



COMMUNITY-BASED REHABILITATION (CBR) for People with Disabilities in Nepal

– An Overview

Study Conducted for the Ministry of Women, Children and Social Welfare

by

Handicap International, Nepal



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The support provided by USAID in conducting this study has been greatly appreciated.



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HANDICAP INTERNATIONAL

Handicap International (HI) is an international non-profit-making and non-governmental organisation founded 25 years ago in France and presently implementing disability related development and relief projects in more than 60 countries. HI is working without any political or religious concerns for the prevention of disability and the physical and social rehabilitation of people with disabilities. Handicap International supports actions towards an inclusive, barrier free and rights based society for people with disabilities and other vulnerable people.

In South Asia, HI is implementing activities directly and through local partners in India, Sri Lanka, Nepal, Bangladesh, Pakistan and Afghanistan. Based in New Delhi, the HI Regional Coordination Office provides technical support and expertise to these country programmes.

In Nepal, Handicap International has been directly implementing activities since 2000, initially through a development project with regional components entitled Community Approach to Handicap in Development (CAHD). Today HI Nepal works for the development of projects and activities for the prevention of disabilities as well as rehabilitation and inclusion of people with disabilities into the mainstream development process.

This Study has tried to analyse and understand the wealth of experience and knowledge gained by Community-Based Rehabilitation (CBR) providers in Nepal over the past 20 years with the aim to propose, within the limits of the Study, constructive and positive ideas and recommendations to support the general development of CBR in Nepal in the best interests of people with disability, their families and communities. It is not therefore an evaluation of specific CBR projects or programmes in Nepal.

Above all the Study recognises the tremendous wealth of experience, hard work and dedication of CBR implementers in Nepal and the challenges that many CBR organisations have faced in their efforts to attain the goals of CBR in Nepal. It is hoped that by documenting the experience and learning of CBR implementers in Nepal, this Study will contribute to the ongoing development of CBR both in Nepal and other countries.

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Handicap International Nepal thanks the Ministry of Women, Children and Social Welfare for entrusting this Study to them. We thank the Ministry further for the cooperation and assistance extended to us which enabled us to carry our task with greater ease. We thank also the Ministry for their time.

We take this opportunity to thank all the organisations that participated in this Study. The time they spent with our field researchers, patiently answering their questions, is appreciated. In particular we thank all those individuals who have a disability and their family members, both those visited at home and the many others who participated in focus group discussions, and the management and staff of the organisations involved in the deeper study.

Finally Handicap International Nepal acknowledges the contribution to this Study of all their staff. We appreciate the willingness with which they shared their experience and their time doing this work. A special thanks to Ms. Sangay Amina Bomzan from the Handicap International Nepal programme and to Ms. Deirdre Keogh from the headquarters of the Handicap International for their relentless support and assistance. Many thanks also to the HI SARC team for their support throughout the process.

Acronyms

CAHD	Community Approach to Handicap in Development
CBO	Community-Based Organization
CBR	Community-Based Rehabilitation
CRC	Community Rehabilitation Committee
DDC	District Development Committee
DMIS	Disability Management Information System
DPO	Disabled People's Organization
ECCD	Early Childhood Care and Development
HI	Handicap International
INGO	International Non-Governmental Organization
MWCSW	Ministry of Women, Children and Social Welfare
NFD-N	National Federation of the Disabled Nepal
NGO	Non-Governmental Organization
OT	Occupational Therapist
PT	Physiotherapist
PwDs	People with Disabilities
PRT	Primary Rehabilitation Therapy
SARC	South Asia Regional Coordination
SHG	Self-Help Group
ST	Speech Therapist
UN	United Nations
VDC	Village Development Committee
VDRRC	Village Development Rehabilitation Committee
WHO	World Health Organization

A Note from Handicap International Nepal

In answer to the kind suggestion from the Ministry of Women, Children and Social Welfare, Handicap International is very happy to present this publication “Community-Based Rehabilitation in Nepal – An Overview”.

After more than 20 years of CBR development in the country, this is indeed a tremendous opportunity to take stock of the great achievements and impacts reached to date by all CBR stakeholders, which have been providing support in the rehabilitation and empowerment of people with disabilities, as a first step towards their true inclusion and full participation in their communities and the society.

We believe that this overview, its analyses, conclusions and recommendations, will greatly help to disseminate within the country and even abroad the numerous lessons learnt, innovations, experiences and successes of 20 years of CBR implementation in Nepal. Consequently, the CBR stakeholders, implementers and their Coordination Network will be able to take advantage of these past experiences for further development and optimal implementation of the Community-Based Rehabilitation approach, for the greatest possible impact for people with disabilities.

I would like also to take this opportunity to extend my deepest congratulations to each of the Community-Based Rehabilitation programmes and organisations for their tremendous work and commendable commitment and dedication during all these years towards the fruitful development of Community-Based Rehabilitation in Nepal. I would like also to sincerely thank the Authorities and the Ministry of Women, Children and Social Welfare for their increasing and very helpful support in the field of disability, and especially their will to further assist and coordinate the efforts in the development of the CBR in the country. Finally, a very particular appreciation to all people living with a disability, and their families, in Nepal and elsewhere, for the impressive and often astonishing use and advantage they make of the limited support provided to achieve their exemplary successes towards their rehabilitation, inclusion and effective participation within their communities.

Jean-Bertrand Lebrun

Country Director,
Handicap International Nepal



सि.बि.आर. राष्ट्रिय नेटवर्क-नेपाल

CBR NATIONAL NETWORK NEPAL (CBR-N)

"NATIONAL WIDE NETWORK FOR PREVENTION AND REHABILITATION OF DISABILITY & PROMOTION OF ABILITY."

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December 18, 2007

Message from:

The CBR National Network-Nepal

Nepal was one of the very first countries in the world to start implementing the Community-Based Rehabilitation (CBR), with the first programme starting as early as 1985. More than 20 years later, there are now more than 50 CBR programmes implemented across the country.

It's with delight and great interest that we receive the publication "Community-Based Rehabilitation in Nepal – An Overview" undertaken and published by Handicap International Nepal in collaboration with the concerned Ministry. This publication is indeed very interestingly describing and acknowledging the achievements and results accomplished to date by the various programmes involved in the CBR, and with them the organisations and individuals who have provided relentless efforts and dedication to reach these results.

Also, this publication is of utmost interest in the way it is describing the successful experiences, proven strategies and efficient approaches developed and tested in Nepal by the CBR implementers. No doubt that all these valuable experiences will strongly help in the future successful development of the CBR in Nepal but also in other countries in the world for starting or strengthening their Community-Based Rehabilitation Programmes. The overview also very helpfully underlines some areas where further improvements can be achieved for the best future progress and further improvement of the CBR in Nepal. And it is giving clear and precious recommendations to all the committed stakeholders that will greatly help them, together with the very informative and wisely selected representative case studies, to even further bettering the CBR in the country, and its true impact for the people.

Finally, we would like to thank Handicap International Nepal for letting CBR National Network, Nepal to write foreword for this valuable documents.

Sincerely yours

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Executive Summary

Community-Based Rehabilitation (CBR) is a comprehensive strategy to include people with disabilities in the development of their communities. With an emphasis on human rights and actions to address inequalities and alleviate poverty, CBR is implemented by people with disability themselves together with their families, communities, organisations as well as government and non-government actors.

In Nepal, CBR is coordinated by the Ministry of Women, Children and Social Welfare and implemented across the country through more than 50 NGOs. The Ministry provides direct financial support to 12 NGOs. Handicap International, Nepal was requested by the Ministry of Women, Children and Social Welfare, to carry out a Study on CBR. The Ministry wished the Study to be in the form of an Overview in order that concerned stakeholders may know the current status from a broad perspective. The Study was also requested to assist the Ministry support the further development of CBR in the country.

Fifty one organisations which have registered themselves with the Ministry and other fora as implementing CBR were included in the Study. It was carried out in the first half of 2007 in two phases. The first phase collected information from all 51 organisations through interviews conducted by six field researchers. The questionnaire used was largely concerned with the range of programme components implemented as CBR, and their quantitative achievements. Conceptual aspects were also investigated to determine the interpretation of CBR. This has implications for what constitutes Nepal's CBR system, its scope and dimensions.

In the second phase of the Study an international and a national researcher interviewed 11 of these organisations. A total of 124 primary stakeholders, namely youth and adults who have disability as well as parents, were interviewed often through home visits and in other situations through focus groups. The interviews focused on approaches and activities and an overall assessment of effectiveness, impact and sustainability of programmes.

The main findings of the Study as presented in this Report are as follows:

- The collective achievements of CBR in Nepal over the past 22 years have been outstanding. Primarily, CBR has demonstrated the role that both individuals who have disability and Self-Help Groups (SHGs) can take in developing rights-based communities.
- CBR has developed as a holistic approach in Nepal, meeting multiple needs of individuals who have disability of all ages and having any disability. Examples of needs met include social interaction, schooling, vocational training and provision of assistive devices. A major exception however, is that Early Childhood Care and Development (ECCD) is not widely available to young children who have disability. Parents are rarely introduced to the concepts of early stimulation at home and children who have disability are as yet mostly excluded from ECCD Centres. Another exception is that individuals who have disability arising from mental illness are rarely included within CBR.
- A significant lesson has been learned from Nepal's CBR regarding the scope of empowerment it offers. Self-Help Groups are empowered to influence because of the recognition they have gained within their communities. Individuals sometimes have gained, and at other times are in the process of gaining, economic, social, functional and civic empowerment. The possibilities for empowerment through education and the importance of knowledge and skills transfer for functional empowerment have been demonstrated. Political, legal and cultural empowerment and empowerment through sports will hopefully take place in the near future.
- A major weakness of CBR in Nepal lies in the area of community empowerment. Control of even micro programmes lies by and large with organisations rather than with communities, which is a barrier to inclusion. Some managers are aware of this and are taking steps to overcome it. The creation of empowered focal groups within communities either by people who have disability or with their active participation is increasing. This bodes well for the sustainability of programmes and needs to be encouraged, facilitated and supported.

The main recommendations arising out of this Study include:

- A National Conference on CBR should be organised to allow CBR implementers share experiences and learning to date as well as to facilitate discussion and agree ways forward on issues such as the UN Convention on the Rights of Persons with Disabilities.
- Community workers need to be further capacitated to act as agents of change in the context of empowerment of individuals, of SHGs and of communities. This will go some way toward ensuring CBR in Nepal moves forward to meet the challenges of a rights-based strategy and the implementation of the UN Convention on Disability. Current training programmes for community workers need to be reviewed in this regard and recommendations for this as requested by the Ministry of Women, Children and Social Welfare are outlined in section 10.2 of this Report.
- The development of a Disability Management Information System (DMIS) to collect, collate, analyze and use information regarding the location, situation and needs of people with disabilities is a necessary pre-requisite to ensure quality in the design and implementation of any initiatives. The Ministry of Women, Children and Social Welfare have already made plans to develop such a system and they should be supported in that aim; recommendations for the implementation of this system have been made in section 10.3 of this Report.

CBR in Nepal has a wealth of innovative experiences to build upon. SHGs, and DPOs; decentralized community administrations and inclusive education; inclusive Child Clubs, Youth Associations and Women's Groups; and not to mention the wide spectrum of individual and organisational experiences and strengths, present a rich resource base for the continued development of rights-based CBR in Nepal. Further recommendations are addressed to government, CBR actors and donors alike with the aim to help CBR in Nepal build upon the wealth of experience to date and the commitment and dedication of all those involved in its implementation.

PART 1

THE STUDY

1. BACKGROUND

In 2005, the Ministry of Women, Children and Social Welfare (MWCSW) requested Handicap International (HI) to conduct a study on Community-Based Rehabilitation (CBR) in Nepal in order to provide the government and stakeholders with a solid overview of the sector and recommendations for its future development. Funding for the study was finally secured in late 2006 and an international researcher with extensive experience in CBR development and management as well as conducting such studies was identified. A detailed Terms of Reference that aimed to meet the needs of government as well as other stakeholders was prepared. The study began in 2007.

1.1 Disability in Nepal

There is as yet no comprehensive updated data on disability in Nepal, due to several factors including the general lack of awareness about disability and the remaining tendency for families to hide their disabled member from public view. As a result prevalence rates vary considerably according to the sources used. While a National Planning Committee/UNICEF¹ study undertaken in 2001, puts the prevalence rate at 1.63% (1.75% for males and 1.52% for females) with 17.4% of that number estimated to have a mobility impairment, the last national census taken in 2001 puts the disability prevalence rate at 0.46% (0.42% for males and 0.50% for females) with just over 39% of that number said to be physically disabled². This is considerably less than the global prevalence rate of 10% as noted by the United Nations (UN)³.



There is however widespread agreement on the fact that people with disabilities are one of the poorest and most marginalized groups in Nepal with women and young girls with disability facing particularly high levels of discrimination and neglect. The majority of people with disabilities remain illiterate, unskilled and untrained. More often than

¹ UNICEF, "A Situation Analysis of Disability in Nepal", 2001, UNICEF, National Planning Commission (NPC), and New ERA, 2001. According to the study, the prevalence rate is highest (2.17%) in the age group 20-59 while for those over 60 the prevalence rate is 2.63%

² CBS & NPC, "The Nationwide Census Report 2001", National Planning Commission and Central Bureau of Statistics, 2001

³ United Nations Enable Secretariat for the Convention on the Rights of Persons with Disability: <http://www.un.org/esa/socdev/enable/convinfofaq.htm#q1>

not, they are ignorant of their inherent rights and deprived of any opportunities for self-development or advancement. Without the means to live they are obliged to depend upon their family members for survival and as a result are considered to be a burden not just for their family but for the nation as a whole⁴. The majority of people in Nepal still seem to view disability as a penance for the sins committed in previous lives and the notion that people with disabilities have equal rights and responsibilities seem to be still largely absent from the popular mindset. As noted by UNICEF over 70% of people with disability face difficulties to live in the community with confidence and self-respect⁵.

1.2 Global Context: UN Convention on the rights of persons with disability

The United Nations Convention on the Rights of Persons with Disabilities that was officially adopted on 13 December 2006 aims to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (Article 1)⁶. It represents a universal commitment towards more inclusive societies, where people with disabilities have equal opportunities and participation; as such it is a milestone for people with disabilities around the world. It clearly states that they must first and foremost be considered as people with equal rights rather than be considered just on their needs. As such it mirrors the guiding principles of CBR and demands the promotion of well planned rights-based strategies and interventions. To date, the Convention still needs to be signed and ratified by the Government of Nepal.

At the regional level, the rights and inclusion of people with disabilities in Asia is promoted through the *Biwako Millennium Framework for Action (BMF)*. Through seven priority areas for action, the BMF outlines strategies to assist Governments to work towards an inclusive, barrier-free and rights-based society for people with disabilities. The seven priority areas align with the key activity areas of comprehensive CBR programs, and include development of SHGs, empowerment of women with disabilities, early intervention and education, training and employment, accessibility, access to information,

communication and assistive technologies, and poverty alleviation through a focus on livelihoods⁷.

1.3 Community-Based Rehabilitation (CBR)

According to the World Health Organization (WHO)⁸, CBR is a comprehensive strategy to involve people with disabilities in the development of their communities. CBR seeks to ensure that people with disabilities have equal access, along with all other members of society, to rehabilitation and other services and opportunities including health, education and income. CBR is an important approach, particularly in low-income countries, where public infrastructure for the inclusion of people with disabilities is not developed. In many places, CBR programs provide the only prospects for inclusion of people with disabilities into education, rehabilitation, livelihoods, social inclusion and empowerment opportunities.

While the main goals of CBR include attainment of human rights, poverty alleviation and socio-economic development, the main principles are participation, inclusion, sustainability and self advocacy. Although there are many areas of intervention in CBR including skills training, social mobilization and so on only those that are of priority and first interest to Nepalese stakeholders are examined in this Study which for the purposes of analysis presents CBR interventions in Nepal under the main thematic areas of ‘Family and Community Living’, ‘Support to Self Help Groups (SHGs) and Disabled Peoples Organizations (DPOs)’, ‘Livelihoods’, ‘Education’ and ‘Health’.

1.3.1 CBR in Nepal

Nepal was one of the first countries in the world to start implementing CBR with the first programme starting in 1985. Today there are between 50 to 60 CBR programmes being implemented by local NGOs and organisations. While 12 of these programmes are supported directly by the MWCSW, others receive support from various International Non-Governmental Organizations (INGOs). Handicap International’s Community Approaches to Handicap in Development (CAHD) is one of the main CBR programmes in the country. Since its inception in 2000 the CAHD programme has been developed in 12 districts by 20 national

4 Dhungana R.P., “An Overview of Disability in Nepal”, MS-Nepal Newsletter- Issue-one, 2003

5 UNICEF, “A Situation Analysis of Disability in Nepal”, 2001, UNICEF, National Planning Commission (NPC), and New ERA, 2001

6 <http://www.un.org/disabilities/convention/>

7 <http://www.unescap.org/esid/psis/disability/bmf/summarybmf.pdf>

8 WHO, CBR: A strategy for Rehabilitation, Equalization of Opportunities, Poverty Reduction and Social Inclusions of People with Disabilities, 2004. <http://www.who.int/disabilities/publications/cbr/en/index.html>

partners and two training organisations, with the support of five international NGOs.

2. OBJECTIVES OF THIS STUDY

This study aims to provide the Ministry of Women, Children and Social Welfare, Government of Nepal, the different partners involved in CBR and all other stakeholders with a global overview of the historical development and current situation of CBR in Nepal, along with recommendations for the future development of CBR. To meet this objective, this report includes an overview of CBR interventions as well as providing analysis of approaches and activities in terms of impact and sustainability.

Specifically, this Study aims to provide the Government of Nepal with the necessary information and knowledge to:

- ◆ Have a clear and global understanding of the situation of Community-Based Rehabilitation in Nepal;
- ◆ Support and ensure continuation and development of CBR to improve the lives of people who have disability in Nepal;
- ◆ Design effective strategies and project plans, to address needs with a clear view of the priorities;
- ◆ Ensure networking with cooperation and coordination between different implementing agencies and programmes;
- ◆ Make necessary amendments and complements to disability policy to improve the output of CBR.

In addition, the Study aims to provide specific information, analysis and recommendations on:

- ◆ The development of an official training course for Community Development Workers and other staff, capitalizing on existing training in CBR developed in country;
- ◆ The development of a data collection system for CBR leading to a Disability Management Information System.

This report, presents the CBR scenario as it is being developed in Nepal. It seeks to assist CBR implementers to examine the effects of their programmes and to compare different approaches

and consequent outcomes. It draws conclusions which have impacted positively as well as negatively on CBR goals and principles. These conclusions may be used in future developments which seek to influence the situation of people who have disability both in Nepal and globally. It is also expected that this overview will stimulate interest in deeper evaluation and research studies which will be continuous and sustained and develop an evidence-base for the practice of CBR in Nepal.

3. STUDY METHODOLOGY/ PROCESS

The Study was conducted in two phases. In **Phase one**, 51 CBR implementers were identified for interview (*see Annex 1 for list and sources and Figure 1 for distribution*)⁹.

A questionnaire (see Annex 5) was prepared and pre-tested for collecting information. It was concerned largely with the range of programme components implemented as CBR, and their quantitative achievements as per the implementing organisations. Conceptual aspects were also investigated to determine the interpretation of CBR. This information has implications for what constitutes Nepal's CBR system, its scope and dimensions. Six field researchers (*Annex 2 for details of the field researchers*) interviewed the management of each of the organisations to obtain information and complete the questionnaires.

Phase two of the Study collected information at a deeper level in order to enable an analysis of CBR approaches, components and elements. Eleven out of the 51 organisations (21%) were selected. Purposive sampling, a non-probability sampling¹⁰, was used in the final selection of the 11 organisations to be interviewed. This was done to suit the nature of the Study, to cover all development regions and to include the widest possible variety of approaches especially ones that were representative of those used in the country. An international researcher and a national researcher conducted interviews with 124 primary stakeholders – including individuals who have disability and parents as well as CBR managers. The latter provided information on

⁹ This is the total number of organisations as registered with the Ministry or other fora that were found to be implementing CBR at the time of conducting the Study.

¹⁰ A sample for which the characteristics are already defined and chosen on the basis of knowledge of the population, its elements and the nature of the research aims.

approaches and activities. The former shared their experiences and views, all of which contributed to the assessment component of the overview¹¹.

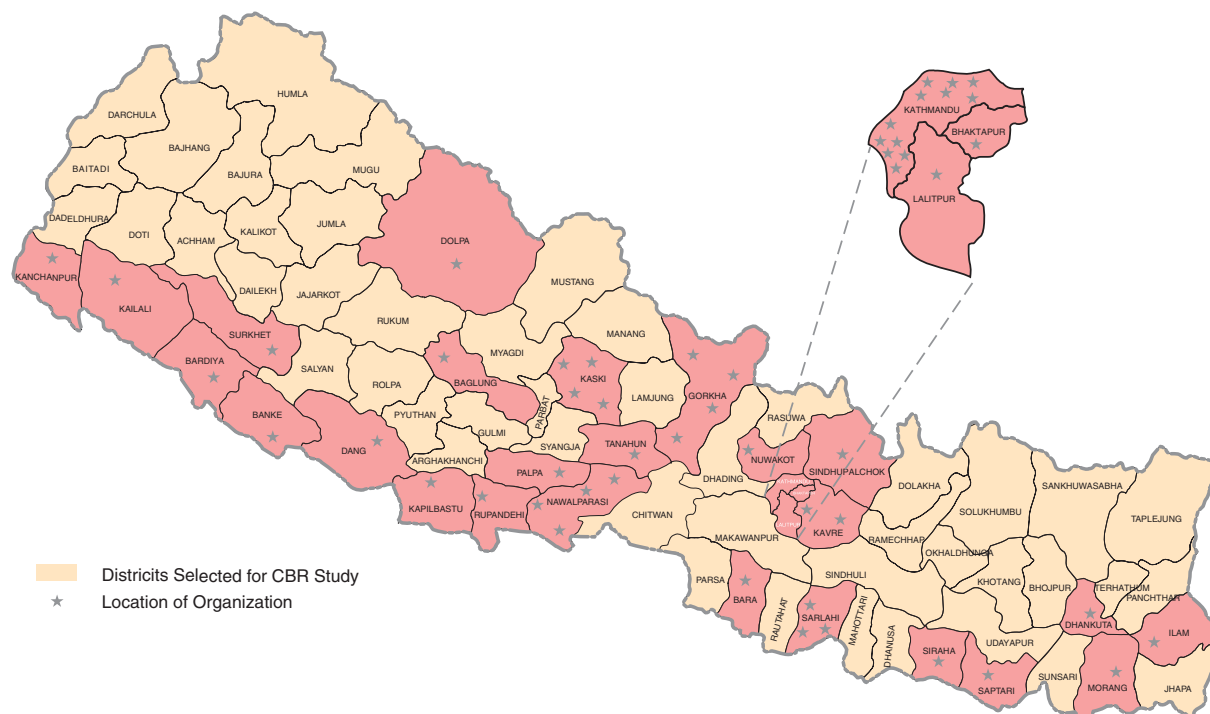
This methodology was selected for two reasons. Firstly to meet the requests of Ministry officials for quantitative data and secondly to meet the requirements and advice of the Advisory Group of Disabled Peoples Organisations (DPOs) representatives and CBR Managers as brought together by the Ministry to provide inputs into the Study. This Advisory Group wished that a wide cross-section of CBR programmes be studied. Case studies from the 11 organisations are presented in Annex 3 as examples of the various situations and approaches that were encountered during the Study. Four Boxes from the various Case Studies are presented in the text of the Report to supplement the analysis.

Both phases of the Study were carried out during February - May 2007. A five week delay was caused by the civil unrest that prevailed in the country during this period.

The analysis of information gathered in both phases of the Study are presented in the following sections of this Report. A wealth of information and experiences was gathered. No doubt there is yet more to be learned from the field. Within the scope of this Report it was not possible to report on everything that was learned. Only those features that are of direct relevance to the objectives as detailed above have been included.

FIGURE 1: Geographical Distribution of Organizations included in the Study

**Handicap International-Nepal Programme
Community Based Rehabilitation (CBR) Study Districts**



PART 2

CBR AT WORK IN NEPAL

4. HISTORICAL PERSPECTIVE

While the first CBR organization in Nepal was set up in 1985 the most recent started in 2007. It was during the 1990s that CBR really took off in Nepal with 17 organisations starting new programmes during that decade which had a total of 29 organisations implementing CBR across the country. The highest entry rate was in 2002 with 11 organisations starting new CBR programmes, perhaps partially linked with a high level of donor interest in CBR at that time. Since then however and as can be seen in Figure 2, entrance figures have returned to an average of between two and four per year. In 2007, at the time of writing this report, just one organization had begun to implement CBR.

The first CBR programme was started by a volunteer group with home visits for 10 children in one Village Development Committee (VDC) in the Central region. Parents' demands had highlighted the need for a day care centre in this semi-urban area. Parents started meeting monthly to share experiences and during these meetings a play group was arranged for their children. A medical doctor, who became part of the volunteer group, gave his time to conduct monthly assessment clinics. Referrals were arranged to hospital for medical and surgical treatment and the group registered themselves as an NGO.



FIGURE 2: No. of Organizations starting CBR by Year

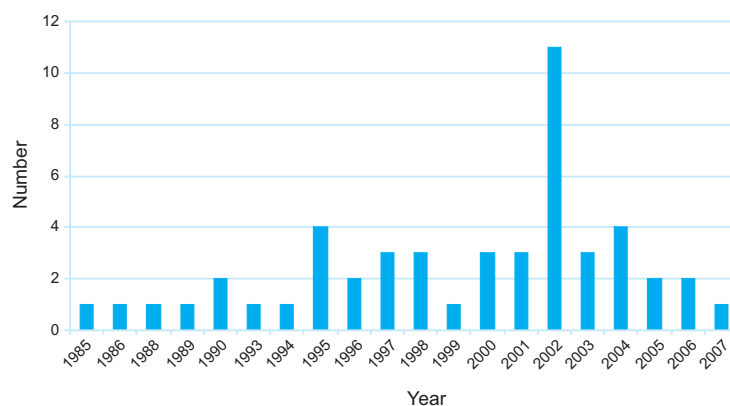


TABLE 1: Coverage by age and sex

	Grouped by age in years; 3 organisations						By age-group; 11 organisations			
	0-5	6-17	18-29	30-55	55+	Total	Children	Youth	Adult	Total
female										
by no.	47	233	152	47	20	499	1	1110	740	3438
by %	4	19.8	12.9	4	1.7	42.4	20.7	14.4	9.6	44.7
male										
by no.	74	303	193	86	22	678	1628	1614	1008	4250
by %	6.3	25.7	16.4	7.3	1.9	57.6	21.2	21	13.1	55.3
total										
by no.	121	536	345	133	42	1177	3626	2724	1748	7688
by %	10.3	45.5	29.3	11.3	3.6	100	41.8	35.4	22.7	100

From these small beginnings the NGO has expanded its activities and now operates as two organisations. One implements field programmes in two Municipalities and 16 VDCs and still meets the needs of children, while the other organization manages a Resource Centre to promote CBR and meet training needs.

5 COVERAGE

This study sought to ascertain the coverage of CBR in Nepal from a geographic perspective as well as in terms of age, gender, type of disability and types of interventions available. Pre-testing indicated that it was not possible to ascertain

programme coverage in terms of population as this information was not being systematically recorded by the organisations.

Geographical:

CBR programmes are running in each of the five Development Regions of the country and in 45 out of the 75 districts¹². Altogether, the Study found a total of 133 CBR programmes being implemented by the 51 organisations interviewed. While the vast majority of programmes are based in rural areas (over 90%), the highest density of programmes (34) was found in the Central Region while 33 were found in the Western, 32 in the Eastern and 10 each in the Far-western and Mid-western regions.

TABLE 2: Coverage by type of disability

Type of disability	Organisations including in CBR		Individuals included in programme (2005-6)	
	No.	%	Orgs.	No.
1 H/S *	41	80.4	25	1819
2 Visual	41	80.4	22	938
3 Intellectual	37	72.5	23	1055
4 Psychiatric	19	37.3	12	283
5 Developmental **	33	64.7	15	1170
6 Moving	44	86.3	25	5132
7 Leprosy	24	47.1	11	561
8 Epilepsy	19	37.3	9	369
9 Multiple	38	74.5	22	711
10 Other***	10	19.6	7	1016

* = hearing and or speaking/communication

** = includes cerebral palsy, does not include intellectual disability

*** = a number of medical conditions were listed e.g. heart conditions, rickets

¹² There are a total of 75 districts in Nepal.

By age and sex:

Data from 20 organisations indicates that there are more male than female beneficiaries¹³. Out of a total of 10,022 people served by these 20 organisations, 4430 or 44.2% were females while 5592 or 55.8% were male. Only three organisations were able to provide statistics by age and sex in years. A further 11 provided statistics by age-groups and sex. These are indicated in Table 1.

While, the sex ratio in the second group of statistics does not differ significantly from the first, both indicate a significant disparity where children have had the greatest coverage. One reason for this may be that community worker training generally focuses on children.

By type of disability:

As can be seen in Table 2, people who have mobility disability, for example people who have difficulty walking or moving themselves and their body parts, appear to be those who have greatest access to CBR. For example out of the 51 organisations interviewed a total of 41 include mobility impairment in their CBR programme while just 19 include epilepsy. Indeed, people who have disability arising from leprosy, mental illness and epilepsy seem to have the least access. This is significant, because these three conditions carry a high level of stigma.

Regarding the coverage of individuals who have disability in CBR programmes; the responses to this question were poor. As can be seen in last column in Table 2, not all organisations were able to give data on the number of beneficiaries of their programmes; for example, out of 44 organisations working with mobility impairment just 25 could give numbers of beneficiaries. The same was true with total numbers of beneficiaries. For this Study, 49 organisations reported a total of 107,504 people with disability as being included in their programmes. This figure is most likely less than the actual number of beneficiaries due perhaps to less than adequate record keeping that was noticed in most of the cases.

By components/interventions:

Table 3 lists the various components or the types of interventions carried out by CBR implementers, for example the provision of assistive devices, or health care. As can be seen, the majority of

TABLE 3: Components/interventions covered by CBR

CBR component/intervention	Organizations including in CBR	
	No.	%
1 Family and community living	46	90.2
2 Functional training	47	92.2
3 Assistive devices	46	90.2
4 Assistive devices	39	76.5
5 Livelihoods/income generation	47	92.2
6 Education	47	92.2
7 Health care	46	90.2
8 Political empowerment	10	19.6
9 Legal protection	22	43.1
10 Other*	-	-

* = obtaining disability ID cards, education about civic rights components/interventions appear to receive coverage by a high proportion of organisations, for example, out of the 51 organisations included in this Study, 47 are involved in education and 46 in health care. The study found that where a particular intervention was not included, the respective organisations were intending to include it at some stage in the future. In some cases an intervention may be implemented indirectly through another source. Political empowerment and legal protection are the least included, perhaps because for the moment at least, priority is given to basic human needs.

6 CONCEPTUAL AND CROSS CUTTING ISSUES

There are several conceptual and cross cutting issues each of which has implications not only on the quality of programmes but also on the sustainability of interventions. These are discussed below under the main headings Participation and Ownership and Technical and Management Capacities.

6.1 Participation and Ownership

Stakeholders:

The overwhelming majority of organisations (86.3%) identified people who have disability as the primary stakeholders. Family and Communities were identified as being the most important secondary stakeholders¹⁴.

¹³ Only 20 organisations had data based on the sex of beneficiaries.

¹⁴ Individuals and families together were identified by 9.7%, families by 2%, and individuals and communities together by 2%.

Participation of People who have Disability:

People who have disability were participating in the programme as members of CBR committees, as volunteers or as staff of the organization in just over 54% of the organisations. In 22 organisations they were resource persons and trainers while in others they participated in planning or as members of SHGs. A total of 139 individuals who have disability were employed in 31 CBR organisations. While comparisons with other countries in the region are difficult, it should be emphasized that CBR depends upon the active involvement of people with disability in programme design and implementation and this should be a priority.

Community Ownership:

Thirty six organisations (70.6%) were said to have community groups/organisations 'taking responsibility' for CBR. The main tasks cited in this regard included raising social awareness, resource mobilization and fund raising, and tasks relating to referrals and livelihoods which implies that in most cases, 'community ownership' is thought to exist when local partners 'participate' rather than 'have control'. In phase II of this study where more in-depth interviews were conducted with 11 organisations, real community ownership appeared to be rare.

Community Participation:

A total of 23 organisations reported various ways by which their respective communities participate in CBR. These were primarily noted to be 'staff', 'volunteers' and 'members of CBR committees'. Twenty three said communities participated in 'workshops and training', 16 said they were involved in 'awareness campaigns' and a further nine said 'information sharing'.

6.2 Technical and Management Capacities

Staff:

Since many organisations did not supply information about the number of employees,

Table 4 can only provide a general overview of the number and type of employees in the participating organisations. It is hoped that in the future more comprehensive information on staff will be available. For now, although a thorough analysis is not possible for the lack of data, there does appear to be a significant gender disparity at the management level with more than twice as many men than women said to be working in this area.

Out of the 51 organisations interviewed, 40 (78.4%) used community workers from the localities in CBR implementation. The most frequent tasks they carried out were noted to be 'counselling' and 'providing information about available resources', 'raising awareness', 'identifying needs', 'knowledge and skills transfer' and 'providing referral linkages'. Most organisations pay their community workers a monthly salary.

Training:

While 38 organisations stated that they had provided training to their managerial staff, six stated that they had not. In comparison, 48 organisations had provided training to their field and support staff while two had not. The duration of training courses for both categories were generally short, often one week or less. For both groups training covered a wide range of topics. For managers the training was some times as short as a one day course in basic CBR. "Management" courses were often anything up to two weeks. One manager had the opportunity of obtaining a diploma relating to hearing impairment after following a course of one year.

Basic CBR training for field/support staff was often three months. Many had followed short courses related to specific disability areas e.g. intellectual disability, counselling, and low vision. One field/support staff had physical therapy training in India for a period of one year. A few orthotic and prosthetic technicians have been sent to India for training.

TABLE 4: NUMBER OF STAFF EMPLOYED

Designation	Number employed		Gender		Full Time	Part Time
	Paid	Unpaid	Women	Men		
1 Managerial & administrative	106 (32)	73 (12)	54 (22)	126 (37)	100 (29)	85 (20)
2 Field & support	452 (41)	161 (17)	269 (39)	285 (43)	446 (42)	167 (16)

(no. in brackets indicates the no. of organisations employing this no of staff)

TABLE 5: Costs incurred by category

	Minimum	Maximum	Total	No. of Organization	Average
Annual Cost	65,000	10,040,000	88,367,016	48	1,840,980
Recurrent Cost	20,600	6,226,100	13,490,586	8	(Not Valid)
Capital Cost	10,000	500,000	1,320,941	6	(Not Valid)
Salaries	6,000	4,250,000	21,359,582	31	689,018
Transportation	3,000	250,000	1,072,243	26	42,889
Training	8,000	651,300	3,442,910	32	107,590

Sixteen organisations had developed training courses/modules, and four shared these with other organisations. A further nine were willing to share them with other organisations.

Reporting, Monitoring and Evaluation and Planning:

A wide variety of recording and reporting forms were collected during this study; for example 60 different types of forms were said to be used to keep records while more than 28 different formats were said to be used for reporting purposes (See section 11.3 for recommendations in this regard).

In relation to monitoring, all the organisations stated that they have regular programme mechanisms in this regard. Forty five used meetings, 49 used field visits, 43 used reports and one used participatory reviews. Frequency of monitoring ranged from 15 days to once yearly. Evaluations had taken place in 47 out of the 51 organisations. Eight of the organisations had only internal evaluations, seven had only external and 32 had both internal and external evaluations. The frequency in evaluations shows a remarkable increase in 2006 (26 and 20 respectively compared to previous years) while in the first three months of 2007 there had already been eight internal and four external evaluations conducted.

Forty nine out of the 51 organisations interviewed have made operational plans. Thirty three organisations made one-year operational plans, six organisations made five year plans, while one has made a 10-year plan of operations.

Financial Management:

Responses to questions related to costs were limited. The information that was collected can be seen in Table 5.

The average cost of salaries at Rs 689,018 appears globally to be quite high (although there are serious differences) which may limit sustainability and result in donor dependence. Average investment of only Rs 107,590 on training on the other hand may be inadequate in terms of capacity building for sustainability.

The Ministry of Women, Children and Social Welfare provides a grant of Rs 100,000 to 12 organisations. Twenty one organisations are supported by one donor partner while six organisations depend on two to three donors and four organisations on a combination of four to five donors. A total of 14 INGOs support CBR programs through budgetary inputs.

Eleven organisations out of the 51 interviewed charge some kind of fee for selected services (Table 6).

While most fees are relatively low, the cost of assistive devices may be high. Given the fact that many people in Nepal live below the poverty line¹⁵, the cost of obtaining services at a centre and having to pay for instance even Rs 10 - 15 for one physiotherapy session, may well be prohibitive for many families with a disabled member. Likewise costs for surgery can be prohibitively high for many people.

TABLE 6: Cost Recovery on Services

Ref	Service	Cost Recovery
1	Registration	Rs 10 - 25
2	Assistive device	10%-65% of production cost
3	Home visits	Rs 10 - 15
4	Services e.g. AT Centre e.g. surgery	Rs 10 - 25 Rs - 875
5	School/Day Care Centre admission	Rs 75 - 300 per month

¹⁵ 30.9% of the population lives under the national poverty line - UNDP, "Human Development Report 2006", UNDP, New York, 2006. The report also notes that 24.1% of the population lives under US\$ 1 per day while 68.5% live under US\$ 2 per day.

Networking:

Forty nine organisations link up in one way or another with at least one other organization. The remaining two organisations have no such links.

The major CBR network in the country is the National CBR Network. Fourteen districts also have their own CBR Networks. The benefits of belonging to a CBR Network include among others, access to training courses at reduced cost and the sharing of information and expertise.

The National Federation of the Disabled, Nepal (NFD-N) has a membership of 174 organisations in 70 districts.

The National CBR Network submitted a list of 38 members for initial mapping in preparation for this Study while the NFD-N had 23 organisations listed as being involved in CBR. Of these, a total of 20 had registered with both.

Some disability organisations have their own networks. These include the National Federation of the Deaf, National Association of the Blind, National Association for the Welfare of the Blind and the Association for the Welfare of the Mentally Retarded. Some organisations are also registered with their local NGO Federations and Coordinating Committees.

7 CBR THEMATIC AREAS

As noted in Part One above this study focuses only on interventions identified as most pertinent to Nepal and that are priorities for Nepalese stakeholders. This section examines these interventions under five main thematic areas including 'Family and Community Living', 'Support to Self-Help Groups and Disabled Peoples Organisation', 'Livelihoods', 'Education' and 'Health'.

7.1 Family and Community Living

Family interaction:

CBR calls for interventions to start in the homes of individuals who have disability. This is the first level where change should come. This Study found that among CBR providers in Nepal the proportion of interventions in the home is globally not adequate. It appears that out of the 51 organisations interviewed, only 19 are promoting family interaction in the home while just 11 transfer

knowledge and skills at the home level, and 19 provide counselling in the home.

The fact that only one organization provides home-level communication training seems perplexing. Similarly the proportion of organisations providing home-level interventions for self-care and mobility training is also indicative that CBR may often not be starting in the homes of individuals who have disability.

In addition, the larger proportion of interventions appear to be provided at community level while the proportion of referral services appears to be inadequate.

Community interaction:

This Report understands community interaction to involve activities that promote positive interaction between the community and the CBR programme important to promote community ownership and improve understanding about disability.

Only 37 organisations promote community interaction. The absence of this intervention in organisations appears to place limitations on the social inclusion of people with disability.

Community mobilization:

Community mobilization is a process of encouraging and supporting communities to analyze their own situations and to take steps to work together to make changes for the better. While 41 organisations carry out awareness raising in the community, only 34 do social mobilization which limits the chances of getting the active participation of community members in CBR, and is a further constraint to the social inclusion of people with disability.

Functional independence:

Functional independence interventions focus on a range of activities that aim to improve an individual's level of independence in daily living skills, communication, and mobility and so on.

Forty seven organisations (92.2%) include interventions related to functional training. As can be seen in Table 7, there are higher levels of interventions in self-care and mobility as compared to communication, reflecting the fact that most organisations include visual and physical disability, and less include hearing and speech impairments.

TABLE 7: No. of organisations facilitating functional independence and level at which interventions are available

Element of Functional Training	Organisations including in CBR		Level at which intervention can be accessed						
	No.	%	H*	C**	R**	H & C	R & C	H & R	H, C & R
1 Communication	28	54.9	1	14	4	3	2	-	4
2 Self-care	45	88.2	15	9	5	10	2	-	4
3 Independence in mobility including orientation	44	86.3	13	9	1	12	1	2	6

H = Home

C = Community

R = Referral level

Assistive devices:

As can be seen in Table 8, the highest number of assistive devices that are provided are mobility devices including, walking aids (78.4%), artificial legs (70.6%) and wheelchairs (70.6%) and the lowest numbers are for hearing aids (37.3%) which corresponds to findings globally, in relation to lower levels of intervention in the area of communication impairment.

Counselling:

Counselling of individuals and families is considered by many organisations to be an important task of community workers. Advice is given to people about understanding their situation and about the services they may seek.

Sports and Cultural activities:

While a range of 10 – 24 organisations state that they are facilitating inclusive and special sports and cultural activities, there was limited evidence of this in the field. The numbers reached through these activities must indeed

still be quite negligible. Sports and cultural activities are particularly important given the benefits accrued to the participants and the wider community in terms of social interaction and so on. A focus on activities such as this in the future would be a welcome development and would undoubtedly lead to the further strengthening of CBR initiatives.

Access to the built environment:

During the field interviews, some organisations were improving the physical infrastructure of schools (improving toilets, roadways etc). However, no direct beneficiaries of efforts to improve accessibility in the home or the built environment in the community were encountered which might mean that perhaps the numbers of those reached on such initiatives may still be quite small.

Knowledge and skills transfer:

As seen in Table 9, 11 organisations facilitate knowledge and skills transfer through training

TABLE 8: Provision of Assistive devices

Type of assistive device	Organisations including in CBR		Level at which device can be accessed							
	No.	%	H	C/M ob	R	H/C	H/C/R	H/M/R	M/R	C/R
1 Hearing aids	19	37.3	-	4	7	1	2	2	2	1
2 Spectacles	25	49.0	-	7	11	2	1	1	3	-
3 White canes	34	66.7	12	10	6	4	1	-	-	1
4 Seating aids	30	58.8	10	9	5	3	1	1	-	1
5 Walking aids	40	78.4	11	8	6	10	1	-	-	4
6 Wheelchairs	36	70.6	4	12	4	3	-	3	1	9
7 Tricycles	22	43.1	3	10	2	3	1	-	1	2
8 Calipers	35	68.6	11	7	8	4	2	-	-	3
9 Artificial legs	36	70.6	3	6	21	2	1	-	1	2
10 Artificial arms	24	47.1	1	5	13	2	-	-	1	2

H = Home

M = Mobile

R = Referral

C = Community

Box A: Profile of a Community Disability Worker

Geeta, works as a Community Disability Worker (CDW) for a CBR programme based in the Far-western Region of Nepal, before this she spent 10 years working as a Development worker with the organization. The only bread winner in her family, Geeta is married to a loving husband and has two adorable daughters aged nine and five years.

As a CDW, her daily routine involves carrying out activities that she plans on a monthly basis. One of the routine tasks that she enjoys is raising the awareness of various groups such as child clubs, schools and community groups through social communication. She also visits homes to give Primary Rehabilitation Therapy (PRT) and to counsel children and families. She also facilitates school enrolment and disability ID cards for those children who need it.

The organization has given her a bicycle to get around the VDCs in her area. This enables her to reach many more children since public transport is very scarce in her district. To get to the nearest home on her bicycle it takes her half an hour and to the farthest it takes her one and half hours.

Geeta says that she has a passion for social work. She describes herself as “a straight forward person who is dedicated to her work”. She would love to learn English and to use the computer. She hopes this will be possible in the future. She says that she does not like people who are not honest.

She loves her work. She feels that the children and families that she visits all show their love and support towards her. Every time she visits a home, she is offered vegetables and fruits or anything that they could afford as a sign of their appreciation.

during home visits. Another 30 carry this out both at home and at community level, and one does this only in the community. Field visits indicated that in most cases the technical content of this could be improved.

7.2 Support to Self Help Groups and Disabled Peoples Organizations:

The empowerment of Self Help Groups (SHGs)

is being supported by many organisations. This occurs most often within communities, as it should. Another positive development is that most support goes to cross-disability groups (62.7%) with 51% of organisations supporting single disability SHGs (Table 10).

Individuals who have visual impairment and those who have hearing impairment are in the comparatively fortunate position of either being

TABLE 9: Elements of Family and Community Living that are Supported by Organisations

Element of Family and Community Living supported	Organisations including in CBR		Level at which intervention can be accessed		
	No.	%	H	C	H/C
1 Promoting family interaction	38	74.5	19	19	13
2 Transfer of knowledge and skills	42	82.4	11	11	30
3 Counselling	44	86.3	19	19	19
4 Promoting community interaction	40	78.4	-	-	3
5 Social communication/raising awareness	41	80.4	-	-	20
6 Social mobilization	34	66.7	-	-	6
7 Organizing inclusive sports	20	39.2	-	-	-
8 Organizing special sports	24	47.1	-	-	-
9 Organizing inclusive cultural activities	19	37.3	-	-	1
10 Organizing special cultural activities	10	19.6	-	-	-
11 Improving housing and access within the home	33	64.7	33	33	-
12 Improving access to the community built environment	36	70.6	-	-	-

H = Home

C = Community

TABLE 10: SHGs and Parents Groups supported by Organizations

		Organizations supporting		Organizations supporting at community level		Organizations supporting at district level		Organizations supporting in community and district	
		No.	%	No.	%	No.	%	No.	%
1	Single disability groups	26	50.9	15	29.4	4	7.8	7	13.7
2	Cross-disability groups	32	62.7	22	43.1	5	9.8	5	9.8
3	Parents groups	24	47.1	21	41.2	1	2.0	2	3.9

in single disability groups or being included almost always in cross-disability groups. The largest number of single disability groups is for people who have these two impairments. Several categorized as being cross-disability in fact include only two types of disability such as visual and hearing or mobility and intellectual.

Many parents groups include parents of children with any type of disability. Not surprisingly perhaps, parents who have children with the same disability have tended to come together and therefore there are separate parents groups for children who have intellectual, hearing, visual and physical disabilities. Fortunately these are not duplicating efforts in the same communities as even if they are specialized, there is usually only one parents group in a community.

Support to all three types of groups, single disability, cross-disability and parents groups, is related mostly to organisational development, capacity building and leadership development. Financial support is also given, or, in some instances, linkage to financial resources.

7.3 Livelihoods

As can be seen in Table 11, 46 organisations stated that they facilitate skills training. Thirty four facilitate microfinance, and 18 facilitate

grants for self-employment, indicating that some organisations must be involved in both. Thirty four facilitate job placement in the open market. However field interviews indicated that this is still generally a weak component of CBR, with many adults who have disability having no livelihood at all. The numbers reached by these organisations must therefore be very small. While small enterprises are promoted through self-employment no business management skills are yet included.

7.4 Education

There are several approaches to ensuring children with disability have access to an education. This section discusses the approaches encountered in Nepal.

Early Childhood Care and Development (ECCD):

This refers to a range of interventions in early childhood. ECCD recognizes that children from 0-8 are at a critical stage of their development and interventions that focus on areas such as nutrition, health care and education are designed to help develop a child's potential.

Twenty nine organisations stated that they include an ECCD component. Field visits however, indicated that providing therapy in the home was often described as ECCD.

TABLE 11: Types of livelihood support and numbers supported

Element of livelihoods/ income generation supported	Organisations including in CBR		Level at which intervention can be accessed						
	No.	%	H	C	R	H/C	C/R	H/C/R	
1 Vocational skills	46	90.2	4	20	5	8	7	2	
2 Microfinance	34	66.7	11	13	5	4	-	1	
3 Grants	18	35.3	4	7	2	3	1	1	
4 Cooperative activities	19	37.3	-	15	1	2	1	-	
5 Open employment	34	66.7	3	6	20	1	4	-	

H = Home

C = Community

R = Referral level

Eighteen organisations indicate that they run inclusive ECCD Centres (preschools) and 11 run special preschools. Considering that many of the organisations in the Study have a mandate only to serve children, the number of inclusive preschools is as yet inadequate meaning that opportunities to maximize the child's development potential starting as early as possible are missed out.

These statistics confirm the fact that CBR programmes generally do not pay adequate attention to the early years of childhood.

Inclusive Primary Education:

Inclusive education is the process of ensuring disabled and other vulnerable children and young people have equal rights and opportunities to education. It is a process towards access, participation and achievement for all in education.

Forty organisations state that they facilitate inclusive primary education (Table 12). Of these, 28 organisations have 2700 disabled children in general schools at the present time. The 12 other organisations have not supplied data. If this is because they do not maintain adequate records, then this is a weakness on their part. Adequate statistics need to be kept so that children can be followed up.

Children who have physical disability are supported by the highest number of organisations (24) for inclusion. Children who have hearing impairment and those who have visual impairment are each supported by 12 organisations. Children

who have intellectual disability are supported by five organisations. There are thus too few organisations supporting inclusive education for these latter groups.

Special Education:

This refers to the education of children with disabilities that takes place in special schools or institutions distinct from, and outside of, the institutions of the regular educational system.

Nine special schools for children who have hearing impairment and five each for those who have visual impairment and intellectual disability are supported. There are two special schools for children who have physical disability. Whereas special schools have an important role, inclusive education needs also to be promoted and it is hoped that where appropriate these children will soon be placed in general schools. For this to happen, the schools would need to ensure physical accessibility as well as teacher training and the sensitization of future classmates.

Integrated education:

Integrated education refers to the inclusion of children with disabilities into some classes in a mainstream school. The process is generally supported by a resource teacher and the children may just attend a selected number of classes during the day.

Integrated education is an opportunity that is available in Nepal essentially to children who have visual impairment; 10 organisations support 486 children with visual impairment.

Box B: Sangeetha's Story.

Sangeetha is 30 years old and is from the Central Region of Nepal. She cannot speak or hear, and has epilepsy and intellectual disability. She cannot look after herself. She first attended the local Day Care Centre about 11 years ago. After only two visits she started going to the School for Mentally Retarded Children. But she didn't go there for long as she kept running away fearing that something unwanted may happen and her mother stopped taking her there. Later with the help of the local CBR Organization she was placed in a boarding school. But again she tried to run away. The school refused to accept responsibility for her so once again she is at home. When her mother goes away on a long trip she takes Sangeetha along with her. If she is only out for a short while she locks her up in a room. Sangeetha's father is also not well. Her mother does not receive much help from other family members. Her neighbours appear not helpful either.

Sangeetha is visited at home by the volunteer from the Organization once or twice every month. The CBR Organization has provided medicine for epilepsy free of cost for the past year. When her mother needs not to be interrupted by her, Sangeetha is given the same medicine to keep her quiet. Sangeetha's mother wants to send her to the Day Care Centre but is unable to pay the fee required. Taking her there and collecting her is also difficult since the time interferes with her own work. However, Sangeetha still has friends that she made while she was at school. They visit her at home and she also goes to school to see them. She has no friends in the neighbourhood though.

TABLE 12: Numbers of organisations supporting various types of education with number of children included and number schools including by disability

Aspect of Education supported	Organisations including in CBR				No. of schools that include children				
	No.	%	Children included		Hearing	Visual	Physical	Intellectual	Multiple
			Orgs.	Children					
1 Inclusive preschools	24	47.1	14	182	5	5	12	7	1
2 Special preschools	11	21.6	6	99	4	6	3	7	1
3 Inclusive primary education	40	78.4	28	2700	12	12	24	5	2
4 Special classes in general schools	11	21.6	7	142	5	6	1	4	-
5 Integrated education for children who have visual impairment	14	27.5	10	486	-	10	-	-	-
6 Special schools	12	23.5	7	271	9	5	2	5	-
7 Teacher training	19	37.3	11	(790)	5	2	3	-	1
8 Non-formal education	12	23.5	8	392	1	2	11	-	-
9 Higher education	26	51.0	20	365	3	10	21	-	-
10 Braille teaching-learning	15	29.4	9	108	-	11	-	-	-
11 Sign language teaching-learning	25	49.0	15	342	16	-	-	-	-

Teacher-Training:

While 19 organisations state that they support teacher-training for inclusion of children with disabilities into regular schools, 11 of them have facilitated the training of 790 teachers to date. In many instances these are just one-day courses for teachers on the management of disability. There needs to be a far greater emphasis on this if inclusive education is to be a reality.

Higher Education:

Twenty six organisations state that they facilitate higher education. Field interviews indicated that this consists largely in provision of scholarships. The highest number with access to higher education by type of disability is those who have physical impairment. Again, field interviews indicated that this was mostly those who have milder degrees of disability. There was no evidence of the built environment of the higher education institutes being adapted to ensure its accessibility for people with disabilities.

Non formal Education:

Non Formal Education (NFE) recognizes the need to address education outside of the normal framework and refers to learning, skills and competencies that are acquired outside the formal educational or school setting.

Of 12 organisations that stated they facilitate Non Formal Education, eight have supported a total of 392 children which is an adequate ratio. This approach is one that could be developed in inclusive settings to benefit the large numbers of children with disability that have had no education at all.

Braille teaching/learning and Sign Language teaching/learning:

Only 15 organisations facilitate Braille teaching/learning, and only 25 facilitate sign language teaching/learning. Although the exact number of people with hearing or visual impairment in Nepal is to be confirmed, the HI CAHD project experiences indicate that hearing and speech impairment appears second to mobility impairment in terms of prevalence. In light of this, the number of organisations teaching Braille and sign language may not be adequate.

7.5 Health**Medical and surgical treatment:**

Forty six organisations provide or facilitate access to medical and surgical treatment for conditions such as club foot, skin and tendon release or amputations. Forty four of these organisations use referrals with a few providing community level services (e.g. health camps).

Physiotherapy, Occupational therapy and Speech and Language therapy:

Forty one organisations state that they provide physiotherapy (29 at home); 21 provide occupational therapy (14 at home) and 29 provide speech therapy (18 at home).

There are at present 12 to 15 physiotherapists registered with the Health Professional Council of Nepal. It is believed, through enquiries made during this Study, that there are just three occupational therapists and one speech therapist currently working in Nepal. While it is unlikely that occupational therapists and speech therapists participate in CBR, a few physiotherapists are employed by NGOs and may be supporting CBR in a few instances.

The statement by 41 organisations that they provide these three forms of professional therapy needs clarification. They refer to the fact their community workers provide “Primary Rehabilitation Therapy” or “PRT”. Some organisations equip their community workers for their field work by sending them to follow 3-month training courses which include a focus on PRT, but it does not equip them to the level of a qualified physiotherapist or occupational therapist.

8 WHAT THE ORGANIZATIONS SAY

On Achievements and Strengths:

All the organisations involved in this study were

pleased with the level and type of services that they have been able to provide. Many felt that they have been able to expand programme coverage and reach more communities. Six organisations stated that one of their main strengths was the increased participation of people who have disability in programme development. Many considered the provision of assistive devices to be another of their main achievements.

On Problems and Weaknesses:

The vast majority (47 out of the 51 organisations) found that irregular, inadequate and time-limited funding was the biggest constraint to their operations. Twenty five organisations indicated that inadequate attention to social mobilization restricted the active involvement of communities in CBR. Those organisations that worked in the more remote areas far from Kathmandu, found that geographical terrain and inadequate public transport were major barriers. Many organisations felt that they had not as yet been able to provide their staff with sufficient training. Other problems mentioned included lack of coordination between implementing organisations and what was seen as limited clear Government policies to direct CBR.

On Sustainability:

Thirty one organisations stated that continuous and adequate financial support was the greatest factor that would allow sustainability of their programmes. Another 23 stated that community acceptance of CBR would be an important factor. Networking to share experiences and resources was stated by 21 organisations while

Box C: A District Self-Help Group

This District SHG from the Eastern Region started in 1998. At that time the local CBR organization was only serving children, and there were very few services for adults who have disability. Led by Kumar who has disability and is employed by the organization, a few individuals got together and established an SHG. A meeting of individuals who have disability was called. Thirty people attended the first meeting to discuss the need for an SHG. The SHG stresses the need for inclusion of disability in the mainstream. It is supported by the CBR organization. Kumar acts as the link between the District SHG and the CBR organization.

One of the major tasks of the SHG is advocacy and lobbying. It advocates about rights with the District Development Committee (DDC), Municipality, Education Office, and Small Cottage Industries and so on. Targeted agencies are visited personally and Interaction Programmes are held with them. After an Interaction Programme with a large NGO for instance, they included disability issues in their annual budget. Now all their partners are called upon to mainstream disability into their gender equity, income generation, skills development, education and health programmes.

One of the most successful outcomes of lobbying was that the DDC allocated Rs 340,000 for disability from its budget. From that, the CBR organization gets Rs 90,000 for surgery, the SHG gets Rs 25,000 for vocational training, and other NGOs and CBOs get varying amounts. With the Rs 25,000 obtained last year the district SHG carried out a vocational training course for 15 members in collaboration with the CBR organization.

Box D: Raju's Story

Raju is 25 years old and is one of a family of four children. He and CBR came into contact with each other during a survey being undertaken by a local CBR programme for people with visual impairment. He was visited at home by the community worker from the organization. To help him be independent Raju was provided with orientation and mobility training. To prepare him for school the community worker taught him Braille which took five months.

At first there were many difficulties. Raju's family thought that he was very different from other children and kept him hidden from society. They needed a lot of counselling before they allowed Raju to come out of the house.

Raju was then admitted to Class 5 of the integrated education school in Town. At first he commuted to school from home but after two years he was admitted to the residential home run by the organization so that he could concentrate on his studies. While at school the organization supported him with the materials that he needed.

He performed very well at school. Raju passed his School Leaving Certificate (SLC) in the first division. With a mark of 71% he came first in the district. His conscientiousness and grades impressed the local College administration and as a result they waived his admission fees. Currently Raju lives alone in a rented room in Town to attend College. Raju is very happy at College. He has many friends and acquaintances who help him when he needs it. He wants to become a teacher in the future. He is also interested to learn music and hopes that he could get some help to pursue this interest. He would like to get married but only after he has obtained his Bachelor degree and has a job. He is a member of the local DPO. The local newspaper has had a feature article about him. He is well known on the campus, in the Town and in his own village. He is popular at social events.

Six years ago the organization gave him a loan of Rs 15,000. He bought a buffalo. That was a good investment since he has already paid the loan, has a saving of Rs 12,000 and a baby buffalo. With this, he can start breeding buffaloes and have a sustainable income to help him with his education.

19 believe that the empowerment of people who have disability will decide sustainability. Twelve organisations would like to be independent of foreign assistance.

On their future plans:

Twenty one organisations stated that their future plans include a major emphasis on increasing opportunities for people who have disability. Many organisations will take steps to improve their monitoring systems, both to identify weaknesses and take steps to overcome them, and to identify strengths and build on them. Sixteen organisations will look for a wider donor base and 13 will develop local networks, both of which will increase sustainability.

Their suggestions to improve CBR in Nepal:

Thirty seven organisations called for more supportive Government policies and actions on CBR. Seventeen would like to see more interest in disability issues from other State development sectors. Stronger networking and increased participation of people who have disability were other factors that the participating organisations stated would improve CBR in Nepal. Some organisations also felt that improved monitoring and programme evaluation by Government, will also help improve CBR.

PART 3

CONCLUSIONS AND RECOMMENDATIONS

9. CONCLUSIONS

Nepal was one of the first countries in the world to start implementing CBR and after 22 years there are many valuable lessons that can help CBR implementers not only in Nepal but in many other countries as they strive to attain the goals of CBR.

One main observation that emerges from this Study is that many organisations implementing CBR in Nepal use it as a holistic strategy. It is refreshing to observe that in Nepal, organisations have responded to the needs of those it seeks to serve rather than enforce their own mandates. CBR interventions are often linked to the social needs of individuals and are not implemented in isolation. For instance, schooling is linked to counselling of families and to Child Clubs while vocational training takes place together with the empowerment of SHGs and promoting community interaction. This approach has increased effectiveness, relevance, impact and sustainability.

A second observation that emerges is the opportunities for empowerment that CBR offers individuals who have disability. This Study has found new and promising dimensions in Nepal's CBR in this regard. These extend from organisational empowerment to individual empowerment seen especially in Boxes 1, 4 and 5 in the Annex 3.

9.1 Conceptual and Cross Cutting Issues

9.1.1 Participation and Ownership:

Community ownership is considered to be a corner-stone of CBR. This is the feature that differentiates CBR from the outreach strategy and it is important for many reasons, chief among them being that it is one of the most effective ways of influencing attitudes and bringing about positive change.

However, a significant observation that comes out of the Study is that in Nepal the locus of control still lies generally with the organization implementing CBR. Only in some instances does it lie with the



communities served. While Box 8 in Case Study V (Annex 3) demonstrates the difficulties faced by individuals, families and organisations when there is no community responsibility and ownership in CBR, Box 13 indicates in Case Study XI (Annex 3) the consequences on schooling for a child when responsibility has not as yet been delegated to the community.

As noted earlier just over 54% of organisations had people with disability participating in the programme as committee members, staff or volunteers while less than half of all organisations reported on methods for ensuring community participation. CBR should be implemented through the combined efforts of people with disabilities, their families, organisations and communities as well as the relevant government and non-government bodies¹⁶. The participation of people who have disability together with their families and communities in both programmes and organisations should therefore be and remain a major priority for CBR implementers.

One possible approach to improve this situation is to ensure community workers are adequately equipped for the role they could take in CBR. Recommendations in this regard are given below in section 10.2.

9.1.2 Management and Technical Capacities:

This study found CBR management in Nepal to be impressive. Structures are effective and CBR managers possess good skills and are capable leaders. However, reporting is limited and data is not always collected and analyzed within programmes, thereby impacting on quality. Furthermore, although some organisations have demonstrated strong capacities in terms of financial management and in the mobilization of local, national and/or international resources¹⁷ there are difficulties in this regard with some organisations reporting problems due to irregular, inadequate and time limited funds. In addition, a large amount of funding is spent on salaries with less spent on training which impacts on sustainability. Moreover, there appears to be a general lack of information which may, in some cases, lead to a lack of transparency. Recommendations that may help organisations address these issues are given in sections 10.1 and 10.3 below.

In terms of technical capacity there are still limitations in this regard. This is evidenced in the weakness related to knowledge and skills transfer noticed in several cases and which has resulted in many individuals still being confined to their homes as they lack skills in functional independence and remain dependent on the sometimes infrequent visits of community workers. In turn, the community workers themselves may not be adequately equipped to meet all the needs of their clients, meaning individuals may have to travel to Centres to receive therapy which for some might not be possible due to great distances or commitments at home.

The vast majority of community workers encountered during this Study do not see themselves as agents of change or empowerment. Often they see themselves as “giving therapy”. This situation where individuals have only a passive role as recipients of therapy can be disempowering and leaves little room for those who have disability to be the decision-makers or to have control over their own lives. It therefore can seriously hamper a major purpose of CBR. One possible solution is discussed below in the recommendations section 10.2.

9.1.3 A note on Gender:

CBR programmes should promote gender equality. Although this report cannot comment in depth about the gender dimension in Nepal's CBR, the little data that is available does indicate that more men than women are reached by CBR programmes (section 5). On a positive note, some very efficient female managers were encountered in some of the organisations participating in this Study; however the majority of managers encountered were men. CBR implementers should make a concerted effort to promote further gender equality in the course of their work and donors and government alike should support such efforts.

9.2 CBR Thematic Areas

9.2.1 Family and Community Living:

Family interaction, community interaction and community mobilization activities have had many positive results. By demonstrating to families the innate abilities of their disabled relative, CBR in Nepal has led to greater levels of acceptance and

¹⁶ WHO, *CBR: A strategy for Rehabilitation, Equalization of Opportunities, Poverty Reduction and Social Inclusions of People with Disabilities*, 2004. <http://www.who.int/disabilities/publications/cbr/en/index.html>

¹⁷ Case Studies I and II in Annex 3

respect for people with disability within the family unit. Moreover, CBR has helped individuals who have disability take leadership roles, gain peer recognition and respect and become more visible in their communities as evidenced for example in Box 2 in Case Study II (Annex 3).

However, in a few organisations interventions in this regard are confined to individuals and there is little or no interaction with families and communities. In such situations, family and social change cannot be foreseen. Furthermore, community mobilization activities need to reach more individuals to better promote the inclusion of people who have disability and while it is interesting to note that one CBR organization¹⁸ has started campaigning for the voting rights of individuals who have disability, the upcoming elections highlight the need for more organisations particularly SHGs, to take action on this issue.

Generally and as reported by most of the organisations, there is inadequate referral between organisations and services which is something that needs to be addressed for the benefit of all.

In terms of functional independence, the ongoing support from international agencies to Physical Rehabilitation Centres in each region of the country and three Satellite Units in hilly regions for the production of mobility devices and/or provision of physiotherapy for people with physical disability is to be applauded; however attention should also focus on functional independence initiatives for people who have disabilities other than mobility impairment.

Overall it should also be noted that people with mental illness, leprosy and epilepsy are generally not as well included as they should be in CBR programmes. Actions to address this issue should be taken as soon as possible by relevant stakeholders.

While counselling is conducted on a regular basis by community workers, recommendations on training as discussed below in section 10.2 may help community workers expand and improve their counselling skills. Sports and cultural activities and access to the built environment are important issues that have the potential to also dramatically improve the quality of life for an individual who has

a disability. However, initiatives in this regard to date seem to be fairly small leaving considerable room for improvement. Again this is an issue for CBR implementers, donors and government alike. Finally, recommendations in relation to the transfer of skills and knowledge are discussed in section 10.2.

9.2.2 Support to Self Help Groups and Disabled Peoples Organizations:

Over 76% of organisations have recognized that through their support of DPOs and SHGs, the collective voice of people who have disability has the potential to influence the ethos that governs their situation. CBR has brought SHGs to the forefront of community decision making in many localities. As can be seen in the case study “Seeds of Empowerment” and Box 3 (Annex 3) many SHGs have demonstrated their capacity to influence through their unrelenting efforts to be included in community-decision-making fora and their persistent and sometimes successful lobbying of local authorities to have their right for a share of financial resources. In this way, SHGs have made clear the potential they have to bring about rights-based communities and they should be supported in that aim.

Several DPOs are themselves managing single disability CBR programmes one example of which is outlined in Case Study VIII in Annex 3. Organizations such as these may find that their work will have a greater impact if they open their doors to people who have other types of disability, however in some situations single disability initiatives maybe the best approach for example in the case of less common disabilities which may not receive due attention in a cross disability group. What is important is that there is a good balance in such initiatives and approaches.

9.2.3 Livelihoods:

While over 92% of organisations have included the livelihoods component within their CBR programmes thereby demonstrating the value they place on economic empowerment, field interviews for this Study indicated that this is still a comparatively weak component of CBR in Nepal (section 7.3).

None the less, attempts at economic empowerment are to be appreciated in the current economic situation of the country and

¹⁸ See Case Study II (Annex 3)

realistically speaking there have been few, if any, options thus far at least, for organisations other than to use their own capacities. It is also important to stress that livelihood interventions have had a significant impact on the lives of many individuals and communities, through for instance the development of role models and by making people who have disability more visible.

However, in undertaking interventions and in certain cases, organisations may be extending themselves at the cost of quality and coverage. For example vocational training can be undertaken by an organization that has no expertise in the area of livelihoods development and in such situations there can be a lack of proper follow-up and support. Promoting the mainstreaming of disability into development organisations would perhaps help resolve this situation by providing CBR implementers and beneficiaries access to further skills and knowledge in for example the area of small business development. The need for the mainstreaming of disability is discussed below in section 10.1.

9.2.4 Education:

Nepal's CBR generally attaches significant importance to obtaining schooling opportunities for children who have disability and this is most often facilitated through material means such as scholarships, provision of educational materials and improving accessibility in schools.

While on the positive side, achievements by children with disability who have had educational opportunities are often remarkable, much work is still required to prepare relevant human resources such as school administrators, teachers, parents, communities and children for inclusive education. All too often children in Nepal are still refused access to school whilst parents are frequently requested by teachers to discontinue their child's schooling. In addition, it appears that children with disability are commonly subjected to abuse by their peers.

While the Ministry of Education has put its policy of Inclusive Education into effect in 220 schools within 22 districts meaning that by the year 2009 they plan to have 500 model schools, there is a need for CBR at the National level to further link up with the Ministry of Education so that Inclusive Education and CBR can develop hand in hand. In addition links need to be strengthened between special schools and inclusive education

opportunities to ensure children with disability benefit from the most appropriate intervention for them.

Non-Formal Education activities are important and can at times ensure the most vulnerable or marginalized groups have opportunities to learn. Given the high number of children with disability that are out of school, activities in this field should be supported to become inclusive.

While sign language training is facilitated by a few organisations it is still largely confined to those who have hearing impairment and it is only on occasion that family members are included in courses. There is therefore a need for much more widespread dissemination of sign language skills.

Furthermore, and as stated by organisations themselves, in most cases detection of disability does not take place as early as it should. Children have often reached the age of seven or eight before CBR finds them or they find CBR. Even for those few children who are detected early, the focus is on therapy and not on ECCD or on a programme of home-based early stimulation. This issue needs to be addressed by all stakeholders including CBR implementers, donors and government.

9.2.5 Health:

As seen in some of the case studies presented in Annex 3 health referrals have proved extremely beneficial to many people and CBR has proved an effective way of linking the health services to people in more remote communities.

However, health referrals can prove very challenging and are relatively costly, thus limiting the numbers of individuals that organisations can support for medical and surgical care. Specialized therapies (physiotherapy, occupational therapy and speech and language therapy) are also still scarce in both the government and private health care systems. In addition, medicines for epilepsy appear not to be available in the government health services and many families cannot afford to purchase stocks continuously.

This can be overcome with improved training of community workers and other field staff and with more effective and extensive networking. In the longer term, to a greater extent and in a qualitative context it will depend on the ability of the health service not only to develop and provide

a referral service for medical and surgical care, but also to provide support and referral through the specialized therapies. Strategies to make the health services more accessible to this most vulnerable group are necessary and should be a priority. There is also a need to clarify minimum criteria for physiotherapists (PT), occupational therapists (OT), speech therapists (ST) and community workers so that programmes can provide a realistic idea of what services they can provide.

10 RECOMMENDATIONS

Three broad recommendations emerge that have the potential to address most of the issues discussed above. Firstly the organisation of a **National Conference on CBR** is recommended to bring stakeholders together to provide them with the space to reflect on the past and to plan for the future from a rights-based perspective. Secondly, a thorough **review of the current training curricula for community workers** is recommended. Community workers are key actors in CBR implementation and a review of their training followed by any necessary updates that are identified would help address many of the weaknesses encountered during the course of this Study. Last and not least, the development of a **Disability Management Information System** to collect, collate, analyze and use information regarding the location, situation and needs of people with disabilities is a necessary prerequisite to ensure quality in the design and implementation of any initiatives.

10.1 A National Conference on CBR - towards a Rights-Based Strategy

The first 22 years of CBR in Nepal has produced a multitude of invaluable experiences. Until now however opportunities for analyzing these experiences and for sharing these with other stakeholders have been few, meaning that opportunities for feeding these back into the CBR system to move it forward towards its goals have been somewhat limited. A National Conference on CBR would be the ideal vehicle to allow this sharing. The Conference could take the following issues into consideration:

UN Convention on the Rights of Persons with Disabilities:

Nepal may soon be a signatory to the UN Convention and take steps to ratify it. Even in

preparation for that event, CBR is ready to provide a vehicle for its implementation. The experiences of the past years present a foundation upon which the rights-based strategies contained in the Convention can be built.

Disability as a Cross-Cutting Issue:

In terms of the Convention, people who have disability have the same rights as all other citizens to access all development and welfare processes. It makes disability a cross-cutting issue of immense dimensions. This in turn provides a clear direction for the future development of CBR. It offers distinct possibilities to include disability in mainstream programmes at all levels of development. It remains for organisations and their donor partners to take up this challenge.

Implications for Donors:

Donor partners have a vital role to play in mainstreaming disability. CBR development requires not only support to the disability sector, it requires also support to the various development sectors (education, poverty alleviation, skills development, employment creation, decentralized development administrations) to promote the inclusion of disability issues.

Locus of Control:

One major re-direction that may be required of CBR for it to be an effective vehicle for the implementation of the Convention is to shift the main locus of control from organisations to grass-roots stakeholders. Individuals who have disability, their families, SHGs and communities need to be further empowered. They need to have control of their lives and programmes to bring about the attitude changes required for the fulfilment of Rights.

Enlarged Role of Organizations:

The principle underlying the rights-based approach is the inclusion of people who have disability in the mainstream. In this context the role of organisations is to promote and facilitate inclusion. With this, organisations will have a more important role in society than they now do. To enhance opportunities for inclusion, organisations need, on the one hand, to provide interventions that will prepare individuals and families for inclusion. On the other hand organisations have a very important role in preparing the mainstream at all levels to accept people who have disability as citizens of equal worth.

Role of Community Workers:

In the context of empowerment and of the enlarged role of organisations, community workers need to be an effective link between them and the grass-roots which they are called upon to empower. They take on a dual role; they are accountable both to the organization and to the communities with which they work, with perhaps a bias towards the latter. This may call for changes in their training (See section 10.2)

Clarify Roles of CBR staff:

As discussed above, clarification of the roles of Community Worker, Physiotherapist, Occupational Therapist and Speech Therapist would help organisations and beneficiaries alike. This is an initiative which could be discussed at the national conference and an action plan developed.

Strengthen and Develop Referral Linkages:

As discussed earlier, referral linkages are not as strong and systematic as they should be. The National Network of CBR Organisations would be an ideal platform where referral linkages at the primary, secondary and tertiary levels can be discussed and possible actions on this issue could be agreed.

10.2 Training of Community Workers

A thorough review of the basic training of community and field workers and making appropriate changes to the current curricula would go some way toward addressing some of the main limitations in present-day CBR in Nepal as encountered in this Study and outlined in this Report. This would in turn help to improve the effectiveness and impact of programmes.

Current training courses are often impairment and/or disease focused. The role that community workers are prepared for is that of extension workers for the organisations that employ them. Essentially they look on their main function as counselling and “providing therapy” to children. They view as their second function “raising social awareness” of the communities they cover. Within this, schooling is facilitated, and this is a strong component. Community workers have responsibility for bringing about some degree of inclusion such as in child clubs. Lack of

knowledge and skills related to disabilities other than mobility however limits the scope of their role. Training in communication (hearing and/or speech) disabilities, intellectual disabilities and visual impairments is insufficient. Consequently the functional independence of children with these disabilities remains limited.

This is a constraint to the development of rights based CBR, to the inclusion of disability in mainstream development programmes and to the implementation of the UN Convention on Persons with Disabilities. Further, these all call for CBR to include all persons who have disability, whatever their age or their disability and not only children.

A review and an updating of the current curricula from the perspective of rights and empowerment and the social definition of disability¹⁹ will help organisations implementing CBR meet these challenges whilst also contributing to the future development of CBR in Nepal.

For this, the tasks that community workers are called upon to carry out in rights-based CBR need to be enumerated first. Many organisations implementing CBR have some experience in this, and certainly have the collective potential to undertake such an analysis. The contribution of the National Federation of People with Disabilities, Nepal (NFD-N) would be essential. However inputs from Sociologists and Human Rights scholars will no doubt provide valuable guidance.

When approached from this new task analysis, curricula will clarify the vision and potential of CBR from a community workers perspective. It will widen their scope of activity from being impairment oriented to being development oriented; from being a training experience to being an educational experience. Collaboration with a University in the preparation and delivery of training is one possibility that would most likely place disability in the development arena where it belongs whilst also raising the profile of disability and of people who have disability.

Once undertaken, Nepal's pioneering efforts in the education of community CBR workers will provide a valuable global learning experience.

19 As noted by WHO, “The social model of disability has increased awareness that environmental barriers to participation are major causes of disability. *The International Classification of Functioning, Disability and Health (ICF)* includes body structure and function, but also focuses on ‘activities’ and ‘participation’ from both the individual and the societal perspective”. WHO, *CBR: A strategy for Rehabilitation, Equalization of Opportunities, Poverty Reduction and Social Inclusions of People with Disabilities*, 2004. <http://www.who.int/disabilities/publications/cbr/en/index.html>

10.3 Developing a Disability Management Information System (DMIS)

The Ministry of Women, Children and Social Welfare has seen the need for developing a Disability Management Information System (DMIS) through CBR so that it can better support organisational and programme development and through this, to manage National disability issues more objectively and effectively.

This Study appreciates this initiative taken by the MWCSW and endorses it fully.

A Management Information System in disability/CBR has three components: 1) a data collection system; 2) mechanisms for learning from information obtained; and 3) feeding this learning back into CBR programmes to bring about improvements.

In current CBR programmes, elements of all three components exist at the organisational level albeit in an ad hoc and extremely diverse manner. They are currently used only for monitoring. These formats and reporting systems can be further developed to meet both the management needs of organisations and, collectively, that of Nepal's CBR through management support that will be available from the MWCSW.

These recommendations are therefore made to assist the MWCSW to collate existing experiences and bring them into a formal DMIS through a consensus of stakeholders. The DMIS is best viewed as an extension, and not a replacement, to the monitoring done by organisations themselves.

Step-wise recommendations to develop a DMIS:

- i. Select a partner to assist the MWCSW and to whom the task of developing a DMIS may be delegated. The National Federation of People with Disabilities – Nepal (NFD-N) may be the most suitable partner. It has a wide coverage in the country with offices in all Development Regions and secretariats in the districts. Its offices may be used as the peripheral focal points and its headquarters in Kathmandu as the National Focal Point of the DMIS. With 174 member organisations in 70 districts, it has the widest representation of people who have disability in the country. It would have the greatest interest and commitment to the development of a DMIS.

- ii. With the NFD-N, appoint a Task Force. Draw up objectives and a plan for the development of the DMIS. Estimate costs for logistics (expertise in database development, computers, accessories, software, duplicating forms, travel) and for personnel if necessary and identify sources of funding.
- iii. Develop recording and reporting formats (Annex 4 for suggestions), components and mechanisms involving as wide a representation of stakeholders as possible.
- iv. Select 1-2 districts for preliminary testing. Allocate the required financial, logistic and human resources. Train community, other field workers and management to use the DMIS and implement.
- v. Evaluate, make changes, train personnel and expand in stages. Continue to monitor, review and update DMIS.

Note on the Data Collection System:

Formats need to be prepared that will collect required data. Core formats that collect information needed for the DMIS could be made. They can be kept flexible so that organisations could add to it if they wish. It is important that the same formats are part of each organization's own management system and are used for monitoring.

In the past in various countries, there has been a tendency to make data collection records and reports complex and time-consuming. These have been severe barriers to the development of a MIS. It is best to make recording and reporting formats as simple as possible. They should only collect information that is essential to meet the objectives of the DMIS.

10.4 Other areas of recommendation, according to the issues raised and discussed in the report:

Additional Recommendations for Government:

- ◆ Ensure increased coordination and communication with the network/forum of CBR organisations.
- ◆ Provide support to the development of criteria for professions such as OT, PT, ST and community workers.
- ◆ Develop links between special schools and inclusive schools.

Additional Recommendations for CBR organisations:

- ◆ Develop and strengthen referral networks.
- ◆ Develop strategically towards further comprehensive implementation of CBR, addressing all components: family and community living, self-help groups, livelihoods, education and health for people with all disabilities: physical, sensory, intellectual and psychiatric.
- ◆ Develop relationships with diverse funding sources (donors, government, INGOs etc)
- ◆ Commit towards further participation and ownership of communities and individuals with disabilities.
- ◆ Develop gender equity, through sensitive recruitment and services targeted towards women with disabilities.

- ◆ Commit to sound data collection and reporting.
- ◆ Ensure representation of all people with disabilities by balancing single with cross-disability groups.
- ◆ Commit to organisational development through training staff and volunteers.
- ◆ Develop education opportunities for people with all disabilities, including Braille and sign language training for people with sensory disabilities.

Recommendations for INGOs/Donors:

- ◆ Actively seek to support CBR organisations through building their capacity to further develop in the areas listed above.

PART 4

Case Studies

This Study found that a wide variety of approaches are used in Nepal to implement CBR. The following 11 case studies cover all development regions, and are intended to represent the widest possible variety of approaches which are representative of those used across the country. The case studies are as follows:

- I. Seeds of Empowerment
- II. The Present Scope of CBR in Nepal
- III. Inclusion and Sustainability through Partnership
- IV. Disability in the Context of Development Organizations - Example One
- V. Disability in the Context of Development Organizations - Example Two
- VI. An Urban Programme for Children
- VII. An Attempt at Sustainable CBR
- VIII. A Programme for Individuals who have Visual Impairment
- IX. The Cost of Dependence
- X. A Hospital as a Resource
- XI. A Programme for Children who have Physical Disability

I SEEDS OF EMPOWERMENT

This case study relates to an organization that was set up in 2001 in a district in the Eastern region of Nepal by a group of young people (some of whom have disability) who decided to start a CBR project as they felt that people like them were kept separate from their families and communities. They had been influenced by the work of two other organisations implementing CBR and they adapted the work of these organisations to develop their own approach.

This CBR programme is one of 12 in the country which receives an annual grant of Rs 100,000 from the Ministry of Women, Children and Social Welfare.

Names has been changed to assure annomity.

Approach

VDCs and Municipal Wards are selected on the basis of contacts that the core group has with local people who have disability. Meetings are arranged with respective groups in the communities where disability issues and the possibilities that CBR offers are discussed. A coordinating committee of 9-12 people with disability is established. One of these, or another community member who may come forward, is selected to work as their rehabilitation facilitator in a voluntary capacity.

The coordinating committee arranges community meetings to increase social awareness of disability and CBR. Individuals who have disability are identified at the community level and are then visited at home by the rehabilitation facilitators and members of the coordinating committee. Their needs and the services they require are determined. Possible interventions commence with knowledge and skills transfer to individuals and families.

Activities

Home visits:

Each rehabilitation facilitator visits the homes of the individuals identified at regular intervals to provide support and follow-up.

Social interaction:

Community meetings continue to further the discussions about disability and the community's role in CBR. These meetings help increase the social interaction of individuals who have disability by giving them the opportunity to get out of their homes and to go to the market, the temple and to attend formal meetings of the VDC and so on.

Sign language training:

Sign language classes are organized. Each course lasts 6-9 months. The classes are taught by their own members, and when necessary assistance is sought from a NGO in Kathmandu.

Assistive devices:

The organization provides assistive devices obtained from the Children's Hospital in Kathmandu and from the NGO running the regional orthopaedic workshop. They are obtained at subsidized rates and distributed free of cost or at a small fee. Costs are met from a grant obtained from the Disability Fund of the Social Welfare Council.

Schooling:

Children who need schooling are linked up with local schools. Scholarships are facilitated whenever possible. School books, uniforms and other materials are sometimes provided for those with limited resources.

The organization has close links with two district schools in particular. Both started as special schools, one for children who have intellectual disability and the other for those with hearing impairment. The two schools have since been absorbed into two general schools to provide a more integrated approach.

Support for livelihoods:

Youth and adults are given loans for self-employment through revolving loans schemes. Skills development courses are sometimes arranged by the organization. In some instances individuals are referred to other district resources for vocational training.

Health referrals:

Referrals are made for those who need medical and surgical treatment. Children, for instance, are referred to a children's hospital in Kathmandu which is approximately 550 kilometres away. Others are referred to the Regional General Hospital or even to tertiary level hospitals in Kathmandu. Costs of referrals are met when needed.

Special programme for children who have cerebral palsy:

Physiotherapy is given to children with cerebral palsy, of which there is a high number. Two volunteers make home visits while some children also come to the CBR office once a week for physiotherapy. One volunteer has received three months training in 'Primary Rehabilitation Therapy' (PRT) in Kathmandu. He has made six home visits in six months. The other volunteer is a physiotherapist from the district centre for children who have cerebral palsy.

Identity cards:

The processing of disability identity cards is facilitated. An identity card will allow the holder access to numerous benefits including: entitlement to a monthly allowance of Rs 250; salaries free of tax for up to Rs 150,000 per annum; government hospital services free of cost; entitlement to free education in schools and

BOX 1: Preethi's experience exemplifies the manner in which this organization works

Preethi, a confident 19 year old with a pleasant personality, attends College. Her childhood was a difficult period. She had to work hard to overcome the emotions associated with a marked facial disfigurement. She was one of those responsible for the initiation of CBR in Municipal Ward No. 01 of which she is a resident. Along with a small group of people who had to live with the consequences of disability, Preethi helped bring others like them together.

They set up a "coordinating committee" to which nine people were elected. She was one of them. Her friend Bhumi was selected to be the rehabilitation facilitator. The coordinating committee together with Bhumi assumed responsibility for taking action to improve the lives of all their members who had disability. They arranged meetings to bring members of their ward together and discussed their situation. They discussed the CBR organization that had been set up in their district and about how they could benefit by joining it.

When they first started the programme they did not quite know what they could do for each other. Some of them participated in a training course on CBR arranged by the organization. Preethi, Bhumi and their fellow-members on the committee concentrated on bringing people who have disability out of their homes to participate in activities organized by various groups in the community. They attended meetings of the VDC and spoke on behalf of people like them. But there are still some individuals, especially those who have more severe disability, about whom they do not know what to do.

Preethi feels that the greatest benefit they have had from the programme is that people who have disability are no longer ashamed to come out and be seen. The second greatest benefit has been the Revolving Loans Fund the CBR organization helped to start in Ward No 1 just over one year ago. They were given a loan of Rs 10,000 and advice on how to operate it. Although the loan has to be paid back in one year in quarterly instalments, many pay it back much sooner. So, now in her Ward there are 10 people who have disability (or parents of children who have disability) who have benefited from the loans scheme. They have taken up to Rs 2,000 each. They pay interest of Rs 100 for one year. Preethi herself took a loan three months ago and bought two goats. They are looked after by her mother because she is busy with studies. There is no cost for feeding the goats since fodder is obtained from the surroundings. She hopes to make a good and sustainable income by breeding the goats.

colleges; up to 25% discount for long distance travel (this is however not applicable in all offices); priority for obtaining a teaching license or any other kind of job and customs fee waiver.

Networking:

This CBR organization has an extensive network that includes the Government sector (VDC, Municipality, District Development Office, schools, Women's Development Office), many local CBOs (women's groups, youth groups), and NGOs and other institutions both inside and outside the district (regional disability resources, NGOs doing CBR, hospitals). It has been, for instance, the local contact for a tertiary level hospital and has participated in organizing mobile camps for the hospital. Many children from its own programme benefited from the mobile camp.

Findings

Impact and overall effectiveness of the programme to date²⁰:

As a result of the actions of this organization:

- ◆ CBR has been started in all nine Municipal Wards and in 10 of the 36 VDCs in the district. So far, 1,027 people have been reached of whom 69 are girls, 85 boys, 368 women, and 505 men.
- ◆ 250 assistive devices have been distributed to date. This includes white canes, walking aids, wheelchairs, callipers and artificial legs.
- ◆ The organization has to date assisted 400-500 people to obtain disability Identity Cards.

In relation to poverty alleviation:

- ◆ 5 wards in the Municipality have started revolving loans schemes, and others will have them soon. By the end of 2006, a total of Rs 80,000 had been distributed to 26 recipients all of whom now have sustainable incomes.

²⁰ While impact refers to the actual results achieved so far the effectiveness refers to the success or value of the actions from the perspective of the beneficiaries in this Study and in the context of CBR in Nepal.

In relation to health:

- ◆ During 2006, nine children finally received cleft palate surgery for which they had waited many years. The total cost was Rs 57,600 as most went to Kathmandu where services must be paid for.
- ◆ 72 individuals were seen at a two-day health camp at a cost to the organization of Rs 1,815 per person. Physiotherapy has also been provided at a cost of Rs 35,572 for a three month period.

The organization feels that both interest and awareness about disability have increased within the communities it serves. Some of the views expressed by community members about the organization include

- ◆ “they identify people who have disability and look at their rights”
- ◆ “it is run by people who have disability, making them visible in community”
- ◆ “they are committed to CBR and to their members and have helped people who have not had access to services”
- ◆ “they mediate between people who have disability and services which will enable them to have their rights fulfilled”

The organization believes it has helped to change attitudes and behaviour of families and communities towards members who have disability. The general perception among the beneficiaries themselves is that people with disability are now better accepted and respected as a result of the work done to date. The CBR office is situated in the centre of a main street in the town, and passerbys often stop to have a word with members inside.

Individuals who have disability and the parents of children with disability, have been brought together and have been empowered. Self-development, self-confidence and self-reliance have been facilitated and the focus on livelihoods has contributed to this.

Effectiveness has been constrained due to levels of technical knowledge and skills within the organization – for example in the area of communication training and functional independence. Only 12 of the rehabilitation facilitators and committee members have had

any formal training, and that was just 2-3 days training run by their own members. The organization itself feels that it does not know what to do about some individuals, particularly those who have more severe disability.

While the programme includes a wide range of disability, people who have mental illness, leprosy and epilepsy are not as yet included; this is significant as the latter are all conditions which generally carry a greater stigma.

Although the organisation has made significant achievements, some areas are not as yet, so advanced, for example, the inclusion of people who have disability in everyday life and in the development sector; the mobilization of local communities and resources for CBR; and networking with other community and local development organisations for the benefit of people who have disability.

Sustainability²¹:

The organization has an effective structure. From the general membership of 39, a General Assembly of 11 is elected, together with an Executive Committee of five members. A four person Advisory Committee is appointed by the Executive Committee. All these have a good gender balance.

One person is employed for office work. All the other workers are volunteers. This includes 11 facilitators, one in each VDC and one for the Municipality. Volunteers mediate between the individual, the family, the community and the organization. They also do home visits. Volunteerism is a strong tradition in Nepal and in rural areas in particular.

The total cost in 2005-6 was Rs 290,000 which includes Rs 70,000, for salaries, Rs 10 - 15,000 for transport, and Rs 25 - 30,000 for training. These costs are met from the Rs 100,000 grant from the MWCSW and Rs 191,902 from the VDC, DDC, Municipality, and the Federation of Nepal Chambers of Commerce and from local industry.

The organization feels that local resources are more effectively mobilized, that it has good networking skills and has established fruitful partnerships. It operates at minimal cost with no

²¹ As above, sustainability concerns factors which influence the continuity of the programme.

direct INGO funding. As such, a strong possibility of sustainability can be observed.

While the project plan is now made yearly, a longer-term perspective may enable the organization to develop more efficiently.

II THE PRESENT SCOPE OF CBR IN NEPAL

This organization was set up to start CBR in 1990 in a district in the Eastern region. Previously there were few services available for adults and no services available in the area for children who have disability.

Approach

The coverage area is decided based on demand for services. The organization advertises in the local newspaper and selects community workers from localities where demand for services is high. The community workers are given 15 days basic training by the organization. The training covers topics such anatomy and physiology, assistive devices, and an introduction to all types of disability.

Meetings are then arranged in all the selected VDC areas²². Invitees include VDC secretary, school authorities, CBOs, NGOs, savings and credit groups. The purpose is to introduce their community workers, to discuss the disability situation, and to ask for their support.

The community worker carries out a door to door survey to identify individuals who have disability regardless of age or type of disability. If people who have psychiatric disability are found, they are referred to the appropriate services.

Activities

Home visits:

Home visits are made once per week to each home for problem and needs identification and disability and background assessment. Skills and knowledge are transferred to individuals/families and followed up.

Interaction with Communities:

Community meetings are organized by community workers and field staff and serve to allow

discussions on the current situation, problems and possible solutions such as costs, schooling, what skills training is most suitable to the area and what products the community might need.

Rehabilitation Centre:

A Rehabilitation Centre was set up by the organization in 2000, enlarging the already existing small orthopaedic workshop. Before the Rehabilitation Centre was established, individuals had to be sent to Kathmandu, (approximately 540 kms away), for many assistive devices. The Rehabilitation Centre serves as the first level of referral in most instances. Physiotherapy is provided to those who need it at a cost of Rs 25 per session.

Assistive devices:

Many assistive devices are made in the orthopaedic workshop at the Centre. These include walking aids, wheelchairs, tricycles and artificial legs and arms. Assistive devices are provided free when not affordable, and renewed/ repaired when necessary.

Support for Inclusive Education:

One hundred and twelve teachers were given a one-day orientation last year on the classroom management of children who have disability. This should be considered to be only a beginning, and much more teacher training is required if children who have disability are to be successfully included.

It has been the practice of the Ministry of Education to integrate Special Schools for the hearing impaired and for the intellectually impaired into general schools. There are two such schools in the district, and the organization supports both of these. For instance, it pays the salaries of two teachers for the hearing impaired in one of the general schools.

Future plans include supporting Early Childhood Care and Development (ECCD) Centres in the district to become inclusive.

Schooling:

The community worker has an important role in getting children admitted to local schools. The organization provides scholarships and educational material for children from families with limited resources.

²² The population of a VDC ranges from 3,000 – 10,000

Child Clubs:

Child Clubs are supported to become inclusive and it appears that children who have disability enjoy these very much (See Box 2).

Parents Group:

The organization supported parents of children who have intellectual disability within the programme area to form a Parents Group. This is now in the process of being registered with the District Administration Office. The organization will encourage the group to enlarge itself and to encourage parents of children with other types of disability to join.

Community Self-Help Groups (SHGs):

The organization currently supports SHGs that are known to be working in the VDCs where it is operating. The groups made contact with the organization and first requested resource persons to provide training in areas such as Rights-Based Approach, Orientation & Mobility and Sign Language. If the organization has no suitable resource persons, they find them from other NGOs. Both SHGs have secured allocations from the VDC budgets.

Vocational Training:

The Organization has started providing skills training. Last year, in collaboration with the district SHG it arranged a six-month skills training in TV, radio, watch and bicycle repair for 15 males. It was carried out in a VDC with the local community providing space for the participant's

residential accommodation. All the trainees are currently earning an income using the skills they acquired.

Braille Teaching/Learning and Sign Language Teaching/Learning:

Twenty four individuals were taught Braille and 50 participated in learning sign language through courses arranged by the organization in 2005-6.

Referral to hospitals/health services:

Individuals are referred by the Centre for surgery and medical care; some referrals are to hospitals in and around Kathmandu. Costs are met when necessary and individuals are followed up at home by field staff.

Advocacy and Mediation:

A situation analysis of people who have disability in the district has been carried out. The analysis will be used to advocate for greater inclusion of people who have disability in the mainstream.

The organization is using the upcoming elections to advocate for the voting rights of people who have disability. They meet political parties to discuss issues related to the voting rights of individuals who have visual impairment and individuals who have intellectual disability and accessibility in voting booths for wheelchair users and others. These issues have also been raised with the Office of the High Commissioner for Human Rights (OHCHR).

BOX 2: Child Clubs

Community workers visit the Child Clubs in their VDCs and encourage them to accept children who have disability whilst also encouraging children who have disability to join the Clubs. The Community workers then provide the Clubs with ongoing support for instance they may meet with the children regularly or provide the staff with training or advice on working with children who have disability. To date, the organization interacts in this way with 15 Child Clubs.

Child Clubs serve as an important forum to develop the abilities of children. Street theater raises issues that are important to children – for example child rights and the need for gender equity and so on. They publish wall newspapers which contain news of importance to the community – about events that are planned as well as stories and poems written by children and articles about child rights issues. People in the community feel that this is a useful way of disseminating information, not only among children but among adult community members as well.

Mohan, who has cerebral palsy and moves and speaks with considerable difficulty, has been a member of his local Child Club for many years. For the past three years he has been the President. He wants to be a politician and make things better for people who have disability. Mohan is 17 years old and is in class nine. Obviously an extrovert, he is very popular both in school and in his neighbourhood. His school performance is very good. His first contact with the Organization was through the community worker in his area very many years ago who encouraged Mohan to join the Child Club. Through the Organisation he obtained a wheelchair so that he could go to school more easily. Before that his father carried him to school. A tricycle now enables him to get around with his friends, go to the cinema and concerts.

BOX 3: District Self-Help Group

The District SHG started in 1998. At that time the CBR organization was only serving children, and there were very few services for adults who have disability. Led by Kumar who has a disability and is employed by the organization, a few individuals got together and established an SHG. A meeting of individuals who have disability was called. Thirty people attended the first meeting to discuss the need for an SHG. The SHG stresses the need for inclusion of disability in the mainstream. It is supported by the CBR organization. Kumar acts as the link between the District SHG and the CBR organization.

One of the major tasks of the SHG is advocacy and lobbying. It advocates about rights with the DDC, Municipality, Education Office, Small Cottage Industries and so on. Targeted agencies are visited personally and Interaction Programmes are held with them. After an Interaction Programme with a large NGO for instance, they included disability issues in their annual budget. Now all their partners are called upon to mainstream disability into their gender equity, income generation, skills development, education and health programmes.

One of the most successful outcomes of lobbying was that the DDC allocated Rs 340,000 for disability from its budget. From that, the CBR organization gets Rs 90,000 for surgery, the SHG gets Rs 25,000 for vocational training, and other NGOs and CBOs get varying amounts. With the Rs 25,000 obtained last year the district SHG carried out a vocational training course for 15 members in collaboration with the CBR organization.

Another successful outcome was achieved through the advocacy they did with the Post-Graduate Campus. They lobbied for the provision of free education for students who have a disability. After some discussions with the authorities this is now being implemented.

Discussions on child rights with emphasis on children who have disability are held regularly with other groups such as nurses, doctors, medical students, government agencies, NGOs, political parties and journalists. Rights-Based training has been given to 61 people who have disability.

Networking:

Realizing that INGO support will one day come to an end, the organization places a heavy emphasis on networking to promote sustainability. Referral networks are in place. Partnerships have been established with Government Agencies, VDCs, and other development CBOs and NGOs. These are sensitized and supported to include disability in their work.

Findings

Impact and overall Effectiveness of the programme to date:

- ◆ The organization now works in all 22 of the Municipal wards and in 45 of the 65 VDCs. A total of 1,185 new children who have disability were identified in these areas in 2005-6.
- ◆ In the same year 505 children and adults received mobility aids from the Rehabilitation Centre. This included 90 tricycles and 37 wheelchairs. The impact on the lives of recipients is undoubtedly considerable, giving them freedom to move about in their

neighbourhood. In the same year the income from assistive devices was Rs 111,940.

- ◆ A total of 858 children had physiotherapy either at the Centre or through home visits. Most were children who have cerebral palsy. Forty nine children were referred for corrective surgery.
- ◆ 15 young males received skills training in TV, radio and watch repair. They are all deriving an income using the skills they acquired.
- ◆ 1,185 disability identity cards were facilitated.

In relation to education:

- ◆ 718 children are enrolled in 18 general schools. This includes 68 new children who registered for the last academic year. It includes also several children who have intellectual disability. A further 148 children are in resource classes. In one inclusive class in a general school, out of 55 students, one with complete hearing loss secured second place in order of merit and the other seven with the same impairment were within the top ten on the list. In many cases parents of children who have disability participate with interest in school activities alongside other parents.
- ◆ Scholarships to the value of Rs 253,000 were procured from the District Education Office for 466 children. Educational material was provided to 92 children.
- ◆ Accessibility in four schools was improved to enable children who have physical disability to access their right to education.

Box 4: The Integrated Development Forum serves as an example of networking and of the partnerships established by the CBR organization.

The Integrated Development Forum (IDF) is a CBO working in 14 deprived Municipal wards that was started five years ago to mobilize people to take action towards improving their situation. The IDF at present implements activities focusing on Women's Rights, Child Labour, the Environment and Disability Rights. The secretary is a dynamic young man named Raju who himself has disability.

The IDF, through its members, has identified 280 people who have disability, among whom there are 180 children. Having found these individuals the IDF contacted the CBR organization to seek their advice and help in their work with their members who have disability. Now, four years later, 80% of children have become functionally independent and are in school. Assistive devices needed by children have been obtained from the Rehabilitation Centre run by the CBR organization. Children who need physiotherapy (particularly children who have cerebral palsy) are receiving it also from the organization. Those who need surgery are also referred with the help of the CBR Organization.

The IDF places heavy emphasis on getting children to school. This is difficult in these poor communities because parents do not see the importance of this for their children, especially for those who have disability. IDF spends time counselling parents. Frequent meetings are held within the communities to discuss these issues. Interaction with schools also takes place, and accessibility in some has been improved with the advice of the CBR organization. Children who are registered in school are followed up to make sure they do not drop out.

The organization has 200 members many from marginalized groups. They pay a fee of Rs 21 per month (Rs 1 is for the organization and Rs 20 goes into their savings account). Monies collected are reinvested and savings accounts earn an interest of 5%. Loans are given to members at 3% interest.

- ◆ As an initial step, 112 teachers in five schools were given a one-day orientation in Inclusive Education. Further initiatives in this regard should be supported.
- ◆ 42 children who have disabilities participate in the 15 Child Clubs. One of these members was selected to be a member of the VDC Planning Committee. Many hold office in the Clubs.

The Rehabilitation Centre and Orthopaedic Workshop enable the organization to better meet the needs of individuals who have restricted mobility. It serves as the Regional Centre. Child Clubs, Parents Groups, SHGs, networking, advocacy and mediation activities all contribute to increasing the relevance of the work done by the organization.

Sustainability:

The organization promotes community ownership of CBR. Out of 41 VDCs, 18 have formed Village Development Rehabilitation Committee (VDRC) to take responsibility for their programmes. The VDRC includes the VDC secretary as the member-secretary of the body. It also includes representatives of major stakeholders - health post, members of SHGs, CBOs, NGOs, mothers' groups and political parties. The organization will advocate for VDRCs to start in all VDCs so as to

promote sustainability of CBR. The prevailing political uncertainty has contributed to delays in this regard.

The organization lobbies VDCs for budgetary allocations for disability. So far four VDCs have granted allocations of Rs 44,500 each.

The organization has a good structure. An Executive Board of 13 members includes only one member who has disability. It has met 11 times over the last year. Staff meetings and meetings with community workers are held regularly.

Emphasis is placed on capacity building of staff. Community workers start with a 15-day introduction to CBR by their own staff. After 2-3 months they participate in a regular three month basic CBR course run by a Training Organization. Ten community workers have had refresher training in CBR at the same Training Organization. Several have had various other short training on topics such as HIV/AIDS, networking, community mobilization and so on.

The 26 community workers have a monthly salary of Rs 2,500 each. The minimum

educational requirement is the School Leaving Certificate (SLC). Turn over of community workers is low and ten have been with the programme since 1990 when it started.

The organization employs four rehabilitation facilitators. They look after the 22 municipal wards as well as provide support to all the community workers in the VDCs. Two of the rehabilitation facilitators are currently doing an MSc. and two have completed Intermediate Level. As well as having the same training as the community workers, rehabilitation facilitators have also had seven days Training of Trainers (TOT) and five days training on Inclusive Education. One has been sent to India for training for one year and another is due to be sent shortly.

The organization has been supported by one INGO from the beginning. It now also has several other international partners thereby increasing its sustainability. Its total budget for CBR is Rs 2,200,000 for 2006-7.

III INCLUSION AND SUSTAINABILITY THROUGH PARTNERSHIP

This Organization, which started in 1975 to serve only patients with leprosy in a hospital, enlarged its activities in 1990 to serve all types of disability. In 1997 it started CBR, first working through SHGs and other CBOs. At the same time it changed from the Project-Based to the Integrated Programme Approach. It is based in the Western region.

Approach

This Organization now has two broad areas of work including:

The Partnership Programme:

This entails community capacity building through local partners to establish sustainable CBR. The organization started its work in CBR with SHGs which are still foremost among its local partners who also include small development or disability CBOs that are selected from applications and contacts. Support is given to partners to increase their capacities until they become sustainable.

In the first phase, partners are mobilized and helped to include disability components into their

programmes and promote the inclusion of people who have disability into the community. This is done through strengthening of management, advocacy and fund-raising capacities and technical training of staff. Small time-based financial assistance is also given (1-5 years).

Partners are also helped to form a network with local development organisations, e.g. with Community Forestry Groups, training organisations, stone and sand quarries, construction contractors, local clubs and interest groups and so on which are all important focal points for inclusion as well as for contributing to programmes in kind - material for housing, boats for income generation etc.

In the second phase the organization “withdraws”. Partners are assisted to register with the District Development Office and with the Social Welfare Council and to seek grants provided by the government (these grants can only be used for activities and not for payment of salaries etc.). Contact is however maintained so that partners can seek technical support (such as for training) when necessary. Also, if necessary, small financial support is given for staff salaries and capital and infrastructure costs. Contacts with other donors are facilitated.

The Outreach Programme:

includes services from the hospital mostly in the form of socio-economic rehabilitation to serve ex-patients - individuals who have had leprosy or HIV/AIDS, or have disability. Five hundred individuals are being reached in this way at present.

Findings

Impact and overall Effectiveness of the programme to date:

The programme has now been extended to 10 districts in two regions of Nepal, including the Mid-West. Advocacy by both the Organization and local partners has encouraged many development organisations to include disability in their programmes and some larger organisations have requested information on disability. Interest in disability has been created in some government agencies such as the District Women's Development Office which acts as a focal point for disability work in the district.

- ◆ With 15 local partner organisations, over 12,000 individuals are now being reached. The value

BOX 5: The Youth Club – from disability to development

The parent organization entered into a partnership with a district-based (local) youth club in 2002. The Club had already showed interest in working towards the inclusion of people who have disability in the mainstream through CBR. It had a few other development activities at the time, but showed commitment and potential to implement CBR. The parent organization supported the development of managerial, advocacy and technical capacities. It also provided finance for staff salaries and some activities. The agreement ended in 2005. By this time the Club could manage its own affairs. It had itself lobbied with Government for an allocation for disability work from the district budget, establishing a trust for the purpose. The club coordinates the administration of the trust. The Club also promoted the formation of a network among organisations working in CBR in the district. The Organization introduced the Club to two other partners for funding to ensure that the activities of the Club would continue to expand.

From being an institution with largely a disability focus, the Club has emerged as a leading development NGO in the district. Among its disability-related activities at the present time are social mobilization leading to the setting up of community rehabilitation committees, home level interventions, support to SHGs, teaching of sign language, the provision of assistive devices., economic empowerment, social inclusion through inclusive schools, child clubs, youth clubs and women's groups, and increasing community knowledge about disability.

In the wider development context it provides comprehensive support to develop schools infrastructure, school health services, child rights promotion, health promotion, provision of drinking water and toilets and support to children affected by conflict. More recently it has embarked on peace management, democratization, and community empowerment.

of services provided to each individual varies from Rs 200 to Rs 100,000 (for a house). Nine of the partnerships are long-term (3 or more years) while the others are short-term (less than 2 years).

- ◆ 9 local partners have so far been made sustainable.
- ◆ In total, the Organization and its partners are interacting with 103 groups of people, including community groups, government agencies and non-governmental organisations.
- ◆ 6 local partners are SHGs of people who have disability, helping individuals within these groups to realize their potential; increasing the potential numbers of leaders and improving the social standing of people who have disability.

This is one of the few organisations that encourage the inclusion of people who have had leprosy in the mainstream through CBR. To date, about 50% of individuals reached by local partners have been affected by leprosy.

Sustainability:

From being an INGO, the organization has now registered as a local NGO. The bulk of its funding however continues to come from international partners. The focus on promoting the sustainability of local partners bodes well for a lasting impact.

IV DISABILITY IN THE CONTEXT OF DEVELOPMENT ORGANIZATIONS - EXAMPLE ONE

Established in 1990, this is a development organization that implements development programmes in all five districts of the Far-Western region. While the main organization is in one district, there are branch organisations in the four other districts. Development activities are organized as four programme sectors including:

Education and Early Childhood Development:

Early Childhood Care and Development (ECCD) Centres, Out-of-School Children's Programme, Child to Child Education, Child Societies, Language Learning and Experience, Adult Literacy.

Health, Drinking Water and Sanitation:

HIV/AIDS, strengthening Outreach Clinics, Training Health Workers, Health Camps, Support to Health Posts.

Opportunity for Economic Development:

Group and Cooperative formation for income generation, Women Empowerment etc.

Natural Resource Management:

Community Forestry, Agricultural Production etc.

Disability Component

CBR implementation was initiated in 2001 with the project Community Approaches to Handicap in Development (CAHD) which is implemented in one district. Previous to this, the organization had done some disability work including community awareness and production and distribution of mobility devices. In 2006 it started a full scale Rehabilitation Centre with an expanded orthopedic workshop and a physiotherapy service.

Approach

Any existing DPOs in selected areas are contacted, as is also the DDC and Women's Development Office. Meetings about the need for CBR are organized and possibilities are discussed. Feedback is obtained, agreement is reached and the disability programme commences.

The organization plans with communities and then supports their work. It also acts as a mediator when necessary. A CBR coordination committee consisting of people who have disability, a representative of the Women's Development Office, NGOs, DDC and any Government organization in that area is formed.

Corresponding to this, a Community Rehabilitation Committee (CRC) is formed in each VDC. There are now 15 CRCs which take responsibility for CBR. The community disability worker facilitates the setting up of the CRC in each VDC and ward. Each CRC has about 11 to 15 members. This includes on average seven members who have disability. The main task of the CRC is to support the work of the community disability worker. Another important task is to lobby for a budgetary allocation from the VDC. They also facilitate free health care and ensure education for children who have difficulty to gain admission to school. They increase awareness about disability. Some CRCs implement Savings and Credit Schemes.

Activities

Inclusive income generation programme:

As part of poverty alleviation, microfinance, vocational training and self-employment are provided as an inclusive programme.

- ◆ For micro finance, a revolving loans scheme

is implemented for 1800 families, including those who have disabled family members. The capital stands at Rs 4,500,000. In addition to this, 12 families with members who have disability have been provided with grants of Rs 5,000 each for activities such as goat keeping, running a barber's shop etc. This grant money has been initially given in the form of loan but after one year of monitoring by the CBR staff, it is turned into a grant.

- ◆ Vocational training is provided in areas such as sewing, cycle repairing and furniture making.
- ◆ For self-employment, the organization provides training, and then the tools and raw materials that are needed by trainees so that they can embark immediately on earning their living. The last training course was provided six months previous to this Study and to date, there has been a 50% success rate.

Rehabilitation Centre:

The Rehabilitation Centre responds to the needs of branch organisations. Technicians from the centre visit localities to assess needs. A range of devices are provided free of cost and according to demand including orthotics, prosthetics and mobility aids.

Annual mobile camps are organized by the Centre in each district. Assistive devices are made locally whenever possible (or later at the Centre) and distributed. Physiotherapy is also available.

Field Programme:

The field programme includes all age groups and disabilities. It is implemented by community disability workers supported by their CRCs and staff who visit from the Centre.

Community disability workers:

Three community disability workers cover the district. They are selected from within their own community and follow a basic training. Home visits are done weekly and later reduced. Tasks carried out by community disability workers include PRT (mainly for children under 14 years); increasing awareness within the family and community; facilitating disability identity cards; and facilitating school enrolment. Community disability workers also advocate for rights, such as for example, supporting citizenship applications.

BOX 6: The profile of a community disability worker.

Geeta, originally from another district moved to this one ten years ago and started working as a Development Worker. Later, when the CBR programme started, she changed to become a Community Disability Worker (CDW). The only bread winner in her family, Geeta is married to a loving husband and has two adorable daughters aged nine and five years.

As a CDW, her daily routine involves carrying out activities that she plans on a monthly basis. One of the routine tasks that she enjoys is raising the awareness of various groups such as child clubs, schools and community groups through social communication. She also visits homes to give Primary Rehabilitation Therapy (PRT) and to counsel children and families. She also facilitates school enrolment and Disability Identity Cards for those children who need it.

The organization has given her a bicycle to get around the VDCs in her area. This enables her to reach many more children since public transport is very scarce in her district. To get to the nearest home on her bicycle it takes her half an hour and to the farthest it takes her one and a half hours.

Geeta says that she has a passion for social work. She describes herself as “a straight forward person who is dedicated to her work”. She would love to learn English and to use the computer. She hopes this will be possible in the future. She says that she does not like people who are not honest.

She loves her work. She feels that the children and families that she visits all show their love and support towards her. Every time she visits a home, she is offered vegetables and fruits or anything that they could afford as a sign of their appreciation.

Schooling:

An important aspect of the community workers role is to facilitate school admission. As of now due to funding constraints there are no students receiving scholarships.

Child Clubs:

There are a total of 136 Child Clubs and all of them are inclusive. Their main task is to advocate on child rights, schooling, hygiene and sanitation etc. They organize street drama, publish wall magazines, and run programmes on FM Radio about these issues. Individual Child Clubs form Federations which are supported by District Child Welfare Committees.

Accessibility to the built environment:

Through the CBR programme, ramps have been built in various offices such as the Chief District Office, District Development Office and the District Education Office.

Findings

Impact and overall Effectiveness of the programme to date:

- ◆ 85 children have had Primary Rehabilitation Therapy (PRT) through home visits or through monthly visits to the Rehabilitation Centre and 32 have been referred to a children's hospital in Kathmandu Valley for surgery.

In relation to education:

- ◆ 47 schools have registered 292 children who have disability.
- ◆ 26 children from very poor families have received scholarships.
- ◆ It appears that parents are increasingly realizing the value of education for their children.
- ◆ Participation of youth who have disability in Non-Formal Education has increased.

In relation to health:

- ◆ Children and pregnant women have better nutrition and are attending health clinics more often. More deliveries are attended by trained midwives. Immunizations have a wider coverage.
- ◆ 5 eye camps have been held where 1,535 people had eye examinations out of which 304 subsequently had cataract surgery. A further 493 received spectacles.

In relation to livelihoods:

- ◆ 16 individuals have had various types of vocational training.
- ◆ 30 individuals are involved in tailoring, cycle and TV repairs, grocery retailing, and goat keeping. Daily income ranges from Rs 50 - Rs 300. Five individuals who have visual impairment are doing bamboo crafts as a group activity.

- ◆ Among the assistive devices provided by the orthopaedic workshop at the Rehabilitation Centre were six walkers, two seating aids, 20 tricycles, four bicycles, 47 pairs of crutches, 37 white canes and six prostheses.
- ◆ 722 Disability Identity cards were facilitated.

Sustainability:

Eight donors in total support the different programmes. Withdrawal by one partner in 2005 resulted in some programme components being phased out.

V DISABILITY IN THE CONTEXT OF DEVELOPMENT ORGANIZATIONS - EXAMPLE TWO

This Organization was established in 1991 for development work. It commenced with female literacy through Non-formal Education. It runs 30 Community Reading Centres in 11 VDCs which women who achieve literacy can use to continue their learning. Gender Equity, Water and Sanitation and Children's Health programmes are among its other development programmes. Social mobilizers were recruited, trained and assigned to the separate programmes.

Disability Programme

The disability programme was initiated in 2001 in two districts. Nine existing social mobilizers were selected for this and trained to implement CBR. They are now 11 in number and work as community disability workers in 22 VDCs.

Approach

Meetings are held with key persons in selected VDCs to discuss the need for CBR. The community makes a proposal and submits it to the organization for approval.

After approval, the first activity is a survey. In one of the districts, five community disability workers carried out a survey that covered seven VDCs and identified 1,414 people who have disability. Results were shared with the communities and as of now approximately 150 individuals are followed up regularly at home.

There are no community groups taking responsibility for the disability programme. The

social mobilizer encourages individuals to join special interest groups of their choice in their communities.

Current activities

As a core component of its development programmes, disability awareness is carried out within schools and the community-at-large and also to reach media personnel. Street theatre is also used to raise disability awareness.

Disability interventions per se are carried out by the specially trained community disability workers.

Home visits:

PRT is provided when needed through home visits.

Assistive devices:

Assistive devices are distributed free of cost and according to need. In 2006 they were provided to approximately 25 individuals.

Vocational training:

Vocational training is outsourced to a professional organization. Eight individuals from the CBR programme are currently undergoing a nine month training. It appears likely that the vocational training organization will itself find job opportunities for participants. For those who set up in self-employment, the organization will assist with marketing.

Referral services:

Individuals are referred to specialized health services and costs are met.

Findings

Impact and overall effectiveness of the programme to date:

Disability issues are included in all the development programmes of this organization. For example, ECCD centres include young children who have disability with the teachers having some orientation. Also, Non-Formal Education programmes include women who have disability.

A major constraint facing the programme appears to be the geographical terrain. This, together with the large population to be served requires the deployment of additional social mobilizers so that more individuals can be reached.

BOX 7: Difficulties some individuals face in obtaining essential referral care is illustrated through Suresh's experience

Suresh, now 45 years of age, was diagnosed as having leprosy. When the initial survey was done in his village six years ago he met Ismitha, the social mobilizer. Ismitha suspected that he had leprosy. He needed to go to Kathmandu for diagnosis and treatment but could not afford to do so. Suresh's only living relative was an uncle. With some financial help from his uncle and with contributions from other community members, Ismitha accompanied Suresh to Kathmandu.

He was admitted to a leprosy centre for treatment. But Suresh was unhappy in the centre and came back home after three months. His treatment was not complete, and the effects of the disease are now becoming increasingly visible. So much so, that when the researchers visited the village, community members indicated that they would like Suresh to be taken away again. But they did not indicate this to Suresh.

Through the CBR programme Suresh participated in a course for seven days and learned bamboo crafts. But he does not use the skills he learned to earn an income. Instead, he does occasional ad hoc work for people in the village and earns his food and some money. Suresh lives alone. The disease he has is as yet not treated. He may well become increasingly disabled.

VI AN URBAN PROGRAMME FOR CHILDREN

Established in 1995 to develop CBR, this organization provides services primarily to children who have disability aged two to 16 years. Its goal is to raise childhood disability issues at all levels. In particular, it focuses on increasing access to education for these children. CBR is implemented in three districts in the Central Region. Two of these are urban and one is semi-urban.

Approach

CBR is started in response to the requests of local people. Areas from which most referrals are made are also considered. Community meetings are held in selected areas to discuss the possibility of starting CBR. The meetings aim to mobilize local resources. Volunteers are then selected by each community. Volunteers and others nominated by the local VDC or municipal ward have 10-15 days training. Topics covered include definition, causes and prevention of disability and referral facilities.

Volunteers supported by staff from the organization visit homes to identify children who have disability. Identification is followed by needs assessment. Individual files are prepared with long and short term goals.

Activities

Day-care Centre:

The organization established a day-care centre (10 am to 3 pm) in 1999 for children who have disability. A monthly fee of Rs 600 is paid by

those who can afford it and Rs 300 by those who are less well off. There are currently 40 children enrolled ranging in age from two to 25 years. The day-care centre was started because other organisations would not accept children who had toileting problems. There was also a high drop out rate for those that had been accepted. In 2007 the day-care centre was registered as an inclusive primary education facility (classes from nursery to 5) with the aim of providing education under one roof to children with or without disability.

Home visits:

According to need, volunteers visit homes for followup and to prepare children for school.

Income Generation:

Currently the organization has two income generation programmes - candy making and envelope making. In each programme eight to 10 children with disability of 14 years and above participate. The products are sold to various individuals and at exhibitions. In 2006, three people with disability (all male with physical disability) were provided loans for vegetable and poultry farming. One was provided Rs 10,000 and the other two were given Rs 5,000 each.

Parents Group:

A Parents Group was formed but is inactive at the present time. However, a mothers' group (mother of children with intellectual disability) is functional with activities like awareness programmes and vocational training. Altogether there are nine board members with around 100 members (relatives and friends). The group holds meetings once a week to discuss and plan activities.

BOX 8: The experience of Sangeetha and her mother illustrate some of the many problems encountered by individuals, families and organisations.

Sangeetha is 30 years old. She cannot speak or hear, and has epilepsy and intellectual disability. She cannot look after herself. She first came to the Day Care Centre about 11 years ago. After only two visits she started going to the School for Mentally Retarded Children. But she didn't go there for long as she kept running away fearing that something unwanted may happen and her mother stopped taking her there. Later with the help of the CBR Organization she was placed in a boarding school. But again she tried to run away. The school refused to accept responsibility for her so once again she is at home. When her mother goes away on a long trip she takes Sangeetha along with her. If she is only out for a short while she locks her up in a room. Sangeetha's father is also not well. Her mother does not receive much help from other family members. Her neighbours are not helpful either.

Sangeetha is visited at home by the volunteer from the Organization once or twice every month. The CBR Organization has provided medicine for epilepsy free of cost for the past year. When her mother does not wish to be interrupted by her, Sangeetha is given the same medicine to keep her quiet. Sangeetha's mother wants to send her to the Day Care Centre but is unable to pay the fee required. Taking her there and collecting her is also difficult since the time interferes with her own work. However Sangeetha still has friends that she made while she was at school. They visit her at home and she also goes to school to see them. She has no friends in the neighbourhood though.

Their next scheduled activity is an orientation programme on intellectual disability. This group is supported by an INGO.

Advocacy and Lobbying:

VDCs and municipal wards are approached and lobbied for the inclusion of disability in their programmes. Out of 39 VDCs, eight VDRCs were formed to take responsibility for protecting rights of children with disability. In all eight VDRCs, parents and people with disability participate.

Findings

Impact and overall effectiveness of the programme to date:

- ◆ In all, the programme covers 39 VDCs and three Municipalities while in a further three VDCs in the neighbouring district assistive devices are distributed

As a part of the awareness programme:

- ◆ 4,530 disability awareness materials (bulletins and stickers) were produced and distributed
- ◆ 1,858 people from various walks of life were sensitized.
- ◆ 132 people (community volunteers, VDRC members, community rehabilitation facilitators, community development facilitators and coordination committee members) enhanced their knowledge and skill on various technical aspects of disability.

In relation to education:

- ◆ A total of 223 children with disability have been enrolled in 74 schools (60 general schools and 15 special schools and resource classes).

Being an urban area the emphasis appears to be on the services provided by the day-care centre. This meets the needs of urban families. Many parents expressed appreciation as they can leave their children in this centre for at least a couple of hours per day. Parents especially mothers felt they could utilize the time either to finish household chores or to earn a living when children are at the day-care centre. Many also wished there would be no charge to send their children to this centre.

Sustainability:

Cost recovery may enable the day-care centre to continue. Other services depended on donor support.

VII AN ATTEMPT AT SUSTAINABLE CBR

This Organization started in 1995 with the support of an Organization in Kathmandu. It was initially a three year project which was extended by another two years at which time a second partner based in the same district provided a further two years support. Since then it is self-reliant.

Approach

CBR started when the first partner supplied a rehabilitation facilitator whose initial task was to mobilize the members of the VDC. As a result of this a steering committee was set up to run the future programme. A house to house survey was carried out in the 1,500 homes in the VDC

covering a population of 9,000. A total of 152 people who have disability were initially identified, including those who have physical, hearing and visual impairments, intellectual disability, leprosy and epilepsy. Now there are 200 people known to have disability.

When the first partner withdrew its support in 1999, the organization prepared its own constitution and obtained registration in the District Administration Office and affiliation to the Social Welfare Council. It now has 38 members (20 M, 18 F) including 30 people who have disability, a working committee of nine (2 F, 7 M) out of which three (1 M, 2 F) have disability. The chairperson of the steering committee was elected to be the chairman of the organization, and remains so today.

Activities at the start of the programme

Once the rehabilitation facilitator and some members of the steering committee had been trained in CBR, the focus started on home visits to transfer knowledge and skills to individuals and families. Other activities included sign language training, meeting economic needs through vocational training and savings and credit groups and on promoting family and community interaction.

Building sustainability

Role of partners:

There was from the start a clear understanding that the support of both partners would be short term and directed at making the organization self-reliant. Each partner provided inputs to develop organisational, advocacy and technical capacities of the steering committee, community members and rehabilitation facilitator. They also provided financial inputs (described below).

Networking:

As a member of the district CBR network, relationships with other organisations were developed. It was one of these relationships that became the subsequent second partnership.

Revolving Loans Scheme:

A revolving loans scheme was started at the beginning of the programme with Rs 10,200 provided by the partner. It still continues today. Loans ranging from Rs 1,000 - 10,000 are given to individuals who have disability (and alternatively to a family member), for goat keeping, small

businesses, fruit farming and buffalo keeping. Loans are to be returned within one year. At first interest was 6% and it is now 12%. Later, the first partner added Rs 35,000 to the scheme and the second added Rs 45,000. The total in the revolving fund now stands at Rs 109,000.

Building for CBR Office:

Land was obtained free of cost from the VDC and a building was erected to serve as the CBR office. Out of the total cost of Rs 250,000, local contributions constituted 20% and came from individuals contributing from Rs 1.00 to Rs 499 and more was raised later by individuals and families collecting donations during festivals etc. The remaining cost was met by the two partners. The building has three rooms, one of which is used for training and meetings while a smaller room serves as the office and the other is rented at Rs 500 per month. The Meeting Room is rented on occasion and brings an annual income of around Rs 2,000.

Sustainable CBR Fund:

Rs 85,000 was granted by the two partners as a capital fund.

Savings and Credit Scheme:

Rs 140,000 was given by the second partner for a Savings and Credit Scheme. See below.

Activities at present

Income Generation Programme:

Sixteen individuals have taken loans at present directly from the Revolving Loans Fund (see above). Two of these are for small businesses; two for buffalo keeping (milk sold at dairy collection centre) and 12 are for goats (breeding and meat).

Loans Programme:

From the Sustainable CBR Fund, loans are given to any community member at 24% interest. These loans are usually used for income generation activities. So far total interest received on loans is Rs 40,000.

Savings and Credit Scheme:

Five small groups were given seed money ranging from Rs 20,000 - 40,000. This is given only to people who have disability and family members. Interest of 12% is payable at the end of each month in addition to a contribution of Rs 20.00 as savings per month. The target is to double this amount.

Results and achievements of the Savings and Credit Scheme vary widely among the groups. For example, one ten member Group took loans ranging from Rs 3,000 - 10,000 some to open small businesses, others for goat keeping. Only some of the members made a profit and as a group they have not made significant profit and savings. The lack of regular follow-up means there is little pressure to return loans. The best performing Group has six members who started with Rs 28,000, and now have Rs 60,000, thus exceeding the target. Two years ago, one of the members took Rs 6,000 for goat keeping and bought one goat for breeding; she now has six goats and is quite satisfied with the considerable gain in capital.

Home visits:

Occasional home visits are made by a member of the working committee for follow-up and monitoring of loans. It is felt that additional home visits would be beneficial.

Other activities:

Costs are met from the Sustainable CBR Fund for the following (figures given are for 2005-6):

- ◆ Support to school children for stationery and books. The organization plans to increase this expenditure from the current rate of Rs 2,000 to Rs 8,000.

- ◆ Referral to hospital treatment, including corrective surgery, Rs 2,000.
- ◆ Networking payment of Rs 30 - per CBR Network meeting.
- ◆ Provision of assistive devices, which is currently minimal.
- ◆ Purchase of books for Library: Rs 5,000
- ◆ Office Management including transport, communication, stationery, accounting, furniture, Rs 10,000 - 12,000.

Findings

Impact and overall effectiveness of the programme to date:

The stated mission of the organization is “to work towards including people who have disability and other community members into mainstream development by mobilizing and utilizing local resources”.

Two partners provided the financial capacity for the organization to continue and expand its activities. Opportunities existed for it to secure further and equally fruitful partnerships. However, the programme does not appear to have made much progress for some considerable time. There is generally a satisfaction that it continues solely as a disability programme.

BOX 9: The story of Swastika illustrates the manner in which CBR has influenced the lives of individuals who have disability.

Now 30 years of age, Swastika went to school until she was in class 5. She left at that age because it was too far to walk to school. She stayed at home to do household work. Swastika calls herself “a little person” and was identified in the survey.

When CBR first started 12 years ago, Swastika would not come out of her room to speak with the rehabilitation supervisor. She says that she was too conscious of her disability and of the stigma that it carried. The rehabilitation facilitator continued to visit her home until he drew Swastika out of her cocoon. She participated in the sewing training organization through the CBR programme. She has made use of the loans programme to add to the income earned from sewing through buffalo keeping. She is a talented artist and now sells her paintings also to add to her income.

Swastika is the Chairperson of the VDC “Women’s Forum for Social Justice” and has been so for the last three years. The Forum has a membership of 130. As the chairperson, she manages a project implemented in collaboration with the “Decentralized Action for Children” supported by a UN agency. She represented the Forum at a Women’s conference held in Darjeeling, India, no small achievement for a woman from this small rural village. She works also in a voluntary capacity in the Development Association for Children and as a social mobilizer for the Community Development Federation, advising women on gender issues and abortion. She is a member of the Working Committee of the CBR Organization.

Her closest friend says of Swastika “She does not think of what she can get from the community, but only about what she can give”. A staff member of the VDC says that “Swastika is an empowered woman and a role model for other women”. Swastika herself says that her leadership capacity was developed by CBR.

As a result of the programme, it is felt that the visibility of people who have disability has increased and that they are respected by their fellow community members and staff of the VDC. They are participating in community activities, and taking office in CBOs. Children are going to school and making progress.

In the socioeconomic climate of the small community in which it works, there is scope for increased cooperation between the organization and the VDC. See the example of the Youth Club in Box 5.

Sustainability:

The organization is completely autonomous. Financial viability has been ensured for its present work, and perhaps for limited expansion. However, for future sustainability the organization needs to redirect its actions. It has the capacity to seek new partners and to expand its sphere of influence both in terms of the rights of disadvantaged groups and geographical coverage.

VIII A PROGRAMME FOR INDIVIDUALS WHO HAVE VISUAL IMPAIRMENT

This CBR programme for people who have visual impairment is linked to a district Eye Hospital. CBR activities were started in 1999 in this district.

Approach

A door to door survey is first carried out in the district. People who are found to have visual impairment are categorized as “curable” and “incurable”. All those in the former category are provided with interventions based on their needs, interest, physical strength, age and type of impairment.

The objective of the programme is “to rehabilitate visually impaired people and help them to seek their rights”. The first phase of a five year programme in this district has been completed. In the second phase the programme has been expanded to the neighbouring district. This is now its third year.

Activities

The current activities in this district are more of a follow-up. However, if they do meet new individuals they are assessed and services are also provided to them.

Activities in this district are provided by three trained field workers. They include follow-up of home visits for early intervention, counselling, orientation and mobility, daily living skills, manual dexterity skills, early intervention for young children, pre-braille training for school-age children. Integrated education is facilitated and individuals are referred for medical interventions and surgery.

Field workers cover a cluster of VDCs. One Field Supervisor and one Field Officer provide supervision in two districts.

Integrated Education:

The Organization uses three models including the residential model intended for poor children from rural areas; the non-residential model for those who can easily attend neighbouring schools and the general schools model.

In the residential model 13 children have been included in integrated education in one school. Community workers first prepare the children for school through home visits. Resource teachers have been trained by the Organization.

Since children who have visual impairment have been attending the same school over a period of many years now, they state that they have no major problems in school. They are provided with educational materials. A teacher at the school has been trained to meet their needs and his salary is paid by the organization. However, sports activities have not been adapted and these children do not participate in sports in school. Outside school some have participated in special sports. Many children in this school wish to become teachers in the future.

Livelihoods:

Vocational training has been provided in chalk, candle, rope and incense making, paper crafts, kitchen gardening, bamboo crafts and knitting.

TABLE A: Record of Activities, 2005 - 6

S. N	Services	No. received
1	Total Identified	5073
a.	Basic Services	
	Counselling	6
	Medically rehabilitated	3347
	Basic training	19
	Early intervention	24
	Integrated education	115
	Follow-up	76
	Case closed	1065
	Total (a)	4652
b.	No rehab services required	
	Refused	2
	Not suitable for training	25
	Expired before providing training	236
	No needed services	41
	Total (b)	304
c.	Curable clients to be operated by hospital	117
	Total c	117
	Total a+b+c	5073

SOURCE: Annual Report, 2005-6

Amounts ranging from Rs 1,000 to 20,000 have been granted as a seed fund for income generation.

The Organization plans to set up a formal Cultural Troupe and individuals have been trained for a period of six months. They will soon start performing and be a source of income for the Organization.

Self-Help Groups:

There are at present 17 SHGs only some of which are active. Some SHGs provide vocational training to their members and sometimes to their relatives. They raise funds which they then distribute as seed money for income generation. Some are engaged in the marketing of products produced by their members. Other activities include lobbying for rights, mobilizing local resources and supporting savings and credit groups. SHGs also carry out leadership training, awareness programmes and cultural activities.

Findings

Impact and overall effectiveness of the programme to date:

- ◆ During the study a total of 5,073 individuals who have visual impairment were found. On

assessment 3,552 were found to be “curable” and 1,521 were “incurable”. Categorization by the organization according to needs and services provided are in Table A.

- ◆ Currently 277 children have been identified out of which 180 are included in the home-based programme, 56 are supported by the District Education Office and the other 41 are awaiting schooling opportunities.
- ◆ A total of 581 individuals have been given vocational training. Rs 755,100 has been distributed as seed money for self-employment to 210 people. Out of this amount Rs 628,000 has been recovered.

The major strengths of the programme lie in the emphasis on education and on livelihoods. Both of these involve home visits to interact with individuals and families. The economic empowerment of individuals assists them to be able to leave their homes and to increase their visibility within the community. SHGs also increase impact and relevance.

IX THE COST OF DEPENDENCE

Established as a branch organization of a Kathmandu-based NGO providing welfare services to people who have visual impairment, this CBR programme was started in 1994. The organization is run by an executive committee of 15, all of whom are sighted.

Approach in 1994

Employing a staff of 23, a survey was carried out in three districts of the Eastern Region to locate people who have visual impairment. Over 1,500 individuals were identified and home-based interventions were started by field workers. There were no direct interventions with community members or organisations or with self-help groups. Those who were not attending school at the time were taught orientation and mobility and Braille. They were then placed in school - either in the special school in the district, or in the nearest general school (with teachers given training in Braille for one month). Others who could not be placed were taught at home by the field workers.

Adults were, according to their needs, given orientation and mobility training and loans for self-employment. Those who required medical treatment were referred to health centres and hospitals. The organization says that once

BOX 10: The effectiveness, impact and relevance of the work done by this single-disability organization because it meets multiple needs is illustrated through the experience of Raju

Raju, 25 years old is one of a family of four children. He and the CBR organisation came in contact with each other during the survey. He was visited at home by the community worker from the organization. To help him to be independent he was provided with orientation and mobility training. To prepare him for school the community worker taught him Braille. This took five months.

At first there were many difficulties. Raju's family thought that he was very different from other children and kept him hidden from society. They needed a lot of counselling before they allowed Raju to come out of the house.

Raju was then admitted to Class 5 of the integrated education school in Town. At first he commuted to school from home but after two years he was admitted to the residential home run by the organization so that he could concentrate on his studies. While at school the organization supported him with the materials that he needed.

He performed very well at school. Raju passed his School Leaving Certificate (SLC) in the first division. With a mark of 71% he came first in the district. His conscientiousness and grades impressed the college administration and as a result they waived his admission fees. Currently Raju lives alone in a rented room in town to attend college. Raju is very happy at college. He has many friends and acquaintances who help him when he needs it. He wants to become a teacher in the future. He is also interested to learn music and hopes that he might get some help to pursue this interest. He would like to get married but only after he has obtained his Bachelor degree and has a job. He is a member of the local DPO. The local newspaper has had a feature article about him. He is well known on the campus, in the town and in his own village. He is popular at social events.

Six years ago the organization gave him a loan of Rs 15,000. He bought a buffalo. That was a good investment since he has already paid the loan, has a saving of Rs 12,000 and a baby buffalo. With this, he can start breeding buffaloes and have a sustainable income to help him with his education.

services became well known, many hidden individuals were brought out.

Then in 1996 civil unrest started and travelling within the districts was difficult. Funding from the centre was reduced. A combination of these factors resulted in the field programme gradually being curtailed.

Current Approach

Now the organization employs two field officers. One does office work and serves one district, the other covers the second district. The third district is no longer served.

Activities

The main task of the field workers is to follow-up schoolchildren and college youth who were identified in the first phase and with whom interventions were started at the time. Occasionally a new child/youth may be referred by those already on the programme. Field workers visit schools to meet children/youth. During the holidays they are visited at home. Visits to each individual averages at about once a month or once every two months. Beneficiaries are

provided with educational material (Braille slates, Braille paper, text books and cassette recorders). There appears to be little community interest or involvement in the programme.

Findings

Impact and overall effectiveness of the programme to date:

The programme is limited in scope and is unable to support all of those in need, even among children and youth who have visual impairment. However, during the year 2005-6:

- ◆ 12 new individuals who have visual impairment were identified.
- ◆ 15 people were visited by the field workers and given orientation and mobility training.
- ◆ 6 were referred for cataract and other forms of surgery.
- ◆ 2 meetings were held with groups of teachers and others.

Overall effectiveness appears to be rather limited, but the children and youth who have been touched by the organization are appreciative of the help that they have received.

BOX 11: The experience of Shrawan describes the relationship between the young people served and the organization.

Shrawan is now 24 years old. He went to the special school for the visually impaired in his district until he was in Class 8. Since the special school had no higher classes he went to a general school. While at school he liked to sing and play music. His ambition is to be a teacher – “not just any teacher, but a good teacher”.

The field worker started visiting him five years ago when he was at college and helped him with Braille materials. He had a scholarship for school and college and from there Shrawan went onto university. But after one year he had to discontinue his studies. His hopes of being a teacher were shattered. Shrawan was dependent on his peers to take him to university and back. While they showed willingness to do this at first, as the year went on they became increasingly reluctant. It came to the point that when he would need help, he had to make a reservation with a peer some 3-4 hours in advance. Even then he was often let down. There were other problems that made university learning difficult. Teaching was of course by the lecture method. There were times when he would take the written notes and have them transcribed into Braille, but this could not be done as often as he needed. A cassette recorder was essential, but he could not afford one.

Shrawan still dreams of pursuing higher studies and achieving his ambition of being a “good teacher”. All he needed was independence to get around, a cassette recorder and someone to support him with a listening ear.

In relation to education:

- ◆ Since it started CBR the organization has supported 30 schools in three districts to provide integrated education opportunities for children who have visual impairment. Twenty of these schools started integration in 1994 and 10 in 2003-2004 but there has been no progress since then.
- ◆ In the year 2005-6 a total of 51 children (30 boys, 21 girls) were in integrated classes.

While there have been no direct interventions in families or communities, there have been indirect effects as the programme has helped families and communities to recognize the abilities and potential of people with visual impairment.

X A HOSPITAL AS A RESOURCE

This programme is managed by a well renowned tertiary-level children’s hospital that is run by an NGO catering to children under 16 who have physical disability. Having started in 1989 just as a follow-up service for children treated by the hospital, it was developed into CBR in 1993.

Approach

Localities are selected from among districts which show greater demand for hospital services. Preliminary information is collected about the local situation and resources through, among others, meetings with district government agencies, DPOs, NGOs, CBOs, and social and political leaders. This is followed by workshops with

stakeholders to share information about disability and discuss disability management and also to fill any gaps in information. Plans are made to start CBR with a focus on establishing partnerships for networking and resource mobilization. Roles of partners are identified. This preliminary phase may take from six to nine months.

When this foundation has been laid the Hospital carries out mobile camps. Local partners inform communities about these events. The mobile camps therefore draw new children for screening as well as those who have received hospital treatment for follow-up.

Mobile camps are carried out by Hospital staff - a CBR supervisor, a facilitator, orthotic and prosthetic technicians, a physician, a physiotherapist, a pharmacist, and administrative staff and nurses, according to need. Members of local CBOs also participate in running the camps. Each child is assessed and the child’s treatment and rehabilitation process is discussed with caregivers and local partners. This may include meeting needs for counselling, referral, schooling and social interaction. The roles of each actor who will intervene with the child are decided. Orientation classes/workshops are then held to transfer knowledge and skills in these areas to caregivers and local partners. Follow-up/review meetings are held after 6-8 weeks.

Mobile camps are followed up at home by the Hospital staff. Home visits are made both to children served by mobile camps as well as those who have been referred direct from hospital.

Findings

Impact and overall effectiveness of the programme to date:

- ◆ Through community mobilizers and CBR facilitators the programme is now operating in 24 districts.
- ◆ In December 2006, a total of 7,052 children who have physical disability were registered and almost 74% of them are in school.
- ◆ In 2006, 4,367 home visits were made (2,672 boys and 1,729 girls), showing a small increase from 3,974 the previous year.
- ◆ Over 300 partnerships have been created both nationally and in the districts to increase the effectiveness of the hospital's work.

Assistive devices (mobility aids) including prostheses are made in the hospital orthopaedic workshop. Production and supply keeps pace with the increasing demand.

Most children have cerebral palsy (22% greatest single diagnosis), trauma comes next (17%), Tuberculosis (14%) and burns (11%). These conditions have potentially devastating consequences on the lives of these children and the intervention of the hospital in each case is to be appreciated.

The hospital states that the most frequent age range of children attending for treatment are those between 13–16 years. Children between 0-4 years are the least seen. This is indicative of a delayed identification of the problem. Children are then deprived of early stimulation and interventions that would enable them to more effectively overcome

the consequences of their disability. It is also a constraint on the hospital, not allowing much time for it to complete courses of treatment within its own mandate and framework.

The hospital serves as a Training Centre providing CBR courses to field workers from other CBR programmes.

The mandate of the hospital is to provide services only to children who have physical disability under the age of 16 years. Estimates of disability prevalence and the pattern of disability in Nepal indicate that up to 45-50% of children with disability have physical disabilities. This leaves an enormous gap of 50% of children who have disability with no access to services, in spite of there being a CBR programme in their vicinity.

Sustainability:

There is ten full-time management staff running the CBR programme with 23 field staff. The hospital has been successful in raising the funds required for it to function effectively. However, the trend of increasing numbers of children presenting with more complex problems will place significant strain on its fund raising mechanisms. Through all this, a high value needs to be placed on its field programme.

The hospital is to be commended on developing this unique approach to extend its services and reach the maximum number of children treated within its mandate. Findings indicate satisfactory levels of effectiveness and sustainability. However, the programme's impact is only on the lives of one group of children who have disabilities.

BOX 12: Diwakar illustrates how hospital based services have changed his life.

Diwakar is 16 years of age. When he was six months old his parents realized he had a problem and took him to the Resource Hospital. They were told that he has cerebral palsy. Since then they have gone to the hospital regularly for follow up, but stopped three years ago. He is visited at home by a rehabilitation facilitator from the hospital.

His parents are very conscious about the need for Diwakar to have education so that he can develop as much as he can. Diwakar started going to school when he was six. One year ago he had to stop. His teacher was reluctant to have him in the class because he was not keeping up with his classmates. His parents are still looking for another school that will accept him. They have not thought of the possibility that it may be time for Diwakar to acquire skills that will enable him to earn an income.

Diwakar has been independent in self-care and has been able to walk around since he was quite young. He is sometimes unstable and falls down. Socially he has friends and goes with them to the cinema, concerts etc. He joins his family on outings, including visits to Kathmandu. His neighbours are friendly towards him. His parents are concerned about his future and have started savings to create a trust to look after his needs. But Diwakar could, with suitable skills training, do a job and earn his own living.

The hospital is one of a kind in the country, and replication of the approach has yet to be explored.

XI A PROGRAMME FOR CHILDREN WHO HAVE PHYSICAL DISABILITY

This organization was set up in 1995 to start CBR. It works in two districts of the Western Region of Nepal, providing rehabilitation and facilitating services which help to reduce poverty. Services are provided at home and at the Organization Resource Referral Centre to children and youth under 25 years of age who have physical disability.

Approach

Programmes are set up using two methods:

- ◆ Community awareness is raised through community meetings where information is collected about children who have disability. These children are then followed up at home by field workers for assessment and rehabilitation.
- ◆ School awareness: Schools in the area are visited by staff who host meetings with teachers and children on a range of disability awareness issues including the need for inclusion, friendships and so on. Children are asked if they know any children who have disability and a second list is compiled. They are next visited at home and individual programmes started.

Three forms are used for initial assessment and recording - history, child development and range of movement, and another for a summary. Goals are set for rehabilitation and children and parents are taught necessary interventions. Referrals are made if necessary including for assistive devices.

Most children are referred from the District Health Service.

Activities

Home visits:

Field workers make home visits once a week to teach home programmes to children and parents. These include exercises, independence in daily living activities and mobility.

Referrals:

Since the Organization only deals with physical disability, children who have other disabilities are referred to hospital and to other NGOs.

Counselling:

Weekly counselling days are held for those children outside the CBR area. Within the CBR area counselling is done at home.

Assistive devices:

Those made at the Centre (standing frames, walkers), are provided free of cost. Others that have to be purchased from elsewhere (wheelchairs) are given at subsidized rates. This facility is available only to those under 25 years due to a donor requirement.

Training:

Basic and upgrading training is provided to own staff.

Inclusive Education:

The Organization acts on behalf of children and parents, lobbying the District Education Office (DEO) to secure benefits meant for children who have disability, such as enrolment and scholarships. For this purpose a list of all children needing schooling and those attending school is submitted to the DEO before the start of the school year. School admission is facilitated and the admission fee of needy children is paid. The Organization continues with student support, providing educational materials.

Income generation and vocational training:

The Organization has three different kinds of income generating projects; 1) loans from the Parents Fund described above, 2) a one-time gift of livestock or vocational training which is funded by a UK charity and, 3) a buffalo scheme.

Child Clubs:

Six child clubs are supported all of which are inclusive. The main aim is to expose the hidden capacities of children who have disability. Sessions on topics relevant to children such as hygiene are conducted; activities such as clean-up campaigns in the vicinity to bring children together are carried out. Each child club links up 5-6 schools in the vicinity through inter-school competitions in song, dance and other cultural pursuits. Membership of each child club is about nine (in hilly areas) to fifteen (in towns). About a third of the members have disability.

Networking:

The Organization is an active member of the District CBR Network which has a membership of 27, including also government agencies. The Network meets quarterly. Members pay Rs 30 to attend each meeting which take the form of two sessions, the first of which involves a discussion on current issues and the second the sharing of experiences and news. It has only a post of Secretary, which rotates every six months. The Office is in the form of a box containing pertinent documents and monies. This is handed over from Secretary to Secretary.

Publication:

A quarterly publication containing recent news and articles of interest is distributed within the district.

Findings**Impact and overall effectiveness of the programme to date:**

- ◆ In 2005-6 the total number of children receiving services was 715, which is an increase from 557 the previous year.
- ◆ 84% of clients were between the age range of 6-25, while only 14% were aged 0-5. The organization states that "this reflects that there is little early diagnosis and early family support".
- ◆ There has been some increase in the provision of assistive devices from 219 in 2004-5 to 287 in 2005-6.
- ◆ There has been an improved gender balance in coverage with 321 girl children in 2005-6 (45%) compared to 201 the previous year (36%).

In spite of a wide network in the district, in 2005-6 no referrals were received from other NGOs. The Organization in turn made only 27 referrals to other agencies.

Child clubs take place only every three months as the social and political insecurity in the immediate past made it difficult to keep them running. Funding issues have prevented the opening of more child clubs.

Meetings of the Parents Group provide valuable support to members enabling them to discuss needs, problems and solutions and share experiences. However while some attend regularly, many find it difficult. While the number of meetings had increased, the average number attending had fallen to 26 in 2005-6 from 48 the previous year. The fall in participation is significant for many reasons – less parent input into running of the organization and its negative effect on sustainability being chief among these.

Awareness programmes used to increase community interest in disability and whilst also helping to locate new children who have disability have been decreasing over the last two years. Community awareness programmes are down to 520 in 2005-6 from 1,457 the previous year, while school awareness has come down from 537 to 209. This reflects decreased participation of community members and schoolchildren as well as reduced numbers of children who have disability being located.

In relation to education:

- ◆ The proportion of girls to boys attending school has increased somewhat. In 2005-6 there were 121 girl children (41%) compared to 56 the previous year (35%). National school attendance figures are 46% girls to 54% boys.
- ◆ The organization places great importance on schooling, and this is indicated in the increased number of children supported in school, now 205, up from 159 last year. A perceived change of attitude in the district Government education sector makes it easier

Box 13: Parents Group and Parents Fund

Parents of children who are served by the Organization are encouraged to join the Parents Group. This meets every two months. The meetings take the form of two sessions - the first for learning and the second for sharing.

Parents pay Rs 10 per home visit made by field workers. This money goes into a Parents Fund administered by the parents themselves. Their main activity is managing a micro credit scheme. They decide eligibility of applicants and provide up to Rs 10,000 per applicant. The loan has to be returned in 24 monthly instalments.

Box 14: The story of Shobana illustrates how the organization typically works.

Shobana is a happy bright little eight year old girl who used to live in a distant village. She has cerebral palsy, communicates, can sit alone, but cannot yet stand alone. She came to the Organization through a neighbour. Her Mother has now moved to Town so she can bring Shobana to the Centre for exercises which she continues at home. The Centre has given her a standing frame.

Her family tried to get her into school this year but failed because of her disability. The main reason apparently given is that she could not use the toilet by herself. She is taught at home by her sister.

Shobana loves watching TV and listening to the radio. She has many friends in the neighbourhood who visit her at home to play with her. Her family show much love and affection towards her and makes sure they take her with them on outings. They give her maximum encouragement, and are very concerned because they failed to get her into school.

The Organization will intervene to get a place for Shobana at school through the subject officer assigned to children who have disability in the District Education Office. When she starts schooling the Organization will enable her to obtain a wheelchair at a subsidized cost.

to gain admission for children who have disability.

In relation to livelihoods:

- ◆ The income generating programme is currently being reviewed. The impact on stakeholders in the year 2005-6 appears to have been limited. The target of 20 was not reached. Four parents and youth were given training in bee keeping and provided with hives. The buffalo scheme included nine families, and has mixed success. Breeding by a few families has enabled young calves to be distributed to other families. Some have chosen to withdraw from the scheme.

The target group is those who have physical disability. Other children who are identified are referred to other NGOs, some of whom have few,

if any, services for children. Of those who have physical disability, cerebral palsy is the single largest group with 322 children with cerebral palsy accounting for 45% of the total. There does not seem to be significant community participation in the programme.

Sustainability:

Financial support comes from three main international partners. The main partner visited the organization in December 2005 and ties appear to have been strengthened during that visit. The building up of a strong Parents Group could be an effective input for sustainability. However, five management and 28 field and auxiliary staff indicates a rather high staff /beneficiary ratio, with consequent high per capita cost.

Annex 1

Listing of Organizations Included in the Study by Development Region and District

ANNEX 1: Listing of Organizations Included in the Study by Development Region and District

Ref	Name of Organization	Development Region	District
1	Nepal National Social Welfare Association (NNSWA)	Far Western	Kanchanpur
2	Nepal Disabled Association	Far Western	Kailali
3	Apanga Navajeevan Kendra	Mid Western	Banke
4	Bardiya Rehabilitation Centre for Disabled	Mid Western	Bardiya
5	Surkhet Society of the Disabled	Mid Western	Surkhet
6	Forum for Human Rights and Disability (FHRD)	Mid Western	Dang
7	Mukuteshwar Disabled Service Committee	Mid Western	Dolpa
8	Goreto	Western	Gorkha
9	Tulsi Mehar UNESCO Club	Western	Gorkha
10	District Development Committee (DDC)/ Local Development Fund (LDF)	Western	Gorkha
11	Centre for Community Development and Research (CCODER)	Western	Gorkha
12	Rehabilitation Centre for Disabled (RECED)	Western	Tanahu
13	CBR Palpa	Western	Palpa
14	Partnership for New Life	Western	Butwal
15	Disabled Upliftment Society	Western	Kapilvastu
16	Disabled Rehabilitation Centre (DRC)	Western	Nawalparasi
17	Nawalparasi Rehabilitation Centre	Western	Nawalparasi
18	Maitri Community Development Forum Nepal	Western	Nawalparasi
19	Deepjyoti Samaj Sewa Kendra	Western	Nawalparasi
20	Gaza Youth Club	Western	Baglung
21	CBRS Pokhara	Western	Kaski
22	International Fellowship Nepal / Partnership For Rehabilitation (INF/PFR)	Western	Kaski
23	Children Nepal	Western	Kaski
24	Spinal Cord Injury Association- Nepal	Western	Kaski
25	Disabled Service Association	Central	Nuwakot
26	Security of Handicap and Rural Development Organization	Central	Sindhupalchok
27	Hospital and Rehabilitation Centre for Disabled Children (HRDC)	Central	Kavre
28	Kavre Deaf Association	Central	Kavre
29	CBR Bhaktapur	Central	Bhaktapur
30	CBR Patan	Central	Lalitpur
31	Nepal Disabled Association (NDA)	Central	Kathmandu

32	National Association for the Welfare of the Blind (NAWB)	Central	Kathmandu
33	National Federation for the Deaf and Hard of Hearing (NFDH)	Central	Kathmandu
34	Association for the Welfare of the Mentally Retarded (AWMR)	Central	Kathmandu
35	Community Support Association of Nepal (COSAN)	Central	Kathmandu
36	Community Worker's Society (CWS)	Central	Kathmandu
37	National Disabled and Helpless Upliftment Association (NDHUA)	Central	Kathmandu
38	Nepal Integrated Blind Development Association (NIBDA)	Central	Kathmandu
39	Rural Self Reliant Development Committee (RSRD)	Central	Kathmandu
40	Nepal Leprosy Relief Association (NELRA)	Central	Kathmandu
41	National Association of the Blind (NAB)	Central	Kathmandu
42	Ankur Foundation for Inclusive Education	Central	Kathmandu
43	CBR Biratnagar	Eastern	Morang
44	Prerana Nepal	Eastern	Sarlahi
45	Rural Women's Upliftment Society (RWUA)	Eastern	Sarlahi
46	Bagmati Welfare Society	Eastern	Sarlahi
47	Bahira Tatha Sustha Shrawan Sangh	Eastern	Siraha
48	Child Welfare Society (CWS)	Eastern	Bara
49	Sagarmatha Disabled Welfare Society	Eastern	Saptari
50	Disabled Service Association	Eastern	Dhankuta
51	Nepal Blind Association	Eastern	Illam

- SOURCES: 1. Ministry of Women, Children and Social Welfare, 2006
2. National Federation of Disabled - Nepal(NFD-N), 2006
3. Register of Members, National CBR Network, 2006
4. Register of Organizations Working in Disability in Nepal, RCRD, 2004
5. Handicap International and Partners, 2007

Annex 2

Details of Field Researchers

A vacancy announcement was placed in a daily newspaper in early 2007 for the position of field researchers. A pool of suitable candidates were selected for interview and out of ten candidates interviewed, six were finally chosen (five female and one male); the selection was based on knowledge and experience of surveys. The six field researchers included:

- Nabin Nagarkoti** : Volunteer in Nepal Pahari Development Association
- Pooja Barija** : Bachelors in Public Health.
Some research experience in public health issues.
- Shanti Uprety** : MA sociology (TU) ongoing
- Srijana Gurung** : MBA, Kathmandu University. Experience in market research on various topics.
- Srijana Shrestha** : MA sociology (TU) (ongoing)
- Sulakchana Rai** : MA sociology Tribuwan University (TU)
Experience in both marketing and development work in Nepal/INGO funded projects

The field researchers were trained for one day covering various aspects of the Study. They were given an overview of the study and consequently each question was explained carefully to help them understand what information the questionnaire was trying to seek. The training session also included a role play where the field researchers had an opportunity to play the role of both interviewer and interviewee. Throughout the course of the Study, the field researchers were in constant contact with the national and international researcher for support and advice. The national researcher also attended some of the interviews for monitoring purposes.

Annex 3

Preparing Formats for Data Collection (Recommendations)

As discussed in Section 10.3, standard formats for data collection are recommended and will prove very useful for all concerned. Prepared formats for data collection are helpful for the following:

Baseline individual records could contain:

- ◆ Pertinent personal information and brief history;
- ◆ Participatory assessment of functional, economic and social situation in terms of rights and needs; also identifying abilities and difficulties;
- ◆ Family and household participation;
- ◆ Social participation;
- ◆ Special interests, hobbies, talents and abilities;
- ◆ Individual CBR plans with priorities, interventions and referral needs.

Record of progress and improvement in quality of living²³

Records related to specific age groups, rights and interventions, for example:

- ◆ For children 0-5, ECCD: a child development checklist. This should preferably be one that could be used as the basis of a home-based early stimulation programme²⁴;
- ◆ For children over 5 years, Education: admission date, type of school, record of progress, achievements, problems in school if any;
- ◆ For youth and adults, Livelihood: choice, requirement for skills development, micro-credit and other forms of support and possible sources, start date, recovery of loans, income generated, progress made.

Records kept by community workers regarding their work:

Community workers often find it easy to maintain a “Diary” in which they record their day to day work. This documentation may, for instance record the following:

- ◆ Home visits;
- ◆ Interactions and meetings with and within communities;
- ◆ Interactions with support and referral resources;
- ◆ Administrative tasks carried out;

²³ Refer Training in the Community for People with Disabilities, Form No. 2, WHO Geneva 1989
²⁴ Ibid, Training Package 26

- ◆ Monitoring and other visits made by organisational staff;
- ◆ Training obtained.

Reports made by community workers to the organization/CBR manager:

- ◆ Format designed for monthly reports with statistics and important information from the Diary.

Records kept by organisations: (These are appropriate to level of operation)

- ◆ Formats for collating data from community workers;
- ◆ Listing of community, NGO, mainstream civil society and state resources that participate or can be harnessed to participate and

provide different inputs, e.g. special interest development groups, health, livelihoods, assistive devices, disability-related and development-related training organisations;

- ◆ Financial records—budgets, income, expenditure;
- ◆ Inventories, stocks and assets;
- ◆ Training facilitated for staff and other stakeholders.

Reports from CBR Manager to District DMIS focal point and reports from District DMIS focal point to National DMIS focal point:

Pre-prepared formats are recommended for both of these. Information flow and processing ensures that the DMIS will meet objectives.

Annex 4

Questionnaire Study of CBR in Nepal

Ministry of Women, Children and Social Welfare (MWCSW)
through
Handicap International, Nepal

February 2007

The Study sets out to review the status of CBR in Nepal. It does so by collecting information about the following from each Organization, and then by carrying out a comparative analysis.

- ◆ period of operation and geographic and population coverage
- ◆ coverage in terms of disability, gender and age
- ◆ CBR objectives, activities, interventions, services and level of implementation (home, community, referral) to determine approaches used
- ◆ human resources utilized and training provided
- ◆ recording, reporting and monitoring systems
- ◆ financial aspects if possible – budgets, partners/donors
- ◆ networking

Name of organization

Date on which information is obtained

Name of surveyor

Name and designation of person supplying information

NOTE:

- (a) as is relevant, write answer in space provided or place tick against appropriate answer on the list provided
- (b) when figures are called for, if documented statistics are not available, an approximate number (assessed objectively) will be adequate
- (c) please make sure that your handwriting is clear so that other people can read it.

NOTE:

- (a) as is relevant, write answer in space provided or place tick against appropriate answer on the list provided
- (b) when figures are called for, if documented statistics are not available, an approximate number (assessed objectively) will be adequate
- (c) please make sure that your handwriting is clear so that other people can read it.

1 In which year was the organization set up?

2 In which year were CBR activities first started?

3 Who would you say are your primary (most important) group of stakeholders in your CBR programme?

.....

4 Who are the secondary (other) stakeholders in your CBR programme?

- (1)
- (2)
- (3)
- (4)
- (5)
- (6)
- (7)

5 What are the objectives of your CBR programme?

- (1)
- (2)
- (3)
- (4)
- (5)

6 What are the 5 most important features which make your programme CBR?

- (1)
- (2)
- (3)
- (4)
- (5)

7 In which parts of Nepal is your organization implementing CBR?

District/s	Total	Towns if any (urban) in each district	Total	Villages if any (rural) in each district	Total

8 In what ways do people with disability participate in your CBR programme?

- (1)
- (2)
- (3)
- (4)
- (5)

9 In what ways do community members participate in your CBR programme?

- (1)
- (2)
- (3)
- (4)
- (5)

10 Is there a community group/committee/organization that takes responsibility for CBR?

Yes No

11 If your answer is yes, what are their responsibilities?

- (1)
- (2)
- (3)
- (4)
- (5)

12 How many people with disability if any does your CBR programme employ?

13 Does your CBR programme use community workers from the Localities who also do home visits?

Yes No

14 If yes, what are their main tasks?

- (1)
- (2)
- (3)
- (4)
- (5)

POPULATION:

**15 How many people are being served by your CBR programme?
(most recent annual figures) (use one of the Tables below)**

	Age group	Sex		Total
		Female	Male	
1	0 - 5			
2	6 - 17			
3	18 - 29			
4	30 - 55			
5	Above 55			
6	Total			

	Age group	Sex		Total
		Female	Male	
1	Children			
2	Youth			
3	Adults			
4	Total			

TYPES OF DISABILITY:

16 What types of disability are served by your CBR programme?

	Type of disability	Place tick if yes, dash if no	number served
1	Hearing and/or speaking (communication)		
2	Visual (seeing)		
3	Intellectual (mental retardation)		
4	Psychiatric (mental illness)		
5	Developmental (e.g. cerebral palsy)		
6	Moving (body, arms, legs)		
7	Leprosy		
8	Epilepsy		
9	Multiple		
10	Other: specify		

INTERVENTIONS and SERVICES:

17 What types of interventions/services are provided within your CBR programme?

Ask this question first, let the person give you the answer in her/his own words, and then fill the table below.

After this, you may ask any further questions to complete each Table relevant in Sections 12 – 18 to the services being provided by the organization.

		Place tick if yes, dash if no	If yes, go to these sections and complete Tables
1	Support to self-help groups or Disabled People's Organizations		If yes, to section 18
2	Functional training		If yes, go to section 19
3	Health Care		If yes, to section 20
4	Assistive Devices		If yes, to section 21
5	Income generation/livelihoods		If yes, go to section 22
6	Family and Community Living		If yes, go to section 23
7	Education		If yes, go to section 24

8	Political empowerment		
9	Legal protection		
10	Other: specify and state relevant support		

18 Self-help groups or Disabled People's Organizations

18a What kinds of Self-help groups or Disabled People's organisations does your CBR programme support?

18b Does this group or organization work on community or district level?

18c What kinds of disabilities do their members have?

18d What kinds of support do you give the organization?

Self-help groups or Disabled People's Organizations						
		Place tick if yes, dash if no	If yes,			
			At community level	At district level	Disabilities members have	Type of support given
1	Single disability groups					
2	Cross-disability groups					
3	Parents' groups					
4	Other: specify					

19 Functional Training

19a What kinds of functional training does your CBR programme facilitate?

19b Is this training facilitated at home, at community centre or through referrals elsewhere?

Functional training					
		Place tick if yes, dash if no	If yes,		
			At home	At community centre	through referral
1	Communication (e.g. speech and/or sign Language)				
2	Orientation and mobility/ moving around home and neighbourhood				
3	Self care (take care of One self)				
4	Other: specify				

20 Health Care

20a What aspects of health care does your CBR programme facilitate?

20b Are these aspects of health care facilitated at home, at community centre or through referrals elsewhere?

Health Care			
		Place tick if yes, dash if no	If yes, does it include people who have disability (yes or dash)
1	Prevention (immunizations, nutrition and health education etc)		
2	Promotion (good health habits)		

		Health Care			
		Place tick if yes, dash if no	If yes,		
			At home	At community centre	through referral
3	Medical and surgical treatment				
4	Early Childhood Care and Development				
5	Physiotherapy				
6	Occupational Therapy				
7	Speech therapy				
8	Other: specify				

21 Assistive Devices

21a What kind of assistive devices are made available through your CBR programme?

21b Are these assistive devices made available at home, at community centre or through referrals elsewhere?

		Assistive Devices			
		Place tick if yes, dash if no	If yes,		
			At home	At community centre	through referral
1	Hearing aids				
2	Spectacles				
3	White canes				
4	Seating aids				
5	Walking aids				
6	Wheelchairs				
7	Tricycles				
8	Callipers/splints				
9	Artificial legs				
10	Artificial arms				
11	Other: specify				

22 Income generation/livelihoods

a What aspects of income generation/livelihoods are facilitated by your CBR programme?

b Are these aspects facilitated at home, at a community centre or through referrals elsewhere?

		Income generation/livelihoods			
		Place tick if yes, dash if no	If yes,		
			At home	At community centre	through referral
1	Vocational skills				
2	Microfinance - provide loans for self-employment				
3	Provide grants for self-employment*				
4	Support for cooperative activities				
5	Support for open employment (job placement)				
6	Other: specify				

23 Family and Community Living

a What aspects of Family and Community Living are

		Family and Community Living	
		Home	Community
		Place tick if yes, dash if no	
1	Promoting family interaction		
2	Transferring knowledge and skills to individuals and families		
3	Counselling		
4	Promoting community interaction		
5	Raising awareness/social communication		
6	Community (social) mobilization		
7	Organize inclusive sports		
8	Organize special sports		
9	Organize inclusive cultural activities		
10	Organize special cultural activities		
11	Improve housing and access within the home		
12	Improve access to the community built environment		
13	Other: specify		

24 facilitated by your CBR programme? Education

a What aspects of education are facilitated by your CBR programme?

b What types of disabilities do the beneficiaries have?

c How many have benefited from these aspects of education?

		Education		
		Place tick if yes, dash if no	If yes	
			types of disability beneficiaries have	How many have been supported
1	Inclusive preschools			
2	Special preschools			
3	Inclusive school education			
4	Special classes in Ordinary Schools			
5	Integrated education for children who cannot see			
6	Special Schools			
7	Teacher-training			
8	Non-formal education			
9	Higher education			
10	Braille teaching/learning			
11	Sign language teaching/learning			
12	Other: specify			

STAFF/WORKERS:

25 What Managerial and Administrative staff (including accounts) work in your CBR programme?

Managerial and Administrative staff (including accounts)						
Designation	Number employed		Gender		Full-time	Part-time
	paid	unpaid	women	men		
Total						

26 What Field staff/workers and support staff/workers work in your CBR programme?

Field staff/workers and support staff/workers									
Designation	Number employed			Gender			Full-time	Part-time	total
	paid	unpaid	total	women	men	total			
1									
2									
3									
4									
5									
6									
7 Total									

27 Has any CBR-related training been provided for your management and administrative staff?

Yes No

28 If yes, please list the training courses.

	Name/type of course	No of staff trained	How long (weeks)	By whom was it provided?
1				
2				
3				
4				

Yes No

30 If yes, please list the training courses.

31 Has your organization developed any training courses/modules related to CBR?

	Name/type of course	No of staff trained	How long (weeks)	By whom was it provided?
1				
2				
3				
4				

Yes No

32 If yes, have any other organisations made use of these?

Yes No

33 If No, would you be willing to make these available to other Organizations in the future?

Yes No

RECORDING AND REPORTING

34 What documents do you keep to record what happens in your CBR programme (list records kept)

- (1)
- (2)
- (3)
- (4)
- (5)

35 What kinds of reports do you use in your CBR programme? (list name of report and/or from whom to whom)

- (1)
- (2)
- (3)
- (4)
- (5)

36 Have you made a plan of action/project plan/operational plan for your CBR programme?

Yes No

37 If yes, for how many years is this plan? years

38 Do you monitor your CBR programme?

Yes No

39 If yes, What kinds of monitoring methods do you use in your CBR programme?

Monitoring method	Monitoring method		If yes,		
	Y	N	Whose responsibility is it?	Who participates in this?	How often is this done?
1 Meetings					
2 Field Visits					
3 Reports					
4 Other: specify					

40 Has your CBR programme ever been evaluated?

Yes No

41 If yes, when was this done and by whom?

	Type of evaluation			
	Internal	When was this done?	External	When was this done?
1				
2				
3				

COSTS

42 How much does it cost to run your CBR programme every year? How is your programme financed?

	Budget item	Cost in NRs	Source/s of funding
1	Total cost		
2	Recurrent cost		
3	Capital cost		
4	Salaries		
5	Transportation		
6	Training		

43 Do you charge fees for any CBR interventions that you provide?

Yes No

44 If yes, for what do you charge fees and how much do you charge?

	Service/item	Amount charge/unit
1		
2		
3		

NETWORKING:

45 Does your organization collaborate with any other Organizations or Institutions about anything related CBR?

Yes No

46 Is your organization member of any of the following networks or federations?

	Type of federation or network	Place tick if yes, dash if no
1	CBR Network	
2	NFD-N (National Federation of the Disabled, Nepal	
3	Other; specify	

SUSTAINABILITY

47 What are the 3 factors that contribute most to the sustainability of your CBR programme?

- (1)
- (2)
- (3)

ACHIEVEMENTS/STRENGTHS

48 What would you say are 3 of the greatest achievements/strengths of your CBR programme?

- (1)
- (2)
- (3)

PROBLEMS/WEAKNESSES

49 What do you consider to be the 3 biggest problems/weaknesses of your CBR programme?

- (1)
- (2)
- (3)

FUTURE PLANS

50 Please give 3 important future plans by which you hope to improve your CBR programme?

- (1)
- (2)
- (3)

SUGGESTIONS

51 Please provide 3 suggestions that would help to improve CBR in Nepal?

- (1)
- (2)
- (3)

DOCUMENTATION:

One of the outputs of this Study will be a recommendation about how to develop a good Information System for Nepal's CBR programmes. Another is to suggest improvements to training of CBR workers.

For this purpose we would appreciate it if you supply us with copies of any recording, reporting and monitoring forms that you may be using, and copies of training schedules.

Copies of Project Plans and Evaluation Reports would also be useful.
Thank you.

ADDED NOTES BY SURVEYOR:

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.....
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.....

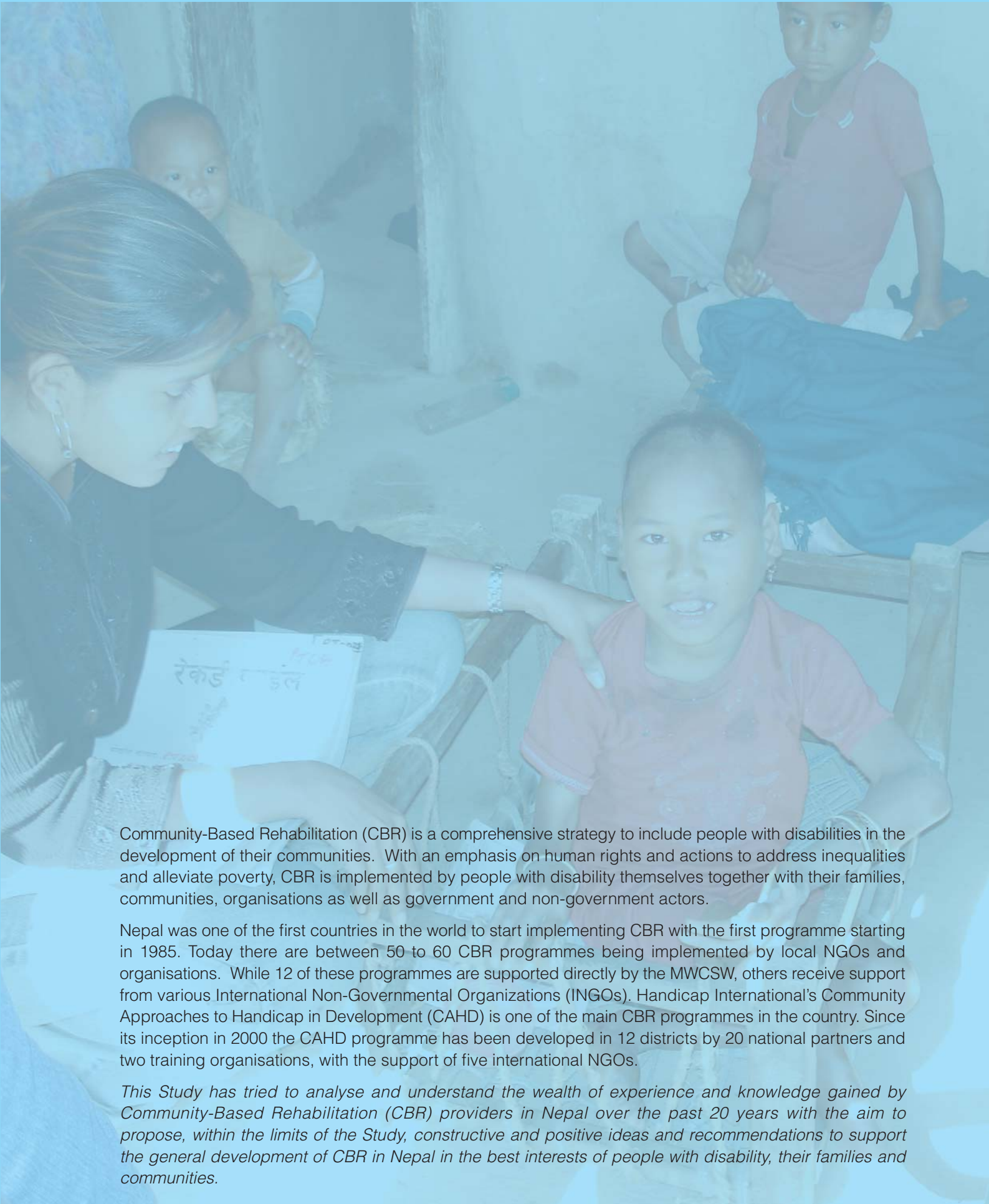
Documentation received:

- (1)
- (2)
- (3)
- (4)
- (5)

The Ministry of Women, Children and Social Welfare and **Handicap International** thank you for your time and cooperation.

Signature of Surveyor:

Date:



Community-Based Rehabilitation (CBR) is a comprehensive strategy to include people with disabilities in the development of their communities. With an emphasis on human rights and actions to address inequalities and alleviate poverty, CBR is implemented by people with disability themselves together with their families, communities, organisations as well as government and non-government actors.

Nepal was one of the first countries in the world to start implementing CBR with the first programme starting in 1985. Today there are between 50 to 60 CBR programmes being implemented by local NGOs and organisations. While 12 of these programmes are supported directly by the MWCSW, others receive support from various International Non-Governmental Organizations (INGOs). Handicap International's Community Approaches to Handicap in Development (CAHD) is one of the main CBR programmes in the country. Since its inception in 2000 the CAHD programme has been developed in 12 districts by 20 national partners and two training organisations, with the support of five international NGOs.

This Study has tried to analyse and understand the wealth of experience and knowledge gained by Community-Based Rehabilitation (CBR) providers in Nepal over the past 20 years with the aim to propose, within the limits of the Study, constructive and positive ideas and recommendations to support the general development of CBR in Nepal in the best interests of people with disability, their families and communities.