Towards a Full and Decent Life

A Study of the Social Impact of Intervention provided by The Hospital and Rehabilitation Centre for Disabled Children (HRDC)

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Ministry of Health & Population

Hon'able Giriraj mani Pokharel
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Message

I was quite amused by the fact that The Friends of the Disabled/The Hospital and Rehabilitation Centre for Disabled Children (FOD/HRDC) operating in the management (treatment, care and rehabilitation) of pediatric physical disabilities at the tertiary level with priority to the poorest of the poor children from disadvantaged families has successfully evaluated the social impact of its intervention in the lives of children with physical disabilities. In Nepal, health services are mostly demand based and many persons with disabilities are not in the situation of assertively demanding their needs, the FOD/HRDC have reached the unreached in the grassroots enabling the children to access the services as their rights to become functionally independent in the community as any other normal children. Children are mostly left out and are highly prone to fall victim making disability complicated.

Quality treatment and rehabilitation service offered to the children by the FOD/HRDC has been a very successful life changing intervention for many as the intervention has made them functionally independent and promoted for enjoyment of rights eventually establishing themselves as contributing member of the society.

On behalf of the Ministry of Health and Population, I congratulate the FOD / HRDC for its services and successfully carrying out the study of the social impact which has positively indicated that persons (children) with disabilities are progressively mainstreamed and are enjoying their rights as any normal person. The overall work of HRDC and the social impact on clients in the community are commendable and replicable by any person / organization concerned with / in disability management.

Thank you very much!

Giriraj mani

Girirajmani Pokharel

Minister

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Message

In the context of disability management where there has been global paradigm shift from charity and welfare to rights, inclusion and development, the Study of Social Impact carried out by the Hospital and Rehabilitation Centre for Disabled Children (HRDC), the referral centre which focuses on the medical rehabilitation of children with physical disabilities is not only exemplary but also is setting a right tone for multiple dimensions involved in the comprehensive rehabilitation process.

Understanding the fact that Nepal is in the process of transition to participatory and bottom-up management in all aspects of development initiatives to build new Nepal and the fact that persons with disability, the largest minority of the total population are still struggling for social inclusion and full enjoyment of fundamental human rights, integrated rather than segregated and empowered rather than welfare, collaborative and comprehensive approaches to change the present plight has no alternative. It is in this background, I sincerely urge all stakeholders to look into and learn from the down-to-earth and comprehensive approach that the HRDC / FOD has adopted in reaching out to the unreached sector of the population throughout Nepal.

On behalf of the Ministry of Women, Children and Social Welfare, I congratulate the HRDC/FOD Team and others who helped to make the study of social impact happen.

Thank you!

Bindra Hada Bhattarai
Secretary

December 31, 2008

Foreword

The treatment and outreach services provided to disabled children by the Hospital and Rehabilitation Centre for Disabled Children (HRDC) have a lasting impact on the families and the communities the patients hail from; this is something I have always believed. This study, commissioned by the Friends of the Disabled (FOD)/HRDC and supported by Foundation Terre des hommes Nepal, establishes the extent of the impact.

HRDC activities now cover over 1,400 out of a total of 3,900 village development communities (VDCs). In addition, our outreach services touch base with 39 out of a total of 58 municipalities, reaching nearly 15% of the children of Nepal.

With this emphasis on outreach services, an evaluation process was considered crucial by all our co-partners. The preparations were not without hitches, but when entire process of conducting a non-biased study started to fall into place the data collection process was implemented according to time frame guidelines.

I found the meetings and interactions to be mature and fruitful. We shared our comments and impressions with Mr. Robert Millman who prepared the final write up of the study.

The results are extremely encouraging for all of us at HRDC. Our intervention has positively impacted the lives of more than 90% of those we treated. The report findings are rewarding and encouraging for both the hospital and its partners. The recommendations will be used to further improve our inpatient services as well as outreach programmes.

Congratulations and thanks to all of you who have helped in this important task.

Dr. Ashok K. Banskota
Chairman
Friends of the Disabled

Making friends at HRDC

Acknowledgements

The Steering Committee for this Study extends its sincere acknowledgement and thanks to the Board of the Friends of the Disabled and to the Hospital and Rehabilitation Centre for Disabled Children (FOD/HRDC) for commissioning this study in order to assess the social impact on the children and young people with physical disabilities after HRDC intervention. The Committee also acknowledges the generous contributions of time, knowledge and experience provided by the FoD/HRDC and The Foundation Terre des hommes (Tdh) staff.

The Committee would like to express its sincere thanks to Tdh for its invaluable support, both financial and technical. Tdh was actively involved in the development and completion of this Study. The planning and preparation for family and community participation in this study was in and of itself a massive achievement. It reflects the careful and attentive listening to the voices of children, families and communities. It is a tribute to those who work in the field and sustain contact with families. This work has in itself contributed to reinforcing the strong bond families and communities have with the HRDC, its services and personnel.

The enumerators, supported by the HRDC's community-based rehabilitation department undertook family interviews and data collection with energy and professionalism. Their respect for families and children and members of local communities has contributed greatly to both the quality and quantity of information generated.

The Committee would also like to acknowledge the contributions from Mr. Nitra Bahadur Deuja, Mr. Dhiraj Sharma Luitel, Mr. Nava Raj Simkhada, Mr. Hari Kumar Tamang, Mr. Laxman Thapa, Mr. Keshav Bastakoti, Mr. Heera KC and other community based rehabilitation workers.

There have been numerous technical contributions, but special thanks go to Dr. Sharad Sharma, the consultant demographer for his work on data analysis and to all contributing members of the FoD/HRDC & Tdh staff who offered guidance, support and constructive criticism.

PLAN Nepal, Banke District, has been a partner of the FoD / HRDC in disability management and advocacy for a long time. But in this particular study it has generously extended its financial and moral support to conduct the social impact of HRDC intervention in its project district in Banke.

The committee extends sincere thanks to the interviewees for their cooperation, valuable comments and sharing their experiences. Their comments and suggestions are purely independent and presented without any judgement.

We would also like to thank Nepal Health Research Council for its constructive input and advice to ensure that the whole study conforms to ethical guidelines.

Above all, the Steering Committee is grateful to the Foundation of Terre des hommes for deputing Mr. Robert C Millman, former Delegate of Tdh Nepal, and providing him financial support and ample freedom to develop the analysis, observations and recommendations that form the main body of this report. The Steering Committee takes this opportunity to express immense gratitude for his work. This was also a good opportunity for a reunion, rejuvenation of old memories, emotions and strengthening of relationships. It was a real privilege working with him and making use of his vast field experience.

From Mr. Millman, we not only received a well written document but also encouragements and strength to continue working for children with disabilities.

Thank you, Mr. Rob Millman for everything.

"When the powerless find voice and join hands with the powerful, when the collective wisdom and experience of children and families is shared, multiplied and replicated by those of us who seek to bring qualitative change to their lives, then we all move forward towards 'a full and decent life'."[1]

Ambika M. Joshee
Coordinator, Steering Committee

Disabled children enjoy singing and dancing at HRDC

Abbreviations and Acronyms

ADL	Activities of Daily Living
CBO	Community Based Organisation
CBR	Community Based Rehabilitation
CRC	The United Nations Convention on the Rights of the Child
CGD	Control Group Discussion
DBase	Database
DDC	District Development Committee
DMIS	Disability Management Information System
DPO	Disabled Persons' organisation
ECCD	Early Childhood Care and Development
FGD	Focus Group Discussion
FHV	Female Health Volunteer
FOD	The Friends of the Disabled
GO	Government organisation
GoN	The Government of Nepal
HI	Handicap International
HRDC	The Hospital and Rehabilitation Centre for Disabled Children
INGO	International Non-governmental Organisation
MWCSW	The Ministry of Women, Children and Social Welfare
NFD-N	National Federation of the Disabled - Nepal
NGO	Non-governmental organisation
NHRC	Nepal Health Research Council
NPC	National Planning Commission
OT	Occupational Therapist
OTEC	Orthopaedic Technician
PRT	Primary Rehabilitation Therapy
PT	Physiotherapist
PWDs	People with Disabilities
Ref	Reference
SHG	Self Help Group
SPSS	Statistical Package for Social Sciences
Tdh	The Foundation of Terre des hommes, Lausanne, Switzerland
ToR	Terms of Reference
UNICEF	United Nations Children's Fund
USD	United States Dollar
VDCs	Village Development Committees
VDRC	Village Development Rehabilitation Committee
WHO	World Health Organization

Compassionate child care starts at the ward

1. Introduction

The Nepalese NGO, the Friends of the Disabled (FoD)[1], and the Swiss INGO, the Foundation of Terre des hommes (Tdh), commissioned this study in order to assess the social impact of treatment offered by the Hospital and Rehabilitation Centre for Disabled Children (HRDC)[2] through its hospital-based community-based rehabilitation and outreach services. The study also builds on previous work undertaken jointly between Tdh, FoD/HRDC and the International Centre for the Advancement of Community Based Rehabilitation, Queen's University, Kingston, Ontario, Canada,[3] which analysed the outcomes of treatment for a sample of 248 children from a total of 1145 closed cases from the opening of the project in 1985 to the end of 1992.

The current study has proceeded with the approval of the Nepal Health Research Council (NHRC). It is based upon a sample survey of 745 families from a total of 1257 closed cases from 11 of the 75 districts of Nepal whose children completed treatment and rehabilitation between 1993 and 2005. The social status of these children is compared with a control group of 351 families living in the same communities whose children experience a similar range of physical disabilities, but who, for a variety of reasons, have not come forward for treatment at the HRDC or other institutions.

The results of this comparative study will be presented in the broader context of the United Nations Convention on the Rights of the Child (CRC), with specific reference to Article 23 which defines obligations of 'States Parties' with regard to the rights of children with disabilities. We also acknowledge that non-state actors make a significant contribution towards the fulfilment of States Parties obligations. It is axiomatic that the CRC does not select or prioritise one set of rights over another. In the context of this study however, Article 23 provides a relevant and practical framework within which to assess the social impact of treatment provided by the HRDC and its CBR programme. It also enables recommendations to be analysed within the broader context of evolving social policy in Nepal during a period of constitutional transition, identifying FoD/HRDC and Tdh as actors and advocates as well as service providers.

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[2] Refer to Annexe 1 for the HRDC / FoD's Vision, Mission and Strategy statement 2001

[3] For comprehensive background material on the HRDC visit the website at http://www.hrdcnepal.org/

[4] "Physically Disabled Children in Nepal : A Follow Up Study" by W Boyce, S. Malakar, R. Miffman, K. Bhattarai, published in the ASIA Pacific Disability Rehabilitation Journal Volume 10 No.1, 1999

2. Executive Summary

The results of this study demonstrate that the Friends of the Disabled, the Hospital and Rehabilitation Centre for Disabled Children, its donors[5], partners and the Government of Nepal, should be encouraged by the positive social impact of the HRDC's institutional and community-based treatment. The study has given voice to the experience of children and families, to their aspirations and hopes, although it is clear that the FoD/HRDC cannot respond to the full range of needs expressed by their clientele.

We have sought to measure social impact through structured interviews with 745 families across 11 districts whose children were treated at the HRDC between 1993 and 2005, as well as interviewing 351 families living with a child or young person with physical disability who has not been treated at the HRDC. We have also carried out 110 in-depth interviews with a range of people involved in the life of a child or youth living with a disability in order to elicit qualitative information. These two sources of data have enabled us to examine the social impact of HRDC intervention using a cluster of indicators including education, employment and marital status, knowledge and attitudes regarding disability and Awareness of the rights of persons with disabilities.

2.1 Executive Summary: Main Findings

Social impact has been analysed and findings presented using the framework of Article 23 of the United Nations Convention on the Rights of the Child, which highlights the rights of children with disabilities.

The Right to Special care

High quality, low cost care - The HRDC's hospital-based services provide high quality, specialised, accessible and low cost treatment for children in a caring atmosphere. Improvements can be made in child and family counselling and post-operative affective care but this does not detract from the high levels of family satisfaction, appreciation for, and understanding of the treatment and rehabilitation process.

Provision of Assistance Free of Charge

Free and subsidised treatment - The HRDC provides free or means-tested contributions to treatment for children from poor families. Direct and indirect financial contributions give recognition to families as service users and as stakeholders in the treatment offered to their children. Although almost all families face financial and economic constraints, they also recognise that HRDC treatment is either free or comparatively inexpensive and see this as a key factor in terms of accessing treatment.

Promotion of Self-Reliance in the Child: Functional Status & Self Care

Improved levels of self-reliance - The physical "starting point" from which social impact is constructed is the child's capacity to undertake normal activities of daily living. 92–95% of HRDC treated children have achieved functional independence, and only 2% remain completely dependent on others for core activities of daily living. Control group children's independence ranges from 76% down to 59%.

Access to and Receipt of Healthcare and Rehabilitation Services

Community based rehabilitation needs expansion - There is consistent awareness of the need for decentralised and specialised services and of the need for the HRDC to increase the number of CBR workers, hold more frequent mobile camps, create service centres in Nepal's five development regions and extend CBR worker networking with disabled peoples' organisations.

Access to and Receipt of Education

Great progress in access to education - Respondents place a high value on education and training as a means of fulfilling individual potential and developing self-confidence. School attendance rates for HRDC treated children are on a par with the national average of 84%.

Access to and Receipt of Training and Preparation for Employment

Prepare disabled for employment - Many respondents felt that the FoD/HRDC should forge a leadership role in advocating training and education for disabled children as well as extending its remit on disability prevention and policy development. The status of working and earning capacity among both HRDC treated youth and control group family youth remains low in terms of formal employment

[5] In alphabetical order: the American Himalayan Foundation, the Austrian Round Table, Christoffel Blindenmission (CBM), the development NGO of the National Federation of Luxembourg Scouts and Guides (FNEL), the Foundation of Terre des hommes, PLAN Nepal and other private donors

opportunities and percentage levels of contribution to the family income. Twenty seven percent of HRDC and 6% of control group youth contribute to the family economy through employment.

Promotion of Dignity and Disability Rights

Advocate for change - General awareness on the Rights of Persons with Disabilities is widespread. There is a strong belief that advocacy is needed to promote understanding of disability and to develop services for children and adults with special needs. A number of respondents suggested that FoD/HRDC should become a leader in national policy development on behalf of persons with disabilities. There is a widespread belief among adults that children with disabilities are still stigmatised, although children themselves *expressed* a far stronger sense of integration and social acceptance.

Promotion of Self-reliance as a Youth and Young Adult

Improved socialisation - HRDC services contribute to a wider and more informed public awareness and understanding of disability, which is complemented by the growth of CBR and Disabled People's Organisations and networks. It is evident that HRDC intervention has had a considerable, positive impact on the socialisation of children within their families and a range of responses suggest that levels of child protection, support, care and integration are consistently higher among HRDC families.

Active Participation in the Community and Preparation for Recreation Opportunities

Improved participation in society - In-depth interviewees share a broad range of perceptions regarding the participation of children and youth with disabilities in community and recreational activities, with many voicing observations of social exclusion rather than inclusion. The ratio of membership of organisations shows similar patterns for both HRDC and control family youth. 91% of HRDC youth and 71% of control family *youth* felt that they had exercised either a great or moderate influence on the organisations to which they belonged. HRDC children report a far higher level of participation in socio-cultural events - on a par with their able-bodied peers - than control family children.

2.2 Executive Summary: Main Recommendations

Access to Treatment and Services

Improve access to treatment - HRDC should *strengthen* links with other orthopaedic and CBR services to provide more accurate and detailed information about HOW and WHERE to access treatment, skills training and other specialised services for children with disabilities. A more holistic approach may be required to develop and promote community systems of family and child support.

Communication, Knowledge and Information about Services

Deploy PWD ambassadors - Information, inpatient counselling and publicity about the HRDC service must be improved. Greater community outreach and information dissemination could be achieved through CBR worker mobilisation of former HRDC patients. They could act as "ambassadors" for people with disabilities and provide information on the range of services available.

Education and Training

Offer play and education to patients - The HRDC should strengthen the identity and contribution of its inpatient services to children and families in the areas of education, literacy recreation and play. The CBR workers should become more *actively involved* in promoting educational and vocational training opportunities for children. The HRDC should also respond to one of the strongest, expressed needs of children and families interviewed in this study – to gain access to specialised educational and vocational training services.

Health

Create access to community based health care - HRDC and its CBR programme should create stronger linkages with primary health care and integrated health services for children including CBR support in its working areas. CBR worker links with *women* community health volunteers must be developed in order to strengthen the impact of HRDC family-based rehabilitation regimes for children and to promote *stronger* local linkages and access to health services.

Advocacy

Advocate for disabled children - Nationally, the FoD/HRDC should sustain its current efforts to remain a key player in terms of advocacy and policy development on behalf of children with disabilities focusing not just on treatment but also on prevention, training, initiatives to sustain national CBR and DPO *networks* deserve support if human resources permit.

Sustainability and Marketing

Highlight HRDC services within society - HRDC's services, including surgery, assistive devices, innovative *intervention* techniques and community-based rehabilitation need to be brought to the notice of a wider audience. Consideration should be given to identifying recognised international figures who would *function* as ambassadors and as potential fund-raisers. Consideration should be given to the establishment of an international trust fund that could manage investments and provide a basis of financial security that would exist alongside donor support.

3. Operational Modalities Of The Study

3.1 Geographical Location

The study was carried out in eleven districts[6] in order to give a representative sample of the total HRDC patient population and of the geography and ecology of Nepal.

Ecological zone	District	Geographical Zone	Development region
Mountain	Sankhuwasabha	Koshi Zone	Eastern Development Region
Mountain	Dolakha	Janakpur Zone	Central Development Region
Hill	Lalitpur	Bagmati Zone	Central Development Region
Hill	Dhading	Bagmati Zone	Central Development Region
Hill	Tanahu	Gandaki Zone	Western Development Region
Hill	Surkhet	Bheri Zone	Mid-Western Development Region
Terai	Jhapa	Mechi Zone	Eastern Development Region
Terai	Bara	Narayani Zone	Central Development Region
Terai	Nawalparasi	Lumbini Zone	Western Development Region
Terai	Banke	Bheri Zone	Mid-Western Development Region
Terai	Kanchanpur	Mahakali Zone	Far Western Development Region

Of the eleven districts, Lalitpur and Surkhet were not covered by HRDC CBR workers during the period under review, thus enabling comparisons to be made on the perceived social impact of treatment in both CBR worker and non-CBR worker districts. At the time of writing, Dhading and Sankhuwasabha were being covered by organisations working in partnership with the HRDC to manage outreach and follow-up activities.

3.2 Study Population & Sampling Method

The initial proposal was to interview 80% closed and 20% ongoing HRDC cases and a significant number of control group cases. Subsequently, the HRDC population was limited to children who had completed treatment between 1993 and 2005 so as to achieve a clear-cut comparison with control group cases who had either not received treatment or who had sought treatment from other sources. Initially it was planned to visit all 1257 families, but some 512 were unavailable for a variety of reasons during the fieldwork phase[7]. The final study population comprises 745 HRDC families and 351 control group families, thus achieving a statistically significant number of control cases.

3.3 Data Collection and Analysis: Method and Process

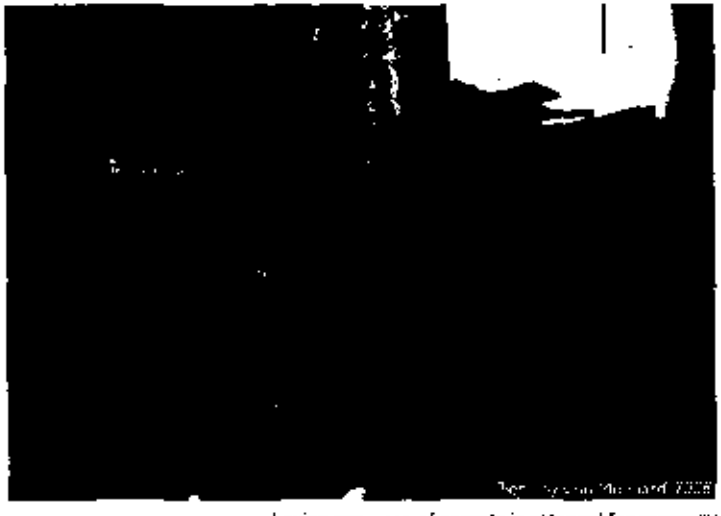
Enumerators[8] were recruited externally by the HRDC. Selection was based on academic qualifications, practical field experience and gender balance. The enumerators participated in a five-day training seminar in the use of the survey instrument and in the conduct of in-depth interviews. Interviews and subsequent data entry were carried out between July and September 2008. Enumerators worked

[6] See Annexe 2 for Map of Nepal showing HRDC CBR national coverage by district.
[7] See Annexe 3 and section 3.4 for details of HRDC and control families interviewed plus explanations for HRDC families that were not seen.
[8] See Annexe 4 for details of the enumerators and the HRDC CBR supervisory team.

In pairs and interviewed both HRDC and control group children and families, the latter group having been identified by community leaders and HRDC CBR fieldworkers and supervisors. Control families had at least one child or youth with a physical disability. Interviews were conducted in Nepali using a pre-tested survey instrument[9].

Data collection comprised household information, the type of physical disability, educational status, marital status, functional status, earning capacity, affiliation with organisations, attitudes towards disability, awareness of rights and issues of discrimination, personal and social status and social inclusion. All participating families consented to be interviewed and were informed of the nature and purpose of the survey. Confidentiality was guaranteed, names quoted in the study have been changed, and only ten families opted out of the survey. Given that there was no direct benefit for either HRDC or control group families, the level of participation was highly satisfactory, achieving a 68% : 32% ratio of HRDC and control cases. Nonetheless, enumerators noted some understandable degree of disappointment among control group families reporting comments such as:

"What is this to do with us? Many people come and ask us questions, but they do not offer any treatment or any cure" [10] – Control group interviewee



Loving presence of parents is essential for recovery

In-depth interviews[11] focused on one HRDC and one control group family per district. The aim was to gain a fuller picture and a range of perspectives on the degree of social integration of the child or youth living with a physical disability by interviewing a parent or guardian, a teacher, an employer where relevant, a social worker/social activist and a friend of the child/youth. Interviews were recorded on cassette tape and transcribed during the period of data entry at the HRDC. 20% of the 110 in-depth interviews were professionally translated from Nepali to English while 80% of the interviews were analysed in Nepali only. Key points were accumulated and aggregated independently by the author and one steering committee member so as to provide qualitative information to complement the family interview data.

Upon completion of the fieldwork, all data were entered by enumerators into Microsoft Access 2007 and data cleaning and analysis was done using the STATA 9 programme. 122 analytical tables were prepared by the consultant demographer during October 2008. The data and transcripts from in-depth interviews were analysed by the author and the final report was reviewed by the joint FOD / HRDC / Tdh steering committee during November 2008.

[9] See Annexe 5 for the survey instrument

[10] Bold text indicates quotations from in-depth interviews

[11] See Annexe 6 for aggregated feedback from the in-depth interviews

4. Constraints And Limitations Of The Survey

This extract from Table 1/2/3, shows that the HRDC sample is proportionally of a more mature age than the control group. Accordingly, every effort was made to ensure age-appropriate consistency when analysing findings and recommendations linked to indicators such as social inclusion, involvement in associations or organisations, awareness and knowledge of disability rights and issues of non-discrimination/discrimination, marriage and earning capacity.

Table 1/2/3 **Total number of cases used in the analysis according to background characteristics, Nepal 2008**

Background characteristics		Number of cases used in the analysis			
		HRDC		Control group	
Current age					
	1-5	2	0.27%	58	16.72%
	6-10	38	5.13%	89	25.65%
	11-14	119	16.06%	92	26.51%
	15+	582	78.54%	108	31.12%
Total		**741***	**100%**	**347***	**100%**
Age at intervention					
	1-5	243	32.84%		
	6-10	179	24.19%		
	11-14	207	27.97%		
	15+	111	15.00%		
Total	**740***	**100%**			

* The total number of HRDC cases is 745 and control cases 351. The figures here indicate that information on current age and age at intervention (for HRDC cases only) was not available for 5 HRDC and 4 control cases when data entry was done. Such discrepancies may be noted in other tables as well.

Financial and time constraints made it impossible to confirm the address and geographical location of all HRDC families prior to deployment of the teams of enumerators. Five factors have thus contributed to a reduction in the size of the HRDC sample population of closed cases from 1257 to 745 (See Annexe 3).

- 141 families could not be traced due to a "wrong address" (11.2%)
- 72 families could not be traced due to an "incomplete address" (5.7%)
- 72 families had migrated, 59 within Nepal, 13 to India (5.7%)
- 116 children and families were not visited due to time constraints (9.2%)
- 75 children had expired, which represents a 5.96% mortality rate in the HRDC population, on a par with the national child mortality rate of 5.9% (UNICEF 2008).

[1] The full version of Table 1/2/3/ is shown in Annexe 6

It is common knowledge that some extended family systems in the Terai districts straddle the southern border with India, which accounts for some of the "wrong addresses" (70/141 are in Terai districts) and "incomplete addresses" (55/72 are in Terai districts). Some of the original information provided by families at the time of treatment at the HRDC may also have been incorrect or incomplete, and was not fully updated subsequently through mobile camp and CBR worker contact in the field. The issue of accurate information-gathering will be addressed under Chapter 6, Recommendations.

In total, Bara (210) and Dhading (261) districts have the highest number of cases and also account for 228 of the 512 HRDC treated children and families who were not available to participate in the survey (44.5%). There is no adequate explanation for this phenomenon nor for the comparatively high number of deaths in Dhading and Bara districts (36/75 – 48%). It is a fact that both districts have been subject to disruption of civil society during phases of the period under review. However this cannot be offered as either a convincing or demonstrable explanation given that similar conditions prevailed in certain other survey districts.

In conclusion, the constraints and limitations noted here neither impede nor undermine the overall relevance and statistical validity of the data since at 32%, the final control group sample is well above accepted research norms.

Building a new future

Tika Bishwokarma (15) once led a normal teenage life, studying and doing household jobs. Until one day she fell out of a tree. In a split second her life changed.

In Nepal most children carry out household chores. They take goats and cows out for grazing, carry water and collect fodder and firewood. Due to falls a disproportionally large percentage of Nepalese children suffers from spinal injuries.

Tika Bishwokarma was 14 when she climbed into a tree to cut branches for fodder, and slipped. She instantly broke her backbone. Despite the grave injury Tika survived but not without severe damage to her spine. The once active, ambitious student was now bedridden and fully dependent on her relatives.

Tika was taken across the border to India for treatment. However, her family soon discovered that surgery and rehabilitation was beyond their financial means. Tika belongs to a marginalised Dalit community, considered untouchable, with a low social and economic status. Tika soon returned to her village in Kallali, in the far-western region of Nepal. Her future seemed sealed: living the life of an inactive paraplegic, bound to her bedroom.

Fortunately, a HRDC Community Based Rehabilitation Facilitator, while visiting the homes of disabled children and organizing community awareness programmes, heard about Tika. He visited her at home and immediately referred the girl to HRDC.

Tika was admitted at the Banepa hospital on 11 January 2008. Intensive and loving nursing care, antibiotics and nutritious food contributed to the healing of bedsores and overall recovery. A big dilemma was the decision to opt for surgical intervention or conservative management (non-surgical procedures). In due time is was decided to surgically open the spine to release the compressed nerves. Luckily Tika reacted well and recovered fast. The motor system of her lower limbs started working again. Intensive physiotherapy helped to regain mobility.

Today Tika is able to walk with the support of walker. The goal of the rehabilitation is to make the teenage patient independent in mobility and self-care. With the progress she is making Tika will soon be able to fully take care of herself.

Tika's smile is a radiant one. The young student is confident that she will complete her education and become a nurse to serve disadvantaged disabled children.

5. Conceptual And Analytical Framework

This study examines the social impact of HRDC treatment and intervention for both individual children and families. It seeks to establish whether children treated at the HRDC enjoy a fuller level of social integration and functioning than their peers who have either not received treatment or who have sought treatment from other sources. The study compares and contrasts the status of HRDC treated children and their families with control group children and families within the framework of Article 23 of the Convention on the Rights of the Child in order to assess the extent to which children and young persons with disabilities enjoy these basic rights[13].

Article 23 of the CRC states that:

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.

4. States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

5. Findings

5.1 The Social Impact of Hospital-based Service Provision of the HRDC

5.1.a The right to special care and assistance appropriate to the child's condition and to the circumstances of the parents or others caring for the child

Both HRDC and Control family in-depth interviews[14] recorded the highest number of comments (27+ HRDC respondents & 16+ control group) revealing both awareness and understanding of the services provided by the HRDC and of the positive impact that those services have on the life and potential of a child. Even control group families were aware that rehabilitation is a long-term process. There was also a high number of responses from both HRDC and control group families (17+ HRDC & 8+ control group) stating that children and adults living with disabilities should be given priority over the able-bodied in gaining ACCESS to health and education services as well as employment opportunities.

Children treated at the HRDC and their families were appreciative of the caring atmosphere created by HRDC staff. Interviewees also recognise the importance and value of curative treatment (6+ HRDC & 8+ control cases). This is of particular note to HRDC personnel who are involved in patient and family counselling, when explaining that not all interventions will produce a 'cure'.

[13] Nepal ratified the Convention on the Rights of the Child on September 14, 1990

[14] See Annexe 5 for the full summary of HRDC and control group family in-depth interview comments. Positive comments will be shown as: number + and negative comments as number - (In Annex 5 positive comments are symbolised by ✓ and negative comments by X)

It is important to plan and discuss intervention in the most positive and optimistic light possible; it is equally important not to raise unrealistic hopes for parents and children whose knowledge of surgical and other forms of intervention is inevitably limited.

There were only three critical observations regarding inpatient services from in-depth interviewees of HRDC treated children:

- Improve patient communication and information-sharing from nurses, physiotherapists and orthopaedic technicians regarding the different phases of treatment and rehabilitation (4-)
- Improve individualised, affective post-operative care and pay more attention to how children are feeling (3-)
- Improve lodging facilities for accompanying parents / guardians and long-stay children (3-)

Observation
The overwhelming impression from in-depth interviewees indicates that HRDC inpatient treatment makes a positive and lasting impression on both children and families. The few critical comments, included above as a guard against complacency, serve as an indicator of the need to sustain respect for and respond positively to the perceptions and experience of service users, both children and family members. It is nonetheless clear that in-depth interviewees perceive the social experience of inpatient treatment as a positive catalyst for the growth and development of children.

5.1.b Provision of assistance free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child.

The HRDC service conforms to this condition, providing free treatment to children from poor[15] families and a means-tested sliding scale of contributions for the slightly better off families. The policy is designed to establish a small contribution to the running costs of the HRDC that has both symbolic and real value.[16] All families cover their own travel costs. Contributions towards the cost of treatment are viewed by FoD/HRDC management as an additional motivating factor to ensure that families understand the value of intervention. Direct and indirect financial contributions give recognition to families as service users and as stakeholders in the treatment offered to their children. There are no quick fixes or immediate "cures" in reconstructive surgery and physical rehabilitation. The family's role in post-operative care and rehabilitation begins in the hospital and will often continue at home for many years if their child's full physical and social potential is to be attained.

In their final feedback session to the Steering Committee, the enumerators, without exception, commented on the financial hardship and poverty that almost all families face. In-depth interviewees were also realistic about the financial and economic constraints (13- HRDC & 12- control group) that limit a family's potential to mitigate physical handicap and seek treatment for their child. A range of factors are at play here: the cost of travel; loss of income and family labour especially in farming communities; non-acceptance of Indian currency; and the cost of accommodation for the parent or guardian who accompanies the child for diagnosis and treatment at the HRDC. Paradoxically however, respondents also recognise that HRDC treatment is either free or comparatively inexpensive (14+ HRDC & 3+ control group) and see this as a key factor in terms of accessing treatment.

HRDC personnel are fully cognisant of the impact of poverty and of the demands that seeking treatment makes on the family economy as this comment from a senior surgeon and highly experienced doctor at the HRDC makes clear:

"Whatever changes and developments take place in future, if we concentrate in surgery on more specialised procedures, treatment should be free. The majority of families in Nepal are poor and cannot afford to go elsewhere." – HRDC medical doctor

Observation
The dialectic between user needs, the cost of service provision and the direct and indirect costs that families incur during treatment and rehabilitation, poses an insoluble problem. HRDC management is aware of the difficulties of accommodating family members and ensures that the parent or guardian accompanying the child stays with the child during inpatient treatment. However the HRDC cannot subsidise travel or external accommodation costs. Until such time as states parties, multilateral and bilateral donors make a stronger commitment to funding social and health provision, the poorest children and families will therefore struggle to access services. This remains a dilemma for the FoD/HRDC and for funding partners.

5.2 The Social Impact of HRDC treatment in the Community for Children and Families

Article 23 of the CRC states that "....special needs should be provided for in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development."

[15] The status of a "poor" family is assessed by a CBR worker based on ownership of animals, land, other assets and disposable income.
[16] Currently contributions are at +/- 6% of recurring annual expenditure.

The special needs defined in article 23 will provide the framework for community-based comparison of HRDC and control group children and families. We will analyse social impact through data collected from family interviews and from the perspective of community peers and leaders as represented in the in-depth interviews. This will enable us to build a picture of the extent to which HRDC treatment contributes towards the social integration and wellbeing of children and young people in their communities.

5.2.a Promotion of Self-Reliance in the child: Functional Status & Self Care

The following table compares family perceptions of the causes of impairment between HRDC and control group children, analysed by district, region, ecological zone, and current age. In many instances, family perceptions of physical disability are multi-factorial, yet it is clear that in both groups of children, congenital conditions, infections and unresolved trauma comprise the major categories of disability. These data enable us to obtain a picture of the physical "starting point" from which social impact is constructed, whether as a result of non-intervention or alternative intervention in the case of control cases, or through intervention, treatment and family-based rehabilitation generated through the HRDC's CBR programme.

Table 4 and Table 4a | **Percentage distribution of children / youth with disability by cause of impairment, according to background characteristics, Nepal 2008**

Background characteristics	Cause of Impairment among HRDC cases and CONTROL GROUP CASES(multiple responses therefore percentages are superior to 100)													
	Congenital		Infection		Trauma		Burn		Tumour		Other		Total Respondents	
District	H	C	H	C	H	C	H	C	H	C	H	C	H	C
Banke	41	55	46	43	8	0	10	2	0	0	0	0	39	40
Bara	45	57	29	17	11	4	9	2	0	2	7	21	91	53
Dhading	43	33	18	15	21	0	11	0	2	0	3	0	152	33
Dolakha	24	33	16	4	34	56	9	7	1	0	7	0	86	27
Jhapa	43	44	14	17	22	17	14	6	2	0	9	11	63	36
Kanchanpur	35	31	32	34	18	9	12	9	0	0	6	20	34	35
Lalitpur	28	44	13	6	28	18	11	15	2	0	23	35	61	34
Nawalparasi	29	75	45	25	15	0	9	0	0	0	1	0	86	12
Sankhuwasabha	41	57	14	11	32	6	14	22	0	0	0	6	22	19
Surkhet	38	39	18	23	18	4	15	7	2	0	3	0	65	44
Tanahun	54	56	21	17	13	0	11	0	0	0	0	6	46	18
Average	*38*	*46*	*24*	*20*	*20*	*38*	*11*	*6*	*1*	*0.28*	*6*	*10*		
Total													**745**	**351**
Region														
Central	37	44	19	12	23	16	10	5	1	1	8	16	390	147
Eastern	42	48	14	14	25	14	14	11	1	0	7	9	85	56
Farwestern	35	31	32	34	18	9	12	9	0	0	6	20	34	35
Midwestern	39	47	29	33	14	17	13	5	1	0	2	0	104	83
Western	38	63	37	20	14	0	10	0	0	0	1	3	132	30
Average	*38*	*46*	*24*	*20*	*20*	*14*	*11*	*6*	*1*	*0.28*	*6*	*10*		
Total													**745**	**351**

Ecological zone														
Hill	41	40	18	16	21	17	12	6	2	0	6	10	324	126
Mountain	28	43	16	7	33	35	10	13	1	0	6	2	108	46
Terai	39	51	33	26	15	6	11	4	0	1	5	12	313	179
Average	*38*	*46*	*24*	*20*	*20*	*14*	*11*	*6*	*1*	*0.33*	*6*	*10*		
Total													**745**	**351**
Current age														
1-5	50	60	0	12	0	3	100	5	0	0	0	10	2	58
6-10	74	44	5	19	16	10	5	11	0	0	0	12	38	89
11-14	61	48	14	18	9	18	8	4	1	0	6	4	119	92
15+	31	37	27	27	23	19	12	4	1	1	6	13	582	108
Average	*38*	*46*	*24*	*20*	*20*	*14*	*11*	*6*	*1*	*0.29*	*6*	*10*		
Total													**741**	**347**
Age at intervention														
1-5	59		14		9		10		0	2	6		243	
6-10	32		22		28		12		2	0	3		179	
11-14	28		28		26		12		0	0	8		207	
15+	20		40		21		13		2	0	6		111	
Average	*38*		*24*		*20*		*11*		*1*	*0*	*6*			
Total													**740**	

Children develop and take their place as active and participating members of their family and their communities through their day to day experience. The potential for self-reliance is created and enhanced by treatment outcomes for children. The promotion of self-reliance is achieved though family-based rehabilitation and progressive accomplishment of the core activities of daily living. The following tables thus analyse core activities of daily living.

Table 5 **Percentage distribution of children / youth with disability by evaluation on the ability to eat and drink, according to background characteristics, Nepal 2008**

Background characteristics	Ability to eat and drink							
	HRDC				Control group			
	Completely dependent	Partially dependent	Completely Independent	Number	Completely dependent	Partially dependent	Completely Independent	Total Respondents
Total	**2**	**3**	**95**	**742**	**16**	**11**	**73**	**350**

[redacted] 6

Percentage distribution of children / youth with disability by evaluation on the ability to clean teeth, according to background characteristics, Nepal 2008

Background characteristics	Ability to clean teeth							
	HRDC				Control group			
	Completely dependent	Partially dependent	Completely Independent	Number	Completely dependent	Partially dependent	Completely Independent	Total Respondents
Total	2	3	95	742	18	11	71	350

[redacted] 7

Percentage distribution of children / youth with disability by evaluation on the ability to wash hands, according to background characteristics, Nepal 2008

Background characteristics	Ability to wash hands							
	HRDC				Control group			
	Completely dependent	Partially dependent	Completely independent	Number	Completely dependent	Partially dependent	Completely Independent	Total Respondents
Total	2	4	94	742	19	11	70	350

[redacted] 8

Percentage distribution of children / youth with disability by evaluation on the ability to wash the body, according to background characteristics, Nepal 2008

Background characteristics	Ability to wash body							
	HRDC				Control group			
	Completely dependent	Partially dependent	Completely Independent	Number	Completely dependent	Partially dependent	Completely Independent	Total Respondents
Total	2	5	93	742	25	16	59	348

[redacted] 9

Percentage distribution of children / youth with disability by evaluation on the ability to dress oneself, according to background characteristics, Nepal 2008

Background characteristics	Ability to dress oneself							
	HRDC				Control group			
	Completely dependent	Partially dependent	Completely Independent	Number	Completely dependent	Partially dependent	Completely Independent	Total Respondents
Total	2	5	93	742	25	14	61	348

Table 10 **Percentage distribution of children / youth with disability by evaluation on the ability to go to the toilet, according to background characteristics, Nepal 2008**

Background characteristics	Ability to go to the toilet							
	HRDC				Control group			
	Completely dependent	Partially dependent	Completely independent	Number	Completely dependent	Partially dependent	Completely independent	Total Respondents
Total	2	5	93	741	21	11	68	348

Table 11 **Percentage distribution of children / youth with disability by evaluation on the ability to walk in / around the community, according to background characteristics, Nepal 2008**

Background characteristics	Ability to walk in / around the community							
	HRDC				Control group			
	Completely dependent	Partially dependent	Completely independent	Number	Completely dependent	Partially dependent	Completely independent	Total Respondents
Total	6	2	92	718	22	2	76	335

On average the scores show that 93.5% of HRDC treated children have achieved functional independence and only 2% remain completely dependent on others for core activities of daily living. Control group children's independence ranges from 76% down to 59% of the activities sampled, with 25% of children / youth totally dependent on others for washing the body and dressing and 21% dependent on others for toileting.

Observation

It is self-evident that children will more easily develop confidence, aspire to realise their potential and gain acceptance alongside their able-bodied peers when they are able to thrive in all aspects of daily living. The tables reveal that HRDC treated children have a 20 – 30% higher level of functional independence than their control group peers. Acquiring functional independence as a result of treatment and rehabilitation enables children to take their place in family and social life as actors, participants and contributors. It minimises their experience of functioning as passive receivers, dependents or mere bystanders and reinforces the social and psychological potential for confidence and self belief to flourish.

On a different note, analysis of the full tables 5 – 11 suggest that for children treated at the HRDC, the different modalities of community-based follow-up (CBR worker + mobile camp, mobile camp + partner organisation, mobile camp only) show no significant differences between modalities in achieving the capacity of children's activities of daily living. This observation merits careful reflection and further analysis in order to review whether the goals of its outreach and CBR programme should be reassessed.

5.2.b Access to and Receipt of Healthcare and Rehabilitation Services

Respondents in both categories recorded a similar number of critical comments (26) when asked about physical access and ease of mobility for families seeking treatment for their child. A teacher in Dhading noted that:

"Even ordinary mobility is a problem. There is a need for better roads. Raj Kumar's leg would have been amputated in any other hospital due to lack of finance of the family or he would now be in a wheelchair. Instead he is standing on his feet and independently walking. I am happy with it. It has also brought physical changes and self confidence in Rajkumar that 'I can do something'. This change is definitely due to the HRDC treatment and consultation." – Teacher from Dhading

In-depth interviewees demonstrated consistent awareness of the need for decentralised and specialised services commenting positively (10+ HRDC respondents & 11+ control group) on the need for the HRDC to increase the number of CBR workers, hold more frequent mobile camps, create service centres in the five development regions and extend CBR worker networking with disabled peoples' organisations.

The HRDC's community outreach service comprised two regional centres during the study period, Itahari in the East and Nepalgunj in the Mid-West. A satellite centre has now been opened in Baglung (West) in partnership with Plan Nepal, and the aim is to expand progressively to a total of five regional centres in the medium term if resources permit. As with the in-depth interviewee comments recorded under 5.1.b (provision of free treatment), there is a strong desire on the part of respondents for services to be more accessible throughout the five development regions.

"I am impressed with HRDC services, the appliances and operations and the nominal fees it charges based on the socio-economic status of the person. It has enhanced the access of poor people with disabilities to the services they need. Treatment at HRDC is very effective but it should expand its services to remote villages to reach marginalised people with disabilities. If HRDC could prepare physical and human resources to expand its services in regional bases it would increase the access to treatment among poor people. If HRDC includes fabrication of devices such as artificial legs, crutches, wheelchairs, and modern equipment, that would make the treatment even more effective." – Social activist from Surkhet

Observation

The inpatient treatment experience is transformational for children, but does not of itself guarantee the promotion of self-reliance. There is sufficient evidence of community awareness and confidence in the quality of HRDC service provision to suggest that with investment of decentralised outreach and CBR service resources, many more children would benefit from early intervention and community based rehabilitation. For almost a decade, the HRDC has been making an important contribution towards the development of decentralised service potential through its post-graduate training programme in orthopaedic surgery in partnership with Kathmandu University. The challenge now is to analyse how this increased pool of skill and experience can be harnessed to take services into the field through incremental development of surgical camps, mobile tracing and follow-up camps, increased CBR coverage, and networking with other DPOs.

5.2.c Access to and Receipt of Education: Educational Status

Giving priority to persons with disabilities to gain access to education and employment opportunities drew the second highest number of positive observations from in-depth interviewees (17+ HRDC & 8+ control group). Respondents gave examples of organisations providing educational scholarships and assistance with transport to hospital and there were a number of comments from in-depth interviewees such as this one from a friend of a disabled child treated at the HRDC who in adult life has now become a teacher. Respondents place a high value on education and training (11+ HRDC & 4+ control group families) as a means of fulfilling individual potential and developing self-confidence. Here is what Ramesh from Kanchanpur had to say about his friend Kiran:

"Children like my friend Kiran should be given special priority because they can't do the things they want to do. Their limbs are handicapped. Though they are mentally prepared to be active they do not get the opportunity. Still, they have a greater mental ability than normal people. If they are given the chance to use it then they can actually develop themselves." - Ramesh from Kanchanpur about his disabled friend Kiran

Table 12 offers important district-based comparisons for school attendance before and after HRDC intervention and is a key child-focused indicator of the social impact of intervention. All districts recorded increased school attendance with Surkhet, a non-CBR worker district showing a 38% increase and Dhading and Tanahun, a 36% increase.

The inherent supposition here is further supported by data contrasting current levels of education between children from HRDC and control group families.

Table 12 **Percentage distribution of HRDC children / youth with disability by school attendance, according to background characteristics, Nepal 2008**

Background characteristics	Before intervention		After intervention	
	Yes	Total Respondents	Yes	Total Respondents
District				
Banke	46	39	77	39
Bara	47	91	74	85
Dhading	52	151	88	151
Dolakha	60	85	83	86
Jhapa	48	63	78	63
Kanchanpur	65	34	76	34
Lalitpur	62	61	77	61
Nawalparasi	57	86	90	83
Sankhuwasabha	55	22	82	22
Surkhet	45	65	83	65
Tanahun	53	45	89	44
Average	53		83	
Total		**742**		**733**

Table 13 **Percentage distribution of HRDC children / youth with disability by current level of education, according to background characteristics, Nepal 2008**

	Current level of education					Total Respondents
	Did not go to school	1-5	6-9	10+	Missing	
Total	17	24	30	17	12	745

Table 13a **Percentage distribution of control group children / youth with disability by current level of education, according to background characteristics, Nepal 2008**

	Current level of education					Total Respondents
	Did not go to school	1-5	6-9	10+	Missing	
Total	42**	30	15	4	9	351

**As per the caveat noted under Constraints and Limitations of the survey, the 42% of control group family children who did not attend school includes pre-school aged children. A more careful reading of the full data table reveals that 35% (102 / 289) of school-aged control group family children did not attend school whereas only 17% of school aged children (126 / 739) treated at the HRDC failed to attend school. Disability was the primary reason for non school-attendance (43% HRDC and 54% control group), followed by a range of other reasons (32% HRDC and 26% control group). Neither distance nor physical access figured as significant barriers to school attendance.

90% of HRDC treated children and 73% of control group children stated that they would help others in accessing school or completing their education[18]. This suggests that children place a high value on the social experience of schooling and learning. The impact of education on a child's employment ambitions in adult life also reveals an interesting degree of aspiration which is not circumscribed by disability. Eight HRDC respondents from in-depth interviews also made strong statements in favour of more specialised educational facilities such as small group teaching for children with disabilities, especially for those with intellectual or sensory impairments.

Table 14 **Percentage distribution of HRDC children / youth with disability by future aim after completing school, according to background characteristics, Nepal 2008**

	Future aim after completing school							
	Disability activist	To be a teacher	To be a doctor	To be an engineer	To be a business woman	To be a politician	Other[17]	Total Respondents
Total	12	32	6	3	10	1	36	552

[17] The majority of respondents fall into the "Other" category and include such aims as: Nurse, Accountant, Carpenter, Driver, Housewife, Pilot, Tailoring, Not Decided

[18] The original research consists out of 122 tables. The tables featured are a selection.

Table 14 a **Percentage distribution of HRDC children / youth with disability by future aim after completing school, according to background characteristics, Nepal 2008**

	Future aim after completing school							
	Disability activist	To be a teacher	To be a doctor	To be an engineer	To be a business woman	To be a politician	Other	Total Respondents
Total	**7**	**33**	**7**	**3**	**4**	**2**	**44**	**201**

Observation

Children treated at the HRDC record an 83% school attendance which represents a massive achievement in terms of social impact, given that the HRDC targets children from poor families, compare to the findings of "A Situation Analysis of Disability in Nepal – 2001"[9] shows that though nearly 95% of the household heads wanted their children with disabilities to go to school, only 56.3 percent of the age group 6 – 20 years were enrolled in school. These figures stand as concrete indicators of behavioural change. They reinforce the relevance and importance of functional status. They may also represent attitudinal change in parents as a result of the HRDC experience when considering the importance of education for their children and for children with disabilities in general. It seems clear that children themselves place a high value on education. While we wish to guard against simplistic extrapolation and avoid attributing cause and effect which cannot be demonstrated beyond reasonable statistical doubt or probability, all of these elements tend towards a picture of positive change that is promoted and reinforced as a result of HRDC intervention.

5.2.d Access to and Receipt of Training and Preparation for Employment: Earning Capability/Contribution towards the family economy[10]

The mission of the HRDC is simple and clear 'To provide comprehensive, quality medical care, rehabilitation and integration to children with physical disabilities'. During inpatient treatment, informal play and education is an integral part of post-operative recovery. Caregivers and children are trained in changing dressings, the use of assistive devices, family-based physiotherapy and exercise routines. However the HRDC community-based service makes no routine attempt to offer scholarships or any other form of vocational training support or sponsorship. Some children are assisted through the specific initiatives of CBR workers through liaison with employers and community leaders as well as networking with other organisations whose focus is on support for vocational training and education. [11]

It is a tribute to the overall impact of the HRDC service that 16 in-depth interviewees (11+HRDC & 5+ control group) expressed the view that the FoD/HRDC should forge a leadership role in advocating training and education for disabled children as well as extending its remit on disability prevention and policy development. There were equally firm comments about the need for Government to extend support for training (11+HRDC & 4+ control group) as a means of guaranteeing the rights of people living with all forms of disability since those with sensory impairment clearly require more specialised training.

The status of working and earning capacity among both HRDC treated youth and adult control group family youth and adult paints an altogether grimmer picture of formal employment opportunities. Although the number of comments is not high in terms of aggregated scores, in-depth interviewees noted that:

- youth and adults with disability are forced to live in poverty because they are rarely educated or assisted towards making a socio-economic contribution (3- HRDC & 3- control group)
- no special provision is made to offer land, housing or other facilities that might promote greater autonomy and independence for disabled persons (4- HRDC & 2- control group)
- the Government does not provide services or incentives such as the disability allowance (6- HRDC & 12- control group)[12]
- there are frequent references to a sense of inferiority amongst observers of children and youth from control group families

[9] "A Situation Analysis of Disability in Nepal – 2001", a study carried out by the New Era under the overall guidance of National Planning Commission and technically & financially supported by UNICEF/Nepal

[10] Family economy is taken to mean the totality of contributions made by family members through earned income, formal and informal labour and age-appropriate working tasks that children and youth undertake in the various mountain, hill and Terai economies

[11] E.g. the Nepal Youth Opportunities Foundation

[12] These comments are purely of interviewees

Table 15 **Percentage distribution of children / youth with disability by evaluation of the means of contribution to the family economy before & after HRDC intervention, according to background characteristics, Nepal 2008**

	Before HRDC intervention				After HRDC intervention			
	Contribution from regular job	Irregular contribution	Does not contribute	Number	Contribution from regular job	Irregular contribution	Does not contribute	Total Respondents
Total	**1**	**4**	**95**	**738**	**8**	**19**	**73**	**738**

Table 16 **Evaluation on the means of contribution to the family income among control cases**

	Means of contribution to the family income			
	Contribution from regular job	Irregular contribution	Does not contribute	Total Respondents
Total	1	5	94	338

The percentage levels of contribution to the family income for children before and after HRDC treatment (Table 15) shows a twenty-two percent increment in contributions to the family economy.. Eight percent of HRDC and one percent of control group youth contribute to the family economy through regular employment (Tables 15 & 16).

The only distinguishing aspect of employment and earning capacity between HRDC and control group (Table 17) resides in the fact that 20% of HRDC families acknowledge that they have sufficient income to run the family economy as compared with 1% of control group families. This difference may be significant in terms of families' financial capacity to afford treatment for their children, but no hard conclusions can be drawn from these data. They are open to descriptive rather than analytical interpretation only since it is a fact that in studies and surveys of this nature, respondents and families rarely disclose details of their income in full.

Table 18 indicates working patterns by district among HRDC families. There were too few respondents to aggregate data from control group families. Over 50% of HRDC families rely on seasonal or sporadic income, which is not linked specifically to the characteristics of the either the region or the ecological zone of Nepal.

Despite this gloomy picture of training and employment opportunities, there are success stories, which reveal the resilience of those who seize opportunities with courage and determination. Priya Kumari works in an organisation for people with disabilities in Dolakha. Here are the words of her employer:

"Priya Kumari can work with us and do everything only because of treatment she had received. She was psychologically disturbed before receiving treatment, but now she is fine." – Employer of disabled staff

Table 17 **Percentage distribution of children / youth with disability by perception on sufficient income to run the family economy, according to background characteristics, Nepal 2008**

Background characteristics	Perception on sufficient income to run family					
	HRDC			Control group		
	No	Yes	Total Respondents	No	Yes	Total Respondents
Total	**80**	**20**	**736**	**99**	**1**	**337**

Table 18 Evaluation of the perception of the number of months of regular income to run the family economy among HRDC cases

Background characteristics	Months of regular income to run the family				
	1-2 months	3-6 months	7-10 months	11+ months	Total Respondents
District					
Banke	83	17	0	0	6
Bara	0	12	18	70	17
Dhading	19	33	7	41	27
Dolakha	58	24	6	12	17
Jhapa	22	33	0	45	9
Kanchanpur	30	30	20	20	10
Lalitpur	29	29	13	29	7
Nawalparasi	41	24	6	29	17
Sankhuwasabha	33	33	0	34	17
Surkhet	12	18	36	36	11
Tanahun	0	50	0	50	6
Average	*28*	*26*	*11*	*35*	
Total					**130**

Observation

Respondents correctly observe that children living with sensory impairments require highly specialised training to achieve optimal functioning that will permit them to benefit from education and vocational training. Judging by the scores on activities of daily living in Section 5.2.a, children treated at the HRDC should be able to compete more closely with their able bodied peers for vocational and employment training opportunities. However, apart from family farming and subsistance agriculture, the broader issue of youth training and formal employment opportunities constitutes a key element of the macro socio-economic challenge that the country faces. It is unrealistic to expect that a single NGO and its surgical, medical and rehabilitation programme, can contribute more fully than it currently does to the training and employment elements of Article 23 of the CRC. Despite some positive indications on the overall sustainability of HRDC family incomes, there is no observable difference between employment opportunities for HRDC & control family children. Comparatively few youth living with disability achieve the dignity and status that comes from formal, recognised employment.

5.2.e Promotion of Dignity: Disability Rights, Discrimination, Inclusion and Exclusion

Knowledge of the Convention on the Rights of Persons with Disabilities would appear to be widespread judging by the responses from both HRDC and control group families. Smaller percentages are recorded for knowledge of individual rights by families of children and youth living with a disability.

This contrasts with qualitative information from in-depth interviewees (18+ HRDC & 7+ control group), which does not reveal specific knowledge of Disability Rights. Instead the majority of respondents acknowledge a broad understanding that children with disabilities have a right to lead a life on a par with their able-bodied peers and require special services and support to achieve their potential. There is an equally strong belief that advocacy is needed to promote understanding of disability and to develop services (13+ HRDC & 4+ control group) for children and adults with special needs. The 6th highest category of comments from in-depth interviewees (11+ HRDC & 5+ control group) stated that HRDC/FoD policy should change, focusing not just on treatment but also on prevention, training, education and advocacy. Two control family interviewees suggested that HRDC/FoD should become a leader in national policy development on behalf of PWDs.

Informal awareness of disability rights appears to go hand in hand with recognition that children and youth with disabilities are finding greater social acceptance, but this does not necessarily imply greater social inclusion. 12- HRDC and 7- control group families expressed the view that social inclusion is a slogan and not a practice, citing the absence of PWDs on local school and community forestry committees. There is a belief that children with disabilities are still stigmatised, even

Table 19 **Percentage distribution of children / youth with disability by knowledge of the Convention on the Rights of Persons with Disabilities, according to background characteristics, Nepal 2008**

Background characteristics	Knowledge of the Convention on the Rights of the Persons with Disabilities					
	HRDC			Control group		
	No	Yes	Number	No	Yes	Total Respondents
Total	**90**	**10**	**731**	**97**	**3**	**350**

concealed (14- HRDC respondents). One school principal observed that the system of District Assessment Centres, designed to assist children with disabilities, is not functioning adequately. There were similar critical comments with regard to the failure of the Government to provide adequate services and disability allowances (6- HRDC and 12- control group families).

Observation

As with the Observation under 5.2.b (Access to and Receipt of Healthcare and Rehabilitation Services), there is sufficient evidence of community awareness and confidence in the quality of HRDC service provision to believe that FoD/HRDC can become an advocate for the persons with disabilities at the level of national policy development and service provision. There is a positive picture emerging of community awareness regarding disability rights and greater acceptance of persons with disabilities. There is a far vaguer understanding of how those rights might be financed and realised in practice.

5.2.f Promotion of Self-reliance as a Youth and Young Adult: Attitudes towards Disability, Personal, Marital and Social Status

Respondents are sanguine about social attitudes towards disability acknowledging that traditional practices, beliefs and attitudes prevail but are diminishing as access to education improves (14+ HRDC & 5+ control group). In both rural and urban areas some of the families openly acknowledged that they consulted a *jankari* or a *guruba*[27]. In this respect a number of HRDC respondents noted that HRDC CBR workers have made a positive contribution to a change in attitude regarding both the cause of disability and the range of interventions that are available to families.

Bir Bahadur, father of Yamuna, in Kanchanpur, (control group family interview) speaks for many:

"Most of the guardians still think disability is the outcome of the sins committed in the previous life. Disability can also be caused due to negligence during pregnancy, according to our orthodox beliefs. Although I am a teacher, my daughter was treated by faith healers and herbal healers as per tradition. When she was not cured, Yamuna was taken to hospital and was kept there for a few days. After that people believed she became disabled due to an injection given to her at the hospital. However, nowadays children such as Yamuna are not taken to faith healers. Instead they are taken straight to a health post or a hospital." – Bir Bahadur, father of Yamuna, a disabled girl

The following set of tables offers an insight into the wide range of beliefs that prevail regarding the causes of disability. They are not susceptible to simplistic reductionist analysis, nor should they be dismissed as the beliefs of the "uneducated". Social anthropology and Jungian[24] psychology emphasise the importance of understanding "archetypes", those sets of symbols and unconscious beliefs which structure our psychic, social and cultural life. From such archetypal beliefs come attitudes; from attitudes behaviours; and from behaviours the point of entry at which we might choose to access and focus upon change.

The low percentage perception that disability is due to bad karma tends to confirm the commentary of Bir Bahadur and other respondents, that traditional beliefs are receding. When comparing pre- and post-treatment responses from HRDC families, there is a consistent 20% increase in awareness of the range of factors that cause disability.[25] Control group family responses show a similar percentage increment with a noticeable reduction in the Belief then / Belief now "Don't know" category. Since families are from the same communities it is reasonable to assume that increased knowledge and awareness may be attributable to the impact of HRDC services. We also assume that the growth of CBR and Disabled

[27] The author understands Jankari and Guruba to have similar meanings, and can be translated as "traditional healers". A Guruba is a healer who uses traditional medicines and rituals, whereas a Jankari is viewed as someone who combines the use of local medicines and rituals with shamanistic practices, hypnotism, the casting out of evil spirits and devils.

[24] Carl Jung 'Man and His Symbols' first published 1964

[25] In addition to tables on poverty, malnutrition and poor hygiene, carelessness and neglect, infection, other tables not shown here show a similar range of responses and include: lack of education, abuse (lowest level of belief among both HRDC and control group families), lack of treatment (highest level of belief for both at 78%), perinatal or hereditary causes and negligence (also high among HRDC respondents).

People's organisations and networks[26] complements and reinforces the impact of HRDC services contributing to a wider, more informed public awareness and understanding of disability.

Moving on to review marital status, the HRDC sample of marital status is numerically far superior to that of the control group with 192 / 745 married respondents (26%) as opposed to 24/351 (7%). This makes it difficult to draw any conclusions about the social impact of treatment on marital status due to age disparities in the overall sample as noted in Section 3.4 (Constraints and Limitations). Accordingly, every effort was made to ensure age-appropriate consistency when analysing findings.

In percentage terms, Tables 25/26a do not reveal any significant differences in marital status, whereas Table 26, indicating intention to marry shows that only 36% of control group family children and their families have positive intentions to marry as compared with 57% of children from HRDC families. There were only 17 children and youth aged >11 years in the

Table 20 **Percentage distribution of children / youth with disability by perception/attitude that the disability was due to bad karma among HRDC cases, Nepal 2008**

	Disability was due to bad karma							
	Before intervention				After intervention			
	Yes	No	Don't know	Total Respondents	Yes	No	Don't know	Total Respondents
Total	19	65	16	737	9	88	3	733

Table 20a **Percentage distribution of children / youth with disability by perception/ attitude that the disability was due to bad karma among control group cases, Nepal 2008**

	Disability was due to bad karma							
	Belief in the past				Belief now			
	Yes	No	Don't know	Total Respondents	Yes	No	Don't know	Total Respondents
Total	14	57	29	346	9	83	8	343

Table 21 **Percentage distribution of children / youth with disability by perception/attitude that the disability was due to poverty among HRDC cases, Nepal 2008**

	Disability was due to Poverty							
	Before intervention				After intervention			
	Yes	No	Don't know	Total Respondents	Yes	No	Don't know	Total Respondents
Total	36	47	17	737	58	40	2	736

[26] Reference "Community-based Rehabilitation for People with Disabilities in Nepal", 2007 p.10

Table 21a Percentage distribution of children / youth with disability by perception/attitude that the disability was due to Poverty among control group cases, Nepal 2008

	Disability was due to poverty							
	Belief in the past				Belief now			
	Yes	No	Don't know	Total Respondents	Yes	No	Don't know	Total Respondents
Total	32	38	30	346	56	37	7	344

Table 22 Percentage distribution of children / youth with disability by perception/attitude that the disability was due to malnutrition and poor hygiene among HRDC cases, Nepal 2008

	Disability due to malnutrition and poor hygiene							
	Before intervention				After intervention			
	Yes	No	Don't know	Total Respondents	Yes	No	Don't know	Total Respondents
Total	40	43	17	736	61	36	3	735

Table 22a Percentage distribution of children / youth with disability by perception/attitude that the disability was due to malnutrition and poor hygiene among control group cases, Nepal 2008

	Disability due to malnutrition and poor hygiene							
	Belief in the past				Belief in the present			
	Yes	No	Don't know	Total Respondents	Yes	No	Don't know	Total Respondents
Total	32	37	31	341	53	40	7	344

Table 23 Percentage distribution of children / youth with disability by perception/attitude that the disability was due to hereditary or perinatal causes among HRDC cases, Nepal 2008

	Disability due to carelessness and neglect							
	Before intervention				After intervention			
	Yes	No	Don't know	Total Respondents	Yes	No	Don't know	Total Respondents
Total	40	43	17	736	61	36	3	735

Table 23a Percentage distribution of children / youth with disability by perception/attitude that the disability was due to hereditary or perinatal causes among control group cases, Nepal 2008

	Disability due to carelessness and neglect							
	Belief in the past				Belief in the present			
	Yes	No	Don't know	Total Respondents	Yes	No	Don't know	Total Respondents
Total	32	37	31	341	53	40	7	344

Table 24 Percentage distribution of children / youth with disability by perception/attitude that the disability was due to infection among HRDC cases, Nepal 2008

	Disability due to infection							
	Before intervention				After intervention			
	Yes	No	Don't know	Total Respondents	Yes	No	Don't know	Total Respondents
Total	45	39	16	733	69	29	2	733

Table 24a Percentage distribution of children / youth with disability by perception/attitude that the disability was due infection among control cases, Nepal 2008

	Disability was due to malnutrition and poor hygiene							
	Belief in the past				Belief in the present			
	Yes	No	Don't know	Total Respondents	Yes	No	Don't know	Total Respondents
Total	37	34	29	346	58	37	5	343

control group who responded to questions about the impact of intervention on their plans to marry. Of those, 65%/11 individuals thought that intervention had favourably influenced their intention to marry, whereas the figure rose to 77%/141 individuals from the HRDC sample of 183 individuals who responded.

In-depth interview feedback offers mixed views on marital prospects with 9 respondents (6- HRDC and 3- control group families) stating that disability is a problem when arranging a marriage, especially if the person needs assistance with washing, toileting and defecating. The difficulty is compounded when arranging a marriage for a girl. This contrasts with 5 respondents (2+ HRDC & 3+ control group families) who believe that disability can be overcome and is not a barrier to marriage as in the case of a 22-year old woman in Lalitpur district whose parents are planning for her to marry after she has completed a sewing and tailoring training course. From a slightly broader perspective there is highly positive feedback about the impact of treatment (10+ HRDC & 4+ control group families) on a child's social status and potential with comments such as:

"The children are happy; they can study, marry, and they enjoy greater acceptance from their peers." - Interviewee

There are a range of perspectives analysing the social and personal status of children. Here we will look at some of the personal and family indicators and then consider broader social indicators in the following section.

Although stress can be defined and experienced in many different ways, it is clear from Tables 27 and 28 that the percentage and real numbers of families of children with a disability treated at the HRDC are in a more favourable situation than their control group peers. The percentage of control group families living under stress is almost 66% higher. Experience of impediment in the growth and development of their children is twice as high.

Family support is acknowledged to be a key factor in sustaining ongoing rehabilitation (11+HRDC & 3+ control group families), with both groups of respondents demonstrating knowledge of local DPOs as well as the HRDC. There is recognition that maintaining orthopaedic aids such as wheel chairs is important, as is the periodic replacement of orthoses and prostheses as children grow and mature. HRDC families in particular recognise that continuity of CBR services is vital if they as a family are to derive the maximum benefit from treatment. It thus seems probable that they experience a major shift in the quality of family life and in the ability of their children to thrive as a result of HRDC intervention and CBR support in comparison with control cases.

Table 25 **Percentage distribution of children / youth with disability by length of time married among HRDC cases, according to background characteristics, Nepal 2008**

	Length of time married				Total Respondents
	0-2 years	3-5 years	6-9 years	10+ years	
Total	30	38	26	6	180

Table 25a **Percentage distribution of children / youth with disability by length of time married among control cases, according to background characteristics, Nepal 2008**

	Length of time married				Total Respondents
	0-2 years	3-5 years	6-9 years	10+ years	
Total	29	14	43	14	21

Table 26 **Percentage distribution of children / youth with disability by intention to get married among HRDC and control cases, according to background characteristics, Nepal 2008**

	Intention to get married					
	HRDC			Control group		
	No	Yes	Total Respondents	No	Yes	Total Respondents
Total	43	57	531	64	36	283

Similarly with capacity to work and carry out household chores (Table 30). Control group family children are almost twice as likely to experience difficulties in working and four times more likely not to participate in any household chores. Given the data identifying causes of disability presented in section 4.2.a where the majority of both HRDC and control group family disabilities fall into three principal categories congenital, infection and trauma, it seems self-evident that HRDC intervention has had a considerable, positive impact on the socialisation of children within their families.

When analysing experiences of mistreatment or feelings of anger and frustration, there is no norm by which to measure and compare the experience of children with disabilities and their able-bodied peers. Cultural definitions and understanding of mistreatment may vary between ecological zones and regions. We nonetheless make the assumption that responses from children and youth recorded here represent perceptions and experiences of mistreatment that are systematic. Knowing nothing further about the nature of that mistreatment, one may hypothesise that the level of caring and protection among HRDC families is higher because the family has sought treatment, but there is insufficient information to draw firm conclusions from these data.

Observation

There are encouraging signs that attitudes towards disability are evolving towards a more informed understanding of aetiology and a more proactive and socially open approach towards intervention. Compared with control group family children, there is an emerging picture of the HRDC child's greater integration into the fabric and activities of family life, thereby laying the foundation for more successful social integration as the child grows into adulthood. This is also reflected in optimism about marital prospects, which is more pronounced amongst HRDC families. Caution demands

Table 27 Percentage distribution of children by stress felt among parents / guardians of a child with disability, according to background characteristics, Nepal 2008

Background characteristics	Stress felt among parents / guardians					
	HRDC			Control group		
	No	Yes	Total Respondents	No	Yes	Total Respondents
Total	58	42	743	30	70	347

Table 28 Percentage distribution of children by impediment in the growth and development of children due to disability, according to background characteristics, Nepal 2008

Background characteristics	Impediment in the growth and development of children due to disability							
	HRDC				Control group			
	Yes	Some	No	Total Respondents	Yes	Some	No	Total Respondents
Total	13	18	69	742	36	26	38	347

that we should not overestimate the positive social impact of treatment. Socio-economic hardships and a physically demanding terrain await children as they advance into adulthood but there is sufficient indication here to suggest that HRDC treatment enables children and families to find their way more positively and with greater confidence than their control group peers.

5.2.g Active Participation in the Community and Preparation for Recreation Opportunities: Status of PWD involvement in community associations and organisations, Social Participation and Social Inclusion

The social context of the period under review when there was steadily increasing and widespread disruption of civil society due to armed conflict was not explored with respondents or their families. It seems reasonable to assume that with greater social stability, the social involvement of young people with disabilities may well have been higher than reported here.

In-depth Interviewees share a broad range of perceptions regarding the participation of children and youth with disabilities in community and recreational activities, with many voicing observations of social exclusion rather than inclusion. In contrast, the data reveals that 24 / 200 Control family youth and 94 / 701 HRDC youth are involved in a range of organisations including clubs, CBR and Disabled People's organisations.[27] The ratio of membership, as with the measure of impact shows similar patterns for both HRDC and control group family youth and offers a more positive and optimistic picture when viewed from the child / youth's point of view. 91% of HRDC youth and 71% of control group family youth felt that they had exercised either a great or moderate influence on the organisations to which they belonged, and 86% HRDC and 70% of control cases felt that membership had greatly or moderately influenced their personal and social development in such areas as knowledge about disability rights organisational management, gaining paid employment and extending their social networking.

The concept and experience of social isolation is relative to age, culture and the country's varied socio-geographic ecology Nepalese culture is associative and family-group oriented rather than individualised as in more industrialised and urban cultures. As with the discussion of "mistreatment", we assume that responses from children and youth offer recurrent perceptions and experiences of social isolation. HRDC children show a higher degree of social integration than their control family peers, which may be accounted for by increased confidence in their social skills and mobility after treatment and rehabilitation.

Table 29 **Percentage distribution of children / youth with disability by facing difficulties in working, according to background characteristics, Nepal 2008**

Background characteristics	Facing difficulties in working							
	HRDC				Control group			
	Yes	No	Don't know	Total Respondents	Yes	No	Don't know	Total Respondents
Total	40	58	2	737	74	25.6	040	335

Table 30 **Percentage distribution of children / youth with disability by participation in household chores, according to background characteristics, Nepal 2008**

Background characteristics	Participation in household chores							
	HRDC				Control group			
	Not at all	Some	Same as other children	Total Respondents	Not at all	Some	Same as other children	Total Respondents
Total	9	39	52	734	38	35	27	323

Table 31 Percentage distribution of children / youth with disability by mistreatment from family members, according to background characteristics, Nepal 2008

Background characteristics	Mistreatment from family members					
	HRDC			Control group		
	Yes	No	Total Respondents	Yes	No	Total Respondents
Total	9	91	739	20	80	336

Table 32 Percentage distribution of children / youth with disability who become frustrated and want to leave their home / village, according to background characteristics, Nepal 2008

Background characteristics	Becomes frustrated and wants to leave home / village							
	HRDC				Control group			
	Yes	No	Would go if able	Total Respondents	Yes	No	Would go if able	Total Respondents
Total	5	93	2	738	8	88	4	336

It is thus useful to compare the children and young people's perceptions of their participation in socio-cultural events and festivals with that of their parents' inasmuch as parents report a far higher degree of social exclusion than children actually experience. It is significant that HRDC children report a far higher level of participation on a par with their able-bodied peers than control family children. It is equally significant that both groups of children and youth perceive themselves as being more participatory when compared with the perceptions of their parents.

Shanthi, a mother from Surkhet, talking about her daughter after HRDC treatment to correct club feet:

"Before my daughter received treatment community people did not behave well with her or with other people with disabilities. They did not even invite her to income generating activities. After my daughter received treatment she was able to use her feet and soon she could walk everywhere. Due to the successful work demonstrated by my daughter and by other people with disabilities the community's perception of disability has changed." – Shanti, mother of a disabled daughter

Observation

While the number of children who are active in organisations, social and cultural events could be higher, the achievements of children, youth and families noted here in both HRDC and control family groups represents a positive accomplishment. There is no strong evidence from the voices of children that they feel unduly marginalised in their local communities and societies. The challenge that faces not only the HRDC but also DPOs and CBR organisations is to promote and advocate for even greater social inclusion and participation whether in social, cultural and sporting activities or in more specialised activities designed to promote the integration of children with disabilities.

5.2.h States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

Observation 34

Although the study did not focus on this aspect of article 23 of the CRC, it is important to recognise that the FoD/HRDC has established itself as an organisation and service that is promoting training. In addition to the post-graduate orthopaedic surgery programme, the HRDC is promoting skill development in orthopaedic appliance production, physiotherapy and family-based rehabilitation for children with physical disabilities. Its work has received international recognition. It is a pioneer in a range of surgical interventions including the treatment of scoliosis and reconstructive surgery to correct congenital and burn deformities that are rarely seen in other parts of the world. There is also a steady flow of exchange visits that have brought new techniques in the treatment of Club Feet and improvements in the management of Cerebral Palsy. Such innovations have materially improved the quality of life for hundreds of children.

Table 33 **Percentage distribution of HRDC children / youth with disability by impact of participation, Nepal 2008**

	Impact of organizational participation among HRDC cases					
	Increased self-esteem	Knowing people better	Knowing more about organization	Enhanced organizational capacity	Don't know	Respondents
Total	50	22	14	9	5	101

Table 33a **Percentage distribution of control children / youth with disability by impact of organizational participation, Nepal 2008**

	Impact of organizational participation among HRDC cases					
	Increased self-esteem	Knowing people better	Knowing more about organization	Enhanced organizational capacity	Don't know	Total Respondents
Total	50	23	7	0	20	30

Table 34 **Percentage distribution of children / youth with disability showing socially isolated / withdrawn behaviour, according to background characteristics, Nepal 2008**

Background characteristics	Social isolation / withdrawn behaviour							
	HRDC				Control group			
				Respondents				Respondents
Total	8	17	75	740	19	20	61	340

Table 35

Percentage distribution of children / youth with disability by participation in so cio-cultural events, according to background characteristics, Nepal 2008

Background characteristics	The child's perception of participation in socio-cultural events							
	HRDC				Control group			
	Same as other children	Participate occasionally	Never participate	Total Respondents	Same as other children	Participate occasionally	Never participate	Total Respondents
Total	**63**	**30**	**7**	**742**	**39**	**33**	**28**	**335**

Table 36

Percentage distribution of children / youth with disability by participation in social events / festivals, according to background characteristics, Nepal 2008

Background characteristics	The parents' perception of their child's participation in social events / festivals							
	HRDC				Control group			
	Rarely	Sometimes	Regular	Total Respondents	Rarely	Sometimes	Regular	Total Respondents
Total	**17**	**48**	**35**	**728**	**45**	**43**	**12**	**300**

How do you go to school when there is no motorable road and you can't walk? You crawl. In his short, eventful life Human Magar has shown great courage and determination to stand on his own two feet.

At HDRC some 12 % of the patients are disabled due to fire accidents inside the home. Human Magar (11) is one of them. Human was only six months old when he fell in the kitchen fireplace, an open, unprotected place.

Human never got a chance to learn to walk. Due to knee contracture he could no longer bend his legs. Ultimately the wounds healed but Human's legs were severely deformed. For several years the child was kept at home. Due to ignorance and lack of information the parents thought this was the best solution.

When it was time for him to join school Human was determined to live a normal life. Travelling by bus was not an option, and neither was walking, and so Human crawled to school. Having overcome the first obstacle Human decided one day he would be able to walk and be an equal to his peers at school.

Human's chances seemed slim. Growing up in Palpa district, in the western hills of Nepal, in an impoverished and marginalised family of nine, Human seemed to wish upon a shooting stars. His illiterate parents, living on subsistence farming for six months a year and searching for daily wage jobs the other half of the year, were unable to help.

Human's luck changed when HRDC conducted a mobile camp in Palpa. Human managed to meet the team and was referred to the Banepa hospital for surgical correction.

On 2 February 2007 Human arrived at HDRC, and underwent reconstructive surgery to release both legs. After series of surgeries and different modalities of physiotherapy Human for the first time in ten years was able to stand on his feet and walk with the help of a walker.

Today Human is back in school, studying in grade two. The days he had to crawl to classes are over. Human can take care of himself and walks to school independently. His greatest wish, to be able walk like his peers, has been fulfilled.

6. Results and Recommendations

This study has analysed the social impact of HRDC treatment within the framework of Article 23 of the CRC. It seeks to establish whether children treated at the HRDC enjoy a fuller level of social integration and functioning than their peers who have either not received treatment or who have sought treatment from other sources. Despite the fact that Nepal has not yet ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD), the degree to which children, youth and adults living with disabilities in Nepal enjoy a full and decent life should also in future be measured against the principal articles of the CRPD:

- Equality before the law without discrimination (article 5)
- Right to life, liberty and security of the person (articles 10 & 14)
- Equal recognition before the law and legal capacity (article 12)
- Freedom from torture (article 15)
- Freedom from exploitation, violence and abuse (article 16)
- Right to respect physical and mental integrity (article 17)
- Freedom of movement and nationality (article 18)
- Right to live in the community (article 19)
- Freedom of expression and opinion (article 21)
- Respect for privacy (article 22)
- Respect for home and the family (article 23)
- Right to education (article 24)
- Right to health (article 25)
- Right to work (article 27)
- Right to adequate standard of living (article 28)
- Right to participate in political and public life (article 29)
- Right to participation in cultural life (article 30)

The results of this study demonstrate that the Friends of the Disabled, the Hospital and Rehabilitation Centre for Disabled Children and its operational and funding partners should be encouraged by the positive social impact of the HRDC's institutional and community-based treatment. If the summary of rights presented above serves as a check-list and a firm reminder of what needs to be achieved for persons with disabilities in Nepal, the recommendations offered below will hopefully contribute to strengthening the contribution of both the FoD and the HRDC towards those goals so that children with physical disabilities can indeed lead a full and decent life.

6.1 Results

The Right to Special Care

HRDC treatment has lasting impact - The HRDC's hospital-based services provide high quality, specialised, accessible and low cost treatment for children in a caring atmosphere. Improvements can be made in child and family counselling and post-operative affective care but this does not detract from the high levels of family satisfaction, appreciation for, and understanding of the treatment and rehabilitation process. HRDC inpatient treatment makes a positive and lasting impression on both children and families. The social experience of inpatient treatment is a positive catalyst for the growth and development of children.

Provision of Assistance Free of Charge

Financial constraints remain - The HRDC provides free or means-tested contributions to treatment for children from poor families. Direct and indirect financial contributions give recognition to families as service users and as stakeholders in the treatment offered to their children. Although almost all families face financial and economic constraints, they also recognise that HRDC treatment is either free or comparatively inexpensive and see this as a key factor in terms of accessing treatment. HRDC management is aware of the financial difficulties faced by families and ensures that the parent or guardian accompanying the child stays with the child during inpatient treatment. The HRDC cannot subsidise travel or external accommodation costs and until such time as states parties, multilateral and bilateral donors make a stronger commitment to funding social and health provision, the poorest children and families will struggle to access services.

Promotion of Self-Reliance in the Child: Functional Status & Self Care

Improved levels of self-reliance - The physical "starting point" from which social impact is constructed is the child's capacity to undertake normal activities of daily living. 92 – 95% of HRDC treated children have achieved functional independence, and only 2% remain completely dependent on others for core activities of daily living. Control group children's independence ranges from 76% down to 59%. In terms of functional capacity to fulfil normal activities of daily living, children treated at the HRDC have a 20 – 30% higher level of functional independence than their control group peers. The study results also indicate that for children treated at the HRDC, the different modalities of community-based follow-up (CBR worker + mobile camp, mobile camp + partner organisation, mobile camp only) show no significant difference in the capacity of children's activities of daily living.

Access to and Receipt of Healthcare and Rehabilitation Services

Community based rehabilitation needs expansion - There is consistent awareness of the need for decentralised and specialised services and on the need for the HRDC to increase the number of CBR workers, hold more frequent mobile camps, create service centres in the five development regions and extend CBR worker networking with disabled peoples' organisations. There is sufficient evidence of community awareness and confidence in the quality of HRDC service provision to suggest that with investment of decentralised outreach and CBR service resources, many more children would benefit from early intervention and community based rehabilitation.

Access to and Receipt of Education

Great progress in access to education - Respondents place a high value on education and training as a means of fulfilling individual potential and developing self-confidence. School attendance rates for HRDC treated children are on a par with the national average of 84%. This represents a massive achievement in terms of social impact, given that the HRDC targets children from poor families and that disability figured as the primary reason for non-attendance in both HRDC treated and control group children. A number of HRDC respondents from in-depth interviews also made strong statements in favour of more specialised educational facilities such as small group teaching for children with disabilities, especially for those with intellectual or sensory impairments. Interestingly, neither distance nor physical access figured as significant barriers to school attendance. 90% of HRDC treated children and 73% of control group children stated that they would help others in accessing school or completing their education. This confirms the high value children place on the social experience of schooling and learning, an aspect which is facilitated by HRDC intervention and family-based rehabilitation.

Access to and Receipt of Training and Preparation for Employment

Prepare persons with disability for employment - The HRDC community-based service makes no routine attempt to offer scholarships or any other form of vocational training support or sponsorship although many respondents felt that the FoD and HRDC should forge a leadership role in advocating training and education for disabled children as well as extending its remit on disability prevention and policy development. Despite some positive indications on the overall sustainability of HRDC family incomes, there is no observable difference between employment opportunities for HRDC & control group family children. The status of working and earning capacity among both HRDC treated youth and control group family youth remains low in terms of formal employment opportunities and percentage levels of contribution to the family income. Only 1% of HRDC and control group youth contribute to the family economy through regular employment indicating that few youth living with disability achieve the dignity and status that comes from formal, recognised employment.

Promotion of Dignity and Disability Rights

Advocate for change - General awareness on the Rights of Persons with Disabilities is widespread. Many respondents acknowledge that children with disabilities have a right to lead a life on a par with their able-bodied peers and require special services and support to achieve their potential. There is an equally strong belief that advocacy is needed to promote understanding of disability and to develop services for children and adults with special needs. There is also sufficient evidence of community awareness and confidence in the quality of HRDC service provision to believe that FoD/HRDC can become such an advocate for persons with disabilities at the level of national policy development and service provision. Belief among adults is widespread that children with disabilities are still stigmatised. Children themselves did not voice such strongly negative sentiments and a more positive picture of community awareness seems to be emerging regarding disability rights and acceptance of persons with disabilities. However, there is less understanding as to how those rights might be financed and realised in practice.

Promotion of Self-reliance as a Youth and Young Adult

Improved socialisation - Respondents are sanguine about social attitudes towards disability acknowledging that traditional practices, beliefs and attitudes prevail but are diminishing as access to education improves. HRDC services contribute to a wider and more informed public awareness and understanding of disability complemented also by the growth of CBR and Disabled People's organisations and networks. It is more difficult to draw any conclusions about the social impact of treatment on marital status although HRDC treated youth expressed a higher percentage intention to marry than their control group peers. Real numbers of families of children with a disability treated at the HRDC are in a more favourable situation than their Control group peers when analysing levels of family stress, childhood growth and development, and the quality of family life. Control family children are twice as likely to experience difficulties in working and four times more likely not to participate in any household chores.

It is evident that HRDC intervention has had a considerable, positive impact on the socialisation of children within their families and a range of responses suggest that levels of child protection, support, care and integration are consistently higher among HRDC families. Attitudes towards disability are evolving towards a more informed understanding of aetiology and a more proactive and socially open approach towards intervention. There is an emerging picture of the HRDC child's

greater integration into the fabric and activities of family and social life, reflected in optimism about marital prospects, which is more pronounced amongst HRDC families. Although socio-economic hardships and a physically demanding terrain await children as they advance into adulthood there is sufficient indication to suggest that HRDC treatment enables children and families to find their way towards adulthood more positively and with greater confidence than their Control group peers.

Active Participation in the Community and Preparation for Recreation Opportunities

Improved participation in society - The social context of the period under review when there was steadily increasing and widespread disruption of civil society due to armed conflict was not explored with respondents or their families. It seems reasonable to assume that with greater social stability, the social involvement of young people with disabilities may well have been higher than reported here. In-depth interviewees share a broad range of perceptions regarding the participation of children and youth with disabilities in community and recreational activities, with many voicing observations of social exclusion rather than inclusion.

The ratio of membership of organisations shows similar patterns for both HRDC and Control family youth. 91% of HRDC youth and 71% of control group family youth felt that they had exercised either a great or moderate influence on the organisations to which they belonged. 86% HRDC and 70% of control cases felt that membership had greatly or moderately influenced their personal and social development in such areas as knowledge about disability rights, organisational management, gaining paid employment and extending their social networking. Children and young people's perceptions of their participation in socio-cultural events and festivals compares favourably with the views expressed by their parents and it is significant that HRDC children report a far higher level of participation on a par with their able-bodied peers than Control family children. While the number of children who are active in organisations, social and cultural events could be higher, the achievements of children, youth and families noted here in both HRDC and control family groups represents a positive accomplishment. There is no strong evidence from the voices of children that they feel unduly marginalised in their local communities and societies.

6.2 Recommendations

Access to Treatment and Services

- **Improve access to treatment** - HRDC should strengthen links with other orthopaedic and CBR services to provide more accurate and detailed information about HOW and WHERE to access treatment, skills training and other specialised services for children with disabilities
- **Develop community support systems** - Thought should be given to the comparatively high levels of family stress reported when reviewing the range and focus of working priorities for the HRDC's CBR programme. A more holistic approach is required to develop and promote community support systems for families and children living with disability.

Communication, Knowledge and Information about services

- **Deploy ambassadors** - Information and publicity about the HRDC service must be improved, and families and children should be told in simple and clear terms how much time is needed for surgery, post-operative care and family-based rehabilitation. In addition to improving inpatient counselling and understanding of the cost recovery system for families with some degree of wealth or income, greater community outreach and information dissemination could be achieved through CBR worker mobilisation of former HRDC patients. They could act as "ambassadors" for people with disabilities and provide information on the range of services available. To achieve this, working links could be explored to link up such ambassadors to the MoH system of one community health volunteer in each VDC.

Education and Training

- **Offer play and education to patients** - The HRDC should identify how to strengthen the contribution of its inpatient services to children and families in the areas of education, literacy, recreation and play, all of which contribute to the rehabilitation of the child and the overall health and wellbeing of the family. Such a development would enable the HRDC to reinforce its social impact on children and families and broaden the marketing potential of its hospital-based intervention.

- **Promote access to education** - The role of CBR workers must be expanded beyond the provision of family-based care to individual children and families. They should become more actively involved in promoting educational and vocational training opportunities for children. CBR workers must become involved in promoting access and accessibility for children with disabilities, by forging even stronger links with schools and teachers so that schools, classrooms, and public spaces are open to children with disabilities of all sorts.

- **Create linkages with educational and vocational services** - Through its networking capacity, the FoD/HRDC should consider creating stronger linkages with competent DPOs to develop partnerships with District

Assessment Centres.[18] By piloting such initiatives, the HRDC's CBR programme could enter a new area of project work which would genuinely extend the positive social impact that treatment has achieved for its clients. By selecting locations where the HRDC has a regional centre or an active fieldworker, such initiatives could mobilise former HRDC patients, persons with disabilities, parents and trained personnel to examine how special education, activities of daily living and vocational training opportunities could be mainstreamed or at least made more available to older children and youth with disabilities. Such initiatives would begin to respond to one of the strongest, expressed needs of children and families interviewed in this study. It is an area in which Tdh could assist by capitalising on experience gained through its urban nutrition project where hundreds of women have been mobilised through the creation of 7 core groups. This model of community work could be replicated in CBR worker communities and is worthy of serious consideration.

Health

- **Create access to primary health care** – HRDC and its CBR programme should create stronger linkages with primary health care and integrated health services for children including CBR support in its working districts to improve childhood immunisation and vaccination campaign coverage. This is an important area of activity for early identification of congenital diseases and would also facilitate early intervention and management of untreated physical trauma such as burns and bone fractures.

- **Strenghten rehabilitation impact** – CBR worker links with women community health volunteers must be developed in order to strengthen the impact of HRDC family-based rehabilitation regimes for children and open the possibility of greater local linkages between families and children and access to the full range of health services.

- **Include youth organisations** – HRDC should be open to extending the CBR networking and information-sharing role with teachers / schools and communities, with DPOs and organisations such as the Junior Red Cross Society of Nepal, and with other youth organisations. The concept of local HRDC "ambassadors" could play an important role in such a development

Advocacy

- **Advocate for disabled children** – FoD/HRDC must sustain its role as a national leader focusing not just on treatment but also on prevention, training, education and advocacy. At least one disabled person should be identified as an HRDC "ambassador/activist" in every VDC.

Sustainability and Marketing

- **Highlight HRDC services within society** – The FoD/HRDC has been successful in creating a national service that offers surgery, assistive devices, innovative intervention techniques and community-based rehabilitation to respond to a wide range of childhood physical disability. It is a service that has established unchallenged credibility with its clientele, nationally, and gained international recognition for its surgical and rehabilitation achievements. It is the responsibility of key institutional donors and supporters to ensure that its achievements are brought to the notice of a wider audience.

- **Identify international ambassadors/fundraisers** – Consideration should be given to identifying recognised international figures who would function as ambassadors and as potential fund-raisers. Such figures exist in the world of international sport e.g. the foundations established by Roger Federer and Andre Agassi in the world of tennis, designed to support work with disadvantaged children.

- **Establish international trust** – Consideration should be given to the establishment of an international trust fund that could manage investments and provide a basis of financial security that would exist alongside donor support for the FoD/HRDC.

- **Sustain advocacy and policy making efforts** – Nationally, the FoD/HRDC should sustain its current efforts to remain a key player in terms of advocacy and policy development on behalf of children with disabilities. Initiatives to sustain national CBR and DPO networks deserve support if human resources permit. Such a role should be taken up by senior FoD/HRDC personnel and would become viable if the middle level management system of the HRDC demonstrates commitment and capacity to guarantee the smooth running of day to day services in line with the Mission of the HRDC programme.

In conclusion, this study has given voice to the experiences of children and families and to their aspirations and hopes. The recommendations outlined above are offered as a means of strengthening the demonstrable social impact of HRDC treatment and intervention in areas of community support and mobilisation, based on the credibility, skill and commitment which the HRDC service has brought to so many children and their families. In the words of a teacher from Kanchanpur responding to one of the enumerators:

"I thank you and the whole HRDC family. You gave me an opportunity to talk and understand about HRDC and disabled people in general; many thanks to you for providing me this opportunity." – Teacher from Kanchanpur

[18] This originated as a programme of the Ministry of Education with financial support and technical inputs from Danida, with the aim of creating teaching skills and special resources to promote the education of children with a range of learning difficulties and disabilities.

Background Reading Materials and References

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National Ethical Guidelines for Health Research in Nepal (2001), the National Health Research Council, Nepal

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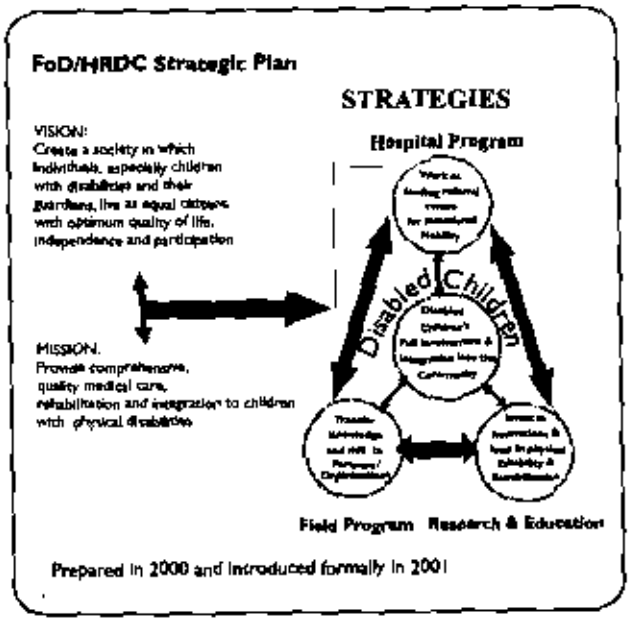
United Nations Convention on the Rights of the Child (1989)

United Nations Convention on the Rights of Persons with Disabilities and its Optional Protocol (2006)

Annexe 1
FoD/HRDC VISION, MISSION and STRATEGY STATEMENT



HRDC SYSTEMS

To achieve the mission of FoD/HRDC mentioned above, we have a tri-pronged approach represented by programmes which consist of several micro-systems called departments.

HOSPITAL PROGRAMME

As we are leading the medical rehabilitation of the children with musculo-skeletal problems in the country, we get referral from all over the country. There is always a long list of the PDCs waiting for reconstructive surgery. This shows patients' confidence on us. We are committed to addressing the need and create functional mobility in PDCs. The micro-systems that work together for this are as mentioned below:

a) Medical Services

- Medical Support Services: The services include running clinic both at the Centre and at different places in the country and handling diagnostic tests to ascertain the nature of problem. The Assessment Team involved in the evaluation process create short term and long term intervention goals with the clients. Accordingly intervention is carried out. Spine intervention (especially Scoliosis) has been added as no organisation is doing it extensively. A total of 600 – 700 new and old patients come to the clinics every months.
- In-Patients Services: (Surgical Services and Wards/Nursing Care)

b) Rehabilitation Services

- Physiotherapy
- Prosthetics Orthotics

FIELD PROGRAMME

CBR Department. The service was initiated in 1989 as a follow up and education to clients when a lot of defaulters (burn contracture, etc.) were received within a few years of surgical intervention. Now the Department has grown. It handles teaching and training in the field, runs outreach services, conducts home visit programme and develops collaboration with the grass-root level organisations, etc. Since the influx of new cases is much higher than the completion of rehabilitation, the volume of our work is continuously increasing. Therefore, HRDC has accepted the reality that empowerment of partners/organisations in the grass-root level, interested to work with us does not have alternative to cope with this progressive growth in the volume of work. Strategically, identifying the partners in the local level to share knowledge and skill for eventual transfer of responsibilities to the local community has got more focus.

RESEARCH and EDUCATION PROGRAMME

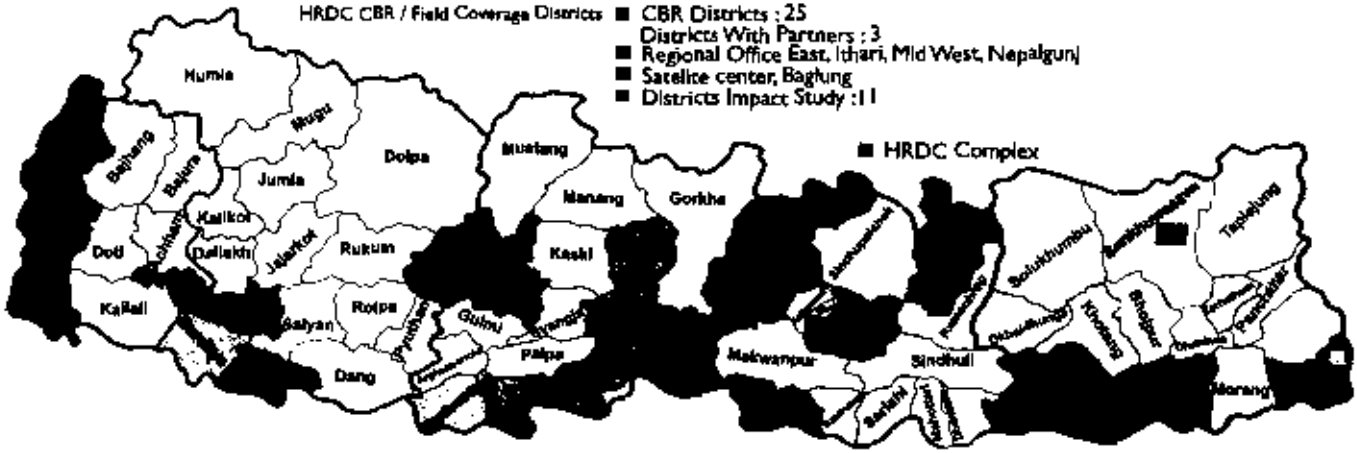
Training and education

HRDC has been conducting basic training on primary rehabilitation therapy. Also HRDC is one of the two Training Centres of Kathmandu University for Masters Programme in Orthopaedic Surgery which is a 3 year long course. We are also continuous sharing our expertise with other partners in the fabrication of orthopaedic assistive devices. We are focusing ourselves more on clinical based innovation and felt the need for more investment in the aspect. Major the training and education activities are given below:

- Primary Rehabilitation Therapy for Community Based Rehabilitation Workers/Facilitators.
- Masters Degree Programme in Orthopaedic Surgery
- In-House Training Programmes:
  - Training of Trainers
  - Communication Skill
  - Mid-level Managers
- On-going Teaching Learning Activities:
  - Weekly Education Session (Every Thursday and Friday)
  - Preventive Education session (on Clinic Days: 3 days in a week)
  - Education to Newcomers - Every Weekend
  - Vocational Training to admitted children - linked to stimulation and vocational skills
  - Awareness activities both at the Hospital and in the community.

Annexe 2

Map showing HRDC Community Based Rehabilitation Coverage



Once AR Chaudhari's legs were curved inside so badly his knees touched. Today he walks like any other teenager and has become a confident member of his community.

Rickets is a painful disability mostly caused by a lack of nutrition during childhood. AR Chaudhari grew up in a poor, landless family in Sunsari District. AR had no major health problems until he studied in class 5. His knees started throbbing with pain and a feeling of coldness. After two years his once healthy legs started to curve inside. It became clear to his family that AR suffered rickets and that his bones were slowly but surely becoming deformed.

After AR's father passed away, his mother started to save money for her son's treatment. She met with representatives from AR's school, the village development committee as well as a local charity, and collected enough money to start AR's treatment. The boy was taken to regular hospitals as well as to traditional healers. However, no improvement was observed. The villagers were now convinced that AR would never recover.

Despite his disability AR did not give up hope. One day he heard that a camp was being organised for people with disabilities at another school in his district. AR travelled to the camp, got a check up and was given an appointment at the HRDC hospital.

AR's mother regained hope and collected money for her son to travel to Banepa. At HRDC the medical team re-evaluated AR's condition, set rehabilitation goals and intervened accordingly. Thanks to corrective surgery, intensive wound care and physiotherapy, AR improved and regained control over his legs.

HRDC's Regional Office, with the help of a funding partner, facilitated in getting educational support for AR. The boy continued his studies and in due time passed the 10th class School Leaving Certificate Examination.

AR now studies in grade 11. He lives with his mother, older brother and one sister. His newly acquired independence has renewed AR's confidence. He recently joined a local organization for people with disabilities. AR's mother has high expectations for her son.

Annexe 3
Summary of Total Closed Cases 1993 – 2005

District	Total Closed Cases1993 - 2005	Families seen			Families not seen									Grand total
		Case	Control	Total	Migration India	Migration Nepal	Expired	Wrong address	Incomplete address	Not visited	Not Interested	Repeated case	Lost case	
Tanahun	84	46	18	64		1	2	10	20	4		1		84
Nawalparasi	123	86	12	98		3	6	12		12	1	3		123
Bara	210	91	53	144	6	15	21	47	24	3	1	2		210
Jhapa	122	63	36	99	1	9	7		11	29		2		122
Kanchanpur	40	34	35	69	1	2	1	1		1				40
Lalitpur	109	61	34	95		2	7	16	4	14	5			109
Banke	51	39	40	79	4		3	3		1		1		51
Dhading	261	152	33	185	1	10	15	39	4	28	3	9		261
Surkhet	92	65	44	109		4	7		6	8		2		92
Dolakha	138	86	27	113		11	5	13	3	16		2	2	138
Sankhuwasabha	27	22	19	41		2	1					2		27
	1257	745	351	1096	13	59	75	141	72	116	10	24	2	1257

District	Explanation of Children and Families that could not be identified									
	Migration		Expired	Wrong address	Incomplete address	Not visited	Not interested	Repeated case	Lost case	Total
	India	Nepal								
Tanahun		1	2	10	20	4		1		38
Nawalparasi		3	6	12		12	1	3		37
Bara	6	15	21	47	24	3	1	2		119
Jhapa	1	9	7		11	29		2		59
Kanchanpur	1	2	1	1		1				6
Lalitpur		2	7	16	4	14	5			48
Banke	4		3	3		1		1		12
Dhading	1	10	15	39	4	28	3	9		109
Surkhet		4	7		6	8		2		27
Dolakha		11	5	13	3	16		2	2	52
Sankhuwasabha		2	1					2		5
	13	59	75	141	72	116	10	24	2	512

Annexe 4
List of Enumerators

SN	Name	Qualification	Background Experience	Working Area	Home base
1	Karuna Pulami Magar	MA in Rural Development	Computer Diploma / Enumerator / Pop. Gender & Dev / Advanced Health System Research Methodology / Field Supervisor / Data Collector / Teaching	Jhapa & Sankhuwasabha	Pyauli 5, Bhojpur
2	Niran Nepal	B.Ed / MA Sociology	Journalism / Basic Health Analysis / Leadership / Conflict Transformation / Teaching / Office Secretary / Field Survey / Field Survey Supervisor	Jhapa & Sankhuwasabha	Sankhuwasabha
3	Mangal Bdr Shrestha	Bachelor	Data Collection and Field Experience / Computer	Jhapa	Kathmandu
4	Manoj Adhikari	Plus 2 Management	Training Diploma in Computer Applications / Worked as Enumerator of NHRC Research	Jhapa	Jhapa
5	Kaushila Lama	Auxiliary Nurse Midwife / Intermediate Arts	Field Experience as a Social Mobiliser and Data Collector	Dolakha	Kavre
6	Kumar Bhandari	Masters in Management	Computer Knowledge and Data Collection while preparing Thesis	Dolakha	Bara
7	Mandira Neupane	B.Ed / M.Ed	Basic Computer / TOT for Research Secretary /Advanced Health System Research Secretary / Field Coordinator /Teaching	Bara	Makwanpur
8	Roshan Karna	B. Public Health	Training on PRA / PLA Action Tools / Field Research on Gender Differences in Immunization / Comprehensive District Health Management Field Practice / Data Collection & Analysis	Bara	Dhanusha, Janakpur

9	Sujan Khadka	Masters in Management	Computer Knowledge and Data Collection while preparing Thesis	Lalitpur	Lalitpur
10	Shailesh Dhakal	Auxiliary Nurse Midwife	Intensive Modular Computerized Accounting / Administrative Assistant	Lalitpur	Morang
11	Gita Devi Sharma	Auxiliary Nurse Midwife / BA study	Data Collection / Worked as a Nurse 3yrs / Field Survey Experience / Community Worker	Dhading	Dhading
12	Saraswati Deuja	Auxiliary Nurse Midwife / BA study	Computer Skills / Community Health & Women's Health Worker / Teaching	Dhading	Sindhupalchi
13	Bina Sunar	BA study	Basic Computer	Dhading	Kavre
14	Tara Sapkota	BA study	Basic Computer	Dhading	Kavre
15	Kiran Bhattarai	Diploma in Mechanical Engineering	Auto CAD / Industrial Orientation & Attachment / Automobile Workshop / Tourism Promotional Event / Health Camp Organizer / Data Collector of War Victims	Tanahu & Nawalparasi	Tanahu
16	Dipa Sharma	Masters in Management	Basic Computer Data Collection Experience	Tanahu & Nawalparasi	Gorkha
17	Pavan Adhikari	BA / Intermediate in Arts	Field Researcher for the Study on Health Service Supply, Environmental, Maternal and Neonatal Healthcare	Surkhet	Dang
18	Krishna Poudel	B. Business Studies	Computer / working experience as NGO Field Supervisor & Officer	Surkhet	Surkhet
19	Jamuna Kafle	Auxiliary Nurse Midwife / Proficiency Certificate Level	Basic Computer / National Level NCD Risk Factor Survey, Vaccination Field & Camp / Post Service KPC Survey	Kanchanpur & Banke	Bhaktapur
20	Durga KC	Auxiliary Nurse Midwife / Proficiency Certificate Level	PRA / Full System Logistics / CB-IMCI Health Worker / TOT on Kalazar Detection / Field Assistant (NFHP) / Field Assistant (Environ. Health Project / Field Assistant (CECT)	Kanchanpur & Banke	Solukhumbu

HRDC Supervisors		Dhiraj Sharma Luitel,
		Nitra Bahadur Deuja
Logistic support	Jhapa & Sankhuwasabha	Hari Tamang
	Bara, Tanahu & Nawalparasi	Laxman Thapa
	Dolakha, Lalitpur	Nabaraj Simkhada
	Dhading	Keshav Raj Bastakoti
	Kanchanpur, Surkhet and Banke	Hira KC

Annexe 5
In-Depth Interview Feedback

Feedback from Sankhuwasabha / Dolakha / Dhading / Bara / Tanahun / Nawalparasi / Surkhet / Banke / Jhapa, / Kanchanpur and Lalitpur Districts 48

District	HRDC Family Issues	Repeated rating	Control Family Issue	Repeated Rating
Enumerators' Meeting 01.10.08				
	✓ Awareness of treatment possibilities	1	x DISAPPOINTMENT -- "What is this to do with us?"	2
	✓ Treatment works	2	x "Many people come and ask us questions, but they do not offer any treatment or any cure"	2
	✓ Treatment is free / inexpensive	1	x Predominance of cerebral palsy affected children (Banke)	1
	✓ Cost Recovery system should continue	1	x Notable number of burn cases were seen	2
	✓ Improved mobility	2	x Families expect treatment to be immediate and CURATIVE	2
	✓ Knowledge about disability	3	x Limitations in ADL e.g. toileting	1
	✓ Encouragement to others to continue / pursue education	2	✓ Mobile with a tricycle	1
	✓ Growth of self confidence and confidence in one's own abilities	2	x Difficulties with paths, roads, general access to public spaces, schools, health facilities	2
	✓ Hopefulness	2		
	x Lack of long-term follow-up (Jhapa) impacts children negatively AND ALSO DPO support / initiatives	3		

	Interviewees of HRDC families	Score	Interviewees of Control families	Score
1st				
43 positive	✓ Good Awareness and Understanding of both the services provided by HRDC and the impact of those services on the life and potential of a child e.g. understanding that rehabilitation is long-term process in some circumstances	14	✓ Cleft Palate, Hair Lip, other physical disabilities successfully treated	2
			✓ Knowledge of treatment of cleft palate and hair lip	1
			✓ awareness of the HRDC and other services via knowledge of other disabled children and adults	13
	✓ **Satisfaction with HRDC service**	13		
2nd				
25 positive	✓ Give priority to Disabled over able-bodied in providing ACCESS to Health Education, Employment e.g. some organisations have given scholarships e.g. transport >Hospital	17	✓ Give priority to Disabled over able-bodied in providing ACCESS to Health Education, Employment e.g. some organisations have given scholarships e.g. transport >Hospital	8
3rd				
21 Positive	✓ Create service centres in the 5 development regions (HRDC) / increase CBR workers and mobile camps and networking	10	x Decentralise specialised services – overly concentrated in Kathmandu / increase frequency of community contact via CBR workers and mobile camps and networking	
	x N.B. development of surgical camps since 2006 via Dr Binod Thapa in Nepalgunj (Banke) & Dr Bistha in Biratnagar (Morang) – for future links with government structures, will trauma take priority over rehabilitative / reconstructive surgery?		x E.g. HRDC should create a link with DPOs in 65 of the 75 districts of Nepal	11
4th				
18 positive awareness but not specific knowledge	✓ No specific knowledge of Disability Rights but understands the principle of a child leading a life on a par with able-bodied persons is attempting to secure the Rights of disabled	11	✓ No specific knowledge of Disability Rights but understands the principle of a child leading a life on a par with able-bodied persons e.g. belief that Govt people e.g. govt scholarship	7
	✓ Some concrete knowledge of disability rights			
5th=				
17 positive	✓ Advocacy needed to promote understanding / services for persons with disabilities	13	✓ ADVOCACY for development of disability services is vital	4
5th =				
17 positive	✓ improve access for the more remote communities	14	✓ Treatment is free / inexpensive / subsidise	3
			x Treatment is expensive (NRs. 4,000 – 5,000)	2
6th				
16 positive	✓ Traditional practices, beliefs and attitudes re disability (referral to jankaris and gurubas) prevail but are diminishing as access to education improves and healers also recommend Medical Treatment	11	✓ Traditional practices, beliefs and attitudes re disability prevail – sins of past life / karma, taking daughter to faith healer for blindness – attitudes and practice changing with education and knowledge	5
	✓ Work of HRDC fieldworker has had a positive impact on change in attitudes and knowledge	1		

6th=			
16 reflect positively on for HRDC to extend services	x HRDC / FoD policy should change – NOT JUST TREATMENT BUT ALSO PREVENTION / TRAINING / EDUCATION / POLICY the need DEVELOPMENT / ADVOCACY	11	✓ Training and education is highly valued for people with disabilities ✓ FoD / HRDC should become a leader in national policy development for people with disabilities
7th=			
15 positive	✓ Value of Education, Training & recognition of potential, growth of self confidence	10	✓ Value of Education, Training & recognition of potential, growth of self confidence
	✓ Educational Scholarship	1	
8th=			
14 positive	✓ Social inclusion resulting from treatment Children are happy, can study, marry, work, greater acceptance from peers	10	✓ Social inclusion resulting from treatment Children are happy, can study, marry, work, greater acceptance from peers
	Membership of organisations		x Membership of organisations
8th =			
14 positive	✓ Importance of curative treatment	6	✓ Importance of curative treatment
8th =			
14 positive	x Ongoing CBR / Rehabilitation follow-up is important e.g. one CBR worker per district	11	
			x Awareness of need for ongoing CBR services and etc e.g. NNSWA, assistance with orthopaedic aids, wheel chairs NGO at Taukhel, Lalitpur; Maitri Nepal (Nawalparasi)
9th			
13 positive	✓ Perception that disabled require different schools / facilities	5	✓ Government should guarantee the Rights of persons with disabilities
10th			
10 positive	✓ Offer / awareness treatment raises HOPE for child and family	7	✓ Offer / awareness treatment raises HOPE for child and family
11th			
10 positive	✓ Importance of prostheses and orthoses for ADL + changing periodically as a child grows	6	✓ Importance of provision of prostheses and orthoses and devices for ADL
12th			
9 positive	✓ Continuity of service is vital e.g. failure NNSWA	8	✓ Continuity of service is vital e.g. success of NNSWA
13th			
8 positive	✓ School and teachers as a supportive factor for the support / promotion / integration of children with disabilities	7	✓ Importance of specialised schools / training / facilities e.g. blind school (11 of 12 students studying)
14th			
7 positive	✓ Access public buildings, schools, seen as reasonable for disabled people	3	✓ Access public buildings, schools, seen as reasonable for disabled people
15th=			
6 positive	✓ Family support as a key factor in ADL	2	✓ Non-treated child needs help with ADL e.g. toileting + Family support as a key factor in ADL
15th =			
6 positive	✓ Make a District-wide census / inventory of disabled people – KNOWLEDGE NEEDED		
	✓ E.g. appoint one stakeholder in each VDC.	6	

itive	✓ Early intervention is essential for treatment, child development and mobility	5		
e				
itive	x Disability can be overcome ref marriage	2	✓ Planning for marriage of a 22 year old woman after she has completed sewing and tailoring training / difficult for case in Lalitpur	3
ative	x Disability is a problem for arranging marriage, especially if the person needs assistance with washing, toileting, defecating (more difficult for women than men)	6	x Marriage is difficult	3
th				
sitive	✓ Successful treatment means that disability is not a curse from God	2		
l positive			✓ Aetiology of disability still subject to much confusion / ignorance	

	Interviewees of HRDC families	Score	Interviewees of control families	Score
1st				
26 negative	x Access / wheelchair mobility even ordinary mobility is problematic, need better "roads"	13	x Access / wheelchair mobility even ordinary mobility is problematic, need better "roads"	13
2nd				
25 negative	x Economic / financial constraints limit potential to overcome disability or seek treatment therefore cheap or free services is essential –	13	x Economic / financial constraints limit potential to overcome disability or seek treatment e.g. cost of travel, non-acceptance of Indian currency: therefore keep treatment cheap or free	10
	x Main issue is travel and accommodation costs		x Main issue is travel and accommodation costs	2
3rd				
19 negative	x Social inclusion is a slogan, not a practice e.g. no disabled persons on the local school or community forestry committees: e.g. adverse behaviour & discrimination by peers / neighbours	12	x Social inclusion is limited due to lack of education in the community. E.g. District Assessment Centre located in interviewee's school but Committee is symbolic rather than functional / active. E.g. some examples of stigmatisation from peer-group friends and teachers	7
			x Social inclusion requires local leadership	1
4th				
18 negative	x Govt does not provide services / incentives	6	x Govt does not pay disability allowance / provide adequate services	12
5th				
14 negative	x Stigmatisation / concealment of disabled children and adults	14		
6th				
9 negative				
5 positive	x Disability is a problem for arranging marriage, especially if the person needs assistance with washing, toileting, defecating (more difficult for women than men)	6	Planning for marriage of a 22 year old woman after she has completed sewing and tailoring training / difficult for case in Lalitpur	3
	x Disability can be overcome ref marriage	2	Marriage is difficult	3

5a

7th			
8 negative	x Organisations do not produce tangible programmes / results / services	6	x Attempts to raise funds from CDO, LDO, private sector and others largely failed
8th=			
6 negative ref income / poverty	x In general, disabled children / people are forced to live in poverty because they are rarely educated / assisted towards making a socio-economic contribution to the family economy	3	x Along with the observation (left reference poverty in which disabled persons live), there are frequent references to a sense of INFERIORITY amongst observers of non-treated children and youth. x Rehabilitation for a person with disability should be done through a more holistic approach including physical, economical, social and psychological support / inputs
8th=			
6 negative ref economic assistance / land	x No special provision made to provide land, housing, other facilities that might promote greater autonomy and independence for the disabled person(s) / adults	4	x No special provision made to provide land, housing, other facilities such as training in agriculture that might promote greater autonomy and independence for the disabled person(s) / adults
9th =			
3 negative	x Family does not support ADL / affectively (1 respondent in Lalitpur talked strongly of the NEGLECT of children left lying in their own excrement and urine etc	2	x Family does not support ADL / affectively
9th =			
3 negative	x Improved communication especially from nursing / physio / Ortho technicians is vital	4	
9th =			
3 negative	x Improve individual/affective post-op care	3	
9th =			
3 negative	x Improve post-op lodging facilities	3	

MORE SERVICES NEEDED

Communication, Knowledge and Information	• Improve info & publicity re HRDC service	9	• Improve info & publicity re HRDC service + other services for those with disabilities e.g. via radio and television	8
Education	• Promote not only access but accessibility for disabled children: schools, classrooms, public spaces e.g. small group teaching (special ed) IMPORTANT FOR INTELLECTUAL AND / OR SENSORY IMPAIRMENT	8		
Health	• Ante-natal Screening needed	1		
Health	• Consider Abortion if child is known to be handicapped	1		
Health	• Improve immunisation coverage	2		
CBR & Other Organisations	• No known DPO organisation in Kanchanpur apart from NNSWA: one active organisation mentioned in Lalitpur, NAMS (Nepal Apanga Mahila Samaj), Action Aid in Sankhuwasabha / Jhapa	4		
CBR and HRDC Role	• HRDC should link up with other orthopaedic and CBR services to provide more ACCURATE and INFORMATIVE DETAIL about HOW to access paediatric and adult services, HOW MUCH they cost, HOW MUCH TIME might be needed / devoted to treatment and post-operative rehabilitation	2 plus RMI observation	• HRDC should link up with other orthopaedic and CBR services to provide more ACCURATE and DETAIL about HOW to access paediatric and adult INFORMATIVE services, HOW MUCH they cost, HOW MUCH TIME might be needed / devoted to treatment and post-operative rehabilitation	3

Annexe 6

54

[redacted] Number of cases used in the analysis, according to background characteristics, Nepal 2008

Background characteristics	Number of cases used in the analysis	
	HRDC	Control
[redacted]		
District		
Banke	39	40
Bara	91	53
Dhading	152	33
Dolakha	86	27
Jhapa	63	36
Kanchanpur	34	35
Lalitpur	61	34
Nawalparasi	86	12
Sankhuwasabha	22	19
Surkhet	65	44
Tanahun	46	18
Total *	745	351
Region		
Central	390	147
Eastern	85	56
Farwestern	34	35
Midwestern	104	83
Western	132	30
Total	745	351
Ecological zone		
Hill	324	126
Mountain	108	46
Terai	313	179
Total	745	351
Current age		
1-5	2	58
6-10	38	89
11-14	119	92
15+	582	108
Total	741	347
Age at intervention		
1-5	243	
6-10	179	
11-14	207	
15+	111	
Total	740	

[redacted]

Annexe 7

Table 43

Membership of organizations

Percentage distribution of children / youth with disability by membership of organizations, according to background characteristics, Nepal 2008

55

Background characteristics	Children / youth with disability by membership of organizations					
	HRDC			Control		
	No	Yes	Total Respondents	No	Yes	Total Respondents
District						
Banke	82	18	39	95	5	40
Bara	92	8	90	92	8	51
Dhading	88	12	151	88	12	33
Dolakha	86	14	86	96	4	27
Jhapa	84	16	63	97	3	36
Kanchanpur	82	18	34	89	11	35
Lalitpur	85	15	61	79	21	34
Nawalparasi	84	16	85	92	8	12
Sankhuwasabha	82	18	22	94	6	18
Surkhet	94	6	65	84	16	44
Tanahun	78	22	45	89	11	18
Total	86	14	741	90	10	349
Region						
Central	88	12	388	89	11	145
Eastern	84	16	85	96	4	56
Farwestern	82	18	34	89	11	35
Midwestern	89	11	104	89	11	83
Western	82	18	130	90	10	30
Total	86	14	741	90	10	349
Ecological zone						
Hill	87	13	322	84	16	126
Mountain	85	15	108	96	4	46
Teral	86	14	311	93	7	177
Total	86	14	741	90	10	349
Current age						
1-5	50	50	2	91	9	58
6-10	84	16	38	94	6	89
11-14	87	13	119	89	11	91
15+	86	14	578	87	13	107
Total	86	14	737	90	10	345
Age at intervention						
1-5	86	14	242			
6-10	88	12	178			
11-14	85	15	206			
15+	86	14	110			
Total	86	14	736			

Annexe 7

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1-5	86	14	242			
6-10	88	12	178			
11-14	85	15	206			
15+	86	14	110			
Total	86	14	736			

Table 44 **Evaluation of the type of organizations to which HRDC-treated cases belong** 56

Percentage distribution of children / youth with disability by type of organization, Nepal 2008

Background characteristics	Type of self help organization					Total
	Club	CBR	DPO	Educational institute	Other	Respondents
District						
Banke	29	13	29	0	29	7
Bara	15	0	71	0	14	7
Dhading	22	0	22	22	34	18
Dolakha	8	8	26	8	50	12
Jhapa	30	0	40	10	20	10
Kanchanpur	33	0	50	0	17	6
Lalitpur	33	0	33	0	34	9
Nawalparasi	7	29	50	0	14	14
Sankhuwasabha	25	0	75	0	0	4
Surkhet	50	0	25	25	0	4
Tanahun	30	10	40	0	20	10
Total	23	7	38	7	25	101
Region						
Central	20	2	33	11	34	46
Eastern	29	0	50	7	14	14
Farwestern	33	0	50	0	17	6
Midwestern	36	9	27	9	19	11
Western	17	21	45	0	17	24
Total	23	7	38	7	25	101
Ecological zone						
Hill	29	3	29	12	27	41
Mountain	13	6	38	6	37	16
Terai	20	11	48	3	18	44
Total	23	7	38	7	25	101
Current age						
1-5	0	0	0	0	100	1
6-10	17	0	50	0	33	6
11-14	33	0	27	27	13	15
15+	22	9	40	4	25	79
Total	23	7	38	7	25	101
Age at intervention						
1-5	23	0	37	9	31	35
6-10	19	5	43	14	19	21
11-14	27	17	33	3	20	30
15+	20	7	46	0	27	15
Total	23	7	38	7	25	101

Table 44a Evaluation of the type of organizations to which control cases belong

Percentage distribution of children / youth with disability by type of organization, Nepal 2008

Background characteristics	Type of self help organization					Total
	Club	CBR	DPO	Educational institute	Other	Respondents
District						
Banke	0	0	50	0	50	2
Bara	25	50	25	0	0	4
Dhading	50	0	50	0	0	4
Dolakha	100	0	0	0	0	1
Jhapa	0	0	100	0	0	1
Kanchanpur	25	25	50	0	0	4
Lalitpur	29	29	42	0	0	7
Nawalparasi	0	100	0	0	0	1
Sankhuwasabha	0	0	100	0	0	1
Surkhet	0	0	57	0	43	7
Tanahun	0	100	0	0	0	2
Total	21	23	43	0	13	34
Region						
Central	38	25	37	0	0	16
Eastern	0	0	100	0	0	2
Farwestern	25	25	50	0	0	4
Midwestern	0	0	56	0	44	9
Western	0	100	0	0	0	3
Total	21	24	43	0	12	34
Ecological zone						
Hill	20	20	45	0	15	20
Mountain	50	0	50	0	0	2
Terai	17	33	42	0	8	12
Total	21	24	43	0	12	34
Current age						
1-5	40	20	40	0	0	5
6-10	0	0	80	0	20	5
11-14	30	40	30	0	0	10
15+	15	21	43	0	21	14
Total	21	24	43	0	12	34
Age at intervention						
1-5						
6-10						
11-14						
15+						
Total						

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ISBN 9937-2-1161-6
9 789937 211617