

# Unaware, Untapped and Under-served

Study Report of the situation of

Persons with Disabilities in North East India

To understand needs and gaps in services and the realisation of rights

(2020 – 2021)



Prepared by:



**Centre For Rehabilitation and Training For Multiple Disability**  
Birubari, Guwahati - 781016, Kamrup (Metro), Assam

Supported by:

**Paul Hamlyn Foundation**

## Acknowledgement

As we write this report of our study of the disability scenario in NE India, we would like to thank everyone who supported us in different capacities in planning and carrying out the study and getting an understanding of the ground realities in the disability sector in the region and in writing up the report.

We gratefully acknowledge the involvement and support of the numerous stakeholders - the 42 non-government organizations and organizations of people with disabilities from Assam, Manipur, Meghalaya, Nagaland, Sikkim, Tripura, Mizoram, and Arunachal Pradesh, and specifically the 21 non-government organizations, who shared their valuable experiences and information about their work. Deep gratitude goes out to 900+ parents of children and the nearly 1500 persons with disabilities, for enriching the study by sharing personal experiences and information to questionnaires and in focus group discussions.

We are grateful to Prof Kalpana Sarathy, Deputy Director, Tata Institute of Social Sciences (TISS), Guwahati campus for readily agreeing to support us in our efforts and even taking the time out to moderate and participate in discussions and consultations that we had with other NGOs and officials and advising us on the way forward. We acknowledge Prof. Prashant Kesharvani, Assistant Professor, TISS Guwahati campus, for his valuable tips and guidance with academic inputs while designing the study and drafting the report.

This study would not have been possible without support from Paul Hamlyn Foundation India (PHF). We are indeed grateful to Ms. Jennifer Liang, PHF NE representative, for mooted this study and patiently guiding us through the process and PHF for backing us with resources to map and analyse the disability scenario in northeast India.

The team involved in the conducting the study included Namita Kalita, Project Coordinator and Research Associates Lunhaolal Kuki and Asit Debbarma.

Ketaki Bardalai  
Executive Director  
Shishu Sarothi

## List of Acronyms

ASD	Autism Spectrum Disorder
BPL	Below Poverty Line
CBR	Community Based Rehabilitation
CRC	Composite Regional Centre
CSO	Civil Society Organization
CwDs	Children with Disabilities
DDDP	Deen Dayal Divyangjan Pension
DDDSS	Deen Dayal Divyangjan Sahajya Scheme
DDRC	District Disability and Rehabilitation Centre
DEIC	District Early Intervention Centre
DEPwD	Department of Empowerment of Persons with Disabilities
DPO	Disabled People's Organization (now referred as Organization of Persons with Disability)
ECCE	Early Childhood Care and Education
FGD	Focus Group Discussion
HBNC	Home-Based New-born Care
ID	Intellectual disability
IDI	In-depth interview
IGNDPS	Indira Gandhi National Disability Pension Scheme
LFW	Light for the World International
LMICs	Low- and Middle-Income Countries
MoSPI	Ministry of Statistics and Programme Implementation
MSJ&E	Ministry of Social Justice & Empowerment
NEC	North Eastern Council
NEI	North-East India
NEP	National Education Policy
NGO	Non-Government Organization
NHM	National Health Mission
NSO	National Statistical Office
NCPEDP	National Centre for Promotion of Employment for Disabled People
PwDs	Persons with Disabilities
RBSK	Rashtriya Bal Swasthya Karyakram
RCI	Rehabilitation Council of India
RPwD	Rights of Persons with Disabilities
RTE	Right to Education
SDGs	Sustainable Development Goals
SLD	Special Learning Disability
SPSS	Statistical Package for the Social Sciences
SSA	Samagra Shiksha Abhiyan earlier known as Sarva Shiksha Abhiyan
UDID	Unique Disability Identification
UNCRPD	United Nations Convention on Rights of Persons with Disability
WHO	World Health Organization

## Table of Contents

<b>Executive Summary</b>	5
<b>Chapter 1: Introduction</b>	8
1.1 Background	8
1.2 Purpose and proposition	9
<b>Chapter 2: Literature Review</b>	10
2.1 Global Disability Scenario	10
2.2 History of Disability Rights	11
2.3 Disability and SDGs	12
2.4 Disability in India	13
2.5 Genesis of Laws relating to disability	14
2.6 Rights of Persons with Disabilities Act 2016	15
2.7 Disability Certification	16
2.8 Rights and Entitlements of Persons with Disabilities	16
2.9 Education of Persons with Disabilities	17
2.10 Disability Scenario in NE India	18
<b>Chapter 3: Methodology</b>	20
3.1 Methods	20
3.2 Sampling and Data collection	20
3.3 Limitations of Study	21
<b>Chapter 4: Data Analysis &amp; Interpretation</b>	22
4.1 Profile of Respondents	22
4.2 Awareness	23
4.3 Utility of Disability Certification and UDID Cards	25
4.4 Awareness of Rights of Persons with Disabilities Act	25
4.5 Early Identification – Diagnosis	26
4.6 Health Care Services	27
4.7 Accessibility of Health Services	28
4.8 Education	29
4.9 Experiences of Rejection	30
4.10 Accessibility of Education	31
4.11 Inadequate Human Resources	32
4.12 Scholarship Schemes	33
4.13 Livelihoods	33
<b>Chapter 5: Non-Government Organizations</b>	35
5.1 Range of Services	35
5.2 NGO Efforts and Challenges Faced	36
5.3 Impact of COVID	42
<b>Chapter 6: Discussion, Recommendations, Conclusion</b>	46
6.1 Discussion	46
6.2 Recommendations	48
6.3 Conclusions	50
<b>References</b>	51
<b>Appendices</b>	53

## Executive Summary

The last decade has seen significant developments in the way we look at disability, with the enactment of the Rights of Persons with Disabilities Act 2016, a landmark legislation rooted in the guiding principles of the UN Convention on Rights of Persons with Disabilities, and inclusion of disability in Sustainable Development Goals and targets. Informed by earlier regional consultations, collaborative experiences, evolving perspectives, policies and programs on accessibility, health and education, this study was initiated to understand the needs and gaps in services and realisation of rights of citizens with disabilities in NE India, with the hope that it will help in developing appropriate need-based interventions, services, training, knowledge and information about disability and related issues, that are relevant and contextual to the region and current times.

This exercise evolved from discussions held way back in 2012 when Shishu Sarothi organised a first-of-its-kind Regional Symposium on the *Disability Scenario in Northeast India: Status, Challenges, and Prospects* with support from the Ministry of Social Justice & Empowerment (MSJ&E), North Eastern Council (NEC), Social Welfare Dept (Govt. of Assam), Action Aid India, and Light for the World (LFW). The symposium saw the participation of nearly 160 representatives from 71 NGOs and Disabled People Organizations (DPOs) who met and shared their experiences with Ministers of Development of North Eastern Region (DoNER) and Social Justice & Empowerment, who also attended the event. The discussions brought issues of people with disabilities to the attention of the state and civil society to effect meaningful changes in policies and programmes and also catalysed the idea of establishing a formal regional level institution to provide knowledge and information about disability that addresses specific needs of people in North East India.

With the help of a grant from Paul Hamlyn Foundation, UK, this study aimed at mapping the sector's gaps and needs to develop plans and advocate for policies that address the needs of people with disabilities in North East India. The study was carried out with the following research objectives in mind:

- To understand the state of disability and work related to mitigating challenges of persons with disabilities in northeast India
- To locate and map the needs and gaps in services and the extent of realization of rights, of persons with disabilities including children with disabilities and their families

Phase I of the study involved the collection of survey data from individuals with disabilities and parents of children with disabilities, NGOs and civil society organizations, and government officials, followed by Focus Group Discussions (FGDs) and in-depth interviews (IDIs) with persons with disabilities and parents of children with disabilities. To analyse the data researchers applied a mixed method (qualitative and quantitative) approach. Qualitative data was analysed using thematic analysis based on the study objectives and categories of inquiry, and survey findings were analysed using Statistical Package for the Social Sciences (SPSS) & Microsoft Excel. In the 1st phase, a total number of 2,385 respondents participated, of whom 919 were parents of children with disabilities and 1466 were individual persons with disabilities, A total number of 81 NGOs across the northeast were approached and responses were received from 42 NGOs along with 4 detailed responses from Govt officials (Manipur, Nagaland & Sikkim). Additionally, data has been collected through 42 in-depth interviews, 12 FGDs with individuals with disability & parents of children with disability across northeast India.

Phase II included state and regional consultation meetings attended by persons with disabilities and parents of children with disabilities, NGOs, civil society organizations, and government officials to disseminate Phase I findings and gather feedback from stakeholders. Based on the recommendations of stakeholders at the regional consultation meeting, 21 in-depth interviews with representatives of NGOs working on disability, were conducted to learn more about their initiatives, challenges, and experiences, as well as services provided to PwDs in the northeast region.

The study was conducted using purposive sampling because the respondents were chosen based on who could provide the best information to achieve the study's objectives. The survey target population included NGOs and civil society organizations, some government officials, Disabled People's Organizations (DPOs) / individuals with disabilities, and parents of children with disabilities. Participants for the focus group discussions and in-depth interviews were drawn from eight states in Northeast India. Individuals with cross-disabilities of both genders (male/female) aged 18 to 60, as well as parents of children with disabilities, were identified through organizations working on disability in northeast India through snowballing method and were purposefully recruited using these selection criteria.

Despite all good intentions and plans for physically visiting and meeting different stakeholders, the information gathering exercise had to initially be shifted online due to the sudden onset of the pandemic in March 2020. The pandemic also impacted the lives of persons with disabilities in a very adverse way, with the initial lockdown causing immense economic hardship to many families. Many of the telecalls to respondents had to include counselling and reassurances before discussing responses to the questionnaires. However sometime in October 2020, physical meetings were possible, and in-depth interviews were conducted with individuals and family members of children with disabilities at different locations in some of the states of North East India.

Preliminary findings were shared and discussed with stakeholders and based on the feedback received from them additional discussions were had with NGO partners. The findings show that the study supported both hypotheses:

- There is a significant lack of awareness among stakeholders in the disability sector, both rights holders and duty bearers, about interventions, services, rights, and entitlements as well as role in implementation of laws, schemes, and programs.
- Services for children and persons with disabilities are very inadequate in most states of North East India

There is an urgent need for improved and efficient delivery of health services. Many respondents spoke of difficulties in accessing hospitals and public health services, particularly in rural areas. Lack of services was a key reason for delays in early detection of disability and interventions thereof. Apart from access to services, families also need to be empowered with knowledge and options to help them to cope and manage their children's disabilities. Sensitising public health officials and medical professionals is critical not just for interventions, but also for resolving problems faced in disability certification that undermine access to rights and entitlements. Access to health services and early intervention is a critical first step in the habilitation/rehabilitation of children and persons with disabilities. The National Health Mission's *Rashtriya Bal Vikas Karyakram* scheme recognises that developmental impairment is a common problem occurring in around 10% of childhood population and more for at-risk children. Plans for setting up District Early Intervention Centres, has immense potential for bridging the current gap in services in the region, along with functional District Disability Rehabilitation Centres (DEPwD) and other local NGO initiatives.

Disability certification and UDID cards are yet to be given to all who are entitled to have them. There is little demand for them in many places, due to lack of awareness and difficulties in the process of getting the certificates and enrolling for the cards. There is a space for facilitation and improvement of the process by involving NGOs and qualified and registered rehabilitation professionals.

Education is the other enabler that unlocks the potential of persons with disabilities. Several NGO respondents shared about difficulties faced in enrolling children with disabilities into mainstream education, especially those with high support needs. Children with disability form one of the largest out-of-school groups in India. 2.13 million children have a disability, 28% are not in school (Census, 2011). While initiatives of Samagra Shiksha Abhiyan have improved the enrolment of children with disabilities, there are gaps in practicing inclusion in spirit with many respondents sharing experience of rejection, inaccessibility, and inadequate educational services, that result in poor learning outcomes and high dropout rates. UDISE+

data indicates that half of the total number of children with disabilities enrolled in the elementary level make it to secondary schooling. Only 29.47% of the schools across the country had children with disabilities enrolled in them in 2018-19. 34.38% (22808 out of 66324) of schools in Assam have children with disabilities (CwD) whereas 31.43% (1230 out of 3913) schools in Mizoram have enrolled CwDs. The 2020 NEP too cites the drop from 1.1% to 0.25% in enrolment of students with disabilities from primary to the higher secondary level as being far sharper than those of other vulnerable groups such as students from the scheduled castes (19.6 to 17.3%) and scheduled tribes (10.6 to 6.8%). The UNESCO 2019 Status of Education Report focusing on education of children with disabilities states that 3/4<sup>th</sup> of 5-year-olds with disabilities do not go to any educational institution, nor do 1/4<sup>th</sup> of the CwD population aged between 5 and 19 years. There are fewer girls with disabilities in schools than boys. The number of CwDs enrolled in school drops significantly with each successive level of schooling. Clearly, far too few persons with disabilities reach and complete higher education with scarce awareness of scholarship schemes that could be availed by the students. Meanwhile, skill development opportunities are hardly being availed of by persons with disabilities, thus reducing their prospects for employment further.

The study indicated that not enough trained rehabilitation professionals and special educators are available to support education needs of children with disabilities. In Assam Samagra Shiksha Abhiyan (SSA) has around 600+ special educators who are tasked with the special education needs of 65000+ students with disabilities enrolled in SSA schools.

This study suggests a need for creating awareness through legal literacy and advocacy of rights and entitlements among rights holders (people with disabilities and their families) as well as duty bearers (Govt officials across all tiers of governance and community members) so that laws, schemes, and programs are properly implemented in the different states of the NE region of India. Many persons with disabilities said they were not aware of their rights.

The discussions in the study iterate increasing and improving access to health, education, and skill development, creating cadres of community-based personnel on the one hand and converging efforts to promote inclusive education so that children with disabilities can be retained and progress through successive levels of schooling. Engagement with skill development missions is another dimension that should be explored so that persons with disabilities can become contributing citizens rather than being relegated as dependent burdens on families.

Existing initiatives, both in the government and non-government sector are limited by resources and disability specific expertise, that is often inadequate to address the diverse needs of children and persons with different disabilities across their life spans and geographies of the region. NGOs and CSOs are committed stakeholders and are often driven by personal experiences. They need to be supported with funding and capacity enhancing opportunities to widen and sustain their efforts. Organizations of persons with disabilities also have an important role to play by becoming responsible self-advocates to assert and avail rights and entitlements.

A collaborative concerted regional effort could provide an array of services, training, and support to fill the gaps and address different needs. This could include academia for research; medical and para medical professionals for health services; special educators, teachers, skill development professionals for education and training; architects and civil engineers for ensuring barrier free access; officials, judicial and law enforcement authorities for implementing legal mandates, ensuring justice and upholding rights; communities of parents, mainstream civil society for enabling inclusion, full participation and enjoyment of fundamental freedoms and recognition of persons with disabilities as part of the diversity of our society.



## Chapter I: Introduction

### I.1 Background

North Eastern India is home to 44 million persons living in 8 states of Arunachal Pradesh, Assam, Manipur, Meghalaya, Mizoram, Nagaland, Sikkim & Tripura. It is one of Asia's most ethnic and linguistically diverse regions comprising over 220 close-knit communities. The region's geography and terrain, although rich in biodiversity and natural resources, is recessed and remote and often difficult to reach and its distance from the country's mainland led to an insularity among many of its people and to some extent their marginalisation from the mainstream. The region has also had a history of conflict and political instability that impacted communication and service delivery and slowed the pace of development on one hand, and the violence related trauma and stress of those times have also impacted the mental health of many people in the region. Within this setting people with disabilities in the region face multiple layers of discrimination due to inadequate coverage of rehabilitation services on the one hand and their inability to avail most public facilities and programs and participate fully in mainstream life due to the acute lack of accessibility.

Although there did seem to be a perceptible improvement in recent times, without much warning the situation has suddenly taken a downturn due to the unprecedented nature of the COVID 19 pandemic, that is throwing up new challenges and compounding exclusion and neglect and further impacting the lives of persons with disabilities throughout the region.

Other challenges of the region include the inadequate delivery of services and realization of rights of persons with disabilities. This lacuna is compounded by the lack of adequate information and disaggregated data on disability in the region. Without proper data it becomes difficult to advocate for and provide appropriate need-based services and facilities. Despite the fact that India has signed and ratified the UN Convention on Rights of Persons with Disability (UNCRPD) way back in 2006 and repealed and replaced earlier legislation with a far more progressive human rights-oriented Rights of Persons with Disability Act 2016, there is still very little awareness about it among all stakeholders – rights holders and duty bearers as well as the general public. Persons with disabilities tend to get systematically left out or at the least included as an afterthought in most official programs and efforts and must fight for their rights constantly.

In the background of this, and informed by earlier discussions and past experiences, Shishu Sarothi conducted this study on the current scenario of people with disabilities in NE India, to understand the needs and gaps in services and realization of rights of its citizens with disabilities. It is hoped that this study will create a case for need based programs/services and institutions that offer knowledge and information about disability rehabilitation that is relevant and contextualized to the region and current times.

This exercise originally evolved from discussions held way back in 2012, when Shishu Sarothi with support from the Ministry of Social Justice & Empowerment (MSJ&E), North Eastern Council (NEC), Social Welfare Dept of Govt. of Assam, Action Aid and Light for the World (LFW), organised a *Regional Symposium on the Disability Scenario in Northeast India: Status, Challenges and Prospects*. This first-of-its-kind symposium was an attempt to raise issues of persons with disabilities to the State and civil society and seek committed changes in policies and programs. Almost 160 representatives from 71 NGOs and Disabled People's Organizations (DPO) met and shared their experiences at this symposium that was attended by the Ministers of DONER and MSJ&E. The discussions seeded and catalysed the idea of a formal regional level institution that will hold knowledge and information about disability contextualized to the needs of North East India. This study is part of a project supported by Paul Hamlyn Foundation to map the gaps and needs of the sector and work out strategies that support interventions and actions to address the needs of people with disabilities in NE India.



### **I.2 Purpose and proposition**

Disability cuts across caste, community, gender, geography and socio and economic status. Persons with disabilities like all humans, have the same civil, cultural, economic, political, and social rights. Ignorance, neglect, apathy, and attitudinal and environmental barriers exclude them from full participation in society. Appropriate need-based interventions, reasonable accommodations and inclusive systems can change this narrative by enabling and empowering them to participate on equal footing with valorised social roles as contributing citizens rather than dependent burdens on families and society.

Although institutions and services for persons with disabilities are available in NE India, they are scarce and scattered across mostly urban locations. The issues investigated by this study relate to

- Understanding the status of disability and related work in the NE region of India
- Mapping available services and facilities; the extent of realization of rights of persons with disabilities and looking at gaps in services and programs and needs of children and persons with disabilities, and their families

The proposition in the study was to assess

- awareness levels of stakeholders – parents, persons with disabilities, service providers about their access to health, education, and rights
  - nature of efforts and initiatives to habilitate/rehabilitate persons with disabilities
  - availability of data on disability in NE India
-

## Chapter 2: Review of Literature

### 2.1 Global Disability Scenario

According to the World Report on Disability, 2011 - “About 15% of the world’s population have some form of disability, of whom 2-4% experience significant difficulties in functioning.” The report also shows that the global disability prevalence is higher in comparison to the 10% figure cited in the previous World Health Organization (WHO) report of the 1970s. The increase in numbers in global disability can be attributed to higher mortality rate (aging), rapid spread of chronic diseases and improvement in methodology and tools used to measure disability (World Report on Disability, 2011).

**More than one billion people in the world live with some form of disability, of whom nearly 200 million experience considerable difficulties in functioning.** In the years ahead, disability will be an even greater concern because its prevalence is on the rise. This is due to ageing populations and the higher risk of disability in older people as well as the global increase in chronic health conditions such as diabetes, cardiovascular disease, cancer and mental health disorders.

---

*Across the world, people with disabilities have poorer health outcomes, lower education achievements, less economic participation, and higher rates of poverty than people without disabilities. This is partly because people with disabilities experience barriers in accessing services that many of us have long taken for granted, including health, education, employment, and transport as well as information. These difficulties are exacerbated in less advantaged communities.*

*Dr. Margaret Chan, Director-General, World Health Organization &  
Mr. Robert B. Zoellick, President, World Bank Group*

---

Robust evidence helps to make well informed decisions about disability policy and programs and understanding the number of persons with disabilities and their circumstances can improve efforts to remove disabilities barriers and provide services to allow PwDs to participate. Different factors affect trends in disability - demographics, health, environment, socioeconomic circumstances, needs and unmet needs etc.

Measuring disability poses challenges and is linked to different aspects - impairment and activity limitations, participation restrictions, related health conditions, environmental factors, data collection methods, definitions. Disability data is usually gathered by censuses or surveys. Countries reporting low disability prevalence rates usually collect data from censuses or use measures based on narrow choice of impairments, whereas surveys used in higher prevalence countries, use measures that record activity limitations and participation restrictions. Using International Classification of Functioning, Disability and Health ICF standards can help to make data relevant and globally comparable.

WHO used their World Health Survey and the Global Burden of Disease (GBD) studies to examine prevalence of disabilities, and although these studies used different approaches to estimate and measure disability, the WHS studies revealed that vulnerable groups such as women, **poorest people and older people had higher prevalence of disability.** The GBD data suggests that 15.3% of the world population in 2004 experienced moderate to severe disability while 2.9% experienced severe disability.

Disability prevalence is the result of a complex and dynamic relation between **health conditions** and contextual factors at the personal and environmental levels. Health conditions include three major conditions - chronic conditions that account for 66.5% of years lived with disabilities in low- and middle-income countries; infectious diseases account for 9% of years lived with disabilities; and among injuries, road traffic mishaps account for 1.7% of years lived with disabilities, while violence and conflict account for another 1.4% of years lived with disabilities.

Demographic analysis indicates that global ageing has a major influence on disability trends, with higher risk of disabilities among older people. About children, estimates of disability differ depending on definitions and measures of disability. However, it was found that **children with disabilities are more likely to come from poorer households**, to face discrimination and restricted access to social services and early childhood education and to be underweight and have stunted growth and be subject to severe punishment from parents.

Environmental factors that affect health conditions could range from malnutrition, low birth weight and poor diet; additionally poor sanitation, lack of access to health care (e.g., immunisation) etc. Natural disasters and conflict situations also affect the prevalence of disability as they change impairments and create barriers in the physical environment.

Although the **disability and poverty connections** vary in different countries, persons with disabilities in developed and developing countries alike, experience worse education and livelihood options, with lower employment rates and poorer educational attainment, and are more likely to be poorer than those without disabilities. This is compounded by the extra cost of living with disability e.g., access to assistive devices and services. Children in poorer households in most countries are also at greater risk of disability than others.

Persons with disabilities require a range of services from relatively minor and inexpensive interventions to complex and costly ones. Unmet needs for support include personal care, aids and appliances, participation in education, employment and social activities and modifications in homes and workplaces.

**Economic and social costs of disability** are significant but difficult to quantify. Some costs are borne by individuals and families, whereas some are borne by society, and they stem from inaccessible environments. Direct costs are the additional costs that persons with disabilities and families incur to achieve a reasonable standard of living as well as the benefits paid by Govt through public programs, health and rehabilitation services, social security, insurance, assistive devices, support services, assistants, sign language interpreters etc. Meanwhile indirect costs are wide ranging and substantial, as they include the lost labour production and productivity of persons with disabilities by excluding them from education and the price of social isolation.

In conclusion it may be said that disability is a universal experience with economic and social costs to families, communities and nations. WHO and World Bank estimate that **over a billion people - 15% of the world's population is estimated to be living with disability**. Disability varies according to complexities of families, age, sex, stage of life, exposure to environmental risks, socioeconomic status, available resources, all of which vary by location. Chronic health conditions and injuries as well as global ageing are major influences on disability trends. Persons with disabilities and their households experience worse social and economic outcomes and incur significant additional costs. Improving **disability data** is essential in changing the scenario and the discourse. The International Classification of Functioning, Disability and Health (ICF) is a reliable tool for measuring disability and harmonising data across countries. (Word Report on Disability 2011).

## 2.2 History of Disability Rights

A brief on the perception of "Disability", amongst people helps to understand the history of disability rights. Although rooted originally in public concern for disabled veterans of World War I and II, it was not until the 1960s and 1970s that collective mobilization and advocacy around issues of disability rights began. For 'disability' to rise as a movement, it was important for people to see it, not only from the biomedical approach, but from the lens of an underlying understanding of **exclusion and discrimination**. It is only when the human value of an underlying movement is realized that collective efforts from society can be expected. The disability movement got the required boost when human rights in general were being recognized on the global platform. In 1993, right after the World Conference on Human Rights was held in Vienna, the acceptance by world leaders in unison regarding the rights of humans, quite organically brought in the concept and concern for persons with disability under the umbrella. This conference saw the participation of 170 countries and many NGOs and resulted in the "Vienna Declaration" that recognized that "all human rights and fundamental freedoms are universal and thus unreservedly include persons with disabilities." The Vienna Conference

recognized that any discrimination, intentional or unintentional, against persons with disabilities is per se a violation of human rights and spoke of elimination of all socially determined barriers, be they physical, financial, social, or psychological, which exclude or restrict full participation in society, and led to the adoption of the UN Standard Rules on equalisation of opportunities for persons with disabilities. Prior to the Vienna Declaration, the UN had slowly been devising various ways to work on disability issues, by adopting various soft law instruments. Thus, by the time the discussions on the treaty began in 2001, the UN had undertaken several measures, including the 1975 Declaration on the Rights of Disabled Persons, which is the first rights - based international instrument on disability, declaring 1981 the International Year of Disabled Persons and 1983 as the beginning of the UN Decade of Disabled Persons and establishing the World Programme of Action Concerning Disabled Persons. In 1993, the UN General Assembly adopted the Standard Rules on the Equalization of Opportunities of Persons with Disabilities, which gave impetus to the legal regulation of disability rights at the international level. Nevertheless, challenges remained in establishing and making people understand the human rights of persons with disabilities, not because of the overwhelming power of the medical profession but the issue of complexity in the terms associated with it (Sabatello, 2013).

In March, 2000, leaders of 6 international disability NGOs, along with about 20 regional and national disability organizations, adopted the "Beijing Declaration on the Rights of Persons with Disabilities in the New Millennium," calling on all governments to support a Convention.<sup>1</sup> Subsequently in 2001 the UN's Adhoc Committee set up a Working Group that included representatives from govt and non govt organizations to draft the Convention Text. Informed by the voices of people with disabilities and recognising their right to heard and consulted, the Convention on the Rights of Persons with Disabilities was duly adopted in December 2006 by the UN, in what is recognised as the quickest negotiation of a UN Convention. Signed by 162 countries and ratified by 182 parties the UNCRPD thus became the first human rights treaty of the new millennium as Parties to the Convention are required to promote, protect, and ensure the full enjoyment of human rights by persons with disabilities and ensure that persons with disabilities enjoy full equality as per law. The UNCRPD is a major milestone in the global disability rights movement enabling a shift from viewing persons with disabilities as objects of charity, medical treatment, and social protection towards viewing them as full and equal members of society, with human rights.

### **2.3 Disability and SDGs**

During the 2012 United Nations Conference on Sustainable Development, Member States agreed to launch a process to develop a set of Sustainable Development Goals (SDGs) to succeed the Millennium Development Goals (MDGs), whose achievement period concluded in 2015. The SDGs address all three dimensions of sustainable development (environmental, economic, and social) and are integrated into the UN global development agenda beyond 2015 with a time horizon of 2015 to 2030.

The 17 current Sustainable Development Goals (SDGs) with 169 targets, also have a relevant framework regarding disability. There is a recognition that Persons with disabilities face barriers of varying degrees - physical, social, economic and/or environmental barriers - to participation, which consequently leads to - inaccessibility in the physical environments and resultant discrimination. This situation contributes to children dropping out from schools as they progress upwards and when the academic pressure builds, and in worst cases, children with disabilities are not even enrolled in schools, thus excluding them from the educational mainstream. It is these barriers and resultant inaccessibility that prevent persons with disabilities from entering the school system, restrict their acquisition of skills, knowledge, and their future ability to work and be of economic value. Those same barriers prevent persons with disabilities from entering the labour market or limit the kind and amount of work they can do, lowering their incomes. In addition, increased expenditures related to disability may have an adverse impact on financial resources and push persons with disabilities downwards into poverty.

It is important to understand how different ratifications have been issued in support of the SDGs. For instance, in SDG 1: the Universal Declaration of Human Rights (1948); the International Covenant on Economic, Social

and Cultural Rights (1966); and the Convention on the Rights of Persons with Disabilities (2006) - Articles 12, 27, and 28 have been cited. **A person with disability has a higher likelihood to experience multidimensional poverty.** According to the Disability and Development reports, persons with disabilities are most likely to face poverty issues, due to lack of accessibility in physical terms, which leads to food insecure households, especially for women with disabilities (Affairs, 2018).

Disability is referenced in various parts of the SDGs and specifically in parts related to education, growth and employment, inequality, accessibility of human settlements, as well as data collection and monitoring of the SDGs, for instance, Goal 4 on inclusive and equitable quality education and promotion of life-long learning opportunities for all focuses on eliminating gender disparities in education and ensuring equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities. In addition, the proposal calls for building and upgrading education facilities that are child, disability, and gender sensitive and provide safe, non-violent, inclusive and effective learning environments for all. In Goal 8, to promote sustained, inclusive, and sustainable economic growth, full and productive employment and decent work for all, the international community aims to achieve full and productive employment and decent work for all women and men, including for persons with disabilities, and equal pay for work of equal value. Closely linked is Goal 10 which strives to reduce inequality within and among countries by empowering and promoting the social, economic, and political inclusion of all, including persons with disabilities. Goal 11 would work to make cities and human settlements inclusive, safe, and sustainable. To realize this goal, Member States are called upon to provide access to safe, affordable, accessible, and sustainable transport systems for all, improving road safety, notably by expanding public transport, with special attention to the needs of those in vulnerable situations, such as persons with disabilities. In addition, the Goal calls for providing universal access to safe, inclusive and accessible, green and public spaces, particularly for persons with disabilities. Goal 17 stresses that to strengthen the means of implementation and revitalize the global partnership for sustainable development, the collection of data and monitoring and accountability of the SDGs are crucial. Member States are called upon to enhance capacity-building support to developing countries, including least developed countries (LDCs) and small island developing states (SIDS), which would significantly increase the availability of high quality, timely and reliable data that is also disaggregated by disability.

## 2.4 Disability in India

According to Rights of Persons with Disabilities Act, 2016, that replaced the earlier Persons with Disabilities Act 1995, and is aligned to the UNCRPD ratified by India, the definition of persons with disability, is 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. “Barrier” means any factor including communication, cultural, economic, environmental, institutional, political, social, attitudinal, or structural factors which hampers the full and effective participation of persons with disabilities in society.

Earlier the Ministry of Statistics and Programme Implementation (MoSPI) in their 2016 Report on Disabled Persons in India, cited that in the 2011 Census, persons with disabilities comprise 2.21% of the Indian population of whom 69% belong to rural areas and 31% belong to urban areas, and the gender distribution pattern indicates that 56% are males and 44% are females. The NSS 76<sup>th</sup> round report shows that 48.2% persons with disabilities are in the age group of 15 to 59 years, and Joshi et al., justified the cause of disabilities as preadolescents are attributed to poor health conditions and among older adolescents it is assigned to self-infliction among girls and road injuries among boys, and depressive disorders are common for both genders. According to the MoSPI report, 28.3 percent of people have had disabilities from birth, while 70.7 percent have had difficulties but not since birth.

It is also important to understand the trajectory of the disability rights movement in India from the context of people with disabilities themselves. Till the 1990s, issues relating to problems faced by people with different disabilities were mostly voiced and raised by disability specific associations and federations. This resulted in a piecemeal approach to issues and sent out mixed signals to the authorities. Organizations of persons with

visual impairment were at the helm of these initiatives. Organizations of persons with other sensory disabilities like hearing impairment etc and those with developmental and neurological disabilities were lower in the pecking order and found it difficult to assert their situation.

Late Javed Abidi, pioneer for the realisation of disability rights, was known for his natural ability to speak about disability. In 1993, he founded the Disability Rights Group (DRG), India's first platform for cross-disability advocacy, and fought for the country's first disability law. He was a driving force behind the establishment of the National Centre for Promotion of Employment for Disabled People (NCPEDP) in 1996, and served as its Director from 1997. He was also the Convener of the National Disability Network, founded in 1999, and the National Committee on the Rights of Persons with Disabilities (NCRPD), a think tank of disability sector leaders and experts focused on mainstreaming disability issues and developing disability policies. His ground-breaking work includes the passage of the 1995 Persons with Disability Act and later that of the Rights of Persons with Disabilities Act of 2016; the inclusion of disability in the Census and the Five-Year Plans; the creation of a movement toward accessible India in terms of public spaces, transportation; making elections accessible; influencing Govt policy on website accessibility; and the establishment of a separate Department on Disability Affairs. He was a driving force behind India's new disability rights law - Rights of Persons with Disabilities (RPWD) Act 2016 and led and mobilised voices of people with disabilities, particularly in the Global South, home to nearly 800 million of the world's one billion people with disabilities, playing an important role in promoting cross-disability civil society participation from the Global South at multilateral platforms such as the Conference of States Parties to the Convention on the Rights of Persons with Disabilities. He mooted the view that empowerment of people with disabilities is linked to education, which in turn is linked to accessibility, and that all three are not possible without enabling laws and policies, and that pressure can be built through awareness.

## **2.5 Genesis of legal framework on disability in India**

The Indian Constitution's Article 243-G, 11<sup>th</sup> and 12<sup>th</sup> schedule promotes social welfare and protects the rights of people with disabilities (Srivastava & Kumar, 2015). However, it may be noted that before Independence, disability was not a priority in the country's administrative affairs, and rehabilitation services were only provided by charitable organizations. Later, under the Jawaharlal Nehru welfare model of development, consolidated and institutionalised services for the welfare and rehabilitation of persons with disabilities evolved throughout the post-independence era. The National Council on Handicapped Welfare was established to give policy guidelines and regulate government and non-government organizations' activities.

During the seventies many countries witnessed and listened to the voices of persons with disabilities for recognition of their rights. When the United Nation declared 1981 as 'International Year of the persons with disabilities' and 1983-1992 as the 'UN Decade of Disabled Person Subsequently, the Government of India also took several steps to address the concerns of the disabled such as gather information about the disability in the 1981 Census (Kothari, Galliara, & Huitem, 2020).

By now in addition to a growing number of private and non govt organizations (*many led by parents*) offer services to children and persons with different disabilities, National Institutes were set up as part of the official framework of institutions to address the rehabilitation and training needs of persons with different disabilities. In addition to the National Institutes, Composite Regional Centres have also been set up to offer comprehensive services across different disabilities and more are planned. Of the 15 CRCs 2 are currently operational in NE India and others are on the anvil. As part of the program to set up District Disability Rehabilitation Centres (DDRC) in different districts of the country, 31 DDRCs have been set up in NE India of the planned 44, but their services were inconsistent and inadequate in addressing the needs of persons with disabilities. (Mobility India Disability Rehabilitation NE India Report 2016).



In an effort to regulate and standardise quality of services for persons with disabilities, the Rehabilitation Council of India (RCI) was set up with the enactment of the RCI Act in 1992 as an autonomous body under the MSJ&E to undertake standardization, regulation and monitoring of the training of professionals in the field of rehabilitation and special education; promote research; maintain a register of rehabilitation professionals; and prescribe a code of conduct and ethics for these professionals, among other tasks. Currently RCI has 14 approved institutions offering courses in disability rehabilitation in 5 states of NE India.

The Persons with Disabilities Act was passed by the Indian government in 1995, to ensure equal opportunities, full participation, and protection of rights through the provision of access to education, employment, social security, and a barrier-free environment, among other things. It stipulated for 3% reservation in employment in government institutions, state educational facilities, poverty alleviation programmes, along with other rights and entitlements for persons with disabilities. The Persons with Disabilities Act established the concept of accessible infrastructure in schools, public spaces, and workplaces. However, it was felt that this law did not consider the acute and extraordinary needs of persons and families of persons with developmental disabilities such as Autism, Cerebral Palsy, Intellectual disability, and Multiple Disabilities. Therefore, in 1999, the National Trust Act (*for the Welfare of Persons with Autism, Cerebral Palsy, Intellectual Disability, and Multiple Disabilities*) was enacted in India. National Trust was also set up as an autonomous organization of the MSJ&E Government of India, to enable and empower the persons with autism, cerebral palsy, intellectual disability, and multiple disabilities to live as independently and as close as possible to the community to which they belong to. (Kothari, Galliara, & Huitem, 2020). Currently there are 17 NGOs registered with National Trust from NE India availing of different schemes of assistance.

### 2.6 Rights of Persons with Disabilities Act, 2016

India was the seventh country to ratify the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) on October 1, 2007. The **Rights of Persons with Disabilities Act (RPwD) 2016** was adopted by the Indian government in 2016 to align the country's legal framework with the UNCRPD. It fixes responsibility on Govt to ensure that persons with disabilities enjoy rights to equality, dignity and respect for their integrity on an equitable basis with others. This Act replacing the Persons with Disabilities Act of 1995, signified a paradigm shift from a charity-based approach to a human rights-based approach. It expanded the definition of disability to cover 21 conditions, including those with physical impairments relating to - *locomotor disability, leprosy cured persons, cerebral palsy, dwarfism, muscular dystrophy, and acid attack victims; visual impairments of blindness and low vision; hearing impairment of the deaf and hard of hearing; Intellectual disability including Autism and Specific Learning Disability; chronic neurological disorders such as Multiple Sclerosis and Parkinson's disease; blood disorders such as Haemophilia, Thalassemia and Sickle Cell disease; Mental illness, Multiple disabilities including Deafblindness; and others as may officially be notified from time to time.* The RPwD Act provides for persons with **'benchmark' disabilities** having a minimum 40% disability as being eligible to avail of all the benefits and entitlements offered by Govt, and it also directs employers to identify, reserve and advertise posts open for persons with disabilities, practice fair play in recruitment and create disabled-friendly workplaces by complying with the standards of accessibility prescribed by the Indian Government. This Act also gives clear guidelines on penalties in case of non-compliance (Jumabhoy, 2017).

The Act speaks of the process of certification of disabilities and specifically draws attention to persons with **high support needs**, as a person needing intensive physical, psychological, or other support for carrying out daily activities and/or for decision making. It also follows a **twin track** approach with a spotlight on **children and women with disabilities**, recognising their acute need for additional support in view of their multiple marginalization. It explicitly stipulates **non-discrimination** on the grounds of disability and provides for **penal action against contraventions**. The law encompasses civil and political rights along with social, economic, and cultural rights and directs that its provisions are implemented in a time bound manner. It also increased reservation quota to 5% in higher education and to 4% in employment for persons with disabilities in Govt jobs.



## 2.7 Disability certification

The Disability Certificate is a proof of disability of the person with disability and an important tool introduced by the Department of Empowerment of Persons with Disabilities (DEPwD) for availing benefits, facilities and rights that individuals with benchmark disabilities are entitled from the Central and State Government under various schemes, programs and facilities such as admission into educational and vocational training institutions, as well as unemployment allowance, travel concessions, and rebates in income tax. Disability certificates also enables persons with disabilities to procure prosthetic aids and assistive devices at subsidized rates (Kothari, Galliara, & Huitem, 2020), and to become eligible for a Disability Certificate, the person with disability has to be assessed by designated medical boards to certify and measure disability with 40% being the benchmark for availing benefits.

In the year 2018 NSO Survey revealed that only 28.8% of persons with disabilities reported having a disability certificate (Times, 2019). Experiences have shown that disability certification is an arduous process involving lot of effort by persons with disability and their family members, compounded by the inadequate coverage of medical services for certification. In an earlier study initiated by Shishu Sarothi, it was found that at that time, no disability certificates had been given to anyone in the district of Kokrajhar, Assam. There is often inadequate coordination between medical professionals of the Health Department, for assessment of disability and extent (percentage) and the authorities of Social Welfare Department that issues the certificates. In order to bring in more transparency into this process and provide a universally recognised identity to persons with disabilities, in 2016, the DEPwD introduced a provision of providing Unique Disability ID (UDID) cards online via a portal (<https://www.swavlambancard.gov.in/>) to enable persons with disabilities to access various schemes launched by the Government (Ghai, 2015) and also to create a national database on persons with disabilities. As of December, 2021, 62.3 lakh UDID cards issued across India of only 82317 cards have been issued in states of NE India.

## 2.8 Rights and entitlements of persons with disabilities

In the Rights of Persons with Disabilities Act 2016, Sections 3 to 15 of Chapter-II (Rights and Entitlements) deal with various aspects such as equality and non-discrimination, women and children with disability, community life, protection from cruelty and inhuman treatment, protection from abuse, violence and exploitation; protection and safety; home and family, reproductive rights, accessibility in voting, access to justice, legal capacity, provision for guardianship, and designation for authorities to support respectively.

However, many studies have indicated that the overall vision of inclusion of persons with disabilities is still a distant dream as they have been consistently discriminated against and left out of various opportunities on account of their disabilities, and these studies also show that persons with disabilities often face discrimination, inequality, abuse, exclusion, and deprivation.

*Equality and non-discrimination* are the core principles of the Rights of persons with Disabilities Act, 2016 that align with the UNCRPD. Sections of the law give instructions to take necessary action and to ensure the persons with disabilities enjoy the right to equality, personal liberty, live with dignity and equally with others, for eg., government must utilize the capacity of persons with disabilities by taking necessary steps and creating appropriate accessible environments and providing reasonable accommodation for them in workplaces. The Act also states that no person with disability shall be deprived and discriminated against because of his/her disability.

Section-5 of the RPwD Act states that the persons with disabilities shall have the *right to live in the community* and not be obliged to live in any institutional arrangement. This needs to be facilitated by ensuring access to a range of in-house, residential, and other community support services, including personal assistance with due regard to age and gender. Sections 6 and 7 ensures protection from any kind of violence, abuse and exploitation, and furthermore, protects person with disability from being made subjects of any research without his/her informed consent obtained through accessible modes, means and formats of communication

and prior permission of a Committee for Research on Disability constituted in the prescribed manner for the purpose by the appropriate Government in which not less than half of the members shall themselves be either persons with disabilities or members of the registered organization as defined under clause (z) of section. (Gupta, 2020). As per Section 7 of RPWD Act and the provision for protection of persons with disabilities from all forms of abuse, violence, and exploitation, if any person or registered organization finds evidence of an act of abuse, violence or exploitation has been, or is being, or is likely to be committed against any person with disability, he/she may inform the Executive Magistrate within the local limits of whose jurisdiction such incidents have occurred. On the receipt of such information, the Executive Magistrate is authorized to take immediate steps to stop or prevent such occurrence and provide protection, and legal aid to the victim or person with disability.

## 2.9 Education of persons with disabilities

Educational issues of children with disabilities have sparked debates in almost every country.

---

*“A dominant problem in the disability field is the lack of access to education for both children and adults with disabilities. As education is a fundamental right for all, enshrined in the Universal Declaration of Human rights, and protected through various international conventions, this is a very serious problem. In most countries, there is a dramatic difference in the educational opportunities provided for children with disabilities and those provided for non-children with disabilities. It will simply not be possible to realize the goal of education for ‘all’ if we do not achieve a complete change in this situation.”*

*Ben Lindqvist, former Special Rapporteur of the Commission for Social Development on Disability*

---

In India, it was the Kothari Commission (1964-1966) where education for children with disabilities was first highlighted. The analysis of education of ‘handicapped’ by the Kothari Commission was conventional and conservative, it spoke of social justice as well as constitutional commitment. It however understood disability as an individual problem. *Their education has to be organized not merely on humanitarian grounds, but also on grounds of utility. Proper education generally enables a handicapped child to overcome his/her handicap, and makes him also a useful citizen”. Kothari Commission Report*

The 2011 Census highlights that in the age group of 5-19, only 61% of children with disabilities were attending the educational institution and among them 57% were boys, and 43% were girls (Verma, et al., 2016). The RTE Act, 2009 and RPwD Act, 2016 incorporated measures for inclusive education, but the outcomes of these Act were seen as mixed. Lacunae exist in awareness of legal rights and entitlements of Children with Disabilities, inaccessibility of grievance redressal mechanisms, and lack of a coordinated enforcement mechanism for implementation that delayed the success of interventions and students with disabilities (N for Nose: State of the Education Report for India 2019 UNESCO).

The National Statistical Office (NSO) report, 2018 indicates there is only 52.2% literacy among persons with disabilities of age 7 years and above, and unfortunately, the literacy rate of the children with disability has not changed in India since 2011. The NSO survey also states that "Among Persons with disabilities from the 15 years of age and above, only 19.3% had educational levels of secondary and above, and the majority of those who never attended school were children with multiple disabilities, and mental illness (NSO, 2019). According to the survey, 62.9% of persons with disabilities between the age group of 3 to 35 years had never enrolled in a regular school (Economic Times, 2019). A Report on 'Inclusive Education in India' (2019) indicates that among the children with disabilities below five years 75% did not receive early childhood education. Despite the Right to Education Act, 2009, ensuring free education, 34% of children with disabilities remain out of school. Most mainstream schools refuse to admit or accommodate students with disabilities, citing lack of infrastructural and human resources.

India is also a signatory to the Declaration on the Full Participation and Equality of People with Disabilities in the Asia Pacific region as a participant of the Biwako Millennium Framework, which aims to make the world a more inclusive, barrier-free, and rights-based society for people with disabilities. It also acknowledges the UNESCO Salamanca Statement and Framework for Action, 1994, as well as the World Programme on Action and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. The Salamanca Declaration declared that every child has a fundamental right to education, and that children with special needs must be able to attend ordinary schools that employ child-centred pedagogy (Ghai, 2015).

During the COVID 19 lockdown in 2020, India received a new Education Policy, implementation of which is currently being planned in several states. The National Education Policy (NEP) of 2020 attempts a paradigm shift in education in India, by including preschool level education 5+3+3+4 formula for school education; setting up school complexes as the most basic level of governance for schools. The new policy includes the establishment of numerous new groups and structures for school quality assessment and accreditation (SQAAP), student assessment (PARAKH), the School Standards Authority, and a drive for using technology in education. The encouragement of both the commercial and governmental sectors is accompanied by a re-opening to alternative kinds of education and different learning pathways, with a strong emphasis on the NIOS system. Teacher education is reconsidered, and new curriculum frameworks are envisaged. Students can expect a wider range of disciplines, including vocational education at later stages, activity-based learning, and personalised learning paths. Another key policy shift is the increased emphasis on ECCE and its integration into the educational system and administrative organizations. While the policy does not explicitly support the RTE Act, it does fully support the provisions of the RPwD Act and "endorses all of its recommendations with regard to school education," promising that the inclusion and equal participation of children with disabilities in ECCE and the schooling system will be given top priority (NEP Opportunities and Challenges, White Paper on NEP, and Disability Inclusive Education, NCPEDP, 2021)

## **2.10 Disability scenario in North East India**

The NE region although a hugely diverse territory in terms of ethnicity, culture, religion, and linguistics and dominated by rich natural resources - forests, rivers, lakes, and mountains – also faces shortages and scarcities linked to terrain and distance from the mainland. For decades, the region was affected by multiple conflicts and insurgencies which along with issues of poverty, backwardness and poor governance led to lags in infrastructure, institutions, communication, and development when compared to the rest of the country. The central government has undertaken bold initiatives to support regional infrastructure development and improve connectivity, with the establishment of a dedicated Ministry for Development of the North East Region (DoNER). There are 6,78,440 persons with disabilities, as per MoSPI data although Census 2011, indicates that the total number of persons with disabilities identified in the North East states was 733,450 (1.65% of the population).

Disability rehabilitation services in the North East face significant obstacles with one major factor being the lack of accessible information regarding disability and rehabilitation programmes. Aside from data collected during Census operations, very little statistical information is available on the lives of people with disabilities in the region. During the last decade, there seems to be some skewed progress in states of the region in terms of services for people with disabilities. Some states have appointed dedicated State Commissioners for Persons with Disability Commissioners, and Composite Regional Centres have been set up in some states. The Regional Rehabilitation and Training Centres and District Disability and Rehabilitation Centres scheme of the DEPwD have also been set up in some states, but all are not functioning smoothly. Samagra Shiksha Abhiyan schemes mandating inclusive education are also being implemented with varying success across states. Efforts are slowly being made to improve disability certification procedures and UDID cards are being issued and different initiatives and schemes are being implemented in the states. However, the plight of children and people with disabilities in small towns and rural areas of the region is still quite grim, with scant and inadequate coverage of services. Some of the major challenges are:

- Lack of trained rehabilitation professionals, with most districts and rural locations grossly underserved when it comes to access to specialists, rehabilitation (physio, speech and occupational) therapy assistants, prosthetic and orthotic technicians, and community-based rehabilitation workers. Lack of infrastructure and appropriate, customized training materials and specific training courses.
- Infrequent and irregular screening and assessment of disability among children in Anganwadi centers and schools, particularly for invisible disabilities like hearing impairment, cognitive deficits, specific learning disabilities etc. leading to the entrenchment of various disabling conditions.
- Difficulties in accessing assistive devices from hearing aids to reading glasses, artificial limbs and wheelchairs is a major issue in most remote areas. In many places devices like hearing aids are distributed without adequate and appropriate follow up and training in speech therapy etc., making these devices redundant in a short period of time. Locomotor devices are not customized and do not always meet the needs of the persons.
- Limited coverage of government services in disability and rehabilitation in the region.
- Scarce opportunities for skill development to create livelihood opportunities, social participation.
- Inadequate awareness raising, information dissemination and legal literacy that could help in empowerment of persons with disabilities.

There are a number of NGOs in major cities and some districts and towns in the NE states that are playing a crucial role in providing disability rehabilitation services. Although some of them do get financial support from the State Govts, this not always regular or adequate, and NGOs are forced to seek other funding opportunities. Some NGOs take on and manage services for persons with disabilities on behalf of state governments, such as running DDRCs and facilitating the distribution of disability certificates and assistive devices.

---

## Chapter 3: Methodology

### 3.1 Methods

This study to assess the ground realities in the disability sector of the NE region, combined quantitative and qualitative exploratory mixed methodologies. The quantitative method entailed collection and analysis of numerical data to enable deduction of the social reality; and the qualitative aspects are covered in open flexible enquiries that aimed to explore the diversity and emphasise the tone of the responses. The study involved the use of both descriptive and exploratory methods of research. Descriptive research is used when attempting to systematically describe a situation, problem, phenomenon, services, or program. Exploratory research on the other hand is used to investigate a problem which is not clearly defined, to have a better understanding of the existing problem but at the same time it does not provide conclusive results. Data is collected using both primary data: questionnaires, in-depth interviews & focus group discussion and secondary data: information gathered from desk-based research - articles, publications, journals, books & websites.

The study was conducted in two phases, using different tools such as questionnaires, google forms, interviews guide and participatory approaches. A significant component of our methodology was that persons with disabilities (PwDs) were involved in every phase. PwDs with different disabilities and socio-demographic backgrounds were also recruited to collect data that reflected at least some of the diversity of the communities.

To expand concepts and categories of inquiry, Phase I involved collection of survey data from individuals with disabilities and parents of children with disabilities, NGOs and civil society organizations, and government officials, followed by Focus Group Discussions (FGDs) and in-depth interviews (IDIs) with PwDs and parents of children with disabilities. FGDs and IDIs were audiotaped and transcribed; qualitative data was analysed using thematic analysis based on the study objectives and categories of inquiry, and survey findings were analysed using Statistical Package for the Social Sciences (SPSS) & Microsoft Excel.

In the 1<sup>st</sup> Phase a total of **2385 survey responses** were collected of which 919 were from parents of children with disability and 1466 from persons with disability. A total number of 81 NGOs across northeast was approached of whom responses were received from 42 NGOs and 4 detailed responses from Govt officials (Manipur, Nagaland & Sikkim). Additionally, 42 in-depth interviews & 12 FGDs of individuals with disability & parents of children with disability across northeast India have been collated.

In the 2<sup>nd</sup> Phase **state and regional consultations** were held and attended by individuals with disabilities and parents of children with disabilities, NGOs, civil society organizations, and government officials to disseminate preliminary findings from Phase I and gather feedback from stakeholders. Based on the suggestions of stakeholders at the regional consultation meeting held online, **21 in-depth interviews with NGOs working on disability** were conducted to learn more about their initiatives, challenges and experiences and services offered to PwDs in the northeast region. In order to maintain confidentiality names of individual respondents have been changed.

### 3.2 Sampling and Data Collection process

The study was conducted using purposive sampling as the respondents/participants have been selected on their ability to provide information to achieve the objectives of the study. The target population for collection of survey data included NGOs and civil society organizations, Govt. Officials, DPOs/Individuals with disability and Parents of Children with disability. For FGDs and IDIs, participants were identified from eight states of Northeast India. Individuals with cross-disabilities of both genders (male/female), aged between 18 to 60 and parents of children with disabilities were selected. They were identified through disability-related organizations from northeast India through 'snowballing' methods and were purposefully recruited using these selection criteria.

### **3.3 Limitation of the study**

Many calls to respondents (individuals and parents) had to be preceded with reassurances and counselling before soliciting responses to the questionnaires, as they were depressed and anxious about the pandemic.

Researchers worked hard on building enthusiasm for the study among some respondents to help them realize the importance of their participation.

Language and communication difficulties faced in understanding accents were overcome with assistance of local translators and close observation of behaviour patterns.

NGOs were reluctant to share/give adequate information about their work. Research associates had to spend time in rapport building to establish trust and gather information.

The unprecedented and calamitous effect of the global pandemic posed a major challenge in collection of study data, restricting intra and interstate travel thus limited the free will approach of the research study.

---



## Chapter 4 - Data analysis & interpretation

This chapter comprises participant’s profiles, quantitative and qualitative analysis drawn from themes that have been identified using thematic analysis. It also merges literature and empirical studies with the results, to show similarities and dissimilarities of the findings. 5 broad themes viz Awareness, Education, Health and Livelihood, NGOs and Covid-19 experiences have been identified using framework methods.

### 4.1 Profile of respondents

2385 respondents included 919 parents of children with disabilities and 1466 persons with disabilities. All respondents were in the 18-60 years age group and 1188 (52%) were men and 1084 (48%) were women. Most (51%) of the respondents (1210) were from Scheduled Tribes, 24% (583) were from OBC, 17% (405) from General and 8% (183) were from Schedule Caste groups. Respondents were from all 8 states of NE India, with the most (558) from Manipur, followed by Assam (447), Mizoram (326), Tripura (311), Meghalaya (285), Sikkim (215), Nagaland (127) and Arunachal Pradesh (116)

Table 1

Demographics		
Male	Female	Age
1188 (52%)	1084 (48%)	18-60 above

Table 2

Social Category			
ST	SC	OBC	General
1210 (51%)	183 (8%)	583 (24%)	405 (17%)

Table 3

Sl. No	State	No of respondents
1	Arunachal Pradesh	116
2	Assam	447
3	Manipur	558
4	Meghalaya	285
5	Mizoram	326
6	Nagaland	127
7	Sikkim	215
8	Tripura	311

The survey questionnaire asked respondents to indicate their disabilities from the officially recognised list of 21 disabilities. The most prevalent disability respondents indicated was Intellectual Disability (596), followed by Locomotor Disability (518), Hearing Impairment (371), Cerebral Palsy (238), Visual Impairment (187), Mental Illness (141), Low Vision (110), Autism (104), Speech and Language disability (76), Dwarfism (42), Muscular Dystrophy (36), Multiple Disabilities (32), Learning disabilities (25), Chronic Neurological conditions (21) Leprosy cured persons (13), Blood disorders (12), Acid Attack victims (2). Although unverified the figures indicate a high incidence of intellectual disability, locomotor disability and hearing impairment, followed by CP and visual impairment.

Table 4

Disabilities of Respondents			
Types of disabilities of respondents	Persons with disabilities	CwDs	Total
Blindness	48 (5%)	139 (10%)	187
Low-vision	29 (3%)	81 (6%)	110
Leprosy Cured persons	1 (0%)	12 (9%)	13
Hearing Impairment (Deaf & Hard of hearing)	167 (17%)	204 (15.10%)	371
Locomotor Disability	114 (11%)	404 (29.70%)	518
Dwarfism	8 (1%)	34 (2.50%)	42
Intellectual Disability	283 (28%)	313 (23.10%)	596
Mental Illness	80 (8%)	61 (4.50%)	141



Autism Spectrum Disorder	62 (6%)	42 (3.10%)	104
Cerebral Palsy	131 (13%)	107 (8.00%)	238
Muscular Dystrophy	23 (2%)	13 (1%)	36
Chronic Neurological conditions	6 (1%)	7 (0.50%)	13
Learning Disabilities	11 (1%)	14 (1.00%)	25
Multiple Sclerosis	4 (0%)	4 (0.4%)	8
Speech and Language disability	11 (1%)	65 (4.80%)	76
Thalassemia	2 (0 %)	3 (0.20%)	5
Haemophilia	2 (0%)	0 (0%)	2
Sickle Cell disease	2 (0%)	3 (0.20%)	5
Multiple Disabilities (+ Deafblindness)	18 (2%)	14 (1%)	32
Acid Attack victim	1 (0%)	1 (0.10%)	2

## 4.2 Awareness

Many countries have social protection schemes through contributory disability benefit programmes that are restricted to those who work in the formal economy; non-contributory programmes open to all persons with disabilities remain limited. Although some social security programmes are available to ameliorate difficulties arising from disability, the coverage of persons with disabilities availing these is limited primarily due to lack of awareness. This study indicates that **a substantial percentage of PwDs and parents of CwDs are unaware of disability certification processes and the scheme for getting Unique Disability Identities (UDID) cards**

Figure 1: Disability Certification (Respondents with disability)

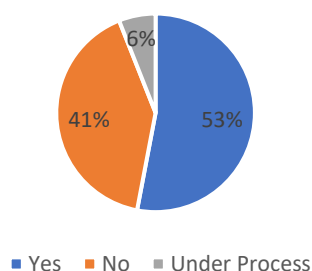
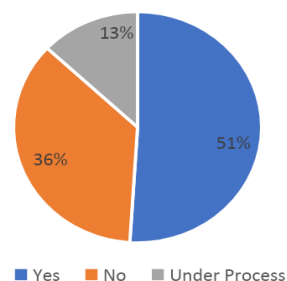


Figure 1 indicates that 53% of the individuals with disabilities have got disability certificates, 41% said they haven't acquired it till date, and 6% responded saying their application is under process. Of those who do not have disability certificates, only 51% know about disability certification and 49% are not aware of disability certificates and its importance. (Figure 1)

51% of the parents of children with disabilities have disability certificates for their children, 36% said they have not acquired disability certificates till date and 13% of the parents said their applications are under process. Among the parents of children with disabilities that did not have disability certification 62% were aware about the disability certificate and 38% parents are not aware about the disability certification and processes involved. (Figure 2)

Figure 2: Disability Certification (Parents of CwDs)



When asked if they were aware about the Unique Disability ID card, only 30% of the persons with disability said they had UDID cards, while 42% did not, 16% of the respondents said their UDID applications were under process and 12% of them were not aware about UDID. (Figure 3)

Among the parents of children with disabilities 45% of them said they have not acquired UDID cards, while 32% had, 13% responded that they are unaware about UDID and another 10% said their applications were under process. (Figure 4)

Figure 3: UDID Awareness among individuals with disability

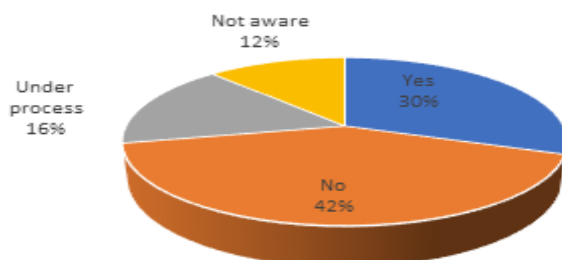
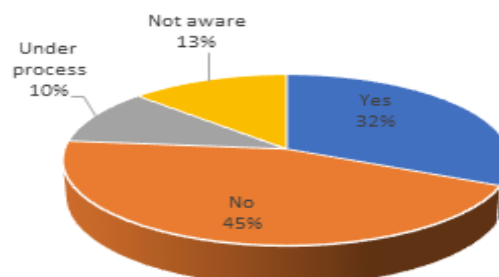


Figure 4: UDID Awareness among Parents of CwDs



During focus group discussion and interviews, persons with disabilities indicated that the process of issuing a disability certificate seems to be regarded as a symbol of 'authority' rather than a service by the officials responsible. They felt the rules around disability certification are drawn up with a view to preventing misuse and wrongful acquisition of certificates to avail benefits and entitlements.

The study found that majority of stakeholders have not obtained disability certificates or a UDID card due to various factors - **a lack of awareness about the process of obtaining a disability certificate, lack of support from concerned government departments tasked with providing this service.** In-depth interviews and Focus Group Discussions (FGDs) with Parents, Individuals, and DPOs revealed **that malpractices and discrimination experienced in acquiring a disability certificate were a common phenomenon.**

*“In the year 2014, he was admitted to hospital the whole year, the following year he was discharged. Thereafter, we were informed that my husband is eligible for a disability certificate as he fulfils benchmark disability criteria. Hence, we applied for the certificate in District Hospital. They keep on telling us to wait. We have spent a lot of money on auto-rickshaw travelling back and forth for a disability certificate. My husband is partially paralyzed and as we don't own a vehicle for commuting purposes and have to hire an auto-rickshaw for registration of a disability certificate. After a long struggle and multiple visits, a doctor who was giving my husband treatment, finally signed a disability certificate and hence he (husband) was issued a medical certificate. At that time, we were informed that we need a form from the social welfare department; the form distributor officially charged Rs. 400 for the form. Thereafter, the official in-charge, while issuing the disability certificate demanded remuneration. I spent more than Rs. 1000 for a disability certificate for nothing; I still did not obtain the certificate. Later, a well-wisher helped obtain the certificate without charging any amount.”* Wife of Person with locomotor disability, Assam

Surprisingly, some also spoke of incorrect diagnosis of disability at government hospitals, although the respondent has not revealed the identity of the medical professional in charge due to confidentiality concerns. During the in-depth interviews, respondents mentioned the struggle of identifying specific neurodevelopmental disorders by the medical professionals. There were instances of confusion of responsibility amongst them in assessment resulting in going from pillar to post to different departments to obtains reports and certifications. All this involved additional travel and time and bearing of financial costs and the burden of navigating inaccessible infrastructure. It was evident that stakeholders and caregivers faced lot of difficulty in obtaining disability certificates and consequently in availing schemes and entitlements.

*“They were not sure of my brother's disability; he did not get proper assessment in his early stages at hospital. Despite his tantrums he is quite quick in learning things, as he is growing.”* Caregiver of person with disability, Sikkim

Govt guidelines also include several flaws that make it difficult to diagnose neuro- developmental disorders like Intellectual disability (ID), autism spectrum disorder (ASD) and Specific Learning Disability (SLD). Due to a shortage of medical professionals in dealing with certification of children with neurodevelopmental disorders, families of children with these disabilities have been suffering in long queues and running from pillar to post. It is imperative to address the issue and adopt a better, more standardised method for assessment. (Thomas John, 2018).

### **4.3 Utility of Disability Certificates, UDID**

While there is a perception among most individuals with disability (77%) and some parents of CwDs (43%) that Disability Certificates are important to avail and access schemes and benefits, despite the difficulties involved in getting the certification, fewer of them have used it for pursuing education and some have not received any benefits.

The lack of awareness among stakeholders concerning disability certification and the UDID card widens the gap between the services available and the potential beneficiaries

Schemes of assistance to persons with disabilities are mostly scant and offer paltry support that does not meet the needs of persons with disabilities. One such example is of the 2009 Indira Gandhi National Disability Scheme of the Ministry of Rural Development under the National Social Assistance Program to fulfil their obligation to support poor and marginalised groups and aimed at ensuring minimum national standard for social assistance in addition to the benefits that states are currently providing or might provide in future. The scheme provides a monthly pension of Rs, 300/- to persons with disability living below the poverty line who have 40% or more disability. The pension is Rs. 500/- for persons with disability who are above 79 years of age. Detailed information of disbursements is not available.

Meanwhile Social Welfare Departments of different states have taken up various welfare schemes for Persons with Disabilities (PwDs) with a view to empower them to cope with various fields with their unique abilities. The “Deen Dayal Divyangjan Pension” is one of the most beneficial schemes under the Social Welfare Department, Assam providing a monthly pension of Rs. 1,000/- to each PwD in their database of persons with disabilities having Disability Certificates issued by the Dept of Health Services. A one-time financial assistance of Rs. 5000/- under the “Deen Dayal Divyangjan Sahajya Scheme” was launched for their health treatment. About 4.5 lakhs PwDs in Assam are believed to have benefited from the scheme in Assam as per the Social Welfare Dept (2021). However, the promises of the scheme contrast the narrative of empirical findings.

*“The only schemes I get are the pension schemes for Persons with Disabilities which is Rs. 1000 per month that does not suffice all four family member needs. I sometimes must bribe the officials to avoid any delay in receiving the schemes” Mr Anil Das, unemployed individual with disability from Karbi Anglong, dependent on his wife’s daily wages for his survival.*

### **4.4 Awareness on Rights of Persons with Disabilities Act 2016**

During the in-depth interviews, it was found that there is widespread lack of awareness on RPwD Act, 2016, some respondents have mentioned that they are aware of the Act, but they lack comprehensive understanding about the ‘rights’ that people with disabilities and their caregivers are entitled to.

*“I know there is a Disability Act but I don’t know much about the RPwD Act, 2016 in detail, we had a workshop organized by our DPOs where they mentioned about the Act,” Raj DebBarma, Person with low vision, Tripura*

The government’s mandate under section 39 (1) of the said law is to conduct, encourage, support, and promote awareness and sensitization programmes in order to ensure that the rights of PwDs provided under the Act are respected. While most states have not done enough to implement this section, in Assam, the Social Welfare Dept engaged with NGOs to create state wide awareness, in addition to other initiatives of

organizing disability screening health camps in schools. However, this study indicated that much more needs to be done to ensure widespread awareness of rights.

*“Most programmes and activities are carried out in collaboration with NGOs/DPOs, who are invited to conduct specific programmes in coordination with the Govt and also submit project/activity plans which are vetted and taken up as per need. The Govt just provides funds to cover expenses for these collaborative programmes and activities.”*

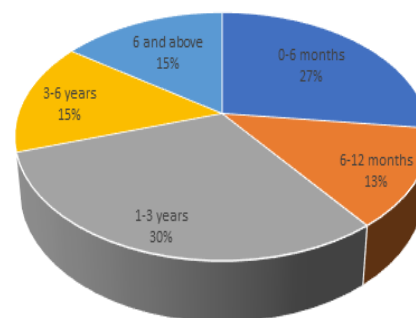
#### 4.5 Health - Early Identification (Diagnosis)

Early childhood is a period of immense possibility for optimum brain development, but it is also a time when children are vulnerable. In these initial years, language, cognition, motor, and socio-emotional domains develop rapidly. As the child learns to be more independent, these areas of development do not operate or develop in isolation, but rather enable and interact with one another. Biological, psychosocial, and environmental factors all have an impact on the form and function of the developing brain. Similarly, early identification and intervention of children with disabilities are crucial as it enables children to maximise their abilities to their optimum capacities and helps them cope better and be less dependent on others as they attend adulthood (Tracey Smythe, 2020).

From the responses of parents of children with disabilities, 27.5% had identified their child’s disability from delays in development and 22.5% from deformities evident at birth. Some parents identified their child’s disability from difficulties in movement (17%), speaking (15.8%), after serious or chronic illness (13.3%) and in hearing (12.5%). Very few parents identified their child’s disability from difficulties in understanding, socialising, doing daily activities.

27% of the parent respondents said that they identified their child’s disability because of delay in development between 0-6 months while 30% of the parents identified their child’s disability between the age 1-3 years and another 30% identified the disability in later years. (Figure 5)

**Figure 5: Age of identification of child’s disability**




---

*“Since birth, he was normal. When he was 1 year old, he had a high fever and a seizure. Post the seizure episode, he was not able to walk, and thereafter, he was taken to an orthopaedic surgeon. Since then, my son has a disproportionate physical structure; the doctor misdiagnosed him as a bone fracture and plastered his lower limbs.”*

---

*Parent of child with cerebral palsy, Assam*

---

During in-depth interviews parents also shared that pre-natal and post-natal events and wrong diagnosis too resulted in disability of their child. Further, due to the invisible nature of some disabilities, parents found it hard to identify problems. During the in-depth interview with one of the NGO representatives it was found that parents are often unaware of their children's problems, particularly with hearing and speech impairments and learning disabilities.

“Late identification is because of the invisible nature of the disability, and sometime people just neglect, because they think that the child is walking, eating, doing everything else ...so they do not understand the impact or the extent to which they can suffer if they are not intervened at the right time or identified as early as possible. the other thing that I wanted to say is that already in mainstream schools, there are at least another 14-15 % children with disabilities like dyslexia and slow learners, who have not been identified.” (A disability-based organization from Meghalaya)

Children and young people with disabilities in urban areas are substantially better than their peers in rural areas, which lack proper diagnostic, identification, and treatment services, as well as interventions in education for children and opportunities for vocational training, and employment prospects for people with disabilities. To address this need, the government has advocated for and promoted Community Based Rehabilitation (CBR) Services in underprivileged communities, both in urban and rural areas. Children with disabilities are identified by community-based multi-purpose workers who are trained to refer them to Samagra Shiksha Abhiyan (SSA) or inclusive education schools and work with their families. The government has identified NGOs as key partners in the implementation of this programme (Lakhumalani).

#### 4.6 Health Care services

When asked where they went for their child’s health needs, 32% of the parents said they went to district level hospitals, 28% went to private hospitals/clinics while 15% of the families went to Primary Health Centres (PHCs), 2% of them went to medical colleges and research institutions and 3% said they relied on traditional healers.

Figure 6: Health Care services used by Parents of CwDs

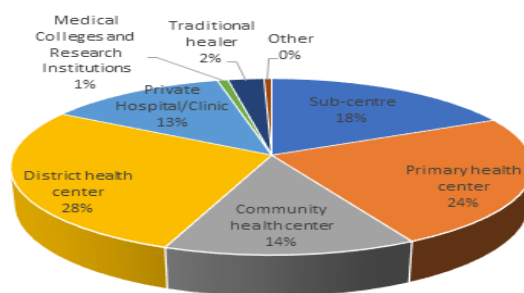
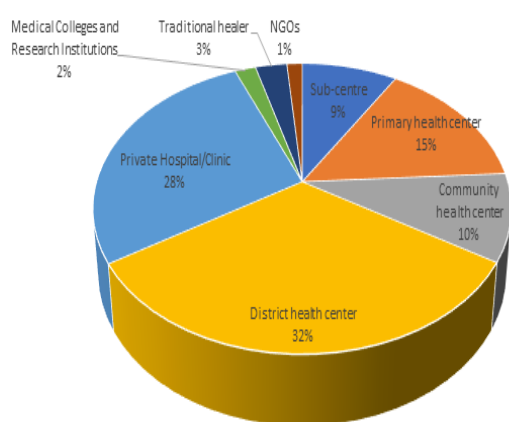


Figure 7: Health care services used by Individuals



From the responses of individual persons with disabilities, we found (Figure 7) that 28% of them availed district level health centres for their medical and health needs, 24% availed primary health care centres (PHCs), 13% went to private hospital/clinics and 2% went to traditional healers and 1% went to medical colleges and research institution for their medical needs.

Clearly most of the respondents availed of public health facilities at the district hospitals and PHC level. Only few went to private hospitals and clinics.

However, during in-depth interviews there seemed to be a significant dissatisfaction in their experience with health and early intervention services at public health facilities in the

region. Respondents also mentioned instances of misdiagnosis of disabilities and sheer negligence of medical professionals in Govt hospitals.

A need was expressed for specialized services catering to specific disabilities. For instance, in the case of the deaf and hearing impaired, identification and intervention required a systematic process involving audiology tests. pure tone audiometry, and speech discrimination tests followed by speech training and teaching sign language. However, all this is an expensive service to avail, for low-income and economically marginalised families

---

*“There was no organization as such, working only for the deaf, there were organizations working in the disability sector which had one section for hearing impaired or deaf children and the actual intervention that was required was not as per how it should be, well most of the time they were mistaken for being intellectually challenged... Today, there are audiologists and speech therapists, but how many are accessible, you know, people who are from the low-income bracket they cannot afford the services.”*

*Representative of disability NGO from Assam*

---

### 4.7 Accessibility of health care services

Accessibility to health services is mandated by law (RPwD Act, 2016) that stipulates access to information about reproductive health, free healthcare in rural areas, barrier free access in all health facilities, priority in attendance and treatment. It also mandates programs be made to promote healthcare and prevention, through research, screening, training, maternal care, awareness raising, and priority in medical interventions during disasters and crises.

65% of the individual respondents with disability said that the health care centres are physically accessible for them, but another 35% responded that health care centres are not accessible and when it comes to the quality of health services, there is a huge gap. Most of participants during in-depth interviews mentioned that in district level government hospitals, early intervention units were dysfunctional.

*“RBSK - there is a fund and there is a project and that’s it and they utilize the fund for something else, and our district has a building for District Early Intervention Centre (DEIC) also. There was a building, and they have staff also but it is not functioning as per the guidelines of DEIC, they don’t function. They don’t provide any early intervention there at all, they have a therapist, she doesn’t have work, she was just sitting at the counter of the OPD” (A representative of a disability NGO from Manipur)*

Individuals with Disabilities respondents too are not satisfied with services that are provided in the government hospitals, and during in-depth interviews they spoke of difficulties faced in accessing services.

---

*“Whenever I visit government district hospitals there is no separate ticket-counter or queue for Persons with disabilities (PwDs), I have to stand in the same queue with people without disability, my leg hurts... the hospital is also very unhygienic.”*

*A person with disability from Sikkim*

---

Rashtriya Bal Swasthya Karyakram (RBSK) of the National Health Mission (NHM) is a significant initiative aimed at early identification and intervention for children from prenatal to 18 years, covering the 4 "D's" related to a child's development i.e., birth defects, deficiencies, diseases, and developmental delays (including disability). The scheme emphasises that the 0–6-year age group will be specifically managed at the District Early Intervention (DEIC) level, whilst 6–18-year age group will have their illnesses managed through existing public health facilities. District Early Intervention Centre (DEIC) serve as a referral linkage for both age groups 0-6 to 6-18. The first phase of screening is to be carried out by existing Medical Officers, Staff Nurses, and ANMs at all delivery points. ASHA will screen new-borns at home after 48 hours and up to 6 weeks as part of the Home-Based New-born Care (HBNC) programme. Dedicated Mobile Health teams will conduct outreach screenings for children aged 6 weeks to 6 years at Anganwadi centres and for children aged 6 to 18 years at schools. Once the child has been screened and referred from any of these points of identification, the necessary treatment/intervention will be provided to the family at zero cost (Rashtriya Bal Swasthya Karyakram (RBSK, 2021).

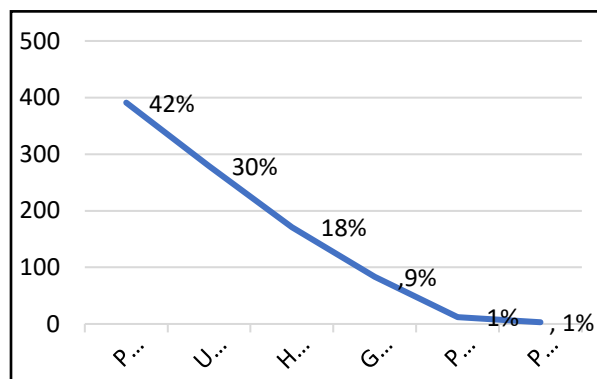


## 4.8 Education

The National Education Policy (NEP) 2020, recognises that over 85% of a child's total brain development occurs before the age of 6, indicating the crucial need for care and stimulation in the early years for healthy brain development and growth. Currently, millions of young children, particularly those from low-income families, do not have access to good-quality Early Childhood Care and Education (ECCE). Strong ECCE investment has the potential to provide such access to all young children, allowing them to engage and thrive in the educational system for the rest of their lives. To ensure that all students entering Grade 1 are school ready, universal provision of high-quality early childhood development, care, and education must be realised at the earliest, before 2030 (National Education Policy, 2020)

68% of the individual respondents with disabilities have enrolled in a school, but another 32% have not enrolled in any of school or educational institution. Among the 68% persons with disabilities who had enrolled in schools, Figure 8 shows a downward sloping curve, indicating an adverse connection between primary and higher education. 42% completed their primary education, 30% completed upper primary education, 18% their higher secondary education, 9% completed graduation and **only 1% have completed post-graduation.**

Figure 8. Educational Status of individuals with disabilities



Higher education has different implications from that of school education as it increases the chance of employability, thus, affirming a life of dignity for the person. There are several NGOs working on the school education of children with disabilities, in northeast India. However, it has not translated into the entry of students to higher education (Jameel, 2011).

The huge gap is cause for concern, because of its implication on unemployment among the young people with disabilities, further perpetuating their dependency on others. There are several factors that contribute to

this, including inaccessible school infrastructure, exclusionary classroom teaching learning approaches for children with disabilities, insufficient family financial support and inadequate number of inclusive and special schools, particularly in the rural areas of North East India.

According to the World Bank reports (2007) children with disabilities are 5 times more likely than children from scheduled castes or scheduled tribes to be out of school (SC or ST). When children with disabilities do attend school, they rarely graduate beyond the primary level, resulting in reduced work opportunities and long-term income poverty (Singal, 2009).

Additionally, as mentioned earlier, 32% of the persons with disabilities who responded to the questionnaire, have not received any form of schooling, indicating that they are unlikely to be employed. As a result, people with disabilities (PwDs) in the north east tend to remain on the fringes and peripheries as marginal and vulnerable groups.

Several NGOs' comments have emphasized the difficulties in enrolling children with disabilities, particularly children with high support needs, in higher education, citing factors such as (i) limited number of seats available for students to attend higher level of education (ii) inability of mainstream schools to facilitate teaching and address the needs of students with disabilities; paucity of inclusive classroom teaching and learning interventions in private as well as government schools (iii) lack of special schools or centres in rural areas.

A representative from a disability NGO from Meghalaya said "... but then what happened was that the system couldn't take them once they went into middle school and so then Sister was forced to start a kind of special school, for the

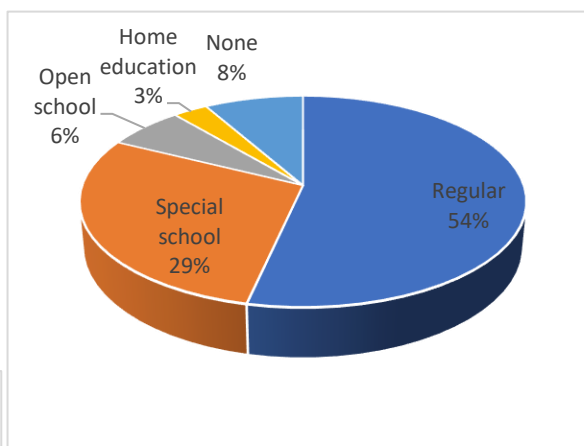


visually impaired and hearing impaired. .... our centre is for basic education and of course after identifying them we segregate into classes, we have upto class 3...our student get admission to private schools because parents prefer private schools over government schools, but they could not cope up with the regular children, and there has been instances where the principal of the school requested our staff to take back the child to our Centre”

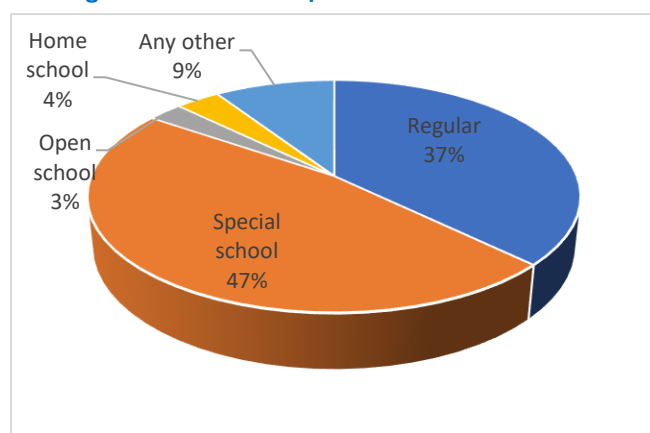
From Figure 9 we see that 54% of individual with disabilities had their schooling in regular schools, 29% from special schools, another 6% from open school and 3% were home educated.

On the contrary, majority of the parents have enrolled their children in special schools. 47% of them are sending their children to special schools, 37% to regular schools. (Figure 10)

**Figure 9: Education availed by respondents with disability**



**Figure 10: Education of children with disabilities**



By 2030, the global education development strategy aims to “ensure inclusive and equitable quality education and promote lifelong learning opportunities for all,” as stated in Goal 4 (SDG4) of the 2030 Agenda for Sustainable Development, which India adopted in 2015. To fulfil all the important targets and goals (SDGs) of the 2030 Agenda for Sustainable Development, the entire educational system will need to be restructured to support and foster learning (National Education

Policy, 2020).

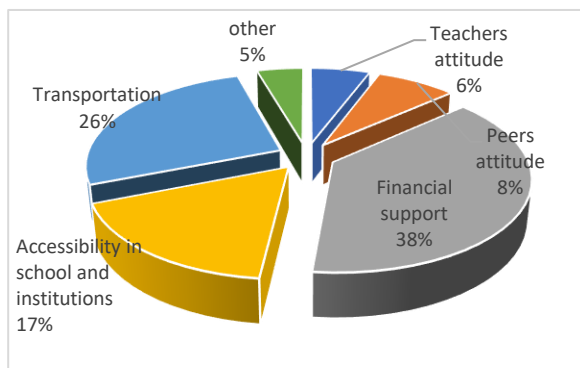
Although a majority (34%) of the NGO respondents said they provide inclusive education services at their centres, there are some underlying challenges that emerged during in-depth interviews and FGDs with various NGOs, DPOs and parents of children with disabilities across north-eastern states. These include experiences of rejection, inaccessible school infrastructure, inadequate special education facilities.

Some respondents stated that, while inclusive education is important, it required a systematic transition into the current educational system. It was also suggested that the teacher education curriculum be revamped to include more child-friendly teaching approaches for both children with and without disabilities. Infrastructure and other gaps are barriers to successful implementation of the National Education Policy 2020 in northeast India, particularly in rural areas. There was a sense that the existing school's facilities and curriculum, which were substandard or dysfunctional, needed to be restructured.

#### 4.9 The Experiences of Rejection

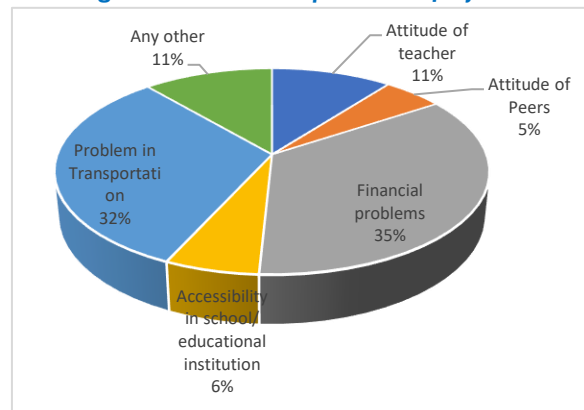
Most (73%) of the individual persons with disabilities said they had faced difficulties in getting an education. These difficulties included need for financial support (38%), 26% cited lack of transportation, 17% mentioned lack of accessibility, 8% spoke of peer attitudes, 6% of teachers' attitudes

Figure 11: Individual experience of rejection



Similarly, in Figure 12 we see that 35% of parents of children with disabilities faced difficulties due to financial problems, 32% spoke of transportation problems, 11 % stated teacher’ attitude issues, 6 % mentioned inaccessibility in school/educational institution and another 5% as attitude of peers.

Figure 12: Parents’ experiences of rejection



During in-depth interviews both individual persons and parents shared experiences of not getting admission in special schools. They mentioned limited seats and the experiences of being in the waiting list for admission.

A representative from a parent-led disability NGO from Manipur shared that “the parents come to school even if the seats are full, they don’t mind even if they must be on the waiting list. I feel the parents are feeling rejected because I already faced the same before. I went to Shillong for my son’s admission. But the waiting list was like a hundred something.”

The findings of this study reflect the gaps in capacities of special schools to cater to the needs of children with disabilities.

Samagra Shiksha Abhiyan (SSA) is aimed at universalizing primary education in a time bound manner, and it is an inclusive program designed to fulfil the guarantee of free and compulsory education mandated in the Right to Education 2009 that stems from the Article 21A of the Constitution. Unfortunately, government schools, particularly in rural areas, are barely functioning and do not always deliver quality education. Hence, there is a tendency for students to enrol in private schools rather than in government schools.

---

*“I think only 10 % of schools are working properly, and yet, the teachers are highly paid, and I believe some of them are highly qualified also, but unfortunately there is no school infrastructure in the villages and there are many school-less schools. We use the term ‘school less school’, because without a school in the village, there are people appointed as Headmaster and Teachers, that’s why we call it school-less schools.”*

---

A representative from a disability NGO in Manipur

---

#### 4.10 Inaccessible Roads & School Infrastructure

Every year, landslides occur in Manipur's hilly terrain, during the monsoon season, particularly along the NH-39 route, which serves as the state's lifeline. Excessive deforestation, unplanned changes in land use and land cover pattern, and slope cultivation, among other anthropological factors, indirectly trigger the landslide process (Balamurugan, 2016).

Difficulty in transportation, unavailability of affordable communication options in bad road conditions compound the challenges of school going students with disabilities, due to inaccessible school infrastructure. During an in-depth interview, a parent of a school going student with high support needs, shared the difficult

experience of his son being unable to use the inaccessible school toilet and shared that “he uses the toilet in the morning before going to school, and he controlled it the whole day because the toilet is inaccessible ...the school hours is from 9:30 am to 3:00 pm...he insists on not using the toilet because he feels shy, even though the teachers constantly ask him.”

### 4.11 Inadequate Human Resources

Although 29 % of NGOs have responded that they provide special education services at their centres, it was found that there is a paucity of special schools for different types of disabilities. It was also found that there is a huge skew in the ratio of students to special educators.

A representative of a disability NGO from Mizoram said “When you come to special educators, every block is given only two special educators, across many schools... once in a month how many times they can reach out to a particular child? it is a big issue, so we can’t get anything done out of these special educators... you can’t blame them also, their reach is very limited.”

---

*“I am saying that in mainstream schools, by default, you’re inclusive ...unless we revamp teacher education, you cannot have a good education. You have to move away from this myth of the average. How do you train teachers to look at 40 different personalities without making 40 lesson plans? What I am trying to say is that what you do for eight to ten students in a special education class... if the teachers are retrained, can be done for 40 students in a mainstream class.”*

A representative from a disability NGO in Meghalaya

---

Another prominent challenge faced by organizations working in disability sector is of retaining skilled staff. Better salary scale and job security offered by government jobs, often prompts trained individuals to opt for jobs in government institutions over the development sector. A representative of a disability NGO from Assam shared that “Some come as trained professionals, and some are trained during the programme. That’s how we manage, but unfortunately our staff don’t stay here long, at most for three years to five years.”

Some NGO respondents said that they believed that their in-house trained staff were as efficient as their counterparts with diplomas certificates from recognized institutions. A representative from a disability NGO from Manipur also shared that “Previously we called them Classroom Assistants, now, we have changed it to Assistant Teacher. They are far better than some special educators... because they spend time here with the children like special educators, they handle them just like professionals”

Nonetheless, the need for sustaining trained staff remains a major concern. Most NGOs felt that having individuals trained from a recognized institutions was still preferable, but funding is a decisive factor in recruiting trained professionals and retaining them as assets for the organization.

---

*“Lot of qualified people are in SSA, they are not willing to join us because we do not have the money to pay them, so, we have ended up taking people who had worked in a block level and who have worked with children with disabilities, and we have trained them inhouse over the years.”*

A representative from a disability NGO in Assam

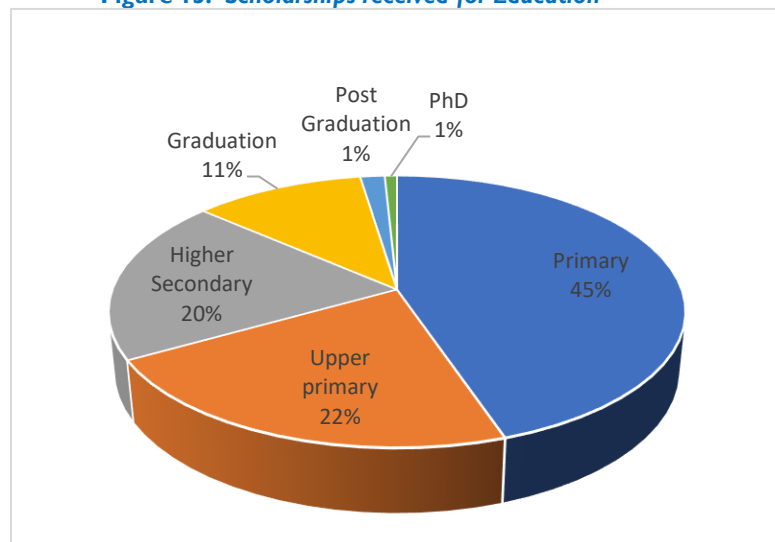
---

#### 4.12 Scholarships schemes:

Although there are numerous schemes for providing scholarships under the aegis of different Ministries and Govt schemes (DEPwD of MSJ&E, Min of Education, Min of P&RD) for education, health, livelihood, and pensions schemes, this often does not reach the people for whom it is intended.

22% of the Individual respondents said they had received scholarships, while 78% did not. Among parents (of Cwds) respondents too only 18% said they received scholarships while 82% had not availed of any scholarships.

**Figure 13: Scholarships received for Education**



Among the PwDs who have received scholarship, 45% of them have received scholarship while pursuing primary education, 22% while pursuing upper primary, 20% for higher secondary education, 11% for graduation and another 1% while pursuing post-graduation and PhD. This is also because far fewer students with disabilities are in higher levels of education. (Fig.13)

Though there are several scholarships available in the state as well as in the centre, it was found that most of the beneficiaries are unaware of the scholarship; and got very little help to

access the scholarships. During the in-depth interviews, it was found that many students are not accessing government scholarships.

*Amy, a student with locomotor disability from Nagaland shared that “I have not received even a single rupee from the government as a scholarship, and I don’t know how my parents managed, and I really thank them for that...”*

*In another instance, a person with locomotor disability from Assam, whose parents faced many difficulties in paying his school fees, said that “my father is the only source of income in the family, earning Rs. 8000 per month, which is not sufficient for me and my two elder siblings’ educational expenses, and I do not avail any scholarship as I am unaware about such scheme”.*

#### 4.13 Livelihood

The United Nations General Assembly adopted the 2030 Sustainable Development Agenda (SDA) in September 2015, stating that it will leave no one behind in its worldwide quest for social and economic development. 'Decent work for all' has been promoted as a vital tool for inclusive economic development as part of the goal for addressing poverty and inequality in Sustainable Development Goal (SDG) 8. This rhetoric is critical in context of the estimated one billion people across the world who are living with disabilities, with 80% of them living in low- and middle-income countries (LMICs). Employment is an important and life changing step toward rehabilitation and empowerment for people with disabilities because it gives a sense of belonging, independence, and promotes their social inclusion and overall well-being.

Figure 14: Source of income of Individuals

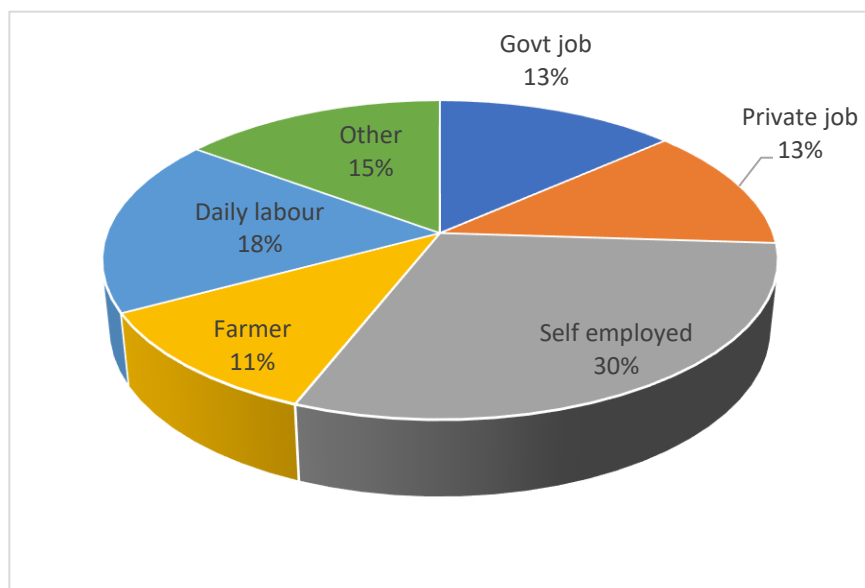


Figure 14 indicates that 30% of the individual with disabilities responded as being self-employed, 18% are daily wage earners, 13% have government job and private jobs, 11% are farmers and 15% of them have other sources of income. This is likely to refer to family income rather than the individual's own income.

In the in-depth interview several participants shared about the difficulties they faced with livelihood opportunities. Both parents of children with disabilities and individual persons with disabilities

expressed concerns over inadequate sources of income. Most of them were Below the Poverty Line (BPL).

In the rural North-eastern states, it was found that there is an acute shortage of structured employment, largely because of the inadequacies in implementation of Govt programs in skill development and creation of employment opportunities. The participants expressed that they do not earn enough to make ends meet.

Amit (name changed) Das, a person with locomotor disability from rural Karbi Along district, Assam raged about his situation when asked about livelihood and employability. He felt frustrated that he has been denied several government employment opportunities due to sheer discrimination because of his disability.

*“I believe I can do any form of job; I have the skills to do daily labour. I am educated enough for office work as well. Even with one arm, I have the potential to work productively and as efficiently as anyone. But because of favouritism in the 5% reservation for PwDs, I am unemployed and dependent on my wife who is earning a living as a domestic worker”*

85% of the responding individuals with disabilities have not received any kind of vocational or skill training, only 15% of them have had vocational skill training. The in-depth interviews suggest that one of the reasons for low enrolment in a vocational skill training is that they are unaware of the benefits of vocational training, and those who have had vocational training stated that they do not have any source of income even after receiving vocational training, and are thus cynical about any vocational / skill training as it did not seem to be worthwhile for them.

A representative of a disability NGO from Manipur shared that “we offered weaving training at our centre, which compared to other places, was close by, all they needed was to walk by themselves around for 500m. Then also, they don't want to come up here. Later, we gave the handloom unit to the instructor who is also a person with disability, and she started weaving at her home. Later, she too gave up on doing that”.

Although vocational education is critical for social and economic growth and entails teaching people skills to prepare them for specific jobs only 42% of the individual with disabilities indicated that they are interested to enrol in a vocational skill training program.

## Chapter 5 Non-Government Organizations:

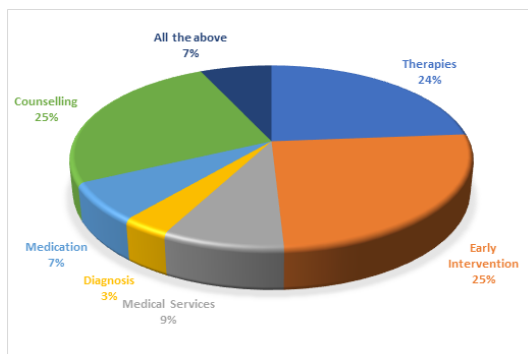
Non-governmental organizations (NGOs) are playing an important role in the empowerment and social transformation of Persons with Disabilities even though many are working at different levels and with varying access to resources.

In this study, a total of 81 NGOs across the northeast were approached with questionnaires for the survey and of them 42 NGOs responded. Based on the recommendations of stakeholders at the regional consultation meeting, 21 in- depth interviews with representatives of disability-based NGOs were conducted to learn more about their initiatives, challenges, and experiences, as well as services provided to PwDs in the northeast region.

### 5.1 Range of Services

Of the 42 NGOs most of them said they provided services relating to Vocational Training, Health, Education, Advocacy, Awareness, Disabled People Organization (DPO) and rehabilitation. A few of them indicated that they were also involved in promoting Human Rights and some were running Shelter and Short stay homes. Although there was very little being done in Early Intervention, there was a clear need felt for it in the region, especially in the remoter rural areas where existing government hospitals and public health facilities are not equipped to address this need.

Figure 15: Health related services by NGOs



Health related Services provided by NGOs do not seem to address all needs of children and persons with disabilities, with only 25% of them saying they worked in Early Intervention, another 25% offered counselling and 24% said they provided therapies. (Fig 15)

Most (86.5%) of the NGO respondents are providing Vocational training, and a large section (81.1%) are working on creating awareness on disability, with many (78.4%) providing education, 73% and health and advocacy (73%), around half of them said they (51.4%) are running rehabilitation centres with

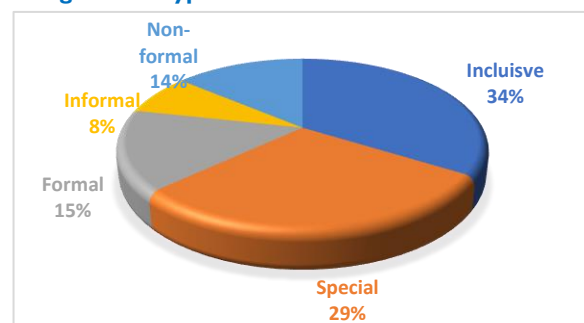
few (37%) of them listing that they are working with human rights, and a smaller number ( 27%) said they are running short stay homes and shelters.

Among the NGOs working in education 34% of the respondents said they are working on inclusive education, while 29% listed special education as their area of work. Only 15% are running formal education programs and fewer (8%) are conducting informal education programs. In-depth interviews with some of the NGOs revealed that their services are insufficient, as they can only work with limited number of children with disabilities due to paucity of resources.

*“See, our school, it is a very small school, maximum capacity is 20, we have increased it to 32 and even then, we get a lot of admission requests from other districts. We don’t have sufficient quality special schools for children with disability. Services available are minimal, so that’s why they are opting for home-based education.” (Respondent from Disability NGO from Mizoram)*

Some NGOs offer community-based rehabilitation (CBR) services when CBR workers visit homes to assist

Figure 16: Types of education services of NGOs





children. However, these home visits and infrequent and services for children with 'high support needs' remain a major concern. Parents with limited alternatives opt for whatever service is available or somehow cope if no services are available in their vicinity.

During the field visits and in-depth interviews with various NGOs across the region, issues such as paucity of trained professionals in the disability sector and dealing with staff attrition due to inadequate funding were recurrent.

18 NGOs have been working in the disability sector for more than 20 years, some said that they initially started with other social issues and along the way they felt the need to work for persons with disability as they realized that persons with disabilities are a vulnerable section of our society.

*"...Bethany Society started in 1981, in a small village in East Garo hills called Mendal, about 30 kilometers from Paikan, by Sister Rosario, a Spanish nun and although often people think it is a church-based organization, it is a secular organization. The major focus was on the mother and child in the belief that if you look after nutrition, and educate the mother and the child, you have then the foundations of a great society. She found many children with disabilities and brought about 20 children, mostly vision and hearing impaired, to establish a centre in Tura way back in the 80s. She started training them and admitted them in 1985 to local government schools... So, inclusion is part of our blood, right from the very beginning, whether it was in the livelihoods programs or whether it was education programs..." (Respondent from Bethany Society, Meghalaya.)*

## 5.2 NGO efforts & challenges faced

Responses to questionnaires followed by discussions and in-depth interviews with at least 21 NGOs working in the disability sector in 8 states of NE India led to some interesting revelations about the nature of the work and the challenges faced by them generally as well as during the COVID pandemic.

In **Manipur**, NGOs indicated that they are working across all disabilities and offering a wide range of services. 1 NGO and a 1 Govt hospital (RIMS) is running RCI approved Diploma, Bachelor courses for Special Education for Hearing Impaired persons and MPhil level courses in Clinical Psychology.

In- depth interviews indicated that they all face challenges of paucity of funds, inadequate support from the Govt. In Senapati, the Govt does not celebrate or mark World Disability Day. Govt officials seem distrustful of NGOs. Inadequate transport and communication facilities to remote hilly areas with difficult terrain results in poor coverage of services and thus poor outcomes for children and persons with disabilities.

No	State/Organization	Year estb.	Area of work	Challenges faced
	<b>MANIPUR</b>			
1	Centre for Community Initiative (CCI), Churachandpur	2008	Education, Health, Vocational Training, Rehabilitation, Advocacy Awareness, DPOs	Lack of Funds, trained human resources, infrastructure, Govt support
2	Manipur North Economic Development Association (MANEDA), Senapati	1991	Education, Health, Shelter, Short stay home, Advocacy, Awareness, DPOs	Lack of funds, awareness on disability; infrastructure; support from community and Govt
3	All Manipur Mentally Handicapped Persons Welfare Organization, Imphal	1989	Education, Health, Human Rights, Vocational Training, Short stay home,	Lack of Funds, awareness on disability



			Advocacy, Awareness, DPOs	
4	Recreation – Spastics Society of Manipur, Imphal	1988	Education, Vocational Rehabilitation, Awareness, DPOs	Health, Training, Centre, Lack of Funds
5	Relief Centre for the Welfare of Differently Abled Persons, Imphal	2011	Education, Health, Human Rights, Vocational Training, Awareness, DPOs	Lack of Funds, awareness on disability; infrastructure; Govt support
6	All Manipur Disabled and Handicapped Person’s Development	1988	Vocational Rehabilitation, DPOs	Training, Centre, Lack of Funds

\* In-depth interviews were conducted with the highlighted NGOs

In **Mizoram**, although funding was listed by all the NGOs, during the in-depth interviews with some of the NGOs they indicated lack of awareness about disability in communities and inaccessible infrastructure as a challenge. They also mentioned discouraging attitudes of Govt officials and malpractices and opacity in implementation of schemes. 1 NGO flagged a need for widespread awareness about rights and entitlements among rights holders and duty bearers. Another NGO spoke of the need to revisit the Mizo spirit of *Tlongina* – selfless service – and to look beyond charity/welfare to empowerment and rights.

No	State/Organization	Year estb.	Area of work	Challenges faced
<b>MIZORAM</b>				
1	Centre for Community Development (CODNERC), Aizawl	2005	Health, Human Rights, Vocational Training, Advocacy, Awareness	Lack of Funds, awareness on disability
2	Samaritan Association for the Blind, Aizawl	1990	Education, Vocational Training	Lack of Funds, awareness on disability, infrastructure
3	Ferrando Integrated Women Development Centre, Aizawl	2005	Education, Health, Human Rights, Vocational Training, Shelter and Short stay home, Rehab. Centre, Advocacy & Awareness, DPOs	Lack of Funds, awareness on disability, infrastructure
4	Spastics Society of Mizoram, Aizawl	1989	Education, Health, Human Rights, Vocational Training, Shelter and Short stay home, Rehab. Centre, Advocacy & Awareness, DPOs	Lack of funds, trained manpower, awareness on disability, infrastructure
5	Zoram Entu Paul, Aizawl	2004	Education, Health, Vocational Training, Rehab Centre, Advocacy, Awareness, DPOs	Lack of trained human resources, awareness on disability, Govt support (skewed support to schemes and entitlements)

\* In-depth interviews were conducted with the highlighted NGOs

The impact of the combined efforts of many of the **Assam** based NGOs can be seen through increased but still inadequate public awareness and some attitudinal changes about disabilities including mental health, early screening for hearing loss etc. although the charity/welfare mindset still prevails.

No	State/Organization	Year estb.	Area of work	Challenges faced
	<b>ASSAM</b>			
1	Prerona Pratibandhi Shishu Bikash Kendra, Jorhat	1992	Education, Health, Human Rights, Vocational Training, Short stay home, Rehab. Centre, Advocacy & Awareness,	Lack of Funds, trained human resources, awareness on disability, infrastructure
2	Mrinaljyoti Rehabilitation Centre, Duliajan	1999	Education, Health, Human Rights, Vocational Training, Short stay home, Rehab. Centre, Advocacy & Awareness, DPOs	Lack of Funds, trained human resources, awareness on disability, infrastructure, support from community and Govt.
3	Ashadeep, Guwahati	1996	Vocational Training, Rehabilitation centre, Advocacy, Awareness, Coordinating Special Olympics Bharat Program	Lack of funds, community support
4	Uttaran Special Education Foundation, Guwahati	2012	Vocational Training, Short Stay home, Rehabilitation Centre, DPO	Lack of funds, trained human resources, awareness on disability, infrastructure, Govt support
5	National Federation for the Blind, Guwahati	1974	Education, Vocational Training, Advocacy, Awareness, DPO	Lack of funds
6	Swabalambi, Sonapur		Education, Health, Human Rights, Vocational Training, Shelter, Advocacy, Awareness, DPOs	Lack of funds
7	Era Amader NGO, Silchar	2012	Education, Health, Vocational Training, Shelter, Advocacy, Awareness, DPOs	Lack of funds, trained human resources, awareness on disability, infrastructure, Govt support
8	Action for Inclusion and Empowerment Trust, Kokrajhar	2020	Education, Advocacy, Awareness	Lack of funds, trained human resources, awareness on disability, infrastructure, community and Govt support
9	VAANI Deaf Children's Foundation, Guwahati	2005	Education	Lack of funds and trained human resources
10	Destination, Guwahati	2005	Health, Vocational Training, Shelter, Rehab centre, Advocacy, Awareness, DPOs	Lack of funds, trained human resources, awareness on disability, infrastructure, community and Govt support
11	SATRA, Sipajhar	2002	Health, Human Rights, Advocacy, DPOs	Lack of funds, trained human resources, Govt support

\* In-depth interviews were conducted with the highlighted NGOs

The challenges faced by most NGOs apart from lack of funds including what is available from foreign sources due to FCRA issues, are of not having enough trained human resources that they can afford to

employ. Lack of awareness and resources with Govt to address disability issues. The NGOs cited the lack of livelihood options, need for skill development, and education. NGOs listed problems in disability certification and UDID processes and flagged the need for early intervention as too much precious time is lost in identification and screening for disability, resulting in learning gaps and loss of potential. They also expressed the need for safeguarding children and women with disabilities from omission, neglect, and abuse on account of their multiple layers of vulnerabilities.

As some of the **Meghalaya** based NGOs have been working in the sector for a number of years, they felt they have impacted access to education and improved the wellbeing of persons with mental illness. They also felt that their efforts have improved the livelihood options for persons with disabilities prospects of availing disability certificates/UDID cards.

No	State/Organization	Year estb.	Area of work	Challenges faced
	<b>MEGHALAYA</b>			
1	Montfort Centre for Education, Tura	1995	Education, Health, Vocational Training, Advocacy, Awareness	Lack of Funds, trained manpower, awareness on disability, community and Govt support
2	Khasi Disabilities Association, Shillong	2011	Human Rights, Vocational Training, Awareness, DPOs	Lack of funds, trained manpower, awareness of disability, community support
3	Ferrando Speech & Hearing Centre, Barapani	1996	Education, Vocational training, Rehab Centre, Advocacy, Awareness, DPOs	Lack of funds and trained manpower
4	Dwar Jingkyrmen, Shillong	1986	Education, Health, Vocational Training, Rehabilitation Centre, Advocacy, Awareness	Lack of funds and awareness of disability
5	Bethany Society, Shillong, Tura	1981	Education, Health, Human Rights, Vocational Training, Advocacy, Awareness, DPOs, Other	Lack of funds, trained manpower, awareness on disability, community and Govt support
6	Nongstoin Social Service Society, Nongstoin	2007	Education, Health, Human Rights, Vocational Training, Rehab centre, Advocacy, Awareness, DPOs	Lack of funds, infrastructure, community and Govt support
7	Mary Rice Centre for Special Education, Society for Welfare of the Disabled, Shillong	1989	Education, Vocational Training, Rehab Centre, Advocacy, Awareness	Lack of Funds, trained human resources, infrastructure, community and Govt support
8	Roilang Livelihood Academy	1996	Education	Lack of funds, infrastructure, Govt support

\* In-depth interviews were conducted with the highlighted NGOs

The common challenges faced by the NGOs includes lack of funding, delayed receipt of Govt grants, inability, and reluctance of families to pay for services to NGOs. Trained human resources and scarce and inadequate, despite the courses and trainings being offered by some of them. Some of the NGOs are extending community-based rehabilitation support and this has helped improved awareness around disability and disability certification and UDID cards, but most DPOs are yet to build confidence and assert themselves as self-advocates on relevant issues. Govt and community support is improving but still inadequate. NGOs also need to develop second lines of leadership and accept staff attrition as an investment for work in the sector. I NGO flagged concerns about imposition of compliance to funding agencies that becomes time consuming and detracts from the passion and creative spirit of their work. Inaccessible infrastructure and environment in hilly terrain is another challenge, where even small efforts to improve physical access can be transformative. While mental health programs are improving the situation of persons with mental illness, compliance with medication remains a challenge.

The **Nagaland** based NGOs felt that their work has helped create more awareness about disability through access to some rights and services and support in small clusters. I NGO felt that they have been able to improve the quality of lives of hundreds of deaf people in Nagaland and other surrounding states that they are from, with some getting employment and living well, thus changing community attitudes towards them.

No	State/Organization	Year estb.	Area of work	Challenges faced
	<b>NAGALAND</b>			
1	Prodigal's Home, Dimapur	1991	Education, Health, Human Rights, Vocational Training, Shelter, Short stay home, Rehab Centre, Advocacy, Awareness, DPOs, Other	Lack of funds, trained human resources, Govt support
2	Cherry Blossoms Society, Kohima	2007	Education, Health, Vocational Training, Rehabilitation Centre, Advocacy, Awareness, DPOs	Lack of funds, trained human resources, community and Govt support
3	Deaf Biblical Ministry, Dimapur	1987	Education, Vocational Training, DPOs	Lack of funds, awareness on disability, community support
4	Jo Foundation, Kohima	2009	Education, Health, Awareness, DPOs	Lack of funds, trained human resources, infrastructure
5	Development Association of Nagaland (DAN), Dimapur	1985	Education, Health, Vocational Training, Advocacy, Awareness, Other	Lack of trained human resources, awareness on disability, infrastructure and community support
6	Kripa Foundation, Kohima	1987	Training, Research, Capacity Building, Mental Health services, awareness, deaddiction	Lack of trained human resources

\* In-depth interviews were conducted with the highlighted NGOs

However, the common challenges listed by the NGOs included lack of funds, trained human resources, inaccessible public infrastructure, and inadequate community and Govt support. The NGOs running inclusive schools had to grapple with complaints of parents of children without disabilities “... we can't keep

our children with the blind and the deaf...” at the cost of sustaining their own schools. NGOs also spoke of slow process of disability certification and scarcity of health professionals specialised to diagnose and certify disability in rural areas. Remoteness of the region and inaccessible infrastructure was another challenge that hindered access to education for children with disabilities. It is difficult to find trained staff and to retain them with commensurate remuneration to provide education and allied services.

Based on the responses and in-depth interview the Sikkim based NGOs have trained and educated children with visual impairment and other disabilities.

No	State/Organization	Year estb.	Area of work	Challenges faced
<b>SIKKIM</b>				
1	National Association for the Blind, Gangtok	1987	Education, Health, Vocational Training, Awareness, DPO	Lack of funds
2	Sikkim Divyang Sahayata Samiti, Gangtok	2001	Education, Health, Vocational Training, Short stay home, Rehab, Centre, DPO	

\* In-depth interviews were conducted with the highlighted NGOs

Their challenges include lack of funds, trained human resources, inadequate community support and awareness about disability. They found it difficult to get local trained experts to work and often had to depend on professionals from outside the state. Additionally, the geographical terrain is very challenging and inaccessible, that often deters people from coming to work for them.

The **Tripura** NGOs felt that their efforts had helped to improve quality of life of persons with disabilities and empowered them for inclusion and independence. The education department is also making conscious efforts to be inclusive, and people are more aware of their rights.

No	State/Organization	Year estb.	Area of work	Challenges faced
<b>TRIPURA</b>				
1	Ferrando Rehabilitation Society for Disabled, Agartala	2003	Education, Health, Vocational Training, Rehab. Centre, Advocacy, Awareness, DPOs	Lack of Funds, trained human resources, infrastructure
2	Voluntary Health Association of Tripura, Agartala	1988	Education, Health, Human Rights, Vocational Training, Shelter, Short Stay home, Rehab Centre, Advocacy, Awareness, DPOs	Lack of funds, Govt support

\* In-depth interviews were conducted with the highlighted NGOs

The challenges listed by the NGOs included lack of adequate funding, trained human resources and infrastructure.

No	State/Organization	Year estb.	Area of work	Challenges faced
<b>ARUNACHAL PRADESH</b>				
1	Donyi Polo Mission for Hearing and Visually Impaired School, Itanagar	1990	Education, Health, Vocational Training, Shelter, Awareness	Lack of trained human resources, awareness on disability, Govt support

\* In-depth interviews were conducted with the highlighted NGOs

Only 1 NGO from **Arunachal Pradesh** responded to the questionnaire and also gave an in – depth interview. Supported by the Donyi Polo Mission, they have been running educational services for children with hearing and visual impairment. They felt challenged by the lack of services for children with intellectual disabilities in different districts of their state, and have recently commenced services for children with intellectual disabilities too. They also shared that there was need for more trained human resources and technical support as well as exposure to experienced disability services. They felt that the capacity of existing community level professionals to provide home based services needs to be built. The quality of inclusive education in SSA schools in the state also needs to be improved and more needs to be done to provide appropriate assistive devices (hearing aids etc) to children and persons with disabilities.

Among the 42 NGOs, 37 (88.10%) are facing challenges with getting **funds**, 24 (57%) in addressing their need for **trained human resources** and for **awareness about disabilities**. 50% also cited challenges related to accessible public **infrastructure**. 45.24% cited **lack of government support** as a challenge, and 38.10% organizations stated **lack of support from the community** as their challenge.

Many NGO respondents spoke about their concerns of finding funding and sustaining their organizations during the in-depth interviews and of difficulties in complying with the eligibility criteria and norms of funding agencies.

*“For me the major challenge is, from the last ten years is that the funding organizations have changed their policies to a certain extent and have killed the creativity in the organization sector... maybe because of their international thinking, that if you want to run a good NGOs you must look like a corporate, people doing all this .... you must have your HR policy, you must have gender policy, you must have this, it has to be like that ..... you have to keep records and you are admitting this that etc. So, I asked at one meeting, when do we have time to go to the village, and with 23 pages of monthly reporting to file, what will the field worker do? I mean it is funders who killed the creativity! They will say, but in your monitoring sheet you have written this, when you did that, this micro management of project I don't understand” (Respondent from disability NGO in Meghalaya)*

Lack of funding, lack of dedicated leadership, misuse of funds, lack of skilled employees, monopolisation of leadership, lack of public engagement, are some of the primary problems and challenges encountered by NGOs. Loosening laws and regulations governing grant-in-aid and sanctioning more grants to non-governmental organizations (NGOs) and creating coordinating groups for NGOs may help to resolve some of the challenges Latha L.K, & Prahakar, K (2011)

### 5.3 Impact of Covid-19 on persons with disabilities:

The global pandemic declared due to the novel SARS-CoV-2 (COVID-19) in late 2019 resulted in close to 600 million confirmed cases as of early August 2022, with over 6.4 million deaths reported to WHO. Approximately 12,355,390,461 vaccine doses have been administered worldwide. In India as of 30<sup>th</sup> June 2022, there were over 44 million confirmed cases that resulted in 526928 deaths. About 67.9% of the population is now fully vaccinated and around 74% of the population has had at least 1 dose of the vaccination. The data as of early Aug 2022, for the 8 states of NE India, indicates that there were over 14.7 lakh confirmed cases through the successive waves of the pandemic with close around 15000 deaths.

The COVID-19 pandemic, as well as the associated isolation and protective measures, caused significant changes in the lives of people. Aside from the possibility of COVID-19 infections and its health-related complications, people experienced significant consequences in their daily lives of high stress, low moods, disrupted sleeping patterns, financial worry, and depression (Lebrasseur, et al., 2021).

Despite the 2030 Agenda for Sustainable Development's promise to *leave no one behind* and the provisions of the UN Disability Inclusion Strategy for persons with disabilities, the Covid-19 pandemic and the lockdowns and resulting restrictions on individual movement imposed by the government posed many challenges from obtaining essential supplies of food and rations to availing of medical treatment and

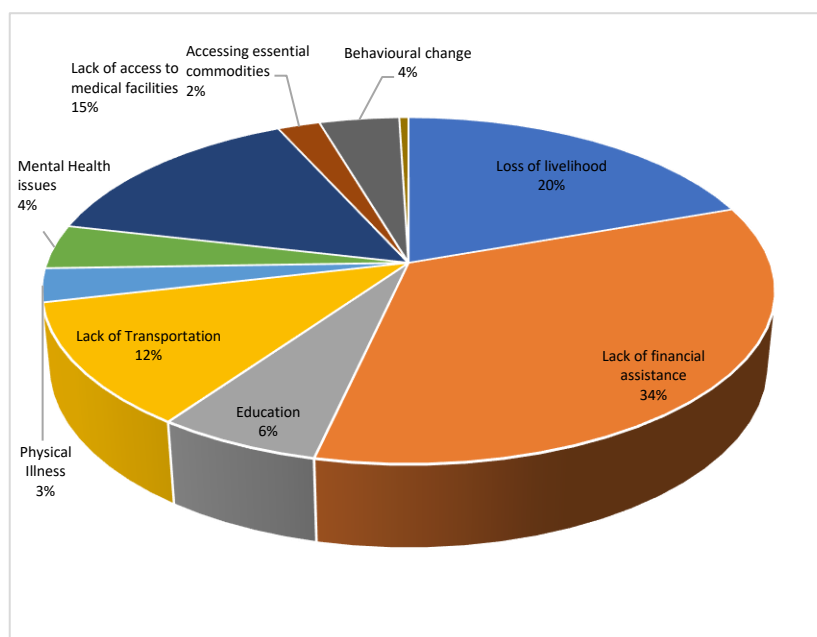


therapy, particularly in the 1<sup>st</sup> phase of the lockdown. These included the lack of accessible information and dedicated helplines, especially for the hearing impaired; access to essential commodities and supplies; unavailability of health care systems, facilities, products and medications; denial of access to caregivers, support groups and assistive devices; financial challenges due to the loss of livelihoods and inability to access free rations despite being in distress; discrimination, violence and abuse due to neglect, abandonment and conflict; psychosocial issues due to reduced access to medication and overall disruptive nature of pandemic; women with disabilities faced the added burden of intersectional discrimination due to patriarchal value systems prejudices stemming from lack of education of older groups; children with disabilities too being most vulnerable, experienced the distress of social isolation as it impacted their all-round growth and development. (Locked down and Left Behind, NCPEDP, 2020).

Recommendations were made for speedy implementation of legal provisions regarding inclusion of persons with disabilities in disaster risk reduction and reconstruction policies; provision of unemployment allowance with simplified procedures and enhancement of ex-gratia cash transfers to persons with high support needs; exemptions in movement of caregivers and support staff, accessible information and dedicated helplines; accessible covid testing facilities, sensitive treatment, doorstep delivery/provision of medicines and urgent health interventions and priority in treatment; doorstep or prioritised distribution of essential supplies and rations.

During this survey, 82% of responding persons with disabilities indicated that they faced difficulties during the Covid-19 lockdown. Most of difficulties related to financial distress, loss of livelihoods, inability to avail of medical facilities and problems in movement and access to transportation.

**Figure 17: Challenges faced by persons with disabilities during Covid-19**

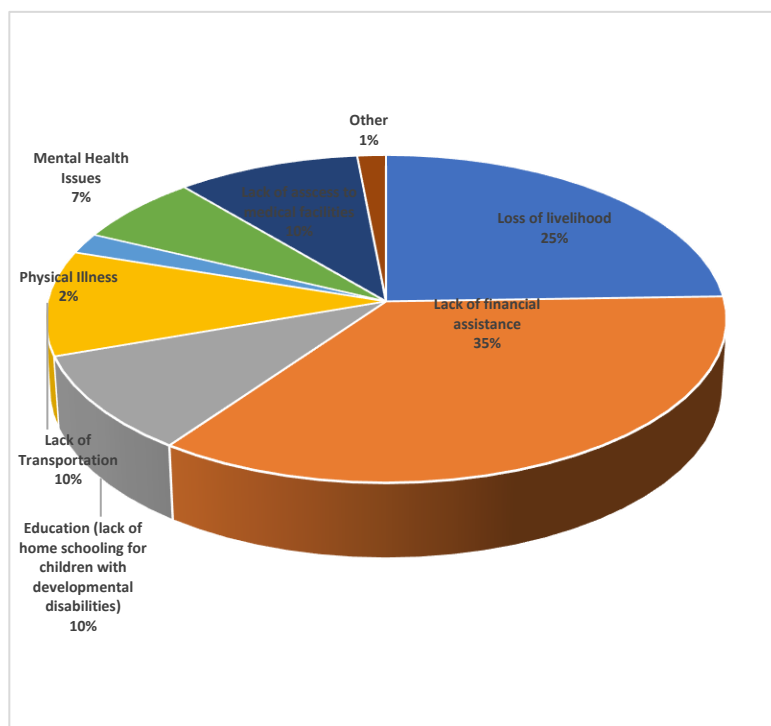


Similarly, 77% of the responding parents of children with disabilities said they experienced difficulties due to COVID. Among them 35% faced financial distress, 25% faced difficulties due to a loss of livelihood. 10% of parents reported difficulties due to a lack of transportation and education, lack of home schooling for children with developmental disabilities and medical facilities, while 7% reported difficulties due to mental health, 2% of them reported physical illness, and 1% reported other difficulties.

Throughout the pandemic, daily life and access to health care worsened for persons with disabilities. They frequently faced challenges in their daily lives of restrictions in mobility, difficulties in accessing public transportation, limitation in availing healthcare services, and communication barriers especially those using sign language and tactile mediums for communications.

It has been seen that Individuals with disabilities have a higher risk of depression, lower life satisfaction, and increased loneliness when compared to the general population. Considering the COVID-19 pandemic, the World Health Organization (WHO) recognised that this could significantly increase the daily challenges faced by persons with disabilities and stated that additional considerations for persons with disabilities are required from governments, healthcare systems, disability service providers, institutional settings, and communities. During the in-depth interviews, parents stated that the Covid-19 lockdown caused behavioural changes not only in children but also in adults.

Figure 18: Challenges faced by Parents of CwDs during Covid-19



However, some respondents indicated that the Covid-19 lockdown and related restrictions threw up new opportunities for access to technology and innovation. As a result of the introduction of those technologies and innovations, teachers, students, and counsellors could communicate via virtual calls, even during these difficult days. Despite the paucity of empirical evidence on the impact of COVID-19 on people with disabilities, the topic was not completely absent from the scientific literature. Some commentaries urged governments to provide adequate health related information and resources to populations, such as the deaf community, that are particularly vulnerable in terms of communication. Other authors emphasised the importance of ensuring equity in medical decisions, as well as gathering data on infection and mortality rates for people with physical disabilities who also have other health conditions. Subsequent discourses have been around the issue of vaccinations and the need for ensuring that persons with disabilities are able to avail of the vaccinations, either through specific drives and camps and even door to door vaccination programs, to ensure that they were covered.

---

*“Not only among the children, but also among adults, we have seen behavioural change, because we are in an open environment in our area but think about those who are living in the flat, those who are living in limited space and then usually they are disturbing others. So, it is not only a problem for the children with disabilities, but it is the problem of whole community at large.”*

A parent of a child with disability

---

It is significant that almost all NGOs reached in this survey responded that despite the difficulties that they faced during the lockdown they got involved in supporting children with disabilities and families in some way or the other.

State	COVID response
Manipur	All the NGOs were involved in <b>distributing relief materials</b> including food items, medicine and even financial help to their beneficiaries and donation to the CM's relief fund. Some were involved in <b>counselling and dealing with mental health</b> issues. However, they <b>had to suspend their services</b> and planned activities were disrupted
Mizoram	NGOs were badly affected as they were unable to meet beneficiaries. <b>Services were curtailed and limited to those staying in residential facilities.</b> This took a toll on their mental health. <b>Funding dried up</b> for many of them. They were unable to switch to online platforms due to the digital divide as many families did not have smart phones and had connectivity issues. <b>Most NGOs shut down their services.</b> However, <b>some did provide essential food items, offer mental health services and counselling.</b> <b>2 NGOs provided financial aid and created awareness on safety protocols with Village level Covid task forces.</b>
Assam	<b>All NGOs provided some level of support to communities</b> – awareness programs on COVID protocols; relief rations, medicine and hygiene kits, android devices and cash transfers ; <b>interventions to CwDs in Covid affected families and for Covid orphans; Vaccination camps and awareness campaigns to diffuse vaccine hesitation;</b> counselling to families, <b>tele-rehabilitation services via whatsapp messages and calls;</b> home visits when situation eased; some faced staff attrition due to <b>inability to pay staff salaries.</b>
Meghalaya	The pandemic disrupted all planned activities. They had to think of new alternative ways to work, as there was a huge gap in education and they <b>tapped the potential of ICT to design new teaching strategies</b> - Immersive Reader, TLMs, Byju's content (offered free to school going children), Translation tools and Nearpod and other applications. Most NGOs encountered major mental health issues and <b>offered counselling and therapy.</b> They <b>distributed rations</b> to relieve hunger crisis, gave financial support. Took up a project to <b>translate Govt's Covid Awareness modules</b> with students
Nagaland	Made <b>videos of public information and safety protocols for deaf students with sign language interpretation;</b> provided news, information and official announcements. Made video calls to motivate students who had gone home to continue learning as parents of deaf children were unable to communicate and discipline some of the children.
Sikkim	Pandemic <b>adversely affected the normal routine</b> due to lack of physical contact.
Tripura	Online and Teletherapy session were not possible as children were not reachable; Faced <b>restrictions in communication</b> with their target group of people with disabilities. <b>Received very little support for relief</b>

## Chapter 6 Discussion, Recommendations and Conclusion

### 6.1 Discussion:

Shishu Sarothi conducted this study to understand the situation of children and people with disabilities in North East India and map the needs and gaps in services, as well as in the realization of rights. The study will help to make a case for need-based programs/services and institutions to provide services, knowledge and information relating to disability, that is relevant and contextualized to the region. The study was conducted extensively across 8 states of NE India, amidst the Covid-19 pandemic, along with all the unprecedented challenges that came in its wake and was thus initially done remotely, using online platforms such as google forms for collection of survey data. Later field visits were made to conduct in-depth interviews and focus group discussions with stakeholders that included parents of children with disabilities and individuals with disabilities, non-government organizations (NGOs) as well as with some government officials and organizations of people with disabilities (OPDs). The extracted data via observation and recorded responses from stakeholders lists various issues of concern.

Major issues were constructed into themes and sub-themes by describing the narrative of lived experiences of stakeholders and service providers. Both quantitative and qualitative data were merged and analysed. The underlying issues of Awareness, Health, Education, and Livelihood were identified as major themes of the study. The supporting sub themes consist of challenges such as inaccessibility of existing infrastructure and services, lack of awareness on disability and implementation of RPWD Act, 2016 and Covid-19 related issues.

The findings revealed that there was **significant lack of awareness across all stakeholders** in the disability sector about interventions, services, rights, and entitlements as well as duties (of officials in implementing laws, schemes and programs), with a high prevalence of uninformed and unaware parents and caregivers of their child's disability at an early stage because of delayed assessment and intervention. Public child health programs such as Rashtriya Bal Swasthya Karyakram (RBSK) are designed to provide services at an early stage, but it was noted that the district level early intervention centres were not functional or adequately responsive in many states. There was evidence of negligence and apathy on the part of medical professionals too. This has thrown up an **urgent need for efficient delivery of health and early intervention services** both in the govt and non govt sector and to improve existing services and facilities.

**Most stakeholders have not obtained disability certificates or UDID Cards** because of a variety of factors, including ignorance about the process of obtaining a disability certificate, as well as insensitivity, inefficiency and opacity of government departments providing these services. In-depth interviews and Focus Group Discussions (FGDs) with stakeholders (Parents, Individuals, and DPOs) revealed that malpractices, **inefficiency, and discrimination were common in obtaining a disability certificate and UDID card.**

The current process involves repeated and arduous trips to Govt hospitals for assessment by doctors, who are often unavailable and unaware of specific guidelines for assessing benchmark disabilities to be followed by Medical Boards. Many Medical Boards do not have the requisite specialists for assessing specific disabilities at the district level. This delays the certification process further and stringent adherence to the rules discourages and demotivates people with disability needing certification. There is a definite case for involving other trained para medical and rehabilitation professionals in this process as they have the knowledge and understanding - many of them have formal disability specific RCI approved training. It has been argued by Srinivasan Venkatesan (2015) that while medical professionals who are not registered with RCI, having little knowledge of disability rehabilitation are authorised to certify disability, trained rehabilitation professionals aware of WHO's ICF guidelines and often better placed to assess extent of

disability, are not allowed to certify disability. Including rehabilitation professionals in certification will make it easier for persons with disabilities and their families to get their disability certificates.

In-depth interviews with parents, revealed that events at the time of pre- and post-natal development and delay or incorrect diagnosis often resulted in disability of their children. **Poor access to health systems and infrastructure**, particularly in rural areas, was a key reason contributing to the delays in early detection of disability. Urban children and youth with disabilities have it much better than their rural counterparts, where there is a paucity of appropriate diagnostic and treatment services, as well as opportunities for education, vocational training, and employment for PwDs.

While most respondents said they chose government hospitals and centers for their health care, in-depth interviews revealed **significant gaps in provision of early intervention services at public hospitals**. Respondents also shared instances of misdiagnosis of disability and negligence on the part of the authorities/medical professionals

### **Inadequate services available for children and persons with disabilities in Northeast India.**

The findings indicated that there were not enough seats or capacity, at available centres/institutions for children with disabilities, that are mostly run by NGOs. Some organizations offer home based services through CBR workers. However, most home-based services are irregular and do not offer comprehensive services particularly for children with high support needs. Parents with limited means settle for whatever services are available or cope and manage on their own if no interventions are available in their vicinity.

Parents spoke of difficulties in enrolling children with disabilities, particularly those with high support needs, in mainstream and higher education citing inadequate rehabilitation professionals, limited seats, exclusionary teaching practices of mainstream schools that did not accommodate needs of children with disabilities. Other reasons, include inaccessible school infrastructure, lack of financial support, non-availability of inclusive and special schools.

Only a very small percentage of PwDs are enrolled in higher education. 42% of respondents had completed primary schooling and **only 1% had post-graduation education**. This disparity is alarming as it suggests poor outcomes for future employability. Although Central and State Govt scholarships are available, there was little awareness among the respondents. 25% of the individual and 18% of parent participants in this survey had availed of scholarships. Many students with disabilities said they had difficulty in getting Govt scholarships.

Many of the individuals-with-disability responders have not completed formal education, indicating that they are unlikely to find gainful employment easily and likely to remain on the fringes and peripheries.

Most NGOs indicated that they worked in the education domain, during IDIs and FGDs with individuals and DPOs, parents of children with disabilities across the north-eastern states revealed **experiences of rejection, inaccessible school infrastructure, communities without school infrastructure (school-less-schools), lack of special education centers and educators**. Some felt that while inclusive education is crucial, there is a need for a paradigm shift in the current educational system with **updating of teacher education curriculum to include more child-friendly inclusive teaching practices for children with and without disabilities**. They also admitted to facing financial constraints and problems in transportation. Many also spoke of difficulties in admissions into the limited special education facilities and long waiting lists there.

During the in-depth interviews, individuals with disabilities spoke of difficulties faced in finding employment and financial constraints and most of them were poor and finding it hard to make ends m **They spoke of their disappointment with the Govt in providing them appropriate and relevant skill development opportunities** that could have enhanced their employability. **Only 15% of individual-with-disabilities respondents have received vocational/skill training**, and during the in-depth interview, they stated that one of the reasons for not enrolling in vocational/skill training is that they were

**unsure of the benefits of vocational training** and if it was worthwhile, as those who had received vocational training had not found any employment afterwards.

**NGOs expressed concern about funding to sustain their work.** Some spoke of difficulties in meeting rigid criteria of funding agencies and following best practices. They were **challenged by the lack of trained and committed human resources.** Their inability to pay high salaries, provide job security and retain staff often resulted in **attrition of trained and experienced staff** to better paid Govt jobs and their own lack of funding challenging new recruitments. They also found it hard to address the need for **public awareness and dispelling negative attitudes and stereotypes about disability.**

The **COVID pandemic**, adversely impacted daily life and **worsened access to health care** for persons with disabilities, compounding their already difficult and challenging situation. Individuals with disabilities were at higher risk of depression, lower life satisfaction and increased loneliness. During in-depth interviews, parents stated that **the prolonged spells of lockdown and being home bound worsened communication and behaviour problems** not only in children but also in adults, **with many having mental health issues.**

However, some NGO respondents also interpreted the Covid-19 lockdown as a **new opportunity for accessing technology and innovation**, and as a result teachers, students, and counsellors could stay in touch, communicate and continue teaching and learning via virtual and online medium, even during the most difficult times.

## 6.2 Recommendations:

To address the issues emerging from the survey and in- depth interviews and focus group discussions with various stakeholders the following recommendations are being made:

- Conduct **public awareness and legal literacy campaigns** urgently among rights holders and duty bearers across all states of NE India, on existing laws, specific focusing on informing rural communities to help change attitudes and break negative stereotypes. These programs can be carried out by Govt authorities (Social Welfare Dept officials, State Legal Service Authorities, SSA officials etc) as well as NGOs working on disability, and would be even more effective if they are led by people with disabilities themselves. Courses, workshops, seminars and discussions on legal provisions can also be conducted at different forum from academia to the community and grassroots level.
- **Facilitate improvement in Disability Certification and UDID card** processes by suggesting decentralization of the process and coopting civil society and non-government organizations as well as field level health, education, women and child development, rural development and other teams at district, block, cluster and village levels, to facilitate and collate information from persons with disabilities on the ground. Rehabilitation professionals with valid RCI registrations and skills and capacities to assess and diagnose disabilities could also be deployed to do preliminary assessments that could be the basis of certification. RCI registered Clinical Psychologists and Special Educators are well placed to do these basic assessments using recognized tools and templates.
- Expand **health related intervention and care services** at existing civil society and non-government organizations, in tandem and collaboration/partnership with ongoing Govt and public health programs. Activate and ensure effective delivery of disability prevention and control programs of the Health Department and facilitate functioning of RBSK and District Early Intervention Centers (DEICs) as well as District Disability Rehabilitation Centres (DDRC) of the Department of Empowerment of Persons with Disabilities.
- Create a **cadre of trained barefoot professionals including therapists, teachers, and community-based workers** for providing appropriate inputs and interventions to children with delayed development, and older persons with disabilities and those with high support needs in remote



rural areas. This could be done by encouraging and regulating conduct of training courses (regular and distance mode) on different disciplines of therapy, education, and social work in collaboration with local universities and institutions as part of the continuing adult learning education programs

- Initiate and **expand coverage of services to remote rural areas through outreach, community based and collaborative programs**. This can be done by initiating services directly with cadres of community-based workers or by supporting initiatives of registered and recognized non-government and civil society organization, or through public private partnerships with Govt programs.
- **Deployment of available software** to track and monitor services and rehabilitation programs – *Goonjan, Early Intervention (mbVREI), Punarjani* - and encourage development of similar software and applications that allow for universalization and contextualization.
- Promote **inclusive education for children with disabilities** by engaging with mainstream public education systems and training schoolteachers in alternate strategies for inclusion. Courses on Universal Design of Learning, trainings on Sign Language Interpretation, use of ICT and Alternative and Augmentative Communication software can be offered by government and non-government institutions in collaboration with local universities. Expand State and National Institute of Open Schooling centers to every district and block level. This can be led by SSA and designated to school complexes.
- Improve **access to scholarships and incentives** for retention and progress in schools and education institutions. Collate and create a knowledge bank of information on all possible (state, national and international) scholarship options available at school and higher education levels from public and private bodies.
- Enable **access and inclusion in skill development programs** to ensure economic independence of persons with disabilities. This would involve converging with mainstream skill and livelihood programs in private and public sector including state level skill development missions. Industries and commercial businesses could be encouraged to provide mutually beneficial job descriptions, training and potential employment and learning opportunities for persons with disabilities. Opportunities for financial inclusion and entrepreneurship could be offered by strengthening existing and creating new strands of support.
- Provide trainings to **empower families, caregivers and support networks** to persons with high support needs to live independently in communities. This could involve creating a network of support services with trained caregivers by NGOs and rehabilitation professionals. The support service network could cover personal caregiving, recreational therapies, support for social participation, respite care as well as interventions during emergency situations for individuals with disabilities and to families of children with high support needs.
- Orient and **sensitize other civil society organizations to engage in disability rehabilitation work** directly and/or through referrals and inclusion in their ongoing health, education, skill development programs. Such initiatives will not only facilitate the participation and inclusion of persons with disabilities in other mainstream social development programs but also catalyze convergence of disability into cross cutting domains of health, education, accessibility and economic empowerment.
- Conduct **regular research studies on status of disability** on the lines of the Pratham ASER report to create a empirical evidence and knowledge on different aspects of disability rehabilitation. This can be done collaboratively as state-specific or regional research studies and focus on different thematic aspects of realization of rights of persons with disabilities.

### 6.3 Conclusion:

It is evident from the findings discussed above that the study supported both the hypotheses

- the lack of awareness among stakeholders in the disability sector about interventions, services, rights, and entitlements as well as duties (of officials in implementing laws, schemes and programs)
- inadequacy of services available for children and persons with disabilities in NE India.

However, the finding from the available data is not adequate to support the research question on lack of disability disaggregated data. The population of PwDs is quite under-represented as reflected in the finding wherein many respondents do not have disability certificates which in turn implies that there are fewer registrations of Unique Disability ID (UDID) cards. Additionally, the digital divide in the country prevents large numbers of people with disability with limited means from accessing online sources of information and services.

The unprecedented and calamitous effect of the global pandemic on the human psyche and health of people in the region, posed a major challenge in collection of study data, restricting intra and interstate travel thus limited the free will approach of the research study.

Considering the limitations, this study does not provide concrete conclusions, rather it gives insights to understanding the needs and gaps of services and entitlements and the realization of rights of persons with disabilities in north east India and it is hoped that these insights can help to guide individual organizations and cohorts and consortiums as well as authorities to take up appropriate plans to address the different gaps and needs of the sector.

---

### References

- Affairs, D. o. (2018). *Disability and Development*. New York: United Nations. Retrieved from <http://shop.un.org>
- Balamurugan, G. R. (2016, 10 01). Landslide susceptibility zonation mapping using frequency ratio and fuzzy gamma operator models in part of NH-39, Manipur, India. *Natural Hazards*, 84(1), 465-488. doi:10.1007/s11069-016-2434-6
- Convention on the Rights of Persons with Disabilities (CRPD). (2006, December 6). Retrieved from <http://www.un.org/esa/socdev/enable/rights/convtexte.htm>
- Deepak, S. (2016). Disability rehabilitation in the North east of India. In S. Deepak, *Disability rehabilitation in the North east of India* (p. 75). Guwahati: Mobility India, North-east (MI-NE).
- DHENKANAL. (2021, 09 21). Retrieved from Indira Gandhi National Disability Pension Scheme (IGNDPS): <https://www.indiafilings.com/learn/indira-gandhi-national-disability-pension-scheme/>
- (2018). *Disability and Development: Realizing the Sustainable Development Goals by, for and with persons with disabilities*. New York, New York 10017, United States of America: United Nations (Department of Economic and Social Affairs). Retrieved from <http://shop.un.org>
- Ghai, A. (2015). Rethinking Disability in India. In A. Ghai, *Rethinking Disability in India* (pp. 94-98). New Delhi 110 001: Routledge.
- Gupta, B. (2020, February). *Rights and Entitlements of Persons with Disabilities in India: An Evaluation*. Retrieved from Research Gate: <https://www.researchgate.net/publication/344666499>
- (2001). *International classification of functioning, disability, and health: ICF*. World Health Organization. Geneva: World Health Organization 2001.
- Jameel, S. S. (2011). *Disability in the Context of Higher Education: Issues and Concerns in India*, 2(7), 1-22. Retrieved from <https://corescholar.libraries.wright.edu/ejie>
- Jumabhoy, F. (2017, 10 26). *India: Implementation of rights of persons with disabilities act 2016*. Retrieved from Herbert smith freehills LLP: <https://hsfnotes.com/employment/2017/10/26/indiaimplementation->
- Karten, T. J. (2008). Embracing Disabilities in the Classroom.
- Kothari, B., Galliara, M., & Huitem, R. (2020). The disability scenario in India: A reality check. *Journal of social work education and practice*, 32-54.
- Kumar, S. (2016). *Rights of Persons with Disabilities Bill - 2016 Passed by Parliament*. Ministry of Social Justice & Empowerment: Press Information Bureau.
- Lang, R. (2000). The role of NGOs in the process of empowerment and social transformation of people with disabilities. *Asia pacific disability Rehabilitation journal*, 1(1), 1-19.
- Lakhumalani, V. (n.d.). HELLO, CAN YOU HEAR ME? Vanni. Retrieved from [www.vaani.in](http://www.vaani.in)
- Lebrasseur, A., Fortin-Bédard, N., Lettre, J., Bussièrès, E.-L., Best, K., Boucher, N., . . . Routhier, F. (2021). Impact of COVID-19 on people with physical disabilities: A rapid review. *Elsevier Public Health emergency Collection*.
- Ministry of statistics and programme implementation, g. o. (2021). *Persons with disability in India - A statistical profile*. New Delhi: NSO India.
- National Centre for Promotion of Employment for Disabled People (NCPEDP). (2021) *NATIONAL EDUCATION POLICY: Opportunities & Challenges*
- National Education Policy*. (2020). Retrieved from Ministry of Human Resource Development, Government of India: [https://www.education.gov.in/sites/upload\\_files/mhrd/files/NEP\\_Final\\_English\\_0.pdf](https://www.education.gov.in/sites/upload_files/mhrd/files/NEP_Final_English_0.pdf)
- NSO. (2019). *Persons with Disabilities in India, NSS 76 round*. New Delhi: Government of India, Ministry of Statistics and Programme Implementation.
- Rashtriya Bal Swasthya Karyakram (RBSK)*. (2021, February 19). (Ministry of Health & Family Welfare, Government of India) Retrieved from National Health Mission: <https://nhm.gov.in/index1.php?lang=1&level=4&sublinkid=1190&lid=583>
- Sabatello, M. (2013). History of Disability Rights. *Research gate*, 12.

Sarthak Educational Trust, *Empowering Differently Abled*. (2021). Retrieved from Disability Information Portal: [https://sarthakindia.org/disability\\_information\\_portal/scholarships.php](https://sarthakindia.org/disability_information_portal/scholarships.php)

Sarva Shiksha Abhiyan. (2019, April 29). Retrieved from Department of School Education and Literacy, MHRD, Government of India: <https://www.education.gov.in/en/schemes>

Simon, K. M. (2018). *Poverty and mental illness*. New York: Psychiatric Times.

Singal, N. (2009). Education of children with disabilities. *Background paper for the UNESCO GMR 2010*, 5-39. doi:2010/ED/EFA/MRT/PI/21

*Social Welfare - Differently Abled Sector, Government of Assam*. (2021, 08 07). Retrieved from <https://socialwelfare.assam.gov.in/documents-detail/guideline-of-deendayal-divyangjan-pension>

Srinivasan Venkatesan, D. S. (2015). Letter to the Editor Disability Certification: Issues and Concerns Corresponding Author. *JAISH*, 34, 1-7.

Stolman, M. (2019). International disability law: a practical approach to the United Nations Convention on the Rights of Persons with Disabilities, *Disability & Society*. doi:10.1080/09687599.2019.1623526

*The Disabled People's Movement* (Vol. 4). (1997). The British Council of Organizations of Disabled People (BCODP).

(2016, Dec 28). *The Rights of Persons with Disabilities Act*. Ministry of Law and Justice, New Delhi: The Gazette of India. Retrieved from The Gazette of India.

Thomas John, A. A. (2018, July-Sep). Strength and weakness of the guidelines of Rights of Persons with Disabilities Act, 2016 (dated January 5, 2018): With respect to the persons with neurodevelopmental disorders. 3, pp. 261-264. doi: 10.4103/psychiatry.IndianJPsychiatry\_326\_18

Times, T. E. (2019, November 23). *India's 2.2% population suffering from disability: NSO survey for July-Dec 2018*. Retrieved from <https://economictimes.indiatimes.com: https://economictimes.indiatimes.com/news/economy/indicators/indias-2-2-population-suffering-from-disability-nso-survey-for-july-dec-2018/articleshow/72202650.cms>

Tracey Smythe, M. Z. (2020, August 11). Early intervention for children with developmental disabilities is low. 1-222. doi:10.1093/inthealth/ihaa044

*United Nations Population Fund (UNFPA)*. (n.d.). Retrieved from Population Analysis for Policies & Programmes: [https://papp.iussp.org/sessions/papp101\\_s01/PAPP101\\_s01\\_020\\_010.html](https://papp.iussp.org/sessions/papp101_s01/PAPP101_s01_020_010.html)

Verma, D., Dash, P., Bhaskar, S., Pal, R. P., Jain, K., R.P. Srivastava, H.P. Kesan. (2016). *Disabled Persons in India A Statistical profile 2016*. New Delhi: Ministry of Statistics and Programme Implementation Government of India.

*World Health Organization*. (2001). Retrieved from international Classification Functioning, Disability and Health (ICF): <http://www.iahw.gov.au>

(2011). *World Report on Disability*. WHO Library Cataloguing-in-Publication Data

**Appendix**

**Annexure I:**

**Classification of Disability as per NSS 76<sup>th</sup> Round Report on Disability 2018**

Sl.no	Types of disability	Classification
1	Locomotor disability	Locomotor disability implies a person's inability to execute distinctive activities associated with movement of self and objects
2	Leprosy cured person	A person who has been cured of leprosy but is suffering from (a) loss of sensation in hands or feet as well as loss of sensation and paresis in the eye and eyelid but with no manifest deformity, (b) with manifest deformity and paresis but having sufficient mobility in the hands and feet to engage in normal activity, and (c) extreme physical deformity which prevents him/her from engaging in normal activity. A person was considered as a leprosy cured person if a medical practitioner had such an opinion.
3	Cerebral palsy	Cerebral palsy means a group of non-progressive neurological conditions affecting body movements and muscle coordination, caused by damage to one or more specific areas of the brain, usually occurring before, during or shortly after birth.
4	Dwarfism	Dwarfism means a medical or genetic condition resulting in very short statured physique. A person of short statured with a normal sized head but with disproportionate bone formation like having short limbs and long trunk or vice versa is considered to be dwarf. Besides, those who are understood or known to be dwarf would also be considered as dwarf.
5	Muscular dystrophy	Muscular dystrophy means a group of hereditary genetic muscle disease that weakens the muscles that move the human body. It is characterised by progressive skeletal muscle weakness, defects in muscle proteins, and the death of muscle cells and tissue.
6	Acid attack victim	Acid attack victim means a person disfigured due to violent assaults by throwing of acid or similar corrosive substance. If the informant reports that he/she was an acid attack victim, he/she was considered as an acid attack victim, irrespective of extent of disfigurement.
	Visual Impairment	
7	Blindness	These are the persons (i) with no light perception or (ii) have light perception but cannot count fingers even with spectacles up to a distance of 3 feet (both who normally use spectacles or those who normally do not use spectacles).
8	Low vision	These are the persons who have light perception but cannot count fingers even with spectacles up to a distance of 3 to 10 feet (both who normally use spectacles or normally do not use spectacles).
	Hearing disability	
9	Deafness &	A person with who cannot hear at all
10	Hard of Hearing	i. The persons' inability to hear properly; ii. Has difficulty in hearing day-to-day conversational speech (hard of hearing); If the person is using a hearing aid, the person is considered as having hearing disability. However, hearing problems in only one ear is not considered as having hearing disability.
11	Speech and Language disability	This refers to persons' inability to speak properly. A person with any one of the following conditions was considered as a person with speech and language disability: i. Cannot speak at all or she/he is unable to speak normally on account of certain difficulties linked to speech disorder. Speech of a person is judged to be disordered if the person's speech is not understood by the listener; ii. Able to speak in single words only and is not able to speak in sentences.

		<p>iii. It also includes those whose speech is not understood due to defects in speech, such as stammering, nasal voice, hoarse voice and discordant voice and articulation defects, etc.</p> <p>iv. Permanent disability arising out of conditions such as laryngectomy or aphasia was also considered as speech and language disability</p> <p>v. Aphasia is an inability to comprehend and formulate language because of damage to specific brain regions.</p> <p>vi. Laryngectomy is the removal of the larynx and separation of the airway from the mouth, nose and esophagus. If a person has a laryngectomy or a report of diagnosis with respect to aphasia, he is considered as having speech and language disability. Diagnosis means a medical diagnosis by a medical practitioner.</p>
12	Intellectual disability	Those who are not classified in any of the categories Specific learning disabilities and autism spectrum disorder but having significant limitation both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behaviour which covers a range of every day, social and practical skills was classified as persons with 'other mental retardation/intellectual disability'.
13	Specific learning disabilities	A condition wherein there is a deficit in processing language, spoken or written, that may manifest itself as a difficulty to comprehend, speak, read, write, spell, or to do mathematical calculations and includes such conditions as perceptual disabilities, dyslexia, dysgraphia, dyscalculia, dyspraxia and developmental aphasia.
14	Autism spectrum disorder	A neuro-developmental condition typically appearing in the first three years of life that significantly affects a person's ability to communicate, understand relationships and relate to others, and is frequently associated with unusual or stereotypical rituals or behaviours.
15	Mental illness	A substantial disorder of thinking, mood, perception, orientation or memory that grossly impairs judgment, behaviour, capacity to recognise reality or ability to meet the ordinary demands of life, but does not include retardation which is a condition of arrested or incomplete development of mind of a person, specially characterised by sub normality of intelligence.
	Chronic neurological conditions like,	
16	Multiple sclerosis	An inflammatory, nervous system disease in which the myelin sheaths around the axons of nerve cells of the brain and spinal cord are damaged, leading to demyelination and affecting the ability of nerve cells in the brain and spinal cord to communicate with each other.
17	Parkinson's disease	A progressive disease of the nervous system marked by tremor, muscular rigidity, and slow, imprecise movement, chiefly affecting middle-aged and elderly people associated with degeneration of the basal ganglia of the brain and a deficiency of the neurotransmitter dopamine.
	Blood disorders	
18	Haemophilia	An inheritable disease, usually affecting only male but transmitted by women to their male children, characterised by loss or impairment of the normal clotting ability of blood so that a minor wound may result in fatal bleeding.
19	Thalassemia	A group of inherited disorders characterised by reduced or absent amounts of haemoglobin.
20	Sickle cell disease	A hemolytic disorder characterised by chronic anaemia, painful events, and various complications due to associated tissue and organ damage; "haemolytic" refers to the destruction of the cell membrane of red blood cells resulting in the release of haemoglobin.
21	Multiple disabilities	Persons with more than one of the above specified disabilities including deaf blindness which means a condition in which a person may have a combination of hearing and visual disability causing severe communication, developmental, and educational problems.



**Annexure II:**

**Questionnaire for Government officials**  
**Situational Analysis of Disability Scenario In North-east India**

1. Email:.....
2. Name: .....
3. Department: .....
4. Post / Designation: .....
5. State : .....
6. District:.....

**Section A: General information**

1. What is the role of your department with regard to persons with disability?  
.....  
.....  
.....
2. What are the services provided by your department for persons with disability? Kindly specify the services that your department is providing  
.....  
.....  
.....
3. Does your department provide financial assistance to persons with disability? If yes, kindly specify the name of schemes/projects with its criteria  
.....  
.....  
.....
4. Does your department collaborate with other non-governmental organization? If yes, what is the procedure to collaborate with your department?  
.....  
.....  
.....

**Section-B: Rights and Entitlement**

**Ø Employment/livelihood**

1. Are there any PWDs employees in your department?
  - i. Yes
  - ii. No

2. What kind of employment/livelihood opportunities does your department provide to PWDs?  
i. Formal Vocational training ii. Non-Formal Vocational training iii. Both iv. None

**Ø Education**

1. Is there any Teacher Training Institute in the district?

- i. Yes ii. No  
iii. Not sure

2. Is there any Disability Resource Centre in your district?

- i. Yes  
ii. No

3. Does your department take an intervention to make schools disabled friendly? i. Yes ii. No  
iii. Not sure

**Ø Health / Curative**

4. Does your department provide health related services to persons with disability?

- i. Yes  
ii. No

**COVID-19 :**

1. How does Covid-19 pandemic impacts your department in providing services?

.....  
.....  
.....  
.....  
.....

2. What are the challenges faced by the department in dealing with the situation of COVID19?

.....  
.....  
.....  
.....  
.....  
.....  
.....

**3. Services**

- a) Does the department provide any kind of Online Services amidst COVID-19 lockdown?

- i. Yes  
ii. No

- b) If yes, what kinds of services are provided?

.....  
.....  
.....  
.....  
.....

**Annexure III:**

**Situational Analysis of Disability Scenario in Northeast India (Questionnaire for Individual)**

Dear Respondent,

We at Shishu Sarothi are conducting a study of the existing disability scenario in NE India, in- order to understand the needs and gaps in services and realisation of rights of its citizens' with disabilities. This study will help us to create a case for need based programs/services and institutions and the knowledge and information about disability that is relevant and contextualised to the region and to the current times.

Therefore, we request you to participate in this study and give us your valuable response.

\* **Required**

1. Email:
2. Contact No:
3. Name \* :
4. Date of Birth :
5. Gender  
Female            Male            Transgender            Other:
6. Kindly share the nature/type of disability that you have :
7. Do you know the percentage of your disability?
8. Which social category do you belong to?  
ST    SC                    OBC                    General

State \*

1. Arunachal Pradesh
2. Assam
3. Manipur
4. Meghalaya
5. Mizoram
6. Nagaland
7. Sikkim
8. Tripura
9. District
10. Address.

**Section A: Health and Services**

1. Do you have a Disability Certificate?  
Yes            No                    Under process
2. If no, are you aware about Disability Certificate?  
Yes            No
3. If yes, do you know how to get it?  
Yes            No
4. If under process, did you face any difficulties?  
Yes                    No

## Unaware, Untapped and Under-served

Study Report on situation of persons with disabilities in NE India -  
needs and gaps in services and realisation of rights



If yes, kindly specify what kind of difficulties.....

5. How do you think the Disability Certificate will help you?
- a. In accessing Govt schemes and grants
  - b. In pursuing education
  - c. In availing scholarships
  - d. In getting a job
  - e. Any other  
If any other, kindly Specify  
.....
6. Do you need any assistive devices/aids and appliances/support services?
- a) Walker
  - b) Gaiters/Splints
  - c) Special chair
  - d) Hearing aid
  - e) White Cane
  - f) Prosthetic device
  - g) Wheelchair
  - h) Speech Therapy
  - i) Physiotherapy
  - j) Sign Language
  - k) Medical advice
  - l) Surgery
  - m) Special education inputs
  - n) Occupational therapy
  - o) Any other, specify .....
7. Where do you go for your health needs?
- a) Sub-centre
  - b) Primary health center
  - c) Community health center
  - d) District health center
  - e) Private Hospital
  - f) Traditional healer
  - g) Others  
If other, kindly specify
8. Is it accessible for you?
- a. Yes                      No
9. Do you get free health services?
- a. Yes                      No
10. Did you get priority treatment?
- a. Yes                      No
11. Do you have health insurance?
- a. Yes                      No  
If yes, kindly specify the name of health insurance  
.....

### Section B: Educational Services

12. Have you enrolled in a school/college/educational institution?



**Section C: Socio-economic status**

1. What is your family's source of income?
  - a) Government job
  - b) Private
  - c) Self-employed (specify)
  - d) Farmer
  - e) Daily labor
  - f) OthersIf other, kindly specify  
.....
2. Have you received any vocational skill training?
  - a. Yes
  - b. NoIf yes, kindly specify what kind of training you have received  
.....
3. If no, do you think you need any training?
  - a) Yes
  - b) NoIf yes, what kind of training would you like to get?  
.....
4. Have you faced any discrimination?
  - a) Yes
  - b) No
5. If yes, kindly specify
  - a) Home
  - b) Workplace
  - c) School/Educational Institution
  - d) Public Space (market, park, religious institution etc.)
6. How do you cope with such situations?  
.....
7. Are you able to express your choice or opinion during any decision-making process in your family?
  - a. Yes
  - b. No
  - c. SometimesIf no, kindly specify why?  
.....
8. Are you able to participate in community functions and programs?
  - a. Yes
  - b. No
9. Are you interested in taking part in politics?
  - a. Yes
  - b. No
10. Do you know about the census process?
  - a. Yes
  - b. No
11. Will you be willing to share information about your disability during the next census?
  - a. Yes
  - b. No



### Section D: Covid-19 Situation

1. Due to Covid-19 lockdown have you faced any kind of difficulties?
  - a. Yes
  - b. No
2. If yes, what are the challenges faced by you in dealing with Covid-19 situation?
  - Loss of livelihood
  - Lack of financial assistance
  - Education (lack of home schooling for children with developmental disabilities)
  - Lack of Transportation
  - Physical Illness
  - Mental Health (behavioural change, change in emotional attitude etc.)
  - Lack of accessing medical facilities
  - Other

If other, kindly specify
3. Have you received any kind of services due to Covid-19 lockdown?
  - a. Yes
  - b. No
4. If yes, from where did you receive services?
  - a. Government
  - b. NGOs
  - c. Both
  - d. Others
5. What kind of services did you receive?
  - a) Essential goods (rice, milk, dal, sugar etc.)
  - b) Mental health services (counselling, therapy etc.)
  - c) Medical services
  - d) Financial aid
  - e) Other
6. Any other
7. comment

**Annexure IV:**

**Situational Analysis of Disability Scenario in Northeast India (Questionnaire for Parents)**

**\* Required Email:**

1. Contact No:
  
2. Name of the respondent \*  
.....
  
3. Gender
  - 1) Female
  - 2) Male
  - 3) Transgender
  - 4) Others
  
4. Name of the child with disability  
.....
  
5. How old is your child?  
.....
  
6. What is the type of disability that your child has?  
.....
  
7. Which social category do you belong to?
  - 1) ST
  - 2) SC
  - 3) OBC
  - 4) General
  - 5) Other
  
8. Which state are you from? \*
  - 1) Arunachal Pradesh
  - 2) Assam
  - 3) Manipur
  - 4) Meghalaya
  - 5) Mizoram
  - 6) Nagaland
  - 7) Sikkim
  - 8) Tripura
  
9. Which district do you live in?

**Section A: Health and Services**

1. Does your child have a Disability Certificate?  
Yes  
No  
Under process
  
2. If no, are you aware about Disability Certificate?  
Yes  
No

3. If under process, did you face any difficulties?  
Yes  
No  
If yes, kindly specify what kind of difficulties .....
4. Does the Disability Certificate help your child in any of the following ways?
  - 1) Accessing Government schemes/programs
  - 2) Pursuing Education
  - 3) Availing Scholarships
  - 4) Any other      If any other, kindly specify .....
5. How did you find out about your child's disability?
  - 1) From deformities evident at birth
  - 2) After any serious or chronic illness
  - 3) Due to delayed development
  - 4) Due to difficulties in movement
  - 5) Due to difficulties in seeing
  - 6) Due to difficulties in hearing
  - 7) Due to difficulties in speaking and learning language
  - 8) Due to difficulties in socializing
  - 9) Due to difficulties in understanding
  - 10) Due to difficulties in daily living activities (feeding, drinking, toileting, dressing, playing)
  - 11) Any other, kindly specify .....
6. When did you find out about the disability of your child?
  - 1) 0-6 months
  - 2) 6-12 months
  - 3) 1-3 years
  - 4) 3-6 years
  - 5) 6 and above
7. What did you do after finding out about your child's problem/disability?
  - 1) Consult a doctor
  - 2) Consult a traditional/faith healer
  - 3) Consult Anganwadi Worker/ASHA
  - 4) Consult a therapist
  - 5) Consult an NGO
  - 6) Any otherIf any other, kindly specify .....
8. Does your child need any assistive devices/aids and appliance/special support services?
  - 1) Walker
  - 2) Gaiters/Splints
  - 3) Special chair
  - 4) Hearing aid
  - 5) White Cane
  - 6) Prosthetic device
  - 7) Wheelchair
  - 8) Speech Therapy
  - 9) Physiotherapy
  - 10) Sign Language
  - 11) Medical advice
  - 12) Surgery

- 13) Special education inputs
  - 14) Occupational therapy
  - 15) Any other
  - If any other, kindly specify .....
9. Where do you go for your child health needs?
- 1) Sub-centre
  - 2) Primary health center
  - 3) Community health center
  - 4) District health center
  - 5) Private Hospital
  - 6) Traditional healer
  - 7) Others
  - If others, kindly specify .....
10. Does your child get free health services?
- 1) Yes
  - 2) No
  - If no, kindly specify amount in rupees .....
11. Does your child have health insurance?
- 1) Yes
  - 2) No
  - If yes, specify the name of health insurance .....

**Section B: Educational Services**

12. Does your child go to any school/educational institution?
- 1) Yes
  - 2) No
13. If yes, what type of school/educational institution?
- 1) Regular
  - 2) Special school
  - 3) Open school
  - 4) Home school
  - 5) Any other      If any other, kindly specify .....
14. During admission of your child to the school/educational institution have you faced any difficulties?
- 1) Yes
  - 2) No
15. If yes, kindly specify what kind of difficulties did you face?
- 1) Attitude of teacher
  - 2) Attitude of Peers
  - 3) Financial problems
  - 4) Accessibility in school/educational institution
  - 5) Problem in Transportation
  - 6) Any other
  - If any other, kindly specify .....
16. Did you receive any scholarship for your child?
- 1) Yes
  - 2) No

If yes, kindly specify the amount and name of the Scholarship  
.....

17. Does your child have UDID (Unique Disability ID) card from the Dept of Social Welfare of your state?
- 1) Yes
  - 2) No
  - 3) Under process
  - 4) Not Aware

• **Section B: Socio-economic status**

1. What is your source of income?
- 1) Government job
  - 2) Private
  - 3) Self employed
  - 4) Farmer
  - 5) Daily labour
  - 6) Others
- If any other, kindly specify?.....
2. Do you participate in community life with your child (attend public meetings programs, events etc.)?
- 1) Yes
  - 2) No
3. Have you or your child faced any discrimination?
- 1) Yes
  - 2) No
4. If yes, where?
- 1) Home
  - 2) Workplace
  - 3) School
  - 4) Public place (market, park, religious institution etc.)
5. How do you cope up with such situations?
- .....
- .....
- .....
6. As a parent of a child with disability, what kind of difficulties do you face?
- .....
- .....
- .....
7. Do you know about the census process?
- 1) Yes
  - 2) No
8. Will you be willing to share information about your child's disability during the next census?
- 1) Yes
  - 2) No

**Section C: Covid-19 situation**

1. Due to Covid-19 lockdown have you faced any kind of difficulties?
- 1) Yes
  - 2) No
2. If Yes, what are the challenges faced by you in dealing with Covid-19 situation?
- Loss of livelihood

## Unaware, Untapped and Under-served

Study Report on situation of persons with disabilities in NE India -  
*needs and gaps in services and realisation of rights*



- Lack of financial assistance
- Education (lack of home schooling for children with developmental disabilities)
- Lack of Transportation
- Physical Illness
- Mental Illness (behavioral change, change in emotional attitude etc.)
- Lack of accessing medical facilities
- Other , kindly specify

.....  
.....

3. Have you received any kind of services during Covid-19 lockdown?

- 1) Yes
- 2) No

4. If yes, from where did you receive services?

- 1) Govt.
- 2) NGOs
- 3) Both
- 4) Others

5. What kind of services did you receive?

- 1) Essential goods (rice, milk, dal, sugar etc.)
- 2) Mental health services (counselling, therapy etc.)
- 3) Medical services (medicines, treatments etc.)
- 4) Financial aid
- 5) Other

6. Any other comments

**Annexure V:**

**Questionnaire for NGOs  
Situational Analysis of Disability Scenario in North-east, India**

General information (section i)

**\* Required**

1. Email address: \* .....

2. Name of the organization: \* .....

3. Organizations' registration: \*

Mark only one oval.

Society Registration Act

Trust Act

Companies Act

Special Licensing

4. Registration no: .....

5. Address:

6. State: \* .....

7. District: .....

8. Contact no: \* .....

9. Email: .....

10. Chief Functionary of the organization \* .....

11. Year of Establishment: .....

*Example: January 7, 2019*

12. Social media platform:

*Check all that apply.*

Web site

Facebook

Instagram

Twitter

Telegram

Any other

13. Kindly provide the link of your social media platform

*Skip to question 14*

**Section ii**

14. Area of work \*

*Check all that apply.*

Education

Health

Human Rights

Vocational training

Shelter

Short stay home

Rehabilitation centre

Advocacy

Awareness

Disabled people organization

Any other

*Skip to question 15*

**Section iii**

15. If education, specify

*Check all that apply.*

Inclusive

Special

Formal



## Unaware, Untapped and Under-served

Study Report on situation of persons with disabilities in NE India -  
*needs and gaps in services and realisation of rights*

Informal

Non-formal

16. If health, Specify

*Check all that apply.*

Therapies

Early intervention

Medical services

Diagnosis

Medication

Counselling

17.If rehabilitation centre, specify

*Check all that apply.*

Occupational

Physical

Speech

any other

18. If any other, specify

19. if Vocational training, specify

*Check all that apply.*

Computer

Executive Housekeeper

Personal Trainer

Art/Design

Auto Repair Training

Hair-styling, Cosmetics and Beautification

Health care and social assistant

Organizational/Leadership Skills

Small Business Management

Disability Support Worker

Food Service Cook

Any other

20. If any other, specify

21. For how many years your organization has been working for persons with disabilities \* .....

22. What are the ongoing services for children/persons with disabilities?

*Check all that apply.*

Inclusive education

Vocational education

Day care centre

Scholarships

Medical treatment/therapy

Livelihood

Short stay home

Any other

23. If any other, specify

24. What are the types of disability that your organization is currently working with \*

*Check all that apply.*

Blindness

Person with Low Vision

Cerebral Palsy

Hearing Impairment

## Unaware, Untapped and Under-served

Study Report on situation of persons with disabilities in NE India -  
*needs and gaps in services and realisation of rights*

Leprosy Cured person  
Locomotor disability  
Mental illness  
Learning disability  
Speech and language disability  
Dwarfism  
Muscular dystrophy  
Parkinson's disease  
Multiple Sclerosis  
Thalassemia  
Haemophilia  
Sickle cell disease  
Autism Spectrum disorder  
Multiple disabilities including deaf blindness  
Chronic Neurological conditions  
Acid attack victim

25. What is the number of beneficiaries .....
26. What is the age group of beneficiaries \* .....
27. What are the reasons for working with persons with disabilities \* .....
28. Describe the impact of your programs/projects .....
29. What are the challenges faced by the organization while working with persons with disabilities

*Check all that apply.*

Funds

Lack of trained manpower  
Lack of awareness on disability  
Lack of infrastructure  
Lack of support from community  
Lack of government support  
Any other

30. How does Covid-19 effects in providing services by your organization.....

31. What are the challenges faced by the organization in dealing with COVID19?

32. Does your organization provide any kind of services amidst COVID-19 lockdown?

*Mark only one oval.*

Yes

No

Maybe

33. If yes, what kind of services is provided?

*Check all that apply.*

Essentials goods (Rice, milk, dal, sugar etc...)  
Mental Health Services (Counselling, Therapy)  
Medical Services (Medicines, Treatments)  
Financial aid  
Other

34. If any other, specify

35. Suggestions/feedback

**Annexure VI:**

**Questionnaire for Government Institutions  
Situational Analysis of Disability Scenario in North-east India**

**Organization Profile**

1. Name of Organization: .....
2. Respondent Name: .....
3. Designation/Position: .....
4. Organization registration: .....
5. Registration Number: .....

**Section A: Nature of work/Area of intervention**

1. What are the types of disability that your organization is working with?
  - Blindness
  - Low Vision
  - Leprosy Cured persons
  - Loco motor Disability
  - Dwarfism
  - Intellectual Disability
  - Mental Illness
  - Cerebral Palsy
  - Specific Learning Disabilities
  - Speech and Language disability
  - Hearing Impairment
  - Muscular Dystrophy
  - Acid Attack Victim
  - Parkinson's disease
  - Multiple Sclerosis
  - Thalassemia
  - Hemophilia
  - Sickle Cell disease
  - Autism Spectrum Disorder
  - Chronic Neurological conditions
  - Multiple Disabilities including Deaf Blindness
2. What is the process of registration for persons with disabilities in your organization?
3. Does your organization conduct any awareness programs for persons with disability?
  - a. Yes
  - b. No
4. If yes, how many programs a year?

**Services**

1. What types of services your organization provides?
  - Education
  - Health
  - Human Rights
  - Vocational Training
  - Shelter
  - Short home stay
  - Rehabilitation Centre
  - Advocacy

## Unaware, Untapped and Under-served

Study Report on situation of persons with disabilities in NE India -  
needs and gaps in services and realisation of rights

- Awareness
- Disabled Organization
- Any other specify

a. Specify the services:

Education	Health	Therapy	Vocational
<ul style="list-style-type: none"> <li>○ Inclusive</li> <li>○ Special</li> <li>○ Formal</li> <li>○ Informal</li> <li>○ Non-formal</li> </ul>	<ul style="list-style-type: none"> <li>○ Early intervention</li> <li>○ Medical services</li> <li>○ Diagnosis</li> <li>○ Medication</li> </ul>	<ul style="list-style-type: none"> <li>○ Occupational</li> <li>○ Physical</li> <li>○ Speech</li> <li>○ Any other, specify</li> </ul>	<ul style="list-style-type: none"> <li>○ Computer</li> <li>○ Executive Housekeeper</li> <li>○ Personal Trainer</li> <li>○ Art/ design</li> <li>○ Auto repair training</li> <li>○ Hair styling, Cosmetic, beautification</li> <li>○ Health care and social assistant</li> <li>○ Organizational/ leadership skills</li> <li>○ Small business management</li> <li>○ Disability Support worker</li> <li>○ Food service/ cook</li> <li>○ Any other, specify</li> </ul>

1. What is the number of beneficiaries?
2. What is the age group of beneficiaries?
  - 0-5 years
  - 6-12
  - 13-18 years
  - 19-24 years
  - 25-30 years
  - 31-40 years
  - 41-60 years
  - 60-80 years
  - More than 80 years
  - All the above

### **Funds**

3. Does your organization receive funds from State/Central Government?
  - a. Yes
  - b. No
  - c. Not sure
4. If yes, specify the name of the schemes/ project for the source of fund
5. Are there any other sources of funds apart from state/central funds?
  - a. Philanthropist
  - b. Welfare Society
  - c. CSR
  - d. Others specify
6. How are the funds allocated? Or what is the structure of allocation of funds? Elaborate/illustrate

### **Challenges / Recommendations/ Feedback**

7. Is your work in line with aspirations of persons with disability you are dealing with?

8. What are the challenges faced by the organization while working with persons with disability?

- Funds
- Lack of trained manpower
- Lack of awareness on disability
- Lack of infrastructure
- Lack of support from community
- Lack of support from government
- Any other, specify

9. What kind of changes need to be done in the disability sector?

10. Describe the impact your programs have made or can make for persons with disability?

**COVID-19:**

1. How does Covid-19 affect your organization in providing services to the people with disability?

.....  
.....  
.....  
.....

2. What are the challenges faced by the institution in dealing with COVID-19?

.....  
.....  
.....  
.....

3. Services

a) Does the institute provide any kind of online services amidst COVID-19 lockdown?

- i. Yes
- ii. No

b) If yes, what kind of services is provided?

.....  
.....  
.....  
.....

**Annexure VII:**

**Interview Guide**

**I. Demographics**

- a. Name of the respondent:
- b. Age:
- c. Gender:
- d. Type of disability:
- e. Family Composition:

	Name of the family members	Relationship	Age	Gender	Education	Sources of income	Monthly Income	Marital status
1								
2								
3								
4								
5								
6								

f. Total family income

g. Family Dynamics: most supportive/ least supportive in the family

h. Type of house: own/rented

i. Living condition ( Probe for home environment, facilities, separate rooms, ventilator)

Home Environment	Facilities	Barrier free nature of space	Ventilation	Number of rooms

j. Describe the neighbourhood? (Probe for attitudinal and infrastructural barrier)

k. Which social category do you belong to? Are there any privileges or disadvantages of the category?

l. In your family is there any past history of disability?

m. Genogram

## 2. Presenting Problem

### Health and Services (Early-Intervention)

#### 1. Health needs

- How did you realize your disability?  
Probe: source of information, emotional, response and
- Where do you access health care services for general health problems and what are your experiences of the same?
- Have you faced any difficulties regarding health care accessibility?

#### 2. Educational Services:

- Have/were you ever enrolled in any school/educational institution? If yes, what type of school/educational institution? If no, Kindly elaborate?
- Is/Was the infrastructure of school accessible for you? If no, kindly explain.
- Can you elucidate the attitude of staff, faculty and students towards you and your disability?
- Did you receive any scholarship or schemes for your educational expenses? If yes, did the funds fulfil your educational expenses? If not, how do you fulfil your educational expenses?

#### 3. Livelihood and employment

What has been your experience with employment (Probe for workplace accessibility and capacity building)?

What are your sources of income? What livelihood generation activity are you looking for?

#### 4. Socio-cultural perspective and participation

- What is the level of engagement in community functions, (probe for participation) If yes, have you faced any discrimination during participation? If no, can you explain why not?
- What has been your experience with discrimination and how did you deal with the discrimination (Probe for filing complaint to concerned authority)
- Have you ever engaged in Political/ public life? if yes, explain? If no, Why not?
- Have you ever participated in sport or sport events?
- Recreational activities: talent/hobbies

#### 5. Accessibility and utilization of services

- If you have to commute, what are the means of transportation that you opt for?

Availability	Access	Adequacy	Affordability

- What are the difficulties you have faced while commuting?
- How do you cope when there is no means of transportation?
- Can you share your opinion on pedestrian footpath? Do you think it's friendly to PWD? If not, what is your appeal or suggestion to the concerned authority in regard to the pedestrian footpath?

Places of worship	Health Facilities	Educational institution	Workplace	Entertainment

What suggestion would you like to give to make it more accessible?

- Are you aware of the Rights of the Person with Disability Act, 2016 ? If yes, Do you think your rights are being protected? If yes, why? If, no, why?

1. Equality and Non-discrimination	
2. Personal Liberty	
3. Rights for Women and Children with disabilities equally with others	



<b>4. Right to live in community</b>	
<b>5. Protection and safety in situation of risk, armed conflict, humanitarian ground and natural disaster- District disaster management authority</b>	
<b>6. Protection from cruelty, inhuman treatment, abuse, violence and exploitation</b>	
<b>7. Right to home and family</b>	
<b>8. Reproductive rights &amp; family planning</b>	
<b>9. Accessibility in voting</b>	
<b>10. Access to Justice</b>	
<b>11. Legal Capacity</b>	
<b>12. Guardianship</b>	

6. As a Person with Disability, can you share about the challenges/problems. Can you suggest any improvement in disability services

7. Can you narrate any significant experiences in regard to disability?

8. What are the tasks you are able to do with independence? What kind of task do you need assistance?

9. What are the dreams and aspirations you have? (Probe for career, feelings)

10. What changes would you suggest to improve the quality of life of Persons with Disabilities?

**Interviewer's Observation (Participatory)**

**Interviewer**

1. Behaviour of the respondent:
2. Eye Movement:
3. Gestures:
4. Body-Speech alignment:
5. Enthusiasm/energy:

**Environment**

- a. House Accessibility:
- b. Attitude of the family members:
- c. Ethical Issue:
- d. Countertransference (How do you feel about this client and how does it affect your work?)

### Notes on IDIs with NGOs

In **Manipur** IDIs were conducted for 4 NGOs and responses were received to questionnaires from 6 organizations

- 4 NGOs are based in Imphal, 2 are in Churachandpur and Senapati districts
- 2 NGOs were set up by family members, while others are led by professionals and social workers motivated by the situation of persons with disabilities in their communities.
- 1 NGO is more than 30 years old. The other organizations have been working for 10-20 years
- 2 NGOs are running RCI approved Diploma and Bachelor level courses. RIMS also offers an MPhil in Clinical Psychology.
- All NGOs said they are working across all disabilities including developmental disabilities
- 5 of the 6 NGOs are running direct services for children and young adults with disabilities, while 1 NGO facilitates access to services via a network of professionals, and liaison with Govt Depts. They are all working across the life span, with a focus on children with disabilities.
- Direct services include education – special, non-formal and formal education. One NGO is involved with promoting inclusive education in Govt schools; All said they are providing appropriate therapies – early intervention and counselling.
- They are reaching approximately 700 children and adults with disabilities through direct services.

Their efforts have impacted the perceptions of local communities about disability. In Churachandpur, CCI's initiatives are helping to restore dignity to persons with disabilities and influence people. "Each member of the team is changing the way people see disability". Efforts such as the UNAU - siblings' events, parents empowerment programs, advocacy with schools to promote inclusion, and with local bureaucracy, despite many hurdles, and convergence with other mainstream development programs is making a difference. MANEDA has also invested in parents empowerment and sensitising district administration. AMMHPWO has set up institutional and residential facilities, vocational training centres for persons with intellectual disabilities apart from running diploma courses for special educators. Recreation has also laid the ground for professionalised services for children and persons with cerebral palsy and is running formal training programs and playing a role of coordination and liaison with authorities on disability issues. Some were involved in counselling and dealing with mental health issues too. However, they had to suspend their own services and planned activities were disrupted.

### Challenges faced

Although all the NGOs are doing considerable work, they all listed paucity of funds, lack of trained human resources to work in the NGOs, apathy of the Government to disability issues and negative and discriminatory societal attitudes as major challenges in their work. *In Senapati, the Govt does not celebrate or mark World Disability Day!* Govt officials are distrustful of NGOs even as they are unaware, ignorant, and often negligent of disability issues – certification, UDID etc. Poor quality of public schooling, dysfunctional government schools and 'school-less' schools, rampant corruption, are some of the reasons leading to a preference for private schooling, that emphasises on scholastic achievement, and is not interested in inclusive education. Traditional practices of seeking faith healers rather than health professionals are reinforced by poor coverage of health services in hill districts. Screening and early intervention is not happening. Poor families of children/persons with disabilities in interior villages are unable to afford the expensive transportation costs of travelling to bigger hospitals and health centres for disability certification, Aadhar cards, bank account opening procedures, that could enable their access to schemes and programs.

**COVID situation** - Despite the difficulties faced by all the NGOs during the pandemic, i.e., lockdown restrictions on movement that prevented them from reaching their beneficiaries, lack of resources, difficulties faced by the children and persons with disabilities in following the COVID protocols, poor connectivity and digital divide, repeated and indefinite suspension of regular activities, **all** the NGOs got involved in relief work within limited resources, distributing essential relief materials including food items, medicine and even financial help to their beneficiaries.

In **Mizoram** 5 out of 6 NGOs who were sent questionnaires responded and IDIs were conducted with 3 NGOs.

- 3 organizations are church based with a commitment to work with persons with disability; 1 NGO was founded by family members of children with CP; 1 NGO headed by trained social work professionals, is working for vulnerable people in society. 3 NGOs are offering institution-based services mostly linked to education and skill development, whereas 2 are working in communities. While 1 NGO is more than 30 years old, the others have

been around for 10-20 years. Together they are working for over 1000+ children and persons with disabilities cutting across the life span.

- The Church is a dominant influence in the state and the Presbyterian denomination has been sensitised to organise a 'Disability' Sunday in their calendar of activities when the spotlight is on children and persons with disabilities. However as one respondent said, the church's priorities are different and they do not always address the root cause of a social issue.
- 1 NGO has been actively involved in CBR work across all disabilities, and setting up DPOs for self-advocacy and engaging in policy influencing in rural and underserved districts; creating a resource library in collaboration with National Institute for Empowerment of Persons with Multiple Disabilities (NIEPMD), a national institute; it is trying to improve the quality of inclusive education in its own school networks; Another NGO works with communities and is more focussed on poverty alleviation, but cognizant of the vulnerability of persons with disability and prioritises working for them by connecting them with Govt schemes, certification etc. ; 3 other NGOs are working directly with children and persons with disabilities, 2 are working on specific disabilities - blind, and hearing impaired, and the 3rd NGO works mostly with children with developmental disabilities and deafness and has put in a lot of effort into "preaching" about these disabilities in communities in Aizawl and other parts of the state. Their engagement with education covers - special education, formal and non-formal education in special schools and improving quality of inclusive education in church-based schools.
- 3 NGOs said they are involved in providing therapies, early intervention at institutions as well as in homes. 2 organizations run short stay /residential facilities, of which one was supported by National Trust initially.
- Access to trained professionals does not seem to be a big problem among the NGOs with the Mizoram University's Social Work Department and some NGOs have trained their staff on the job including their community workers. The State Council for Education Research and Training (SCERT) is a resource centre offering training opportunities for professionals. A recently opened Composite Regional Centre (CRC) under the aegis of National Institute for Persons with Locomotor Disability (NILD), however does not seem to be very actively involved in hands on work with service delivery yet. 2 NGOs mentioned that they are not very sure about their work. One NGO wants to become a training centre on developmental disability and has been given a new building by NEC, but at the time of the interview, it was still to be handed over to them, as it had been converted into a Covid Care Centre during the pandemic. They however do not seem to have the resources to sustain their work and have been badly affected by the pandemic.
- There does not seem to be much networking among all the organizations. They are aware of each other's presence but not really synergising their combined efforts.
- The Young Mizo Association (YMA) is a powerful local youth organization actively involved in community service, particularly during times of crisis. They could be sensitised and co-opted to proactively engage with disability and related issues. 1 NGO said their mission was to revisit the Mizo spirit of *Tlongina* - selfless service-altruism and encourage communities to look beyond charity/welfare to empowerment and rights and address the root cause of various issues including disability and impoverishment.
- Most of the NGOs are doing vocational training or skill development work that is popular and relevant to the local situation. Some have taken on persons with disabilities in their teams.
- The NGOs working in communities who have set up DPOs feel that their status has improved somewhat and there is a lessening of stigma around disability. The NGOs working with more profound and developmental disabilities, feel that they have helped to improve the quality of life of the child/person with disabilities and the families too, with their talents being recognised, as they received awards and accolades at the state and national level too, having taken a team to participate in the Special Olympics in 2015 and performing at various forums.

### Challenges

- Not all NGOs who were interviewed talked of funding as a challenge, although some are in a crisis because of unsustainable financial support.
- They all talked of the **lack of awareness** about disabilities in communities and **lack of accessible infrastructure**.
- They also spoke of **discouraging attitudes of Govt officials**, who often treat them shabbily, who are not always collaborative. There was mention of **malpractices in implementation of Govt schemes** - the woefully inadequate disability pension scheme that is restricted to limited few in perpetuity! **Lack of transparency** in employment and implementation of reservation in jobs, as well as the opaque way NHFDC

schemes were disbursed to favoured persons who were not encouraged to repay loans. This contrasts with the superior track records of DPO based SHGs whose members are regularly repaying loans.

- One NGO suggested that persons with and without disabilities **need to be made aware of the rights and entitlements** as detailed in the RPwD Act and information about schemes and programs must be widely disseminated to all stakeholder

### COVID situation

- NGOs were badly affected by the situation due to their inability to go out and meet with the children and persons with disabilities and their families. Their services had to be curtailed and limited only to those staying within their residential facilities and took a toll on their own mental health.
- Funding dried up for many of them. They were unable to switch to online platforms due to the digital divide, as many of the families did not have smart phones, connectivity issues. Most had to shut down their services.
- Most of the NGOs provided essential food items to their communities during the early phase of the lockdown. Some also offered mental health services - counselling. 2 organizations got involved in supporting communities with financial aid and in creating awareness about safety protocols and in village level Covid task force.

In **Assam**, In Depth Interviews were held with 5 NGOs and 10 NGOs responded to questionnaires ·

- 5 of the NGOs are in Kamrup district and 5 others in district of Assam - Cachar, Kokrajhar, Darrang, Jorhat & Dibrugarh.
- 2 NGOs have more than 25 years' experience while the others have 10-20 years' experience
- 8 NGOs are working with persons with multiple disabilities, 1 is working with parents of young children with Hearing Impairment and 1 is working primarily with persons with Mental illness as well as Intellectual Disabilities. 5 NGOs said they serve people from 0-65 age group, 4 work with persons from 3-40 years, while 1 provides services to all age groups
- 5 NGOs are working with a combination of special, formal, informal, inclusive education, and 4 are running special education schools only.
- The impact of the combined efforts work can be seen in some attitudinal changes among the public regarding acceptance of disability, although the charity/welfare mindset is still very prevalent. There seems to be some understanding of the importance of early intervention, and persons with disabilities have become more capable of asking for their rights with the formation of DPOs, but the DPOs are not powerful and have limited capacity. There is some awareness about Legal Guardianship and rights under National Trust as well as the right to education.
- 1 NGO said they could motivate more players to work for mental health issues and had become involved in formulation of Government policies for rehabilitation of homeless persons with mental illness. Another NGO said they had helped to increase awareness on rights and entitlement of persons with disability especially in their intervention area. Another NGO said their inputs had ensured that ear moulds are measured and given along with Hearing Aids now. They have also created awareness on early detection and are looking at promoting a non-invasive screening device (SOHAM) for new born hearing assessment.
- 5 NGOs are also providing vocational training along with other services.
- 4 of them are running short stay homes along with providing therapy services.

### Challenges

**Lack of trained manpower**, getting the right, qualified people for the job. The teachers in deaf schools, are not all always qualified to education of the hearing impaired. NGOs manage with Diploma holders (over Bachelors) due to limited funds, but need more qualified staff to train others in their teams, some prefer to work with untrained/volunteers and slowly train and build their capacities instead

**Paucity of funds** - Lack of visibility of their work and networking with prospective funders & donors were major challenges. Not having FCRA registration further limits opportunities for funding. Organizations growing in response to needs on the ground.

**Lack of Awareness** among govt officials and communities - Little or no support from Health Department is a major issue - "Darrang district with 12 lakh populations has only one psychiatric doctor available at civil hospital Mangaldoi". Economically weaker people have no capacity to visit hospitals, as they cannot go unaccompanied, compounding

their financial burden, so they prefer to visit traditional healers locally. Govt supply of medicines for persons with MI are irregular causing huge problems and disruption in medication and treatment. Attitude and mindsets still largely steeped in charity and welfare, despite herculean efforts of NGOs. Socio cultural practices and the lack of awareness about practices that predispose towards disability - alcohol consumption among tea tribes, constant bending of pregnant tea pluckers, child/adolescent marriage and eloping, malnutrition, stresses and strains of survival.

**Livelihood options** - Many young people with locomotor disabilities contact NGOs frequently to seek livelihood options. Interventions in this domain is essential, as they have untapped potential but remain dependent and a burden on families instead.

**Inadequate education** - need for deploying appropriate resources to ensure that children with disabilities avail their 'right to education' - SSA focus is on enrolment rather than retention, a tendency for relegation to home-based education, children with disabilities are mostly segregated as the model of itinerant teaching by special educators is inadequate - they are thinly stretched over a large number of children and geographical areas and services of community volunteers involvement have also been discontinued

**Disability Certification** - processes are not user-friendly as many living in remote rural areas are unable to access them. Certification often incorrect both in type and extent of disability

**Safety and security of children, women with disabilities** whose vulnerabilities are multiple - accessibility in movement, bodily integrity threats, frequent incidents of abuse, neglect, and omission from rehabilitation. There is a conundrum of institutionalisation vs community acceptance, participation and inclusion

**Early Intervention** - so critical for identifying invisible disabilities like hearing impairment, specific learning disabilities etc, as too much precious time is lost before formal screening and assessments are done, resulting in huge learning gaps and loss of potential.

### COVID situation

All NGOs provided some level of support to the communities during COVID - this included

- awareness programs on COVID protocols
- relief rations and medicine and hygiene kit and android device distribution and cash transfers - SATRA is an OXFAM partner and has considerable DRR expertise, others distributed as per availability of resources from funders and other sources
- Interventions to CwDs in COVID affected families and COVID orphans - Prerona's Childline service
- Vaccination camps and awareness campaigns to diffuse hesitation were organised by some NGOs
- Counselling of families, providing services through WhatsApp messages and calls was done by most NGOs
- Staff attrition among some organizations due to inability of pay salaries of staff
- Home visits as and when situation eased.

In **Meghalaya**, In-depth interviews conducted with 4 NGOs and a total of 8 NGOs responded to questionnaires

- 4 NGOs are in East Khasi Hills, 3 in West Khasi Hills and 1 in Ribhoi District of Meghalaya.
- 4 NGOs have been working for nearly 40 years, the other organizations for 10-25 years
- 7 NGOs are working for people with multiple disabilities; 1 is working for children with Hearing & Speech impaired and language disability
- 6 NGOs provide services to people from 0-65 age group; 1 NGO provides services to people from 2-50 years of age; 1 NGO provides services to 0-18 years age group.
- 4 NGOs are working with a combination of special, formal, informal, inclusive education; 2 are running special schools only; 2 are running inclusive education schools.
- 4 NGOs are providing services in Health, Education, Vocational Training, Awareness; 3 NGOs are offering human rights advocacy along with other services; 1 NGO is working in only in the area of Education.

As per the responses the scenario in Meghalaya for persons with disabilities and the impact of the work of the NGOs is that many persons with disabilities have been empowered through education and training. Some of them are employed and living independent lives. One NGO has helped in the promotion of well-being and mental health and removal of stigma around mental illness, along with provision of medication and treatment. They have enhanced livelihood options for persons with disabilities and improved prospects of getting certificates/ ID Cards and access to Govt schemes, pensions, scholarships etc.

### Challenges faced

Common challenges faced by the NGOs included the **lack of funds**, delayed receipt of Govt grants in aid (DDRS, National Trust schemes) inability and reluctance of families to pay for services to NGOs compounded by pandemic situation

**Trained human resources** are scarce and inadequate; Efforts are being made for sensitization about inclusion in education, even having a paper on education of children with disabilities in the NEHU syllabus but implementing these ideas on the ground and realising it is still far away due to financial difficulties, lack of trained special educators. Majority of schools have no special educator or trained teachers to teach the children with disabilities enrolled in the mainstream schools.

**Awareness on disability** - although the situation is improving with consistent community-based rehabilitation programs in some places that has raised awareness among persons with disabilities about their rights and entitlements with DPOs taking the lead on certification/identity cards, but they still need to build their confidence and assert themselves as self-advocates on issues.

**Lack of support from the community and Government** for interventions is improving but not adequate.

Need **for developing second lines of leadership within NGOs** for sustained governance and for coping with **staff attrition**. Recognising that investments in training and competency building of staff will help the disability sector overall, by improving and expanding services.

**Imposition of prescribed compliances** in reporting and documentation **by funding agencies** running the risk of killing the creativity of the sector.

**Inaccessible infrastructure and environment**, compounded by the hilly terrain topography of the state, leads to perpetuation of exclusion of persons with disabilities, particularly those with limited mobility. But even some efforts (30-40%) are made to improve physical access, much will change.

**Mental health programs** have begun to change situation for many persons with mental illness, but compliance with medication is still a challenge.

### COVID situation

The pandemic disrupted all planned activities. One NGO said they had to think of new ways to work, as they found huge gaps in education. They looked at the potential of ICT offering a new dimension in Education and designing new ways of teaching and some examples include *Immersive reader tools, TLMs using UDL strategies, Byju's content made free for their own school and SSA partner school children; Translation tools that could do instant translation of manuals, Use of Nearpod and other free and open-source tools.*

Most NGOs encountered major Mental Health issues in their communities, and did counselling, therapy, provided medical services, medicines and treatments. They distributed rations to relieve the hunger crisis with kits for essential rations of rice, milk, dal, sugar etc to needy families and even gave money to needy families.

One NGO took up the Meghalaya Govt modules for COVID Awareness as a project in their school and involved staff and students in the project with some doing very good work. They also distributed rations and gave money to the people concerned with support from others

In **Nagaland** In-depth interviews with 4 NGOs and responses to questionnaires from 6 organizations.

- 3 of the NGOs are in Dimapur and 3 others in Kohima.
- 1 NGO is 33 years old; the others have been working for 10-15 years
- 5 NGOs are working for people with multiple disabilities, 1 is working with mental health conditions
- 5 NGOs provide services to people from 0-65 age group, 1 works with 3-16 years age group.
- 2 NGOs are working with a combination of special, formal, informal, inclusive education, and 1 is running special education and a formal school. 2 NGOs are running inclusive education schools.
- 5 NGOs are providing services in Health, Education, Vocational Training, Awareness. 1 of them is working in Education, Vocational training, and setting up Disabled People's Organizations.

The impact of their work has helped create more awareness on Rights of Persons with Disability (PwD), better quality of living through more access to rights/services and support groups (Disabled People Organization) in clusters. One of them have been able to reach out to hundreds of deaf people in Nagaland & its surrounding states, many of whom are employed, married and leading successful lives. Community attitude towards disability has changed for the better.



### Challenges

Some of the common challenges mentioned by the NGOs included **lack of funds, trained manpower** as well as **inaccessible infrastructure, inadequate support from community and government.**

**Attitude of parents of non-disabled children:** “when we started the response was very good, many non-disabled children were coming to their school, the trouble started in 2015-16, when the parents started withdrawing their children, saying that ‘we can’t keep the children with the blind, with the deaf’. It was really hurting but they did not step back, although it was really taking a toll on the strength of their students, so year by year they had fewer number of students, and last year, because of this pandemic, it is really affecting the economy and the sustainability of the school.

**Certification of disability is slow** particularly in interior places and the government should take up this challenge with their machineries, but it is true there are technical difficulties like **availability of experts** to assess and certify disability and for prognostics of treatment and management of disability

**Remoteness of the region** is another challenge. Most of the disabled children are from villages in different districts, their parents are small farmers and petty shop owners in the village. Bringing the children from these places together and teaching them is a huge challenge.

Finding **qualified staff and paying them commensurately.** Thus, although Govt and people expect education to be free for children with disabilities, it is difficult to provide free educational services without properly paid staff.

#### COVID situation:

- Lack of information about what is happening during the COVID and the precautions to be taken was a major issue. The Deaf Biblical Ministry made videos with sign language interpretations on the precautions, of the situation, with the latest news from the state government, the Chief Minister and Prime Minister’s offices.
- They had to make video calls to motivate and tell the child to study and learn, as parents were unable to communicate with their children and discipline them

In **Sikkim** In depth interview was held with 1 NGO and responses to questionnaires were received from 2 NGOs. Based on their responses, the scenario in Sikkim for persons with disabilities is as follows:

- One of the NGOs is in Ingding Dara Indira bypass Road P.O Tadong and the other one is in Zero-point NH 10 Gangtok.
- One NGO was established 21 years ago while the other is 35 years old.
- 1 NGO said they are working with people having locomotor disability, multiple disability including deaf blindness, acid attack victims, the other NGO is working with persons with blindness.
- 1 NGO provides services to people from 7-25 age group, while the other provides services to 16-35 years age group.

The impact of their work includes empowering visually impaired children in terms of education, employment, and self-reliant and social upliftment. One NGO helped train more than 300 people on vocational training.

### Challenges

Some of the common challenges mentioned by both the organizations include **lack of funds; lack of trained manpower; lack of awareness on disability; lack of support from community.**

Difficulty in getting trained experts to work in disability sector. 1 NGO had to get a special educator from outside from the State. Geographically their location is quite challenging, so it is difficult to get volunteers to work due to accessibility issues.

#### Covid situation

The pandemic adversely **affected the normal routine** of the people with disabilities as well as the people working in the sector due to lack of physical contact

In **Arunachal Pradesh** response was received from only one organization

### Challenges

There is a **need for** a centre or institution that provides **services to children with intellectual disabilities** and developmental disabilities in each district of the state. They require more **trained staff**, as there is lack of technical staff in the region. Even though some of their staff are trained **they lack exposure.**

Capacity of existing professionals to provide **home based education and rehabilitation services is not adequate.** The quality of inclusive education in SSA school is not up to the mark in Arunachal Pradesh. **Students**



**do not even receive hearing aids and assistive devices** from SSA. There is a **paucity of institutions and NGOs to cater to children and persons with other disabilities.**

In **Tripura** responses to questionnaires were received from 2 NGOs and an in-depth interview was held with 1 NGO.

- Both NGOs are in West Tripura district.
- 1 NGO was established 34 years ago and the other 19 years ago.
- 1 NGO works with those having low vision; cerebral palsy; hearing impairment; locomotor disability; learning disability; speech and language disability; muscular dystrophy; autism spectrum disorder; multiple disabilities including deaf blindness. The other NGOs ticked all the 21 recognized disabilities.
- Both NGOs provides services to people with disabilities from all age groups.
- Both NGOs are working in Education; Health; Vocational training; Rehabilitation centre; Advocacy; Awareness; Disabled People's Organizations. Additionally, 1 NGO runs a short stay home facility. The impact of their work has helped improve quality of life of persons with disabilities and empowered them for inclusion and self-dependence. There is a positive change in attitudes of families and community.
- The education setup is inclusive, and vocational training, livelihood and credit programmes have increased. People are now aware about rights and entitlement of persons with disabilities and DPOs are empowered and they are doing sustainable activities.

### **Challenges**

Some of the common challenges mentioned by them includes **lack of adequate funds; lack of trained manpower; Lack of infrastructure.**