

Executive Summary

The last decade saw significant developments in the discourse on disability, with the enactment a landmark law rooted in the principles of the UN Convention on Rights of Persons with Disabilities, and inclusion of disability in Sustainable Development Goals and targets. Informed by earlier consultations, recent collaborations, 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. The findings point to the need for scaling up legal literacy and rights awareness among duty bearers and rights holders, expanding services and convergence with mainstream agenda, creating more human resources, and increasing financial outlay for disability work, so that people with disabilities are more aware, and can avail services to tap their potential to participate and be included as part of the human diversity of NE India.

Introduction:

Disability is the result of a complex and dynamic relation between health conditions and contextual factors at the personal and environmental levels.

Persons with disabilities need health, habilitation / rehabilitation services at the earliest to optimise abilities .

Implementation of laws and realisation of rights, improves prospects of persons with disabilities. Ignorance and apathy compound their marginalisation .

Arduous disability certification and UDID processes, particularly in remote rural areas excludes persons with disabilities .

People with disabilities incur additional costs of living for treatment, assistive devices and services .

Inaccessible infrastructure, inflexible curriculum & assessments predispose students with disabilities to poorer attainment of education .

Exclusion from education and skill training opportunities perpetuates the vicious cycle of poverty and disability .

Convergence of efforts by government and non-government organisation can improve prospects for persons with disabilities.

Main Findings:

Significant lack of awareness across all stakeholders about disability, services, rights, and entitlements

Poor coverage of health systems and infrastructure in rural areas; delays in detection, assessment and interventions; gaps in early intervention services at public health facilities

Disability certificates/ UDID Cards not obtained due to ignorance, malpractices, inefficiency, and technical difficulties.

Inadequate coverage of services in NE by too few NGOs mostly in urban and semi urban areas; limited resources, low intake capacity, long waiting lists, scarce professionals

Inaccessible and sometimes non-existent school infrastructure, insufficient human resources, exclusionary and unaccommodating teaching practice, experiences of rejection

Poor progression through education (only 1% respondents were post graduates); implications for future employability. Ignorance of scholarships schemes, difficulties in availing them

Inadequate job oriented vocational skilling opportunities to tap potential and improve prospects of economic empowerment.

NGOs concerned about paucity of funding, lack of trained human resources and constant struggle to change perceptions and negative stereotypes around disability.

COVID pandemic, adversely impacted daily life, worsened access to health care for children & persons with disabilities, compounding already challenging situation. Prolonged lockdowns caused communication, behaviour and mental health issues for many. Most NGO respondents provided some relief and counselling support. NGOs also learnt to adapt ICT to sustain and minimise disruption of services.

Recommendations:

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.

Improve Disability Certification and UDID card processes by decentralizing to district, block, cluster and village level officials, and co-opting civil society and non-government organizations to facilitate and collate information. Rehabilitation professionals with valid RCI registrations and skills and capacities can be deployed to do preliminary assessments that could be the basis of certification

Expand **health related intervention 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 RBSK, DEICs, DDRC services

Create **tiers of trained personnel, including barefoot therapists, special educators and teachers, community-based workers** to provide services. Deploy software to track, monitor and evaluate application of training on ground

Initiate and **extend services to remote rural areas through outreach, community based and collaborative programs.**

Promote **inclusive education** by engaging with mainstream schools and training schoolteachers. Conduct courses on Universal Design of Learning, Sign Language Interpretation, use of ICT and Alternative and Augmentative Communication software. Expand study centres for Open Schooling at school complexes and at district and block levels.

Improve **access to scholarships and incentives** for better retention and progress in schools and education institutions.

Enable **access and inclusion in appropriate and mainstream skill development programs** for employability, enterprise, and economic empowerment of persons with disabilities

Provide trainings to **empower families, caregivers and support networks** of persons with high-support-needs, to live independently in communities. This will include personal caregiving, recreational therapies, social participation, respite care and emergency services.

Orient and **sensitize other civil society organizations to engage in disability rehabilitation work** directly and/or through referrals and inclusion in their ongoing programs, to catalyse convergence of disability into domains of health, education, accessibility and economic empowerment.

Conduct collaborative and **regular research studies on status of disability** on the lines of the Pratham ASER report to create empirical evidence and knowledge on different aspects of disability rehabilitation and rights realisation, with state-specific or regional focus.

The Research Study

The purpose of this study was to

- Map the situation of persons with disability in NE India
- Understand needs and gaps in services and realisations of rights of persons with disabilities

Methodology and Approach

This study combined quantitative and qualitative exploratory mixed methodologies and involved both descriptive and exploratory methods of research. Conducted in two phases, the study gathered primary and secondary data using questionnaires, google forms, in-depth interviews & focus group discussion with interviews guide and participatory approaches as well from desk-based research - articles, publications, journals, books & websites.

In the 1st Phase **2385 survey responses** were collected, of which 919 were from parents of children with disability and 1466 from persons with disability. Responses were also 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 were collated over phone calls, emails and physical meetings. In the 2nd Phase **state and regional online consultations** were held to disseminate preliminary findings from Phase I and gather feedback from stakeholders. Based on the suggestions, an additional **21 in-depth interviews** were conducted with NGOs working with disability to learn about their services, as well as challenges and COVID experiences.

The study used purposive sampling as respondents/participants were 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 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 organisations from NE India through 'snowballing' method and were purposefully recruited using these selection criteria. Notes were taken and IDIs were also recorded and transcribed. No photographs were taken during the study.

Limitations 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 indicated that 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.

Voices from the Field:

“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*

“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*

“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, 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*

“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.” - *R DebBarma, person with low vision, Tripura*

“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... 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” - *Representative of disability NGO in Manipur*

“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.” - *Representative of disability NGO in Manipur*

“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.” - *Representative of disability NGO in Mizoram*

“... 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 8-10 students in a special education class...if the teachers are retrained, can be done for 40 students in a mainstream class.” - *Representative of disability NGO in Meghalaya*

“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.” - *Person with disability, Karbi Anglong, Assam*