



## Learning Brief

# Community-Based Rehabilitation (CBR) for children with complex disabilities in Bangladesh.

## 1. INTRODUCTION

The district of Manikganj is only 53 km from Dhaka, but it may take up to 3 hours to reach, due to heavy traffic and poor roads. In the village of Putiajani and in Ghior Upazila[1], Niketan and its local implementation partner DRRA[2] started 20 years ago a centre for children[3] with disabilities. Long-term programmes were developed to address the various rehabilitation-, health- and educational needs of these children.

Unfortunately, many parents in more remote and poor communities were not able to reach these centres as transport is expensive, and parents struggle to continue to carry their children. These parents therefore requested for support to be given within their own communities. As such the need for Community Based Rehabilitation (CBR) is and was based on the needs felt and expressed by parents.

CBR is a multisectoral approach aiming to equalise opportunities and include children/adults with disabilities, while combatting the vicious cycle of poverty and discrimination. It is a common strategy used to promote disability awareness and inclusion and participation of children/adults with disabilities. CBR consists of health, rehabilitation, education, livelihood, social and empowerment components. A key thread running through a CBR process is participation. This helps to ensure that the programme responds to the needs of a community and that the community helps to sustain the programme in the long term.

In 2013, based on a participatory needs assessment and a baseline survey, a 6 month pilot was initiated in Manikganj district. Pilot goal setting was undertaken together with parents and as much as possible with children and youth with disabilities. During the 6 months, regular monitoring took place, through observation, interviews, meetings with parents, children, and other stakeholders. This way in 10 communities so-called community resource centres for children with disabilities (CRCD) or “veranda-schools” as they are often called, were set up. Most are situated around 15 km from the centre in Putiajani and Ghior, but some are located at a distance of 25 km or even more.

[1] Upazila formerly called Thana, is an administrative unit below district (sub-district)

[2] DRRA: Disability Rehabilitation and Research Association.

[3] In this Project Learning Brief a child is defined as a person from birth up to 18 years, as in the UN Convention on the Rights of the Child (CRC). DRRA and Niketan however, also work with older people with disabilities.

## 2. WHAT PROBLEM WAS TO BE ADDRESSED?

Children with complex and/or multiple disabilities are often not taken care of by existing disability networks and programmes, as these may prioritize to offer services to less complex disabilities such as visual, hearing impairments or physical disabilities. Children with a neurological disorder or multiple disabilities such as a combined intellectual and physical disability are often perceived as (too) difficult to work with. This may be due to absence of inclusive policy, scarce resources, lacking disability and child development knowledge of staff, and no or poor understanding of these children's, at times, exceptional behaviours.

Lack of disability knowledge and negative attitudes have resulted in marginalization of these children within their own families, in schools as well as in communities. In Bangladesh where guilt, shame and fear are associated with the birth of a child with disabilities, these children may be hidden from view, ill-treated, and excluded from activities that are crucial for their development. As a result, they tend to experience poor health and education outcomes, have limited interaction with other people and a low self-esteem. Invisibility makes them also at higher risk of violence, abuse, neglect, and exploitation.

From the very start Niketan and DRRA have been aiming to improve the quality of life, health, development, and educational prospects for these children.

## 3. OBJECTIVES OF THE PROGRAMME

3.1 Disability prevention, identification, early intervention, and rehabilitation by organising community-based rehabilitation and education services close to where families live who need such services.

3.2 The programme also wanted to help those affected by disability to organise themselves in OPDs[1] and parent forums, while building their capacity for self-advocacy to lobby for disability mainstreaming in UP[2] government committees.

3.3 Promote and demonstrate inclusive environments for children with complex disabilities and their families at local level, e.g. sport days, storybooks about characters with disabilities, showing talents of children with disabilities, etc.

3.4 Meaningfully engage youth in identifying necessary life- and vocational skills for a future as independent as possible, while also building knowledge and capacity of parents/caregivers for income generating activities to support their families.

3.5 Collaboration with and building capacity of (local) government and non-government actors to mainstream disability, to share knowledge and experience and contribute to equal opportunities through (inclusive) education, health, etc.

3.6 Engage community groups and individuals as volunteers for localization of CBR

[1] DPO: Disabled People Organisation

[2] UP: Union Parishad (the smallest rural administrative and local government unit in Bangladesh consisting of around 9 villages)



## 4. WHAT DID THE CBR PROGRAMME ACHIEVE?

4.1 Now in 20 communities in Manikganj district something unusual is happening. Where once children with complex disabilities were hidden, they now benefit from physiotherapy and education close to their homes. Members of the community volunteered to provide space on a veranda, mats to sit on and other low-cost local materials. These have become community resource centres for children with disabilities (CRCD) or veranda-schools. Two community development organisers and an assistant physiotherapist support veranda-schools in each Upazila. Activities are based on individual needs of a child, while parents are trained to continue rehabilitation and education activities at home. The education curriculum and physiotherapy exercises, developed by the programme, are well-structured while preventing further disabling and promoting independence, self-esteem, and empowerment. Local and low-cost resources are used to help children to improve functional daily living skills and prepare them for inclusive education.

4.2 Up till now 4 parent forums have been established. Each forum consists of 25 parents/caregivers. They meet monthly. At these meetings, parents learn more about the disability of their children, how to engage them in daily activities and how to stimulate them. They also learn about children's rights, and about what services the social welfare department can provide. But even more important, these meetings create opportunities for parents/caregivers to share experiences and learn from each other. This way, they empower themselves and start to act as 'changemakers'. They support each other by sometimes taking care of each other's children and in two communities, parents have taken over the running of the veranda-schools. Some of these parents have been elected as members of UP committees and were able to promote disability inclusive decision making, such as during the open budget meetings of the local government.

### What parents say:



*"We used to only see what our children could NOT do, now we see improvements and what our children CAN do. We have learned how to communicate with our children and gained knowledge and skills through training and meetings with other parents. We can now better support our children and each other and solve our problems together. Due to lobbying by this programme, local government has increased its support with disability allowances and education scholarships".*

4.3 Support was given to youth with disabilities to gain vocational and entrepreneurship skills and get (self) employed, while parents got the opportunity to participate in livelihood projects to generate their own income, such as by producing and selling vermin compost, livestock rearing and vegetable gardening. Some youth with disabilities started their own enterprise, while others found work e.g. in small restaurants or workshops.

### What a youngster say:



*"I received tailoring training and a sewing machine. Now I can make dresses for my family members as well as my neighbors. I earn 20 euro a month and recently opened my own savings account. I am so proud that I could do this all by myself".*

4.4 Local volunteers, men and women between 16 and 30 years, have come forward to become buddies for children with disabilities. They receive training, such as e.g. about total communication, and share experiences during regular meetings. Volunteers spend one to two hours a week with the child. They may take the child for a walk in the village, do games with the child or help with schoolwork, where possible also engaging peers without disabilities. These volunteers have been instrumental in making communities more aware of disability. Through their activities children with complex disabilities have become visible as children who need care, love, and friends just like other children. This has been an important step towards more positive and disability inclusive communities. Volunteers were also able to demonstrate that disabilities are not transferable and because of their involvement, parents had a bit of free time to socialize or do some work.

**What a volunteer say:**



*"My name is Gopal Serkar. I am 23 years old and the buddy of Rafi Mia, a young boy in my village who has autism. During my training I have learned that I can influence people's behavior by sharing knowledge. I therefore see it as my duty to inform the villagers about Rafi's disability. There is now more understanding for his sometimes strange behavior. He is no longer called the village fool."*

4.5 No single programme or organisation can make the change that is needed for children with complex disabilities and their families on its own. Therefore, collaboration with local government and private sector as well as other actors and (disability-related) NGOs were seen as critical right from the start. Such collaboration has resulted in sharing of resources and knowledge, joint capacity building of staff, recognition of the programme, increased local government support, and successful local fundraising.

4.6 Recognition of the CBR programme also resulted in official permission to partner with nearby regular government schools to sensitize and train children, teachers, and school directors on disability inclusive education.

## 5. WHAT LESSONS HAVE BEEN LEARNED?

After nearly 10 years, the following valuable lessons have been learned:

- Both long- and short-term goals have been important for the CBR process to achieve positive results and impact. Goals are, as much as possible, identified together with parents and children. Long term goals are listed in the Individual Rehabilitation Plan (IRP) for each family. Regular monitoring and reality checks, linked to the short-term goals, have been critical for identifying (positive or negative) change and potential need for adjustments as children develop – physically, emotionally, intellectually, and age-wise. This is done every 6 months and documented in a progress report.
- Rather than working for children with complex disabilities and their families, working with these target groups has proven to be one of the most critical success factors. Relationships like between parents and children, volunteers and families, children and professionals are what makes everything happen. The programme from birth to young adulthood was truly developed and implemented through such nurturing relationships.
- The combination of awareness raising for disability prevention and providing information about which services and support are available to families with a child with complex disabilities should go beyond just the mothers of children with a disability and involve the whole community.

- As the CRCDs/veranda schools only function once a week, it has been important to build the knowledge and skills of parents to do basic physiotherapy and stimulation activities with the child at home.
- It is not always easy to plan and budget for interventions each year. The programme may plan for a certain number of children and families, but more and more families join as they heard about this CBR programme.
- Keeping volunteers involved in the programme can be difficult at times. The volunteers are keen to work together with the physiotherapists, teachers, and other professional project staff. Such teamwork is what motivates them and could therefore be encouraged more.
- Ongoing capacity building, including persons with disabilities, their families, community members, service providers, and local leaders is critical for the continuation, ownership, and sustainability of the CBR programme, while connections with other professionals, such as community clinics, pharmacies, representatives of Upazila Social Welfare Office, local businesses and entrepreneurs, financial institutions, must be sustained.



## 6. HOW TO FURTHER STRENGTHEN THE PROGRAMME?

- Though the CBR programme is based on a survey undertaken at the start of the pilot and the M&E framework uses indicators to measure results, there may be a need after nearly 10 years to re-visit those indicators. These should be as SMART as possible, such as “the number of children with disabilities with improved physical functioning” or “the number of volunteers trained” and “the number of volunteers who dropped out” and “the number of families with a child with disabilities feeling valued in their communities” or “the quality of life of families”. Such indicators would give information about dedication of parents; commitment of professional staff/volunteers; attitudinal change in the community, and general functioning and quality of the programme.
- As most physiotherapists are undergraduates and the “special needs” teachers trained by the programme (without officially recognized diplomas) there is a need for more regular one-day refresher training opportunities each month to promote a “community of learning” among staff. Official certification may also need to be explored, e.g. with the Open University.
- While volunteers and others have been instrumental in enhancing the visibility and understanding of children with disabilities in the community, it is less clear how regular schools deal with disability inclusive education. Mainstream schools seem to mostly enrol children with a disability that they expect they can manage, such as children with mild or moderate hearing or physical impairments. For the inclusion of children with more complex physical and/or neurological disabilities the CBR programme may need to come up with additional strategies such as examples of good practices from other, but similar contexts. There is a need to explain how the project promotes, implements and monitors disability inclusion in regular schools. Evidence for such societal change will be important to document.



- Open air cinemas are organized to make community members aware of disability issues and to promote inclusion. Such awareness raising may need to become a more continuous project component as children with disabilities continue to be excluded by their peers living in the same community. Disability champions – children and adults -, disability-inclusive storybooks, disability inclusive play areas in community and schools and other strategies can be used. This is a long-term change process and is likely to be most successful starting with children as early as possible!
- It is important to explore and document what has changed since the start of the programme and whether those changes are likely to be sustainable. For example, how many CRCDs/veranda-schools are now being run by parents? How long do volunteers commit to working as a buddy with a child and what happens when a volunteer no longer can or wants to do this work? What knowledge and skills are various stakeholders now applying that they did not do before the programme started?
- Lessons learned from other programmes showed that it is important to recruit CBR staff from local communities, especially persons with a disability, and in particular women. This Niketan/DRRA programme too has successfully recruited personnel from local communities; however, they are mostly men and without disabilities. This is clearly an area for improvement.
- It is important to identify visible signs that the CBR programme is achieving its results, e.g., have self-help groups been formed that are sustainable beyond the project and has decision-making and budgeting at UP level become disability inclusive? It may be beneficial to take stock and critically reflect on programme activities developed up till now to see whether these benefit the whole community or mainly children with disabilities and their families.

For community ownership, a programme that aims to change community perceptions and expectations, planning, implementation, and monitoring must be done engaging a broader representation of the whole community. Also, the CBR process may have resulted in unexpected (and even negative) outcomes that need to be reflected on for impact measurement.

## 7. POTENTIAL FOR THE FUTURE

- Change towards more tolerant and inclusive communities and schools may have to start with children themselves. Rather than having an annual sports day for children with disabilities in each community, the programme could organise a fun day for all children in a community. Games could be adapted in such a way that children without disabilities have an extra challenge (or “disability”) by for example blindfolding them or tying their legs together. It would be important to adapt existing games in such a way that they can be played by all children irrespective of their physical or intellectual challenges. Children with disabilities could be teamed up with a child without a disability and compete together as a team against other such teams. Activities could also include music, dance, singing, or creative arts.
- There may be a need for an external independent evaluation after 10 years. The CBR programme may have to be evaluated on: [1] the impact of the programme on children with disabilities and their families, [2] the impact of the programme on local communities, [3] the quality of service, and [4] the quality of the management of the programme.
- Explore whether and how the CRCDs/veranda schools can be replicated and scaled up in a sustainable manner, preferably institutionalised within the local government structure.