

CBR Practice and Inclusion: Persons with Disabilities in Northeast India

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ABSTRACT

Purpose: *This paper explores the long-term impact of CBR programmes implemented in the Northeast region of India. The aim was to understand the ways in which targeted interventions led to changes in the lives of persons with disabilities and their families, to discern the extent of their inclusion within communities and any systemic changes brought about towards accessing their human rights.*

Method: *Data was collected from three CBR programmes for persons with disabilities in Northeast India, 3 years after financial support to the programmes had stopped. Persons with disabilities were selected through stratified random sampling. In-depth interviews were conducted and the primary data was analysed in the light of the baseline and endline surveys/reports, reports of DPOs, and implementing agencies.*

Results: *As a result of CBR initiatives and their sustainability after conclusion of the structured programmes, persons with disabilities, their families and communities experienced a change in the quality of their everyday lives and had better access to a range of rights and entitlements. Persons with disabilities also have improved status within their families and communities, enjoy better quality of relationships, play an active role in family and community decision-making, and gain dignity and respect.*

Conclusion and Implications: *The CBR programmes brought visible changes in the lives of persons with disabilities in terms of self-sufficiency, independence, inclusion in education and within the community, as well as securing livelihoods. Those who benefited the most from the CBR programmes were persons with mild to moderate disabilities, while people with severe disabilities were pushed to the periphery, especially after cessation of the programmes. There is a need for continuous upgrading of skills and information/ knowledge among families,*

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DPOs and communities so that advocacy for entitlements, rights and systemic changes is constant.

Key words: *CBR programmes, Northeast India, inclusion, sustainability*

INTRODUCTION

In low- and middle-income countries (LMICs), Community-based Rehabilitation (CBR) was advocated as a core strategy in the 1970s-80s for improvement in the quality of life of persons with disabilities by providing them facilities for rehabilitation at the community level. CBR developed from within a medical model perspective, implemented in the context of the health sector to deliver primary rehabilitation services to persons with disabilities in their communities (Nilsson & Nilsson, 2002). The current practice of CBR, based on the social model and human rights, includes medical interventions, rehabilitation strategies, advocacy for equal opportunities and basic rights, as well as building linkages and networks leading to empowerment. Although the western social model of disability advocates for a shift from service delivery (only) to the human rights models of CBR, in low- and middle-countries CBR often is a community development programme which is multidisciplinary and addresses all areas that are central for the improvement of quality of life of persons with disabilities. It is seen as a strategy to promote the rights of persons with disabilities to enjoy health and well-being and to participate fully in educational, social, cultural, religious, economic and political activities. CBR is implemented through the combined efforts of persons with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services (ILO, UNESCO & WHO, 2004). CBR emphasises that persons with disabilities should be active partners in the planning and implementation of all measures affecting their civil, political, economic, social and cultural rights. Though limited in scope and coverage, CBR works well in smaller communities where the majority of persons with disabilities do not have any access to any form of rehabilitation (Velema et al, 2008). Most CBR developments are more bottom-up grassroots initiatives managed by non-governmental organisations (NGOs), rather than by governments (Corneilje, 2009).

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2007) and the CBR Matrix (WHO, 2010) in the CBR Guidelines (WHO, UNESCO, ILO & IDDC, 2010) touch upon different key aspects of life including

education, health, work and employment, social protection and participation (Deepak et al, 2014). The CBR Guidelines launched in 2010 promotes CBR as a comprehensive strategy for implementing the Convention on the Rights of Persons with Disabilities (Yuenwah, 2012). Mannan et al (2012) use the CBR Guidelines and CBR Matrix to highlight that CBR needs to engage with rehabilitation along with issues such as advocacy, community mobilisation, self-help, livelihood, and social dimensions. CBR activities are designed to improve the quality of life and meet the basic needs of people with disabilities, reduce poverty, and enable access to health, education, livelihood and social opportunities – all these activities support the aims of the UNCRPD (IDDC, 2012). The social and rights-based approaches focus on change within communities and society to become more inclusive, with increased attention to equal opportunity and full participation. CBR is complex as an approach and strategy; it has many dimensions, layers, contexts and aspects. As CBR involves many layers (from the medical to the social), it uses multiple strategies and different ways of responding, and involves many contexts and stakeholders (Jones, 2011). The components of the CBR Matrix, namely health, education, livelihood and social inclusion, relate to key development sectors, while the fifth component, empowerment, is fundamental to ensuring access to the development sectors, and to the rights and quality of life of persons with disabilities (Yuenwah, 2012). In LMICs, issues of poverty, hunger and inequalities, and emerging challenges from, for instance, urbanisation to the economic developments or its lack of development, shape CBR programmes addressing the needs of persons with disabilities, their families and communities in which they live (Bongo et al, 2018).

Evidence from multiple and diverse sources, and the use of a variety of methods, are required to understand the effects of CBR. The collection of evidence has to be collaborative in nature, with a focus on participatory knowledge generation, with pertinent involvement of people with disabilities, their families and communities. While there have been many studies on the efficacy of CBR in India, many of these are not available in the public domain. However, there are studies that have demonstrated the way in which CBR has effected attitudinal change at community level and increased participation of persons with disabilities in communities. Chatterjee et al (2003) demonstrated how the CBR approach has been effective in reducing the extent of disability and building acceptance within community in rural central India. Deepak et al (2014) demonstrated that CBR programmes in India did have a positive impact across all the five domains

of the CBR Matrix. However, the impact on communities and the changes in lives of persons with disabilities varied by type of disability and social location: different groups of persons with disabilities benefited differently from different activities. Persons with physical disabilities seemed to benefit from CBR in more areas compared to persons with other types of disabilities (Deepak et al, 2014). Mijnaerends et al (2011) identified conditions needed for a sustainable CBR programme, which included the availability of human resources, training, monitoring and evaluation, collaboration, commitment and financing. While human resources and awareness of disability are always poor in the contexts of LMICs, evaluation of CBR programmes suggest that persons with disabilities are more satisfied with comprehensive programmes than with those that only provide medical interventions.

With poor access to health, education, rehabilitation services and livelihoods, persons with disabilities in India have low status within their families and communities. This prevents their participation and inclusion in larger social processes. In Northeast India, persons with disabilities and their families are further disadvantaged by the geographical terrain, the climatic conditions and the resultant lack of services.

Objective

CBR programmes usually keep persons with disabilities and the community as their twin foci. This paper explores the long-term impact of CBR programmes undertaken in the Northeast region of India, in to order understand the ways in which targeted interventions led to positive changes in the lives of persons with disabilities and their families. It also aimed to discern the extent of their inclusion within communities and any systemic changes brought about towards accessing their human rights.

METHOD

Study Setting

CBR has usually been initiated in regions which are remote and underserved in terms of services for persons with disabilities. It is often implemented in rural areas with the purpose of empowering persons with disabilities and facilitating the creation of a favourable environment for their effective participation and

inclusion in the community. The CBR programmes evaluated for the current research were located in the largely mountainous states of Assam, Mizoram and Nagaland in Northeast India.

Guwahati, Aizawl and Dimapur were the three field contexts in Assam, Mizoram and Nagaland respectively. All three areas, whether the rural outskirts of Guwahati, urban Aizawl or semi-urban Dimapur, have steep hilly slopes and are vulnerable to floods and landslides. The summers are hot and humid, followed by torrential monsoons and severe winters. Roads are poor and public transport is very limited, with few buses, autorickshaws, and shared taxis. The population in Aizawl and Dimapur comprises mainly tribal Christians, while in Guwahati it includes Scheduled Castes/Scheduled Tribes and other groups. Many of these people are landless and are engaged in rural occupations like agriculture, collection of forest produce, fish culture, livestock rearing, and traditional trades like bamboo craft, weaving, pottery, as well as casual labour or earning daily wages in different sectors. They have little access to social amenities.

Study Design

Three community-based rehabilitation (CBR) programmes mentored by Caritas India CBR (CI CBR) and supported by Light for the World were part of this evaluation study conducted during 2018-2019. The main point of assessment was to understand the extent and ways in which the interventions undertaken during the pendency of a CBR programme impacted the lives of persons with disabilities within families and communities, as well as to find out how far the initiatives have sustained, three years after the completion of the programme. On one hand the study mapped the extent to which CBR interventions led to inclusion and effective participation of persons with disabilities in education, livelihoods and social activities within communities. On the other hand, it attempted to understand the knowledge and skills built up within communities with regard to the identification of persons with disabilities, referral for services and entitlements, and caring for those with severe disabilities. The evaluation also analysed the situation of the Disabled People's Organisations (DPOs) developed during the period of the CBR project, in order to understand the nature of their operations, their sustainability and self-sufficiency.

Study Sample

The three CBR programmes were mentored and supported for a period of 9 years

by CI CBR and Light for the World. CI CBR works primarily in rural areas, and in 2020 it had 62 NGO partners implementing 77 programmes across 20 states and 1 Union Territory of India, reaching out to about 83, 785 persons with disabilities. CI CBR facilitates CBR in rural areas primarily through building capacities, first at the level of the NGO and its staff to implement the CBR programme, and then through the transfer of knowledge and skills to persons with disabilities and their families and to members of the community to enable the development of more inclusive communities. Light for the World, an international disability and development organisation which works with people with disabilities in some of the poorest regions of the world, supported all the three projects throughout the whole period of project implementation. The three programmes selected for evaluation had all started their CBR interventions around 2007-08 and had been active in the selected communities till the years 2016-17.

Data Collection

Multiple methods, primarily qualitative, were used to gain an understanding of the present situation of persons with disabilities and their families within the communities where they are located. To get an idea of the achievements and the status at the time the programmes were terminated, archival analysis was done of reports generated during the final years of the three programmes. Baseline and end line surveys/reports, reports of DPOs, implementing agencies and CI CBR were consulted. Primary field-based data was collected in 2 phases for each programme, with one resource person visiting the field area at the initial stage of the evaluation, followed by a second resource person to ensure coverage of all categories of persons with disabilities, along with interactions with a wide range of government and other functionaries. The study area included 76 villages across 4 blocks of 3 districts in the 3 states. The total number of persons with disabilities identified in the three programmes can be seen in Table 1.

Table 1: Type of People with Disabilities

Sl. No.	Type of Disability	Total		
		M	F	Total
1	Blindness	13	11	24
2	Low Vision	45	26	71
3	Leprosy Cured	1	1	2
4	Hearing Impairment	129	86	215

5	Locomotor Disability	182	98	280
6	Mental Illness	16	21	37
7	Intellectual Disability	82	47	129
8	Autism	2	0	2
9	Cerebral Palsy	34	18	52
10	Multiple Disabilities	20	16	36
11	Others	5	4	9
Total:		529	328	857

It was decided to sample 10% of the population for the evaluation study, i.e., 86-90 people, primarily persons with disabilities and their family members, as well as community members like school teachers, representatives of the local administration, church officials, health workers etc., across the three CBR projects. Data was collected from a total of 64 persons with disabilities, with 32 men and 32 women (see Table 2). The persons with disabilities in this study were selected using proportionate stratified random sampling, after stratifying the entire population with disability by different disability categories, then selecting proportionate samples from each category to ensure all groups were represented. Care was taken to ensure representation by gender and ethnic group. The evaluation study thus covered 29 villages out of 76 villages from the selected CBR programmes.

Table 2: Sample of Interviewed People with Disabilities

Type of Disability	Total
Locomotor Disability	22
Cerebral Palsy	14
Hearing Impairment	7
Intellectual Disability	13
Low Vision	3
Psycho-social Disability	3
Multiple Disability	2
Total	64

Data was also collected from 27 family members in these areas, primarily representing children with disabilities and 23 members of 12 DPOs. Additional data was collected from 20 key informants in the community which included village headmen, village council members, schoolteachers, integrated child development workers, health workers and other influential members of the

community, members of other Community Based Organisations and government officials.

Data was collected using semi-structured questionnaires, through interviews and focus group discussions.

Data Analysis

As the data is primarily qualitative, evidence collected through field-based study was compared with the existing quantitative and qualitative data documented during the final phase of the programmes, and analysed to elaborate the changes that took place within communities which contributed to inclusion of persons with disabilities in different areas of their lives. The major thrust of the analysis was to ascertain the extent to which the interventions that were started during the implementation of the CBR programmes had endured after the withdrawal of the structured interventions, and the ways in which the lives of persons with disabilities and their families had changed, leading to enhanced participation, dignity, and inclusion within communities. Hence the analysis followed the case study method, where the three programmes were seen as cases, and all the persons met for the evaluation were informants to build the case. The data collected has been analysed at case level and across cases, revealing interesting details about contexts, CBR programmes and their implementation and long-term implications.

Ethical Considerations

Ethical principles have been followed in the reporting of the data, whereby all names have been anonymised.

RESULTS

In all the three areas, persons with disabilities were regarded as a burden by their families and communities. In the primarily tribal Christian communities of Dimapur and Aizawl they were well cared for within families, but in Guwahati there was a sense of neglect, especially in poor families. There were very few services or service providers available in the area for persons with disabilities. Families, who were able to seek some sort of care, had to take their children with disabilities to urban centres, which was both time-consuming and expensive, and hence untenable in the long run as disability interventions require prolonged

periods of involvement. There was little knowledge and few skills available to manage and address rehabilitation needs of people with different impairments. Ideas of incapacity and dependence kept persons with disabilities confined to homes and excluded them from education, livelihood and social participation. The limited knowledge and skills to manage and address rehabilitation needs, resulted in limited physical and mental development of persons with disabilities; subsequently this was used to justify exclusion from education and livelihoods. Given the inhospitable hilly terrain, and the poverty and lack of available services, persons with disabilities were isolated from society at large. There was very little awareness about their rights and little knowledge about how to claim entitlements.

The Effects of the CBR Programme

The lack of knowledge and services in these areas meant that there were very few people available who were trained in disability work. As Kuipers and Cornielje (2012) have pointed out, CBR programmes can become sustainable if they contribute towards improving the quality of life of persons with disabilities. One of the major aspects of sustainability is the availability of human resources, which means skilled and trained personnel who can offer meaningful interventions to persons with disabilities, families and communities, while at the same time building the capacity of people in the community. Across the 3 sites, long-term support in the form of intensive training and mentoring to the implementing agencies, contributed to changes at the grassroots level. The strategy was to train teams on disability work and CBR strategies - from identification to planning and implementing of interventions, along with field-based support and training - by people vastly experienced in 'doing' CBR in the following years. As a CBR worker from Aizawl reported,

"We learnt so many things during the training, from identifying persons with disabilities to mobilising groups and communities to advocacy with the administration."

Another CBR worker from Dimapur stated,

"The field-based training gave us confidence as we could actually see how the activities were to be implemented at the ground level."

The hand-holding support by experienced people in the field of disability helped in identification of persons with disability, planning and implementation

of area-specific interventions, support at home and in schools, training in life skills and preparing for livelihoods, and organising persons with disabilities into groups. Another facilitating factor for programme sustainability in CBR is the organisational setting, coordination and programme management (Jacobset al, 2007; Gruen et al, 2008). The partner organisations implementing the CBR programmes had strong connections and acceptance within the community, and good networking with the state administration and other service providers; this had a strong impact on the effectiveness of the CBR programmes. While one was a church-based organisation (in Aizawl), the others had strong roots in the selected communities through their work with disadvantaged groups.

At the end of the programme period of 9 years, there was evidence of changes that had taken place at the individual, family and community levels, through the interventions at home and linkages with the service providers as well as provision for inclusion into larger systems and processes. CBR programmes were able to successfully link persons with disabilities to health, education and administrative systems. These enabled access to schools, the provision of aids and appliances, medicines, treatment and therapy, all of which contributed to improved quality of life and led to increased participation within communities. As knowledge and skills of family and community members increased, there was enhanced awareness on disability, health and rehabilitation concerns, and improved access to rights and entitlements. With families realising the potential of their relatives with disabilities and investing in terms of time, effort and other resources, there was vast improvement in the skill sets and capabilities of persons with disabilities. Livelihood support to families through the DPOs led to activities such as piggery, pickle making, tailoring, weaving, starting petty shops, etc., which in turn contributed to families and communities valuing and respecting persons with disabilities. CBR programmes also resulted in local systemic changes through sensitisation of the different government departments, like education, transport, social welfare, and health. As a result, persons with disabilities were better linked to social security entitlements and other social schemes, and classrooms and health services became inclusive. Community-level advocacy has resulted in the inclusion of persons with disabilities in cultural, recreational, social and religious life of the community, like church events, Sunday school, youth and children's groups. As people in the community realised that persons with disabilities could be included in different ways in everyday life activities, stigma has reduced within communities and measures to facilitate participation, such as creating barrier-free environments, have been implemented

in places like schools and banks.

In keeping with the CBR Matrix, these programmes promoted the formation of DPOs at the village level which were federated at the block level. The DPOs, trained on rights and advocacy strategies as part of the CBR interventions, established networks among themselves and together developed relationships with the block and district-level officials. Many of the DPO members participated in community meetings, meetings of the *Gram Sabha* (the primary body of the Panchayati Raj system where discussion takes place on local governance and need-based plans for the village), cultural programmes, sports, competitions, plays, etc. Some of them also contested local body elections. The block-level DPOs lobbied with the block-level administration to resolve issues of persons with disabilities and collaborate with various networks and other alliances and groups at district, state and national level. For example, effective advocacy by the Nagaland State Disability Federation led to the revival of the District Disability Rehabilitation Centre in Dimapur, which provides aids and appliances for persons with disabilities.

Long-term Impact: Lessons for Sustainability

The impact evaluation, done two years after the CBR project and direct support to communities had ended, reveals that contextual realities combined with systemic changes influence the extent of inclusion of persons with disabilities within families and communities. In a context where there was little knowledge about disability and development, where the geographical terrain and weather conditions are adverse, where there were few support services for persons with disabilities, the CBR programmes have been able to entrench within communities an entire range of knowledge and skills around disability identification, referral and interventions, provision of services and promoting inclusion within communities.

Inclusion into Communities

The major impact of the programme has been in terms of changing attitudes towards persons with disabilities. The CBR and later DPO interventions have ensured that most communities and their leaders and service providers are aware of disability and persons with disabilities. In Aizawl and Dimapur, which are Christian dominated communities, the major advocacy had been with the churches and church groups like Sunday-school teachers, youth groups, and

women's groups. Advocacy with these groups ensured inclusion not only in church activities but also in the community, as church groups are drawn from community members themselves and have proved to be influential in changing attitudes.

"We did not think persons with disabilities could do anything. During the programme we learnt about including them and we are continuing it. This year we have taken a decision to make all churches under our parish accessible"
(Parish priest in Mizoram).

People now believe that persons with disabilities also can be capable of doing many things, and there is enhanced acceptance of disability. However there is still more work to be done in terms of changing community attitudes and ensuring that persons with disabilities have equal status as citizens. Improved inclusion is demonstrated in the increased participation of persons with disabilities in community activities, an increasing trend of marriages of persons with disabilities, and persons with disabilities being candidates in local elections.

Knowledge of identification and referral by community people, and support for accessing disability identity cards and associated entitlements, are being taken up actively by church leaders, teachers, families and persons with disabilities themselves, as well as ASHA workers (Accredited Social Health Activists or trained female community health workers) who are envisaged to be the first port of call for any health-related demands of deprived sections of the population, especially women and children, who find it difficult to access health services.

"We are now easily able to identify children with disabilities in our area. We learnt to screen, identify and refer at risk children during the CBR interventions"
(Anganwadi worker).

The relationships built within the community at village level, with the village council members, service providers, families and neighbours of the persons with disability, have helped in sustaining the efforts initiated during the CBR programmes. One of the major outcomes is the presence of a group of committed people, both staff of the project and persons with disabilities who have emerged as leaders during the project period.

"Now the church leaders and Village Council members always take into account persons with disabilities while planning development and other activities"(Young woman with locomotor disability, Dimapur).

“As we are also in the same community, families of persons with disabilities and even village leaders come to us or call us if they have any specific problem. We share the necessary information or link them up with services”(CBR coordinator, Guwahati).

Family members of persons with disabilities and DPO leaders became resource persons within the community, linking other persons with disabilities to support services and entitlements, both within and outside the project area. Many of these entitlements include access to proper housing and toilets, which make life easier and more comfortable.

“When I went to the Village Council, the headman asked me to talk to a family with a child with disability in another village. They wanted information on what to do. I have spoken to them many times and helped to get a disability certificate also”(DPO leader, Aizawl).

“Through continuous advocacy, we have managed to get a ‘pucca’ house built under the Panchayat housing scheme, which helps the people with severe disabilities to move around easily within the home” (Female DPO leader, Guwahati).

“With the help of a women’s group, our DPO has ensured that a girl with disability in our village got an accessible toilet constructed within the house. Now she not only has access to proper hygiene but is also safe as she does not have to go out for using the toilet.” (Female DPO leader, Dimapur)

Within communities, as discrimination has become less and awareness around issues faced by persons with disabilities has increased, people help families of persons with disabilities seeking medical care and other services to access different schemes and programmes. Although the CBR work was difficult in terms of limited financial resources, working with communities and convincing families, the long-term impact is sustainable in terms of people in the community taking responsibility and connecting with CBR staff and the implementing organisations on a regular basis. Larger developments that came out of the CBR programmes were the Parents’ Associations, setting up of District Disability Rehabilitation Centres (DDRCs), State-level Disability Federations and a sports organisation called ‘Special Olympic Bharat’.

Inclusion of Persons with Disabilities in Different Spheres of Life

The CBR programmes provided a stimulus for the individual physical, mental and educational development of persons with disabilities by building their capacity and that of their family members. The knowledge and skills of parents and families that developed to improve the quality of life of persons with disabilities, has remained as an asset within the community. Families and persons with disabilities themselves realised the utility of such interventions in terms of, for instance, developing independent living skills, access to education and livelihoods, improved family and personal lives. The strategies for physical, mental, educational and social development transferred to families have been used to improve daily living skills, promote independence of persons with disability and enhance their quality of life. This has become an important resource on which the families depend since the withdrawal of the project.

“During the programme we were taught different ways of stimulating our daughter, who has cerebral palsy, for mobility, functional activities like eating, dressing and also for speech. We continued the same, and she has kept improving”(Mother of a girl with disabilities, Guwahati).

“We had learnt to make a low cart for her mobility using local resources. I have made a new one for him when the previous one broke down”(Father of a boy with disabilities, Dimapur).

“The school has been very encouraging. Whenever required, I can go and share my concerns and they try to respond. The teachers often tell me to communicate with my son, when they find it difficult”(Mother of a boy with hearing impairment, Aizawl).

Some of the Mothers’ Groups are at present providing support to one another to the extent possible with their limited skills, along with helping families with newly identified children with disabilities to navigate fears around the uncertain development of their children. Families that have members with disabilities are supporting one another and DPOs are connecting families to enable exchange of ideas and skills.

People with epilepsy and mental illness also have been continuing to take medicines and counselling services available free of cost at the Government Hospital. The availability of such essential medication has ensured that these people can participate better in the activities within their homes and in the community.

"I know where to get the medicines but if I have problems in going to the hospital, the community people support me. Either someone accompanies me, or they get the medicines for me" (Person with mental illness, Guwahati).

The impact of the CBR programmes is clearly visible in the increased participation by children and young adults with disabilities in schools, church-based and Children's Groups and other community activities. The CBR programmes have engendered social and community-level inclusion, with friendships being forged with peers without disability on whom they can rely in times of need.

"My friends carry my bag as I find it difficult to walk with a heavy bag up the hill to school" (Boy with locomotor disability, Dimapur).

"The young boys in the neighbourhood, my son's friends, take turns to help my son with his daily needs. As he has grown up, he feels shy if I attend to his personal needs, and I also find it difficult to carry him from the room to the toilet" (Mother of a 24-year-old man with spinal injury, Aizawl).

Livelihood had been an important component of the CBR programmes, linking adults with disability to work and income, instilling self-confidence, and thereby mitigating poverty. This component has brought about a visible change in the lives of persons with disabilities across the three sites where this study was conducted. For those who were linked to self-employment programmes with support for training and start-up funds, trades like piggery, poultry, bee-keeping, livestock rearing, tailoring and carpentry, as well as setting up petty shops in their own area, have helped them to gain respect within their communities by supporting their own families. In Aizawl and Dimapur, people with disabilities were helped with petty business and group livelihood activities such as kitchen gardens and betel nut packing. People have increased incomes and are now being recognised as contributors to society.

"I have extended my betel nut packaging business, which I had been doing before, with a small loan from the group. We all use the same supplier, so it is like a group business" (Woman with locomotor disability, Aizawl).

"From the village level group, we have started a kitchen garden where all the families of the persons with disabilities grow vegetables and once a week we sell them at the local market. Whatever is earned is then distributed according to the contribution each person has made. So now all of us have an income. When we sell at the market, people see us as contributing to our families" (Woman with disability, Aizawl).

The major change was seen in Guwahati, where a DPO has established firm linkages with the local government and claimed access to Right to Food and Work programmes. The names of all persons with disabilities have been included in the list of workers of this programme and the persons with mild to moderate disabilities, as well as family members of those with severe disabilities, have found work from the Government schemes on a regular basis. The continuous lobbying by some active DPOs has ensured that persons with disabilities are included under the poverty alleviation schemes. Besides, DPOs are now linked to the National Rural Livelihood Mission (NRLM) through the local administration.

Limitations to Sustainability

Despite the community sensitisation and individual development of persons with disabilities in all the three sites, there are two areas of concern which need to be highlighted. Two of the major initiatives have been continued, but only with limited success. This is mainly because the systemic and structural initiatives required did not take place, and subsequently persons with disabilities, their families or the DPOs have not been able to sustain them on their own.

The first one relates to access to education, and although there are internal differences across the three sites, continued inclusion within the mainstream education system is restricted, not just due to the geographical terrain but also due to scant resources and poor implementation. During the CBR programme period, school enrolment and attendance of children and young adults had increased, with access to scholarships and transport allowances. While some children with locomotor and visual disability are continuing their education, most of the children with hearing impairments and intellectual impairments have dropped out of school, due to lack of support during the shift from primary to secondary schools which are at a distance from their homes and where the administration and infrastructure are not inclusive or even sensitive towards the needs of youngsters with disability. Continuing sensitisation of schoolteachers and networking with district-level school administrators has stopped. As a result the quality of education for children with disabilities has declined. Teachers cited a number of reasons why students with disability are neglected in their classrooms. While families with limited knowledge and resources, and living in poverty, find it difficult to advocate for their children, DPOs also have been unable to effectively attend to the education needs of children with disabilities, due to poor connections with schools and district-level administrative and support personnel.

The other limited success relates to Disabled People's Organisations (DPOs), organised to collectively work to sensitise communities, and advocate for rights and entitlements along with livelihoods. In the post-programme period, while the livelihood activities have survived to a great extent, the advocacy activities have become very limited. Village-level DPO meetings have become rare, and some DPO members say they are not active as the community is now sensitised. As the leaders of the DPOs lack the vision and skills for advocacy to take the concerns of all persons with disabilities forward, they have not been able to properly include, reflect upon and support these persons to address their developmental as well as care requirements. DPO leaders are individually supporting people to get and renew disability certificates and access other entitlements, as well as referring them to rehabilitation services. The groups that are doing well have very strong leaders, with good contacts in the local administration. In Dimapur and Aizawl, with a majority of Christians having the philosophy of helping their fellow people, DPOs help members with financial support, Christmas gifts etc. Some DPO members expressed difficulty in continuing without the guidance of the CBR staff, while CBR workers felt that the interest in being part of a DPO is waning as many people feel that they have received all possible entitlements. The reasons for weakening of DPOs range from economic concerns around poverty, socio-cultural issues of heterogeneous communities in terms of communication, and different needs and requirements of people with different impairments. However, the block-level DPOs are doing better, with effective leaders having good contacts within the community and the district-level administration.

CONCLUSION

Community-based rehabilitation programmes are looked at favourably by community development organisations and are dismissed by proponents of institutional rehabilitation. However, this model of CBR promoted by CI CBR and supported by Light for the World has attempted to blend medical interventions and other forms of rehabilitation with community-level initiatives, which has ensured the sustainability of the programme in the long run. The cycle of development set in motion by the CBR programme is most prominently visible in terms of the changes - individuals with disabilities have continued to develop beyond the project in terms of self-sufficiency, independence, inclusion in education and within the community, as well as in terms of earning a livelihood. As a result, persons with disabilities have also improved their status within their

families and communities, enjoy better quality of relationships, play an active role in family and community decision-making, and have gained dignity and respect. Knowledge and skills endure within communities, in families and DPO leaders, and are now being extended to others in need of support. With greater acceptance and respect for persons with disabilities within communities, there is more inclusion in everyday activities and decision-making processes. Systemic processes have been activated, resulting in better access to identity cards, aids and appliances, pensions, and locally available subsidy schemes. In Northeast India, where there was little awareness about disability and persons with disabilities, there has been a perceptible shift in terms of inclusion of persons with disabilities in different areas of social living.

Lessons learnt at the end of a long period of CBR interventions have been assessed not only in terms of promotion of rights and community-level awareness and inclusion, but also in terms of shortcomings. People who most benefited from the CBR programmes are those with mild to moderate disabilities, whose needs are relatively easier to address than those of persons with severe disabilities. Most of the initiatives however have left those with severe disabilities at the periphery, with very few of them participating and being included, and few needs being addressed by the CBR programme. In homogenous and closed communities, families with persons with severe disabilities are somewhat helped by community members in terms of care and support. The CBR initiatives have also had limited impact on poverty-stricken families where survival is a major issue, forcing families to discontinue many necessary interventions for the development of their children and young adults. Many of these families have children with severe disability and the progress made during the project period was lost, as their children's condition either relapsed or became worse with advancing age.

The impact of the CBR programme demonstrates that an exit strategy needs to include mechanisms for upgrading skills and information/ knowledge among families, DPOs and communities. This will enable continuity in advocacy for entitlements, rights and systemic changes. The impact assessment exercise has also laid bare the extent of community integration – DPOs are working well in homogenous communities, but the bonding of people has been limited in heterogeneous populations. DPOs need to be empowered to develop a long-term vision and sustainability plan, and build a core of dedicated leaders who are motivated and interested in learning more and looking beyond entitlements. The vision for the DPOs needs to be cohesive and passed from CI CBR to the

training organisation and on to CBR workers and DPOs. There may be a need to extend further hand-holding support to the DPOs and to nurture the ability of leaders with a disability to assert their rights, engage in networking and seek disability convergence into all mainstream development-oriented programmes. If such efforts can be promoted locally and through mentors, there is a greater chance of proactive change continuing within local communities. Lastly, CBR programmes need to find the language and strategies to build a positive attitude towards disability, moving away from deficiency, care and support mode to a rights-based one. This can only be done by inculcating within the CBR programme an orientation towards rights and responsibilities, recognition of diversity and respect for differences among all people in the community, especially the persons with disabilities and the team implementing CBR.

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