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Sustainability: lessons from a community-based rehabilitation programme in Karnataka, India

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Community-based rehabilitation (CBR) is a recognised strategy to promote inclusion, rights and equal opportunities for persons with disabilities within their community (WHO 2010). CBR programmes have been effective but it has been a challenge to make them sustainable beyond the funding period (WHO 2010). In this case study, we describe a sustainable CBR programme that was undertaken from 2008-2012 in 44 villages of the peri-urban Attibele community in the Karnataka district of Bangalore in India. The programme employed a twin-track approach to development across all five domains of the CBR-matrix[i], alongside the development of strong community structures (a registered society, self-help groups, children's parliaments, community education centres, and a disabled people's organisation). The case study presented is based on an evaluation conducted in 2013, one year after cessation of programme funding. It found that the programme supported the sustainability of interventions through activities involving the community structures. Drawing on lessons learned from the programme, we reflect on the importance of establishing, capacity building and promoting community structures to support CBR sustainability.

Keywords: community-based rehabilitation; mainstreaming; empowerment; disability inclusive development; sustainability; disabled people's organisations; stakeholder engagement; rights-based approach; twin-track approach; Karnataka; India

Introduction

Community based rehabilitation (CBR) was first promoted by the World Health Organisation (WHO) as a strategy to improve access to rehabilitation services for persons with disabilities in low-income and middle-income countries, by making optimum use of local resources. CBR has now evolved into a multi-sectoral strategy to improve the quality of life of persons with disabilities and ensure their empowerment, participation and inclusion in society (WHO 2010). It is predominantly implemented by using local resources, through the combined efforts of persons with disabilities themselves, their families, relevant (governmental and non-governmental) organisations and communities, working in the areas of health, education,

vocational, social and other services (WHO, ILO and UNESCO 2004). Community participation is seen as a central tenet of CBR (WHO 2010). The UN Convention on the Rights of Persons with Disabilities (UNCRPD) further supports the participation and decision making of persons with disability in development processes as subjects with rights, and not as 'objects' of charity, medical treatment and social protection (UNCRPD 2007).

CBR sustainability is understood in this article as the complete ownership of a project and capacity to run it by the local community. The conditions needed to sustain CBR programmes as identified by Mijnarends et al. (2011) in a study conducted in Vietnam, include availability of human resources, training, monitoring and evaluation, commitment, collaboration between sectors and with local authorities, and financing and knowledge about how to maintain financing. Due to the number of factors required for continuation of activities beyond the funding period, sustaining CBR programmes once funding ends is a challenge. This especially so for community based organisations in low-income and middle-income countries (Gruen 2008). Evidence from different studies suggests that 40 percent of all new programmes do not continue beyond the first few years following termination of initial funding (Savaya et.al., 2008).

The WHO CBR guidelines clearly state that "government-led programmes or government-supported programmes provide more resources and have a larger reach and better sustainability, compared with civil society programmes. However, programmes led by civil society usually make CBR more appropriate, make it work in difficult situations, and ensure better community participation and sense of ownership. CBR has been most successful where there is government support and where it is sensitive to local factors, such as culture, finances, human resources and support from stakeholders, including local authorities and disabled people's organizations" (WHO 2010).

This case study contributes lessons learned from an evaluation of a CBR programme which ran for five years from 2008-2012 in 44 villages of Attibele hobli[ii] in Anekal Taluk[iii] in Karnataka, India. The programme was funded by a leading international organization working in the field of disability and development, which sought to build the capacity of a local NGO to implement a sustainable model of CBR. The project followed a twin-track approach (disability-specific and mainstreaming interventions) in each of the five domains of the CBR matrix (health, education, livelihoods, social inclusion, and empowerment) to enhance the quality of life of persons with disabilities and promote their inclusion and participation in all aspects of development (WHO 2010).

Along with this broad focus, from the day-one of programme implementation, emphasis was placed on ensuring sustainability of interventions. This focused on: sustaining relationships and commitments among the various stakeholders and institutional partners involved; sustaining the knowledge, capacity and values generated from the partnership; sustaining funding, staffing arrangements, programme activities and policy changes. To achieve all this,

the implementing agency aimed to leave behind vibrant, living community structures in the form of a registered society, self-help groups (SHGs), children's parliaments, community education centres (CECs) and a disabled people's organisation (DPO) (see Figure 1). The constitution of these structures and their roles are briefly described below:

Registered Society

The programme supported SHGs (see below) to become a Registered Society at the sub-district level, under the Indian Trust Registration Act 1882, to take responsibility for continuing programme interventions in the target area.

Self-help groups (SHGs)

Inclusive SHGs were established to address some of the common problems faced by persons with disabilities in the target area such as lack of awareness about their rights and entitlements, lack of education, livelihood opportunities and social discrimination; to achieve goals of inclusion and ownership in programme activities by persons with disabilities; and to enhance their participation in development processes.

Community education centres (CECs)

The programme established CECs at village level, to meet the needs of children requiring additional support beyond what school teachers could provide. Children referred by teachers as having difficulties in learning and children with multiple disabilities who are not able to attend regular school were enrolled and given additional support to improve their learning outcomes. These centres ran mostly in one of the classroom of the schools in the target area, through evening classes.

Children's parliaments:

Children's voices and opinions are seldom heard and often recognized as disobedience in Indian society. Children with disabilities face exclusion on a constant basis which includes discriminatory enforcement of laws, denial of equal opportunity in education, exclusion from political participation, imposition of negative stereotypes, subjection to physical violence and denial of a healthy family life. To create a platform for all children to raise their voices, the programme established inclusive children's parliaments in 28 villages.

Disabled people's organisation (DPO)

DPOs are the best vehicle to carry out the aspiration of persons with disabilities. It is an opportunity to have a voice of their own in decision-making processes, identifying needs, expressing views on priorities, advocating for change and building public awareness. The project facilitated formation of a DPO at the sub-district level, with representation of two-three members from each SHG at the village level. The purpose was to create a platform for persons with disabilities to voice their concerns and to play a central role in ensuring that their human rights are translated into concrete measures that effectively improve their quality of life.

In the next section, we describe the findings of the baseline study of the target area conducted by the implementing agency, prior to programme implementation. This is followed by an overview of programme interventions and results in each of the five domains of the CBR Matrix (Health, Education, Livelihood, Social and Empowerment). A programme evaluation conducted one year after cessation of programme funding found that the programme had a positive impact on the quality of life of persons with disabilities in the target area, and supported the sustainability of programme activities through the involvement of the community structures (Thomas 2013). In the discussion section, we reflect on the importance of the community structures to sustain CBR activities. Finally we provide recommendations for CBR programmes more generally, drawing on lessons learned from the programme.

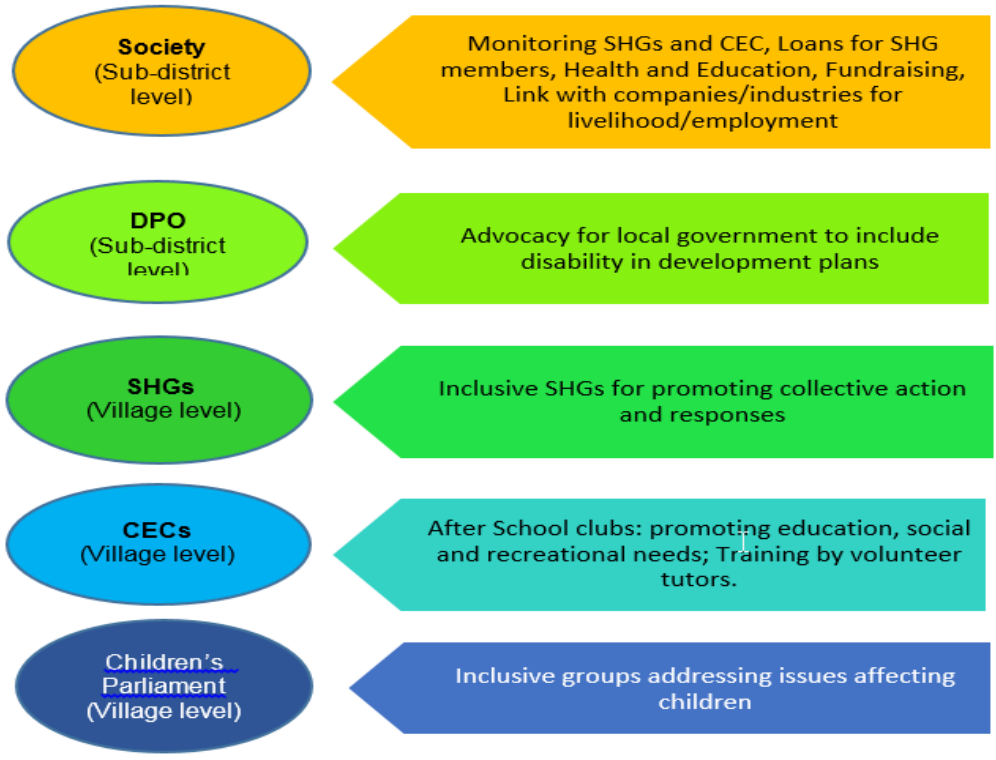

Figure 1: Community structures established and their roles

Pre-intervention situational analysis

The target area for the programme included 18,116 households with a total population of 72,467. More than 60% of the population are migrants from different parts of the country, including Tamil Nadu, Andhra Pradesh and North-East, who moved there in search of employment. About 55% of the population are engaged in agricultural work; 40% are daily wage workers in brick kilns and automobile industries; and 5% are self-employed. Average household income is Rs. 3000/- to 4000/- per month (US$60-80).

Programme staff carried out a needs assessment survey through household visits and focus group meetings in the villages; they identified 993 persons with disabilities in the target area (See table 1). Despite proximity to the large urban centre of Bangalore, the survey indicated clear need for a CBR programme to address the following problems:

- 80% of persons with disabilities did not access relevant entitlements from the government, such as disability pensions.
- Awareness of causes and prevention of disabilities, early identification and the benefits of assistive technology was low among residents. 432 persons with disabilities were not accessing therapy and rehabilitation services locally; 512 persons needed assistive devices; and 70 persons needed support for surgeries.
- Total enrolment rates of all children (with and without disabilities) aged 6-14 years in elementary classes was 68.74% for Karnataka as a whole in 2007-08. The proportion of children with disabilities aged 6-14 years in elementary classes was just 0.79% (NUEPA 2009: DISE 2007-2008).
- Persons with disabilities had limited access to vocational training and livelihood opportunities. They were not included in existing self-help groups which could help to empower members in this area.
- The local government administration, including village governments (panchayats) and sub-district governments (taluk), did not plan or make budgetary provisions for persons with disabilities. 3% reservation for persons with disabilities in various government schemes was not being followed, though it was mentioned in the Karnataka State Policy for Persons with Disabilities (notified in 2004 and amended in 2007). Disability was also excluded from the agenda for discussions at panchayat meetings, and the gram-sabhas (village-level contact meetings for different government departments).
- Attitudes of family members, community and persons with disabilities themselves needed to be changed to become more positive and accepting of diversity. Visibility of persons with disabilities was very minimal, and they did not participate in social activities within families, school and community due to stigma, local taboos and discrimination.

Programme approach and interventions:

Of the 993 persons with disabilities identified in the target area, 788 were from households living below the poverty line (BPL)[iv] (see Table 1). These people were selected as target beneficiaries of the programme, along with 149 persons from marginalised groups[v], single parents and widows. The programme aimed to address the needs of target beneficiaries in all 5 domains of the CBR matrix, with a clear focus on needs identified during the baseline study. The following interventions highlight but do not provide a comprehensive account of all programme activities.

Health:
Working in partnership with 7 hospitals[vi] and other institutions specialising in health and rehabilitation for persons with disabilities, the programme held awareness camps in order to build community awareness of the causes and prevention of disabilities, the importance of early identification and benefits of assistive technology.

Table 1: Types of disability in the area

Type of disability	No. of persons identified	Percentage of disability
Locomotor[vii] disability	473	48%
Intellectual	123	12%
Hearing and speech impairment	143	14%
Visual impairment including low vision	116	12%
Multiple disability[viii] including cerebral palsy[ix]	105	11%
Psychosocial, affected by leprosy and others	33	3%
Total	**993**	**100%**

Efforts were made to train 1 district hospital, 5 primary health centres, and 11 other hospitals and institutions on the health and rehabilitation needs of girls and boys, women and men with disabilities, and to train staff to provide specific treatments, therapies and rehabilitation services, including assistive devices (see Table 2 for an overview of activities in the health sector). Trainers were community health doctors and professionals from partner organisations, including physiotherapists, occupational therapists, psychologists, prosthetic and orthotic professionals, and community facilitators who are recognised agents of change (Werner 2009: 408). Trainees were primary health centre doctors, nurses and health workers including ANMs (auxiliary nurse midwives) and ASHAs (accredited social health activists) from participating institutions in the target area. The programme also supported 17 persons with disabilities and their family members to become ASHA workers, embedding them within the local healthcare system.

To facilitate continuity of care for persons with disabilities in the target area, health professionals were not alone in determining the appropriate course of action for their clients; persons with disabilities and their family member/s also had a central role (See Cornielje 2009). Individual health and Rehabilitation Plans (IRPs) were developed jointly by relevant professionals, persons with disabilities and their parents/care-takers. Parents/care-takers also received training in basic therapeutic activities and a therapy calendar was developed to guide them and reduce dependence on professionals. A local person with a disability was trained as

a 'Rehabilitation Therapy Assistant' through an 18 month training course, to continue to guide parents and caregivers in providing therapy to persons with disabilities beyond the programme period. Meanwhile, local carpenters, welders, masons and others in the community were trained in making developmental aids and adaptations to assistive devices.

Table 2: Innovative approaches in health

Disability Specific	**Mainstreaming efforts**
Training persons with disabilities and their families in maintenances and simple repair of assistive devices, mainly orthoses, e.g. spinal braces, hand/leg splints or callipers, prostheses, e.g. artificial legs or hands, wheelchairs and positioning devices e.g. standing frames.	Educating the community about nutrition, breastfeeding, immunization and sanitation.
Supporting and building capacity of persons with disabilities and their family members to become ASHA workers.	Participation by SHG members in organising health screening camps at participating primary health centres; conducting eye screening camps at local government schools; and supporting public health campaigns, e.g. the pulse polio campaign, eye donation campaign, etc.
Supporting and training parents and caregivers in home based care of children with severe disabilities.	Training and networking with government and non-government hospitals and other health service providers on health needs and services for persons with disabilities.

Education

The programme supported enrolment in local schools under the Sarva Siksha Abhiyan (SSA), Education for All programme of the government. As recommended by the WHO (2011: 223), activities included referring children with disabilities to appropriate schools, lobbying schools to accept children with disabilities, assisting teachers to support children with disabilities in the classroom, and creating links between families of children with disabilities and relevant organisations. Discussions and planning meetings were held with schools in the target area and communities were sensitized through awareness campaigns, street plays and wall writings on the need to educate children with disabilities and provide equal opportunities in the learning process. Orientation programmes were conducted to train teachers in how to include children with disabilities in the classroom (see Table 3) for an overview of educational activities).

Table 3: Innovative approaches in education

Disability Specific	Mainstreaming efforts
Establishment of 28 Community Education Centres (CECs) at village level. Conducting evening classes for children with and without disabilities. Specific attention given to children with disabilities through adoption of disability specific teaching and learning methodology.	Training CEC tutors and school teachers in inclusive teaching and learning methodology, developing inclusive teaching and learning materials, techniques to adapt activities to facilitate participation by children with disabilities in classroom and extra-curricular activities (including sports and recreation).
Persons with disabilities, their family members and SHG members encouraged to get jobs as home based tutors.	3 schools developed as model accessible schools with support from the programme and community.
Home based tutors trained in learning and teaching methods for working with children with disabilities (to supplement training given by the Department of Education) and in daily living skills and therapeutic skills.	Child rights, child protection and inclusion of girls in education emphasized.

Table 4: Innovative approaches in livelihood:

Disability Specific	Mainstreaming efforts
Initiated an income generation programme and trained persons with disabilities in marketing, communication and accounts maintenance.	Supported SHGs to be federated and be registered under the Trust Act as a local organization in order to access financial support and secure loans for members.
Provided career counselling, training and job placement services to persons with disabilities based on their individual interest and capacity.	Worked with training institutes to include persons with disabilities in their training courses.
Facilitated access by persons with disabilities to government credit schemes.	Worked with companies to build awareness and create employment opportunities for persons with disabilities.
Supported SHG members to open bank accounts.	Worked with companies to outsource jobs for persons with disabilities and their family members to work from home.

Livelihoods

The programme initiated and promoted various skill development programmes for persons with disabilities and their family members, while also working to include persons with

disabilities in 'family livelihood activities', in both farming and non-farming sectors (see Table 4). Subsequently, individual rehabilitation and livelihood plans were developed, giving persons with disabilities the choice and the opportunity to choose their vocation, according to their individual interests, by undertaking skills training in 11 different trades, such as agriculture, dairy, sheep rearing, carpentry, tailoring, assembly level work in industries, beautician courses, etc. A concentrated effort was also made to make local industries and businesses understand how they could employ persons with disabilities.

Social Inclusion

Efforts were made to increase participation of persons with disabilities in areas of recreation, celebrations, festivals, and marriage, including the right to family. Awareness programmes were conducted with local political and religious leaders, teachers, youth groups, women's groups and NGOs (see Table 5).

Table 5: Innovative approaches for social inclusion

Disability Specific	Mainstreaming efforts
Assisted persons with disabilities, their family members and other marginalized groups to access social security schemes.	Awareness raising and promotion of inclusion of persons with disabilities in institutions of self-government.
161 homes were made accessible with modifications such as ramps, standing frames and suitable furniture. Through local fundraising and support of the government for construction of toilets, 12 households were supported to build accessible toilets. This increased the sense of dignity too among persons with disabilities and their household members.	Held inclusive summer camps, sports and cultural activities.
Awareness building about the rights and opportunities for persons with disabilities to get married[x] on the basis of free and full consent (CRPD 2007: Article 23, 1(a).	Conducted an access audit of public places, and submitted recommendations to relevant government authorities.

Empowerment

The programme aimed to empower persons with disabilities, their family members and communities by building and strengthening community structures, including self-help groups, children's parliaments and a DPO (see Table 6 for overview). Awareness programmes were conducted for local government officials (Zilla panchayat, taluk panchayat and gram panchayat members)[xi] on the rights of persons with disabilities and their obligations as per the legal requirements to evolve programmes for persons with disabilities and to extend services through their departments. Awareness programmes were also conducted to change their

perceptions on disability and that persons with disabilities can be equal contributing members of the society.

Table 6: Innovative approaches for empowerment

Disability Specific	Mainstreaming efforts
Facilitated the formation of a Disabled Peoples' Organisation (DPO)	Developed inclusive SHGs and built the leadership skills of members.
Facilitated participation of DPO members in government forums to influence decision-making processes and policy outcomes	Established inclusive Children's Parliaments, providing leadership experience for children
To make existing and planned public places accessible for all, the programme formed an access audit team consisting of persons with different types of disabilities and trained them in auditing based on universal design standards.	Supported panchayats to draft a plan of action on utilization of 3% budget allocation as per the State government policy for persons with disabilities

Outcomes and results

A year after cessation of programme funding, an evaluation was conducted to assess changes in the quality of life of persons with disabilities in the target area as a result of the various interventions described in the previous section and to assess the ongoing sustainability of programme activities (See Thomas 2013). The evaluation team was led by an external consultant with a team of experts including community members. The project log-frame and was reviewed by the external evaluator to assess progress against planned activities, and additional data was collected on coverage, effectiveness and impact.

Data on outcomes and impact was gathered through review of records, observation of activities, interviews with programme staff, namely 6 staff of the implementing agency (4 men, 2 women), and focus group discussions with various stakeholders, namely 2 volunteers in charge of programme activities (1 man, 1 woman); 101 members of 9 SHGs (14 men, 87 women); 13 members of the Registered Society (7 men, 6 women); 10 CEC tutors (all women); 16 members of the DPO (8 men, 8 women); 13 children with disabilities (mainly cerebral palsy and intellectual disabilities), including 6 children seen in their homes (4 boys , 2 girls) and 7 children seen at 2 schools (5 boys, 2 girls); 4 livelihoods clients (all men); 2 company managers (both men) and 4 employees placed by the programme (2 men, 2 women); and 3 local government (panchayat) representatives (all men).

A questionnaire was also completed by persons with disabilities to evaluate their satisfaction with assistive devices provided by the programme. This consisted mainly of orthotic devices,

followed by wheelchairs/tricycles, hearing aids and other developmental aids. Persons with locomotor disabilities were the main beneficiaries of the devices, including post-polio conditions and amputees, followed by persons with cerebral palsy and those with speech and hearing disabilities. A total of 149 clients responded to the questionnaire which programme staff distributed and helped respondents fill in. Of the respondents, 60% (89) were males; 36% were from the 0-15 age group, 30% in the 16-30 age group and 24% in the 31- 50 age group. The number was much less in the 50+ age group. The following outcomes and results were found across the 5 domains of the CBR matrix.

Health

A total of 857 persons with disabilities received health and rehabilitation services during the project period (see Table 7). When compared to the baseline study of persons with disabilities in need of these services, the programme supported 61% of persons with disabilities requiring surgeries (43/70), 90% requiring assistive devices (460/512), 66% requiring rehabilitation therapy (286/434) and 76% requiring medication (68/90). In total, the programme supported 77% of persons needing health and rehabilitation services in the target area (857/1106).

Table 7: Health and Rehabilitation services

Type of disability	Surgery		Assistive devices		Therapy		Medication		Total
	M	F	M	F	M	F	M	F	
Locomotor disability	23	5	141	77	48	28	0	0	**322**
Speech and hearing	0	1	30	24	49	36	0	0	**140**
Visual / low vision	4	3	43	53	11	18	7	9	**148**
Intellectual	1	0	0	0	16	21	9	4	**51**
Multiple disability / Cerebral Palsy	5	1	57	35	31	28	14	11	**182**
Psychosocial	0	0	0	0	0	0	5	9	**14**
Total	**33**	**10**	**271**	**189**	**155**	**131**	**35**	**33**	**857**

Other key outcomes in the health domain include:

- Increased community awareness and capacity of local health service providers and professionals to provide health and rehabilitation services, including assistive devices, to persons with disabilities.
- 63% of people who accessed health and rehabilitation services, showed between 75-100% improvement in functioning.

- Persons with disabilities and their families came to understand the importance of early intervention, rehabilitation and regular usage of assistive devices in preventing secondary complications; 291 persons with disabilities prevented/corrected secondary disabilities by accessing relevant services.
- Of the 149 clients who responded to the questionnaire about assistive devices: 130 used them regularly; 44% reported they were very satisfied with the device; 52% were satisfied and 4% were somewhat satisfied. Additionally, respondents reported the following improvements to their quality of life:
    - 111 persons were able to participate in family and community activities
    - 94 were more independent
    - 43 were able to go to school
    - 41 were able to earn a living
    - 20 were able to participate in other activities
- 139 parents and caregivers received training in home based therapy, out of which 130 were continuing to provide therapy to children with severe disabilities, including maintenance and use of assistive devices.
- 17 persons with disabilities and their family members gained employment as ASHA (health) workers, becoming a key link between PHCs and persons with disabilities and others in the community.
- Greater awareness about disability prevention resulted in improved ante-natal and post-natal health care practices, along with higher rates of immunisation for children; increased deliveries were taking place in hospitals, and no new-born with disabilities was reported in the last 6 months of the programme; mothers were breastfeeding their children for 18 months when previously they were only breastfeeding for 6-9months.
- Training in monitoring child development under 8 broad categories (Cognitive, Gross motor, and Fine motor, Emotion, Language, Physical, Social and Communication) helped mothers to identify delayed development of their children and seek professional diagnosis and early intervention as needed.
- The community now contributed towards health care activities for persons with disabilities, for example, screening programmes, surgeries, mobility aids and so on. General health camp for community members was organized by the SHGs with support of primary health centres.
- Community members have undertaken organ donation pledges. In one of the campaigns conducted with a reputed eye care hospital in Bangalore, 165 people had registered their names for donation of eyes after death, at the time of the evaluation.

Education

While 102 children with disabilities were already in the inclusive education system in the target area, this number more than doubled with an additional 114 children with disabilities enrolled in schools during the programme period (60 boys, 54 girls), exceeding the

programme target by 30. The programme also exceeded targets in other related areas (see Table 8).

Table 8: Education: targets and achievement at the end of the programme

Targets	**Achievement**
Completion of primary education by 30 children with disabilities	47 children with disabilities completed primary education (Class 5th).
220 children with disabilities will access inclusive informal education	285 children with disabilities (167 male, 118 female) accessed inclusive informal education through the CECs
187 children with disabilities will attend school regularly	213 children with disabilities (123 male, 190 female) were attending school regularly
60 children with severe disabilities will access home based education	61 children were accessing home based education

Other key outcomes in the education domain include:

- 96% of children who enrolled in school during the programme period were still in the education system at the time of the evaluation.
- 14 local government schools were made accessible to children with disabilities. 3 schools were developed as accessible models, with contributions from the programme budget and the community. This encouraged and motivated the panchayats and school management committees to make another 11 schools accessible.
- Twenty-eight CECs were set up in the target area, focussing on education, social inclusion and recreation, following the index for inclusive schooling (UNESCO 2005). The CECs increased community participation and societal responsibility for improving learning levels of children with disabilities through the involvement of local leaders and SHGs. They motivated schools and panchayats to offer spaces for CECs and to monitor their activities.
- A total of 589 children (296 boys, 293 girls) had attended the CECs at the time of the evaluation (see table 9). Of the 285 children with disabilities in inclusive and informal education (167 boys, 118 girls), 210 (115 boys and 95 girls) attended the centres during the programme period. Many children with disabilities and learning difficulties were referred to the centres by school teachers for additional support. This created a symbiosis between the schools, the community and the CECs.
- CEC tutors were initially paid a small honorarium by the programme. Subsequently the panchayats agreed to provide tutor's salaries to support the learning of children with disabilities. During the evaluation, 19 tutors were paid by the panchayats; and 9 by the

Registered Society, which showed ownership in improving education of children with disabilities within their villages.

- CECs have become an integral part of the lives of children with disabilities in the target area. Every Saturday, an inclusive play group is conducted in all of the CECs where children enjoy playing games together, singing, dancing and learning crafts.
- The CECs trained SHG members, persons with disabilities, their family members and some motivated community members as home-based tutors. Of the 61 children with severe disabilities who accessed home based education during the programme period, 32 (52%) were continuing at the time of the evaluation. The rest discontinued due to migration (12), health problems (2), death (6), and because they were over the age limit of 14 years (9).

Table 9: No. of children in Community Education Centres at the time of the evaluation

Type of disability	Boys	Girls	Total
Locomotor	34	20	54
Speech and hearing	8	12	20
Visual	1	3	4
Low Vision	16	18	34
Intellectual	12	15	27
Cerebral Palsy	6	3	9
Multiple disability	3	2	5
Psychosocial	0	2	2
Others (children on persons with disability/from marginalised groups)	4	1	5
Children with learning difficulty	212	217	**429**
Total	**296**	**293**	**589**

Livelihoods

Of the 50 persons with disabilities were identified as in need of vocational skills training, 32 (64%) received training through the programme. (Of those who missed out, 11 moved away and 7 discontinued for personal reasons). Training was provided by mainstream training institutes, at concessional rates or free of cost. 21 local businesses participated in orientation programmes and received technical support to adapt the work environment and enable employment of persons with disabilities. The programme succeeded in expanding

employment opportunities (See Table 10) and consequently increasing household income (See Table 11) for persons with disabilities, due in part to the target area's proximity to the industrial belt.

Table 10: Number of persons who received livelihoods support

	Persons with disabilities		**Family**		**Total**
	Male	Female	Male	Female	
Employment in formal labour market	34	32	3	14	83
Micro enterprise/ self-employment/ Income generation programme	21	10	7	31	69
Total	55	42	10	45	152

Table 11: Change in income with livelihoods support

Persons with disabilities	**Average family income before in rupees**	**Average family income now in rupees**	**% change**
Locomotor	4,336	7,754	79%
Speech and hearing	3,823	7,130	86%
Visual/Low Vision	4,144	7,644	84%
Intellectual	3,218	6,031	87%
Multiple disability	2,470	6,650	169%
Psychosocial	1,000	3,500	250%
Leprosy affected	6,000	11,000	83%
Others	3,300	8,675	162%
Total	28,291	58,384	

Other key outcomes in the livelihoods domain include:

- 88% of those persons with disabilities who underwent skills training were continuing in the same trade at the time of the evaluation.
- 91% those who accessed livelihoods support were able to improve their income.
- Local businesses in the target area now provide employment opportunities for persons with disabilities and their families. They also outsource jobs to inclusive SHGs, for the benefit of those who cannot work outside of the home.
- The companies visited by the evaluation team were very positive about their employees with disabilities and are keen to recruit more.

Social Inclusion

The results of social inclusion interventions are more qualitative and subjective than other CBR domains. However, an improvement was reported by the evaluation team, with temples now permitting access to and performing marriages of persons with disabilities, and allowing their inclusion in SHGs. A more objective result was the number of persons with disabilities who gained access to government schemes and entitlements (see Table 12). Not all persons who were identified as needing entitlements were successful in accessing relevant benefits, as they were unable to furnish details (address proofs/identity cards/income certificates, etc.) to access a Disability ID card which is a basic requirement to access related benefits. For example, migrant workers did not have relevant documentation.

Table 12: Government schemes and entitlements accessed by persons with disabilities

Schemes/Entitlements	Baseline data Total No. of persons needing the entitlements	Total No. of persons who accessed the entitlements
Disability Identity Card (ID)	840	652
Pension	580	565
Railway pass	358	223
Bus pass	363	140
Election identity card	650	259
Ration card	710	621
Yashasvini card (Medical)	412	373
Scholarship	-	146
Birth certificate	240	115

Other key outcomes in the social inclusion domain include:

- Promotion of a barrier free environment to support persons with disabilities to be independent, to lead a productive, safe and dignified life, resulted in 21 public places being made accessible (See Table 13). In addition, ramps are now provided at gram sabha meeting venues, and at election booths during the recent state assembly elections.
- Awareness raising and promotion of inclusion of persons with disabilities in institutions of self-government has resulted in: all 8 panchayats in the target area now include disability issues in their agenda and action plans and utilise the 3% budget allocation for persons with disabilities, with many allocating funds in all five domains of the CBR Matrix (2 panchayats allocate more than 3% of funds for this purpose); persons with disabilities are now invited to attend and speak at gram sabha meetings and also avail themselves of relevant benefits; and the district commissioner (administrative head of the district) and

taluk level officials are open to the DPO approaching them directly on behalf of persons with disability.

Table 13: Public places made accessible

Public Places	No. of them made accessible
Schools	14
Taluk court	1
Taluk office	1
Police station	1
Panchayat office	2
Temple	1
Primary Health Centre	1

Empowerment

The results of empowerment interventions centred on the establishment, capacity building and promotion of community structures, including self-help groups, children's parliaments and a DPO.

Key outcomes relating to SHGs included:

- The establishment of 33 inclusive SHGs in the target area, involving 193 persons with disabilities (90 men, 103 women) and 139 of their family members as SHG members. 149 people from poor families were also included.
- The election of 7 SHG members to local government (panchayats)
- The employment of 13 SHG members as ASHA workers in the government's rural health mission
- The employment of 19 SHG members as home based tutors under the Education for All (SSA) programme of the government.
- The majority of the SHGs were rated 'good' or 'excellent' by members in terms of their functioning on different parameters at the end of the programme (See Table 14). The self-assessment was facilitated by programme staff as part of the evaluation. The SHGs were by and large seen as vocal, confident and clear about their goals, achievements and future plans. Some of the benefits reported by members were:
    - Reduced isolation of persons with disabilities
    - Increased independence and confidence in persons with disabilities
    - Mutual support and sharing between members
    - Increased awareness on health, disability and development
    - Increased savings and incomes of members

Table 14: Rating of selected aspects of SHG functioning
(1= very poor, 2= below average, 3= average, 4= good; 5=excellent)

SHG functioning	No. of SHG rated as 1	No. of SHG rated as 2	No. of SHG rated as 3	No. of SHG rated as 4	No. of SHG rated as 5
Leadership	-	2	5	15	7
Independent conduct of meetings	-	1	3	7	18
Savings/livelihood operations	-	-	1	5	23
Awareness on health and rehabilitation	-	4	13	10	4
Income generation of members	-	-	7	14	8
Awareness on disability issues	-	2	6	16	5
Participating in social community activities	-	2	6	14	7
Can sustain itself without assistance	-	3	2	10	14

Key outcomes relating to the children's parliaments included:

- The programme supported the creation of 25 children's parliament groups at the village level including a total of 78 children with disabilities (39 boys, 39 girls) and 425 children without disabilities (215 boys and 210 girls) (See Table 15). Each group met at their local CEC every Saturday to discuss issues relevant to them and their village
- As in the regular Parliamentary system, four ministers, for Social Affairs, Education, Health and Protection, along with a Speaker and a Reporter were elected by the children for a period of two years. Preference was given to children with disabilities to be ministers. The selection was a voluntary process after the roles and responsibilities were defined by the children.
- The children's parliaments identified 10 children who had dropped out of school and motivated their family members to send them back to school.
- The children's parliaments identified a school toilet with no door so girls could not use the toilet. Their efforts resulted in a decision to construct not just a toilet but a new school with better facilities.
- Leadership training for the leaders of the children's parliaments, conducted with support from external resources, led to two children getting selected to represent the district in the state level consultation meeting with the Chief Minister of the State.

Table 15: Children's parliament

Children's parliament details-28				
Children with disabilities		**Other children**		**Total**
M	**F**	**M**	**F**	
39	**39**	**215**	**210**	**503**

Key outcomes relating to the DPO included:

- A DPO was formed at the sub-district level, with representation of two-to-three members from each SHG at the panchayat level. The members decided that the DPO would have cross disability representation, ensure women's participation and include parents of children with disabilities (See Table 15).
- DPO members advocated for poor, landless people to get land; 43 persons received land from the government due to their efforts which continue on behalf of around 40 other people who lack necessary documentation.
- The president of the DPO was elected as Joint Secretary of the State level DPO, creating new connections between local and state level campaigns; the DPO participated in the state level campaign on social security schemes; and members took part in state consultations such as the shadow report for Convention on Rights of the Child, right to education policy, etc.
- The DPO reported to the Registered Society (see below). Together with the Society, it initiated a disability grievance redress meeting by the district commissioner; successfully advocated for the disability office to be shifted to an accessible location; lobbied authorities to ensure psychiatric medicines be made available in the taluk hospital and primary health centres; and to ensure implementation of 3% allocation from the panchayat for persons with disabilities in all developmental programmes.

Table 16: DPO membership

Members	**Total**
Persons with disabilities	**55**
Family members	**12**
Total	**67**

Key outcomes relating to the Registered Society included:

- A Registered Society was set up at sub-district level as a federation of the DPO and SHGs. This was not part of the initial planning but evolved as the DPO and SHGs strengthened. With 367 members (See Table 17), the Registered Society consisted of 15 board members and 3 committees (an executive committee, a loan committee and a monitoring committee). The 15 board members were involved in all aspects of the programme as volunteers and their capacity was built to take responsibility for

continuation of interventions beyond the funding period. Currently the Registered Society continues its functions in a rented premises.

Table 17: Registered Society membership

Members	**Total**
Persons with disabilities	**115**
Family members of persons with disabilities	**174**
Members from poor families	**78**
Total	**367**

Discussion

Organisational structure, human and financial resources, and the social and political environment are all key factors for sustainability (Mijnarends 2011). Many CBR programmes aim to become as financially self-sufficient, but the biggest obstacle they face is poverty within the communities who need to take ownership and responsibility for continuation of relevant activities (Werner 2003: 482).

In this CBR programme, establishing, capacity building and promoting strong community structures including the SHGs, CECs, children's parliaments and DPO, was the most important factor which attributed to the sustainability of the program.

As depicted in Figure 2, the Registered Society took over from the implementing NGO and has been able to continue programme interventions in the Attibele Hobli, using local resources. The favourable social and political environment, cohesive community support, committed facilitators and volunteers, and the factor of the target area being situated near the industrial belt of the peri-urban location all contributed to the sustainability of interventions beyond the cessation of programme funding.

As for human resources need to sustain programme activities, two persons with disabilities from the community were identified and involved from start, and their capacities were fostered and strengthened to empower them to take ownership of interventions through various trainings and exposure programmes. The Registered Society now employs these two former volunteers as community facilitators to continue the facilitation process, working with other volunteers, at the village level.

To ensure ongoing financial sustainability, the programme also did the following:

- Developed linkages with local industries and businesses, encouraging them to become involved in funding and providing employment opportunities for persons with disabilities.

- Lobbied local government to make budgetary provisions for persons with disabilities aligning to the five components of the CBR Matrix.
- Made a revolving fund available as loans for members of the SHGs, with interest being reinvested for the benefit of the group.
- Individual donations were sought mainly for procuring quality assistive devices and for promoting livelihood opportunities for persons with disabilities.

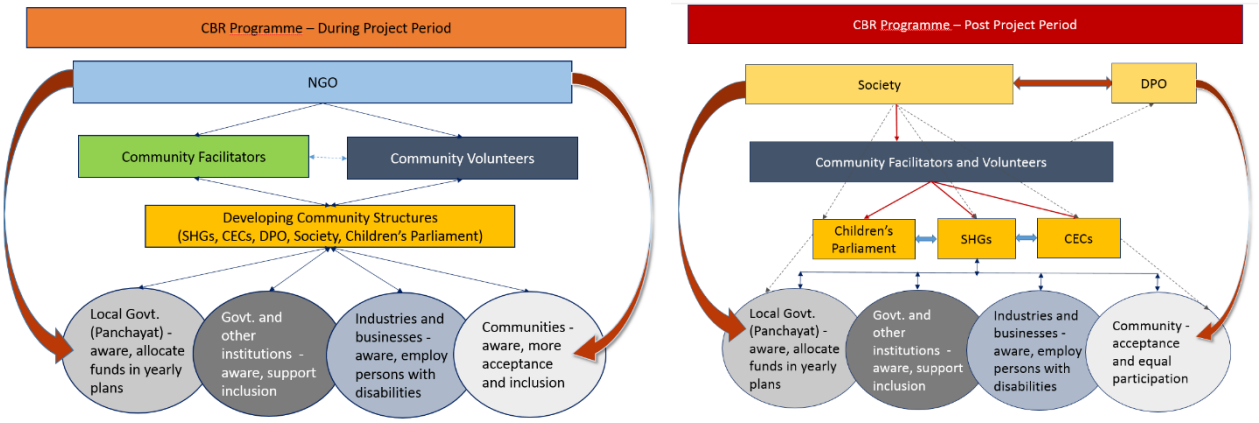

Figure 2a: shows the implementing agency taking the lead in developing the structures and building networks towards sustainability, during the program period.

Figure 2b: shows the Registered Society taking the lead and working work different structures and stakeholders to continue the intervention.

Figure 2: Programme framework during and after the funding period

Other factors that helped to ensure the success of the programme and contribute to its ongoing sustainability included:

- Planning based on the needs of persons with disabilities as identified by themselves, their families and communities.
- Good rapport between programme staff and the community, especially with the panchayat officials and local leaders.
- Strong involvement of diverse local stakeholders including persons with disabilities and their family members, health services providers and professionals, schools and teachers, vocational training institutions, potential employers, banks and other financial institutions, government officials, community leaders, and so on.
- Developing linkages with various other community groups and citizen's movements, including women's groups and farmers groups, for solidarity and mutual support.
- Building the capacity of community members to contribute and in some cases fully execute programme activities as volunteers, health workers, carers and tutors etc. meant the programme was able to function with a reasonably small number of staff. This reduced programme implementation costs and the costs of setting up expensive institutions to

sustain activities (Thomas, 2003: 4). Meanwhile community members who took up new roles developed self-confidence and respect of people in the community.

- Establishing, capacity building and promoting strong community structures and systems such as the registered society, self-help groups, children's parliaments, community education centres and disabled people's organisation, resulted in supportive environment for community organisations and advocacy groups, and helped continue work on disability inclusive development. For example: The Registered Society established bank/donor linkages; the Registered Society and DPO developed action plans and assigned responsibilities; and self-help group members were trained as volunteers responsible for implementation.

These factors laid the foundation for sustaining the CBR programme activities, but capacity building on leadership, governance, effective communication and management of groups, finances and resource mobilization including fundraising, still needs to be continued by the structures and systems put in place by the programme. The programme adopted elements of "reverse mainstreaming" partly to try to facilitate this, and to address issues of general concern to the community, (e.g. health, water and sanitation, child rights) including marginalised groups. Motivating community members to participate in diverse development processes should, over time, support the acquisition of skills needed to shoulder the responsibilities to take over the CBR programme in future (Thomas, 2003). The Registered Society and DPO are motivated and confident about meeting this challenge but may not yet have the level of maturity needed to do this without some level of external support.

Recommendations

The CBR programme worked with existing systems; it strengthened the work of local government and mobilised local resources from the community for various activities and to ensure their continuance after cessation of funding. This made the programme efficient, but may not be replicable in other settings where local resources are weak or absent. Some lessons learned from the programme which may be useful to ensure sustainability of CBR programmes more generally are as follows:

- The implementing agency was well established in the target area and built partnerships with local service providers. Where needed, it strengthened their capacity to provide services for persons with disabilities. Where these institutions not available or willing to partner with the implementing agency, a large part of any CBR programme will consist of service provision.
- The programme was located close to a metropolitan city and very near the industrial belt of small businesses and factories. It provided opportunities for earning livelihoods, wage employment for persons with disabilities and also for mobilising financial support from

potential donors for the programme. These contributed greatly to the success and sustainability of the programme.

- The programme had a strong emphasis on education. For children who are not disabled, contact with children with a disability in an inclusive setting can, over the longer term, increase familiarity and reduce prejudice. Inclusive education is thus central in promoting inclusive and equitable societies.
- A committed and concerted effort by the implementing agency and programme staff to work with local government on disability issues, for promoting equal opportunities for person with disabilities in the community, was critical to the programme's success. Development of human resources along with conducive social and political environment is vital for disability mainstreaming.
- Community rehabilitation activities led and staffed by disabled persons themselves added more meaning to the programme. As mentioned (Werner 2003: 409), they became role models for persons with disabilities and their families.
- Considerable effort was put into making local service providers, government, and the wider community aware of disability inclusive development processes in all five domains of the CBR matrix. In a mobile and changing society, it is possible that as people move, activities catalysed by the programme will die out. However, in another intervention in Vellore (WHO 2013) it was found in an urban setting that the community knowledge persisted for many years after the intervention.

Conclusion

From this study, we can conclude that CBR sustainability is not only about establishing robust community structures such as the self-help groups, community education centres, children's parliaments, and disabled people's organisations. Investing in building capacities of persons with disabilities and involving them in planning, implementation and monitoring processes by keeping them at the forefront of the programme right from the start, will enable local ownership. This also enables the community structures to work towards complementing the services of the local government to ensure lasting benefits for people with disabilities in accessing services and opportunities in the health, education, livelihood and social sectors. It leads to natural progression of persons with disabilities as leaders and advocates of disability inclusive development and sustainability of the CBR programme.

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[i] CBR Matrix has five components (health, education, livelihood, social, and empowerment). WHO 2010: pp 24-25.

[ii] A hobli is a term used for a cluster of adjoining villages administered together for tax and land tenure purposes in the State of Karnataka

[iii] Taluk is an administrative division below the district level

[iv] Following the multi-dimensional index considered to measure backwardness, a person spending less than Rs.1,407 a month (Rs.47/day) is considered poor in cities and in villages, those spending less than Rs.972 a month (Rs.32/day) is considered poor. Source: Rangarajan panel estimates 2012 - http://planningcommission.nic.in/reports/genrep/pov_rep0707.pdf

[v] Marginalized groups include Scheduled Castes, Other Backward Classes, Senior Citizens, Victims of substance abuse, Denotified, Nomadic and Semi-nomadic tribes, Beggars and transgender (as listed under the Ministry of Social Justice and Empowerment)

[vi] Partnering hospitals specialising in health and rehabilitation of persons with disabilities for the CBR programme in Attibele - Sparsh Hospital: for corrective surgeries in orthopaedics; St.John's Hospital: for programmes for prevention of blindness, deafness and in orthopaedics; National Institute of Mental Health & Neuro Sciences (NIMHANS): for neurological problems; Sanjay Gandhi Hospital: for orthopaedics; Indira Gandhi Children's Hospital: general health for children, free surgeries for clubfoot and cross-disability care; Narayana Netralaya: eye care and prevention of blindness programme; Narayana Hrudayalaya: Cardiac problems.

vii "Locomotor" means disability of the bones, joints or muscles leading to substantial restriction of the movement of the limbs

[viii] "Multiple disabilities" means a combination of two or more disabilities – e.g. person with locomotor and hearing impairment, person with intellectual and locomotor disability

[ix] "cerebral palsy" means a group of non-progressive condition of a person characterized by abnormal motor control posture resulting from brain insult or injuries occurring in the pre-natal, perinatal or infant period of development – The National Trust Act 1999

[x] Marriage is also an important aspect and considered respectable in Indian traditions. Many traditions and customs are also centred on persons who are married, compared to those who are not married. Through the project interventions, community members were sensitised and about 10 persons with disabilities in the community were encouraged to get married by fellow members in the SHGs and DPOs. Most of the persons with disabilities got married to persons without disability.

[xi] Panchayat is a local self-government at the village or small town level in India. Panchayats come under the constitution of India and they are endowed with such powers and authority as may be necessary to enable them to function as units of self-government. Zilla panchayat, taluk panchayat and gram panchayat members are part of the administrative members.