

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)

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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.

References

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4. Maloni, P.K., et al., *Perceptions of disability among mothers of children with disability in Bangladesh: Implications for rehabilitation service delivery*. Disability & Rehabilitation, 2010. **32**(10): p. 845-854.
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9. Craft, M.J., et al., *Siblings as change agents for promoting the functional status of children with cerebral palsy*. Developmental Medicine & Child Neurology, 1990. **32**(12): p. 1049-1057.
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MODULE 1:

Introduction



Materials

Flipchart, display material, pens



Icebreaker

Welcome everyone to the first session. Explain how long the training programme will run and how long each session will run for. It is assumed that the parents/caregivers will already have been involved in the planning for the training; in choosing the suitability of the venue and the timing of the sessions.



Ask

the group to introduce themselves, and to say what their expectations are for coming to the group today. Clarify what expectations will be met through the training course, and what will not. It is important to manage expectations from the outset.



Explain

the overall outcomes (goals, aims) of the training programme.

Use this as an opportunity to clarify what the training programme can and cannot cover, and how this relates to their expectations. Display diagram 1.00 which provides an overview of the different sessions.

Emphasise that 'treatment' can also be through play, through making small changes to everyday activities, and through caregivers coming together and sharing ideas and strategies within the group.





Explain

Outcomes for the module (on flipchart).

As a caregiver you will:

1. Have an overview of the overall training programme and what it will cover.
2. Understand what cerebral palsy is and its causes, and how the brain influences movement and posture.
3. Recognise and understand some of the challenges and associated conditions often found in connection with cerebral palsy.



Explain

how the training will be run. Sessions are not planned as lectures, and are intended to be **participatory**. It's as much about learning from each other's experiences. You will be getting to know more about your child's disability (cerebral palsy) together, and having the opportunity to share your experiences of caring for a child with a disability. Comments and questions are always welcome.

Ground Rules: You may want to discuss with the group some simple guidelines for how the groups should be run.

In the Bangladesh project **Managing Expectations was an essential part of this introductory session**. Our project found many parents were expecting a cure for their child, as well as expecting to receive a sophisticated wheelchair and/or medication. Most parents had never had a diagnosis for their child despite numerous trips to health services and traditional doctors. Managing expectations will of course depend upon how this training fits in with other services available locally for families, and what your project is able to offer. In Bangladesh this training was delivered as a 'stand alone' project with very limited other rehabilitation services available for parents, and thus expectations were high for 'therapy', provision of assistive devices, and 'medical treatment'.

WHAT IS YOUR UNDERSTANDING OF CEREBRAL PALSY?



Materials

Flipchart and pens



Ask the following questions and discuss as a group.

- *Has anyone ever told you why your child is not developing as expected, or why your child is disabled? What has the doctor or nurse, or traditional doctor told you?*
- *What do your family or neighbours say about your child?*
- *Have you ever heard the words **CEREBRAL PALSY**?*
- *Can other children catch cerebral palsy? Is it contagious? No. It cannot be passed from one child to another.*

- *Can cerebral palsy be cured?* Cerebral palsy cannot be cured. Early help and training can help children's development.
- *Has anyone told you that CP is caused by witchcraft or because you have done bad things in your past?* Discuss their experiences. Refer to the example below in Bangladesh, and ask how this compares to their experience?

In Bangladesh, as in many other countries, one of the most commonly held views is that cerebral palsy is caused by witchcraft and bad spirits. Many families in the project had spent a considerable amount of time and money visiting various traditional healers. It was really important to take time to discuss these issues and to emphasise that cerebral palsy is not caused by witchcraft.

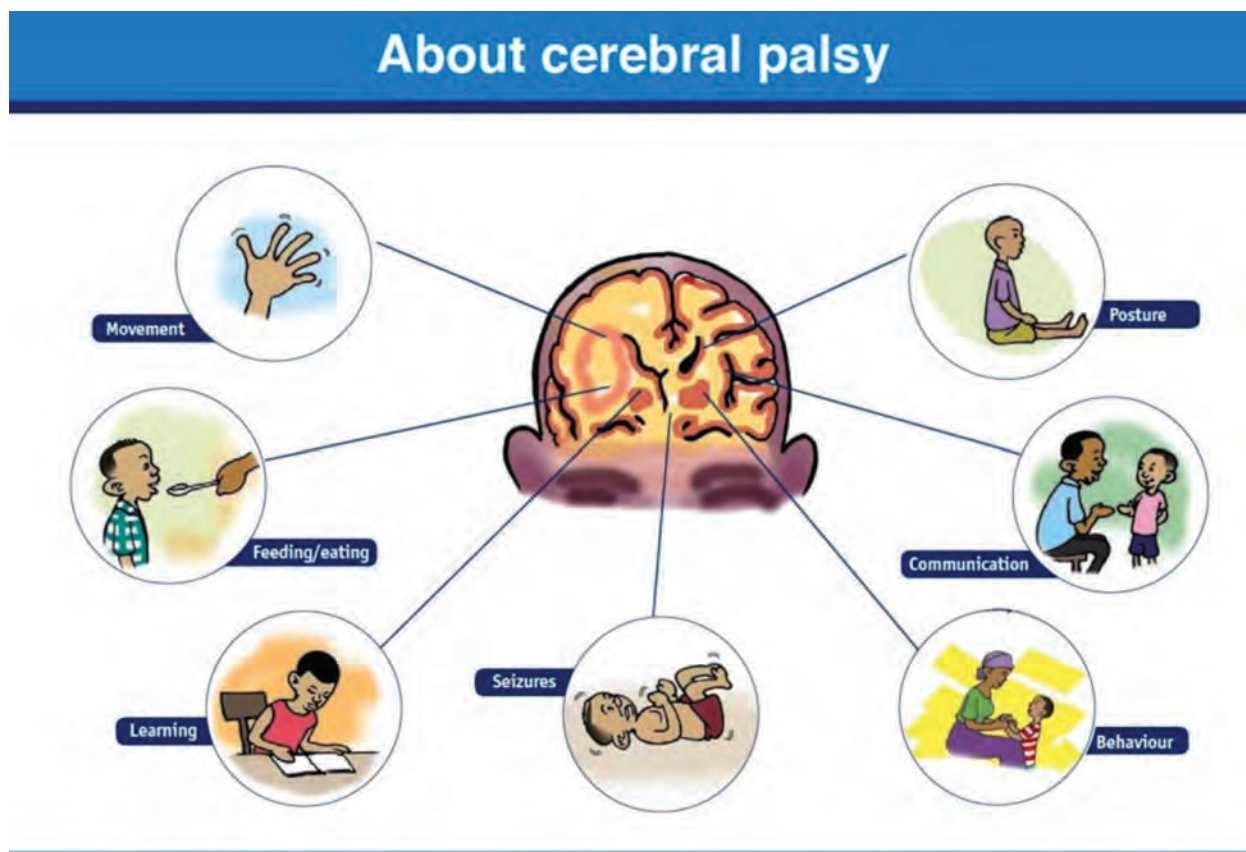
"I took her to a traditional healer after examining the child the healer told us that she was encountered by a bad spirit. The healer came to our house many times. He told us, if you sacrifice two pigeons, then your child will be fine. After I gave her the pigeons, the healer applied witchcraft and gave her a talisman. But she did not recover at the treatment of the healer. After that I took her to almost 20-30 healers. All of them gave similar treatments, and it did not cure her."

Parent, Bangladesh

WHAT IS CEREBRAL PALSY?



Materials Diagram 1.02 (from CBM International 2012, How can you help your child with cerebral palsy (flipchart) available at <http://www.cbm.org/Publications-252011.php>)





Explain Put up the diagram above and discuss. Explain that cerebral palsy is damage to the brain causing problems with movement and posture, and often communication, feeding/eating, seizures, learning, and behaviour.

Go through each picture in the diagram above and give an explanation for each. Below are some explanatory notes to aid discussion. Additional background references for the facilitator are suggested in the Resource section of Module 10. Encourage discussion and ask the caregivers for each if their own child shows these symptoms.

Feeding problems: A child may have difficulties with sucking, swallowing and chewing. She may choke or gag often. Even as the child gets bigger, these and other feeding problems may continue.

Communication difficulties: The baby may not respond or react as other babies do. This may partly be due to floppiness, stiffness, or lack of arm gestures, or control of face muscles. Also, the child may be slow in beginning to speak. Later, some children develop unclear speech or other speaking difficulties. Although caregivers find it hard to know exactly what the child wants, they gradually find ways of understanding many of the child's needs. At first the child cries a lot to show what they want. Later they may point with an arm, foot or using their eyes.

Intelligence: Some children with cerebral palsy do have intellectual difficulties. Some children may seem dull or lacking intelligence, because they are limp or move slowly. Others move so much and so awkwardly that they may also appear to lack intelligence. Sometimes their faces twist, or they may drool because of weak face muscles or difficulty swallowing. This again can make an intelligent child appear mentally slow.

Seizures (epilepsy, fits, and convulsions) occur in some children with cerebral palsy.

A child disability study in Bangladesh showed that 14% of children with cerebral palsy also had epilepsy [1].

Behaviour: Sudden changes of mood from laughing to crying, becoming frightened fits of anger, and other difficult behaviour may be present. This may partly be due to the child's frustration at not being able to do what he wants with his body. If there is too much noise and activity the child can become frightened or upset. The brain damage may also affect behaviour. These children need a lot of help and patience to overcome their fears and other unusual behaviour.

POSTURE AND MOVEMENT



Materials

Display photos 1.03a-c

Muscle stiffness: Some children have **muscle stiffness**, or 'muscle tension' (this can be called Hypertonia). This causes part of her body to be rigid, or stiff. Movements are slow and awkward. Often the position of the head triggers strange positions of the whole body. The stiffness increases when the child is upset or excited, or when her body is in certain positions. **The pattern of stiffness varies greatly from child to child and she has no control over these movements.** Muscle stiffness is the most common way that individuals are affected by cerebral palsy.



Picture 1.03a



Picture 1.03b

FLOPPY



Child hangs in upside down 'U' with little or no movement

Picture 1.03c

Floppy: Another type of cerebral palsy is when the child's muscles are very floppy. Children who have very floppy muscles often look like the children in these pictures. The floppiness of the muscles can make it difficult for the child to move easily, and she may get tired quickly, for example when trying to sit by herself. When she lies on her back, her legs will often flop outwards.

Uncontrolled movements: Some children with cerebral palsy will have uncontrolled movements. They have difficulty staying still and stable. They cannot control these movements.

Poor Balance: The child, who has 'ataxia', or poor balance, has difficulty beginning to sit and stand. She falls often, and has very clumsy use of her hands.



Explain that there are other conditions which may be associated with cerebral palsy. Remember that children may have one, a few, many, or none of these associated conditions:

- Poor eyesight/squint
- Hearing difficulties
- Growth problems
- Dental problems
- Constipation
- Sleep problems



Ask the caregivers if any of their children have problems with these associated conditions. We will be discussing some of these conditions as we go through different modules of the training.

In the child disability study in Bangladesh 6% had a bilateral hearing impairment and 2% had a bilateral visual impairment [1].

CAUSES OF CEREBRAL PALSY



Ask What do you think causes your child's condition (cerebral palsy)? What do you know about the causes? What have you heard? What do you believe?



Explain There are many possible reasons why a child may have cerebral palsy. A cause can be any incident that causes damage to a part of the brain, or which affects the development of the brain, such as lack of oxygen. This damage can happen either (1) before birth, (2) during birth, or (3) shortly after birth. Often the doctors don't know what caused the cerebral palsy.

The following table shows some key risk factors that are associated with cerebral palsy – either before, during or after birth.

Before birth	Around the time of birth	After Birth
<ul style="list-style-type: none">● Unknown cause● Alcohol and other drugs● Infections and illnesses of the mother while she is pregnant	<ul style="list-style-type: none">● Unknown cause (in 1/3rd of cases no cause can be found)● Lack of oxygen (air) at birth● Birth injuries● Baby born too early	<ul style="list-style-type: none">● Brain infections● Malaria● Head injuries● Lack of oxygen

WHAT DOES CEREBRAL PALSY LOOK LIKE?



Materials Photos 1.04a-1.04h in display material (you can add in your own pictures to this set).



Activities Ask the caregivers to walk around the room looking at the different pictures of children with cerebral palsy. Give them adequate time to look at these and to discuss the questions below. Can you see any pictures that remind you of how your child looks? Maybe you have seen another child who looks similar?



Explain As you will see in the pictures, no two children look exactly the same. It is important to remember that cerebral palsy affects every child differently.



Ask each group member to share their story and think about the following questions: How do you feel about having a child with cerebral palsy? What do you hope for your child? They can share as much or as little as they feel comfortable with, and use whichever language they prefer. If they prefer not to share their stories at this time that is also fine, as they may feel more comfortable later on, when they know other members of the group.

At baseline, the main caregiver was significantly more likely to report that they felt more isolated, lacked support from others, and that there were problems with talking to others about their child's health. This was compared to other local families who did not have a child with a disability¹. The training sessions therefore offer valuable spaces for sharing and discussing their experiences in caring for their child.

"There are many children with physical disabilities in our village. I didn't know them before. As a result of coming to the training, we have now got to know each other Everyone wants to know about the development of each other's children, and I can talk about my child's health."

Parent, Bangladesh

Allow plenty of time for this group discussion – it's probably THE MOST IMPORTANT part of this module. Summarise the time of sharing before moving on. For example, if it has been an emotional experience for some, acknowledge their feelings. Emphasise the many experiences shared between them and remind them that they have the opportunity and ability to support each other because of this, and that no one should feel alone in the group.

The Bangladesh project found that caregivers really valued looking at the various pictures of different children with cerebral palsy, and discussing similarities with their own children. For most of them it was the first time they had seen pictures of other children with cerebral palsy, and for others it was the first time they had met other parents of children with cerebral palsy – even from within their own village. This activity created a lot of discussion and sharing of stories in the group.

"Initially, I thought my child may be cured by a doctor or traditional doctor. Then I saw that he wasn't cured I understand more about the condition [cerebral palsy] by participating in the training and as a result of this my child has been developing. Now I feel less physical and mental pain."

Parent, Bangladesh

¹ 135 families with a child with cerebral palsy were compared to 150 'normative' families using a standard Paediatric Quality of Life (PedsQL™) Family Impact Module. The results related to emotional functioning and communication have been simplified.



MONITORING PROGRESS

Explain to caregivers that it is very important that you understand this information yourself. Additionally, it is just as important that you share the information you have learned with the other members of your household, and with your neighbours and your community. You will probably need to practice sharing this information so that you feel comfortable doing it.

In pairs/threes, ask the caregivers to tell each other in their own words what cerebral palsy is. Encourage them to give feedback to each other about their explanations, based on what they have learnt in this module.

Ask each participant to say one thing that they found most useful about coming to today's session and that they will share in their family? Is there one thing they found less useful (if anything)?



Materials

Flipchart with take home messages.

Take Home Messages:

- Through training together we can make a big difference to the quality of life of every child with cerebral palsy.
- Share what you are learning with the other people who are part of the child's life – family, friends, and neighbours.
- Cerebral palsy is damage to the growing brain. The earlier you start to help your child to learn, the more she can develop.

References

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MODULE 2:

Evaluating Your Child



Materials

Pencils, flipchart, copies for each participant of skills cards 2.01, development charts (2.02-2.03), home visit/individual assessment forms (template in resources).



Icebreaker

Remind the group that in the last session we learned about cerebral palsy and what it is. Ask *Did you try to explain what cerebral palsy is to someone else in your home? Was it easy to find the right words to do this? What was the response from other family members? Are there any issues from the last session that anyone wants to cover again?*



Explain

Outcomes for the module (on flipchart).
As a caregiver you will:

1. Have a clearer understanding about the basics of how children develop and be able to explain this to someone else.
2. Be able to observe your child with cerebral palsy, and show where she is on the development chart
3. Be able to plan some activities that could be suitable for your child to learn next.
4. Be able to recognise 'fits' (epilepsy) and know what action to take.



Activity In small groups discuss the following: *Think about your child and what you do with her every day. What are some of the skills you would like her to learn or get better at? They could be very small skills or something much bigger.*

Hand out copies of cards below (Display material 2.01) showing a set of four skills and accomplishments. Ask the group to discuss the sentences and put them in order of priority: *Which skills are **MOST** important to you for your child to learn first, then second, third, and fourth?* They can then look at how each group has prioritised the issues and discuss altogether how they have come to the decision.





Materials

Materials 2.01

Make sure you have cut each card into four separate sentences beforehand!

1. Communication	2. Self-care activities such as eating, dressing, toileting
3. Moving around from place to place	4. Walking (if possible)



Explain

that communication is one of the most important skills that their child can learn. *Ask if they can say why?* As the training progresses, we hope they will come to agree, even if they do not yet. Explain that being able to communicate in some way with others, allows us to build a relationship with them. Additionally, a child with a disability can learn to help with her self-care skills even if she is not able to move around from place to place, or walk.

DEVELOPMENT AND PRACTICE



Materials

Pictures 2.02 on card

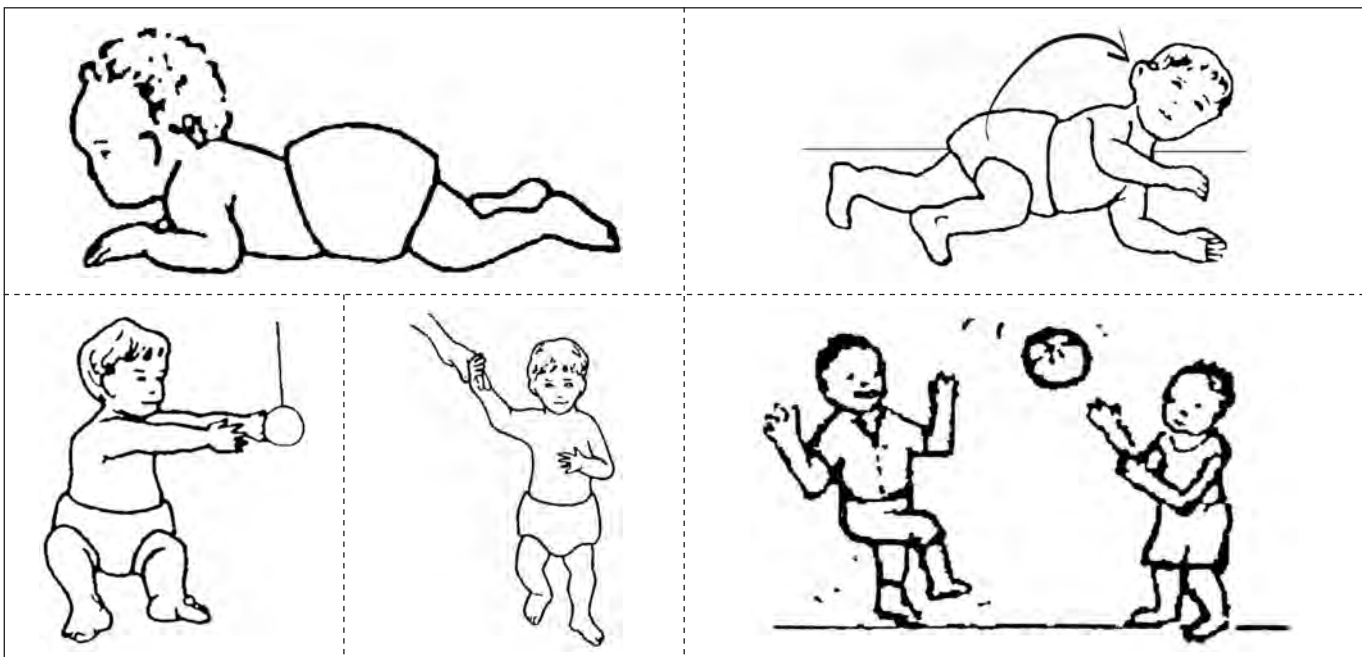
(enough copies for one set per group)



Activity

Put up the five pictures below in random order (Pictures 2.2). Discuss the pictures in small groups. *Decide on the correct order in which you think most children usually develop.* Explain that you will now look at the usual order of development for babies and children, and lay the pictures out in the correct order.

Pictures 2.02





Ask the groups the following questions. *Can you think how you have seen your baby or child trying to do things? And what happens? If a child has difficulty moving what do you think it needs to help it to learn to do things?*



Explain Babies learn by doing the same activity over and over and over again until they get better at it. We know, however, that a baby or child with cerebral palsy has damage to areas in her brain, and therefore **may not be able to move by herself**, or perhaps only with great difficulty. Or maybe when she does try to move by herself, her tongue or limbs or head keep going into really difficult positions, meaning that she cannot learn to do things by herself. That is why development in a child with cerebral palsy is slowed, or blocked, or seems to be stopped. If your child has difficulty doing things on her own, you will have to help her practice, over and over again. Thus a child with cerebral palsy needs **extra time** and **extra help** to keep developing.

DEVELOPMENT CHARTS



Materials

Development Charts 2.03a, b and c (see resources at end of the Module).
Make sufficient copies for each caregiver



Activity Hand out the development charts to each participant (enough for 1 copy per person). Explain briefly what is happening in each of the pictures.

There will be four categories for **Movement**:

- Head and body control
- Sitting
- Moving from place to place
- Using hands

Plus

- a category for **Thinking and Playing**
- a category for **Communication and Interaction**
- a category for **Social and Self-help skills**

Deal with one section at a time, and allow time for lots of discussion and interaction. Working in small groups, ask the parents to mark (in pencil) where their child is on the development charts.

*Look at each section of each page of the development charts, and tick off all the things that you have seen your child do. If you are unsure, when you get home, ask other people in your family, or a friend, or a health worker to help you. Put your child into each of the different positions to see what she can do. When you have finished, the chart should show where your child fits in each row. Remember, there is no right or wrong answer. You are building up a picture of where **YOUR** child is with her development.*



Ask *How do you picture your child in 2 months time? In 1 year? What do you hope for your child?*
Allow time for discussion.



Activity Give out the **Home Visit/Individual Assessment Form** to each participant and talk through the form with them (see template in resources). This activity will provide an important link between the training session and any home visits/individual assessment. Ask the caregivers to consider the following, and use this to help fill in the home visit form:

- *What your child can do*
- *Your priorities in caring for your child*
- *Which activities you can try next with your child*

Physiotherapist making the initial assessment, Bangladesh



In Bangladesh, the home visit form was essential for helping to clarify the parents' priorities, and in monitoring progress of the child. We found that community workers, even with some training, found it difficult to set suitable short term goals with the parents. Ideally, an initial assessment will require both a therapist and community worker to help set achievable targets. Caregivers enjoyed discussing the development chart and it created considerable discussion about where their own child was on the chart.

EVALUATING YOUR CHILD FOR EPILEPSY (SEIZURES)



Materials

Pictures 2.4a and 2.4b

We know that some children with cerebral palsy will also have seizures.



Ask the group *What do you understand by a seizure?*

Do any of your children have seizures?

What are some of the warning signs?



Explain the following in the discussion

- There can be a change in your child's mood. Your child may suddenly seem afraid or suddenly start crying
- Most seizures occur without warning. During a seizure the person may fall down, stiffen, throw up, drool, urinate (pee), or lose bowel control. Other seizures are less dramatic. Someone might just stare into space or have jerking movements in one part of the body.
- When the seizure is over, the person may feel sleep and won't remember what happened.



Ask *What should you do when your child is having a seizure?*



Explain

- During a seizure, protect the child, but do not force movements.
- If needed, lay your child on their side.
- Do not put anything in the child's mouth.
- Turn the child's head to one side.
- Go to the clinic for medication and follow-up with a doctor about medications. It cannot be treated by a visit to a traditional doctor to remove 'evil spirits'.



Ask *What do other people in the community or in your family say about children who have seizures or fits? Use the example from Bangladesh below, or use a case study from your own context to prompt discussion. Do you have any similar experiences to share?*

In Bangladesh, 14% of the children with cerebral palsy also had epilepsy [1]. As in many countries, evidence shows that epilepsy is often stigmatised, and associated with evil spirits. Many parents had spent a significant amount of money visiting traditional doctors to have the evil spirits removed.

"After examining the child, the traditional healer told us that she was encountered by a bad spirit. The healer came to our house many times. He told us, if you sacrifice two pigeons, then your child will be fine. At that time I gave two pigeons But she did not recover. After that I took her to almost 20/30 healers. All of them said the same and gave similar treatments."

Parent, Bangladesh

¹ Available in the CBM Prevention toolkit on cerebral palsy available at <http://www.cbm.org/Publications-252011.php>



Explain A child with seizures does not have an evil spirit or a curse. Refer back to the diagram in the introductory session which shows how damage to the brain causes the seizures. Allow time for caregivers in the group to talk about any stigma attached to the fits, as in many communities this can be quite significant.



Ask the group to come up with some suggestions for how stigma could be addressed within their own communities.



MONITORING PROGRESS

Ask each participant *Can you share something important that you have realised about your child after being here today? What else would you like to know about cerebral palsy?* Write up any comments or suggestions that are made.

One of the greatest challenges is that caregivers, most often mothers, are incredibly busy, and do not have extra time to spend practising the different activities they had learnt in the training with their child. This highlights the importance of involving other members of the family in the training itself, and encouraging caregivers to share information from the training with other family members once they returned home. Make sure grandparents or siblings or other caregivers are made to feel really welcome at any training.



Materials

Flipchart with take home messages.















Take Home Messages:

- All children have the potential to learn and develop new skills. Sometimes they can follow the usual sequence of steps and sometimes they have to miss some steps out and find an alternative way to do something.
- Each child will learn and develop at her own pace and in her own way.
- Sometimes, your child may need help to practice skills or activities. It is important to encourage your child to learn to do things for themselves, rather than being helped by you all the time.









RESOURCES

Materials Development Chart 2.03a



DEVELOPMENT CHART: Movement	
<p>Head and Body Control</p>  <p>Lies on stomach and holds head up</p>  <p>Rolls from stomach to back.</p>  <p>Pushes self into sitting</p>	
<p>Sitting</p>  <p>Sits only with support.</p>  <p>Sits leaning on hands.</p>  <p>Sits alone.</p>  <p>Twists and reaches</p>	 <p>Moves into and out of sitting.</p>  <p>Balances self if tilted.</p>
<p>Moving from place to place</p>  <p>May crawl or shuffle on bottom.</p>  <p>Pulls to stand.</p>	 <p>Walks alone or with hand held.</p>  <p>Squats to play.</p>  <p>Kicks a ball</p>



DEVELOPMENT CHART: Movement and Thinking/Playing	
Using hands	 <p>Holds with whole hand.</p>
Thinking/ Playing	 <p>Plays with or explores body</p>
	 <p>Can hold one object in each hand.</p>
	 <p>Holds between thumb and finger.</p>
	 <p>Puts objects into container and takes them out.</p>
	 <p>Enjoys building</p>
	 <p>Discover and explore objects – push, pull, throw, shake</p>
	 <p>Sorts different objects.</p>



DEVELOPMENT CHART: Social Interaction and behaviour	
<p>Communication / interaction</p>	<div data-bbox="383 1433 702 1803"> <p>Expresses self using sounds and facial expressions</p> <p>Makes eye contact.</p> <p>Coos and gurgles when talked to</p> </div> <div data-bbox="702 1433 965 1803"> <p>Repeats sounds and gestures</p> <p>Responds to simple commands.</p> </div> <div data-bbox="965 1433 1396 1803"> <p>Sucks breast.</p> </div>
	<div data-bbox="383 627 702 1008"> <p>Expresses self using gestures or pointing</p> <p>Able to make choices</p> </div> <div data-bbox="702 627 965 1008"> <p>Drinks from a cup and feeds self most foods without help.</p> <p>Helps with undressing. Indicates toilet needs.</p> </div>
	<div data-bbox="383 224 702 1008"> <p>Express self using words</p> <p>Talks about what she does</p> </div> <div data-bbox="702 224 1396 1008"> <p>Uses the toilet without help.</p> </div>

USEFUL GUIDELINES FOR HOME VISITS AND OUTREACH WORK

These guidelines are adapted from Timion, and the original is available from www.timion.org²

Most children will receive therapy only once per month, even less, or no ‘therapy’ at all. 30 minutes of therapy per month is very unlikely to make a difference for the child’s development on its own. Positioning and handling of the child during the other 700 hours of the month however can make a big difference – either harmful or helpful. Therefore it is VERY important that the therapist or community worker uses the time during an outreach or home visit, to teach the caregiver how she can position, handle and play with the child daily in a way that helps to make muscle tone more normal, that prevents secondary problems and that helps the child to learn and develop.

The community workers/therapist should use their time to:

- ✓ Check on activities/any equipment that was given to the parent at the previous session.
- ✓ Find out if there are any particular problems/successes and demonstrate activities again if necessary.
- ✓ If the child is **receiving equipment** such as a seating device, sidelyer or standing frame, the community worker/therapist’s time is best spent fitting and adjusting the device and teaching the caregiver how and why to use it. Let them position the child more than once to make sure they are confident in doing it well. Remember: if the child is positioned well every day it will be of much greater benefit than a single session of therapy. Therefore a session spent only on fitting equipment is not wasted.
- ✓ The community worker must have an **achievable, realistic, short-term goal** for the child. The parent should also be involved in deciding on this goal and should be clear about it. If the parents have unrealistic expectations, they are likely to become frustrated and discouraged. They will fail to notice small steps of progress if they think therapy aims to make their child normal, or to walk and talk.
- ✓ It is important to **keep a record** of the short term goals, what has been taught to the parent, what works and what does not. It is in the child’s best interest that everybody works towards the same goals, that time is not wasted in re-assessing the child by each new therapist, and that conflicting information and instructions are not given, as these discourage the caregiver.
- ✓ It is important to have an idea of **how the child usually spends the day** – Which positions does the child sit/lie in? What are the things that the caregiver does with the child daily (e.g. washing, dressing, and holding her on her lap)? HOW does she do it? Changing these positions and the way activities of daily living are carried out can make a much bigger difference than giving a “home-exercise”. The caregiver might be too tired or have no time for exercises, but there are certain things that she will do daily and if these can become “an exercise” the child is getting “therapy” daily.
- ✓ Spend some time **handling the child**. It is necessary to find out which positions and key points are helpful to influence the child’s muscle tone and help the child to achieve some normal, active, functional movement. All children with CP will not respond the same, so there is no one set of home exercises that can just be given to everybody.

² Reproduced and modified with permission of Timion

- ✓ Choose one activity that worked well. The therapist/community worker should demonstrate and **teach it to the caregiver**, explaining why it is helpful, pointing out where to place your hands. Let the caregiver practice it more than once – until she is confident to do it well. Guide her hands if necessary. Give some specific instructions about when and how often to do it. Try to incorporate it into her activities of daily living and daily routine as much as possible.
- ✓ **Feeding** is a very big problem for many of the children. This is something that forms a very important part of the child and caregiver’s life and can therefore be very important goal. It can affect a child’s nutritional state and overall health and can require hours of time from the caregiver. A session spent advising about positioning and a technique for feeding is essential of this is identified as a problem. Try to **involve and teach volunteers** in what the worker is doing, such as using positioning equipment. If they learn how to do this well, they can spend time helping caregivers when the worker moves on to work with another client.

2.04 TEMPLATE: INDIVIDUAL ASSESSMENT/ HOME VISIT FORM

We found in Bangladesh that community workers, even with some training, found it difficult to set suitable short term goals with the parents. So an initial home visit will probably require both a therapist and community worker to help set achievable targets.

You may want to adapt this form to fit with your own project requirements.

Name:

Date of birth:

Age:

Child ID Code:

Date form completed:

Existing medical conditions:

Has anybody observed your child having fits?

If yes, are they receiving medication?

What are the main difficulties experienced by your child?

**Are there any concerns you have around caring for your child?
What would help you the most?**

Your priorities. In order of 1 to 5, can you list your most important priorities/concerns?

1) e.g. Toileting – I want my child to be able to tell me when they need the toilet

2)

3)

4)

5)

What can your child do with regards to each of the following?

Sitting/standing/walking:

Communication:

Eating and drinking:

Activities of Daily Living (Toileting, bathing, dressing etc):

Community workers observations/additional notes

--

Referral checklist (for community worker to fill out)

Physiotherapy	Crawling	<input type="checkbox"/>
	Sitting	<input type="checkbox"/>
	Standing	<input type="checkbox"/>
	Walking	<input type="checkbox"/>
Occupational Therapy	Toileting	<input type="checkbox"/>
	Bathing, dressing etc.	<input type="checkbox"/>
	House hold activities	<input type="checkbox"/>
Speech and Language Therapy	Speaking/communication	<input type="checkbox"/>
	Eating/drinking	<input type="checkbox"/>
Other needs	Medical	<input type="checkbox"/>
	Epilepsy	<input type="checkbox"/>
	Economic	<input type="checkbox"/>
	Attending School	<input type="checkbox"/>

Plan of action and home visit monitoring form

Date of home visit	Notes (what was discussed, were any goals set, were any assistive devices provided and explained, were any suggestions for referral made etc.)	Feedback from parents (What is working well/less/their observations)

Review of changes achieved and satisfaction

Review each of the priorities identified at the start of the training. This can be included as part of the exit strategy when caregivers 'graduate' from the programme.

Priority	What change has there been, if any? (scale 1-4) <ul style="list-style-type: none"> ● 1 = no change ● 2 = some small improvement ● 3 = Good improvement ● 4 = Excellent improvement 	How satisfied are you with the changes, (scale 1-4) <ul style="list-style-type: none"> ● 1 = not satisfied ● 2 = fairly satisfied ● 3 = Satisfied ● 4 = Very satisfied
1.		
2.		
3.		
4.		
5.		

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 3:

Positioning and Carrying



Materials

Blankets, pillows and towels, sandbags, carpet on the floor, a doll with floppy limbs that can be positioned i.e. not a hard plastic doll, display materials.



Icebreaker

Ask the group to stand facing you in rows of three each. The front person should stand with their back to you, facing the other two. Now ask the person at the back to adopt any strange position they wish to – arms, legs, head, body, whatever they like, and hold it. Now the front person must try to get number two into this same position, giving instructions, using words only. She may not show the second person what to do. Let them all have a turn to be in each position, depending on how much time you have.



Explain

Outcomes for the module (on flipchart).

As a caregiver you will:

1. Understand the importance of correct positioning
2. Be more confident to position your child with cerebral palsy, and be able to show others in your family or community better ways to position your child

INTRODUCTION TO POSITIONING



Materials

Pictures 3.01a, b, c and d



Activity Put up the various pictures and ask caregivers to work in small groups and look at the pictures. Ask them to point out some of the difficulties you might have with handling and positioning a child in any of these pictures. Discuss why the positions are not helpful. Prompt with questions such as:

Do you think this child will be able to play, communicate, socialise, or eat? Focus on showing difficulties, such as: She can't lift her arms, she can't look around, she can't move, or play.



Explain

Poor handling and positioning:

- will hinder your child from developing
- will make it more difficult for you to pick up, carry and handle your child every day
- can cause problems such as:

Pressure areas – Due to pressure from the outside on to a body part, blood is prevented from flowing easily through the muscles in that area, and then sores develop. These begin with dark red or purple areas. Sores like these don't tend to get better quickly as the blood flow is not good, and can cause major discomfort to the child.



Contractures – If a limb stays in one position for a long time, the muscles get shorter and the joint becomes stiff – this is called a contracture.

Deformities – Even if you care for your child really well, such as keeping her clean and dry and free from pressure areas, feeding her well, etc. – the pull of the muscles when the child spends long hours in any one position can cause the child to become deformed. Her back can become crooked and twisted, and her hips can move out of place or dislocate.

GOOD HANDLING AND POSITIONING:



Ask *Why do you think good handling and positioning are important for a child with cerebral palsy and her caregiver?* Discuss the reasons and ensure that the following issues are covered:

- How you handle and position your child influences what she can do and how she develops.
- Helps to make eating, drinking, playing and communicating easier for your child
- Makes eating and drinking ‘safer’
- Makes it easier for you to care for your child
- Is the basis for all activities that you do with your child
- Helps to prevent disabling positions that lead to deformities
- Is worth learning more about, with a therapist if possible
- Should be used with your child all the time

HOW TO POSITION YOUR CHILD



Explain what you can do to position your child in more helpful ways. Encourage discussion. Cover the following key points and ensure that the participants are aware that correct and appropriate positioning will vary from child to child. It is very important that they understand that not all positions are helpful for all children

1. Learn helpful ways to move your child

- If she is stiff you need to loosen her first.
- You can't force her into a position, and expect her to stay there. Ask a therapist/community worker how to do this.

2. Try to get your child into the best position that you can

- Aim for ‘ideal positions’ (see below).
- She may not be comfortable in a new position at first. Persevere, and ask advice from a therapist or community worker if she continues to be uncomfortable.

3. Change her position often, about every 30 minutes

- Encourage her or help her to change her position herself.
- Remember, if you leave a child in one position for many hours, she may develop pressure sores and her body may gradually stiffen into that position which will increase her disability. She needs to be placed in a variety of helpful positions throughout the day.



Materials

Pictures 3.06-3.16



Activity In small groups, ask the caregivers to look at the following photographs of different positions. Ask the groups Use the following checklist to help you decide if the child is in a poor or helpful position. Discuss why the position is poor, and then why the following position is good.

CHECKLIST (put on flipchart):

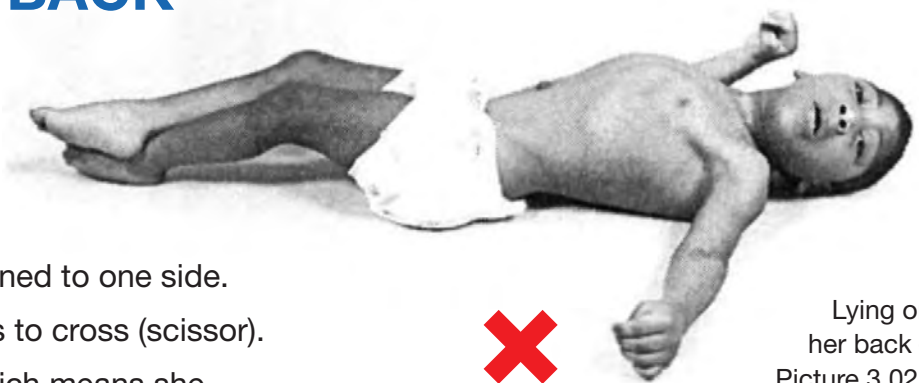
- Head and body
- Legs and feet
- Shoulders and arms

LYING ON HER BACK

Poor Position

Cover the following points in your discussion. This is a poor position because:

- Head pushing back and turned to one side.
- Hips turning in causing legs to cross (scissor).
- Feet are pointing down, which means she can't get them flat if she is sitting.
- Hands and arms away from body.
- Hands fisted and closed.



Lying on her back –
Picture 3.02a

Helpful Position

Discuss in the group why this is a better position for lying on their back. Clarify that this can be a good position for resting, although it does not allow the child to engage with other activities.



Helpful position –
Picture 3.02b

Head and Body

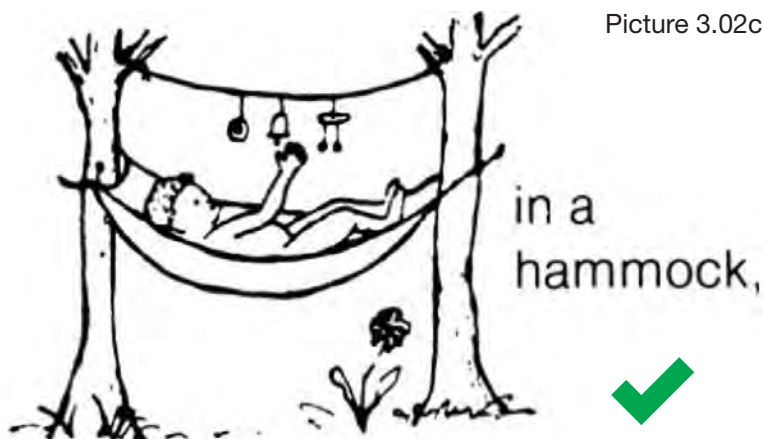
- If she can move her head on her own, make sure it is comfortable.
- If she cannot move her head on her own, make sure it is in the middle and comfortable.
- Her body (spine) must be straight – support on her sides if needed with a rolled up towel to keep her straight.

Legs and Feet

- Bend her hips – this helps to release tension in her lower back which is often arched, and it helps to relax stiffness in her legs. Place support under her knees to keep hips bent (not under her feet).
- Keep her legs open and uncrossed – use a pillow between them if needed.
- Feet should be as close to a standing position as possible – if her feet push down, talk to a therapist about the need for an ankle/foot orthosis.

Shoulders and Arms

- They should be forward and supported, especially if her arms pull back. This position also helps to relax her upper back, and allows her hands to open more easily.
- Lying in a hammock can help to relax tight muscles.
- Babies/small children can hang in a large towel (held by two adults) to relax tight muscles.



LYING ON HER TUMMY



Activity One group member to volunteer to lie on the floor imitating the position of the child in the poor picture. Ask the group to change this position to make it more helpful, using pillows or blankets. Encourage discussion as changes are made. Then put up pictures showing a more helpful position and discuss why.

Poor Position

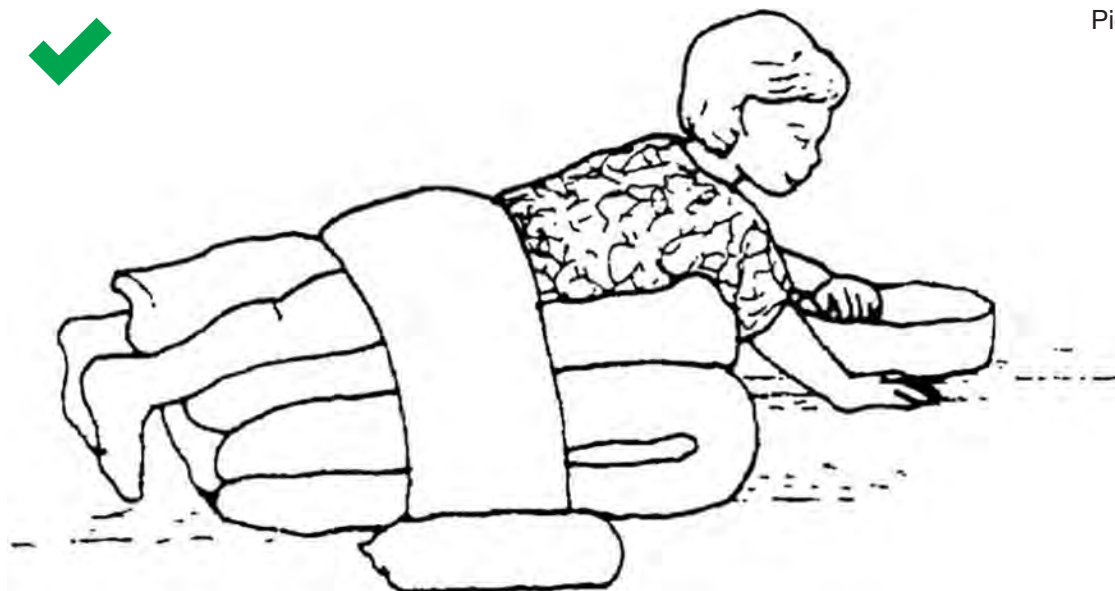
Discuss reasons for being a poor position because:

- Body is not even, because her head is turned to breathe
- There is no muscle work
- She can't see anything
- Legs may be crossed
- Hands are in a fist
- She can't do anything



Picture 3.03a





KEY ISSUES TO COVER

Head and Body

- In a straight line
- Encourage her to lift her head and look at something in front of her on the floor. This is a good time to get a sibling, also lying on the floor, to play with her.

Legs and Feet

- Straight – push down on her bottom from side to side in a rocking motion to help her straighten her hips.
- You can put weighted bags over her hips.

Shoulders and Arms

- Her arms should be in line with, or slightly in front of, her shoulders (make sure the pillow or towel she is lying on comes all the way up to her armpits to help keep her arms forward).
- If possible, encourage her to open her hands and push down on them (you may need to gently open them out for her; if too stiff to stay open, keep helping her each time you use this position).
- **MOST IMPORTANT** about this position is that it is not for all children! The most suitable positions can be discussed as part of a home assessment.



Activity If there is a willing child to volunteer, demonstrate this position with one of your children in the group. Discuss the possible benefits of this position, for example showing how they are in a much better position to play.

SIDE-LYING

Helpful Position



Materials

Picture 3.04a



Head and Body

- Head supported on a pillow so her chin is level (in the middle, with her head and spine in a straight line).
- Give good support at her back, from the top of her head to her feet.



Legs and Feet

- Bending one leg and keeping the other straight helps to relax the stiffness in her legs.
- Keep her bottom leg straight.
- Support her top leg, bent at her knee, with pillows or blankets so her knee is level with her hip – this is important to help prevent injury to her hip (dislocation).

Shoulders and Arms

- Her lower shoulder and arm must be brought forward so they are not trapped underneath her.
- Keep both arms forward to bring her hands together – encourage her to use her hands by playing a game with her, or putting a toy nearby for her to touch and reach for.

During the day this position should be changed from one side to the other, or to another position every half an hour. This is also a good position for the child to sleep in.

It was very important to follow up the positioning issues during the home visits, in order to be able to observe how the child spent most of their day, and in order to work with the family members to review all the information on positioning and establish which positions were most helpful for individual children.

SITTING WITH A CAREGIVER


Poor Position



Materials

Pictures 3.05a, b, c and d

These are poor positions because:

- His head is hanging backwards, or to one side, or just leaning against the caregiver.
- He is just lying, and not sitting on her bottom.
- His hips are not bent, and wrong muscles are working.
- His hands are not free to do anything.
- His arms aren't helping her to sit.
- He is not able to do anything with her hands. 



Helpful Position



Materials

Pictures 3.13a, b and c

Head and Body

- If she cannot hold her head upright, make sure she is sitting up straight with her head and back supported.
- If she can hold her head upright, use your hands to support her chest and/or hips just enough to help her stay up straight and control her head.
- She should be working her muscles to move her body and keep it upright.

Legs and Feet

- Bend her hips to at least a right angle – this will help keep her back in a good position and help stop her from pushing backwards and sliding off your lap. If possible, have her feet supported.

Shoulders and Arms

- Her shoulders should be slightly forward so that her arms and hands are in front of her body, and she can explore objects and her own body.



Activity Ask a volunteer to demonstrate a good position with their child, and encourage help and input from the rest of the group.



Explain It is also important for your child's development to give her the opportunity to practice using the muscles she needs to balance in sitting. Play a game with her, or help her explore her own body, toys, or other objects. This photo shows a more active way of playing with your child in a good position.



Materials

Pictures 3.06a, b, c and d





SITTING ON A CHAIR OR BUGGY

Poor Position



Materials

Pictures 3.01a and b
(see beginning of section)

This is a poor position because:

- Her head is pushing back, and she tends to slide herself out of the chair
- Hips are too straight and stiff
- Shoulders are not supported, and are either pulling back, or pushed too far forward
- She leans sideways and is not stable
- Leg problems can develop from twisting of leg bones



Helpful Position



Materials

Pictures 3.07c, d and e

Head and Body

- She sits upright with her back straight and her head upright
- Her buttocks are all the way to the back
- If she has a lap strap, make sure it is tightened firmly enough to stop her from sliding down in the chair

Legs and Feet

- These must be supported

Shoulders and Arms

- These should be supported slightly forward and in front of her body. ✓



SITTING ON THE FLOOR

Poor Position



Materials

Picture 3.08a



Key points to cover:

- This position can hurt the knees and hips of the child.
- She does not need much control to sit like this, so she does not need to learn to or practice balancing her upper body over her pelvis.
- She does not learn to develop a good sitting balance if she is always in this position. She may therefore never learn to sit with good balance in any other sitting position.
- However, if it is the only way that allows your child to be independent in sitting, then it should be supported, but do not let her sit in this position all the time.

Helpful Position



Materials

Pictures 3.08 b and c



He can sit independently with legs crossed



He should sometimes sit with legs straight, not always bent (beware of contractures)

SESSION – PART 2

STANDING



Materials

Pictures 3.09a, b and c



Icebreaker

This icebreaker shows the group the importance of balance.

- Ask the group to stand on one leg. Give each a sheet of paper and ask them to neatly fold and tear it into four equal parts while balancing on one leg.
- Now do the same thing, but let them stand on both legs.
- Compare how easy or fast they could do this activity with a lack of balance and with good balance.
- Now link this to the next pictures, looking at balance and how a lack of balance makes it difficult for a child to do anything with her hands.



Poor Position (Picture 3.09a)



Poor Position

- She has stiff leg muscles (one or both legs), so she can't stand on flat feet with her knees and hips straight
- Her balance isn't good enough to let go to do something with one or both hands
- She has to hold on for support
- All she can do is stand there, with her hips and knees bent

Helpful Position

- Explain this is just a simple piece of wood
- Her balance is not difficult in this position
- Her hips and knees are in a good position, helping to keep her feet flat
- Her shoulders and arms are forwards
- She no longer needs to hold on for support
- Her hands are now free to do something
- Look at her smile!



Helpful Position (3.09b)



STANDING FRAMES

Helpful Position

Ask the group to discuss the good things, and cover the key points below in the discussion:

Head and Body

- Her back is straight – if her body leans to the left or right, put a rolled up towel on either side of her in the frame to keep her body straight
- Her hips are facing the front – adjust gently if necessary
- Her shirt is covering her tummy so that her skin is not touching the Velcro in front

Legs and Feet

- Her feet are firmly on the ground (including her heels), her toes are facing forward, and her feet are not falling in or out
- If you can easily move her feet, she is not putting enough weight on them. Loosen the frame, and let her fall more onto her feet before easing her into standing again and closing the frame. Recheck her hips and feet
- If the child's feet are in a very poor position, she should only stand once she has been assessed for, and is using, orthotics

Shoulders and Arms

- Her arms should come forward onto the tray/table, which should be at about nipple height.
- It is good if she pushes on her arms, or uses them to touch a toy or object she likes on her tray.



Ask the group *Why do you think standing is important?*

Ensure the following points are covered in the discussion:

- Standing is an important position for children with cerebral palsy to be in.
- If a child is positioned correctly in a standing frame it assists in the development and strengthening of the hip joint and in preventing the development of contractures in the leg joints.
- If a child never stands, her hips do not develop well, become weak and can easily dislocate as she gets older, causing pain and other problems.
- A child who never stands has weaker, less dense bones that can more easily break.
- For assisting breathing and blood circulation.
- For assisting the emptying of the bladder and bowels.
- For weight bearing which can help to reduce stiffness and uncontrolled movements in the legs.

Many children with disabilities who are unable to stand spend their time lying or sitting. By placing a child into a standing frame, he/she is able to see the world around differently, and they are able to engage and interact with peers at the same level. This offers broader stimulation for the child, and will contribute to overall social development and thinking skills.



Helpful position (Picture 3.09c) – using a standing frame

PICKING UP



Materials

Pictures 3.10a and b



Activity Put up the following two pictures and ask the groups to decide which shows a good way to pick up your child. In the discussion, cover the following key points.

Taking care of your own back!

Remember to pick your child up in such a way that you are not harming your back.

Poor Position

- **The harmful way:** Bending forward with your legs straight will cause small injuries to your back every time you do it. Over time you may develop severe back pain. ❌



Helpful Position

Pick up the child in a way that protects your back and provides the best position for her:

- Bend your **KNEES** and keep your back straight or even slightly hollow.
- It is sometimes easier to pick the child up with one foot slightly in front of the other one.
- Hold the child as closely to your body as possible before lifting.
- Lift by using the strong muscles of your legs, and not your back
- If your child becomes much bigger and heavier, preferably do not lift her alone, but ask someone to help you.
- If lifting with another person, count before lifting so that both people lift at the same time.



CARRYING



Materials

Picture 3.11a, b, c and d



Activity Put up the range of pictures and discuss the good and poor carrying positions, covering the following key points. To finish the activity, give the caregivers the opportunity to discuss in small groups which of the helpful ways of carrying they would like to try at home with their child. Then ask them to demonstrate their techniques on the doll or with their own child. Encourage the other caregivers to support each other to find the best position for carrying.



Poor Position

This picture shows a poor carrying position.

- Her head is falling back
- She can't see
- Her body is stiff and straight
- Her arms and hands can't do anything



Helpful Position

Head and Body

- A more upright position will help her to hold her head up and look around, even if it can only be for short periods at a time.

Legs and Feet

- Use positions that keep the hips and knees partially bent and the knees separate

Shoulders and Arms

- She can hold on with her arms or she can free her arms for playing





MONITORING PROGRESS

Ask each member to demonstrate one new useful position that they have learnt about today and which they will demonstrate to another member of the family at home.



Materials

Flipchart with take home messages.

Take Home Messages:

- It's not really possible to be doing something with your child all the time. So you need to leave her in one position or the other at various times.
- Good positioning helps make daily activities easier for your child.
- Instead of leaving her in a poor position, guide her into as helpful a position as you can and support her in moving herself. You need to try different positions with your child, and see what helps, or what works for her.
- If you have access to equipment like buggies and positioners, then use them. Ask your hospital to help you get the most helpful items for your child.
- If you have access to therapists at your clinic or hospital, discuss how best your child can benefit from a combination of positioning and specific therapy, some of which you as caregiver can do.

MODULE 4:

Communication



Materials Flipchart paper, pens, toffees (or other chewy sweets), empty crisp packets, other items with different textures or sounds such as rattles, squeaky toys, ball, doll, cell phone (or objects of reference for range of daily activities), communication boards for the tea game (2 boards), toy tea set.



Icebreaker Check with the participants what they have tried out at home since the previous session. Ask for a volunteer to tell the group her name, her favourite food, and what she would do if she won a large lottery sum. The hitch is that she must have three or four toffees in her mouth. How does it feel for the volunteer?



Explain

Outcomes for the module (on flipchart).
As a caregiver you will:

1. Understand what communication is and why it is so important
2. What you can do to help your child to communicate



Activity Ask the group what they think communication involves. (i.e. listening to others, understanding what they are saying, telling others what you think, want or feel). Explain the following definition (on a flipchart):

Communication means understanding what others say to us, and expressing our thoughts, needs and feelings to them. Communication is a basic human right.

Discuss *How do we communicate?* Cover the following ways:

- Talking
- Smiling
- Pointing
- Laughing
- Others e.g. drawing, reading, writing and singing

Ask for two or three volunteers. Give each volunteer one of the following sentences (either by writing it down or whispering it):

1. My foot is painful
2. I want to go outside
3. I'm tired



They need to try and “explain” the sentence to the rest of the group without using words. They can use sounds, facial expressions, gestures etc. Tell the group they need to work out what the volunteer is trying to say.

Then ask them *How did the person communicate what they meant?* Cover the following:

- Voice: crying, whining
- Facial expression: smiling, frowning, look of pain, big eyes
- Body movement: nodding head, shrugging shoulders
- Gestures: waving goodbye
- Pointing: using eyes or a finger
- Other



Ask *Why do we communicate?*
Why is communication so important?



Explain Here are some important reasons for communicating:

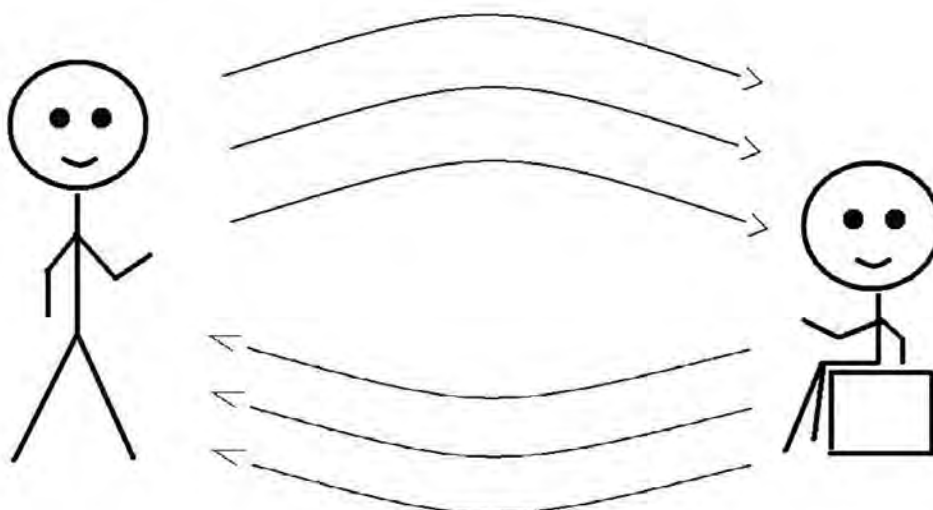
- Establishing relationships and making friends
- Exchanging information, communicating ideas and giving directions
- Communicating needs and wishes
- Developing thinking skills e.g. helping us to remember, make plans, solve problems
- Becoming happy and successful members of our community



Ask the group to think back to the activity they completed at the beginning of the session, where they were speaking with the toffee/chewy sweet in their mouth: Ask how they felt when they were the speaker, and also when they were the listener. Try to elicit that they had difficulties **expressing** themselves when they had the sweet in their mouth and difficulties with **understanding** the person who had the sweet in the mouth.



Explain When communicating with a child with cerebral palsy, the cycle of successful expression and understanding between the two of you often breaks down. Draw up the diagram below on a flipchart to illustrate the cycle of communication.



WHY MIGHT COMMUNICATING BE MORE DIFFICULT FOR A CHILD WITH CEREBRAL PALSY?



Materials

Doll



Ask *What parts of your body do you use to **UNDERSTAND** a message?
What parts of your body do you use to **EXPRESS** yourself and get a message across?*

Using a doll sitting on your lap, point out the different parts of the body which are used in communication, **EXPLAIN** the following:

To **understand** a message you need:

- Ears and eyes to hear and see the message
- The part of your brain that makes sense of what you have heard or seen (intellect)

To **express** yourself you need:

- The intellect to think of what you want to express
- Control of the mouth and voice, to speak (tongue and mouth)
- Control of your body parts to point, make gestures etc.

Which of these things might be difficult for a child with cerebral palsy? In the discussion they should see some, or all of these things may be difficult, depending on the child.



Explain Communication will be harder or easier depending on the severity of the cerebral palsy. It will also depend on the how well the child can think and learn. A child who has cerebral palsy and has **no problems with thinking and learning easily**:

- Will not have difficulty with understanding.
- Will not have difficulty thinking about what to say but her speech may be unclear.
- If her speech is unclear and expressing herself is difficult, people may think she has an intellectual disability even though she hasn't.
- She will need to be taught and encouraged in other ways to express herself; otherwise her communication cycle breaks down.

If the child does have problems with intellect she may have some difficulties:

- Making sense of what she hears (understanding)
- Thinking about what to communicate (expressing herself)

ADDITIONAL INFORMATION ON CHILDREN WHO MAY PRESENT CHALLENGING BEHAVIOUR¹



Explain Children with challenging behaviour can often cause the most stress for parents. Discuss the issue of challenging behaviour, how they feel about this, and how they cope with it. Encourage wider discussion in the group and cover the following points:

- Your child needs love and attention. A child who feels loved will behave better.
- It is important to understand that all behaviour is a form of communication, so your child is trying to tell you something in the way they behave. Try to work out what that is.
- Make your instructions clear. Speak in short sentences and don't give too many instructions at one time.
- Be consistent in the way that you respond.
- Reinforce the behaviour you want. You can do this by:
 - Giving a reward after the desired behaviour. This could be a kiss or a snack.
 - Praising the behaviour, not the person.
- Ignore behaviour you do not like.
- Do not spank or beat your child.
- Physical punishment does not teach good or correct behaviour.
- For behaviour you cannot ignore, try "time out". This means taking the child to a safe place where you can see him but away from where the fun/activity is happening.

USEFUL THINGS TO KNOW ABOUT YOUR CHILD'S COMMUNICATION SKILLS AND HOW THEY DEVELOP



Explain

- Communication skills develop in a sequence of steps.
- Listening and understanding comes before talking.
- Foundation skills for developing communication include making eye contact, listening, taking turns and making choices. Playing is a great way for your child to learn these skills.
- **Important:** Make sure you attend to any sign of earache in your child. If left untreated, this could lead to ear damage and loss of hearing, which can cause additional problems in communication.



Ask *What do you think is the most important thing that you can do to help your child to develop communication skills?*

Talk to her!!!

¹ This Information on behaviour is adapted from the *CBM Prevention toolkit on cerebral palsy* (see resources in Module 10).

HOW TO TALK TO YOUR CHILD AND ENCOURAGE THEIR SKILLS TO DEVELOP



Materials

Pictures 4.01 on card (photocopy and cut out the pictures for group work) – you may need to enlarge them.



Activity

Work in small groups and share out the picture cards (Don't give out the explanations – use that to prompt discussion in the group). Ask participants to discuss what they see happening in each picture, and ask each group to feed back on one or two pictures. Go through the explanations for each.

Talk to your child about what is happening around her.

Communicate through everyday activities. Talk as you bathe, feed, and dress your child. Talk about what you are doing, where you are going, what you will do when you arrive, and who and what you will see.

Talk about the objects used in everyday activities, e.g. during dressing say “*here is your shoe; this is your jersey..... it is nice and warm; feel how soft it feels...*”

You can later ask her to identify objects, e.g. “*show me your shoes; where is the chair?*” etc.

You can teach her different categories, for example body parts; animals; food; objects in the house; people she knows.

Expand vocabulary, name body parts, and identify what you do with them.
“*This is my nose. I can smell flowers with my nose*”.



Get down to her level and face her when you talk.



Before you talk to your child, get her attention by tapping her and calling her name. Make sure she is looking at you when you talk.



Show her what you are talking about and, if possible, bring objects to her, to feel or look at. Tell her what things are called.

Use short and simple sentences when talking to your child.



Encourage, but do not force her to speak.



Look out for any attempt she makes to communicate and always respond to her.



Encourage any means of communication such as looking, pointing, smiling etc.

Repeat what your child says or is indicating. Build and expand on what was said. *"Want juice? I have juice. I have apple juice. Do you want apple juice?"*



Give your child time to respond. If they can't respond at all, then respond for them.



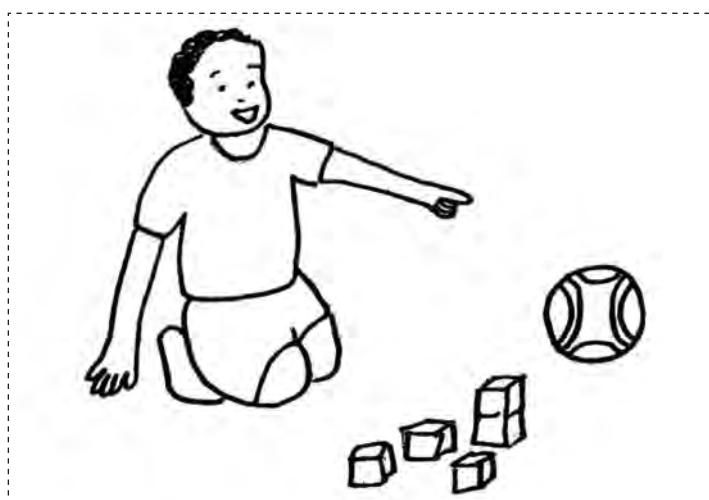
Take time to interact with your child.

Sit with your child and talk to each other without lots of other distractions.



Give your child choices during the day. This can increase her motivation to let you know what she wants. For example, let her choose between two different tops/pants or skirts when dressing her in the morning. You could also let her choose whether she wants something to eat or something to drink first at a mealtime.

Ask questions: *"Do you want an apple or an orange?"* *"Do you want to wear your red or blue shirt?"*



Ask the group to summarise the key points.

Checklist

- ✓ Get your child's attention first
- ✓ Make sure you are both positioned well – facing one another, on the same level, and with the child well supported
- ✓ Use eye contact
- ✓ Talk about what is happening
- ✓ Use facial expression and gestures
- ✓ Take turns, and encourage participation
- ✓ Offer choices
- ✓ Praise and encourage – clapping, cheering etc.
- ✓ Do not force her to speak, but encourage any attempt to communicate
- ✓ Do NOT use baby talk



Activity The trainer illustrates the following points through **demonstrated play** with one or two children in the group. At the end of each demonstration you should talk parents through the key concepts. You can also make short video clips demonstrating the different approaches, and discuss as a group.

In Bangladesh, the training was with groups of parents with very low literacy levels. Feedback from the groups showed that they welcomed the role plays and 'acting' out examples by the facilitator to demonstrate key issues. This was welcomed more than endless talking!

How to encourage your child to make eye contact

- Hold your face close to your child's face and talk to her. Try to encourage her to look at you.
- Call her name; when she looks at you, praise her by smiling and talking. Use lots of facial expression.
- Sing songs to her. She will enjoy the rhythm.
- Play Peek-a-Boo.
- Show her different objects. Shiny objects such as a crisp packet turned inside out will draw her attention. You can also use everyday objects with different textures or sounds. Let her play and explore objects. Talk to her about the different objects.

How to encourage your child to take turns when communicating

- When she makes a sound, or uses facial expression or body movement, copy her and then take turns talking. With babies, imitate their laughter and facial expressions.
- Respond immediately to any attempt she uses to initiate communication.
- Clap your hands and then ask her or help her to clap her hands.
- Hold a ball in front of her, ask her to wait, and then to hit the ball.
- Play music on the cell phone. When it stops, wait for a response from the child before switching it on again.

How to encourage your child to make choices

- Give her a choice of things to play with or to eat.
- Show her the things where she can see them best. Start by offering a choice between two things only, then increase it to three or four later.
- Eg. Hold one object in front of the child and say what it is. Then take it away and show them the other item and say what it is. Then take that one away. Now show the child both of the items and ask her to choose. E.g. *'Do you want water or milk?'* or *'Do you want the ball or the doll?'* Wait for a response, which could be pointing or looking towards one of the objects. Give her the object she is looking at or pointing to immediately and say *'you chose the ball by looking at it, so let's play with the ball'*.

OTHER WAYS OF COMMUNICATING



Materials

Display picture 4.02



Explain All young children with cerebral palsy should be helped to develop **ALL** methods of communication. As they get older, if it becomes clear that speech will be their main way of communicating, then concentrate on developing their speech.

Talking (speech) is their easiest link with other people. Sometimes, even when speech is the child's main form of communication, it is necessary to use additional methods as alongside speaking, as the child's speech may not always be clear to everyone.

However, for many children with cerebral palsy it will become clear that spoken language will **NOT** be their main way of communicating. For these children, we must concentrate on helping them to develop their skills in using **other** ways to communicate, such as using eye-pointing and finger pointing, objects, gestures, picture boards, signing or written language.

Other ways of communicating

Gestures

Facial Expressions

Sounds



Pointing

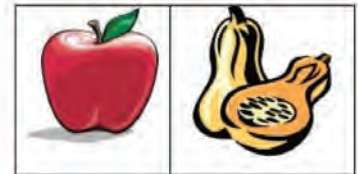
Using hands



Using eyes



Pictures



Ask the group to describe the ways of communicating that they can see in Display picture 4.02 and in which ways their children are already indicating their needs. Discuss ideas amongst the group on how they can encourage their children to express their needs non-verbally. Cover the following:

Firstly, it is important to respond immediately to any attempt she uses to initiate communication.

(i) Using sounds, gestures or facial expressions:

- Watch your child to try and understand what she means when she uses sounds, facial expressions, body movements or gestures.

- Talk to your child about what she needs or wants you to do for her. Ask her to show you how she indicates some of her daily needs such as, 'I am hungry', 'I am thirsty', 'I want to rest', 'I am cold', and then practice these together. Encourage her to indicate 'yes' or 'no' if you ask her if she is hungry, or thirsty.
- Show her how to make gestures, and help to make them by molding her hand(s).
- Encourage her to show her choices by using gestures. Ask 'do you want water, or milk?'

(ii) Pointing (using eyes, or hand) or touching

- Keep a selection of objects in a box, or hanging from a set of hooks on the wall that represent different activities of the day, e.g. a cup represent drinks time, a flannel represents wash time etc. Use these to show your child what she is about to do, holding the object up in front of her and telling her what is happening next. Also use objects to offer choices by holding two objects up in front of her and letting her show you her choice, through her eyes or by pointing or touching.

(iii) Using pictures

- Start by showing her an object or a person. Then match a large picture with the object or the person. Later, when your child points to a person or object to communicate with you, encourage her to point to the picture instead. Once your child is comfortable communicating with you in this way, she may be able to use smaller pictures, on a board.
- Some children may have just a few basic pictures which they use to express their needs. Others may have a big collection of pictures to use for quite complex communication. Pictures can include social expressions, people, things, actions, feelings, daily needs.
- In a role play of a parent and child (trainer acts as the parent), demonstrate the use of a picture board (3 pictures representing different games/play activities) for choosing which game to play. (The 'child' chooses making tea). Demonstrate the use of a picture board for 'the child' to select the items needed to have a pretend tea party (pictures include tea cup, saucer, teapot, milk jug, sugar, spoon) – ask 'the child': "What shall I take out of the box next...etc". Take each item out of the box as 'the child' selects them, and lay them out ready to 'have tea'.



Picture 4.03

Photo: Case study Parent and child, Parent training project Bangladesh

Sahid is 12 years old and lives with both his parents and two other siblings. He doesn't go to school, has very limited speech, and has an intellectual disability. He requires help with all aspects of self-care. He does not have any problems with his hands but does continuously suck his fingers, and as a result has an infection in both his fingers and mouth.



His mother reported on some of the changes after following the training course:

- My child used to drool a lot, but now through the training we have shown him how to swallow his saliva and wash his face.
- He used to put fingers inside the mouth all the time and now we encourage him not to do this, so the infections in his hands and mouth have decreased dramatically.
- He is now able to communicate about when he needs the toilet and also when he is hungry.
- Going to school remains a challenge: I took him to school 8 or 9 times last year, but after that he did not go to school anymore because other children at the school were scared of him that's why we don't take him to school anymore. Sahid cries when he sees his brother going to school.



Activity Read out the case study above from Bangladesh. Ask the group *What key issues arise from the case study?* It provides a useful summary of some of the key issues covered in this module, especially the importance of communication, and that it can improve – even with an older, non-verbal or intellectually disabled child. Encourage the group to think of some ways that the school issue can also be addressed.



Ask *Which other people should be involved in helping your child to communicate? Why?*

It is important that everyone who is involved with your child knows and uses the same ways of communicating (e.g. objects, picture board, signs etc) and so includes your child in conversations. This means the extended family, teachers, children in the local school, your child's friends and other people who know your child should all be taught to communicate with your child in a way that your child is comfortable with.

Only repetition and consistency will help her to learn this new way of communicating. If people do not respond to her efforts to communicate, she will not be motivated to use it.



Materials

Flip chart with take home messages

Take Home Messages:

- Children with cerebral palsy may need help to develop their communication skills.
- We communicate in many different ways, and there are many different ways in which children with cerebral palsy who have difficulty with speaking can also communicate.



MONITORING PROGRESS

Ask *What two things have you learnt today that you will teach to at least two members of your family in order to improve communication with your child? Be prepared to come back at the next session and tell us how it went.*

MODULE 5:

Everyday Activities



Materials

Buttons/bottle tops, everyday household objects such as plastic cups, cutlery etc., Flip chart and Pictures 5.1-5.5



Icebreaker

Put a handful of buttons/bottle tops (different sizes and colours) on a blank piece of paper in the middle of the group. Ask each group member quickly to give one idea of how she could use the buttons to teach things to her child/ren (not necessarily children with disabilities). For example: counting, colours, shapes, building, threading, using them to create pictures etc. (Feel free to use other objects, such as plastic cups, cutlery, etc, if you don't have buttons available).



Explain

Outcomes for the module (on flipchart).
As a caregiver you will:

1. Have a clearer understanding about how to use everyday activities to help your child with cerebral palsy to develop.
2. Be able to explain this to others in your family or community.



Activity

Put up picture 5.1 (or individual photos of everyday activities from your local context).
Prompt questions for discussion:

What activities are shown in the poster? What activities do you do every day or every week? Which of these activities do you do with your child? Are there any other things you do with your child that are not shown in the poster?

Remind the parents/caregivers that they are the most important caregiver for their child. Think about the time you spend every day with your child, doing everyday things with her. List the various everyday activities on the flipchart.





Picture 5.01

? **Ask** *What skills does your child need to learn in order to develop and become more independent with these everyday activities? (HINT: remember the development chart that you ticked off in Module 2 and the goals that you set for your child?)* Allow for discussion and use the checklist below as needed.

This is what your child needs to learn:

- moving and balancing
- using her hands
- communicating and interacting with others
- thinking and playing
- learning to do things for herself

With all the washing, feeding, dressing, giving medication and the other things that you have to do with your child, you may already be very busy and feel quite stressed. Plus, you may be caring for other children as well. Maybe you are wondering when you will also find the time and energy to help your child to develop. Do you feel like this? Allow sufficient time in the group to discuss these feelings. Use the example from Bangladesh below to prompt discussion.

In Bangladesh, many parents talked about feeling tired, or not having enough time to care for their child, with variable amounts of support from other family members.

A 'Quality of life' questionnaire was used [1] to measure the 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. They were more anxious, more tired and stressed, felt less supported, and found it more difficult to communicate their concerns to other members of their family [2]. High levels of stress in caregivers are frequently reported in other studies [3-4].

Building 'treatment' for their child into everyday activities is therefore essential for parents who have limited time for caring for their child.



Explain that as caregivers you need to do all these daily things with your child anyway. So if you can do them in such a way that you are stimulating your child **at the same time**, this will help your child **a lot** with her development without taking up any additional time.



Materials

Doll and basin of water

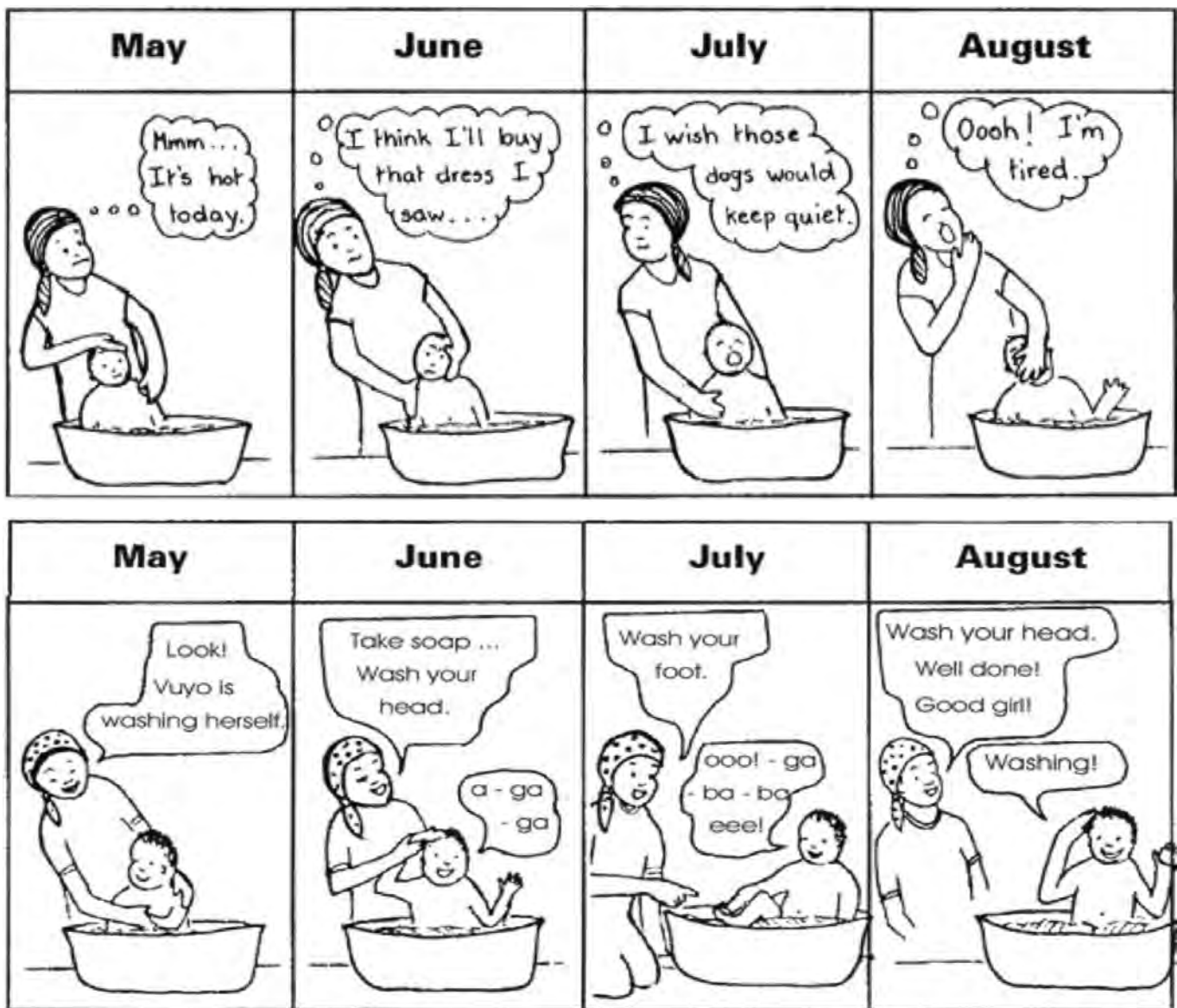


Activity Act out a role play of the two picture strips below, using a doll. Alternatively, you can ask for a couple of volunteers in the group to act out the picture strip. Ask the group to provide feedback on each role play and use the following questions to prompt discussion:

What do you like, or not like, in each of the role plays (or picture strips)? What do you think about the different ways that these two caregivers bathe their child?

In the feedback from the group, summarise the following main points, which were also covered in the Communication Module. The story/role play demonstrates how to communicate with your child in an everyday situation:

- Talking to your child about the things happening around her
- Showing her what you are talking about, and getting her to look at and feel the objects
- Offering choices wherever possible (e.g. *do you want the red cup or the blue cup?*)
- Note: You can also offer choices during bathing, such as, *what shall we wash next, your arms or your legs?*



Pictures 5.02a-5.02b



Ask Apart from communication, how is the caregiver in the second bathing role play/picture strip also helping her child to develop other skills? Cover the following checklist:

Movement and Balance

In the second bathing picture strip, the caregiver is helping the child:

- to sit by holding her in a **helpful position** (ie. Supported) while she moves her arm to reach up to her head.
- by encouraging her to **balance** while moving her limbs. (In the top row, the caregiver always holds onto her child, so her child has not been given the opportunity to learn some balancing for herself).

Using her Hands

- The caregiver involves the child in the washing by helping her to hold the soap or wash-cloth.

Social and Emotional

- The child is learning a self-help skill, bathing. Over the months, this child is learning to bathe herself, with just the amount of help and encouragement she needs on each occasion.

Thinking and Playing

- The child is playing and having fun while learning.
- The caregiver first performs the activity but involves the child by communicating what she is doing – then she involves the child by helping the child to do it with her – then she lets the child do more by herself and only points out what is needed – then makes the request and stands back while the child does it herself.

Summary

- A helpful (comfortable, supported and stable) position:
 - Makes it easier for a child to be more involved with everyday activities.
 - Allows her to look around and watch what is happening in the room and communicate more easily with others.
 - Allows her to use her arms more easily during activities.
- Remember that cerebral palsy affects each child differently, so don't expect the same abilities for each child. However, all children need to be stimulated in order to develop as much as they can.



Activity Ask a volunteer to sit like a child in an unhelpful position and try to stack bricks. Ask them to explain how that feels. Now ask them to sit in a helpful position (thinking about the position of the feet and legs, hips, body, shoulders, arms and hands, head). Do the same activity. Ask them to explain how that feels. Is it any easier? If necessary, it may be useful to refer back to the positioning and handling module and review the key elements of good positioning and handling.

Ask the group to summarise the key points about being in a comfortable and helpful position:

Head and Body

- The head is not pushing back or falling forward. It is not turned to one side. It is upright and facing forwards.
- The body is not pushing back or folding forward. It is not leaning to one side. It is upright and facing forwards.

Legs and feet

- The hips are not rotated or leaning to one side. They are level and centred. They are bent, not pushing straight or pulling up too much.
- The legs are slightly open, not pressing together or crossing.

Shoulders and arms

- The shoulders are not too far back or too far forward.
- The arms are not pulled up above the shoulder or stiff at the side of the body. They are close to the body and forward so that the child can use her hands. The hands are open if possible.

EVERYDAY ACTIVITIES: WASHING AND BATHING



Materials

Picture strips 5.03

(Photocopy onto card, enough copies per small group)



Activity Look at the picture strip . Discuss in small groups what you can see in the pictures, and what is being done to stimulate the child's development in each example. As a whole group, ask how they can use bath time to stimulate their own child's development

Pictures 5.03



DRESSING POSITIONS:



Activity Look at the picture strip . Discuss in small groups what you can see in the pictures, and what is being done to stimulate the child's development in each example. As a whole group ask how they can use dressing to stimulate their own child's development. **Key points:** Give her just the help that she needs, give her encouragement, and the words she needs, and be creative in trying new positions that might work for her. The last two positions shown in the pictures work well with children who move a lot.

Pictures 5.04



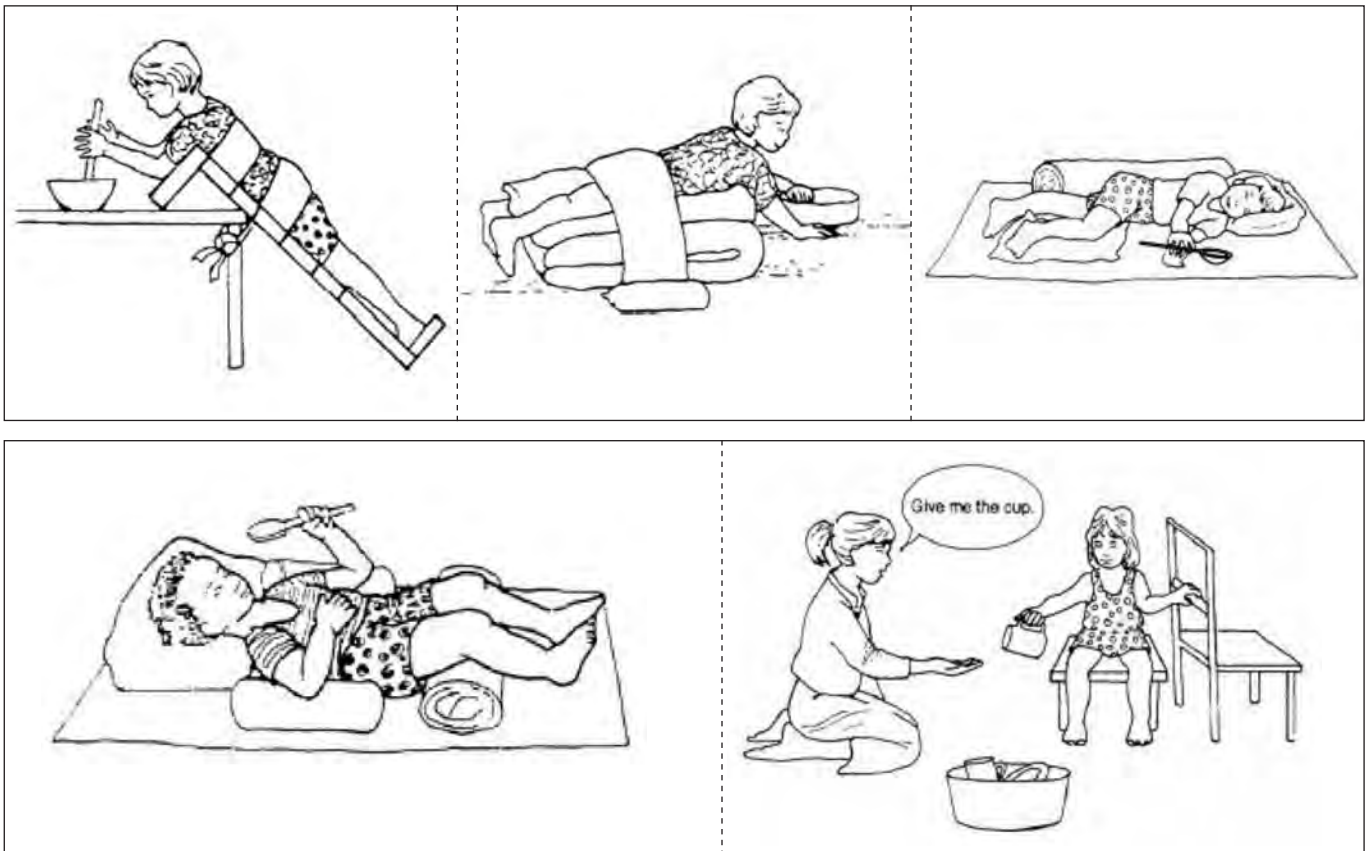
WHILE YOU ARE COOKING, CLEANING AND WASHING



Activity Look at the picture strip . Discuss in small groups what you can see in the pictures, and what is being done to stimulate the child's development in each example. Cover the following key issues in the group discussion:

- Make sure that your child is in a comfortable and helpful position.
- Talk to your child about what you are doing.
- Give some kitchen cleaning equipment to your child so that she can imitate what you are doing as she plays.

Pictures 5.5





Activity In small groups, ask each caregiver to share one or two areas of daily living activities that they would like to work on with their child (refer back to their home visit/individual assessment form).

Take some examples of activities of daily living activities they have chosen and ask the group to break the tasks down into small steps. Ask them to draw these if it helps. Then ask them to think about what their own child is able to do/which steps in each of the tasks. Encourage the caregivers to help each other to come up with ideas.

Then, ask them to consider the following:

- *Which everyday activity/ies are you going to work on? (Think of an activity that you would really like your child to become more independent in.)*
- *Which step in each activity does your child need to learn or practice next?*
- *How will you support your child to learn that next step?*
- Look specifically at the positioning and how you are going to encourage your child to be more involved in the activity.

Encourage caregivers to share any success stories during this session and the following session.

TOILETING



Explain You may be wondering at what age to start toilet training, or to teach your child to give an indication that she needs to use the toilet. You may also wonder at what age your child will decide what clothes to wear or when she will play with other children.

A general guideline is that you can start to encourage or help your child to do things at about the same age at which a child without cerebral palsy would start to do them. The abilities of your child will determine how much you need to adapt the way each activity is carried out and how much you will need to help your child.

In Bangladesh, issues related to toileting were a priority for many parents. These included needing children to be able to communicate clearly when they needed the toilet, or helping children to be independent in toileting, where possible. Extra time was needed to address this.

Two case studies of parents who stopped coming to the training sessions highlighted the stress of the parent and neglect of the child. Children were lying in their own urine for several hours until their parents had time to clean them.

“I do pottery all day long, and I have to cook food three times a day. My father-in-law is ill and I have to take care of him. During sharecropping, when the crops arrive at our house, I have to work on that and I have to look after my disabled child all the time.”

“My husband sometime helps me a bit in household work, but he does not help me in any work with our child. He has almost no interest in the child. I feel stressed working so much I never get the chance to relax. That’s why I always feel weak. My daughter urinates and defecates lying down and it gets on her body, and I find it difficult to clean her up.”

Mother, Bangladesh



MONITORING PROGRESS

Ask the caregivers to share one or two ideas that they have learned today and that they will share with other family members/caregivers at home, such as the different ways in which they are going to approach certain activities they do every day with their child.



Materials

Take home messages on flipchart

Take Home Messages:

- It is important to identify helpful positions for everyday activities.
- Every time you do something with your child, help her to be more involved in the activity, and communicate with her.
- Cerebral palsy affects each child differently, so don't expect the same abilities in each child. However, all children need to be stimulated in order to develop as much as they can.

References

1. Varni, J.W., et al., *The PedsQL™ family impact module: preliminary reliability and validity*. Health and quality of life outcomes, 2004. **2(1)**: p. 55.
2. London School of Hygiene and Tropical Medicine, *The Impact on family life of caring for a disabled child; lessons learnt from Bangladesh*. Forthcoming publication
3. Hartley, S.O. V.P., Bagawemu, A., Ddamulira, M., Chavuta, A., *How do carers of disabled children cope? The Ugandan perspective*. *Child: Care, Health and Development*. 31 2 167-180. 2005.
4. Mobarak, R., et al., *Predictors of stress in mothers of children with cerebral palsy in Bangladesh*. *Journal of Pediatric Psychology*, 2000. **25(6)**: p. 427.

MODULE 6:

Feeding Your Child

Facilitator note: This is a long module split over 2-3 sessions. As a facilitator you are not expected to be an expert on nutrition, but it will be helpful if you can identify opportunities to link with any local or regional nutrition programme; all low and middle income countries will have a nutrition programme.



Materials

For activities: Jug of water, glasses, dessert spoons, yoghurt and face cloths. Pictures of positions. Laptop and projector for showing video clips and recipe sheets. There is a short feeding video clip available from Hambisela (contact info@hambisela.co.za) and the film 'Wrong from the Start' (available from the organisation MAITS at <http://www.maits.org.uk/>). For more information check out Module 10 Resources.

For demonstrations: Large rag doll, special seat with straps, small towels you can roll up, normal chair, large glass, small plastic beaker, dessert spoon, plastic teaspoon,

For explanations: Pictures for positioning section.

For practical feeding session: Small plastic beakers and plastic teaspoons (enough for the whole group).

In Bangladesh, malnutrition was noted as an issue for a number of the children on the training course. Ten out of 153 children died during an 18 month period, and in most cases these children were malnourished. This would link in with other available evidence about the increased vulnerability of disabled children to being malnourished and it is of critical importance in the training sessions to minimise this risk [1-3].

It's not enough to only address improved feeding practices! The project identified possible linkages with national and local nutrition programmes in order to clarify how the most vulnerable children and families could be linked into their services.



Activity This activity is designed to help caregivers understand what it feels like to be fed by someone else and not very well. ASK mothers/caregivers (NOT children) to work in pairs: ASK them to take turns to feed one another. The person being fed should be given a mouthful of yoghurt or a sip of water with their head leaning back, and then turned to one side, then flopping forwards. ASK How easy or difficult is it to swallow in each position? How does it feel to be fed?





Explain

Outcomes for the module (on flipchart).
As a caregiver you will:

1. Understand the range of difficulties that a child with cerebral palsy may experience with eating and drinking, and the implications of these.
2. If your child is not independent in eating then you should be able to work out how to make feeding her easier and more enjoyable for both of you. You will also know what strategies to use to reduce the risk of food and/or drink going onto the lungs.
3. If your child has some independence in eating, then you should be able to teach her to eat more independently.
4. Know what a balanced diet is and have ideas on how to maximise your child's nutritional intake.

FEEDING YOUR CHILD



Materials

Display Poster 6.01

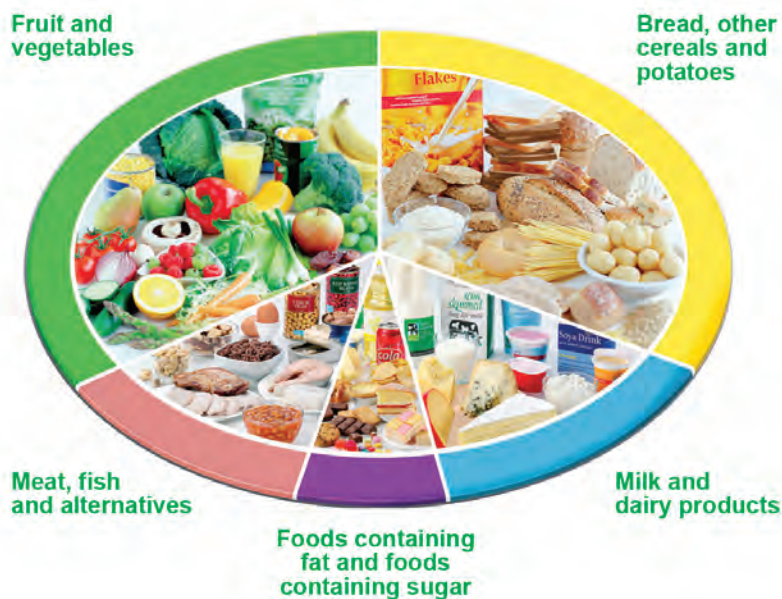


Ask the group *Why are eating and drinking important?* Discuss the main benefits in the group: That good eating and drinking are important for nutrition and hydration, and therefore for growth and health.



Activity Ask the group *What is a nutritious or 'balanced' diet?*

Display Poster 6.01



Show the poster and discuss the food groups and that a combination of these will give energy and vitamins, which are vital for ALL children, including disabled ones. Help the group to list what items in the local diet provide the main sources of nutrition.



Explain that many children with cerebral palsy have feeding difficulties. These affect their ability to eat and drink enough (leading to malnutrition and dehydration) and can cause chest infections due to food and drink going down the wrong way and into the lungs.

Possible feeding difficulties and associated problems for a child with cerebral palsy



Ask the group to discuss the sort of difficulties that they experience with feeding their own child. Write up responses and use the list below to ensure all the following difficulties are mentioned and discussed.

Difficulty controlling her head

- Her head is floppy and she struggles to keep it upright
- She pushes her head backwards

Difficulty controlling her body

- She cannot sit by herself and struggles to keep her body upright
- It is difficult to hold her body upright when feeding her as she pushes back or struggles to keep her body still

Difficulty controlling her mouth/lips/tongue

- She struggles to close her mouth and food or drink spills out
- She struggles to chew her food
- She struggles to swallow/takes a long time before swallowing her food
- She chokes/coughs a lot when eating
- She pushes the food out of her mouth with her tongue
- She struggles to eat what other children her age are eating and only eats soft food

Difficulty eating on her own

- She struggles to hold things and bring them to her mouth

Mood

- She is often very unhappy during mealtimes and cries or screams and rejects her food

Other problems

- She often vomits after eating
- She suffers from frequent constipation
- Sometimes parents feel extremely frustrated and angry because feeding her is so difficult

Voices of Parents

“I feel angry sometimes and hit him when I have to force him hard to eat. At that time I have to hold all his limbs down in lying position.”

“I beat her because it’s hard work for me and it takes a long time.”

I always feel impatient because he cries a lot, so I shout at him and bite him.” [4]

HELPING YOUR CHILD TO EAT AND DRINK



Explain There are 6 key aspects to helping your child eat and drink more healthily and easily. The whole of this session will be exploring each of the 6 issues:

Picture 6.02



1. Environment and hygiene

- Make sure you feed your child in a clean space where there are as few distractions as possible.
- Make sure you have washed your hands, your child's hands and the utensils, in 'good water'.

2. Diet

- Children with cerebral palsy need a balanced diet that is especially high in energy, which comes from fat and oil. If you follow this diet your child will be stronger, healthier, and happier and be able to do more things.
- These children get tired easily, so they need small meals given more often e.g. 5 meals per day.
- As drinking is difficult, these children need sips of water given throughout the day the equivalent of at least 5 tall glasses. This will help reduce their constipation and give them more energy.

3. Food consistency

- The more solid food is, the more nutritious it is. However, as we know, these children have difficulties chewing, as they don't have the muscle power, so we need to make food a bit moister and softer so they can manage it.
- We also need to make it one smooth consistency as they cannot manage a mixture of things in the mouth at once.
- Just as solids are difficult, thin fluids are also difficult for all of these children as they travel very quickly and can go down the wrong way, onto the lungs. Thin fluids should therefore be given very carefully.
- Start with food of a smooth consistency – not too runny, not too solid, and not mixing solid with liquids (e.g. lumpy soups). As your child starts to develop better control over her tongue and mouth, you can increase the thickness of the food. This will encourage her to learn to chew and in time, she may be able to manage more solid food.



Discuss the foods the participants usually feed their children. *What nutritional value do they have? What is their consistency? How might you modify the diet of your children and ensure the food is of a good consistency. Discuss recipes e.g. usual weaning foods, and ways to mash up family foods etc.*

4. Positions for feeding



Materials

Cards 6.03a – photocopy enough for the group and cut out.



Activity Remind the group that they have already had a module on positioning, and check what they remember from that. In small groups or pairs, look at the card sets (a+b) showing different positions. *Can you choose which you think is the best position for feeding, from each set. Can you say why you chose one position rather than the other?* See Resources at end of module for answers to this activity.

Cards 6.03a



Explain that it is also important to keep your child sitting up for 30 minutes after meals. This will reduce the risk of vomiting after eating.

FACILITATE the group to summarise the key aspects of good positioning, i.e.
HEAD AND BODY: Sitting upright. Head facing forwards and neck long
SHOULDERS AND ARMS: Forwards
LEGS: Hips and knees bent at 90°



Materials

Rag doll and pictures 6.04a-6.04d

DEMONSTRATE AND EXPLAIN the following ways to position a child for feeding using a rag doll and a supportive seat for demonstration. Put pictures 6.04 up to illustrate the discussion.

If you're sitting on a chair, couch, or bed to feed:

- Make sure that you are comfortable, with a cushion behind your back and another under your supporting elbow.
- Keep your upper arm firmly against the top of her head, and not behind her neck. Make sure you can see your elbow.
- Hold your child's bottom firmly between your legs so that she cannot push back.
- Support her knees with one leg and her back with the other. Raise the leg that is supporting her back, by putting something under your foot, to make her back straight.
- Bring her arms forward so that her shoulders also come forward.



Picture 6.04a

Explain or demonstrate other strategies that can be used to help good positioning:

- If your child is sinking down too far between your legs, try putting a firm folded towel/blanket under her bottom.
- Remember her back must be straight, not rounded.
- If her back is still too rounded, slip a folded towel over a piece of board behind her back to give her something to lean against.
- Your child may have a specially adapted seat, which is ideal to use when feeding her.

If you are sitting on the floor:

- Try to sit with your back against a wall to rest your back. Keep your upper arm firmly against the top of your child's head – not behind her neck. Make sure you can see your elbow.



Picture 6.04b

- Put a cushion under your raised knee to keep yourself comfortable and to keep her back straight.
- Make sure your child's bottom is well between your legs so that you can keep her hips firmly bent.
- For the bigger child, or for one who pushes back very strongly, try resting her bottom firmly on the floor and then push her legs up towards her chest.
- Place your leg firmly across her feet to hold them flat on the floor.

Sitting in a supportive chair



Picture 6.04c



Picture 6.04d



Picture 6.04e

- A seat like this can give your child all the body support that she needs, leaving you free to concentrate on your feeding technique.
- Make sure she is correctly seated and positioned, using rolled up towels or cloths if necessary to support your child well, as you have been shown.
- Positions for feeding the child on her mother's lap are likely to be very difficult with older/ bigger children, and are more suitable for younger children.
- For those older/bigger children, a supportive seat will probably be the only way to achieve a good feeding position. As a child grows you need to make sure that the chair still fits. Do not squeeze a child into one they have grown out of.



Explain the following summary points:

- Be sure your child is in a good position before you begin feeding her!
- The position you use will make feeding either easier and safer, or more difficult and unsafe.
- It is especially important that the head is not leaning back or flopping sideways and that the chin is tucked in slightly, to make swallowing easier and safer.
- You can play with your child in these positions too – that way she gets used to the position before you try feeding her, and you also get comfortable with using these positions.

5. Utensils

Show a dessert spoon and plastic teaspoon.



Ask trainees *Which is better for feeding their child and why?* Make sure the following points are covered:

- The teaspoon is better, both in terms of giving small, manageable mouthfuls as well as preventing harm caused by biting hard onto it.
- The best way to feed using a spoon is to give food from the front and straight – place gently on the lower lip so that the child can feel it.
- It should **not** be dragged up over the top lip when taken out. Correct placing of the spoon in the mouth helps the child to develop the lip control needed for taking food off the spoon.
- Feeding by hand may be appropriate, if the child can manage a more solid consistency.

Show a tall glass and a short plastic beaker (e.g. medicine cup or lid of baby's bottle).



Ask participants *Which is better for feeding their child and why?* Make sure the following points are covered:

- The tall glass makes the child's head tip back, meaning that drink will not be swallowed well and may go onto the lungs.
- The small beaker is easier to control in terms of giving small sips and again prevents harm if bitten.
- **Avoid** using bottles beyond the normal age for suckling as they prevent the development of normal drinking skills.

6. Helpful and Responsive Feeding



Explain

- Make sure that your child takes only small mouthfuls and one mouthful at a time.
- Don't rush! Give your child plenty of time.
- Your child may need support to keep her mouth closed and encouragement to Chew. If her mouth is closed when eating, she will find swallowing easier, lose less food through spillage, and therefore eat more.
- You can help her by providing support to her jaw, as shown in the pictures below. Your child may resist this at first, so it is helpful if you allow your child to get used to her face, lips and jaw being touched, when you are sitting or playing with her.
- Be sensitive to your child's needs and support them as required.
- Talk to your child to encourage her to eat and have fun at mealtimes. Be gentle in your words and actions.
- Watch your child's reactions and feed them in a sensitive manner. Watch to see when they are ready for the next mouthful. Pause or take breaks if needed.
- Never force feed.
- Stop when the child indicates they are tired or have eaten enough.
- Interaction and fun at mealtimes improve a child's communication skills, and the caregiver-child relationship.
- Active and sensitive feeding encourages the child to want to eat. Research shows that children fed in all of these ways eat more and put on weight.



Picture 6.05a



Picture 6.05b

Demonstrate this on the doll, and put the pictures (6.05a, 6.05b) on display.



Activity

1. Show the 'Before and After' clips you have prepared (See Resources). Each time, show the Before clip and ask people to comment on the feeding methods and the difficulties the child is having. Watch the After clip and ask participants to comment on what is different. Discuss what the caregiver was doing differently to improve feeding and how the child was responding.
2. Practical feeding session: If there is time, ask parents to sit in a circle and either give their child a drink or feed them some yoghurt, trying to follow all the advice. Go round the group helping them. Encourage parents to help one another.

If there is no time, ask them to practice what they have learnt at home.

In Bangladesh the video clips were a very popular activity and prompted considerable discussion. You will need to make your own video clips of children demonstrating good and poor feeding practice – don't forget to get permission from parents to make the clips and explain how you will use them with training other groups.

MODULE – SESSION 2



Materials

Pictures 6.06-6.07

For activities: A laptop with DVD drive and projector, and the film 'Wrong from the Start'.

For practical feeding session: Families to bring food they would normally give their child for lunch (cooked). Plastic teaspoons (not flimsy or brittle) – enough for the whole group.



Activity ASK the group how feeding has gone since the last session – have they been able to follow the recommendations? If not, what has been difficult? What positive things have they been able to do?

As a recap of all the points covered in the last session, show the educational film (25 mins). Provide support and advice to those who state that following the recommendations has been difficult.

TOWARDS INDEPENDENT EATING



Materials

Pictures for promoting independent eating 6.05a-e



Activity Ask parents to work in small groups and read out the case study from Bangladesh below (Replace this case study with another one if not suitable for your context).

Questions for parents: *What would be your advice to the mother/parents of this child? What could be done differently (allowing the child to eat with their left hand, eating with a spoon in the left hand may be more culturally acceptable)? Why? Who else needs to be involved in finding solutions (raising awareness within the wider family)? How do you feel about letting your child try to feed herself? How do you feel if your child makes a big mess whilst they are eating? Does it worry you?*

Voices of Children

Ansar is 9 years old. He attends school and is in class 1. He has a weak right leg and hand, and needs help with dressing himself. He feels happy that his adoptive father loves him very much. He loves swimming in the river, playing with his friends, and going to school. He feels sad when he can't join in and play with other children.

"I feel sad when I see other children playing as I cannot run and play like them." He also feels sad because: "I can't eat with my right hand. If mother doesn't want to feed me, I cry I cry in anger when I'm hungry and my mother delays feeding me."

Child, Bangladesh



Explain the advantages of their child becoming independent. Some of the parents may not think this is appropriate, either because it would mean you are not 'looking after' your child properly, or because it is not normal for young children to feed themselves.

The child will be more interested in eating and less reliant on their parent. As a parent you are very busy and may not always have enough time to feed the child. It is important to realise that children enjoy the sense of independence and react against a feeder that is 'controlling'. Yes, yes, yes! There WILL be a lot of mess, but remember that all children make a mess when they are learning to eat. Children with cerebral palsy may make more mess, but it is part of learning and developing control.



Activity In small groups, Look at each of the pictures below in turn and discuss how the child is being helped to eat independently. Ask if anyone in the group has tried this with their child? Explain that these pictures give some ideas on how you can help your child to feed herself:

Pictures 6.06a



Let her rest her elbow on the table if it gives her more control

Picture 6.06b



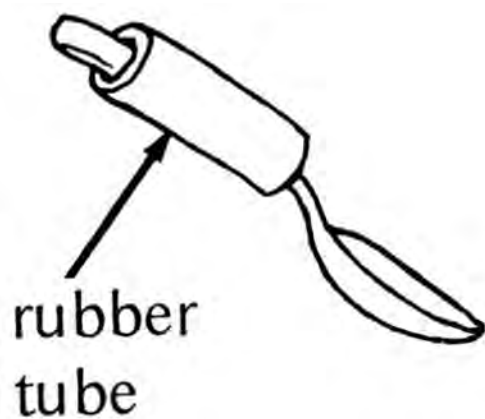
Lifting the table up on blocks to bring the bowl of food closer to her mouth may also give her more control.

Picture 6.06c



If she has difficulty controlling a cup with one hand, try using a cup with two handles.

Picture 6.06d



Explain and demonstrate on a doll: Hints to encourage your child to eat more independently:

- In the beginning, guide her hand to help her learn to feed herself
- Put a biscuit in her hand, guide it to her mouth, and see what she does with it...you might be surprised at how much she manages to feed herself
- Don't stop her putting her hand in her food and trying to feed herself
- Put a wet cloth under the bowl to stop it slipping on the table
- Try bending the spoon so the food still comes towards her at the right angle
- Put some padding round the handle to make it easier for her to grip and hold the spoon

BRUSHING TEETH



Ask *Why do you think it is especially important to clean the teeth of your child with cerebral palsy?*



Explain that a child with cerebral palsy is very much at risk of developing problems with her teeth and gums. Discuss in the group and ensure the following points are covered:

- We all use our tongues all day long to clean our teeth, however as your child has difficulty moving their tongue, this is not happening.
- The child who drools a lot does not swallow properly and has an open mouth most of the time. This allows germs to collect in the mouth.
- It is important that your child's mouth is always as clean as possible to prevent germs going down into the lungs if they have swallowing problems.

Therefore:

- You should clean your child's teeth carefully after every meal and especially after sugary snacks and drinks!
- Some children with cerebral palsy have very sensitive mouths which can make it difficult to clean their teeth well, so extra care is needed.



Explain

Some top tips for teeth cleaning:

- Make sure that you and your child are in a good position before starting. Pay special attention to the position of her head and neck.
- Rinsing can be very difficult. You may have to bring her body forward so that the water can run out.
- It is easier to use a small bowl for spitting out and rinsing, rather than a fixed basin.
- Giving firm pressure on the cheeks towards the lips could help the child to spit out.
- If there is any area with problems like pain or sensitivity, do those first so it can get done while your child is still relatively relaxed.

FACE CLEANING



Explain

- Some children with cerebral palsy need to have their faces cleaned often. This can be because of drooling or food spilling out of the mouth when eating.
- It will help your child to learn to close her lips if cleaning her face is done in such a way that it gives her the feeling of a closed mouth. This can also help to teach your child to swallow her saliva instead of letting it dribble out.
- Use firm pressure on the cheeks and lips using a dabbing movement – not wiping.
- Always dab towards the mouth, as if you are helping to close the lips.
- Dab from the left and right side of the mouth. Then the chin and lower lip. Then the upper lip.
- Tell your child to swallow when you are doing this.

Picture 6.07





Materials

Flipchart with take home messages.

Take Home Messages:

1. Children with cerebral palsy often have problems with eating and drinking. These problems can result in malnutrition and chest infections. There are a lot of things a caregiver can do to help reduce these difficulties.
2. You can:
 - Feed your child small and frequent meals of a balanced diet which has extra fat or oil in it.
 - Give food of a texture your child can manage – e.g. smooth, not too runny, not too solid or chewy.
 - Position her correctly – in an upright or almost upright position, with her chin tucked in slightly.
 - Give her small mouthfuls of food and small sips of water, slowly, using a small utensil.
 - Give positive verbal encouragement and NEVER force feed.
 - Help and encourage your child to feed herself.
 - Teach other family members to feed your child or to support her to feed herself.
3. Children with cerebral palsy need special care with regards to teeth-cleaning and face-washing.



MONITORING PROGRESS

Ask each parent to identify at least one thing that they will do differently at home as a result of today's session. Ask parents to teach this to at least two other members of the household so that they are also able to help. In the next session they can feed back on how successful this was.

In Bangladesh parents recipes for khichuri or suji were shared with caregivers (see Resource section). Suji can be made thicker by cooking for longer and runnier by adding more milk/water; Khichuri can be made thicker by adding less water during cooking and thinner by adding water afterwards. If necessary, try to modify the consistencies of the food they have brought today. You can use cereal powder (like Cerelac) to thicken the food they have brought.

Additional guidance is available through The International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR,B) which has a nutrition unit that provides guidance and useful recipes for home treatment of malnutrition. More information is available at

<http://www.icddrb.org/>

MODULE – SESSION 3

Facilitator note: If time allows, this is a really valuable session which allows an opportunity to test out parents' learning in a supportive environment. Remember that these training sessions are also important social support mechanisms for caregivers as well. Try to make it an enjoyable and social occasion.

In preparation for this session, ask parents to make a suitable nutritious dish from locally available foods, and bring it along to the session. Alternatively, if cooking facilities are available, ask parents to bring the ingredients and prepare the food together.



Activity Ask parents to show the group the food they have prepared for this session. Discuss together the consistencies, whether they seem appropriate for their children, and how they might be modified to be thicker or runnier. Ask the parents to sit in a circle, or in small groups, and feed their child the food they have brought, trying to follow all the advice. Support them individually and encourage parents to help one another.



MONITORING PROGRESS

Ask each parent to identify at least one thing that they will do differently at home as a result of today's session. Ask parents to teach this to at least two other members of the household so that they are also able to help. In the next session they can feed back on how successful this was.

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RESOURCES

Video Clips: Short video clips on feeding can be obtained from Hambisela at www.hambisela.co.za and from MAITS at <http://www.maits.org.uk>. MAITS is an international organisation which exists to empower education and health professionals to enhance and develop the services they provide to individuals with disabilities in resource-poor settings through sharing knowledge and practice. Alternatively you can make your own 'before' and 'after' video clips to illustrate improved feeding practices.

Answers to the Positioning Quiz

Cards 6.03b

1. b.



Child held upright to make lip closure and swallowing easier. It is very difficult to swallow with your head back.

2. a.



Don't force head forward. Cradle base of head in your bent arm using same arm to bring child's arm forward. Use your other hand to press firmly on child's sternum.

3. a.




Support base of head in bend of your arm. Hold child's arms firmly forward. This, and .. pressure on sternum (mentioned in 2), help to reduce extensor pattern.

4. b.




Use your legs to support child in a good, upright position with child's hips and knees flexed.

5. b:

















While sitting, hips and knees should be flexed at 90°. Arms should be forward with tray as support. Feet should be supported.

6. a.



Give food from the front, slightly below. Ensure child's head is symmetrical. This makes eating and swallowing easier.

Recipe Sheet (for Bangladesh – for *Khichuri* and *Suji*). You will need to find suitable local recipes for the country where you are running the course.

রেসিপি	
<p>খিচুড়ী</p> <p>ভাত </p> <p>ডাল </p> <p>শব্জি (মিষ্টি কুমড়া এবং শাক) </p> <p>তেল </p> <p>পেঁয়াজ </p> <p>হলুদ </p> <p>অল্প পরিমাণে লবণ </p> <p>পানি </p> <p>সম্ভব হলে মাছ </p>	<p>দুধ সুজি</p> <p>গুড়া দুধ </p> <p>চালের গুড়া </p> <p>চিনি </p> <p>তেল </p> <p>পানি </p>
<p>ক্রিমির ঔষধ (এ্যালবেন)</p> <p>১-২ বছর ১ চা-চামচ ১ ডোজ প্রতি ৩ মাসে একবার</p> <p>২+ বছর ২ চা-চামচ ১ ডোজ প্রতি ৩ মাসে একবার</p>	

MODULE 7:

Play

Facilitator note: use this module to organise play activities for all the training sessions (see notes in Module 0 – Before You Begin).



Materials

Everyday objects (for example empty cereal boxes, match boxes, plastic cold drink bottles and lids, brightly coloured material, clothes pegs, tin cans, plastic containers, stones, seeds, beans or rice, plastic cups), floppy doll, examples of home-made toys. Check the Resources section of this module for examples of how to make low cost play equipment. When using household objects as toys, avoid using very small objects with younger children as they may accidentally swallow/choke on them.

In Bangladesh, playing with the children during the training sessions was an integral part of every training session from the outset. This did require careful organisation and planning to ensure there was suitable play equipment, and that community workers were suitably prepared.



Icebreaker

Place some inexpensive everyday objects on the mat and ask the participants to show what a child might do with these things. Summarise this activity by emphasising that most children naturally enjoy and find ways to play with any objects or things that are around them.





Explain

Outcomes for the module (on flipchart).
As a caregiver you will:

1. Understand and explain to other caregivers the importance of play for a child's development.
2. Help your child with cerebral palsy to enjoy types of play that promote her communication, movements, social and emotional skills, and learning.
3. Explore ways in which other children can be encouraged to include children with disabilities in play.

In Bangladesh there was a high demand from parents for medicine and 'therapy' for treatment. It was more challenging to get across the value of play. In our research, we found several children who sat or lay alone at home all day without any opportunities at all for play and/or interaction with other children. Unfortunately, in some cases, there appeared to be no change in play activities over the lifetime of the training project.

There needed to be far stronger links between the theory of the training session, and applying this to everyday activities at home. The home visits needed to be strengthened to ensure that they involved other members of the household. Caregivers themselves, generally mothers, often had very limited time to spend in caring for their child, which is why it is so crucial to involve other family members.

For the play module, involving siblings in the discussions is important.



Materials

Picture 7.01.

Alternatively, find other local pictures of children playing.



Ask the participants:
What is play?



Explain that play is any activity that a child **CHOOSES** to do, and has **FUN** whilst doing. Through play, a child uses her **SENSES** to explore and learn.



Ask the participants:
What are our senses?



Explain what the senses are and write these up on a flipchart:

- Seeing
- Hearing
- Touching/Feeling
- Smelling
- Tasting

Something else that works very closely with our senses, and is involved in play, is movement.



Activity In pairs, discuss which senses are being used in the following examples. Demonstrate the following play activities. If possible involve some of the children in the group:

- Enjoying the sound of a rattle/music (Answer – hearing)
- Handling different objects – soft, hard, prickly etc (Answer – touching/feeling)
- Hide and seek (hiding an object under a lid or box and getting the child to try and lift the box to find the object, or hiding yourself from them and seeing if they can move or look for you (Answer – seeing)
- Singing and clapping games (Answer – sight, movement, hearing)
- Splashing in water (Answer – feeling and movement)



Materials

Picture 7.02

Picture 7.02 – Photo: Playing with children during sessions, Bangladesh



Ask *Why is play important for all children? Does a child with cerebral palsy need to play?* Put up the picture7.02 and allow time for discussion.





Explain that play is important for your child because:

- It gives her an opportunity to explore and therefore learn about things in her environment.
- It gives her opportunities to use and develop her senses.
- When she is having fun she will be motivated to move.
- It gives her opportunities to interact with other people and to learn to communicate.
- It gives her the opportunity to think and learn.
- Play is **FUN**, and every child has a right to it.

Voices of Children

In all the children's interviews, being able to play was what made them happy. Conversely, not being able to join in and play with other children, and being left on their own, was one of the main issues which made them sad.

"I play alone at school and at home. I like to play. [Why do you play alone?] All the other children run around and play, but I cannot run. I like to go to the training and I feel happy when I hear that I'm going to training. [Why do you feel happy at training?] I can play there and they teach us many things. [When do you feel sad?] I feel sad when I see my friends playing and running around, as I cannot run like them."

Child, Bangladesh



Ask Do children need expensive toys to play? Do they need help to play? What do you observe about the experience of children playing during the training sessions?



Explain that during the training sessions the children are not playing with expensive toys.

- Favourite toys are most often household items.
- Play is more important than toys. Almost anything can be used as a toy, if it is used in play.
- Some children will need help to play. All children will need the encouragement of their parents/caregivers, siblings and other children.
- Children with cerebral palsy may need additional encouragement, and may need special help and attention from caregivers, or from other children.

MAKING AND ADAPTING SUITABLE TOYS



Materials

Various suitable local materials. Pictures of different toys which can be made, and simple instructions (see Resource section).



Activity Look at a variety of simple toys that you can make. For each toy, briefly discuss how you can make it, and ensure everyone will get an opportunity to make at least one toy which they will be allowed to take home. This session can be run as a separate workshop session, where siblings can also invited along to help make toys.

In Bangladesh, suitable toys were available for all the training sessions. By only discussing the toys 'in theory' we found that, perhaps not surprisingly, toys were not made at home. A key recommendation is for a more practical session, where parents and other siblings are allowed to make the toys and take them home. During the home visits, there needs to be more time supporting suitable play activities, and adapting/using household objects to play with the child.



Icebreaker Ask each participant to talk about the toy they made in the previous session, and whether their child used it at home. Where possible, involve the children in saying whether they liked the toy, and/or demonstrating the toy.



Materials

Case studies (have printed on card, one case study per group). You can also make your own case studies from your local context.



Activity Split the participants into small groups. Give each group a story and a picture of a child with cerebral palsy. Ask them to read through the information about the child, and then choose two games or activities to play with her. They should be activities that they think the child would like, and be appropriate to the child's level of ability.

Taking the child's disability into account, ask them to think about what they would do to help the child to play – what additional help might the child need? Then ask each group to feedback their ideas and discuss.

Case Study 1 (Picture 7.03)

This girl is stiff in her arms and her legs. She can move her arms a little by herself, but moves very slowly. Her mother takes care of her and has noticed that her eyesight is not good; she only responds to light or shiny objects.

Is this child in a good position to play? What could you do to improve her position to play? What kind of play activities could be encouraged?



Case Study 2 (Picture 7.04)

This girl is stiff in both arms and legs. Her head often pushes back, and her hands are always closed. She cannot sit without help, and doesn't move by herself. She cannot talk, has poor eyesight, and responds with babbling and smiles when someone speaks to her. She lives in a tin shed house that has two rooms and an outside toilet. She is looked after by her grandmother.

She normally sits all day on a red plastic chair outside her house. She doesn't play with anything, as her grandmother says she cannot hold anything in her hand. Her grandmother is very busy working on the handloom during the day.



Is this girl in a good position to play? What could be done to improve her position? What kind of play activities could be encouraged? Who can help the child to play?

Case Study 3 (Picture 7.05)

This boy uses a special sitting chair. His speech is slurred and difficult to understand, but he can understand everything. Grasping with all of his fingers is difficult, but if you put something in his hand he can hold it for a few seconds with some of his fingers. His eye sight is good. He lives with his mother, grandmother, uncle and three siblings aged 4, 7 and 12 years old. *What kind of play activities could be encouraged? Who else could be involved in the play activities?*



Explain in the plenary some additional Guidelines for children who have difficulty hearing or seeing:

- If a child has been diagnosed with blindness or deafness, focus mostly on other senses for play.
- However, still try to practice the sense through play by giving opportunities to use that particular sense e.g. shiny mobile or vision box for a child who has difficulty seeing.



Ask the group the following questions. *How much time do you have to play with your child? How can you involve others? Why is it important to involve others in playing with and caring for your child?*



Explain in the plenary in the plenary discussion that, in reality, caregivers (mainly mothers) do not always have the time to play with their child. Make sure you cover the following points:

- It is really important to involve other members of the family in playing with the child.
- Instead of just asking another caregiver or other children, “Please play with my child,” be very specific. Tell her about one of the games we have discussed in this session or in the appendix. Show her how to play it with your child, and explain how and why it is important to your child’s development.
- With other members of the family, discuss the types of play, those that your child finds easy or difficult, and especially your child’s development needs.
- Involve other caregivers in thinking of games that can be played with your child.

Inclusion in play: What can we all do to promote greater inclusion?



Materials

Case study Jatul (you can replace this with you only case study example from your local context).



Activity In small groups ask caregivers to read the short case study below. Ask them to discuss the case study in their group and consider the following questions:

What are some of the main challenges faced by this child and the family? Are these issues that you have come across in your own community? What can be some of the barriers to children with disabilities being included in play in their own community? Is it important that they are included in play? Why? (Think about your own child or another child that you know.)

Case Study

Jatul is 12 years old. He has some difficulties with communication, but can express himself with a combination of words and signs. He cannot do anything with his right hand, and his right leg is weak.

He loves to go to school and is studying in class 5.

“I never miss school even on rainy or stormy days I like it when my friends come and chat with me. The teachers are very nice.”

Jatul plays alone at school and at home. [Why do you play alone?] *“All the other children run around and play. I cannot run that’s why I play alone. I feel sad when I see my friends playing and running around, as I cannot run like them.”*



Finding Solutions: Ask each group to think about ways that play can be more inclusive. Feed back to the wider group. Some possible solutions might include:

- Share what you learn from this training with neighbours and friends, so that they can better understand and can help with caring for your child.
- Take time to talk to siblings and other children and show them activities that your child can do. Adapt toys, games and activities to allow for children with disabilities to be included in play with other children.
- Enlist the help of a teacher at the local school. Ask them to talk to the children about how they can better include children with disabilities in their play. Perhaps they could set up a 'buddying' system to encourage children to buddy with children with disabilities in the community – especially when so many children with disabilities are not going to school.
- Set up your own parent support group. Children will get huge benefits from meeting up and playing with other children in the group. Your group could consider running a session on disability in your community.
- Look at how you may be able to change the local environment to allow those with a disability to access where children gather and play.



MONITORING PROGRESS

Ask each caregiver to share one activity that she plans to try at home with her child. During the next home visit, take each of the goals you set for your child during module 2 from the developmental chart and think of a game that you could play with her to develop that skill. What objects at home can you use to make a toy or toys that she can play with? How can you make everyday activities such as bathing, eating or dressing playful? Plan to discuss these with the community worker.

Alternatively, in the absence of follow up home visits, run this as an activity during the training session.



Materials

Flipchart with take home messages.

Take Home Messages:

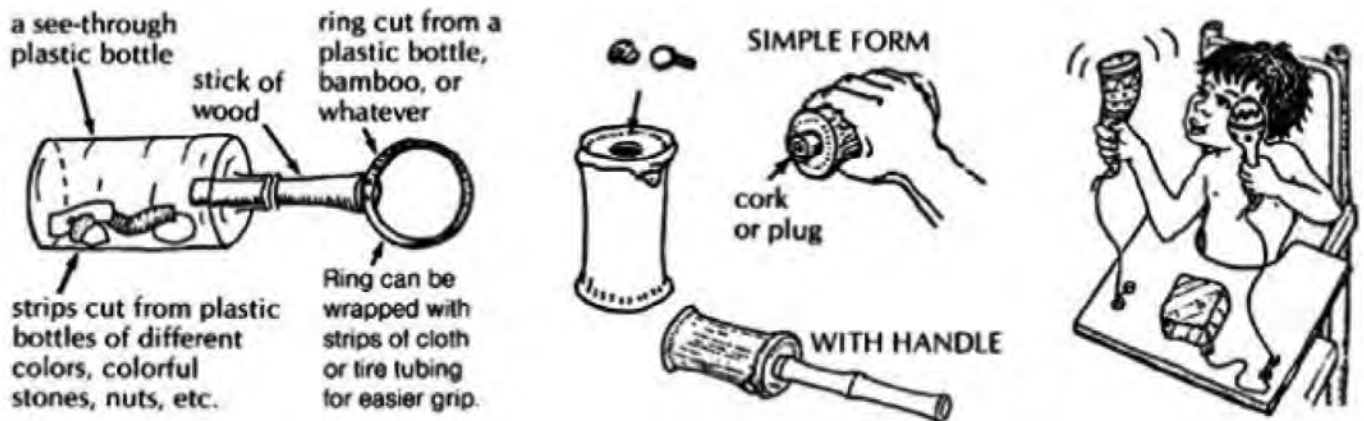
- Play is very important for a child's development. A child who does not play will not develop as much.
- We can use everyday simple household objects for play. Involve other children in making toys which are suitable for your child to play with.
- We can always find ways to help ensure that play is inclusive for all children.

RESOURCES

How to make simple toys

Most of the resources below on how to make simple toys are taken from Werner, D., Disabled village children. 1999: The Hesperian Foundation available at <http://hesperian.org/>. The book chapters are free to download.

Rattles



Making it: Plastic bottle/tin or bamboo. Stones or seeds or beans or rice to put inside. Lid or cork to close the hole.

Using it: Hold it a short distance away from the child's face and encourage her to look towards the sound and movement when you shake it. Shake the rattle for a bit then wait for the child to react before shaking it again. Don't shake it continuously. Encourage her to move her head towards the sound. Help her to hold the rattle, and encourage her to move her arm to make the rattle make a noise. Help her to practice holding and letting go of the rattle (taking it from someone, giving it to someone else). If the child drops or throws her toys, try attaching strings and help her learn to get them back by herself.

Mobiles



Making it: Tinfoil/CDs/bottle tops. Beads or seeds. Bells. Brightly coloured material. Egg boxes. Hang any shiny object or something that moves easily in a gentle breeze (e.g. tissues).

Using it: Hang above the child when she is lying on her back or on her side – she can enjoy watching the objects, and may try to reach and take them so that she can feel them, or make them move to hear the sound (e.g. bells).

Vision Box

Making it: Cardboard box. Mobiles – placed above her waist; not more than 3 objects. These can be shiny things (like an old CD or pieces of foil), brightly coloured beads, or light pieces of material that will move with a gentle breeze or blowing.



Using it: The child lies on her back with her head and upper body inside the box. This can be used for a child who cannot see well. The dark box with the shiny or brightly coloured mobiles may help her begin to use and train her eyes. She will enjoy looking at the bright or shiny colours, or watching the light material blow in the wind.

Texture Bag/Box

Making it: Material of different textures – soft; silky; corduroy; woolly; embroidered; netting. Piece of steel wool or plastic hair curler (scratchy feeling). Something hard – marbles, steel teaspoon, glass bottle. Soft toy – teddy bear. Clothes peg. Plastic packet or noisy paper. Seeds or pods of different textures – smooth, rough etc.



Using it: This is especially good for children who have problems seeing well, and for those who do not move easily by themselves. Help the child to feel the different textures on the outside and inside of her hand. First touch the outside of her hand – then open her hand and let her feel it on the inside of, or put it in her hand. A child who can move her hands can practice taking and giving the objects.

Drum

Making it: Can or plastic container or pot. Stick or wooden spoon or metal spoon.

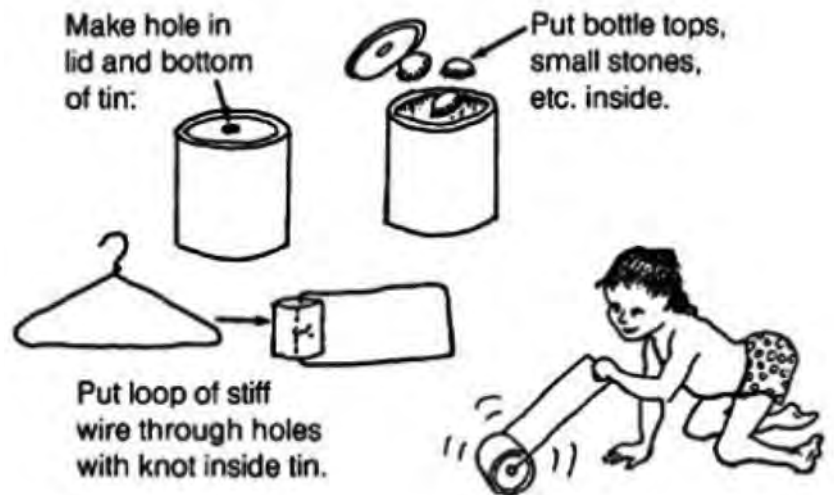
Using it: Help the child to hold the stick and to play the drum (involve the family and get others to sing with her. Involve the child in family or church gatherings where there is music or singing). Encourage the child to hold the sticks by herself if possible. Encourage her to move her arm by herself to hit the drum.



Push/Pull Rattle

Making it: Use a tin or plastic container that has a lid. Make a tiny hole in the lid and bottom of the tin. Put some small stones or seeds into the tin. Use a wire hanger to make a rectangular loop through the holes.

Using it: Help/encourage the child to hold the wire and push the toy away and pull it back towards her. Encourage her to walk/crawl while pushing the toy.



Putting In/Out

Making it:

Large tin or plastic container.
Small items (seeds, bolts, match boxes, stones, small plastic cups, scrunched newspaper balls, bottle tops or lids).

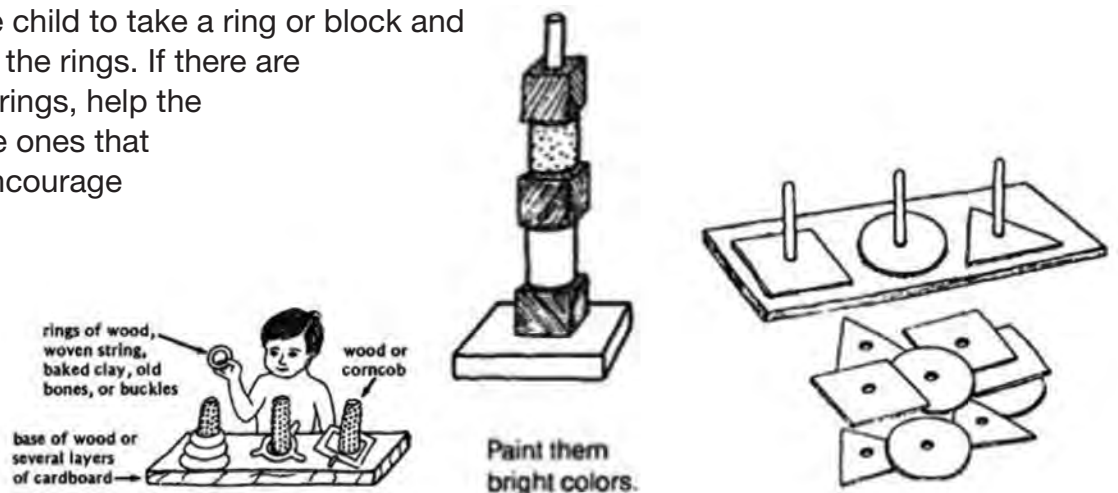
Using it: Encourage the child to pick up the small objects one by one. She can take them out of the container, and put them back in. Encourage her to talk about what she is doing – “in” and “out”.



Stacking Poles

Making it: Wooden base with stick or small poles or long paper towel rolls. Rings (cut holes into plastic lids, make ring out of foil, soft branches, woven grass, cut up toilet rolls). Blocks (out of cardboard from empty boxes or scrap wood) – make a hole in the centre.

Using it: Help the child to take a ring or block and place it on one of the rings. If there are different types of rings, help the child to match the ones that look the same. Encourage the child to count the rings as she puts them on.

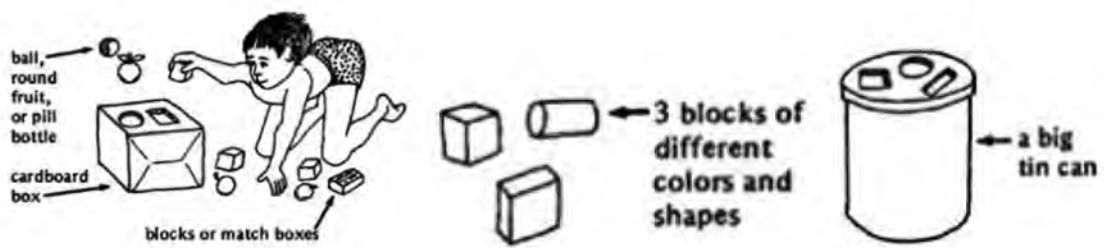


Posting

Making it:

Plastic container or tin with plastic lid and shaped holes cut out.

Find small objects, and cut the holes in the lid to the same size and shape – use bottle tops, match boxes, small lids, and pieces of wood. Simple toy – objects and holes are all one shape. Complex toy – objects and holes are a variety of shapes.



Using it: Encourage the child to post the object into the correct shape and size hole. Help her to pick up and let go of the objects (if she has difficulty using her hands). Let her guide the object into the hole she wants to put it in. Talk to her about the size and shape of the different objects as she plays.

Visual Rattle

Making it: Plastic bottle filled $\frac{3}{4}$ with water, dishwashing liquid or something to make bubbles, small plastic beads or seeds that are brightly coloured or dark.

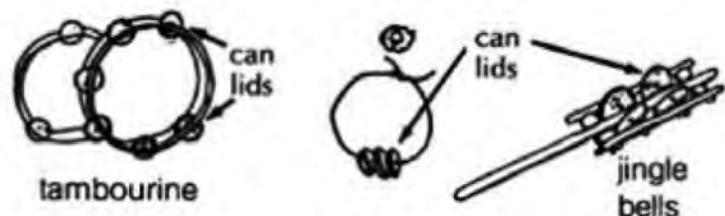


Using it: Use it the same way as the rattle discussed earlier in the module. Because of the different things to look at inside the rattle, the child can be encouraged to look at it for longer and longer periods of time when lying on her back, stomach, or in side lying. This can improve getting her attention for communication.

Other Musical Instruments

Making it: Bottle tops on a piece of wire. Container with small stones or seeds.

Using it: Help her to hold and play the instrument. Encourage her to take and let go by herself. Encourage her to move her hand or arm by herself so that the instrument makes a noise.



Soft Toy Rattle

Making it: Small bottle with seeds or stones inside. Material cut out into shape (ball, animal, bear).

Stuffing. Needle and thread to sew it together.



Using it: Encourage the child to hold, touch and handle the toy. Show her that if she shakes it, it makes a sound. Encourage her to shake it by herself.

MODULE 8:

Disability in Your Local Community

Facilitator note: This module is developed for a session with caregivers, but can also be used in the community. Ideally you would run it with the caregivers first, and then in the local community. Although this is the 8th module many of the activities can be slotted in anywhere during the training programme. Ideally you might plan some of this work earlier in the training programme, to allow time for follow up and linkages with other organisations. If your training programme is embedded within an existing CBR project then many of the issues may already have been covered.

This module has some overlap with Module 9, Running Your Own Parent Support Group, which also looks at disability and rights.



Materials

Flipchart paper, pens. Copy of *IT'S ABOUT ABILITY: An explanation of the Convention on the Rights of Persons with Disabilities* (see Resources), and material about national legislation on the rights of persons with disabilities (this will vary between countries).



Icebreaker

For caregivers: Ask them to walk around the room and find someone that they do not know or don't know very well, and ask them to *Share the funniest thing that's happened to you as a parent of a child with a disability*. Ask for a selection of funny stories to be fed back to the group.

For a session with the community: Get each person to turn to a person next to them and *Tell your partner a story about one disabled person that you know (in your family, work place, community), and highlight what surprised you when getting to know that person*.



Explain

Outcomes for the module (on flipchart).
As a caregiver you will:

1. Identify some of the main barriers to inclusion of children with disabilities in your community and the ways these might be addressed.
2. Understand the basics about the UN Convention on the Rights of the Persons with Disabilities (UNCRPD), and of national legislation on disability, and be able to communicate this to others.



Activity Community mapping: In small groups ask parents from the same village to map out, on a large piece of flipchart paper, the key services and key stakeholders in their community. This can include: health and social services, NGOs, mosques, churches, and schools. Ask parents to mark their own homes, as well as the services which they access. Put up the different community maps around the room and ask parents to explain their maps. During the plenary consider what, if any, are the barriers to accessing some of the services that they have mapped. Discuss what could be done to make access to these services easier for them and their families.



Photos: Mothers mapping out their village and key services in Bangladesh

In Bangladesh a “community mapping” exercise was undertaken early on in the training programme. This helped to identify key NGOs and government projects working in the project area, and identified linkages that could be made with the training project. For example, a number of children in the groups were severely malnourished and there was a need to identify opportunities for connecting families to the government nutrition programme, and for linking families with existing livelihoods programmes.



Activity An alternative activity for a session with the community is the ‘Game of Life’ activity. Full details are available from the World Vision resource ‘Travelling Together’ (see Resources for a summary).

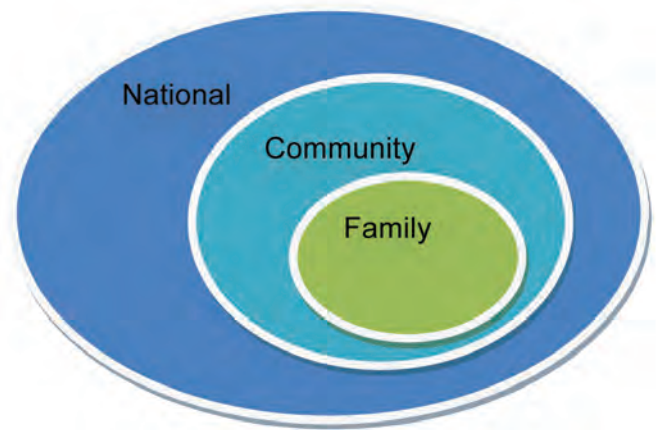


Activity Barriers faced in your community. In small groups refer to the community maps, and ask participants to brainstorm what they think are some of the main challenges faced by families of children

with disabilities in their community. Consider the challenge at different levels. Prompt them not to only think about physical barriers:

- Within families and extended families
- Within community (e.g. school, health services)
- At district level and national level

Note these down on a flipchart paper, and then get each group to provide feedback.



In Bangladesh research highlighted a number of barriers to the uptake of referrals and services by families.[1-2]

Physical or environmental barriers to participation and inclusion are often easiest for the community to identify as barriers, for example steps or uneven pathways, not being able to walk to school, and not able to access the toilet independently. It was important to not only focus only on these issues, but also to unpack some of the attitudinal barriers which they faced with their family and community.



Explain during the plenary some of the key barriers under the following headings. You can use some of the case study examples below prompt further discussion – are these stories familiar to them?

Attitudinal barriers may include:

- Stigma and discrimination within the family and community
- Parents themselves don't consider taking their child to school
- Other family members can stigmatise the child

“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.' 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

Physical barriers may include:

- Inaccessible/cramped home environment which make it impossible or difficult to perform activities of daily living
- Inaccessible roads and public buildings – for many children who cannot walk/have difficulty in walking getting to school or to other services can be difficult inaccessible transport – vehicles, public transports are too crowded, and often refuse to carry disabled people

Voices of Children

In all the children's interviews, being able to go to school was the most important priority for them. Not being able to attend school was a key reason given for feeling sad. One of the main barriers to access was transport – they were often dependent upon members of the family carrying them to school. How could you address this at community level?

“My mother can't take me to the school regularly anymore because she is sick. If I was healthy, then my mother would not have to take me to school. When I see the pain of my mother, I feel like leaving school. It's really painful for me to go to school.I walk on a stick and I rest every now and then. Sometimes when I really want to go to the school, but my mother can't take me, I cry.”

Girl, 12yrs, Attending Grade 1 primary school, Bangladesh

Institutional/service barriers:

- It can be a difficult process for families to get a disability identity card, and even harder to get a disability allowance
- Difficulty in getting admission to school
- Educational institutions lack appropriately trained staff to meet the needs of certain students with disabilities
- Lack of adequate of health and rehabilitation services in rural areas

Discussing community solutions was a really important component of the session which prompted a wider discussion at the community level about how the community can promote greater inclusion of children with disabilities.



Activity Finding community solutions: In small groups ask the participants to look at each of the barriers to inclusion, and ask them to discuss possible ways to address them. You can also ask groups to prepare a short role play to illustrate how some of the issues might be addressed. For example:

- If transport is problem for a child getting to school, what could they do? What can others in the community do? How can other children help?
- If there are lots of myths about what causes disability how might they address this? For example, could a religious leader be asked to give a sermon?
- How could they work as a parent support group to address some of the issues?
- What can be done to help these families get a disability identity card and disability allowance (in countries where available)?



Photo: Role Play to illustrate how to get a disability card, Bangladesh

In Bangladesh only 11 of 153 families were registered for the government disability card at the start of the project, and by the end of the training all had been supported to register. Most families had heard of the card but did not have the relevant information about the registration process. A key part of the training was a role play activity by the community workers, where they acted out how to approach the local leaders and the necessary steps to be taken to access the disability card. This was very amusing and made everybody laugh! After the session many parents immediately acted to register the birth of their child at the Union office.

Participants were really keen to know more about their rights and there was a lot of discussion about the Bangladesh Persons with Disability Welfare Act 2001. For the full details of the Welfare Act and the disability card application process, check out the appendices of this module.

RIGHTS OF PEOPLE WITH DISABILITIES



Materials

Copy of *IT'S ABOUT ABILITY: An explanation of the Convention on the Rights of Persons with Disabilities* (see Resources), and material about national legislation on the rights of persons with disabilities (this will vary between countries).



Ask the groups what they have heard about the rights of persons with disabilities.



Explain briefly the key points from the UN Charter on the Rights of Persons with Disabilities (UNCRPD), and nationally relevant legislation related to people with disabilities. Where possible, invite someone from a local Disabled Person's Organisation (also known as DPO) to present this information, as they will also be able to outline opportunities for local level advocacy.

PLANNING FOR A SESSION IN THE COMMUNITY

Ask them to think about running for a session on disability in their own community; what would be the key points that they would want to get across? Who do they think it is important to invite? There would need to be separate planning time for running a session in the community. Parents and other caregivers should be at the heart of any community session if they feel confident with this. They may require some support.

In Bangladesh sessions were run for parents first, and then for local community leaders, including Union members, teachers¹, health personnel, etc. At the start of the community session basic information was covered about “what is a disability?” and more specific details about cerebral palsy. There are a lot of myths about the causes of disability, and it was useful to spend time on challenging some of those myths. Module 1 of this training programme was used to explain some of the basics about cerebral palsy.



MONITORING PROGRESS

Ask each participant to explain one thing they found useful from the session and that they will explain to other members of their family and/or community. Provide them with a handout explaining national legislation.



Materials

Flipchart with take home messages.

Take Home Messages:

1. Children with disabilities have the right to access services including education, health, transport and employment.
2. Together we can find local solutions to the challenges experienced by the children with disabilities and their families.

References

1. Nesbitt, R., et al., *Predictors of referral uptake in children with disabilities in Bangladesh-Exploring barriers as a first step to improving referral provision*. Disability and Rehabilitation, 2011(00): p. 1-7.
2. Bedford, J., et al., *Reasons for non-uptake of referral: children with disabilities identified through the Key Informant Method in Bangladesh*. Disability & Rehabilitation, 2013(0): p. 1-7.

¹ Union Councils are the smallest rural administrative and local government units in Bangladesh.

RESOURCES

Check out Module 9 'Running your own parent support group' which has additional material on Rights of Persons with Disabilities.

UNICEF. *IT'S ABOUT ABILITY* An explanation of the Convention on the Rights of Persons with Disabilities. 2008; Available from: http://www.unicef.org/publications/files/Its_About_Ability_final_.pdf. This is a very simple and user-friendly version explaining the Convention on the Rights of Persons with Disabilities.

Coe, S. and L. Wapling (2012). *Travelling together*, Milton Keynes, World Vision. Available at <http://www.worldvision.org.uk/what-we-do/advocacy/disability/travelling-together-publication/>. This training material aims to boost disability inclusion in development programmes, and is developed primarily for programming staff who have not considered disability inclusion before.



Activity The 'Game of Life' (Coe, S. and L. Wapling (2012). p.25) can be used as a stand alone activity for training in the community. A summary of the activity is outlined below:

1. Ask for four volunteers from among the group (ideally, two men and two women), willing to stand for about 30 minutes to represent the following groups: • non-disabled men; • disabled men; • non-disabled women; • disabled women.
2. Assign each volunteer a role. Explain how you'll be telling a life story, taking the characters on a journey from birth to old age. As you reach each significant life event, you'll ask them to respond as they think their character (or their family) would react. They'll need to take:
 - two steps forward for a very positive or very successful experience;
 - one step forward for a positive or successful experience;
 - one step back for a not-so-positive or not-so-successful experience;
 - two steps back for a negative or unsuccessful experience.

Also, their response should be based on what they think is currently accurate for their culture and situation – not what it ought to be. After each life stage and volunteers' responses, allow time for the others to react and comment. If there's disagreement, the group should decide by consensus and the volunteer may be asked to alter their move.

3. Set the scene for the story. Since you want to emphasise links between disability and poverty, consider placing the story in a typical village.

‘One fine day, after a long wait of nine months, your character is born. How does your family feel when they see who you are? Make your moves.’

Note what might happen:

- family is very happy (non-disabled son born), two steps forward;
- quite happy (disabled son/non-disabled daughter), one step forward;
- not happy (disabled son), one step back;
- very unhappy (disabled daughter), two steps back.

‘Now you are a bit older, and it’s time to start thinking about school. How likely is it that you will be able to attend school? Make your moves.’ ‘Now you are 20. You’d like to get married, or form a relationship. How much do you think this will be possible for you? Make your moves.’

‘You like to keep busy and want to make some money for your family.

You try to get a job. How easy will it be for you to find one?’

‘A few years go by. Everyone in your age group is having babies.

How much will this be a possibility for you?’

Check if the disabled woman takes two steps back, or is instructed to do so by the group. Why did this happen? They may say it’s because most disabled women are physically unable to have children – a common myth.

Two steps back may well be an accurate response for a different reason – disabled women often don’t have children because society thinks they can’t or shouldn’t.

‘Now you’re in your 40s. You have a lot of experience of life. You want to help your community by becoming involved in local politics. How likely are you to achieve this goal?’

Ask the group:

- Who is in the best position now? Who is in the worst place?
- Volunteers, how does this make you feel?
- Does any of this surprise anyone?
- Is it helpful as a tool for reminding us that disability and social exclusion seriously affects people’s abilities to avoid poverty?
- The non-disabled man at the front of the exercise is regarded as living in poverty – what does this imply for disabled people?

The most powerful way to end this session is to ask the group to look once again at where the characters are standing. Recall that this was all taking place in a rural location where general levels of poverty are quite high. Even though the non-disabled characters are well ahead of the disabled ones, they’re by no means wealthy. Ask the group – who benefits from your development programmes at the moment?

Bangladesh – A Step by step guide to obtaining a Disability Identity Card in Bangladesh

- ✓ Collect birth certificate from the Union Parish office,
- ✓ Collect nationality certificate from the Union Parish office,
- ✓ Determine blood group and obtain a certificate from a nearby government or non government hospital or clinic/diagnostic centre.
- ✓ Collect a certificate from the Thana Health Officer (THO) about the type of disability. Please note that THO usually do this verification only on specific days of the week.
- ✓ Complete the application form at the social welfare office and get it signed by the respected union field officer.
- ✓ Attach two passport size and two stamp size photographs of the applicant and the certificates with the application.
- ✓ Submit the complete application pack to the sub-district social welfare department office and get it signed by the authority. Sub-district social welfare office shall forward your application to the district social welfare office. Please note that applicant (CP children) may have to be present at the both sub-district and the district offices of the social welfare department for inspection by the social welfare officer. If the office accepts your application they will give you a date (usually one week later) to collect the disability identity card.

Bangladesh Persons with Disability Welfare Act 2001

- ✓ As a human being and a citizen of Bangladesh persons with disabilities have all fundamental rights and state parties shall take all necessary measures to ensure there effective enjoyment on an equal basis with others.
- ✓ A person or children with disabilities have the rights of accessing **health and disability rehabilitation services**. Government shall ensure adequate supply of medical utilities for treatment of the PWDs and arrange training of physicians/health professionals attending the PWDs.
- ✓ **Education** of the PWDs: State parties shall establish specialised education institutions to cater the special needs of the children with disabilities, to design and develop specialised curriculum and write special text books and to introduce special arrangement for examination if needed by a disabled student.
- ✓ Create opportunities for free education to all children with disabilities below 18 years of age and provide them with books and equipments free of cost or at low-cost.
- ✓ Endeavour to create opportunities for integration of students with disabilities in the usual class-set-up of regular normal schools wherever possible.
- ✓ **Rehabilitation and Employment** of the Persons with Disability: Identification of appropriate job/employment areas for the PWDs and arrange employment opportunities thereto. Ensure equity of opportunities for employment while recruiting employees in the Government Departments, Statutory Bodies and Local Authorities for suitably qualified persons with disabilities.
- ✓ **Accessibility and Transport Facilities:** To set up appropriate facilities at all buildings and establishments and transports belonging to the Government, Statutory Bodies and private organisations to facilitate easy movements and communications for the PWD.

MODULE 9:

Running Your Own Parent Support Group

Facilitator note: If you are running a number of caregiver training groups then you may want to identify 'parent leaders' to represent each group. Invite key staff from local organisations (e.g. social services, micro-credit, health care, DPOs etc.) who can present information to the group about what services or support they can offer. Prepare additional background information on national-level legislation about rights. As one of the last modules in the training package, this is also a useful opportunity to undertake more in-depth evaluation of the training. See Resources for additional links on M&E.



Materials

Flip charts, pens, map of the locality, copies of the *Convention on the Rights of Persons with Disabilities* (See Resources) and information on national legislation regarding the disability rights.



Icebreaker

Welcome the parents. Check on their expectations for attendance. If they are representing different parent groups then ask each participant to introduce themselves, the village that they are from, as well as the parent group they are representing. Ask them to mark their village/group on the map.

Review together the map of all the different villages, and using a marker pen, join up the groups. Explain that the purpose of the training is also about sharing experiences across the different groups.



Photo: Parent presentations, Bangladesh

In Bangladesh two parents from each of the 14 parent groups were identified as leaders and this module was run with them. This provided an important opportunity to meet parents from other groups, and encouraged a wider exchange of information.

“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 Whenever we hear about a child improving, we meet him at their home, and try to find out more.”

Parent, Bangladesh, during session on running a support group



Explain

Outcomes for the module (on flipchart).

As a caregiver you will:

1. Identify good practice for running and organising self-help parent groups.
2. Explore some of the benefits of wider networking with other parent groups.
3. Understand basic information in relation to rights of persons with disabilities, and have a basic understanding of the role of advocacy in their local community.

DISABILITY AND RIGHTS



Materials

Cards for diamond ranking activity (see Resources)

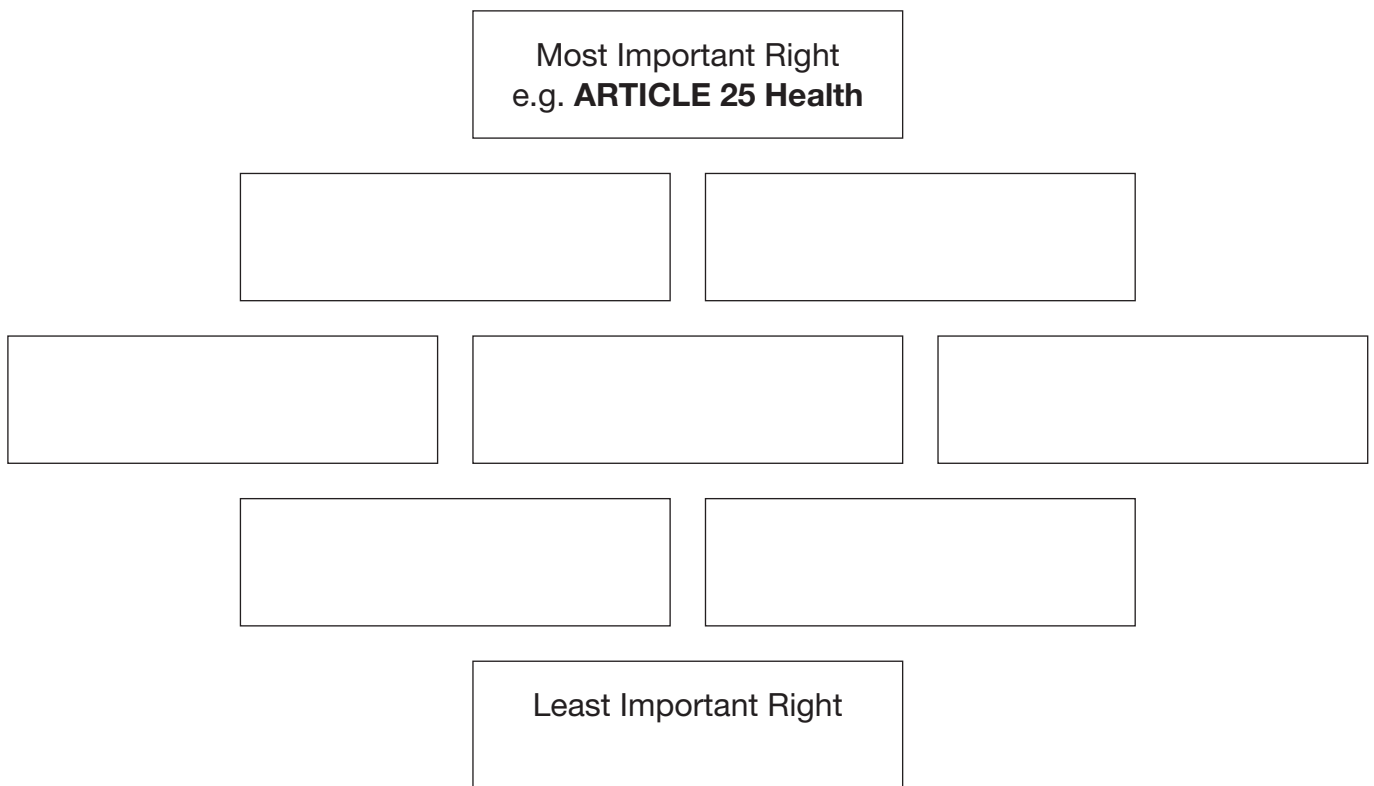


Explain

that this session repeats some of the material on rights covered in the *Disability in Your Community* session. Check what they remember from this session, and what they found most useful. Remind them that the CRPD (Convention on the Rights of Persons with Disabilities) is a convention which explains different rights that people with disabilities have.



Activity In small groups ask them to carry out a *Diamond ranking activity* (see below) with a selection of Rights taken from the UN Convention on the Rights of Persons with Disabilities. Put a selection of nine rights on pieces of card, and ask the groups to rank which they consider are most urgent/important for them in their lives at the moment.



In plenary ask each group to share their ranking and what they think are the top 3 rights for them and why. There is no 'right or wrong' as some rights will have more relevance to certain people. Link this to information on the National Laws and regulations in the country where you are running the training.



Ask the group how they, as parent leaders, can best share this information on rights with other members of their community. Document some of the ideas on a flipchart.

DISABILITY RIGHTS IN YOUR COMMUNITY

One concrete aspect of realising rights can be registering for a disability card. In many countries there is some form of registration for a disability card, although the nature of the registration process will vary widely. The disability registration can bring a number of benefits, including a disability allowance in some cases. This activity may need to be modified in different settings.



Activity Ask if 2-3 members of the group will volunteer to present a short role play to the rest of the group about how you can register for a Disability Card. This role play is then followed by a question and answer session to clarify the processes. Involve parents who have already been successful in registering for a card. Alternatively, in countries where there is no disability registration process, conduct a role play to illustrate how families are eligible for other benefits, for example social protection programmes.

In Bangladesh this Rights Activity prompted lots of discussion and interest. Participants were very keen to understand the Bangladesh 2001 Disability Welfare Act. One of the most popular activities was the short role play about how to register for a Disability Card, followed by a question and answer session. At the beginning of our training only 11 families had registered for a card, and by the end of the training programme all 153 families had registered for a card, or were in the process of registering for one.

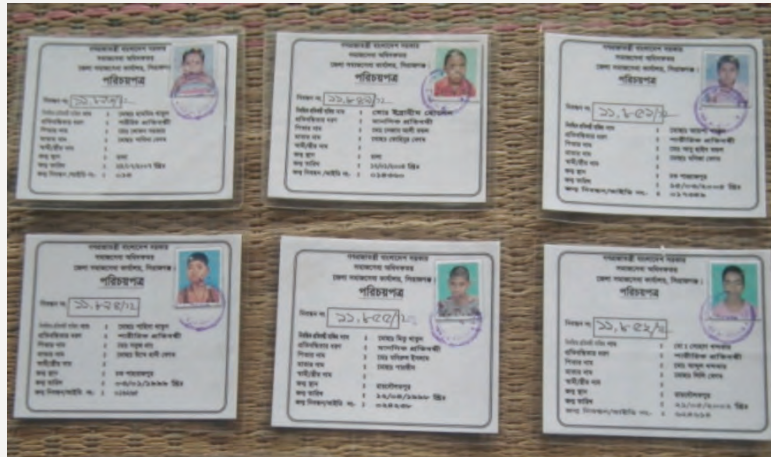


Photo: Disability Registration Cards, Bangladesh

THE VALUE OF NETWORKING



Materials

Two different coloured marker pens and flipchart.



Activity

Social network mapping. This activity can serve two purposes. It can highlight how well linked up with other parents they have become, and at the same time can be a useful monitoring activity. Give each participant ONE coloured pen and ask them to draw a circle in the centre of the paper with a picture of themselves and their child. At the top of the sheet write the name of their village. Ask them to mark outside the circle – like the spokes of a bicycle – how many other mothers/families they knew who had a child with a disability **BEFORE** they started the training. Use the same coloured pen. Give them a **DIFFERENT COLOURED MARKER PEN**, and ask them to mark how many new parents they know as a result of the training (prompt them to think about how many are coming to their group).

As an extension to this activity, participants can map out (in a different colour) the other services locally, and organisations they have been linked to as a result of the training.

Put up the posters so that everyone can see how many caregivers are now linked up through the training, and the wider linkages.



Photo: Bangladesh – mapping social networks which result from training



Ask the group the following questions and allow plenty of time for discussion.

- *How do you feel about being networked with other parents/caregivers and other groups?*
- *Is it useful? What are the benefits?*
- *Do they ever get an opportunity to meet up with any of the other parents outside of the training sessions?*
- *Is it useful why? Why not?*
- *In what ways can you facilitate meeting of parents and gaining support from each other? Document suggestions and ways forward for steps.*

“There are many physically disabled children in our village. I did not know them before this time, and we also were not aware of those who arrive from other villages. As a result of coming to the training we know each other.”

Parent, Bangladesh

Recent research in Bangladesh highlighted the important role of networking of self-help groups in promoting greater social inclusion for disabled adults and children [1].

PRACTICALITIES OF RUNNING PARENT SUPPORT GROUPS



Icebreaker

Ask everyone to stand in a line in the following order: from the person who had the longest journey to get to the workshop today through to the one who had the shortest journey. Briefly ask each person to say how they got to the meeting, whether it was an easy journey or difficult journey? Was it more difficult if they were bringing their child with them? We know that transport for children with disabilities is often one of major barriers to accessing services. Ask what suggestions they have for improving transport and access issues.



Ask Imagine a parent support group in your village. *What would a **GOOD** group be like? What would be important qualities?* Brainstorm the ideas.

Possible ideas for a good Parent Support Group might include:

- A welcoming group
- A group that meets regularly
- A place where you can feel safe to discuss your problems
- A space where you can share ideas and access more information
- Importance of confidentiality in the group



Ask Brainstorm ideas for *What makes a good facilitator/coordinator of the group?*
Possible suggestions might include:

- A good listener
- Someone you can trust and maintains confidentiality
- Able to 'signpost' to different services available locally



Ask them to plan how they might run their own parent support group. Emphasise that **there is NO BLUEPRINT** of a perfect group and every group will be different. Each parent will have a different amount of time to give to this. Some questions to think about:

- *Would it be a group that meets regularly? How often or not at all?*
- *Is there something that is important for your group that you want to work together to change? How might you do this? Is there anything you could do as a group?*
- *Could you meet at someone's house? Could you rotate and meet at different people's houses?*
- *How will you communicate with each other about the meetings?*
- *How can you find out what other opportunities there may be for your group to access services? For example, group savings schemes.*
- *What might be some of the challenges for your group? How might you address some of those challenges?*

SIGNPOSTING TO OTHER SERVICES

Ideally invite other organisations to come in and give a short talk about their services.



Materials

Leaflet detailing local organisations and services (You will need to develop this for your context)



Explain that one purpose of a parent support group is to help refer other parents to available services. For example, how to get hold of the disability registration card, how to find out if they are eligible for any social protection programmes etc.



Activity Work in small groups to look at the leaflet detailing local services. Discuss in their groups the services which they are aware of, whether they have accessed them, and their experience of using the service.



MONITORING AND EVALUATING PROGRESS



Activity Most Significant Change stories: Work in groups of four or five. Each person is asked to tell one story of Most Significant Change (MSC) as a result of the training. Each sub-group selects one story that they regard as most significant to share with the whole group. As important as the stories themselves are the reasons given for the selection – ask the parent groups why they consider them to be the Most Significant Change Story? Out of the selected stories, the whole group selects one most significant story of change. Ask parents to consider “Most Significant Changes” at different levels: a) for themselves as parents/mothers/caregivers, b) for their children, and C) within the family.

For more information on MSC tools check out the Resources section.

Some of the Most Significant Changes identified by parents in Bangladesh included:

- Having stronger networks with other caregivers of disabled children in their own community. As a result, being able to better support each other.
- Increased knowledge about their child’s condition, and confidence in caring for their children.
- Increased confidence in sharing this information with others in the wider community.
- Improvements in the functioning of their child, and increased opportunities for their child to participate with other children.
- The parent having more free time because of the improvement in their child’s development.
- A change in the attitude in their family and community towards their child, and towards the family as a whole.

References

1. Miles, S., et al., *Education for diversity: the role of networking in resisting disabled people’s marginalisation in Bangladesh*. Compare: A Journal of Comparative and International Education, 2012. **42**(2): p. 283-302.

RESOURCES

Know your Rights Activity

A selection of information extracted from UNICEF ABOUT ABILITY An explanation of the Convention on the Rights of Persons with Disabilities. 2008; Available from: http://www.unicef.org/publications/files/Its_About_Ability_final_.pdf.

Background: The Convention makes many promises. Its 50 articles clearly explain what these promises are. The principles (main beliefs) of this Convention are:

- (a) Respect for everyone's inherent dignity, freedom to make their own choices and independence.
- (b) Non-discrimination (treating everyone fairly).
- (c) Full participation and inclusion in society (being included in your community).
- (d) Respect for differences and accepting people with disabilities as part of human diversity.
- (e) Equal opportunity.
- (f) Accessibility (having access to transportation, places and information, and not being refused access because you have a disability).
- (g) Equality between men and women (having the same opportunities whether you are a girl or a boy).
- (h) Respect for the evolving capacity of children with disabilities and their right to preserve their identity (being respected for your abilities and proud).

Diamond Ranking Activity Cards Activity

- Cut out on separate pieces of card (enough for each group to have a copy of all articles).
- A selection of rights given below. You can choose a different selection of rights if you prefer.

Article 5: Equality and Non-Discrimination

Governments recognise that all people have the right to be protected by the law, and that the laws of a country apply to everyone who lives there.

Article 6: Women With Disabilities

Governments know that women and girls with disabilities face many different types of discrimination. They agree to protect their human rights and freedoms.

Article 7: Children With Disabilities

Boys and girls with disabilities have the same rights as all children. For example, every child has the right to go to school, to play and be protected from violence, and to be involved in decisions that affect him or her.

Article 8: Awareness Raising

Governments should educate everyone about the rights and dignity of persons with disabilities and their achievements and skills. They agree to combat stereotypes, prejudice and activities that might harm people with disabilities. Your school, for example, should promote an attitude of respect towards people with disabilities, even among very young children.

Article 9: Accessibility

Governments agree to make it possible for people with disabilities to live independently and participate in their communities. Any place that is open to the public, including buildings, roads, schools and hospitals, must be accessible by persons with disabilities, including children.

Article 16: Freedom from Violence and Abuse

Children with disabilities should be protected from violence and abuse. They should not be mistreated or harmed in their home or outside. If you have faced violence or maltreatment, you have the right to get help to stop the abuse and recover.

Article 17: Protecting the Person

No one can treat you as less of a person because of your physical and mental abilities. You have the right to be respected by others just as you are!

Article 20: Personal Mobility

Children with disabilities have the right to move about and be independent. Governments must help them do so.

Articles 25 and 26: Health and Rehabilitation

People with disabilities have the right to the same range and quality of free or affordable health care as provided to other people. If you have a disability, you also have the right to health and rehabilitation services.

Article 28: Adequate Standard of Living and Social Protection

People with disabilities have a right to food, clean water, clothing and access to housing, without discrimination. The government should help children with disabilities who live in poverty.

MODULE 10:

Assistive Devices and Resources

Facilitator note: This module is a little different from the other modules. It can be delivered as part of the training to parents as a stand-alone session or integrated into one of the other modules, such as positioning. It can also be used as additional resource information for facilitators with useful top tips for providing assistive devices, particularly in poorer resource settings, where there are limited or no rehabilitation services available.

This Module is divided into two sections:

Section 1: Assistive devices

Section 2: References and resources

Outcomes of the module on Assistive Devices

- For project staff to understand lessons learnt on the provision of assistive devices in poor resource settings.
- Caregivers will understand what assistive devices are and how some children can benefit from locally produced aids.

Lessons learnt on effective provision of assistive devices

Lessons learnt are drawn from experience in rural Bangladesh, from literature available, and from direct correspondence with organisations working with assistive devices in low and middle income countries [1].

1. If you provide an assistive device you **MUST provide some follow up** to the family about how it can be best used and maintained. Research in Bangladesh [2] found that without follow up parents often did not use the assistive devices appropriately, or more commonly didn't use them at all! For example, corner sitting chairs were rarely used, in part because parents did not fully understand their benefits, and in part because the corner chair was of poor quality.



Photo: A poorly made corner chair without padding – never used!

2. Manage expectations from the beginning! It's important to take time explaining to parents that **Not ALL CHILDREN will benefit from assistive devices**, and it is not that every child will benefit from an expensive wheelchair!
3. Project staff need to build up a relationship with a local carpenter for making low cost simple assistive devices such as corner chairs. The quality of the equipment should be monitored by staff. If the devices are of poor quality we found that they were not used.
4. Do not prescribe indiscriminate assistive devices. This might limit functional performance. For example, a wheelchair might inhibit a child from trying or practicing walking.
5. Always assess the home environment before giving an assistive device. For example, a paper based chair is not appropriate in a rural village of Bangladesh because of muddy floor and tropical weather. It gets soaked with water easily and become unhygienic and unusable in a short time. If there is not enough space at home or outside to manoeuvre a costly wheelchair perhaps a cheaper alternative such as modified wooden chair is reasonable.
6. It is preferable to use local products to manufacture assistive devices so that people can mend when required locally. For example in Bangladesh wheelchairs were made with rickshaw wheels, and Motivation has used bicycle wheels in their Africa programmes. If there is any problem with wheels people can then get it easily repaired.

WHAT ARE ASSISTIVE DEVICES?



Materials

Pictures of children with different types of assistive devices.



Ask *What are assistive devices?*

Are you able to name some assistive devices?



Explain that anything that assists a person with a disability in completing everyday activities independently is an 'assistive device'. This is important not only for someone's independence, but for their integration and access into society. Assistive devices can come in all sorts of shapes and sizes.



Ask Are you able to name some assistive devices? This is not an exhaustive list but some examples are:

- Glasses
- Walking frame
- Wheelchair
- Adapted cutlery
- Toileting Aid
- Walking stick
- Communication board



Activity Post up pictures of children with assistive devices. Ask parents: *What can you see in these pictures? What materials are some of the assistive devices made of? Why do some children have certain types of devices and not others? Are there some which appear to be made locally of low cost resources? Are there any children without 'assistive devices'? Why?*

Cover in the discussion:

- Some children won't benefit from having any kind of 'assistive device'.
- Identify the individual needs of each child and to see whether the use of assistive devices would assist in encouraging independence.
- Each child's abilities are different, and different assistive devices should be used. E.g. a child who has some difficulties in walking may not require the use of a wheelchair, but will benefit from the use of a walking stick or frame.



Photo Left:
Child using
walking stick,
Bangladesh

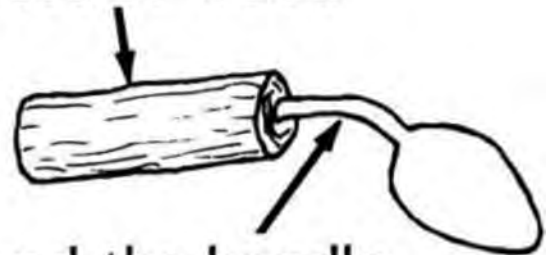


Photo Right:
Child in
wheelchair,
Bangladesh,

Photo Below:
Child in special
sitting chair



piece of wood



bend the handle
to fit the
child's grip



Diagram left: Home-made assistive device to help with toileting. Reproduced with permission from CBM International

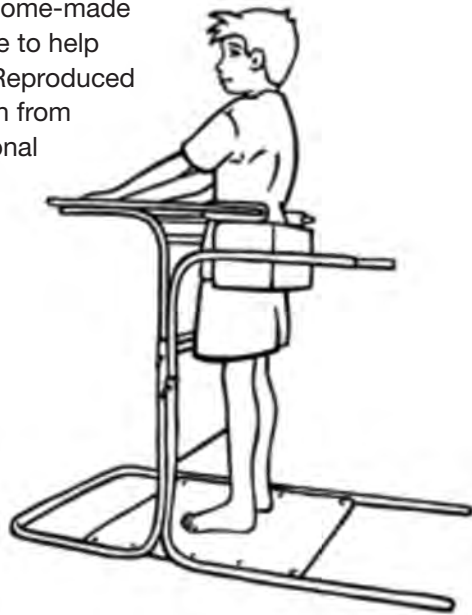


Photo above: Child with standing frame



Photo above: Child walking with locally made parallel bars



Photo above: Child with home-made plank of wood to aid with standing

BENEFITS OF ASSISTIVE DEVICES

1. Standing Frames



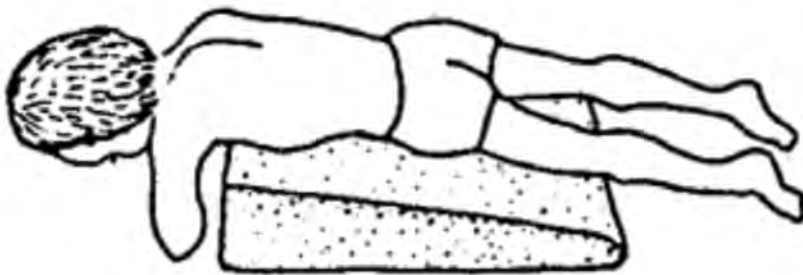
Ask What benefits do you think a standing frame can bring?

In discussion cover the following points:

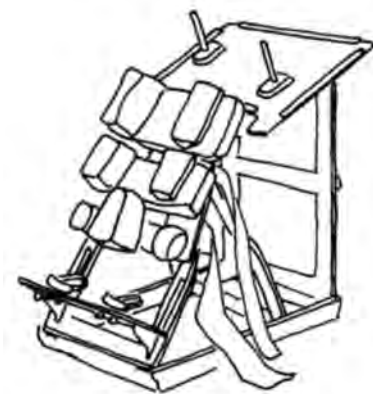
- Standing Frames assist in providing support for children with disabilities in standing.
- Standing is an important position for children with cerebral palsy to be in. Remind the group of the positioning module and the benefits of standing.
- Many children with disability who are unable to stand spend their time lying or sitting. By placing a child into a standing frame, he/she is able to observe the world around them from a different perspective, they are able to engage and interact with others from a different level. This offers broader stimulation for the child, and will contribute to overall social and cognitive development.
- Prone stander: child leans forward on the device which is angled slightly forward. Good for children with lower levels of ability, who struggle to keep their body/head upright or who have spinal deformities. The position will make it easier to lift the head and trunk.
- Discuss the 'good' and 'poor' positions in the diagrams below



Child is unable to lift head up in prone



Prone stander



Child standing badly in an upright standing frame



Head control easier on prone standing board



Child standing well in a standing frame



2. Supportive Seating – corner seat/special seat or ‘CP chair’



Ask What benefits can a child gain from sitting in a supportive seat?



Photo: Example of a seat made from Appropriate Paper Technology (APT)¹

In discussion cover the following points:

- Prevents or slows down the development of contractures or deformities which can disable the child further. It can also help the bones to grow strong.
- Spending a lot of time lying down or sitting in a slumped posture is unhealthy for everyone. Upright sitting can help to maintain a person’s health by improving breathing, digestion and blood circulation
- The child is able to make eye contact with those around him/her. This makes verbal and non-verbal communication easier and contributes to dignity and self-esteem.
- Providing a child with support while sitting can help them to control their head, hands and to concentrate for longer. This can have a positive effect on the following activities: self care (eating, toileting, dressing); playing; learning; reading; writing
- In order to benefit from a seat, the child should be supported to sit upright. Use the diagram below to cover main points. This covers material from the positioning module.

- **Pelvis:** upright
- **Hip joints:** 90°, knees slightly apart
- **Knees and ankles:** 90°
- **Back:** up straight
- **Shoulders:** relaxed with arms free to move
- **Head:** upright in the middle, chin tucked in
- **Side view:** Ear, shoulder, hip – in line
- **From the front:** Eyes, shoulders, hips, knees are all level



A corner seat may be used for children with a higher level of ability as it gives less support. Useful for young children up to five years old for floor activities or for long-sitting with or without leg splints.

¹ For more information on Appropriate Paper Technology (APT) for making assistive devices please see <http://www.paperfurnitureenterprise.com/>

3. Wheelchairs



Ask *How can your child benefit from using a wheelchair?*

- Provides mobility for children who are not otherwise able to move around independently.
- Children may be able to go to school
- Get out in the community to play with other children,

However remember that not all children with difficulties with mobility will benefit from a wheelchair.



Explain In order for someone to gain maximum benefit from a wheelchair, it must be appropriate for them. The World Health Organisation (WHO) has defined an appropriate wheelchair as one that:

- Meets the wheelchair user's needs
- Can be used in their home environment
- Fits well and provides good support
- Is safe and lasts well
- Is available and can be maintained at an affordable cost.

Wheelchairs come in all different shapes and sizes, and should be properly prescribed and fitted to ensure it meets the child's needs. This requires an assessment by someone who is trained to provide appropriate seating. If you feel your child needs a wheelchair, consult a therapist or wheelchair service.

Children who are unable to sit upright on their own, require special adaptations to a wheelchair which will support them to sit upright. Putting them into a standard wheelchair in which they sit badly, will cause further disability.

4. Walking Frame



Ask *What benefits can they see from using a walking frame?*

A walking frame is useful for children who will be able to stand on their own, but require assistance to take steps and walk. The use of the frame will allow the child to walk independently and provides mobility around the community. A walking frame brings the child to the same level as his/her peers and allows him/her to interact with those around them.



5. Glasses



In Bangladesh 180 children with cerebral palsy were tested for visual impairment. An estimated 32% were visually impaired, of which 18% required glasses. For the remaining children, the problem was associated with processing vision in the brain (REF).

Photo: Child with cerebral palsy having an eye test, Bangladesh

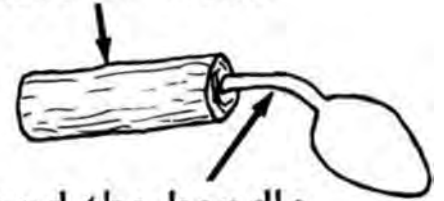
6. Adapted cutlery



Ask When would you use adapted cutlery?

For a child who struggles to hold a spoon or fork. The handle is built up to make it easier to hold. If completely unable to grip, the child's hand could be gently held in place by tying a scarf around the hand.

piece of wood



bend the handle to fit the child's grip

7. Communication boards



Ask When might you use a communication board and why?

- Communication boards offer an alternative communication method to children who are unable to communicate verbally. This is generally in the form of pictures
- A communication board offers children a way to communicate with their peers
- Enables them to express themselves and be better understood by others.
- Communicate is a great tool for empowering children by allowing them to interact with others, thereby providing an avenue for inclusion in the community.



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SECTION 2 – RESOURCES AND REFERENCES

This list is not exhaustive but covers the key references and resources which were used to develop and adapt this manual. In some cases references were used to inform for more than one module.

General Core References

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Modules 8-9

These are two quite overlapping Modules which address Disability and Rights

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Module 10 Assistive Devices

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Monitoring and Evaluation

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Ideas from many sources have helped us to develop the Hambisela programme. The following material and references have been particularly helpful, either as sources or as inspiration on how to present training, and we gratefully acknowledge their use. In many cases we have been given permission to use photographs. Where permission could not be obtained, the faces have been re-touched in order to protect identity.

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Additional Useful Websites for Accessing Resources

EENET (Enabling Education Network) website <http://www.eenet.org.uk/>

SOURCE http://www.asksource.info/res_library/disability.htm

MAITS at <http://www.maits.org.uk/>. MAITS exists to empower education and health professionals to enhance and develop the services they provide to individuals with disabilities in resource-poor settings through sharing knowledge and practice.