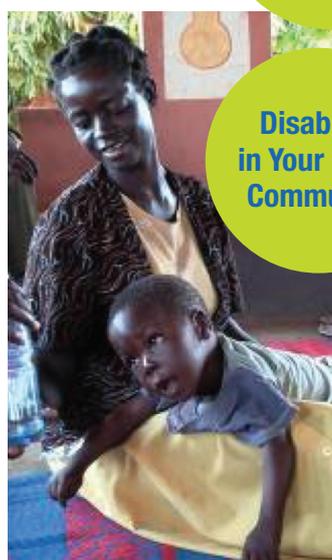


GETTING TO KNOW CEREBRAL PALSY

Working with parent groups – a training resource for facilitators, parents, caregivers, and persons with cerebral palsy



Modified from Hambisela

London School of Hygiene & Tropical Medicine (LSHTM)

LSHTM is the United Kingdom's national school of public health, and is one of the foremost postgraduate institutions in the world for research and postgraduate education in global health.

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The International Centre for Evidence in Disability (ICED)

ICED was established in 2010, and is located within the London School of Hygiene and Tropical Medicine. Researchers in the Centre have extensive experience undertaking surveys and assessing the impact of disability on daily life, including poverty, quality of life, activities and participation, using both quantitative and qualitative approaches. The Centre provides the academic support and contacts with governmental and non-governmental organisations needed in order to work with local stakeholders and translate the findings into practice.

<http://disabilitycentre.lshtm.ac.uk/>

Cerebral Palsy Association (Eastern Cape)

The Cerebral Palsy Association (Eastern Cape) was established in Port Elizabeth, South Africa, in 1955. The primary mission of the Association is to encourage, assist and care for all persons affected by cerebral palsy, and assist them to attain their maximum potential and independently integrate into the community. The Association is a registered non-profit organisation, and is affiliated to the National Association for Persons with Cerebral Palsy in South Africa.

Child Sight Foundation

First established in 2001, CSF is a non-government organisation that aims for the prevention and treatment of children with disabilities. It is an organisation which focuses on establishing a right's based enabling environment for children with disabilities in Bangladesh. CSF services included the detection and referral of children with disabilities for surgery and treatment, primary eye care, assistive devices, therapy, rehabilitation, inclusive education, advocacy and training.

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Cover Photos: Community mapping with parents, Bangladesh (top) and Parent training, Uganda (bottom)

PROJECT TEAM LONDON

Project Team

Parent Training Project Team London School of Hygiene and Tropical Medicine:

Research Coordinator and Main Editor (manual): Maria Zuurmond

Project Coordinator (London and Bangladesh): Ilias Mahmud

Technical Advisor: Joerg Weber (CBM and LSHTM)

PI: Prof. GVS Murthy

Parent Training Project Team Bangladesh:

Pediatric Physiotherapist and Project Coordinator (Bangladesh): Md.Monzurul Alam

Paediatric Speech and Language Therapist: Md Shafiqur Rahman

Paediatric Occupational Therapist: Elaine Lee (Australian Volunteer Service)

Research Associate: Khaled Hossain Joarder

Finance and Project Manager (Bangladesh): Md Ansar Ali

Community mobilisers: Md Sadekul Islam, Md Lokman Hossain, Amiya Kumar Sarker,

Md Anis Lohani, Md Mizanur Rahman, Anjumanara Bima, Md Nejab Uddin

Independent consultants and reviewers

Dr Mel Adams who helped to edit the manual and contributed significantly to the development of the modules on Feeding, Communication, and Everyday Activities.

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Material Design:

RW Design Ltd, Herts t: 01707 876007 m: 07957208962 e: rwdesign@btinternet.com

BANGLADESH CAREGIVER TRAINING PROJECT FOR CHILDREN WITH CEREBRAL PALSY



“Previously I thought that my child would not get better. There is now some development in my child due to participation in the training and I have more confidence that my child will have some development”

Parent, Sirajganj, Bangladesh

BACKGROUND

The overall purpose of the project was to develop and evaluate the acceptability of a model rehabilitation training programme for families of children with cerebral palsy (CP) in rural Bangladesh, where there is no access to community rehabilitation or support services. Furthermore a key objective was to develop a training resource that empowered families, and thus placed greater emphasis on use of a participatory approaches to training at community level.

“Before, my family and people in my community used to say, this child’s suffering is a result of parent’s sin. After taking the training I have explained what causes cerebral palsy to others. Now, no-one says anything like this.”

Parent, Bangladesh



“I had no knowledge about this condition [cerebral palsy] As a result of the training, I have come to know more about the condition and also how to take care of the child. From following some of the methods taught, my child has experienced some development as a result I feel more positive and happier.”

Parent, Bangladesh

The need for a training programme for caregivers emerged following a large survey of children with severe disabilities in Bangladesh [1]. Cerebral palsy was the single most common impairment diagnosed amongst children with a severe disability, with a prevalence of 3.7/1000 children. One quarter of children with cerebral palsy had other impairments, for example, 14% of these children also had epilepsy, 6% had a bilateral hearing impairment and 2% with a bilateral visual impairment. Very few children had accessed assistive devices, therapy, or other related services. Local services available for cerebral palsy were scarce. Uptake of referrals was poor, for a variety of reasons, including lack of support for treatment from other family members.

The parent training program was conducted from June 2011 to December 2012. It was delivered at village level to 14 parent groups, targeting 153 families¹, 63 girls and 90 boys.

Through action research the material was continually adapted and modified to the local context in order to identify what was acceptable and relevant to the target families. This included baseline research to identify the main priorities for families and caregivers, ongoing feedback and reflection from parents/caregivers and staff, case studies with parents/caregivers, and consultation with children.

MODIFICATION OF HAMBISELA TRAINING MATERIAL

The *heart* of this training package is the original training material called ‘Hambisele’, developed by the Cerebral Palsy Association (Eastern Cape) in South Africa.

After extensive reviewing of available resources and training material, this existing training package emerged as one that offered a participatory approach to empowering caregivers. There was no need to re-invent the wheel! In agreement with the Cerebral Palsy Association of Eastern Cape, we agreed to adapt and modify to the rural Bangladesh context. We have simplified many of the sessions, whilst also adding in some additional training sessions, and bringing in additional resource material.

This training manual is intended as a *‘living document’*, that is a document which we expect to be further modified and adapted as it is rolled out and adapted to local context . An impact evaluation will be a useful next step in fully understanding the potential of this training manual in changing the lives of children with cerebral palsy and their families.

ABOUT HAMBISELA

Parents and caregivers are in the front-line of caring for individuals affected by cerebral palsy and assisting with their treatment. Typically, in most low and middle income settings, individuals in rural and under-developed areas had no or limited access to skills and training to assist them with skills development. This very often compromised the level of primary care and therapy that individuals affected by cerebral palsy could obtain in these areas.

¹ 153 families targeted for the training, but unfortunately ten children died during the project period.

To address this problem and improve the level of daily care available to individuals affected by cerebral palsy, especially in rural and under-developed areas, the Cerebral Palsy Association (Eastern Cape) identified a need to transfer skills to parents and caregivers through the following measures:

- Develop training programmes in basic therapeutically-correct skills used in everyday activities for parents and primary caregivers of individuals affected by cerebral palsy;
- Present these training courses to parents and primary caregivers;
- Present group facilitation/“train-the-trainer” workshops to empower facilitators to present these groups in a manner based on adult education principles. Training facilitators from local communities will help to transfer skills into the communities.
- Develop community-based support structures to support parents and caregivers within their local communities.
- Support community-based therapists with specialised skills for the management of cerebral palsy.
- Further development of the pool of specialised therapeutic skills relevant to the treatment of individuals affected by cerebral palsy.

In 2005 the Cerebral Palsy Association (Easter Cape, South Africa) initiated the Hambisela project as Center of Excellence in Therapy for Cerebral Palsy, to develop and promote excellence in therapy for cerebral palsy through community-based programmes. Hambisela is a Xhosa word which means “make progress”.

If you are interested in obtaining Hambisela material, contact info@hambisela.co.za or Web: www.hambisela.co.za. You can also look at a short film about their work at http://www.youtube.com/watch?v=z3UGfBD_I7k

USE OF PHOTOS AND CASE STUDIES

We have used both a mix of photos from Bangladesh and original photos from the Hambisela training material. We found from the early days of training that parents were interested to see children with cerebral palsy from other parts of the world. In all cases there has been parental permission to use the photos.

For the purpose of child protection, in line with CBM’s child protection policy, we have changed the names of all children in the photos and case studies.

References

1. Mactaggart, I. and G. Murthy, *The Key Informant Child Disability Project in Bangladesh and Pakistan Main Report 2013*. International Centre for Evidence in Disability, London School of Hygiene and Tropical Medicine.

MODULE 0:

Before You Begin

“Before, my family and people in my community used to say, this child’s suffering is a result of parent’s sin. After taking the training I have explained what causes cerebral palsy to others. Now, no-one says anything like this.”

Parent, Sirajganj, Bangladesh



Photo: Parent training group, Ullahpara, Bangladesh

THIS MODULE COVERS THE FOLLOWING INFORMATION:

- Why run training for groups of parents and caregivers of children with cerebral palsy?
- An outline of the different modules and how they are structured
- How should the training be organised?
- Who should be involved in the training?
- Planning for home visits
- Monitoring and evaluation – participatory approaches
- Final preparations – top tips

WHY RUN TRAINING FOR GROUPS OF PARENTS/CAREGIVERS?

There are many reasons why it makes sense to run group training courses for parents/caregivers of children with cerebral palsy. Below are just a few reasons drawn from both reviewing the literature and discussions with key disability and other organisations:

- Parents and caregivers are in the front-line of caring for individuals affected by cerebral palsy. Typically, in rural and undeveloped areas, these caregivers have had no, or limited, access to skills and training [1].
- It can make practical sense in contexts where there are scarce opportunities for specialist therapy.
- The benefits of community mobilisation through women's groups in the field of maternal and child health is well evidenced [2-3]. We are borrowing some of those same ideas to see what the potential benefits are for caregivers, most commonly mothers, caring for a child with a disability.
- Training sessions can offer much more than increasing knowledge and understanding amongst caregivers. By setting up a parent/caregiver group, it can offer an both opportunity to improve their skills in caring for their child, and in finding strategies at the community level to address some of the issues which affect them and their child [4-5].
- Parents/caregivers can gain a huge amount of mutual support from meeting with other parents/caregivers.

"I have come know most of the other parents from coming to training. Before training I didn't know them. Now we always talk to each other Whenever we hear about a child developing we can meet at each other's houses, and try to know something better."

Parent, Sirajganj, Bangladesh

Evidence shows that mothers can feel depressed and anxious about caring for their disabled child [6]. Our own research demonstrated a significant difference in emotional and psychosocial wellbeing in parents of children with disabilities compared to other families who did not have a child with a disability [7]. Setting up support groups can offer invaluable opportunities for support for caregivers [2].

In Bangladesh a 'Quality of life' questionnaire was used [8] to measure impact on family life of caring for a child with a disability. The main caregiver – mainly mothers – scored significantly higher in terms of impact on Quality of Life (compared to local parents without a disabled child), on a whole range of measures, indicating worse quality of life. They were more anxious, more tired and stressed, felt less supported, and found it more difficult to communicate about their concerns within the family [7].

"I face terrible problems as my child does not sleep at night. If I can't sleep at night, I feel really bad and tired. I don't get any help from anyone apart from my family. A lot of my relatives and neighbours made remarks like 'this is the result of their sins'. Some of the neighbours say 'Why do you need to take care of him? He is mad, leave him like this'."

Mother, Bangladesh

Stigma is often associated with having a child with a disability. Working together in a group can offer a safe and supportive environment for sharing experiences and discussing how to work to address that at community level.

“I feel very bad, I feel like committing suicide. A few days ago I put my sister-in-laws child on the chair of my disabled child, and she said very bad things to me ‘you want my child to become disabled like yours, that’s why you put him on that chair.’ My husband cried for a while after hearing such comments from his own sister.”

Mother, Bangladesh

WHAT DOES THE TRAINING PACKAGE CONSIST OF?

The training manual is divided into 11 modules¹.

- At the end of some modules there are Resources which can be photocopied.
- There is a separate Display Manual, mainly of photos, which accompanies the training. This material can be laminated and used for running sessions.

For each module there are:



Icebreaker

A suggested activity to start the session



Ask

Suggested questions to ask



Explain

Notes for the facilitator to explain



Activities

Group activities



Materials

Materials you will need for each session. There is some video

material and you are encouraged to make your own short video clips where appropriate to demonstrate issues and help bring the training alive.



MONITORING PROGRESS

The term ‘caregiver’ is used throughout, sometimes used interchangeably with caregiver/parent.

Our experience from running 14 caregiver groups in Bangladesh is highlighted in a green text box in each module. Most of our main caregivers were mothers, but it also included fathers, grandparents, siblings, and adoptive parents.

You may want to provide your own examples and case studies from your own country and context. The training package is intended to be very flexible.

¹ The original Hambisela had 7 modules: Introduction, Evaluating your child, Positioning, Communication, Feeding your child, Everyday Activities, Play. These have also been modified.

LIST OF MODULES



Module	Overview
Module 0: Before You Begin!	This module aims to help you plan for your training. It also provides some useful tools for monitoring and evaluation.
Module 1: Introduction	This provides an introduction to the whole training course, and an introductory session about cerebral palsy.
Module 2: Evaluating Your Child	This helps parents to understand where their child is in terms of development, and setting of some suitable short term goals to achieve. It also provides some basic information about epilepsy.
Module 3: Positioning and Carrying	This provides practical advice to help caregivers to understand the importance of correct positioning and carrying.
Module 4: Communication	This session explores what communication is, why it is so important, and gives practical advice about what you can do to help your child communicate.
Module 5: Everyday Activities	This looks at how to use everyday activities to help your child with cerebral palsy to develop.
Module 6: Feeding Your Child	This is a long module focusing on feeding practices and challenges, and at least 3 sessions is recommended, including a final practical session.
Module 7: Play	This looks at some simple ideas of how parents/caregivers can encourage their child to play using simple local resources and introduces challenges around inclusion in play in the community. There is a third recommended practical session in making toys.
Module 8: Disability in Your Local Community.	This provides basic information on the rights of persons with disabilities and explores some of the main barriers to inclusion of disabled children in the community and the ways these might be addressed.
Module 9: Running Your Own Parent Support Group	This session looks at the value of setting up or continuing parent support groups in your local community, the value of networking, and some top tips for parents/caregivers around how to get the most out of running a group.
Module 10: Assistive Devices and Resources	This provides some useful information about providing assistive devices in poorer resource settings. It also details available resources and materials.

HOW SHOULD THE TRAINING BE ORGANISED?

How often should the training run? Every week? Every month? These are obviously key questions and it very much depends upon your setting, and what works best for the parents in your local context. It is important to discuss these issues with representatives of the target group and to balance needs with available resources to decide on the optimum organisation of the sessions.

How long should each session be? Again this depends on a variety of factors such as the size of the group, parent preferences, and availability of trainers. Don't underestimate how long the sessions will take, especially when you want to be participatory with the group and allow a lot of time for questions and discussions. If you are running shorter more frequent sessions, then you will find that some modules will require 2-3 sessions to cover all the material.

In Bangladesh we ran groups once or twice a month. This allowed time for the community workers to visit families in between sessions, and conduct follow-up visits on an individual basis. However in some contexts, where distances are greater, parents may prefer to come together for a short condensed residential training period of 2-3 days.

We found parents (mainly mothers) wanted no more than 2-3 hours per session, as they could fit that into their busy day. It was also difficult to run longer training sessions because of having a large number of children in the group. Most modules required at least two training sessions to cover all of the material. Parents expressed a preference not to have residential courses. In some cases it was hard for mothers to get permission to attend the courses – husbands and other family members were key gatekeepers in allowing them to attend the training.

WHO SHOULD DELIVER THIS TRAINING MATERIAL?

This training material was developed to be delivered by a community worker and/or therapist who has had previous experience of working with children with cerebral palsy.

- It is expected that trainers have background knowledge of the condition. Most important of all, involve the parents where possible in the training.
- Use this training to identify parents who would be good facilitators in the future and provide them with additional capacity building. Module 9 on 'Running your own parent group' is intended to build the capacity of parent leaders.
- All facilitators should have training experience using participatory approaches. Plan additional training for facilitators, if necessary. The aim of this training is to be **EMPOWERING** to parents, which must come from a more participatory approach.
- Where possible, involve adults who have cerebral palsy in your training.
- Ensure you appoint as many female staff/community workers as possible. Most of the caregivers will be mothers. There is an important component of providing support for the caregiver – generally a mother – as well as for the child, and in many cultures this is more likely to be better accepted with a female community worker. Better still if you train up some of the parents to provide support to other parents.

In Bangladesh the training was delivered by a therapist (physiotherapist, occupational therapist or speech and language therapist) working alongside community workers. The community workers already had some experience of working with children with disabilities. An ongoing debate focused around how much support community workers required to deliver effective training sessions *on their own*. And what, if any, expert ‘therapist input’ was required. It was beyond the scope of this project to explore and evaluate this issue, and it would an important area for future research, particularly in poor resource settings with few rehabilitation services, and where therapists are extremely scarce.

Who should you invite? This training is aimed at Mothers/Fathers/Caregivers/Grandparents of children with cerebral palsy. This training is suitable for children with cerebral palsy of any age. Of course the earlier age that you can start working with children, the better. Encourage them to bring the child to the sessions, as for some children it may be one of the few times that they leave their home and is an important opportunity for playing with other children.

Working at a village level we found that parents of children with other long term disabilities also attended. Some modules, such as the ‘Disability and community module’, are more generic and suitable for everyone. Our project focused on children <12 years, but older children also attended and we found that all the families were able to gain benefits. We found from our case studies that the children really enjoyed coming to the training, most importantly the opportunity to meet and play with other children. For some children it appeared to one of the very few opportunities that they have to leave the house.

HOME VISITS

Some initial lessons learnt from our pilot work included:

- Parents/caregivers can sometimes experience difficulties in applying the information provided during the training sessions, and they often need some additional support at home.
- Community workers can use the home visit to check through with parents what they learnt from the session.
- A ‘home visit/individual assessment’ monitoring form is essential for recording the priorities of the family and the progress of the child. You can focus on individual issues and set realistic short term targets together with the caregivers. A template is provided in Module 2.
- The role of other family members is vital in the care of the child. We found that other family members and neighbours have a real influence on whether a caregiver/parent even attends the training, so a home visit provides an opportunity for engaging with others.



Photo: Child and parents during home visit, Bangladesh

“Before participation in training, our family would not allow us to take our child to other places for treatment. At that time, family members would say that a lot of money has been spent on him, but all for nothing Following the training my child’s physical condition has improved slightly, and my family members now encourage me to attend more training.”

Parent, Bangladesh

- One parent, on their own, can often forget information provided, and a home visit can allow you to review the material with other family members. This can be particularly important where literacy levels are likely to be low and there is more emphasis on spoken learning.
- If limited resources mean that only a small number of home visits are feasible, make sure you encourage more than one member of the family to come to the training.
- Parents can struggle to find time to share information from the training course with other members of the family. A home visit can be vital to help facilitate the sharing of information between family members. We also know that siblings can play an important role in caring for a child with a disability [9] and a home visit can engage with siblings. Try to schedule a home visit for a time when siblings and other family members are likely to be at home.

From our pilot project, home visits appeared to be incredibly **IMPORTANT**. Originally we hadn’t planned any, but the project found that it was essential to have some follow-up at home in order to help caregivers apply what they had learnt in training to their day-to-day lives. There is no one ‘blue-print’ for home visits.

- We found from case studies that a home visit can demonstrate a really positive example of how a child with a disability can be ‘loved’ and can help to address the negative attitudes and stigma which may exist and lead to exclusion at the community level.

“Previously the neighbours did not allow my child to get close to them, they didn’t like him and they also used to push him away. But recently this attitude has changed a bit because they have noticed that you come to our house, and you take him on your lap and adore him. If officials like you can take him on your lap and adore him, then why the neighbours should hate him?”

Mother, Bangladesh

INDIVIDUAL ASSESSMENT OF CHILDREN

The training sessions are intended to be as participatory as possible and to allow caregivers the opportunity to try out the practical advice given. Build in extra time, either before or after the training session, to be able to meet with parents and children individually. It is useful to target children who require some additional support.

In Bangladesh there was a demand from parents to have more individual time with their children, and for example, to have more time for practical advice e.g. reviewing suitable positions or exercises appropriate for their child. We ran some short individual support sessions before and after the training.

WORKING WITH THE CHILDREN

Don't forget the children! Engaging with the children during the training is **KEY!** You will find that most parents will attend with their child with cerebral palsy, especially as the majority of these children are not at school. They will also bring along other siblings. It is really important to plan carefully for this. Caregivers will gain more from seeing how well their child is stimulated through play, rather than through lectures!

"All the trainers are very good. Apart from teaching, they all show affection for the disabled children. Sometimes due to illness and work pressure it is very difficult for my husband and I to attend the training, but my daughter starts to cry if we don't take her. My daughter loves attending the training."

Mother, Bangladesh

Checklist

- ✓ Check out the **PLAY** and **COMMUNICATION** modules and use some of the ideas for planning the work with children for all of the training sessions. It is important that the community workers/volunteers are very familiar with both of these sessions *before you start and use the ideas for all sessions.*
- ✓ Have everyday household objects available for the children to play with such as empty cereal boxes/match boxes/egg boxes, empty plastic cool drink bottle, stones, plastic cups etc.
- ✓ If possible have some low cost locally-resourced simple toys available – check out the play module for some ideas.
- ✓ 1-2 community workers/volunteers should be appointed to be in charge of coordinating activities for children.
- ✓ Make sure the session is fun for the children. Begin or end the sessions with a song which involves the parents and children, and becomes a routine for the training.
- ✓ Remember that parents will learn most from observing how their children can learn to play and communicate in the group setting. If children really enjoyed playing during the sessions, then these ideas are more likely to be taken home.

Voices of Children

In Bangladesh all the children said they really enjoyed coming to the sessions. They felt valued and cared for by the community workers. For some children it was one of the few times that they ever left the house, and it was an important opportunity to meet and play with other children. For some parents their main stimulus for finding time to come to the sessions was because their child really enjoyed it!

“The uncles (community workers) care for me very much and play with me. I like that very much. They teach us exercises. After the meeting they give us biscuits and juice I can play with Aisha and other children I didn’t know the other children before coming to the meeting. Now we are all friends. I love to be with them and play with them.”

Shajna, Child Interview, Bangladesh



MONITORING PROGRESS AND MEASURING IMPACT

It is beyond the scope of this training package to provide a very detailed overview of how to monitor and evaluate the training programme. However some key tips are provided and additional resources recommended at the end of the module. Within individual sessions there are references to participatory M&E tools which were piloted out in Bangladesh.

- Build plans for M&E from the start of your training. Don’t leave it until the end to find out what has worked best and why!
- Decide on what baseline and endline data you want to collect. Baseline data will also help you to understand how best to adapt the training material to your local context and any future group sessions.
- At the end of each module is a Monitoring Question. Document the parent responses and their feedback in terms of how they apply the training at home.
- Conduct a quick and simple evaluation of each session with parents and community staff to check on what went well/what could be improved for next time.
- Have a simple registration form so that you can monitor those who drop out of the courses. You may find that those who drop out are the most vulnerable, and need extra support at home. It is important to follow up with people who leave the training to understand their reasons and how to best support them.

In Bangladesh a very small number of families dropped out of the training. We looked at some families who stopped attending the training sessions in order to understand some of their challenges, and how best to address these issues.

“I don’t want to go to training because I go back to work after coming back from the training, and I don’t get the time to implement what I learn from the training at home. I did not even share what I learned from the training with my wife.”

Father, Bangladesh

- A home visit monitoring form allows more tailored evaluation of the progress for each individual child, and for measuring impact. (See Module 2 for example of home visit form.)
- Evaluating some of the softer outcomes, such as measuring the ‘empowerment’ of parents can be a harder challenge. There is no one simple tool. Decide with your team what indicators you might use to measure this, and how you will collect the data.
- There are useful participatory monitoring and evaluation tools which can be used. Check out the resource section of Module 10 for additional materials for M&E.

In Bangladesh one aspect of empowerment which was evaluated was how parents benefited from being organised into parent groups; what new networks they developed at the village level as a result of the training, and what was the impact of that. We asked parents to map out which families they knew had a disabled child before the training, and which families they knew after the training.

“I have come to know most of the parents through going to training before training they were unknown to me. Now we always talk to each other. We all meet Whenever we hear about a child developing, we meet him at their home, and try to find out more.”

Parent, Bangladesh



Photo: Mapping networks at village level. Black pen = families with children with disabilities known before the training. Blue pen = families known as a result of the parent training.

A tool which is popular for evaluating impact is the ‘Most Significant Change’ (MSC) methodology. For details of how to use this approach in a simplified way, check out the resource section of Module 10.

In Bangladesh, families were asked to tell a story about the most significant changes which had resulted from their participation in the training. Families initially focussed on the physical changes that they saw in their child as a result of the training. The project coordinator was a physiotherapist, which may have had an influence on this. Parents were prompted to also consider changes for (1) themselves, (2) at the level of the family/ community and (3) for their child.

- **It is essential that you involve the children in monitoring and evaluation.** Ultimately they are the beneficiaries. Ask the children about their lives and what is important for them, what they think of the training, and how might it be improved. It may take more time to involve children who have difficulties with communication, or have an intellectual impairment, however there are a variety of approaches that you can use. For a fuller range of resources on how to involve children check out the resources at the end of this section.
 - Use pictures and diagrams and ask children to point to what they enjoy/don't enjoy.
 - Work with a familiar caregiver who knows the child and is much more familiar with how the child communicates – they can help to translate.
 - Use more participatory approaches that engage with the children and don't depend upon an 'interview'.

Voices of Children

In Bangladesh we adapted a participatory tool approach called the 'Feeling Dice' to 'interview' children [10]. Children were given a dice to play with. They were asked to draw different expressions on the dice (each side was a mini white-board). You could also use a dice where the pictures are already drawn.

According to which side of the dice was showing they were asked they were asked about their everyday lives and prompted to say *"I am happy when, I am sad when, I am frustrated when"* This approach was also used to prompt questions about what they liked/disliked about the training.

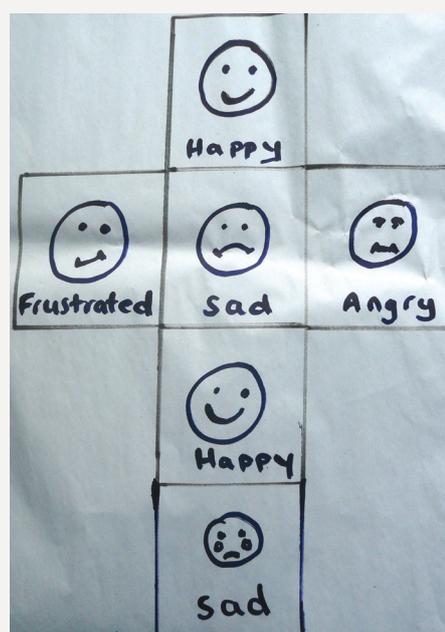
Some children needed help with the drawing on the dice. In some cases we used pictures, and asked the child to point to pictures to explain what they enjoyed doing. For one child who had more difficulties with speech, closed questions were used which required a 'Yes' or 'No'.

"If my mother does not take me to the school I feel sad. My mother is busy, which is why sometimes she can't take me to school. Taking me to the school is very pain-staking job for my mother; I feel bad seeing her pain."

Atia, 14 yrs old



Photo: Child using the Feeling Dice to explain their views, Bangladesh



FINAL PREPARATIONS

If your parent group is already running, or if your training is embedded in a wider CBR programme, then many of the following conditions may already have been planned for.

Checklist

- ✓ Involve parents in the planning and organising of the groups from the beginning. This will help facilitate ownership of the training, and will support future sustainability of the groups.
- ✓ The suitability of the meeting venue is really important. Involve the parents in deciding what a suitable venue is for them. Physical access and transport to the venue site are important.
- ✓ A number of the children will have problems with toileting and incontinence, so access to water and to a toilet are important. Have some towels and cleaning materials available. Plastic-covered foam mats for children to sit on can be useful as they will be easy to clean.
- ✓ Engage with local key stakeholders, to explain the purpose of the training, and the importance of a suitable (and clean!) venue. Remember that some of the children may need to lie on the floor.
- ✓ Privacy can be an important consideration – although not always easy! A venue right next to a school or marketplace may result in lots of observers, and parents may not feel so comfortable. Check out with the parents what they feel comfortable with.
- ✓ Make sure that the sessions are **FUN!** Many parents work full time, and many mothers work full time as well as being the main caregiver. Taking time out of the day can be a big commitment. Have some good icebreakers at the beginning and end of the session. A good way to do this is to use songs with the children – this is popular with children, as well as helping with communication.

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