FACILITATOR MANUAL

Working together with families of children with developmental disabilities
THIS MODULE COVERS THE FOLLOWING INFORMATION:

CHAPTER 1: ABOUT THE PROGRAMME

• Background and history
• What is early intervention?
• Why have a separate module for younger infants?
• How to identify babies and young children that are at high risk for cerebral palsy
• Aims and objectives
• How the programme works
• The facilitators
• Approach to training

CHAPTER 2: RUNNING A SESSION

• How to follow the manual
• List of modules
• Preparation for your session
• Before, during, and after the session
• Top tips
• Common mistakes
• Monitoring progress and measuring impact

CHAPTER 3: CONDUCTING A HOME VISIT

• Guidelines and top tips
CHAPTER 1: ABOUT THE PROGRAMME

BACKGROUND

This work is a sub-study of the ABAaNA studies (‘Associations between Birth Asphyxia and infection amongst Newborns in Africa: perinatal risk factors for neonatal encephalopathy in Uganda’), which since 2010 have been investigating the causes for and outcomes of neonatal brain injury in Uganda. These studies have shown a high risk of neurodevelopmental impairment amongst infant survivors of NE, with around a quarter affected by global developmental impairment, cerebral palsy or seizure disorders. A qualitative study looking at the caregivers’ experience revealed huge impacts on their social, emotional and financial well-being, and high levels of stigma. Formative work on the development of an early intervention programme for affected children and their caregivers has shown improvement in quality of life and health outcomes.

The aim of this programme is to supplement the original Getting to Know Cerebral Palsy programme to include children from as young as 6 months.

WHAT IS EARLY INTERVENTION?

Early Intervention is the process of providing specialist intervention and support services early in life after the onset of problems.

There is no standard definition of early intervention (how early it should be commenced and what it should include). Generally it is thought that the first year is a sensitive period for development of motor (movement) skills, as well as being important for the early development of communication and self care skills.

Several studies have shown the positive effects of early developmental intervention in at risk infants such as preterm and low birth weight infants. There is currently no published research looking specifically at early developmental intervention in survivors of early brain injury, however, common sense tells us that timely family support and therapy for affected infants and their families is of the utmost importance. For example, facilitating daily stretches and optimal positioning in the home from the earliest opportunity is important in helping to prevent secondary physical difficulties (such as contractures and scoliosis). Providing peer support for families early in their journey may help allay some of the feelings of isolation and fear often experienced by families facing the new and unknown challenge of childhood disability.

“We had a lot of fear and used to think they were ‘wasted’ children but meeting other mothers has taught us a lot. Fellow mothers give us hope that our children will improve and this kept us strong.” Parent, Fort Portal Uganda

“It gave me confidence and I got to know what happened to my child and I appreciated the fact I was not alone.” Parent, Fort Portal Uganda
AIMS AND OBJECTIVES

The aim of this programme is to supplement the original Getting to Know Cerebral Palsy programme to include children from as young as 6 months. Through earlier interventions, designed to enhance a child’s development in the first few years after birth, we have greater opportunities to positively influence the care-giving environment and participation of the child in family and community life, as well as limit developmental and cognitive impairments.

Key objectives:
• To increase the knowledge and confidence of care-givers regarding their child’s condition and their needs.
• To encourage positive attitudes towards having a child with a disability within the family.
• To improve problem solving and peer support amongst caregivers.
• To promote inclusion of children within the family and community.
• To equip participants with skills to care for their child and promote optimum development, and reduce further disability e.g. contractures, limb deformities.
• To enable early identification and management of malnutrition.
• To support parents in identifying common health problems, seizures and pain and assist them to treat them quickly.

WHY HAVE A SEPARATE PROGRAMME FOR YOUNGER INFANTS?

This programme has been specifically designed to meet the needs of 0-2 year olds. This is a key period of development and promoting change needs a tailored approach.

The benefit of having a programme dedicated to younger infants is to allow us to focus on topics which are of particular importance in this age group. These include:
• Encouraging parents to utilise everyday activities to positively impact on the development and wellbeing of their child.
• Improving breast/ bottle feeding techniques and weaning to optimise growth and nutrition in early life.
• Facilitating good positioning and handling in order to prevent secondary physical problems.
• Promoting small steps along the developmental pathway at the earliest opportunity (as close to normal developmental progression as possible for each child).
• Facilitating early identification of and promoting helping seeking behaviours for associated health problems e.g. seizures, constipation and pain.

All the suggested activities within the programme are geared towards developmental milestones of 0-2 year olds.
HOW TO IDENTIFY BABIES AND YOUNG CHILDREN THAT ARE AT HIGH RISK OF DEVELOPING CEREBRAL PALSY

Identifying Cerebral Palsy early is difficult as it often become more obvious with time. The observation of slow motor development, abnormal muscle tone, and unusual posture are common initial clues to the diagnosis. Some early warning signs include:

- Delay in meeting motor milestones – e.g. head control/ sitting/ crawling
- Recurrent seizures
- Stiffness or floppiness of the body
- Poor sucking/ feeding ability
- Persistently fisted hand or not using one hand well (asymmetry)
- Decreased rate of head growth
- Difficulty in seeing and hearing

The risk is highest if the child:

- Has a history of a difficult birth or pregnancy
- Needed resuscitation/ help to breathe at delivery
- Was born too early
- Had a serious illness as a newborn baby

It is often a child’s care-giver who first notices that their baby is not developing in the same way as other children of the same age. Any concerns raised should be actively listened to.

HOW THE PROGRAMME WORKS

It is a multi-session group activity involving caregivers (parents and families) and their children who are affected by Cerebral Palsy, run by two facilitators. This manual helps to guide facilitators through the programme, providing a layout of each session and descriptions of group activities.

THE FACILITATORS

Facilitators deliver the training programme, and are key to ensuring the success of the group. We call them facilitators rather than trainers/ teachers, because their role is to ‘facilitate’ the group to interact with one another, rather than to ‘teach’ all of the content themselves (known as a ‘participatory approach’, which will be discussed later).

Facilitators are therapists (physiotherapists or occupational therapists), and parents/ caregivers of children with cerebral palsy – these are both considered to be ‘experts’ in the area of raising and supporting a child with a disability: a therapist has been trained in certain skills, techniques and approaches, whilst a caregiver brings her own personal experiences of the challenges that can be faced in raising a child with a disability. The two facilitators are equal partners in the programme, and need to work well together. Some sessions may feel more natural to be led by one person more than the other. The manual gives some suggestions for this, though these are not compulsory rules to follow.
APPROACH TO TRAINING

• This programme is designed to be participatory. Parents are not viewed as passive persons to impart expert knowledge too, but experts in their own children and active members of the group. Each session should be a balance between; group discussions, group facilitators sharing knowledge and experience and parents asking questions.

• This programme is built on the evidence on the value of self-help groups to improve maternal and child health outcomes. These groups are initially run by an outside ‘facilitator’, but over time the aim is for the group to become independent and self-organised.

• Work with families and children in a nurturing and supportive way. Compassion should be shown and “telling off” must be avoided.

• Convey that the parents did nothing to cause their child’s disability and that we know that they are doing the best they can for their child.

• Emphasise that children with cerebral palsy do learn, but they take extra time and need more support. They can and should be active participants of their families and communities.

• It is important throughout the training sessions and interactions with primary caregivers, that the training does not add to the burden of caregiving.

• Engaging and involving family members including fathers, and the wider community is key. How you do this will depend on the context, and needs to be planned for right from the beginning.

• It is recommended that children and their caregivers receive training as soon as possible after diagnosis.

• Children need therapeutic management all the time, not only during therapy sessions.

• This programme is not intended to replace therapy, but to complement it.

• Local service provision needs to be strengthened and the quality improved for children with disabilities. This will complement the training, and strengthen referral processes. This is not explored in this manual, but you can find ways to offer training to local services.
CHAPTER 2: RUNNING A SESSION

HOW TO FOLLOW THE MANUAL

The training manual is divided into 10 modules.

There is a separate Display Manual, mainly of photos, which accompanies the training. This material can be laminated and used when running sessions.

For each module there are:

**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.

**ICEBREAKER**
A suggested activity to start the session. This is linked to the topic and should encourage participation, discussion, and fun!

**ASK**
Suggested questions to ask.

**EXPLAIN**
Notes for the facilitator to explain.

**ACTIVITY**
Suggested tasks and activities to encourage everyone in the group to participate and learn from each other.

**MONITOR PROGRESS**
A check at the end of each session to see what participants have learned.

- The term ‘caregiver’ is used throughout, sometimes used interchangeably with parent or participant.

- Our experiences of other groups are highlighted in GREEN text boxes. These may be from the Zika Programme or Getting to Know Cerebral Palsy. These notes are for the facilitators’ reference and are not necessarily used in the session. They can be useful to help with answering questions.

- Facilitator tips are in BLUE text boxes- these are top tips to assist you with running the sessions.
LIST OF MODULES

1. Let’s get started
   - About the training programme
   - Ground rules for the group
   - Understanding cerebral palsy and how to find more information about it
   - Personal stories and start of the posters (Discussion around thoughts and feelings is a theme explored throughout the sessions, using personal posters)

2. Know your child
   - Development milestones for young children
   - Determining each child’s progress
   - Epilepsy

Early Intervention Programme Module 0 | © LSHTM 2021_Version 1.2
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| **3. Positioning and carrying** | The importance of correct positioning  
How to position a child correctly  
How to assist children to learn to move |
| **4. Eating and drinking** | Feeding challenges with children who have neurodevelopmental issues  
Practical skills to address challenges for individual children |
| **5. Learning to move** | Understand different types of movement  
Practical skills for helping their child learn to move |
| **6. Communicating** | Importance of communication  
Practical advice to help your child communicate |
| **7. Play and early stimulation** | Importance of early stimulation and play for children to develop  
Making simple toys and how parents/ caregivers can encourage their child to play  
Challenges around inclusion in play with the family and broader community |
| **8. Everyday activities** | How to use everyday activities to help your child develop  
Managing seizures  
Catch up from previous sessions |
| **9. Our community** | Who is in your community?  
Discussion about common barriers to inclusion  
Addressing stigma  
Understand the context of disability rights  
Thoughts and feelings  
*Social Activity - this week contains a chance for you to invite 2-3 members of your community to join in the group for a social discussion and some food/ games* |
| **10. Next steps** | Planning to run your own group  
Summing up  
What have you learned?  
What haven’t you learned?  
Endpoint data collection |
PREPARATION TO RUN A SESSION

It is important to involve the parent group in planning for the training sessions - where the training should be held, duration of the session, and how often to meet. Below are key questions to ask within your setting and make decisions about according to the parents and stakeholders within your local context. The responses in blue represent the decisions we made about our programme.

• How often should the training run? Once or twice a month
• How long should each session be? 2-3 hours
• How many parents and children should be invited to the group? 6-8 parents and children. Once the assigned group has started no further additions will be made
• What language should the sessions be run in? Luganda
• Who should run the training sessions? Our group facilitators were mothers of children with Cerebral Palsy who received training in running this programme

The environment:

Where possible involve the parents in making decisions about the location of the group. It should be:

• Accessible and easy to reach location for the sessions.
• A safe, clean room with space for parents and babies to sit/ lie on the floor on mats.
• A room that provides some privacy to allow the parents to feel comfortable to discuss their concerns.
• Access to toilets and water. Consider providing nappies, wipes, toilet paper and cloths for cleaning and toileting.

Resources for the sessions:

All resources will be provided in the local language, Luganda.

• Aims for the session will be written on flipchart paper and displayed on the wall at the start of each session.
• Take home messages will be written on flipchart paper and displayed on the wall at the end of each session.
• Handouts will be available at the end of each session. These will summarise the main points of the session. These handouts will have visual learning aids (photos and drawings) as much as possible.
• Simple goal setting sheets, will be used at the end of each session for parents to identify what they are going to try at home from the session.
• At the end of each session, parents will be asked to give feedback on what they have learnt and what they have enjoyed/ not enjoyed. A simple feedback form will be completed in each session.
Before the session:

- Make sure you are familiar with the content of the session, as well as all instructions for how to present the information.
- Meet with your co facilitator/s to decide on roles for each session.
- Print and prepare all training materials, aids and activities in good time.
- If possible provide simple refreshments for the parents and children, including thickened fluids for children with swallowing difficulties, if appropriate.
- Ensure any videos you need are accessible, on your laptop or cell phone.
- Prepare a box of simple developmentally appropriate, locally made toys. Parents should be invited and encouraged to interact with their children and use these toys before, during and after the sessions.
- Have a flipchart and marker pens ready to use.
- Write the outcomes of the session on flipchart.
- Arrive at least 30 minutes before the starting time to prepare your venue and organise your training materials.

During the session:

- Plastic-covered foam mats for children to sit on can be useful as they are easy to clean.
- Provide simple refreshments for the parents and children, including thickened fluids for children with swallowing difficulties, if appropriate. This also gives an opportunity to reinforce lessons learnt on feeding and drinking.
- Follow the guidelines in the manual - the activities are the core of this programme and should not be left out to save time. Rather add another session if it is taking longer than expected.
- If responses to a question are not as expected, rephrase the question.
- If you don’t know the answer to a question, say you will find out – bring the answer next time.
- If a discussion goes off the topic, gently bring the discussion back to the topic, while also allowing time for members to express what they are feeling. If appropriate, place it in a ‘parking lot’ and return to it later.
- Make the sessions FUN! Many caregivers work, and have other chores, which they combine with full time caregiving, so taking time out of the day can be a big commitment. Use the icebreakers suggested, and add your own as required. For example, use songs to change the group energy if everyone is looking sleepy - this is popular as well as helping with communication.
- Recognise participants’ contributions - draw on their life experiences. Use participant stories to illustrate points where possible.
• Encourage everyone to participate - you may need to address some remarks directly to someone who is very quiet and withdrawn.

• Be aware of the influence of your mood on the group - be honest about your feelings and state of mind.

• Be flexible within the modules especially when there are young children in the group - you may need to change the order or the time of a break to accommodate their needs.

• Use opportunities to model interaction with children and involve them in the session where appropriate.

After the session:

• At the end of each module there are questions and suggestions to help participants reflect on what they have learnt - record these to help with future planning.

• Make parents aware that they can ask facilitators for time to discuss individual concerns before or after sessions, if they do not feel able to discuss them within the group.

• Ask everyone whether they have suggestions for next time.

• Make sure that you leave the venue tidy and clean.

• Make sure you pack up all your training materials and file them carefully for next time.

• Ask your co facilitators for feedback on how you presented the session and suggestions for improvement in your training techniques

• Reflect yourself on what went well and what needs to be changed.

Identifying issues and referring:

• As a facilitator, you are not expected to be an expert in everything.

• Use your contacts and networks to ensure participants get the intervention they need, e.g. a mother needing psychological support, or a child who needs nutrition advice.

• Children with disabilities can be vulnerable to abuse. Caregivers may be the perpetrators of abuse, but may also be vulnerable adults who are abused within the family due to stigma.

• It is important that if you recognise signs of abuse or violence, you should respond in a timely manner. Check local and national child protection structures so you know how to refer these children to the appropriate services.
### TOP TIPS

- Be well prepared for presenting your session. Know exactly how you will do each section.
- Give enough time for the activities as outlined in the manual.
- Have simple toys available - involve the children and model good interactions with them.
- Sit at the same level as the group - you are not a teacher, but a facilitator.
- Ideally you should sit in a circle and make eye contact with everybody.
- You are a facilitator, not a therapist or expert. Your role is to guide the group to find / share their own solutions.
- After a discussion, briefly summarise what was said - be careful not to repeat too much.
- Make sure that the sessions are FUN!
- Encourage participation of all members.
- Make your own learning active - reflect on how each session went and plan for improvements.

### COMMON MISTAKES

- Leaving out activities to save time.
- Adding too much extra information and then not being able to complete the materials.
- Forgetting to ask questions and delivering a lecture.
- Focusing eye contact towards one part of the group and neglecting others.

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### 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.

- 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.

CHAPTER 3: CONDUCTING A HOME VISIT

The guidelines below are adapted from Timion, and the original is available from
www.timion.org

WHY IS THIS IMPORTANT?

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 carer 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 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 carer.
• 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 carer 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 carer 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.

• Choose one activity that worked well. The therapist/community worker should demonstrate and **teach it to the carer**, explaining why it is helpful, pointing out where to place your hands. Let the carer 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 carer. A session spent advising about positioning and a technique for feeding is essential if 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 carers when the worker moves on to work with another client.
Module 1
LET’S GET STARTED

MATERIALS Display materials 1.01 -1.04

EXPLAIN
Welcome everyone to the first session. Explain how long the training programme will run for and how long each session will be. The overall aim of the training programme is to maximise developmental progress, and improve health and quality of life for young children with cerebral palsy, for caregivers and their families.

ICEBREAKER
Throw a ball to a person in the circle, that person then says their name and introduces their child, and answers a question about themselves (maybe guide this: what is your favourite food? how many sugars do you like in your tea?) Let each person have their turn.

0-2 YEARS
For parents of children less than two years old they are less likely to have heard the term ‘Cerebral Palsy’ in reference to their child. However, many of the aspects of this module are the same as for older children.

Use diagram 1.01 to explain what the programme will cover.

Emphasise that making small changes to everyday activities and interacting well with your child, can help them to develop. Coming together as a group and sharing ideas will also provide learning, support and encouragement.
EXPLAIN outcomes for the module

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, what causes cerebral palsy, and how the brain affects movement and posture.
3. Recognise and understand the conditions and challenges for children and families associated with developmental disabilities.

The information shared in this session can do more than just increase knowledge: it can also build hope and start to challenge stigma. The following quotes show the value of increasing your understanding of what cerebral palsy is:

"I have learnt that parts of the brain got spoilt and that (developmental) changes will come slowly, I have hope that my baby will pick up (improve). Parent, Uganda

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 my child has been developing. Now I feel less physical and mental pain. Parent, Bangladesh

I have learnt what happened and how to care for my child, now I will not listen to the unkind things other people say. Parent, Uganda"

EXPLAIN how the training will be run:

Sessions are not planned as lectures, and are intended to be participatory. It is as much about learning from each other’s experiences as from the group facilitators. During our time together we are going to get to know one another. We are here to learn from each other and our experiences.

You will be get to know more about your child’s strengths and their disability, and have the opportunity to share your experiences of caring for your child. Comments and questions are always welcome. There is no such thing as a silly question. We are all learning together.

ASK

What would you like to get out of attending this group?
Encourage people to contribute.
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 not developing like other children?
- 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?
- Can cerebral palsy be cured?
- Has anyone told you that cerebral palsy is caused by witchcraft or because you have done bad things in your past?

Discuss the experiences of the caregivers. Allow time for the caregivers to share their understanding of cerebral palsy and their experiences.

FACILITATOR TIP

MANAGING EXPECTATIONS is a very important part of this first session. It is important to give time to explore expectations and clarify what the programme will and will not cover.

Caregivers may come wanting a cure for their child, or a special piece of equipment or medicine to make them better. In Uganda, we found that, as the children were still very young, their caregivers often didn’t really know what to expect. Expectations may also change over time as the child gets older and the difficulties they face change or become clearer. Managing expectations will depend on how this training fits in with other services available locally for families. In many places there will be very limited rehabilitation services like physiotherapy, but in others local service provision may be used in partnership with this training programme.

It may be useful to write down the expectations of the group and for the facilitators to refer to it as the programme progresses.

GROUND RULES

You may want to discuss with the group some simple guidelines for how the groups should be run: these may cover issues like being supportive, confidentiality and practical issues like breaks within the sessions.

WHAT IS YOUR UNDERSTANDING OF CEREBRAL PALSY?

In many countries, one of the commonly held views is that cerebral palsy is caused by witchcraft and bad spirits. This creates a lot of stigma for the families. Many families who attended the initial groups had spent a considerable amount of time and money visiting traditional healers.

It is important to take time to discuss these issues and to emphasise that cerebral palsy and other developmental disorders are not caused by witchcraft.
Another common experience for the mothers in Uganda was to be told by others that their child's condition was because of something they did wrong eg. being unkind to others. This caused a lot of distress for the mothers and often meant they were stigmatised by their families and husbands. It was common that the fathers blamed the mothers for the child's condition.

ACTIVITY

Refer to the examples below. You can write out the quotes onto card and then ask the women to reflect on their own experience, and how this compares. This can be done in smaller groups of 3-4 caregivers where they might feel more comfortable to share their experiences, and then feed back to the group.

"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

Most of the time people were saying it is a curse from someone, or he is from a river...... In the olden days if you give birth to a child like this, we cook for that child and we send that child to the river side, they will shoot a gun, the child will then turn into a snake and will go into the river. Parent, Ghana

People blamed me saying that during pregnancy I used to abuse people, but I don’t remember abusing anyone. Parent, Uganda

Describing why a child’s father had left the family a mother reported that he had said that ...he did not produce children like that. Parent, Uganda"
WHAT IS CEREBRAL PALSY?

MATERIALS Diagram 1.02*

*Adapted 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 injury 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 notes to aid discussion. Encourage the caregivers to share their experiences and ask if their own child shows these symptoms.

**Feeding problems:** Your child may have difficulties with sucking, swallowing and chewing and this can continue as the child gets older. She may choke or gag often. This may mean that she does not get enough food and struggles to gain weight.

**Communication difficulties:** You child may not respond or react as other children do. Although you may find it hard to know exactly what your child wants, you will gradually find ways of understanding many of your child’s needs. When she is young, she may cry a lot to show what she wants. Later she may communicate what she wants with gestures like pointing with an arm, foot or using her eyes. She may be slow in starting to talk.
EXPLAIN continued

Learning: Some children with cerebral palsy have learning difficulties, but many do not. Sometimes people may think that a child has learning difficulties because they move differently to other children. Sometimes their face can twist or they may drool and this can make them appear to have learning difficulties but they may not.

Seizures: Some children have seizures (sometimes called epilepsy, fits, or convulsions).

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

Behaviour: Your child may show sudden changes of mood from laughing to crying or becoming frightened or even angry. If there is too much noise and activity your child can become frightened or upset. She may also have problems with her sleep. She may need a lot of help and patience to overcome her fears and other unusual behaviour.

Discomfort: Your child may experience discomfort and pain. This may be due to the stiffness in her muscles or her inability to move out of a position when it becomes uncomfortable. Or it may be due to constipation or reflux.

POSTURE AND MOVEMENT

MATERIALS Display photos 1.03

Muscle stiffness: Your child may 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 your child is upset or excited, or when her body is in certain positions. The pattern of stiffness varies greatly from child to child and it is important to remember that she has no control over these movements. Muscle stiffness is the most common way that the body is affected by cerebral palsy. (2)

Floppy: Another type of cerebral palsy is when your child’s muscles are very floppy. This may look like the children in these pictures above. The floppiness of the muscles can make it difficult for her 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: Your child may have uncontrolled movements and have difficulty staying still and stable. She cannot control these movements.

Poor balance: Your child may have poor coordination and balance which means that they often fall and can look like their movements are clumsy. They also have difficulty beginning to sit and stand. Doctors describe these children as having 'ataxia'. (2)

EXPLAIN that there are other conditions associated with cerebral palsy and other developmental disorders.

Children may have one, a few, many, or none of these conditions: (3)

- Poor eyesight or eyes that do not move together (a squint)
- Hearing difficulties
- Slow growth
- Problems with their teeth
- Constipation
- Sleep problems

In a child disability study in Bangladesh, 6% had a lack of hearing in both ears and 2% had a visual impairment. (1)

ASK

Does your child have problems associated with these conditions? We will be discussing some of these conditions as we go through different modules of the training.
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 has cerebral palsy.

Any incident that causes injury to a part of the brain can result in cerebral palsy. This damage can happen either before birth, during birth, or shortly after birth. Sometimes the doctors don’t know what caused the injury.

The following table shows some key factors that can cause cerebral palsy – either before, during or after birth (2). Discuss the different factors and encourage discussion.

<table>
<thead>
<tr>
<th>During pregnancy</th>
<th>Around the time of birth</th>
<th>After birth</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Infections, injury and illnesses of the mother while she is pregnant</td>
<td>• Lack of oxygen or blood supply to the baby during delivery</td>
<td>• Severe jaundice</td>
</tr>
<tr>
<td>• Genetic causes</td>
<td>• Birth injuries</td>
<td>• Brain infections like meningitis</td>
</tr>
<tr>
<td>• Unknown causes</td>
<td>• Baby born too early</td>
<td>• Malaria</td>
</tr>
</tbody>
</table>
<pre><code>                                                                                  | • Unknown causes                                              | • Head injuries                                              |
                                                                                  |                                                                | • Lack of oxygen to the brain                              |
</code></pre>

In Uganda, we found it was common for other family members to think that the cerebral palsy had been caused by birth control methods being used by the mother before and during early pregnancy. We found that we needed to reassure to the mothers that this was not true.
WHAT DOES CEREBRAL PALSY LOOK LIKE?

MATERIALS Photos series 1.04 in display material

ACTIVITY

Ask the caregivers to look at the different pictures of children. You can hand out the pictures to the group or put them up on the walls, and ask the caregivers to move around and look at each one and discuss what they can see. 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 with cerebral palsy look exactly the same. It is important to remember that cerebral palsy affects every child differently.

Seeing other children with cerebral palsy and realising that they aren’t alone, is often very important to caregivers. The caregivers in the groups commented:

“I didn’t know that there were other caregivers who have a child like mine so now I feel better. Now I am not the only one who has a child like this. Parent, Uganda

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

Before I came here I kept looking at the child next door who could do more than my baby and was only 3 months old. That child did everything on time. I was crying all the time wondering is my baby bewitched? But when I see others here, I am strong. Parent, Uganda

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, that is also fine, as they may feel more comfortable later on, when they know other members of the group.
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.

A powerful part of the group process is meeting other caregivers with similar experiences of bringing up a child with cerebral palsy. In Bangladesh, Uganda and Ghana, caregivers valued looking at pictures of different children with cerebral palsy and discussing similarities with their own children. Many had not met other parents of children with cerebral palsy – even from within their own village.

“It comforted us, we got to know that we are not alone. Parent, Uganda

We got the courage to work towards the wellbeing of our children. Parent, Uganda

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

It taught us to ignore people’s talks about us and our children. We learnt that they were mere words because almost each one of us heard someone say a word that was hurting. Parent, Uganda

In Uganda, the mothers were observed to have formed a strong group identity and at the beginning of the sessions were often observed talking and smiling about their children’s progress. They were also observed to advise each other and share knowledge and experiences.

MONITORING PROGRESS

EXPLAIN

Explain that it is very important that you understand this information yourself. In addition, 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.
ACTIVITY
In pairs, explain to each other in your own words what cerebral palsy is. Give feedback to each other about your explanations, based on what you have learnt in this module.

In a group, 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
Give out handout of diagram 1.02 to parents to take home and flipchart with take home messages (if used).

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 your child’s life – family, friends, and neighbours.
• The earlier you start to help your child to learn, the more she can develop.

References
1. Mactaggart I, Murphy G. The Key Informant Child Disability Project in Bangladesh and Pakistan Main Report. International Centre for Evidence in Disability, London School of Hygiene and Tropical Medicine. 2013.
Module 2
KNOW YOUR CHILD

MATERIALS  Pencils, skills cards 2.01 cut into pieces, skills cards 2.02, development charts (2.03 a-c) and seizure management handout sheet (2.04)

0-2 YEARS
Many important developmental milestones happen in the first two years of life and it is really important that we use these early months and years to maximise developmental progress. Understanding your child’s individual needs is important at all ages and you will find that much of this module is similar to the module ‘evaluating your child’ in the manual for older children. However, in this module we have introduced the idea of goal setting to help support caregivers focus on the best ways to maximise their individual child’s development.

ASK
What was your experience of trying 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?

ICEBREAKER
1. Form a line and ask everyone to hold hands to make a long chain.
2. Choose someone at one end of the line to start. Explain that when they feel their hand being squeezed they will pass it on to the next person by squeezing with their other hand.
3. Ask everyone to close their eyes.
4. Squeeze the hand of the person at the end of the line.
5. Each person passes along the squeeze once they feel it so that it passes to the end.

Ask the group to sit down. Discuss how that in order to feel the squeeze at the end of the line it had to happen in steps. One hand squeeze led to another until it was passed along the line. In the same way, children’s development happens in small steps. Today we will discuss the steps in your child’s development.

EXPLAIN Outcomes for the module (with flipchart if available)
By the end of this session you will:
1. Understand how children develop and be able to explain this to someone else.
2. Observe your child and show where he is on the development chart
3. Identify what your child may learn next.
4. Recognise ‘fits’ (epilepsy) and know what action to take.
EXPLAIN that young children with cerebral palsy do learn and change but that they need **extra time** and **extra help** to keep developing.

It is important to encourage your child to learn to do things for himself. If you set up the space around him with simple toys / things to look at this will help him play and learn more independently.

**ACTIVITY** In small groups discuss the following:

Think about your child and what you do with him every day. What are some of the skills you would like him 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** DISPLAY MATERIAL 2.01

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

<table>
<thead>
<tr>
<th>1. Communication</th>
<th>2. Self-care activities such as eating, dressing, toileting</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Moving around from place to place</td>
<td>4. Walking (if possible)</td>
</tr>
</tbody>
</table>

EXPLAIN Communication is one of the most important skills that your child can learn.

*Why is communication important?* 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 his self-care skills even if he is not able to move around from place to place, or walk.

**DEVELOPMENT AND PRACTICE**

**MATERIALS** Pictures 2.02 cut up and stuck on card (2 or 3 copies)

**ACTIVITY**

Put up the five pictures below in random order (Pictures 2.02). Discuss the pictures in small groups. Ask the groups to decide on the typical order in which they 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.
Display material 2.02

Shown in typical order above: 1 – lifting the head, 2 – rolling, 3 – sitting and reaching, 4 – walking with support 5 – running/throwing/kicking

**ASK** the groups the following questions:

*How do you think children learn something new? If your child has difficulty moving what do you think is needed to help them learn to do things?*

**EXPLAIN**

Children learn by doing the same activity over and over and over again until they get better at it. We know, however, that a child with cerebral palsy has damage to areas in her brain and this often means it takes them longer to learn. The damage to the brain may cause difficulty co-ordinating parts of her body to move or do things. Or maybe when she does try to move her limbs, head or tongue keep going into really difficult positions and make it hard for her to learn to do things by herself. That is why development in a child with cerebral palsy is slowed or seems to be stopped.

If your child has difficulty doing things on his own, you will have to help him practice, over and over again and break the learning into smaller parts. Thus a child with cerebral palsy needs **extra time** and **extra help** to keep developing.

**Your child may not do things at the same time as other children but the first 2 years are particularly important to do lots of practice as the brain is developing very quickly.** Every small improvements your child makes is important and cause for celebration.
DEVELOPMENT CHARTS & GOAL SETTING

FACILITATOR TIP

TIPS for facilitators on goal setting (finding the next steps)

Useful for this session and other sessions

To reach a goal there are lots of smaller steps to help us get there. Like crossing a small river, if the goal is getting across to the other side of the river, we need stepping stones to help get us across. Think about what are the stepping stones for the goal, how are we going to get to the other side? You may want to explain this to the caregivers to help them to understand the process.

Improvements are more likely to be noted if caregivers select the goals that are important to them. The steps are simple and can be practised daily at home. So, we need to help the caregivers create simple activities that they can do at home to enable them to reach their goals. Discuss with caregivers that the modules we are going to cover will help them to identify these for their child.

Encouragement is really important in helping caregivers feel positive and keep working on their goals. So, facilitators need to give positive feedback and encouragement to caregivers at every session and help identify the small changes they are noticing in their child.

MATERIALS Development Charts 2.03 a, 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

Explain briefly what is happening in each of the pictures.

FACILITATOR TIP

The aim of this exercise is to increase caregivers’ understanding of what their child is able to do now and to start them thinking about what skills they would like their child to learn next. Before starting the exercise with the caregivers, read through the case study below so the caregivers understand the activity better. It is also helpful to use the example of stepping stones to help explain about goal setting. If you have two facilitators you can split the group into 2 smaller groups each with a group facilitator.
EXPLAIN There are four categories for Movement:

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

PLUS a category for

- Thinking and Playing
- Communication and Interaction
- Social and Self-help skills

EXAMPLE CASE STUDY:

This is Joseph:
He can currently lift his head up and sit with support. His mum is aiming to do exercises to help him learn to sit by himself. Positioning and learning to move modules will help them with this goal.

<table>
<thead>
<tr>
<th>DEVELOPMENT CHART: Movement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Head and body control</td>
</tr>
<tr>
<td>Lies on stomach and holds head up</td>
</tr>
<tr>
<td>Rolls from stomach to back</td>
</tr>
<tr>
<td>Sits with support</td>
</tr>
<tr>
<td>Sits alone</td>
</tr>
<tr>
<td>Twists and reaches</td>
</tr>
</tbody>
</table>

These circles show what Joseph can do already. He can lift his head up and sits with support.

The next step is circled in red. Joseph’s mum would like to help him learn to sit.

<table>
<thead>
<tr>
<th>DEVELOPMENT CHART: Communication, social interaction and behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comm and interaction</td>
</tr>
<tr>
<td>Expresses self using sounds and facial expressions</td>
</tr>
<tr>
<td>Makes eye contact, coos and gurgles when talked to</td>
</tr>
<tr>
<td>Repeats sounds and gestures</td>
</tr>
<tr>
<td>Responds to simple commands</td>
</tr>
</tbody>
</table>

He can make eye contact and smile currently and his mum is aiming to play with him and help develop the sounds he can make. The play and communication modules will help them with this goal.
ASK The caregivers to look at the development chart

What can your child do now?

Look at one section at a time, and allow time for lots of discussion and interaction. Mark with a circle or a tick what their child is able to do. Try to focus on what their child CAN do and circle/tick it and avoid them putting crosses on items their child cannot do. Remember, there is no right or wrong answer. You are building up a picture of where YOUR child is with his development.

FIND THE NEXT STEPS

ASK some of the following questions (to encourage the caregiver to understand their child’s development and the next step)

- What does your child like doing?
- What can your child do now?
- What does your child find a bit more difficult to do?
- How do you know what is easy for your child and what is difficult?
- What is your child trying to do?
- What do you think your child will learn to do next? (keep it small)
- What do you think your child needs to help him do the things that are difficult?
- How will you know that your child is improving? (This part is really important to help the caregivers to see changes)

Allow time for discussion in between questions.

If the caregivers are struggling to identify the next step, ask them to look at the next step up on the development charts and think whether that is the next step for their child.

EXPLAIN

Now you have identified the next step for your child, the following modules will support you in working towards meeting those goals. We will teach you ways to help your child learn to sit, move, hold things and eat and play.

If parents have selected a long-term goal rather than a short-term goal, help them think about what might come next (before the long-term goal).

FACILITATOR TIP

Facilitators should remind the caregivers at the end of each subsequent session about identifying activities that will help them achieve their goal.
EVALUATING YOUR CHILD FOR SEIZURES

MATERIALS Pictures 2.04a and 2.04b and handout on seizures

Some children with cerebral palsy will also have seizures.

0-2 YEARS

In 0-2 year olds it is essential that we teach parents to recognise seizures and get appropriate treatment early. Untreated seizures further delay in development and importantly can even result in death.

EXPLAIN the following in the discussion

• Seizures happen when messages in the brain are mixed up and the child loses control of their muscles.
• There can be a change in your child’s mood. Your child may suddenly seem afraid or start crying.
• Most seizures occur without warning. During a seizure the person may fall down, stiffen, vomit, drool, urinate (pee), and have shaking of the limbs. 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, your child may be very sleepy and may not remember what happened.

ASK

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

EXPLAIN What to do when a child is having a seizure:

Pictures 2.04a and 2.04b
EXPLAIN Some general advice about seizures

• Go to the clinic if your child has seizures for medication and follow-up with a doctor.
• Medication for seizures should be taken daily to stop seizures happening.
• Medication dose may need to be increased to work well and also as children grow in size.
• Medication for seizures should NOT be stopped suddenly – make sure you don’t run out of medication.
• Seizures are NOT caused by evil spirits or from being cursed.

ACTIVITY Community mapping of local services

Where is the nearest health centre/ clinic or hospital to your home? Do they have medicines for seizures?

Discuss as a group the health centres and hospitals in the local area that can treat seizures.

ASK

What do other people in the community or in your family say about children who have seizures or fits?

Use the examples from Bangladesh and Uganda 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 had encountered a bad spirit... he told us to sacrifice 2 pigeons, then your child will be fine... but she did not recover. **Parent, Bangladesh**

I thought it was a ghost which brought the seizures but now I know the reason is not a ghost. **Parent, Uganda**

I was told to treat seizures I should mash an onion and put it next to my child’s nose to inhale and the seizure will stop. **Parent, Uganda**

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**EXPLAIN** that seizures are not caused by evil spirits or a curse

Refer back to the diagram in the introductory session which shows that injury to the brain can cause the seizures. Seizures cannot be treated by a visit to a traditional doctor to remove ‘evil spirits’. 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.

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**FACILITATOR TIP: MAKING REFERRALS**

Depending on the set up of your group, and how it links in to healthcare services and what rehabilitation services are available locally, this session is a good time to consider making referrals or offering advice and signposting to appropriate services for:

- Malnutrition
- Epilepsy
- Physiotherapy
- Occupational Therapy
- Speech and language therapy

If a child has uncontrolled (un-medicated) seizures or malnutrition it is likely to slow their development, so it is important to support caregivers in accessing appropriate medical interventions.
MONITORING PROGRESS

ASK

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.

FACILITATOR TIP

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 important 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 return home. Discuss with the caregivers about inviting family members to the trainings sessions. Make sure that fathers, grandparents or siblings or other caregivers are made to feel welcome at any training.

MATERIALS Give out handout on managing seizures to caregivers to take home

Encourage caregivers to discuss the information on managing seizures with others that care for their child.

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.
- Your child will learn and develop at his own pace and in his own way.
- Sometimes, your child may need to practice skills or activities. It is important to encourage your child to learn to do things for himself.

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.
MATERIALS Display materials 3.01-3.08
Blankets, pillows and towels, mats on the floor, a doll with floppy limbs that can be positioned i.e. not a hard plastic doll, display materials

0-2 YEARS
In this module we have focused on the positions that are particularly important in the early months and years when children are just beginning to learn to roll, sit and move around. Positioning a child well is really important as it can support developmental progress and promotes inclusion. Young children with cerebral palsy find it difficult to get themselves into a good position, and poor positioning can be uncomfortable and makes it harder for children to learn and be a part of family life.

In this module we have focused on positioning for very young children who are not yet able to sit or stand, and that are of benefit to a child’s development. These include lying on the tummy, side lying and supported sitting. For older children who are sitting independently or standing, information can be found in the Getting to Know Cerebral Palsy manual (module 3).

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 – 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 everyone have a turn to be in each position, depending on how much time you have.

EXPLAIN: Outcomes for the module
By the end of this session you will:
1. Understand the importance of good positioning to help your child’s development.
2. Be more confident to position your child comfortably, and be able to show others in your family or community.
INTRODUCTION TO POSITIONING

MATERIALS  Photo series 3.01

ACTIVITY
Show the various pictures and ask caregivers to work in small groups and look at the pictures.

• Do the pictures show good positioning?
• How might good positioning help your child’s development?
• Are there any positions helpful for eating, playing or communicating?

Focus on showing difficulties like: She can’t lift her arms, she can’t look around, she can’t move or play...

Photo series 3.01
EXPLAIN

Good handling and positioning can help to improve your child’s development while poor handling and positioning can make the daily activities harder and may slow development.

If you leave your 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. It is helpful to place your child in a variety of positions throughout the day.

Pressure areas – Due to pressure from the outside on a body part, blood is prevented from flowing easily through that part of the body, 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 your child and can become infected.

Deformities – Even if you care for your child really well, such as keeping her clean and dry and free from pressure areas, the pull of the muscles when your child spends long hours in any one position can cause increased stiffness in joints, and in the long term your child to have deformities. 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:

A good supported position (like the ones we will show you today) will help your child develop and:

• Control her head and body movements
• Allow her to use her hands and learn to reach for things, play, learn to feed herself
• Allow her to see her environment and interact with your family
• Make eating and drinking ‘safer’
• Feel more comfortable
• Help reduce stiffness and develop strength.
In this module it is important to emphasise the relationship between good positioning and helping your child to develop.

For each position demonstrated, let the caregivers practice in the session so the facilitators can check that each caregiver is able to position their child correctly.

"I was using these positions at home but I didn’t know that these positions were helping my child to develop and protecting him from other damage."

Parent, Uganda

“When I came here and learnt positioning, my child learnt to sit.”

Parent, Uganda

**FACILITATOR TIP**

**HOW TO POSITION YOUR CHILD**

**EXPLAIN**

We are going to discuss 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 to understand that not all positions are helpful for all children.

1. **Learn helpful ways to move your child**
   - If she is stiff you may need to loosen her first.
   - Positions should never be forced.
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. Keep trying, and ask advice from a therapist or community worker if she continues to be uncomfortable.
3. **Change her position often, about every hour**
   - Encourage her or help her to change her position herself.
   - Don’t leave her for a full hour if she is uncomfortable.
   - Don’t leave your child in the same position for longer than an hour, as it can cause problems like pressure sores discussed above.
CHECKLIST

(Draw a diagram on flipchart and colour code the following 3 areas or use display material 3.02)

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

MATERIALS Picture 3.02

It is useful to keep this image out and refer to it for each of the positions that are demonstrated in the module.

SIDE-LYING

Side lying is an important position:

- It is a comfortable position for children who are very stiff.
- It allows children to get hands together, which is really essential for development and play.
- It is also very good for children who produce a lot of saliva as it helps the saliva drain out of the mouth safely.

MATERIALS Picture 3.03

Show to caregivers to illustrate helpful and poor positioning
Poor positioning

- Head and back are extended.
- Arms and legs are stiff.
- Stiff limbs mean that she would not be able to play.

Helpful positioning

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 as straight as possible.
- 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 your child to sleep in.

ACTIVITY

Demonstrate helpful positioning and encourage mothers to work in pairs and practice it with their own children. Ask them to support each other in correctly positioning the child. Walk around the group providing additional support, as needed.
SUPPORTING YOUR CHILD TO LIE ON HER TUMMY

MATERIALS: Picture 3.04
Show to caregivers to illustrate helpful and poor positioning.

EXPLAIN

Lying on the tummy is really important for developing strength in the head, neck and back. Children learn to roll, crawl and move, by spending time on their front and then being encouraged to push up through their arms.

- Often children don’t like being on their front when they are not used to it, so start with small amounts of time; build up slowly to longer periods.
- Sometimes a small rolled towel under your child’s chest or shoulders and positioned around her on either side can help her to hold this front -propping position for a longer time.
- Try and play with your child while she is on her front to help distract her.

Poor positioning
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 fists.
- She can’t do anything.

Helpful positioning

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)

ACTIVITY

Demonstrate good positioning and encourage everyone to work in pairs and practice it with their own children. Ask them to support each other in correctly positioning the child. Walk around the group providing additional support, as needed.

LYING ON HER BACK

MATERIALS Picture 3.05
Show to caregivers to illustrate bad positioning.

ACTIVITY

Ask 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.
**EXPLAIN**

**Lying on the back** can be a good position for resting in, but it does not help a child develop control over their body and learn ways they can move their body and head, as compared to being in other positions. The older your child gets, the less time they should spend on their back when they are awake.

**Poor positioning**

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

- Head turned to one side.
- Body is twisted.
- Hips turning in causing legs to cross (scissor).
- Feet are pointing down, which means she can’t get them flat which may cause difficulty in standing later on.
- Hands and arms away from body.
- Hands fisted and closed.

**Helpful positioning**

Discuss in the group why this is a better position for lying on their back.

**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 but slightly forward 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 a splint.

**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.

**ACTIVITY**

Ask one caregiver to volunteer to put their child in this position, encourage help and input from the rest of the group.
SITTING WITH A CAREGIVER

MATERIALS Pictures 3.06

Show to caregivers to illustrate bad positioning.

ACTIVITY

Get the caregivers to look at the 2 pictures below and describe the differences that they see. Which is the better position and why?

Poor positioning

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 his bottom.
- His hips are not bent, and wrong muscles are working.
- He is not able to do anything with his hands.

Display material 3.06
Helpful positioning

Make sure the caregivers consider their own comfort eg sit against a wall for support and make sure they are comfortable and well positioned.

**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**

Demonstrate the position and encourage mothers to work in pairs and practice it with their own children. Ask them to support each other in correctly positioning the child. Walk around the group providing additional support, as needed.

**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.

**SUPPORTED SITTING**

**MATERIALS** Picture 3.07

If your child cannot sit on her own, it is really important to support her in a sitting position. This helps her see more of the world around her and can also help protect her hips from problems in the future (lying down all the time does not help the hips develop in the right position and this can cause pain in the future.)
ACTIVITY

Ask a volunteer to demonstrate a good position with their child, and encourage help and input from the rest of the group. Then share the following ideas for supported sitting.

Some easy ways to help your child sit with some support are:

- In a strong cardboard or wooden box, or basin covered with blankets/bedcover to make them comfortable and help support them.
- Corner of room/sofa/chair, if your child pushes themselves backwards then this position can be hard. You need to make sure your child’s hips and knees are bent to stop them pushing back. Use a heavy rolled towel, bedspread or sandbag.

These photos can be used to demonstrate different options.

One of our mamas used this position using a basin (above) with her child... we really liked it!
CARRYING

MATERIALS Picture 3.08
Show to caregivers to illustrate bad positioning.

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 positioning
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 Positioning

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.

ACTIVITY
Demonstrate the position and encourage everyone to work in pairs and practice it with their own children. Ask them to support each other in correctly positioning the child. Walk around the group providing additional support, as needed.
CARRYING YOUR CHILD  (Ugandan perspective):

While it is fairly easy to carry a floppy child on your back providing you can give sufficient support for their head, this position doesn’t help your child develop their head muscles and control of their head movements; a better position would be to carry your child on your hip with both of their arms at the front of your body.

It may be very difficult to carry a stiff child on your back especially if they tend to push back a lot. Carrying your child lying on their back is also likely to be very hard work and can reduce their active movements and make them uncomfortable.

A better way to carry her is on your hip with her knees bent, this will help stretch her hip muscles and be more comfortable for both you and your child.

With a child who is stiff, the key is for her hips and knees to be gently bent and separated, this loosens the stiffness.

Another position for both stiff and floppy children is carrying them on your front with their knees bent against your chest.

Box 3.0
In Uganda, caregivers were hesitant and reluctant to carry their child on their hip rather than on their back as it is associated with another tribe or country. We tried to emphasize the benefits to their child’s development in carrying them on the side.
PICKING UP

MATERIALS Picture 3.09

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.

Don't pick your child by their arm, as it can cause damage to their shoulder and arm and be very painful.

Poor positioning

- The harmful way: Bending forward with your legs straight will cause small injuries to your back every time you do it.

Helpful positioning

Pick up your 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 your child up with one foot slightly in front of the other one.
- Roll your child towards you as you pick her up
- Hold your child as closely to your body as possible before lifting.
- Lift by using the strong muscles of your legs, and not your back.
MONITORING PROGRESS
Ask each caregiver 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.

ASK
Think back to session 2 where you looked at stepping stones to help your child learn:

- What have you learnt today that would help your child practice these?
- What are you going to do at home from today’s session to help your child’s development?

FACILITATOR TIP
You may want to provide a simple form for the caregivers to write down the activities they have chosen to do with their child to help remind them. Or, as facilitators, you may want to keep a written log of caregiver’s goals and planned activities to help you monitor progress and offer feedback and encouragement to the caregivers.

In many countries, as in Uganda, the local languages are spoken rather than written and the literacy levels of caregivers may make it challenging for them to read and write in English.

TAKE HOME MESSAGES:

- Good positioning means that you can be helping your child’s body develop even when they are resting, or you are busy.
- Good positioning helps protect your child’s body from developing further problems.
- Good positioning helps make daily activities easier for your child.
- If you have access to equipment like chairs, 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.
Establishing eating and drinking skills early is very important for the health and growth of children with cerebral palsy. In programmes in Uganda, Bangladesh, and Ghana malnutrition has been noted as an important issue for many children. In Ghana 70% of children with cerebral palsy had malnutrition (1). In Uganda, around a quarter of infants with cerebral palsy after complications at birth (birth asphyxia) had malnutrition at one year of age. In a study amongst older Ugandan children with cerebral palsy, half had malnutrition (2).

Whilst improving feeding practices is important, identifying linkages with national and local nutrition programmes in order to clarify how the most vulnerable children and families could be linked into their services is also key. Poverty and lack of time to prepare special food can also be challenging for many caregivers.

**MATERIALS**

Display materials 4.01 – 4.05

For icebreaker: Jug of water, cups.

For demonstrations: Large rag doll, small towels you can roll up, large plastic cup, small cut away cup, dessert spoon, plastic teaspoon, display materials. Local foods from each category of nutritional group (photos or real items).

For explanations: Pictures for positioning section.

For practical feeding session: Small sieves, small bowls, plastic teaspoons and cut away cups for each caregiver and child. Home-made child food (e.g., bean soup, vegetables, porridge), bananas/soft fruit and biscuits.

**0-2 YEARS**

This Feeding Module’s content is different to programmes for older children as it focuses on introducing solid foods and the use of utensils to young children. Solid food should be introduced to babies at six months of age, and this applies to children with developmental disability too.
The muscle tone and coordination of young children with cerebral palsy can be different to other babies, and this may change the way they eat and drink. This module will help you to show caregivers ways to feed their child so that they can grow well and stay healthy. These tips will help children who are breast feeding to grow and gain weight when solid food is introduced.

This is quite a long module and you may need to split it into 2 or 3 smaller sessions. Remember to re-visit feeding during following weeks when you are running the other modules. You can offer food at all training sessions.

ICEBREAKER

This activity is designed to help caregivers understand what it feels like to be fed by someone else in a difficult or unsuitable way.

1. Ask caregivers (NOT children) to work in pairs:
2. Ask them to take turns to feed one another with sips of water HOWEVER

The person being fed should hold their head first leaning far back, and then turned to one side and then flopping forwards.

How easy or difficult is it to swallow in each position? How does it feel to be fed?

EXPLAIN

Outcomes for the module (with flipchart if available).

By the end of this session you will:

• Understand the range of difficulties that children may experience with eating and drinking, and why these are important.
• Learn ways to feed your child safely.
• Know what a balanced diet is and how to maximise your child’s nutritional intake and prevent malnutrition.
• Understand the importance of introducing solid foods to your child at the right time.
• Know strategies for introducing solid foods and develop your child’s feeding skills.

ASK

• What does your child eat and drink?
• Does your child drink out of cups or bottles?
• Have you started giving your child solids?
• What kinds of food do you give?
• What utensils do you use?

Write a list of the foods they mention to use later in the food grouping activity.
INTRODUCING SOLID FOOD

FACILITATOR TIP

In Uganda, we found that we needed to change the order of these key sections because the children were ready to eat at the start of the training. It is OK to change the order of the following sections to feed the children when they are ready. You can do other activities/discussions with the caregivers when the children are asleep.

FEEDING DIFFICULTIES

ASK

What kind of difficulties do you have with feeding your child?

Write up responses and use the list below to ensure all the following difficulties are discussed.

Difficulty controlling your child's head
- His head is floppy and he struggles to keep it upright
- He pushes his head backwards

Difficulty controlling your child's body
- He cannot sit by himself and struggles to keep his body upright
- It is difficult to hold his body upright when feeding him as he pushes back or struggles to keep his body still

Difficulty controlling your child's mouth/lips/tongue
- He struggles to close his mouth and food or drink spills out
- He struggles to chew his food
- He struggles to swallow/takes a long time before swallowing his food
- He chokes/coughs a lot when eating
- He pushes the food out of his mouth with his tongue

Mood
- He is often very unhappy during mealtimes and cries or screams and rejects his food

Other problems
- He often vomits after eating
- He suffers from frequent constipation
- Sometimes I feel frustrated because feeding him is so difficult
HELPING YOUR CHILD TO EAT AND DRINK SAFELY AND DEVELOP THEIR SKILLS

MATERIALS Display materials 4.01 & 4.02

EXPLAIN

There are 6 key aspects to helping your child learn to eat and drink safely:

1. ENVIRONMENT AND HYGIENE
2. DIET
3. POSITIONS FOR FEEDING
4. UTENSILS
5. FOOD TEXTURES
6. HELPFUL AND RESPONSIVE FEEDING

1. ENVIRONMENT AND HYGIENE

When feeding your child, it is important to:

• Wash your hands with soap and water
• Wash your child’s hands
• Wash the utensils with soap and water
• Feed your child in a clean space
• Feed your child where there are fewer distractions

2. DIET

ASK

When and why are children introduced to solid foods?

EXPLAIN

When a child reaches 6 months of age they need to have solid food as well as milk in order to grow, even when they have developmental difficulties.

Eating and drinking are important for nutrition and hydration, and so for growth and health. Eating and drinking are also important for practicing moving parts of the mouth and for learning to socialise.
What is a nutritious or ‘balanced’ diet?

Show the poster and discuss the food groups, explain that a combination of these will give energy and vitamins, which ALL children need, especially children with cerebral palsy. Help the group to list what items in the local diet provide the main sources of nutrition.

**FACILITATOR TIP**

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 families with any local nutrition programme. Consider inviting a local nutritionist into part of the meeting so that families are aware of the additional support available.
**ACTIVITY**

Draw a circle divided into three sections labelled: body building foods, protective foods, and energy giving foods. Show the different local foods and ask the caregivers to place into the three groups. Also use the list you made earlier of foods they give their children. Help the caregivers to understand that each child needs a combination of these foods to grow, develop, and gain weight.

![Diagram of a circle divided into three sections labeled: body building foods, protective foods, and energy giving foods.](image)

**EXPLAIN**

- Children with developmental disorders can get tired easily, so they need small meals given more often (e.g., 6 small meals instead of 3 bigger meals).

- Children with developmental disorders 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, happier and able to do more things.

- Avoid adding sugar to your child’s food and drinks. Even if your child is not keen to feed at the beginning, they will get better. Try to add pureed fruit instead. If children get used to sugar added to their food, they will not accept food that is not sweet later on. Also, sugar causes teeth decay and health problems later.

- As drinking is difficult, children need sips of fluid given throughout the day. Children need the equivalent of at least 4 cups of fluid. This will help reduce their constipation, dehydration, and give them more energy. Constipation is more common in children with developmental disorders and can cause them pain and discomfort.
Progression of intake of solids vs. liquids with age:

As infants grow, they start to breastfeed less and eat more, and begin to drink water from a cup. For example:

<9 months old:
- Mainly breastfeed.
- Start learning to drink sips of water from a cup
- Start eating 2-3 small meals (of approximately 2 full tablespoons) a day.

Between 9 and 12 months old:
- May start breastfeeding less and drink more water
- Start eating 4-5 meals (of approximately 4 full tablespoons).

Over 1 year old:
- May continue to breastfeed, but take more water from a cup.
- Now need to eat more food (approximately 6 meals a day).

The following table is a summary of the transition from breastfeeding to eating and drinking:

<table>
<thead>
<tr>
<th></th>
<th>&lt; 9 months</th>
<th>9-12 months</th>
<th>&gt; 12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Solids</td>
<td>2-3 small meals (of 2 full tablespoons)</td>
<td>4-5 meals (of 4 full tablespoons)</td>
<td>6 meals (of 4 full tablespoons)</td>
</tr>
</tbody>
</table>

MATERIALS Display materials 4.03 & Handout 4.2

FACILITATOR TIP

You will need to find suitable local recipes from the country where you are running the course. Provide examples of high protein and carbohydrate meals. Ask the caregivers to provide examples from their own cooking.

On the following page is an example of a high protein, high carbohydrate meal from Uganda. Think of a similar recipe that is suitable to your setting. (Consider giving this recipe out as a handout.)
**RECIPE**

**Kitobero**

Kitobero is a Luganda word for a mixture of more than one food cooked together. Kitobero includes all the food groups in one dish and contains 1 portion of carbohydrates to 2 portions of protein.

**Ingredients**

- 1 handful of any carbohydrate rich food (Maize or cassava flour/ matoke/potato)
- 30g (2 teaspoons) of ground silverfish (mukene) - grind this at home
- 2 handfuls of groundnuts or beans - grind this at home
- Water
- 1 pinch of salt

**Method**

- Put the washed and peeled potatoes in a saucepan
- Add 2 handfuls of groundnuts
- Add 2 teaspoons of ground silverfish
- Add a pinch of salt
- Add a litre of water to cover the food
- Stir well
- Cook for about 2 hours
- Puree using a sieve
3. POSITIONS FOR FEEDING

**MATERIALS** Display materials 4.03a & 4.03b
- photocopy 2 sets and cut out into 6 cards.

**ACTIVITY**

In 2 groups, 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 below for answers to this activity).

**EXPLAIN**

Both the child and the caregiver need to be positioned well. Children are held in a reclined position when they are breastfed. As they get older and their neck becomes longer, they need to be held more upright, to make sure food doesn’t go down the wrong way and feeding is safe.
FACILITATE the group to summarise the key aspects of good positioning:

**Head and body:** Sitting upright. Head facing forwards, neck straight, chin tucked in

**Shoulders and arms:** Forwards or on the sides of the body

**Legs:** Hips and knees bent at 90°

DEMONSTRATE using a doll (or one of the children in the group) how to position a child for feeding.

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

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

**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 his neck.
- Make sure you can see your elbow.
- Put a cushion under your raised knee to keep yourself comfortable and to keep his back straight.
- Make sure your child’s bottom is well between your legs so that you can keep his hips firmly bent.

If your child is very stiff and finds it difficult to maintain an upright position, he can be placed lying down with his back raised with cushions, and a rolled-up towel under his head if needed so that his head doesn't fall back.
Sitting in a supportive chair (for older children):

- A seat like this can give your child’s body all the support he needs, leaving you free to concentrate on feeding him well.
- Make sure he 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 the caregiver’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.

ACTIVITY

Allow the group time to try out the positions and see which works best for their child. Facilitators can assist by checking positions and helping caregivers to problem solve, and to encourage and support each other to adjust the positions.

EXPLAIN

It is also important to keep your child either upright or lying on his side on a cushion for 20-30 minutes after meals. This will reduce vomiting (reflux) after eating.

Children with developmental difficulties can seem uncomfortable after eating and may vomit even when they don’t have an infection. This is due to their stomach muscles being weak and causing the food to come back up from the stomach during or after feeds.

(Use the side lying Picture 3.03 from module 3 on positioning to remind caregivers).

EXPLAIN the following summary points for positioning:

- Be sure your child is in a good position before you begin feeding him.
- The good position you use will make feeding easier and safer.
- It is especially important that his head is not leaning back or flopping sideways. This makes swallowing easier and safer.
- You can play with your child in these positions too — that way he gets used to the position before you try feeding him, and you also get comfortable with using these positions.
4. UTENSILS

Cup Feeding
Show a plastic cup and a plastic cup with one side cut away. Pass them around for participants to try.

ASK
*Which is better for feeding your child and why?*
Make sure the following points are covered:
- The cup that is not cut away makes the child tip his head back to drink, making swallowing the liquid harder.
- When using the cut away cup you can see the liquid in the cup and how much you are giving the child.
- You can also use a short clear cup that you can see through like a medicine cup.

EXPLAIN
A cup is introduced when the:
- Child cannot suck on the breast or bottle.
- Mother is unavailable to breastfeed (ill or child orphaned).
- Child is unable to attach to the breast.
- Child is getting too tired from sucking a breast/bottle.
- Child uses a bottle: using a bottle for a long time, makes it harder to develop good drinking skills. Start teaching him how to use a cup as soon as possible.
- Child is 6 months and ready to drink sips of water.

ASK
Ask the group to discuss what could go/has gone wrong with cup feeding.
Write up responses and use the list below to ensure all the following difficulties are discussed:
- Child may not wake up.
- Child may not actively suck.
- Milk may spill from the mouth.
- Child may cough/choke.
- Child might breathe milk into the lungs.
- Child may not control how fast the milk comes out of the cup.
**EXPLAIN**

Demonstrate cup feeding:

- Your child needs to be alert and able to suck / sip
- Position your child upright.
- Present the cup at your child’s lips and tilt a little allowing the milk to touch the upper lip then wait. Do not pour milk into the mouth.
- If your child’s mouth is too open, help him by placing your finger under the jaw for support.
- Give single sips and observe the swallow.
- If your child is sucking and swallowing, lower the cup after every 3 sips for a short break.

**ACTIVITY**

Help caregivers adapt a cup to make it suitable for cup feeding. Allow the caregivers to try out cup feeding. Facilitators observe and advise to ensure correct technique.

Next, we will learn about how to prepare food of the right texture for spoon feeding. After this you will get to practice spoon feeding.

**Spoon Feeding**

Show a small metal spoon, a big metal spoon and a plastic teaspoon.

**ASK**

*Which is better for feeding your child and why?*

Make sure the following points are covered:
- A good quality plastic teaspoon is best, both in terms of giving small mouthfuls as well as preventing harm if the child bites hard onto it. Metal is often too hard/sharp for a child’s mouth.

**EXPLAIN**

Demonstrate spoon feeding:

A child’s tongue moves forwards and backwards when he drinks from the breast or bottle. As he gets older, your child has to learn to keep his tongue inside his mouth when he eats and drinks.

The best way to feed using a spoon is:

- To give food from the front and straight
- Place the spoon with the food touching the top lip so that your child can feel it and use his top lip to remove the food from the spoon.
- He will suck on the spoon like he did on the breast/bottle at first.
- Your child should bring his jaw up, but if he doesn’t, place your finger under the jaw and give some support.

Don’t lift the spoon up and drag it against the top gum when taking it out, keep the spoon straight as you take it out of the mouth.

Remember, some children who are breast or bottle fed may not like to eat from a spoon or drink from a cup at first. You must keep trying and they will get used to it.
5. FOOD TEXTURES

MATERIALS Display materials 4.04.

ACTIVITY

Show a banana, a biscuit, and other common foods. Ask the caregivers to discuss if the food items are:
- Hard or soft?
- One type of texture or more?
- Can they be made into smooth puree?
- How can they be made into puree?

Liquids: Liquids are runny and can be difficult to control in the mouth. Liquid runs quickly and can go down the wrong way, into the lungs, if the child cannot control it well. Liquids should therefore be given very carefully.

Solids: When we introduce solids, children must get used to eating food that’s firmer than milk, and feels different in their mouths. Your child may have difficulties chewing. This is because he does not have the muscle power or co-ordination, so we need to make solid food moist and soft so he can manage it.

We start with smooth food – not too runny, not too solid. As your child starts to develop better control over their tongue and mouth, you can slowly increase the thickness of the food.

Children with developmental disability have difficulty controlling food that has more than one texture, with both hard bits and liquid, such as bean soup.

For example, banana can be pureed by mashing with a spoon. A biscuit can be moistened with some milk.

It is difficult for children to manage a mix of textures in the mouth at the same time. All foods that are not puree must be made into smooth puree until your child is able to chew.

ACTIVITY

Give each caregiver a sieve, a spoon, and a bowl. Place some bean / vegetable soup with liquid into the sieve and show how to crush the bits into a smooth puree as seen in the pictures below.

Display material: Pictures 4.04
Once the caregivers have made a smooth textured food, they can then use it to feed their child and try out the spoon-feeding technique described earlier. Facilitators, observe and advise to ensure correct technique.

6. HELPFUL AND RESPONSIVE FEEDING

- Give your child small mouthfuls, and one mouthful at a time.
- Don’t rush! Give your child plenty of time.
- Your child may struggle to keep his mouth closed when there is food inside. If his mouth is closed when eating, he will find swallowing easier and he will spill less food, and therefore eat more. You can help him by providing support to his jaw.
- Talk to your child to encourage him to eat and have fun at mealtimes. Be gentle. If he cannot finish his food because he is getting tired, offer him more milk until he is satisfied.
- Watch your child’s reactions and feed him in a sensitive manner. Watch to see when he is ready for the next mouthful. Pause and take breaks if needed. Never force feed.
- Start with food and then finish with water or milk. Don’t let him fill up on liquid before eating.
- Stop when the child indicates he is tired or has eaten enough.
- Interaction and fun at mealtimes will improve your child’s communication skills, and the caregiver-child relationship.
- Active and sensitive feeding encourages your child to want to eat. Research shows that children fed in all of these ways eat more and put on weight.

LEARNING TO CHEW AND BITE

EXPLAIN

When your child is able to eat smooth thick consistency foods well, he can be taught to chew soft foods.
- Most children will continue to have smooth texture foods as their main meals.
- He can practice chewing when having a snack/food outside main meal times.
- Cooked vegetables such as cassava and potato, biscuits, soft fruits are good for teaching your child to chew. The food should break easily in the mouth and become puree when chewed a few times.
Chewing

ACTIVITY

• Wash your hands in clean water.
• Use a soft food as described in the point above (cooked potato, biscuit).
• Position your child as practiced earlier.
• Break a half bean size piece, crush it and place this to the side of your child’s mouth on the gums.
• Your child may try to move the food by moving his cheek and later his tongue.
• Place your finger in his mouth to make sure the food has been swallowed before placing another piece.
• Swap sides – now place food in the other side of his mouth.

Increase the size of the piece of food when the child’s skills at chewing improve. It is important not to give children lumpy foods before practicing chewing skills as they can gag, choke and breathe food into their lungs.

Biting

When your child is able to chew soft foods like banana you can help him learn to bite harder foods like biscuits.

IMPORTANT

Only introduce biting at a later visit or session, when the child is able to chew and swallow without gagging, choking, or vomiting. It is dangerous to introduce biting before the child is ready as they might choke on a piece of food they bite off.

ACTIVITY Display material 4.05

• Wash your hands in clean water.
• Position your child upright as practiced earlier.
• You can use a biscuit or soft fruit like banana.
• Biscuit: dip a biscuit in milk and place the wet part of the biscuit on your child’s top gum. If he does not close his mouth, support him by bringing his jaw up to take a bite. The wet piece of biscuit will dissolve easily in your child’s mouth. As he gets better at biting and chewing, the biscuit does not have to be very soaked in milk.
• Banana: scrape some of the banana and put it back on the top of the banana (pictures 1 to 4 on the following page), then place it at your child’s top gum below (picture 5).
• Place your finger in his mouth to make sure the food has been swallowed before giving more.
MONITORING PROGRESS

Ask each caregiver to identify 2 things that they have learnt today about feeding that they will try at home and share with another member of the family.

ASK

Think back to session 2 where you looked at stepping stones to help your child learn:

- What have you learnt today that would help your child practice these?
- What are you going to do at home from today’s session to help your child’s development?

FACILITATOR TIP

Encourage caregivers to bring back the plastic spoons and cut away cups provided for future sessions so you can monitor their progress with feeding and provide support as needed.
TAKE HOME MESSAGES:

- Children with developmental disability can take time to learn to chew and eat solid foods and drink from a cup. They need help to learn these skills in the right way.

- They often have difficulties with eating and drinking and this can result in malnutrition and chest infections. There are a lot of things a caregiver can do to help reduce these difficulties.

- You can:
  - Position your child in an upright or almost upright position, with their chin tucked in slightly.
  - Feed your child small and frequent meals of a balanced diet which has extra fat or oil in it.
  - Introduce foods that are smooth and moist. Not too runny, not too solid or chewy.
  - Give your child small spoonfuls of food and small sips of water, slowly, using a small plastic spoon and small cup.
  - Give positive verbal encouragement and NEVER force feed.
  - Teach other family members to feed your child in the same way you do.

- Children with developmental disability need special help to eat and drink safely without coughing or choking. They also need more time to swallow and finish their small meals. They will make a mess when eating but this is ok. It does not mean they do not like food or drink.

References
1. ICED. Getting to Know Cerebral Palsy. LSHTM, 2016.
Module 5
LEARNING TO MOVE

MATERIALS Display materials 5.01 – 5.05 and selection of toys

0-2 YEARS
In the first 2 years of life a child’s development is focused a lot on learning to move. These movements include controlling their head, to rolling, sitting, standing and even walking. Progress for young children with cerebral palsy is slower than for other children. This module focuses on practical ways to maximise your child’s movement skills in these important early years.

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.
• Explain how a lack of balance makes it difficult for a child to do anything with her hands. In this module we will be talking about how to support your child to reach and hold items with their hands.

EXPLAIN Outcomes for the module (with flipchart)
By the end of this session you will:
1. Understand ways to help your child learn to move and control their body.
2. Be more confident in interacting, moving and playing with your child with cerebral palsy in a way that promotes her in learning to move.
3. Be able to explain to other members of the family and community how they can help your child learn to move.
As group facilitators you need to model how to interact well with the children in the group, to help the caregivers see exactly what we mean. With each ‘explain’ section, demonstrate what you are explaining using one of the children in the group.

Encourage the caregivers to try out the activities during the session. Please reinforce content of previous sessions, in particular the positioning module.

Give the caregivers positive feedback on the good things they are already doing to help their child develop. Each time a caregiver gives an example of what they are already doing, confirm that they are doing well.

You need to be flexible with this session to take into account the children sleeping, and to maximise practice time for all the caregivers and children for each activity.

**EXPLAIN**

The most important thing you can do for your child’s development is to interact and play with them. Children learn by copying and by trying. The more you practice a skill with them, the easier it is for them to learn.

**ASK**

Which of these things can your child do already?

Which of these things do you want to help your child to learn?

(Think about the development charts in the second session)

- looking at you/ following you with his eyes
- smiling
- holding his head up well
- reaching for or holding toys
- sitting
- crawling
- standing

**HELPING YOUR CHILD LOOK AT YOU AND FOLLOW YOU WITH THEIR EYES**

**ASK**

How do you think you can help your child to look at you/ follow your movements and smile? What things have you tried at home?
EXPLAIN

Your child looking at you or watching you while you move around may seem very simple, but eye contact is a first step towards communication. Being able to follow a moving object or person is important for head control and getting the eyes and hands working together.

Some things you can try are:

- **Get everyone involved to help; fathers, grandparents and other children.**
- Have fun and be playful... that is most likely to make your child smile!
- Give your child things to look at – put simple pictures/toys within reach or place them near whatever activity is going on at home. (Homemade toys, mirrors or a bright scarf/hat on the caregiver are all really good, you will learn how to make homemade toys in a few weeks time in the play module.)
- **Your child’s favourite thing to look at is your face!**
- Simple black and white images (or red/white or yellow/black) are good to help a child’s eyes to focus – and they are easy to make yourself.
- Remember to use bright colours as light ones are hard for children to see.
- Making a noise can help to get attention – e.g. singing, clapping, toys that rattle. (Some children can be scared by loud noises so be sensitive to your child.)
- Talk to your child, tell them what you are doing and seeing, even if they don’t appear to understand. It’s good for them to hear your voice.
- **Your child may need more time to respond. Wait and watch for a reaction**
- If your child has trouble seeing then they may like to look at the light on your mobile phone or shiny things like foil or mirrors.
- If your child has trouble seeing and hearing, use toys that stimulate touch like soft and fluffy fabrics, cool smooth stones, rough safe items like loofahs etc.
- When doing the exercises suggested below, make sure you praise your child if they try to roll/reach/sit. Keep praising them with every little effort and improvement they make.
ACTIVITY
Encourage caregivers to practice getting their child to look at them and follow them with their eyes, using the ideas discussed above.

DEVELOPING A STRONG NECK AND HEAD

ASK
How do you think you can help your child learn to control their head movements and hold their head well? What things have you tried at home?

MATERIALS Pictures 5.02, 3.04 and 3.07

FACILITATOR TIP
As we talked about in the positioning module, getting children sitting with support or lying on their tummy is really important for developing their strength and movement skills. Have the pictures of supported sitting, lying on tummy out in this session as reminders.

EXPLAIN AND DEMONSTRATE
It is good to lie your child on their tummy several times every day. Get down on the floor with them so they can see you and encourage them to look up at you.

- If your child tends to push herself backwards, try to encourage her to look down when on her tummy to help change the habit of pushing backwards.
- Place a toy on the floor in front of your child so she can look at it or try and reach for it. A toy that won’t roll away or a mirror is useful in this position.
- Move a toy slowly in front of her, side to side and up and down or in a circle, to encourage her to follow you (or the toy) with her eyes and head, developing her control.
- Support your child in a sitting position by holding her around her hips/middle to help her develop strength in her neck and head.
- When practising sitting, place your child somewhere where she can see other people to give her interesting things to look at, to encourage her to hold her head up and look around.
ACTIVITY
Encourage caregivers to practice with their child the positions and exercises discussed above.

SUPPORTING YOUR CHILD TO LEARN TO SIT

ASK
How do you think you can help your child to learn to sit? What things have you tried at home?

MATERIALS
Picture 5.03 and Pictures 3.06 & 3.07

EXPLAIN AND DEMONSTRATE
• Use supported sitting suggested in the positioning module.
  • Interact and engage with your child in these positions. Sing and play.
  • Over time, reduce the support offered to your child. Remember to stay close and make sure your child does not lose balance and fall.
  • Always offer the least amount of help possible. Once she can stop herself falling forward, make her environment safe by placing cushions or rolled up blankets around her and allow her to sit independently.
  • **Have your hands lower down on your child’s back as they need less support; the higher your hands the more support you are giving and the less work they are doing, so as they get stronger lower the position of your hands.**

Hands high on child’s back – high level of support
Hands low on child’s back – lower level of support
Child sitting more independently
ACTIVITY
Encourage caregivers to practise ways to help their child learn to sit.

SUPPORTING YOUR CHILD TO REACH AND HOLD ITEMS

ASK
*How do you think you can help your child learn to reach and hold things?*
*What things have you tried at home?*

MATERIALS
Picture 5.07

EXPLAIN AND DEMONSTRATE

- Reaching for things when lying on your back means your body has to work against gravity and is very hard, so work on reaching in side-lying and supported sitting instead.

- Start in a very supported sitting position, so your child feels confident and balanced to reach forward. If your child doesn’t feel safe and comfortable then she’s unlikely to try and reach out. If she cannot hold her head well then do this in side-lying with her arms forward and hands together in front of her.

- Get your child’s attention; use a toy/object that is brightly coloured and that your child likes. Hold it close to your child and encourage her to look at it first and then reach for it.
• It is easier to reach for objects and toys when they are put down low in front of your child.

• If your child doesn’t reach out, you can help guide her arm, from the elbow, towards the object.

• If your child can reach towards the object but can’t open her hand to grasp it, help her by gently opening her hand when it reaches the item and help her to hold it.

These 2 actions also help stretch your child’s arms and hands if they are stiff.

• It is easier to reach for objects and toys when they are put down low in front of your child.

• If your child doesn’t reach out, you can help guide her arm, from the elbow, towards the object.

• If your child can reach towards the object but can’t open her hand to grasp it, help her by gently opening her hand when it reaches the item and help her to hold it.

These 2 actions also help stretch your child’s arms and hands if they are stiff.

• Once she has an object in her hand let her explore it, shake it, move it to her mouth. If she cannot do these actions herself you can help by gently guiding her hand.

• For holding toys, think about the size and shape of the toy/ item to make sure they can fit easily into small hands.

ASK

*What things at home do you have that would be easy and safe for your child to hold?*

Noisy, shiny or bright objects or foods can be good to motivate a child to try and reach out.

ACTIVITY

Encourage caregivers to practice getting their child try to reach and hold using the ideas shared above.

SUPPORTING YOUR CHILD TO LEARN TO ROLL

MATERIALS Picture 5.04

ASK

*How do you think you can help your child to learn to roll? What things have you tried at home?*
EXPLAIN AND DEMONSTRATE

• Start with side lying and get your child’s attention with a toy. Move the toy in the direction needed for her to roll onto her back. As she follows with her eyes and head, her body will start to follow. If needed you can encourage her gently by bending the top leg at hip and knee, and gently twisting the hips, to get her to roll back.

• Then try laying your child on their stomach. Pull the arm forward on the side you want her to roll towards, then do as above, encourage her to follow a toy with her eyes and head. Assist the hip if you need to.

• Keep repeating this exercise, using less and less support as your child’s body gets more used to the movement.

• If your child is very stiff then it may be hard for her to learn to roll and she may not learn until she is older. Keep practising rolling but also make sure you are practicing the other skills too.

ACTIVITY
Encourage caregivers to practice rolling with their child.

MAKING YOUR CHILD’S BODY STRONGER

MATERIALS Pictures 5.05 and 5.06

EXPLAIN AND DEMONSTRATE

Even if your child can’t crawl or stand on their own, helping her carry her own weight through her arms or legs by supporting her in these positions, helps to make your child’s bones stronger, reduces stiffness and increases strength in a floppy child.
**Good ways to start weight bearing are:**

- Lying on the stomach using her arms, elbows or hands to hold herself up.
- Kneeling – hold your child in position.
- Crawling position – You can place your child in this position over your legs or over a rolled up blanket to start with.
- Safe standing practice.

**Supported standing is important:**

- To strengthen the legs.
- To protect the hips from damage.
- For children who have chest infections or trouble breathing (being upright helps).
- For assisting the emptying of the bladder and bowels (useful if your child is often constipated).
- It also offers your child a different view of the world and helps her to be more involved with family activities and communications.

**How to practice standing with your child:**

- Standing on your knee while you hold her body (good for smaller children).
- Standing in between your legs while you are seated, use one leg to support her legs and hips and the other to support her bottom.
- Leaning your child against your legs either while you are standing or when you are sitting. (This position and the following one need the child to be more stable in standing than the first 2 positions.)
- Leaning your child against a stable object – a bed or armchair. Make sure you stay next to them so they don’t fall.
- Using a standing frame (these are good as your child gets bigger, ask the local hospital if they make them).
- Make sure your child’s back and legs are straight and her hips are facing forward when they are standing.
- In all these positions make sure your child’s feet and hands are flat on the floor and not turning inwards or curled up/ fisted.
ACTIVITY
Encourage everyone to practice the positions above with their child.

STRETCHING

EXPLAIN
For children whose muscles are stiff, stretching can help to increase movement and reduce stiffness, making it easier for you to handle and care for your child. There are two ways to help stretch your child’s muscles:

1) **Good positioning is essential to stretch stiff muscles** and keep them stretched for longer periods of time. The positions discussed in the positioning module are good examples. If your child tends to “curl/ bend” themselves up then lying on the tummy and standing are good stretches.

2) **Using opportunities during the daily routine**
For example;

- Playing with your child, encouraging her to move will help her to stretch her muscles.
- Helping your child reach for toys (guiding her hand out or up towards a toy).
- Helping your child open her hand to hold a toy.
- When changing/ bathing your child, bend her legs up to the chest and gently move them side to side to rock the hips and then open the knees out (like a frog) and bend her knees up towards their chest and then straighten the legs, one leg at a time
- Make sure you are gentle and slow with your stretches otherwise you may hurt your child. **Do not force the joints to move, watch and listen for signs your child is in pain and reduce your effort.**

A physiotherapist is the best person to speak to about this, so please visit your physiotherapist to get a programme that is designed for your child.

FACILITATOR TIP

Demonstrate the stretches above on one of the children in the group. Alternatively, if any of the caregivers have been accessing physiotherapy and have been shown how to do stretches, get them to demonstrate what they have been shown on their child.

ASK

*Where/ who provides advice and treatment to children with disabilities in the local area? Are there any physiotherapists/ occupational therapists in the local area? Can they provide specialist exercises to help your child’s development?*
MONITORING PROGRESS

Ask each group member to demonstrate one thing they have learnt today that they will try at home and share with other family members.

MATERIALS Pictures 5.01

Give handout with black and white images for positions to make your child’s body stronger at home.

TAKE HOME MESSAGES:

• Children with cerebral palsy do learn and develop but they need extra time and support.
• You can help your child develop by spending time each day playing and practising the skills they need to learn (head control, sitting, rolling etc).
• The more you practice skills with your child the more likely they are to learn.

The caregivers in Uganda said that the things they learnt in this module resulted in changes and improvements in their child's development.

"I didn’t know that my child can improve. My brother came to see me and told me….do not waste time on this child. I had given up and was beating her. I was putting the blame on the medical people who delivered my wife. I was not expecting more to this child and I had given up. But now from what I have learnt I am going to put in more effort. I will take my child wherever you are telling me and do what is needed for this child. Parent, Uganda

My child is now turning which she couldn’t do before. Parent, Uganda

I am noticing that my child is now responding more to me as I am playing with him. Parent, Uganda"
**Module 6**
**COMMUNICATING**

**MATERIALS** Doll, toys (including toys that make a noise e.g. rattles or plastic water bottles with stones/dried beans), display material 6.01 and 6.02

**0-2 YEARS**

Developing skills in communication starts in the very earliest weeks and months after birth. Early communication skills, such as eye contact, copying and turn-taking, do not involve speech (called ‘non-verbal communication’) and are therefore the focus of this module. Promoting early communication skills can also have positive impacts on child-caregiver bonding and supports caregivers in being responsive to their child’s needs.

**ICEBREAKER**

For this activity, the caregivers are separated into two groups.

- **Group A** will be taught new foreign words using pictures and signs.
- **Group B** will be taught new foreign words only through speech.

1. Position Group B so that they cannot see the facilitator, either facing away from them or lying on their tummy’s. Tell both groups that they are going to learn some words from a foreign language (Danish).
2. Tell Group B they will not see the facilitator, but they should try to guess what the words mean.
3. The facilitator says the Danish words and teaches Group A the words, using the gestures and/or facial expressions below, (while Group B listens).

   - “Sove” = “Sleep”  
     (gesture: hands at side of inclined head, eyes closed)
   - “Sur” = “Angry”  
     (angry facial expression)
   - “Sulten” = “Hungry”  
     (facial expression + gesture: rubbing tummy)
   - “Jeg” = “I”  
     (gesture: point to self)
   - “Du” = “You “  
     (gesture: point to someone else)

4. Now rearrange groups so everyone can see

   Which group understood more of the words learnt? And why?

The aim of this activity is to raise awareness about the need for inclusion and engagement to promote communication and learning.
EXPLAIN
Outcomes for the module (on a flipchart if using). As a caregiver, you will:
1. Understand what communication is and why it is so important
2. What you and your family can do to help your child to communicate

ACTIVITY
Ask the group: What do you think communication is and what does it involve? This discussion should include listening to others, understanding what they are saying, telling others what you think, want or feel.

Communication means understanding what others say to us and expressing our thoughts, needs and feelings to them. Communication is a 2-way process and a basic human right.

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 and gestures (non-verbal communication). 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, turning themselves towards or away from someone or something
• **Gestures:** waving goodbye
• **Pointing:** using eyes or a finger try to roll/ reach/ sit. Keep praising them with every little effort and improvement they make.

ASK
Why do we communicate? Why is communication important to young children?

DISCUSS the following reasons:
For young children communication is an important part of:
• **Bonding with care givers**
• **Expressing our needs and wants**
• Establishing **relationships and making friends**
• **Learning new things**, which is very important in early stages of development
EXPLAIN

When communicating with a child with cerebral palsy, the cycle of successful expression and understanding between the two of you often breaks down. Use display material 6.01 to illustrate the cycle of communication.

Display material 6.01

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, get the caregivers to point out the different parts of the body which are used in communication, and EXPLAIN the following:

To UNDERSTAND a message, you need:

- Ears to hear  and eyes to 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 (including tongue), voice, and breathing, to speak
• Control of your head and body parts to point, make gestures, and make eye contact

ASK

Which of these things might be difficult for a child with cerebral palsy?

In the discussion, they should see that some, or all of these things may be difficult, depending on the child.

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 (looking) and 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 are the most important things that you can do to help your child to develop communication skills?

Talk to your child

Even if your child cannot use speech to communicate, don’t stop speaking to him.

In Uganda, the caregivers often commented that they felt their child was disturbing them with the noises that they make. It is important to emphasise that these basic noises are the start of communication and should be responded to and encouraged.

ACTIVITY

The trainer illustrates the following three types of basic communication skills, through demonstrated play with one or two children in the group (or by watching short videos prepared by the facilitators). At the end of each demonstration you should talk caregivers through the key concepts below.

1. How to encourage your child to make eye contact

- Hold your face close to your child’s face and talk to him. Try to encourage him to look at you.
- Call her name; when he looks at you, praise him by smiling and talking. Use lots of facial expression. Make sure you allow him time to look at you, it may take him a little while at first.
- Sing songs to him. He will enjoy the rhythm.
- Play Peek-a-Boo.
- Show him different objects. Shiny objects such as a DVD or tin foil will draw his attention. You can also use everyday objects with different textures or sounds. Let him play and explore objects. Talk to him about the different objects.
- Notice the things that your child looks at; if they look towards a person or an object, point to where they are looking and name it for them and show them that you can see what they are paying attention to.
2. How to encourage your child to take turns when communicating

• When he makes a noise, or uses facial expression, copy him, and then try taking turns.

3. How to encourage your child to make choices

• Give him a choice of things to play with or to eat.

• Show him the things he can choose from – place them in front of him where he can see them best. **Start by offering a choice between two things only**, then with time increase it to three or four choices.

• For example, hold one object in front of the child and name it. Then take it away and show them the other item and name it. Then take that one away. Now show the child both of the items and ask him 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. (Children point with their eyes (looking) before they learn to use their hands).** Give him 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’.

**ACTIVITY**

Encourage caregivers to practice the **three types of communication skills** you have just demonstrated. Allow them time to play and interact with their child.

**EXPLAIN Thinking ahead; other ways to communicate**

It is not possible to predict the future and no one knows how well your child will communicate when they are older. Children with cerebral palsy differ a lot in their abilities to understand and express themselves. Many children with cerebral palsy can speak, some less clearly than others. For some children, their speech is not clear enough to communicate and some have no speech at all. It is possible for many to learn how to communicate using other methods than speaking.
**Activity**

- In pairs; practice eye pointing at objects and or pictures held up by a partner, to make choices
- In pairs; practice using a simple communication board (see display material 6.02)

Discuss what they learnt from this activity. Cover the key points below:

- Gestures, pictures, photos and drawings can all be used to communicate.
- Children can point with parts of the body (a finger, a foot, an elbow). Some children point with their eyes by looking at objects or pictures.
- Research shows that teaching a child to use pictures or signs does not stop them from learning to speak if they are able.

*Display material 6.02*

This module aims to help caregivers became more aware of their child’s communication and the importance of communication following this module.

*My child has different voices when she is annoyed and when she is happy. She can understand my voice even though she can’t see me.* **Parent, Uganda**

*By looking into my child’s face (getting eye contact) and calling his name, we can communicate well.* **Parent, Uganda**
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.

Ask each caregiver to share one activity that she plans to try at home with her child. These can be reviewed on a community visit. Think back to session 2 where you looked at stepping stones to help your child learn:

• What have you learnt today that would help your child practice these?
• What are you going to do at home from today’s session to help your child’s development?

ASK

Where/ who provides advice and treatment to children with disabilities in the local area? Are there any physiotherapists/ occupational therapists in the local area? Can they provide specialist exercises to help your child’s development?

TAKE HOME MESSAGES:

• Children with cerebral palsy may need extra time and 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.
• Opportunities to practice communication skills are everywhere, for example practice eye contact while changing your child, practice making sounds and turn taking when bathing.
Module 7
PLAY

FACILITATOR TIP

Use this module to organise play activities for all the training sessions (see notes in Module 0 – Before You Begin). You might consider inviting siblings to this session.

If you have a child who has sensory impairments within your group, it can be useful to use these children in play demonstrations to show caregivers how to use the other senses, particularly touch, in play.

Making the toys with the parents is a fun activity. It does take time, and you may need to run a longer session to allow for this. You may want to invite other siblings to this session to encourage their understanding of the importance of play for their brother or sister.

Don’t forget to start collecting household objects and bits of recycling in advance. Also, ask each caregiver to bring some things to the session.

MATERIALS Display materials 7.01-7.02

Everyday objects (for example empty boxes, match boxes, plastic cold drink bottles and lids, brightly coloured material, clothes pegs, tin cans, plastic containers, stones, seeds, fabric, beans or rice, plastic cups), floppy doll, examples of home-made toys.

Check the Resources section at the end of this module to make low cost play equipment.

0-2 YEARS

In this module, we describe how play can ‘awaken the brain’ to promote a child’s development. The way children play changes as they grow and develop. In this module, we have focused on the types of play activities that are most suitable in the very early months and years for children with early cerebral palsy. Information on play for older children and those with more advanced development can be found in the Getting to Know Cerebral Palsy manual.

ICEBREAKER

Place some inexpensive everyday objects (e.g. cup, spoon, bottle tops, containers etc.) on the mat and ask the caregivers 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 Objectives for the module.

As a caregiver you will:

1. Understand and explain to other caregivers how play ‘awakens’ the brain (meaning that it’s important for the 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.

Play is often not valued as culturally important. In Uganda and Ghana, we found that children generally play without adult involvement. This is challenging for a young child with cerebral palsy, who may need support and encouragement to learn to play. Play may not come naturally as it does to other children and yet it is vital for the child’s development.

In Ghana, there was little improvement in the level of play activities after the training, and this highlighted the need to conduct more follow up in the home, and to involve other family members, especially siblings. Caregivers themselves, generally mothers, often had very limited time for playing, which is why it is so crucial to involve other family members.

ASK the participants:

What is play?

Use the resource below as a visual prompt to facilitate the discussion. If the caregivers struggle to answer the question then you could ask them to describe what is happening in the photos.

EXPLAIN

Explain that play is any activity that a child Chooses to do, and has Fun whilst doing it. Through play, a child uses her Senses to explore and learn.
**ASK** the participants:

*What are our senses?*

**EXPLAIN** what the senses are:

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

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

**ACTIVITY**

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 your 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)

**ASK**

*Why is play important for children?*

*Does a child with cerebral palsy need to play?*

**Cover the following key points in your discussions:**

- ‘**Play AWAKENS the brain**’ - 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 fun is what motivates children to move and learn.**
- Every child has a right to play.
The term that was used to best sum up the importance of play in Uganda, is that **PLAY AWAKENS THE BRAIN!**

A key recommendation from Bangladesh and Ghana is for a more practical session which encourages parents and siblings to make the toys and take them home. If you conduct home visits then encourage suitable play activities and adapting/using household objects to play with the child.

**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?*

**DISCUSS** in the group

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

- Almost anything can be used as a toy, if used in a fun and playful way. Favourite toys are most often household items (pan, wooden spoons, cups etc.).
- Children with cerebral palsy may need special help and attention from caregivers, or from other children. They may not play if just given a toy, so support them to play and interact with them.
- How you and other family interact with your child is a key part of play.
- Use the tips learnt in communication about turn taking and waiting for a response while playing with your child.
- Play is more important than toys.

*Play helps my child to be happy. It keeps the brain alert and helps him to learn things that he doesn’t know, like clapping his hands. You can be jolly and have fun together all the time.* **Parent, Uganda**

*I made this to help my child’s eyes see (toy with reflective surface) and a bottle with beans to help him hear.* **Parent, Uganda**
MAKING AND ADAPTING SUITABLE TOYS

MATERIALS Various suitable local materials.

Picture series 7.02: Pictures of different toys which can be made. See the resources section at the end of this module.

ACTIVITY Various suitable local materials.

Make toys!! Encourage the caregivers to use their imagination and use the materials provided to make a simple toy for their child.

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. See the Resources section for pictures of different toys which can be made.

When the toys are complete ask each parent to show the group their toy and explain why they made it and how it helps their child play and develop.

Allow them to take the toy home and encourage them to ask any siblings and other family members to use the toy – not just the caregiver.

ACTIVITY

Split the participants into small groups. Give each group a case study. Ask them to read through the information about the child, and discuss the questions.

The case studies should be printed on card, one case study per group. You can also make your own case studies from your local context, if more suitable.
CASE STUDY 1

Theo’s arms and legs are very stiff. His hands are always closed so it is difficult for him to hold things. He has poor eye sight but will respond and smile when spoken to.

Is this child in a good position for play? Which positions are good for play? What kinds of play activities could be encouraged? Who can help the child to play?

CASE STUDY 2

Samuel is 20 months old. He is unable to hold his head upright or to sit. He spends his days either tied to his mother’s back while she works in the shop or lying on a mat in the room at the back of the shop.

Mama finds it difficult to find the time to play with her son, as she is so busy with work and household chores.

Other family members do not talk or play with him, and when she takes him outside the neighbours talk badly about him, and will not let their children come near him.

What are the main challenges faced by this child? What challenges are faced by the mother? Do any of you have similar experiences? Are there any ways that you can encourage others to include your child in play? Do you have any experiences to share?
CASE STUDY 3

Bernadette is a very busy mother. She has 3 children and her husband has left her. As well as full time caring for her son, who has cerebral palsy, she is trying to work.

After attending the training course, she makes a toy for her son, and explains to the other siblings that “PLAY awakens the brain”.

She explains clearly to her other children how to use different toys: “I made this bottle with beans inside, to help him hear.” (Uganda).

What do you understand when Bernadette says that “Play awakens the brain”. How can you explain this to other people in your family? How much time do you have to play with your child? How can you involve others in your family?

EXPLAIN

In the discussion, ensure the key points below are covered:

Case study 1: 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 e.g. using touch for a child who has difficulty seeing and visual toys for a child who has difficulty hearing.
- However, still try to practice the sense through play by giving opportunities to use that sense e.g. shiny mobile for a child who has difficulty seeing or rattles for a child with difficulty hearing.

Case study 2: How can we all promote greater inclusion

- This case study brings up the issue of community stigma and discrimination – what ways could you and other members of your community begin to address that?
- Share what you learn from this training with family and neighbours, so that they can better understand and help your child.
- Take time to talk to siblings and other children and show them activities that your child can do and ways to play with them. Adapt toys, games and activities to allow children with disabilities to be included in play with other children.
- Set up your own parent support group to allow your child to spend time around other children. 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.
Case study 3: How do we build play into our busy lives

- Think about how to involve short periods of play in your daily activities with your child, e.g. at bath time or when dressing your child.
- It is important to involve other members of the family in playing with your child. Discuss the types of play, those that your child finds easy or difficult, and especially your child’s development needs.
- Siblings or other children can also help your child play. Instead of just saying: “Please play with my child,” be very specific. Tell her about one of the games we have discussed in this session. Show her how to play it with your child, and explain how and why it is important to your child’s development.

MONITORING PROGRESS

Ask each caregiver to share one activity that she plans to try at home with her child. These can be reviewed on a community visit.

Think back to module 2 where you looked at stepping stones to help your child learn:

- What have you learnt today that would help your child practice these?
- What are you going to do at home from today’s session to help your child’s development?
- 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?

MATERIALS

Give Picture 7.02 and Resources 7.04 as handouts

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.
EVERYDAY ACTIVITIES

MATERIALS Display materials 8.01-8.03
Basin, doll, wash cloth, toothbrush

0-2 YEARS
Children under two years of age are still very dependent on their carers for everyday activities and then move towards independence as they get older. In this module we have focused on how caregivers can support the development of their children during the everyday things they do with their young child like bathing and dressing.

ICEBREAKER
Ask if one of the caregivers has a song they like to sing with their child that they can share with the group. Encourage all the caregivers to take part and sing with their child.

ASK
How does the song help their child’s development? Include in the discussion the role that singing may play in developing communication, encouraging eye contact and promoting bonding between caregiver and child.

EXPLAIN Outcomes for the module
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 demonstrate this to others in your family or community.
3. Recap on learning from previous modules.

FACILITATOR TIP
Building ‘treatment’ for their child into everyday activities is essential for caregivers who have limited time for caring for their child. This module is about helping the caregivers identify how to help their child develop while doing the things they need to do. It’s about exploring solutions and suggesting practical ways to do ‘treatment’ in everyday activities, and considering who else in the family can help them such as siblings for play activities or grandmothers for feeding.
ACTIVITY

Look at the pictures in the Display Material 8.01. Ask the caregivers to work in pairs and choose one or two of the pictures to discuss using the following questions.

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 caregivers that they are the most important person for their child. Think about the time you spend every day with your child, doing everyday things with her.
With all the washing, feeding, dressing, giving medicines 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?
Do you find it hard to find time to do everything you need to?
Have you found ways to make time for your child’s development?
Are there other people who help you with your everyday activities?
Allow sufficient time in the group to discuss these feelings.
Worldwide, many parents of children with cerebral palsy talk about feeling tired, or not having enough time to care for their child, with mixed amounts of support from other family members.

Research has measured the impact on family life of caring for a child with a disability. Many caregivers, mainly mothers, are anxious, tired and stressed and find it difficult to communicate their concerns within the family. Stigmatising attitudes within the family can often blame the mother for having a child with disability, which may make it more difficult for a mum to engage with their family members (1).

**ACTIVITY**

Use the following pictures to promote discussion about how they can use everyday activities to maximise their child’s development.

What are the caregivers doing in the photos? How do they think it is helping the child’s development?

Bring up some of these issues in the discussion:

- Think about the position they leave their child in while they are busy, choose a position that maximises their development rather than simply leaving them on their back, for example, sitting their child in a basin or a corner safely nearby while they work rather than carrying them, this way their child can be developing strength in head and neck or practicing using their hands playing with a toy.

- Think about leaving toys in close reach of your child to encourage them to use their hands.

- The value of talking to their child while carrying them and working.
**EXPLAIN**

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 his 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. Either the facilitators or a few of the caregivers can act out the role play. 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?*

![Display Material 8.03](image-url)
In the feedback from the group, summarise the following main points, which were also covered in the module on communication (Module 6). The story/role play demonstrates how to communicate with your child in an everyday situation:

- Talking to your child about the things happening around him
- Showing him what you are talking about, and getting him 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? Watch for your child’s response, eye pointing, gestures or sounds.

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 their child:

- to sit by holding him in a helpful position (i.e. supported) while he moves his arm to reach up to him head.
- by encouraging him to balance while moving his 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 himself).

Using her Hands

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

Social and Emotional

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

Thinking and Playing

- Your child is playing and having fun while learning.
- The caregiver first performs the activity but involves their 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 himself.
Summary

• A helpful (comfortable, supported and stable) position:
  - Makes it easier for a child to be more involved with everyday activities.
  - Allows him to look around and watch what is happening in the room and communicate more easily with others.
  - Allows him to use his 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.

Now let’s think about your child’s day and how you can use each activity to help their development:

This will allow us to recap on some of the things we have covered in the group sessions over the last few weeks/months, as well as looking at some new ideas too.

In Uganda, we found that having this opportunity to recap and bring together all the information learnt during the sessions was valuable for the caregivers.

The caregivers were able to demonstrate what they had learnt, consolidate their learning, and reflect on HOW they can build this into everyday activities.

This session is a good time to ask if other family members would like to attend as it gives a good summary of the whole programme’s learning and allows caregivers an opportunity to share their learning with their family members.

1. CARRYING

ASK

Do you remember how we suggested that you carry your child from the positioning module? Can someone demonstrate how they carry their child?
EXPLAIN
Give the caregivers feedback if their demonstration was correct, if not get the group to help correct the positioning.

Review the information in the positioning module.

ASK
Why is this a better carrying position for your child’s development than carrying them on your back?

EXPLAIN
Explain that these positions allow your child to practise using their head and neck muscles more than carrying on the back. We know it can be practical to carry your child on your back but make sure you also carry them in the other positions to help their development.

2. FEEDING

ASK
What position do you to feed your child in? And why?
Get the caregivers to demonstrate the positions that they are using.

EXPLAIN
Give the caregivers feedback if their demonstration was correct, if not get the group to help correct the positioning.
A child should be seated when they are fed solid foods. Their head, neck and body should be upright and straight, so that the food can go down to the stomach easily. If a child is fed lying down, or with their head falling back, food can get stuck at the...
A child needs food to build their growing body, such as beans, fish and milk. They need food that gives them energy like potatoes and oil. They also need foods that help protect them such as fruit and vegetables. You may not be able to give them all three types of food every day, but it is important to remember to add some of each as much as possible.

### 3. FACE CLEANING

**EXPLAIN AND DEMONSTRATE**

- 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 so 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.

**ACTIVITY**

Ask a caregiver to volunteer to demonstrate in front of the rest of the class. Ask for input from other parents. Then ask caregivers to work in pairs and practise with each other.

### 4. BRUSHING TEETH

**ASK**

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

That a child with cerebral palsy is very much at risk of developing problems with his 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.
- A 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 start cleaning your child’s mouth even before they have teeth, once they are eating/drinking more than milk.
- 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.

We found that caregivers in Uganda were not doing any cleaning of their child’s mouth until they had many teeth, and in Ghana they were not brushing their teeth even when there were teeth!

We found in Bangladesh that poor hygiene, and constant drooling, meant that children may be more likely to develop sores around the mouth, so it’s important to develop good practices early.

EXPLAIN

Some top tips for teeth cleaning:

- Use clean and safe water for teeth brushing (cooled boiled water).
- Make sure that you and your child are in a good position before starting. Pay special attention to the position of his head and neck.
- Rinsing can be very difficult. You may have to bring his body forward so that the water can run 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.
5. MANAGING THICK SALIVA

Children with cerebral palsy may find swallowing saliva difficult. It can pool at the back of the throat and cause noisy obstructed breathing. Keeping a child in side lying can help drain the saliva out of the mouth, so it does not get stuck at the back of the throat.

If the saliva does get stuck and you can hear the saliva ‘bubbling’ at the back of the throat, you can use a clean piece of cotton or gauze rolled up, slide it along the inside of the cheek and gently twist it around. This can help bring out the saliva. Never push the end of the cloth or finger out of sight.

6. UNDRESSING AND DRESSING

ASK

How can you use dressing and undressing to help your child develop their skills?

EXPLAIN

Conduct a simple role play/demonstration using a doll or ask a parent to volunteer with their child.

- Find a safe position to place your child in when he is being undressed or dressed.
- Encourage your child to look at you, by calling their name and playing with them. Help develop their eye contact and head control.
- Talk softly about what is happening. This helps your child to anticipate what is coming next as he is being dressed, for example, by asking him “Where is your arm?” “Where is your vest?” Help develop their communication skills.
- Pause for your child to look at his arm or move it up. Help them learn to reach out and use their hands.
- You can use some supported standing in dressing too, to help make your child’s body strong.
- Smile and praise the behaviour.
- Encourage your child to get involved in dressing and undressing with you.

7. TOILETING

ASK

What is a good age to start to toilet train your child?
8. SLEEPING AND RESTING

**ASK**

*How do you position your child when they sleep?*

**EXPLAIN**

- Create a safe sleeping place (a cot/bed) where your child is at no risk of falling out or being injured.
- If your child is unable to move and usually lies in one position, position him or her into different positions from time to time, using cushions and rolled up towels to support your child to lie with the knees and hips bent. This encourages them to be less stiff.

9. GOING OUTSIDE

Caregivers in Uganda reported that they felt this section on going outside with their child was really valuable and reported getting out more with their child after this session. A supportive discussion on how to deal with stigma is a key.
Scovia & Bridget

Scovia is a woman, aged 28 years, with a child who was “born tired” (birth asphyxia).

Her daughter, Bridget, has poor neck control and she couldn’t sit or hear very well, even at 6 months.

Scovia didn’t take her outside, because there were many questions from people who used to come to her home to visit her. She found this very stressful.

How she overcame this was through a neighbour:

“He was an old man and he counselled me so that I started putting my child outside my house. But still people would come and stare at her – and this old man would talk to them about the child’s condition.”

Whenever they woke up, this old man would call Scovia to bring her child outside and told her to move with Bridget whenever she needed to go somewhere. Bridget can now sit, stand, walk and she is able to go to school.

CASE STUDY

**Scovia & Bridget**

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Whenever they woke up, this old man would call Scovia to bring her child outside and told her to move with Bridget whenever she needed to go somewhere. Bridget can now sit, stand, walk and she is able to go to school.

**“Walking with my child has helped to make him alert.”**

**ASK**

*Is it important that your child goes outside with you? Do you find it difficult taking your child out with you? Why? Do you experience any stigma or judgements when you go outside?*

**EXPLAIN**

It is important to try and take your child with you wherever you go, for example, to the fields, to the shops. Talk to your child about what is happening around them, and encourage other people to talk to your child.

“Walking with my child has helped to make him alert.”
ASK
the group what they think of the story of Scovia and Bridget. How does it compare to their own experience? Encourage the group to share their experiences.
Ask the other caregivers to make suggestions about how to cope with attitudes in the community or family. Emphasise some of the following points:
• Why it is important for the child to be taken out, as they would do with any other child?
• It is not their responsibility to do everything on their own! How can they involve other people – their own family/a neighbour/a church member- who can work with the local community to make it more inclusive of children with disabilities? Is there a disability ‘champion’ in their community?

MONITORING PROGRESS
Ask each caregiver to share one activity that she plans to try at home with her child. These can be reviewed on a community visit.
Think back to session 2 where you looked at stepping stones to help your child learn:
• What have you learnt today that would help your child practice these?
• What are you going to do at home from today’s session to help your child’s development?

MATERIALS

TAKE HOME MESSAGES:
• It is important to identify helpful positions for everyday activities.
• Every time you do something with your child, help him to be more involved in the activity, and communicate with him.
• 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.
TOGETHERNESS AND BELONGING

MATERIALS

Paper, pens, flipcharts, materials 9.1 – 9.16.

Make enough copies so that everyone can take 1-2 pictures home.

Video of James the Investor (7-minute film from Uganda, translated into English), or photo-story Materials 9.1 (a-f).

You are welcome to translate this film into your local language or find a suitable alternative that shows positive examples of inclusion. If you cannot show a film, use the ‘photo-story’.

• https://www.youtube.com/watch?time_continue=2&v=nZ2VlrqWzM

FACILITATOR TIP

• ‘Togetherness and Belonging’ is intended as a very flexible module. It can be included as part of the Ubuntu, Early Intervention and Juntos programmes, or used as a module on its own. There is no ‘one size fits all’ for addressing stigma and discrimination experienced by children with disabilities and their caregivers. There will be important differences across countries and contexts.
• There can also be differences between urban and rural settings, so you will need to tailor this module to your community.

• We provide a variety of stories that you can use. We strongly recommend that you add or replace with 1-2 examples from your own context. Be aware of safeguarding issues, so that you don’t put any child/caregiver at risk. We suggest you do not use real names and photos.

• We also encourage you to include some examples from other countries, as it is useful for people to understand that ‘they are not alone’ and that facing stigma and discrimination occurs everywhere.

• This module can be run in 3-4 hours but can also take much longer. In Burkina Faso they ran the session over 2 days!

• The main approaches we use are low cost. However, if you have additional resources, you might be able to do some of the suggested extras. E.g. making a participatory video.

• Although this module is focussed on caregivers, service providers will often have low levels of knowledge and awareness. We strongly recommend that some training is provided to service providers as part of a more comprehensive programme.

• This module may bring up some very sensitive discussions. We recommend that you ensure that you know what you will do if there are any concerns about the safety of a child or caregiver, which arise from the session. Refer to your own organisation’s guidelines on this, so that you know the best process for this.

‘Safeguarding’ means taking action and having policies to ensure that children and vulnerable adults are safe and to promote their wellbeing. Research shows that these children, and mothers, are commonly more vulnerable to abuse. As a team you will need to be clear about your own procedures.

An example is of a mother attending a parent support meeting with her young daughter Chipo. When she got home her husband was angry and refused to let her in the house because she had talked about Chipo and the social problems they were facing. The mother was very worried that he would take Chipo to the village and that she would be killed as her husband had not accepted Chipo’s condition, and believed that it was caused by evil spirits. The local organisation that was running the training immediately advised the mother to go to the Department of Social Affairs; they quickly convened a meeting with the father. He was ordered not to take Chipo out of the capital city where they lived, and the local organisation is now supporting BOTH the mother and the child and monitoring the situation closely.
REFLECTION ON CHANGING YOUR INDIVIDUAL BELIEFS

ICEBREAKER

Draw/create a line from one end of the room to the other. Explain that one end of the room is ‘Strongly Agree’, and the other end of the room is ‘Strongly Disagree’. Read the following statement and then ask everyone to move to a part of the line that reflects how they feel. Emphasise there is no right or wrong. Give everyone time to reflect, and then ask the group to put themselves somewhere on the line from Agree to Disagree.

“I have changed how I feel about being a caregiver of a child with a disability over time.”

Ask for 2-3 volunteers to explain what changes there have been and what brought about this change in their individual beliefs and feelings. “What do you think have been important ‘ingredients’ in making this change?”

Show the group material 0.1. Just like important ingredients are used to create a delicious meal, there are important ‘ingredients’ that can bring about change in people’s attitudes, beliefs and feelings. Draw a picture of a plate on a flipchart and add the ingredients as people speak about them.

ASK

“What ‘ingredients’ make a delicious ‘togetherness and belonging’ meal?”

Ensure the following points are emphasised:

1. Learning new information – this addresses myths and fears.
2. Making contact with other families/caregivers who have a disability.
3. Being more visible in your community.
4. Understanding that you and your children have rights, which include the right to be treated with dignity. BUT you, your family, and your community, also have a responsibility to help achieve those rights.

FACILITATOR TIP

Keep this picture of the plate on the wall throughout the session and as more ideas come up, add them to the picture. Encourage everyone to think about ingredients in togetherness and belonging more broadly in their community through the session.
FAMILY AND COMMUNITY INCLUSION

FACILITATOR TIP

• We are looking to transform society’s view of disability. We understand from learning from others that this can take a long time.
• Do not expect caregivers to be responsible for challenging stigma and discrimination on their own. Encourage ways to include ‘allies’ (friends, ‘disability champions’) who can help with this change. For example, encourage your group to think of people in their community who can help them ‘champion’ the rights of people with disabilities.
• Be as creative as possible, build on the strengths of your group, and your local community. You could involve art, local craft skills, drama, film, and music to deliver key messages within their community.

ACTIVITY 1

“James the Investor” video
Show the film, or pictures form the photo story around the group.
After watching ask the following questions and discuss in the whole group. As people describe things that helped a more inclusive experience, add the ideas to the meal on the flipchart.

This module is all about inclusion.
Inclusion is being a part of what everyone else is, being welcomed and embraced as someone who belongs. Inclusion means that everyone can use their own abilities as member of their community (www.kidstogether.org).
Inclusion is the process whereby every person who wishes to, can access and participate fully in all aspects of an activity or service in the same way as any other member of the community (CBM Barriers to Inclusion 2013).

ASK

“How does this relate to your experience in your community?”
Encourage everyone to talk about similarities and differences.
“What do you think helped James to be included?”
“Often mothers are the main caregivers and play an important role. In this case, we can see a father being involved. What can we learn from this?”
“What do you think of James? If you showed this film to people in your family or community, what do you think they will think of James?”
Explain that James in a great role model, and that we know that is important to
help change people opinions.

“What are the lessons we can learn about promoting a more inclusive school environment?”
Ask everyone to consider teachers, friends or peers, environment.

“Overall, what are the most important lessons we can learn for your situation from this film about promoting more ‘Togetherness and Belonging’ in your family and community, and school?”

**FACILITATOR TIP**

- In many cases caregivers may not feel that they have that power (yet!) to challenge views, and that this is a journey you are taking them on.
- Understand that through giving people education, you can provide them with better knowledge (we can call this ‘information for the head’).
- It is also important sometimes to make people feel differently (we can call this ‘information for the heart’).
- Contact, direct (e.g. encouraging positive interactions between the people in the community and people with disabilities) or indirect (e.g. through a film or radio), allows us to engage with others, and we know this can be an important way to break down myths and change social and cultural norms.

**ACTIVITY 2**

**Our stories**

Divide into 3 groups and provide each group with one set of stories (we sometimes call these case studies).

Each set contains at least:

- A story from families
- A story from the community
- A story from health and education services

- **Togetherness and belonging within the family.**
  - Example story: Steven

- **Togetherness and belonging at the community level.**
  - Example story: John

- **Togetherness and belonging in the health and education services.**
  - Example story: Blessing
ASK
Ask everyone to discuss in their small groups:

“What do you think of the story? Has something similar happened in your family/community? If so, do you want to share?”

“Are the child and parent being treated with respect and dignity? What helped improve the situation in stories that were positive?”

“What advice would you give to improve the situation in stories that were less positive? What other people could or should be involved?”

“Do you think this could work in your community?”

FACILITATOR TIP
Stay in groups of three for this activity to encourage everyone to voice their thoughts and discuss together in smaller groups. This can be less intimidating than discussing all together in a large group and gives an opportunity for those who are quieter to speak.
ACTIVITY 3

Role Play

In groups of three, ask everyone to choose one image (from the selection in the previous page) that they could take home and share with someone in the family. Conduct a short role play about what you would say to the family member.

One person acts as the caregiver, one person is the family member, and a third person is a friend and/or someone they would identify can help them with the discussion.

Here are some questions to think about in preparing your role play:

“What do you want to be able to say to some of your family members? Who could help you with this discussion? As the father or mother- in-law, what do you think about what you have been told?”

FACILITATOR TIP

Support the groups in the role play. These may bring up some difficult issues, so also encourage some humour and fun in the acting out the role play. We know that humour can play an important role in helping to talk about difficult issues.

ASK

“Who are the key ‘gatekeepers’ in your family and in your community?”

These are people who have influence; they can make obstacles but can also be people who can help you.

“Is there anyone in your family or community who can be a useful ally (friend who is a good champion for disability) and can help with some of these discussions?”

Some examples might include: a health worker, a teacher, a special needs teacher, the head of a local woman’s group, someone you can trust, someone who can help your group, someone who has power in your community, someone who is listened to.

Record some of these ideas on a flipchart – and come back to them when you make the Action Plan (at the end of this session).

What causes the negative attitudes that the other people have? What are the triggers to negative attitudes in your own context?

Discuss possible solutions to address this. If your group does not come up with some feasible ideas, here are some ideas from other groups around the world that have aimed to ‘transform’ views on disability. You can discuss how suitable these ideas would be in your context.

- Invite family/community members for a ‘Celebration day’ and/or a social activity with your group.
- Conduct some awareness raising with local traditional healers, including faith leaders.
• Plan a celebration for Father’s Day/International Day of the Child /special day in your community.
• Look at different ways of engaging with siblings, and fathers.
• Share educational resources with the family.
• Engage with local community radio to tell your stories.
• Link into traditional ceremonies in your community where you can promote more awareness raising. For example, families organising a coffee ceremony for community members in Ethiopia, or Durbar meetings (traditional community meetings) in Ghana.
• Reach out to a local DPO and find ways to work together. Often a united voice on promoting inclusion has more power. We can call this ‘advocacy’.
• There are a wide range of other resources on how to promote inclusion e.g. inclusion in education. This module is just a starting point.

INCLUSION IN SERVICES (EDUCATION, HEALTH AND SOCIAL)

FACILITATOR TIP

• This activity is called ‘hot seating’. The idea is that after a group acts out a short role play, they get advice and support from the rest of the group.
• Questions are asked to someone sitting in a chair - the ‘hot-seat’ - and then others can give advice, and ideas of what could be said or done differently to improve the situation.

ACTIVITY 4

‘Hot seating’ - Treating each other with dignity

In groups of 2 or 3, briefly reflect on past experiences when receiving health, rehabilitation or education services with your child or social services e.g. to get a disability card.

Ask one group to act out a short role play which reflects this experience.

Ask the person who acted as the health worker/teacher to sit in the ‘hot seat’ (they can sit on a chair or one a mat in the middle of the group) and to stay in their role.
Encourage the group to ask her questions about why she treated the caregiver in a certain way.

“What could she have done differently in order to treat the family with more dignity? Why did you talk to the mother like that?

What could you have done differently? How do you think the mother felt?”

Then ask the caregiver to take the ‘hot seat’ and ask the rest of the group to ask questions and give some ideas about what she could do or say differently, as well as ideas of who could help her.

“How did you feel when you we meeting the nurse? What would have helped you?”

From the discussion draw up a list of how children with disabilities and their caregivers should ideally be treated to improve their experience of inclusion, and ideas of what could be done to improve the inclusion in these contexts. These ideas could be added as ‘ingredients’ to the ‘meal’.

Possible ideas and solutions to include which have been drawn from other experiences:

• Ask another parent or friend to accompany you to a health or education service for the first time.

• Invite community health workers/teachers to a training and use ideas from this session.

• Involve local community health workers as soon as possible in planning care for your child.
GROUP ACTION PLAN

ASK

“What will your community look like when you are included and belong? What will it be like to live there?”

FACILITATOR TIP

Starting the action plan with this question will help the group to have a vision for change. Write down key words or draw picture on a flipchart. Refer back to the delicious ‘meal of inclusion’. Ask everyone to look at the ingredients of what is needed.

ASK

“What activities can you carry out as a group to improve the ‘togetherness and belonging’ of your children and their families?”

Discuss ideas and help to ensure that practical activities are suggested. “What is the most feasible action to start with and what is the one thing that you will plan to do for the next month?”

“What will help you to do this? Who are people who could help you? What materials (resources) will you need?”

Encourage the group to decide together about one action that they can work on together in the coming month. Put in a simple table, such as like the one in the next page.

<table>
<thead>
<tr>
<th>Activities that we can carry out as a group:</th>
<th>What will help us to do this – People who could help us? Any materials we need?</th>
<th>Who can be responsible for what?</th>
<th>Timings – When will we do this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Offer to speak on the radio</td>
<td></td>
<td>E.g. who would be happy to speak, who would be willing to go to the radio station?</td>
<td></td>
</tr>
<tr>
<td>Invite family/community members for a ‘Celebration day’ and/or a social activity with our group</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**ASK**

“What is one thing that you found useful from the session and how do you think that you can contribute to the action plan?”

**FACILITATOR TIP**

- Children with disabilities and their caregivers have rights.
- Families and community members have a responsibility to help them fulfil those rights, and to challenge stigma and discrimination.
- It is important to find ‘allies’ in the community and family to help facilitate change.
- It is important to provide people with information, but you also need to have contact with people e.g. take your child outside of the house, be willing to talk with others about your experience. Ask for other people’s help with this.

**SHARING EMOTIONS AND FEELINGS**

**ASK**

“How did you feel in this session about togetherness and belonging? How was it for you to talk about today’s subject?”

“What did it raise any emotions and feelings that you did or did not expect?”

“How have you felt this week? What did this week bring you?”

“What did anything change for you?”
OUR COMMUNITY

Important: This module can be discussed with caregivers first and then also used to raise awareness in the local community about disability.

MATERIALS

Flipchart paper, pens, copy of the diamond ranking activity (IT’S ABOUT ABILITY: An explanation of the Convention on the Rights of Persons with Disabilities) cut into sections, and information explaining national legislation on the rights of people with disabilities.

ICEBREAKER

Tell the following story (Have the drawing of a path and wall on the flipchart ready):

We are starting today with a story with a difference. The story has a beginning and an end, but no middle.

Your task is to fill in the middle of the story:

Imagine you are walking along a path in the countryside. Suddenly you reach a huge wall that blocks you continuing on your path. It’s hundreds of metres high and there is no away around it. The only item you have is a small hammer...

... at the end of the story, you have got past the wall. You carry on up the path that you were on, feeling happy about having beaten the obstacle that was in front of you and continue on your journey.

ASK

“What happened in the middle?”

Ask people to discuss ideas in groups of three, then share ideas with the group. Discuss the pros and cons of each solution (examples given below, but there are many more).

There is no right or wrong answer – encourage people to be creative (the more creative the better) about how they got past this obstacle.

Examples include:

You managed to get a lift over by a passing aeroplane (this is great for you but what happens to next person who comes along and still has a wall to overcome).

You hammer at the wall by yourself for months, eventually managing to make a hole in the wall that you can climb through.
A sudden storm breaks away part of the wall and you can climb over. You gather hundreds of people come to help knock down the wall.

You find the group who built the wall and request them to add a gate.

Today’s session is about our community and our rights. We are met with many walls in our life and getting past them, through them, around them or breaking them down is something we will need to face. It is easier to tackle obstacles together and are united, because together we are stronger. Lots of people working together on the wall will be quicker than one.

**EXPLAIN**

By the end of module 10, you will:

1. Understand about disability rights and be able to communicate this to others.
2. Understand your right to health and how to get the most out of your medical visits.
3. Understand more about future education for your child.
4. Have considered where you can go for services within your area and community.

If you are using this module in the community, you may just explain point 1 at the start of the session before moving on to the first activity.

**RIGHTS OF PEOPLE WITH DISABILITIES**

**ASK**

Image 10.01 (at the end of module). Cut out the rights on pieces of paper so that groups can receive the text to rank, flipchart paper with diamond drawn on it for each group.

“What do you understand by your own rights?”

**ACTIVITY 1**

In small groups of 3-4, ask everyone to carry out a Diamond ranking activity (see below, and in facilitator materials) with a selection of Rights taken from the UN Convention on the Rights of Persons with Disabilities. Put a selection of eight rights on pieces of card, and ask the groups to rank which rights they consider are most urgent/important for them in their lives at the moment.
**Equality and Non-Discrimination**

Everyone has the right to be protected by the law, and the laws of a country should apply to everyone who lives there.

**Women With Disabilities**

Women and girls with disabilities face more discrimination. Their human rights should be protected.

**Children With Disabilities**

Children with disabilities have the same rights as other children. Every child has the right to go to school, to play and be protected from violence.

**Awareness Raising**

Governments should educate everyone about the rights of people with disabilities, their achievements and skills. They will work against stereotypes, stigma and activities that might harm people with disabilities.

**Accessibility**

People with disabilities should be able to live independently and be included in their communities. Any public place must be accessible.

**Freedom from Violence and Abuse**

Children with disabilities should be protected from violence and abuse in the home and outside.

**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!

**Personal Mobility**

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

**Health and Rehabilitation**

People with disabilities have the right to the same health care as other people. If you have a disability, you also have the right to health and rehabilitation services.

**Adequate Standard of Living and Social Protection**

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

Ask each group to share their ranking and what they think the top 3 rights for them are and why. There is no ‘right or wrong’ answer 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 group. Explain that there is no ‘right or wrong’, all the rights are important, but some will be more important than others to individuals at different times (or something like that).

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) is a global law that protects the rights of people with disabilities. Many countries have signed this and pledged commitments to achieve what is laid out. It is broken down into articles that are designed to protect and ensure the rights of people with disabilities at all ages, such as education, health, personal mobility, accessibility.

FACILITATOR TIP

Ideally, if available, invite someone from a local Organisations for Persons with Disabilities (also known as OPD or DPO) to present this information, as they will also be able to detail opportunities for local level advocacy.

ASK

“Where can you go to get help to better understand your rights, or with accessing your rights e.g. your right to a disability grant?”

EXPLAIN

There may be many advocates on disability already working within your communities. Disabled People’s Organizations from many countries were a major driving force behind the creation of the CRPD and often hold the latest information about disability laws and right in your country.

Today we will focus more on two aspects of the UNCRPD: the right to health and the right to education.
FOCUS ON THE RIGHT TO HEALTH

ASK

“What health professionals have you seen in relation to your child’s condition? Can you tell us what their roles are?”

List the professionals on the flipchart paper.

“What is your experience of going to see healthcare professionals? Can you list some good/bad points?”

FACILITATOR TIP

This section aims to bring a discussion on how meetings with healthcare professionals can be better. It is EXTREMELY important that you acknowledge that the responsibility does not lie with the caregivers. Much of the time it can be attitudes or time limitations or lack of knowledge on the part of the healthcare provider that can cause a health visit to not go as planned.

There needs to be more training for healthcare workers. Referral services and follow up to health services also needs to be strengthened. While this is outside the scope of this session, it could be something else that the group plan to do at a later stage, recognising its importance.

These sessions are about how families can be more empowered to support their child and this section discusses ways that they may be able to get more from their interactions with healthcare workers.

EXPLAIN

Good communication is key to ensuring safe and appropriate care for your child. This is everyone’s responsibility. Although communication between multiple health workers can be challenging, it can be helpful to think about strategies that can be used to help things go more smoothly.

ACTIVITY 2

In groups of three:

“What communication challenges have you experienced in seeking health care for your child? What approaches did you use to deal with these challenges?

What did you learn? What strategies might help with this in the future?”

Practical tips may include:

- **Learn as much as possible** about your child’s health, how it affects your child, local support and health services.
- **Think about your questions** between visits, prioritise and take them with you to health visits.
- You or your family can take a video of your child to show the health care worker what she is like at home.
Ask for:

- Things to be explained in words you understand.
- Information to be repeated when you need it.
- More information or a second opinion if needed.
- **Remember that you are an expert** about your child and an important member of your child’s care team.
- **Take a support person** to appointments if you can.
- Think in advance about **what support you will need to get to health facilities** in an emergency (e.g. transport, care for other children). Ask your health worker about any available support for this.
- **Ask health workers to write down information or changes in care plans for your child.** If you have a written record of major changes in treatment, this can help with communication between health workers in different places and at different times. Consider simple strategies, like keeping a communication book, to help with this.

**ACTIVITY 3**

**Role play**

Ask if 2-3 people will volunteer to present a short role play to the rest of the group about how to discuss your concerns about your child’s health and development with a Doctor or how you can register for a disability card if used in your country. Follow with a question and answer session to clarify the processes.

This time of sharing is important for everyone to discuss their difficulties, and as a group talk about what has worked well and share experiences so that we can all learn together.

**FACILITATOR TIP**

If the session is going well, you may want to discuss: Developing a written care plan, especially for emergencies.

Every time you see a health worker, you will need to communicate information about your child’s health and developmental needs. This can be challenging especially when the health worker has not met you or your child before, when your child is unwell or the visit is rushed. Ask your child’s main health worker if you can get support to write a summary of your child’s health needs and plans, especially for emergencies. This might include the information such as:

- Your child’s name, date of birth and address.
- Next of kin/emergency family contacts.
- Emergency health contacts: usual doctors/specialists/other health workers.
- Major health problems and how these can present in an emergency (e.g. what seizures look like in your child, choking, chest infections, feeding difficulties).
FOCUS ON THE RIGHT TO EDUCATION

ASK

“When children have a disability, can they go to school? What sort of school might they go to?”

“What types of support do you think schools and teachers in your area might need to allow children with disabilities to go to school? How can they best get this? What might your role and that of your family be to support this?”

Allow time for discussion and raise key points:

• Children with disabilities have just as much right to go to school and have an education as children without disabilities.

• It is good, if possible, for children with disabilities to go to their local school. This allows them to remain part of their local community.

• To enable this, inclusive education needs to take place where schools and teachers are supported to be able to provide education to children with and without disabilities.

Much of what this programme has focused on has been the individual steps.

SHARING COMMUNITY BARRIERS

ACTIVITY 4

Get into groups of three: list some of the main challenges faced in your community. Consider the challenge at different levels.

Prompt everyone to not only think about physical barriers but also attitudinal and institutional/service barriers:

• Within families and extended families.

• Within communities (e.g. school, health services).

• At district level and across the country.
ASK
Ask one person per group to share. As the group feedback, note barriers down on a flipchart paper.

ACTIVITY 5
Link this activity back to the story of the wall. Ask everyone to call out some of their main barriers – these are the ‘bricks’ of the wall. As you talk about each ‘brick’, you can break the wall down.

Attitudinal barriers may include:
- Attitudes from your family.
- Attitudes from people that you do not know.
- Your (caregivers’) own attitudes and fears about taking your child out.

Physical barriers may include:
- Steep hills or steps to get into and out of house.
- Inaccessible roads and 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.

Institutional/service barriers:
- Difficulty in getting a disability identity card or a disability allowance.
- Teachers have not had training on how to support children with disabilities.
- Lack of adequate health and rehabilitation services.
- Going to a local health clinic for a routine issue only to be sent to a specialist hospital.

MAPPING OUR COMMUNITIES

ACTIVITY 6
In small groups, ask everyone to draw a map of their community, showing the important services and people. Draw where your home is also.

Services might include; health and social services, NGOs, mosques, churches, and schools.

Display the maps, and ask everyone to explain theirs.

ASK
“What makes it difficult to access any of the services?”
“How could you make it easier?”
FINDING COMMUNITY SOLUTIONS

ACTIVITY 7

Go back to your groups of 3.

Look at each others’ barriers to inclusion and discuss possible ways to address these. Each group should select their favourite solution and act this situation out as a role play back to the others.

Examples:

If transport is a 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).

In Bangladesh, a “community mapping” exercise was done in one of the first sessions. This helped to find local projects that might be helpful. For example, many children were underweight, so it was helpful to connect families to the local nutrition programme.

FACTORS TO CONSIDER

- Identifying key members of the community is important to help support your child.
- Together we can help find solutions to the challenges experienced by children with disabilities and their families.

MONITORING PROGRESS

ASK

Ask everyone to explain one thing they found useful from the session.

“How can you share the lessons that you have learned in this group with your community? Can you work as a group? Who else can work with you and help you? E.g. through community radio, social media, engagement with local faith-based organisations.”
SHARING EMOTIONS AND FEELINGS

ASK

“How did this session feel? Did it raise any emotions or feelings that you did not expect? How have you been feeling this week?”

END OF SESSION

The rest of the session is a ‘social event’ for the invited members of the participants. Introduce them to the programme and show the image 1.01 as an overview.

ASK

Ask everyone to introduce themselves.

You could start with an ice-breaker such as the ‘game of life’ outlined below.

Explain what everyone has been learning and that today’s session has been about how the community can support families of children with developmental disabilities.

Ask one or two participants to explain what they have enjoyed/learned from coming. Encourage the community members to ask questions to the caregivers or the facilitators.

Another game to play in the community session is the ‘game of life’ (see next page).
1. Ask for four volunteers from among the group (ideally, two men and two women), willing to stand for about 30 minutes to act as: • 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, from birth to old age. Ask everyone to respond to significant life events as they think their character 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 less positive experience;
   • Two steps back for a negative experience.

   Their response should be based in what they think would happen now, not what they think should happen. Allow time for discussion after each response.

3. Set the scene for the story in a typical rural village.

   “One day, after a 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 20. You’d like to get married, or form a relationship. How much do you think this will be possible for you?”

   “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 told to by the group and ask why. They may say most disabled women cannot have children – a common myth.

   Disabled women also often don’t have children because society thinks they can’t or shouldn’t.

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

   Ask everyone:
   • “Who is in the best position now? Who is in the worst?”
   • “Volunteers, how does this make you feel?”
   • “Does this surprise anyone?”
   • “Was this a helpful tool for learning how disability affects people’s chances of living in poverty?”
   • “The non-disabled man at the front is seen as living in poverty – what does this suggest for disabled people?”

   Ask:
   • “Who benefits from your development programmes at the moment?”
Module 11
NEXT STEPS

MATERIALS
Flip charts, pens. Personal posters 1.06, session overview 1.01

EXPLAIN
This is the last session that we have together. For some of you it might feel quite sad to be finishing and for others you might feel relieved to be done! Reflect on the changes that have occurred over the course, and how it has impacted you, your family and your child. Today we have an opportunity for us all to think about what we have learnt and for you to ask any questions that you have. We are here to help clarify anything you are not sure about.

First of all, congratulate the caregivers on their commitment to coming to the sessions and thank them for caring for their children. Everyone is doing really well and we can see improvements. Every child develops at their own rate and that is ok, but we can see changes and improvements with all the children in the group.

Remind the caregivers to continue to work with their child to help them develop and learn. We know some caregivers get tired and the effort it takes to help their child learn but we know that this work gives results, so encourage the caregivers to keep going as both them and their children are doing well.

ICEBREAKER
Show the session overview 1.01 to the group. Ask everyone to tell you their favourite moment over the course of the programme. Allow time for sharing of stories. Facilitators should also share their favourite moments.

EXPLAIN Outcomes for the module
As a caregiver you will:

- Answer any questions that caregivers have about their children
- Review parts of the course that have been difficult and offer extra support in these areas
- Learn about local resources and organisations that maybe useful, and how you can connect with these.
- Understand some benefits of networking with other caregivers and parent groups.
- Discuss good practice for running and organising your own parent groups sessions.
MONITORING AND EVALUATING PROGRESS

Activity Most Significant Change stories:

Work in groups of four or five. Looking back over the last 10 weeks, what do you think was the most significant change that you or your family have experienced because of our time together?

Each person tells one story of the Most Significant Change as a result of the training.

Ask each group to select one story that they regard as most significant to share with the whole group. Ask the group to give the reason that they chose this story, this is just as important as the story. Out of the selected stories, the whole group selects one most significant story of change.

Ask everyone to consider “Most Significant Changes” at different levels: a) for themselves as parents/mothers/caregivers, b) for their children, and c) within the family/ community.

ASK

What things have you found most helpful about the course? Ask the caregiver to demonstrate things which she finds helpful.

Example: ‘I have found learning new ways to communicate with my child useful such as making eye contact with him and talking to him’. Ask the caregiver to show the rest of the group how she does this.

ASK

What things have you found more difficult to do? Try to understand the difficulties the caregiver is having and demonstrate to the group how to address the problem.

Example: I find it difficult to teach my child how to sit up. The facilitator should ask the group to show the different ways in which we can help our child learn to sit. The facilitator should refer back to the relevant section of the manual to ensure all points are covered.

Example: ‘I find it difficult to take my child with me when I go to work.’ Ask for suggestions from the group about how these problems can be tackled.

Allow time to practice and go over the things that are difficult.

Offer caregivers time at the end to discuss their difficulties in private as some caregivers may not wish to discuss in front of the whole group.
WHERE TO GO FOR FURTHER HELP

ACTIVITY

Community mapping: In small groups ask caregivers, 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, services that provide advice and advocacy as well as mosques, churches, and schools. Ask parents to mark their own homes, as well as the services which they access.

During the discussion 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.

THE FUTURE...

ASK

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 you 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 this.

PRACTICALITIES OF RUNNING PARENT SUPPORT GROUPS

ASK

Ask everyone 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:

What makes a good group? 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 and 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? What makes a good group leader? How would new people find out about a group?
Suggest to caregivers that they might like to swap contact details with other caregivers in the group so they can continue to meet and support each other and remind each other of what they have learnt.

If the group is in agreement, maybe set a time and date for the group to meet again soon.

**Finish with congratulating the caregivers on all their hard work and encouraging them to continue at home.**

"Ugandan comments from this session on the value of attending the groups:

The caregivers spoke of how they felt confused before the group and had lost hope but being part of the group had helped them learn and their children had improved. The caregivers said that they had realised that their children were not a shame and they were not to blame; this increased the time and effort they made with their children.

*We didn’t feel happy because our children were not well but we have hope since we started with you, you have encouraged us.*

*I am proud of my child now, she is improving and I have hope.*

*I have learnt to show love to my child. I didn’t know that and I was hating the child. But now I have learnt about loving your child and I feel better.*

*Had it not been for this group I would have gone mad or abandoned this child when the father left me. But this group has encouraged me.*

*She was floppy but since coming to the group, she is growing more firm. Even I thought she was bewitched but I was taught and now I know what happened. I went home and explained to my husband and now hope is growing.*

*I didn’t know my child could improve. My brother told me I had produced a stupid child and not to waste time on him. I had given up and was beating the child. I was putting blame on the doctors who delivered the child. But from what I have learnt I am going to put more effort in and do what is needed for this child. **Father, Uganda***
THE FUNDERS:

WITH THANKS TO: