Evaluation Report

COMMUNITY BASED REHABILITATION DISABLED REHABILITATION & RESEARCH ASSOCIATION (DRRA) AND NIKETAN

Period: 28th of March – 6th of April 2023

Consultants
Enablement® (The Netherlands)

Huib Cornielje and Esmot Zarin
Enablement
A van Leeuwenhoekweg 38 unit 16a
Alphen aan den Rijn
The Netherlands
Tel: +31 6 28485083
E-mail: h.cornielje@enablement.nl

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ABBREVIATIONS

CBO	Community Based Organisation
CBR	Community Based Rehabilitation
DPOs	Disabled People's Organisations
ECD	Early Childhood Development
MoH	Ministry of Health
NGOs	Non-Governmental Organisations
SRHR	Sexual and Reproductive Health Rights
UNCRPD	United Nations Convention on the Rights of People with Disabilities
WHO	World Health Organisation

EXECUTIVE SUMMARY

The overall conclusion is that the Community Based Rehabilitation (CBR) program is managed by an enthusiastic team working in Ghior amd Doulatpur. The CBR program is financially supported by - especially - Niketan. The evaluation reveals a large number of positive developments affecting the effectiveness of the program. There are however some concerns related to the sustainability of the CBR program. In terms of **its effectiveness** the evaluators come to the following conclusions:

- The program is very relevant to the beneficiaries i.e. children and youngsters with disabilities, their (grand)parents and their families at large.
- The program is of good quality. However, access to good quality of assistive devices needs more attention.
- The program is effective until the moment that children /youngsters become adults. Besides, their caregivers – often grandparents because the own parents left their children in their care - fear for the future of their children when they are not capable of taking care of them.

The veranda schools became a household name and flourished because of the high level of community participation. Staff, parents and communities at large are all extremely positive about the veranda schools. It is robust model that finds its strength in the active participation of community members who responded positive to make their compounds and verandas available as a place for children with disabilities to enjoy themselves; to have fun; to make friends and to learn and develop. The veranda schools are also place where therapy is provided by motivated physiotherapy technologists.

In terms of its **sustainability** the evaluators come to the following conclusions:

a. There is a strong and vibrant network of partners, both public and private.
b. The DRRA CBR program in Manikgonj is much dependent on Niketan (funding). Government funding adds up to max. 10% of all investments in childhood disability in Manikgonj according to the management team and includes disability allowance.
c. For the CBR program to continue and become (financially) sustainable it should become part of existing public services

The evaluators **recommend** the following:

1) Concerning **scaling up** we wished to advise to expand the CBR program to more unions. Given the fact that this largely depends on additional funding which in our view should come from government we strongly advise to consolidate current work in the 7 unions.
    a. Extraordinary efforts should be made to attract public /government funds for the long-term continuation of the current programme.
    b. Scaling up should only take place if government becomes much more involved in funding and further development of the CBR program.
    c. If new unions or more villages will be covered it is advised to always start with a ‘quick and dirty’ identification of all children with disabilities and finding out what their needs are.

2) About Capacity Building

a. DRRA should start/step up lobby efforts for short but robust training programs for teachers of primary schools in handling the child with specific disabilities. An alternative may be the development of an annually to be offered Summer School which focusing on upgrading the capacity of teachers in working with children with special needs.
b. Continue to invest in training of partners e.g. in early identification for staff community clinic and leadership and organisational development training of the Parent Platform.
c. Invest in continuing education/training in which field staff learn specific competences on the job.

3) Concerning the quality of rehabilitation interventions

a. Seek options to adapt homes (e.g. with ramps), toilets (of schools) and use community people in making such adaptations.
b. Lobby for better paediatric wheelchairs. Shonaquip South Africa has a great name; Farida is already in contact with them and DRRA or organisations such as CRP may wish to form an alliance with them.
c. Develop and introduce more entertaining forms of awareness raising e.g. drama, puppetry or very simple and without any costs the so-called Game of Life.

LIST OF CONTENTS

1) INTRODUCTION

Disabled Rehabilitation and Research Association (DRRA) and Niketan developed for the past 25 years services for children with disabilities in 2 areas in Bangladesh namely Manikganj and Dhaka (See Attachment X). The activities in Dhaka are 'limited' to a special needs school. The services in Manikganj however are more comprehensive and evolved since the year 2014 into a community-based rehabilitation (CBR) approach that developed in 2 subdistricts namely Doulatpur and Ghior. The focus of this evaluation is the Community Based Rehabilitation (CBR) program. CBR is a community development strategy that aims to enhance the quality of life for people with disabilities and their families and ensure their inclusion and participation in the community. It is a strategy to promote disability awareness, inclusion, and participation of children/adults with disabilities.

With almost ten years of experience with the implementation of CBR, DRRA and Niketan commissioned this evaluation. The evaluation focused on:

- an assessment of the process.
- progress made during the past (almost) 10 years with attention to outcomes.
- guiding the teams in Bangladesh and the Netherlands in appropriate ways of sharing the lessons learnt from the used approach, and
- make recommendations to disseminate and promote the DRRA/Niketan approach with stakeholders at a local level.

The objectives of the current program are:

- To contribute to disability prevention, identification, early intervention, and rehabilitation of children with disabilities through community-based rehabilitation and education services close to where families live who need such services.

- To help those affected by disability to organise themselves in organisations of people with disabilities (OPDs) and parent forums, while building their capacity for self-advocacy to lobby for disability mainstreaming in UP[1] government committees.

- To 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.

- 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.

- 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.

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

- Engage community groups and individuals as volunteers.

2) OBJECTIVES AND KEY QUESTIONS OF THE EVALUATION

2.1 Evaluation Objectives

To find out how the CBR program has made a difference in the lives of children with disabilities and their families with attention for aspects such as inclusion, empowerment and improved living conditions.

- To give an insight into the relevance, quality and effectiveness of the CBR program including its success factors and possible limitations.
- To provide insight into the extent and functioning of the existing (community based) network of the program.
- To gather information about the sustainability of various aspects of the program and direction for the scaling up of the CBR program.
- To provide recommendations on how to strengthen the CBR program.

2.2 Key Evaluation Questions

There are five sets of evaluation questions to be answered. While compiling the report we increasingly realised that there is some duplication in some of the questions. While we tried to stick in the report as much as possible to the format of these questions when duplication was too obviously leading to the same information, we either ignored the questions or referred to previous sections.

Outcomes

1. Assess to what extent the CBR approach effectively reached its goal(s) and outcomes?
2. Determine the kind and extent of the outcome of the program on children and youngsters with disabilities and their families.
3. Assess the outcomes of the program on local communities and (strategic) stakeholders in these communities.
4. To what extent are the 5 CBR components addressed?

Effective Partnership networks

5. Review the current (local) partner networks and review if the networks are functional i.e. if stakeholders sufficiently involved in the development and operations of the program.
6. To what extent are local authorities involved.

Critical (success) factors

7. Determine the critical success factors and those that may have (had) a negative influence on the development of CBR.
8. What activities undertaken with what kind of materials and do these effectively contribute to the achievement of the CBR goals?
9. What are the lessons learned to influence the different phases of CBR development positively?
10. Which part of the program was most effective for (the families of) a child with a disability?

Scaling up

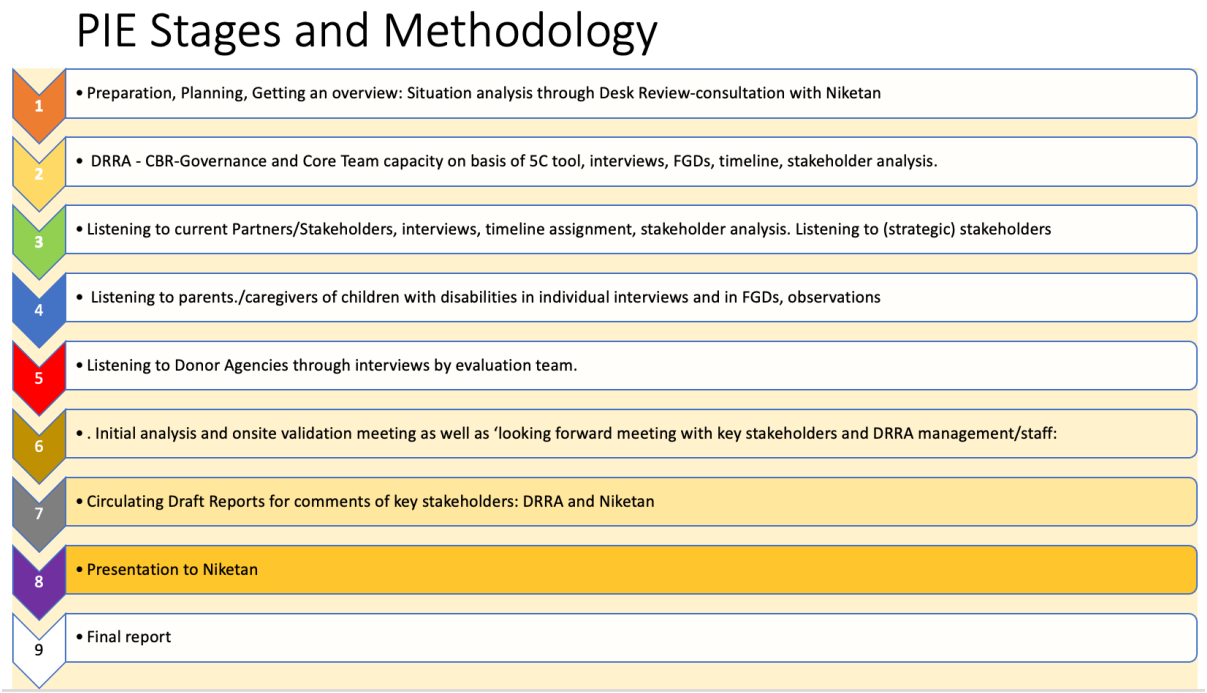
11. What are the Strengths, Weaknesses, Opportunities and Threats for replicating and scaling up this approach?
12. How well are the veranda schools which are now managed by parents and/or/volunteers are sustainable and what are critical factors that led to a well-functioning management of these veranda schools?

Sustainability

13. What is the likelihood of continuation and sustainability of outcomes and benefits after completion of outside support?

3) EVALUATION METHODOLOGY

Use was made of various tools that are part of the Participatory Inclusion Evaluation (PIE) toolkit: see also https://enablement.eu/publication/pie-toolkit. An Evaluation Framework is provided in this toolkit that has a focus on outcome (and impact). It consists of a set of participatory tools to collect data from different stakeholders. The PIE toolkit is loosely based on outcome mapping/harvesting.



Step 5 was skipped as it wouldn't add much information about the outcome of the CBR program in Ghior and Doulatpur.

3.1 Evaluation Tools

A selection of (adapted) PIE Tools were used in this evaluation i.e:

- A document study of proposals, reports and other information related to the program.
- Timeline assignment.
- Stakeholder Analysis assignment.

- 5-Capabilities Tool to be used in internal staff involved in CBR.
- In-depth interviews with key stakeholders (at community level).
- Interviews with project staff.
- Home visits with in-depth interviews and observations.
- Interviews with the management team (at the end of the evaluation).
- Interviews with (parents/caregivers) of children with disabilities.
- Focus Group Discussion (FGD) with mothers of children with disabilities.
- Focus Group Discussion (FGD) with fathers of children with disabilities.
- Focus Group Discussion with volunteers.
- Meeting with a diverse group of stakeholders.
- Validation meeting with management team and selected stakeholders with a presentation of the findings, preliminary conclusions and followed by a discussion about selected recommendations that could be leading to action planning.

3.2 Sampling

The 6-day field period didn't allow us to talk with everyone i.e. not all beneficiaries nor all stakeholders. It was thus of importance to select a representative sample. The selection of this sample was made in close collaboration with the DRRA staff and Antoinette Termoshuizen. The sample taken consisted of children/youngsters who were living relatively close to each other in either Ghior or Doulatpur; a selection of children/youngsters where clear successes were achieved and those whereby field staff indicated the existence of challenges; and a good balance of boys and girls.

4) LIMITATIONS

The limited available time could have been of influence on the quality of this evaluation as we weren't able to visit project sites at random and had to resort to purposive selection of project sites. Decisions about field- and home visits were made in collaboration with the management team of the CBR program. Such decisions primarily considered factors such as available time, proximity of sites. However, ideally, we should have allowed for more visits – especially home visits – to have more in-depth reflections about the quality of CBR interventions. Now, a pragmatic selection of partner- and home visits was taken by the leadership of the CBR program in collaboration with Antoinette Termoshuizen and the evaluator. Given the short time available, we didn't visit the ideal number of partners and beneficiaries. We had preferred to see more children and talk with them as well as their parents . Overall, however, while we had hoped to have a selection process that probably was more objective of nature, the partners and beneficiaries visited, interviewed and observed offered a sound insight into successful and less successful aspects of the program

5) FINDINGS

In this section answers will be given to the evaluation questions which in principle focus on two vital aspects of the program:

1) The **effectiveness** of the program and will thus review how the program is being implemented, its strengths and its weaknesses.
2) The **sustainability** of the program and will review on one hand the top-down developments and involvement of government structures and systems and on the other hand the bottom-up developments (from) within the community as well.

In addition, the study also touched upon strategies and how useful the strategies happened to be. References to these strategies will be found throughout the report.

1.1 Outcomes

In this section answers about the outcomes of the program will be presented. However, clearly there is at times some overlap with other sections as well.

Findings will be presented which relate to the following evaluation questions:

1. Assess to what extent the CBR approach effectively reached its goal(s) and outcomes?
2. Determine the kind and extent of the outcome of the program on children and youngsters with disabilities and their families.
3. Assess the outcomes of the program on local communities and (strategic) stakeholders in these communities.
4. To what extent are the 5 CBR components addressed?

5.1.1 Effective outcomes in general

In Doulatpur with 8 unions and a population size of 427.913 people, a government population study found 5823 people with disabilities. In the 3 unions covered the following number of people with disabilities were found:

- Chokmirpur with 21161 inhabitants a total of 989 people with disabilities.
- Kolia with 20141 inhabitants a total of 795 people with with disabilities.
- Jionpur with 19123 inhabitants a total of 869 people with with disabilities.

In Ghior with 7 unions and a population of 146.293 people, the same government population study found 3547 people with disabilities. In the 4 unions covered the following number of people with disabilities were found:

- Ghior with 30288 inhabitants a total of 685 people with disabilities.
- Poyla with 18288 inhabitants a total of 683 people with disabilities.
- Sinjure with 19054 inhabitants a total of 421 with disabilities.
- Borotia with 22591 inhabitants a total of 537 people with disabilities.

The program which organically evolved during the past decade has been effective in working together with local Disabled Peoples Organisations (DPOs) and the Parent Platform which consists of very active and strong leaders which clearly have a mission in their life and are very well capable in achieving this. They are organised in 5 groups of each 20 parents. The Parent Platform is active in raising awareness at schools; it works with local authorities about acceptance of children with disabilities and helps parents in applying for Disability ID Cards (Golden Citizen Card) which is necessary in applying for a disability allowance and other safety net support. They are recognised by government, and they run a mobile library service to schools. All in all they are 'the voice of children with disabilities', largely operate as activists who lobby for acceptance and better services. In 5 years' time they want to be fully independent, they want to run a vocational training centre for children/youngsters with disabilities, and they want to run a special school for children with severe/multiple disabilities. They indicate that they need more training in inclusive education; they want more support in the rehabilitation of their children and are eager to have a training in how to run an organisation. The parents forum asked Niketan and others to financially support the development of the above-mentioned activities.

The Ghior Centre where 2 teachers work with 8 children with various forms of disabilities is a place where things are happening. Children as well as their mothers are active and come 3 days a week together in a small building where senso-motoric training is provided. The place is a place where one notices friendship; there is fun for both mothers and children and some mothers indicated that they see improvement in the lives of this children. All children receive a disability allowance of Tk 850 per months. The mothers have ambition and wish to have a similar place as there is at what they call the 'main campus'.

Through the CRCD (veranda schools) awareness about childhood disability and the importance of therapy and play in the development of the child is created. According to the staff this has led to increased acceptance of the child with (severe) disability. The CRCDs are providing (early) intervention/stimulation for the most vulnerable children in a quite unique and low-cost model of early intervention services.
Through the veranda schools model a number of children with disabilities are now included in mainstream schools.

Various vocational training opportunities for youth have been identified/provided for instance via vocational training provided by the Centre for the Rehabilitation of the Paralysed (CRP). However, the needs and demands in this life domain are ever-increasing and the management team of DRRA developed a proposal directed at livelihood opportunities.

The CBR program has been able to develop – as mentioned in an organic way - a vibrant network of (strategic) partners both public and private and realises that they cannot do without them. They also work with a substantial number of (120) of young volunteers and community groups as well (e.g. parent platform). This network is committed and of vital importance and instrumental to the success of the CBR program. Its further development – according to some of the interviewed stakeholders – could be an area that could be even more exploited.

5.1.2 Outcomes on children with disabilities, parents and families

A total of 8 children/youngsters with disabilities were visited i.e. 3 in Doulatpur and 5 in Ghior. Their personal stories can be found in Appendix 3. The overall findings are that children themselves as well as their (grand)parents and/or other relatives all show a lot of appreciation for the work done by DRRA. Confirmation of such opinions were given by the 8 fathers and 2 grandfathers who attended the fathers focus group discussion. The fathers rated the services provided by DRRA between a 7 and a 10 on a scale from 1 to 10 (1 being least satisfied; 10 being totally happy).

This CBR program clearly shows comprehensive outcomes in terms of improved quality of life of the child as well as the entire family. Quality of life was often expressed in terms of improved functioning for instance regarding communication skills but also concerning intellectual as well as motoric functioning. Beyond these specific quality of life domains the evaluation team noticed lots of improvement in terms of overall quality of life/wellbeing of the family. More specific indicators for such statements were made by caregivers (of interviewed children) and relate to economic empowerment, improved social acceptance and even security/safety (see stories Azim or Jannat).

The home visits as well as focus group discussions show that (grand) parents with severely disabled children (mostly those with CP or having an intellectual disability) are most worried about the future of their (grand) child and basically ask themselves – and us – the question *"What will happen with my (grand)child when we/I die?".*

The program shows to be very relevant for the direct beneficiaries i.e. children with disabilities, their (grand)parents and families at large. The program is in general of good quality. Access to good quality of assistive devices needs more attention but the evaluators realise that such devices for instance good quality paediatric wheelchairs are hardly available and if available can only be purchased at high costs. In terms of the quality of physiotherapy some critical remarks could also be given. The role of passive exercises/stretching– as noticed on a number of occasions- is not only questionable but should as much as possible be avoided. While the literature is not in full agreement about the role of doing such exercises the overall view is that functional therapy is the preferred approach and only in occasional situation there is role of slow carefully executed passive movements to prevent contractures. The physiotherapy technicians with relatively little training do however a remarkable job in challenging conditions (e.g. at the veranda or in small therapy rooms).

The program is effective until the moment the beneficiaries are adolescents who become adults. While initiatives in the area of vocational training, employment and income generating activities are happening a number of youngsters interviewed struggle with leading a meaningful life and worry about their own future in terms of independence/autonomy often combined with worries about relationships/marriage. Such worries are often the concerns of (grand)parents as well. See for instance the stories from Alpona and Azim (Appendix 3). For grandparents who realise that their grandchild has been abandoned by her/his parents this concern is even more pressing.

Economic development/improvement was often indicated as of great importance. On various occasions beneficiaries provided evidence that the one goat or van given to their family helped them greatly to improving their quality of life.

5.1.3 Engagement of mainstream government and private structures/services

The program as stated is limited to 2 subdistricts: 1) Doulatpur where 3 out of the 8 unions but unions are covered is thus not yet fully covered and 2) the same applies for Ghior where 4 out of the 7 unions are covered. Altogether in these 2 subdistricts 8 unions are not yet covered.

The program has been able to develop a vibrant, strong and highly motivated network of (strategic) partners both public and private and realises that they cannot do without them. The team of DRRA work with a substantial number of (120) volunteers and several community groups as well (e.g. the parent platform).

Various strategic stakeholders in this program - i.e. local government at various administrative levels – became involved in realizing the inclusion of children/youngsters with disabilities within mainstream developments and programs. Examples of such involvement are the inclusion of children with (physical) disabilities in local schools (in part because there is a national inclusive education policy but in reality, mainly as a result of the effective collaboration between DRRA with local authorities as well as school management and teachers. Another example is the relationship in the health domain whereby DRRA works very well with local community health centres (public services) and pharmacists (private) in identifying children with disabilities, referring them to services provide by DRRA partners including for instance good quality collaboration with the district level health centre or hospital in Doulatpur. The community health care centre sees at average 60 to 70 children with disabilities (old and new cases) and referred to them DRRA for therapy or admission at a veranda school. The most frequent conditions seen at the community health care centre are CP, physical and intellectual disabilities. They maintain a general register; however, no specific registration related to disability takes place. Probing for their possible role in early identification didn't give much insight into a pertinent role for health care centres in this field. This may be an important area of work to further explore and set up a system whereby on a routine basis developmental delays and disorders are being screened while children come for growth monitoring and immunisation.

The CBR program works with a large and diverse network of stakeholders (see Figure X, Appendix 4) and while on paper this already looks promising visiting the field and having various discussions one observes that the network is essential and vibrant. Visits were paid to a local community health centre, a pharmacist a local primary school, the Parent Platform, community leaders, local authorities, social workers, religious leaders. Discussions were held with volunteers and a group of fathers.

Specific community-based activities were visited such as the Veranda Schools (CRCD), and a 'Right to Decide' training for young girls. In a discussion with 3 young women who recently had followed this training the women indicated that the training was very important to them as much of the content of the training was new to them. It helped them in knowing and understanding their bodies much better. It helped them to prevent themselves from sexual harassment and defend themselves as well. One of the 3 women was left by her husband after 5 months of marriage because of her disability. She reported the case to the police and the man was punished with paying a fine. She now lives on her own and so far, seems to be happy.

Unfortunately no training of parents - where existing training videos are being used was attended.

5.1.4 The 5 CBR components

The previous section gives already a clear indication that there is a strong and effective network. This network has and is pretty fundamental in this evolving CBR program as DRRA is a relatively small organisation with a small number of staff who never could provide all services that are now provided in the 7 subdistrict. The multisectoral network is at the core of the success of the CBR program and encompasses basically all domains. As stated, the livelihood domain could be strengthened, and this is much in line with proposal being made for vocational training and income generating activities.

5.2 Effective Partnership Networks

1. Review the current (local) partner networks and review if the networks are functional i.e. if stakeholders sufficiently involved in the development and operations of the program.
2. To what extent are local authorities involved?

These 2 questions are already adequately answered in the previous sections. We therefor don't want to elaborate further on the findings other than stating and repeating that the partner network is essential and well-functioning. Maybe one remark regarding the involvement and collaboration with the local authorities. One of the stakeholders who participated in the validation session – someone representing local government - stressed that in her opinion there was ample room for improvement and even more collaboration.

5.3 Critical (success) Factors

1. Determine the critical success factors and those that may have (had) a negative influence on the development of CBR.
2. What activities undertaken with what kind of materials and do these effectively contribute to the achievement of the CBR goals?
3. What are the lessons learned to influence the different phases of CBR development positively?
4. Which part of the program was most effective for (the families of) a child with a disability?

5.3.1 Critical success factors

The CBR project coordinator, Dalima Rahman, and Nizam Uddin, the project manager are highly committed persons with the right attitude and passion. They are knowledgeable and managed to develop a large network in the various communities with (strategic) stakeholders who appreciate and respect them a lot. The community at large and in particular children with disabilities and their caregivers and larger family like them a lot. They are truly the backbones of the program. Without them there wasn't such a good program.

Another success factor is the extensive and vital network that exists, and which developed over the years in an organic way. This is a network of public facilities in the health (clinics and hospital) and education (schools) domains in particular. Linkages with local authorities are strong as well. Next to the public sector there are also important private service providers such pharmacists that play an important role in the timely identification and referral of children with disabilities to either health centres/hospitals or to DRRA.

While high lightening these 2 factors it should be obvious that what is done in the field is supported by many more people. In the first place the community-based ones (the community development organisers, and social worker) but they cannot do without the office staff as well as the workshop staff

making good quality standing frames. Last but not least the physiotherapy technicians are playing their role in more clinical work either in the hospital or in the community with services provided at the veranda schools. What we noticed is true teamwork which is well-managed by Nizam Uddin; someone with right background, commitment and a strong focus on the community.

5.3.2 Effective activities.

Much has been stated already about effectiveness. While effectiveness in terms of improved quality of life is formed by a combination of services and activities some specific services/activities are more essential. The most essential and effective activities are:

- The attention given to individual children through home visits whereby the needs of the child are central, without forgetting the fact that the child lives in a family and that often the family needs support in order to be able to support their child with disability better/best. While this is much in line with contemporary approaches towards the care for children with disabilities the evidence shown in this program supports the existing theory. The evaluation team clearly feels that the family-centred focus is strong and effective!
- Another theoretical concept at the core of CBR is the multisectoral collaboration as one of the main principles of CBR. More than in any other program evaluated this has been shown to be effective and of essential importance. The CBR program is several times more valuable than what DRRA is doing on its own.

5.3.3 Lessons learned to influence different phases of CBR development

The past

The identification of children with disabilities is of importance. Time and again evidence was given about the importance of the surveys that took place during the initial stages of the program in the villages. CBR is not about that one child with a disability receiving therapy and other services. CBR is about identifying all children (and adults) with disabilities in a certain catchment area and providing services for and with them irrespective age, gender, type and extent of disability.

The present day

The importance of the network is vitally important as this will lead to the much-required system change! To enhance that system change it becomes important to step up local and national advocacy efforts. It becomes urgent for national government to become serious about the delivery and financing of community-based services. Financing institutional rehabilitation services such as is done with the expansion of CRP services is great and necessary, but DRRA/Niketan have a case to make that with relatively little funds but with a commitment from a community network much can be achieved at most likely a fraction of the costs of more institutional care/rehabilitation. For DRRA/Niketan which are working at the grassroot level and focusing on doing something instead of talking the effective networking done in the 7 subdistricts together with the track record of offering tangible and effective services it becomes time to look for new ways that lead to sustainable development and expansion of services and thus becoming more meaningful for more people.

The future

Given the mandate of DRRA and Niketan it is logic that the focus during the past decade has been on children. However, in order to become essential to all in society one should seek possibilities to respond to the needs of those adults with disabilities as well. This of course is only possible if there is funding or if there are partners who have a broader or another mandate than DRRA/Niketan. In order to become efficient in running a comprehensive CBR program it is almost obvious to not concentrate on children only. Considering its sustainability and relevance (children become adults too) it would be useful to explore avenues of incorporating adults in programs as well.

5.4 Scaling up Opportunities and Sustainability

1. What are the Strengths, Weaknesses, Opportunities and Threats for replicating and scaling up this approach?
2. How well are the veranda schools which are now managed by parents and/or/volunteers are sustainable and what are critical factors that led to a well-functioning management of these veranda schools?
3. What is the likelihood of continuation and sustainability of outcomes and benefits after completion of outside support?

Replicating/Scaling up

The s**trengths** of the program have been well-explained in the previous sections. We keep our comments therefore to weaknesses, opportunities and threats.

With regards to **weaknesses** we observed the following:

- Regarding therapy provided to children with cerebral palsy we notice that passive exercises still play a too large role in therapy. It is only in exceptional cases that passive exercises can play a postie role in the prevention of contractures but in such cases, they should be given in a very careful way.
- The quality of assistive devices especially the absence of quality (paediatric) wheelchairs is a concern. Wheelchairs for some children are essential in terms of their independence and mobility (See story of Fahima in Appendix 3).
- Regarding inclusive education we notice that there is a national policy; that schools compulsory should admit children with disabilities but that the reality is that teachers are not trained to work with children who are deaf or hard of hearing, children who are blind or have low vision let alone children with intellectual or behavioural disabilities. We also notice the lack of accessible toilets for children with physical disabilities. The reality is that schools only admit children with physical disabilities.
- The number of field staff of DRRA with a robust CBR background is very small and largely depends on Dalima Rahman. While her commitment and qualities are a strength at the same time her pivotal role makes also that the program is very vulnerable too.

Opportunities are formed by the fact that the national government is investing in rehabilitation services (especially CRP seems to be benefitting from this); that there is an inclusive education policy and that there are thus opportunities for successful lobby/advocacy. DRRA more than any other (large) NGO is in our view able to lobby for stronger government involvement and/or funding in Manikgonj.

DRRA/Niketan has a tangible ad successful CBR program, and we strongly advise to disseminate that information on a large scale in professional journals etc.

Given the earlier remark about among teachers to work with children with disabilities other than physical ones and at the same time the existing expertise which exists within DRRA concerning the development of children with intellectual and multiple disabilities it may be worthwhile to discuss opportunities to play an even more pertinent role in education i.e. training teachers in working with such children.

Threats are formed by the fact that this CBR program is much dependant on foreign funding via Niketan. Niketan should ask themselves how long they can and will continue funding this program want what are means there are to make the program (more) sustainable. Sustainability as well as the need to scaling up the program require a serious involvement of government. After 25 years of successful working in this field and after almost one decade of developing this model of CBR it is urgent to promote this model and step-up initiative to effectively lobby national government.

Sustainability and scaling up veranda schools

The veranda schools became a household name and flourished because of the high level of community participation. Staff, parents and communities at large are all extremely positive about the veranda schools. It is robust model that finds its strength in the active participation of community members who responded positive to make their compounds and verandas available as a place for children with disabilities to enjoy themselves; to have fun; to make friends and to learn and develop. The veranda schools are also place where therapy is provided by motivated physiotherapy technologists.

The veranda schools are prospering because of stakeholders' involvement and enthusiasm. These are places where the many volunteers, parents and DRRA staff set an example of a model learning environment at minimal costs and thus with continued interest of those people a model that is feasible and can be sustainable. Given the voluntarily involvement of owners of compounds one needs continuously invest in relationships.

Another strong point of the veranda schools is that the services provided in those school is very accessible though many parents wish that more days a week these services would be available.

How to ensure that the veranda schools become sustainable depends largely on the answer to the question how well the entire CBR program can become sustainable. In our view the 1) vibrant network and 2) firm partnerships form a strong element in terms of **institutional sustainability**.

There is furthermore a 3) high level of acceptance, 4) recognition of the impact of the program on children with disabilities and their families, as well as 5) community mobilisation with active community groups in the program which are essential aspects in terms of its **social sustainability.**

The management team of the CBR programme is a small highly dedicated team strongly believing in the CBR model that they are developing. They may need to understand far more the importance of ensuring that there should be a sound balance between service delivery on one hand and the

development of a sustainable public CBR system on the other hand. The latter would mean that far more attention needs to be given to research (showing the impact of a successful program) and advocacy (based on the fact that there is a robust program which makes difference in the lives of children with disabilities and their families).

The **organisational sustainability** was measured with the (adapted) 5C tool and scored basically at all domains with remarkably high scores. The capability of the core team to 1) commit and engage, 2) to deliver, 3) to adapt and self-renew, 4) the capability of the core team to relate and attract resources and support for the CBR program, and 5) to use key principles, balance and coherence scored with averages of a 4 out of 5.

There were two exceptions: 1) the extent to which the supporters and stakeholders in the community see the core team as doing things it is expected to do scored a 3 out of 5 and 2) the extent to which there is a clear relation between the vision of the core team about CBR and what actually is being done scored also a 3 out of 5.

A surprise to us was the fact that the core team scored a 4 out of 5 concerning the extent to which they are able to ensure that there is government funding and other sources of funding for CBR and/or inclusive development activities. With some probing the remark was made that 'we are trying" and that approximately 10% of activities were funded by government. This however includes also the expenses related to for instance disability allowances (see also the next paragraph for more detailed information concerning financial sustainability.

Based on the results of the 5C tool one easily gets the impression that all goes well in terms of organisational sustainability. If more time would have been available for critical probing the scores may have been lower than the ones given by the team.

Financial sustainability of the program is at stake. If donor support stops the program will seriously suffer and possibly will continue doing the things that have been done so far but at lower quality and reduced scope and won't be able to further build a system that is viable and that ultimately can and will be continued by government. To us that is where ultimately the **financial sustainability** needs to be found: an embedment of the CBR program within the mainstream of service delivery of all involved government sectors. The challenge though is that all major/strategic governmental stakeholders are faced with limited budgets. Even DRRA is struggling with its finances. Some of the staff informed us that they struggle with their low salaries and high costs for transport and current price hikes in the country of even the most essential expenses. The way DRRA/Niketan developed the CBR program which is great (see earlier). However, while it is a noteworthy development it is the opinion of the evaluator that (financial) sustainability only can be achieved if government structures are increasingly taking over expenses for CBR (development). It therefor seems to be timely to start a debate among all stakeholders how best this can be realised and in which timeframe. DRRA/Niketan may argue that what they do with this community service is part of their responsibility and that is fine. However, ultimately it is and should be government that has an obligation to ensure that public services including access to rehabilitation services become available and accessible to every citizen and not only to the lucky ones belonging to the 7 subdistricts in Manikgonj.

5.4.3 Sustainability of outcomes and benefits after completion of outside support

It is in our view a misconception to think that the CBR program is ever completed. New children with disabilities are born and disabilities will occur among other children due to diseases or accidents. So, a CBR program needs to continue and become part and parcel of preferably public services. It is logic for such a sustainable development to use the same typical principles as observed in the DRRA/Niketan CBR program i.e. multisectoral collaboration, high level of community participation, empowerment and (self)advocacy.

6) CONCLUSIONS

2) The CBR program which is managed by highly motivated DRRA team in Manikgonj with tremendous support by Niketan and has in a period of almost one decade been able to develop a well-established and comprehensive CBR program. This program evolved in an organic way and covers in general all CBR domains.

3) The process of identifying children with disabilities through a simple survey to identify children with disabilities which takes place at the start of CBR in villages is a strong element in the program.

4) In terms of **its effectiveness** the following can be concluded:
    a. DRRA delivers good quality comprehensive services that are much appreciated by parents and society at large.
    b. The veranda schools are well-established, much appreciated, and this concept has become a household name. They are successful because of high levels of community participation.
    c. Wheelchairs are often not in good condition nor appropriate or at times not available while they could be great help in terms of mobility and independence.
    d. Physiotherapy technicians still make use of passive stretching exercises while the effectiveness of such activities is very controversial. This is done in spite of training received in the past. The instruction videos also present a functional approach.
    e. There is a need for vocational training and income generating activities for youngsters with disabilities. Rather than organising this oneself DRRA/Niketan would be smart if they make optimally use of existing vocational training opportunities such as the ones offered by CRP.

5) Concerning **critical success factors** the evaluators conclude that:
    a. The DRRA team is highly motivated.
    b. The leadership has sound CBR knowledge.
    c. The combined child and family-focus is excellent and is one of the key success factors of the CBR program.
    d. The existing partnership network with both public and private partners is essential in ‘doing CBR’.

6) In terms of its **sustainability** the evaluators come to the following conclusions:
    a. There is a strong and vibrant network, but it could even become stronger and is willing to become more involved.
    b. There are opportunities to work even more closely with the hospital in Doulatpur where there is now an orthopaedic surgeon.
    c. The DRRA CBR program in Manikgonj is much dependent on Niketan (funding). Government funding adds up to max. 10% of all investments in childhood disability in Manikgonj according to the management team and includes disability allowances.
    d. For the CBR program to continue and become (financially) sustainable it should ultimately become part of existing public services. However, it is clear that for the time being this is a dream which may only become reality if government will recognise that their efforts in providing services to people with disabilities can in the foreseeable future not be achieved without community based rehabilitation and the employment of a grassroots rehabilitation cadre.

7) There are some concerns that require refection and possible action i.e:
    a. Many (grand-)parents struggle with the knowledge that they may (soon) die which mean that their (grand-)child won't have a caregiver anymore.
    b. Parents indicate that they don't have toys – such as those that are available at the therapy rooms - at home.
    c. The Parent Platform, fathers and staff indicate the urgent need to pay attention to the livelihood needs of youth/adolescents. Such efforts means that children with disabilities are becoming am asset in the family instead of being a (financial) burden.
    a. The Parent Platform wishes to 1) run a vocational training centre for children/youngsters with disabilities, and 2) to run a special school for children with severe/multiple disabilities. While these desires are understandable the costs related to such developments are serious and besides the large initial investment one needs to be made aware that running costs will become an annual burden as long as government is not paying such expenses. It is therefore much better to refer children/youngsters with disabilities to already existing vocational centres. A lobby by DRRA, the Parent Platform and where possible other influential stakeholders for adequate training of teachers in working with children with special needs seems to be essential. However, such a lobby will not soon in timely developments. Therefore it may be appropriate for DRRA/Niketan to build themselves capacity of teachers in working with children with intellectual, behavioural and multiple disabilities.

8) Regarding existing government policies we observe that schools struggle with children with some type of disabilities as teachers don't have the right competences (see also point 7d). There is an inclusive education policy. However, implementation is poor because some essential conditions are not in place with the most urgent one the fact that teacher lack training in effectively working with the needs of children with hearing, visual, intellectual and behavioural disabilities.
    a. We discussed on a number of occasions the use of indicators to measure success in the inclusive classroom and recognise 3 different levels of which – in the absence of

proper training of teachers the at best *presence in classroom* can be observed for children with disabilities other than physical disabilities. (nice window dressing…).

b. A more useful indicator would be the level of *participation in class* (which is already much better but not enough to measure success!).
c. Ultimately, we wish to see that children are *performing* but that seems to be out of reach with the current capacity of teachers in Manikgonj.

9) There is still a need for further training of some categories of staff or stakeholders.
    a. The staff of the community clinic is eager in receiving more training on disability. They face situations whereby the need more in-depth knowledge.

7) RECOMMENDATIONS

On basis of the above findings and conclusions the evaluators wish to make a selected number of recommendations to the management team of DRRA and Niketan.

4) Concerning **scaling up** we wished to advise to expand the CBR program to more unions. Given the fact that this largely depends on additional funding that in our view should come from government - which is unlikely to happen in the near future - we strongly advise to consolidate current work in the 7 unions.
    a. Extraordinary efforts should be made to attract public /government funds for the long-term continuation of the current programme.
    b. Scaling up should only take place if government becomes much more involved and in the long run becomes responsible for financing essential activities in the program.
    c. If a decision in future is being made for expansion, it also means that at least one other CBR fieldworker (equal to the role of Dalima) needs to be appointed.
    d. If new unions or more villages will be covered it is advised to always start with a 'quick and dirty' survey in order to identify most children with disabilities.

5) About Capacity Building

a. DRRA should start/step up lobby efforts for short but robust training programs for teachers of primary schools in handling the child with specific disabilities. An alternative may be the development of an annually to be offered Summer School which focusing on upgrading the capacity of teachers in working with children with special needs.
b. Organize a toymaking workshop for parents.
c. Continue to invest in training of partners e.g. in early identification for staff community clinic and leadership and organisational development training of the Parent Platform.
d. Invest in continuing education/training in which field staff such as the community development coordinator learn specific competences on the job . Training in lobby and advocacy as well as sensitization seem to be of importance. The community

development organiser will benefit from training in working with children with intellectual disability.

e. Volunteers indicated that they will more in-depth training related to disabilities.

6) Concerning the quality of rehabilitation interventions

a. Seek options to adapt homes (e.g. with ramps), toilets (of schools) and use community people in making such adaptations.

b. Lobby for better paediatric wheelchairs. Shonaquip South Africa has a great name; Farida is already in contact with them and organisations such as CRP may wish to form an alliance with them i.e. a consortium with Shonaquip, CRP and DRRA could form a strong consortium as they have mutual interests in providing high quality paediatric mobility devices such as buggies and wheelchairs. Similar consortia have been formed in other countries and have been successfully in developing a local industry for such assistive technology. Given the current global attention for such developments successful fundraising may very well be possible.

c. Develop and introduce more entertaining and effective forms of awareness raising e.g. drama and puppetry which fits much the local (traditional) context or make use of the very simple and no costs methods such as the so-called Game of Life.

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- The staff of all stakeholders who we visited; and talked with their welcoming attitude, and for their engagement in at times critical discussions.
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- Niketan and in particular Antoinette Termoshuizen for ensuring proper preparations.
- Last but not least the children, (grand)parents of children who gave their time and were willing to openly talk about their challenges, concerns, hopes and dreams.

APPENDICES

Appendix 1: Manikgonj District in Bangladesh

Appendix 2: Sub-Districts Manikgonj

Appendix 3) Home Visits

Visit 1: Alpona Akter

Alpona Aker is an 18-year-old young woman. She is hemiplegic (right side) as part of Cerebral Palsy. She was identified by DRRA during a survey which took place 10 years ago in her village Boinna, Jionpur, Doulatpur in Mainkgonj). During that survey 18 children with disabilities were identified. Alpona lives with her father and mother, and other relatives.

Alpona and her parents indicated that she improved a lot over the years. She is now able to walk independent; able to take care of herself (dressing, bathing etc) and she tries to help in the household. She likes to clean the house but finds it more challenging to help with cooking because of the limited right-hand function. Alpona went to the local elementary school which she finished but due to her disability and the long distance to secondary school she was unable to continue her studies. She feels well-accepted by society and attends social events which are close to her home. She however feels depressed because of looniness and boredom and she feels that she is a burden to her family. She wished she could be involved in income generating activities. She got training in sexual and reproductive health rights (SRHR). Her parents worry about her marriage prospects and indicate that they wonder what will happen to her in the future.

The family is very thankful to DRRA for all support they received in the past. DRRA helped them to improve their quality of life in several ways. They got a cow which gave them young cows; they were helped in building a house; purchase land and now the father is a farmer instead of a daily labourer.

Considerations

- This is an excellent 'case' to illustrate that in CBR one should focus not only on the child with a disability in terms of functionality and quality of life. Instead, one should see the child with a disability in her (poor) context and try to improve the living conditions and thus the quality of life of the entire family.
- Children become adults and CBR should be offered from that perspective even when the mandate of an organisation is limited to children only. It means for instance preparation for adulthood as was done with the SRHR training. It also means attention for the loneliness and boredom. As Alpona literate it may be more reading for her to read books than watching all day TV. Are there possibilities to help Alpona with work? Maybe offer vocational training for tasks that she likes and help her inn setting up an income generating project. Opening small petty shop may be an option too. Still there is that concern from her parents and herself about her future. Should the project think about ways to help her and others to meet youngsters?

Visit 2: Nasrin Akter

Nasrin is a 16-year-old bright girl with severe physical disability as a result of cerebral palsy. She can walk. She is unable to talk but communicates well with gestures and is able to lipread. She lives with her maternal grandmother for almost her entire life. Her parents divorced when she was 1 year of age, both got married again but abandoned their daughter. She helps her grandmother with some cleaning tasks in the house though it is very difficult for her.

The grandmother gets an old-age allowance and Nasrin a disability allowance. Besides, the grandmother owns land which is being cultivated by local labourers which she hires. The live in a house which is in a reasonable condition.

DRRA provided throughout the year physiotherapy support and as a result Nasrin is now able to walk. She followed also the SRHR training. DRRA with financial support of Niketan provided the family during Covid-19 time an amount of Tk7,500.

At the age of 13 years she was raped by someone from the village. While her grandmother and other wished to keep quiet about this Nasrin herself made it known and reported this to the Domestic Violence Committee. This committee referred the case to the Social Protection Council and the perpetrator was found guilty and physically punished and had to pay a fine of Tk 1,50,000 (one Lac fifteen thousand) which has been deposited in a bank account on name of Nasrin.

The grandmother is at least 70 years old and looking depressed and tired and extremely worried about the future of her grandchild. Nasrin indicates that she wants to live with Dalima the CBR worker.

Considerations

It is obvious that the future of Nasrin is bleak. Who will take care of her when her grandmother dies. She shouldn't expect much from her parents and in fact she indicated that she doesn't want to stay with her mother. The only answer to this questions seems to be the need for residential facilities for those children/youngsters who are left on their own for whatever reason. The story of Nasrim is a such not unique as it is also the story of Alpona and Azim. While the answer is obvious, to making this reality is something else and decisions to raise funds for such a facility need to be taken carefully. The short to medium term results of lobby to government (Ministry of Social Affairs) are also very uncertain.

Visit 3: Azim Uddim

Azim is a 22-year-old young men being paralysed as a result of a spinal cord injury due to an accident at the age of 10 years. He fell from a bridge. He is paraplegic and uses a wheelchair. He has no bladder control. He has bowel control but he toilet is too far from his home and not accessible. At times he suffers from bedsores. The standard foldable wheelchair which he is using is not in a too good condition and for a person with spinal cord injury not the ideal wheelchair. No proper backrest and footrests are absent too. The upholstery is in a bead condition. The castors are not appropriate for the road conditions and while walking the road we wondered how one could ever drive in a wheelchair on such roads.

He used live with his mother near the river, but their house got flooded and now – thanks to the lobby of DRRA to the Upazilla chief - they are since the year 2022 renting a house. They don't own land.

He didn't go to school but can count. He is a self-made artist: making wooden toys and other pieces of art. DRRA organised a carpentry toolbox and sewing machine. Niketan provided a goat (which now is pregnant) and carpentry equipment.

The mother of Azim – having serious goitre for which she never consulted a medical doctor - is very worried about the future of her son. She wonders what will happen when she dies; will he be able to stay on how own; will he be able to ever marry someone?

Considerations

All support given by Niketan is great and was necessary. The next questions are however:

- How can Azim become engaged in an income generating project? His current artistic skills are not of such quality that there is a market for the products he is making. If he will be able to generate income his marriage prospects may increase. Would it be possible to start in this village a sort of a club where the many young people that have been identified years ago during the survey can meet each other; become friends and build relationships or better does such a place exists in the village where other youngest meet each other?
- What can be done to make life easier/better for both the mother and her son in terms of selfcare/hygiene? A commode could in part alleviate the burden which there is now.

Visit 4: Marufa Akter

Marufa is a 17-year-old girl. At the age of 9 months she got high fever and most likely as a result of meningitis developed CP. She developed epilepsy and had serious issues with gross motor development due to hemiplegia. DRRA got to know her 10 years ago and provided physiotherapy, an Ankle-Knee Orthosis (AFO); parallel bars were made at her home so that she could regular exercise.

Now she is able to walk although with serious difficulties. She walks on flipflops and indicated that it is better than walking with the AFO which she used in the past. She is attending the local high school (class 10) and hopes to continue education at a college to study humanities. The college is situated at 3 km from her home. and she will stay in a nearby village. After her studies she prefers to work with children/people with disabilities and hopes to get a job with DRRA. She has a neatly organised room for herself in a poor-quality house. DRRA helped the family in several ways: providing a goat, a van and during Covid-19 helped them with cash (Tk7500), food parcels, blankets and sweaters.

DRRA helped Marufa to set up a small petty shop, but she sold a while ago everything because money was needed. In fact, the goat and van were sold as well.

Marufa attended various DRRA trainings i.e. training about handling money, training in leadership and SRHR training. She learnt from the latter about fertility, safety and protection and got knowledge about menstruation.

Considerations

Refer to an orthopaedic surgeon in the nearby situated hospital for an assessment and possible Achilles tendon lengthening surgery. Such surgery should be done in a specialised hospital in Dhaka. She however needs to be motivated for this because it will mean that she requires physiotherapy for a while (and she indicates that it is difficult for her to get treatment from a male physiotherapist) lifelong, she needs to use an AFO and walk on (better) shoes.

Visit 5: Jannat Ara

Jannat is a n 8-year-old girl with CP. And lives with her brother and parents in a house from corrugated iron on rented land. Previously they had their own house and land close to the river, but the house was washed away during a flood.

Jannat is a shy girl; she communicates with her parents but not with strangers. Her speech is impaired, and she slightly drools. Her parents discovered at the age of 8 months that she couldn't sit and had no head control. A neighbour referred them to the veranda school and DRRA helped with physiotherapy, parallel bars and a walker. She greatly improved as she is now walking independent. She is brushing her teeth but not properly; she cannot wash herself; she can dress herself; she eats/drinks on her own. She indicates when she needs to go to the toilet. She is not attending school except for the veranda school once per week.

The mother hopes that the child will further improve and eventually will marry. Probing about play and the importance of it for development the mother states that she doesn’t have time for it. The parents are hard workers and work on the land and take care of their cows. Other children from the neighbourhood play with her.

DRRA provide a goat which delivered 4 small ones. They also received family development/care training; goat training; and financial support during Covid-19. Their quality of life greatly improved. They owe 3 cows, a motorbike and are very happy with the way they are living.

Jannat continues to attend the veranda school where she is stimulated in her development. Attention is given to ADL and the mother received caregivers training. They hope for possibilities for Jannat to get more training.

Visit 6: Jahidul Islam

Jahidul Islam is an 8-year-old boy with Downs Syndrome who has been abandoned by his mother and father at the age of 1 year. The parents of the mother take care of him and especially the 75-year-old grandfather has a very close relationship with him. The grandparents have 3 sons and 1 daughter the mother of Islam but don’t have contact with her anymore.

Islam is a happy boy. The grandparents are very worried about the future of Islam . “who will take care of Islam?’ is their biggest concern as they are not yest sure if one of their sons will do this.

Islam goes to CRCD and learn there many things. DRRA provide a goat, Covid-19 funds, seeds and helped in getting a disability allowance. The feel that he starts talking better and more. He can brush his teeth.

Visit 7: Fahima

Fahima is a 9-year-old girl with hydrocephalus living in a family with 4 children. She was born at home but after 6 weeks it became clear that she had hydrocephalus . She went to hospital and a shunt was placed.

She is a lively girl; attending the CRCD at the age of 6 months. Five months later she went to hospital in Dhaka. Intellectually she seems to do reasonably well; she is eating on her own; has not problems with incontinence; now her head balance is fine as is the way she is sitting. A DRRA- made standing frame if used frequently. She indicates herself when getting tired or when it hurts. She is not able to stand independent. The special corner sheet which came from CRP is now broken but also not needed anymore. The CRCD (Veranda School) is based at her parents' compound.

The support given by DRRA is comprehensive and varies from the appliances to surgery and physiotherapy ; from Covid-19 funds and blankets and sweaters to assistance in getting a disability allowance.

Comment:

While rightfully attention is given to the importance of mobility (and the use of the standing frame is for many reasons fine) we wonder in how far it may be useful to organise a paediatric wheelchair for her. The compound where she lives is clean and flat and a wheelchair will greatly improve her mobility around the house as well as her independence.

Visit 8: Shawkot

Shawkot is a 16-year-old boy who lives with his father, mother and grandmother. With the exception of the grandmother all other family members have an intellectual disability. Shawkot is known by the DRRA team since he was a baby. While not having been able to offer Shawkot much help in his development DRRA provides quite some support to the family at large. They got a goat which got several young ones over time. They were helped in getting disability grants, Covid-19 allowance of Tk 7,500, blankets and sweaters during the winter.

Shawkot takes care of the goats and occasionally he works on the land of others as a daily labourer. HE also helps his grandmother with tasks in and around the house. Shawkot wants to marry but it is unlikely that this will take place because of his disability and his inability to live independent. He has no friends and prefers to be with older people. Shawkot is about to handle money; at least he recognises the value of notes but is not able to count.

The grandmother is worried about the future as she knows very well that the 3 other members of the household won't be able to live independent.

Appendix 4) Stakeholder mapping