

## 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

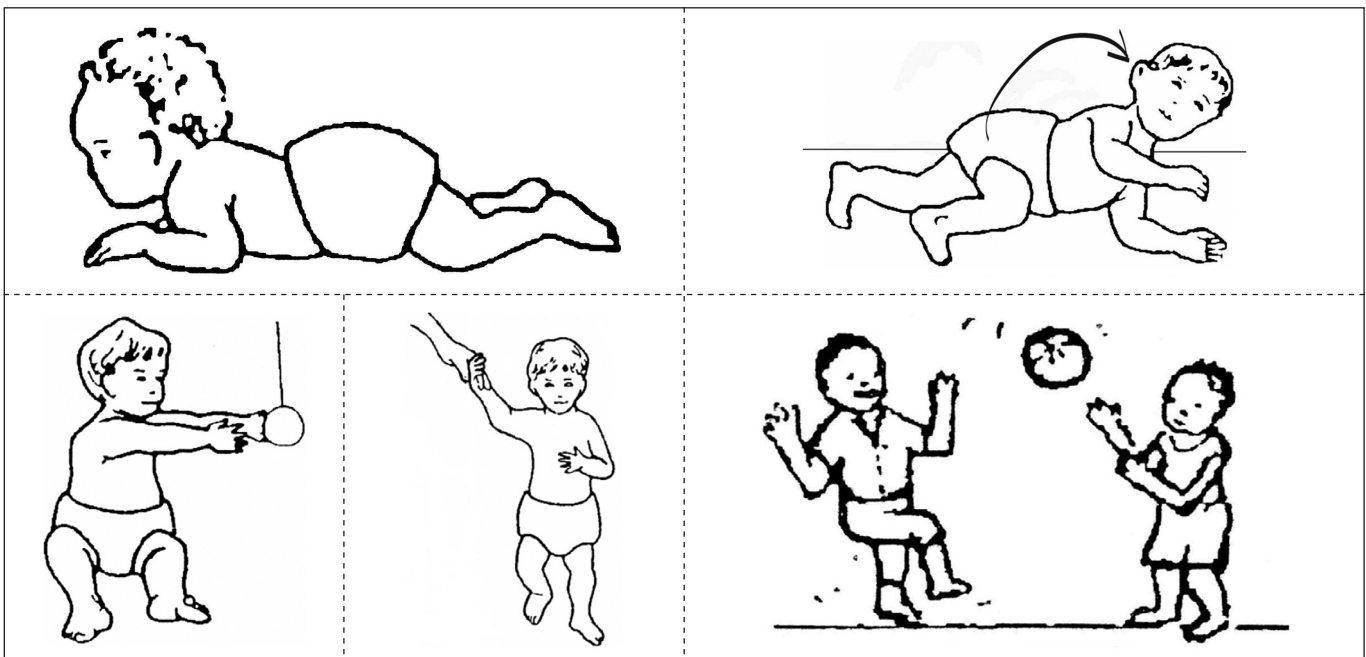
Pictures 2.02 on card

(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**

<sup>1</sup> 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



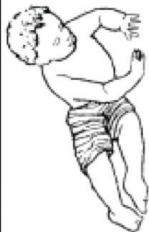










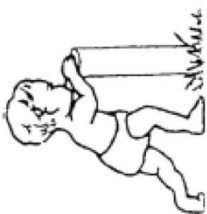

Flipchart with take home messages.







### 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.


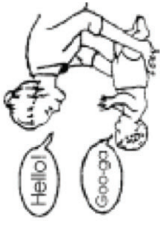











# RESOURCES

Materials Development Chart 2.03a

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

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



DEVELOPMENT CHART: Social Interaction and behaviour	
Communication / interaction	<div>  <p>Expresses self using sounds and facial expressions</p>  <p>Makes eye contact.</p> <p>Coos and gurgles when talked to</p> </div> <div>  <p>Repeats sounds and gestures</p>  <p>Responds to simple commands.</p> </div> <div>  <p>Expresses self using gestures or pointing</p>  <p>Able to make choices</p> </div> <div>  <p>Drinks from a cup and feeds self most foods without help.</p>  <p>Helps with undressing. Indicates toilet needs.</p> </div> <div>  <p>Express self using words</p>  <p>Talks about what she does</p> </div> <div>  <p>Uses the toilet without help.</p> </div>
Social / Self-help skills	 <p>Sucks breast.</p>  <p>Chews solid food</p>

# USEFUL GUIDELINES FOR HOME VISITS AND OUTREACH WORK

These guidelines are adapted from Timion, and the original is available from [www.timion.org](http://www.timion.org)<sup>2</sup>

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.

<sup>2</sup> 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"><li>● 1 = no change</li><li>● 2 = some small improvement</li><li>● 3 = Good improvement</li><li>● 4 = Excellent improvement</li></ul>	How satisfied are you with the changes, (scale 1-4) <ul style="list-style-type: none"><li>● 1 = not satisfied</li><li>● 2 = fairly satisfied</li><li>● 3 = Satisfied</li><li>● 4 = Very satisfied</li></ul>
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.