

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."

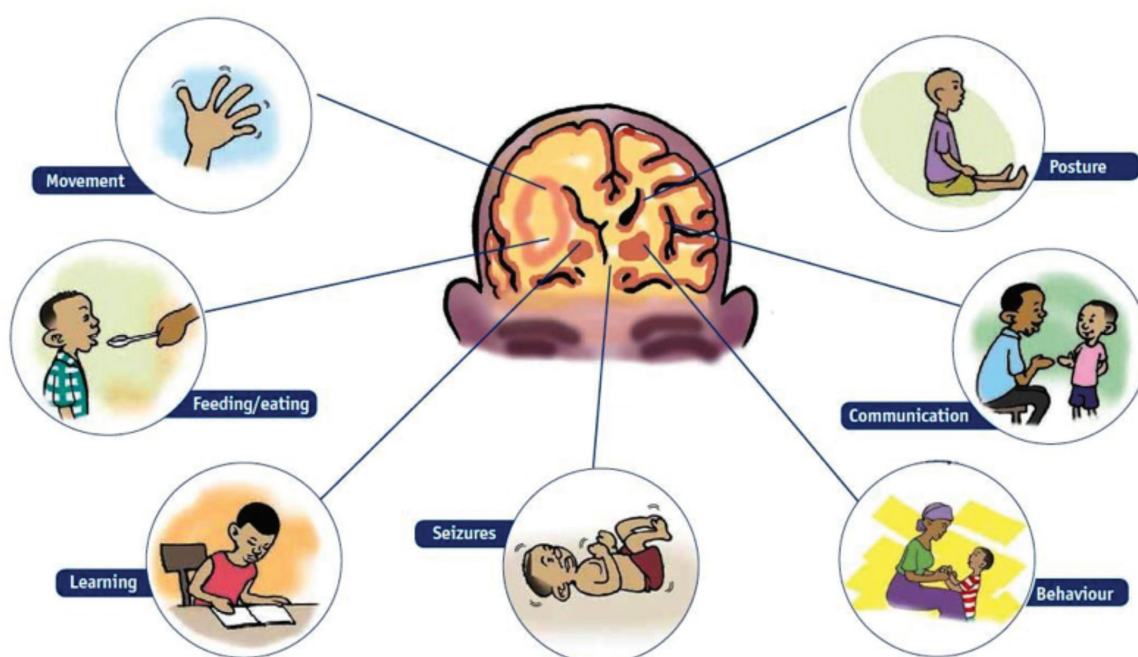
Parent, Bangladesh

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>)

About cerebral palsy





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.

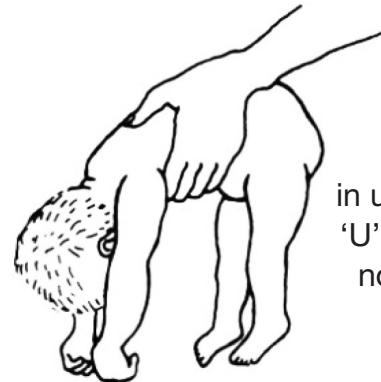


Picture 1.03a



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 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

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.