RAYS OF HOPE

EVOLVING INCLUSION IN CBR

CONTENT

ADD INDIA

Caritas INDIA
The Joy of Service...

Caritas India CBR Forum

Basic Needs India
...promoting mental health and development

MISEREOR IHR HILFSWERK

"We acknowledge the support of MISEREOR in bringing out this publication."

ACKNOWLEDGEMENT

Caritas India CBR Forum (CBRF) with Caritas India, Delhi as its legal holder, Action on Disability and Development India (ADD India) and Basic Needs India (BNI) promote CBR in rural India. These three NGOs have come together to bring out this publication.

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Last but not the least, we are grateful to our NGO partners and Persons with Disability but for whom this publication would have been a distant dream.

FOREWORD

According to the National Census of India 2011, there are 2.9 million people with disabilities (PwDs) in India, who represent 2.13 % of the total population. This includes people with visual, hearing, speech, locomotor and mental disabilities. 75% of the people with disabilities live in rural areas, 49 % are illiterate and only 34% are employed.

For MISEREOR, PwDs are one of the most vulnerable and "left behind" groups in the society, whose rights and needs have to be addressed in order to fight inequality and contribute to their inclusion in society. In line with its aims to fight poverty and disease, MISEREOR works with its partners in order to promote disability inclusive development.

Caritas India CBR Forum is a longstanding partner committed to the field of disability. Today, they touch the lives of 34,341 PwDs in rural areas through their Community Based Rehabilitation Strategy and 26,401 PwDs through programmes with Disabled People's Organizations covering nineteen states and one Union Territory of India by joining hands with 58 Non Governmental Organisations (NGOs) and 15 DPOs. Their work, based on the principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), is an important contribution to achieve sustainable development. In South India, they are assisted by two other partners of Misereor – while ADD India, a training organization in CBR and Disability, imparts training to their NGO Partners at field level, Basic Needs India cares for the training in Mental Health. ADD India also has some direct interventions at field level.

This document showcases the experience of the above organizations. It presents case studies that intend to share the experiences, understanding and challenges related to inclusion of PwDs in society.

We would like to thank all those who participated actively in the development of this document and wish that this document will be useful and inspiring for other people's organizations intending to walk along the same path.

Dr. Nina Urwantzoff
Health Advisor, Misereor
17.3.2016

PREFACE

The purpose of this booklet is to document and highlight the efforts of various community based rehabilitation programmes in different parts of the country that have brought about changes in the lives of Persons with Disabilities (PwDs) and their families. These programmes have contributed greatly to changes within community structures, practices and attitudes.

This booklet aims to bring to the fore experiences that, in varied ways, have favoured the inclusion of PwDs and their families within their community. This inclusion has occurred within both the formal and informal structures of society. The focus of this publication is to emphasise the small but sure gains in terms of changing attitudes, practices and systems effected within local communities that have impacted the lives of PwDs in a positive way.

The efforts of PwDs, whether individuals or in groups, along with their families and communities have resulted in achieving a better quality of life. Many of these PwDs have also emerged as role models and leaders in their own right. It also shows the effort they have put in to achieve this change for the better. For each person featured here, there are many more out there living their lives within their communities with dignity and grace and with the sure confidence that, despite their impairments, they too are part of the daily lives of their families and communities!

This document is a tribute to their achievements.

INTRODUCTION

In India, according to the Census 2011, there are 26,810,557 persons with disabilities (PwDs), of whom 2.41% are male and 2.01% female. PwDs constitute 2.21% of the total population of India. Children constitute 1.6% of the population of PwDs. Considering the disability wise break up, persons with locomotor impairment (20.3%) constitute the most common form of disability followed by visually impaired people (18.8%). Of the other disabilities, persons with speech and hearing impairments (14%), persons with multiple disabilities (7.9%), persons with intellectual impairments (5.6%) and persons with mental illness (2.7%) are the more prominent categories.

The State's response to PwDs in India had been more charitable and welfare oriented till the 1990s when international developments and national level activism created a pressure to enact appropriate legislation to ensure their rights. Till then, efforts towards establishing and protecting the rights and dignity of PwDs in India had been sporadic and subject to the wishes of successive governments. The Persons with Disabilities (Equal Opportunities, Full Participation and Protection of Rights) Act 1995 and the National Trust Act 1999 promise the fulfilment of basic rights to survival, health, education, employment and social protection. Both these laws ensured that there were different schemes and programmes undertaken by both the central and state governments for the upliftment of PwDs in India. After India became a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), there have been concerted efforts to draft a rights based legislation to ensure the enjoyment of rights and social protection of PwDs in India. This draft bill is soon to be placed in the parliament for debate and passing to become a law.

As India is a vast country, the specific situation of PwDs varies greatly from urban to rural areas. While most of the disability related services are well established, mainly through state and public funded institutions in urban areas, the implementation of state sponsored community based programmes in rural areas has remained limited and piecemeal till date. Most PwDs in India live in rural, resource and service poor areas with very little access to state guaranteed services for identification, early intervention and management of impairments. Hence, most PwDs and their families either have no access to services and guidance or cannot access the same. In such a scenario, much of the responsibility for ensuring community based rehabilitation provisions for persons with different disabilities has been taken up by Non Governmental Organisations (NGOs) that have worked intensively in small pockets and effected community level changes that have ensured a minimum quality of life for PwDs and their families. The approaches have been diverse, the strategies varied and the impact on PwDs, their families and communities often unprecedented.

The evolution of Community Based Rehabilitation as an alternative form of service delivery began in the 1970s, with increasing realisation that in developing countries, rehabilitation services were practically non-existent or grossly inadequate, with lack of national planning and co-ordination of (medical, educational, vocational, social, etc.) services. There was a call for services that would reach out to all PwDs providing at least

the essential services and opportunities in ways that would be suited to the cultural, social, educational and health realities of the developing regions. Community involvement was seen as a necessary component, with local micro-management and control of resources.

PwDs and their families were to be involved and empowered as part of this process, along with promoting a service delivery system that uses local human resources and multi-purpose personnel. CBR is a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities. CBR is implemented through the combined efforts of PwDs themselves, their families and communities, and the appropriate health, education, vocational and social services within the community. As all communities differ in socio-economic conditions, terrain, cultures and political systems, there cannot be one model of CBR for the world.

There have been various efforts by different NGOs in India to implement CBR programmes in different parts of India, all having a similar purpose but varied in terms of delivering the programmes, as communities, locales and needs of people are different. This booklet aims to document the efforts of 3 such organisations that have been working in different parts of India, either directly or through partners to promote CBR as a strategy to bring about changes in the lives of PwDs in India. These 3 organisations are Caritas India CBR Forum, Basic Needs India and Action on Disability and Development, India.

Caritas India CBR Forum (CBRF) embarked on its journey in June 1996 with a focus on Community Based Rehabilitation (CBR) in terms of interventions at the individual, family and community level. At present, CBRF works with 58 NGO Partners and 15 DPOs implementing 79 programmes spread across nineteen states and one Union Territory reaching out to 60,742 PwDs. Over the years, CBRF has moved from working with large projects to micro projects, while partners were invited to work with around 300 to 400 PwDs. Working with and within communities, there was a lot of learning which led to the further evolution and strengthening of the strategies and approach of CBRF. CBRF sought out NGO partners in remote rural areas from backward districts of the country where PwDs and their families had very little access to services, entitlements and awareness. Today, the CBRF supported programmes are exclusively rural based, as these are the areas where resources are least available. Women and children are placed at the top of its list of priority stakeholders. To ensure that the quality of CBR programmes is maintained, CBRF collaborates with three training organizations – ADD India based in South India, SANCHAR based in Kolkata and Bethany Society, in Shillong, NE India – to train the CBR teams of its NGO Partners. It joins hands with Basic Needs India to ensure that its partners in the south are trained in promoting the inclusion of those with Mental Illness in the local community.

Working with communities brought in a new insight – the need for active advocacy by the PwDs themselves. CBRF encouraged its CBR partners to form Disabled People's Organisations (DPOs) in their project area and to federate them at Block level. These DPOs are then federated at National level.

CBRF also commenced a new approach, the District Level Initiative (DLI) approach, the first of its kind in the country! Here, five to eight NGO Partners in the same District were selected, their task being to identify PwDs and build DPOs that would be able to lobby and advocate for desired change, mostly at the systemic level. In the DLI approach, DPOs formed by each individual NGO partner are federated at Block, District, State, Regional

level. Through discussions at each level, DPOs identify issues that are then taken up for redressal with local authorities at different/ various levels – village, panchayat, block, district, state and region.

The process of including DPO members in various high level Government committees like the District Planning Committee, the Divisional Railway Users' Consultative Committee of Southern Railway, Chennai, has commenced.

CBRF has also been experimenting in mainstreaming of PwDs into the existing work of the NGO Partner without commencing a disability specific programme.

More recently, CBRF has expanded its vistas by exploring with Fellowship Programmes. In addition, programmes aimed at working with communities, families and individuals to "Lift Barriers" that prevent PwDs from participating in everyday life within their communities have also been initiated.

CBRF's option to help PwDs have a voice of their own was given a fillip with the latest developments at the national and international levels, particularly the ratification of United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) by the Indian Government. Today, its focus and priority is to enhance the participation of PwDs in the decision making process in the family and in the community and their inclusion in mainstream development processes.

CBRF, through its partners, has now commenced working directly with DPOs in view of building their capacities to manage their own affairs. In March 2016 CBRF crossed a new milestone, it initiated the formation of a National Disabled People's Organization (NDPO), with representatives from across the country.

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Basic Needs India (BNI) was conceived in 1999 even though it was formally registered as a Trust in 2001. This was the time when, even though recognised as a disability under the Persons with Disabilities Act 1995, persons with mental illness were conspicuously absent in CBR programmes. Influenced by the spirit and ethos of the CBR movement in the country, the pioneers (Founding Trustees and the Chief Promoter) of BNI who were products of the CBR / Development movement, decided to develop community based programmes geared to include persons with mental illness within the family and community.

Through a series of stakeholder consultations in their communities (especially primary stakeholders), the Vision and Mission of BNI was developed with a focus that broadened the approach to mental illness, focussing not on the individuals but on the wider dynamics within the communities that not only cause but also perpetuate stigma and discrimination against people and families so affected. Thus programmes were conceived and developed out of the belief that the rights of people who experience mental illness, especially the poor and marginalized, need to be addressed within communities. The major resources available in the mental health sector are either institution based rehabilitation or hospital based services, both of which are limited and impractical for the needs of the poor persons with mental illness, especially for those living in rural areas.

BNI's main role is that of a resource organization that works with partner agencies to implement programs to create a caring, accommodating, understanding environment, to ensure service provision, social inclusion, livelihood options and the right to equal opportunities for the persons with mental illness and their families. Such an effort is multi-sectoral and involves liaising with a host of stakeholders - people affected by mental illness, family members and other care providers, community members, medical

professionals, other organisations working in the region, policy makers and government authorities.

In the past 15 years, through the strategy of partnership with 'development agencies' spread out in 8 states, BNI and partners have been able to positively touch the lives of over 27,000 persons with mental illness (PwMIs) and their families. CBRF's vision and value guided approaches in the DLI programmes have matched with BNI's own approaches and has facilitated the integration of community mental health and development (CMHD) into the overall CBR programmes.

Action on Disability and Development (ADD) India was set up in 1989 by a group of people with different disabilities in Bangalore, with the main purpose of enabling persons with different disabilities to advocate for their rights for inclusion and to mainstream disability into existing structures. Seeing the potential of the mainstream NGO sector in India, especially in rural areas, it developed a strategy and a methodology to influence and build their capacity to include PwDs in the work they do with other people living in poor communities facing exclusion and discrimination. The major focus of ADD India is to work as a resource agency to motivate PwDs to form Self-Help Groups (SHGs) in villages and later to form Disabled Peoples Organisations (DPOs) at local, block and district levels.

ADD India pioneered the idea of Self-Help Groups of PwDs in villages and mainstreaming disability 25 years ago. Over the years, it has successfully equipped over 250 NGOs in the five South Indian states to work with thousands of persons with disability. It has trained and built the capacity of DPOs to function effectively in the southern region to improve the quality of life of PwDs. Presently, hundreds of DPOs have been formed and are functioning effectively in the southern states, enabling PwDs to avail their entitlements and promoting their inclusion in schemes and programmes of the government. These DPOs advocate for the rights of PwDs and take up issues of discrimination faced by them.

All the three organisations – CBRF, BNI and ADD India – have used the strategy of community based inclusive development to impact the lives of PwDs and their families.

Changes have been effected at individual level and within families and communities, through provision of services for development as well as facilitating access to their rights to health, education, livelihood and social security, using advocacy by both PwDs and their families in different parts of the country. While the CBR approach promoted by these 3 organisations broadly follows the CBR matrix in terms of the five key components – health, education, livelihood, social and empowerment – the programmes have been allowed to develop in response to local needs, priorities and resources. The aim has been to improve the quality of life of PwDs and to ensure that they enjoy human rights. This has, in turn, created space for the realisation of the philosophy enshrined in the UNCRPD, which makes a difference at the community level. CBR has helped in promoting advocacy activities which aim to develop or strengthen dialogue between local and national levels. This is realised by strengthening local groups or DPOs to stimulate the growth of inclusive national and local policies relating to sectors such as health, education and livelihoods.

The case studies presented here are of real people living in communities where, over the years, they have been empowered to enable PwDs and their families to realise their full potential as well as to take responsibility for the PwDs who need support, care and protection.

North Eastern India

The North Eastern region comprises of eight states which are Assam, Tripura, Meghalaya, Manipur, Nagaland, Mizoram, Arunachal Pradesh and Sikkim. There are around 220 tribes in the region with 36 major languages and 200 dialects being spoken in the entire region. There are also many sub tribes and dialects especially in Nagaland, Meghalaya and Manipur. The majority of the tribal population are Christians, while there are both tribal and non tribal people practicing other religions that include Hinduism, Islam and Buddhism.

Geographically, the region is dominated by dense forests, rivers, lakes and mountains. About three quarters of the region is covered by hilly terrain, with steeply rising hills adjoined by deep river valleys and one quarter is made up of the plain areas in Assam, Tripura and Manipur. This region has some of the Indian sub-continent's last remaining rain forests, which support diverse flora and fauna and several crop species. The main source of livelihood is based on agriculture and the forest produce. Little land is available for settled agriculture. Along with settled agriculture, jhum (slash-and-burn) cultivation is still practised by a few indigenous groups of people. The inaccessible terrain and internal disturbances have made industrialisation difficult in the region.

Health and other services are mainly situated in the capital cities. Apart from Assam, and to an extent Meghalaya, the government services are poor. The geographical terrain also becomes a major barrier to access the few facilities that exist. Transport is available mainly on the main roads. In the interior areas, there is virtually no transport, except on market days. As villages are actually small hamlets on top of or at the base of hills, scattered and remote, schools are clustered around market towns, which make it difficult for young children to access education as they have to walk long distances to schools.

In the plains, the mechanism of governance is through elected representatives whereas in the hills the traditional system of governance by locally selected/nominated/elected representatives continues. There are special laws, constitutional provisions, which seek to protect the traditions, lands and rights of various hill communities. 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.

The challenges for PwDs living in small district towns and rural areas of North East India, in terms of access to disability and rehabilitation services, remain huge as the minimal available services are concentrated in the urban areas. Government services in disability and rehabilitation are extremely limited in the region. As most areas are remote and underprivileged, access to even information about disability and rehabilitation services becomes problematic. For children with disabilities living on top of the hills, unable to even go out of the home, there is a great impact not only in terms of their physical development but also in terms of their social and cultural development. Families of children with disabilities are further disadvantaged by lack of access to early identification and early intervention services available locally, limited provisions for community level rehabilitation workers and lack of support services for PwDs. This is further impaired by the difficult terrain, lack of roads infrastructure and physical accessibility including access to buildings and public transport. In addition there are climatic issues such as frequent rains and landslides.

Ferrando Integrated Women Development Centre - Peace Home (FIWDC) was started in the year 2005, in Aizawl District of Mizoram to help women and young girls live more dignified and purposeful lives. FIWDC provides service to recovering drug users, alcoholics, sex workers, those affected with HIV/AIDS and the most vulnerable young girls of the society. FIWDC has been implementing a CBR programme for PwDs since 2010 with the guidance of Caritas India CBR Forum.

Samuel, 24 years old, lives with his parents and sister in a village in Aizawl, Mizoram. The youngest child in the family, Samuel was affected by Cerebral Palsy (CP) when he was about 10 months old. He studied in Gilead Special School in Aizawl but preferred to continue his studies at home under the guidance of a home tutor.

When he was about 7 years old, he fell in love with drawing - first he started sketching with pencil and pen and after that he began started using water colours. When he turned 9 his parents, recognising his unique talent, hired a tutor to teach him drawing and painting hoping to nurture his interest. With increasing deftness and skill, Samuel started participating in drawing competitions and won many prizes. His parents encouraged and promoted his interest within their meagre resources. The CBR programme helped Samuel develop his skills further by organising training not only in painting but also in computer aided design and drawing.

Samuel started using computers to express his creativity. At present he is a free lance artist who uses technology. He is now a well sought after artist who also gets contracts for his designs and drawings from foreign countries. His paintings sell for a high price both in the country and abroad.

"If there is a will there is a way. If we try our level best in everything we do, success is in our hand. Always believe that, 'I Can Also Do'."

- Samuel

Swabalambi started working from 1997 with Persons with Disabilities in the area of health, mainly in and around Kamrup district in Assam. Swabalambi facilitated assessment of disability, required corrective surgeries, free medicine, regular physiotherapy, speech and occupational therapy, that improved the conditions of the people with disabilities. Since 2005, Caritas India CBR Forum supported Swabalambi to start working within the CBR matrix of Health, Education, Livelihood, Social and Empowerment with an overall aim of creating an inclusive community.

SUCCESSFUL LIVELIHOOD THROUGH HANDICRAFTS

Raju, 32 year old, lives with his wife Sonali and two sons - one is a ten year old studying in Class V and the other is a three year old going to the local Anganwadi Centre. Raju had polio in his childhood which resulted in paralysis of both his lower limbs. He had never been to school. They belong to a local Kabri tribe. He has two elder brothers and sisters who are married. The family used to think that he was of no use and would become a burden on them.

In his village there was an artisan who used to make bamboo craft and sell them in the locality. Raju was fascinated by the artisan. He used to go to the artisan's home and watch how he worked. Slowly the artisan started teaching him some skills. Having obtained some money from his mother, he purchased some bamboo and a tool and started making some bamboo craft on his own. Some of these were sold to the local population.

Coming in contact with Swabalambi, he requested them to accommodate him in their training centre in Sonapur to learn more about bamboo craft. Through Swabalambi he was trained in bamboo craft by different organisations, including the State Institute of Rural Development, Ministry of Textiles, and ARUNIM (the National Trust). He also

participated in National fairs. His work was appreciated by all.

When he decided to get married, he found a young lady who was willing to marry him. The family organised the marriage while Raju took care of the expenses. After marriage his father gave him a plot of land on a small hill top so that he could build his own house and a small plot of arable land. Raju has built a small mud house on the plot.

Now Raju is engaged full time in making bamboo craft, making furniture out of bamboo to supply orders he gets from people in the area and outside. Swabalambi also plays an active role in marketing some of his products in the state capital. Apart from furniture, he also makes decorative items, baskets, products for fishermen and some products which are used in most local households. He earns about Rupees fifty to sixty thousand a year. His wife has joined a local micro credit group and has taken a loan of Rupees Ten Thousand - this amount has been invested in his business and the plot of land that they have.

"I am now confident about myself. I am planning to have my own shop in the local market so that my business grows," says Raju with a confident smile.

Care and Support Society was established in Mokokchung district of Nagaland state in1995. Since the area has a large scale of drug addiction problems among the youth and HIV/AIDS related issues, Care and Support Society chose to intervene to address these problems. Besides, it implements a Community Based Rehabilitation programme for persons with disabilities commenced in partnership with Caritas India CBRF from 2012.

Katipenla, 10 years old, who has the physical look of a 4 year old child, lives with her family in a village of Mokokchung District in Nagaland. Her father, Mr. Rongsenungba, is a school teacher and her mother is a home maker. Katipenla is the youngest of three children (2 girls and 1 boy). She is unable to walk long distances due to mobility restrictions.

During 2014, with the intervention of the CBR staff she was enrolled in the Putir Menden Primary School, Khensa, in the nursery section. After some months of schooling she did not like to continue her schooling due to accessibility issues and she became irregular. CBR workers continued to support her by teaching her reading, writing and arithmetic at home and she was encouraged to attend the same school. The family members and the CBR staff enabled her to take part in Sunday school, where she participates in activities like singing, poem recitation etc. At this very young age, she has the ability to sing well, and this special talent was recognised by the facilitators of the Sunday School.

As she was a good performer with outstanding talent in singing, she was invited to perform on various occasions. Having become the talk of the locality, a board member of the Care and Support Society decided to help her to broadcast her talent to the world beyond. With the help of the CBR team and financial support from her well wisher, Katipenla recorded a music video album, which was released on 3rd Dec 2014, in a function organised on the occasion of International Day of Disable Persons. The Government of India, in recognition of her talent, honoured Katipenla with a national award under the category "Best creative child with disabilities" on 3rd December 2015.

COLLECTIVE ACTION FOR COMMUNITY PARTICIPATION

Meimlong Disabled People's Organization, Nagaland.

Aoyimkum village in Nagaland was found to have the highest number of PwDs in the CBR field area. However there were no disability specific services or facilities available within the community. There was a general community attitude of charity and protection of PwDs and their families. This was one of the reasons that initially CBR interventions were not looked upon favourably by the villagers. Through regular visits and meetings with the village stakeholders including PwDs and their family members, a Disabled People's Organisation (DPO) was formed for people to come together, share their problems and address the issues by themselves.

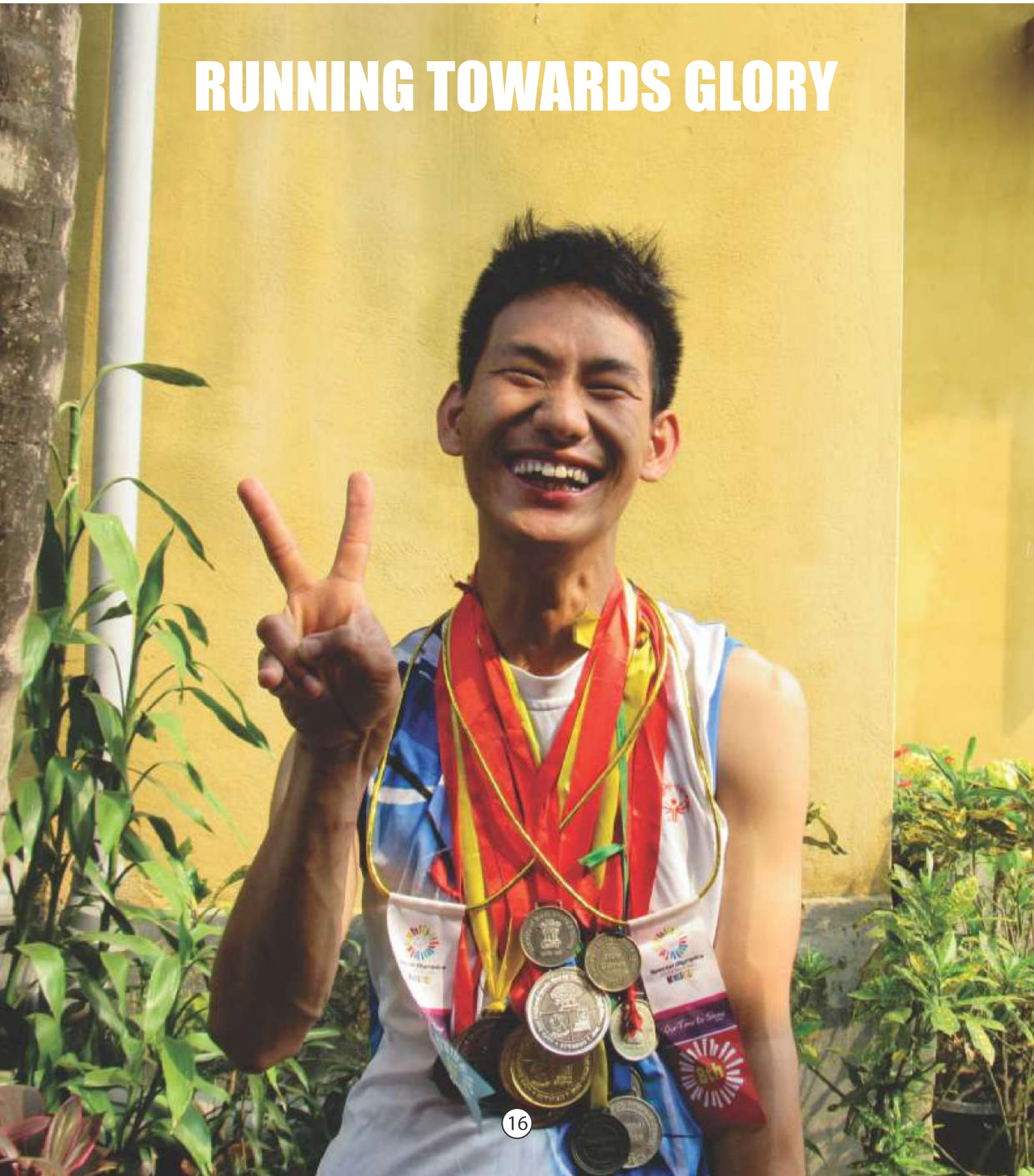
The members of the DPO realized the importance of income generation activities, and for starters,they started monthly savings for each member. Seeing their active participation, Prodigals' Home sourced funds from Caritas India CBR Forum and two other organisations to start income generation activities. The group members are now actively engaged in different income generating activities in the community such as petty business, selling of dry fish, tea leaves, fermented soyabean, vegetables, collecting of scrap and reselling the same, selling home-made detergents etc. At present they are in the process of availing a loan from NRLM to further their economic activities.

The DPO decided to take up community level sensitisation and organized meetings with village council leaders to advocate for a ramp in the newly constructed Village Council community hall. In addition, the village leaders and church leaders have been sensitized about the inclusion of persons with disabilities in the NREGA programme and these leaders have provided job cards to adults with disability under this programme. Going a step further, the Village Council has also reserved 3% funds in all poverty alleviation schemes for PwDs. The response of the village leaders and community has created an enabling environment for the PwDs!

Meimlong DPO is one of the strongest and most active DPOs in the North East Region. Both children and adults with disabilities are represented in the group and carry out the activities by themselves. Financially, they are secure and pursue their individual income generation activities with zest. They engage in advocacy activities at the village level as well as in the District. Recently, they have joined the National level DPO started by Caritas India CBR Forum.

Prodigals' Home, established in 1990, works with people from diverse backgrounds and on varied issues such as Health, Social, Economic, Rural Livelihood, Disability and Policy Advocacy. Currently, it implements a HIV/AIDS prevention/intervention Programme for the Injecting Drug Users, Street Children, School Dropouts and Female sex workers of Dimapur. Since 2007, Prodigals' Home joined hands with Caritas India CBR Forum to implement a Community Based Rehabilitation Programme for PwDs in the Dhansiripar area of Dimapur District.

RUNNING TOWARDS GLORY



Mhachio, 21 years old, lives with his family, which includes 3 sisters, in Dimapur. His younger sister is severely affected by Cerebral Palsy since birth. Mhachio had delayed development of milestones and though he started school at the proper age, his speech, comprehension ability, visual capability and physical growth began to show signs of impairment and comparatively slow growth.

It was during his second year in the same class (Standard V), that CBR field workers of Prodigals' Home came into contact with him and his family members. He would leave the house only to go to school. Initially, when the CBR team visited him, he refused to meet them and remained in his bedroom. The CBR workers however persisted and slowly developed a relationship with the child and the family. Mhachio was encouraged to attend Sunday school and other social gatherings apart from going to school. He was always invited to attend and participate in the programs related to disability organized by Prodigals' Home.

The CBR team worked with the school authorities to discuss the need of inclusive education, particularly for Mhachio. The school responded positively by engaging a teacher to provide remedial teaching after school hours whilst also providing a teacher solely to facilitate him during his examinations. The school also gave concession on his monthly school fees because of the impoverished condition of his family. Despite his disabilities and numerous challenges, he continued his school education. He dropped out a few times but continued again with the active support of his school teachers, the school authorities, his friends and in particular – his persistent parents. He has recently passed his Class X exams – a major milestone in his life

Initially, when the CBR team encouraged him to participate in sports events within and outside the state, he was not confident enough and even his parents refused to send him on the ground that, “he needs special care.” With constant encouragement, the team was able to convince him and his parents, who agreed that he participates in such events on the condition that one CBR team member would always accompany him. He thus began participating actively in social and sports activities, which in turn gave him confidence and a strong self-esteem. In addition, he proved his mettle in the field of sports.

Mhachio was selected to participate in different State Games, National championships and even in the International Games in Australia held in December 2013. He has won 3 silver Medals in 100m race and Long jump and 1 bronze Medal in standing long jump in the State Games. At the National level games he got 1 silver medal in football and 1 bronze medal in 100m race. He has also participated in Special Olympics Asia Pacific Regional Games held from 29th November - 7th December 2013 in Newcastle, Australia.

Today he is confident and can travel around with his team mates, participating in sports at different levels.

Wellspring Social Service Society (WSSS) run by the Holy Cross Sisters in Mairang, West Khasi Hills District of Meghalaya focuses primarily on building a 'Holistic Healthy Society' keeping in mind the cultural, economic and community background of the Khasi tribe that they work with. They have been organising the women of the area into self help groups since 2001 and also provide various kinds of vocational skill training like tailoring, embroidery, knitting etc. with support from government training institutions. They also run a hospital and community health services for the local communities. As a partner of Caritas India CBR Forum, they have initiated CBR in the area since 2009.

INCREASING CONFIDENCE TO ASPIRE FOR MORE

Eleven year old Lucky lives in a small rented house with his parents, one elder brother and two younger sisters. When Lucky was two years old the family noticed that he had white patches in his eyes. They went to a local village practitioner who reportedly put tobacco water in his eyes. This apparently increased the problem in the eyes and they started bulging out. He complained of pain. The family got some eye drops from a local shop but could not take him for further treatment. Lucky slowly started to lose his eyesight.

In 2009 the CBR worker (CBRW) visited them and convinced the family to take Lucky for an eye check-up. The doctor told them that the eyes were already destroyed because of vitamin A deficiency and that they had to be removed as they were infected. The family was reluctant to go in for a surgery. After a series of counselling sessions, they finally agreed. Lucky's left eye was operated upon, with the support of Sarva Shiksha Abhiyan (SSA). The doctors informed them that the other eye also needed similar treatment. Today, WSSS is in touch with SSA and the plan for the second surgery is under process.

Lucky had never been to school. The child has now been admitted to Class I in the local school. He is accompanied to school by his mother or a friend from the neighbourhood. His friends also bring him home after school hours. When the CBRW found that the child was completely dependent on his mother for his mobility and Activities for Daily Living (ADL), she helped the mother to train Lucky in self care activities and to move in and around the house. Lucky is now fully independent in his ADL. He can even move around in the neighbourhood. He has a few friends in the neighbourhood who play with him – they are also in the same school as him. Lucky's world has expanded.

“Earlier I used to be completely dependent on my mother. I did not even dare to move around the house on my own. My interaction with the world was limited to my parents and siblings. Now, I have learnt to be on my own. I can manage my daily activities on my own. I can go out and roam in the locality and I have friends in the locality with whom I play cricket and cards,” says Lucky with a smile on his face.

The CBR team is exploring possibilities of helping Lucky to learn Braille from a young man living in the area. They are trying to obtain a Braille slate and other support from SSA so as to ensure that Lucky is able to maintain the progress he has made in the last few years.

Eastern India

The eastern region is comprised of the states of Bihar, West Bengal, Jharkhand and Orissa. All these states are home to a considerable number of Adivasi communities. Each of the tribal groups has its own language and traditional customs that cover governance, relationships among members of the tribe and with other people, law and order, celebration of rites of passage and festivals, and practically most aspects of day to day life.

Geographically situated in the eastern part of India, the terrain of the area is mostly hilly with considerable forest coverage. The Adivasis and a considerable proportion of people of other ethnic groups who depend on agriculture have their own cultivable land and most families also have livestock. Cultivation is seasonal, linked to and dependant on the monsoon, as there are limited irrigation facilities in the area. Consequently the economic level of the majority of families is very low, with communities largely dependent on forest products and using forest resources to produce items for sale in the local markets. People live mostly in small villages of 50 – 100 households, grouped in several hamlets with families of different ethnic groups usually living in separate hamlets. Villages are quite far from each other and people from different villages meet mostly at the local weekly or bi-weekly market.

Road connectivity has improved in recent years but over half of the villages are still reachable only by cycle or on foot, more so during the rainy season when even two-wheelers cannot be used on kaccha roads. Public transport is limited, even where roads have been constructed. Electricity has reached around 60% of the villages. Safe water supply is mostly from deep bore wells with streams and dug out ponds being used for bathing and washing. Health services are provided through the national network of Primary Health Centres and sub centres, Anganwadi Centres, ANMs and ASHA workers, but a considerable proportion of people prefer going to the traditional healers and / or the itinerary 'doctors' who speak their language, understand their mentality and serve them at their doorstep.

Most villages have a primary school, enrolment is high, especially in view of specific benefits available for ST and SC students; but attendance does not match the enrolment figures and is often conditioned by the menu of the mid-day meal which is given to children who attend school. Many schools have 2-3 teachers for Class I – VI, resulting in poor academic performance.

Among the Adivasi population, each village follows a system of self governance with a traditional headman and council who call village meetings to discuss and decide anything and everything pertaining to village life. The system of governance is egalitarian and decisions are reached by consensus, which may take considerable time and effort to achieve. The traditional form of governance has been given recognition by the State in the form of the PESA Act 1996 which ensures that matters concerning the village including law and order, except for criminal cases, must be dealt with in the village council and referred to other authorities only when necessary by the traditional leaders themselves.

Service provision for the rehabilitation and development of PwDs is even more limited. Doctors at District hospitals usually prescribe medication for developmental delay and cerebral palsy and leave it to parents to look for rehabilitation services. At the PHC and village level there is even less knowledge about appropriate interventions or even referral. Professional therapists are few and found only in larger towns. DDRCs have been set-up but they function mainly as channels for the provision of wheelchairs and tricycles.

The resilience and struggle against adversity of yesteryears that characterised Adivasi villages reflected the mutual cohesion and support within their community. However, the parallel panchayat system, the courts, the arrival of many Government benefits and schemes, as well as increased exposure of Adivasi youth to different life styles has considerably eroded the traditional self-sufficiency and self-determination of the Adivasis.

SADHANA is a voluntary organisation implementing Community Based Rehabilitation since the year 2000 in the predominantly tribal area of Baripada and Suliapada Blocks of Mayurbhanj District in Odisha. In promoting inclusive communities, SADHANA accords equal importance to rehabilitation and inclusion, both aspects being held together by the common, constant effort to reduce barriers of all types and at all levels. CBR efforts have ensured that a "resource pool of knowledge and sound practice" is built within the village community. This resource pool is made up of family members, individuals with disability, members of Collectives of persons with disability and their representatives, as well as concerned villagers. This is crucial for sustainability as well as for self-determination of the community and its members with disability.

HARNESSING COMMUNITY AND FAMILY SUPPORT

In 2007 when Guha Marandi, a Santal, got married to Rani, they bypassed many of the tribal customs regarding marriage that are prevalent in their community. Since Guha could not afford a goat and rice beer, which would cost around Rs. 2000, he dispensed with the feast for the villagers. By doing this, he actually cut himself and his wife off from the villagers, and the couple were ostracised by the villagers. No one spoke to him or his wife and a fence was constructed in the courtyard, dividing his area from that of his brother. Finding themselves completely isolated, Guha and Rani found a job as caretakers on a farm in another village and lived in a shed on the premises.

In 2008, their son Indrajeet was born at home, delivered by the local dai (midwife). Soon after, he had high fever and had to be hospitalised. Over time, the parents realised that Indrajeet was not developing like other children: at 6 -7 months he could not hold up his head and he also had difficulty with vision. About 2 years later, worried and helpless, Rani approached the SADHANA CBR worker (CBRW) who was visiting a child with disability in the area. When the CBRW found out that the family was from a different village, she visited their family members in Guha's village but they were reluctant to talk to her. Talking to other villagers, the CBRW came to know the whole story and began to understand why Indrajeet's parents were so disheartened and helpless - they had to deal with the problems of Indrajeet on their own.

The CBR worker realised that reintegration into the village was the priority. She spoke to the village headman and other villagers about the difficulties being faced by the parents in dealing with Indrajeet's limitations. She indicated that they could help the family overcome their problems so that the child could be helped to grow and develop. This was enough for the village leaders, who traditionally are responsible for preserving the integrity of the tribe, to find a way of receiving Guha and his family back into the life of the village. He was asked to give a hen for a village meal to make up for his wrong doing. With this done, Guha returned to his ancestral land and home with his family.

With support from the extended family in his ancestral village, Indrajeet is progressing slowly with the help of systematic interventions started by the CBRW and taught to the child's mother. In the company of cousins, Indrajeet has developed both physically and socially. He walks independently despite of his right side weakness. He communicates his needs and likings through speech, though this is limited. He has some friends, who along with the grandmother and cousins play with him and help him to learn to count.

One of Indrajeet's main impairments was his lack of vision due to congenital cataracts. With the help of the SADHANA CBR worker, he was operated in a hospital in Bhubaneswar, where they could avail of total subsidy since the family is below poverty line. The surgery, carried out in March - April 2014, brought considerable improvement in his eyesight and consequently also in his development process. Indrajeet has started attending the local primary school and is now in Class II. He is accompanied to the school by his mother and at times by his friends. Rani is highly protective of her son and is reluctant to allow him to go to school with his peers. At school he is looked after by his two cousin sisters who help him wash his plate after eating his mid-day meal. He is independent for other activities.

"My grandson is a lot better than before. He is getting better. He fetches things for me whenever I ask him. I want him to get stronger so that he can work and be self dependent"

Grandmother

"Indrajeet has improved a lot. My mother-in-law, brother-in-law and sisters-in-law and their families, my son's playmates and some neighbours are very supportive. I expect him to go on improving and to continue his studies."

Rani (Mother)

Motivating Families

Budhuni, now 16 years, a girl with intellectual impairment, hails from a village in Bankisole Panchayat of Mayurbhanj District, Odisha. She is the third child in a family of five children. Her father is a daily wage labourer and the family does not own any land except the plot on which they have built a thatched house. A premature baby, Budhuni could not walk or speak until the age of two years and neither was she able to do any self-care activities. Despite visiting different doctors, the parents could not find any solution for her improvement.

Budhuni was identified by SADHANA when she was two years of age. At that time she was malnourished and had to be fed well for a few months before any intervention could be planned. Then comprehensive interventions aimed at teaching her to sit and stand with support were initiated with active involvement of family and neighbours. Gradually she was taught to be independent in self-care activities. A daily routine was developed for the child and the siblings took much interest in learning the skills from the CBR Worker and ensuring the same was continued regularly.

She was admitted in the regular village school in the year 2006. Home based education support was provided with collective effort of the CBRW and elder siblings. Last year she was admitted in a residential school in Class 8 as the village school was only up to Class 7. She is staying with her sister who has been trained to teach her about taking care of her menstruation. She has been included in most of the extra-curricular activities of the school and for academic lessons she needs a lot of support which is being provided by her sister.

Budhuni is now leading a happy life. Her parents are happy that with support from SADHANA they could bring a lot of change in the life of Budhuni. Like other children, she is being included now in most of the activities within the community.

"Through support of SADHANA we gradually learnt to help our child to learn most of her life skills and we could manage to put her in school. Now she is studying in a residential school with her sister and we are very happy"

Parents

"We did not know how to support the child and the family. When we saw that with training the child was able to walk, we took interest and would follow up what the CBR Worker was telling the family to do. Now our whole idea about the child has changed and we have come to believe that she is part of our village like other children".

Neighbour