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## WHAT HAPPENS WHEN WE LEAVE?

Documenting what remained after the closure  
of three programmes for disability inclusion  
in community development

Light for the World and  
Caritas India CBR Forum, 2020







**Fr. Poly Varghese**  
Executive Director  
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*Caritas India, through its Community-Based Rehabilitation (CBR) Programme Unit, has been working for the inclusion of persons with disabilities in their communities since 1996. Today, its programs are spread across 19 states and 01 Union Territory of India reaching out to over 95,000 persons with disabilities. While Caritas India has been working in the northeast since the early 2000's, it joined hands with Light for the World in 2005 to reach the unreached persons with disabilities and their communities in the northeast region of India.*

*An impact evaluation was conducted in three locations in the North East two years after funding by Light for the World to these programmes had ceased. The evaluators intended to document what remained in the community with regards to disability inclusion post-funding. It is envisaged that the lessons learnt will help plan future interventions that would be even more sustainable.*

*The teams of Light for the World and Caritas India CBRF have put in tremendous efforts to conduct the impact evaluation and have come out with a very informative "Learning Publication" for the benefit of all, especially those in the disability sector.*

*I wish to extend my warm greetings and best wishes to the Light for the World and Caritas India CBRF teams for their future efforts in bringing about sustainable changes in the lives of persons with disabilities.*



**Rupert Roniger**  
CEO Light for the World

*Light for the world is delighted to share the lessons learned from the Disability Inclusion in Community Development work in the northeastern states of India. Thanks to our long-lasting partnership with Caritas India CBRF and local partners on the ground we have managed to see the importance of a community approach to inclusion. With the unique and systematic approach of Caritas India CBRF in communities in various states of Northeast India we managed to see what remains when our direct support has phased out. We are happy to share these findings together with Caritas India.*

*Light for the World is committed to reach the hardest to reach and this report shows that through a systematic approach of building capacities in the communities we can make a difference in the lives of people with disabilities that are not easily reached by mainstream interventions.*

*Light for the World is thankful for the partnership with Caritas India CBRF and is happy that through this report "our" lessons learned can also support learning beyond Northeast India.*

*We hope you will enjoy this report and will benefit of what we have learned for your practices too.*



## Introduction

In India, as in many places throughout our world, women and men, girls and boys with disabilities have poor access to health, education, livelihood opportunities and rehabilitation services, as a result of which they are often not included and do not participate in families and communities. In Northeast India, this is further compounded by a difficult geographical terrain and a lack of infrastructure, meaning that access to services is limited. Since 2005, Light for the World and the Caritas India CBR Forum have been partnering together to work on community-based rehabilitation (CBR) through which disability inclusion in community development was promoted in the region.

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### What is disability inclusion in community development?

Disability inclusion in community development is an approach aimed at triggering systemic change and the sustainable realisation of the rights of men and women, girls and boys with disabilities. Programmes which use this approach work with communities to make them inclusive for people with disabilities, while at the same time offering targeted support to people with disabilities themselves. Topics range from accessible health care to inclusive education and economic empowerment, social inclusion and participation. To do so, the involvement of the disability movement is critical. Using this two-pronged approach, we witness how attitudes change

from the notion that an individual should be rehabilitated to fit into society, to the vision of inclusive communities where every individual has the equal right and opportunity to participate.

The process of disability inclusion started in the early nineties as an approach to make rehabilitation accessible on a community level. In 2000, the approach was documented in the CBR guidelines under the name Community Based Rehabilitation. Light for the World, emphasizing the focus on the local implementation of the UN Convention on the Rights of Persons with Disabilities (UNCRP) uses the term disability inclusion in community development. Both names are used in this document.

In communities of the northeast states of Nagaland, Assam, Tripura, Meghalaya, Manipur and Mizoram, Caritas India CBR Forum has been supporting disability inclusion in community development since 1996, carried out by local individual partner organisations. These projects have each been funded between seven to nine years, after which the community approach was expected to continue independently.

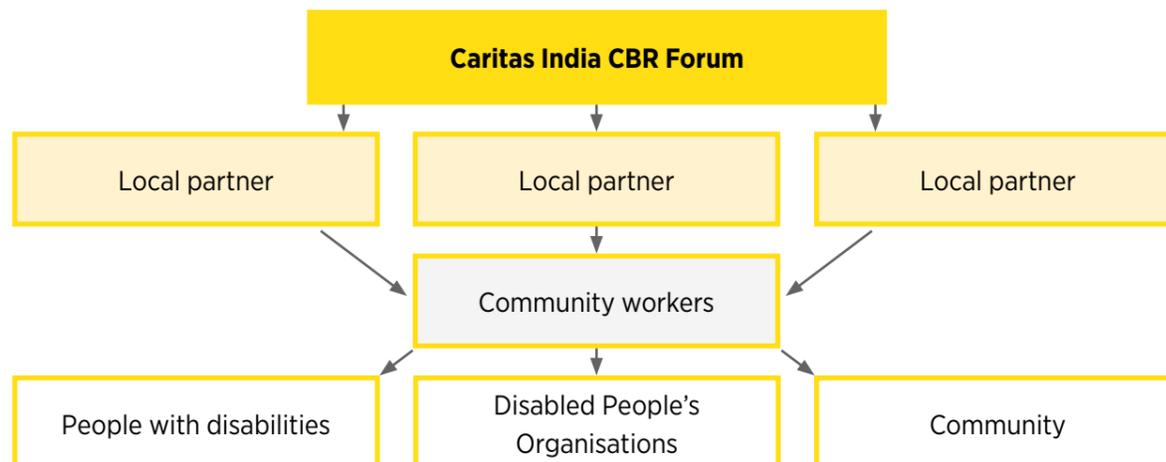
PROJECT CYCLE								
Preparatory phase	2nd phase		3rd phase		4th phase		phase out years	
Y1	Y2	Y3	Y4	Y5	Y6	Y7	Y8	Y9

We wanted to understand what the lasting effects are of a disability inclusion in community development programme in a community. What had the most impact? What disappears when funding stops? And what does this mean for how we set up and develop our community approach in the future?

We thus carried out impact evaluations in three communities, two years after the CBR programme stopped. This publication summarizes the results and the learnings of these evaluations. Its aim is to guide the development of future CBR programmes so that they are sustainable.

### Community-based rehabilitation and inclusion as implemented in Northeast India

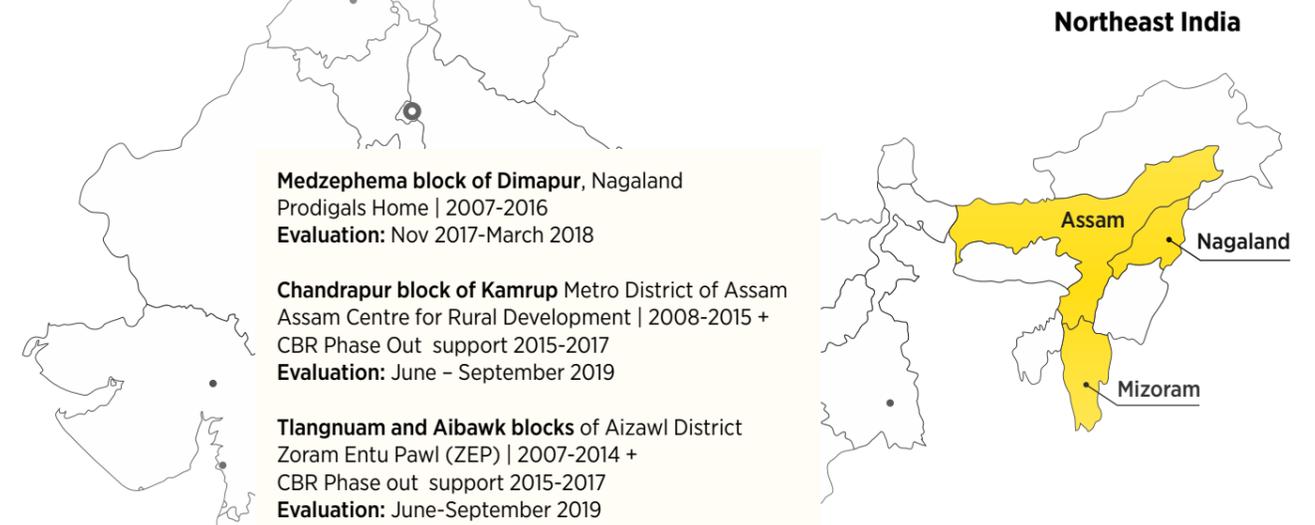
The Caritas India CBR Forum was established in 1996 to promote community-based rehabilitation and inclusion for people with disabilities in Northeast India. This is done by providing at-home support for individuals with disabilities, strengthening the disability movement by working with disabled person’s organisations, and lastly at community level by engaging with duty bearers and community leaders to ensure women and men, girls and boys with disabilities can use government schemes and public services. A CBR project consists of the following elements. Partner organisations – local non-governmental organisations that have been active in their community for a long time – are asked to take up the implementation of community-based rehabilitation for a period of seven to nine years. The partner organisation then recruits staff to do the work, generally one coordinator and three or four community workers who work in an area of about 20 to 30 villages. Staff work closely with the community and the local government to advocate for and facilitate the inclusion of people with disabilities, and at the same time provide support at home for people with disabilities and their families.



### Methodology

In 2018 and 2019, Light for the World and Caritas India CBR Forum carried out evaluations of three of their CBR projects, two years after the projects were phased out. The evaluations consisted of a desk research, interviews and focus group discussions in all three communities. A workshop was held in November 2019 with key stakeholders to discuss and triangulate the main findings of the evaluations, and to develop lessons learned for future disability inclusion in community development programmes. This publication is based on the findings of this evaluation process.

The ex-post evaluations did not look at the questions from a gender perspective. However, we know from other studies<sup>1</sup> that gender roles are very strict in Northeast India, that roles within families and communities are not equal, and that men and women do not have the same access to opportunities and resources. In consequence we can assume that the situation for women and girls is and continues to be more challenging than for men and boys. Please bear this in mind when reading the results.



### What stays?

Through our analysis of what remained of the CBR work two years post-implementation, we found eight key results. In the next chapters, we want to share the results, and what this means for developing programs for disability inclusion in community development that aim for sustainability and impact.

<sup>1</sup> Light for the World and Caritas India CBR Forum. (Forthcoming). Disability and Gender in the Northeast of India.

## Quality of life has improved significantly for individual people with disabilities and their families.

People with disabilities, and their families, reported that the quality of their lives had increased significantly as a result of the work done through the disability inclusion in the community development programme. More importantly, they not only reported this directly at the end of the programme, but also referred to it two years after all activities of the community workers and local organisation had stopped in their community! So what contributed to this increased feeling of positivity?

“  
Initially my family and I were reluctant to meet the CBR team members. But CBR has changed my life in many ways. - Akloka

People with disabilities and their families said that their lives had improved in terms of physical development, access to services and social protection and livelihood. Regular home-based interventions meant that both children and adults with disabilities enhanced their daily living skills, improved mobility, and boosted communication. Children with disabilities who had been supported in education reported greater academic success. The provision of mobility aids and other assistive devices, such as hearing aids, augmented motor and communication skills for those with mobility, visual or hearing impairments. Others were able to access medication, leading to better health, or received corrective surgery which improved daily functioning. People with disabilities and their families said that although these improvements started during the project period, they themselves then built on them and continued the work.

“  
Being part of the CBR programme led me to participate in different programmes and physical development, and I was selected to go to Australia for Special Olympics in 2012. - Mhachio

### What are home-based interventions?

Home-based interventions are when community workers regularly visit women, men, girls and boys with disabilities and their families at home. Together with the person with a disability and his/her family or caregivers, the community worker develops a plan and carries out activities to support the development of that person in all aspects of life, including the stimulation of early childhood development skills, daily living activities, communication and functional mobility. Those who require therapeutic services are referred to local facilities where they exist. Community workers help parents to follow up and continue the physical exercises learnt through therapeutic sessions.

Seeing their family member with a disability improve their abilities and social participation as a result of interventions, social inclusion, access to services and income generation, encouraged many families to invest more time, effort and resources in these family members. This led to an even larger improvement in the daily functioning, skills sets and capacities of people with disabilities. In addition, improved functioning also led to increased participation in the community as well as socialization.

Families and caregivers, too, experienced an increased quality of life as a result of these activities. As their family member with disability gained or improved independent living abilities, the care needs decreased. Where family members with disabilities started earning an income, the economic situation of the entire household improved.

This impact has remained. People who had started on medications continued using them free of charge from the government hospitals. Families and people with disabilities realized how useful interventions were in terms of developing independent living skills and accessing education and livelihood, and they thus continued the work themselves. Families had been shown how to come up with creative solutions, and they are innovating in different ways – from wooden chairs with rotating wheels used inside the home, to adapting furniture in schools and modifying toilets. Families, Disabled People's Organisations (DPOs), and parent groups shared the information they had received over the years between themselves and with new parents and caregivers, exchanging skills and ideas.

All the above therefore demonstrates that working on personal support and development for people with disabilities was crucial to improving their quality of life as well as that of their families – in the short and long term. Despite the fact that the programme only lasted several years, it provided the start and the empowerment that people with disabilities and their families needed to keep going even without external support.

## Recommendations

- ▶ Home-based interventions, access to services, and providing a push to start making a change, all play a key role in improving the quality of life of individuals with disabilities and their families. To achieve this, it is important to look at all different areas of life – taking a comprehensive approach as mentioned in the CBR guidelines<sup>2</sup> – to gain improved results throughout the sectors as defined in the CBR matrix (health, education, livelihood, social and empowerment).
- ▶ As each situation is different, it is crucial that community workers have the space and freedom to look at the person they are working with and their respective situation, needs, and barriers. Providing each individual with a personalized approach and plan increases the likelihood of achieving positive results.
- ▶ Including families in home-based interventions proved a good strategy in transferring ownership of the work to persons with disabilities and their families. Community workers involving families in the steps they are taking provides an opportunity for knowledge and skills transfer, increases household involvement, and embeds sustainability of the work as the family is more likely to continue investing in improving daily living skills, motor and communication skills, and family and community participation.

## Involving the whole community helps build inclusion in all aspects of society

The CBR programme chose to work actively through community leaders, focusing on reaching out to village leaders, early childhood development workers (anganwadi<sup>3</sup> workers) and church leaders, amongst others. Leaders were asked to help in identifying women and men, girls and boys with disabilities in the villages, a role they still fulfil to this day. In the project villages in Assam, for example, anganwadi workers have been assigned responsibility for identifying people with disabilities as well as for processing their pension applications. Getting community leaders on board was a significant strategy in building inclusion in the community – as community leaders are listened to by all community members.

<sup>2</sup> World Health Organization, UNESCO, International Labour Organization & International Disability Development Consortium. (2010). Community-based rehabilitation: CBR guidelines. World Health Organization. <https://apps.who.int/iris/handle/10665/44405>

<sup>3</sup> Anganwadi is a type of rural mother and child care centre in India, which provides basic health care in Indian villages. The centres provide supplementary nutrition, non-formal pre-school education, nutrition and health education, immunization, rehydration salts, basic medicines, contraceptive counselling, health check-up and referral services.

During the programme, CBR staff and DPO leaders targeted government authorities and community structures, carrying out advocacy activities and providing training. As a result, communities have since been working on modifying infrastructure to make it more accessible for people with disabilities. Some churches have built ramps to improve access, for example. Primary health centres and hospitals have become more responsive to the needs of people with disabilities, thus improving their access to health care. Village councils and church bodies are making active efforts to include people with disabilities in their activities, leading to increased participation of people with disabilities in community activities. Advocating with the district administration has resulted in the administration proactively including people with disabilities in and linking DPOs to the National Rural Livelihood Mission, a poverty alleviation scheme run by the Indian government. As a result, people with disabilities in Assam were regularly able to find work and thus earn an income from these schemes.

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**We did many awareness programmes. I was involved in the project from [the start] and helped the children to get an education. – Lhaikhochin, Anganwadi Worker**

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Lastly, another way that communities got involved is by demonstrating the added benefit of inclusion. For example, in Mizoram community members gather to clean the village once a month. DPO members participate in this activity regularly, leading to recognition of people with disabilities as full-fledged community members. By involving the community in different aspects of the programme, community members felt that they were part of the work, and saw the added benefit of including people with disabilities in the community as a whole.

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**The Pastor was deeply involved in the CBR project. [I had positioned] her as advisor in the locality. She used to arrange to observe International Day of Persons with Disabilities each year in the locality. – CBR worker**

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## Recommendations

- ▶ Brand the programme as a community programme which includes people with disabilities, rather than as a disability project. Framing the message in a way that is interesting to the whole community can lead to increased interest and involvement by non-disabled community members.
- ▶ Encourage people with disabilities and the DPOs that represent them to take up activities that are beneficial for the whole community, such as participating in village clean-up events. This increases the visibility of people with disabilities, and demonstrates to community members that they can be of value in community activities.
- ▶ Involve community members in activities, where possible, right from the start of the programme. Using community leaders and people who already have a natural role in the community (such as early childhood development workers) embeds disability inclusion in the community in a logical way.
- ▶ Encourage women and men with disabilities to become community leaders, so that their needs become more visible and they have a natural place to voice their concerns.

## Livelihood opportunities lead to increased acceptance and confidence

Livelihood, income and financial independence are primary concerns for people with disabilities, yet many have no secure and regular source of income. This is particularly so for women, who have fewer options to earn an income, and whose labour towards family income generating activities and domestic work is not considered important.

Throughout the years of their involvement, the community development workers specifically emphasized building up livelihood opportunities for the people with disabilities and their families involved in the programme. There were various ways that this could happen. Some were provided training and financial support to set up self-employment activities, such as raising pigs, making pickle, tailoring, and making soap. Several people with disabilities were supported to attend vocational training programmes which helped them to learn a trade. Another option set up in some communities was to involve people with disabilities in livelihood support funds, which enabled them to take out a loan to, for example, sell fish and vegetables in the market or start up a small shop in their home. In places where the Mahatma Gandhi National Rural Employment Guarantee Scheme (MGNREGS) was active, people with disabilities were linked to the scheme and supported to gain employment through it. In all cases, however, it was more often men than women that benefited from the employment opportunities.

The programme encouraged many different ways of earning a livelihood, and the end result was that a large number of people with disabilities gained an income because of the programme, and still have this means of earning an income after the programme ceased. This is of major impact to the individuals involved. Gaining a livelihood has provided people with disabilities with enough money to support themselves and contribute to the family income. With families relying on this added income, people with disabilities have gained increased confidence and are increasingly involved in family and community decision-making.

## Recommendations

- ▶ Actively invest in and give priority to skills building and livelihood development activities for people with disabilities during the course of the programme. The effects of gaining a livelihood lasts beyond the duration of a development programme. In addition, investing in building up an income is extremely effective in all aspects of inclusion and quality of life, as it increases an individual's value within the family and community and also gives them the funds to invest in their own health, nutrition and other needs.
- ▶ Make sure women with disabilities have access to livelihood opportunities, and challenge gender norms and unpaid domestic work.



## Interventions for people with (severe) disabilities at home need continued mentoring

Like almost all programmes for disability inclusion in community development, one of the services provided by community development workers are home-based interventions. As described on page 7, home-based interventions can include accessing or developing equipment and aids and practising therapeutic interventions that improve basic day-to-day activities. These interventions support children and adults with disabilities in their physical, social, cognitive and educational development. They also increase their quality of life as they boost confidence and the skills to carry out daily activities such as bathing, dressing and feeding. This is of specific importance in communities which are remote and under-served by state rehabilitation efforts.

The impact of the home-based interventions have lingered for people with mild to moderate disabilities who were able to sustain these even after the programme had ended. However, for families that live in extreme poverty where survival is a daily concern, and in cases where family members have severe disabilities, many families have slowly stopped interventions after the field workers stopped visiting, despite enthusiasm and visible improvements during the years of home-based intervention. As a result, the well-being and (physical) capabilities of people with severe disabilities have regressed in many cases, and some have even passed away.

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**The CBR project gave us an opportunity to know the rehabilitation and education of our child. The activities of daily living improved. We [were encouraged] to take forward the intervention and social inclusion was ensured. - Father of a child with a disability.**

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In addition, as children with disabilities gain abilities or as their bodies change when they become older and heavier, carers need to be equipped with new skills to adapt therapy and care routines to the needs and abilities of the child at that moment. Without regular upgrading of skills and knowledge, carers may lapse or get stuck in old routines, risking the development of their family member with a disability. Field workers had trained caregivers to support their children, but when the field workers left as the programme ended, caregivers were not able to adapt exercises and care when the needs of their child changed.

In conclusion, caregivers of people with disabilities will need access to services and long-term mentoring and support, as needs of the disabled person and the household situation may change over time, meaning new skills and continued encouragement is needed.

### When stimulation stops

Women and men, girls and boys with disabilities, particularly people with severe disabilities, need continued therapy or stimulation. Stopping stimulating exercises may lead to regression – with individuals losing skills they once had – or even death. This is because people with severe disabilities often spend a long time in the same position; causing contractures of the limbs, an increased risk of pressure sores which can lead to infection. Other risks associated with lack of movement and stimulation include a heightened risk of urinary tract infection and pneumonia.

## Recommendations

- ▶ Start looking at the referral chain right at the beginning of the programme: which government services, NGO services and other exist already, how are they linked to each other, and what services are still missing. The gaps that are identified define the priority topics for advocacy: work on closing those gaps already from the start of the programme, in order to build up a sustainable comprehensive rehabilitation system. The success of this work differs since not every need is high on the agenda of local governments, making that some gaps are more easily covered than others.
- ▶ Build a system for referring children with (multiple) disabilities to appropriate organisations which can provide interventions for these children. Develop links to, e.g., parent support groups or parent organisations that are already operating in the area.
- ▶ Parents and caregivers need a lifelong system of support, as the needs and abilities of their children change throughout their lifetime. Setting up and fostering the development of parents' groups is crucial to ensure that caregivers have a source of support once the programme ends. Within a parent group, caregivers can motivate each other as well as exchange knowledge on how to support their children through different stages of life.

## CBR work leaves a lasting positive attitude towards people with disabilities

One major change in the communities as a result of nine years of CBR work was the lasting positive attitude towards people with disabilities. As in many impoverished communities around the world, people with disabilities had initially been seen as a family burden, often neglected and with little expectations. This attitude had changed by the end of the programme, and was still seen in the communities years after the community workers had left.

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The programme gave us acceptance in the community, and not feeling different. As I am now participating in social activities, I also got self-respect. – Laldusaka

Attitudes changed as women and men, girls and boys with disabilities were seen in public spaces and as they started participating in cultural and social events in their communities. An increasing number of people with disabilities are getting married, and some have stood for local elections. Individuals are called by their given name rather than by their impairment. Families that used to hide their children were now actively seeking out rehabilitation and treatment. People with disabilities have also become more vocal about their needs and demands. Individual people with disabilities are now going out more, some have become motivational speakers and others have started their own business. Positive attitudes were also a result of families and communities seeing the added benefit and value of their members with a disability: accessing livelihoods and disability services helped increase household income. Working on disability inclusion for a longer period thus helps change community attitudes towards people with disabilities as a positive side effect.

### Recommendations

- ▶ Make sure that people with disabilities participate in all spheres of life. By supporting them to become active and contributing community members, attitudes will change towards them as the community sees their work and recognizes their value.
- ▶ Encourage activities that are beneficial for the whole household or community, such as developing income generating activities or participating in community events such as road reconstruction or garbage collection. This will help community members see people with disabilities in a positive light as individuals that are contributing to the household/community.

- ▶ Attitudes take time to change. Make sure that projects and programmes last long enough – in this case between 7 and 9 years – for attitudes to really change.
- ▶ Include as many family members as possible – fathers and mothers, uncles and aunts, grandparents - in training, support and rehabilitation of the child with a disability.

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I love the happiness in the face of my boy when his friends take him around in the wheel chair. – mother of Malromkini

**14-year old Parag** has a hearing impairment. Although he was enrolled in school, he never went. His parents were worried: he had to cross a railway track to reach his school and they were afraid that he would be in an accident due to his lack of hearing.



Field worker Revati started giving him education at home, and at the same time met with his family to discuss the possibility of his attendance at school. They met with the school teachers to advise them how to support Parag: by placing him in the front row so he could see the blackboard and asking the teachers to face Parag when they speak, and use signs and gestures. Revati also enlisted some of Parag’s peers to help him walk to school, particularly when they came to the railway crossing.

Parag was re-enrolled in the government school, and is currently in class VIII. His family now lets him go to the market on his own to buy food and essentials, and he is active on social media platforms. He aims to become a police officer when he grows up.

## Disabled People's Organisations need continued guidance and support.

Disabled People's Organisations (DPOs) can be powerful places for people with disabilities to find community and support, and to come together to advocate for their rights and equal access to services. The CBR programme therefore invested actively in setting up DPOs in the communities where they work – and with success! With repeated meetings with their members, helping them understand the benefits of being part of a group, DPOs started fundraising, discussing issues, taking up activities and networking and initiating advocacy activities. Many DPO members were participating in community meetings, local government (gram sabha) meetings, cultural programmes, sport competitions, plays and other activities. The state and district level DPOs lobbied with the block level administration to resolve issues of people with disabilities and collaborate with various networks and alliance 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 disability aids and appliances for people with disability.

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**We visit uncovered areas and motivate them to form DPOs. The CBR programme gave me the confidence to do so. - Thangna Khao**

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By the end of the programme, 47 village level and 3 block level DPOs had been formed and mentored in the three states, most of which were in a strong position when the programme ended and the financial and moral support of the field workers stopped. The block level DPOs in all three states were linked to the higher level DPOs at district and state level so that they could address issues at various levels.

Two years later, very little remains. Of the 47 village level DPOs set up during the course of the programme, only a few are still functioning efficiently, with many others in suspended animation, having lost momentum. Regular meetings have declined and advocacy activities dried up, with the majority of action going towards generating income.

The few DPOs that are doing well are the ones that have strong leaders with good contacts amongst the local administration. When they face issues, they are able to get in contact with the right people to ask how to go about things. These leaders have been able to build up strong rapport with government authorities at various levels, and have been asking for inclusion for people with disabilities in government schemes. Others have been supporting individuals in accessing disability certificates or linking people with disabilities to rehabilitation services.

The non-functional DPOs, however, have not fostered a bond between members. This seems to be more likely in areas where people come from diverse tribes and backgrounds. Members have slowly discontinued contact, seeing little benefit in being part of a collective. The DPOs that worked on concrete and everyday benefits, such as livelihood and savings activities, were more likely to survive; those that promoted more abstract rights or dealt with the government were more likely to falter. Developing DPOs that continue functioning without the input of a CBR programme thus requires more and careful intervention.

## Recommendations

- ▶ Give Disabled People's Organisations space to grow naturally. Give the members of the organisation time to come up with their own vision of how they want to increase their ownership of the organisation. Focus on issues of common interest to the members and guide them, from the beginning, to look at their long-term goals.
- ▶ Choose to strengthen existing DPOs, if relevant, instead of investing in new ones. Similarly, aim to align forces with other, already existing, disability movements or likeminded community-based organisations.
- ▶ DPOs with strong leaders are more likely to survive. Therefore, set up a leadership programme and peer-to-peer mentoring for leaders with disabilities. Invest in building the capacity of promising DPO leaders.
- ▶ When the programme stops, consider funding the DPOs for a continued period of time. Continuing (limited) support to DPOs after phasing out the rest of the activities can be a valuable tool to build up DPOs in their role to assure that work done during the years of support will continue to flourish, and upcoming barriers can be addressed.

## Working on disability leads to organisational changes

In this programme in India, the work on disability inclusion in community development is carried out by local organisations that – generally – don't focus on disability at all. They are organisations that work on general community development, education, health and/or livelihood, but have been selected to carry out activities towards disability inclusion in community development. For many, this was the first time working with and for people with disabilities.

The CBR programme was only one project in an often much larger project portfolio for these organisations. Staff that would work on inclusion of people with disabilities were recruited and trained specifically for this programme, and were supported throughout the years by mentors on disability inclusion in community development.

### The Caritas India CBR Forum training approach

Working with mainstream development organisations to implement CBR programmes also means working with organisations and staff who have never worked on disability. This means needing to spend time in training and mentoring the team on disability, rehabilitation and inclusion. Hard work, but also a unique opportunity to get development organisations involved in the topic of disability. To do this thoroughly, Caritas India CBR Forum has an extensive training and support approach that involves professional training centres, a pool of resource people as well as the CBRF team that provide both formal and informal training and mentoring.



This work on disability inclusion left lasting effects on the organisations, which became more inclusive towards people with disabilities in their other projects. For example, in Mizoram, Zoram Entu Pawl involved people with disabilities and their families in livelihood activities. Prodigals Home, based in Nagaland, has extended social protection and care

to people with disabilities and their families. This shows that implementing disability inclusion in community development through general development organisations is not only beneficial while the programme lasts, but also extends to the organisation's other activities once the programme ends.

## Recommendations

- ▶ Working with existing local organisations to implement CBR work can widen the scope and impact of the work. These organisations which are often already working in and are embedded in the community, are sure to remain even after the funding for CBR stops. Although actual CBR activities may no longer happen, the staff (with their newly gained skills and networks on disability) remain and can still support DPOs and communities on a more informal basis. Another added benefit is that disability inclusion may seep into other parts of the organisation, and they may become more inclusive towards people with disabilities in the other areas they work in.



**Mr Thanhnuna** is a person with a visual impairment. He had been living alone since his three daughters got married and he had separated from his wife, and had been earning a living with menial jobs. When the CBR programme team started a Disabled People's Organisation in his village, he was enrolled as a member and soon became an active member. There, he learned that he could get a loan with a low interest rate from the National Handicapped Finance Development Corporation. He got the loan, started poultry farming, and was soon able to pay off his debt with interest. He now has a regular income from renting out a portion of his house, as well as the old age pension that he has been able to access. In addition, he is president of his local DPO and vice president of the district DPO. Mr. Thanhnuna has become an active participant in community and church activities, and never misses a Sunday service in church.

## Investing in transfer of skills and knowledge keeps those skills in the community

Besides simply doing their work and getting on with it, the community workers that were active over the years were additionally focusing on transferring the skills they had to the people and communities they worked with. This reaped benefits years after the CBR work had ended.

For example, one of the key activities carried out under this CBR programme was the identification and referral of people with disabilities to access disability certificates – a form of identification which entitles the holder to items such as subsidised housing, travel concessions on public transport, assistive devices, financial support for self-employment or other benefits, varying per state. In some of the communities, access to disability certificates and identity cards was almost universal amongst people with disabilities when the programme stopped. DPO leaders and people with disabilities are now so familiar with the process that when a new individual with disabilities is identified, they are able to guide them through the process of applying for a disability certificate. They can also refer and support people with disabilities to apply for therapy or rehabilitation services. The skills and knowledge that were transferred while the programme was running, such as identifying different types of impairments, referral mechanisms, access to disability cards and services, and existing government schemes, remain with the communities. This knowledge is still being used to initiate early identification and intervention if a child with disabilities is born in the community – improving their quality of life as they are now, much earlier than before, able to access the services they need.

As another example, community workers had shown families and people with disabilities how to use local materials to produce assistive devices, such as special chairs, modified toilets, or modified school furniture. This continues with, in some cases, local groups such as church committees and youth groups donating funds for a local carpenter to make adapted furniture and toilets. Similarly, families continued to use the skills they learned when it comes to independent living and improving daily functioning for their children or family members with a disability. Many continue therapeutic activities, and some continue to meet in parents' groups to share the skills and knowledge they have learned with others in similar situations.

This example proves that some specific knowledge and skills, once practised enough, remains within the community and can benefit newcomers, resulting in long-lasting impact.

## Recommendations

- ▶ Community workers should involve DPO leaders in actions they are taking (e.g. bring them along when applying for a disability certificate or health allowance), so that DPO leaders can learn from them. Giving them 'on-the-job' guidance teaches them how it works, so that they feel comfortable sharing this knowledge with other people with disabilities, once field workers have left the community. The same applies to other key stakeholders such as caretakers, community leaders and government staff.
- ▶ People with disabilities and those around them often simply don't know about many of the services that are available to them. They need to be made aware of what they are entitled to and how they can access it. Once the community has this knowledge, they will keep sharing it by word of mouth – spreading even more awareness.



## **Making disability inclusion in community development sustainable: with changing life needs, continuous services and input are vital**

Over the years of working on disability inclusion in community development, great results were achieved. People with disabilities started going to school, received therapy and improved their physical and communication skills. They also acquired equipment to support them in their daily lives. Disabled People's Organisations were established, which advocated for participation and access to services, and people with disabilities started gaining livelihoods. Community attitudes changed, as people with disabilities were recognized as individuals and included in community activities.

However, people change. As individuals grow older and their bodies change, so do their needs. But once the programme finished, it was not always clear where they could go to get new information, skills or equipment appropriate to their changed bodies or phase of life. For example, children with intellectual and hearing impairments were found to have dropped out of school, mostly when they needed to transition from primary to secondary school. The primary school had, during the years of the CBR programme, been prepared to meet their needs. The secondary school had not. As another example, without regular access to rehabilitation services and materials, people with disabilities over time were using aids or materials that were no longer appropriate, such as wheelchairs that had become too small for growing bodies or glasses that were of no use with deteriorated eyesight. DPOs stopped meeting when they weren't sure what purpose they had without field workers supporting them. Likewise, key stakeholders changed as government staff, teachers and health workers found new positions, and their replacements may not have been trained on disability inclusion.

If CBR programmes are to contribute to the quality of life of people with disabilities, their services must be sustainable. These types of services need to be supported, ideally, by the government in a dependable, structured way so that people with disabilities can be assured of support throughout their lives. To ensure that our work is sustainable, we have to continue to push for system change. This means building in and mainstreaming the referral and rehabilitation process into government services at local community level. We need to create strong, inclusive community structures and invest in strong leaders for a disability movement that drives change.



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## **Publishing Information**

**Editor and publisher:** Light for the World International

**Graphic Design:** Susanne Fröschl grafikdesign

**Fotos:** Light for the World, Gregor Kuntscher, Kalyanil Odhia, Grites India, CBR Forum