Lessons learnt from a Community Based Rehabilitation (CBR) model in Manikganj (Bangladesh)

Authors: Els Heijnen, Antoinette Termoshuizen, Huib Cornielje
Date: June 2024

Abstract

Since 2013, a CBR project was initiated by the Disability Rehabilitation and Research Association (DRRA) in association with the Dutch supporting organisation Niketan in Manikganj district in Bangladesh to better respond to the needs of children with complex and/or multiple disabilities.

As in most countries where CBR has been implemented there have been serious concerns about the limited evidence-base regarding the effectiveness and efficiency of CBR and subsequent sustainability. Therefor an in-depth external evaluation took place in March 2023.

The CBR project has been able to develop a thriving network of (strategic) partners both public and private including parent platforms and local Organisations of People with Disabilities. Challenges that remain are the lack of access to quality assistive devices such as wheelchairs and quality physiotherapy as well as a concern about it's (financial) sustainability.

The CBR project is of enormous importance to its beneficiaries, stakeholders as well as the broader community. The project is a model which deserves a lot of attention because it could contribute to new insights about community- and home-based care and rehabilitation in a country where national government increasingly invests in professional rehabilitation services but

seems to ignore the importance of community services for those who are poor and live far away from services that are offered in urban areas.

Keywords: Community Based Rehabilitation (CBR), empowerment, neurodevelopmental disabilities, effectiveness, sustainability, Bangladesh, DRRA, Niketan

The context of CBR in Manikganj

One of the main principles behind the CBR approach is that the process of rehabilitation must be comprehensive, multisectoral and close to the homes of where people live. The CBR approach as from the early nineties of the last century, developed from a mostly medical model, into a more social model approach and gradually into a rights-based approach. CBR, as was and is seen by those in favour of it, promotes the active involvement of community members ("the grassroots"), and above all, must be participatory and inclusive of nature to ensure that the project responds to the felt needs of individuals with disabilities and their families. The importance of involving the broader community was, and still is recognised as well. Therefore, the community had to be made aware of the position and needs of people with disabilities. Specific attention should be given to using the network of services and resources within communities including the deployment of local field workers – be it volunteers or not – to provide contextualised services and interventions, build trust in society and build a foundation to ensure that the community becomes increasingly inclusive and can sustain the CBR project in the long run.

Having a Child with a Neurodevelopmental Disability

The district of Manikganj is divided into 7 upazilas or sub-districts and 1643 villages. It is only 53 km from Dhaka, the capital of Bangladesh, but it may

take up to a 3 hours' drive by car to reach the district, due to heavy traffic and poor quality of roads. Most of Niketan's activities take place in the more rural sub-districts of Ghior and Daulatpur. The 453 children supported by Niketan live across 185 villages in Manikganj.

Niketan, a small Dutch NGO, and its partner in Bangladesh, Disability Rehabilitation and Research Association (DRRA), have been running day-care centres for children with disabilities and their caregivers since 1998. Since then, projects were developed to address the rehabilitation-, health- and educational needs of the children using these centres. These children made great improvements and their quality of life improved significantly. However, many children in Ghior and Daulatpur could not access these centres due to distance and transport challenges. Parents/caregivers requested for more day-care centres.

Although the need for such day care was evident, it also became clear that scaling up the existing day-care centres would be too costly and not sustainable. Therefor it was decided to start in the year 2013 with the development of a CBR pilot. The CBR pilot commenced with a participatory needs assessment and a baseline survey. Furthermore, the CBR project was designed in consultation with parents, and as much as possible also involved the ideas and opinions of children with disabilities themselves. In 10 communities so-called community resource centres for children with disabilities (CRCD) or 'veranda-schools' as they are usually called, were set up. The uniqueness of the 'veranda schools' is that they are organised at the verandas of the houses of local people; sometimes at the houses of parents of children with disabilities; sometimes at the houses of ordinary or influential community members. It means that the expenses of those 'veranda-schools' are minimal and that it is the community itself who is responsible for the organisation and continuation of the centres. Most are situated around 15 km

from a rehabilitation centre, but some are located at 25 km distance or even more. Since then, projects have been developed at these 'veranda schools' to address the rehabilitation-, health- and educational needs of these children.

CBR implementation in Upazila Ghior and Daulatpur

These Upazilas Ghior and Daulatpur are located between the Jamuna and Dhaleshwari rivers. Residents often deal with natural disasters, such as floods and river erosion. The people who live on these so-called chars (sediment islands in the floodplains) are generally poor and illiterate. They have little or no access to health care, education, and other public services, and do not have the opportunity to escape a life of extreme poverty.

Discussions with several international non-governmental organisations in Bangladesh revealed that children with complex and/or multiple disabilities are often not taken care of by existing disability projects, as they may prioritize to offer services to less complex disabilities such as visual, hearing impairments or physical disabilities which are relatively easy to handle in the larger hospitals where orthopaedic services and physiotherapy services are offered. Children with a neurodevelopmental disorder (e.g. Cerebral Palsy) or multiple disabilities such as a combined intellectual and physical disability, are often perceived as (too) difficult to work with and often with disappointing results (UNICEF, 2014). This may be due to scarce resources, lack of disability- and child- development knowledge, and poor understanding of these children's, at times, exceptional behaviours. In addition, we notice a tendency in the NGO- and donor sector to 1) increased focus on short term results which one wouldn't see in the group of children with neurodevelopmental disorders and 2) emphasize the importance of system change. While we don't deny the importance of systems change, we have the opinion that efforts in this direction often take place at the expense of (funding) service delivery.

Furthermore, it is especially this group of children that won't benefit from therapy provided by therapists working in the larger urban based hospitals. They require intensive support from their parents who are trained and supported by well-equipped community-based rehabilitation providers (Robertson J. et all 2009).

Lack of disability- and contemporary functional rehabilitation knowledge and practice, identification, referral, and intervention starting late as well as prevailing negative attitudes in society and low expectations regarding children with disabilities, often result in the marginalization of these children within their own families, in schools and in their communities (UNICEF, 2022).

In Bangladesh where guilt, shame and fear are associated with the birth of a child with disabilities, these children may be hidden, ill-treated, and excluded from activities that are crucial for their development (UNICEF, 2012). Fathers tend to leave their spouses as soon as they realise that their child has a severe disability (Rohwerder, 2018). This may lead to a chain of events whereby even the mother may feel stigmatised and abandon her child leaving the child into the custody of grandparents. Children with neurodevelopmental disabilities in general 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.

Something unusual happening in Manikganj

In 20 communities in Manikganj something unusual has happened. Where once children with complex disabilities were hidden, they now benefit from rehabilitation services and education close to their homes. Community members volunteer to provide space on their veranda, mats to sit on, toys and other low-cost local materials. These have become community resource centres or ‘veranda-schools’. In each Upazila there is a community

development organiser, a volunteer and an assistant physiotherapist supporting the veranda-schools. Interventions provided are based on the individual needs of a child, while parents are trained to continue rehabilitation and educational activities at home and support their children's overall development. The curriculum used at the veranda-schools and the physiotherapy exercises, developed by the project, are well-structured and aim to prevent further disability while stimulating the child to develop at its own pace. The project also promotes independence, contributes to increased self-esteem, and empowerment of both the child as well as the parents. Local and low-cost resources are used to help children to improve their functional daily living skills and where possible prepare them for education in existing inclusive mainstream primary schools (Niketan/DRRA, 2023).

Four parent forums have been established. Each forum consists of a group of 25 parents of children with disabilities. Together they make their voices being heard for the rights and needs of their children. During the monthly meetings, parents learn more about the disability of their children, how to engage them in daily activities and how to stimulate their development. They also learn about children's rights, and about the type of services that are offered by the local Ministry of Social Welfare. But even more important, these meetings create opportunities for parents/caregivers to share their experiences and learn from and with each other. This way, they empower themselves and become 'changemakers'. They support one another by taking care of each other's children when needed. In two communities, parents have taken over the management and running of the veranda-school. Some of these parents have been elected as members of the Upazila committees and as such promote 'disability inclusive decision making'. During the open budget meetings of the local government, they have lobbied for and been able to

access disability allowances; they did receive building materials for house improvements; and got financial support to buy medication for their children.

Local volunteers - men and women between 16 and 30 years - have come forward to become *buddies* for children with disabilities. The volunteers receive training, for example about total communication. They meet regularly to share experiences and learn from each other. Volunteers spend one to two hours a week with the child. They may take the child for a walk in the village, play 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 contagious. Because of their involvement, parents also have a bit of free time to socialize or do some work.

Support has been given to youth with disabilities to gain vocational and entrepreneurship skills and become (self) employed. Parents got the opportunity to participate in livelihood projects to generate their own income, such as by producing and selling vermin compost, through livestock rearing and vegetable gardening. Some youth with disabilities started their own enterprise, while others found paid work in for instance small restaurants, carpentry- or tailor workshops.

No single project or organisation on its own can make the change that is needed for children with complex disabilities and their families. Therefore, collaboration with local government and the private sector as well as other

actors and (disability-) NGOs were seen as critical right from the start. Such collaboration has resulted in the sharing of resources and knowledge, joint capacity building of staff, recognition of the project, increased local government support, and successful local fundraising (Cornielje H. / Zarin E., 2023).

Recognition of the CBR project also resulted in official permission to work in nearby mainstream government schools for sensitization and capacity building of children, teachers, and school directors on disability inclusive education.

As stated, an in-depth evaluation was done in order to reflect on the past and draw lessons for the future. This manuscript is a brief report of this evaluation.

Objectives

The objectives of the evaluation were to ascertain the changes in terms of acceptance, inclusion, and quality of life of the children with complex and/or multiple disabilities, their families and the community at large. This involved examining the role of parents, key stakeholders and the community at large; as well as measuring the extent to which the quality of life of children with disabilities and their families had improved; in how far they were having access to basic social services; and the sustainability of the project.

Methodology

As CBR projects differ, are complex and are multi-sectoral in nature, a toolkit was developed in the year 2015 by a consortium of different partners i.e. The University College of London, The University of Cape Town, the Royal Tropical Institute in Amsterdam and Enablement a consultancy in the field of CBR and disability and development. This toolkit comprises of participatory tools. These tools will stimulate and maximise interaction. The participatory tools and

methods with specific attention to children/youth with disabilities and their caregivers i.e. usually mothers or other women) and participatory methods of research focused on creating respondent ownership and facilitating a dialogue for learning. The evaluation involved a large diversity of stakeholders to contribute meaningfully to the evaluation.(The Participatory Inclusion Evaluation (PIE) toolkit (E. Post et al, 2016).

The PIE Evaluation Framework is focused on outcome and impact and is based on diverse evaluation theories and methods used in mainstream international development. All such theories and methods have its own merits and shortcomings; therefore a mix of participatory tools was developed to ensure an approach which is pragmatic and flexible. PIE involves the participation of three types of stakeholders for data collection: people with disabilities, the CBR core team, and the network of strategic partners. With these PIE tools the impact and the factors that contributed to the CBR project in Manikganj were assessed. This inclusive and participatory method collected data by using, document analysis, key informant interviews and focus group discussions, resulting in a mix of quantitative and qualitative data. Especially the perspective of people with disabilities has been critical in the data analysis. Impact has been defined as changes in inclusion, empowerment, and living conditions.

Data Collection Methods

The following data collection methods were employed:

A document review of available progress and annual reports. During the development of a timeline, key team members of the CBR project established the external developments – both positive and negative – that had a significant influence on developments in the project area.

A stakeholder mapping was done to identify stakeholders and their importance in the childhood disability field and CBR developments. In-depth individual Interviews were held with various – strategic - stakeholders such a local authorities, school management and teachers, pharmacists and religious leaders. Home visits and interviews with caregivers/parents of children with disabilities formed an important means of getting insight into the living conditions and wellbeing of families with children with a disability.
Focus Group Discussions (FGDs) were held with groups of stakeholders such as local authorities, young volunteers and key staff.

Sampling procedure

A purposive sample was selected, consisting of children and youth who were living relatively close to each other in the two project areas. Two groups were selected: those where clear successes had been achieved and those whereby field staff indicated achieving results was more challenging. A good balance of boys and girls was another criterium that influenced the sample. Though lack of time prevented visits to all project sites and homes, the partners and beneficiaries visited, interviewed, and observed offered a sound insight into successful and less successful aspects of the project.

Ethics

Consent of participants – children and adults – was asked for and given before the start of the project evaluation.

Outcomes

The CBR project has been effective in collaborating with parent platforms and local Organisations of People with Disabilities (OPDs). Parent platforms and OPDs have been active in raising awareness in schools, advocating with local authorities for acceptance of children with disabilities and supporting parents

in applying for Disability ID Cards, necessary to have, when applying for a government disability allowance. Parent platforms are 'the voice of children with disabilities' and operate as activists who seriously lobby for disability mainstreaming and improved services for children with disabilities. The parent platforms want to become independent in the coming 5 years.

In the Ghior Centre, teachers and physiotherapists work with children with different disabilities. Children and their mothers are actively engaged. They come 3 days a week together for senso-motoric training. It is a happy place for both mothers and children. Mothers indicated that they see improvement in the lives of their children. Through the veranda-schools, awareness about childhood disability and the importance of therapy and play in the development of the child has been established. According to the staff this has led to increased acceptance of the child with complex disabilities. The veranda-schools provide (early) intervention/stimulation for the most vulnerable children using a unique and low-cost model. Because of the early interventions and training at the veranda-schools, several children with disabilities are now included in mainstream primary schools. Various vocational training opportunities for youth were also identified and provided, for example at the Centre for the Rehabilitation of the Paralysed (CRP) in Savar.

The CBR project has been able to develop a robust and vibrant network of (strategic) partners both public and private. This truly is one of the strengths of this project. It is unique because it operates smoothly, and forms as such a critical component of the institutional development and with it an important element of sustainability. The project cannot do without this network, which includes a substantial number of (120) of young volunteers and community groups (e.g., the earlier mentioned parent platforms). This network has a wide variety of committed public and private partners and is instrumental to the

success of the CBR project. Its further development – according to some of the interviewed stakeholders – could be even more exploited.

Challenges that remain are the lack of access to quality assistive devices such as wheelchairs and quality physiotherapy. Some young people with disabilities who were interviewed, struggle with leading a meaningful life and worry about their future in terms of independence. This concern is often combined with uncertainties about possible relationships or marriage. Such are also the worries of several interviewed (grand)parents who take care of their (grand)child with disability. They go so far that they even fear that something bad may happen to their (grand) child. An improved economic situation was often mentioned as of critical importance in having a better quality of life as a family. On various occasions beneficiaries showed evidence that a goat or rickshaw-van, given to the family helped them greatly in improving their quality of life.

Discussion

As stated earlier, the quality of physiotherapy is still 'old-school' despite the attention given to this by visiting experts who tried hard to change old ineffective practices into an approach that is more functional and contributes to improved participation in society as an outcome. It however is not so much the physiotherapist or physiotherapy assistants who to be blamed for this. Rather it is the continued universities' training of therapists that should ensure that their curricula are in line with new insights regarding effective interventions. Children with neurodevelopmental delays and disabilities in Bangladesh would greatly benefit if current physiotherapy students as well as professionals would be (re)trained in contemporary approaches of working with children with neurodevelopmental delays and disabilities. It would imply that curricula of all rehabilitation professionals need to be reviewed, changed

and be made more meaningful. This would entail a pertinent focus on childhood disability; a focus on functional therapeutic interventions; and ensuring that curricula are contextualised to the eco-social circumstances of Bangladesh. Knowledge centres in low- and middle-income countries are often not in the forefront of introducing new developments. They tend to be reactive and are not bold enough to introduce elements in their curricula which are not in line with directives and (Western) standards from for instance global professional bodies. Yet, the reality in which physiotherapists work in remote rural parts of Bangladesh requires therapists who are well-trained to work with for instance the large numbers of children with complex disabilities. The context should in our view determine the curricula. In terms of effects of therapeutic interventions, we notice that therapy should be(come) more functional and be more the responsibility of mothers/caregivers. The current sessions whereby the therapist provides therapy need to become instruction sessions for caregivers whereby the therapist coaches the parent/caregiver who then tries out similar practices in daily life activities such as bathing, dressing, eating etc. Besides, the child needs to be stimulated to develop through play and interactions with siblings, family members and friends. During this evaluation we observed that therapists still focus too much on 'handling' the child with neurodevelopmental disability.

The parent platforms have become strong frontline advocacy bodies for children with disabilities. And despite their focus on disability mainstreaming, they acknowledge the importance of having a school especially for children with *severe* disabilities. Critics would easily comment and point out that this is not what is desired as it may contribute to segregation. However, these parents face the daily reality whereby – despite policies on inclusive education in Bangladesh, it is mainly children with mild and moderate disabilities who will have access to mainstream inclusive schools. As is often the case, theories

about inclusion are great and commendable. However, the reality of life for the poorest and most deprived often requires alternative solutions.

Parent platforms also indicate that there is a wish for more knowledge- and skills building in inclusive education and in how to support the rehabilitation of their children and are eager to learn how to run their own organisation. Therefore, they need capacity building in organisational development.

The CBR project is of immense importance to direct and indirect beneficiaries, stakeholders as well as the community at large. The project gradually moved into a model project that deserves much more attention than it receives now. This model could contribute to new insights about community- and home-based care and rehabilitation in a country where national government increasingly invests in rehabilitation services in the form of building infrastructure, i.e. institutions, but seems to ignore the importance of community services for those who are poor and live far away from services that are offered in urban areas. A CBR project like the one described in this review can form a strong basis for scaling up CBR into a public multisectoral system with a focus on prevention, early detection, referral, early intervention, and rehabilitation of children with neurodevelopmental disabilities. The evaluators recommend that Niketan/DRRA invests in evidence building and set up targeted advocacy and lobby efforts towards key government ministries. For example, early detection of neurodevelopmental, and other disabilities must take place on a routine basis, i.e. developmental delays and disorders need to be screened when young children come for growth monitoring and immunisation. To make this happen, the network of Niketan/DRRA must lobby for such essential services the Ministry of Health.

Critical success factors

The following critical success factors have been identified:

1. Having committed project staff and ensure right from the onset the participation of the community at large.

2. Use a simple survey tool to identify children with disabilities.

3. Work towards tangible evidence of project effects i.e. document the challenges and changes in the lives of children with disabilities and their families.

4. Give attention to individual children through home visits. Make sure that the needs of the child are central, without forgetting that the child lives in a family and that the family often also needs support to be able to support the child. The family-centred focus in this project proves to be strong and effective!

5. The multisectoral collaboration has been very effective. The network is of critical importance as this has resulted into the much-required system change at Upazila level!

6. This CBR project demonstrates that with a relatively small amount of money but with the commitment from a vibrant community network, much can be achieved.

A CBR project is never completed. New children with disabilities are born and disabilities will occur among other children due to diseases or accidents. Donor dependency needs to slowly decrease, and this can only happen if the national government becomes involved in financing and running such projects.

Acknowledgements

This CBR review could not have been undertaken without the staff of DRRA, Nizam Uddin and Dalima Rahman in particular. The insights they provided regarding systems and structures as well as the role of various stakeholders in the disability and rehabilitation field have been invaluable. We met with many other individuals and organizations - such as local government officials. We thank them for their engagement and at times critical discussions. We are grateful to those who took part in the focus group discussions, and we would like to especially acknowledge the children and their (grand)parents who gave their time and were willing to openly talk about their challenges, concerns, hopes and dreams.

References

- Brigitte Rohwerder (2018), Disability stigma in developing countries, Institute of Development Studies, https://assets.publishing.service.gov.uk/media/5b18fe3240f0b634aec30791/Disability_stigma_in_developing_countries.pdf
- Centre for Disability Research (CeDR) / Lancaster University (UK) / Robertson J., Emerson E. & Hatton C. (2009) – The Efficacy of Community-Based Rehabilitation for Children with or at risk of Intellectual Disability in Low- and Middle-Income Countries: a review. https://eprints.lancs.ac.uk/id/eprint/27957/1/CeDR_2009-4_CBR_for_Children_with_ID_in_LAMI_Countries.pdf
- Cornielje H. / Zarin E. (2023) Evaluation Report – Community Based Rehabilitation DISABLED REHABILITATION & RESEARCH ASSOCIATION (DRRA) AND NIKETAN, https://www.niketan.nl/nieuws/evaluatie-cbr-programma/
- E. Post, H. Cornielje, K. Andrae, A. Maarse, M. Schneider, and M. Wickenden. 2016. Participatory inclusion evaluation: a flexible approach to building the evidence base on the impact of community-based rehabilitation and inclusive development programmes. Knowledge Management for Development Journal 11(2): 7-26 https://enablement.eu/wp-content/uploads/2019/10/PIE_article.pdf
- Niketan/DRRA (2023) – Community Based Rehabilitation (CBR) for children with complex disabilities in Bangladesh – A project Learning Brief, https://www.niketan.nl/wp-content/uploads/2016/09/Learning-brief-CBR2.pdf
- UNICEF (2012), Early Childhood Development and Disability: A Discussion Paper, https://www.unicef.org/media/126501/file/ECD-and-Disability-WHO-2012.pdf

- UNICEF (2014) – Situation Analysis on Children with Disabilities in Bangladesh.
- https://www.unicef.org/bangladesh/media/2046/file/SA-disablity%20report.pdf
- UNICEF (2021) – Disability-inclusive education practices in Bangladesh. A country profile. https://www.unicef.org/rosa/media/16986/file/Country%20Profile%20-%20Bangladesh.pdf
- UNICEF (2022), UNICEF Factsheet Children with Disabilities, https://www.unicef.org/media/128976/file/UNICEF%20Fact%20Sheet%20:%20Children%20with%20Disabilities.pdf