

This Working Paper "Disability & Rehabilitation in the North-East of India" has been prepared by Dr Sunil Deepak, as a consultant to Mobility India; Cover & back images are also by Dr Sunil Deepak

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Mobility India North East (MI-NE) is the North-Eastern office of Mobility India based in Guwahati (Assam) and operates in the eight states of the North Eastern Region.

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ACRONYMS

ACP	Association of Challenged People
ACRD	Assam Centre for Rural Development
ADIP	Assistance to Differently Abled Persons for Purchase/Fitting of Aids/Appliances
AIFO	Italian Association Amici di Raoul Follereau
ALIMCO	Artificial Limbs Manufacturing Corporation of India
AsSRLM	Assam State Rural Livelihood Mission
BPL	Below Poverty Line
CBM	Christoffel Blinden Mission
CBID	Community-Based Inclusive Development
CBR	Community-Based Rehabilitation
CBRF	CBR Forum
C-NES	Centre for North East Studies & Policies Research
CRC	Composite Regional Centre
DAN	Development Association of Nagaland
DDRC	District Disability Rehabilitation Centre
DPO	Organizations of Persons with Disabilities
GDP	Gross Domestic Product
HDI	Human Development Index
HRDD	Human Resource Development Department
IDDC	International Disability & Development Consortium
IGDP	Indira Gandhi Disability Pension Scheme
IIRM	Indian Institute of Rural Management
ILO	International Labour Organisation
IMR	Infant Mortality Rate
ISPO	International Society of Prosthetics and Orthotics
MI	Mobility India
MI-NE	Mobility India North East (Inclusive Development Resource Centre)
MNREGA	Mahatma Gandhi Rural Employment Guarantee Act
MRC	Multipurpose Rehabilitation centre
MzSRLM	Mizoram State Rural Livelihood Mission
NCPEDP	National Centre for Promotion of Employment for Disabled Persons
NECHA	North-Eastern Community Health Association
NGO	Non-Governmental Organization
NLRM	National Rural Livelihood Mission
L	

NSDF	Nagaland State Disability Forum
PINF	People In Need Foundation
PwD	Person with Disability
RCI	Rehabilitation Council of India
SDC	State Disability Commissioner
SGSY	Swaranjayanti Gram Swarojgar Yojana (Rural self-employment scheme)
SJE&WD	Social Justice, Empowerment and Welfare Department
SRC	State Resource Centre
SSA	Sarva Shiksha Abhiyan (Universal Education Campaign)
SSN	Sri Sankaradeva Netralaya
UNCRPD	United Nations Convention of Rights of Persons with Disabilities
UNESCO	United Nations Educational, Scientific and Cultural Organisation
VRW	Village Rehabilitation Worker
WHO	World Health Organization

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EXECUTIVE SUMMARY

The **North East (NE) region** of India is home to 44 million persons who live in eight states – Arunachal Pradesh, Assam, Manipur, Meghalaya, Mizoram, Nagaland, Sikkim and Tripura. It is an area of enormous ethnic, cultural, religious and linguistic diversity. Geographically, the region is dominated by dense forests, rivers, lakes and mountains. Except for the Brahmaputra valley in Assam, large parts of the region have a very low population density.

The NE region has been affected by numerous conflicts for decades, which continue to flare up periodically. Due to all these reasons, the development of infrastructure, institutions, communication and services is lagging behind the rest of the country. However, in recent years, the national Government has made ambitious plans to promote the development infrastructures in the region, improving its connections with rest of India and linking it with neighbouring countries.

Significant challenges affect the disability and rehabilitation services in the North East. Lack of accessible information about disability and rehabilitation services is another key issue that makes it difficult to understand the gaps and the challenges. Apart from the data collected during national censuses, very little statistical information is available about the lives of PwDs and their families in the region.

Sarva Shiksha Abhiyaan, a Government programme promoting Universal Access to Education is often the only source of periodic reports on this theme, though these reports focus only on the children, including the children with disabilities, of the school-going age.

Yet, in spite of all these challenges, the last decade has seen some impressive gains in many areas, including the setting up of services for PwDs. However, it is often difficult to generalize about the NE since the situation in densely populated towns in Assam is very different from that of the small populations living in large mountainous areas of Arunachal Pradesh or Sikkim. Sometimes, a service or a programme may be working well in one district of a state and not working or partially working in other districts.

In December 2014, **Mobility India** (MI) commissioned a **situation analysis of disability and rehabilitation services** in the North Eastern (NE) Region of India. Mobility India promotes an inclusive and empowered community where persons with

disabilities (PwDs), their families and other disadvantaged groups have equal access to education, health and livelihood and enjoy a good quality of life.

Following the initial situation analysis, in April 2015, MI opened a regional office for the North East in Guwahati (Assam). Since then, over the past one year, the initial report on the situation analysis has been updated and expanded with new data and information in this version of the Working Paper.

The past decade has seen **important progress in the NE region** in terms of services for PwDs, including the setting up of offices of the State Disability Commissioners (SDCs) and District Disability and Rehabilitation Centres (DDRCs). Slowly there are efforts in different states of the North East to provide disability certificates and access to various government schemes aimed at poor families and those with PwDs.

However, the challenges for disability and rehabilitation services remain enormous, especially for persons living in small district towns and rural areas. Some of the **key challenges are**:

- Access to qualified rehabilitation professionals, from specialists to rehabilitation therapy assistants, prosthetic and orthotic technicians and community level rehabilitation workers, is extremely limited in most of the districts and rural areas.
- Appropriate training materials and specific training courses for persons working at community level and in rehabilitation services in districts and rural areas are needed.
- Access to different assistive devices from hearing aids to reading glasses, artificial limbs and wheel chairs is a major issue in most remote areas. Even when available, there is lack of services related to systematic evaluation of needs, training and adaptation for use of appliances, follow-up, maintenance and repair.
- Due to difficult terrain, lack of roads and other infrastructure and climatic issues such as frequent rains and landslides, physical accessibility including access to buildings and public transport is a big challenge.

- Government services in disability and rehabilitation are extremely limited in the region. There are many large and small voluntary organizations active in the area, however their coverage is limited to a few blocks while many districts and rural areas are not covered. This also applies to the coverage of Community-Based Rehabilitation (CBR) programmes.
- Except for the CBR programmes and some rare institutions, activities in the livelihood, social participation and empowerment domains of rehabilitation are inadequate.
- The movement for the creation and strengthening of Organizations of Persons with Disabilities (DPOs) in the region is fairly recent. There are some good examples of DPOs starting as grassroots organizations and creating a democratic setup covering areas up to district level. There are also a few state and regional level federations and networks. However, these need to be strengthened, to become more active and to represent a wider cross-section of persons from the North East.
- Documentation, sharing of information and data, along with research into different aspects of disability and rehabilitation issues are extremely limited. For these issues, the region hardly appears in peer-reviewed journals or on the Internet. Information about CBR programmes and DPOs is particularly scarce. *Sarva Shiksha Abhiyan* (SSA), the Government programme for promoting Universal Access to Education, is usually the only programme in the region providing regular reports on children with disabilities in the school-going age group.
- NE shows many of the trends visible in other parts of India and the world linked to increasing prevalence of persons with disabilities such as increase in the life expectancy with rise in the number of elderly persons, increase in chronic conditions and rising incidence of road traffic accidents. Thus, region needs to review its strategies for the rehabilitation services and to strengthen these, with particular emphasis on the CBR programmes.

Role of MI Regional Centre in the NE: There are a many important voluntary organizations in the North East active in the area of disability and rehabilitation, especially in the larger cities. Among the Non-Governmental Organisations, CBR Forum has played an especially important role for the promotion of CBR and DPOs in the region. However, the CBR programmes are very few and their coverage remains extremely limited. Innovative approaches to Community-based Inclusive Development (CBID) are rare in the region.

Access to assistive technology products, training of rehabilitation personnel and of persons working in community programme, and research on the needs of PwDs and on the effectiveness of rehabilitation services are some other areas with huge gaps in the NE.

Mobility India has already collaborated with many of these voluntary organizations in the North East over the past decade. A regional centre of MI can play a significant role in promoting CBR and CBID programmes together with other activities such as improving the access to assistive technology products, training and research.

This **Working Paper** on the situation of PwDs and of rehabilitation services in the North East is a work-in-progress. Feedback and comments about this Working Paper are welcome. Individuals and organisations active in the field of disability & rehabilitation in the NE region are also invited to share their views and case studies to improve this Working Paper.

VOICES FROM THE NORTH EAST

Mohan, 46 years old, locomotor disability (with a leg amputation): "Getting pension is not easy. For every certificate, I had to give some money. Then, some big function was organized in the city and we had to go there to get our pensions. It was not easy. There were persons who had a lot of difficulties in moving, so to take them to the city was difficult. A minibus was rented to take us. We had to pay the expenses to go to the city. In the end to get my pension, I had to spend so much money."

Momi, 34 years old, low vision: "In the school, I could not see the blackboard properly. Other girls used to call me blind. I felt so bad, so I decided that I will not go to school. Then my aunt told my mother that there is a school for disabled children and to send me to this school in Shillong. We did not have money but my aunt said that I will not have to pay for anything. They saved my life. They gave me a place to live and to study. I have achieved success in my life. Now, I look back and think that I only had very low vision! I only needed eyeglasses. But in the village, this disability was going to destroy my whole life, make me remain illiterate and poor. That is not fair. How can we leave the persons in the villages without any help, that they have to suffer so much for disabilities?"

Ahmed, father of a 14-year-old boy with a hearing disability: "He had fever and then he lost his hearing. He is my only son. I took him to Guwahati medical college. I took him to Kolkata. He was admitted in the hospital in Dibrugarh for two months. I did everything I could. We sold off some land, my wife's gold, even our bicycle. I took a loan of 60,000 Rs. In the end I have accepted defeat. Now he sits alone in room, he does not go out, he cries. What can I do? How will I pay off my debt?"

INTRODUCTION

Background

North-East (NE) region of India is composed of eight states – Arunachal Pradesh, Assam, Manipur, Meghalaya, Mizoram, Nagaland, Sikkim and Tripura.

In November 2014, Mobility India commissioned a situation analysis of disability and rehabilitation programmes and services in the NE region. The initial study focused on three states – Assam, Meghalaya and Nagaland.

Following the initial situation analysis, in April 2015, MI opened its regional office for the North East (MI-NE) in Guwahati, the capital of Assam. Since then, over the last one year that initial situation analysis has been updated and expanded with additional information from different parts of the NE, in the present version of this Working Paper.

Mobility India: The vision of Mobility India is to work for "an inclusive and empowered community, where people with disabilities, their families and other disadvantaged groups have equal access to education, health and livelihood and enjoy a good quality of life".

Since 2004-05, MI has been supporting and facilitating organizations benefitting PwDs in the North Eastern Region of India. The Guwahati office was set up with the aim of strengthening its support to the eight states of the region. MI-NE is working on capacity building and training, assisting in setting up or upgrading prosthetic and orthotic workshops and physiotherapy and occupational therapy units. More information about Mobility India and its North-East office is available in **Annex 1** (p. 72) of this document.

This **Working Paper** brings together snippets of information from different parts of the North East. Except for the census data and results of some systematic reviews, you will find little scientifically valid data in this Working Paper. This is because of paucity of serious research on the theme of disability & rehabilitation in this region. Rather, this Working Paper provides glimpses of the diverse achievements, challenges and gaps about the disability and rehabilitation services in the region through the voices of people, newspaper reports and information collected from reports of non-governmental organisations.

Conceptual Background & Methodology

A methodology of situation analysis of health programmes was developed in 1989 and has been used for situation analysis of disability and rehabilitation services in a number of countries (Kumar, Jain and Bruce, 1989). For example, during 2013-14, it was used for the situation analysis of rehabilitation services in Tajikistan (Mishra and Rahmatulloev, 2015).

According to this methodology there are four main objectives of a situation analysis:

- 1. Evaluate the legal framework such as laws, policies and strategies at national or state level
- 2. Evaluate the service provision (including standards, staff, facilities, equipment)
- 3. Evaluate the services received by the beneficiaries (perception of quality of services)
- 4. Evaluate the impact on the beneficiaries (beneficiary knowledge, behaviour).

A complete situation analysis of disability and rehabilitation services to fulfil the above four objectives requires multi-disciplinary and inter-sectorial participation of the different stakeholders including PwDs as well as governments and the different service providers. It would also require specific data collection from an adequate sample of PwDs, their families and communities, in order to understand their perception of the services and to measure the impact of specific services on the lives of people.

Objectives of this Situation Analysis: The situation analysis presented in this Working Paper did not completely follow the above methodology, being limited by resources and time.

The focus of this situation analysis was on the second and third of the above objectives - service delivery and perception of beneficiaries. Regarding the fourth objective, some life stories and experiences were collected during the field visits and during meetings with PwDs but no systematic survey was carried out.

Methodology: The situation analysis was initially conducted by review of the scientific literature, published books and reports, articles in peer review journals and grey literature such as the reports of the voluntary organisations. This was complemented by field visits to different parts of the North East. There were visits to state institutions such as DDRCs, social welfare departments and state disability commissioners. At the same time, there

were visits to NGOs engaged in any disability and rehabilitation related activities and field visits to CBR programmes.

During these field visits, a significant amount of time was spent in discussions with DPOs as well as, individuals benefitting from specific rehabilitation services and programmes. Discussions were also held with service providers and professionals.

In addition, all the organizations and centres visited were asked to share their reports and documents, including research reports and any specific survey reports related to disability and rehabilitation.

The Acknowledgements Section of this report provides a list of organizations and institutions visited during the situation analysis. As can be seen, a large number of organizations and persons contributed to providing the information that underpins this report. Thus, while the report does not provide a "scientifically valid" analysis, it does provide a sample of the situation on the ground.

Ongoing Work on this Situation Analysis: This Working Paper is a work-in-progress, that should be modified and updated regularly, as new and additional information becomes available. Comments, suggestions and critical feedback about this paper will be appreciated. Individuals and organisations active in the field of Disability & Rehabilitation in the NE are invited to share their experiences and case studies, to be included in the future versions of this document.

MI-NE is engaged in a series of activities for the strengthening of rehabilitation services in the region. Documentation, training and research are key components of this work. Thus, it is expected that in the coming couple of years, this situation analysis will be enriched by more specific data and information about PwDs and rehabilitation services in the North Eastern Region of India.

Organisation of This Working Paper

The working paper is organised in different chapters. Each chapter focuses on a different aspect of the situation of the disability & rehabilitation information and services. Thus there are chapters looking at medical rehabilitation, community based rehabilitation (DPO), access to technical appliances, education, livelihood and organisations of persons with disabilities (DPOs).

GENERAL & DEMOGRAPHIC INFORMATION ABOUT NE

The North East (NE) is the eastern-most region of India, a little cut off from the rest of the country and connected only to West Bengal State via a narrow corridor of land squeezed between Nepal and Bangladesh. The North Eastern Region is composed of **eight states** — Arunachal Pradesh, Assam, Manipur, Meghalaya, Mizoram, Nagaland, Sikkim and Tripura. Sikkim is separated from the other seven states by Bhutan and parts of West Bengal.

Together the eight states occupy an area of about 262,000 sq. km, which is about 7% of India's land area and more than the surface area of United Kingdom. The region shares international borders with five countries - Bangladesh, Bhutan, China, Myanmar and Nepal.



The Assam valley along the Brahmaputra River forms the central densely populated core of the North Eastern Region, the rest being covered with forests, hills and mountains.

Demography, Infrastructure and Development

The population of the North East (around 44.3 million in 2011) is roughly 3.6% of India's total population. About 70% of this population lives in the state of Assam, the most populous state of the region. The remaining seven states have very small populations and include large areas of mountains and forests. Therefore in many parts of the North East the population density is very low. Arunachal Pradesh, with the biggest surface area and a tiny population, is the least densely populated state of the region.

There is a great **religious diversity** in the North East. Arunachal Pradesh, Assam, Manipur and Tripura are predominantly Hindu, with a significant Muslim minority in Assam. Christianity is the major religion in Meghalaya, Mizoram and Nagaland.

There is also a wide **ethnic diversity** in the region. Each NE state hosts different tribes, each with its own language and culture. For example there are 68 Naga tribes, most of which live in India, a few live both in India and Myanmar and a further small number of Naga tribes live only in Myanmar. The Indian Naga tribes live mainly in Nagaland, but significant numbers also live in Manipur, Arunachal Pradesh and Assam.

In addition to the indigenous tribes, there are tribal groups in the NE from other parts of Indian subcontinent. For example, there are tribal groups from central and eastern India, sometimes called "the tea tribes", who were brought here by the British colonialists during 19th and early 20th centuries, to work in the tea gardens.

Linguistic diversity is often linked to ethnic diversity. For example, the 68 Naga tribes speak more than 130 languages and dialects. Different Naga tribes, depending upon their geographic location, speak more than one language. Thus belonging to the same ethnic group does not mean that people share all the different cultural attributes. (Nekha, 2015)

Except for Assam, where the major language is Assamese, and Tripura, where the major language is Bengali, the region's predominantly tribal population speak numerous Tibeto-Burman and Austro-Asiatic languages. Meitei, the third most spoken language in the region is a Tibeto-Burman language, and is spoken mainly in Manipur valley. Many of these languages are only oral and have no written scripts.

In terms of infrastructure, **the road and rail network** is extremely limited outside Assam and in many parts of Assam. The NE has just 4% of the rail network and 7% of the

road network of India. In addition, floods, landslides and soil erosion regularly affect the region and the real road connectivity is further reduced. The highways connecting the capitals of the eight states are lacking or incomplete, though there are plans to complete these in the next 2 years. The highway connecting Guwahati to Shillong was completed recently in 2015.

Regarding the railway network, in August 2015, the Government of India explained, "Against a national average of 20 km per 1,000 sq. km railway network density, the North-Eastern states have an average railway network density of 10.1 km per 1,000 sq. km". The North East Frontier Railway serves the eight states of the North. Only recently the process of updating and strengthening the railway network from Assam and West Bengal to Tripura, Mizoram and Arunachal Pradesh has been reactivated. In 2015, Arunachal Pradesh was finally connected to railway services.

Important road connections are plagued by different problems. For example, in West Jaintia Hills in Meghalaya, the main road connecting Guwahati to southern Assam (Cachar and Hailakhandi districts) as well as to Mizoram state, is clogged by trucks carrying coal from the mines. Thus, journeys that should last hours take days to complete, creating serious bottlenecks and impeding the development of the region.

Nothing is more emblematic of the poor infrastructure of the region than the situation of the bridges crossing its most important river. The **Brahmaputra**, starting on the Tibetan plateau in China, passing through Arunachal Pradesh and Assam, and then flowing through Bangladesh, is one the largest rivers of the world. In Assam, there are places where the river is more than 10 km wide. The course of the Brahmaputra in Assam covers more than 750 km and divides the valley into north and south parts. These are connected by only three bridges – one in Tezpur, one in Guwahati and one in Bongaigaon. Two more bridges are under construction – one near Dibrugarh and the second at the Arunachal Pradesh-Assam border. In the remaining parts of the Assam valley, people spend hours waiting for ferries to cross the river.

While some **mobile telephone networks** reach most parts of the North Eastern Region, availability can be patchy and in some rural, hilly and isolated parts, access is extremely difficult. Similarly **Internet access** is severely hampered in various parts of the North East. During 2015, a new Internet gateway in Tripura was announced. When completed

this should improve Internet access in the region. At present, internet access for the North-East is through a gateway in faraway Chennai in South India.

According to a report on the **economic indicators** prepared by the Centre for Development and Peace Studies, 36% of the population of Assam lives below the poverty line. Industrial production contributes just 2.16% of the GDP of the North East compared to the national average of 27%, indicating a severe lack of industry in the region. Thus, people are forced to depend upon Government schemes for their livelihoods.

The debt burden to the nation of the North-Eastern states is very high. For example, Assam had a debt burden of about Rs 4 crores in the 1950s, it increased to Rs 704 crores in 1979. (Sharma and Sharma, 2006). In 2014-15, this is estimated to have increased to about Rs 31,000 crores (310 billion Indian Rupees).

Lack of industry and exports, lack of tourism coupled with high debt burdens, make the funding of essential schemes in the North East dependent upon grants received from National Government. However to receive national funds, states are asked to contribute a small percentage from local resources. Many North-Eastern states are unable to provide a local contribution of even 10% to receive national funds. This has a profound negative impact on different services, including essential services for PwDs.

The **Human Development Index** (HDI) evaluated by the United Nations is based on an analysis of income, education and health indices. According to the national HDI report for India (UNDP, 2010), if we exclude Assam, the rest of the North East has a higher HDI ranking than some of the more developed states like Maharashtra, Tamilnadu and Gujarat. On the other hand, in terms of HDI, Assam appears below the national average, together with states like Bihar and Uttar Pradesh. This means that even with limited local capacities and other challenges, the other North-Eastern states have been able to build good primary health care and primary education services.

Over the past decade, all the states of the region have made progress in improving the literacy rates and reducing the Infant Mortality Rates (IMR) in children below five years old. The highest IMR occurs in the most populous state Assam, which also has the lowest HDI.

Table 1 provides an overview of some demographic and development indicators in the eight states of the North East.

Table 1: Demographic and Development Indicators in the North East

State	Total	Surface area	Literacy rate	<5 yr. IMR
	population (million)	(sq. km)	(%)	(per 10,000 live births)
Arunachal Pradesh	1.4	83,743	67	32
Assam	31.2	79,000	73	54
Manipur	2.6	22,327	79	10
Meghalaya	2.9	22,429	76	47
Mizoram	1.01	21,087	92	35
Nagaland	1.9	16,579	80	18
Sikkim	0.6	7,096	82	22
Tripura	3.7	10,491	95	26

Note: All data above is from the 2011 Indian national census.

However, the HDI ranking provides only a partial picture of the existing situation in the NE. Many other health indicators are much worse in different parts of the NE and thus point to the weaknesses in the health systems.

For example, a recent report (MDG-India, 2015) presents the following information about some health indicators in Nagaland: The situation of underweight and malnourished children below 3 years of age in Nagaland had actually worsened between 1998-99 and 2005-06, from 18.8% to 23.7%. Nagaland had a low coverage (52.2%) of essential immunization among infants below 1 year. Percentage of child births assisted by trained personnel was also low (43.8%). It also had the highest percentage of pregnant women who were positive for HIV.

Conflicts in the North East

Though there have been improvements in the peace situation and visiting different parts of the North East has become easier over the past few years, the region remains hostage to frequent crisis. Over the past decades, different parts of the North East have been involved in conflicts linked to demands for autonomy, as well as to religious and ethnic tensions. There are regular reports of bomb blasts, robberies, kidnappings and armed conflicts.

For example, in 2015, there were agitations by Meitei population groups in the Manipur valley asking for "regulation of the entry of outsiders in the state and the rules related to buying of land". Finally the state legislative assembly passed the Manipur Land Revenue and Land Reforms (Seventh Amendment) Bill, 2015. However immediately after this, the hill tribes of Manipur started a counter-agitation against this law, which they fear will take away their land and give more power to Meiteis. A report in the national newspaper Hindustan Times dated 3 September 2015 noted the following situation:

"The first thing that strikes a new visitor to the capital of Manipur, Imphal, is that there are hardly any billboards or advertisements on the city's walls. This — though a rudimentary one — is a handy indicator that shows that the state's economy is in a deep freeze. This had been the case for years now. The static state of the economy, along with lack of good educational and health facilities, employment opportunities, infrastructure and the deep social divide between the tribals and the non-tribals, makes the state fertile ground for regular episodes of social flare-ups and insurgency."

After more than 10 years of peace, in 2015 the situation in Nagaland also became critical. Some separatist groups, after a decade of "non-conflict agreement", became active and killed some military personnel. Thus, in August 2015 Nagaland was declared a "disturbed area" and military with heavy weapons arrived in different parts of the state, including the state capital. In the same period, national government had signed a new peace agreement with one of the main Naga groups, raising hopes for a return to normality.

Periodic reports of conflicts, kidnappings and bomb blasts from certain Bodo districts of Assam and from Garo Hills of Meghalaya are other examples of crisis points in the region.

The region is rich in cultural diversities. However, tribal identities and rivalries can also be linked to the conflicts and tensions. For example, Kohima, the capital of Nagaland, is a beautiful city, with offices and schools scattered on different hills, where persons from different Naga tribes as well as persons from other parts of the North Eastern Region and India, seem to live peacefully. Yet, if you want to take a taxi going towards the south of Kohima along the road towards Senapati district of Manipur, you can only go in taxis belonging to the Angami tribe, who live in this part of the state. They do not allow persons

belonging to other groups to carry passengers on this road. Thus, even when there are no open fights, low-level conflicts may be present.

Tribal populations from central India were brought to work in the tea gardens of the North East, mainly Assam state, during the colonial period. More recently immigrants from Bangladesh and from other states of India including West Bengal and Bihar, have come to the region. They have all been linked to some of these conflicts and social tensions that are both a cause of and aggravated by the lack of economic and industrial development.

Signing of a recent agreement between India and Bangladesh, which permits certain immigrants from Bangladesh to become legal residents in India, has stimulated protests in Assam against the persons from Bangladesh. In 2016, there will be legislative elections in Assam; these conflicts create a risk of ethnic and religious polarization for electoral gains.

Changing Identities and Development

The Government of India is making ambitious plans to promote infrastructural and economic development in the North Eastern Region. One example is to build a Trans-Asia highway connecting the North East to Myanmar, Thailand and further east. As mentioned above, setting up of new railway links, highways and an Internet gateway are some other plans. Improved infrastructure and economic development are certain to bring persons from other parts of India to the North Eastern Region. At the same time, every year, thousands of persons migrate from the North-East to other parts of India in search of livelihoods.

The North-Eastern communities, isolated for centuries, were first forced to deal with diversity when British rulers decided to develop tea gardens and brought millions of persons from other parts of India to work in those gardens. Reduced to slavery and fragmented in small groups under the rules of the tea planters, these "tea-tribes" had difficulty in creating a unified identity. At the same time, they had limited interaction with local tribes and communities. Thus after having lived in the North East for more than a hundred years, even now many of them continue to be perceived as "outsiders" by the local groups.

Christian missionaries accompanying the British tea planters provided essential services of health care and education. At the same time, their influence has changed religious identities in some North-Eastern states. Refugees and immigrants from Bangladesh have also changed and continue to change the demographics of different parts of the North East. Many of these new arrivals are forced to live in ecologically fragile and disaster-prone areas such as the river islands in Brahmaputra river in lower Assam. In addition, the rise of radical and more conservative groups among the Hindus is adding to this ongoing transformation. These demographic changes can create social tensions in communities.

Over the past couple of decades with Internet, television and films there are other social and cultural changes under way, especially in the big cities. If we look at all these changes together, it is easy to understand the struggle between the old and new cultures and societies. Sometimes, small events in this tug-of-war have a big impact, leading to violent backlashes and the sudden flare-up of conflicts.

Another recent report (KPMG-FICCI, 2015) looks at the potential of the NE in terms of development, infrastructures and connectivity needs. While considering NE as a potential contributor to the growth of India, this report identifies the following weaknesses in the region (p. 7):

- Lack of proper connectivity. A large part of the region comprises of hilly terrain which makes the states dependent on the road network which is not particularly good. Lack of sufficient airports also reduces connectivity.
- Scarcity of skilled and unskilled labour.
- Floods and landslides in monsoons make places inaccessible.

Thus, overall there is hope for more development and peace in the region. However, it is equally possible that over the next decade, there will be periodic local set-backs to the peace and development processes with conflicts, massacres and suffering affecting disproportionately the poor persons and immigrants.

PERSONS WITH DISABILITIES IN THE NE

According to the first World Report on Disability (WHO and World Bank, 2011), around 15% of the population of a country has some disabilities. Of them, on average, about 2.2% of persons have significant difficulties in functioning and require support.

Thus, out of the 44.31 million total population of the North Eastern Region, based on the World Health Organization (WHO) estimates, we can expect a total of 6.6 million persons with some disabilities (15%). Out of them, we can expect about 970,000 persons (2.2%) with significant functional limitations who require some rehabilitation services. Considering the state population, around 690,000 persons with disabilities can be expected in Assam. In other North-Eastern states, the numbers will be much smaller – for example, in Meghalaya we could expect around 64,000 persons.

However, in the national census in 2011, the total number of PwDs identified in the North East was 733,450 (1.65%), a little less than the figures estimated by WHO. One reason for the difference may be that in the Indian census, the questions were limited to certain disabilities and were different from those of the WHO surveys. The following sections look at the disability data collected in the national census exercises as well as in some other studies from NE.

Disability Data from the National Censuses and Reports

The national census carried out in India in 2011 collected information about persons with eight categories of disability (seeing, hearing, speech, movement, mental retardation, mental illness, multiple disabilities and any other disabilities).

Through the census, a total of 26.8 million persons with disabilities were identified (around 15 million men and 11.8 million women) in India. Therefore, at national level about 2.21% of the population had a disability. Globally, rural areas had a slightly higher percentage of persons with disabilities compared to the urban areas – 2.24% compared 2.17%. Globally, the states with the highest and lowest prevalence of persons with disabilities were both in the NE – Sikkim with 2.98% and Mizoram with 1.38%.

At global level, the prevalence of persons with disabilities in India increased with age. For example, in 0 to 4 years age group it was 1.14% and in 5 to 10 years age group it was 1.54%;

in 30 to 39 years old it was 2.09%; in 70 to 79 years old it was 6.22% and in 80 to 89 years old it was 8.41%.

Table 2 presents an overview of 2011 census data regarding PwDs in the North-Eastern states.

Table 2: Basic Demographic Information about PwDs in the North East

State	Total PwDs (% of	Men with	Women	Children
	the total population)	disabilities	with	below 18
			disabilities	yrs.
Arunachal Pradesh	27,634 (1.93%)	14,245	12,489	8,438
Assam	480,065 (1.54%)	257,385	222,680	134,479
Manipur	54,110 (2.11%)	28,783	25,327	16,181
Meghalaya	44,317 (1.49%)	23,326	20,991	17,413
Mizoram	15,160 (1.38%)	8,198	6,962	3,748
Nagaland	29,631 (1.50%)	16,148	13,483	7,740
Sikkim	18,187 (2.98%)	NA	NA	NA
Tripura	64,346 (1.75%)	35,482	28,864	16,509

Note: All the data is from the 2011 National Census. At the time of preparation of this report, some details of Sikkim data were not yet available.

The census questions for identification of persons with disabilities were impairment-based. The initial question used as a filter to identify the persons with disabilities was ,"Is this person mentally/physically disabled?" (Census GOI, 2013)

A study done by the National Centre for Promotion of Employment for Disabled Persons (NCPEDP, 2011) showed that using activities-based or functions-based questions compared to impairment-based questions results in a higher prevalence of disabilities in populations. For example, in Zambia if people were asked, "Do you have a disability?" the prevalence of PwDs was just 1%; when they were asked functions-based questions (such as "Do you have difficulty seeing, even if wearing eye glasses?" as proposed by the

Washington Group of the United Nations Statistics division) the disability prevalence was 13%. Thus, considering the questions used in the Indian national census in 2011, the 2.21% national prevalence of disability is along expected lines.

The census data does not always coincide with other data collected by the states. For example, according to the 2011 census, there were 44,317 PwDs in Meghalaya. However, according to the Annual Report of the State Disability Commissioner (SDC Meghalaya, 2009-13), in 2012-13, there were 39,089 PwDs in the state. This may be due to different definitions and methodologies used for identifying PwDs at different points in time.

Comparing the 2011 Census Disability Data with the Previous Data Collections: In the 2001 census, PwDs were 2.1% of the total population of the North Eastern Region while in the 2011 data the percentage of PwDs was 1.9%. The 2001 data had shown the highest prevalence in Arunachal Pradesh (3%), followed by Assam (1.9%) and Mizoram (1.8%). In all other states the percentage of PwDs was even lower. This contrasts with much lower prevalence in Assam and Mizoram in the 2011 census.

However, it is not correct to compare the 2011 disability data with the 2001 census data. In 2001 information had been collected for five groups of disabilities, while in 2011 it was for eight groups. Thus, the two data sets are very different. and cannot be compared to look for changes occurring in the ten-year period between the two censuses.

Some of the definitions used for specific groups of PwDs were changed between the two censuses. (Census GOI, 2013) For example, in the 2001 census, persons with loss of vision in one eye were considered as disabled while in the 2011 they were not considered as disabled. Conversely persons using hearing aids were not considered disabled in 2001 and were considered disabled in 2011.

There were some other changes in the methodology between the two censuses (for example in the training of the census enumerators and in the specific conditions linked to movement disabilities).

In 2002 another important disability related survey (NSS, 2002) was carried out by the National Sample Survey Organization. This survey collected information about seven groups of PwDs (mental retardation, mental illness, blindness, low vision, hearing disability, speech disability and locomotor disability). According to this survey 1.8 % of the population of India had a disability. NE region was also covered in this survey. However,

due to use of very different criteria and methodology, it is not possible to compare these data with the 2011 census data.

However, there has been some criticism of the way disability related questions are posed in the surveys and census in India: "... the method of questioning on disability in both census and NSS which relies on a traditional "diagnostic" identification of disability by untrained interviewers, which recent work coming out of a UN expert group suggests is the method which yields the lowest disability estimates" (Mitra, 2012).

Information about PwDs in the State Reports: The North-Eastern states rely mainly on the census data to plan their disability related services. For example, the Annual Reports (2011-12) of the State Disability Commissioner of Assam (SDC Assam, 2001-12) and Meghalaya (SDC Meghalaya, 2009-13) quote only the national census data. However, the state reports do quote the number of persons benefiting from different government welfare schemes.

At the state level in the NE, the only other reports presenting disability data are those prepared under the national education scheme for children, called "Sarva Shiksha Abhiyan", which also promotes the inclusion of children with disabilities in the education system. For example, in 2011-12 SSA in Assam (SSA, 2013) had identified more than 99,000 children with disabilities in the 6 to 14 years age group, in a total population of about 5.6 million children. Thus, according to this survey, 1.7% of the 6 to 14 years child population in Assam had a disability.

Disability Data from the North East in other Reports

A review of data on disability and rehabilitation in India from Medline and other sources (Kumar et al, 2012) concluded "Systematic research into prevalence and determinants of disability has been scanty from India although it is an important public health problem. Disability is the best example of the iceberg phenomenon of disease. This is because of difficulty in identifying the mild and moderate degrees of physical and mental disability which are unrecognized by the health care delivery system and the survey team members. ... A recent community based study in India found the prevalence of all types of disability as 6.3%...".

Information about PwDs in the North East in Research Reports: If information on prevalence and determinants of disability in India is scarce, specific studies on the

situation in the North East, published in peer-reviewed journals, are almost non-existent. The only available information is in the grey literature, that is, reports and documents prepared by organizations about their activities. However, usually these provide information about their own services and do not present an overview of the global situation.

Only one population survey for PwDs in the North East was identified – it was carried out by an NGO in Gabharu block of the Sonitpur district of Assam (Singh et al, 2009). According to this survey, a total of 333 PwDs were identified in the block that had a total population of 108,301 persons. Thus, the prevalence of disability in this survey was only 0.3%. The survey was carried out through a pre-tested questionnaire covering the five areas of the CBR matrix. However, the specific methodology used for identifying PwDs in this survey was not clear.

The key health related issues affecting PwDs identified in this survey included difficulties in accessing medicines and a lack of rehabilitation services.

Information about PwDs in the North East in NGO Reports: NGOs reports provide information about their own activities. For example, *Operation Smile* had initiated surgeries for cleft lip and palate in Guwahati in 2009. A newspaper report (The Telegraph, 22 October 2013) had informed that they had conducted "10,000 safe cleft surgeries within a span of less than four years". This project focuses only on children below 13 years of age.

In another example, *Swabalambi*, an NGO carrying out a CBR programme in 50 villages of Sonapur block of Kamrup Metropolitan district (Assam) noted in its Annual Report that in 2013 there were 289 persons with different disabilities directly benefitting from its activities. (Swabalambi, 2014)

Thus, these reports provide information about the persons who benefit from the programmes and activities of the voluntary organizations. However, they do not provide information about the overall situation or the gaps and challenges such as — how many PwDs are not part of the CBR programme or are not covered by specialized services, what kind of disabilities do they have and what are their rehabilitation needs? Therefore, their usefulness in understanding the disability and rehabilitation needs is limited.

Gaps And Challenges Facing Disability Related Services And Programmes In The North East

Rehabilitation services are not just about specific impairments but also, in a holistic vision, deal with every aspect of life. The **CBR matrix** defined by the WHO (WHO, 2010) considers the disability related issues in five domains – health, education, livelihood, social and empowerment.

To understand some of the gaps in rehabilitation services and the challenges faced by the PwDs and their families, the author visited different rural and urban areas in the North East and talked to different individuals, families, service providers, associations and institutions. Additional information, reports and publications were also sought on the disability & rehabilitation issues.

Some examples of the issues identified during these visits and discussions are illustrated below. These cannot be taken as *evidence* describing the existing situation but rather as general directions in which more systematic future enquiries can be directed.

Conclusions about Disability Data in the NE

The only reliable global data about persons with disabilities is from the last national census carried out in 2011, with the disability prevalence varying between 1.38% to 2.98%. The identification of persons with disabilities in the national census was based on questions related to specific impairments. Therefore, these are likely to be persons with visible impairments or those with significant functional limitations.

As explained in the World Disability Report (WHO, 2011) and shown in some studies in India and in other countries, if surveys can be done that focus on different functional limitations, the number of persons with disabilities in the NE would be much higher.

DISABILITY & REHABILITATION SERVICES IN NE

The medical rehabilitation services include services for diagnosis, specific and specialised interventions and specific rehabilitation services such as physiotherapy, occupational therapy, speech therapy and provision of the assistive devices and technical appliances. Some of these services are organised and implemented not as part of the Health Ministry but as part of Social Welfare Ministry. Apart from the Government services, medical rehabilitation services are provided by non-profit sector such as non-governmental and charitable organisations. Finally commercial enterprises and for-profit companies also provide some rehabilitation services.

Regional Rehabilitation Services: There is no overarching regional rehabilitation centre or body that coordinates the provision of different rehabilitation services in all the eight states of the North-East region. The rehabilitation services are scattered and not coordinated between them in the different states.

Assam and Mizoram have regional centres that cover the state capitals and some neighbouring areas. Medical colleges in the region provide other services. Some districts have centres covering one or more districts. It is not easy to come up with a composite image of different rehabilitation services, as there are many overlaps and equally, many areas of gaps.

Composite Regional Centre (CRC) in Guwahati is responsible for providing rehabilitation services in the NE region including training of the personnel and provision of aids and appliances. It is located in the campus of Guwahati Medical College. It runs an out-patient service from Monday to Friday, where therapy, counselling, and fitting of assistive devices are provided.

According to its website, CRC also runs some long-term training courses including a diploma course in hearing language & speech, diploma in special education (for children with intellectual disabilities), post graduate diploma in disability management and post graduate diploma in CBR. However, in practice all these training programmes have not yet started.

At the same time, even with some outreach activities, it is difficult for CRC to reach and cover all the rehabilitation needs of the NE region. Thus, though called the regional centre, its activities cover only Guwahati and some neighbouring areas. In some districts of

Assam, the rehabilitation services are provided under District Disability & Rehabilitation Centres (DDRCs). In others, which lack DDRCs, the rehabilitation services are provided through some NGOs.

In Mizoram state, in Aizwal, there is another regional centre of the National Institute of Orthopaedically Handicapped, which covers part of that state.

District Disability and Rehabilitation Centres in the North-East: The DDRC is a nation-wide programme of the Ministry of Social Justice and Empowerment of the Government of India. The objective of the programme is to provide rehabilitation services to all PwDs at the district level. The National Institutes, District Rehabilitation Officers and the Artificial Limbs Manufacturing Corporation of India (ALIMCO) were involved in establishing district centres in collaboration with the state governments. The major rehabilitation services that DDRCs were expected to provide included the following (DDRC, 2014):

- Disability Certificates: Facilitation and provision
- Assistive devices: Assessment of the need, provision, fitting, follow-up and repair
- Clinical services: Therapeutic services including speech therapy, occupational therapy, physiotherapy, teaching mobility skills, prevention of disabilities, early detection and intervention and knowledge and skills to individuals and families on early stimulation and motivation
- Community awareness, accessibility and barrier free environment
- *Education*: Supportive and complimentary services to promote education, orientation and support for teachers, referral services for existing educational services and preschool and parent-infant programmes
- Livelihood: Supportive and complimentary services to promote vocational training
 and employment identifying suitable jobs or vocations keeping in mind local
 resources and designing and providing training courses or referral services for
 existing vocational training and job placement services.

As can be seen from *Table 3*, not all the DDRCs planned originally in 2000 are functioning in 2015. For example, in Nagaland, the only existing DDRC in Dimapur has been closed since early 2013.

Table 3: Planned and Actual DDRCs in the North East (2014)

State	Total	Existing DDRCs	DDRC not yet
	DDRCs		created
	planned		
Arunachal	5	3 (Itanagar, Tawang & East	2 (Papumpare &
Pradesh		Kamang)	West Siang)
Assam	17	12 (Tezpur, Dibrugarh, Silchar,	5 (Cachar, Darrang,
		Karimganj, Dhubri, Nagaon,	Bongaigon, Tinsukia
		Jorhat, Barpeta, Dhemaji,	and Udalgiri)
		Sivasagar, Golaghat & Lakhimpur)	
Manipur	4	3 (Imphal, Thoubal &	1 (Imphal West)
		Churachandpur)	
Meghalaya	5	4 (Shillong, East Garo Hills, Jantia	1 (West Khasi Hills)
		Hills & West Garo Hills)	
Mizoram	3	3 (Aizawal, Lunglei+Lunglit,	0
		Kolasib+Mamit)	
Nagaland	3	1 (Dimapur – closed for more than	2 (Tuenseang, Mon)
		2 yrs)	
Sikkim	3	1 (Gangtok)	2 (South Sikkim and
			West Sikkim)
Tripura	4	4 (North Tripura, West Tripura,	0
		Dhalai and South Tripura)	

The DDRC scheme was initiated in 1983. It involved establishing centres, preferably in the premises of district hospitals, as primary rehabilitation units. They were to be manned by specific staff at three levels (Venkatesan, 2004, p. 219).

• District level: specialized rehabilitation professionals

- *Primary health care centre level:* multi-purpose rehabilitation workers or assistants, therapists and technicians
- Community level: village rehabilitation workers.

The DDRC scheme was relaunched in 2000 when national government had provided funds for establishing DDRCs in the NE (as shown in the table above). In 2014, Ministry of Social Justice and Empowerment had launched a call for the evaluation of the impact of DDRCs. The results of this evaluation are not yet available.

During the field visits in the NE, some DDRCs were visited. The situation was found to be very inconsistent, as the roles played by DDRCs vary greatly across the North East.

For example, in one district in Assam, the DDRC run by an NGO since 2008 had two physiotherapists, one psychologist and one community rehabilitation worker. They had a post for an occupational therapist but it had been vacant for at least three years. They maintained a block level register and a list of all the persons who had received disability certificates. They facilitated access to technical appliances. For a small fee, they provided therapy services and mobility training to persons who came to the centre in the district headquarters. However, only a small number of persons could benefit from their clinical services, as persons from the blocks could not come to their centre. This DDRC seemed most efficient at facilitating the access to disability certificates and to some degree, at providing technical appliances. (SSM, 2013)

In another district of Assam, the DDRC run by another NGO since 2009, was mainly involved in facilitating access to disability certificates and to assistive devices. However, the same NGO also ran a special school and a vocational training centre on the same campus as the DDRC. In addition the NGO conducted many other of the activities foreseen in the role of DDRCs including training of community health workers and schoolteachers.

In a third district in Assam, an NGO involved in a CBR programme shared their experience of dealing with DDRC staff in their district. "They have the staff but they have not been provided proper training. They don't know much about different government schemes and programmes. They were asking us to share information with them."

These examples show that the situation and functioning of a DDRC can be very different, depending upon who is managing it and the skills of staff employed in these centres. Many

if not all DDRCs in the NE seem to be managed by NGOs, who receive funds from state governments for their functioning.

DDRCs are under a national scheme, though the states are asked to take an active role and to facilitate their working. Thus, it would be useful to organize state or North Eastern regional level meetings for DDRC staff, aimed at strengthening and expanding their roles. In addition, the North East states need to look at the areas that do not have DDRCs and define strategies for providing certain basic services to PwDs in those areas. For example, in Assam, in some areas where DDRCs are not present, NGOs have been identified to facilitate the process of accessing disability certificates and assistive devices.

State Disability Commissioners: Some information about the SDCs in the NE has been provided above. The Offices of the National and State Commissioner for Persons with Disabilities were set up under Article XII of the Persons with Disabilities (Equal Opportunities, Protection of Rights & Full Participation) Act, 1995. According to this Act, the Chief Commissioner role is to take steps to safeguard the rights of persons with disabilities, and more specifically:

- (a) Coordinate the work of the Commissioners;
- (b) Monitor the utilization of funds disbursed by the Central Government;
- (c) Take steps to safeguard the rights and facilities made available to Persons with disabilities;
- (d) Submit reports to the Central Government on the implementation of the Act at such intervals as that Government may prescribe.

In addition, the Chief Commissioner may of his own motion or on the application of any aggrieved person or otherwise look into complaints with respect to matters relating to -(a) Deprivation of rights of persons with Disabilities. (b) Non-implementation of laws, rules, byelaws, regulations, executive orders, guidelines or instructions made or issued by the appropriate Governments and the local authorities for the welfare and protection of rights or persons with disabilities, and take up the matter with the appropriate authorities.

The appointment and roles of the SDCs follow that of the Chief Commissioner but are circumscribed in the respective states. Thus, according to the PwD Act 1995, even the SDCs

should be persons who have "special knowledge or practical experience in respect of matters relating to rehabilitation."

It is not always easy to find information about the activities of the SDCs in the NE. However, office of SDC of Meghalaya maintains a specific website that provides access to different information and annual reports (http://megscpwd.gov.in/index.html). The office of SDC of Mizoram also maintains a specific website where information and forms for some schemes are available. (https://pwds.mizoram.gov.in/) However it does not provide access to any annual reports. Finally, In Sikkim, there is no information about SDC but it has a State Welfare Commission that provides information about disability related activities and schemes (http://sikkimsocialwelfare.in/General/SocialWelfare/sswc.aspx).

In the NE, some states do identify persons with specific expertise and personal experience of disability and appoint them as SDC. In other cases, SDCs are state level officers from different services who are transferred to this role for a few years. In both instances, it is possible that persons appointed to the role of SDCs do not understand the different facets of their roles and how to effectively implement them in their work. By the time these persons acquire the necessary information and skills related to disability and rehabilitation, they may be retired or transferred to another post.

Therefore, preparation of an information kit for all the new SDCs and organization of periodic meetings for sharing of information and experiences, orientation courses and training could be useful. The North Eastern Region can also bring together the SDCs to reinforce their capacity to handle disability issues. Centre for Internet and Society (CIS) has done some work in this area by bringing together laws, policies and programmes for persons with disabilities in different states of India under the national resource kits (CIS, 2013) programme.

NGOs Active in Disability and Rehabilitation Services in the NE: Major cities and some district towns of the NE have a few NGOs that play a leading role in providing some disability and rehabilitation services. Many of these receive some funding support from the state governments, but usually they have other funding partnerships as well. They also manage many of the services for persons with disabilities on behalf of the state governments, such as for running the DDRCs and for facilitating the distribution of disability certificates and assistive devices.

Voluntary organisations like Shishu Sarothi in Guwahati and Prerona in Jorhat in Assam, Prodigal Home in Dimapur, Cherry Blossoms Society in Kohima and Bethany Centre in Shillong, run a number of important disability and rehabilitation services. Their role is especially important in answering unmet needs since the role played by the states themselves is often limited. Often, these organisations work in close cooperation with the Government bodies. In the NE voluntary and faith-based organisations provide majority of services to persons with disabilities.

Commercial enterprises and for-profit rehabilitation services in the NE: Big cities of the NE region have private hospitals and specialists that provide service-for-fee. Though often, the commercial enterprises and for-profit private hospitals and centres have some concessions for poor persons, most of the time these services are not easy to access to poor persons as well as to persons living in rural areas and smaller towns in the districts.

Many private hospitals collaborate with Government and philanthropic bodies for provision of subsidised or free services for specific interventions such as specialised operations.

ACCESS TO DISABILITY CERTIFICATES & OTHER SCHEMES IN THE NE

Information about PwDs who have a disability certificate was collected during the 2001 and 2011 censuses. In 2011 among the different states of the North East, Tripura had the best coverage (97.72%) in terms of PwDs having a disability certificate while Nagaland had the least coverage (5.17%). The national averages for the coverage of disability certificates was 47.4% in 2001 and 39.3% in 2011.

Table 4 presents an analysis of these data taken from the Annual Report 2013-14 (MSJE, 2014) of the Department of Empowerment of Persons with Disabilities, Government of India.

Table 4: PwDs in the North East with a Disability Certificate

State	Percentage of PwDs with a Disability Certificate		
	2001 (%)	2011 (%)	
Arunachal Pradesh	5.99	7.46	
Assam	30.21	33.37	
Manipur	63.38	33.39	
Mizoram	49.3	52.07	
Meghalaya	82.4	53.56	
Nagaland	5.78	5.17	
Sikkim	39.59	44.27	
Tripura	106.69	97.72	

In the 2001 census, in Tripura the number of persons with disability certificates was higher than the number of PwDs. A similar situation was reported in the Union Territory of Chandigarh in 2011. These results raise some questions about how PwDs are identified and the process for the issue of disability certificates.

Comparing the coverage in the two censuses, some states show a worsening while others show an improvement. The worsening of the coverage between 2001 and 2011 can sometimes be explained by local conflicts, such as in Manipur. However, it may also be linked to issues such as difficulty in the renewal of certificates. Finally, some of these differences may arise from the different grouping of PwDs in the two censuses, as explained earlier.

Disability Pensions in the North East: Disability pension schemes were started only in the past few years in the North East. For example, in Meghalaya, disability pensions were initiated in 2012. These pensions are given only to PwDs who are Below the Poverty Line (BPL), are between 18 to 59 years of age and have a certain percentage of disability.

Probably because the disability pension scheme is so recent, the different stakeholders frequently do not have clear ideas about who should receive it and the monthly amount. During the visits in the field, sometimes even the DDRC staff did not know the rules governing the disability pensions. These rules are still evolving so some lack of clarity may be expected. The schemes differ between the different states of the NE.

From the available information, it seems that only some PwDs who have a disability certificate get the disability pension. This may be because they do not belong to a BPL family or because of a low percentage of disability. Other possible reasons include a lack of awareness about the criteria for receiving the disability pension. During some field visits, PwDs complained that getting all the certificates to access a pension was a difficult process and sometimes there were demands of bribes by local authorities.

The Government of India website Purnabhava (http://punarbhava.in/), provides information about the state disability pension schemes. However this does not always match the information at state level. For example, according to a report on Purnabhava (prepared in February 2015), there was no disability pension scheme in Assam. However, according to NGOs in Assam, until 2013 only BPL persons with more than 70% disability could receive the pension but in 2014 this criterion was relaxed and now BPL persons with 40% disability can receive it. The annual report (2011-12) of the SDC Assam 7,534 PwDs had received disability pension. (SDCA, 2012)

According to the Office of the State Commissioner in Meghalaya in 2014 a total of 7,270 PwDs in the state received a pension. According to the 2011 census a total of 23,735 PwDs

in Meghalaya had a disability certificate. Therefore only about 30% of PwDs in the state received a pension in 2014. (SDCM, 2015)

PwDs in Sikkim also must belong to a BPL family to access the disability pension. Those with 80% or greater disability receive a monthly pension of Rs 700 through the Indira Gandhi Disability Pension (IGDP) scheme rising to Rs 1000 for those aged over 80. Those not qualified for the IGDP but with at least 40% disability get a monthly subsistence allowance of Rs 600 from the state.

Thus different states of the NE have different criteria for awarding disability pensions and amount of monthly pension also vary. The states need to have a more transparent mechanism for informing persons with disabilities about the criteria for the award of monthly pension.

Other Schemes for Persons with Disabilities in the North-East: Apart from disability certificates and pensions, each state has some specific schemes to help persons with disabilities. For example, there are schemes to help them access the technical appliances. However, the scopes, target groups, prerequisites and amounts of funds of different schemes vary between the states.

For example, according to the Annual Reports of the State Disability Commissioner (SDC Assam, 2001-12) **Assam** has the following additional schemes:

- A monthly allowance of Rs 500 for unemployed PwDs. In 2010-11, this allowance was provided to 5,179 persons. In 2011-12, the allowance was provided to 5,460 persons
- A monthly allowance of Rs 500 for families with a disabled child. In 2010-11, this allowance was given to 480 families
- A monthly scholarship of Rs 200 is given to students with a disability studying in school, college or university. In 2010-11, it was received by a total of 842 students
- A rehabilitation grant to start self-employment for youths with disabilities between 18 to 45 years old. During 2010-11, it was received by 181 persons.

Meghalaya also facilitates self-employment with financial assistance to disabled youths for skills and entrepreneurial development. Meritorious students in Meghalaya also get scholarships ranging from Rs 2,000 to Rs 5,000 for high school and university level education.

In Nagaland, the State Disability Pension scheme is managed by the Directorate of Social Welfare of Nagaland. The monthly grant of the pension is Rs 200. To be eligible for this pension, the persons must have at least 40% of disability, have more than 18 years, must belong to a BPL family (Below Poverty Line) and should not be receiving any other pension or financial assistance.

Another pension scheme called "Indira Gandhi National Disability Pension scheme" provides 300 Rs per month to persons with severe disabilities, belonging to a BPL household and of 18 - 79 years.

Disabled students belonging to BPL households and with at least 40% of disability in Nagaland can also receive financial assistance (scholarship) of Rs 200 per month for school studies from class three of the primary school onwards. Free bus passes can be given to blind persons and their accompanying persons.

In addition, persons below the poverty line in Nagaland have the right to receive free technical appliances. However it was not possible to find out the pre-requisites of this scheme and other information such as - how many persons had received free appliances in 2014-15, what kind of pre and post delivery care/training was given to those who had received the appliances.

On the other hand, **in Sikkim**, Persons with disabilities can benefit from two different pension schemes, which are the most generous in the whole of North-East region. A recent report (SJEW Sikkim, 2015) indicates that the state government is considering an increase in the disability pension:

- Indira Gandhi Disability Pension (IGDP) scheme provides 700 Rs per month to persons in the age group of 18 to 79 years, and 1000 Rs per month to persons above 80 years. To get this pension, persons must belong to Below Poverty Line with at least 80% disability. For this pension, Rs 200 per person come from central Government while the remaining is provided by the state government.
- A state subsistence allowance provides 600 Rs per month to persons with at least 40% disability, who are not covered under the IGDP.

In 2013, Sikkim launched another programme to support marriages of persons with disabilities, where couples get Rs 2 lakh one time grant, if one of them has a disability. SJEW also runs a sheltered workshop for making handicrafts for the youth with locomotor disabilities in Jorethang town in South Sikkim district. In 2015, there were 15 persons with disabilities employed in this workshop who received free accommodation and a monthly stipend of Rs 2000. (Sikkim, 2015)

The Government of Sikkim provides 3% reservation for persons with disabilities in the allotment of housing sites. State bodies like SABCCO and State Bank of Sikkim can provide loans to persons with disabilities to start their own business or income generation activities. Two seats in all state run buses are reserved for persons with a disability passbook, who can travel free of cost.

Accessibility in the North East: No published surveys or sample surveys on accessibility of civic services and specific health, education, social and livelihood services for PwDs in urban areas of the North East could be identified. Anecdotal reports and newspaper stories paint a difficult situation in terms of physical accessibility for persons with locomotor disabilities. For example, a report dated 11 March 2015 in Guwahati section of the Times of India newspaper stated, "Notoriously unfriendly towards differently abled persons, the city's attitude, many feel, has worsened."

The physical barrier are not just for PwDs, they also make the life difficult for elderly persons and other vulnerable groups such as pregnant women and mothers with small babies.

A casual walk in the Guwahati's principle roads (A.T. Road and G.S. road) shows that sidewalks are impossible for wheel chairs and very difficult for persons with locomotor difficulties because of frequent dis-levels and gaps. They are designed with concrete slabs to help in the drainage of the excessive rainwaters. The situation in other NE states is similar. Often there are no sidewalks. When there are, they are full of obstacles for persons with disabilities, especially for persons with locomotor and visual disabilities.

Therefore, often the only way for persons on wheel chairs to go anywhere is to use the roads and risk going under a car or a truck. Thus it is extremely rare to see any wheel chairs in public spaces in the NE.

Frequent rainfalls and marshy areas also mean that often houses are built raised up from the ground. Therefore, it is rare to find a house without any stairs in the region. Hospitals, government offices, schools and other buildings often pose these barriers to access for this reason. Thus, physical accessibility is also a problem in different health-care facilities including hospitals and health centres.

Regarding accessibility for persons with other kinds of disabilities such as sign language accessibility for persons with hearing disabilities or braille accessibility for persons with vision disabilities, no information could be identified.

In 2015, Government of India has launched the *Sugamya Bharat Abhiyaan* (Accessible India Campaign). Under this campaign, there are plans to conduct an accessibility-audit of 50 important Government buildings in capital cities of the eight states of the NE – Guwahati (Assam), Shillong (Meghalaya), Itanagar (Arunachal Pradesh), Imphal (Manipur), Aizawal (Mizoram), Kohima (Nagaland), Agartala (Tripura) and Gangtok (Sikkim). Following the audit, accessibility of those buildings will be improved by 2019 through ramps in public buildings, provision of accessible toilets for wheel chair users, providing braille symbols and auditory signals in lifts and providing ramps in hospitals, health centres and rehabilitation centres. (PIB-GOI, 2015)

Thus, in summary the NE Region does not have a common set of benefit schemes for PwDs. It is not always easy to identify the criteria for the award of the allowances paid to PwDs under different schemes in the different states. Thus, in terms of different schemes to help persons with disabilities and their families in the NE, each state has some specific programmes and there is little effort at arriving at some common minimum standards at the regional level.

Accessibility of buildings and services in terms of physical accessibility, Braille language and audio books accessibility, sign language interpretation, etc., the situation in the NE is dramatic. Though the Government has announced some plans to improve the physical accessibility of essential buildings, the challenges remain enormous.

MEDICAL REHABILITATION SERVICES IN THE NE

There are no official data available on the numbers of different rehabilitation specialists in the North Eastern Region. Information about the number of physical medicine specialists, rehabilitation therapists, occupation therapists, speech therapists or other specialists in the NE and their coverage is not readily available. Anecdotal evidence from the region shows the presence of specialists and specialized services in a few big cities like Guwahati, Jorhat, Imphal, Gangtok, Shillong and Dimapur. Even in these cities, the specialists are mainly based in medical colleges and regional institutes. Many more specialists are based in private hospitals that may not be accessible to poor persons.

If we look at overall availability of health personnel, NE is lagging behind. For example, if we look at number of doctors per 1000 population, at national level there are 1.44 doctors while in the NE there are only 0.39. (Hazarika I., 2013) Even when specialists are present in public services, they may be engaged in other work. For example, Nagaland has only one specialist in physical medicine in the state service but during 2015, he was transferred from Dimapur to a remote district.

For example, under the ADIP scheme, **cochlear implants** are provided for some persons with hearing impairment. There are six centres for cochlear implants in the NE – 2 in Guwahati, Assam (Guwahati medical college and Pratiksha hospital), 2 in Agartala, Tripura (ILS hospital and Agartala medical college), 1 in Shillong, Meghalaya (NEIGRIHMS), and 2 in Imphal, Manipur (RIMS and NJ Institute). (ADIP, 2015) The cost of the implants is subsidized by the Government. Usually such implant surgery should be carried out as early as possible among the children – ideally before 3 years and possibly before 6 years, to facilitate the development of language skills. Information about the scheme should be available at the DDRCs but it is not easy for persons in rural areas and small district towns to access this service. Greater information and involvement of NGOs working at community level is needed to increase the coverage of this scheme.

Operational Smile provides the opportunity of corrective surgery of children born with **cleft lip and/or palate**. Over the years, DDRCs and NGOs active at community level have information about this facility at the Smile Regional Care centre in Guwahati (Assam). Families may also receive transport costs to bring their children for the surgery. However, such operations should be available also at the medical colleges and state level health care institutes in all the NE.

Another organisation called Cure India trains health personnel and runs clinics in the NE for the treatment of **children born with club feet**, using the Ponsetti method. This method provides an opportunity for treatment in out patient clinics. "Club Foot" affects 1 in 500 children. There are nine (9) Cure India centres in the NE – 3 in Assam (Guwahati medical college, Dibrugarh medical college and Silchar medical college), 1 in Mizoram (Civil hospital Aizawal), 1 in Nagaland (Naga hospital, Kohima), 1 in Manipur (JN Institute Imphal), 1 in Arunachal Pradesh (State hospital Itanagar), 1 in Tripura (Agartala medical college) and 1 in Meghalaya (Civil hospital, Shillong). (Cure India, 2015) However, knowledge about this facility is lacking in the DDRCs and the access for families from rural areas and small towns is not easy.

A study in 4 states of the NE (Bhattacharjee et al, 2008) in 376 children attending a blind school had shown that in 36% of children the visual impairment was caused by corneal scarring and in another 10%, it was caused by conditions of the ocular lens. Both these conditions can be treated surgically. Corneal surgery requires transplant and eye banks, present in the Guwahati Medical college and Sri Sankaradeva Nethralaya (SSN) in Guwahati. SSN accepts that it is not able to meet the community demand for **corneal transplants** because of "a) lack of awareness about 'eye donation' among masses, b) lack of a systemic eye banking structure, c) lack of Human Cornea Retrieval Programme (HCRP) and d) lack of eye donation centres in remote areas." These difficulties are coupled with lack of awareness and barriers to access among poor families living in remote areas. (SSN, 2015)

A study (Bardalai, 2008) showed some common challenges in different parts of the North East including a lack of awareness of disability laws and schemes displayed by decision makers in the health and education services as well as by other government officials.

For example for persons with **spinal cord injury** in the North-East, the nearest rehabilitation centres are in Odisha in Cuttack and Bhuvaneshwar.

For children with **cerebral palsy**, there are 3 centres in Assam (Shishu Sarothi and Manovikas Kendra in Guwahati and Prerona Pratibondhi Shishu Vikas Kendra in Jorhat); one centre in Mizoram (Society for Rehabilitation of Spastic Children in Aizwal); and one centre in Tripura (Spastic Society of Tripura in Agartala). For children living outside these cities, the only hope of some support comes from community-based rehabilitation (CBR)

programmes, which are few and often their staff lack specific training skills for working with these children.

Children with **developmental disabilities** such as cerebral palsy, Down Syndrome, Autism, etc. also require other support services such as those from speech therapists. Even these support services are not available outside a few big cities of the North-East.

While disabilities due to chronic conditions, old age, traffic accidents and mental illness are on rise, those caused by **infectious diseases** are becoming increasingly less significant. Among the infectious diseases causing disabilities, the NE has periodic cases of encephalitis and a low but relatively stable number of leprosy.

Regarding **leprosy**, with support from Amici Trust and AIFO, the NE has a programme for control of this disease under the National Leprosy Eradication Programme. India has the highest number of new cases of leprosy in the world and compared to some of the states of states of north and central India, the number of new cases in the NE is relatively small. However, if we compare data at Global level, the NE still has significant number of cases of leprosy.

Table 5 presents the situation of new cases of leprosy in the NE during 2012-13 and 2013-14. As shown by the data, though the actual numbers do not seem to be high, when compared to the tiny populations of many NE states, the rates of new case detection are quite high. Nagaland, Assam, Mizoram, Arunachal Pradesh and Sikkim show high rates of new cases of leprosy. (NLEP 2013 & NLEP 2014)

Table 5: New Cases of Leprosy in the North-East

State	Total population (million)	New Cases in 2012-13	New Cases in 2013-14	New case detection rate (per 100,000) 2013-14
Arunachal Pradesh	1.4	48	23	1.6
Assam	31.2	1,147	1,048	3.4
Manipur	2.6	24	12	0.5
Meghalaya	2.9	26	24	0.8

Mizoram	1.01	18	30	2.9
Nagaland	1.9	138	158	8.3
Sikkim	0.6	12	10	1.6
Tripura		23		1
-	3.7		37	1
Total	45.3	1,436	1,342	3.2

Note: All data above is from NLEP report 2012-13 and 2013-14

A large number of new cases of leprosy have grade 1 disability, which means that they may have sensory loss in hands and/or feet and thus are more susceptible to develop more serious disabilities. In addition, a little more then 10% of the new cases of leprosy are detected when they already have more serious grade 2 disabilities. State leprosy programmes provide free medicines for the treatment of leprosy as well as organise specific interventions such as reconstructive surgery. However, no report could be identified regarding the total disability burden due to leprosy in the NE and the related gaps and challenges.

During the field visits in the NE, the author heard many stories from persons with disabilities and their families regarding difficulties in accessing specialist services due to distance from rural areas and district towns and due to high costs. However, a proper study on barriers to access the specialized health and rehabilitation services is missing. As explained above, for some specific rehabilitation interventions there are programmes and centres in the North-East region, it becomes difficult to find similar support for chronic conditions that require lifelong support for persons living in rural areas and smaller district towns.

COMMUNITY-BASED REHABILITATION (CBR) & COMMUNITY-BASED INCLUSIVE DEVELOPMENT (CBID) IN THE NE

The CBR strategy was launched by the World Health Organisation in the 1980s. The U.N. Convention on the Rights of Persons with Disabilities and the first World Report on Disability (WHO and World Bank, 2011) recommend the CBR strategy to reach persons with disabilities and families in the communities where they live.

The implementation of CBR strategy is based on the five domains of the CBR Matrix – health, education, livelihood, social and empowerment. (WHO, 2010) CBR programmes are usually implemented by community workers in collaboration with persons with disabilities, their families and communities.

Often self-help groups and grassroots organisations of persons with disabilities play a key role in CBR. Home visits, teaching self-care skills, transferring simple care skills to the parents and families, promoting independence and self-sufficiency, promoting peer support groups, promoting inclusion in the education system and access to livelihood opportunities are some of the activities of the CBR workers at community level.

CBR in the North-East: In the NE region, CBR programmes were initiated mainly non-governmental organisations (NGOs). For example, since 2007 CBR Forum (CBRF) based in Bangalore, with funding from different international organizations, had supported the setting up of pilot CBR projects in various states of the North East. Typically these projects covered one block in a district. These projects promoted activities across all the five domains of the CBR matrix. They had a special focus on setting up of DPOs and linking them with each other for a North Eastern Region network.

CBRF funding for these CBR projects in the NE has tapered off in recent years, though there continue to be a few significant projects. There are also a few CBR projects set up by other local organizations with international development support. Two examples are the Baptist Christian Hospital with CBR project in Udalguri (Assam) and the International Medical Association working in Manikbond/Silchar (Assam).

Some organizations that no longer receive funds for CBR programmes through the CBRF, continue to carry out some CBR activities such as the Prerona in Cinnamara (Jorhat,

Assam), the Institute of Integrated Resource Management (IIRM) in some areas near Tezpur (Assam) and People in Need Foundation, in Dimapur (Nagaland).

CBR programmes supported by State Governments in the North-East: A report from Meghalaya (SSA-NE, 2013) provides the following information about a state programme of CBR, "The Health Department has set up multi-purpose rehabilitation centres having multi-purpose workers. There are 40 MRCs, one in each of 39 blocks and one in Shillong Urban. Each MRC has 5 community based rehabilitation (CBR) workers who undertake survey for prevention of disability. These CBR workers are trained by the staff in State Resource Centre (SRC) once in each quarter."

The Meghalaya report also noted that SRC is providing 2 months training to MRC and CBR workers. It will be important to look at the impact of this initiative and the quality of services provided by the state level CBR programme, to see if this could be followed by other states of the NE.

Need for expanding CBR in the North-East: The Disability Action Plan 2014-2021 (WHO, 2014) of the WHO underlines the importance of strengthening CBR programmes. Research done in India on CBR (Biggeri M., Deepak S., et al, 2012) has shown that it has a strong positive impact on the quality of life of PwDs, especially in rural areas and resource-poor settings.

As mentioned above in the section about DDRCs, they are also expected to support village rehabilitation workers (VRWs) and CBR programmes. For example, the training syllabus for CBR workers proposed by the Rehabilitation Council of India (RCI, 2007) also specifies that CBR is part of the DDRC scheme. Some state governments in India have supported the appointment of VRWs. For example, a study in Mandya district of Karnataka state (Biggeri, Deepak et al, 2012, pp. 129-130) showed that out of 237 village panchayats in the district, 228 had a village rehabilitation worker. They were selected by the village panchayats. The example from Meghalaya, of CBR programmes in 40 blocks, each with 5 CBR workers, can be considered as the beginning of something similar in the North East Region.

Reaching out to PwDs and their families in the NE is particularly challenging for the disability and rehabilitation services because of the hilly terrains, poor communications, lack of infrastructure and the many different tribal communities with their own languages and cultures. CBR programmes are effective in such remote areas as they work with local

community workers. However, today only a small part of the NE has been covered with CBR programmes and these are all NGO managed projects where funding and continuity of activities are often problematic.

Strategies are needed to identify resources to support and expand CBR throughout the North East. Much stronger commitment and support for starting and expanding CBR programmes are needed, not just from NGOs but also from state governments.

Persons with Disabilities And Other Vulnerable Population Groups

Over the past years, there has been some debate on persons with chronic conditions and elderly persons who have some functional difficulties, but are not considered as persons with disabilities and are usually not included in the CBR programmes. It has been proposed to widen the scope of CBR programmes so that they can include these and other marginalized population groups that can benefit from a community-based development oriented approach. Thus, Community-based Inclusive Development (CBID) projects have been proposed.

There are particular groups of persons and communities in the North East that are particularly vulnerable to disabilities. Poverty, lack of adequate nutrition and diseases all increase their vulnerability to disabling conditions. Poverty also reduces the capacity to access pay-for-services provided in private hospitals and rehabilitation centres.

Elderly persons: According to HelpAge India, an NGO working with elderly persons, traditionally, elderly persons in the North East were looked after by their families. This situation is changing rapidly especially in metros and small towns. For example, in Guwahati, there were no old age homes until five or six years ago, today there are four homes. Even organizations with experience of working with elderly persons do not always appreciate their disabilities related needs such as for technical appliances.

Among the elderly persons, those with disabilities such as memory loss (dementia or Alzheimer's) are part of a group that is vulnerable to violence and abuse. They are a serious burden for families that do not know how to deal with the condition and have no access to support services. There is also need to develop specific technical appliances to support cognitive functions such as Apps that can be used with smart-phones. Though some smart-phone Apps have been developed in India to help persons with disabilities, there are no Apps in Assamese or other North-Eastern languages.

Persons working in garbage dumps: Guwahati has a big garbage dump in Boragaon in the south-western periphery of the city. People living and working at the garbage site include children. They are poor and illiterate and have limited and difficult access to health services. There is almost no information about their health needs or about PwDs working at the site. Among children and adults working in garbage dumps, addictions and substance abuse such as glue sniffing, tobacco use and alcoholism are recognized problems that are related to disabilities.

Street children: Guwahati has a large population of street children who come from different parts of the North Eastern Region. These children are vulnerable to violence, accidents, injury, and sexual abuse in addition to health risks such as malnutrition, disease and addiction. According to Snehalaya, an NGO working with street children in Guwahati, there are between 5,000 and 7,000 street children in the city (DBRC, 2013).

Riverine population groups: Another vulnerable group is that of persons living in the riverine islands in Brahmaputra river. Except for some large islands like Majuli, most of the riverine islands of Brahmaputra river have no health care facilities. It is estimated that around 3 million persons live in these riverine islands in Assam. C-NES an Assamese NGO in collaboration with National Rural Health Mission is running a boat-clinic programme in 13 districts of Assam to provide basic health care services to the riverine population.

Developing innovative CBID programmes in the North-East: The above are some examples of the vulnerable groups that are also likely to be more vulnerable to disabilities. Understanding the specific vulnerabilities and disability-rehabilitation issues linked to such groups requires multidisciplinary bio-social-psychological research. CBR approach can be important in reaching out to these population groups.

There is a need to develop and test innovative approaches to CBID where traditional CBR activities are expanded to cover the needs of these other vulnerable groups in the NE.

ACCESS TO AIDS & APPLIANCES IN THE NE

Composite Regional Centre (CRC) in Guwahati is the regional centre for aids and appliances in the North-East. Under the ADIP scheme it provides appliances free of cost to those with monthly income of less than 15,000 Rs once every three years (children below 12 years can receive the appliances every year) and with at least 40% disability. Persons with a monthly income of 15,000 to 20,000 Rs need to pay 50% of the cost of the appliance, while persons with higher incomes need to cover all the costs. (CRC, 2015)

The DDRCs have taken the responsibility of identifying persons who need appliances, to source them from ALIMCO and to distribute them through the "camp approach" where appliance camps are organized in different blocks of the districts. In those districts where a DDRC is not present, other institutions especially medical colleges and NGOs may facilitate distribution of appliances, but this process does not cover all the districts and remote areas.

For example, according to the Annual Reports of the State Disability Commissioner of Meghalaya (SDC Meghalaya, 2009-13), the following technical appliances were sourced from ALIMCO and distributed during the past few years: 506 appliances in 2009-10, 518 appliances in 2010-11, 814 appliances in 2011-12 and 444 appliances in 2012-13.

ALIMCO also collaborates with the national education programme (*Sarva Shiksha Abhiyan*) for distribution of technical appliances to children. However, there is no statelevel database identifying persons who need appliances and persons receiving appliances.

Thus, the appliances are provided to a certain percentage of persons in need, especially to persons living close to the DDRC or an NGO or some other responsible organization. There are many other issues linked to technical appliances, including users' satisfaction, support for users to ensure proper use of the appliances and adjustments and repairs. Distribution of appliances through a camp approach is unlikely to meet these needs.

Challenges regarding assistive devices in the North-East: An NGO involved in a CBR project explained that upper limb prosthesis were impossible to get in the North East, although their need may be limited. However, in more remote and difficult to access areas of districts, it is likely that PwDs face difficulties in accessing all kinds of appliances.

During the field visits, some persons with disabilities in the North-East who had received wheel chairs and appliances from ALIMCO lamented that the quality of the wheel chairs and appliances they had received was not good and they did not last very long.

A National Sample Survey conducted in 2002 had looked at the issue of use of aids and appliances. (NSS, 2002). Different states of the NE had also been involved in this survey, though the results for all the states have been put together to provide national level data. The next two tables present this information.

Table 5 presents information (NSS 2002) about different groups of PwDs who had received assistive devices but were not using these because these were "uncomfortable" or because they had problems related to repair and maintenance.

Table 6: Use of Received Assistive Devices (NSS 2002, Table 35 Rural+Urban)

Kind of disability	% not using Assistive Devices Received because		
	Were uncomfortable	Problems of repair &	
		maintenance	
Blind persons	38%	7.7%	
Persons with low vision	46%	8.8%	
Persons with hearing	46.5%	19.2%	
impairments			
Persons with speech	10.9%	0.5%	
disabilities			
Persons with locomotor	47.8%	9.7%	
disabilities			

The data from the National Sample Survey in 2002 shows that cost of the appliances and their availability determine if PwDs can have access to them. However, even if they have access to them, if they are not fitted and adapted properly and if they are not trained to use them, they may have the appliances but still not use them.

Table 6 presents information (NSS 2002) about different groups of PwDs who were advised assistive devices but who did not get (buy) them because of unavailability or high cost.

Table 7: Persons Not having Assistive devices (NSS 2002, Table 36 Rural+Urban)

Kind of disability	% did not receive/buy assistive devices because		
	Were unavailable	Too expensive	
Blind persons	5.6%	46.2%	
Persons with low vision	4%	57%	
Persons with hearing impairments	2.6%	60.2%	
Persons with speech disabilities	7.9%	47.2%	
Persons with locomotor disabilities	5.4%	49.2%	

In 2013, an evaluation of the Government of India scheme for provision of assistive devices was carried out (ADIP 2013). This scheme was launched in 2005. The evaluation was carried out in 53 sample districts and in the NE involved the states of Assam, Meghalaya and Sikkim. This evaluation showed that the appliances were distributed mainly to children and young adults while elderly persons above 75 years were a tiny part (4%) of the beneficiaries. The responses on the quality of appliances were mixed, as some persons received them in damaged conditions. Maintenance of the appliances was lacking and community awareness about the programme was limited.

Level of satisfaction among the beneficiaries was very poor for 47.2% of PwDs in Assam. Assam was able to use 54.5% of the total funds approved for this scheme for the period 2007-2010. The evaluation of the scheme in Assam concludes that "There is a discrepancy in the fund allocation and fund release, as there are very few implementing organisations working for the disability sector in Assam. It has also been observed that there is no monitoring and evaluation mechanism at district or State level. Therefore, local government authorities are in no position to keep a check on the development/progress of the ADIP scheme."

In Meghalaya the level of satisfaction among the beneficiaries of appliances was much better. The state was able to utilise a little more than 90% of the funds allocated for the period 2007-2010. The evaluation report concludes that "throughout Meghalaya State, ADIP scheme is being implemented by the Artificial Limb Manufacturing Corporation.

There is single local organisation which is responsible for the implementation of the scheme. There are two District Disability Rehabilitation Centre in the State responsible for looking after the disability relief scheme initiated by the State itself. It has also been observed that there is no monitoring and evaluation mechanism at district or State level. Therefore, local government authorities are in no position to keep a check on the development/progress of the ADIP scheme in the State."

In Sikkim also the level of satisfaction of beneficiaries was adequate. The state was able to utilise only 49.4% of the funds allocated for the period 2007-2010. The evaluation report concludes that "In Sikkim, Artificial Limb Manufacturing Corporation and Narayan Seva Sansthan are the implementing agencies associated with ADIP scheme during the reference period. Both organisation are based outside Sikkim and has no institutional facilities in the State. Therefore, coordination amongst implementing agencies and State and local authorities is lacking. Agencies based outside State, have no option of follow-ups with the beneficiaries. They conduct camps as per their planning/ schedule in the concerned areas in some specific times. They also have no institutional setups in the State which also makes them inaccessible for the Differently Abled people." The report also noted that most funds were being used for East district, that means in Gangtok and surrounding areas. Thus PwDs in other districts which were more distant from the capital had less access to the appliances under this scheme.

Thus, though there are schemes for distribution of assistive devices to PwDs, these services are uneven and quality of services can be improved.

ACCESS TO EDUCATION FOR PERSONS WITH DISABILITIES IN THE NE

The 86th amendment of the Constitution of India in 2002, made the Right to Education a fundamental right, by providing the right to free and compulsory education to all children between the ages of six and fourteen years. *Sarva Shiksha Abhiyan* (SSA) is a national programme implemented in collaboration with state governments for promoting universal access to basic education for children between 6 to 14 years of age.

SSA was launched in 2001. Among other things it promoted right to primary education for children with disabilities by promoting mainstreaming and inclusive education. For children with severe disabilities who were unable to access local schools, it proposed home-based education.

The impact of SSA was evaluated in 2008 in eleven states, including Assam (both in urban and rural areas) from the NE. Regarding the overall impact of SSA on children with disabilities, the report of this evaluation (PEO, 2010) concluded that "An impressive increase was also observed in the enrolment of differently abled children with their share rising from 0.43% of the total enrolment in 2003 to1.17% in 2007 in rural areas. In urban schools, their share declined during the reference period. Though the children were provided financial and non financial incentives, few schools had individualised education plans."

The evaluation report mentioned that "Under the scheme "Integrated education for Disabled" training was provided to teachers on teaching techniques and for preparation of individualized education plans, children were provided assistive devices such as hearing aids, spectacles, wheelchairs, braille kits etc., In some states, surgical operations were carried out for children with severe disabilities. ... Retention rates for such children are known to be poor in the absence of supportive academic and school environment" (p. 39)

Inclusive Education through Sarva Shiksha Abhiyan in the North-East: The evaluation had shown that in Assam the school enrolment of children with disabilities had increased from 0.26% in 2003 to 1.69% in 2007. However, only 25% of the schools in Assam had children with disabilities, in no school plans for inclusive education were

prepared and no incentives were provided to these children to attend school. (Table 7.7, p. 72)

A regional meeting on SSA and inclusive education in the NE was held in Shillong in 2013 (SSA-NE, 2013). The workshop concluded that the inclusive education strategy in NE needed to focus on capacity building of general teachers and acknowledged huge gaps in data collection on children with disabilities. The meeting also took note that in Arunachal Pradesh, Manipur and Mizoram, the first camps by ALIMCO for distribution of appliances to children with disabilities were held only in 2013, and that more comprehensive camps were needed to answer the needs of children with different disabilities.

Annual report of Human Resources Development Ministry at national level for the year 2013-14 informs that under SSA they provide Rs 3000 for the integration of each child with disability in the school and cover actual costs for assistive devices, books and stationary, uniform and transport. For blind children the cost of a reader are covered and girls with disabilities get a monthly stipend of Rs 200. For every 10 children with severe orthopaedic difficulties, the cost of one attendant is covered. A national institute of open schooling has been created to provide pre-university level distance education and distance vocational training. A 3% reservation for students with disabilities for receiving scholarships for higher education is also created, that can cover 82,000 students. This report also provides a long list of various schemes and services to support education for children and young adults with disabilities. (MHRD, 2015)

Since 2011, Ministry of Human Resource Development has also initiated an survey on higher education at university level. This also provides information about students with disabilities enrolled in universities in India. A review of the annual reports of this survey between 2011 to 2014 provides the following information about total **students with disabilities in higher education institutions in the North-East**: in 2011-12 they were 663 (66% male and 34% female); in 2012-13 they were 867 (66% male and 34% female); and in 2013-14 they were 2,182 (61% male and 39% female). Thus, between 2011-12 and 2013-14, there has been more than 100% increase in enrolment of students with disabilities in the universities in the North-East and this increase has been much higher for female students. (AIHES, 2015)

However if we look at the data from individual states of the NE, the increase in enrolment in higher education has occurred mainly in Assam and Tripura, and to a lesser degree in Manipur and Meghalaya. In Mizoram and Nagaland, the increase was minor and the total number of students was also very small. While in Arunachal Pradesh and Sikkim, the number of students with disabilities in higher education has actually decreased. In terms of enrolment of female students, the positive change is almost exclusively due to Tripura.

Detailed data from these three survey reports for the NE states is presented in table 8.

Table 8: Students with disabilities in higher education in the NE

States	Students with Disability in higher education			
	2011-12	2012-13	2013-14	
Arunachal Pradesh	53	32	31	
Assam	384	517	996	
Manipur	80	93	150	
Meghalaya	24	106	63	
Mizoram	9	13	12	
Nagaland	10	10	15	
Tripura	96	92	914	
Sikkim	7	4	1	
Total	663	867	2,182	

Thus, the specific attention shown by Ministry of Human Resource Development and state governments has had a positive impact in enrolment of students with disabilities in higher education in some states of the NE. In future it will be important to see what percentage of students with disabilities complete school and what percentage joins the institutes of higher education compared to non-disabled students. While disaggregation of data between male and female students is important, it will also be important if data on different disabilities is also disaggregated.

2011 census data on education levels of persons with disabilities in the NE states is not yet available.

LIVELIHOOD OPPORTUNITIES FOR PERSONS WITH DISABILITIES IN THE NE

The National Sample Survey in 2002, had found that 74% of persons with disability had no livelihood opportunities. A more detailed analysis of the data from this survey shows persons with locomotor, hearing, speech and low vision disabilities had better opportunities compared to persons with blindness, mental illness and intellectual disabilities. The livelihood opportunities considered in this survey included – agricultural work (including in family farmlands), self-employment, casual or informal work and proper employment. (NSSS, 2002).

- In all the groups persons with proper employment earning a salary were very few, varying between 0.2% among persons with intellectual disabilities to 4.2% among persons with locomotor disabilities.
- Persons working in agriculture including in the family farmlands varied between 0.9% among persons with intellectual disabilities to 12.2% among persons with locomotor disabilities.
- Persons with self-employment varied between 1.5% among persons with complete blindness to 7.2% among persons with speech disabilities.
- Persons engaged in casual or informal work varied between 2.1% in persons with intellectual disabilities to 13.6% in persons with hearing disabilities.
- Globally persons engaged in any kind of livelihood activity varied from a minimum of 5.6% in persons with intellectual disabilities to a maximum of 34.3% in persons with hearing disabilities. All together, 25.7% of persons with disabilities were involved in some livelihood activity.

This survey had covered all almost all parts of the NE, however only the aggregate global data was presented. Thus the information presented above is not specific to the NE.

A 2011 report (Ghosh S., 2011) had looked at the employment and vocational training data for persons with disabilities under the Swaranjayanti Gram Swarojgar Yojana (SWGY) data for 2006-07 and under the Mahatma Gandhi National Rural Employment Guarantee Act (MNREGA) data for 2009. This report had shown the following situation for the **persons** with disabilities in the working age group in the North-East:

Table 9: PwDs of Working Age Group in SGSY and MNREGA in NE

States	Total PwD In SGSY (2006-07) In MNREGA (In SGSY (2006-07)		GA (2009)
		Trained	Assisted	Benefited	Registered
Arunachal Pradesh	20,625	0	0	0	3
Assam	1,73,178	138	320	517	10,996
Manipur	10,252	6	6	3	423
Meghalaya	11,789	0	0	9	364
Mizoram	7,485	36	36	41	261
Nagaland	11,625	0	0	39	75
Sikkim	10,174	2	19	50	131
Tripura	20,131	139	0	10,010	15,186

Except for Tripura where almost 50% of the PwDs benefited from MNREGA in 2009, the data shows a dismal situation in the remaining parts of NE in terms of benefiting from rural employment schemes targeted at poor persons.

Information from the National Census 2011 about involvement of persons with disabilities in livelihood opportunities in the eight states of the NE is not yet available.

In 2010-11, SGSY programme was converted into National Rural Livelihoods Mission (NRLM). Under this programme State Rural Livelihood Mission plans have been prepared, also in the NE. Different activities such as vocational training under the NRLM foresee a 3% reservation for PwDs. However, not all state level action plans for implementing this programme specifically mention PwDs as one of the target groups. For example, Mizoram State Rural Livelihood Mission programme in its 2012-14 implementation plan (MzSRLP, 2012) does not mention PwDs. On the other hand, Assam State's Aajeevika skills (livelihood skills) training programme for 2013 specifies that 3% of the beneficiaries will be PwDs (AsSRLM, 2013).

In December 2012 Ministry of Development of North-Eastern region had signed an agreement with the World Bank for a loan of 120 million USD for promoting livelihoods in four states of the NE – Nagaland, Mizoram, Tripura and Sikkim. The five years project will cover 2 districts in each of the four selected states. The document for the project implementation (NERLP, 2013) looks into the challenges for livelihoods in the region. For

example, regarding the challenges in Mizoram, the document notes that "Virtual absence of credit facilities in the rural areas, lack of capacity building and training due to inadequate institutional infrastructure, entry level barriers, high costs and distant locations, absence of risk coverage for the beneficiaries etc. are the key livelihood issues in Mizoram".

The NERLEP project foresees a focus on community-based approaches including women Self-Help Groups (SHGs), youth groups of men and women (YG) and Community Development Groups (CDG). Among the priority target groups of beneficiaries of this project, the document mentions persons with physical disabilities, "Most disadvantaged people first approach and empathy with community – providing livelihood opportunities for the most disadvantaged is the priority. The most disadvantaged people include women led households, physically handicapped, tribal community, poorest of the poor, etc."

Thus, different on-going programmes related to livelihood specify PwDs among their target groups. However actual accessibility of these programmes and their real impact on PwDs can only be known through appropriate monitoring and evaluation reports. However, during their implementation, there is role for district, state and regional level DPOs in advocacy and monitoring to ensure that these benefit all the PwDs and especially those persons who are usually left out of such programmes. This is one area for which DPOs in the North-east need to be trained and strengthened.

ORGANIZATIONS OF PERSONS WITH DISABILITIES IN THE NE

With few exceptions, the DPOs in the North East are small local groups, only a few of them are linked to any local, regional or national networks.

Meghalaya Parents Association of the Disabled (MEPAD) is a State federation of family/parents of the people with disability. It is one of the oldest DPOs in the North-East, active since early 1990s. MEPAD had tried forming a network of similar associations of parents in the other seven states of the NE. The Regional Body of the Parents Organization for the North East is member of Parivaar, the National Confederation of the Parents Association in India.

Another regional network of DPOs in the region is linked to CBR projects in different states. CBR projects supported through CBRF have supported the creation of village and block level DPOs. These DPOs met in February 2015 and created their North-Eastern network.

A report of this DPO meeting stated that: "The CBRF started its work in the NE through promotion of CBR aimed at the inclusion of PwDs in education, health, livelihood and the socio-cultural area. Later, in view of helping PwDs to make their own decisions, the CBRF and its partners formed them into village, block, district and state level organizations (DPOs). It may be noted that these DPOs are at various stages of formation in the different states of the NE. Once the NE regional DPO will be constituted, DPOs from villages to the block level will concentrate on building the confidence of PwDs and supporting their members to access the different government programmes to meet their needs. Those from the district to the regional level, however, will focus on sharing experiences and bringing uniformity across districts, states and the region in the implementation of the Disability Act and related schemes."

Linked to the CBR-DPO regional network, there are some state level DPO networks. For example, Meghalaya has a few significant DPOs including a cross-disability DPO called Association of Challenged People (ACP) with members from 39 villages around Shillong (ACP, 2012), the Khasi Deaf Association, and DPOs linked to CBR projects in Mairang and Nongstoin. However, at present there is no state-level federation of DPOs, where all of them can come together.

Nagaland has a state level federation of DPOs called Nagaland State Disability Forum (NSDF), formed in 2014. In August 2015, Mr Kezhaleto Zecho, president of NSDF explained that at present their network includes only the DPOs formed through CBR projects, even though there are other DPOs in the state (such as the Mon District Handicapped Society) but they are not invited to be a part of NSDF.

In Manipur, some of the districts have DPOs including APDS (Association of Persons with Disabilities of Senapati), UDF (Ukhrul Disabled Federation), TDA (Tamenglong Disabled Association) and CDF (Chandel Disabled Federation).

There are also reports of some state-level DPOs linked with political parties in the region. Other state-level DPOs focus on specific groups of PwDs (such as associations of blind persons and spastic societies).

In 2014, there was a meeting, attended by many DPOs and NGOs of the NE, which was organized by Shishu Sarothi, an institution based in Guwahati (Assam), with the aim of starting a North-Eastern network of DPOs and NGOs. However, after the initial meeting, this network has not been very active.

All these initiatives indicate a growing movement among PwDs to come together and set up state and regional level bodies to raise issues, to advocate and fight for their rights in the NE. They need support to facilitate communication and create stronger networks and federations.

They also need capacity building to understand the potential of DPOs and the diverse actions they can take, not just limited to demands for disability certificates and pensions, but playing a more active role in state policies and practices. For example, as explained under the situation of livelihood opportunities for persons with disabilities in the NE, DPO should have a role in monitoring the different livelihood schemes. They also seem to have no or limited contacts with national and international level DPOs.

CONCLUSIONS

Against the background of a region composed of eight states, covering a large area, many parts of which are difficult to reach, terrain with hills, mountains and rivers with significant communication and transport difficulties, and with the presence of a widely diverse population, the North East Region of India presents many challenges. These become even more daunting for PwDs and their families and among them particularly for girls and women. Their lives are surrounded by physical, attitudinal, social, cultural and economic barriers.

There are enormous gaps in the availability of health, education, livelihood, social and other support services for PwDs in the region, especially in remote districts. Even in the larger cities, the better quality services are often located in private institutions with limited access for poor families and for those who live in rural areas.

The past decade has seen important progress in the region in terms of availability of services for PwDs including the establishment of offices of SDCs and DDRCs. Slowly there are efforts in different states to provide disability certificates and access to various government schemes aimed at poor families and those with PwDs. However, the challenges remain enormous, especially for the persons living in smaller district towns and rural areas.

Availability of qualified rehabilitation professionals, from specialists to rehabilitation therapy assistants, prosthetic and orthotic technicians and community level rehabilitation workers, is extremely limited although systematic information about them is lacking.

There are few CBR programmes functioning in the North East, and their coverage is extremely limited. Even when present, the health component of the CBR activities is often weak and is usually limited to support for buying medicines, accessing assistive appliances and referral to specialists in the nearby cities and hospitals. There are limited opportunities in the region for simple training for community workers to equip them to promote self and family care for maximising independence and reducing complications.

There are some significant activities in the area of education and fundamental work has been done by the *Sarva Shiksha Abhiyaan* (SSA) in this direction. Often, SSA is the only programme providing regular reports about the situation of children with disabilities in the region.

In terms of livelihood support, the opportunities for vocational training, bank loans for starting business and job placement are all areas that require considerable strengthening.

In the most remote and isolated areas grassroots organizations, NGOs and faith-based organizations play a crucial role and sometimes are the only support received by PwDs. But they often lack specific skills and knowledge for running effective programmes. Appropriate training materials and training courses for persons working at community level and in rehabilitation services are needed.

Documentation, reports, and research on the issues of disability and rehabilitation in the North Eastern Region are extremely limited. Even when produced, usually by NGOs, these are printed reports intended for private circulation and are difficult to access. Better information collection systems, sharing of information and systematic research studies are needed. In particular, participatory action research initiatives aimed at understanding gaps and challenges and to test innovative strategies are required.

DPOs can play a fundamental role in advocacy for improving services and access to different programmes. DPOs in the region have started to work together in recent years. However many of them are still weak — their activities are limited to local efforts to get disability certificates and pensions. Strong DPO federations at state and regional levels with effective leadership, programme implementation and advocacy capacities have yet to emerge. The region requires support to set up, strengthen and organize networking of the DPOs.

In future as they become stronger, DPOs such as those set up through the CBR programmes will have the potential to play an important role in advocacy for the rights of PwDs because they are rising from community organizations of the North East.

There are many positive examples of providing cost-efficient services and promoting empowerment of PwDs in the region, especially through the CBR approach. However these are reaching a small percentage of those in need. Promoting a wider coverage of CBR programmes with support from appropriate referral services, in order to reach all the PwDs in the area would require sustained and concerted action from all the stakeholders. At the same time, innovative CBID approaches aimed at wider groups of persons including those with chronic conditions and elderly persons should be promoted.

There are many important voluntary organizations in the North Eastern Region active in the area of disability and rehabilitation including Shishu Sarothi, Assam Centre for Rural Development and Swabilamban in Guwahati; Prerona in Jorhat; Baptist Christian Hospital in Tezpur; Bethany Centre in Shillong; Prodigal Home, Development Association of Nagaland and People in Need Foundation in Dimapur; YARD and Cherry Blossom in Kohima; and Voluntary Health Association and Ferrando Rehabilitation Centre in Agartala. CBRF has played an especially important role for the promotion of CBR and DPOs in the region. More organisations need to join these efforts for expanding the coverage of CBR and CBID programmes.

There are some important interventions targeting specific rehabilitation needs in the region such as cochlear implants, surgery for cleft lip and palate and therapeutic plasters for children with club feet. Expanding CBR and CBID programmes will help in improving the reach and effectiveness of these interventions. The pilot example of CBR programme in Shillong urban area under the Government of Meghalaya needs to be expanded and emulated by other states.

MI has collaborated with many of these voluntary organizations in the North East over the past decade especially through training of their personnel and helping them to set up prosthetic and orthotic services. However, there are still large areas of the region where people living in rural areas, remote from big cities and SDCs, face enormous difficulties in accessing any services for PwDs.

MI-NE can play a significant role in this region in strengthening the health component of rehabilitation services including capacity building of rehabilitation personnel and CBR workers, helping to develop research and documentation capacities, improving access to quality assistive devices and strengthening DPOs and their networking. For this, MI-NE needs to work together with organizations active in this sector.

REFERENCES

ACP (2012), Nothing About Us, Without Us, Annual report 2011-12, Association of Challenged People (ACP), Meghalaya

ADIP (2013), Evaluation study on "The scheme of Assistance to Differently Abled Persons for Purchase/Fitting of Aids/Appliances (ADIP)", Planning Commission, Programme Evaluation Organisation, Government of India, New Delhi, December 2013

ADIP (2015), List of Hospital Empanelled for Cochlear Implants, AYJN Institute for the Hearing Impaired, India, http://adipcochlearimplant.in/ADIP_PDF/list_of-hospitals.pdf (consulted on 8 December 2015)

AIHES (2015), Annual reports of All India Survey on Higher Education 2011-12, 2012-13 and 2013-14 (provisional report), Website of AIHES - http://aishe.nic.in/aishe/reports;jsessionid=76ADC9772C7569D2A61866DF46CB88E0 (consulted on 10 December 2015)

AsSRLM (2013), Aajeevika Skills Training Learn Earn, Government of Assam, Dispur

Bardalai K. (2008), Status of Implementation of Disability Legislation in the North East, in "Disability, Citizenship and Social Exclusion" edited by Sudhir K. Singh & A. Kachhap, Anamika Publishers, New Delhi, India, 2008

Bhattacharjee H. et al (2008), Causes of childhood blindness in the northeastern states of India, Indian J Ophthalmol. 2008 Nov-Dec. 56(6): 495–499

Biggeri M., Deepak S., et al (2012), Impact of CBR – Community-Based Rehabilitation Programme in Mandya district (Karnataka, India), AIFO, Bologna, India

Census GOI (2013), Data on Disability – Census of India 2011, Office of the Registrar General and Census Commissioner, New Delhi, India, 27 December 2013 (consulted online on 7 Dec 2015) - http://www.languageinindia.com/jan2014/disabilityinindia2011data.pdf

CIS (2013) National Resource Kits project, Centre for Internet and Society, 35 state reports - http://cis-india.org/accessibility/resources/national-resource-kit-project (Consulted on 24 November 2015)

Cure India (2015), Cure Clubfoot clinics across India, https://cureinternationalindia.org/clubfoot-clinics/ (consulted on 28 November 2015)

DBRC (2013), Rapid assessment of street involved children: a study in Guwahati, Snehalaya and Don Bosco Research Centre

DDRC (2014), Call for tenders for evaluation of DDRC scheme, Department of Disability Affairs, Ministry of Social Justice and Empowerment, Government of India, 2-2-2014/DDRC, http://pratapgarh.nic.in/Notice_Board/ddrc.pdf (Consulted on 24 November 2015)

Ghosh S. (2011), Disability scenario in India with reference to livelihood of PwDs – Country Status, Shodhana Consultancy, Pune, India

Hazarika I. (2013), Health work force in India: Assessment of availability, production and distribution, South East Asia Journal of Public Health, WHO, New Delhi, India, April-June 2013

KPMG-FICCI (2015), Emerging North-East India – Economically and Socially Inclusive Development Strategies, KPMG and FICCI, India, November 2015

Kumar G. S., Roy G. and Kar S. S. (2012), Disability and Rehabilitation services in India: Issues and Challenges, in Journal of Family Medicine and Primary care, 2012 Jan-Jun: 69-73

Kumar S., Jain A. and Bruce J (1989), Assessing the Quality of Family Planning Services in Developing Countries, available online http://www.popline.org/node/369190 consulted on 20 October 2015

MDG-India (2015), Millennium Development Goals – India Country Report 2015, Social Statistics Division, Ministry of Statistics and Programme Implementation, Government of India

MHRD (2015), Annual Report 2013-14, Department of school education and literacy, Ministry of Human Resource Development, Government of India, New Delhi, 2015

Mitra S. (2012), Disability data in India, Disability and Development core course, May 7 to 11, 2012, Washington DC, USA

Mishra S. and Rahmatulloev S. (2015), Situation Analysis – State of Rehabilitation in Tajikistan, WHO Europe and Ministry of Health & Social Protection Tajikistan, available online http://www.euro.who.int/ data/assets/pdf file/0009/276480/State-Rehabilitation-Tajikistan-Report-en.pdf (consulted on 30 October 2015)

MSJE (2014), Annual Report 2013-14, Department of social Justice and Empowerment, Ministry of Social Justice and Empowerment, Government of India, New Delhi

MzSRLP (2012), Mizoram State Rural Livelihood Mission, Annual Action Plan 2012-14, Government of Mizoram, Aizawal

NCPEDP (2011), NCPEDP study on disability question in Population census of India 2011, NCPEDP & Disability & Equal Opportunity Centre (DEOC), New Delhi, India

Nekha K. N. (2015), The Nagas – Culture and Education, Heritage Publishing House, Dimapur, Nagaland, India

NLEP (2013), NLEP – Progress Report for the Year 2012-13, Central Leprosy Division, Director General of Health Services, Nirmal Bhavan, New Delhi, India

NLEP (2014), NLEP – Progress Report for the Year 2013-14, Central Leprosy Division, Director General of Health Services, Nirmal Bhavan, New Delhi, India

NSS (2002), Disabled Persons In India, Report n. 485 (58/26/1), NSS 58th Round, July-December 2002, National Sample Survey Organisation, Ministry of Statistics & Programme Implementation, Government of India, New Delhi

PEO (2010), Evaluation Report on Sarva Shiksha Abhiyan, Programme Evaluation Organisation, Planning Commission, Government of India, New Delhi, May 2010

PIB GOI (2015), Press release, Press Information Bureau, Government of India, 17 August 2015, http://pib.nic.in/newsite/mbErel.aspx?relid=126123 (Consulted on 7 Dec. 2015)

RCI (2007), Syllabus on Diploma in community-based rehabilitation (D-CBR), Rehabilitation Council of India, New Delhi, India (http://www.rehabcouncil.nic.in/writereaddata/dcbr.pdf consulted on 6 November 2015)

SDC Assam (2001-12), Annual Report 2001-12, Office of the Commissioner for Persons with Disabilities, Government of Assam, Latakata, Basistha, Guwahati 781029

SDC Meghalaya (2009-13), Annual Report 2009-10, 2010-11, 2011-12, 2012-13, Office of the Commissioner for the Persons with Disabilities of Meghalaya, Lower Lachumiere, Temple Road, Shillong 793001

SDCM (2015), Activities undertaken by the office of the commissioner for persons with disabilities, Information sheet, Shillong, Meghalaya

SJEW Sikkim (2015), Report of Government of Sikkim on Implementation of National Disability Act 1995 (consulted 30 November 2015) - http://www.sikkimsocialwelfare.in/General/General/PDF/Persons Disabilities.pdf

Sikkim (2015) Annual plan for financial year 2015-16, Department of Social Welfare, Gangtok, Sikkim

Sharma S. K. and Sharma U. (2006), Documents on North-East India – An exhaustive survey, Volume 5 (Assam: 1958 to modern times), Mittal Publications, New Delhi, India

Singh P., Benjamin P., Mochahari C. et al (2009), Needs assessment of the status of persons with disabilities in view of the WHO CBR matrix in Gabharu block, Sonitpur district, Assam, report of Baptist Christian Hospital, Tezpur, Assam

SSA (2013), Inclusive Education in Sikkim (2013) – a handbook on disabilities, its causes, symptoms and management, State Project Office (SSA-RTE), Human Resource Development Department, Government of Sikkim

(SSM 2013), Annual Report 2012-13 of District Disability Rehabilitation Centre, Nagaon, run under Sreemanta Sankar Mission, Nagaon, Assam

SSA-NE (2013), Sarva Shiksha Abhiyan – Minutes of the Regional Workshop on "Consolidation of CWSN Academic Support Structures & Activities", Shillong, Meghalaya, 9-10 July 2013

SSN (2015), Sri Sankaradeva Nethralaya, http://www.ssnguwahati.org/eye banking.htm (consulted on 8 December 2015)

Swabilambi (2014), Annual Report 2013-14, Guwahati, Assam, India

UN (2006), Convention on the Rights of Persons with Disabilities and Optional Protocol, available online at: http://www.un.org/disabilities/documents/convention/convoptprotee.pdf

UNDP India (2010), Human Development in India: Analysis to Action, UNDP (India) and Government of India, Compiled by Pia Lindstrom, New Delhi, October 2010

Venkatesan S. (2004), Children with developmental disabilities: A training guide for parents, teachers and care-givers, Sage Publications, India

WHO (2010), CBR Guidelines, WHO, UNESCO, ILO and IDDC, Geneva, Switzerland, 2010

WHO and World Bank (2011), The World Report on Disability, World Health Organization and the World Bank, Geneva, Switzerland, 2011

WHO (2014), Global Disability Action Plan 2014-2021, Available online at: http://apps.who.int/gb/ebwha/pdf files/WHA67/A67 16-en.pdf (consulted on 23 November 2015)

ANNEX 1

MOBILITY INDIA

MI, an independent, democratic and secular disability and development organization, was established in Bangalore as a registered society in 1994. Its vision is to work for "an inclusive and empowered community, where PwDs, their families and other disadvantaged groups have equal access to education, health and livelihood and enjoy a good quality of life". It promotes inclusive development by providing rehabilitation services, education and training programmes in assistive technology (prosthetics, orthotics and wheel chairs), rehabilitation therapy, CBR and accessibility.

Its Rehabilitation Research and Training Centre in Bangalore was set up in 2002. Many of the training courses of MI are recognized by the International Society of Prosthetics and Orthotics (ISPO), RCI and Rajiv Gandhi University of Health Sciences (Karnataka).

MI's Regional Resource Centre in Kolkata was established in 1998. In addition, MI has undertaken some pioneering work in the promotion of CBID in the urban slums and rural areas.

MI is an innovative organization with an approach that addresses the real needs of people and strives for the inclusion of PwDs in all development activities. MI has a team of 151 persons of which 30% are PwDs and 45% are women. In December 2014 MI received a National award in recognition of the high quality of its work with and for PwDs. MI has a long history of collaboration with different international partners including the WHO, ISPO, the Christoffel Blinden Mission (CBM), Handicap International and USAID.

MOBILITY INDIA NORTH EAST

The Inclusive Development Centre is the North-Eastern office of MI. It is based in Guwahati (Assam) and was established in April 2015. MI also has a Regional Resource Centre based in Kolkata (West Bengal) and a Rural Resource Centre in Chamrajnagar (Karnataka).

MI-NE is planning activities in the following areas:

- ✓ Set up a Regional centre for Assistive Technologies for the North East that can answer the needs of different groups of PwDs, persons affected by chronic conditions and elderly persons.
- ✓ Capacity building: Prepare and distribute appropriate and accessible training materials in local languages on disability and rehabilitation issues for the different stakeholders in the North East; organize and strengthen training courses and opportunities for rehabilitation personnel, community workers and other stakeholders active in areas of disability and rehabilitation.
- ✓ Promote innovative approaches for development of new models and implementation of a small number of CBR and CBID programmes in the North East; promote documentation and research for building the evidence-base about effectiveness of CBR and CBID approaches; organize multi-disciplinary participatory action research to understand gaps and challenges in relation to disability and rehabilitation issues.
- ✓ Promote and strengthen networking between different stakeholders involved in disability and rehabilitation issues in the North East; support strengthening of DPOs; develop partnerships with organizations and institutions focusing on vulnerable and marginalized population groups and involved in community development, in promoting the inclusive development approach that keeps account of PwDs among those groups.

MI-NE builds upon the strengths of its activities and resources in its centres in Bangalore, Kolkata and Chamrajnagar. It believes in the human rights approach and works actively with PwDs, their families, organizations and communities. It works together with governmental and non-governmental institutions, academics, grassroots organizations, movements and federations.

