] WHO. (2013). Disability in the SouthEast Asia Region. Retrieved, 15 April 2019, from http://www.searo.who.int/entity/disabilities_injury_rehabilitation/topics/disability_factsheet.pdf

[42] WHO. (2013). Disability in the SouthEast Asia Region. Retrieved, 15 April 2019, from http://www.searo.who.int/entity/disabilities_injury_rehabilitation/topics/disability_factsheet.pdf

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[43] Maulik, P., Mascarenhas, M., Mathers, C., Dua, T., Saxena, S. (2011). Prevalence of intellectual disability: a meta-analysis of population-based studies. Res Dev Disability. 32:2, 419 – 436.

[44] WHO. (2013). Disability in the SouthEast Asia Region. Retrieved, 15 April 2019, from http://www.searo.who.int/entity/disabilities_injury_rehabilitation/topics/disability_factsheet.pdf.

[45] Hussain, A. et al. (2017). Autism Spectrum disorders (ASD) in South Asia: a systematic review. BMC Psychiatry.

[46] Maulik, P., Darmstadt, G. (2007). Childhood Disability in Low- and Middle-Income Countries: Overview of Screening, Prevention, Services, Legislation, and Epidemiology. Paediatrics; 120 Suppl 1:S1-55.

AFGHANISTAN

Capital: Kabul
Population: 34,656,000[**]
Rank in HDI: 168[*]
World Bank Income Classification: Low[#]

* UNDP: Human Development Reports 2018
** World Health Organisation 2016

GNI Per Capita (PPP): USD 1824[*]
Health Expenditure Per Capita (PPP): USD 183.9[**]
Life Expectancy at Birth (years): 64[*]
Population with disability (%): 2.7[$]

\# World Bank 2019
$ National Disability Survey 2005

Afghanistan has an unfortunate history of continuing struggle that has lasted decades. Because of the longstanding war conditions in the country, disability is seen very much as a war issue in the country. Hence a greater focus of the programmes and policies is on disabled war veterans leaving little attention for others with disability. The responsibility for welfare of people with disability has also been placed in the Ministry of Martyrs and Disabled.

It was not until the mid-1980s that a primary mental health care initiative created a modern system that integrated mental health into primary health care. Following the extensive turmoil and fall of the Taliban government in 2001, the Afghan national healthcare system was shattered and was no longer able to cope with increasing health demands. The fact that disability has been regarded as a war issue has further added to the problem.[47] A Task Force on Disability was established in February 2003 with the primary task of developing a comprehensive disability strategy for Afghanistan. This Task Force included representatives of all stakeholders including persons with disability and their organizations, thereby giving them a voice in policy formulation. In 2004, the Minister of Health declared mental health as a top priority.[48]

In keeping with the conception of disability as defined by the WHO in the ICF, a person is considered 'disabled' in Afghanistan when: "she/he suffers of any kind of restriction resulting from impairment. This implies a lack of ability to perform an activity in a manner, or within the range considered normal for human beings".[49] Despite the progressive understanding of disability, there is a great variation in the estimates available, largely because a single definition of who is considered disabled is not applied. The National Law of Rights and Benefits of People with Disabilities enacted in the early 2000s, provides for economic, social, political, cultural, educational and rehabilitation support, protection of rights, and active participation in society to persons with disability. According to the law, 3% of all jobs in both government and private sector are reserved for persons with disability.[50]

Results of a survey undertaken by the Centres for Disease Control show a prevalence ranging between 1% and 4% for disability among children.[51] People and families of people with disability have been pushed into social exclusion and poverty. It is difficult to identify and survey all people with disability because of the negative attitudes and perceptions of family and society as well as lack of access to insecure areas, poor infrastructure and lack of resources to conduct rigorous research.[52]

Table 3: Prevalence Rate according to various surveys[53]

Sources	Year of Survey	Prevalence Rate
UNDP/UNOPS[*]	1991	3% (total 700,000)
Multi Indicator Cluster Survey (MICS)[#]	2003	2.5% for children under 5 3% for persons between 7 & 17
National Risk and Vulnerability Assessment (NRVA)[$]	2003	2% for physical disability; 1% for mental disability
NDSA	2005	2.7% for overall population

[*] UNDP/UNOPS. (1999). Comprehensive Disabled Afghan's Programme: Integrating Disabled and Marginalised People in Afghanistan. Journal of Mine Action Fall 1999 Vol 3. No. 3

[#] Ministry of Education, UNICEF and CSO. (2003). Multi Indicator Cluster Survey Report.

[$] Government of Afghanistan, Ministry of Rural Rehabilitation and Development, Vulnerability Analysis Unit. (2004). Report on Findings from the 2003 National Risk and Vulnerability Assessment in Rural Afghanistan, Retrieved, 11 May 2019, from www.mrrd.gov.af/vau/NRVA_2003.htm#WFP.

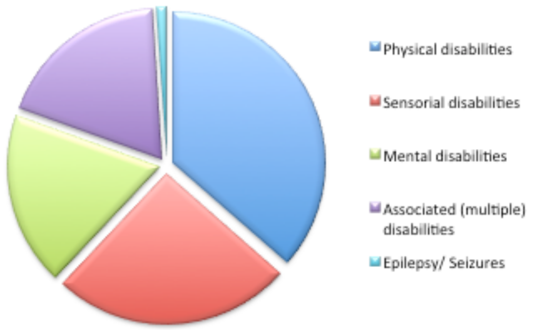
Trani et al have reported the various types of disabilities found in Afghanistan in 2002. Physical disability was reported to be 28.1% and multiple disability 26.1%. Mental disability at 4.6% is a clear underestimation because of social and traditional beliefs, tendency to hide people with mental disability, perception that it is the wish of God, or is caused by war distress. Trani et al note that the investigators were not well trained and did not have skills necessary to identify mental disability.[54]

In 2002, Afghanistan developed a Basic Package of Health Services covering 7 health categories: maternal and newborn health; child health and immunization; public nutrition; communicable diseases with concentration on tuberculosis and malaria; mental health, disability and physical rehabilitation services; and supply of essential drugs. In 2005, the Ministry of Public Health formulated a complementary Essential Package of Hospital Services which defines the basic services to be offered at district, provincial, and regional and specialty hospitals and also updated the Basic Package of Health Services to bringing increased focus on mental health, disability and physical rehabilitation. [55]

Under the revised Basic Package of Health Services, disability interventions have been revised to be more appropriate for each type of health facility – primary or tertiary. Services are provided at all posts. Disability Services include disability awareness, prevention, and education; home visit program for paraplegics (in urban settings); referral for war injuries, traumatic amputations, and prostheses patients and referral for disabled children with physical anomalies. The Basic Package of Health Services and the Essential Package of Hospital Services together outline the Afghan health system's entire referral system, from health post to tertiary care.

Lack of data on prevalence and numbers of intellectual and developmental disability has resulted in lack of opportunities to develop policies and programmes to address the needs of this cohort of people.[56] The National Disability Survey undertaken in 2005 reports on the types of disability experienced. Physical disability was reported to be 36.5% followed by sensorial disability (25.5%). Both categories include multiple physical or sensorial

Figure 4: Distribution of disabilities, Afghanistan 2005



Source: Government of Afghanistan. (2005). National disabilities. Similar percentages were reported for mental and associated disability. These categories too have high proportions of persons with psychological disability and learning disability.

The underestimation of mental disability has been reported in other surveys undertaken in Afghanistan. These figures are based on 2.7% of the population who have serious difficulties in performing daily chores.[57] Trani and Bakshi reporting in 2008 note that the National Disability Survey 2005 estimated disability prevalence rate in Afghanistan to be 2.7% of the population,[58] but that the disability rate increases to 4.6% when various forms of mental diseases are included in the data. Of the disability at birth or acquired in the first year of life, an estimated 26.4% is from the following causes: lack of antenatal and maternal care, incomplete vaccination cycles, congenital disabilities (spiked perhaps by high levels of marriage among first cousins), inadequate health care services, accidents, malnutrition and preventable diseases like polio. The high rate of childhood disability is compounded by birth complications, particularly among undernourished women who are married early and do not receive adequate care.[59]

A study conducted in 2003 in 65 schools in Kabul estimated that congenital disability accounted for over 30% of overall causes of disability, highlighting the limited access to antenatal care and treatment of infectious diseases.[60] A study using data from two large household surveys carried out in 2005 and 2013 report that the proportion of people with physical disabilities increased from 40% in 2005 to 59% in 2013, while the percentage of people with mental and associated disabilities declined from 36% to 20%. Disability acquired after birth increased from 51% in 2005 to 68% in 2013.[61]

A recently concluded mental health survey undertaken with 4445 adults and 3747 children reports high psychological distress and role impairment due to poor mental health. It reported an overall prevalence of experiencing high psychological distress in one month preceding the interview (47.7%) and high role impairment (24.3%). The report goes on to indicate that at least one out of two Afghans suffers from psychological distress (50%) and one out of five is impaired in his/her role because of mental health problem (20%).[62]

Stigma and discrimination: The lack of awareness about causes of disability, especially intellectual and developmental disability leads to stigmatisation, prejudice and discrimination.

Thakkar et al report that there is a complex relationship between perceptions of disability, with gender, traditional beliefs, knowledge and attitudes which in turn guides the degrees of stigmatisation or discrimination of different groups of disabled persons. Persons with disability are called by two different names – *malul* are those whose disabilities are associated with war; the other category is *mayub* who are those whose disabilities are associated with congenital factors, birth accidents and malnutrition. The *malul* are respected and admired and are considered to be heroes due to political and religious pressures.[63,64] Those whose disabilities are associated with congenital factors, birth accidents, malnutrition (*mayub*) are believed to have been cursed. Thus, the way society views them and degree of exclusion they experience depends on whether the disability is the result of war injury or caused by other factors.

For persons with intellectual and developmental disability, the situation is much worse. Intellectual and developmental disability that cannot be attributed to a specific cause is perceived as a curse, shameful, punishment or bad luck; children may be locked up or given food but no affection or care.[65,66] Intellectual and developmental disability are often denied altogether, and the cause attributed to stress of bomb attacks that the children may have seen or been exposed to, and labelled post traumatic stress disorder. However, since post-traumatic stress disorder is not well known in Afghanistan, it is often believed that this is caused by evil spirits.[67]

As compared to people with physical disability, those with intellectual and developmental disability feel isolated and withdrawn from others, they may be violent, have difficulty in communicating and experience anxiety and depression.[68] The National Disability Survey (2005) elaborates on the situation of people with intellectual and developmental disability. The survey findings report the among the proportion of persons with mental disability: 74.6% feel sad and cry; 79.4% sit and think; 72.6% feel oppressed; 77.8% feel suffocated and 69.8% feel angry and resentful. These findings indicate that this sub-population is aware of their situation and may feel that they are a burden on their family and feel rejected by society.[69]

Gender and marginalisation: In a traditional society like Afghanistan where women's place is clearly defined, girls and women with disability are at a greater disadvantage as compared to their male counterparts. But the status of women is changing in Afghanistan, albeit slowly. War has resulted in a breakdown of the existing family structure; men can no longer be guaranteed to be providers for the family. This has forced the women to go out in society to earn a livelihood and take care of the family needs. However, deep patriarchy and the religious attitude make this shift challenging for the women.[70]

In a country torn with war, women suffer not only loss of their loved ones, but they too are displaced along with their children, are victims of violence, experience mistreatment and do not have access to basic amenities. Not surprising then that more women report feeling anxious and depressed as compared to men in the same situation. The caveat here is that the survey findings do not distinguish between those with physical disability or intellectual and developmental disabilities. Suffice to say that the mental condition of women in the country is distressing.[71]

Being a woman with disability, particularly mental and learning disability is very challenging and there is a clear association of disadvantage with gender and disability. Bakshi and Trani report that fewer girls with disability are in school, reiterating the discrimination girls with any disability face in Afghanistan.[72] Added to this is the lack of female teachers, because women are not supposed to step out of their compound in rural Afghanistan. Changes, albeit slow, are taking place in (only) urban areas and access to education for girls is easier in those settings.[73]

Health: Although an integral part of Basic Package of Health Services and Essential Package of Hospital Services, disability and mental health are neglected areas in the health programmes in Afghanistan. Thus, resource allocation is limited even though disability rehabilitation is a priority of the government. Other factors contributing to uneven health coverage are widespread insecurity, lack of access for women to services outside the home, stigma and negative attitude of healthcare providers, absence of roads and transportation, and the long distances that the family has to travel to access services. There is a shortage of trained staff to deal with specific needs of people with disability, especially learning and intellectual and developmental disabilities.[74] The most excluded group is people with severe intellectual disabilities.

To quote from the report of the Afghanistan Interim Health Strategy of Ministry of Public Health 2002-2003, the Ministry of Martyrs and Disabled states: “Disability in this policy document has been included within wider discussion of vulnerable groups such as homeless, women and displaced people. The Ministry of Public Health after consultations with various stakeholders concluded that mental health and disability issues do not constitute a priority for the Basic Package of Health Service in Afghanistan ‘at this stage’.” Although the Ministry of Public Health recognizes the significant proportion of people with disability in the country, the availability of resources has unfortunately determined their priorities and influenced overall health planning”.[75]

Using data from 2 representative national level household surveys in 2005 and 2013, Trani et al find an association between formal education and higher asset levels with improved availability of health care and positive experiences with coverage of health care needs. However, between 2005 and 2013 surveys, these perceptions changed. For example, perceived availability of health care services reduced from 69% in 2005 to 44% in 2013. Similarly, positive experiences were reported by only 45% in 2013 as compared to 78% in 2005. This could be attributed to loss of connectivity through paved roads and increased time to reach a health facility.[76]

Educational attainment: Available evidence does not provide in-depth information on education related achievements or challenges faced by persons with intellectual and developmental disability.

Access to inclusive education for children with disability in Afghanistan is not universal. The education system is under considerable strain with class sizes of 60 students. Teachers teach teachers 3 shifts of 4 hours per day in order to accommodate the large numbers of students. Less than 50% of school currently have a building.[77] In a situation where there is a lack of teachers and building for children, the possibility of accommodating those with intellectual disabilities becomes even more challenging. Findings from a study carried out between 2004 and 2007 reports that there is a general belief that children with learning or intellectual difficulties are not able to learn. Teachers do not accept them as they feel that these children will not be able to learn and hence, they do not have a place in the class. Further, children with certain conditions like epilepsy are rejected because of false beliefs that epilepsy is contagious. The teachers are not trained nor do they have the pedagogical training to understand how to teach children with special needs.[78] Perception of physical disability is strongly linked with war injuries and martyrdom. While the *malul* are able to access education, those whose disabilities are associated with congenital factors, birth accidents and malnutrition – the *mayub* - are shunned resulting in only 23% of *mayub* children aged 7-18 years being able to access schooling.[79]

The study mentioned above reports that highest level of exclusion faced in schooling was by children with epilepsy, those with sensory disabilities, with learning difficulties or emotional problems. In Afghanistan, hearing and speech disability is often merged with learning disability. These children had lowest rate of completion of primary level of schooling. On the other hand, children with mobility challenges faced limited exclusion and fared better in primary and secondary levels of schooling as compared to those with sensory or learning or emotional challenges.[80]

Economic participation and poverty: There is limited evidence on employment opportunities available for persons with intellectual and developmental disabilities.

In the absence of data, it is difficult to relate disability with level of poverty, particularly for those with intellectual and developmental disability. The situation is much worse for those whose disability is not the result of war injuries. Persons whose disabilities are caused by war (*malul*) can access services and may even get employment. On the other hand, persons with disability associated with congenital factors (*mayub*) find it difficult to find employment or make a living, and hence are dependent on charity or already extended resources of their family. The hostile environment and external shocks and risks they face worsens their situation.[81]

Assistive devices: There is almost no evidence on availability of, access to or use of assistive devices, especially for persons with intellectual and developmental disabilities. One can assume that because of the decades of war and conflict, there are a number of persons who are physically disabled and in need of assistive devices. However, there is no specific mention of availability of assistive devices, including wheelchair or hearing aid or braille except in policy documents as suggestions.

International Committee of the Red Cross (2016) reports that over 19,000 artificial legs, arms and other orthopaedic devices are manufactured every year. International non government organisations (NGOs) have played a key role in the provision of services for persons with disability.[82]

Key Takeaways

- Disability concerns in Afghanistan are dominated by sensorimotor disability as an outcome of the prolonged conflict situation in the country.
- Disability rates in Afghanistan are relatively higher than those recorded in other countries in the region.
- Persons with intellectual and developmental disabilities experience isolation and depression due to the stigma associated with their condition. This is worse for women with disability.
- Intellectual and developmental disabilities are covered under the Basic Package of Health Services, but they are not prioritised.
- Discrimination against children with intellectual and developmental disability is widespread, and coverage with schooling is poor.
- Persons with disability from birth are disadvantaged in their search for livelihood.

GOOD PRACTICE CASE STUDY

International Assistance Mission
Herat, Afghanistan

Mark Allan, Executive Director **www.iam-afghanistan.org**

The International Assistance Mission, a not for profit organization, works in Herat, to improve lives by building local capacity in health, education and community development in partnership with the Afghan government.[83] While not strictly operating in the intellectual and developmental disability space, the organisation supports children with challenges and advocates for inclusion.

It addresses the problems of suicides, violence against children, intellectual disabilities, challenges faced by people with psychosocial disabilities. The approach is focused on community training and development in order to build self-reliance. Since 2006, the organisation has trained primary health care providers, teachers, religious teachers to raise awareness about mental health issues.[84] The Mental Health Training Centre established in Herat handed over to the Ministry of Public Health in 2016. Training has been imparted to 253 governmental staff with special focus on community based mental health interventions and 483 key community members (Shura, Mullahs, community volunteers) were also trained. The training activities also benefitted 21 psychiatrists/residents. At the school level, 401 Education Directorate staff and teachers received the training related to mental health, life skills and increased inclusion of children in education system.

It has four projects: Community Based Mental Health Project which aims to improve the lives of people with psychosocial disability through integrated usage of psychological and medical care and social inclusion; Youth Emotional Resilience Project which facilitates life skill trainings for students and regular parent-teacher meetings to make youth more emotionally resilient; Child and Adolescent Psychiatry Project which focuses on improvement in the lives of children with psychosocial disability by providing with one-on-one psychiatry and counselling services, support groups and assistance to parents to understand the problems; and finally, Positive Parenting Project which seeks to reduce violence against children by training of parents on mental health disorders and non-violent classroom management skills for teachers.[85]

The programme can be scaled and replicated. The program has been quite effective as they have positively impacted the lives of the people suffering from mental illnesses.

End Notes

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[47] World Health Organization Geneva: WHO Press. (2013). Building Back Better: Sustainable Mental Health Care After Emergencies.

[48] Government of Afghanistan, Ministry of Public Health. (2011). Afghanistan National Health Workforce Plan.

[49] Bakshi,P., Dubois.J., Trani,J. (2004). Enhancing Security and Social Sustainability, Strengthening Capabilities: The case of Persons with Disability in Afghanistan. Paper presented at 4th International Conference on the Capability Approach "Enhancing Human Security", University of Pavia, Italy

[50] Sida. (2014). Retrieved, 10 April 2019, from https://www.sida.se/globalassets/sida/eng/partners/human-rights-based-approach/disability/rights-of-persons-with-disabilities-afghanistan.pdf

[51] Bakshi,P., Dubois.J., Trani,J. (2004). Enhancing Security and Social Sustainability, Strengthening Capabilities: The case of Persons with Disability in Afghanistan. Paper presented at 4th International Conference on the Capability Approach "Enhancing Human Security" 5-7 September 2004, University of Pavia, Italy

[52] Coleridge, P. (2002). Community Based Rehabilitation in a Complex Emergency: Study of Afghanistan, in M. Thomas, and M.J. Thomas (eds), Selected Readings in CBR Series 2: Disability and Rehabilitation Issues in South Asia, National Printing Press Bangalore, pp. 35-49.

[53] Handicap International. (2006). National Disability Survey, Afghanistan 2005.

[54] Bakshi,P., Dubois.J., Trani,J. (2004). Enhancing Security and Social Sustainability, Strengthening Capabilities: The case of Persons with Disability in Afghanistan. Paper presented at 4th International Conference on the Capability Approach "Enhancing Human Security", University of Pavia, Italy

[55] Islamic Republic of Afghanistan, Ministry of Public Health (2005). A Basic Package of Health Services for Afghanistan 2005/1384

[56] Trani, J. et al. (2011*)*. Disability in Afghanistan: Taking a Capabilities Approach to look at Research Challenges and Policy Implications. ALTER, European Journal of Disability Research 5 pg. 143–157

[57] Handicap International. (2006). National Disability Survey, Afghanistan 2005.

[58] Handicap International. (2006). National Disability Survey, Afghanistan 2005.

[59] Trani, J., Bakhshi, P., Nandipati, A. (2012). Delivering education; maintaining inequality. The case of children with disabilities in Afghanistan. Cambridge Journal of Education Vol. 42, No. 3, September 2012, 345–365

[60] Bakshi,P., Dubois.J., Trani,J. (2004). Enhancing Security and Social Sustainability, Strengthening Capabilities: The case of Persons with Disability in Afghanistan. Paper presented at 4th International Conference on the Capability Approach "Enhancing Human Security", University of Pavia, Italy

[61] Trani, J. et al. (2017). Assessment of progress towards universal health coverage for people with disabilities in Afghanistan: a multilevel analysis of repeated cross-sectional surveys. Lancet Glob Health; 5

[62] Government of Afghanistan, Ministry of Public Health DG-Diseases Control & Prevention PHC Directorate Mental Health Department (2019). Mental Health Survey 2018.

[63] Thakkar, M., Cerveau, T., and Davin, E. (2004). Afghan perception on disabilities, a research project on the perceptions and practices regarding disability in Afghanistan, to Inform a Communication Strategy', Study carried out by ALTAI Consulting for UNICEF, UNOPS, UNDP, Kabul

[64] Bakshi,P., Dubois.J., Trani,J. (2004). Enhancing Security and Social Sustainability, Strengthening Capabilities: The case of Persons with Disability in Afghanistan. Paper presented at 4th International Conference on the Capability Approach "Enhancing Human Security", University of Pavia, Italy

[65] Bakshi,P., Dubois.J., Trani,J. (2004). Enhancing Security and Social Sustainability, Strengthening Capabilities: The case of Persons with Disability in Afghanistan. Paper presented at 4th International Conference on the Capability Approach "Enhancing Human Security", University of Pavia, Italy

[66] Trani, J. et al. (n.d.) Disability in Afghanistan: Taking a Capabilities Approach to look at Research Challenges and Policy Implications. UNESCO, Paris

[67] Trani, J. et al. (n.d.) Disability in Afghanistan: Taking a Capabilities Approach to look at Research Challenges and Policy Implications. UNESCO, Paris

[68] Handicap International (2006). National Disability Survey, Afghanistan, 2005

[69] Handicap International (2006). National Disability Survey, Afghanistan, 2005

[70] Handicap International (2006). National Disability Survey, Afghanistan, 2005

[71] Handicap International (2006). National Disability Survey, Afghanistan, 2005

[72] Bakhshi, P., Trani, J.F. (2011). A gender analysis of disability, vulnerability and empowerment in Afghanistan. In J.F. Trani (Ed.), Development efforts in Afghanistan: Is there a will and a way? The case of disability and vulnerability. Paris: L'Harmattan.

[73] Trani, J., Bakhshi, P. Nandipati, A. (2012). Delivering education; maintaining inequality. The case of children with disabilities in Afghanistan. Cambridge Journal of Education Vol. 42, No. 3, September 2012, 345–365

[74] Trani, J. et al. 2017. Assessment of progress towards universal health coverage for people with disabilities in Afghanistan: a multilevel analysis of repeated cross-sectional surveys. Lancet Glob Health

[75] Grove, S., Grove, N., Myerscough, T.(n.d.). As quoted in Intellectual Disability and War: Issues for Consideration. Journal on Developmental Disabilities.

---

[76] Trani, J. et al. (2017). Assessment of progress towards universal health coverage for people with disabilities in Afghanistan: a multilevel analysis of repeated cross-sectional surveys. Lancet Glob Health

77 Hossein, N. (2017) ‘Half of schools nationwide without buildings’ Retrieved, 15 May 2019, from https://www.pajhwok.com/en/2017/03/23/%E2%80%98half-schools-nationwide-without-buildings%E2%80%99

[78] Trani, J., Bakhshi, P., Nandipati, A. (2012). Delivering’ education; maintaining inequality. The case of children with disabilities in Afghanistan. Cambridge Journal of Education Vol. 42, No. 3, September 2012, 345–365

[79] Trani, J., Bakhshi, P., Nandipati, A. (2012). Delivering’ education; maintaining inequality. The case of children with disabilities in Afghanistan. Cambridge Journal of Education Vol. 42, No. 3, September 2012, 345–365

[80] Trani, J., Bakhshi, P., Nandipati, A. (2012). Delivering’ education; maintaining inequality. The case of children with disabilities in Afghanistan. Cambridge Journal of Education Vol. 42, No. 3, September 2012, 345–365

[81] Bakshi,P., Dubois.J., Trani,J. (2004). Enhancing Security and Social Sustainability, Strengthening Capabilities: The case of Persons with Disability in Afghanistan. Paper presented at 4th International Conference on the Capability Approach “Enhancing Human Security” 5-7 September 2004, University of Pavia, Italy

[82] International Committee of The Red Cross (ICRC). (2016). The ICRC's physical rehabilitation work, Afghanistan

[83] International Assistance Mission. (n.d.) Retrieved, 1 July 2019, from https://iam-afghanistan.org/who-we-are/

[84] International Assistance Mission. (n.d.) Retrieved, 1 July 2019, from https://iam-afghanistan.org/c/health-sector-work/

[85] International Assistance Mission. (n.d.) Retrieved, 1 July 2019, from https://iam-afghanistan.org/iam-wp/wp-content/uploads/Annual-report-English.pdf

BANGLADESH

Capital: Dhaka
Population: 162,952,000**
Rank in HDI: 136*
World Bank Income Classification: Lower middle#

* UNDP: Human Development Reports 2018
** World Health Organisation 2016

GNI Per Capita (PPP): USD 3677*
Health Expenditure Per Capita (PPP): USD 88**
Life Expectancy at Birth (years): 72.8*
Population with disability (%): 7%$

World Bank 2019
$ Household Economic Expenditure Survey 2016

Bangladesh first articulated its response to the issues of persons with disability through the Bangladesh Persons with Disability Welfare Act enacted in 2001. In addition, it signed the United Nations Convention on the Rights of Persons with Disabilities in 2007.[86,87]

The 2001 Act has since been replaced by the Rights and Protection of Persons with Disabilities Act 2013 which defines a person with disability as: "any person who can't take part actively in the society is considered to be disabled. Persons with disability have rights equal to all citizens, including fundamental basic human rights that are mentioned in this Act and other laws. This Act gives persons with disability the opportunity to lead their lives like other people without facing any obstacles".[88] This Act has made major strides in recognising a much wider range of persons within its ambit, as well as taking cognizance that all people – including those with disability - have rights provided under the laws of the country.

There is limited evidence on prevalence of disability in Bangladesh. An account of pattern and differentials of disabilities of various kinds is missing, largely because there has not yet been a comprehensive national survey on persons with disability in Bangladesh. The prevalence of disability is expected to be high because of extreme poverty, population, illiteracy, limited awareness and lack of medical care and related services. There are several sources of disability prevalence in the country; however other sources either have a flawed methodology or a lack of statistical representation. The most eminent of these is the Ministry of Social Welfare's widely quoted but erroneous disability estimates of 2013 which puts disability prevalence at about 1%. The reason for the inaccuracy stems from a self-reporting register with selective coverage and no sampling methodology to make it statistically representative.

While routine data collection and the health surveillance system do not include disability statistics, the national level Census, Sample Vital Registration System, surveys conducted by NGOs and international organisations provide some information. The methodology is not always rigorous and there is a lack of statistical representation in some of the sources of disability related data. As per the Fifth National Population and Housing Census conducted in 2011, persons with disability constituted 1.4% of the population, an increase from 0.6% in the Census of 2001. The Bangladesh Bureau of Statistics estimated in 2011 that persons with disability constituted some 9.07% of the population, while the World Bank's estimation of the same year was 31.9%.[89] A survey conducted in 2013 by the Ministry of Social Welfare estimated disability prevalence to be about 1%. As noted above, this data may not be accurate as it is not based on a rigorous, statistically representative sampling methodology. The latest data on disability comes from Household Income and Expenditure Survey, 2016. It estimates that persons with disability constitute 7% of the population, with a higher percentage in rural Bangladesh compared to urban Bangladesh (7.2% and 6% respectively). [90]Disparities could be with disability attributed to different approaches to measuring disability prevalence. Statistics on prevalence of disability have been a matter of serious debate.[91] The underestimation of the actual number of persons with disability by the government is felt to affect prioritisation of issues of people with disability and their inclusion in mainstream development approaches.[92] The Department of Social Services has identified and prepared a database of 1,644,000 people who are "differently abled", including those with autism. Currently, about 1,000,000 receive allowances from the government.[93]

There is a paradigm shift in Bangladesh from charity and medical model to a rights based model. Concerted efforts are being made by the government and there is a 'disability movement' in the country, with a particular focus on autism and neurodevelopmental disorders. At present, the Disabled People's Organisations (DPOs) and NGOs work together to improve pathways to better economic and social inclusion of persons with disability by promoting leadership, skills and ensuring their inclusion in various spheres. Since 2011 the Government of Bangladesh has initiated steps to deal with autism and neurodevelopmental disorders. An Advisory Committee and a Technical Guidance Committee have been established to help the National Steering Committee on Autism and Neuro-developmental Disorders develop priorities, design programmes, devise implementation strategies, provide guidance on the appropriate use of resources, and identify necessary resources. However, there is an urgent need to translate the strategies into implementation by formulating strategies, ensuring multidisciplinary planning and evidence-based action.[94]

Jatiyo Protibondhi Unnayan Foundation (National Foundation for the Disabled) is the only government agency that works under the Ministry of Social Welfare. It conducts training programmes for mothers of children with intellectual disability, behaviour modification and parents' role in management of autism and development disorders.[95] It has 103 Integrated Disability Service Centres across Bangladesh which provide cost-free centre based rehabilitation services to children and adults. Yet UNICEF 2014 reports that there is a lack of commitment and capacity to implement programmes and policies resulting in inadequate allocation of adequate resources. There appears to be somewhat limited coordination between the government and civil society organisations working in these areas that further hinders progress.[96] Additionally, inter-ministerial coordination and coordination between different government constituted committees appears to be weak with the onus of implementing the tasks falling on the Ministry of Social Welfare. For example, one-stop service centres operated under the Ministry of Social Welfare do not have a referral mechanism to the mainstream health system. Thus, those who may need specific health services may not always get them.

Evidence is limited on the six variables that are addressed in this report, namely, stigma and discrimination; gender and marginalisation; health outcomes; educational attainments; economic participation and poverty; access to assistive devices and enabling infrastructure. What is available focusses mainly on prevalence and epidemiology of intellectual and developmental disabilities as described above. Programme and evidence uses 'disability' as a broad term, with the emphasis on a range of physical disabilities.

Stigma and discrimination: The literature reviewed highlights the anxiety, stigma and discrimination faced by parents of persons, particularly children, with intellectual and developmental disabilities. It may also be pointed out that while anecdotal accounts of the stigma and discrimination faced by persons with disability in their everyday lives abound, studies have highlighted the stigma and discrimination that parents and caregivers have to face.

Parents of children with autism face a range of emotional and social pressures. They cannot talk about their child's condition openly because of fear of negative comments from the family and society at large and the stigma attached to the condition. Parents are often not aware of appropriate diet for their child, how to 'control' their child's behaviour during celebrations and special occasions, or even how to teach their child basic tasks such as brushing their teeth or interacting with peers.[97,98]

Parents of children with disability are at a disadvantage in economic, social and educational fields. They not only have to worry about feeding and caring for the child but also have to contend with non-availability of educational options and need to protect the children from social ostracisation. Their own lack of awareness of the disability and parenting challenges of the children's special needs adds to the burden of caring.[99] Parents of children with intellectual and developmental disability are worried and anxious about their children's future, including about care later in life, and marriage for both boys and girls. There is an added burden of caregiving which is exhausting in the absence of support. If both parents are working, this then adds to the burden on the mother as she is seen as the primary caregiver for the children. This results in parents feeling isolated, vulnerable and may act as a factor contributing to a child being stigmatised and neglected not only by the parents, but also by wider society.[100]

Gender and marginalisation: Globally, women and girls with intellectual and developmental disability face more hindrances and obstacles as compared to their male counterparts. The situation in Bangladesh is no different. Literature review reiterates the emotional, physical, and sexual abuse faced by women and girls in this cohort.

Girls and women with disability are at a greater disadvantage compared to their male counterparts. Girls with disability, particularly intellectual disabilities, are subject to emotional, physical and sexual abuse. Parents are reluctant to send their children, especially girls, to school.[101,102] Instances of abuse by traditional healers during treatment or therapy have also been recorded. These instances go unreported because of social stigma or threats. It is also possible that because of their intellectual and developmental challenge these girls and women either did not understand the event of sexual abuse or they were unable to explain what happened to anyone.[103]

For girls, the onset of puberty is a major milestone and even more so for girls with intellectual and developmental disability for whom this event can be a traumatic experience. This is because not only have they not been told about this, but also because they cannot explain what is happening to them. Parents also find it difficult to teach them how to take care of themselves during menstruation.[104]

Health: Available evidence for people with intellectual and developmental disability is limited to health outcomes of children, especially autism, Down syndrome and cerebral palsy. Health outcomes for people with disability are poorer compared to those with no disability. Disability has not yet been fully mainstreamed in the health infrastructure and most of the services remain inaccessible to persons with disability. There is a limited understanding of neuro-developmental disability, particularly autism in the country as it was neither a part of the medical curriculum nor understood by the community. As a result children were often diagnosed with cerebral palsy or epilepsy and perhaps, Down syndrome by most paediatricians and neurologists. Since the medical fraternity had limited understanding of autism, children presenting with signs and symptoms of autism were misdiagnosed as having mental retardation, understood by the community to mean *'pagol'* (crazy/mad).[105]

There is a shortage of healthcare service providers who are important to facilitate physical and social rehabilitation of persons with disability. Physiotherapists, occupational therapists, speech and language therapists, clinical psychologists, orthotics and prosthetics technicians, audiologists etc. are not recognised under the mainstream health workforce. Since these are not systematically embedded within the health service of the Bangladesh. On the other hand, private institutions have demonstrated that there is appropriate infrastructure to train these specialists.

Results of a cross-sectional comparative study undertaken in six centres of Dhaka with 115 children in the sample (57 autistic and 58 children without disability) indicates that 54.4% autistic children had poor physical function, 94.7% had poor emotional function and none had good social function skills.[106] The situation is exacerbated for the poor as they are excluded from even basic health services, including prenatal care and early interventions that for prevention and treatment of disability.[107] There are limited human resources including specialist physicians and screening facilities for autism. To address this, according to a 2014 report by Centre for Research and Information, initiatives taken by the government include training of 3676 doctors, 480 nurses, 270 physiotherapist, and 186 special educators in the Centre for Neurodevelopment & Autism in Children, Banglabandhu Sheikh Mujib Medical University and National Institute of Mental Health. Additionally, at the community level, 2575 health workers and social activists were trained through 103 batches on autism and neuro-developmental disabilities in 70 sub-districts of 64 districts of Bangladesh.[108]

Bangladesh Cerebral Palsy Register is an on-going population based surveillance database of children with cerebral palsy from a specific geographical area. Between January 2015 to December 2016, 726 children were identified with cerebral palsy. Findings highlight the poor nutrition status of the children with cerebral palsy and reported severe underweight, stunting and acute malnutrition and wasting.[109] The same study indicates that children with cerebral palsy have associated impairments for example, speech or hearing or visual impairment. These children may also have intellectual impairment or epilepsy which further aggravates their situation.[110,111]

A retrospective study undertaken with children with Down syndrome admitted to a hospital with diarrhoea, reports that these cases presented with severe acute malnutrition, congenital heart disease, developmental delays, hypothyroidism, sepsis, hypocalcaemia and often developed hospital acquired infection during hospitalization and required prolonged stay at hospital. This indicates a need to have better clinical management of such children.[112]

Another retrospective study undertaken in an out patient department of a hospital with 149 cases between January to August 2015 corroborates these findings. The study found moderately impaired nutritional status among children with cerebral palsy, epilepsy, speech delay and vertigo while those with attention deficit hyperactivity disorder were at risk of being overweight or obese. Children with autism had mostly normal nutritional status, while children with cerebral palsy and epilepsy were at risk of having mildly impaired nutritional status.[113]

Educational attainments: To the extent that children with intellectual and developmental disabilities such as cerebral palsy, autism, physical disabilities and multiple disabilities have access to education, it is provided by NGOs, many started and sustained with international donor support. Of the more than 40,000 NGOs in Bangladesh, approximately 400 NGOs claim to be working in the area of disability.114 Additionally, there are about 200 Disabled People's Organisations (DPOs) DPOs and thousands of grassroots Self Help Groups that work towards promoting leadership, skills and inclusion of persons with disability in the mainstream society.

Taking cognizance of the need to put in place policies to ensure that children with disability are not left out of education system, a number of policies have been enacted by the Government of Bangladesh. For example, the Rights and Protection of Persons with Disabilities Act 2013 prohibits discrimination in school enrolment on the grounds of disability. The Education Policy 2010 and Comprehensive Early Childhood Care and Development Policy formulated in 2013 also seek to address the inclusion of children with disability. The Education Policy was revised in 2016 with a focus on inclusion issues at all level of education.[115]

Despite these progressive policies, the inclusive education concept and practice is at a nascent stage in Bangladesh. Awareness and understanding of inclusive education is limited, and the mainstream school system is not equipped to meet the varied needs of children with disability. Implementation continues to be a challenge and it appears that the notion of inclusive education is still at a nascent stage in the country. There are not enough skilled teachers and personnel who understand the concept of inclusive education, nor are they equipped through training to be able to deal with children with special needs. Awareness and sensitivity to the special needs are sadly lacking.[116]

Education services are provided by the government as well as NGOs and civil society organisations. Government run schools cater largely to children with physical, visual and hearing impairment while NGOs provide special education services for children with autism or intellectual impairments. Schools run by NGOs are heavily dependent on donor funding which clearly is not a sustainable model.[117]

Ackerman et al indicate that children with intellectual and developmental as well as physical disabilities are a most marginalised and neglected group. His study found that of an estimated 2.6 million children with disability, less than 1500 children could access the special schools sponsored by the government and these, largely restricted to children with hearing, vision and intellectual disabilities. Children with intellectual disabilities and those with physical disabilities are most marginalised and neglected.[118]

While children with physical disability, visual or hearing impairment may have better access to schools, those with any kind of intellectual or developmental disability are not in the immediate focus of inclusive education programmes. This group faces a number of challenges in accessing education opportunities. Children with intellectual and developmental disability are different – their behaviour, limited intellectual development and slower learning levels result in non-acceptance by their peer and teachers. They cannot learn at the same level as a students with no disability and the teachers do not know how to work with this group in a mainstream education environment. An additional factor is the lack of trained teachers, who do not know how to deal with students with special needs.[119,120] Access to education for children with special needs is also restricted due to lack of special education schools as well as non-availability of special educators or teachers who are trained to work with this cohort.[121,122] These children are not admitted to mainstream schools mainly because there is no curriculum to train the teachers on working with group with special needs.[123] Parents cope with an additional financial burden as they have to pay special school fees, transport costs and related treatment costs. Children with autism are at a disadvantage because associated stigma and lack of awareness resulting in late diagnosis. Additionally, there are few centres for providing diagnosis and services and often the physicians who screen the children may not know where to refer the parents.[124]

Since 2019, Bangladesh government has implemented the Comprehensive Education Policy 2010, which caters to persons with neurological disability in three ways, i.e. (i) inclusive education (for mildly disabled), (ii) comprehensive education (for moderately disabled) and (iii) special education (for severely disabled). According to National Foundation for Disable under Ministry of Social Welfare, as of 2019, there are 62 National Disability Development Schools reaching out to about 8000 disabled children in the country.[125] The University of Dhaka has a National Centre for Special Education and a Special Education Department that trains teachers in working with children with disability and special needs. There are 46 focal points constituting different ministries and organisations, each having a specific defined role to play. For example, some are responsible for education; others may be given the task of ensuring accessible spaces and so on.[126] A report by the Centre for Research and Information documents the initiatives taken to protect the rights of persons with intellectual disability and developmental disability. Special schools are run by NGOs catering to the needs of children with autism and neurodevelopment disorders.[127]

Centre for Research and Information reports that the education policy of the country has been modified to accommodate children with autism in schools and ‘autism’ itself as a subject in textbooks. The report highlights steps taken by the government of Bangladesh to recognise autism and integrate children with autism into mainstream education. For example, a strategic action plan has been developed for children with special needs under the umbrella of inclusive education; a module on sensitisation to autism has been developed by the National Academy for Education; autism as a subject in Physical Teaching, Health Science and Sports curriculum for Classes IX and X as well as in Economics curriculum for Class VIII has been included. Further, 2% of seats are reserved for children with autism in private academic institutions and they are given an extra 20 minutes in public examinations.[128]

Economic participation and poverty: The link between education and poverty is well established. Lack of education denies people with disability with the opportunities to earn, resulting in dependency on others throughout their lives. Furthermore, poverty and dependency on others prevents them from accessing or using devices that could improve their quality of life.[129,130] Those with intellectual and developmental disability are even more at risk because of the complexity and variations in the manifestation of the disability. They need greater protection and support to deal with their daily life. Even when employed, this cohort faces wage discrimination and employment opportunities are often denied to them.[131,132]

The findings of a study entitled 'Employment Situation of People with Disabilities in Bangladesh' (2002) reflects the situation of the employment of people with disability. A majority of the respondents were in the category of physical disability (44%) followed by visual impairment (23%). The other two groups were under-reported with just 16% in speech and hearing group and 9% in intellectual disability group. Findings reiterate the need to create more opportunities for skills development and professional training. Negative attitude of people was indicated to be a key barrier to be addressed.[133]

Employment opportunities for persons with disability are often limited in number and restrictive in nature. While this is a human rights issue, the impact is felt on the country's economy as well. Studies indicate the impact of exclusion on the economy of the country. For example, a 2008 estimate by the World Bank calculates the annual cost of disability in Bangladesh (computed from forgone income of persons with disability and their caregivers as a result of missing out on educational and employment opportunities) to be USD 1.2 billion – about 1.7% of Gross Domestic Product.[134] An estimate by the International Labour Organization based on a study of 10 low income countries computes a loss of 3-7% of Gross Domestic Product because of exclusion of persons with disability from workforce because of limited opportunities for education attainment.[135]

Assistive Devices: Borg & Östergren report that government facilities in Bangladesh provide only 1% of the assistive technology devices needed. The report indicates that about two-thirds of the users of hearing aids and three-quarters of the users of wheelchairs had their assistive technologies provided by NGO facilities. About one in five of the respondents using wheelchairs had received them from other sources, which included, community members, clubs and volunteer organisations.[136]

Non-availability of assistive devices at the public sector may lead to high out of pocket expenses that the user may not be able to afford. In Bangladesh about two thirds of respondents who did not have a hearing aid or wheelchair indicated that cost was the key factor.[137]

Assistive devices for people with mobility impairments are mainly made locally but quality of the products remains a concern. During the past few years, artificial limbs have been produced at the Orthopaedic Hospital in Bangladesh. Some entrepreneurs have produced local designs of wheelchairs, trolleys, tricycles, walkers, callipers, braces and crutches. People who can afford to import these devices from China, India, Norway, Singapore, United Kingdom and United States, as there is no import duty on them.

However, imports and donation from developed countries and NGOs meets only 15% of the total demand. Modern assistive devices produced in the country do not meet demand, primarily due to a lack of funds, technological support and skilled personnel.

KEY TAKEAWAYS

- Despite enacting a law on disability as early as in 2001, Bangladesh has not yet carried out a national survey on persons with disability. Data from other surveys suffer from an absence of a rigorous methodology.
- Bangladesh established a Cerebral Palsy Register in January 2015.
- Persons with intellectual and developmental disability are among the poorest and most vulnerable populations of the country.
- What evidence there is on disability, focuses on children. Children with intellectual and developmental disability face multiple challenges. Girls with intellectual and developmental disability are at the receiving end of emotional, physical and sexual abuse, making parents fearful of sending young girls to school.
- National Disability Development Schools reach out to only about 8000 disabled children in the country, clearly indicating the gaps in service delivery.
- In particular, parents of children with challenges are at a disadvantage because of the financial and effort cost of interventions. Further, they live with constant anxiety, stigma and discrimination.
- Links have been established between the poor educational attainments of those with intellectual and developmental disability, and poverty. Not only are they discriminated against in schooling, even when employed they must confront wage discrimination.

GOOD PRACTICE CASE STUDY

National Disability Identification Survey

Dr. Ashrafi Ahmed, Programme Director **www.dis.gov.bd**

In 2014, the Department of Social Services, Dhaka initiated a National Disability Identification Survey with the broad objective of facilitating the inclusion of persons with disability in Government programs and projects. The survey is countrywide, addressing all persons with disability. Every public hospital (570 in all) has a Social Welfare Officer in charge for registration and identification of persons with disability across the 65 districts in Bangladesh[138].

By taking stock of the nature and magnitude of disability, the Government of Bangladesh would be able to capture the actual numbers of persons with disability in the country, type and level of disability and determine specific causes of disability. It was felt that because persons with disability were not identified, they did not receive the services that they required, such as special education, psychological/ clinical therapy, health, social security, and related issues.

Initiated as a door-to-door paper survey, the identification process gradually shifted to a web-based application to capture information about the person with disability, including type of disability once identified by a doctor[139]. The web-based inventory is designed to provide information relevant in designing programmes for persons with disability. Once registered, persons with disability are entitled to a range of services including monthly allowance, identity card, access to special school, access to inclusive school, priority-based service in public transport. By July 2019, a total of 16,65,115 persons have been identified in 12 categories.[140]

One of the challenges of an online registration system is the availability of an internet connection. However, this was resolved as the forms were accessed through the internet enabled offices of Social Welfare Department which are spread throughout the country. Further, the caregiver can register the person with disability without the person with disability having to visit the office. The system was supported by mass media activities for awareness on identification cards and allowances, which turned out to be more beneficial than the door-to-door survey.

This web based application survey is replicable and scalable. It involves collaboration of Ministries of Social Welfare and Health as well as the community, parents/ caregivers as well as the disabled persons.

End Notes

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[86] Government of Bangladesh. (2001). Bangladesh Persons with Disability Welfare Act, 2001

[87] Bangladesh Bureau of Statistics. (2015). Disability in Bangladesh: Prevalence and Pattern. Population Monograph: Volume-5

[88] Women with Disabilities Development Foundation (WDDF); (n.d.) Persons With Disabilities Rights And Protection Act In Bangladesh User-Friendly Booklet Retrieved, 15 March 2019, from http://www.apcdfoundation.org/?q=system/files/Persons%20with%20Disabilities%20Rights%20and%20Protection%20Act%202013_0.pdf

[89] National Grassroots and Disabilities Organization (NGDO), National Council for Women with Disabilities (NCDW) & Bangladesh Legal Aid and Services Trust (BLAST). (2015). Current status of Rights of Persons with Disabilities in Bangladesh: Legal and Grassroots Perspectives. (n.p.)

[90] Bangladesh Bureau of Statistics. (2017). Household Income and Expenditure Survey, Bangladesh. 2016-2017.

[91] Bangladesh Bureau of Statistics; (2015). Disability in Bangladesh: Prevalence and Pattern. Population Monograph: Volume-5

[92] National Grassroots and Disabilities Organization (NGDO), National Council for Women with Disabilities (NCDW) & Bangladesh Legal Aid and Services Trust (BLAST). (2015). Current status of Rights of Persons with Disabilities in Bangladesh: Legal and Grassroots Perspectives. (n.p.)

[93] Over 47 thousand people living with autism in Bangladesh. (2019) Retrieved, 5 April 2019, from https://www.dhakatribune.com/bangladesh/dhaka/2019/04/01/47-500-people-in-bangladesh-living-with-autism

[94] Centre for Research and Information. (n.d.) Bangladesh Development Updates on Autism Awareness. CRI Retrieved, April 15 2019, from http://cri.org.bd/2014/09/03/global-autism-movement-and-bangladesh/

[95] Centre for Research and Information; 2016. Global Autism Movement and Bangladesh. Retrieved from http://cri.org.bd/2014/09/03/global-autism-movement-and-bangladesh/

[96] UNICEF Bangladesh. (2014). Situation analysis on children with disabilities in Bangladesh

[97] Ehsan, U. et al. (2018). Confronting Autism in Urban Bangladesh: Unpacking Infrastructural and Cultural Challenges. EAI Endorsed Transactions on Pervasive Health and Technology Volume 4, Issue 15 e5

[98] Zuurmond, M. (2015). Understanding the Lives of Caregivers of Children with Cerebral Palsy in Rural Bangladesh: Use of Mixed Methods. Disability, CBR & Inclusive Development Vol. 26, No.2

[99] Ackerman, P. et al (2005). Assessments of educational needs for disabled children in Bangladesh. USAID

[100] Zuurmond, M. (2015). Understanding the Lives of Caregivers of Children with Cerebral Palsy in Rural Bangladesh: Use of Mixed Methods. Disability, CBR & Inclusive Development Vol. 26, No.2

[101] Ackerman, P. et al. (2005). Assessments of educational needs for disabled children in Bangladesh. USAID

[102] Nirafat, A. (2002). The Feminine Dimension of Disability-A Study on the Situation of Adolescent Girls and Women with Disabilities in Bangladesh. Centre for Services and Information on Disability (CSID)

[103] Nirafat, A. (2002). The Feminine Dimension of Disability-A Study on the Situation of Adolescent Girls and Women with Disabilities in Bangladesh. Centre for Services and Information on Disability (CSID)

[104] Nirafat, A. (2002). The Feminine Dimension of Disability-A Study on the Situation of Adolescent Girls and Women with Disabilities in Bangladesh. Centre for Services and Information on Disability (CSID)

[105] Karr, V. et al. (2016). Situation Assessment of Autism and Neurodevelopmental Disorders in Bangladesh. Institute for Community Inclusion at University of Massachusetts Boston

[106] Safa, F, Islam, M.N. (2017). Health related quality of life in children with autism spectrum disorder in Bangladesh. IMC Journal of Medical Science; 11(2): 40-44

[107] Ackerman, P. et al. (2005). Assessments of educational needs for disabled children in Bangladesh. USAID

[108] Centre for Research and Information; (2016). Global Autism Movement and Bangladesh. Retrieved, 20 April 2019, from http://cri.org.bd/2014/09/03/global-autism-movement-and-bangladesh/

[109] Khandaker, G. et al. (2018). Epidemiology of cerebral palsy in Bangladesh: a population-based surveillance study. Developmental Medicine & Child Neurology

[110] Khandaker, G. et al. (2018). Epidemiology of cerebral palsy in Bangladesh: a population-based surveillance study. Developmental Medicine & Child Neurology

[111] Jahan, I. et al. (2018). What makes children with cerebral palsy vulnerable to malnutrition? Findings from the Bangladesh cerebral palsy register (BCPR). Disability and Rehabilitation

[112] Das, R et al. (2015). Experience with Clinically Diagnosed Down Syndrome Children Admitted with Diarrhea in an Urban Hospital in Bangladesh. International Scholarly Research Notices

[113] Akter, S. Shefa, J., Hasan, M. (2018). Nutritional Status of Children with Neurodevelopment Disorders from a Tertiary Medical Center of Bangladesh. Birdem Medical Journal Vol. 8, No. 2

[114] Ackerman, P et al. (2005). Assessments of educational needs for disabled children in Bangladesh. USAID

[115] Hassan, S,. (2 July 2019). Personal Interview

[116] UNICEF Bangladesh. (2014). Situation analysis on children with disabilities in Bangladesh

[117] UNICEF Bangladesh. (2014). Situation analysis on children with disabilities in Bangladesh

[118] Ackerman, P et al. (2005). Assessments of educational needs for disabled children in Bangladesh. USAID

[119] Ahsana, M., Burnip, L. (2007). Inclusive Education in Bangladesh. Australasian Journal of Special Education Vol. 31, No. 1, pp. 61–71

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[120] Ackerman, P. et al. (2005). Assessments of educational needs for disabled children in Bangladesh. USAID

[121] Khandaker, G. et al. (2018). Epidemiology of cerebral palsy in Bangladesh: a population-based surveillance study. Developmental Medicine & Child Neurology

[122] UNICEF Bangladesh. (2014). Situation analysis on children with disabilities in Bangladesh

[123] Chowdhury, K., Rahman, S., Haque, S. (2014). Current status of service centres serving Autism Spectrum Disorder in Dhaka City. Bangladesh Journal of Dental Research and Education Vol. 04, No. 01

[124] Ackerman, P. et al. (2005). Assessments of educational needs for disabled children in Bangladesh. USAID

[125] Hassan, S.. (2 July 2019). Personal Interview

[126] Government of Bangladesh, Ministry of Social Welfare, Bangladesh. (n.d.) Special Education in Bangladesh: Present Trend and Future Needs.

[127] Centre for Research and Information. (2016). Global Autism Movement and Bangladesh. Retrieved, 5 May 2019, from http://cri.org.bd/2014/09/03/global-autism-movement-and-bangladesh/

[128] Centre for Research and Information. (n.d.). Bangladesh Development Updates on Autism Awareness. CRI

[129] Ackerman, P. et al. (2005). Assessments of educational needs for disabled children in Bangladesh. USAID

[130] Nokrek, P et al. (2013). Livelihood challenges for extremely poor disabled people in the southwest coastal region of Bangladesh. Shiree. Retrieved, 3 May 2019, from www.shiree.org

[131] Nokrek, P et al. (2013). Livelihood challenges for extremely poor disabled people in the southwest coastal region of Bangladesh. Shiree. Retrieved, 3 May 2019, from www.shiree.org

[132] Khan, M et al. (2002). Employment Situation of People with Disabilities in Bangladesh. Centre for Services and Information on Disability (CSID)

[133] Khan, M et al. (2002). Employment Situation of People with Disabilities in Bangladesh. Centre for Services and Information on Disability (CSID)

[134] The World Bank. (2008). Project Appraisal Document on a Proposed Credit to the People's Republic of Bangladesh for a Disability and Children-at-Risk project

[135] Buckup, S. (2009). ILO Employment Sector Working Paper No. 43, "The price of exclusion: The economic consequences of excluding people with disabilities from the world of work". ILO

[136] Borg, J., Östergren, P-O. (2015). Users' perspectives on the provision of assistive technologies in Bangladesh: awareness, providers, costs and barriers. Disability and Rehabilitation: Assistive Technology, 10:4, 301-308).

[137] Borg, J., Östergren, P-O. (2015). Users' perspectives on the provision of assistive technologies in Bangladesh: awareness, providers, costs and barriers. Disability and Rehabilitation: Assistive Technology, 10:4, 301-308

[138] Hassan. S. (3 July 2019). Personal Interview

[139] Government of Bangladesh, Ministry of Social Welfare. (2014). Disability detection survey: A new horizon of development. Retrieved, 10 July 2019, from https://www.dis.gov.bd/en/

[140] Ashrafi. (3 July 2019). Personal Interview

INDIA

Capital: Delhi
Population: 1,324,171,000**
Rank in HDI: 130*
World Bank Income Classification: Lower middle#

GNI Per Capita (PPP): USD 3653*
Health Expenditure Per Capita (PPP): USD 237.7**
Life Expectancy at Birth (years): 68.6*
Population with disability (%): 2.2$

*UNDP: Human Development Reports 2018
**World Health Organisation 2016

World Bank 2019
$ Census of India 2011$

India has a long history of work in disability. The first legislation in the area of disability was the Persons with Disability Act of 1995. The law defined a "person with disability" as a person suffering from not less than 40% of any disability as certified by a medical authority (any hospital or institution, specified for the purposes of this act by notification by the appropriate government).[141] India has also signed and ratified the United Nations Convention of the Rights of Persons with Disability in 2007.

The 1995 law was replaced 10 years later by the Rights of Persons with Disability Act, 2016 which defines three categories of persons with disability under its remit: (i) "person with benchmark disability" means a person with not less than 40% of a specified disability where specified disability has not been defined in measurable terms and includes a person with disability where specified disability has been defined in measurable terms, as certified by the certifying authority; (ii) "person with disability" means a person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others; (iii) "person with disability having high support needs" means a person with benchmark disability certified under clause (a) of sub-section (2) of section 58 who needs high support.[142]

Table 4: Disabled population by type in India 2011

Type of Disability	Persons (millions)	Proportion of each type	Males (millions)	Proportion of each type	Females (millions)	Proportion of each type
Total	26.8	100.0	15.0	100.0	11.8	100.0
In Seeing	5.0	18.8	2.6	17.6	2.4	20.2
In Hearing	5.1	18.9	2.7	17.9	2.4	20.2
In Speech	2.0	7.5	1.1	7.5	0.9	7.4
In Movement	5.4	20.3	3.4	22.5	2.1	17.5
Mental Retardation	1.5	5.6	0.9	5.8	0.6	5.4
Mental Illness	0.7	2.7	0.4	2.8	0.3	2.6
Any Other	4.9	18.4	2.7	18.2	2.2	18.6
Multiple Disability	2.1	7.9	1.2	7.8	1.0	8.1

Source: C-Series, Table C-20, Census of India 2011 as reported in: Measurement of Disability through Census : National Experiences: INDIA. Census 2011. Office of the Registrar General & Census Commissioner, India

Data on prevalence of disability has been collected through last two national Census - 2001 and 2011. While the 2001 Census collected data on only five types of disabilities, the 2011 Census included information on 8 types including – seeing, hearing, speech, movement, mental retardation, mental illness, any other and multiple disabilities. According to Census 2011, there are of 26.8 million persons with disability in India constituting 2.21% of the total population.[143] However, the narrow definition of each of the disability type excludes people from the survey. Additional factors to be borne in mind while looking at the data are social stigma that prevents families from reporting disability, lack of adequate knowledge and understanding of disability among data enumerators which may result in persons who may strictly not fit into the definition being left out. Hence, the data gathered needs to be interpreted with caution.[144,145]

India has a range of services available for persons with intellectual and developmental disability. Some innovative programmes include formation of parents' associations, family focused interventions and community-based programmes. But these do not seem to have the impact sought on the lives of those with challenges and their caregivers.

Stigma and discrimination: The way a person with disability is looked at in India depends on the type of disability, social, family and community dynamics. Persons with intellectual and developmental disability face the most discrimination. The predominant view is that these people are passive and require charitable help.[146]

Marginalisation is reported in a study with persons with intellectual and developmental disabilities undertaken in select states and Union Territories in India. A majority (60.7%) did not have a disability card and 80.5% did not avail of any disability scholarships. The study reiterates the marginalisation faced by this cohort as the lack of access may be due to lack of parental initiative, living in hard to reach or remote areas, inability to access government schemes and inflexible formalities and procedures in obtaining benefits.[147] The Patang Project study reports that approximately a fourth of children with intellectual and developmental disability experience discrimination in the form of systematically being avoided in social interactions, being verbally abused or insulted, being threatened or harassed, and being discouraged by the teacher to continue education. Even when controlled for family circumstances by comparing to their siblings, children with challenges come out significantly worse on acceptance, social capital and stigma and discrimination.[148] A number of studies have also been conducted in India that focus on the views and experiences of parents with autism and identifies the challenges faced by them in obtaining a diagnosis and finding appropriate care and treatment and the impact it has on their family and relationships.[149,150]

Parents of children with intellectual and developmental disability go through a process of trying to come to terms with their child's disability. Their attribution of the onset of a child's symptoms varies from blaming self, to wrong medical treatment, to God's will. In the latter case, they often feel that they have been chosen by God to take care of a child with these disabilities or blame their own and the child's past life deeds (*karma*).[151] Studies in India report that the first reaction to diagnosis of autism is disbelief, distress, guilt and self-blame as well as a feeling of helplessness and anger. The entire family as a unit is affected but the impact is also felt on an individual level, particularly by the mother who is the primary caretaker. There is an impact on her own sense of motherhood, marital dissatisfaction and chronic stress and fatigue.[152,153] Similar findings were reported by a study undertaken in north-eastern India with families of children living with autism. The study findings reiterate the stress in parenting process as the care continues from infancy to adulthood including providing physical, emotional, financial, social and intellectual development and care to this group. Though the children may learn basic functional skills through dedicated training, they continue to need support in decision making or problem solving through the course of their lives and this is a stressful situation for most parents.[154]

Literature reiterates that although it is important to take care of the needs of caregivers of persons with intellectual and developmental disability, this is rarely taken into consideration. One needs to acknowledge that the caregivers also need support to deal with emotional, mental and physical stress. The maximum support comes from the spouse, extended family, relatives and friends.[155] A study from the national capital reports that caregivers struggle not only with the sheer physical exertion of caring for a child with intellectual or developmental disability, but have to deal with the mental stress of stigma and discrimination, poor availability of social services and their own work crises.[156] A study that documents coping mechanisms in families with children with mental retardation using self administered questionnaire using the global adaptation scale, indicates that 74% families had adapted adequately to having a child with mental retardation while 26% had not.[157] A study with 116 caregivers of children with disability indicates that 28% of the parents were well adapted while 8% showed very poor coping or adaptation, again using global adaptation scale.[158] The Patang Project notes that caregivers of children with cerebral palsy get more support from their friends, helping to boost social outcomes for the child. On the other hand, the study reports that children with intellectual disability have a much lower social capital index in comparison to their caregivers. Caregivers of persons with autism report a much greater sense of isolation than by caregivers of children with other challenges. They are significantly more likely to feel they have been unfairly treated at work, that others look down upon them, and that their family distances itself from them.[159]

A qualitative study in Goa reiterates the impact of having a child with autism on professional lives of parents. This study reports that mothers adapted their aspirations and gave their jobs to become the primary caretakers and fathers took over the financial burden of running the household. Isolation, feeling alone and an obsession with taking care of the child with autism affects the quality of relationships be it spousal or with other children or even supportive extended family. Lack of awareness about cause of autism results in parents being blamed for the disability.[160] Similar findings are reported from studies done to understand the impact of having a child with cerebral palsy. These studies reiterate the depression, fatigue and trauma in mothers while taking care of their child.[161,162]

Little is written about the lives of adults with autism in India. A mixed methods study undertaken with 54 adults with autism was undertaken in New Delhi reports that 59% of the respondents had a structured daily routine and engaged in activities both inside and outside of their homes. Interestingly, the study found that these adults were not 'hidden' but were out in the society participating in functions. However, parents talked about stress in terms of dealing with their challenging behaviour and lack of opportunities or options for this cohort to participate more in activities – the challenge being particularly high for working mothers.[163]

Gender and marginalisation: Statistics report that there are fewer disabled women than men, clearly highlighting the bias that women face in the gendered nature of Indian society. Women and girls who are disabled, particularly with intellectual and developmental disability, are vulnerable to sexual abuse and physical exploitation. Mohapatra and Mohanty in their survey of women who are disabled, report with that 100% of the disabled women were beaten at home and 25% of the women were raped. The survey reports that these women are denied their right to their basic sexuality by forcible sterilisation - 6% of physically disabled and 8% of intellectually disabled women were forcibly sterilised.[164]

A report by Shah and Ramkumar shows similar findings in Puducherry. Women with disability are at least two to three times more likely than women without disabilities to experience violence and abuse, and they are likely to experience abuse over a longer period of time, resulting in more severe injuries. Women and girls with disability are also denied needed care, face abandonment, neglect, involuntary sterilization and "other medical procedures performed without free and informed consent, including those related to contraception and abortion"; involuntary institutionalization; and "the administration of electroshocks, chemical, physical, or mechanical restraints" without consent.[165]

Girls with psychosocial or intellectual disabilities are often locked up, chained or institutionalised because of fear of them wandering away and becoming targets for potential sexual or physical abuse.[166] Similar findings are reported in a report by Women with Disabilities India Network. The report reiterates the vulnerability of women and girls where they are forced to be institutionalised and given medical treatment under the pretext of care and protection. Women and girls who are institutionalised are at a great disadvantage, as they do not have a voice in their treatment, are subject to sexual abuse, and are often at the mercy of their family or the personnel at the institutions. Forced sterilisation, hysterectomies and abortion of women with intellectual and developmental disabilities in the institutions has been reported under the garb of helping them manage their menstruation and avoid sexual exploitation.[167]

In the absence of state resources and support, the onus of managing disabilities falls on the parents. Parents of girls with disability are concerned about managing menstruation and protecting them from the effects of abuse, while parents of adolescent boys face the challenge of controlling masturbation and inappropriate touching of either own or others' body parts.[168]

Gender and marginalisation usually focuses on women's situation. There is a need to understand marginalisation from a male perspective. There is limited evidence on how men with intellectual and developmental disability are treated in India society and marginalised. They are called simple (*bawla*) or innocent (*bhola*) and are given tasks that are usually a woman's domain like fetching water, weeding or grazing cattle. A person is called 'mad' or *'paagal'* only if he shows aggressive behaviour. These men are objects of pity by the family and society and are not even considered 'men' in the first place and they are included in the category of women through assignment of work duties.[169]

Health: Over 50% of children with intellectual and developmental disability have never seen a psychiatrist or psychologist. Two thirds have not visited a physiotherapist or speech therapist and only 10% have utilised occupational or vocational therapy.[170] Clinical services continue to be inadequate and unevenly distributed and focus on clinical evaluation, physical and psychological testing, parental counselling, comorbid physical and mental disorder and genetic counselling.[171] These services are largely available only in urban areas – those in rural and hard to reach areas are left behind.

A study conducted by Human Rights Watch between December 2012 and November 2014 highlights stigma, lack of government services, lack of awareness about intellectual and developmental disabilities among family members. The report goes on to illustrate the state of institutions where these people are sent, in particular where women and girls are kept and the range of abuses they face including neglect, verbal and physical abuse and involuntary medical treatment.[172]

Children with psychosocial or intellectual disabilities are forced to take medications or given inappropriate medical treatment. Girls are held down, their mouths forced open or are given medication in food. Despite India's commitment made as a signatory to the United Nation Convention on Rights of Children and the United Nations Convention on the Rights of Persons with Disabilities, Human Rights Watch reports that girls are subjected to electro convulsive therapy simply on the basis of permission from their guardians. This does not recognise their right as an evolving person.[173]

A range of associated health problems are seen among persons with intellectual and development disabilities. A paper by Kalgotra and Warwal reports behaviour problems like restlessness, poor concentration, temper tantrums, irritability, aggressions and self injurious behaviour. The paper reports convulsions in 25% of this cohort; sensory impairment in 5-10%; as well as cerebral palsy, language development disability and autism.[174]

Medical professionals are usually the first point of contact by parents to diagnose symptoms of their children. However, not all professionals have adequate awareness to properly diagnose certain disabilities like autism nor do they have required knowledge for appropriate referrals or rehabilitation options. Parents often resort to alternative Indian systems of medicine like homeopathy or Ayurveda.[175,176,177] There are few centres in the public health system that can diagnose autism. Healthcare access is determined by a host of factors like place of residence, levels of education and caste and income levels of the family. Social stigma about disability delays care seeking. Lack of awareness among both parents as well as primary healthcare providers like paediatricians is another important determinant of seeking timely and appropriate services. Once diagnosed, there is further delay in seeking care when the parents consult with their extended family and friends before approaching a psychiatrist.[178]

A study undertaken among 240 children with cerebral palsy in the department of Paediatrics in a city in Rajasthan between 2010-2014 reports that the most common aetiological risk factors are perinatal asphyxia and low birth weight, neonatal convulsions, and respiratory distress in postnatal period. These are factors that can be avoided with effective and efficient care during the peri- and post- natal period.[179] A descriptive study undertaken with parents of 307 persons with cerebral palsy at a rehabilitation centre in Allahabad reports that more parents from urban or semi urban areas came for treatment. This could be because parents from rural and low income group may not be able to afford this treatment or not be aware of these facilities or treatment options. Parents who came to this centre were highly educated and mothers had given up their jobs to be able to look after the child, often leaving the husband to be the sole providers for the family.[180] This has been reiterated in other studies which indicate that mothers give up their jobs or curtail their work aspirations in order to be able to spend time taking care of their child with intellectual and developmental disability.[181,182]

Further, a study with 100 children with cerebral palsy aged 3-10 years receiving rehabilitation care at a Child Development Centre was undertaken to assess health related quality of life by administrating a lifestyle assessment questionnaire to their parents. The findings report on health-related quality of life - 9% had good, 24% had mildly-affected, 37% had moderately-affected and 30% had severely-affected health-related quality of life. Physical independence, mobility and social integration were more affected than clinical and economic burden and schooling dimension.[183]

Educational attainment: The Government of India advocates a twin track approach to education of persons with disability. However, the focus has been on special schools rather than on inclusive and mainstream educational opportunities. Nevertheless, there has been a range of programmes that have addressed inclusive education for persons with disability over the past decades.

For example, Integrated Education for Disabled Children was introduced in 1974 initially by the Ministry of Social Welfare and later on handed over to the Ministry of Human Resource Development, Department of Education. As a signatory to the Salamanca Statement, inclusive education in India, the Integrated Education for Disabled Children programme evolved into Inclusive Education of the Disabled in 1992. While the District Primary Education Programme and its successor, Sarva Shiksha Abhiyan, use the concept of inclusive education, there is lack of clarity around the words 'integrated' and 'inclusive' as well as what defines 'special education needs'.[184] The revised program is being implemented in almost all states and union territories of India. It provides for 100% assistance to schools providing inclusive education and integrating students with disability. A teachers' training programme aims to equip the teachers with necessary skills to teach and work with children with disability. A report by Government of India indicates better management skills of teachers, and enhanced capacity of states to implement the programme. Training has also resulted in greater receptiveness towards students with disability among students and teachers in regular schools.[185] Sarv Shiksha Abhiyan provides for home based education options for children with severe intellectual and physical disabilities and those who cannot access neighbourhood schools. Home based education is provided after a comprehensive assessment by a team of doctors and specialists. Currently, 134,229 children with special needs are provided home schooling under the Sarv Shiksha Abhiyan.[186]

Data from 2011 Census gives a picture of percentage of people with disability by type of disability and levels of literacy (see Table 6). Only 15.6% of those with mental retardation and 21.8% of those with mental illness have completed secondary level of education. Compared to them, those with seeing, hearing or speech disabilities are somewhat better off at 23.1%, 24.5% and 23.6% respectively. Sadly, the likelihood of graduation and above is less than 10% overall, and much lower for those with mental illness and mental retardation.[187]

A paper in Global Education Review (2016) explores challenges in access to education by children with disability. Although the paper does not distinguish between different types of disabilities the challenges and obstacles mentioned in the paper can be extrapolated to the challenges faced by children with intellectual and developmental disabilities. In India, special schools are largely for children with visual, hearing or intellectual impairment and are located in urban areas. Children in these special schools lack proficiency in basic numeracy and literacy skills thereby discouraging the parents from sending their children to these schools and bear the extra financial burden. Negative attitude of fellow students as well as staff in the school is yet another discouraging factor. Teachers are not comfortable teaching these students nor are they sensitive about specific needs of this cohort. There is a lack of training of teachers and staff and limited exposure to children who are disabled. There is also a shortage of teachers and those who are in special schools may be teaching two to three classes at the same time and hence not be able to give adequate attention to these children.[188]

Table 5: Educational profile of persons with disability in India 2011

Type of Disability	Below primary	Primary but below middle	Middle but below matric/ secondary	Matric/ Secondary but below graduate	Graduate and above
Total	19.4	24.3	16.7	23.6	8.5
In Seeing	20.8	24.6	16.3	23.1	8.9
In Hearing	18.9	23.7	16.2	24.5	9.3
In Speech	20.8	23.6	15.1	23.6	9.3
In Movement	16.3	24.6	18.8	25.6	8.6
Mental Retardation	28.1	26.9	14.7	15.6	4.6
Mental Illness	19.0	25.6	18.9	21.8	5.6
Any Other	17.9	23.3	16.9	24.6	9.3
Multiple Disability	27.4	26.7	14.5	16.4	4.1

Note: 'Literate' includes figures for 'literates without educational level' and 'educational levels not classifiable ‘and hence, the sum total of percentage shares will not add up to 100.

Source: Government of India. (2011). Census of India, Table C-29,

It was in mid 1990s that the Government of India recognised autism as a separate disability with special needs. Those with autism are not entitled to any concessions or benefits offered by the government unless they are diagnosed as mentally retarded. But because persons with autism are often not intellectually disabled, their disability is different from those labelled as mentally retarded. Special needs to children with autism are generally not present in any educational institutions – be it special schools or mainstream schools – these services are rare and far between. There is need to train the teachers and enable them to understand their special needs, so that these children can learn in mainstream schools.[189]

The Human Rights Watch reports that in three institutions visited by the team, girls with psychosocial or intellectual disability did not have access to any education. Girls from two institutions attended a non formal education programme. Those who went to a local school did not have an opportunity to learn as the curriculum was not adapted to suit their special learning needs.[190] Mukhopadhyay and Mani estimated that only 1-4% of persons with disability ever attend school.[191] Even when they do, children with intellectual and developmental disability are likely to attend special schools that are geared to providing specialised education and vocational training. A rigid educational system, negative attitude of teachers and lack of clarity about the concept of inclusive education are barriers that prevent children with intellectual and developmental disabilities from attending formal schools.[192]

Economic participation and poverty: The situation of children with challenges varies with their socio-economic situation. The Patang Project evidence indicates that children with disability belonging to families with higher material assets tend to be distributed across the spectrum of severity, while children belonging to families with low material assets have an 85% chance of having a moderately or severely disabling challenge. In fact, about 50% of these children have severe challenges in functioning, “indicating that perhaps their fullest potential could not be drawn out due to resource constraints”.[193] The poorest also have even worse availability of disability certification, legal and financial arrangements than the norm. The unequal access also extends to education and special services.[194]

Data from Census 2011 paints a dismal picture of economic participation of persons with intellectual and developmental disability. Disabled workers by type of disability is recorded as 300,000 for those with mental retardation, 200,000 for those with mental illness and 400,000 for those with multiple disability.[195] The same report provides a sense of rate of work participation. Work Participation Rate is calculated as the percentage of workers among disabled to the total disabled population. For persons with mental retardation, this was 21.4; for those with mental illness, this was 21.4; and for those with multiple disabilities, this was 18.5.[196]

Job reservations as indicated by the government at 5% go largely for persons with physical, auditory or visual impairment. There is limited scope of employment for persons with intellectual and developmental disabilities despite concerted efforts made by organisations like Disabled Rights Group.[197] Services for this cohort are underdeveloped as vocational training and job placements are difficult to find.[198] The negative attitude of co-workers stems from lack of knowledge and awareness as well as stereotypical views on disability.[199] The Rights of Persons with Disabilities Act (2016) specifies 1% reservation for differently abled with low vision and blindness, another 1% for deaf and hard of hearing, 1% for those with locomotor disability including cerebral palsy, leprosy (cured), dwarfism, acid attack survivors and muscular dystrophy and 1% for those with autism, intellectual disability, specific learning disability and mental illness.[200]

A baseline report entitled Employability of Disabled Persons in India mentions some initiatives taken by private companies. Mention must be made here of efforts by Intel's Centre for Economic Empowerment of Intellectually Challenged which has developed a specialised curriculum based on the needs and intellectual capabilities of people with below average intelligence quotient. Of a total of 105 individuals trained until 2009, 62 have found job placements. The National Trust Act, 1999 focuses on initiatives for promoting vocational training and economic opportunities for persons with autism, cerebral palsy, mental retardation and multiple disability.[201] For example, they started a Marketing Federation, 'Association of Rehabilitation under National Trust Initiative Marketing', a non-profit society to market products made by persons with disability, especially intellectual and developmental disability covered under the National Trust Act. A scheme entitled Uddyam Prabha promotes vocational training and economic activities for this cohort of people.[202]

Assistive devices: Some interesting innovative programmes have been reported with people with autism. Based on increasing evidence on the success of computer supported interventions for autism, an exploratory study on a collaborative gesture based application called Balloons reports improvements in social interaction with typically developed peers, opportunity to customize the intervention to cater to a large spectrum of children and the potential of this application to reduce fear of certain objects among children with autism.[203]

Two assistive tools for children with autism were developed by International Institute of Information Technology Hyderabad, India. One, AutVisComm, is an assistive communication system developed on ubiquitous tablets, and second Autinect, is a set of activities to teach social skills to children with autism that use Microsoft KinectTMas, a controller. The systems were developed in collaboration with caregivers of these children – parents and teachers. The results indicate that a major factor to be considered while developing an interface and interaction design for children with autism is the cognitive profile of the children.[204]

Augmented Reality is a technology that is proving to be a useful teaching -learning and assistive aid for children with autism and mild mental retardation. This uses day-to-day real time objects, parents' voice for narration and associates virtual 3D images and renders them on mobiles to enhance learning among these children. This application supports functional reading, visual schedules and speaking albums for the children to learn from real life scenarios they are familiar with.[205]

KEY TAKEAWAYS

- Official estimates of disability are 26.8 million or 2.21% of the population. This is likely an underestimate due to the stigma associated with disability and inadequate training of enumerators etc.
- A range of mistreatment of persons with disability has been recorded, from neglect to verbal and physical abuse and involuntary medical treatment. Sexual abuse and physical exploitation of women and girls with disability is common.
- Caregivers have been found to suffer high levels of stress and anxiety.
- There is a shortage of services, community organisations and peer groups. Those that exist, do so in urban settings leaving the rural areas underserved.
- The countrywide education programme, Sarva Siksha Abhiyan, supports the concept of inclusive education. But operationalising inclusive education remains challenging.
- Poor training of service providers - teachers, paraprofessional staff and doctors - bedevils the sector, making care difficult to access. In particular, it contributes to delay in seeking and receiving the special care that persons with challenges require.
- The poorest children with challenges are doubly disadvantaged – they have less access to services and less likelihood of getting government assistance.
- Fewer than 1 in 5 persons with any disability find their way into the workforce. A preponderance of them are those with sensorimotor disability.
- Assistive tools are beginning to become available. Several initiatives relate to use information technology interfaces to address the issues of persons with disability.
- The National Trust was set up in 1999 as a national body to focus on issues relating to persons with autism, cerebral palsy, mental retardation and multiple disability.
- Some private sector entities such as Lemon Tree Hotels are taking steps to include persons with intellectual and developmental disability into the workforce.

GOOD PRACTICE CASE STUDY

National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities
India

Shakuntala D Gamlin, Chairperson **www.thenationaltrust.gov.in**

The National Trust is a statutory body under Department of Empowerment of Persons with Disabilities (Divyangjan), Ministry of Social Justice & Empowerment. Established through and Act of Parliament, it has its headquarters in New Delhi. Its mission is to create an enabling environment for persons with disability and their families leading to development of an inclusive society.[206]

The National Trust has been set up to discharge two basic duties; legal duties are discharged through Local Level Committees and providing Legal Guardianship; and welfare duties are discharged through schemes such as caregiver training; day care and residential care for persons with disability; vocational training and assistance in marketing products made by persons with disability, especially persons with intellectual and developmental disability. The Trust also offers affordable health insurance.[207]

Every State/UT Government has been requested to set up a State Level Coordination Committee for effective implementation and monitoring of the schemes of the National Trust under the guidance of the Secretary of the State Government.[208] At the government level, it works with other departments and verticals organised and funded by the Central Government including the Ministry of Social Justice and Empowerment. Special and specific budgetary allocations are made for specific departments and the disabilities they cater to.

Data available from the National Trust website are encouraging. Local Level Committees at the district provide guardianship for persons with intellectual and developmental disabilities and have been formed in all districts; 26 State level Coordination Committees are also in place. Since 2003, a total of 33,588 legal guardians have been appointed. There are 634 Registered Organisations that implement the activities.[209] In order to carry out the activities[210] of the National Trust, a reputed NGO in every state capital is appointed as State Nodal Agency Centre.

Under the ICT initiatives of the National Trust, a new interactive and user-friendly website (www.thenationaltrust.gov.in) and a Scheme Management System have been developed for providing an up to date information on the activities of the National Trust. The Scheme Management System will enable online implementation of the schemes of the National Trust.

The National Trust model is a replicable and scalable model of a sustainable, government-led initiative for persons with intellectual and developmental disability.

GOOD PRACTICE CASE STUDY

Lemon Tree Hotels - Inclusive Business Model
India

Patu Keswani, Founder **www.lemontreehotels.com**

Lemon Tree Hotels is India's biggest mid-market hotel chain with properties across India. Lemon Tree believes that the brand should stand for more than 'just profit' and has focused its efforts on creating a socially inclusive work environment.[211] Lemon Tree Hotels believes that people with disability (physical, social or economic disabilities leading to an opportunity deprivation) must have the same opportunities as others to realise their full potential by creating a supportive environment that allows them to deliver their best.[212]

This is done through a range of dedicated activities. A programme called 'Expressions' teaches all employees to use Indian Sign Language with speech and hearing impaired colleagues. Employees with disability are trained through special training modules using visual aids thereby increasing the understanding of tasks and leading to greater productivity.[213] A sensitivity training is conducted every month for all employees of the establishment. At the customer level, guests are alerted about the presence of employees with disability through photo frames in lobbies and videos on TV in hotel rooms. Staff is available to talk about the hotel policies on inclusivity. Employees with Disability Cards introduce the employee to the guest and explain how best s/he can serve the guest, which helps to set expectations.

The journey has not been easy. Hiring new employees can be difficult because disability is seen as a social stigma. Sensitising all employees about disability and then about specific disabilities requires considerable investment of time and effort. While in the early stages, employees with disability were inducted only in back-end roles, this has changed to guest-facing roles; similarly, the chain has moved on from personnel with speech and hearing impairment to orthopaedically challenged, and now to Down syndrome employees. This has required both job mapping and re-engineering of the relevant service processes.

Currently, 12% of Lemon Tree Hotels' 4600-strong workforce is people with disability.[214] Employees with disability do not quit jobs and have a sense of loyalty for being given an opportunity. At the company level, having employees with disability has increased the brand value of Lemon Tree Hotels and given them an edge in the industry. At the guest level, there is appreciation about the initiative that are posted on travel websites. Lemon Tree Hotels received the national award for Best Employer in 2011 by the Ministry of Social Justice and Empowerment.[215]

The work done by the Lemon Tree Hotels is eminently scalable and replicable while also ensuring that it becomes sustainable through normalization of disability among employees and guests.

End Notes

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[141] Ganjiwale, D., Ganjiwale, J., Sharma B., Mishra B. (2016). Quality of life and coping strategies of caregivers of children with physical and mental disabilities. J Family Med Prim Care

[142] Government of India, Ministry of Law and Justice. (2016). The Rights of Persons with Disabilities Act.

[143] Government of India, office of the Registrar General & Census Commissioner. (2011). Measurement of Disability through Census: National Experiences: India.

[144] Islam, K. (2015). Disability in India-Needs Urgent Attention. International Journal of Humanities & Social Science Studies Volume-II, Issue-I, Page No. 176-181

[145] Tarshi. (2018). Sexuality and Disability. Working Paper. Retrieved, 5 April 2019, from http://www.tarshi.net/inplainspeak/tarshis-corner-working-paper-sexuality-and-disability-in-the-indian-context-2018/

[146] Thomas, P. (2005). Mainstreaming disability in development: India country report. Policy Project of the Disability Knowledge and Research (KaR) programme. UK Department for International Development (DFID)

[147] PARIVAAR. (A National Confederation of Parents' Organizations for Persons with Intellectual & Developmental Disabilities). (2011-2012). A Study on Understanding the Socio-Economic Status of Persons with Intellectual and Developmental Disabilities (PwIDDs) and their Families in India. (n.p.)

148 Amrit Foundation of India. (2017). Patang Project. India, Amrit Foundation Pg 42

[149] Brezis, R., Weisner, T. et al. (2015). Parenting a Child with Autism in India: Narratives Before and After a Parent–Child Intervention Programme. Cult Med Psychiatry, Springer Science+Business Media, New York

[150] Perumal, V. et al. (2014). Quality of life in families of children with autism spectrum disorder in India. Journal of Pharmacy Research pg. 791-797.

[151] John, A., Bailey, L., Jones, J. (2017). Culture and context: exploring attributions and caregiving approaches of parents of children with an intellectual disability in urban India. Child and Family Social Work, 22, pp 670–679

[152] Gupta, A., Singhal, N. (2005). Psychosocial support for families of children with autism. Asia Pacific Disability Rehabilitation Journal. 62 Vol. 16 No. 2

[153] Singh, P., Ghosh, S., Nandi, S. (2017). Subjective Burden and Depression in Mothers of Children with Autism Spectrum Disorder in India: Moderating Effect of Social Support. J Autism Dev Disord

[154] Das, S., Das, B., Nath, K., Duta, A., Bora, P., Hazarika, M. (2017). Impact of stress, coping, social support, and resilience of families having children with autism: A North East India based study. Asian Journal of Psychiatry

[155] Ganjiwale D, Ganjiwale J, Sharma B, Mishra B. (2016). Quality of life and coping strategies of caregivers of children with physical and mental disabilities. J Family Med Prim Care

[156] Amrit Foundation of India. (2017). Patang Project. India, Amrit Foundation Pg 46

[157] Farheen, A., Dixit, S., Bansal, S., Yesikar, V. (2008). Coping strategies in families with mentally retarded children. Indian J Pract Doct

[158] Ganjiwale D., Ganjiwale J., Sharma, B., Mishra, B. (2016). Quality of life and coping strategies of caregivers of children with physical and mental disabilities. J Family Med Prim Care

[159] Amrit Foundation of India. (2017). Patang Project. India, Amrit Foundation Pg 70

[160] Divan, G. et al. (2012). Challenges, Coping Strategies, and Unmet Needs of Families with a Child with Autism Spectrum Disorder in Goa, India. Autism Research

[161] Deepthi, N., Aditi Krishnamurthy, A. (2011). Mental Health and Quality of Life of Caregivers of Individuals with Cerebral Palsy in a Community Based Rehabilitation Programme in Rural Karnataka. Vol 22, No.3

[162] Prakash, V., Patel, A., Hariohm, K., Palisano, R. (2016). Higher Levels of Caregiver Strain Perceived by Indian Mothers of Children and Young Adults with Cerebral Palsy Who have Limited Self-Mobility. Physical & Occupational Therapy In Paediatrics

[163] Daley, T., Weisner, T., Singhal, N. (2014). Adults with autism in India: A mixed-method approach to make meaning of daily routines. Social Science and Medicine. 116 142-149

[164] Thomas, P. (2005). Mainstreaming disability in development: India country report. Policy Project of the Disability Knowledge and Research (KaR) programme. UK Department for International Development (DFID)

[165] Shah, C., Vidyaa, V. (n.d.). Access to justice for women with disabilities – Status Report Puducherry. (n.p.)

[166] Barrige, S. et al. (2017). Children with disabilities: Published in Deprivation of liberty in the name of care and treatment: Protecting children against torture in detention. Human Rights Watch.

[167] Women with Disabilities-India Network. (n.d.) Special Chapter 1a WOMEN WITH DISABILITIES IN INDIA. WwD

[168] Tarshi. (2018). Sexuality and Disability. Working Paper. Retrieved, 4 July 2019, from http://www.tarshi.net/inplainspeak/tarshis-corner-working-paper-sexuality-and-disability-in-the-indian-context-2018/

[169] Mehrotra, N., Vaidya, S. (2008). Exploring Constructs of Intellectual Disability and Personhood in Haryana and Delhi. Indian Journal of Gender Studies, 317–340

[170] Amrit Foundation of India. (2017). Patang Project. India, Amrit Foundation Pg 29

[171] Girimaji, S. (2011). Intellectual disability in India: the evolving patterns of care. International Psychiatry Volume 8

[172] Human Rights Watch. (2014). “Treated Worse than Animals” Abuses against Women and Girls with Psychosocial or Intellectual Disabilities in Institutions in India. India, HRW

[173] Barrige, S. et al. (2017). Children with disabilities: Published in Deprivation of liberty in the name of care and treatment: Protecting children against torture in detention. India, Human Rights Watch

---

[174] Kalgotra, R., Warwal, J. (2017). Intellectual Disability in India: An overview. J. Disability Study., 3(1), 1-8

[175] John, A., Bailey, L., Jones, J. (2017). Culture and context: exploring attributions and caregiving approaches of parents of children with an intellectual disability in urban India. Child and Family Social Work, 22, pp 670–679

[176] Malhotra, S., Vikas, A. (n.d.). Pervasive Developmental Disorders: Indian Scene Department of Psychiatry Post graduate Institute of Medical Education & Research Chandigarh, INDIA. JIACAM Vol. 1, No. 3, Article 5

[177] Divan, G. et al. (2012). Challenges, Coping Strategies, and Unmet Needs of Families with a Child with Autism Spectrum Disorder in Goa, India. Autism Research

[178] Barua, M., Kaushik, J., Gulati, S. (2015). Legal Provisions, Educational Services and Health Care Across the Lifespan for Autism Spectrum Disorders in India. Indian J Pediatr

[179] Goyal, S., Ojha, N. (2015). Trends of Cerebral Palsy in Rajasthan, India. International Journal of Advanced Ayurveda, Yoga, Unani, Siddha and Homeopathy, Volume 4, Issue 1, pp. 275-281

[180] Jain, V., Singh, G., Jain, J., Dayal, A., Gupta, Tapas Pal, T. (2015). Socio-demographic Profile of Cerebral Palsy affected patients: An Indian Scenario. Int J Cur Res Rev Vol 7 Issue 12

[181] Divan, G. et al. (2012). Challenges, Coping Strategies, and Unmet Needs of Families with a Child with Autism Spectrum Disorder in Goa, India. Autism Research

[182] Ganjiwale D., Ganjiwale J., Sharma B., Mishra B. (2016). Quality of life and coping strategies of caregivers of children with physical and mental disabilities. J Family Med Prim Care

[183] Dobhal, M., Juneja, M., Jain, R., Sairam, S., Thiagarajan, D. (2014). Health-related Quality of Life in Children with Cerebral Palsy and Their Families. Indian Pediatrics Volume 51

[184] Thomas, P. (2005). Mainstreaming disability in development: India country report. Policy Project of the Disability Knowledge and Research (KaR) programme. UK Department for International Development (DFID)

[185] Jagran Josh. (2010). Integrated Education for Disabled Children. Retrieved, 15 May 2019, from https://www.jagranjosh.com/articles/integrated-education-for-disabled-children-1287811471-1

[186] National Institute for Educational Planning and Administration. (2016). Elementary Education in India, where do we stand, District Report Cards. Retrieved, 15 May 2019, from http://udise.in/Downloads/Publications/Documents/District_Report_Cards-2016-17-Vol-I.pdf

[187] Office of the Registrar General & Census Commissioner, India. Census 2011.: Measurement of Disability through Census: National Experiences: INDIA.

[188] Limaye, S. (2016). Factors influencing the accessibility of education for children with disabilities in India. Global Education Review, 3 (3). 43-56

[189] Fazil, H. Sulman, N. 2014. Perceptions of School Administrators about Facilities Available in Schools for Children with Autism in Pakistan Academic Research International Vol. 5(4)

[190] Barrige, S., et al. (2017). Children with disabilities: Published in Deprivation of liberty in the name of care and treatment: Protecting children against torture in detention. (n.p.)

[191] Mukhopadhyay, S., Mani, M. (2002). Education of children with special needs. In: India Education Report: A Profile of Basic Education (edsR.Govinda), pp.96–108.OxfordUniversityPress: New Delhi.

[192] John, A., Bailey, L., Jones, J. (2017). Culture and context: exploring attributions and caregiving approaches of parents of children with an intellectual disability in urban India. Child and Family Social Work, 22, pp 670–679

[193] Amrit Foundation of India. (2017). The Patang project. Delhi, Amrit Foundation pg 47

[194] Amrit Foundation of India. (2017). The Patang project. Delhi, Amrit Foundation pg 65

[195] Government of India, office of the Registrar General & Census Commissioner. (2011). Measurement of Disability through Census: National Experiences: India.

[196] Government of India, office of the Registrar General & Census Commissioner. (2011). Measurement of Disability through Census: National Experiences: India.

[197] Diversity and Equal Opportunity Centre (DEOC). (2009). Employment of Disabled People in India: Base Line Report. National Centre for Promotion of Employment for Disabled People (NCPEDP)

[198] Girimaji, S. (2011). Intellectual disability in India: the evolving patterns of care. International Psychiatry Volume

[199] Shenoy, M. (n.d.) Persons with Disability & the Indian Labour Market: Challenges and Opportunities. International Labour Organisation

[200] Government of India, Ministry of Law and Justice. (2016). Rights of Persons with Disabilities Act.

[201] Government of India, Ministry of Law, Justice and Company Affairs. (1999). The National Trust for the Welfare of Persons with autism, cerebral palsy, mental retardation and multiple disabilities Act.

[202] Diversity and Equal Opportunity Centre (DEOC). (2009). Employment of Disabled People in India: Base Line Report February 2009. Prepared for National Centre for Promotion of Employment for Disabled People (NCPEDP)

[203] Sharma, S., Srivastava, S. et al. (2016). Promoting Joint Attention with Computer Supported Collaboration in Children with Autism. CSCW, San Francisco, CA, USA

[204] Sampath, H., Agarwal, R., Indurkhya, B. (2013). Assistive Technology for Children with Autism - Lessons for Interaction Design International Institute of Information Technology Hyderabad, India. APCHI' 2013, Bangalore, India.

[205] Vullamparthi, A., Nelaturu, S., Mallaya, D., Rashtree. C. (2013). Assistive Learning for Children with Autism using Augmented Reality Speaking Albums and Visual Auditory Schedulers. IEEE Fifth International Conference on Technology for Education

---

[206] Government of India, Ministry of Social Justice and Empowerment. (n.d.). National Trust. Retrieved, 25 July 2019, from http://thenationaltrust.gov.in/content/innerpage/introduction.php

[207] Government of India, Ministry of Social Justice and Empowerment. (2018). National Trust: Empowering Abilities, Creating Trust Annual Report (2017-18). Retrieved, 25 July 2019, from http://www.thenationaltrust.gov.in/upload/uploadfiles/files/Annual_Report_2017-18_English.pdf

[208] Government of India, Ministry of Social Justice and Empowerment. (2018). National Trust: Empowering Abilities, Creating Trust Annual Report (2017-18). Retrieved, 25 July 2019, from http://www.thenationaltrust.gov.in/upload/uploadfiles/files/Annual_Report_2017-18_English.pdf

[209] Government of India. (1999). National Trust. Retrieved , 25 July 2019, form http://thenationaltrust.gov.in/content/registered_organization.php?start=630

[210] Government of India, Ministry of Social Justice and Empowerment. (n.d.). National Trust. Retrieved, 25 July 2019, from http://thenationaltrust.gov.in/content/registered_organization.php?start=630

[211] Green Hotelier. (2016). Lemon Tree Showcases inclusive employment. Retrieved, 10 July 2019, from https://www.greenhotelier.org/our-news/industry-news/lemon-tree-showcase-inclusive-employment/

[212] Lemon Tree Hotels'. (n.d.). Lemon Tree Hotels' Business Model Demonstrates What It Takes To Be A Truly Inclusive Employer

[213] Sharma, M. (2015). Differently abled youth on a new high at Lemon Tree. Retrieved, 10 July, http://timesofindia.indiatimes.com/articleshow/50293365.cms?utm_source=contentofinterest&utm_medium=text&utm_campaign=cppst

[214] Green Hotelier. (2016). Lemon Tree Showcases inclusive employment. Retrieved, 10 July 2019, from https://www.greenhotelier.org/our-news/industry-news/lemon-tree-showcase-inclusive-employment/

[215] Lemon Tree. (2012). Lemon Tree Hotels honoured with 'Best Employer' National Award. Retrieved, 10 July, from https://www.lemontreehotels.com/getattachment/a4127ed9-c735-42c8-adb7-a3f7fa965aad/Lemon-Tree-Hotels-honoured.aspx

MYANMAR

Capital: Naypyidaw
Population: 52,885, 000**
Rank in HDI: 148*
World Bank Income Classification: Lower middle#

GNI Per Capita (PPP): USD 5567*
Health Expenditure Per Capita (PPP): USD 267.2**
Life Expectancy at Birth (years): 66.7*
Population with disability (%): 2.4$

*UNDP: Human Development Reports 2018
**World Health Organisation 2016

World Bank 2019
$ Union of Myanmar 2009

Myanmar signed the Convention on the Rights of Persons with Disabilities in 2011. In spite of this, there is no explicit or widely understood definition of disability. Explanations or definitions used by most stakeholders are considered out-dated and reflect a charity model rather than the rights approach to disability.[216] Ordinarily, the definition of disability is limited to physical disability and communication disability. Those with intellectual disability are described in derogatory terms like ‘low IQ [intelligence quotient]’ or ‘mental or learning’ disability.

The first Disability Survey was carried out in 2008 - 2009 by Myanmar Ministry of Social Welfare, Relief and Resettlement and the Leprosy Mission International (Myanmar). The definition of person with disability used for the purposes of the survey was based on a pre-survey exercise, and the definition finally used on that basis was: “an individual who is limited in function and/or ability to conduct activities in daily living to participate in society due to physical, hearing, seeing and intellectual or learning impairment”.[217] The findings report a disability prevalence of 2.32% translating into prevalence of one person with disability in every 10 households. Physical disability was the highest (1.58%), followed by seeing (0.31%), hearing (0.24%) and intellectual (0.18%)[218] The disability survey conducted in 2010 also found that “almost half of the population does not believe that (intellectually impaired children) are capable of engaging in simple tasks” and hence they are excluded from society.[219]

The 2014 Myanmar Population and Housing Census provides detailed data on disability prevalence in the country. For the purposes of the census, disability was defined as: “a situation where a person is at a greater risk than the general population of experiencing restrictions in performing routine activities (including activities of daily living) or participating in roles (such as work) if no supportive measures are offered”. It included 4 dimensions of disability, namely, (i) walking (wheel chairs, crutches, limping, problems climbing steps); (ii) seeing difficulty (low vision, blind); (iii) hearing difficulty (partially or completely deaf); and (iv) mental/Intellectual difficulty (slow learning development making it hard to compete with their counterparts at school, other mental conditions).[220]

Data were collected on four domains of disability along four grades - no difficulty, some difficulty, a lot of difficulty and cannot do at all. The Census questionnaire on mental and intellectual disability gathered data on difficulties in remembering or concentrating.[221] This is a limited definition for the purposes of capturing data on intellectual and developmental disability. At least one type of disability was reported by 4.6% of the sample. The most common type of disability was seeing (2.5%), followed by walking (1.9%), remembering/mental (1.7%) and lastly hearing (1.3%). (Table 1)

Table 6: Persons with disability by prevalence and type[222]

People with disability	Number	Percent
Any form of disability	2,311,250	4.6
Walking	957,736	1.9
Seeing	1,249,737	2.5
Hearing	673,126	1.3
Remembering	835,598	1.7

Source: 2015. The 2014. Myanmar Population and Housing Census The Union Report Census Report Volume 2.

Myanmar's mental health policy is incorporated within the general Health Policy. A Mental Health Plan and a Disaster Preparedness Plan for Mental Health is in place, which was revised in 2006.[223] The Rights of Persons with Disabilities Law was passed only in 2015. It defines persons with disability as "those who have one or more long terms physical, vision, speaking, hearing, mental, intellectual or sensory impairment from birth or not". The aim is to implement more effectively, the provisions made for rights of persons with disability including education, health, job opportunities with a focus on women and children. A National Committee on Rights of the Disabled Persons was set up to ensure inter-ministerial cooperation as well as work with national and international non governmental and business organisations and entities.[224]

Literature review carried out for this report highlights the limited information available on the context of persons with intellectual and developmental disability. Information that is available encompasses disabilities as a whole.

Stigma and discrimination: The available evidence highlights the stigma faced by people with disability but the literature does not focus on people with intellectual or developmental disability. Census 2014 reports that nearly one half of persons with a disability live in joint or extended families and hence there is someone present to take care of special needs.[225]

Mothers are usually the main caregivers for all children with disability. A UNICEF report (2016) indicates that of the 75 parents/ caregivers interviewed almost half said that this does not impose on their time but more than 1 in 4 reported that they did not have time for other household chores. The report indicates that children with disability are not treated differently from those without disability. Community was reported to be generally supportive and understanding and there was an agreement that all children including those with disability have the right to live a happy life. However, despite these positive statements, there were reports of children with disability being bullied by children and adults. Again, only 11% of the community members reported having seen children with disability participate in social life thereby reiterating their "invisible" status in the society and the possibility that they may encounter shame and discrimination. The same study highlights that parents/ caregivers feel overwhelmed by the task of raising a child with disability. Parents reported that they were not prepared emotionally to take care of their child and felt that they did not get adequate support to take care of their children's health or financial needs or to receive routine services.[226]

Available evidence highlights the need to design programmes for caregivers enabling them to deal with the challenges in caring for persons with intellectual challenges and developmental disability. Parents/ caregivers of children with intellectual and developmental disability get basic training from the school. The Eden Centre for Disabled Children, an NGO working in this space in Yangon, not only provides the training in its day care centre but also in the community, through various projects around the country.[227]

Gender and Marginalisation: Literature throws light on marginalisation and abuse of young girls and women with disability. However, there are no specific data on those with intellectual and developmental disability.

In a qualitative study undertaken in 3 commercial centres of Myanmar, namely Yangon, Mandalay and Taunggyi, people with mild intellectual disabilities voiced their desire to communicate with their peers and be a part of the community. However, in the absence of peer workshops or shelter workshops, institutionalisation is an option not only for orphan children with disability but also for adults with disability with or without families.[228]

A shadow report by Disabled Persons' Organisation on United Nations Convention on the Rights of Persons with Disabilities, reports that the Rights of Persons with Disabilities Law, 2017, (Article 27 (f) in Chapter (6) states that reproduction of women with intellectual disabilities is controlled, if necessary, with the consent of parents or custodians in accordance with the reproductive health care policies. This denies women the right to consent by women with intellectual disability and is violation of basic human rights.[229]

Health: Myanmar has yet to develop a diagnosis system to train doctors to diagnose disability during pre-natal, natal and post-natal periods. This is particularly needed for pre-natal women with the possibility of a child with Down syndrome.[230]

While there is no specific legislation or policies that govern access to health services by persons with intellectual challenges and developmental disability, the law indicates that health services can accessed by them at any public hospital around the country from general health care professions such as medical doctor, therapist, etc. However, these services are not easily accessible by this cohort because they are largely available in urban centres and, cost needs to be borne by the client. Other barriers include lack of awareness among service providers and limited human resources trained to work with those with intellectual challenges and developmental disability. There is a proposal to start training medical professionals at township level on screening and classification to ensure that there are doctors available for diagnosis and classification of children/adults presenting with signs/symptoms of intellectual challenges or developmental disability. It is also proposed that early childhood services will be delivered by trained para-professions who go through an intensive one-month training.

Accurate data on the current availability of health delivery facilities were not available. An assessment of mental health systems in Myanmar undertaken by the World Health Organisation and Ministry of Health, Myanmar in 2006 found that there are 25 outpatient mental health facilities, 2 day-treatment facilities, 17 community based psychiatric inpatient units and 2 mental hospitals to cater to the entire population of the country. Refresher training on mental health was not adequate with only 1% of primary health care doctors, 3% nurses and 2% non-doctors/non-nurse having received a 2 days refresher training.[231]

Child disability and risk of developmental disabilities is strongly linked with severe anaemia, extensive micronutrient deficiencies, low birth weight and high infant mortality rates. All these factors are prevailing in Myanmar. The micronutrient supplementation programmes that are in place vary in quality. Many pregnant women may not take required doses of iron-folic acid supplements either because of lack of knowledge, lack of supplies or willingness to comply with the regimen. Skilled birth attendants play an important role in identifying risks during labour and at birth. They handle emergencies and hence are responsible for preventing babies to be born with impairments that can lead to disability like cerebral palsy. But even until 2014, only 72.3% of births were attended to by a skilled health care provider.[232]

Though there are more than 1500 psychiatrists in Myanmar, a 2011-12 qualitative research study on disability and development reports that 31% of families of children with intellectual disabilities and autism do not have access to trained doctors who can understand these children and deal with them effectively. For example, children with intellectual and developmental disability including autism do not like to take medicines or injections. The doctors have to be trained on how to deal with this and control their behaviour.[233]

Cerebral palsy is a severe childhood disability that is a burden on the families and makes demands on health, education and social services. A hospital based study looked at the nature of cerebral palsy ‘type’ among 60 children with cerebral palsy. It reported that 42 children (70%) had bilateral spastic type, 6 children (10%) had unilateral spastic type, 3 children (5%) had dyskinetic type, 4 children (6.7%) had ataxic type and 5 children (8.3%) had mixed type of cerebral palsy. Recognition of the types and topography is important to design prevention and rehabilitation programmes for children with cerebral palsy.[234]

Department of Social Welfare runs one residential centre at Yangon for people with severe disabilities, including intellectual disabilities. There are no private run institutions in Myanmar.

Educational attainment: The National Education Strategic Plan (2016-2021) mentions right to education for children with disability, but does not make any specific mention of those with intellectual disability. While Myanmar’s policy framework leans towards inclusive education, the reality is far from this. Providing the right to persons with disability to attend mainstream schools is not enough. There is a need to put in place, trained teachers, a special curriculum and an environment that is conducive to persons with disability. The Disability Rights Law (2015) mentions: “Every person with disability can attend any mainstream government schools in their accessible area”.[235] In practice however, this is not possible because of lack of trained teachers in government schools to work with special children. Additionally, there are not enough government or private special schools.[236]

According to Census 2014 those reporting difficulty in remembering or concentrating are a great risk of being illiterate. Literacy rates, school attendance of primary and secondary school children, and education completion rates of persons with disability were all much lower than for persons without disabilities. Using the grading of disability, those who reported experiencing some difficulties in remembering or concentrating have double the chances of being illiterate; a person with a lot of difficulties has just over five times the chances; and a person who cannot remember or concentrate at all has more than 10 times the chances of being illiterate than someone with no difficulties at all.[237]

Myanmar Special Education Association formed in 2013, is the only civil society organisation that provides special education teachers training in Myanmar. It collaborates with the Ministry of Education to train teachers employed by the Ministry of Education. The National Education Strategic Plan (2016-2021) addresses the right to education of children with disability but there is no specific mention of children with intellectual disabilities.[238]

A study conducted by Eden Centre for Disabled Children and Voluntary Service Overseas report that "intellectually impaired children were less likely to go to school than children with physical disabilities because of the general perception that they would not benefit from an education".[239] Parents keep their children with disability at home because of impairment, financial reasons and difficulties with teachers.[240]

Ministry of Social Welfare, Relief and Resettlement and its Department of Social Welfare are responsible for services for people with disability, including education for children with disability through special schools. However, special schools are located in only two cities – Yangon and Mandalay – thereby restricting access to a large population that lives in rural areas. Hauschild and Htet report that of the 12 special schools, seven are for children with visual impairment, three for children with hearing impairment, and two for children with developmental and physical impairment.[241]

Economic participation and poverty: No data is available specifically for the disadvantage faced by people with intellectual and developmental disability. The available literature focuses on disabilities at large and reiterates the limited opportunities for vocational training or employment for persons with intellectual and developmental disability.

Limited or no access to education is a main cause for unemployment of persons with disability. It also results in low wages and poor quality of jobs offered to them. Myanmar Centre for Responsible Business and Deaf Resource Centre reported that in 2014 about 85% of persons with disability were unemployed. Persons with disability reported that they were engaged in casual labour such as collecting bottles, plastic etc.[242]

Census 2014 also reports lower labour force participation rates and employment to population ratio among persons with disability as compared to persons without disability.[243]

Assistive devices: There is limited evidence on availability of and use of assistive devices in Myanmar. Services are mainly provided by NGOs and international NGO who provide assistive devices among other services to persons with disability. It appears that there is lack of universal coverage of assistive devices unless they come in form of donations or charity from other organisations.

KEY TAKEAWAYS

- The overall availability of published literature on disability in Myanmar is low.
- Myanmar conducted its first Disability Survey in 2008-09, which returned a rate of 2.32% for all disabilities in the population. It revealed antagonistic attitudes to people with intellectual and developmental disability.

- Girls and women with disability experience marginalisation to a greater extent, but data specifically on those with intellectual and developmental disability is not available.
- The Rights of Persons with Disabilities Law was passed in 2015 with provisions for education, health, job opportunities with a focus on women and children for persons with disability.
- Health infrastructure is limited and training of service providers needs to be updated. Available data indicates that children with intellectual and developmental disability often do not attend school.
- Institutionalisation is often the recourse for persons with intellectual and developmental disability.
- Data on economic participation and stigma and marginalisation is lacking.

GOOD PRACTICE CASE STUDY

Eden Centre for Disabled Children
Yangon, Myanmar

Mr. Tha Uke, Director **www.edencentre.org**

Recognising the barriers faced by persons with intellectual disabilities and developmental disability, Eden Centre for Disabled Children was established in 2000 to provide basic services for children with physical and intellectual disabilities by trained persons. The Centre is a pioneer organisation which has disseminated the 'Social Model of Disability' in the country since 2006 in many ways including publishing literature, implementing project activities, research projects.[244]

The Centre uses a holistic child development approach. It focuses not only on service provision, social inclusion, and personal hygiene of the child, but also working with family members as well as with the community. It provides caregiver training, awareness on child protection, disability and importance of early childhood intervention. It has a pre-vocational training programme for children with intellectual and developmental disabilities of age 18 - 25 years. The Centre also recognises the need to work with community at large, holding awareness raising programmes in communities with the aim to encourage social inclusiveness and integration in mainstream society.[245]

The Centre has about 235 students with intellectual and developmental disabilities. Currently, 13 teachers, 6 therapists, 1 social worker and 2 sports officers run the programme. In a continuum of care, the Centre provides vocational training to these students and wherever possible, facilitates job opportunities for them. The Centre has ex-students in its staff as assistant teachers while others have been placed in jobs in the private sector.

The Centre collaborates closely with various departments of the government including department of Social Welfare, focal ministry for persons with disability, Education department and local administrative offices. Advocacy efforts have been undertaken on ensuring right to education for children with disability in Amendment National Education Law (2015) and inputs have been given to ensure inclusive education policies in National Education Strategic Plan (2016-2021).[246]

However, challenges remain: (i) funding; (ii) trained specialists as there is no training available for required services; (iii) marketing of the products made by children trained in vocational skills as there is no strong linkage between disability and mainstream businesses.[247]

Scaling and replication of this model is possible and very much required in Myanmar to ensure that there is a modicum of support to children with intellectual and developmental disability in the country.

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[216] UNICEF. (2016). Situation Analysis of Children with Disabilities in the Republic of the Union of Myanmar. YanGovernmentof Nepal, UNICEF Myanmar

[217] Govt of Myanmar. (2010). Report First Myanmar National Disability Survey

[218] Govt of Myanmar. (2010). Report First Myanmar National Disability Survey

[219] UNICEF. (2016). Situation Analysis of Children with Disabilities in the Republic of the Union of Myanmar. YanGovernmentof Nepal, UNICEF Myanmar.

[220] Govt of Myanmar. (2014). The Myanmar Population and Housing Census.

[221] Zietzer, I. (2018). A Situational Analysis of Disability and Aging in Myanmar. HelpAge International Myanmar country office

[222] Govt of Myanmar. (2015). The Union Report Census Report Volume 2.

[223] WHO. (2006). A report of the assessment of the mental health system in Myanmar using the World Health Organization - Assessment Instrument for Mental Health Systems. Myanmar, WHO

[224] Govt of Myanmar. (2015). The Rights of persons with Disabilities Law 2015.

[225] 2017; Thematic Report on Disability; as above; Census Report Volume 4-K

[226] UNICEF (2016). Situation Analysis of Children with Disabilities in the Republic of the Union of Myanmar. YanGovernmentof Nepal, UNICEF Myanmar.

[227] Uke, T. (5 July 2019). Personal communication

[228] Bawi, S. (2012). Understanding the challenges of disability in Myanmar. Internships Asia and Hussman Foundation

[229] Myanmar Federation of Persons with Disabilities (MFPD) (n.d.) Disabled Persons Organisation’s Report on State of Implementation of Initial Report. (n.p.)

[230] Bawi, S. (2012). Understanding the challenges of disability in Myanmar. Internships Asia and Hussman Foundation

[231] WHO. (2006). A report of the assessment of the mental health system in Myanmar using the World Health Organization - Assessment Instrument for Mental Health Systems. Myanmar, WHO

[232] UNICEF. (2016). Situation Analysis of Children with Disabilities in the Republic of the Union of Myanmar. UNICEF Myanmar

[233] Bawi, S. (2012). Understanding the challenges of disability in Myanmar. Internships Asia and Hussman Foundation

[234] Thu, A., Aung, A., Myint, K., Myint, A. (2017). Motor Function and Manual Ability in Children with Cerebral Palsy: A Primary Report. International journal of child development and mental health

[235] UNICEF (2016.) Situation Analysis of Children with Disabilities in the Republic of the Union of Myanmar. Nepal, UNICEF Myanmar.

[236] Report of Myanmar Down Syndrome Association (2018). Country Report 2018 Myanmar.

[237] Government of Myanmar, Department of Population Ministry of Labour, Immigration and Population. (2014). The 2014 Myanmar Population and Housing Census.

[238] Govt of Myanmar. (2016). National Education Strategic Plan (2016-2021)

[239] UNICEF. (2016). Situation Analysis of Children with Disabilities in the Republic of the Union of Myanmar. UNICEF Myanmar.

[240] UNICEF. (2016). Situation Analysis of Children with Disabilities in the Republic of the Union of Myanmar. UNICEF Myanmar.

[241] Hauschild, A., Htet, Z. (2015). Analysis of Inclusive Education in Myanmar Final Report. Elsevier Sponsored Documents.

[242] MCRB and Danish Institute for Human Rights. (2015). Human Rights and Business Country Guide Myanmar.

[243] Government of Myanmar, Department of Population Ministry of Labour, Immigration and Population. (2014). The 2014 Myanmar Population and Housing Census.

[244] Deresa, V. (2008). History of Eden Center For Disabled Children. ECDC

[245] Uke, U. (28 July 2019). Personal communication

[246] Uke, U. (28 July 2019). Personal interview

[247] Uke, U. (28 July 2019). Personal interview

NEPAL

Capital: Kathmandu
Population: 28,983,000**
Rank in HDI: 149*
World Bank Income Classification: Low#

*UNDP: Human Development Reports 2018
**World Health Organisation 2016

GNI Per Capita (PPP): USD 2471*
Health Expenditure Per Capita (PPP): USD 150.6**
Life Expectancy at Birth (years): 70.6*
Population with disability (%): 1.9$

World Bank 2019
$ Census of Nepal 2011

In Nepal, disability has had the attention of policymakers since 1982 when the Disabled Protection and Welfare Act was enacted. A National Policy and Plan of Action on Disability followed in 2006 included intellectual disability and autism (mentioned separately) under mental disability among seven other categories of disabilities. The most recent Act of Government on this matter is the Rights of Persons with Disabilities Act (2017) which defines persons with disability as: "those who have long-term physical, mental, intellectual or sensory impairments, functional impairment or which in interaction with various barriers may hinder their full and effective participation in social life on an equal basis with others". It further classifies disabilities into seven categories: (i) physical disability; (ii) disability related to vision; (iii) disability related to hearing; (iv) deaf-blind; (v) disability related to voice and speech; (vi) mental disability; and (vii) multiple disability.[248]

There is no consensus on incidence and prevalence of disabilities in Nepal. The last Census conducted in 2011 reported that about 1.94% of the population lives with some form of disability while data gathered through National Living Standards Survey (2010-2011) estimated that about 3.6% of the population lives with disability. In line with the new Act, the survey provided disaggregated data that indicated that (i) 29.2% are physically disabled; (ii) 22.3% have visual disabilities; (iii) 23.4% have hearing disabilities; (iv) 2.4% have vision and hearing related disability; (v) 8.6% have speech related disability; (vi) 6.8% have mental health conditions; and (vii) 7.3% have multiple disabilities.[249]

Table 1 shows the distribution of disabilities as per the 2011 Census. The number of people with reported physical disabilities was 10 times higher than those intellectually disabled, reinforcing the notion that there is underreporting of mental and intellectual disabilities.[250]

Table 7: Persons with Disabilities, Nepal 2011

Sex	Type of disability								Total
	Physical	Visual	Hearing	Deaf-Blind	Speech	Mental	Intellectual	Multiple	
Male	108,279	47,041	41,204	4803	33,190	16,787	8280	20,502	280,086
Female	78,170	47,724	38,103	4633	25,665	14,210	6608	18,114	233,235
Total	186,457	94,765	79,307	9436	58,855	30,997	14,888	38,616	513,321

Source: Government of Nepal, Central Bureau of Statistics. (2011). Nepal census report.

People living with intellectual and developmental disability remain underreported and underserved in Nepal. As in many other South Asian countries, the stigma and taboos attached to this group of people results in hiding information about them and not enrolling them for any assistance programmes of the government, thus isolating them from the society. Failure to capture actual statistics is compounded by cultural barriers and sociocultural beliefs that lead the families to hide members with disability, and that data on children with disability is limited because these are not captured in birth registration forms. Evidence also supports the strong link between disability and poverty resulting in higher levels of disability in lowest wealth quintile – poverty, poor sanitation and lack of access to services are linked to disability.[251] Conversely, disability may keep those with disability in a cycle of poverty because of limited access to employment opportunities and public services.[252]

Nepal has policies and programmes in place that pledge a rights-based approach and non-discriminatory environment for people with disability. Different programmes and services are in line with the Disability Act, Policies and Guidelines and include discounts, subsidies and social protection including disability allowance, free education for children with disability, reservations in schools and scholarships, free healthcare and discounted medicines, financial support or free provision of assistive devices (prosthetics, wheelchair, hearing aid etc.). Additional support is provided through orphanages, rehabilitation centres and hospitals, reservations in public and private employment, discounts in transportation and barrier free new buildings. Persons with disability are required to get a disability card that entitles them to benefits. There are four categories in the card - profound disability (red card), severe disability (blue card), medium disability (yellow card) and minor disability (white card).[253] Only those holding a red or blue card entitled to disability allowance. The cash benefit varies from Nepali Rupee 3000 (USD 27) for those with profound disability to Nepali Rupee 1000 (USD 9) for persons with severe disability per month. Reports suggest that since this amount is not enough even to cover the cost of basic medicines, most people do not claim it.[254] People with intellectual and developmental disability find it difficult to get a card because of general lack of knowledge among the officials about the nature of this kind of disability and lack of diagnostic services. When they do get a card, it is only after the caregiver/parent has spent a considerable amount of time in getting a medical diagnosis, which is a prerequisite for a disability card.[255]

However, an individual is required to re-register for the allowance every year. Allowance is paid every quarter and to receive it the individual needs to present the disability card and the log book at their Village Development Committee. Recently, the government has started direct transfer to bank accounts, but this may not work for everyone as not all beneficiaries have a bank account. Another challenge in fully implementing the allowance is the limited staff and capital resources at the Village Development Committees to manage the Disability Allowance. In particular, the challenge is reaching out to people who live in hill and mountain areas where transport is unavailable and often the allowance is distributed only once or twice a year.[256]

Nepal has undergone a political transition and has restructured the government with three layers of governance namely federal, provincial and municipal. The country is ready for formal, organised and strategic interventions on issues of intellectual and developmental disability. The key players include the government which strives to provide an enabling environment by endorsing laws, policies, programs and schemes; and the NGOs, parents' associations and Disabled Person's Organizations which implement the programs at the grass root levels.

While Nepal has formulated progressive acts and policies, implementation of these continues to be a challenge. For one, disaggregated data on persons with disability, by types and other characteristics is scarce. Second, inadequate funds and resources to implement the programmes on ground. Third compounding factor is that the policies are not always clearly articulated and laid out leaving the interpretation to bureaucrats and donors. Fourth, the concept and related understanding of disability is still limited in both political and development discourse. Fifth, implementation is challenging because of the country's inadequate resources. So, while the country goes the way of decentralisation of federalism which offers a sound base for increased flexibility for implementing programmes and policies, there is a need for more clarity on concept, procedure and quality.[257]

A person with intellectual disability has been defined as "someone who was unable to perform activities or to learn tasks as their peers could and was diagnosed with this inability before the age of 18 years".[258] Two categories were identified (i) persons who could manage their daily lives with training and (ii) those who could not do manage activities like eating, dressing, speaking, and going to the toilet even with training.[259] A study conducted by the Association for the Welfare of Mentally Retarded/ Maryknoll Fathers found a higher prevalence in the northern mountainous regions of Nepal (10%) as compared to Terai and lower hills (2.8%).[260] Ali et al (1991) attribute this to lack of development because of remoteness of the area, use of non-iodized salt, lack of health facilities and acute poverty.

Nepal suffered major damage from earthquakes in April and May 2015 and in response, the disability allowance was scaled up as part of the Emergency Cash Transfer Programme. It provided a one off, top-up cash benefit of Nepali Rupee 3000 to existing social security allowance beneficiaries to help them cope with the effects of the earthquake. However, not all people with disability were able to avail of this benefit because they had lost their disability card in the earthquake, they did not have adequate information on relief programmes, or the programmes did not reach them because they find it difficult to reach the offices of the programmes.[261]

Available literature from Nepal reviewed for this report largely focuses on prevalence and aetiology of intellectual and developmental disability including prevalence, recognition of the disability and treatment. The review indicates that most of the programmes and interventions are for people living with physical, visual or auditory impairments. Programmes for people with intellectual and developmental disability are few and mostly run by national or international NGOs with support from developmental partners.

Stigma and discrimination: People with intellectual and developmental disability are most marginalised because of a lack of awareness about causes and types of intellectual disability as well as limited understanding on mainstreaming this group in social and economic life.[262] Intellectual disability is often mistaken for mental disability or other conditions.

Superstitions and myths surround how a person with intellectual and developmental disabilities is viewed in Nepali society. Mothers of these children are often deemed responsible for giving birth to a child with disability because of sins that she may have committed in her past life. These children are thought to be possessed by evil spirit and are taken to faith healers instead of trained professionals. These beliefs are prevalent even among educated and economically well off people. In a situation like this, it is challenging to provide rehabilitative services as the families want a 'cure' or for the person to 'become normal'.[263]

Those who take care of persons with disability may themselves suffer from health problems, caused largely due to stress and anxiety associated with their caretaking role. In a study conducted by the Self-help Group for Cerebral Palsy, Nepal with caregivers of persons with cerebral palsy indicated that 69% of participating carers reported a current physical or mental health problem. In the same study, caregivers voiced their concerns about ability to continue their caregiving role in future and worried about what will happen in future to the person they are caring for. They reported drifting away from family and friends and a feeling of isolation as a result of their responsibilities.[264,265] Parents and caregivers are worried about the future of their children with intellectual and developmental disability, even when they are adults including care once they are gone.[266]

Some international and national NGOs have started working with caregivers. For example, Carers Worldwide, an international NGO works with caregivers of all types of disabled population. It works closely with cerebral palsy in Nepal around five key elements: health services including disaster preparedness, respite and short breaks, employment, training and education and advocacy.

Adults in the family are usually the main support for older people with intellectual disability and their attitude towards disability plays a key role in accessing existing services. However, parents do not always make a plan for the future of adults with intellectual disability, except for their sons whom they plan to marry to ensure social security in adulthood.[267] Denial of inheritance is yet another way of social discrimination faced by people with intellectual and developmental disabilities. Parents are unwilling to give them property rights because they feel that they will not be able to manage it.

Government of Nepal gives red and blue disability cards yet not all have this social security allowance because they are not aware of this and nor have they applied for getting the card. Additionally, the amount of the allowance is small and those receiving it feel that this does not give them extra money to take care of persons with disability. The amount of the allowance is small and often it appears that the trouble the family or the recipient has to go through is not worth the amount. Though the amount of allowance has increased over time, it has been widely acknowledged that the amount is not sufficient to cover even the basic living costs of people with severe disabilities who require continuous and significant support.[268]

Gender and marginalisation: Girls and women with disability are at a greater disadvantage as compared to boys and men. Girls are not sent to school, not allowed to play outside with other children and often not taken to hospital for treatment. The need to protect the girl, especially with intellectual disability is a major concern of parents. Girls with intellectual and developmental disability may also skip school during menstruation as they may not know how to take care of themselves. Schools do not always have facilities where these girls can be helped and hence, they miss school which affects their studies and they may drop out of school.[269]

A Shadow Report submitted by 13 disability rights groups to the Committee on the Rights of Persons with Disabilities in Nepal in March 2018 highlighted the situation of people with disability. The report mentions the high risk of sexual violence girl children with autism, Down syndrome and intellectual disability face, and the lack of support the parents get in taking care of these girls. A quote from a mother in a focus group discussion aptly describes their situation: “I wish my daughter would never grow up to become beautiful or attractive because that would increase her risk of being sexually harassed”. The report goes on to say that women and girls with intellectual and developmental disabilities are subject to forced sterilisation and contraceptives without being given proper information to avoid unwanted pregnancy from sexual assault and violence. Parents of girls with autism and Down syndrome were told to sterilize their daughters to manage their menstruation.[270] This is a clear violation of their rights as laid out in the constitution of Nepal.

Parents and teachers of children with intellectual and developmental disabilities want to inform girls about sexual and reproductive health and rights, but they lack materials and tools to impart this information. This is particularly pertinent while managing menstruation and forces girls to skip school because of limited or no support in the school.[271] Awareness raising programmes at the community level are not targeted strategically. For instance, a study done by Marie Stopes International with young persons with disability in select districts of Nepal reported low sexual and reproductive health awareness and uptake of services by this group. This highlights the urgency to implement programs that would directly target increasing awareness among this population. The study identifies three key barriers including absence of translator, lack of friendly infrastructure and attitude of health care service providers towards persons with disability.[272]

Health: Literature on health outcomes of people with intellectual and developmental disability is limited. What is available discusses disabilities at large and does not specifically address health of people with intellectual and developmental disabilities. Evidence on intellectual and developmental disability focuses primarily on the recognition and treatment, particularly of cerebral palsy and Down syndrome.

In Nepal, people with disability are entitled to free medical examination and care. However, they can avail of these services only if they can present their disability identification card or are visibly disabled. Disability cardholders receive additional services like waiver of registration fees, X-rays etc. at no cost. The policy mandates that all hospitals with more than 50 beds should allocate 2 beds for the use of people with disability.[273,274] However, there are no designated health care units designed for persons with intellectual and developmental disability. Lord and Sijapati report that rehabilitation and physiotherapy services are limited to those with mobility related disabilities or musculoskeletal conditions, and there are very few treatment options in public facilities for persons with intellectual and developmental disabilities.[275]

A prospective study was undertaken in outpatient department of a hospital between October 2011 and September 2012 to evaluate children with Down syndrome regarding frequency and types of congenital heart disease and associated pulmonary hypertension. Of the 50 children evaluated, 80% (n=40) had an associated congenital heart disease, indicating that these children develop pulmonary hypertension at a younger age, and early diagnosis, screening and management would help avoid irreversible damage.[276] Another study with 36 children with Down syndrome evaluated visual impairments through a detailed optometric examination. The study found that these children have a high prevalence of refractive error and nystagmus and suggests regular eye examinations for early diagnosis and appropriate care to improve their vision and provide better quality of life.[277]

A retrospective study with 219 children with cerebral palsy between January 2014 and June 2016 highlighted the epilepsy seen in these children, especially those with spastic cerebral palsy. The study encourages early recognition and treatment of epilepsy to improve quality of life and to reduce comorbidities.[278] Access to services and treatment for children with cerebral palsy is delayed because of delayed recognition of symptoms due to lack of awareness and access to appropriate facilities and specialist as well as beliefs and myths about cerebral palsy.[279] A cross sectional study with 206 Nepali children at a Hospital and Rehabilitation Centre for Disabled Children during February 2015 to April 2016 reported that children with spastic hemiplegic cerebral palsy had greater disability as compared with counterparts in higher income countries with similar symptoms. They concluded that limited access to health services results in greater motor disability. This study highlights that this cohort represents a substantial disease burden that could be prevented by medical and surgical interventions.[280]

A cross sectional prevalence study was carried out in one district of Nepal between January 2014 to January 2015 using Autism Quotient-10 tool among 4098 rural children aged 9 -13 years. The prevalence was found to be 3 in 1000 (95% confidence interval 2–5 in 1000) among this group. The study found that almost all children who screened positive for autism also tested positive for physical, learning and behavioural disabilities. They were also more likely to be stunted and have cognitive difficulties. They concluded that these limitations contributed to the failure of these children to achieve their full developmental potential within the bounds of their marker disability.[281]

Access to services for children with autism is confounded by lack of adequate knowledge among service providers. A study undertaken to assess knowledge and management practices of paediatricians about autism indicated out of 54 respondents, 65% did not have adequate knowledge and 59% did not carry out adequate practice for autism. More than half reported rarely handling a child with autism and a majority said that they found it difficult to diagnose this disability.[282]

Educational Attainments: Children with disability in Nepal are eligible for integrated education provided through the Ministry of Education. Three types of education policy for children with intellectual disability are in place: (i) resource classes in government primary schools with hostel facilities; (ii) special education programmes run by NGOs through government grants; and (iii) inclusive education for children with all types of disabilities, including intellectual disability.

Education for all children in Nepal is free until grade 8, but there are still indirect costs (e.g. fees for school supplies, uniforms, to register for exams) that may be prohibitive for families living in poverty. Children with disability attending school may face additional costs, such as for transportation, assistive devices or boarding. To help offset some of these costs and increase the enrolment of children with disability, the Government provides scholarships for students with disability (who have a disability card) between grades 1 to 8. The scholarship system was set up in 2004 and has expanded significantly in the interim, in terms of both coverage and benefits. Applications and decisions for the educational scholarships are managed by the District Education Office.

Educational scholarships are provided according to the severity of the disability and the difficulties the student faces in accessing school. There are four categories: students with disability who board at the school, residential provision NR 3000 [US$29] (mountain districts) NR 2500 [US$24] (hill, Terai districts); students with disability who require assistive devices and personal assistance while in school, non-boarding NR 500 [US$5]; students with disability who use assistive devices or transportation to commute between home and school NR 300 [US$3]; for all other school-going children with disability, non-boarding NR 100 [US$1]. However, although a disability card is a precondition for receiving a scholarship, the four levels do not correspond to the four colours of cards because factors like distance from the home to school are considered.[283]

Children with intellectual and developmental disability do not receive any formal, academic education. The curriculum developed by the Curriculum Development Centre limits education of these children to learning practical life skills in resource centres or special schools for up to 10 years. The focus is on teaching them personal hygiene, brushing teeth, going to the toilet, getting dressed and eating. Children who are 14 and 15 years old can learn vocational skills like candle making, sewing or origami.[284] This does not account for this cohort's ability to learn through other teaching-learning methods. Opportunities for schooling for girls with intellectual and developmental disability are almost zero, because parents are not aware of these special schools or resource centres.[285]

A research undertaken by the Department of Education in four districts of Nepal explores facilitating and hindering factors in inclusive education in resource class schools. The facilitating factors included disability friendly infrastructure, disability specific skill-based learning, awareness raising, provision of hostel facility, rewards, etc while the hindering factors included lack of trained teachers, lack of disability specific study materials, lack of support from parents and families, etc. According to the educationists and the subject expert under the study, the inclusive education program practiced now has not been able to include disabled children with full retention, sometimes not even a single child with disability but often the education system is called inclusive education.[286]

Gaps remain in service delivery. Inclusive educational institutions do not have appropriate environment to welcome children with disability, particularly intellectual, autism, deaf, blind and multiple disability. Anecdotal evidence reiterates the gaps in training of teachers and that the generalised curriculum does not fit the needs and capacities of the children with intellectual and developmental disabilities. Even when trained, teachers are still not clear about the concept of inclusive education and are not able to meet the special needs and learning requirements of children with disability and do not have systems of comprehensive evaluation mechanisms in place.[287,288] The teachers and staff are not fully equipped to work with children with intellectual and developmental disabilities. A study carried out with 63 teachers in four private schools in 2018 reported that less than half of the teachers had adequate knowledge on autism and levels of knowledge was directly associated with educational qualifications and exposure to autism.[289]

Even within the disabled community, those with intellectual and developmental disability are marginalised. Data from education flash reports are not disaggregated by disability or by type of disability making it difficult to monitor and ensure that children with intellectual disabilities receive good quality and accessible education. Girls are at a greater disadvantage as being a female coupled with intellectual and developmental disabilities ensures almost zero access to school and quality education.[290]

A UNICEF evaluation of Nepal's education system in 2003 has reported that "the educational system [in Nepal] does not adequately meet the learning needs of diverse learners due to the existing school physical infrastructure, the teaching-learning practices, the shortage of trained and motivated human resources, and the lack of assistive devices and learning materials".

Economic participation and Poverty: Data on economic participation of people with intellectual and developmental disabilities is sparse, almost non-existent. Available data focuses on employment opportunities for people with physical, visual or auditory impairments.

The government of Nepal has reserved 5% of all jobs in the civil service industry for persons with disability.[291] Additionally, Nepal has a policy that provides vocational training and employment for people with intellectual disabilities. However, in practice a few NGOs which run sheltered workshops, are responsible for creating the few employment opportunities for this cohort. The stipend paid is minimal and these workshops are located in towns and therefore limited in access for a majority of people with intellectual disability.[292] Poor management has prevented the government run programmes from touching the lives of a large majority of persons with disability.

Assistive devices: Evidence on assistive devices for the use by persons with intellectual and developmental disability is limited. Private sector is the main provider of assistive devices and products. However, quality of products is not assured as there are not standard guidelines on quality of products. There is limited awareness on assistive devices among people. Manufacturing becomes challenging as custom clearance for components and raw materials is a big issue for importing assistive devices.[293]

Community Based Rehabilitation Biratnagar is a nongovernmental organization that has been providing rehabilitation services in the eastern region of Nepal since 1990. Working in partnership with Handicap International (Nepal) they have developed a comprehensive service which includes fabrication, provision and repair of assistive devices. Local people (women and men, with and without disabilities) were trained as technicians in Nepal and India and integrated into the existing team of the organisation. Community Based Rehabilitation Biratnagar now provides quality orthoses (e.g. callipers, braces, splints), prostheses (e.g. artificial legs and hands) and mobility devices (e.g. crutches, tricycles, wheelchairs) to people living with disability in 16 districts of eastern Nepal. Community Based Rehabilitation Biratnagar personnel, therapists and workshop technicians all work hand-in-hand to enhance the quality of life of people with disability.[294]

Independent Living Centre for Persons with Disabilities, Kathmandu (CIL-Kathmandu), a non-profit, non-political, self-help organization is run by and for persons with disability. In Nepal, persons with disability often obtain assistive devices as donations from local and international non-government organisations. Whilst this generosity does not go unappreciated, CIL-Kathmandu believes that assistive devices should be need based, using a rights-based approach and not charity approach.[295]

In Nepal, there are very few organizations providing wheelchairs and assistive devices with detailed assessment and measurement of the users as it requires importing the costly, tailored, measured devices from abroad.

Post 2015 earthquake: People with intellectual and developmental disabilities faced challenges in accessing relief and aid because of a number of reasons. Difficult terrain, age, different locations where relief was available, are some of the reasons. For parents or caregivers of people with intellectual and developmental disability, the situation was compounded in absence of men who could work with a crowd of people pushing and jostling along with the requirement to be physically present to receive aid. Additionally, this group was most affected because of lack of preparedness for disaster where no effort was made to explain what happened in a manner that could be understood by them. The anxiety they faced because of moving to an unfamiliar place or living in tents/shelters with a large number of people was not addressed. Girls and women with intellectual and developmental disability were exposed to sexual abuse and trafficking. And finally, there was the sense of alienation faced by persons with intellectual and development challenges if their primary caregiver had died in the earthquake, as they were often marginalised by their family. The study noted that temporary shelters established post-earthquake pose a great risk of sexual and other types of violence for girls and women who have intellectual and developmental disabilities. Their caretakers have to be extra vigilant and ensure that they are not left alone in the shelter.[296]

A post disaster needs assessment undertaken by the government, clearly articulated the disproportionate impact of the disaster on vulnerable and marginalized groups including persons with disability.[297] A study supported by UNDP undertaken Research Baha reports Disaster Risk Reduction (DRR) did not include persons with disability in the consultations or planning, further reiterating the systemic social and spatial biases and limiting this cohort's awareness about disasters.[298] The same study highlighted the importance of disaggregated data on disability to understand the unique risks poses by different disabilities—particularly in terms of intellectual or developmental disabilities (the most marginalized and therefore at risk) and mental disabilities (the most misunderstood). Access to and availability of health care facilities emerged as crucial for persons with disability in the post-disaster situation. Three respondents of the survey ranked problem in accessing health services and medicines as top most challenge in the post-earthquake context in their localities.[299]

KEY TAKEAWAYS

- Nepal was the first country in the region to formally legislate for disability – the first law was enacted in 1982 and the most recent in 2017.
- The numbers of those with sensorimotor disability is about 10 times higher than for intellectual and developmental disability reinforcing fears of underreporting. The rate in the higher mountainous region is reported to be much higher than in the southern flatlands.
- Several progressive policies and programmes have been put into play. But persons with intellectual and developmental disability find it difficult to get their benefit.
- Stigma and discrimination is rampant, with karma used to explain the occurrence of intellectual and developmental disability. Caregivers experience health issues relating to the high levels of stress and anxiety that they face.
- Girls and women are at a disadvantage due to perceptions of greater sexual vulnerability.
- Health support provided includes free medical examination and care for those with a disability card as well as 2 reserved beds reserved for those with disability in every medical facility with more than 50 beds.
- Studies have shown that persons with intellectual and developmental disability have several health issues that require intervention and care in order to improve the quality of their lives.
- Education of children with intellectual and developmental disability has been limited to learning practical life skills up to age 10 years with no government support for formal academic education. Few girls make it to these special schools/ resource centres.
- Data on economic participation of persons with intellectual and developmental disability is extremely sparse. A few non governmental organisations provide limited employment opportunities in sheltered workshops, mostly in towns.
- In disaster settings such as the post-2015 earthquake, persons with intellectual and developmental disability are often left out due to difficulties of access to centres of aid distribution.

GOOD PRACTICE CASE STUDY

Parent led Day Care Centres- Self-Help Group for Cerebral Palsy Nepal

Bimal Lal Shrestha, CEO **www.cpnepal.org**

Self Help Group for Cerebral Palsy Nepal, an associate member of the International Cerebral Palsy Society, is a non-governmental organization dedicated to improving the quality of life of children and adults with cerebral palsy and neurological conditions.[300]

Acknowledging that not everyone can be brought to a rehabilitation centre, centres have been established at community level so that rehabilitation processes can be carried out in the children's own setting. The broad objective of the programme is to empower parents of children with cerebral palsy and neurological conditions to establish and run day care centres for these children. Support is provided by the organization in the form of teachers, therapists and specialist doctors who visit the day care centres and provide targeted interventions where needed. Regular medical check-up of children is done by the doctors through medical camps in day care centres and they are provided nutritious lunch at the centre. Local resources are generated through linking the day-care centres with municipalities and rural municipalities.

There are 25 Day Care Centres in 14 districts of Nepal reaching about 275 children with cerebral palsy and neurological problems. Self Help Group for Cerebral Palsy Nepal prefers to open day care centres in public schools so that the notion of inclusion is disseminated. Coming to the Centre gives these children an opportunity to leave their four walls and interact with their peers.[301]

Improved acceptance of children with cerebral palsy among families is a major benefit. Other benefits of the intervention include improved parental capacity to take care of their children with cerebral palsy, and enrolling children with cerebral palsy in mainstream schools. However, the most significant benefit is the solidarity generated by parents coming together to share their feelings and work together. The Day Care Centres have freed up caregivers' time and enabled them to engage in economic activity.

Challenges include getting a place to set up Day Care Centres. Availability of transport facilities to bring children to the centres, and of trained human resources to work with children and parents are important challenges. Many schools did not understand the concept of inclusiveness and were thus hesitant to enrol children with cerebral palsy and other neurological problems. The Centres also face financial difficulties.[302]

Nevertheless, the concept is scalable and replicable as the decade long experience has shown.

GOOD PRACTICE CASE STUDY

Inspire2Care – Karuna Foundation
Nepal

Deepak Sapkota, Director **www.karunafoundation.nl**

Inspire2Care programme is a community-based model aimed at preventing avoidable disabilities among children and adults and creating an enabling environment for those with intellectual and developmental disabilities and their families by strengthening local communities. Inspire2Care is implemented as a partnership between municipalities and Karuna Foundation Nepal, Disabled People's Organization and Self-Help Group (locally called Milijuli Samuha). The three unique principles that anchor the practice are: partnership with local government, cost sharing among Karuna Foundation and local government, and local responsibility and ownership of the local government.

Developed and piloted in 2011, Inspire2Care is being implemented in all the villages of one district in Nepal with plans for scale up to 13 districts of one province. A cross sectional baseline study conducted in 12 villages of Ilam district found that only 34% of persons with disability had disability ID card and 55% of eligible persons had been receiving disability allowance. Only 6% of them reported to have ever received any form of rehabilitation service.[303] Among those with intellectual and developmental disabilities, the access to ID rose from 32% at baseline to 83% in 2019. By 2019, over 95% had access to social security allowances and other schemes and all had access to inclusive and special education.

Activities include identifying and training a local CBR facilitator; holding a comprehensive disability assessment camp led by a multidisciplinary team; and development of individual rehabilitation plan in partnership with the family members. Identify-Accept-Include is the main thrust.[304] The programme helps with medical treatment, assistive devices and specialised services by type of disability; linking to social security schemes including government scholarships; vocational training and loan support; helps in formation of Self-Help Groups and saving and credit activities. Advocacy for disability friendly structures and behaviours is integral to the programme as are awareness on issues of persons with disability at the family, community and local government which ensures inclusion of persons with disability in policies and programmes.

Inspire2Care has been evaluated by two independent evaluators; both reported that this model is cost effective[305], relevant, effective, efficient, impactful and has underscored the sustainability strategies established through partnership with local government and cost sharing principle.

By making disability the agenda of the annual and periodic plans of the local government, it assures the sustainability of this replicable and scalable model of self care.

End Notes

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[248] Government of Nepal. (2017). Policy on the rights of persons with disability, Kathmandu as cited in Holmes et al. (2018). Nepal's cash allowances for children with disabilities. UNICEF

[249] Government of Nepal. (2015). Education for all. National Review Report 2001–2015. as cited in Holmes et al. (2018) Nepal's cash allowances for children with disabilities. UNICEF

[250] Government of Nepal, Central Bureau of Statistics (CBS). 2011. Nepal census report. Kathmandu, Nepal

[251] Holmes et al. (2018). Nepal's cash allowances for children with disabilities. UNICEF

[252] Human Rights Watch (2011) Futures stolen barriers to education for children with disabilities in Nepal. Kathmandu: HRW

[253] Holmes et al. (2018). Nepal's cash allowances for children with disabilities. UNICEF

[254] Budhathoki. G. (2017). Disability Sensitive Concept of Local Government. Retrieved, 5 May 2019, from ww.sarokar.com.np

[255] Lord, A., Sijapat, B. (2016). Disaster, Disability, & Difference: A Study of the Challenges Faced by Persons with Disabilities in post-Earthquake Nepal. Nepal, UNDP

[256] Lena M. Banks, et al. (2018). Disability-inclusive social protection in Nepal: A national overview with a case study from Tanahun district. International Centre for Evidence in Disability Research Report: London, UK.

[257] Banskota, M. (2015). Nepal Disability Policy Review. Disability Research Center, School of Arts, Kathmandu University

[258] Crishna, B., Prajapati, S. (2008). Comparative Policy Brief: of Intellectual Disabilities in Nepal. Journal of Policy and Practice in Intellectual Disabilities Volume 5 Number 2 pp 133–136

[259] Crishna, B., Prajapati, S. (2008). Comparative Policy Brief: of Intellectual Disabilities in Nepal. Journal of Policy and Practice in Intellectual Disabilities Volume 5 Number 2 pp 133–136

[260] Ali, A. (1991). Mental retardation in Nepal. Association for the Welfare of Mentally Retarded/Maryknoll Fathers

[261] Holmes et al. (2018). Nepal's cash allowances for children with disabilities. UNICEF

[262] Lord, A., Sijapat, B. (2016). Disaster, Disability, & Difference: A Study of the Challenges Faced by Persons with Disabilities in post-Earthquake Nepal. Nepal, UNDP

[263] Crishna, B., Prajapati, S. (2008) Comparative Policy Brief: of Intellectual Disabilities in Nepal; Journal of Policy and Practice in Intellectual Disabilities Volume 5 Number 2 pp 133–136

[264] Waddell, M. (2017). Caring for Carers of Children with Cerebral Palsy in Nepal. Carers Worldwide

[265] Government of Nepal (2017). Policy on the rights of persons with disability, Kathmandu as cited in Holmes et al. (2018). Nepal's cash allowances for children with disabilities. UNICEF

[266] Lord, A., Sijapat, B. (2016). Disaster, Disability, & Difference: A Study of the Challenges Faced by Persons with Disabilities in post-Earthquake Nepal. Nepal, UNDP

[267] Shrestha, S., Weber, G. (2002). The situation of older people with intellectual disability in Nepal: A pilot study. Journal of Intellectual & Developmental Disability, 27, 242–254.

[268] Lena M. Banks, et al. (2018). Disability-inclusive social protection in Nepal: A national overview with a case study from Tanahun district. International Centre for Evidence in Disability Research Report: London, UK.

[269] Holmes et al. (2018). Nepal's cash allowances for children with disabilities. UNICEF

[270] Autism Care Nepal Society (ACNS), et al. (2018). Shadow Report submitted to the Committee on the Rights of Persons with Disabilities in its 19th session for the Country Review of the Federal Democratic Republic of Nepal. (n.p.)

[271] Autism Care Nepal Society (ACNS), et al. (2018). Shadow Report submitted to the Committee on the Rights of Persons with Disabilities in its 19th session for the Country Review of the Federal Democratic Republic of Nepal. (n.p.)

[272] Rajbhandary, R., et al. (n.d.). Understanding the sexual and reproductive health needs of young persons with disability in Nepal. Marie Stopes International.

[273] Banskota, M. (2015). Nepal Disability Policy Review. Disability Research Center, School of Arts, Kathmandu University

[274] Eide, A. Neupane, S., Hem, K. (2016). Living conditions amongst people with disability in Nepal. SINTEF

[275] Lord, A., Sijapat, B. (2016). Disaster, Disability and Difference: A Study of the Challenges Faced by Persons with Disabilities in post-Earthquake Nepal. Nepal, UNDP

[276] Shreshtha, M., Shreshtha, U. (2013). Down Syndrome and Congenital Heart Disease: Single centre, Prospective Study. Nepal Journal of Medical Sciences

[277] Paudel, N. et al. (2010). Visual defects in Nepalese children with Down syndrome. Clin Exp Optom

[278] Thapa, R. (2017). Epilepsy in children with cerebral palsy as observed in Nepal; European Journal of paediatric neurology

[279] Thapa, R. (2017). Symptom Recognition and Diagnosis of Cerebral Palsy in Nepal. Autism Dev Disord

[280] Le brun. DG. et al. (2019). Socioeconomic Status Influences Functional Severity of Untreated Cerebral Palsy in Nepal A Prospective Analysis and Systematic Review. Clin Orthop Relat 6

[281] Heys, M. et al. (2018). The Estimated Prevalence of Autism in School-Aged Children Living in Rural Nepal Using a Population-Based Screening Tool. Journal of Autism and Developmental Disorders

[282] Khatri, G. et al. (2011). Knowledge and Management Practices of Paediatricians about Autism Spectrum Disorder in Kathmandu, Nepal. J. Nepal Paediatr. Soc.

[283] Lena M. Banks, et al. (2018). Disability-inclusive social protection in Nepal: A national overview with a case study from Tanahun district. International Centre for Evidence in Disability Research Report: London, UK.

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[284] Human Rights Watch. (2018). Nepal: Barriers to Inclusive Education Segregation, Lack of Accessibility for Children with Disabilities. HRW

[285] Lord, A., Sijapat, B. (2016). Disaster, Disability, & Difference: A Study of the Challenges Faced by Persons with Disabilities in post-Earthquake Nepal. UNDP

[286] Dynamic Institute of Research and Development (P) Limited. (2014). Analyzing Educational Status Of Children With Disability And Identifying Critical Intervention To Promote Their Enrollment, Retention And Success In Schools

[287] Eide, A. Neupane, S., Hem, K. (2016). Living conditions amongst people with disability in Nepal. SINTEF

[288] Lord, A., Sijapat, B. (2016). Disaster, Disability, & Difference: A Study of the Challenges Faced by Persons with Disabilities in post-Earthquake Nepal; UNDP

[289] Rai, S., Bhattarai, J., Chaudary, S. (2018). Knowledge Regarding Autism among Primary School Teachers of Birgunj, Parsa. Internal Journal of Health Sciences and Research; Vol.8; Issue: 11

[290] Human Right Watch. (2011). Future Stolen- Barriers to Education for Children with Disabilities in Nepal.

[291] Thapaliya, M. (2016). A Report on Disability in Nepal. Australian Himalayan Foundation (AHF) Sydney, Australia

[292] Waddell, M. (2017). Caring for Carers of Children with Cerebral Palsy in Nepal. Carers Worldwide

[293] Government of Nepal. (2018). Priority Assistive Product List of Nepal

[294] Khasnabis, C., Heinicke, K., Achu, K., et al. (2010). Community-Based Rehabilitation: CBR Guidelines. Geneva, World Health Organization

[295] CIL Kathmandu. (n.d.) Retrieved, 10 May 2019, from https://www.cil.org.np/

[296] Lord, A., Sijapat, B. (2016). Disaster, Disability, & Difference: A Study of the Challenges Faced by Persons with Disabilities in post-Earthquake Nepal; UNDP

[297] Government of Nepal. (2015). Post-Disaster Needs Assessment

[298] UNDP and Social Science Baha. (2016). Disaster, Disability and Difference. A study of the challenges faced by persons with disabilities in post-earthquake Nepal. Retrieved, 11 May 2019, from https://www.un.org/disabilities/documents/2016/Disaster-Disability-and-Difference_May2016_For-Accessible-PDF.pdf

[299] UNDP and Social Science Baha. (2016). Disaster, Disability and Difference. A study of the challenges faced by persons with disabilities in post-earthquake Nepal. Retrieved, 11 May 2019, from https://www.un.org/disabilities/documents/2016/Disaster-Disability-and-Difference_May2016_For-Accessible-PDF.pdf

[300] Self Help Group for Cerebral Palsy Nepal. (n.d.). Retrieved, 15 July 2019, from http://www.cpnepal.org/about.html

[301] Waddell, M. (2017). Caring for Carers of Children with Cerebral Palsy in Nepal. Carers Worldwide

[302] Lord, A., Sijapat, B. (2016). Disaster, Disability, & Difference: A Study of the Challenges Faced by Persons with Disabilities in post-Earthquake Nepal. Nepal, UNDP

[303] Karuna Foundation. (2015). Baseline Study of Inspire2Care Programme in Nepal. (n.p.)

[304] Khasnabis, C., Heinicke, K., Achu, K., et al. (2010). Community-Based Rehabilitation: CBR Guidelines. Geneva, World Health Organization

[305] Karuna Foundation. (n.d.) Retrieved, 16 July 2019, from https://www.karunafoundation.nl/en/inspire2care-also-cost-effective-at-larger-scale/

PAKISTAN

Capital: Islamabad
Population: 193,203,000**
Rank in HDI: 150*
World Bank Income Classification: Lower middle#

GNI Per Capita (PPP): USD 5311*
Health Expenditure Per Capita (PPP): USD 134.4**
Life Expectancy at Birth (years): 66.6*
Population with disability (%): 2.1$

*UNDP: Human Development Reports 2018
**World Health Organisation 2016

World Bank 2019
$ Census of Pakistan 2017. Adapted from SEARO 2013. Calculations are the authors' own.

Taking cognizance of the International Year of Disabled People in 1981, Pakistan promulgated an Ordinance called the "Disabled Persons (Employment & Rehabilitation) Ordinance 1981. As per the Ordinance, it is the responsibility of the State to prevent disabilities, protect the rights of persons with disability, and provide medical care, education, training, employment and rehabilitation to these people.[306] Forums were convened to make the society aware of the rights persons with disability. In 1981, physical and mental disabilities were included for the first time in Census. Data were gathered on blind, deaf and dumb, crippled, mentally retarded, insane and 'other' handicapped. However, the accuracy of this data is questionable as reporting depended on the respondents' perceptions and judgement. The society did not permit talking about disability, particularly mental/intellectual disability and hence may negatively affect reporting of incidence of mental disability.[307]

But it was not until 2002 however, that a National Policy on Disability was articulated; the policy defines a person with disability as someone: "who, on account of injury, disease, or congenital deformity, is handicapped in undertaking any gainful profession or employment, and includes persons who are visually impaired, hearing impaired, and physically and mentally disabled".[308] However, this policy does not contain any reference to women with disability.[309] This was followed by a National Plan of Action in 2006 that identified 17 key steps to be taken to support the rights of persons with disability.[310]

Disabled Persons Organisations (DPOs) in Pakistan play a crucial role in sensitising the government and ensuring articles mentioned in the are implemented and there is a dignified space for persons with disability, particularly those with intellectual disability. Through regular forums and discussions, DPOs aim to create a right based, barrier free and inclusive society for persons with disability.

In Pakistan, responsibilities for provision of mental health care was moved from federal to provincial level in 2010 and the onus was on the provinces to pass appropriate legislations through their respective assemblies. As of now, only Sindh and Punjab have a mental health act in place.[311]

A draft bill on mental health pending approval from the National Assembly holds a ray of hope as it includes provisions for rightful living and appropriate services to persons with intellectual disability in the country.

Pakistan Bureau of Statistics reports disabled population by nature of disability. The last official count of persons with disability was in 1998. Disability data provided by the 1998 Census, groups data into seven categories – crippled; insane; mentally retarded; multiple disability, blind; deaf;

mute and others. According to the Census data, the Persons with Disabilities constituted 2.49% of the total population.[312] A country profile on disability undertaken by the Japan International Cooperation Agency in 2002 reports a distribution among categories of 40% physical disability; 20% visual impairment; 10% hearing impairment; 20% mental disability and 10% overlapping.[313]

In absence of clear definition of disability and various data sources, the estimates of persons with disability ranges from 3.3 million to 20 million, depending on whether it is a government source or surveys done by other agencies.[314]

Table 8: Disabled population by nature of Disability, Pakistan 1998[315]

Administrative Unit	Total disabled population	Blind %	Deaf/ Mute %	Crippled %	Insane %	Mentally Retarded %	Multiple disabilities %	Other %
Pakistan	3,286,630	8.06	7.43	18.93	6.39	7.60	8.23	43.37
Balochistan	146,421	8.42	5.24	14.81	4.60	5.61	6.35	54.96
Islamabad	8434	9.22	12.09	29.89	12.46	8.05	4.55	23.73
Khyber Pakhtunkhwa	375,752	7.24	7.69	31.73	5.90	7.43	8.11	31.90
Punjab	1,826,623	8.48	8.17	20.83	6.75	7.87	8.07	39.84
Sindh	929,400	7.48	6.18	10.56	6.13	7.45	8.92	53.29

Source: Government of Pakistan, Pakistan Bureau of Statistics. (1998). Census of Pakistan
Note: The terminology used is as per Census, 1998

As there are no fresh data available on the numbers of persons with disability, policies and programmes continue to use data from 1998 based on a total population of 132 million. In the 16 years since 1998, the population of Pakistan has grown to 186 million. The persons with disability are therefore at a great disadvantage as their numbers are just not recognised. In an attempt to address some of data collection issues, the government of Pakistan introduced a Special National Identity Card in 2009 that entitles persons with disability with modest travel discounts on state transport. By 2011, the National Database Registration Authority had reportedly registered over 600,000 people, of whom 334,000 had physical disability; 125,973 had intellectual disability; 85,254 had visual impairments and 93,869 had hearing or speech impairment. This was the first time when persons with disability were brought into the system but the numbers fall short as children who are very young and cannot apply for cards are not included.[316]

Stigma and Discrimination: Available literature does not provide information on the context of persons with intellectual and developmental disability. What is available describes the situation for persons with disability and clearly indicates the high levels of stigma and discrimination faced by those with any disability.

One can extrapolate the stigma to persons with intellectual and developmental disability. Low education levels and limited economic development results in persons with disability being hidden from the society, especially those with intellectual and developmental disability. There is also a belief that those with disability bring shame to the family and threaten the social status of the family.

In deeply conservative society, religion plays a role in further stigmatising a person who is born with or develops a disability. They are considered to be influenced by ‘extra-terrestrial’ forces or suffering from an affliction from God. The whole family is ashamed, there is a fear that they are being punished for some misdeed or are being tested on their faith.

This results in families keeping their children at home, locked up out of the eyes of the society.[317,318]

A qualitative study in Northern Pakistan conducted with parents of 19 families with children with Down syndrome highlights the ambivalence deep rooted in Pakistani society towards these children. They are either characterised as cursed or abnormal or as being closer to God. Concerns about these children varied depending on the age of the child. Common issues raised included the child's intellectual development, independence and care when the parents died. There was a great concern about sexuality once menstruation started in young girls and increased sexual awareness among boys. Parents were apprehensive about the safety of girls. Parents reported feeling stigmatised and isolated with limited support from extended family. Lack of knowledge and awareness about Down syndrome and related physical characteristics resulted in parents' anxiety about the future of their children.[319]

A cross sectional study in a tertiary care hospital with 198 parents of 100 children with intellectual disability aged 2-18 years assessed anxiety and depression in the parents. It found that mothers had higher anxiety, depression or both symptoms (89%) as compared to fathers (77%). Having a child with intellectual disability is fraught with challenges – physical and emotional crises, schedules that have to be organised around the life of the child, expenses creating financial burden on the families.[320]

Other studies have also highlighted the high levels of anxiety and depression among mothers of persons with intellectual and developmental disability. A study undertaken with 100 mothers of children with intellectual disabilities in Karachi, Pakistan reiterates the stress, anger, anxiety and depression of these mothers. The stress was caused by financial constraints, inappropriate behaviour of the child and lack of resources or facilities for these children. Family life gets affected because of anger, loneliness and depression among the mothers of children with intellectual and developmental disability.[321,322,323] In a patriarchal society like Pakistan, women have to bear the burden of taking care of persons or children with intellectual and developmental disability and face a range of social and economic challenges. The burden of managing a house, taking care of a child with intellectual disability and paid work results in stress and anxiety that may result in divorce or separation. Often, the female sibling of the child with intellectual and developmental disability is most affected as she is expected to stay out of school and provide emotional and physical care for the disabled sibling.[324]

Interestingly, a descriptive qualitative study undertaken with 54 mothers of children with mental retardation in a private day care centre Karachi, Pakistan shows quite different results. While there was an acceptance of disability as a result of fate and a sense of blame and stigma, mothers reported that caring for their child made positive contribution to their family life. There was a feeling of happiness and fulfilment while providing for their child with mental retardation and they reported a sense of self growth. The authors of the study caution that the families do face stress and challenges but it highlights that positive experiences contribute to building family resilience.[325]

Gender and marginalisation: Available evidence and studies refer to disabilities as a whole and no specific references were found that addressed gender and marginalisation of women and girls with intellectual and developmental disability. One can extrapolate the marginalisation to this cohort.

A woman who is disabled is treated differently from her male counterpart. Men have better opportunities for education or employment or marriage prospects while women are largely denied these and find it very difficult to find a marriage partner. There is a fear that children born to a woman with disability may also have disability or the other siblings may also face similar stigma which further compounds the situation.[326]

The focus on persons with disability is either charity or a medical approach to disability. There is a need to shift the approach to a rights based lens, recognising the diverse needs of this group and that they need to be empowered.[327]

Health: Available literature focuses on mental health and mental impairment related acts and legislations enacted by the government of Pakistan. Limited information is available on health outcomes of persons with intellectual and developmental disability.

As mentioned earlier, no reliable data post the 1998 Census exists. As found in other countries under review, persons with intellectual and developmental disability are often left out of the planning process and do not participate in decision making on new policies and programmes. Most of the policies as well as identification systems focus on persons with physical disability. World Health Organisation (2008) reports that with only 0.49 trained psychologists and psychiatrists per 100,000 in Pakistan, coming to the conclusion that there is a clear dearth of trained professionals in Pakistan.[328]

Health is the responsibility of the provinces which have the right to formulate laws, pass them in their constituencies and act upon them. The Mental Health Ordinance 2001 is therefore not in force in the provinces. Only the provinces of Sindh, Punjab and Khyber Pakhtunkhwa have a Mental Health Act in place.[329] Thus, despite the laws being in place, implementation is a big challenge in Pakistan. There is no recognised authority which the psychiatrists or families can approach in case of emergency. Additionally, there is a wide variation in services and treatment for mental disorders with families often resorting to physical containment as a method of treatment thus violating the basic human rights of persons with intellectual and developmental disability.[330]

Child psychiatric services are almost invisible in Pakistan with no formal systems of referral or diagnosis for children. For example, a diagnosis of autism in children requires multiple health professionals including family physician, paediatrician, psychiatrist, psychologist, neurologist and speech therapist.[331] A cross sectional survey with teachers in select private and public schools of Karachi to assess their knowledge and perceptions on autism indicated that 55% of teachers knew about autism mostly through media and just 9% were trained at workshops.[332]

A collaborative project between Pakistani and Swedish university institutions and the Swedish Agency for Research Cooperation with Developing Countries followed up all pregnancies registered in 4 different areas of Lahore between March 1984 and July 1986. Babies born to the mothers were followed up from the fifth month of pregnancy. The study findings report an overall incidence of birth defects of 5%; cumulative incidence of severe mental retardation per 100 live births at 1.1 and an overall prevalence of mental retardation among children aged 6-10 years as being 6.2 per 100.

Most common causes of mental retardation were poverty, malnutrition, birth trauma and consanguinity in Lahore.[333]

Prevalence of cerebral palsy was studied in district Swabi, Khyber Pakhtunkhwa through a study of children aged 4-10 years between February -June 2014. Of the total 278 children identified as having cerebral palsy, the most affected children were in the age group 9-10 years. The study estimated prevalence rate to be 1.22 per 1000 live births. Of the 278 children, 109 (39.2%) were severely affected; 112 (40.3%) were moderately affected and 57 (20.5%) were mildly affected. Spastic quadriplegia was reported by almost half the children.[334]

Parental involvement and its impact on developmental maturity among children with Down syndrome was assessed through a community based cross-sectional study in Khyber Pakhtunkhwa. The results found parental involvement to be an effective way to bring about emotional maturity in children with Down syndrome and enabled the child to cope with social activities and learning expectations from parents.[335]

Educational Attainment: The constitution of Pakistan denotes primary education as a fundamental right. However, this is not reflected in the implementation. For example, the Punjab Compulsory Primary Education Act of 1994 does not make any reference to the special needs of children with disability. However, the Sindh Right of Children for Free and Compulsory Education Act of 2013 does, and defines special education as “educational programmes and practices designed for students, as handicapped or gifted students, whose mental ability, physical ability, emotional functioning, require special teaching approaches, equipment, or care within or outside a regular classroom”. Although progressive, this is not incorporated in the statute and hence does not have any relevance.[336]

According to a 2002 report by Japan International Cooperation Agency (JICA), there are 46 special education centres set up by the Directorate General of Special Education of which 12 are for children with intellectual disabilities; 12 for those with hearing disabilities; and 11 each for persons with visual impairment and physical disability.[337] A study conducted with 19 school administrators from 6 major cities in Pakistan assessed the levels of satisfaction about the facilities available for children with autism. The findings reiterate the lack of professionally trained staff, no exposure to foreign training for staff, and lack of healthcare professionals at school. Additionally, the buildings or furniture was also not found to be appropriate for children with autism.[338]

Economic participation and Poverty: The available literature focuses on employment and economic participation of persons with disability as a whole group. Little disaggregated information on the situation of persons with intellectual and developmental disabilities is available.

Stigma and negative attitudes towards persons with disability creates major barriers to persons with disability getting employment. Even if this stigma is overcome, infrastructure barriers and the lack of sign language are challenges in those with physical, hearing and visual impairment. For those with intellectual and developmental disability the situation is worse, as there is no educational or rehabilitation services specific to their needs, making employability a distant dream.[339]

With limited education opportunities or vocational skills training, the link between poverty and disability can be broken only by providing opportunities to this cohort of people. Limited employment opportunities arise from limited access to education and resultant limited skills for the labour market; limited support for job seekers; attitude of employers.[340]

The National Training Centre for the Disabled is responsible for providing specialized skill training, vocational training and rehabilitative services to persons with disability. They are also responsible for finding suitable jobs for the trainees.[341]

According to a 2002 report by Japan International Cooperation Agency (JICA), there was only one vocational training centre for women in Darakhshan where women with visual, physical and light intellectual disabilities are taught daily routine skills, income generating skills, mobility skills, adult and religious education for half a year.[342] The number of vocational training institutes, run by the government or by NGOs are not enough to cover the needs of persons with disability.[343]

Assistive devices: There is limited literature available on assistive devices available for persons with intellectual and developmental disability. A report by United Nations indicates that the government does not impose duties or taxes on motorized wheelchairs and special vehicles. Pakistan produces all prosthetic and orthotic devices indigenously and is able to meet the "official" demand for these devices. However, many persons with disability, especially in rural areas, have not been identified and are unaccounted for in the "official" demand.[344] Hearing aids, aids for visual correction, white canes, braces, corrective boots and crutches are available free-of-charge for students enrolled in the national or provincial special education centres.[345]

A newspaper article by Dawn reports a pilot project undertaken by Pakistan Bait-ul-Mal (PBM) and the WHO to provide assistive devices to people with disability. The project will be conducted in 12 districts across the country and later will cover the whole country. Under the project, 10,000 individuals with disability will be provided with 25 most prioritized assistive devices free of cost starting with providing wheelchair, white cane and hearing aid. The article indicated that there is limited information on availability and affordability of assistive devices and few institutions that offer degree or diploma courses for training in related disciplines.[346]

KEY TAKEAWAYS

- Pakistan was the first in the region to address disability, albeit through an Ordinance in 1981. But a National Policy on Disability was only put in place in 2002.
- Prevalence of disability varies widely between agencies ranging from 3.3 – 20 million. Data has not been updated since 1998 when the disability rate was found to be 2.49%
- High levels of stigma and discrimination are faced by those with any disability and can be extrapolated to persons with intellectual and developmental disability. Common beliefs are that disability bring shame to the family.
- A Special National Identity Card offering a modest travel discount has received a robust response with 600,000 persons applying.
- Primary education is a fundamental right of children, but education policy does not promote mainstreaming of children with disability. The Directorate General of Special Education has set up 12 special centres in the country for children with intellectual disabilities.

- Limited information is available on health outcomes.
- Stigma and negative attitudes towards persons with disability prevents those with intellectual and developmental disability with gaining employment.

GOOD PRACTICE CASE STUDY

Milestone Society for the Special Persons
Lahore, Pakistan

Shafiq-ur-Rahman, President **www.milestone.pk**

Recognising the need to provide services to persons with intellectual and developmental disability, Milestone Society for the Special Persons was established in March 1993. It provides a platform to improve the overall quality of life of the special persons regardless of their gender, religion, social and economic status.[347]

Milestone provides independent living to persons with disability in general and to the persons with severe disabilities in particular. It focuses mainly on independent living by training persons with disability in self-management skills, education, creating a barrier free society, awareness raising, capacity building, provision of basic facilities and 'normalizing' persons with disability to become an integral member of society. Milestone provides a platform to improve the overall quality of life of special persons regardless of their gender, creed, social and economic status. Milestone provides counselling to parents/ caregivers about working with persons with disability, encourages them to treat their children as equal to their 'non-disabled' children and not discriminate against them.[348]

A unique activity is that of providing personal assistant services to persons with severe disabilities at their homes. Peer counselling is an integral part of the programme aimed at encouraging and empowering persons with disability. It also provides equipment like wheel chair, catheters, and white canes. Milestone has established a wheelchair making unit where customized wheelchairs are manufactured for persons with disability.[349]

Advocacy efforts include dialogue with the government to introduce/ draft right based policies for persons with disability, promoting accessibility in public places and educating concerned departments, promoting accessible transportation for person with disability and reserved accessible public parks for disabled persons in Lahore city.[350]

An assessment of the programme reported that many persons with disability could manage their life independently, and they have started using personal attendant service to carry out their daily activities. The assessment also reported that persons with disability have started working, enrolled in colleges and universities and are confident about going to markets and buying household for their families by themselves. They are more visible and are heard by the society.

The provision of independent living self-management skills trainings and provision of wheelchairs have helped provide independence to persons with disability. A scalable replicable model that requires support.

GOOD PRACTICE CASE STUDY

Rising Sun Education and Welfare Society
Lahore, Pakistan

Parveen Tawaab, President **www.risingsun.org.pk**

Acknowledging the need to work intensively with persons with intellectual and developmental disabilities, the Rising Sun Education and Welfare Society was established in 1984. The aim of the organisation is to make special children confident and self-reliant members of the society through education and training to enhance children's capabilities and enable them participate in the life of the society.[351]

A distinctive characteristic of Rising Sun Education and Welfare Society is the emphasis on physical activities through indoor and outdoor sports using sports training as a way to enhance the capabilities of intellectually disabled children.[352] Several students have been selected international sporting events - 8 of the 19 children selected for Special Olympics from Pakistan in 2013 were from the organisation.[353] Students have brought back 91 medals (33 Gold, 33 Silver and 25 Bronze medals) in various International games held around the world.[354]

Rising Sun has developed a successful sheltered employment project named 'Special Chef'. This project was initiated with one cooking teacher and three semi-trained students with special needs. After a period of two years, the team has increased to 13. Initially they delivered ready products to their own school canteen but have since diversified their clientele. Members earn according to their share in the work. Many students have been placed in various organizations, and some have started their own businesses. They now support their families and are no longer seen as a burden.[355]

Challenges faced include irregular attendance because of health issues. Discrimination is deep rooted in the society and parents are reluctant to bring their special children to the Institute. However, the meetings and workshops with parents to create awareness and provide guidance to the parents are slowly but steadily ensuring equal treatment of these children.

The initiatives of the Sun Education and Welfare society, particularly the focus on sports training is effective. Their programmes are replicable and scalable and greatly relevant in the context of Pakistani society.

End Notes

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[306] Ahmed, M. et al. (2011). Policies for Special Persons in Pakistan Analysis of Policy Implementation. Berkeley Journal of Social Sciences Vol. 1, No. 2

[307] Ahmed, T. (1993). Disabled Population in Pakistan: Disabled Statistics of Neglected People. Sustainable Development Policy Institute

[308] Ahmed, M. et al. 2011. Policies for Special Persons in Pakistan Analysis of Policy Implementation. Berkeley Journal of Social Sciences Vol. 1, No. 2

[309] The Economist. (2014). Moving from the margins Mainstreaming persons with disabilities in Pakistan. Te British Council

[310] The Economist. (2014). Moving from the margins Mainstreaming persons with disabilities in Pakistan. Te British Council

[311] Tareen, A. (2016). The mental health law in Pakistan. BJPsych International.

[312] Ahmed, M. et al. (2011). Policies for Special Persons in Pakistan Analysis of Policy Implementation. Berkeley Journal of Social Sciences Vol. 1, No. 2

[313] Oracle Research & Information Services. (n.d.). Country Profile Study on Persons with Disabilities. (n.p.)

[314] The Economist. (2014). Moving from the margins Mainstreaming persons with disabilities in Pakistan. Te British Council

[315] Government of Pakistan. (n.d.). Disabled Population by Nature Of Disability. Retrieved, 29 March 2019, from http://www.pbs.gov.pk/content/disabled-population-nature-disability

[316] The Economist. (2014). Moving from the margins Mainstreaming persons with disabilities in Pakistan. Te British Council

[317] Ahmed, T. (1993). W13-Disabled Population in Pakistan Disabled Population in Pakistan: Disabled Statistics of Neglected People. (n.p.)

[318] The Economist. (2014). Moving from the margins Mainstreaming persons with disabilities in Pakistan. Te British Council

[319] Ahmed, M. et al. (2012) Experiences of parents with a child with Down syndrome in Pakistan and their views on termination of pregnancy. J Can Acad Child Adolesc Psychiatry

[320] Azeem, M. et al (2013). Anxiety and Depression among Parents of Children with Intellectual Disability in Pakistan. J Can Acad Child Adolesc Psychiatry

[321] Sajjad, S. (2011). Stress Faced by Pakistani Mothers of Children with Intellectual Disabilities and its Impact on Their Family Life. Journal of the International Association of Special Education

[322] Malik, A. et al (2016). Depression in Mothers of Children with Mental Retardation Reporting at Tertiary Care Hospital

[323] Kumar, R., Lakhiar, M., Lakhair, M. (2016). Frequency and Severity of Depression in Mothers of Cerebral Palsy Children. J Liaquat Uni Med Health Sci

[324] Ahmed, A., Sanauddin, N. (2016). Patriarchy in Family Care-Giving: Experiences of families of children with intellectual disability in Pakistan. Journal of Post Graduate Medical Institute

[325] Lakhani, A. (2014). The impact of caring for children with mental retardation on families as perceived by mothers in Karachi, Pakistan. J Pak Med Assoc

[326] The Economist. (2014). Moving from the margins Mainstreaming persons with disabilities in Pakistan. Te British Council

[327] The Economist. (2014). Moving from the margins Mainstreaming persons with disabilities in Pakistan. Te British Council

[328] The Economist. (2014). Moving from the margins Mainstreaming persons with disabilities in Pakistan. Te British Council

[329] Tareen, A. (2016). The mental health law in Pakistan. BJPsych International.

[330] Tareen, A. (2016). The mental health law in Pakistan. BJPsych International

[331] Imran, N. et al. (2011). A survey of Autism knowledge and attitudes among the healthcare professionals in Lahore, Pakistan. BMC Pediatrics

[332] Arif, M. et al. (2013). Awareness of Autism in Primary School Teachers. Autism Research and Treatment

[333] Gustavson, K. (2005). Prevalence and aetiology of congenital birth defects, infant mortality and mental retardation in Lahore, Pakistan: A prospective cohort study. Acta Paediatr

[334] Ahmad, A., Akhtar, N., Ali, H. (2017). Prevalence of cerebral palsy in children of district Swabi, Khyber Pakhtunwa, Pakistan. Khyber Medical University General

[335] Haider, S., Khan, S. (2015). Positive Effects of Parental Involvement On Down's Syndrome Children In KPK. Isra Medical Journal

[336] The Economist. (2014). Moving from the margins Mainstreaming persons with disabilities in Pakistan. Te British Council

[337] Japan International Cooperation Agency Planning and Evaluation Department. (2002). Country Profile on Disability-Islamic Republic of Pakistan. (n.p.)

[338] Fazil, H., Sulman, N. (2014). Perceptions of School Administrators about Facilities Available in Schools for Children with Autism in Pakistan. Academic Research International Vol. 5(4)

[339] The Economist. (2014). Moving from the margins Mainstreaming persons with disabilities in Pakistan. Te British Council

[340] The Economist. (2014). Moving from the margins Mainstreaming persons with disabilities in Pakistan. Te British Council

[341] United Nations. (1999). Asian and Pacific Decade of Disabled Persons: Mid-Point - Country Perspectives.

[342] Japan International Cooperation Agency Planning and Evaluation Department. (2002). Country Profile on Disability-Islamic Republic of Pakistan. (n.p.)

[343] The Economist. (2014). Moving from the margins Mainstreaming persons with disabilities in Pakistan. Te British Council

[344] United Nations. (n.d.). Production and Distribution of Assistive Devices for People with Disabilities.

[345] Japan International Cooperation Agency Planning and Evaluation Department. (2002). Country Profile on Disability-Islamic Republic of Pakistan. (n.p.)

---

[346] Junaidi. I. (2019). Dawn. Persons with disabilities to receive assistive devices for free. Retrieved, 26 July 2019, from https://www.dawn.com/news/1460224.

[347] Milestone. (n.d.). Retrieved, 20 July 2019, from, http://www.milestone.pk/User/AboutUs

[348] Milestone. (n.d.). Retrieved, 20 July 2019, from, http://www.milestone.pk/User/Projects

[349] Special Talent Exchange Program. (n.d.). Retrieved, 23 July 2019, from http://www.step.org.pk

[350] Rahman, S. (21 July 2019) Personal Interview

[351] Rising Sun Education and Welfare Society. (2017). Annual Report. Retrieved from Annual Report 2017

[352] Global Giving. (n.d). Project Proposal: Sports Kits for Special Children. Retrieved from https://www.globalgiving.org/projects/rising-sun-institute/

[353] Gloabl Giving. (n.d). Project Proposal: Sports Kits for Special Children. Retrieved from https://www.globalgiving.org/projects/rising-sun-institute/

[354] Rising Sun Education and Welfare Society. (2017). Annual Report. Retrieved from Annual Report 2017

[355] Special Chef. (n.d.) Retrieved, 25 July 2019, from https://www.risingsun.org.pk/special-chef/

THE WAY FORWARD

This literature review has focused on understanding the situation of persons with intellectual and developmental disabilities in six countries, namely, Afghanistan, Bangladesh, India, Myanmar, Nepal and Pakistan, and the policies and programmes in place in each of the countries.

The review indicates that literature on intellectual and developmental disability is scant. The available evidence is from larger studies encompassing disability in its wider sense, covering both physical (sensorimotor) and intellectual and developmental disability. Available on intellectual and developmental disability are small-scale studies, focusing mainly on the prevalence and incidence of one or the other condition, and rarely discussing intellectual and developmental disability as a whole.

In the six countries under review, one of the major challenges is estimating the prevalence and incidence of intellectual and developmental disabilities. The definition, quality and methods of data collection, rigour of sources and disclosure rates affect the calculation of prevalence and incidence of disability. The data are also skewed because of underreporting and stigma as well as lack of uniform method of data collection in the region. The training of those conducting surveys has been questioned, as has their understanding of disability and how to elicit information from families and individuals on persons with intellectual and developmental disability. This is a population that is largely hidden and not talked about when enumerators come to the household for data collection. Studies from India highlight this aspect.

A key issue is that there does not appear to be any commonly understood definition of intellectual and developmental disability. A variety of approaches have been used to come to grips with important notions relating to disability in the various countries. Survey categories range from ‘difficulty in remembering’ in one country to ‘mental illness’ or ‘insanity’ in another. Thus, being able to collate or compare data is difficult and making sense of the data for the region as a whole, is near impossible. Consequently, the data is patchy, and a complete picture does not emerge in any of the countries under review, nor indeed from the countries taken together as a geographical or cultural unit. Myanmar is a clear example of this situation. In Afghanistan, evidence suggests that there is an urgent need to capture the prevalence of people with intellectual and developmental disability. In Bangladesh, there is no uniform method of measuring the incidence and prevalence disability. This makes it difficult to arrive at a rate of disability prevalence in the country. Additionally, underreporting on intellectual and developmental disabilities further muddies the data and consequently, estimates of the prevalence in the country. The review has thus highlighted the lack of information on the situation and context of the lives of people with intellectual and developmental disabilities.

The context of the countries varies considerably. In Afghanistan, where a war has been in progress for over two decades, the focus is (understandably) on physical disability caused by war. But that has meant that other causes of disability have been pushed to the sidelines and little data could be accessed for intellectual and developmental disability in the country. Added to this is the simple preponderance of sensorimotor (physical) causes of disability. Sensorimotor causes of disability can overshadow intellectual and developmental disability simply by sheer numbers – the ratio of prevalence is to the tune of ten is to one. In Bangladesh, the focus of most of government programmes is on physical, visual and hearing impairments. Interventions for people with intellectual and development challenges are few and those that are available are run by national or international NGOs with support from donor agencies or development partners. On the other hand, Nepal has disability promoting policies and programmes in place for persons with intellectual and developmental disability. However, there are gaps in translating these to action.

It was noted that the various countries often showed a greater volume of information on a particular condition. So, in Bangladesh and Nepal, there is much more information on cerebral palsy than on other causes of intellectual and developmental disability, while in India, much of published data focuses on autism. Intellectual disability is not sufficiently recognised as a condition in its own right and demanding attention due to its own importance. It is more often than not, treated as an associated condition of other conditions, such as Down syndrome, autism or cerebral palsy.

Evidence on stigma and discrimination faced by persons with intellectual and developmental disabilities is not available in all six countries. This reinforces the 'hidden' nature of this population where the parents/caregivers are not willing to talk about the challenges they face and/ or have minimal expectations from the government in terms of social security or employment opportunities. Stigma and discrimination often results in persons with intellectual and developmental disability not utilising public spaces and events to the same degree as their peers. This has consequences for research, both in terms of design and methodology as well as in terms of training of researchers.

Myths around the causes of intellectual and developmental disabilities compound their condition and make programmatic responses even more difficult. In all six countries, intellectual and developmental disabilities are attributed to either God or the past sins of parents/ child to being tested by God for 'strength'. Not only does this influence treatment seeking behaviour but also it also negatively impacts them by making them 'invisible'. They are kept under lock and key or not allowed to go out to socialise removes them as a member of the society or the community they live in. The six countries under review do mention programmes aimed at making this population a part of mainstream society, but these are at small scale and fraught with challenges.

An important intersectionality highlighted by the data is that with gender. Being a girl/ woman with intellectual and developmental disability makes them more vulnerable as compared to their male counterparts. Review of literature from all six countries reiterated the gender-based violence against these girls/ women and the sexual abuse and rape experienced by them either at home or at the institutions they have been placed at. Anecdotal reports of forced hysterectomies were reviewed in Bangladesh, India and Nepal. Girls/ women are at the mercy of their parents/ caretakers and do not have any recourse to seek justice or asylum. Evidence pointing towards abuse and mental torture experienced by boys/ men is also available. Thus, the gender matters, but it appears that both male and female with intellectual and developmental disabilities are vulnerable and at risk.

Access to health services is limited and almost negligible. There is a huge gap in number of specialists needed and the numbers that are available. What this translates into is that persons with intellectual and developmental disabilities are neither diagnosed correctly nor do not get required treatment because they are not able to verbalise their needs because of their disability. Poor awareness of intellectual and developmental disabilities among healthcare providers at all levels of services as well as government bureaucrats there appears to be an overall apathy to the situation of people in this cohort. Parents are also at a loss because they do not know where to take them for diagnosis or treatment.

There is gross shortage of trained (medical, educational and rehabilitation) personnel who can support the special needs of those with intellectual and developmental disability. Insofar as community-based rehabilitation is concerned, and which may well be an important approach to disability care as numbers swell, the community health worker is the first point of contact with the health system. But she is not equipped to address the needs of this segment of the population and their needs go largely unmet. If trained to identify learning or other disabilities, educate families and provide support through referrals to appropriate agencies.

Bangladesh typifies the situation across the region. Diagnostic and referral services are not in place. Doctors and physicians do not know where to send parents of children with intellectual and developmental disability. In Nepal, there are not enough professionals trained to diagnose types of intellectual and developmental disability. Most of the services are located in urban towns and cities. Distance and high transport costs prevent parents from taking their children for any diagnostic and treatment services.

Education opportunities are limited for children with intellectual and developmental disabilities. To begin with, since early diagnosis is a challenge, children are often sent to a mainstream school and then removed because s/he cannot cope with the regular schooling. In instances where special schools are available, teachers are not often equipped to deal with the special needs of the children. Special schools remain out of reach for a large majority of the population in the six countries under review. Most of these facilities are located in urban areas and are unaffordable because of the high fees, transport costs and time cost to bring the child to the special school. There are simply not enough special schools and teachers to cater to the needs of these children thus preventing them an opportunity for basic education or training that would help them gain some employment or income generating activities in the future.

Linked to this is the finding that there is also little literature on inclusion and mainstreaming along the life cycle of those challenged by intellectual and developmental disabilities. In Pakistan, the status of education among those with intellectual and developmental disability is poor as it is in much of the region. Special schools are largely private with high and often unaffordable fees. This is the situation in many parts of India as well; with the result that educational attainment of persons with intellectual and developmental disability is low; far fewer than 10% reach graduation level in the case of India. It is critical to put in place inclusive education within the reach of people, especially those with intellectual and developmental disabilities.

The direct link between education and poverty is well established. Lack of education denies people with intellectual and developmental disabilities with the opportunities to participate in economic activities and opportunity to earn, resulting in dependency on others throughout their lives. These data suggest the need for both skilling up persons with these challenges, as well providing suitable employment options. Even though all countries have stipulated reservation in jobs for persons with disability, this largely remains on paper. Those with intellectual and developmental disability are at a greater disadvantage, as their situation is different from those with sensory-motor disabilities. While the latter group may have more chances of being integrated, the former needs special provisions and an ability to understand their unique needs.

The focus of programmes in Nepal, including those focusing on employment opportunities, are for those with physical, visual or auditory impairments. Persons with intellectual and developmental disability are not part of any programme, be it vocational training or employment recruitment. Nepal is a prime example, where the link between poverty and disability works to exacerbate the already stressful and tenuous condition of this group of people. In Pakistan too, there are almost no opportunities for employment or economic participation for persons with intellectual and developmental disabilities. There is a need to build an ecosystem that would provide vocational training and appropriate opportunities for this cohort.

It is clear that even though all six countries under review are signatories to various international treaties, including the 2030 Development Agenda that ensures non-discrimination and inclusion of persons with disability in development programmes, the reality is far from this. Persons with disability, particularly, intellectual and developmental disabilities, continue to face challenges in being included in the society to be able to participate and contribute to the country’s development.

Social security remains a cause of concern among persons with intellectual and developmental disability. Those who are either not able to verbalise their needs and desires because of their disability or due to other reasons of marginalisation that are piled on top of the disability are especially at risk of being excluded or worse, penalised. This is worsened because of poor awareness of intellectual and developmental disability among government officials, and their overall apathy to the situation of those with these conditions.

In Nepal, persons with intellectual and developmental disabilities are often excluded from social security benefits they are entitled to through issuance of disability cards. Government officials who have been tasked with assessing disabilities do not understand what does intellectual and developmental disability mean, how is it caused, how does it impact the lives of these people. Further, certain types of disabilities are not well understood including psychosocial impairments, moderate forms of intellectual impairments which may lead to incorrect categorisation of people and deny them the benefits of social security they are entitled to. Parents and caregivers are not aware of the categorisation of disability cards and they may not get the colour of card they need or should be eligible for, because there is a lack of understanding about the assessment criteria among the officials.

The notion of rehabilitation, particularly in respect of community approaches to rehabilitation has remained squarely on sensorimotor aspects of disability. Much of this relates to use of assistive devices that can extend the range of abilities that a person with disability has. While many persons with intellectual and developmental disability could benefit from this, training to use assistive devices successfully would need to be tailored to their learning style and pace. Access can also be significantly affected by the topography and situation of a country.

For example, in Afghanistan, access to rural areas is a challenge and as the roads are not no longer paved, reach of programmes to rural areas is wholly limited. In India, information technology-based innovation is bringing assistive technology to the support of those with autism. In Pakistan, the same situation is highlighted. Recently, Community Based Inclusive Development network which connects organisations of people with disability on one platform and works with provincial and national governments to implement the Convention of the Rights of Persons with Disability has been formed. However, with their focus largely on providing assistive devices, there is limited work being done for persons with intellectual and developmental disability

That said, it must be acknowledged that all the countries included in this review have made efforts to collect data on disability, including intellectual and developmental disability, and attempts have been made to respond to the principal needs in the disability space in each country. It may be noted that each country has standalone legislation on disability. But the literature is equally aware that legislation is a long way from effective implementation in every country that is part of this review.

All in all, the situation of those with intellectual and developmental disability in the countries of the region is depressing. Their numbers are not accurately available and what numbers are available, are certainly short of the actual prevalence. Diagnosis and intervention are a distant dream for caregivers and their wards especially outside urban centres, albeit that the situation in urban centres is in itself grim. Both girls and boys face their own challenges in finding a place in society that accepts their special needs and is responsive to their requirements. Myths and mistaken beliefs about the causes and therapy for these disabilities means that the general public may not be aware of the needs of these persons, nor have a positive and supporting attitude to their requirements. Parents and caregivers of these children thus face great hardship not only because of lack of professional support, but also due to ill treatment and exclusion at the hands of their families and communities. The special schools that are available are for the most part run by national and international non governmental organisation to make up for the lack of satisfactory government services. Rehabilitation services are lacking and much of their focus is on providing assistive devices which while useful to this group, are not sufficient to enable their full participation in society. Preparing young adults with intellectual and developmental disability for employment is near absent, nor is there enough awareness and empathy in the general community for there to be a near adequate response to their employment. The absence of reasonable livelihood options is compounded by the scant social security systems in place for persons with intellectual and developmental disability.

There is an urgent need to address the issues and plan approaches to work with persons with intellectual and developmental disabilities. Actions can be taken by the state, the families and the society at large. As citizens of countries, persons with intellectual and developmental disability should enjoy the same privileges and rights that are available to others.

Given below are some suggestions and thoughts on way forward:

Discrimination and security are core issues faced by persons with intellectual and developmental disability. There is widespread ignorance of the issues that they face as well as their special needs in respect of mobility, communication and social interaction. They are often at the receiving end of physical and sexual violence.

1. Address discrimination and stigma: Two actions can be considered to uphold the dignity of persons with such challenges: (i) building support for an Anti-Discrimination Law; and (ii)

encouraging a 'watchdog' function by every member of society so that all incidents of discrimination are identified and reported. In particular, an awareness generation programme on identifying cases/instances of abuse and reporting to appropriate authorities can be encouraged at the community and school level.

2. Provide social security and safety net: The onus of providing social security for persons with disability is on the government. There is a need for greater attention to inadequate and almost non-existent social protection of those with disability. Where available, the beneficiaries do not get the benefits, either because they are unable to access them or are not aware of the schemes. The quality of services provided at residential institutions for persons with intellectual and developmental disabilities needs to be improved to ensure that they are not victims of abuse or violence in any form. There is an urgent need to strengthen rehabilitation services and implementation of laws that protect the rights of persons with disability, particularly those with intellectual and developmental disabilities. At the health facility level, training of doctors and nurses to deal sensitively with reported cases of abuse is needed.

3. Educate persons with intellectual and developmental disabilities about sexual abuse: A critical need is to ensure that persons with intellectual and developmental disability are aware of what they should do if they face sexual and physical abuse or violence. This can be done in a language and manner that they feel comfortable in and understand easily. This is not a one-time conversation but needs to be repeated so that it is understood by them. Again, the conversation should not be limited to females. Men and boys are as much at risk and hence should be made aware of what can happen to them as far as violence or sexual abuse is concerned.

4. Provide safe public spaces: Creating friendly physical infrastructure will go a long way in ensuring equal participation of persons with intellectual and developmental disabilities. Roads, health facilities, schools and colleges, offices, etc. need to be made user-friendly including through creation of ramps, toilets etc. Further, not only is it necessary to ensure that persons with disability can have the physical infrastructure for their ordinary needs, but it is also important to ensure that public spaces meant for recreation and entertainment allow the participation of those with such challenges. It is critical to ensure that the right to entry and right to use of public facilities of persons with intellectual and developmental disability is safeguarded.

Social security safeguards, which are at the core of the enabling actions that increase mainstreaming of persons with disability, must be made available to every person with intellectual and developmental disability. This calls for progressive policy decisions by the government within the ambit of existing programmes.

5. Provide identity cards to all to make access to specialised care possible: Most countries in the study report that while available, most persons with intellectual and developmental disability have difficulty in obtaining an identity document that is the gateway to government entitlements for which they are eligible.

Not only must such a provision be available, but also simplified procedures to obtain this identity documentation must be put in place. Further, the documentation must not only be an end in itself but must automatically ensure that entitlements due to the person are unlocked without additional actions being undertaken.

6. Ensure appropriate healthcare services for those with intellectual and developmental disability: At the individual level, early diagnosis is an option that needs to be addressed by training healthcare providers who provide basic services to children in their homes. Information materials such as directories or pamphlets on local services would help to ensure that health professionals and community workers have information on screening and early intervention programmes in their area for referral. Training of service providers, nurses, healthcare workers could be provided through specialised module during their pre-service training or as an additional in-service training during their employment. Most of the services are located at urban level; but even in urban situations, there is a general lack of appreciation for the difficulties that children with challenges and their parents/ caregivers face.

   Further, there is a need to ensure that the poorest and most marginalised who live in rural and difficult to access areas receive services close to their homes. Providing training to healthcare worker at the village level and at the facility level may improve the quality of advice and support that they can provide to the families. They would be in a position to guide the family about where to go for diagnosis and treatment. In addition, there is a need to train doctors also since they are also not necessarily aware about different types of intellectual and developmental disability.

7. Provide inclusive education: There is a need to train teachers at school to identify children with intellectual and developmental disabilities as well as train them in behaviour and classroom management techniques. Teachers often feel ill-equipped to deal with children with disability. In particular, there is a need to train special education teachers who can use a child centred approach by being creative. This could be done either at current teachers' training courses or be a part of in-service training.

8. Provide incentives to employers that employ persons with disability: This is found in the law of several of the six countries that are reviewed in this report. However, while this is available in the law, in fact few persons with intellectual and developmental disability find work and are often seen as being a burden on families. This means that the cycle of discrimination goes endlessly on. Employers of persons with intellectual and developmental disability could be offered incentives to accustom the private sector to the value that this population brings to the workforce.

Persons with intellectual and developmental disability are not only excluded by people who do not understand them, but also by those who are their caregivers and well-wishers. Their caretakers often underestimate their ability to assess and express their own needs. This is compounded by the failure to build institutions that can support their aspirations.

9. Include persons with intellectual and developmental disabilities in committees: If the needs of this population are to be represented and included in national and state level policies and

programmes, it is imperative that their views are taken on board. This could be when discussing disaster risk reduction and management processes or education or employment opportunities. Persons with disability should not be viewed as passive receivers of 'charity'; rather they must be seen to be active participants in their own progress. They have a voice and right to be heard and their contributions would go a long way in making actionable plans.

10. Create support groups for parents/caregivers: Support groups play a crucial role in helping parents/ caregivers deal with anxiety, depression and physical and emotional stress of taking care of persons with intellectual and developmental disability. These groups provide peer support, counselling and if needed direct psychological intervention with the parents/ caregivers. By supporting caregivers in this way, these groups also make exchange of ideas and experiences possible.

11. Support civil society organisations: Civil society organisations play a key role in providing care and opportunities to enable persons with intellectual and developmental disabilities to play a role in the society. They can organise awareness raising programmes and promote inclusion of children at school and adults at workplace. Working with organisations for persons with intellectual and developmental disability, NGOs can build a network that would facilitate cross learning and encourage community-based rehabilitation. Persons with challenges need sustained efforts for vocational training and linkages with employment opportunities. Conversely, employers and co-workers need help in understanding the special needs of this cohort of people which the NGOs can provide and guide the employers on how to deal with them.

12. Build awareness at community level: Stigma and discrimination is reduced when more people become aware of intellectual and developmental disabilities. This could be done in a variety of ways. At the family level, health promotion intervention information could be provided during routine child care services at a hospital or at schools. Once diagnosed, parents could be offered individualised counselling and support, if needed and guidance on where to go for specialised help. At the community level, awareness could be promoted through special needs counsellors who organise informal meetings with the community members to inform them about the causes of intellectual and developmental disability in a simple, easy to understand language. A (government supported) website can be used to share information with the public on the different types of intellectual and developmental disabilities, where can one go to seek help, who the qualified service providers in their area are, what are government social security schemes or benefits available to them, and so on.

13. Build the support of society at large: By drawing upon well-wishers in secondary groups of the parents/ caregivers, a wider community of those well-disposed to persons with intellectual and developmental disability can be created. Formal institutional mechanisms such as workplaces, clubs, organizations, media and religious places can be galvanised to address the discrimination and marginalisation experienced by persons with intellectual and developmental disability.

    The medals won by persons with challenges at international sporting events from the region as in Pakistan and India, often outnumber those won by mainstream sportspersons. Media, including print and social media can be used to build support. Movies have a great deal of influence on society's perceptions in the region. Several in India have already cleared the space for greater discussion. By holding events that celebrate the small and big accomplishments of those with intellectual and developmental disability and continuing to participate in the everyday life of communities, the walls of ignorance can gradually be worn down.

14. Increase the availability of quality data: There is a need to standardize the definition of intellectual and developmental disabilities to facilitate availability of data that are comparable. The ICF (2001) provides an understanding of disability as a mismatch between a person's health condition and personal and environmental factors as mediated by body structure and function, activities and participation. Persons with intellectual and developmental disability should thus be viewed as potential participants in every aspect of the community of fellows.

    The Washington Group on Disability Statistics aims to provide basic information that is comparable through the world through a set of short questions to be used in a country's censuses and surveys. The stigma behind intellectual and developmental disability is a fundamental reason for underreporting. It is imperative to work with data enumerators and build their understanding of disability and how to elicit information sensitively. Capacity building is also needed at the level of those who analyse, disseminate and use the data for programmes and policy level interventions. There is also need to undertake research on the exclusion of persons with disability so that policy and programming can be informed by their situation.

15. Ensure inter-departmental and inter-ministerial collaboration: There is a need to have on-going dialogue between different ministries and departments that deal with persons with intellectual and developmental disability. It is not one portfolio that is responsible for the welfare of this group. For example, education needs are looked at by education ministry but if they need to revamp a school building and make it disabled friendly, then another ministry needs to be a part of the dialogue. There needs to be a formal and continuous ways of talking, coordination and working in partnership if the programmes are to be implemented successfully. This can be done by sensitising and raising awareness about the needs of persons with disability.

To conclude, the way forward is to work with persons with intellectual and developmental disabilities in ensuring that they get their rights, are socially included and empowered to live a meaningful and full life.

ANNEXURE I

Following themes and key words have been identified for the literature review:

Health	Education	Economic Participation	Poverty	Stigma and Discrimination	Intersectionality with other causes of marginalisation	Dependency and Restricted Participation
Status	Status	Status	Status	Status	Status	Status
Services	Services	Livelihoods	Causes	Vulnerability	Gender	Community based Rehabilitation
Access	Access	Workforce	Income	Gullibility	Female	Community Structures
Eye problems	Achievement	Employment	Socio-Economic Status	Abuse	Women	Public Spaces
Heart problems	Inclusive Education	Inclusive Workplaces	Equality	Violence	Girls	Rights
Psychosocial problems	Teacher Training	Sheltered Workshops	Equity	Inclusion	Caste	Entitlements
Mobility	Special Needs	Supported Employment		Discrimination	Indigent	Assistive Devices
Lifespan	Colleges	Self-Employment		Prejudice	Equity	Enabling Infrastructure
Nutrition	Vocational Training			Stereotype	Immigrants	
Rehabilitation	Skills Development				Religion	
DALY	Capacity Building				Language	
QUALY	Financial Inclusion					