



# Community Centre Based Care and Education for Children with Neuro Developmental Disability

Experience from BRAC



Utpal Mallick

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July 2016

BRAC Research and Evaluation Division

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## CONTENTS

Acknowledgement

Abbreviations

Abstract

**01** Introduction

**05** Methodology

**09** Findings

09 Management strategies

17 Services provided: inside the centres

23 Services provided: outside the centres

27 Changes NDD centres made

35 Challenges in providing services

41 Stakeholder's thoughts on service provisions

45 Expectation of families, teachers and other staffs

**49** Discussion

**53** Conclusion and recommendations

**56** References



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## ABBREVIATIONS

AI	Apasen International
BEP	BRAC Education Programme
BPS	BRAC Primary Schools
BSMMU	Bangabandu Sheikh Mujib Medical University
CAMPE	Campaign for Popular Education
CDD	Centre for Disability in Development
CNAC	Centre for Neurodevelopment and Autism in Children
CP	Cerebral Palsy
CRC	Convention on the Rights of the Child
CSN	Children with Special Needs
DSS	Department of Social Service
FGD	Focus Group Discussions
GAIN	Global Alliance for Improved Nutrition
HNPP	Health, Nutrition & Population Programme
ID	Intellectual Disability
IDI	In-depth interviews
IEP	Individualized Education Plan
IPNA	Institute of Paediatric Neurology and Autism
MAM	Multi-agency Meeting
NASPD	National Association of Sports for the Person with Disability
NDD	Neuro Developmental Disability
PECE	Primary Education Completion Examination
PO	Programme Organizer
PWDs	People with Disabilities
SAHIC	Society for Assistance to Hearing Impaired Children
SS	Sector Specialist
TLM	Teaching-Learning Material

## ABSTRACT

Since its inception, BRAC Education Programme (BEP) has been including children with disabilities in its various educational initiatives. To foster this inclusion initiative BEP developed Children with Special Needs (CSN) unit in 2003. From 2014 this unit launched Neuro Developmental Disability (NDD) centres for poor communities in Bangladesh in cooperation with Health, Nutrition & Population Programme (HNPP) of BRAC. Till June 2015, four centres were established; one in a slum in Dhaka city and three others in Pabna, Khulna and Gazipur districts. Preparation of opening another centre in Sylhet district is in progress.

As this is relatively a recent initiative of BRAC, this research study was done to document and analyze its processes, outcomes, problems and solutions. Overall aim of this study was to explore in detail about these centres including strategies taken, successes achieved, challenges faced and scope of further improvement in operation. Qualitative research design was followed as the study intended to document entire development of the centres from the perspectives of policy and personnel, lives of the children and their families and communities. The study involved review of programme documents (e.g. policies, curriculum, materials etc.), repetitive nonparticipant observations of the centres combined with semi-structured interview and focus group discussions (FGDs) with a range of stakeholders including children, parents, teachers and other officials from BRAC.

Findings indicated positive learning outcomes of children with disabilities and the joy of having a school like centre for them, changing attitudes and perceptions of families and communities regarding disability and a genuine goodwill among most staffs involved. Certain problems were also voiced. Some concerns were expressed over limited resources in the centres, problem with transportation of children, inadequate medical support including therapies, lack of intrinsic motivation of teachers and caregivers for poor honorarium and so on. Major area of expressed concern was the need for intensive training of teachers and other staffs and the need for a more structured approach. Curricular and other activities for children could be improved if appropriate activities were implemented by the teachers even in such resource constraint situations. Based on these analyses, some recommendations for advancing growth of these centres have been made. It is hoped that this report will provide useful information for better implementation of the NDD centres.

**Key Words:** Community Centre, Children, Neuro Developmental Disability, BRAC



# INTRODUCTION

# INTRODUCTION

## Background

The government of Bangladesh was among the first countries to ratify the United Nation's "Convention on the Rights of the Child (CRC)" in 3 August 1990. Bangladesh is committed for proper implementation of CRC. Article 23 of the convention states that children with disabilities should have right to special care and assistance to ensure their fullest possible inclusion in development (The United Nations, 1989, art. 23). Article 28 states child's right to education on the basis of equal opportunity (The United Nations, 1989, art. 28). Khan and Anisuzzaman (2011) conducted a country study for Campaign for Popular Education (CAMPE) to see the status of un-served children in education. They found that access to education of children with disabilities is extremely limited. According to them Bangladesh has about 1.6 million children with disabilities within the primary school-going age and the total number of children among them enrolled in special and integrated education programmes is estimated to be 5,000. UNICEF (2014) conducted a situation analysis on children with disabilities in Bangladesh which reported that government has not given enough consideration to the rights of children with disabilities and they are not yet fully recognized in mainstream development plans.

In recent years substantial efforts were made in Bangladesh to change laws and policies to properly include children with autism and neurodevelopmental disabilities. In July 2010, government initiated the first Centre for Neurodevelopment and Autism in Children (CNAC) on the premises of Bangabandhu Sheikh Mujib Medical University (BSMMU). CNAC is now known as the Institute of Paediatric Neurology and Autism (IPNA). A multidisciplinary team provides comprehensive care to children with disabilities and their families under one roof. Neurodevelopmental Disabled Persons Protection and Trust Act 2013 was passed in November 2013. Autism and neurodevelopmental disabilities have been included in the five-year National Strategic Health Plan.

According to UNICEF (2014), special education services for children with disabilities are provided by the Ministry of Social Welfare and most government-supported programmes accommodate children with physical, visual and hearing impairments. In their report Khan and Anisuzzaman (2011) mentioned that the Government is operating 13 primary schools for children with disabilities– seven

schools for those with hearing impairment, five for visually impaired children, and one school for those with intellectual disabilities. UNICEF (2014) reported that NGOs are playing a key role in promoting human rights and equity in providing basic social services for children with disabilities in Bangladesh. Special education services for children with autism and with intellectual impairments are primarily provided by NGOs and private organizations. They also confirmed that these services are available in Dhaka and Chittagong city and only children from well-off families are privileged to access.

## BRAC Initiative

In pursuit of the goal of providing basic education for all, BRAC made visible efforts from its inception to include children with disabilities in the educational mainstream. However, BRAC Education Programme (BEP) formally established the Children with Special Needs (CSN) unit in 2003 with the objective to realize the potential of children with disability and to provide them a better life. Since then about 200,000 children with disabilities have graduated from BRAC schools and more than 50,000 are currently enrolled. Along with creating inclusive teaching-learning and physical environment in BRAC schools, BEP provides corrective surgeries and assistive devices like wheelchairs, crutches, hearing aids and glasses. The first cohort of children with visual impairment attended the Primary Education Completion Examination (PECE) last year.

To comply with the call from the Prime Minister Sheikh Hasina and Saima Wazed Hossain, a leader of the autism movement at national, regional and global level, another important initiative has recently been implemented by BRAC with regard to health and education of children with neurodevelopmental disabilities. From 2014, the CSN unit launched the Neuro Developmental Disability (NDD) centres in Bangladesh in cooperation with the Health, Nutrition & Population Programme (HNPP) of BRAC. These centres are meant to be truly 'community based centres' for poor, unserved communities in the country. Till June 2015, four centres were established; one each in Dhaka, Pabna, Khulna and Gazipur districts. Preparation for opening another centre in Sylhet district is in progress. Four types of children—(a) autism, (b) intellectual disability (ID), (c) Down syndrome, and (d) cerebral palsy (CP) or multiple disabilities combining any two types from a, b, c, d are eligible to enroll in these centres.

Additionally they allow children with hearing impairment (HI) as well though they do not directly fall under the neuro developmental disability category. As children with HI cannot talk, society considers them as children with ID and BRAC picks some of them for schooling who would otherwise not have the schooling opportunity. When HI children come to NDD centres they cannot be pushed out unless they are admitted to mainstream or special school for them.

Each centre accommodates 15-20 children from 03-18 years with the mentioned categories of disability. Female teachers and care givers are recruited from the same community. BEP is financing these centres from its core funds. From September 2014, the Apasen International (AI) has been providing some financial and technical support for two NDD centres.

## Motivation of the Study

BRAC's attempt to implement education for children with neurodevelopmental disability is limited to small pilot centres. Since this is relatively a recent development, research is needed to document and analyze the processes, outcomes, problems and solutions of these centres to suggest recommendations for rolling out further centres with this model and improvements in implementing the existing ones. UNICEF (2014) also urged that gathering and disseminating information on services for children with disabilities is extremely important.

## Study Justification

It is hoped that this report will provide detailed accounts of selected centres including both demand and supply side constraints and how BRAC has been addressing those challenges so far with the resources they had. Additionally, the report will provide useful guidance to programmes to modify, reorganize and develop their approaches where necessary to enhance the experiences of children with disabilities and their families.

## General Objective

To describe in detail about BRAC Neuro Developmental Disability (NDD) centres, including strategies taken, successes perceived, challenges faced and scopes of further improvement in operation.

## Specific Objectives

- ▶ To find out what management strategies are in place to assist children with disabilities in dealing with their unique needs.
- ▶ To explore what changes these centres have made on children, their families and the community.
- ▶ To identify existing challenges of the centres in providing the services they offer to children, parents and communities.
- ▶ To examine what the families and community think of the support they receive from the centres and their wishes to improve the situation.



## METHODOLOGY

# METHODOLOGY

## Design

Qualitative research design was followed as the study intended to document overall development of the NDD centre from the perspectives of policy and personnel, lives of CSN and their families and communities.

## Techniques

Each NDD centre was considered a unique case and thus case study was chosen to answer specific objectives of the study based on Yin's (2009) assertion that case study is appropriate for answering the how and why questions in the context of a contemporary event. According to Gerring (2007), the study of one case as a means to better understand similar cases can be both instructive and informative.

- ▶ Analyzing the cases, the study included review of programme documents (e.g. policies, curriculum, materials etc.). The researcher had access to relevant files of the centres concerning children's health and education plan, attendance etc.
- ▶ In-depth interviews (IDI) were used to gather information from teachers, NDD centre staffs and other officials from BRAC head office. Interviews were held in three NDD centres, branch offices and in the head office. Before each interview, the purpose of the study was explained to the participants, it was also made clear that there would be no consequences to their centre and to their job in any other way for any comment they will make. All interviews were face-to-face and took about an hour or more in order to get in-depth answers needed for this study. Informal interviews were done with children who could talk and with community members directly involved with the management of the centres. Follow up interviews were done when required for all cases.
- ▶ Focus group discussions (FGDs) were organized with parents or significant else from the family. For FGDs eight to ten participants were organized in a centre each day with the help of teachers and programme organizer without interrupting regular classroom activities. There was no compulsion to participate in FGDs and consent was obtained from them before discussion.

- ▶ Repetitive nonparticipant observations were also employed. Observations were conducted in each of the classroom, therapy room, and the community to note different procedures of the centres and interactions of different people including children.

## Tools

Having formal training on education and rehabilitation for children with disabilities, the researcher alone collected data from all sources. However, he received help from the following items.

- ▶ For observation, a checklist was followed based on potential thematic areas that answered one or more of the objectives.
- ▶ The IDIs were conducted with the help of individual guides that contained list of issues considered essential for the investigation after extensive review of the literature on services for children with disabilities. Interview questions were structured in a way that enabled respondents to narrate their experiences regarding the NDD centre in their own ways. Those questions intended to gain an understanding of how disability was viewed in community, how meaningful placements these children were having, what activities centres did to improve abilities of these children, how teachers and other staffs regarded themselves as part of the centre, what were the challenges they were facing and their suggestions to resolve those and so on.
- ▶ FGDs were conducted with the help of another guide that contained similar but slightly different list of issues like IDIs. Participants were given the opportunity to comment on ways in which they thought NDD centres were making changes in the lives of their children, how the community accepted the centres, how they saw the future of their children, how centres could be improved, how families could be better supported and so on.

## Respondents

Twelve interview participants included six teachers, three Programme Organizers (PO) and three Sector Specialists (SS) from field offices. Among all participants eight were female and five male, ages 35–45, with various levels of education, training and experiences. Seven children (five boys and two girls), three female caregivers and two male community members were informally interviewed. In six of the FGDs (two in each centre), 52 parents/guardians participated.

## Data Collection

IDIs and FGDs were recorded and transcribed directly into English by the researcher. Substantial on-site notes were taken during centre observation

days that were later processed for analysis. Observations, IDIs and FGDs were conducted from June to August 2015.

### Data Analysis

Data were manually analyzed by the researcher. Doing that the researcher coded and categorized data into themes using a six-step approach described by Braun and Clarke (2006): (a) become familiar with the data, (b) generate initial codes, (c) search for themes, (d) review themes, (e) define and name themes, and (f) produce the report.

### Strengths of the Study

During the 1980s there was a huge disability movement worldwide saying that “nothing about us without us” meaning that all policies for their development must be made after consensus of people with disabilities (PWDs) and their families. This study considered the voice of parents and families of children with disabilities. The researcher claimed that the findings presented and recommendations made were based on the thoughts of these children, their families and other people serving them in NDD centre capacity and not a single idea they provided was intentionally ignored. The researcher was very much objective to what was actually happening with these centres.

### Limitation of the Study

This study is limited in its scope due to only three centres of the same kind covered. IDI and FGD guides, and observation checklist were developed by the researcher, but they were not tested for reliability or validity prior to the study. Another limitation would be that the different respondents brought under this study might voice issues considering their interest vested into the project and the desire to get benefits in their own way and from observation of only few days could not confirm either all their responses were consistent with their actual activities or not.



# FINDINGS

## MANAGEMENT STRATEGIES

# FINDINGS

## MANAGEMENT STRATEGIES

### Area Selection

At this moment BRAC management wants to open NDD centres at district level only. As a priority plan they want to reach one district in each of the seven administrative divisions (regions) with at least one centre, preferably in a village nearby district town. There is flexibility with this policy where more than one centres can be opened in a district which again can be located outside the district town if there is any real/practical ground. Density of population, number of disability cases, existence of HNPP activities in that area are some other primary things taken into consideration prior to setting up NDD centres. The very first pilot centre was made in Dhaka slum considering its proximity to BRAC head office as senior officials can make frequent visits there and can easily learn things necessary to plan for further centres in other districts. Detail procedures of area selection are given below.

After getting instructions from BRAC head office BEP staffs of a particular branch sit together and suggest village names from their experiences working in those areas where they found or were informed that there are some children with disabilities who were not enrolled at all or dropped from other schools. Then Programme Organizers (POs) and Sector Specialists (SSs) of NDD centres go to those suggested villages, do yard meetings in large and small groups, jot down information together and share those with each other coming back from field. In the meantime they collect village wise disability information from union parishad (local government body), from district office of the Department of Social Service (DSS) and from other development organizations of that area. Compiling information from all these sources mentioned and consulting with head office staffs they finalize one village where the centre will be located and other villages near to them from where children can come.

### Survey and Identification

As a primary job, BRAC staffs do thorough surveys in the selected villages at household level to find out children with disabilities that fit with enrolment criteria of NDD centre. They collect information of children with disabilities age range between 03-18 years that has potential to get enrolled to NDD centres.

Currently the policy is to select children with moderate to profound degree of disability that otherwise are not received by mainstream schools. Mild cases are also selected if they have multiple disabilities. However, this is not an easy task since there is a cultural tendency to hide children with disabilities and some families refrain from sending them to any centre when BRAC staffs consider them as potential enrollee. So they have to make a primary and a waiting list. Surveying and mobilizing parents go simultaneously. Ultimately there is provision that children can join anytime of the year when their parents/guardians approach the centre. While surveying for children NDD staffs also collect information on potential teachers, caregivers and house owners that they can approach later to involve with NDD centres.

### Getting Rooms for Centre

After household surveys BRAC staffs work hard to find a suitable house to open NDD centres. While selecting location of centre, BRAC considers that children from two kilometers distance within their catchment area can come to centre with the help of their parents/guardians. However, lots of efforts have to put for that by the staffs. The researcher makes those long stories short to give a sense how difficult it can be at times. Khulna centre is currently operated in an old building of a government secondary school. This building was initially made for student's hostel of that school. It was kept unused for couple of years. Local BRAC staffs made all out efforts to convince the school authority and the Deputy Commissioner (highest administrative position of a district) to allow them opening a NDD centre there. After many rejections and denials from subgroups of teachers and other government officials they finally got permission. Agreement was signed between two parties with additional privilege given to BRAC that they do not have to pay for the rooms. Staffs of Pabna centre followed quite similar approach and convinced a madrasa (Islamic school) committee with the help of parents interested in opening a NDD centre in that village to give them a room within the madrasa building. As the madrasa had few students villagers insisted them so that their room is used in a better way and BRAC received permission for NDD centre in that premise. BRAC staffs were in a very difficult situation to find the kind of house they need for Dhaka slum NDD centre. Because of the nature of the slum housing it took more time than they planned to get one. They started to think either they can make a house of their own or not and stepped back because of financial constraints. At the meantime they found a room near a non-governmental secondary school which was built for office of the slum development committee. It was found that the committee was mostly using part of the room and they did not use it daily. After repetitive meetings with the committee they finally agreed to provide BRAC unused part of the room with some conditions that will be discussed later.

## Physical Structures

As a policy BRAC wants to have three brick built (paka/semi-paka) rooms in a NDD centre; bigger one (30/12 feet) for classroom so children can move easily, one for therapy (15/12 feet) and other for sensory integration room (12/12 feet). Arrangements for enough light and ventilation should be made- one door in each room and five windows in the bigger room, four in the therapy room and three in the sensory room. Availability of electricity is another requirement included in the policy. This house should be located in a place where children can easily enter from the road. Ramp must be built if physical access to rooms is restricted to wheelchair users. Ideally there should be playground/open space in front of the centre. Disability friendly toilets with easily accessible water source and soaps are meant to be there.

Actual structures in all the centres were found different to some extent than envisaged. No comprehensive physical structure was noticed in either of the centre though each has some setups as listed above. For example, Khulna centre has two relatively large spaced rooms; one for classroom and the other is used as therapy cum waiting room for guardians. Children can easily move around the classroom and small group activities with different arrangements can be conducted with little distractions. Except Khulna centre two other centres have one room with limited space for free movement of children. Sometimes teachers face difficulties in accommodating children with different types of disabilities in a single class. Dhaka slum centre made a small therapy room with bamboo and other materials; Pabna centre had no separate therapy room. Parallel bars in both Dhaka and Pabna centre were placed outside the centre which were found unusable during rainy days. Parallel bar of Khulna centre is placed in the therapy room and was found in condition. There were shared washrooms in Dhaka and Pabna centres and the conditions were not so good. Children of Pabna centre was seen struggling with hot weather as there was no facilities for electric fan. Lighting in three of the centres seemed okay. Inner side of all the centres was found clean and most materials were kept organized. Internal decoration was also very good, especially that of Khulna centre was very attractive. Since three of the centres are in the premise of a secondary school or madrasa they can share part of their playground too. Dhaka centre is placed in a very noisy place, just beside a local bazar, leading interruptions in instructions. No such concern was found in Khulna and Pabna centres.

## Teachers

Policy says that each NDD centre will be attended by two female teachers with age ranging between 18-35 years with at least secondary school certificate (SSC). No teaching experience is expected at this moment though preference is given to those teachers who were previously involved with BRAC pre-primary or primary schools. Neither education nor experience, management prefers to involve those

mothers and elder sisters as teachers who have one child with disability of their own and who will join with other children in the same centre. This strategy was taken with an assumption that they will be a resource for other children because of their personal life experiences and they are likely to be much caring than those who do not have any child with disability. Only married women can join as teacher though in special circumstances interested and experienced unmarried women can be recruited with permission from head office. Interested women from the same or nearby villages who talk the same language as children is encouraged to join as teacher. Apart from meeting these listed requirements they should be motivated enough to helping children with disabilities with a mindset to support their families as well. They are expected to provide a commitment that they will be available to receive training at the nearest BRAC learning centre (BLC) and will serve the NDD centre for at least three-four years. They will be given a lump sum honorarium and they can enjoy one day monthly leave.

Centre data shows two female teachers are working in each centre with education ranging from higher secondary to bachelor level. Except Khulna, two other centres managed to get one teacher each having a child with disability. Out of six, one teacher was unmarried; they all belong to the same community and talk the same language. Only two of them received training on BRAC pre-primary education though none of them directly taught in any of the non-formal school including BRAC.

### Caregivers

In principle there should be one female caregiver in each centre with junior secondary level education, but preference is given to those having SSC. Like teachers caregivers are supposed to be married women, age ranging between 18-35 years, living in the same community and having enough patience to take care for children with disabilities. No condition of previous experience was also given for them.

All three caregivers had JSC certificate and all other requirements were fulfilled. Like teachers, there was no intention to involve mother or sister having a child with disability as caregiver but that of Pabna centre has one such child.

### Teaching-Learning Material (TLM)

BRAC pre-primary book and some story books are used in class. Notebook, slate, hardboard, chalk, wooden pencil, color pencil are given to children free. One blackboard is placed in a wall convenient for most children to see easily even in sitting position. Some pictorial charts of different items appropriate for elementary schooling are always displayed in all four walls of the classroom at nearly appropriate eye levels of most children. There are flash cards for socialization and communication training, picture cards of daily living activities, picture-word cards, color matching cards, number cards and letter cards.

## Toys/Play/Therapy Materials

All three centres have few toys and play materials of different types like plastic cars, boats, motorcycle, carom board, balls, building blocks, cube, plastic whistles, old-unused calculators, telephone, keyboards etc. There are picture cards, pocket cards, communication board, rubber ball, dotted ball, hand punch, sticky roll, ring puzzle, animal puzzle, velcro board, roll velcro board, dummy “lock-key” board, parallel bar in these centres for use in therapy. One colorful wooden horse was given to Khulna centre. Items listed here do not mean that all these are used regularly or are in good condition; researcher just wanted to report material preparation of NDD centres in this section.

## Individualized Education Plan (IEP)

There are individualized education plan (IEP) for children in all three centres. In cases these are made for a year or for six months target. Before making IEP children were brought to nearest medical centres for assessment. Based on their special needs, instructions given by doctors and other professionals, parental expectations and more importantly on the current ability of children IEPs are determined. Teachers said they make IEP after “multi-agency meeting (MAM)” and consider those targets and activities that they think are likely to benefit children in the coming months. Programme personnel from head office are reported to be involved with the development of IEP. These are made in written form, stored properly and are said to have been shared with guardians time to time. On a follow-up question to guardians, many of them agreed that they were informed about IEPs of their children.

## Parents Meeting

Mandatory meeting with parents/guardians takes place in each NDD centre once in a month on a mutually determined date and time. To get more guardians present teachers and staffs knock them repetitively days before the meeting date and thus they reported to have a sizeable group in most meetings. During FGDs guardians from Pabna and Khulna also showed their enthusiasm to attend monthly meeting and explained why they do not want to miss unless faced with any family emergency or so. Main part of this meeting that guardians like is the suggestions provided to them for the care and education of their children which is detailed in parental education section. Also they like to hear progress and problems of their children and that of others and how the centre is responding to the unique situations.

## Parental/Community Education

Apart from monthly parental meeting some of the guardians have to come to NDD centres with their children more on a regular basis. Also, as part of their

responsibilities teachers and other staffs visit households with a view to take other family members and neighbors on board so that it becomes a collective journey. In all these contacts teachers and other staff members provide guardians and community people with ideas they think might help them dealing with their children. It is somewhat obvious that all staffs cover a wide range of issues and that emerge as they continue moving with these children. However, few points are listed here based on the idea given both by guardians, teachers and staffs. Referring to their individual child, guardians are guided how to take care of their children while they stay at home like ensuring their cleanliness, feeding and medications timely, brushing, bathing, using shoes and other devices properly, finding time to practice lessons and exercises taught in centre, and so on. Parents having children with hearing impairment are instructed to talk loud with them face-to-face instead of communicating through gestures. Children with autism, and intellectual disabilities get most rejections and ignorance so their family and community members are requested to behave positively with them. They are informed that behaving badly with them will ultimately worsen their condition and will limit their scope for improvement. Parents are particularly requested not to chain their children or to keep them locked in house. They are asked to take these children while they visit family, friends, relatives, market places and any places outside home. Everybody close to children are forbidden to involve themselves in punishing them both physically and mentally. They are taught to consider these children as human beings. They should not be ignored for being different than others. Staffs try to make larger community understand the diversity human have and the beauty of that. Examples of successful personalities with disabilities are shared with them to encourage them. They also inform community people what to do if they find any child born with some problems or growing up with disabilities. To get confidence of families and communities teachers and other staffs clarify that as new centres they might get something not happening properly and timely but all they need is their patience and cooperation to fully function these. This education helped service recipients convince and be hopeful in the future.





## SERVICES PROVIDED INSIDE THE CENTRES

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### Curricular Activities

Developing a customized curriculum is underway. Until having that teachers are instructed to use some parts from BRAC pre-primary text books. From repetitive observations of classrooms in all the centres under this study and also talking with their teachers and other staffs it was noticed that no fixed item from any text was in practice. That does not mean there was no activity in classes at all. Many curricular activities were there to motivate children in a joyful manner some of which can be labelled as hidden curriculum. Detail description of all these activities are presented here.

When drill and national anthem time ends, children are asked to stand in a circle and formal teaching-learning begins with greetings and knowing each other. Not many children can do that functionally, they are prompted by teachers. Keeping those standing children are taught counting like 1, 2, and 3...with clapping hands. In the same position they are also taught several body parts-identification, labeling based on function of the organs. Then they are asked to sit in circle.

Formally academic tasks start with the distribution of writing board and pencils. These are not given directly to children. Instead children are called by teachers by names. This is to get individual attention from each child. Thus who are not so interested or have problem with getting teachers instructions must have to request materials. Children having hearing impairment respond to gesture and others having intellectual disabilities are brought to teachers either by caregiver or by their guardians if they are present there.

Teachers go and distribute materials to those who have limited physical mobility. Then children are asked to write letters or numbers on their board, individual assistance are provided to those needed. Teachers comment or correct children's writing. After that using alphabet charts, letter cubes teachers try to make children familiarize with new Bengali and English letters. Those who have already mastered identifying letters they are given higher tasks of making words with teachers and are asked to tell those to others in class.

Different charts of fruits, flowers, animals and so on are introduced in groups in alternative days. For this, again, each child has to go to individual posters teachers

use that day and show the item asked using fingers or scale. Communication training, brushing training, toileting training, puzzle making activity and naming colors are also practiced. When one teacher instructs the whole group, the other teacher takes one-to-one care side by side to those who need help to get all the instructions given for different tasks. Teachers spend first two hours doing these sorts of activities every day with slight variation depending on the progression of the children.

Last hour is usually used for co-curricular activities; description of these will be made later. It should be noted that planning for curricular and co-curricular activities are not that hard and fast; customized adjustments are made based on total atmosphere of the day and on other weekly and monthly schedule. According to the teachers they always consider current capacities of the children and try to teach them easier to harder items based on progressions.

Talking about hidden curriculum, first emphasis is given on socialization training for these children. They are taught how to say “*saalam*” (showing respect), how to ask “how are you”, how to behave with parents, how to behave with others around, how to help parents in their work and similar other civic education are provided.

Teachers also train them how to maintain cleanliness to keep their health well. For this they are shown how to wear costumes and use of it, how to wear sandals, how to use toilet, how to wash hands before meal and after toileting, how to use road and so on. Teachers said they help children cutting their nails and managing hair during their stay in centre. They also try to wash children’s hand with soap once in a day.

### Co-curricular Activities

When most children come to the centre they are asked and helped to stand in two parallel lines for reciting national anthem followed by drills. Children who cannot stand alone are arranged to sit on little wooden benches with back support from their guardians, teachers, and care givers. For both lines there are gender mix and smaller size children are placed in front. Standing a little distance of the lines and facing the whole group, one of the children leads them. Leader is chosen in a rotational basis though who are regular, older and learnt better than others usually get preferences.

In the class children are taught to reciting poems, singing songs, dancing and acting with rhymes and songs. All teachers and caregivers, except Korail slum centre, actively participate in doing all these things and they seemed to be very good role models for children. They have innovative ways of activating children’s interest and they were found to capitalize children’s motivation in doing co-curricular activities to curricular tasks. They were very often found to appreciate

each attempt of children irrespective of the level of their mastery of doing any co-curricular activities.

According to the teachers of all three centres, children are brought to open field attached to them twice/thrice a week for physical play like running, jumping and for playing football, cricket etc. But because of Ramadan and rain during data collection not many examples of outside play were noticed. Teachers also agreed that all the children they have cannot participate equally but all of them enjoy being involved or even seeing others playing. At least they are learning how to go and come back from playground maintaining line and touching one's shoulder with that of another. With this practice many of them can identify their own shoes and can wear those alone.

### Physical Exercises (Therapy)

Instead of frequency or quality of use, the following description intends to report the way physical exercises were practiced and some of the therapy items were in use in these centres. From their limited knowledge on effective physical therapies, teachers do practice some exercises with three-four younger children each day on a priority basis. Same rotational format is followed in this case as well. Each day they take some children with cerebral palsy to parallel bar and make them walk using this. Children are given opportunity to ride on wooden horse for their physical exercise and balancing activity inside the centre.

For fine motor movement practice they give small buttons to some children and ask them to put these in one container/jar to other. This activity also simultaneously helps to teach children counting. Squeezing rubber ball activity is done for some children to strengthen their weak/affected hand. Dough made with mixing flower and water is occasionally given to some children for the exercise of their fingers. They are guided to make shapes with play dough. Blowing paper pieces for breathing exercises was also reported in the practice. Some older children are taught how to stitch clothes. Boys are taught how to put and open button of shirts and zippers of pants; girls are taught how to put and open ribbon of pant as therapy activity. Some children are given beads to put on threads. Hand punch is also used to increase their finger movement. No tactile and other sensory learning activities were observed in any of the centre.

Using "lock-key" board all children are taught how to open and close door, window, water tap and bottle. This is emphasized because these children need to know how to lock and unlock doors and windows for safety purpose and how to drink water independently where there is none to help them at home. Using communication picture cards children are given brushing and toilet training. With these cards they are also taught how to communicate some of their basic needs. Also teachers do some face-to-face speech training for children with hearing and speech difficulties.

Whatever the therapy activity teachers try to teach children those skills necessary for their independent living. They also show those to the guardians who later provide therapies to their children inside and outside the classroom.

### Medical Help within Centre

MBBS doctor from Health, Nutrition and Population Programme (HNPP) of BRAC visits each NDD centre once in a month, usually on Monday or Thursday of the first week, to check health condition of the children. S/he suggests medicines, provides advices to guardians and teachers and refer to other medical centres for further required treatment. PO from HNPP also visit these centres on specific days and guide parents for healthy living of their children. With limited approved budget centres buy some medicines for some of the children. Few of the children were given wheelchair from the centre. Using those they can easily come to centre with support from any family members.





## SERVICES PROVIDED OUTSIDE THE CENTRES

## SERVICES PROVIDED OUTSIDE THE CENTRES

### Medical Consultation Outside

Since most parents expect to get medical help from BRAC, programme staffs recognize these community needs and try to find ways to help them from best possible existing options. Most children are brought to the nearest specialized medical college/institute, general hospital or other private or NGO run centres for assessment and treatment of their vision, hearing or other needs they have. This also happens in the form of taking them to related special medical camp close to their reach organized by other organizations. Hearing assessment of some children of Dhaka centre was done by Society for Assistance to Hearing Impaired Children (SAHIC) hospital based in Dhaka. Some of the children from the same centre are getting treatment from IPNA of BSMMU, Dhaka. Children from Khulna centre are brought to Shishu Bikash Kendro (Child Development Centre) of Khulna Medical College and Hospital and Sheikh Abu Naser Specialized Hospital in Khulna from time to time. Some children from Pabna are getting therapy from another national NGO named Centre for Disability in Development (CDD) when their mobile therapy van visits the area. BRAC manages diagnosis and treatment outside free of cost or shares greater amount of money spent for it along with bearing costs related to travel, accommodation and food for children and their families.

### Co-curricular Activities Outside Centres

To increase their efficiency and to inspire them further, these children are also given the chance to participate in sports that take place at regional and national levels organized by upazilla and district education offices locally and nationally by the National Association of Sports for the Person with Disability (NASPD). BRAC itself arranges annual sports and cultural programmes in different venues of Dhaka and other districts for CSN where some children from each NDD centres are also included. Some of them were already brought for exposure trips to Cox's Bazar beach and tea gardens at Sylhet.

## Connecting with other Facilities

Staffs of NDD centre are trying to connect these children with other government facilities like DSS who provides disability allowance to these children. They also connect them with locally available stipend programmes offered by both government and non-governmental organizations dealing with disability and safety net. Programme staffs interact with teachers of neighboring formal schools to help ensure participation of any child to their capacity when s/he is ready. For this two-three children from NDD centres were mainstreamed already.





# CHANGES

## NDD CENTRES MADE

## CHANGES NDD CENTRES MADE

A general impression that the researcher got from the study is that changes NDD centres made on children, their parents, teachers and communities are manifolds. Some parents and staffs noticed improvement of children in some of the areas after their enrolment. One teacher from Pabna centre mentioned that all children progressed in a way or other; if one child improved in speech communication other did so in learning alphabets.

While reading this section, everybody should keep in mind that some changes can be very minor if those are compared with high expectations of different stakeholders. Also, it is understandable that pre-set expectations may demotivate anyone to report on minor changes or success when they were asked to. However, based on the research design the researcher only presented changes that different respondents reported or perceived and tried to provide a 'bigger picture' by creating themes combining some of the 'minor achievements' that may fall under certain theme.

### Children's Curricular and Co-curricular Achievements

Most people involved with these centres reported that some children can tell and write some letters/words. Most of them learnt few songs, rhymes. Some of them is doing well in acting and dancing. Some of them can draw pictures on teachers' instructions and from their own imagination. These skills that children developed were not only reported, their practical demonstrations were observed by the researcher during visiting centres twice. He had a feeling that children were at least having a sense of reading-writing here.

### Case of an Academically SUCCESSFUL GIRL

Sathi (not actual name) a 13 year old girl with moderate hearing impairment and mild intellectual disability came to NDD centre in February 2014. She could not hear most words said to her and all she used to talk sounded like a single word. Given hearing aid from a centre her hearing capacity improved. She now can talk some words and sentences that others can understand without much effort. Using charts she can read aloud different letters, numbers, fruits, flowers, animal and so on. She also can write independently and most people appreciate her hand writing. She mastered most drills practiced in the centre and can lead the group during morning assembly. She comes to centre regularly; even natural calamities cannot stop her. She also voluntarily brings other children to centre from nearest households. Back home she shows to her older siblings what is taught in centre and requests them to help her in study.

### Children's Improved Self-esteem

Most children were happy to get a centre specially made for them. Those with a little or no problem in communication expressed their joy having a “school” of their own where they were getting friends, teachers, books, writing boards, play materials, playground and so on. Before coming here they thought they were “disabled” and school things were not for them. Like their other siblings they were going out of home, they were having routine, they were given importance in centre — for all these their self-esteem was reported to be going up leaving behind their ‘disabled’, ‘inferior’ feelings. Seeing that their rights of socialization were met at the centre they started to feel as ‘humans’ for the first time.

### Children's Added Enjoyments Playing with Peers

Literally there was no opportunity for these children to form friendship and to play with friends in home environment. Other children rarely showed interest to interact with them. Parents used to feel ashamed having these types of children so they did not dare to bring them out from home and allow them to mix with other children of their age. Some of them were said to be chained at home previously. NDD centre was providing them with opportunities to play both indoor and outdoor games which they were valuing with wider personal accomplishments.

Some of the children from all three centres expressed that they were very happy for toys and play materials given and participating in different games. One teacher from Khulna centre said,

Most enjoyable part I find among children is the play time. Because it is giving them the pleasure of inclusion in group activities.

Another teacher from Pabna centre said,

None from the families want to spend time with these children; they live alone. Coming to centre, they enjoy singing, dancing, reciting, playing in team. They don't feel alone here. They are excited with joy during these fun activities and sometimes we cannot stop them doing these. Children often request for continuing these activities for few more minutes.

### Progress in Physical Movement

Given the opportunity to expose outside home on a regular basis and having some physical exercises, drills, outside play options and so on functional mobility of some children with cerebral palsy were reported to have improved. Teachers reported that following their facial exercises they found less drooling (salivation) in some children. Parents also observed and reported the same thing. This little change most parents were considering very helpful for their children as people as well as other children now feel less hesitated to come in close contact of these children.

### Improvement in Communication

It was reported that some of the children with hearing impairment, down syndrome had no or few verbal communication prior to joining NDD centres. They already learnt and were using many words and some sentences that teachers and guardians repeatedly practiced with them. Some children were also reported to have improved social communication. Most of them learnt to say "saalam" to guests coming to their centre or when they meet teachers and superiors from family and community. Referring to Pabna centre, SS said- "One very young girl cannot talk but greets with gestures and shakes hands to familiar and unfamiliar persons. This single behavior she learnt from us which shows her improved communication, I believe."

## Children's better Understanding on Personal Cleanliness

Teachers mentioned that many of their children now know the norms of washing hands before eating food and after using toilets. Children answered correctly to the researcher regarding these norms though he was not fully sure that they were maintaining these at home or not. Some of the children were reported that they can use toilets properly now. Open defecation is always considered a culturally inappropriate thing and according to some parents they less worry about that as their children were in a toileting routine and some of them can use toilet on their own.

## Improved Understanding of Children's Immediate Environment

It was reported that some children of all centres used to go somewhere in their locality without informing family but could not come back home alone. This happened frequently putting much pressure and tensions on their families. Some of them were kept under chain for this. A few of them now were reported to come to and go from their centres independently. They also can go to the nearest shops, bazar, playgrounds, relative's house and come back home alone. One SS from Pabna claimed that children were getting familiar with the village roads coming to the centre regularly and teachers were guiding them how to use it. These two experiences were providing those children a sense of their immediate environment.

## Positive Changes in Children's Behavior

It was very difficult for the teachers and guardians to keep some children inside the classroom immediately after their enrolment. They used to run away each time they were brought to centre. After a few months most of them, except a few in each centre, showed their desire to come to the centre and started to spend three hours without much interruptions. When asked, most respondents including parents said they are seeing changes in behavior among the children after their admission and most of them liked to come to the centre and enjoy being here. One mother narrated progress she found in her son's behavior,

### Case of CHANGED BEHAVIOR

Abu Amin (not actual name), a 13 year old boy with autism. He used to scream all day long. Neighboring children and adults were very disturbed and afraid of him. Very often we were yelled by neighbors to change our residence and we had to do that a couple of times. We only know the feeling we had at that time. We gave him to this school. The way he used to scream was a cause that other children were afraid of coming to centre. After repetitive corrections and modeling positive behavior by teachers here during the first few months, he started to scream less at the centre. Now he is quiet at home as well and is following our instructions and requests. We do not have to face social pressure now. This, we think, happened as he was brought to this school and was given the chance to see other children.

Some children had a tendency to hit others which was only occasionally seen in a few children during centre observation by the researcher. Some of the children used to spit at others frequently which was seen less during the second observation held one and half month later. Teachers said that during the initial stage of training some children used left hand for “saalam” and greetings who now do not make that mistake. Some of them already learnt that they have to use right hand to receive anything from anyone, especially from elders. It can be said in this regard that going through certain disciplines in the centres, children’s behavior is getting better and NDD centres can claim this change as an outcome of their services.

### Empowerment of Parents

Many parents of Pabna and Khulna centres were busy in doing household tasks and agricultural activities. Most of the parents from Korail slum community were involved as day labor; mothers as part-time home maid and fathers as rickshaw puller. Before sending their children to NDD centres they had to manage from both ends; earning livelihoods and taking care of these special children. These parents can now concentrate on their livelihoods activities as their children stay part of the day in the centres. Most parents mentioned that they believed their children were safe in the centre so they went to work outside free of tension

at least for three hours. Also they felt empowered in the society as BRAC was taking care of their children and their voices were counted in the management and planning activities of the centre.

## Reducing Parental Frustration

Some of the parents said previously they were very frustrated thinking that their children will never improve. Sending their children to these centres and seeing some progress their frustration reduced to some extent. One mother from Dhaka slum centre said,

### Case of A HAPPY MOTHER

My son is eight plus now. He was diagnosed with cerebral palsy. We are very poor but we did everything from our capacities for his treatment. None gave us any hope. When BRAC requested to send my son to their centre we initially rejected them as the whole family was so frustrated. Just for a fair try we gave him to this centre when he was six though truly we were not expecting any improvement there. After one year and half he started walking independently and I heard him calling me “mom” after waiting for long eight years. I am so happy that I cannot express in words. Instead of the previous frustration we the parents and other relatives now believe that he will show much improvement in future.

Before admitting their children to NDD centres, not many parents got the opportunity to meet other parents having children with disabilities. Like their children their life was also limited to their home and their very personal sufferings. Now they can share each other’s sufferings and experiences. They can better plan for their children seeing how other parents are trying to help their children. Some parents said they see that their dignity and acceptance in the larger society now increased so they feel good about their children.

## Community’s Acceptance and Understanding of Disability Increased

When SSs and POs surveyed households and told them that they were going to open a NDD centre in the area, most people thought some organizations

come with this sort of desire, collect information but actually they do nothing and no exception will happen for BRAC. Thus they paid little importance to BRAC staffs. When staffs increased their communication with families by frequent home visits and activities of centres were in progress people started to believe them. When children came in centres, they tried to serve them with their best possible capacities and parents became hopeful day by day. Other members of the family, their friends, relatives, and community people started showing interest in helping other children with disabilities. They started to believe that children with disabilities are not burden rather they can be educated. Mentioning one boy of Pabna centre, SS described what changes he found in society,

When Amina (not actual name) used to call her uncle “chacha” (Bengali name of uncle) in public he did not respond. Because he was afraid that people will understand their relationship. He felt bad recognizing that girl as a part of their family. Amina’s uncle is now curious to know how she is doing in the centre. He also brings her niece’s name in public gossip and tells others that they should send such children to any centre like this one.

Their previous views to causes and consequences of disability were also changing. They were reported to have better knowledge on what to do or not to do with/for these children. From these centres they were getting information on rights to education and health services for these children and what support they could receive from the state. They were learning how families and societies could act to ensure safety and security of the children with disabilities.

### Changes in Teachers' Attitudes

During the initial months teachers of NDD centres too had problem in accepting children with disabilities. Like others they also laughed at children’s actions. They had belief that this situation of these children will not change. Their attitudes changed over time and so they were believing that many things can be done by these children. Changes in attitudes of other teachers of primary, secondary schools and madrasas next to these centres were also noticed and reported by BRAC staffs. Those teachers from regular schools who denied providing space for this centre now praise BRAC’s efforts for these children.



## CHALLENGES IN PROVIDING SERVICES

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### NDD Centres have to Rely on Inappropriate Diagnosis

As said earlier BRAC takes children to the nearest hospitals for assessments and screening. They also refer families to other facilities as well. Whatever the case, it is likely that diagnosis of some children made by local hospitals may not always be accurate. This particularly may happen because the country is yet to develop adequate professionals with necessary clinical and functional screening skills. Consequently BRAC has no choice than to rely on persons without proper training in the field of disability. Teachers and other staffs of NDD centre believed the diagnosis to be true and they made individual education plans based on this. The researcher wonders either specific capacities or abilities of individual child are properly identified or not. If not, it may lead to a situation where some children are placed in wrong activities so they are not achieving as they should have following this intervention.

### Medical Support Provided is not Meeting Actual Needs

In FGD, most parents said they believe that only proper treatment can lessen sufferings of their children. Those parents also seemed are not much concerned about educational support provided by the centre. In interviews BRAC staffs confirmed that they got a similar motivation from parents while they approached them before opening centres. Just to get their confidence parents were given some promises regarding provisions of required medical support in the centres for their children. In practice centres tried best and managed to offer some

medical support to some children. Those who got and those who did not receive showed dissatisfaction to some extent because services provided are far behind their expectations.

## No Permanent House for Centres

All the centres are currently running in houses given by communities free of cost; one is given by a slum development committee, one is given by a madrasa and the other is taken from a government secondary school. It is likely that operation in the existing setup depends very much on the mood and attitudes of the owners of the houses. It is difficult to make necessary renovation to make those rooms conducive for children as house owners do not allow in most cases. Moreover, both Dhaka slum development committee and Pabna madrasa authorities informed NDD staffs that they have their own plan of using rooms from 2016 that is they asked the authorities to find other options for NDD centre. This is creating anxieties among parents, teachers and other staffs of these two centres.

## Accessing Centres is Difficult for Some Children

For some children home-centre distance is much to get there on foot. Pabna centre is located little far from the village road which becomes inaccessible during some parts of the rainy season. On the other hand, not all children with restricted physical mobility were given wheelchair. Moreover, public transport is not always available in the area. So mothers or aged grandmothers in majority cases carry their children on lap to reach the centre. It is really difficult for mothers having healthy, older children. Pain is no less for the few relatively lucky guardians who have to cross more than a kilometer pushing wheelchair of their children from the back. Some guardians can sacrifice their physical labor but their commitments to other livelihood tasks do not allow them to go to the centre each morning. Ultimately, problem with transportation was reported to be the single most cause of irregular attendance. A teacher from Pabna said,

Due to problem with transportation some children cannot attend the centre even though they want to. We do not have to struggle in getting children if they are provided with transport facilities. Though authorities want us to bring children from home, this is not practically always possible for us.

## Curriculum is not Meeting Individual Needs

As said earlier, curriculum of NDD centres is not tailored to needs of individual learners– currently part of the BRAC pre-primary curriculum is being put in place. Some children were getting benefits from the joyful approach of some curricular and co-curricular activities. At the same time some children in each centre were observed sitting in the room but were not given any task. Some parents mentioned that educational support given was not that appropriate and adequate for the needs of all children.

## Lack of Therapy and Play Materials

There were very few materials in these centres to provide therapy needs of the children. Teachers said they feel helpless when many children demand same toys at a time. A messy situation arises when children cry, fight and insist on getting certain toy they see in the hands of their peers. This is a common tendency of children which, according to teachers, is more here as most children do not get any such items in their houses.

## Few Teachers, Caregivers and Associated Problems with their Salaries

Various types of children with diverse needs are brought to these centres. Two teachers and one caregiver in each centre are not enough to address most needs of these children. Having been exposed to BRAC primary and pre-primary schools, teachers argued that tasks at NDD centres are very different with that of other schools mentioned and they considered this a laborious job. There was teacher drop out in one of the centers and suitable replacement was not as easy as in other BRAC schools. Teachers involved with BEP are not considered as salaried staff rather they are given small honorarium. The same philosophy is also applied for teachers working in the NDD centres. All teachers interviewed confirmed that they are not satisfied with their honorarium. Sometimes their families discourage them to continue this work referring to the less amount of honorarium they receive. They may also come from economically better off families that they think little money given to them is actually dishonoring them. Overall, poor salary given was identified as the single most cause of demotivation of some teachers. May be some of them were requested to continue even

though they were not interested to. However, demotivation of teachers leading these centres in a challenging situation is a major issue because teachers are the ultimate engines to effectively help children with special needs. Provisions of caregivers in any BRAC education initiative is new. So they have no direct experience on how much to pay and how to deal with caregivers. Because of the nature of the job all three caregivers said they are taking care of all the cleaning things and they believe none will work like them with this poor salary.

### Insufficient Training of Teachers

Teachers of NDD centres themselves said that they did not receive enough training on care and education of children with disabilities though BRAC hired national and international experts on disability management and arranged couple of training for teachers along with other staffs. Additionally, two teachers received short duration training from BEP on teaching in non-formal pre-primary schools before that. Two of them learnt few things from their personal experiences dealing with their own children with disabilities. One of them from Pabna said she is going to different hospitals with her daughter for the last five years and learnt some therapies. She is doing the same therapies for other children with a hope that they will benefit but she is not sure about it. One teacher from Khulna said,

I didn't receive any training on education and management of these particular types of children yet. I don't have enough knowledge on different types of disability. I don't know how to get attention of these children, working with them in which way that may make them happy. I am doing everything here in my own way with some instructions from doctor and my supervisors.

According to one PO from Khulna, apart from the BRAC training, teachers are learning from their current involvement with these children. Ss and other senior officials from the head office also guide them time to time. Regardless of the classroom training and day-to-day supervision, most teachers mentioned that they are struggling in providing appropriate services to children and their families and thus preparing teachers need further attention.

## Absence of Service Protocol for Local NDD Staffs

POs reported that they were not getting full cooperation from their local BEP management. They were given a number of regular BRAC Primary Schools (BPS) for supervision. Covering those they did not find enough time to see NDD centres properly; instead of three days they go to NDD centre once or twice a week. There were reports that Area Managers and Branch Managers of BEP, with little exception, rarely visited the NDD centres during data collection time. They said that SS is responsible for this centre. On the backdrop, SSs have to work in other branches two-three weeks in a month so they cannot properly look after the NDD centres. POs of Manoshi project of HNPP is supposed to provide support to these centres twice a week. Most SSs and PO of BEP said they did not see much presence of HNPP POs in these centres. No specific activities from them were found or reported during data collection time.

## Reluctance of Some Parents

Some parents sometimes do not cooperate when teachers go to households to bring their children to the centre. Some parents also do not send children timely. Parents/guardians of Dhaka slum centre in particular do not want to come to the monthly meeting. According to SS of the centre,

This centre is performing relatively poorly because of the different kind of slum culture and unwillingness of parents. If parents cooperate with them regarding this issue they can help their children much in the centre.



## STAKEHOLDER'S THOUGHTS ON SERVICE PROVISIONS

## STAKEHOLDER'S THOUGHTS ON SERVICE PROVISIONS

During interviews and FGDs different stakeholders raised some positive remarks, complains and concerns about NDD centres of BRAC. Some of the issues need to be brought to light so that BRAC knows the level of acceptance and/rejections from both demand and supply side perspectives.

### Thoughts of Parents/Guardians

Most of the parents never thought of any schooling for their children. Those few who tried to get their children enrolled to mainstream school experienced direct refusal. Those remaining were lucky. They managed to enroll but could not continue much long because of varied reasons. With those disappointments and having little hope further, their first satisfaction came after getting NDD centres within their reach. Also meeting with people who were eager to take some responsibility of their children gave them some relief and hope of better future. Most parents expressed that they were satisfied with the curricular and co-curricular activities conducted in these centres over the months. Most of them felt that their children were safe in these centres.

Some parents never went to consult with doctors for their children. They were getting doctor once in a month in these centres where they could ask any question about their children. They also valued BRAC effort to take their children to other medical centres for further assessment and treatment. Though very minimum, they acknowledged getting medicines from the NDD centre.

Before coming to NDD centres, most parents had firm believe that their children will never improve. They saw some changes with them and were hopeful that much improvement will happen in course of time if they continue sending their children here. Parents having young children were much motivated than others as they saw rapid changes. Many parents developed a belief that someday these children will be able to do activities for their daily living.

Some parents were concerned about how long BRAC will provide services to their children. By this they basically meant the sustainability of these centres and what will happen to their children when BRAC closes their operation here. They knew better that there is truly none to take care of their children after their deaths.

Also they seemed not to be sure what BRAC will do when their young children will grow old and will mature enough to do some vocational activities.

## Thoughts of Teachers

One teacher from Pabna centre said this is a new project and she is not sure whether all guardians are satisfied or not about the centre. She also said there could be some failures from their side. There were teachers who believed that BRAC is trying to improve NDD centres and activities done under these centres are quite good. As teachers they were happy with what they were offering to these children. One teacher from Khulna said an interesting thing, "We do not know how perfect our activity is but we are sure it is actually not doing any harm to children". Other teacher from Dhaka mentioned,

Quality of our services can be questioned and things can be even better. But we are at least happy because we are serving a very special group of children who otherwise won't get any service at home. We are also happy meeting some of the unmet needs of these children.

One thing teachers especially care about is children have disability and they are from very poor households where most services do not reach. They feel proud shedding little lights on double vulnerabilities of disability and poverty. One teacher said, "Children like me very much. Seeing their faces I become affectionate to them".

Another teacher from Khulna said,

None of the family members except parents love these children at home. They are getting our love coming to this centre. My heart touches seeing such children. So I am working here as if they are my children.

Similar feeling was echoed by another teacher from Pabna, she said,

I enjoy working with these children. I feel good when I do anything worthy for them because none help them like us. They are usually excluded for teaching and playing but we teach and play with them. When I see joy in their eyes I feel motivated.

Two teachers expressed mixed feelings about their services. They were happy and at the same time were unhappy to some extent. They thought some children learnt many things and were continuously improving but improvement was very slow and low considering their actual age. They said their happiness would increase if they could do something more for these children. They seemed exhausted in trying many different things with these children with impact less than they expected. This may happen because of the traditional understanding associated to teaching and learning and for the lack of experience working with

these children before. Teachers also mentioned that parents did not come up with many complaints on the NDD centres rather they were happy seeing that many of their children were getting benefits.

### Thoughts of Programme Organizers

One PO from Khulna said activities they were doing in the NDD centre were quite good but inadequate for the needs of the children. But he was happy that children were, at least, brought to the centre and were given some kind of education and treatment facilities. He also mentioned that further improvement in service quality was not possible if additional budgets were not given. Another PO from Dhaka said that some parents informed them that they were grateful to BRAC as their children were welcomed here whereas other mainstream school did not. They were happy getting services free of cost. Some of them were seeing changes in children's life. Previously these parents had a feeling that no significant improvement was possible with these children. They now believe that if this centre is managed properly that will certainly impact on their children. According to him, most parents of his centre were different than those of living in the villages. He considered parents as one important factor that they are failing to provide consistent services. Regarding teachers another PO from Pabna said their attitudes were "good" towards these children and they were trying their best.

### Thoughts of Sector Specialists

The SS of Pabna centre said "I believe this centre is contributing a lot on lives of these children and their families". According to him, teachers and caregiver of his centre loved children from their heart and were willing to help them. He believed involving one mother having child with disability as a teacher and other one as a caregiver was the very first reason that they loved other children as their ones. He also said that what activities teachers were doing with children were needful for them. At the same time he believed teachers and other staffs have to gain more skills to run these centres. Regarding performance of teachers, SS of Dhaka slum centre expressed his dissatisfaction. To him teachers of this centre were not serious in their job, their knowledge and skills were poor. For all these reasons, he had concerns over this centre. Another SS from Khulna said he was personally fifty percent satisfied with their activities. He also mentioned that parents were not fully satisfied with the services they were getting from NDD centre. According to him they cannot provide necessary therapies, only provided few medicines to some of the children. Since children were improving even after their inability to provide mentioned services parental demands for those were said to going up day by day, he added.



## EXPECTATION OF FAMILIES, TEACHERS AND OTHER STAFFS

## EXPECTATION OF FAMILIES, TEACHERS AND OTHER STAFFS

### Improving Physical Environment, Establishing Residential Facilities

Setting centres in BRAC's own premises were suggested by different individuals involved with this initiative. As BRAC is committed to provide these children with better life experiences, more space should be there for teachers so that they can offer more one-to-one care. Commonly they said that improved physical environment in these centres will lead to further improvement of the children and it is only possible if they can build centre houses according to their plan instead of restrictions given by other house owners. In line with this expectation, suggestion came for providing residential facilities for all children. Programme Manager said their children will benefit much if they are given full time care in residential facility equipped with necessary furniture and trained personnel.

### More Trained Teachers, Caregivers and other Staffs

At least two more teachers and one more caregiver in each centre should be engaged immediately. Grouping children with their diagnosed disability type or on the current ability should be considered. Then one teacher, primarily, for each group might provide more teacher's time for each child. Combined group activities will also be there and can be better managed by four teachers. Apart from recruitment, centre staffs must be given enough training. According to one SS, all staffs under NDD project including teachers, should be given intensive training on every details of managing and teaching children with disabilities if BRAC really means to provide quality services. He also mentioned that capacity building of staffs involved must get first priority otherwise proper use of time and other resources will not be possible. Another SS suggested that teachers can learn more if they are given the opportunity to see other special schools run by NGOs and private owners for few weeks.

## Qualified Therapists

All the SSSs urged to recruit qualified therapists for providing therapies to these children at least for one week per month in each centre. This they think might show some improvements of the conditions of these children and thus they will feel good, mentally and physically. Qualified therapists may play an important role in training both teachers and guardians so that they can practice on their own. This will ultimately motivate parents to come, teachers to expand their instructions.

## Meals for Children

Children of Dhaka slum centre were given free lunch for few months in 2014 with support from Global Alliance for Improved Nutrition (GAIN). This was reported to have improved eating habits of the children. Thus idea of providing foods for children at centre arose from guardians and teachers of Dhaka centre. Similar respondents from two other centres also expected meals for children as they heard of the positive impact. This was suggested for couple of reasons like food will motivate children to come to centres and parents will worry less about food of their children while they are in the centre. Also this will provide community a sense how much BRAC cares about these children.

## Centre Van

Most parents requested to provide a van for them so that their children are easily picked up from home. This initiative will certainly lessen parental cost for transportation and will allow them to spend more time in doing their household activities. Teachers also think that by providing a van in each centre BRAC can expand their coverage so that more such children can be served.

## One Television in each Centre

Knowing that most of the children coming to NDD centres are visual learner, most teachers expected one television in each centre. They mentioned that training children with audio-visual materials will help mental development of these children. This can only be given after making clear planning on when and how much to spend with watching television and what contents/items should be there considering the needs of the children.

## Uniform for all Children

Both parents and teachers requested to provide uniform to all children so that they feel more like they have school and uniform like their siblings. Also, this will

ensure equity in the centre as most parents belong to poor community, but some are poorer and cannot even buy dresses for their children.

### Training/education for Parents/Guardians

Training parent/guardians on management of children with disabilities is urgent to get the most from them. Since children spend more time at home with their parents/guardians they need to have better ways to deal with their children. Participation of their father in such training must be ensured because without their cooperation mothers cannot do much for their children. As part of NDD centre operation more activities on educating future parents about the prevention of childhood disability can contribute immensely.

### More Community Awareness

BRAC can make more people and communities aware about rights of children with disabilities using their existing networks and capacities. This can start with more promotional activities around NDD centre catchment areas so that more families show their interest to send their children. It is also possible that some parents have some prior understanding of BRAC activities and are coming with their children just to get immediate benefits of cash or kind. This is the kind of social dynamics already developed because of long presence of so many development organizations in this country. Thereafter, solid campaign, mobilization and one-to-one sharing with parents and families are urgent to make people aware and to get possible cooperation from them.

### Vocational Activities for Children

There was consensus among parents and teachers that most of these children perhaps automatically be dropped out from the centre as they grow up physically. So they suggested BRAC to think of vocational training for their children. Suggestions came to train their children with skills they can use for earning money. Some of the guardians seemed to believe that BRAC will initiate that sorts of activities someday.

### Income Generating Activities for Attendants

As some mothers or grandmothers come to the centre regularly with their children and spend three hours, some money making activities for them can be introduced to get better use of their time. If they find opportunity to earn while attending their children at centre they are likely to be more motivated to continue helping them as many months as required.



## DISCUSSION

## DISCUSSION

PWDs are the most neglected and isolated persons in the Bangladeshi societies as people at large do not have clear understanding about disability. On top of that, experience of children with neurodevelopmental disability might be even worse. Many superstitions are still discussed about disability issues within families and in the societies. They are given bad names based on their physical impairments which destroy their self-esteem. This negative tone creates a barrier for their further improvement. Mothers who give birth to a child with disability are still treated very badly and are sometimes held responsible. Because of their physical limitations along with people's behaviors towards them, PWDs cannot do many things as easily as others without disabilities can. But most societies take it for sure that they cannot do anything. As human they cannot express many needs. So they are ignored or neglected by many people.

Criticism, bullying has reduced in the community to some extent in recent years. Many people treat them positively though few people really act for them. If children with disabilities are given treatment, education, vocational training and assistive devices they can improve from their handicapped situation and can do something for themselves, for their families and communities. Believing in this philosophy BRAC is trying to do something for children with disabilities though it is not so significant compared to other development interventions it has in Bangladesh and in some other countries.

Analyzing the situation of children with disabilities in Bangladesh, UNICEF (2014) reported that children with intellectual and developmental disabilities tend to be the most marginalized as their education is dependent on NGOs. On a similar note, Das and Kattumuri (2010) mentioned that NGOs of India play an active role in education for children with disabilities since the early 1950s, particularly in urban areas. Some of these NGOs are making consistent efforts towards including children with disabilities into regular educational settings. BRAC's community approach to disability covers children with neuro developmental disability in their NDD centres. There is currently no centre of that kind in the country for the poor communities that cater four plus categories of children in the same class.

In the NDD centres children are provided with lessons and demonstrations to develop their daily living skills to the best of their abilities. Along with some basic literacy activities they are given the opportunity to participate in cultural activities like singing, dancing, and acting and in both indoor and outdoor games. Article 31 of Child's Right Convention urges that state parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts (The United Nations, 1989, art. 31). According to UNICEF (2014), recreation, culture and sport may seem like luxuries for children with disabilities, but in fact they are fundamental to their full development.

Parents and teachers of this study reported that they are seeing physical and mental development of their children due to co-curricular activities they are getting in these centres. Now these children should be given exposure to a range of community environments so that they get more societal integration and expanded opportunities. Children of these centres also need to take care of to connect with mainstream schools.

As discussed earlier, there is a growing realization in Bangladesh that the main constraint faced by children with disabilities is not the child's impairment, but widespread prejudice and discrimination (UNICEF, 2014). This study reports that the NDD centres are contributing to changing attitudes and beliefs about disability in society. As families are seeing some improvements with their children, more people are becoming interested to these centres and more importantly to these children. They are also having more information on prevention of disability and their responsibilities to anyone going through disabling situation. Thus this project can be considered a successful one as service recipients accepted it regardless of the constraints they have. According to Elkins, Kraayenoord and Jobling (2003), parents have to have confidence in the capacity of the schools to understand and effectively educate their children with special needs. There are also scopes for BRAC to involve parents with different activities of NDD centres. According to Blok, Peetsma and Roede (2007), it is important for parents to feel that they are involved in the education of their child and if parents participate in this way, they will gain a better understanding of the school's aims and methods, and will feel more closely involved.

There is lack of teachers in NDD centres and those working do not have necessary skills to address needs of all children. Parents found the teachers are willing to meet the needs of children, but they lacked the understanding or skills required for effective teaching. The researcher also felt that the teachers lacked the knowledge about the special needs of the children. Teachers reported that they did not have the necessary formal training to handle such classes. They all

reported that they were doing their best for the children but were not confident about this. Obeng (2012) did a survey in Ghana and found that most of the teachers did not use special instructional activities that could have benefited the children. In particular, some of the surveyed participants indicated that they did not conduct any special activities unique to the needs of children which resulted in a lack of academic participation from some of them. Blok et al, (2007) suggested that a high level of expertise is required. BRAC needs to employ more teachers in the NDD centres and that should be proportionate with the extent of disabilities of children enrolled. More importantly they have to train teachers as much as needed so that their job no longer is unpleasant as well as burdensome to them. They have to make sure that teachers are providing support in not only caring for the physical needs of the children such as eating, toilet care but also in their academic work. Specialist services like speech therapy, occupational therapy and physiotherapy should also be in place for gross development of the children they are bringing to NDD centres. Adequate special equipment for children's therapy needs were not available in any of the centre. As these centres are not fully equipped yet to properly serve all these different categories of children BRAC management must pause a while and think of creating environments needful for the children. Because including children with different disabilities is good as long as they are given the support and resources they needed.

Another stricken thing about the NDD centres was the absence of service protocol for local staffs. Probably there was a gap between instructions given from the head office to the field offices and thus synchronized provisions of services are yet to establish. One thing was very clear that local staffs from BEP and HNPP were given additional charge of looking after NDD centres. They were basically part-timers and for this they had no choice than to see this as "proxy" activity although they were said to be instrumental for whatever success the NDD centres achieved so far.

Most of the challenges reported here are primarily due to inadequate budget given for this very special project. BRAC management has to understand that running these types of special centres is usually far more expensive per head than regular school setups. According to UNICEF (2014), this type of service depends heavily on external funding and individual, corporate donations from within the country. Although this is seen as a challenge for BRAC, it has opportunities for linking with development partners for funding in order to enable these centres function properly.



## CONCLUSION AND RECOMMENDATIONS

## CONCLUSION AND RECOMMENDATIONS

BRAC established the NDD centres to help a specific group of children with neuro developmental disabilities. The purposes of this study was to examine and describe the services provided to children of NDD centres and to identify supportive factors and challenges. Areas that needed improvement were also identified. The teachers and programme staffs were formally interviewed. Some children, caregivers of three centres and two community members were met for informal interview. FGDs were conducted with parents/guardians. Data obtained from multiple sources was combined and triangulated to prepare this report. Seven main themes were reported with a number of interrelated sub-themes with each.

Children with disabilities identification survey at household levels is the first task BRAC staffs do before setting a NDD centre. The parents play an important role in deciding whether or not to send their child to centre and BRAC staffs spend much time convincing them. After all these ground works about 100 children between the ages of three and 18 years with varying degrees of disabilities were brought to three centres under this study. It was found that most children came from the surrounding areas of the centres and most of their families were very poor. Children were brought to the nearest hospitals and centres for initial diagnosis and assessment was done on a case-by-case basis. Two teachers were working in each centre and one caregiver supported them to ensure that the children could participate as much as possible. Children attended here for three hours in the morning session, six days a week. Some parents often stay during the hours to help their children learn what is taught.

At the NDD centre children received a range of care including education, exercise, opportunities to both indoor and outdoor games, socialization training, toilet training, activities for self-care and so on. Individualized education plan were also followed. Interviews, FGDs and observations showed that most activities were intended to help children become more independent through functional skills training. Curriculum included teaching about body parts, fruits, flower, and vegetables, colors and co-curriculum activities include singing, dancing, acting, reciting poems, drawing and storytelling. Health check-ups were carried out once

in a month by doctors of HNPP programme. Mothers were shown exercises and activities to stimulate their children. Medical support given was reported as minimal though. Parents meeting held once in a month to discuss children's progress and problems.

Some parents experienced lots of difficulty in getting their children into any school over the years, but they were very pleased on BRAC that their children had finally been accepted into NDD centre. Some parents felt that their children were "safe" in these centres and most of them commented that the work centres do was "good". They seemed very positive about the support given to their children. Finally gaining entry into a school like centre some children were reported to smile more, interact more, and their aggressive behavior reduced to some extent. Meeting other mothers with children having similar difficulties their frustrations were lessening. When children were staying in the centre parents got time to work at home or outside which was reducing their workloads. Attitudes and perceptions about disability were also changing for parents' education and community awareness raising activities.

A number of parents did not feel comfortable sending their children to the centre after few days. This can be because their expectations were not met or they were not convinced worth spending time here. For children with most profound disability, centres did very little than family expected. One centre was located in place that became inaccessible for children during rainy season. Enough mobility aids like wheelchairs were not there. Getting local transport was another concern families mentioned. Lack of resources was also marked. Because of shortage of teachers and caregivers it was not possible to provide children the time they needed.

There was a genuine goodwill among most staffs involved with NDD centres. Their favorable attitude toward the children was evident during personal conversation with the researcher. Some teachers described a strong feeling to serve children with disabilities. But they were experiencing difficulties as they did not have the training and expertise necessary to teach and manage these children. None of them had previously worked with children with disabilities; only two teachers had experience dealing with their own kids with disability. All of the teachers said that though they did not know many things but they were trying to figure out ways to help their children. They should be supported so that more educational activities can be incorporated responding to the needs of children.

The NDD centres are still in the preliminary stage and are doing "good" job though some of the performance indicators are still long way to achieve. For this they need a lot more time. Things can be done in a better way only when

its management does not make “perfect” the enemy of the “good”. And drastic measures need to be carried out in order to correct the lapses. Some very relevant aspects recommended below need to be implemented.

- ▶ Valuing and recognizing the importance of NDD centre, BRAC management should mainstream disability by mainstreaming the project. For this, more organized shared efforts should be made within BRAC programmes making disability as a cross cutting theme, otherwise interventions are becoming fragmented and ineffective.
- ▶ Long-term plan including building permanent NDD centres in accessible locations; developing modes of services delivery, code of conducts for teachers and other staffs is must to enhance quality of service.
- ▶ Additional resources like financial, personnel, therapy and play materials and so on need to be made available. To get financial and technical assistance, more partnerships and network should be built with government institutions and with other national and international organisations.
- ▶ Proper linkages need to be established between BEP and HNPP field level staffs and their line managers and to make them accountable for tasks they are assigned for the NDD centres.
- ▶ Create learning environments responsive to individualized needs. Teachers and other staffs must be trained with principles and philosophies of special education and best practices to provide instructions for these children.
- ▶ Ensure active participation of parents in planning and implementation to get them as active contributors rather than passive recipients.
- ▶ Vigorous awareness raising campaign about practical issues that affect children with disabilities should be initiated round the year under the leadership of NDD centre staffs.
- ▶ Presence of NDD centres must be felt and in doing this they should invite the media to cover their activities and stories. This model should be shared with other countries and donors. Further research and dissemination is suggested.

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