# **Karuna Foundation Nepal**

# **Evaluation of the Community Based Rehabilitation Projects**

# in Nepal

(3<sup>rd</sup> of March to 7<sup>th</sup> of March 2012)



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## **Executive Summary**

From the 3<sup>rd</sup> to the 7<sup>th</sup> of March 2012 a rapid assessment took place of the Community Based Rehabilitation (CBR) programme of the Karuna Foundation Nepal. The CBR programme has resulted in increased awareness of the needs and challenges of children with disability among the community at large. CBR field workers or facilitators play a major role in the actual services and activities of the programme. They focus on identification and referral of children with disability and are capable, though to a limited extent, to provide also basic therapeutic /rehabilitative services to these children. They struggle mostly with the more complex type of disabilities. It is advisable to strengthen the capacity of field staff by means of focused training in handling techniques of children with cerebral palsy and intellectual and behavioural disability.

Next to the focus on individual children and their families there is ample attention for group formation such as children clubs and self-help groups for mothers. While the concept of forming groups is commendable, there are two risks: 1) special groups for special children may reinforce isolation and exclusion, and 2) groups need to serve (the needs of) their members and the focus of the groups is not always clear. Another important aspect of the CBR programme is the pressing need to even more network with (mainstream) organisations and (public) services in order to ensure optimum use of scarce resources, build an 'inclusion attitude' and as such develop sustainable structures,

The community structures, which are in charge of the CBR programme are enthusiastic supporters of the programme and recognize the importance of continuing this programme even after the withdrawal of the Karuna Foundation.

Given the positive developments and support so far given and shown by the various VDCs for this area of work; the relative small amounts of money that are needed to meet the needs of children with disability and the unmet needs in other VDCs of Sunsari district it is recommended to scale up the programme in terms of magnitude and scope. In order to do so amole attention should be given to 1) networking and collaboration with other stakeholders including those in the mainstream of society as well as 2) advocacy in areas other than health.

# **Acknowledgements**

Thank you to all participants in this evaluation: some of whom we know and remember by name; others who are not mentioned with a name, but their situation and their stories have proven to be invaluable in better understanding the needs and challenges but also the hopes and dreams and achievements of all of you! This evaluation report belongs to you.

I am thankful for the management committee and all staff of the Karuna Foundation for your openness and for making yourself vulnerable to an outsider who pretends that he knows something about CBR.

# Huib Cornielje

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## 1. Introduction

The Karuna Foundation Nepal started its operation in the year 2008.inSunsari district in the eastern part of Nepal. The office of the Karuna Foundation Sunsari is situated in Inaruwa, the district Headquarters. During the first day of this assignment, the coordinator of the Share& Care, Yogendra Giri, gave an overview and Prevention&Rehabilitation programmes. The Share&Care programme was initiated in 2009 and takes place in the following village development committees (VDCs):

- Bhokraha
- Madhesha
- Bhaluwa

Aurabani

The Prevention&Rehabilitation programme was introduced during 2011 and is taking place on the following VDCs

- Madhuban
- Dumraha
- Baklauri

While the Share&Care programme is much broader than offering rehabilitation to children with disabilities only, the Prevention&Rehabilitation was introduced in order to get a more prominent focus on disability, as this is a focal area, which specifically belongs to the mandate of the Karuna Foundation.

The Community Based Rehabilitation (CBR) programme for children with a disability is to a large extent build on the principles of the current CBR thinking within the World Health Organization, other UN bodies as well as the International Consortium on Disability and Development (IDDC). Naturally it tries to work within the 5 main components of the newly launched CBR Guidelines (though the Guidelines itself are not known by the team). It is mainly the CBR matrix that is being referred to in discussions and meetings. This matrix is having 5 main components: i.e. Health, Education, Social, Livelihood, and Empowerment

The organisational structure for implementing CBR within the Share&Care programme is as follows: the Health Facility Operation and Management Committee (HFOMC) among other sub-committees has established a Community Based Rehabilitation Sub-Committee. This sub-committee is responsible for the supervision, support and control of the CBR Worker. The CBR worker is involved in identifying children with disabilities, assessing them (at time with a qualified physiotherapist from CBR Biratnagar and a pediatrician); establishes rehabilitation goal and an intervention plan. Besides s/he may decide to establish self-help groups and/or clubs of children with disabilities. The relevant staff of the Karuna Foundation provides technical support. The CBR worker is being employed by the Health Facility Operation Management Committee (HFOMC), and his/her salary is paid from local income i.e. funds from the Village Development Committee (VDC) as well as the Share&Care programme.

The structure in newly started CBR programs – the Prevention&Rehabilitation programme is as follows: a Village Disability Rehabilitation Committee (VDRC) is being formed. The VDRC appoints and employs a CBR Facilitator (in Share&Care called the CBR worker who in turn is accountable to the VDRC. Tasks and responsibilities of the CBR Facilitator are similar to the CBR workers in Share&Care supported VDCs. Given that the CBR staff are having a more liaison and facilitating role it was agreed that the new name for the CBR workers would be CBR facilitator.

The following Table gives an overview of the types of disabilities identified in the various VDCs.

Table 1: Types of disability by VDC

VDCs	Physical	Hearing	Visual	Intellectual	Mental	Vocal and speech	Multiple	Total
Bhokraha	54	20	5	8	5	2	7	101
Madhesha	16	5	0	2	3	2	1	29
Aurabani	17	6	1	4	0	1	0	29
Bhaluwa	12	2	2	4	1	2	0	23
Madhuban	10		2		5	3	2	22
Dumraha	33	6	3	9	6	2	2	61
Baklauri	21		1		2	11	5	40
Total	163	39	14	27	22	23	17	305

Table 2 gives insight into the division between disabled boys and girls in the 7 VDCs that belong to the coverage area of the Karuna Foundation.

Table 2: childhood disability by gender and VDC

VDCs	Male	Female	Total
Bhokraha	57	44	101
Madhesha	18	11	29
Aurabani	17	12	29
Bhaluwa	17	6	23
Madhuban	13	9	22
Dumraha	37	24	61
Baklauri	19	21	40
Total	178	127	305

The following interventions as part of the Health component of the CBR matrix are taking place:

- Assessment of all children with disabilities with the assistance of a pediatrician, physiotherapist, assistive device maker.
- Development of individual rehabilitation plans based on the recommendations of above mentioned professionals.
- Parents of children with disabilities have been motivated and trained to regularly to necessary exercises with their child.
- Other family members are also encouraged to participate in the rehabilitation of the disabled child.
- Family members of disabled children are offered opportunities to participate in the Community Based Health Insurance programme (which is one of the other activities within the Share&Care programme). Participation in this insurance scheme will improve access to quality health services and livelihood opportunity for these families.

Table 3 gives an overview of the frequency of provide medical services to children with disabilities: i.e. rehabilitation, physiotherapy and support in accessing assistive devices. It should be obvious for the good reader that there are no results yet to mention in the VDCs where the Prevention&Rehabilitation programmes was only recently started.

Table 3: Frequency of medical interventions offered in the Share&Care VDCs during the inception of the programme.

VDCs	Physiotherapy	Medical treatment	Assistive devices
Bhokraha	36	98	12
Madhesha	10	27	7
Aurabani	12	10	3
Bhaluwa	10	7	1

In the component Education the following activities were undertaken:

- Supporting educational materials to motivate children with disabilities to enroll in school and/or to continue their study.
- Providing regular counseling to the families of children with disabilities and motivate them to ensure that their child will continue their study.
- Vocational or skill development trainings to some CWDs who are 14 years of age or older.

Table 4 gives insight into school attendance of children with disabilities in the Share&Care supported VDCs. No actual results can be presented from the Prevention&Rehabilitation programme.

Table 4: school attendance of disabled children by VDC

VDCs	Normal School	Special School	Total
Bhokraha	53	2	55
Madhesha	23	3	26
Aurabani	17		17
Bhaluwa	18	1	19

As part of the livelihood component the Community Based Entrepreneurship (CBE) programme has been developed within Share&Care. This programme aims at supporting marginalized families and families of children with disabilities in income generating activities through providing vocational skills training and seed capital and enroll them in a savings and credit programme.

The social component consists of raising awareness about disability and disability rights. This means in practice: lobby directed at local government in order to work towards disability friendly public buildings.

Empowerment of children with disabilities and their families is stimulated through the formation of self help group; the formation of CBR sub committees; and children with disability clubs who have been formed in order to raise awareness about rights and build capacity to protect their rights. Furthermore, training is given to children with disabilities about the rights of children and the rights of disabled children.

The strengths of the CBR programme are presented by the Karuna staff as follows:

- Structures and trained Human Resources are in place to implement CBR activities
- CBR is an integral part of a more overall programme
- The community has been sensitized and empowered regarding disability related issues
- The quality of life of children with disabilities is gradually improving
- VDCs started to allocate budget for the disability sector.
- There is sound coordination and collaboration with other stakeholders working in the disability sector.

Learning point according to the Karuna staff are:

- The community seeks visible and tangible results and inputs
- It takes a long time to make change happen in the life of children with disabilities, but it is possible
- Small assistance for skills development and using the right opportunities can become a milestone in the life of a child with a disability

The challenges the CBR programme is facing according to the Karuna staff:

- Society at large is illiterate, poor, superstitious and backward
- CBR itself is not a priority in the community because of small numbers of disabled children /people
- Parents of disabled children sees free service even if they can afford it, because either they do not believe in possible change or believe that government should be providing all services freely to children with disabilities
- Dealing effectively with children with Cerebral Palsy intellectual and behavioral disability
- The quality of work/interventions provided by the CBR staff closely associated with their limited training
- Lack of (referral) facilities and services

# 2. Evaluation Methodology

The evaluation methodology consisted about a total number of meetings that were held in the 4 VDCs with various stakeholders, namely:

- the VDC secretary

- HFOMC members
- The CBR worker/ facilitator
- Child club members
- Self help group members
- Parents of children with disabilities
- Local leaders

Three Share&Care VDC were visited; i.e. Madesha, Bhokraha and Aurabani One Prevention&Rehabilitation VDCs were visited namely Madhuban

In Bhokraha VDC a meeting was held with the VDC secretary as he was not able to attend the meeting with all stakeholders in the morning.

In all VDCs visits were paid to the households where children with disabilities were living and observations and discussions with field staff were being held.

Documentation provided prior to the evaluation and primarily focusing on CBR were studied.

#### 3. Results

Visits were paid to the following VDCs:

- Madhesha VDC (Share and Care project) on the 4<sup>th</sup> of March
- MadhubanVDC (Prevention and Rehabilitation project) on the 5<sup>th</sup> of March
- Aurabani VDC (Share&Care project) on the 5<sup>th</sup> of March
- Bkokraha VDC (Share and Care project) on the 6<sup>th</sup> of March

Meetings were held with various groups of stakeholders and home visits were paid to a number of children with disability.

#### 3.1 About attitudes towards disabilities

The various meetings with VDCs, VDRCs, community people and leaders clearly indicate that part of the community still has negative attitudes towards children/people with disability. Simple questions (part of a quiz which was developed by Enablement for an inclusion project of Light for the World) showed for instance negative attitudes towards blind people and people affected by leprosy.

Asking if people would allow their daughter to marry a blind man there were quite some people who indicated that they never would do so as 'this is a social code in our society, which doesn't allow this...'or 'my heart doesn't allow me to do so'. On the other hand someone stated that 'I will do as it serves a noble cause...'.

These negative attitudes are largely determined by old ideas; lack of knowledge but also by lack of trust in the abilities of persons with disability. To a large extent people continue to think in a charity model rather than a more empowering social- or human rights model type of thinking. During the various meetings the question was asked to define disability and with some exception this usually was defined as:

- 'people who are different (in terms of activities of daily living)'
- 'people who can't do things easily'

- 'people who need help'
- 'as soon as a child is disabled the entire family is disabled'
- 'if any body part is not functioning'
- 'in the past it was seen as a curse from God...'. While most people see this nowadays different there are still some people who see it like this...'
- 'kind of weakness in hearing, sight etc'
- 'being deprived of information'

Some of these views are still traditional, deeply embedded in either a moral, medical or charity model of thinking. However some are interesting and showing that people also have different opinions. A real exception was formed in the Madhesha VDC where the former VDC chairman stated that it is 'people who are excluded from opportunity' indicating that he had far better understood the concept of exclusion and rights.

During discussions it was noted that more knowledge needs to be conveyed to various groups of people in society in order to change attitudes. It was stated that it was in the first place the parents who need to be made more aware of the potential of their children. However, it was also felt that political leaders should be targeted as well as they are examples to the community at large. A third group mentioned were the locally employed staff and professionals such as health workers and teachers, since an attitude change from their side will most likely ensure that persons with disability will be included into mainstream development projects.

While awareness raising is important and should be continued various community members made it also clear that with the success of the CBR programme automatically more attention will be given to disability issues. Success as the best PR for the work being done as an important and logical motto! The CBR has been able to identify several children with disability who otherwise were even not known by the community (11 out of the 28 children were not known).

#### 3.2 The structure of responsibility and accountability

It appears that the structure in Prevention&Rehabilitation villages with the VDRC or in Share&Care villages with the HFOMC being on top of rehabilitation are both working quite well. They employ the field staff and indicated to continue with supporting CBR and pay the salary of the field worker, also after financial support from the Karuna Foundation is being terminated. During the first year 50% of the salary is paid from local resources, in 2<sup>nd</sup> year 70% en in 3<sup>rd</sup> year 100%. However, the benefit from the new structure in Prevention&Rehabilitation villages is that the scope of CBR may - hopefully – not be restricted to the health domain only (as this typically is the domain, which falls under the responsibility of the HFOMC.

#### 3.3 Costs effectiveness

No breakdowns have been made of average costs of rehabilitation per child as these simple calculations can be made at the Karuna office as well. However, it is evident that:

- Expenditure for CBR are (relatively) low even if the (low) salaries of CBR field staff is added to the total expenditure.

- The costs per capita in some villages is lower than in others. While this is true we need to be careful in drawing conclusions. However, it would be useful to get more insight into the reason of the differences that exist among the various villages.
- The CBR component of the work of the Karuna Foundation renders essential services and support to families with disabled children at such low costs that the one would expect that eventually these costs can be funded from government sources, either central or local (NB: please note that this is not confirmed with evidence and it may be a point for further investigation).

#### 3.4 Sustainability

Asking community members and leaders about the importance and success of the CBR programme they stated that 'it brings about change in the community' or 'it is not a waste; it is worthwhile even if we see only 20 to 40% improvement!'

On a scale from 1-5 with 1 being not sustainable at all and 5 fully independent the community in Madhesha VDC indicated that their CBR programme is scoring a 3 with a range from 1 to 5. However, most people scored a 3 and after some discussion consensus was reached about this. Five stages of growth of trees (see figure) were used as a metaphor. A lot of lively debate took place during this part of the discussion.

Reasons for low to moderate scores are as follows:

- Based on previous experiences with other projects that left working in the VDC
- Seeds have grown but it needs ongoing water and fertilizer
- It needs at least another 2 more years to be supported
- More stakeholders need to become involved
- It is not money only; it is a change of mindset that is needed
- Remarkable changes have been observed; there is more acceptance in family and within the community
- If Karuna leaves the project will collapse in 6 months time
- More focus on CBR is needed otherwise the programme will detoriate
- In the Prevention and Rehabilitation programme people indicated that not much could be said about sustainability as the programme has just been started.
- A 3-year agreement with Karuna Foundation is not enough. People in one of the Share&Care villages asked if a system could be developed that raises funds for the time after Karuna Foundation is leaving the VDC
- The Bhokraha VDC indicates that it is the (disabled) CBR field worker who made and makes the programme to be successful. He is dedicated; oversees the rehabilitation of over 100 children and in spite of his physical disability moves around in the village by foot.



The village secretary in Bhokraha VDC indicated that if Karuna Foundation leaves his VDC the CBR work would continue to exist. He states that there are already alternative funds such as those from government. He however acknowledges that there is still gap between the available funds and the needs of many children (and adults) with disability. He is furthermore extremely positive about the role of the (disabled) CBR fieldworker.

#### 3.5 Scaling up

The question if CBR is always needed, and asked by one of the participants in one of the meetings on the 6<sup>th</sup> of March with the Bkokraha VDC is an interesting question. A question that shows that this person realizes that we will always have children and adults with disabilities among us and that thus CBR will be needed for ever. At the same time one should realize that at the beginning of a project usually a serious backlog exists in terms of needed services. As the programme progresses and more and more persons with disability are being identified, properly referred, managed and assisted in all domains of life (as indicated in the CBR Matrix of WHO), the programme may become less intensive and will cost less money. Given the enormous unmet needs of children with disability; the positive developments in the Share&Care villages (and promising structures in Prevention&Rehabilitation villages) CBR needs to, and could be expanded to other VDCs whereby it appears to be logical to follow the Prevention&Rehabilitation village model for further expansion of the CBR programme (and structure).

#### 3.6 Networking

CBR is about multi-sectorial collaboration, as inclusion of persons with disability never can be achieved by one single organisation. The Karuna programme is part of several networks at national level and that is of great importance. At the district level possibly more results can be achieved if the networks will further be extended. There is – as stated – a network with for instance CBR DCC, CBR Biratnagar and so on. It may be wise to further expand this network to <u>mainstream organizations</u> such as World Vision as mainstream organizations should increasingly open up their programmes for children with disability as well.

#### 3.7 Mobilization of other resources

Networking with disability-specific organisations such as the Liliane Foundation could prove to be useful regarding the ability to generate additional funding. People indicated also that there are many adults with disability and that it would be very useful if they could be helped as well. For that reason additional funds from other organisations need to be generated as well.

Another – in potential - increasingly important area for funding is formed by government funds.

#### 3.8 Social inclusion focus within CBR

Discussions about social inclusion were usually limited to inclusive education the lack of educational opportunities is one of the most pressing areas of need of children (and their parents). It is obvious from visiting all 4 sites that an inclusive approach to education is not simple. Children with physical impairments can relative easily be admitted to local schools. However, children with intellectual disability and hearing disability in some cases can be referred to a special school but in most situations these, and children with hearing and speech disability as well as visual disability are having no chance at all to be admitted at local schools. It is not always resistance or a negative attitude that is responsible for this situation. Moreover, it is the lack of skills and expertise from the side of the teachers that prevents these children from being educated.

The SHGs and children clubs forms another area of work, which seems to be directed towards inclusion. Unfortunately these developments are directed at parents of children with disability, some older disabled children and respectively children with disability. The SHG as well as the children Clubs lack focus. Just talking about rights will not help much to claim rights... and in the case of children it is very doubtful if these clubs should focus on issues that don't belong to the world of children.

## 4. Discussion and Conclusions

#### Something about the evaluation itself...

- It obviously was difficult to evaluate the recently started Prevention&Rehabilitation programmes as they only exist a few months.
- The Share&Care programme though initially much focused on health insurance and the prevention of childhood disability has been able to move steadily into the direction of CBR. It is interesting and noteworthy to see that village leaders do appreciate and actively support this development. This certainly is an indicator that awareness surrounding disability issues has been pretty successful. The advantage of the Share&Care approach is that the interest in disability probably emerged as a natural development from the existing and successful health care interventions. In other words, there was already a fertile soil (trust), which enabled the community to look beyond their immediate own and collective (health) needs.

#### About attitudes...

- Various stakeholders in the VDCs visited have still negative attitudes towards persons with disability. This thus would require additional efforts to influence attitudes and practices. This is and cannot be a once-off event/intervention but should be a continuous part of the work of the Karuna Foundation. Cheap interventions such as the Game for Life (see Traveling together from World Vision) are useful ways to confront community members with their attitudes and values
- Staff seems to struggle with innovative ideas regarding raising awareness. These are restricted to mainly conventional methods such as the use of posters and meetings.

#### **Human resource development issues:**

• Training in RCRD in Bhaktapur is taking place during a period of three-months. It is questionable if field staff has the right competencies. Actual skills to handle multiple and severe cases such as Cerebral Palsy are lacking and certainly not up to date. Innovative thinking about adapting the homesteads as well as appliances such as wheelchairs is missing. So much more could be done at low cost in order to make the life of children with Cerebral Palsy much better. Better and more training of rehabilitation skills would be important. Sometimes field staff needs to resort to the so-called 'zero-option': no therapy or other interventions to be offered, but just encouragement of parents to continually give optimal care and love to their disabled child would be of importance.

#### Inclusion but...

- How to deal with education of children with hearing and speech disorders as well as visual problems if special schools are not accessible (at a too far distance from the village) and regular school staff is not trained/equipped to deal effectively with such children? If children with disability go to school it is only those with physical disability. In Madhuban, out of the 25 children with disability only 5 children go to a local school and all of them are physically disabled. Referral of the other children with sensory impairments is not possible as the nearest special school is at a distance of 30 km from the village and has no boarding facilities. Other barriers mentioned:
  - Lack of interest from the side of the parents
  - Lack of knowledge and ideas to solve problem
  - Lack of funds

Reviewing the reality of the inclusive education in Sunsari district one wonders if the Karuna Foundation could play an advocacy role in order to at least address this problem to central government and share these experiences and realities within the existing (CBR and disability) networks. As such the Karuna Foundation may have a role in exposing the gap between (well-intended) policies and the reality at the grassroots level.

#### Groups, groups and more groups...

- The various groups of persons with disability seem not to function properly because of:
  - Lack of focus
  - Geographical distance: people live far from each other

- Disabled Peoples Organisations, when and where they exist they do not function properly. Would it be useful to assess if these Disabled Peoples Organisations can be strengthened? In view of the evaluator this is a far better direction to be undertaken, than just starting Self Help Groups who act more or less as a substitute to these local and small Disabled Peoples Organisations.
- Self Help Groups are at times not active anymore because:
  - The members don't see the benefits of being member of such a Self Help Group. If other regular self help groups do exist why setting up special ones for persons with disability? Rather integrate persons with disability and/or parents of children with disability in the already existing ones.
  - Funds for livelihood activities are limited and amounts are too small to see a viable business

#### Children's Rights and empowerment

- The Children Clubs seem to exist in order to empower children. Should however, children not be allowed to just play, make friendships; go to school rather than empowering them and making them aware of their rights? Is it not far more the parents who need to be empowered? It is in view of the evaluator impossible to ask from children that they demand access to right. However, some staff seem to believe and be convinced that children can be empowered to demand for instance disability ID cards.
- There is a strong desire among the staff to 'use' children with disability as role
  models as a strong means to advocate for inclusion of disabled children in society. It
  may be useful to identify success stories of children who have been able to overcome
  various barriers in their life and make a documentary of it.

### **CBR limits and challenges**

- CBR field staff recognizes a need for additional funds. If funds needed for rehabilitation are too large, collaboration with other donor agencies may need to take place.
- The mandate of the Karuna Foundation is limited to children up to the age of 18
  years only. While this is of course a deliberate choice made by the Board and
  directorship CBR itself can and should not focus on specific target groups only. It is
  advisable to make sure that the CBR activities include also at least identification and
  where possible referral of adults with disability to facilities that can be of assistance
  to them.

#### **Finally**

The CBR work done by the Karuna Foundation is highly appreciated by the community at large; its leadership; and the immediate beneficiaries. The strength of the programme is formed by the integral approach. It is not just focusing on disabled children only but views children in their context and tries to influence also that context in order to contribute towards a more inclusive society (which is the main goal of CBR). As such the work of the Karuna Foundation in the field of CBR is distinctively different from the small-scale individual oriented child assistance provided by for instance the Liliane Foundation.

#### 5. Recommendations

#### Attitudes – Awareness raising

- Use simple and cost-effective methods as well as innovative thought-provoking interventions such as the Game to Life to further influence attitudes and practices of the community towards children and adults with disability.
- Ensure that attitude change and raising awareness will be an ongoing aspect of the tasks of CBR field staff.

#### **Human Resource Development - Capacity Building**

- Training to be organized for all CBR field workers and coordinators with a focus on complex and severe childhood disability. Ask BIKASH Training Centre in Phokara to organize such training. Training needs to be very practical and it is suggested to ask Mrs Christine Miles (only ticket, board and lodging is needed as she won't be asking a fee)
- Ensure that all field staff is having a copy of the book *Disabled Village Children* from David Werner. This book has been translated in Nepali. Make also sure that the book is being used and organize on a regular basis continuing education for the field workers. Such training could be offered by visiting professionals (both local as well as international); it should focus on challenges and real life situations/experiences of field staff. Where possible such continuing education should become part of an organisational culture that fosters a keen interest to improve the quality of services provided.
- It would be useful for Mr Yogendra Giri and Mr Rajesh Bhujel to attend a formal course in CBR.

#### **Advocacy**

- The Karuna Foundation should focus its advocacy work also on the Ministry of Education in terms of the necessary improvements needed in making schools more inclusive. Ensure that such advocacy efforts are part of broader actions (of stakeholders already active in this field)) and contribute by means of giving the evidence of failing (special as well as inclusive) systems/schools to effectively deal with the needs of especially children who have sensory or behavioral disabilities.
- Identify a child or children who successfully have been assisted and make a short documentary/movie of the life of the child and how the child did overcome serious barriers in life.

#### **Group Formation**

• In the large villages where larger numbers of children with disability live it may be advisable to start thinking about setting up parent support groups. Such groups could receive technical support in terms of treatment and management of their disabled

- child. It would strengthen the position of mothers and would help them to be released on a rotational basis from taking care of their disabled child.
- Faith in power of kids, as members of community, to spread messages to younger kids, peers; families and communities could form a strong basis to change attitudes and practices towards children and adults with disability. While this is true probably the best way to make Children Clubs more meaningful is to open them up for children without disability as well (as part of inclusion) and function as an ordinary child club, not specifically directing abstract issues such as rights but just organising a place where children including disabled children can be child; meet each other; build friendship etc.
- Self Help Groups should and could function better by defining clear roles and
  responsibilities and even more ensure that members see that it gives then benefits.
  Such groups could be transformed in savings-and credit groups; in groups that
  generate income; or in groups that play a role in raising awareness about disability
  issues and as such (start) function as a local Disabled People Organisation.

#### Networking

- Build linkages with other donor agencies and refer appropriately or share (certain) costs
- Develop a network with other donor organizations in order to generate funds to meet the needs of adults with disabilities as well.

### Scaling up

- Given the success of CBR development in the villages visited (NB: in the Share&Care villages in particular) the Karuna Foundation is strongly advised to scale up its CBR work in terms of:
  - Size: i.e. expand to other villages in Sunsari, whereby it seem to be logical to follow the new structure of the Prevention&Rehabilitation village model for further expansion of the CBR programme (and structure). Following the Prevention&Rehabilitation village model is more appropriate as it gives better guarantees that CBR is not restricted to the health domain only (which more automatically may happen with the HFOMC being in charge in the Share&Care village model).
  - Scope: i.e. while ensuring that children remain the main focus build linkages to ensure that adults with disability may become part of CBR development as well

# **Appendix I: Terms of Reference for**

# EXTERNAL EVALUATION/RAPID ASSESSMENT OF CBR COMPONENT within Karuna's community programs of Share&Care and Prevention&Rehabilitation

# By Huib Cornielje

**DATE**: 4 - 7 March 2012

**PLACE:** Sunsari district: Bhokraha (started in October 2009), Madesha (Started in march 2010), Maduban (started in November 2011), Baklauri (started in November 2011)\*

#### **EVALUATION**

The general purpose of the external evaluation is to get clear picture of the ownership, priority, cost effectiveness, and probability of (financial) sustainability of the Community based rehabilitation (CBR) activities within two projects of Karuna: Share&Care' and 'Prevention&Rehabilitation'.

## Main research question:

• Is CBR integrated in a sustainable manner within Share&Care and/or P&R and can/will it continue to be so after Karuna exits the program?

In other words:

- What is the attitude of the local leaders, committees, and government towards disability/CBR in general and in Share&Care?
- Is there enough support and political will(ingness) within the Share&Care communities and district authorities to also include CBR in the budget of the HFOMC and VDC in the longer run, after Karuna pulls out? Has this support and political willingness grown in the last 3 years in the S&C VDS?

#### Setting

To be able to compare the priority of this issue within Share&Care and Prevention&rehabilition VDCs, it would be good also to visit 2 Share&Care VDCS (Bhokraha and Madesha) and 2 P&R VDCs (Maduban and Baklauri) as a comparison.

Limitation: P& R is recently started thus may be there will be no comparability with SC but the course it is taking or bringing in the community could be felt....

Objectives

- ✓ To evaluate the following aspects of the projects
  - The impact the project is creating
  - Attitude towards disability and inclusive development of local committees, leaders, local government, district government authorities.
  - o Ownership of CBR in the 2 projects
  - Structure of responsibility and implementation (VDRC in P&R and HFOMC/Consumer Cooperative in Share&Care).

- Cost effectiveness of CBR in the 2 projects
- o Chance of sustainability in the 2 projects
- Chance of replicability in other parts of Nepal
- Coordination with other parties (other (I)NGOs, district authorities, hospitals, referral centres, like HRDC, CBR Biratnagar, etc.
- Mobilization of local/other resources
- o Social inclusion focus (inclusive development) within CBR
- ✓ To provide critical comments and recommendations for the CBR work in the projects as well as other issues that arise.

#### Stakeholders to be involved in the research

- Karuna staff from Sunsari (Yogendra, Sita Ram, Jaya, Devi and Gyanu), as well as Deepak, Rita, Dhiraj and Mandar
- Some district authorities, like LDO, WDO, DHO.
- VDC secretary and some representatives of the Health Facility and Management Committee
- CBR worker/facilitators in the VDCs
- Health workers In Charge and other health staffs
- Some community people (parents of CWD, FCHVs, etc)

### **OTHER ACTIVTIES/AGREEMENT:**

- On 7<sup>th</sup> of March Huib will give ½ orientation training for AIN members:
- To be organized after consultation with Deepak.
- Second half of the day: Visit Ministry of Children and Social Welfare: RabindraAcarya and the Joint Secretary Mr.Adhikari

#### **Practical issues:**

Karuna Foundation Nepal is responsible for arranging and paying the logistics from 3 to 8 March (air ticket to Biratnagar, hotel in Inaruwa and Kathmandu, etc). In Kathmandu on 3-3 and on 6 and 7 March Tushita hotel can be booked.

#### Extra notes

One of the VU students will measure the effect of the CBR work on lives of the children with a disability and their families. Therefore this Rapid assessment focuses on the overall attitude of several stakeholders, ownership, sustainability and cost effectiveness.

\*Although the Prevention&Rehabilitation projects have just started, we think it will be possible for Huib to evaluate the different modality, actors, structure, strategy and chance of sustainability.