Ubuntu

FACILITATOR MANUAL

Working together with families of children with developmental disabilities

Welcome to the Ubuntu manual, the second edition of Getting to Know Cerebral Palsy.

We have updated the original GTKCP manual to include useful information for caregivers of children with a range of developmental disabilities, including down syndrome, congenital zika syndrome, microcephaly, and cerebral palsy.

The content has been developed in partnership with a number of organisations and individuals, acknowledged over the coming pages, whose contribution we are incredibly grateful for.

London School of Hygiene & Tropical Medicine (LSHTM)

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

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Material Design

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BEFORE WE BEGIN

0

This module covers the following information:

Chapter 1: About the programme

How the programme works

Who the facilitators are

Our approach

Chapter 2: Running a session

How to follow the manual

Preparing to run a session

Identifying issues and referring

Top tips and common mistakes

Monitoring and evaluation

Chapter 3: Home visits

Guidelines

1. ABOUT THE PROGRAMME

1.1 Aim:

To help families and caregivers of children with developmental disabilities to understand their child and to build support networks that will improve the care and inclusion that their child receives in their local community.

Key objectives:

- To improve the knowledge of caregivers and family members about their child's condition.
- To promote positive attitudes towards having a child with a disability within the family and the community.
- To equip caregivers with skills to care for their child.
- To promote problem solving and peer support amongst caregivers.
- To engage with the wider family and community on how to improve care and support.
- To strengthen linkages and referrals and promote wider inclusion.

1.2 The facilitators

The facilitators deliver the programme and are key to ensuring success of the group. We call them facilitators rather than trainers or 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 'participatory approach', which will be explained later.)

Facilitators can be health workers (e.g. physiotherapists, occupational therapists, nurses) and caregivers of children with developmental disabilities – 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 caregivers bring their own personal experiences of the challenges that can be faced in raising a child with a disability.

We reccomend two facilitators for each session.

The two facilitators need to work well together as equal partners. Some sessions may feel more natural to be led by one person more than the other. This manual gives some suggestions for this.

1.3 Approach

Core to our approach is group work with caregivers, which is driven by adult learning

theory and a participatory approach. Participants are encouraged to share their experience through discussion and reflection. They identify and prioritise problems and choose ways to solve these problems together. This process is built into the modules.

This programme is built on the evidence of 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. How to achieve this needs to be considered during your planning phase.

The caregivers start an empowerment 'journey' over the course of the programme. It is recommended that children and their caregivers participate in these groups as soon as possible after diagnosis.

The programme sessions are the key component of this manual, however, engaging and involving the other family members, including fathers, and the wider community is important. How you do this may vary in different countries and contexts, and needs to be planned for right from the beginning.

The programme is not intended to replace therapy, but to complement it. Children need to be supported in a therapeutic way during all activities of the day, not only during therapy sessions. It is also important that the sessions and your interactions with caregivers do not add to their burden of caregiving.

Local healthcare and education services may need to be strengthened and the quality improved to enable the inclusion of children with disabilities. This will complement the caregiver programme, and strengthen the referral processes. This is not explored in this manual, but you can find ways to offer training to local services.

> *"Work with us, not for us; don't tell us what to do to change our lives but share your knowledge and skills so we can figure out how to do it; you cannot do much for us economically, but help us eradicate the poverty of our ideas and dreams – show us new ways of understanding the world. Help us to be heard by those who don't listen to us. And when we find the path we wish to tread, first walk in front of us; then, when we are stronger, walk beside us; and finally, when we are truly strong, walk behind us, so that if we should stumble and fall, you will there to help us get up and walk again."* **Batliwala, S. (2015). Engaging with Empowerment: An intellectual and experiential journey, Women Unlimited.**

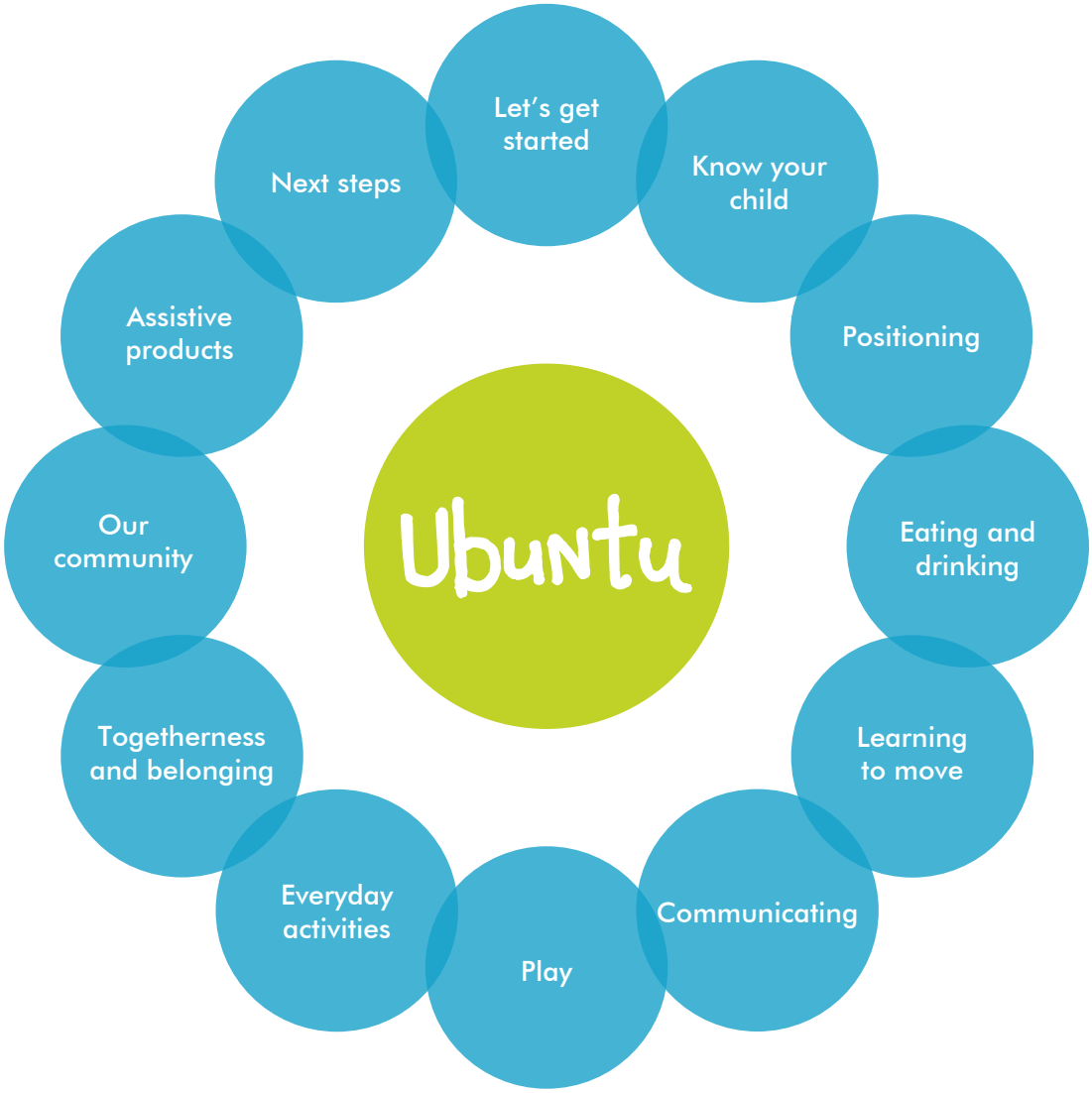
2. FACILITATING A SESSION

2.1 How to follow the manual:

The manual includes:

- 12 modules of activities, including group work and discussion.
- Example images for all modules. These can be found in the facilitator manual, to be printed large or presented on an electronic device eg. iPad.
- Case studies. These are included throughout, but you might want to use information relevant to your local context.

LIST OF MODULES



Module 0: Before you begin	Helps you plan the groups, and provides some useful tools for monitoring and evaluation
Module 1: Let's get started	About the programme Information about developmental disability Personal stories (with posters)
Module 2: Know your child	Introducing close family and friends (with posters) Development milestones for young children Determining each child's progress Managing seizures
Module 3: Positioning	How to position children who need support
Module 4: Eating and drinking	Understanding eating and drinking difficulties Practical skills to address feeding difficulties
Module 5: Learning to move	How to help children learn to move
Module 6: Communicating	Importance of developing communication skills Practicing communication
Module 7: Play	Importance of play for children to develop and learn Early stimulation Making simple toys Inclusion of play in the family and wider community
Module 8: Everyday Activities	How to use everyday activities to help children develop
Module 9: Togetherness and belonging	Starting to address stigma and discrimination at home and in communities

Module 10: Our Community	Identifying our community Discussion about common barriers to inclusion Addressing negative attitudes and exclusion Social Activity – this week contains a chance for caregivers to invite 2-3 members of their community to join in the group for a social discussion and some food/games
Module 11: Assistive Products and Resources	Information on assistive products and available resources in areas with less resources
Module 12: Next steps	Planning for how to continue the group Summing up Endpoint data collection

For each module there are:

Materials

Materials you will need for each session. There is some video material that can be found at www.ubuntu-hub.org and you can make your own short video clips where appropriate to demonstrate issues and help bring the session 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.

Monitoring progress

A check in at the end of each session to see what participants have learned.

Sharing emotions and feelings

A chance for the group to share how they have felt about the topics covered in each session and to reflect together.

The term 'caregiver' is used throughout this manual, sometimes used interchangeably with parent or participant.

Our experiences of other groups are highlighted in GREEN text boxes.
These notes are for the facilitators' reference and are not necessarily used in the session. They can be useful to help you with answering questions.

Facilitator Tips are in BLUE text boxes.
These are Top Tips to assist you with running the sessions.

2.2 Preparing to run a session

How often and how long should sessions be?

- Ask caregivers what is best for them, consider the size of the group, and availability of facilitators. Groups may meet weekly, twice a month or monthly. 6-10 children with their caregivers are ideal.
- Allow enough time in each session to include discussion, questions and a break in the middle, up to 3 hours.
- Some modules may need 2-3 sessions to cover all the material.

Who should you invite?

- Mothers/fathers/caregivers/grandparents of children with developmental disabilities.
- More than one family member can attend sessions (its good if they do).
- Children of any age can join but the earlier you begin the better. If siblings come along, this is a nice opportunity for play.
- 1-2 community volunteers. They can facilitate play with the children. Caregivers will also learn more from seeing how their child can be stimulated through play.

Initial Planning:

- Involve parents in planning and organisation from the beginning, particularly in deciding which venue to use. Consider physical access and transport to the venue, as well as privacy – a quieter area may be preferable.
- Access to water and a toilet is important as some children will have problems with toileting.
- Engage with local stakeholders to explain the importance of the training. They could help find a suitable venue.
- Before starting, read the modules on play and communication as some of the ideas will help with all of the sessions.

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
- Teach the community volunteers how to support child with developmental disabilities in play and go through ideas on fun activities they can do with the children. If the children enjoy themselves, the parents are more likely to use the ideas at home.
- Print and prepare all materials, aids and activities in good time.
- Ensure any videos you need are accessible, on your laptop or cell phone.
- Arrive at least 30 minutes before the starting time to prepare your venue and organise your materials.
- Have a flipchart (or similar) and marker pens ready to use.
- Write the outcomes of the session on flipchart.
- Prepare a box of simple developmentally appropriate, locally made toys. Caregivers should be invited and encouraged to interact with their children and use these toys before, during and after the sessions.
- Find some mats (preferably plastic-covered foam) for the children to sit on. Try to also find some simple supportive seats (eg. made from cardboard or other local materials) for the children who cannot sit up unsupported. Mats and seats should be easy to clean.

During the session:

- Provide simple refreshments for the caregivers and children, including thickened fluids for children with swallowing difficulties, if appropriate. This also gives an opportunity to reinforce lessons learned on feeding and drinking.

Facilitator Tips:

- 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.
- Make sure that the sessions are 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.
- Engaging the children is very important as caregivers often learn more from seeing the difference in how their child is stimulated through play than through lectures.
- 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, or ask for a volunteer to find information to share with the group (if it is not a technical question).
- 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' eg. By saying. "Let's park that for now and come back to it later".
- Recognise caregivers' contributions – draw on their life experiences. Use their stories to illustrate points where possible. Encourage everyone to participate – you may need to speak directly to someone who is very quiet and withdrawn to help them join in.
- 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 of the activities or the time of a break to accommodate their needs.
- Use opportunities to model interaction with the children, as well as other things that are being taught where possible.

After the session:

- At the end of each module there are questions and suggestions to help participants reflect on what they have learned - record these to help with future planning.
- Ensure caregivers are aware that they can ask you 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, for what went well and what could be done differently next time.
- Reflect yourself on what went well and what needs to be changed.

2.3 Identifying issues and referring

As a facilitator, you are not expected to be an expert in everything. Use your contacts and networks to ensure caregivers get the intervention they need, e.g. a mother needing psychological support or a child who needs nutrition advice.

We know that children with disabilities can be very vulnerable to abuse, and that children with intellectual and communication impairments are particularly vulnerable to abuse. We also know that children with disabilities are often 'missed out' of child protection pathways. Caregivers may be perpetuators of the abuse, but they may also

be vulnerable adults who are abused within the family because of the stigma associated with having a child with a disability.

'Safeguarding' means taking action and having policies to ensure that children and vulnerable adults are safe and to promote their wellbeing. The sessions may bring up some very sensitive discussions. Key messages to promote are: 'Protection is everybody's business!' and 'Children with disabilities and their caregivers have a right to be protected'.

As part of your preparation, check you are familiar with national and local child protection structures or resources that might be able to offer good quality referral services to children. It is important to be clear from the outset of your programme what you will do if faced with child protection concerns. It is important to recognise early signs of violence and abuse and respond in a timely and comprehensive manner. As a team you will need to be clear about your own procedures. 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.

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. She was very worried that he would take Chipo to the village and that Chipo may 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 the family.

2.4 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 in one part of the group and neglecting others.

2.5 How will I monitor and evaluate?

- Plan how you will measure progress before you begin. You will find suggestions for how to monitor at the end of every module.
- Decide what information you want to collect from your group to learn how to improve future sessions. It is difficult to measure things like empowerment so decide what indicators you will use before you begin.
- If there are older children in the group then it is very important to get their feedback, so ask them what is important for them and how you can improve. If the child finds communication hard, use pictures and work with a familiar caregiver who can translate.

- Check in with parents before or after each session and keep a record of parent feedback.
- Keep a register so you can see who is not attending regularly or who drops out. Follow up with these people to understand their reasons for not being able to attend and see if you can support them any other way..

3. WHY ARE HOME VISITS IMPORTANT?

- Caregivers often need some help applying learning at home.
- Home visits are good opportunities to engage other family members, including siblings who often help with caring duties.

A home visit form is used to keep track of a family's priorities, progress with goals that have been set and the development of the child. A template is provided in Module 2.

Please note:

This is a guide to organising educational group activities for caregivers (parents and families) and children with developmental disabilities.

This manual guides facilitators through the programme, with step by step guidance for each session's activities.

The term **developmental disabilities** covers a range of childhood conditions and is used differently across different settings and cultures. In this manual we define developmental disability as a diverse group of conditions that can impact on the development of children's function (e.g. sensory, cognitive, physical), with a very wide range of effects. Developmental disabilities include cerebral palsy, intellectual disability, sensory impairments, congenital zika syndrome, microcephaly, Down syndrome.

LET'S GET STARTED

1

This module covers the following information:

Let's get started

What are developmental disabilities?

Our children

Our family and support

Monitoring progress

LET'S GET STARTED

Materials

Flipchart, ball, Diagrams 1.01 – 1.04, pens.

Icebreaker

Welcome everyone and introduce yourself.

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.

It is important to manage expectations, so ask everyone what their hopes are for these sessions. Clarify what will be possible and what may not. You may also want to introduce some ground rules, such as not interrupting each other when speaking.

Ask

"What you would like to get out of coming to the group?"

Write everyone's answers on a flipchart. Encourage people to contribute.

Explain

"Our aim is to help you to understand your child and to build support networks that will improve the care that your child receives in your community. This will help your child to reach her potential. These sessions are not lectures, they will be participatory and interactive. Please share your experiences."

Present diagram 1.01 (previous page); explain this is the content of the programme, and each bubble shows the focus of each session.

Explain

Explain that 'treatment' is not always medical, and includes interactive play, gentle exercise and small changes to everyday activities.

Emphasise that the group is a space for everyone to learn more about developmental disabilities, and share ideas and experiences that can help others.

Explain

Explain what we will learn together today.

In Module 1 you will:

1. Introduce yourselves and your child to each other.
2. Understand more about developmental disabilities and how they can affect children's health, development and well-being.
3. Recognise some challenges and conditions associated with developmental disabilities.

Facilitator Tips:

During this first session, caregivers may want to introduce their child and talk about the challenges their child has. Allow for this and make a note of names for later in the session when you talk more in depth about their stories and fill in poster 1.03. This helps to avoid repetition later in the day and for you to move to discuss day to day activities or hopes and dreams.

The following quotes show what other caregivers have valued from this session:

"At the beginning of the group I didn't like to take my child to my mother's house because I have a sister who has a child the same age as my son, but now I do." **Parent, Colombia**

"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**

"Here I have learned how to fight for my son's rights, to exchange information, to know what rights he has and to know how to fight for it." **Parent, Brazil**

WHAT ARE DEVELOPMENTAL DISABILITIES?

Ask

Ask the following questions and discuss as a group.

"Has anyone told you why your child is not developing as expected, or why your child is disabled? What has the doctor or nurse, or traditional doctor told you?"

"What do your family or neighbours say about your child? Has anyone told you that your child's disability is caused by witchcraft or because you have done bad things in your past?"

Discuss experiences.

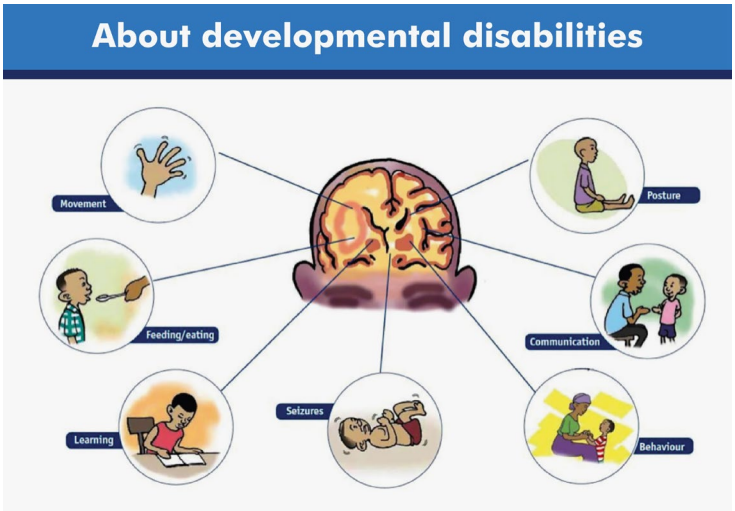
Ask

Have you ever heard the words developmental disability? What do you think causes your child's condition?

Explain

Explain that developmental disabilities include damage to the developing brain either during pregnancy, birth, or in the first few years of a child's life. Often doctors cannot know the specific cause because it could be any incident causing an injury, infection, or restricted oxygen (perhaps during birth).

Explain that developmental disabilities are a group of conditions that impact on the development of a child's function. Damage to areas in the brain may cause problems with movement and posture, and often communication, feeding/ eating, seizures, learning, and behaviour.



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

Developmental disabilities include cerebral palsy, intellectual disability, sensory impairments, congenital zika syndrome, microcephaly, down syndrome.

Present diagram 1.02.

Feeding problems: your child may have difficulties with sucking, swallowing and chewing, which can cause gagging or choking. These difficulties may worsen as children get older.

Communication difficulties: your child may not respond or react as other children do. She may be floppy or lack movement, and may not have control of her face muscles. Your child's speech development may be slow, and she may struggle to speak clearly. She may cry a lot, and initially you may find it difficult to know what she wants, but in time your child can learn to point at things with her hands, feet or eyes.

Learning difficulties: some children may have learning difficulties. Other children may not, but their physical appearance can make them look less intelligent than they are (eg. drooling, slow movement).

Seizures: some children experience epilepsy, fits, and convulsions.

Behavioral issues: sudden changes in mood are not uncommon. This can be caused by your child's frustration at not being able to do what they want with their body. Over-stimulation, loud noise, and high-levels of activity can cause your child to become frightened or upset. Your child will need a lot of patience and support to overcome these difficulties.

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.

Encourage the caregivers to share their experiences and ask if their own child shows these symptoms.

Ask

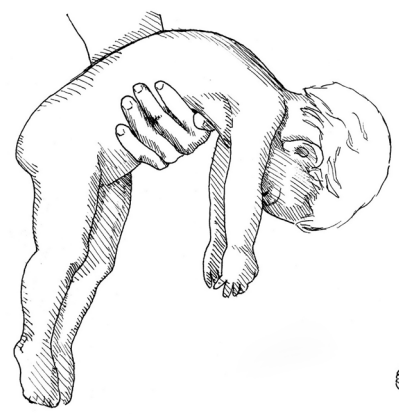
Can other children catch developmental disabilities? Is it contagious?
No. It cannot be passed from one child to another.

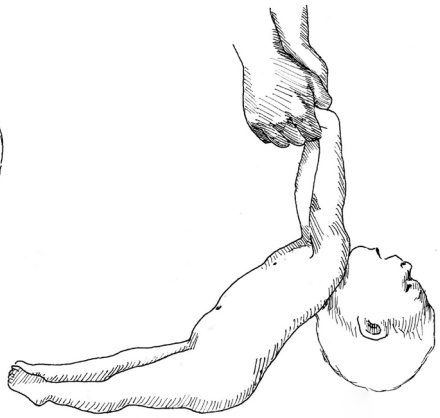
Can developmental disabilities be cured?
No, but early help, therapy and learning together in this group can help achild's development and it can help their participation in the family and community.

OUR CHILDREN

Activity 1

Display photos 1.03 a-d.





Ask everyone to walk around the room looking at the different pictures of children with developmental disabilities. Give them enough time to look at these and to discuss that no two children look the same. Each child is an individual.

Ask

"Do the children look the same? Have you seen another child who looks similar to your child?"

Describe the physical symptoms shown in the pictures.

Muscle stiffness: developmental disabilities may cause muscle stiffness which can cause parts of the body to be rigid, slow down movement, and can cause spasms. The parts of the body this affects varies from child to child, but it will increase when the child is upset, excited, or in certain positions. Spasming is often triggered by the positioning of the head.

Floppiness: floppy arms and legs are caused by low muscle tone. This can make it difficult for your child to move or sit up without help, everyday movements can be exhausting, and she may get tired very easily.

Uncontrolled movements: some children will have difficulty staying still and stable, and may not be able to control their movements.

Poor balance: some children will have 'ataxia', which causes poor coordination. It may be difficult to sit, stand, or use their hands. They may look clumsy and fall over a lot.

> In Bangladesh caregivers really valued looking at the pictures of children with cerebral palsy. This was the first time most of them had seen pictures of other children with a developmental disability, and many had never met other parents of children with disabilities before. This activity stimulated valuable discussion and encouraged story sharing.
>
> *"Initially, I thought my child may be cured by a doctor or traditional doctor. Then I saw that he wasn't cured... I understand more about the condition [cerebral palsy] by participating in the training and as a result of this my child has been developing. Now I feel less physical and mental pain."*
> **Parent, Bangladesh**

Explain

Explain that there are other conditions associated with developmental disabilities and that a child may experience one or many of the following:

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

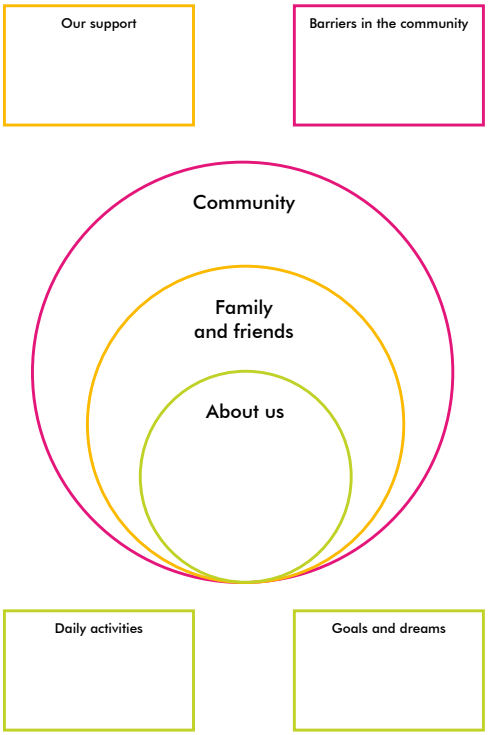
Ask

Ask if anyone has experience of caring for children with these conditions, and explain that all will be discussed in detail throughout the different modules.

OUR FAMILY AND SUPPORT

Activity 2

Give one image 1.04 to each family



Allow plenty of time for this discussion as it is probably the most important part of module 1.

Explain

Explain each week you will fill in a different part of the circle. Today you are going to fill in the centre circle – about you and your child. This is a safe and supportive space to learn and share, without judgement. By sharing with each other you can support each other.

Draw the mother, father (if appropriate) and child in the center circle. Then add 1-2 activities that you do and 1-2 hopes and dreams for your child. Next week, you will fill more in about the rest of your family (in the second circle).

Ask

Ask everyone to share their story and think about the following questions:

"How do you feel about having a child with a developmental disability? What do you hope for your child?"

Everyone can share as much or as little as they feel comfortable with, and use any language they prefer.

This can be an emotional experience for some and may not be easy. If you are not yet ready to share much, you can do so in future.

> Caregivers of a child with a disability are more likely to report feeling isolated and that they lack support than parents of children without disabilities. These sessions offer valuable spaces for discussion, support and connection.
>
> *"There are many children with physical disabilities in our village. I didn't know them before. As a result of coming the training, we have now got to know each other... Everyone wants to know about the development of each other's children, and I can talk about my child's health."* **Parent, Bangladesh**

Summarise the time of sharing before moving on. For example, if it has been an emotional experience for some, acknowledge their feelings. There will be 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.

> Discussing similarities between their stories is valued by caregivers and the activity with pictures of other children creates a lot of discussion and sharing of stories in the group.
>
> *"I see the power of this group, this is one of the most important things, it is good to know that there are others who have the same situation as you, that gives you a greater strength"* **Father, Brazil**

MONITORING PROGRESS

Take Home Messages:

- Through our sessions we can make a big difference to the quality of life of our children.
- 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.

It is important that everyone understands the content so they can share it with others. Sharing the information will probably require practice, so:

- Split into pairs or threes.
- Ask each person to explain to the others what developmental disabilities are.
- Encourage them to give feedback to each other based on what they have learned so far.

Ask

"What is one thing that you found most useful about coming to today's session and what will you share in your family?"

"Is there one thing you found less useful (if anything)?"

Encourage everyone to share what they have learnt today with a member of their household.

KNOW YOUR CHILD

2

This module covers the following information:

Know your child

Introducing skills

Development, learning and practice

Development charts

Epilepsy and seizures

Family and support

Monitoring progress

Sharing emotions and feelings

KNOW YOUR CHILD

Materials

Pencils, flipchart, skills cards 2.01 (one set per group), pictures 2.02 on card (one set per group), development charts 2.03 a,b and c (one for each person), home visit forms (template in resources), image 2.04, cut out statements 2.05, image 2.06 and 2.07, and posters 1.04 from last session.

Icebreaker

- Form a line and ask everyone to hold hands to make a long chain.
- 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.
- Ask everyone to close their eyes.
- Squeeze the hand of the person at the end of the line.
- 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

By the end of module 2, you will:

1. Understand how children develop.
2. Observe your child and identify where she is on the development chart.
3. Be able to plan activities that can help your child's learning and development.
4. Be able to recognise 'fits' (epilepsy) and know what to do.
5. Understand the importance of talking about your own thoughts, feelings and emotions.

INTRODUCING SKILLS

Activity 1

"We will share tips for caring for our child and how we can be supported by other family members and our community. Young children with developmental disabilities do learn and change but that they need extra time and extra help to keep developing."

In smaller groups (suggested 2-3 per group), discuss the following"

- What does your child's average day look like?
- How would you like their skills to improve?

Hand out copies of skills cards 2.01 (cut into four separate cards – also in resources).

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

Each group should discuss the skills and decide which are most important for their child to learn, then place the cards in this order.

Gather the group back together and discuss how everyone has prioritised the skills and why.

Explain

Communication is one of the most important skills your child can learn, because it will help your child build relationships with people who can support her.

DEVELOPMENT, LEARNING AND PRACTICE

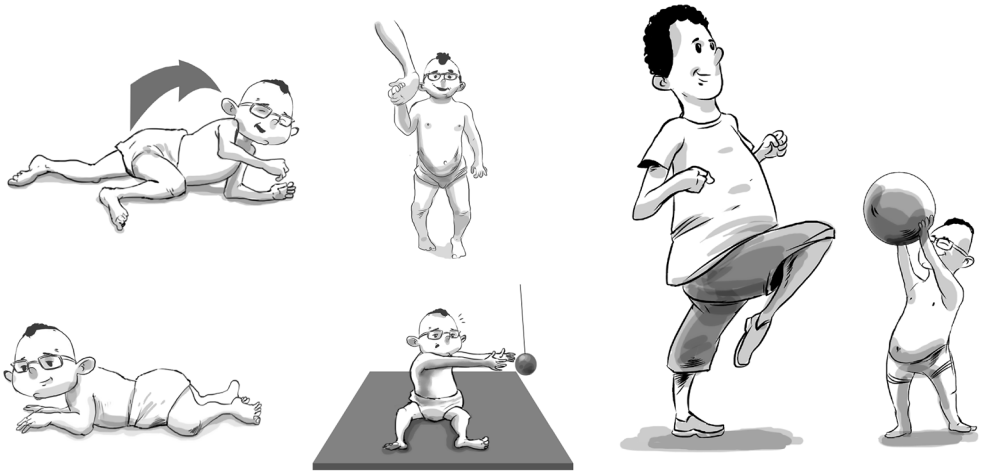
Activity 2

Return to the smaller groups of 2-3 (mix everyone up).

Share copies of pictures 2.02

The images show the different developmental stages of a child. Ask the groups to place the cards in order of how most children would develop as they get older.

Show the correct order.



Explain

Children learn by repeating movements and activities, but children with developmental disabilities find it difficult to do these things alone because of the damage to their brain. This means they may not learn or develop at the same pace as another child.

Ask

- Have you noticed your child struggling to complete tasks?
- What do you do if you see her having difficulty?
- What do you think she needs to help her learn to do things?

If your child has difficulty doing things on her own, you will have to help her practice. You will need to be patient as your child needs extra time and extra **help** to keep developing.

DEVELOPMENT CHARTS

Activity 3

The aim of this exercise is to increase caregivers' understanding of what their child is able to do now and for them to start thinking about what skills they would like their child to learn next.

Facilitator Tips:

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 everyone create simple activities that they can do at home to enable them to reach their goals. The modules we are going to cover will help them to identify these for their child.

Encouragement is really important and you need to give positive feedback and encouragement to caregivers at every session and help identify the small changes they are noticing in their child.

Explain

Hand out the development charts 2.03 a, b, c and explain briefly what is happening in each of the pictures.

There are four categories for Movement:

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

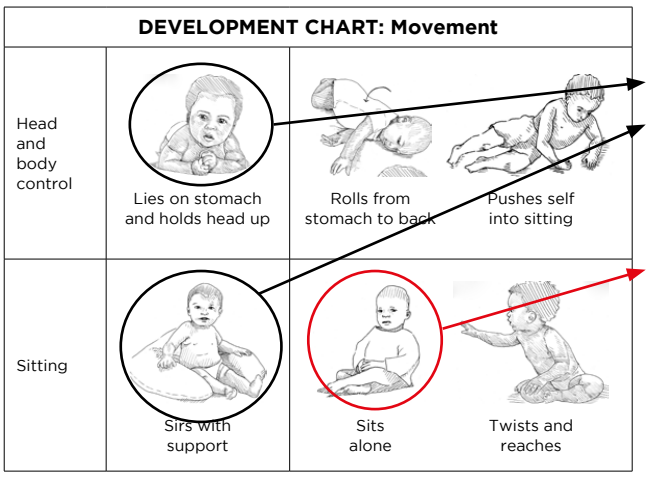
There are also categories for:

- Thinking and playing
- Communication and interaction
- Social and self-help skills

Describe the example about how everyone will fill in the developmental chart.

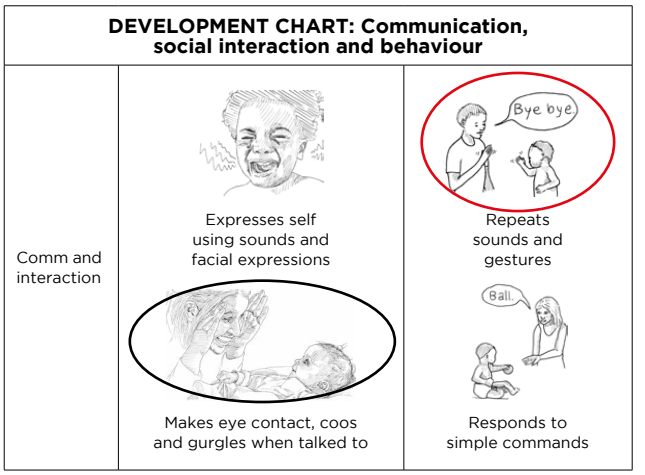
This is Joseph:

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.



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

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



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.

"Mark where your child is on the development charts. Circle things that you have seen your child do."

"Put your child into each of the different positions to see what she can do. When you have finished, the chart should show where your child fits in each row."

If anyone is 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. The following questions may also be useful.

Ask

"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 goals 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)

Explain

Explain there is no pressure for your child to be at any particular point. We are finding out where your child's development is, to make sure these sessions are helpful. Through this we can work out what skills or activities will be helpful to learn next.

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.

In Bangladesh, the home visit form was essential for monitoring the child's progress, and to clarify the parents priorities in caring for the child. It can be difficult to set short-term goals with parents, so the assessment will ideally include collaboration with a therapist and community worker, to outline achievable targets. The form is included in resources and includes guidelines for your visit.

EPILEPSY AND SEIZURES

Explain

We are now going to learn together about seizures. Seizures are common in children with developmental disabilities.

A seizure is an electrical overload in the brain, which causes mixed messages in the brain and a child loses control of their muscles.

Activity 4

Cut out the statements on pieces of paper and ask groups of 3-4 people to separate the statements into 'correct' and 'incorrect' statements.

Seizures are caused by evil spirits
My child can get help and early treatment from health workers for her seizures
If my child has a seizure it is because she is cursed
Medical treatment can help my child's seizures
Other children can catch seizures from my child
Uncontrolled seizures can affect my child's development
A seizure is an electrical overload in the brain and my child can lose control of her muscles when she experiences a seizure

Highlight and reinforce the correct answers:

- Seizures are not caused by evil spirits or from being cursed.
- Seizures are not contagious.
- Seizures are not harmful to other children.
- A seizure is an electrical overload in the brain which can cause a child to lose control of her muscles.
- It is important to recognise and seek early treatment from a health worker if there are concerns about seizures.
- Untreated seizures are harmful to a child's health, well-being and learning.
- Many seizures are treatable, but if uncontrolled can affect a child's development.

Managing seizures

Ask

"Do any of your children have seizures? What happens?"

Signs include:

- 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 your child may fall down, stiffen, vomit, drool, urinate (pee) or have shaking of the limbs.
- Other seizures are less dramatic. Your child 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?"

DO:

- Protect your child from injury by making sure she is in a safe place, away from fire or anything else that might injure her.
- Put your child on her side when possible
- Make sure she is breathing.
- Send someone to bring or call the nearest health care professional in the case of:

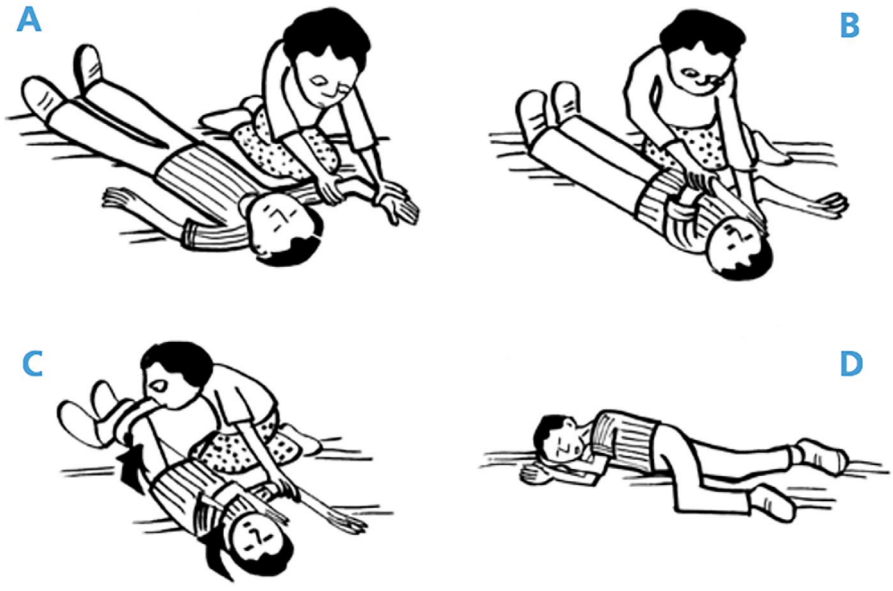
  1. Breathing difficulty.
  2. Seizure lasts longer than 5 min.
  3. Your child does not wake up after the seizure.

- Stay with your child until the seizure stops and she wakes up.

DO NOT:

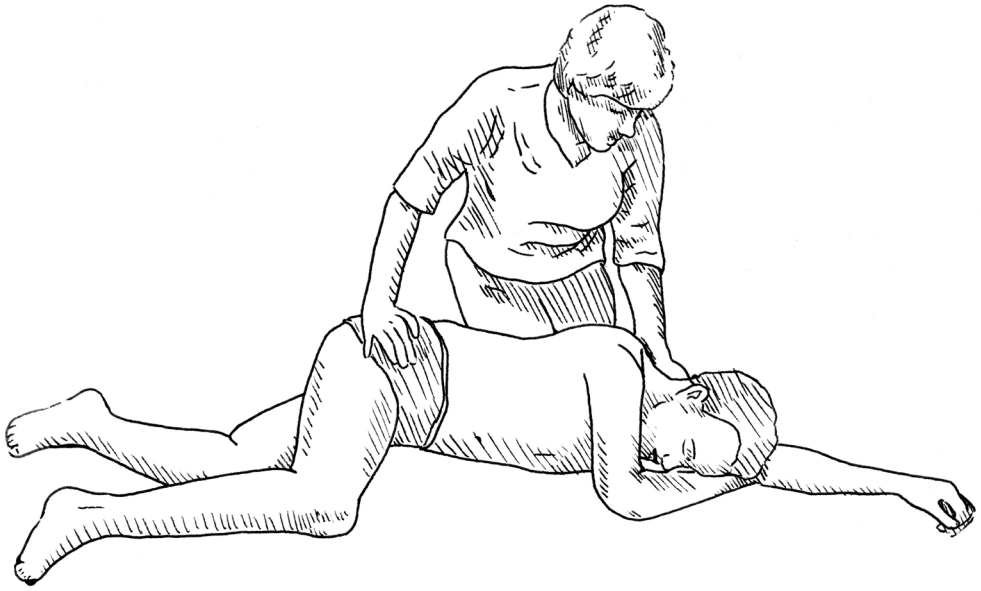
- Put anything in your child's mouth.
- Do not hold your child down during the seizure.

Image 2.06 (Diagram reproduced from WHO mhGAP).



Activity 5

In pairs, practice placing each other in this position.



Ask

"If you think your child is having seizures you need to consult a health professional. What information might be useful?"

Keep a diary or think about:

- How it started, how long it took, what happened afterwards.
- What did the seizure look like, was there loss of consciousness.
- What preceded the seizure (certain behaviour, activity, situation, illness).

Explain

Some general advice about seizures:

- Medication for seizures should be taken as prescribed by the doctor.
- The amount may need to be adjusted over time, especially as your child grows, so follow-up with a doctor is important.
- The medication might make your child drowsy. If there are any side effects that you are worried about, it is helpful to take a video of your child to show your doctor.
- Medication for seizures should NOT be stopped suddenly – make sure you don't run out of medication and remember to take it with you if you travel.

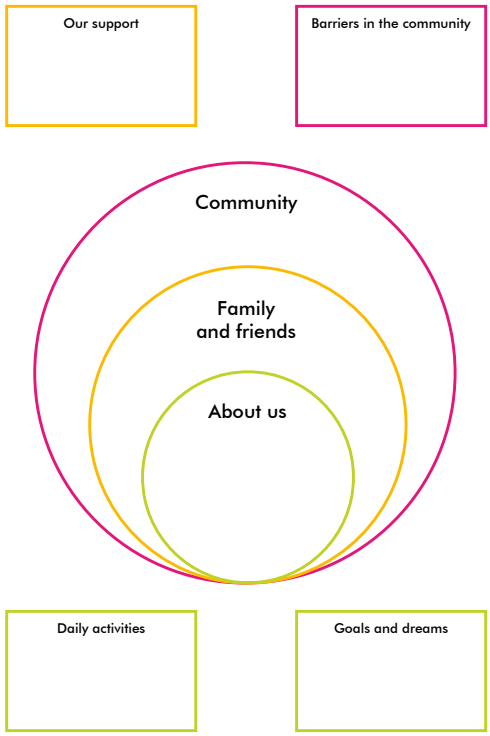
FAMILY AND SUPPORT

Activity 6

Use image 1.04 Split into two groups.

"Last week you told us a little bit about yourselves and your child. This week we'd like to hear a little bit more about other people who make up your family and close friends. Using the second circle of the chart, can you draw some of the people who are involved in your day to day life and tell us a little bit about how they contribute to helping look after your child."

When everyone is introducing their family, ask: *"Did you speak to people at home about what you learned last week? What was the response from the person you tried to talk to?"* Allow 5-10 minutes for discussion then ask for the group to feedback some of the issues they discussed.



Ask

"Has anyone in the group got any suggestions on how to talk to other members of your family when it is not easy?"

MONITORING PROGRESS

Ask

Ask if anyone would like to share:

- *"Something new you have realized about your child after today's session?"*
- *"Something else you would like to know about developmental disabilities?"*
- *"Any other comments and suggestions?"*

Take Home Messages:

- All children can learn and develop new skills.
- Sometimes they will learn at a different pace and in a different way to other children.
- You may have to find new ways of doing things to help your child.
- You may need to help your child practice, but if you support them in learning to be independent they won't need your help all the time.

Facilitator Tips:

One of the greatest challenges is that caregivers, most often mothers, are incredibly busy, and do not have extra time to practice activities with their child. This highlights the importance of involving other family members in the training, making them feel welcome, and encouraging caregivers to share information with the wider family so they can also take an active role.

SHARING EMOTIONS AND FEELINGS

Each week we are going to have a session at the end that focuses on how you, as a caregiver, are. We will talk about your thoughts, feelings and emotions that are quite normal to have when raising a child.

Ask

"How many different types of mood/feelings can you list?" (e.g. happy, sad, anxious, annoyed, frustrated, delighted etc).

"When it comes to moods and feelings, what is normal?" There is no normal, everyone feels different things at different times.

"What different thoughts feelings and emotions do you think all parents feel when they have a new child? Do you think these are different for a child with developmental difficulties? How?"

Again, it is important to emphasize that ALL parents feel a range of emotions at different times. This is normal. If anyone has other children, they may be able to support this statement.

When you have a child, especially a child with developmental difficulties, it can sometimes feel that your whole life is focused on them. You take them for medical appointments, care and support them during the day. Even this programme is about learning more about your child. It may feel like it is rare that anyone asks how YOU are doing.

At the end of each week, we are going to ask that. We are going to ask how things have been this week for you and how things felt during that session.

You don't have to say anything, and it may feel uncomfortable at first. One of the most important things with coping is being able to share your feelings and emotions with others, when you feel comfortable to do so.

Facilitator Tips:

There are many cultural differences in expressing emotion and supporting group members who may become distressed. Ensure that participants know that they don't have to say anything, and it may feel uncomfortable at first. One of the most important things with coping is being able to share feelings and emotions with others, when someone feels comfortable to do so.

Health care workers have often said that they felt uncomfortable asking personal questions that may cause a caregiver to feel sad or anxious. Some caregivers and health workers may believe that crying is inappropriate, especially if the facilitators themselves show emotion. In our discussion with caregivers, they have said that it is important for their stories and their voices to be heard, and that speaking with other caregivers about this is not as difficult as the health care worker perceives. It was also important to be permitted to show emotion.

Asking caregivers to ask other caregivers about their thoughts and emotions may help to create a space where more participants feel comfortable to share. We include self-reflection and small group work in this session and it may also be easier for you to support people telling and listening to stories in these small groups.

POSITIONING

3

This module covers the following information:

Positioning

Introduction to positioning

Good handling and positioning

How to position your child

- Lying down
- Seated
- Standing
- Picking up
- Carrying

Monitoring progress

Sharing emotions and feelings

POSITIONING

Materials

Blankets, pillows and towels, sandbags, carpet on the floor, strong cardboard or wooden box a doll with floppy limbs i.e. not a hard plastic doll, pictures 3.01a, b, c and d, positioning photographs.

Facilitator Tips:

You can decide if this module should be in one session or spread over two sessions. It is important to explain **why** families and caregivers should use positions and facilitating of movement in every day activities at home. Sometimes participants know about the positions to use at home but do not understand the benefits for themselves and their child. Also, some participants may be afraid to show that they don't know how to use some positions, or of hurting their child.

Parent experiences in Uganda include:

"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."

"When I came here and learnt positioning, my child learned to sit."

Icebreaker

Ask everyone to stand facing you with three people in each row. The front person should stand with their back to you, facing the two behind.

Ask the person at the back to make an unusual shape with their body and hold it.

The front person must get the middle person into the same position by giving verbal instructions only – no touching or showing them what to do.

Repeat so everyone has a go in each role.

Explain

Explain what we will learn together today.

By the end of module 3, you will:

1. Understand the importance of good positioning
2. Be able to position your child well, and be able to show others
3. Understand ways to help your child move and be able to explain to others how they can do this
4. Share some thoughts and feelings about looking after a child with a disability.

INTRODUCTION TO POSITIONING

Activity 1

Positions build a base for movement and in the next weeks we will discuss how good positions are needed for eating and drinking, communication, play and activities that we do every day. The key today is building a foundation of good positioning and then to help your child to move.

Ask

In pairs, discuss:

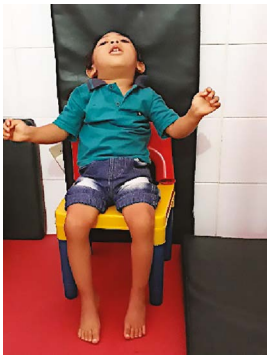
"In which positions does your child like to be in most of the time?"

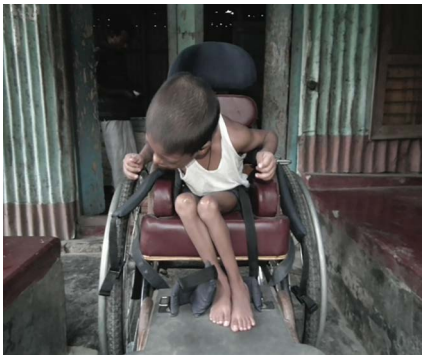
Allow time to discuss in pairs so that everyone identifies which positions their children prefer to be in and start to think of why.

Facilitator Tips:

It is important to emphasise the relationship between good positioning and helping children to develop. Some caregivers said that they were doing exercises and stimulation at home but they did not know that those positions were helping their child develop and protecting them as they grow. By learning about good positions, their children learned new skills.

Display pictures 3.01a-d. In smaller groups of 3-4 discuss why these children may not be positioned well.





Ask

Ask everyone to consider whether children in the photos will be able to:

- Play
- Eat
- Communicate
- Socialise
- Move (can she lift her arms?)

Explain

Explain that poor handling and positioning;

- Will slow your child's development.
- Will make it more difficult for you to pick up, carry and handle her every day.
- Can cause other problems, such as:
    - **Pressure areas** – leaning or lying on a body part for too long can stop blood from flowing through the muscles and cause painful sores. These begin as dark red or purple areas, and can take a long time to heal.
    - **Contractures** – if a limb stays in one position for a long time muscles become shorter and the joint becomes stiff.
    - **Deformities** – spending too long in one position can cause her back to become permanently crooked and twisted, and her hips can move out of place or dislocate.

GOOD HANDLING AND POSITIONING

Ask

"Why is good handling and positioning important for you and your child?"

Explain

After the group offers suggestions, explain.

How you handle your child affects all the activities you do with her, and good positioning should be used all the time because it:

- Is the basis for all the activities you do with your child.
- Influences what she can do and how she develops.

- Helps to make eating, drinking, playing and communicating easier and safer.
- Makes it easier for you to care for your child.
- Helps prevent other conditions which can cause further disability.

Explain

Explain how to position in more helpful ways, using the following steps:

1. Start to move your child

- You can't force her into a position.
- If she is stiff you need to loosen her first. Ask a therapist how to do this.

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

- Aim for 'ideal positions' (see below).
- She may not be comfortable in a new position at first. Keep trying, and ask the therapist for help if she is still uncomfortable.
- You may need to initially limit the amount of time she is in that new position, and gradually increase the length of time as her tolerance increases.

3. Change your child's position often, build up to about every 60 minutes

- Encourage or help her to change her own position.
- If you leave your child in one position for many hours, she may develop pressure sores and her body may stiffen which will increase her disability. She needs to be moved into many helpful positions throughout the day.

The best position will be different for each child. We are learning some options; a therapist will help find the best position for your child on a home visit.

Encourage discussion and questions before starting the next activity.

HOW TO POSITION YOUR CHILD

Facilitator Tips:

Everyone should look at the photos of different body positions, discuss what they show and decide which positions are good or poor. The group should practice each good position as they go along, as this is the best way of learning how to position your child correctly.

Part 1: Lying Down Positions

Ask

Ask someone to volunteer to lie on the floor and copy the position of the child in picture (3.02a).

The rest of the group should observe and change this position to make it more helpful, using pillows or blankets. Encourage discussion as changes are made.

Return to the smaller groups.

Ask

Ask participants to look at the photographs of each position, describe the body position and decide why the position is good or unhelpful.

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

After discussing each photo, return to the main group and ask a volunteer to 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.

POSITION 1: LYING ON BACK

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

- Head is pushing back and turned to one side which can be unsafe and uncomfortable.
- Hips turning in causing legs to cross.
- Toes are pointing down, which means she can't get them flat when she sits.
- Hands and arms are away from her body, unsupported.
- Hands are closed in fists and may stiffen.

GOOD POSITIONING

Head and body

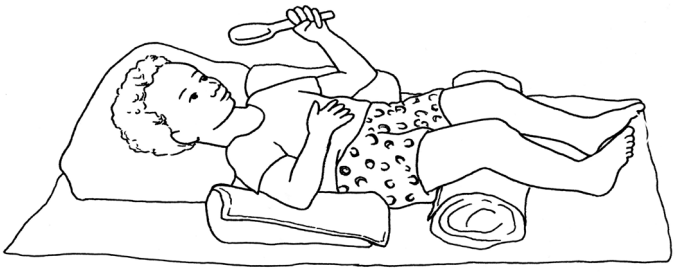
- Always make sure her head is comfortable.
- Her spine must be straight – support the sides of the body with rolled up towels.

Legs and feet

- Bend her hips – this helps to release tension in her lower back, and helps to relax stiff legs. Place support under knees to keep hips bent (not under feet).
- Keep legs open and uncrossed – use a pillow between them.
- Feet should look the same as they would in standing – if toes point down, talk to a therapist about getting an ankle/foot orthosis.

Shoulders and arms

- Forward and supported. This helps to relax the upper back, and allows the hands to open more easily.
- Lying in a hammock can help to relax tight muscles.
- Babies and small children can hang in a large towel (held by two adults) to relax tight muscles.



NOW PRACTICE WITH YOUR CHILD

POSITION 2: LYING ON THE TUMMY

Explain

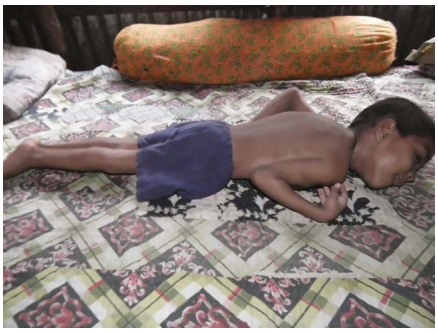
Lying on the tummy is really important for developing strength in the head, neck and back. Children learn to roll, crawl and move, by spending time on their front and then being encouraged to push up through their arms.

- 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

- His muscles are not being used.
- He cannot see with his face flat on the floor.

- His legs may be crossed.
- His hands are in fists and he cannot use them in this position.
- He will struggle to move from this position.



GOOD POSITIONING

Head and body

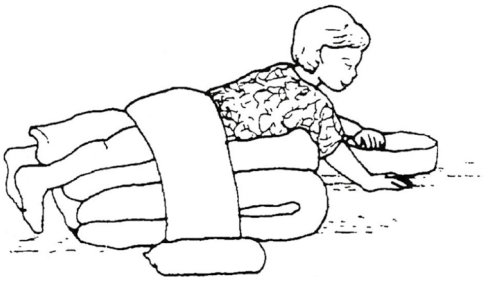
- In a straight line.
- Encourage her to lift her head so she can play.

Legs and feet

- Push down on the hips or bottom and rock from side to side to help straighten the hips, legs and feet.
- Support between the legs prevents them from crossing over.

Shoulders and arms

- Arms should be in line with or slightly in front of shoulders. Place a pillow or towel under her armpits to help keep arms forward.
- If possible encourage her to open her hands and push down on them. You may need to gently open her fingers.
- This position may not work for all children so consult a therapist before trying it.



NOW PRACTICE WITH YOUR CHILD

POSITION 3: LYING ON THE SIDE

Explain

Side lying is an important position because:

- 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.

GOOD POSITIONING

Head and body

- Use a pillow to keep her head in the middle of her shoulders with her back straight.
- Using a pillow or towel along the back helps support the whole of the body.

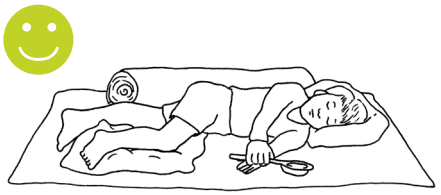
Legs and feet

- Bending the top leg at the knee and keeping the bottom one straight helps to relax stiffness, whilst allowing your child to support herself.
- Keep her top leg supported with pillows or blankets so it is level with the hip. This will prevent dislocation of her hip.
- Regularly reposition her to lie on the other side to switch the supporting leg

Shoulders and arms

- The lower shoulder and arm must be positioned forward so they are not trapped underneath her body.
- Position both arms in front so she can bring her hands together and use them to play.

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.



NOW PRACTICE WITH YOUR CHILD

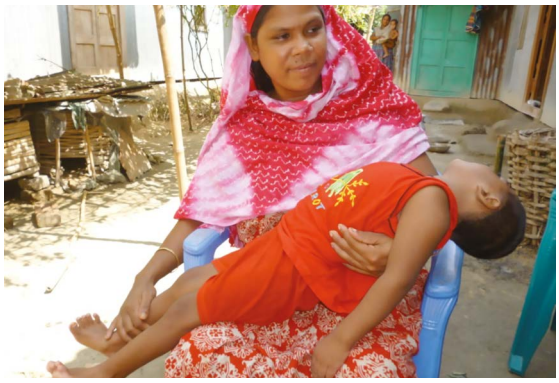
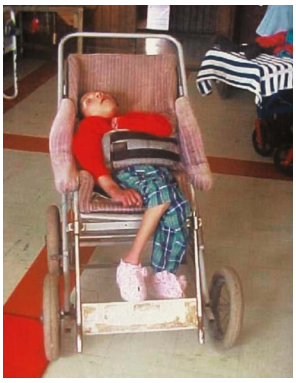
Part 2: Seated Positions

SITTING WITH A CAREGIVER, SITTING ON A CHAIR, OR ALONE

Explain

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).

POOR POSITIONING

Sitting with a caregiver and on a chair this way is not best for a child, because;

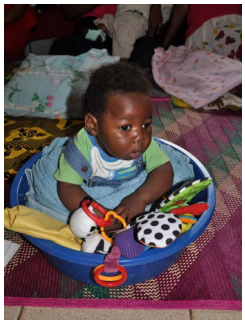
- His head is hanging backwards or to the side, so he can't see ahead of him to use his hands or to communicate with anybody.
- His arms and hands are away from his body and not in a good position to do anything.
- Shoulders are not supported, and are either flopping back or pushed too far forward.
- His hips are not bent, so he is lying rather than sitting on his bottom.
- His body is leaning sideways and is unstable.
- His legs are twisted which can be harmful, and feet are not supported.

The kneeling position pictured is not best for a child, because:

- He does not need much control, so will not need to learn how to balance her upper body.
- He may not develop good balance for sitting in other positions if always in this position.
- This position can damage the knees and hips.

If this is the only way your child can sit independently then it should be done safely but not too regularly.

GOOD POSITIONING



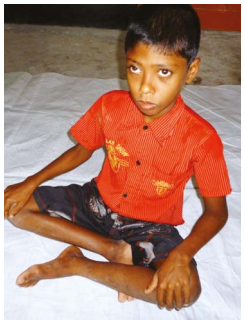
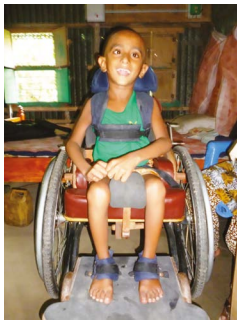




Photo by:
CECHE Foundation

Photo by:
CECHE Foundation


Head and body

- Upright with a straight back and head.
- If your child cannot hold her own head upright, make sure she is sitting up straight with her back supported. Use your arms and hands to support her head, chest, and hips in position.
- Buttocks are at the back of the seat.
- If there is a lap strap, make sure it is tight enough to prevent sliding down the chair.

Legs and feet

- Bend her hips at a right angle to keep her upright and stop her sliding off your lap or chair.
- Must be supported.
- She can sit independently with her legs crossed.
- She should sometimes sit with legs straight, not always bent (to avoid stiffening).

Shoulders and arms

- Shoulders should be slightly forward so her arms and hands are in front of her body, making it easier to play with a toy or person.
- Shoulders should be level.
- Arms should be supported slightly forward and in front of the body.

Ask

"How does your child sit in a chair or buggy?"

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

Your child will need to develop muscles to balance when she sits. You can help her to play a game, or explore what her body can do with toys and other objects.

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: Make sure your child's hips and knees are bent. If your child pushes themselves backwards then this position can be hard – try using a heavy rolled towel, bedspread or sandbag to stop them pushing back.

Demonstrate both

NOW PRACTICE WITH YOUR CHILD

Return to sitting together with children on caregiver's laps.

Ask

"How is your child sitting with you now? What should you change?"

Now practice with your child

Encourage caregivers to work together to change the position of their child and

to discuss what the most useful change for their child will be.

Ask

"What is one thing that you will do at home differently when your child sits with you?"

Ask everyone to discuss in pairs the one thing that they will change at home. Encourage participants to show others at home how to hold their child, and to take photographs to show the group next week.

Part 3: Standing Positions

Ask

Ask everyone to stand on one leg. Hand out sheets of paper for everyone to fold and tear into four equal parts while balancing.

Repeat the activity with everyone standing on both legs. Compare how much easier it was with more balance.

Explain

Explain that this is the same for a child with developmental disabilities. Lack of balance makes it difficult for her to do anything with her hands.

Return to the smaller groups and distribute the pictures showing standing positions.

Activity 2

Discuss the images and why they show poor or good positioning. After discussing each image, practice the good position with your child.

Facilitator should walk around the room helping each group as they discuss and practice.

POOR POSITIONING

- She cannot stand on flat feet with her knees and hips straight probably due to stiff leg muscles.
- She is not able to balance without holding on with both hands for support or leaning on a caregiver. This means she cannot do anything else whilst standing.

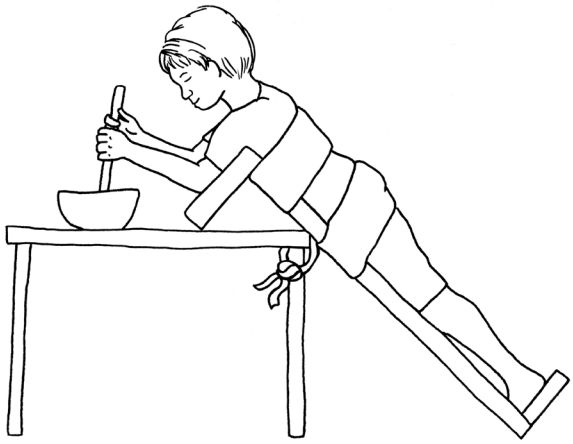


Photo by: The International Committee of the Red Cross

For images 3.08A and B:

- Balancing on a simple home made device puts less pressure on the rest of her body.
- Her hips and knees are in a good position which helps to keep her feet flat.
- She does not need to hold on as she is well supported.
- Her shoulders and arms are forwards and hands are free to play.

For Image 3.08C

Head and body

- The frame keeps his back straight. Add a rolled up towel on either side if your child's body leans sideways.

- His head is upright and in the middle of his shoulders.
- His hips are facing the front.
- He is wearing a top so the frame is not touching or irritating the skin.

Legs and feet

- The frame supports the hips and knees in a standing position
- The soles of his feet are firmly on the ground with heels down and toes facing forward.
- Make sure your child is putting enough weight on his feet by checking if they can be easily moved. If you can move them loosen the frame whilst supporting him and reposition his hips and feet.
- If it is difficult to get your child's feet flat he should only start standing after a home-visit assessment or if he is using orthotics.
- His arms should come forward onto the table (which should be at bent elbow height) so he can use them.

NOW PRACTICE WITH YOUR CHILD

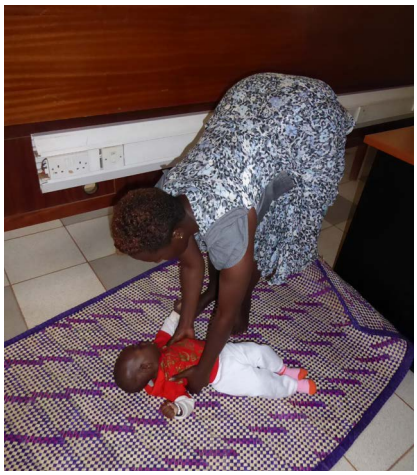
Part 4: Picking up

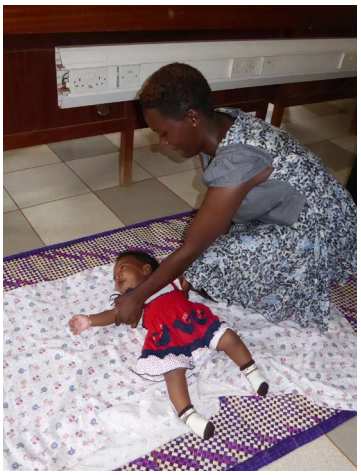
Ask

"Which picture shows the correct way to pick up a child?"

Explain

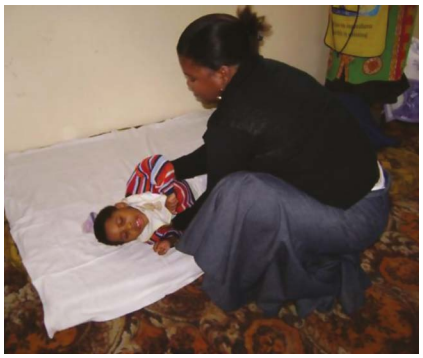
Explain the left image shows poor positioning and the right shows good positioning.





POOR POSITIONING

- If you bend forward with your legs straight you can injure your back. Over time you could develop painful back problems



GOOD POSITIONING

- Bend your knees, keep your back straight, and lift using the muscles in your legs not your back. This will protect your back from injury.
- It can be easier to pick your child up with one foot slightly in front of the other.
- Turn your child towards you, then lift and hold her close to your body before standing up.
- If your child becomes too heavy for you to lift alone, ask someone to help you.
- If lifting with another person, count before lifting so that both of you lift at the same time.

NOW PRACTICE WITH YOUR CHILD

Part 5: Carrying

Activity 3

Show everyone the pictures.

In small groups, discuss the positions and try out carrying techniques with the doll or with your child. Everyone should try and find the best position for them.

POOR POSITIONING

- Her head is unsupported and falling backwards.
- She cannot see.
- Her body is stiff and straight not relaxed or comfortable.
- Her arms and hands are not able to do anything.

GOOD POSITIONING

Head and body

- Carrying your child in a more upright position allows her to hold her head up and look around.

Legs and feet

- Keep her hips and knees partially bent, and her knees apart.

Shoulders and arms

- She can either hold on with her arms or use her arms to do something else.

NOW PRACTICE WITH YOUR CHILD

MONITORING PROGRESS

Ask

Ask everyone to act out one new position they have learnt today which they will show to another family member.

Take Home Messages:

- It's not possible to always attend to your child so you need safe and supportive positions that you can leave her in when necessary.
- Good positioning helps make daily activities easier for your child.
- Instead of leaving your child in a poor position guide her into as helpful a position as you can. You need to try different positions to see what works best for your child.
- If you have access to therapists at your clinic or hospital ask for their advice on how your child can benefit from positioning and therapy and what you can do on a day to day.
- If you have equipment like buggies and positioners then use them. Ask your hospital to help you get the most helpful items for your child.

Ask

Ask if anyone has any questions before ending the session.

SHARING EMOTIONS AND FEELINGS

Ask

"How did you find talking about today's subject? Did it raise any emotions or feelings that you did not expect? How have you been feeling this week?"

Allow time for discussion and interaction with each other. This should be a guided session between everyone with only short prompting from facilitators.

Facilitator Tips:

In the first sessions, everyone may not be comfortable to share their emotions. You could help by recognising that talking about emotions can be tough.

EATING AND DRINKING

4

This module covers the following information:

Eating and drinking

Feeding your child

Helping your child to eat and drink enough and 'safely'

1. Environment and hygiene
2. Diet
3. Food textures
4. Positions for feeding
5. Utensils
6. Kind and supportive feeding methods

Practical feeding session

Towards independent eating

Monitoring progress

Sharing emotions and feelings

Important: This is a long module that can be split over 2-3 sessions.

EATING AND DRINKING

Materials

Flipchart, pens, jug of water, glasses, dessert spoons, yoghurt and face cloths, poster 4.01, pictures 4.02, cards 4.03, pictures 4.04a-e, 4.05a-b and 4.06a-b.

For demonstrations: Large rag doll, supportive seat with straps and a tray if possible, small towels, normal chair, large glass, small plastic beaker, dessert spoon, strong plastic teaspoon.

Feeding session: Small plastic beakers and plastic teaspoons.

Facilitator Tips:

Eating and drinking are important for the health and growth of all children. Muscle tone and co-ordination of children with disabilities can be different to other children and this may change the way that they eat and drink. This creates a risk of food or drink going down the wrong way, onto the lungs, and a child being unable to eat or drink enough (risking malnutrition and dehydration).

Some of the advice in this module includes asking caregivers to modify the food they prepare so that it is easier (and safer) for their child to eat and more nutritious. It is important to recognise that preparing food that is made especially for their child can be challenging for many caregivers due to a lack of money and time, or maybe because they are sharing cooking facilities with many other families. These barriers, and possible ways round them, need to be discussed.

Identifying local nutrition programmes and knowing what they offer is important, to help you to clarify how the most vulnerable children and families could be linked into their services. Some services don't work with children with malnutrition caused by disability alone but only those with diarrhoeal disease, for example. During routine health appointments, the medical team will assess a child's growth and body weight. It is important parents understand this is to help them access local services and support if there are any issues with nutrition that could slow a child's development.

Icebreaker

In pairs, take it in turns to feed one another yoghurt using a dessert spoon. The person being fed should have their head leaning back, then turned to one side, then flopping forwards.

"How easy or difficult is swallowing in this position? How does it feel?"

Explain

Explain what we will learn together over the next few sessions.

By the end of module 4, you will:

1. Understand the difficulties your child may have with eating and drinking.
2. Find feeding her easier, more enjoyable, and safer.
3. Know how to help her eat more independently.
4. Know how to give your child a balanced diet and increase her nutritional intake.

FEEDING YOUR CHILD

Ask

"What does your child eat and drink? Does your child drink out of cups or bottles?"

"Have you started giving your child solid foods yet? What kinds of food do you give? (eg. runny, mushy, crunchy, chewy?)"

"What utensils do you use?"

Write a list of the foods that everyone mentions to use later in the food grouping activity.

Facilitator Tips:

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 session. 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 everyone when the children are asleep.

Ask

"What problems do you have feeding your child?"

Explain

The following are common:

Difficulty controlling her head

- Her head is floppy and she can't keep it upright/

Difficulty controlling her body

- She cannot sit upright by herself.
- It is difficult to hold her body upright when feeding her as she pushes back and can't keep still.

Difficulty controlling her mouth/lips/tongue

- She struggles to close her mouth and food or drink falls out.
- She struggles to chew her food.
- She pushes the food out of her mouth with her tongue.
- She only eats soft food.

Difficulty with food/drink going down properly

- She coughs or chokes when eating/drinking.
- She finds it hard to breathe.
- She vomits her food back up during the meal.

Difficulty eating on her own

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

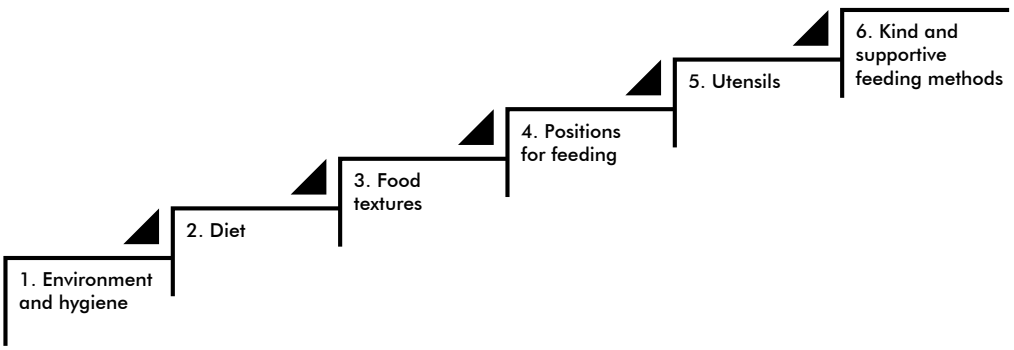
Mood

- She is often unhappy during mealtimes and won't eat.

Other problems

- Vomiting after eating due to 'reflux'.
- Frequent chest infections cause by food and/or drink going down the wrong way into the lungs.
- Constipation, due to problems with digestion and/or dehydration.
- Parents often feeling very frustrated because feeding is so difficult.

HELPING YOUR CHILD TO EAT AND DRINK ENOUGH AND 'SAFELY'



Activity 1

There are 6 things to consider in helping your child eat and drink better. We will learn together about how these steps lead to safe and responsive feeding.

1. Environment and hygiene
2. Diet
3. Food textures
4. Positions for feeding
5. Utensils
6. Kind and supportive feeding methods

1. Environment and hygiene

Ask

"Has anyone got any tips on hygiene?"

For example: don't use a dirty cloth to clean with because our children are at a high risk of infection.

Write the list of examples on the flip chart.

Ask

"Where do you choose to feed your child, and why? What is your routine before you feed your child?"

Discuss that everyone may have different places where they like to feed their child for different reasons. Cleaning routines should include washing both your hands and the hands of your child with soap and good water, as well as the utensils.

Ask

"If your child gets distracted when eating, what is she distracted by?"

Ask what solutions everyone has found to decreasing distractions.

2. Diet

Activity 2

Discuss with a neighbour: *"When and why was your child introduced to solid foods?"*

Explain

When a child reaches 6 months, she **needs to have solid food as well as milk** in order to grow, even when she has developmental difficulties.

Eating and drinking are important for nutrition and hydration, and so for

growth and health. Eating and drinking are also important for exercising parts of the mouth that are helpful for learning to talk.

If your child finds eating and drinking difficult, giving small amounts often will build up her nutrition.

Ask

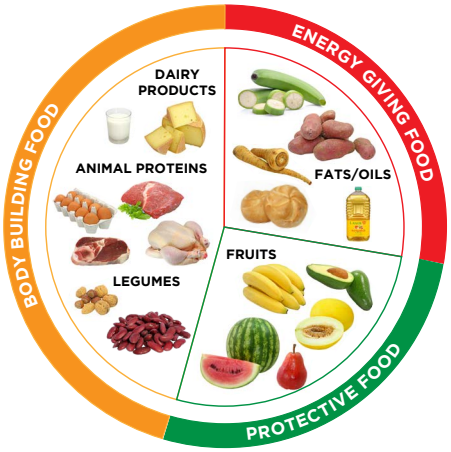
"What is a nutritious or 'balanced' diet?"

Good eating and drinking helps your child stay healthy, hydrated, develop and grow.

Explain

Explain that poster 4.02 shows all the food groups that your child needs.

On the flipchart, list what foods you eat the most.



Activity 3

Draw a circle divided into three sections labelled:

- Body building foods
- Protective foods
- Energy giving foods

Show the different local foods and ask everyone to place the food into the three groups. Also use the list you made earlier of foods that they give their children. Each child needs a combination of these foods to grow, develop, and gain weight.

Explain

Children with developmental difficulties need a balanced diet that is especially high in energy, which comes from fat and oil.

Your child may get tired easily when eating and this will increase the risk of food going down the wrong way to her lungs. It will also mean that she can't eat a large amount of food at one time. She therefore needs small meals given more often (e.g. 6 small meals instead of 3 bigger meals).

Children need the equivalent of at least 4 cups of fluid per day. As drinking can be difficult, your child will need to take sips of fluid throughout the day. This will help reduce the side-effects of dehydration, such as constipation, and give her more energy. Constipation is very common in children with developmental disabilities and can cause them pain and discomfort.

Ask

"How can your family help to increase the amount of water that your child drinks through the day?"

Avoid adding sugar to your child's food and drinks. 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 tooth decay and health problems later.

Changes as your child gets older:

As children grow, they start to breastfeed less and eat more, and begin to drink water from a cup.

For example:

Children who are less than 9 months old

- Mainly breastfeed.
- Start learning to drink sips of water from a cup.
- Start eating 2-3 small meals (each meal about 2 full tablespoons) a day.

Children 9 and 12-month old infants

- May start breastfeeding less and drink more water.
- Start eating 4-5 meals (each meal about 4 full tablespoons).

Infants over 1 year

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

3. Food textures

Activity 4

Show a banana, a biscuit, and other common foods.

Ask

Ask 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 your child cannot control it well. Liquids should therefore be given very carefully or thickened by missing something with them.

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 she does not have the muscle power or coordination, so we need to make solid food that is moist and soft so she can manage it.

We start with smooth food – not too runny, not too solid. As your child starts to develop better control over her tongue and mouth, you can slowly increase the thickness of the food. This helps to develop chewing skills and enables your child to eat food that is richer in nutrition (because it is less liquid).

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 5

"Knowing what you now know about nutrition and food texture, which of these are easy or difficult textures to eat?"

- Biscuits
- Ugali or kichuri
- Rice with cabbage or kale strips
- Chappati
- Pumpkin
- Mandazi or samosa
- Mashed avocado
- Mashed beans or dhal
- Stew or fish curry
- Matokeor banana
- Yoghurt

"Why did you give those answers?"

Explain that, in addition to avoiding runny or mixed consistencies, children with chewing and swallowing difficulties should avoid 'tricky' textures (such as

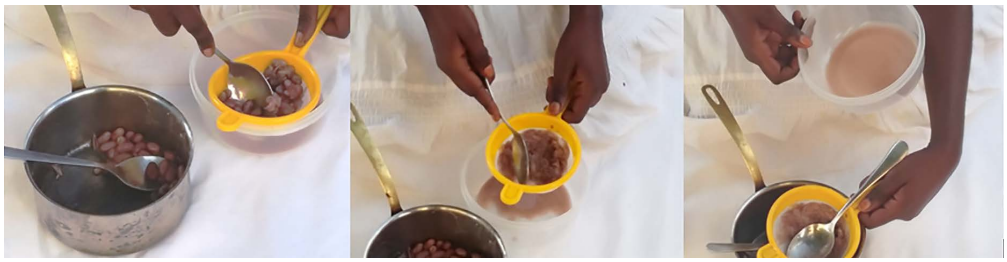
bitty, crumbly, dry, crispy, chewy, stringy, floppy), as these may cause choking -prevent your child from breathing- or it may go down the wrong way and cause a chest infection.

This is the right answer:

✗	✓
Biscuits (dry, crumbly and not usually nutritious)	**Ugali or kichuri** (smooth and nutritious)
Rice with cabbage or kale strips (rice breaks up in the mouth and cabbage or kale is floppy)	**Pumpkin** (smooth and nutritious)
Chappati (chewy)	**Mashed avocado** (smooth and nutritious)
Mandazi or samosa (crispy, chewy and dry)	**Mashed beans or dhal** (smooth and nutritious)
Stew or fish curry (mixed consistency)	**Yoghurt** (smooth and nutritious)
Matoke or banana (smooth and nutritious but can be quite chewy - some children might manage this, some not)	

Activity 6

Give everyone 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.



4: Positioning for Feeding

This is a good time to reinforce positions learned in last session.

Head and body: Sitting upright. Head facing forwards and neck long.

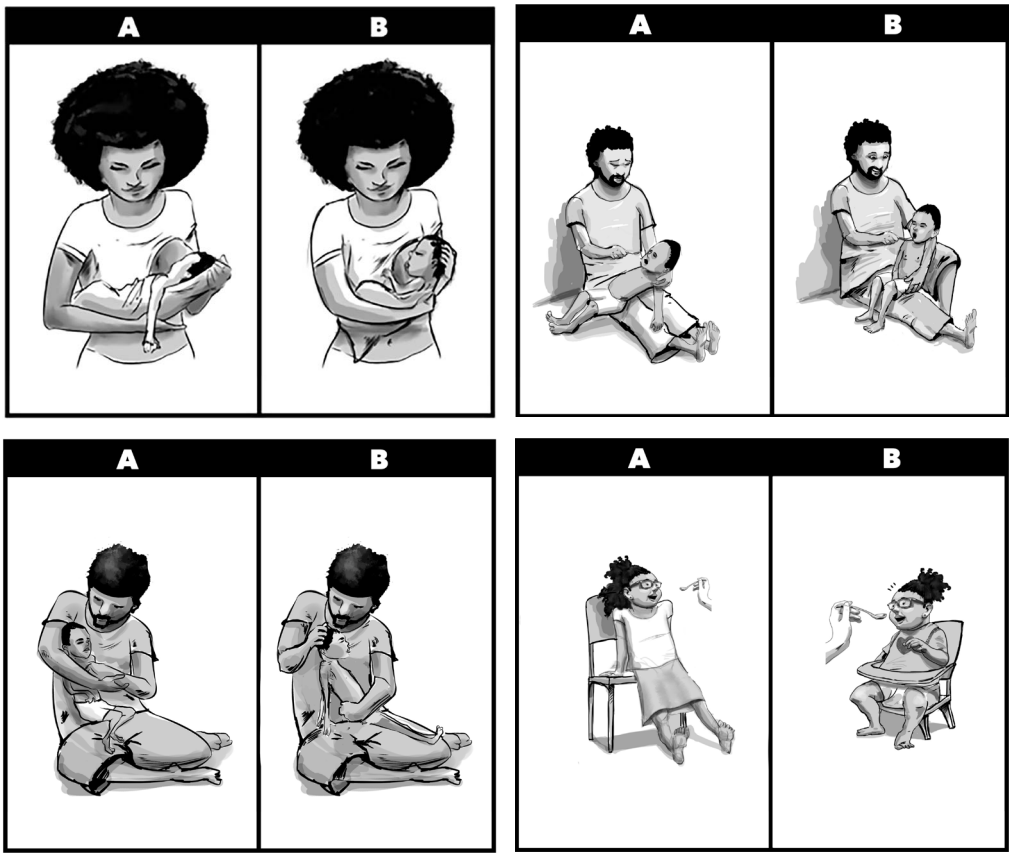
Shoulders and arms: Forwards.

Legs: Hips and knees bent at 90°.

Activity 7

In 2 groups, look at the card sets (a+b) showing different positions.

Ask the groups to choose which they think is the best position for feeding from each set.



Ask

Ask a different person each time to explain one card: *"Can you say why you chose one position rather than the other?"*

Explain

Both a 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 onto their lungs. Lying down is not a 'safe' way to feed as it causes chest infections, which are dangerous for your child.

Sitting up also allows children to chew and swallow more easily and to learn to feed themselves. It also reduces the risk of vomiting.

Activity 8

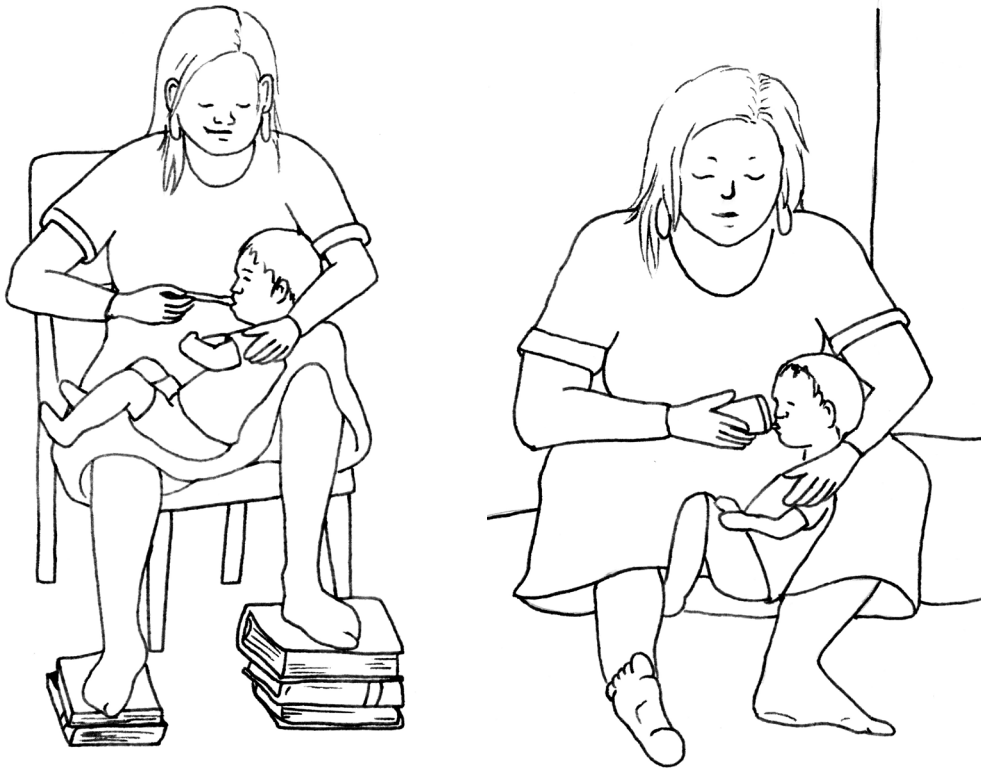
Sit on a chair in the middle of the group in a poor position.

Ask the group how they would change your position to make it better for eating. As each person makes a suggestion, ask them to come and correct your position.

Point out that if you start with the bottom and hips and get them centred and at the back of the chair, it is easier to position the rest of the body.

Use a doll (or one of the children in the group) and demonstrate how to position a child for feeding when sitting on a chair or sitting on the floor.

Show pictures 4.04a and b, act out the positions with the rag doll, and explain how to position well.



Lap feeding:

Feeding your child on your lap is more suitable for younger smaller children.

On a chair, couch or bed:

- Make sure you are comfortable.
- Keep your upper arm against the top of her head and not behind her neck. Make sure you can see your elbow.
- Hold your child's bottom firmly between your legs so that she cannot push back.

- Support her knees with one leg and her back with the other. Raise the leg that is supporting her back by putting something under your foot.
- Bring her arms forward and shoulders forward.

On the floor:

- Lean against a wall.
- Put a cushion under your raised knee.
- Make sure your child's bottom is well between your legs with her hips bent.
- For a bigger child, or for one who pushes back very strongly, try resting her bottom on the floor and push her legs towards her chest.
- Place your leg across her feet to hold them flat.

Other ways to help good positioning:

- If your child is sinking down too far between your legs try putting a towel/ blanket underneath her.
- If her back is rounded give her something to lean against.
- Use a supportive chair.

Feeding in a supportive chair (4.04 c-e)

Photo by: CECHE Foundation

Photo by: Motivation

It is good to get children used to sitting in a supportive seat as early as possible. Independent sitting is an important part of developing and being able to learn about the world around you. At mealtimes, a supportive seat can help children to learn to eat better and feed themselves more easily. It also allows the caregiver to concentrate on providing sensitive and supportive feeding methods, not having to worry about positioning as well.

Supportive seats can be made locally out of low-cost materials. Children who need full support for sitting will need a seat with a slightly tilted back. Tilting the seat as well as the backrest will keep a 90 degree angle so that a child will not slide out. A soft, washable lining will help a child to be more comfortable. Rolled up towels can be used as padding, to make sure children

are well supported around hips and body, as well as behind the head and neck. Also make sure the seat is the right size - a child should be able to sit with their buttocks against the backrest, or they will slide forward.

Summarise:

- Position your child well before feeding her.
- Good positioning will make feeding easier and safer.
- Make sure her head is not leaning back or flopping sideways, and that her chin is tucked in so she can swallow safely.
- Playing with your child in these positions will help her get used to them.

5: Utensils

SPOON

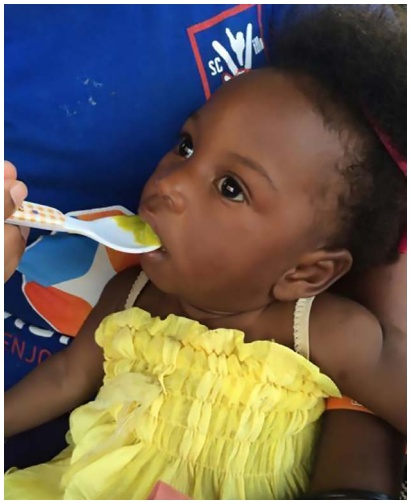
Show a small metal spoon, a big metal spoon and a strong plastic teaspoon.

Ask

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

Make sure the following points are covered:

- A good quality plastic teaspoon is best, it gives small mouthfuls, which are easier and safer for your child, and it prevents harm if your child bites hard onto it.
- Metal is often too hard/sharp for your child's mouth.



Activity 9

In pairs:

- One person is the caregiver and the other is a child.
- Take the caregivers away from the group so that the 'children' cannot hear what you are telling them.

- Tell the caregivers that they must feed the 'child' **very quickly** with the big spoon.
- The caregiver then feeds the 'child' with a few big spoons of yoghurt very quickly.

Explain

A child's tongue moves forwards and backwards when she drinks from the breast or bottle. As she gets older, your child has to learn to use different tongue movements to manage more solid food.

When using a spoon to feed your child:

- Give food from the front and straight.
- Give food at the right pace for your child.
- Place the spoon with the food touching the top lip so that she can feel it and use her top lip to remove the food from the spoon.
- At first she will suck on the spoon like she did on the breast/bottle but this will change.
- Your child should bring her jaw up, but if she doesn't, place your finger under the jaw and give some support.

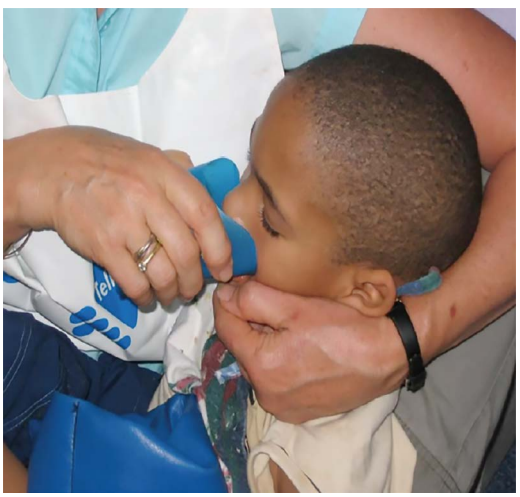
Don't lift the spoon up and drag it against the top gum when taking it out - keep the spoon straight as you take it out of her mouth.

Remember, some children who are breast or bottlefed may not like to eat from a spoon or drink from a cup at first. Keep trying and they will get used to it.

You can encourage your child in independent feeding by putting her hand on the spoon. You can put your hand over her hand. Together, hand over hand, you can help your child to learn to feed herself.

CUP

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



Facilitator Tips:
The cut-out section in the cup allows the cup to be tipped upward without having to move a child's neck back in order to finish drinking. Children drink from the side that is not cut out.

Activity 10

Ask everyone to look up to the ceiling and try and swallow.

"How difficult does it feel? What kinds of cups do you think are better for giving your child a drink and why?"

Make sure the following points are covered:

- The cup that is not cut away makes your child tip her 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 your child.
- You can also use a short clear cup that you can see through e.g., a medicine cup.

Explain

A cup is introduced when

- Your baby cannot suck or gets tired on the breast or bottle.
- Your child is 6 months and ready to drink sips of water.

Ask

"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:

My child:

- May not wake up enough to drink.
- May not actively swallow.
- May spill liquid from her mouth.
- May cough/choke.
- Might breathe the liquid into the lungs.
- May not control how fast the liquid comes out of the cup.

Explain

- 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 it a little allowing the liquid to touch the upper lip then wait. Do not pour liquid into the mouth.
- If your child struggles to close her mouth, help her by placing your finger under the jaw and lips for support.
- Give single sips and observe the swallow.

BOTTLE FEEDING

Ask

Many parents use bottles to feed their child when they are older.

"Who feeds their child with a bottle? Can you explain why?"

Facilitator Tips:

Many participants are apprehensive about changing the way that they feed their child, because either it is easier or they find it difficult to feed their child with a spoon or a cup. This is a good place to gently start this conversation.

- Reinforce the message that the cup will help their child to learn to sip and swallow well.
- Bottles encourage tongue patterns that babies use.
- This makes it harder for your child to learn to eat food.
- Being fed with a bottle discourages independence and self-feeding.
- Feeding purees through a bottle is unsafe as your child needs to use more mature tongue movements and be sitting more upright in order to swallow puree safely.
- The teat of a bottle can easily carry germs and so is less hygienic.

Activity 11

Allow everyone to try out cup feeding.

Observe and advise to ensure correct technique.

6. Understanding how your child eats: kind and supportive feeding methods

Activity 12

In groups of three, discuss other things that you think are important in helping your child to eat and drink well.

"What do your child's reactions to food and drink tell you?"

Ask the groups to share their ideas.

Ensure that the following points are covered:

- Give small mouthfuls, and one mouthful at a time.
- Give your child plenty of time.
- Provide support to her jaw if she struggles to keep her mouth closed when there is food inside. This will reduce the amount of food she spills from her mouth and therefore help her to eat more.
- Talk to her and encourage her to eat and have fun at mealtimes.
- Be gentle. If she cannot finish her food because she is getting tired, stop and offer her a little more later.
- Watch your child's reactions to see when she is ready for the next mouthful. Never force feed. Allow her to be involved eg. touching your hand/the food/the spoon etc.
- Start with food – finish with a sip of water or milk so that she doesn't fill up on liquid before eating.

Summarise that being kind and sensitive protects children from feeding methods that put their health at risk (eg. force feeding), they make mealtimes more relaxed and enjoyable for both a child and person feeding them, and they encourage a child to want to eat more.

PRACTICAL FEEDING SESSION

Activity 13

Show the 'Before and After' clips.

After each 'before' clip, ask everyone *"What difficulties the children are having and how you could improve? What is different in the 'after' clip?"*

Sit in a circle and either give your child a drink or feed her some yoghurt, trying to follow all the advice. Encourage everyone to help one another.

In Bangladesh the video clips were a good way of encouraging discussion. You will need to make your own video clips of children demonstrating good and poor feeding practice –ask parents if they are happy for you to film their children and explain you will use them to help other parents.

TOWARDS INDEPENDENT EATING

Explain

Explain why it's good:

- You are very busy and may not always have enough time to feed your child.
- Your child will be more interested in eating and less reliant on you.
- Children enjoy feeling independent and react against a feeder that is 'controlling'.
- Try not to worry about mess, all children make a mess when they are learning to eat.

"Has anyone tried to do this with their child?"

Explain using a doll:

- Guide her hand to help her.
- Put a banana in her hand and guide it to her mouth. You might be surprised at how much she manages to feed herself.
- Don't stop her putting her hand in her food and trying to feed herself.
- Put a wet cloth under the bowl to stop it moving.
- Bend the spoon and put padding on the handle to make it easier to grip and get into her mouth.

Ask

"What one thing have you learned today that you will now do differently at home?"

"What one thing will you try to help your child feed herself?"

MONITORING PROGRESS

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?"

Take Home Messages:

- Your child may take time to learn to chew and eat solid foods and drink from a cup. She needs help to learn these skills in the right way.
- She may have difficulties with eating and drinking. These difficulties can result in malnutrition, dehydration and chest infections. There is a lot that you and your family can do to help reduce these difficulties.
- If your child frequently vomits during or after meals, it is important that she is seen by your medical team.

Things you can do:

- Position your child in an upright position, with her chin tucked in slightly.
- Feed her 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 do not force feed.
- Teach other family members to feed your child in the same way you do.

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?"

Allow time for discussion and interaction with each other.

Facilitator Tips:

Situations that can be challenging is if answers is unspecific: for example "everything is ok" or "I am tired". You can encourage everyone to talk more by asking "why?" or "what happened" or "how do you feel about that?"

LEARNING TO MOVE

5

This module covers the following information:

Learning to move

Help your child look at you and follow you with their eyes

Supporting your child to reach and hold items

Learning to roll

Making your child's body stronger

Massaging and stretching

Monitoring progress

Sharing emotions and feelings

LEARNING TO MOVE

Materials

Flipchart, towels, toys, Diagrams 5.01 – 5.04, pens.

Icebreaker

In pairs, ask one person to sit on a chair or lie on the floor in an uncomfortable position. The other person observes and changes the position to make it more helpful, using pillows or blankets. Swap roles after a few minutes so everyone has a turn.

Discuss how each position felt.

Explain

Children learn to move initially by controlling their head, rolling, sitting, standing and even walking. Progress for young children with developmental disabilities is slower than for other children. Today we will learn practical ways to maximise your child's movement skills.

HELP YOUR CHILD LOOK AT YOU AND FOLLOW YOU WITH THEIR EYES

Activity 1

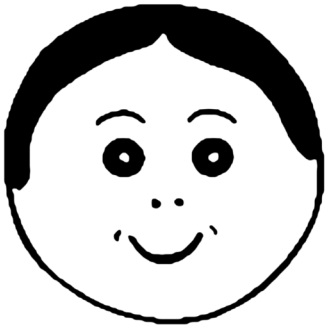
Eye contact is a first step towards communication and your child first learns this by looking at you and watching you while you move. Following a moving object or person is important for your child's head control, and for eyes and hands to work together.

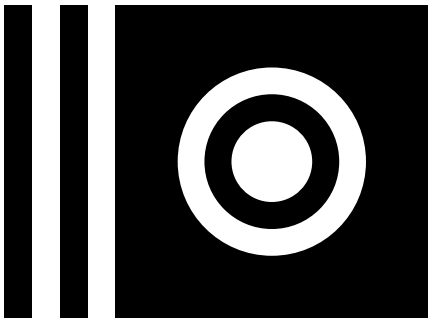
Get everyone involved; fathers, grandparents and other children, and have fun and be playful... that is most likely to make your child smile!

Some things you can try are:

- Give your child things to look at – put simple pictures/ toys within reach or nearby (Homemade toys, mirrors or wearing a bright scarf/ hat are all really good, you will learn how to make homemade toys in a few sessions' time).
- Bring your face near to your child - her 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.





- If your child has trouble seeing, 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 she can touch like soft fluffy fabrics, cool smooth stones, rough safe items like loofahs etc.

NOW PRACTICE WITH YOUR CHILD

SUPPORTING YOUR CHILD TO REACH AND HOLD ITEMS

Ask

"How can you help your child learn to reach and hold things? What have you tried at home?"

Explain

- Reaching for things when lying on your back is harder because your body has to work against gravity, so practice reaching from side-lying and supported sitting instead.
- Start with your child in a very supported sitting position, so she feels balanced. If your child doesn't feel safe and comfortable then she's unlikely to try and reach forward. 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 brightly coloured toy/object that she likes. Hold it close and encourage her to look at it then reach for it.
- It is easier to reach for objects when they are placed low and in front of your child.
- If your child doesn't reach out, you can help guide her from the elbow, towards the object. If your child can reach towards the object but can't open her hand to hold it, gently open her hand and help her. This will helps stretch stiff arms and hands.
- Once she has an object in her hand let her explore it, shake it, move it to her mouth. If she cannot do this alone 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, bright objects or foods can be good to motivate a child to try and reach out.

NOW PRACTICE WITH YOUR CHILD

When practicing reaching and holding, praise your child if they try. Keep praising them with every effort and improvement, even if small.

LEARNING TO ROLL

Ask

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

Explain

- 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 her stomach. Pull her arm forward on the side you want her to roll towards, then as before encourage her to follow a toy with her eyes and head, assisting if needed.
- 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 practicing rolling but also make sure you are practicing the other skills too.

NOW PRACTICE WITH YOUR CHILD



MAKING YOUR CHILD'S BODY STRONGER

Explain

Even if your child can't crawl or stand on her own, you can help her learn to hold her weight with her arms or legs. This helps to make your child's bones stronger, reduces stiffness, and increases strength in a floppy child.

Good ways to start weight bearing are:

1. Lying on the stomach using her arms, elbows or hands to hold herself up.

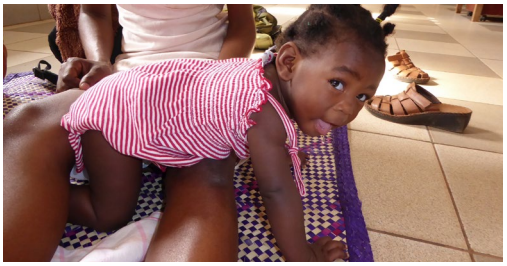
2. Kneeling

Hold your child in position.

3. Crawling position

You can place your child in this position over your legs or over a rolled up blanket to start with.

4. Supported standing (briefly discussed in the positioning module).



Reinforce that it is important:

- To strengthen the legs.
- To protect the hips.
- Being upright helps children who have chest infections or trouble breathing.
- To help the emptying of the bladder and bowels (useful if your child is often constipated).
- Helps your child see around her and 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 her so she doesn't fall.

• Using a standing frame (these are good as your child gets bigger, ask the local hospital if they make them).

NOW PRACTICE WITH YOUR CHILD

MASSAGING AND STRETCHING

Explain

Moving, twisting, massaging and stretching are all ways that we can loosen your child's stiff body. This will help her to move and you to handle and care for her.

1. Good positioning

If your child is stiff and does not move enough, her muscles will become tight and short. A good position can keep her muscles long. For example, if your child tends to 'curl/bend' herself up then lying on her tummy and standing are good stretches.

2. Use time in your daily routine

- Playing with your child and encouraging her to move. Movements help her stretch her muscles.
- Helping your child reach for and hold toys (guiding her hand out or up towards a toy).
- Make sure you are gentle and slow with 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. It is best to consult a health worker - or a therapist (such as a physiotherapist) if they are available locally.

NOW PRACTICE MASSAGING YOUR CHILD

MONITORING PROGRESS

Ask

Ask everyone to act out one new movement they have learnt today which they will show to another family member.

Take Home Messages:

- Children with developmental disabilities 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 opportunity they have to learn.

SHARING EMOTIONS AND FEELINGS

Ask

"How did you find talking about today's subject? Did it raise any emotions or feelings that you did not expect? How have you been feeling this week?"

Allow time for discussion and interaction with each other.

COMMUNICATING 6

This module covers the following information:

Communicating

How we communicate and why it is important

Helping your child develop good communication skills

1. Show how to encourage your child to make eye contact
2. Show how to encourage your child to take turns
3. Show how to encourage your child to make choices

Other forms of communication

Additional information on children presenting challenging behaviour

Monitoring progress

Sharing emotions and feelings

COMMUNICATING

Materials

Flipchart, paper, pens, toffees, empty crisp packets, other everyday objects with different textures or sounds such as rattles, squeaky toys, ball, doll, cell phone, 2 picture boards for the tea game, toy tea set, pictures 6.01 and 6.01, 6.02, 6.03 and 6.04 on card (photocopied and cut out for group work).

Icebreaker

In pairs: ask for a volunteer to put three or four toffees in their mouth and start chewing. Whilst they are chewing they must tell the group their name, favourite food, and what they would do with the money if they won the lottery.

Ask

Ask the speaker how it felt to do this, and ask the rest of the group how they felt listening.

The speaker will have difficulties expressing themselves with a sweet in their mouth and everyone else will find it hard understanding them.

Children with developmental disabilities often find it difficult to speak clearly, which means the cycle of expression and understanding often breaks down.

Explain

Explain what we will learn together today.

By the end of module 6, you will:

1. Understand what communication is and why it is so important.
2. Be more confident to help your child understand better.
3. Learn what you and your family can do to help your child to communicate.

HOW WE COMMUNICATE AND WHY IT IS IMPORTANT

Ask

"What do you think communication is?"

This discussion should include listening to others, understanding what they are saying, telling others what you think, want or feel.

Communication is:

- Understanding what others say to us.
- Expressing our thoughts, needs and feelings.
- A 2-way process.
- A basic human right.

Discuss the ways we communicate:

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

Activity 1

Split into groups of three. Give one person in each group one of the following sentences (either by writing it down or whispering it):

- My foot is painful.
- I want to go outside.
- I am tired.
- I am bored.

The person goes back to their group and tries to 'explain' the sentence 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.

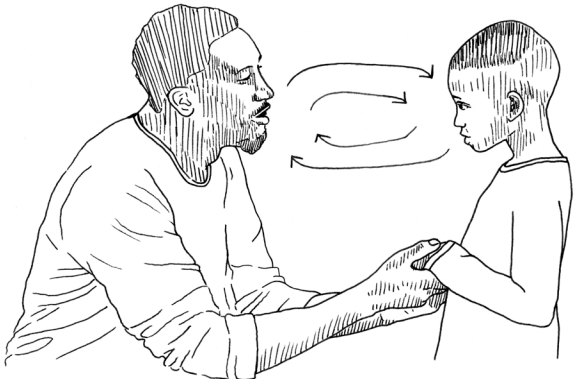
After two minutes the person moves on to another group and tries to explain to them.

Ask

Regroup and ask:

"How did the person communicate what they meant? Was it easier or harder to explain as you went to different groups?"

Use image 6.01 to explain the cycle of communication.



Discuss the communication techniques used and what others can be used, making sure the following are covered:

- 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.

Facilitator Tips:

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.

Ask

"Why is communication important to young children?"

Discuss the following reasons:

- It is an important part of **bonding**.
- **Expressing** our needs and wants.
- Establishing **relationships and making friends**.
- Key in **learning new things**.
- When communicating with a child with development difficulties, the cycle of successful expression and understanding between the two of you often breaks down.

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?"

Explain

Using a doll, point out the different parts of the body we use in communication, describing the following;

To **understand** what someone is trying to communicate, you need:

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

To **express** yourself you need:

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

Explain

Explain communication will be harder or easier depending on the severity of the developmental disabilities, because it affects how well your child can think and learn. A child with **no problems thinking and learning**:

- Will understand what others are saying.
- Will think about what to say but her speech may be unclear.
- If her speech is unclear and expressing herself is difficult, people may think she have an intellectual disability even though she doesn't.
- She will need to learn other ways to express herself otherwise her communication cycle breaks down.

If your child **does** have learning difficulties she may find it hard:

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

Speech is generally the easiest way to communicate, but young children with developmental disabilities should be helped to develop **all** methods of communication.

If she struggles to speak clearly, other communication methods can help get her message across, such as eye-pointing, finger pointing, using objects, gestures, picture boards, signing or written language are very helpful.

HELPING YOUR CHILD DEVELOP GOOD COMMUNICATION SKILLS

Explain

Communication skills develop in a sequence of steps:

- Listening and understanding comes before talking.
- Foundation skills include making eye contact (looking) and listening, taking turns and making choices. Playing is a great way for your child to learn these skills.

Talk to your child.

Even if your child cannot use speech to communicate, don't stop speaking to her. Other family members, friends and neighbours can talk to her too.

Important: Make sure you pay attention to any sign of ear ache in your child. If left untreated this could lead to ear damage and loss of hearing which can cause additional communication problems.

Facilitator Tips:

In the break think about which children you would like to demonstrate eye contact, turn taking and making choices and ask their caregiver if they will be happy to show the rest of the group.

Activity 2

Ask one person to:

1. Show how to encourage your child to make eye contact

Ask

"What did you see the caregiver do? What did you see the child do? What does using our eyes help us to do?"

Ensure the concepts below are covered:

- Hold your face close to your child's face and talk to her. Try to encourage her to look at you.
- Call her name; when she looks at you, praise her by smiling and talking. Use lots of facial expression. Make sure you allow her time to look at you, it may take her a little while at first.
- Sing songs to her.
  She will enjoy the rhythm.
- Play Peek-a-Boo.
- Show her different objects. Shiny objects such as a DVD or tin foil will draw her attention. You can also use everyday objects with different textures or sounds. Let her play and explore objects. Talk to her about the different objects.
- 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.

Activity 3

Ask one person to:

2. Show how to encourage your child to take turns

Facilitator Tips:

Caregivers have said that they did not know that it was possible for them to help their children to make choices. This is a good time to explore this and how choice making can work for each family. Everyone enjoyed having their children in the same room so that they could practice.

Ask

"What did you see the caregiver do? What did you see the child do?"

Examples may include:

- Clap your hands and then ask her to clap hers. Help her to clap if she finds it hard on her own or has difficulty understanding.
- Hold a ball in front of her, ask her to wait and then hit the ball.
- Play music. When it stops, wait for a response from your child before switching it on again.
- Play music on the cell phone, then stop the music, or bounce your child on your knee and then stop and wait for a response from her (for example looking at the phone/looking at you/making a noise) before switching it on again/ starting bouncing again.
- Roll/throw a ball between you, or build a tower of little blocks together say eg Mummy's turn…your turn etc.

"What does waiting during play help us to do?"

- Waiting is very important, children with developmental delay are often slow to respond, so give your child plenty of time.
- When she makes a sound, uses facial expression or body movement, copy her and then take turns talking. With babies, imitate their laughter and facial expressions.
- Respond immediately to any attempt she uses to initiate communication.

3. Show how to encourage your child to make choices

Ask

"What did you see the child do? What did you see the caregiver do? How may understanding your child's choice help you and your family? How will your child being understood help her?"

- Give her a choice of things to play with or to eat.
- Show her the things she can choose from – place them in front of her where she can see them best. **Start by offering a choice between two things only**, then with time increase it to three 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 her to choose. E.g. 'Do you want water or milk?' or 'Do you want the ball or the doll?'

Wait for a response, which could be pointing or looking towards one of the objects. (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'.

Facilitator Tips:

Encourage participants to call their child by her name so that she can recognize her own name, and not just a nickname. Using words and a tone of voice that people would use to talk to each other is helpful to stimulate children to learn more words.

Ask

Ask everyone to summarise the main points, and write them up on the flipchart.

Checklist:

✓ Get your child's attention first.

✓ Make sure you are both positioned well – facing one another, on the same level, and with your child well supported.

✓ Use eye contact.

✓ Talk about what is happening around you and what you are doing.

✓ Use facial expression and gestures.

✓ Take turns, and encourage participation.

✓ Offer choices.

✓ Praise and encourage – clapping, cheering etc.

✓ Do not force her to speak, but encourage any attempt to communicate.

✓ Do NOT use baby talk.

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

OTHER FORMS OF COMMUNICATION

Activity 4

It is not possible to predict the future and no one knows how well your child will communicate when they are older.

Children with developmental difficulties differ a lot in their abilities to understand and express themselves. Many children with developmental difficulties 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 5

Discuss how we can help our children express their needs non-verbally. Reinforce the following:

It is very important to respond immediately when your child tries to communicate.

Using sounds, gestures or facial expressions:

- Watch your child to try and understand what she means when she uses sounds, facial expressions, body movements or gestures.
- Talk to your child about what she needs. Ask her to show you how she communicates things like 'I am hungry' 'I am thirsty' 'I want to rest' 'I am cold' and then practice these together.
- Help her respond 'yes' or 'no' and make choices with gestures. Mold her hands for her if she needs help.

Pointing (using eyes, or hand) or touching:

- Use objects to show your child what she is about to do, holding the object up and telling her what you are about to do e.g. a cup for drinks time, a flannel for wash time etc.
- Also offer choices by holding two objects up and letting her show you her choice, by looking, pointing or touching.

NOW PRACTICE WITH YOUR CHILD

Using pictures:

- Show your child an object or a person. Match the object with a picture showing the same object or person. Later, when she points to a person or object, encourage her to point to the picture instead. Once your child is comfortable communicating with you in this way, she may be able to use pictures on a board.
- Some children may use a few basic pictures to express their needs.
- Others may have a big collection of pictures to use for quite complex communication. Pictures can include questions, people, things, actions, feelings, daily needs.

A simple communication board may be useful. This is something to discuss with your speech therapist or occupational therapist. Some children may not be able to speak but they will still be able to communicate (image 6.04).

Photo by: Enablement

ADDITIONAL INFORMATION ON CHILDREN PRESENTING CHALLENGING BEHAVIOUR

Explain

Explain children with challenging behaviour can often cause the most stress for parents.

Ask

"What kind of challenging behaviours does your child have? How does it make you feel? How do you cope with it?"

Activity 6

Discuss the following:

- Your child needs love and attention. Children who feel loved behave better.
- All behaviour is a form of communication, so try to work out what your child is trying to tell you.
- Make your instructions clear. Speak in short sentences and don't give too many instructions at one time.
- Be consistent in the way that you respond.
- Reinforce the behaviour you want. You can do this by:
  - Giving a reward after the desired behaviour.
  - Praising the behaviour, not the person.
- Physical punishment does not teach 'good' or 'correct' behaviour – so do not spank or beat your child, instead ignore behaviour you do not like.
- For behaviour you cannot ignore, try "time out". Take your child to a safe place where you can see her, away from where the fun/activity is happening.

MONITORING PROGRESS

Take Home Messages:

- We all communicate in many different ways.
- All children can communicate, we just have to understand how they are trying to do it.
- Children with developmental difficulties may need extra time and help to develop their communication skills.
- Opportunities to practice communication skills are everywhere, for example practice eye contact while changing your child, practice making sounds and turn taking when bathing.

Ask

"What two things have you learnt today that you will share with at least two other members of your family to help improve communication with your child?"

"Does anyone have any questions?"

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?"

Allow time for discussion and interaction with each other.

Facilitator Tips:

Situations that can be challenging is if answers is unspecific: for example "everything is ok" or "I am tired". You can encourage everyone to talk more by asking "why?" or "what happened" or "how do you feel about that?"

PLAY

7

This module covers the following information:

Play

What is play?

Why is play important?

Making and adapting suitable toys

Case studies

Monitoring progress

Sharing emotions and feelings

PLAY

Use this module to organise play activities for children attending all sessions.

Playing with the children is an important part of every session. This needs to be planned, so there is play equipment and support workers.

Facilitator Tips:

Start collecting household objects and bits of recycling in advance and ask each caregiver to bring some things to the session.

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.

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.

Materials

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

Pictures of toys you can make, materials to make them and instructions.

Don't using very small objects with younger children as they may choke on them.

Icebreaker

In groups of 3, give each group one inexpensive everyday item (eg cup, piece of cloth, container, ball). Ask everyone to use their imagination to transform the object into something else.

"Now we are going to use our imagination and creativity."

You can give an example, such as holding up a roll of tape and saying *"This is not a roll of tape, this is my red shiny apple."*

Pretend to take a bite and make a disgusted face 'with a worm inside'.

Ask

Ask each group for a few examples.

The object of the game is to show how our imagination works with play and how children have an even greater imagination than adults.

Explain

Explain that most children will find ways to play with any objects around them. We will learn together about how play can **'awaken the brain'** to promote a child's development.

Explain

Explain what we will learn together today.

By the end of Module 7, you will:

1. Understand and explain how play 'awakens' the brain.
2. Help your child 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.

Facilitator Tips:

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 developmental disabilities, 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 these sessions, 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.

WHAT IS PLAY?

Ask

"What is play?"

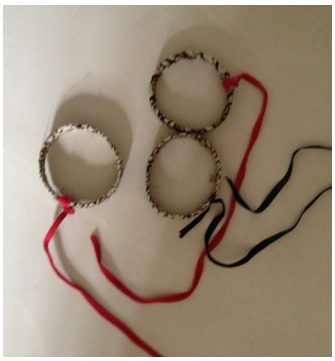
Use the images 7.01 (a-f) as a visual prompt to facilitate the discussion.

If everyone struggles to answer the question then you could ask them to describe what is happening in the photos

Play is any activity your child **CHOOSES** to do, and has **FUN** doing. Through play, she uses her **SENSES** to explore and learn.





Ask

"What are senses?"

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

Note: Movement isn't a sense but we use our senses to move and we move when we play.

Activity 1

Demonstrate the following play activities and discuss which senses are being used. If possible involve some of the children in the group:

- Enjoying the sound and feel of a rattle.
  Answer: hearing.
- Handling different objects – soft, hard, prickly etc.
  Answer: touching/ feeling.
- Hide and seek - hide an object under a lid or box and get your child to try and lift the box to find the object, or hiding yourself from her and seeing if she can move or look for you.
  Answer: seeing.

- Singing and clapping games.
  Answer: sight, movement, hearing.
- Splashing in water.
  Answer: feeling and movement.

WHY IS PLAY IMPORTANT?

Activity 2

Turn to your neighbour and discuss:

"Does your child need to play?"

"Have you seen any ways that play helps your child?"

Explain

Play is important for your child because:

- Play is fun, and it helps her learn about things around her.
- She will use and develop her senses.
- Having fun will make her want to move more.
- Playing with others helps to develop her communication skills.
- Every child has a right to play.

> Being able to play together makes children happy, and not being able to play with other children makes them feel sad.
> *"I play alone at school and at home. I like to play, but I cannot run. I feel sad when I see my friends playing and running around, as I cannot run like them." I like to go to the training and I feel happy when I hear that I'm going to training. I can play there and they teach us many things."*
> **Child, Bangladesh**

Ask

"Does your child need expensive toys? Does she need help to play?"

"What do you notice when your child plays during the sessions?"

Explain

- During the sessions children aren't playing with expensive toys.
- Favourite toys are often household items, and almost anything can be used as a toy for play.
- Your child may need help to play. Encourage her.

Facilitator Tips:

In Bangladesh, toys were not made at home, so making toys in the session to take home was a really helpful activity. During the home visits more time should be spent on play, so families know how and why to play with their child.

MAKING AND ADAPTING SUITABLE TOYS

Activity 3

Make toys - encourage everyone to use their imagination and the materials provided to make a simple toy for their child.

Ensure everyone gets an opportunity to make at least one toy which they will be allowed to take home. When the toys are complete ask everyone 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.

You can run this as a separate session and invite siblings to join.

In the facilitator resources are example of toys that could be made, use these are reference to help you – you do not need to explain them in detail to the group, the aim of this session is to create toys to play with.

CASE STUDIES

Activity 4

Split everyone into 3 groups. Give each group a case study (found in the facilitator materials). Ask them to read through the information about the child, and discuss the questions. Case studies (have them printed on card, one case study per group). You can also make your own case studies from your local context, if more suitable.

Ask each group to nominate one person to feedback to the group discussion.

Case study 1 discussion points:

- If a child has been diagnosed with blindness or deafness, focus mostly on other senses for play.
- How could you or your family help to do this?
- Eg using touch for a child who has difficulty seeing and visual toys for a child who has difficulty hearing.
- BUT: 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.

'If you have a child who can see, but not well, you can use your words and let her touch and smell toys and objects. This will help her to understand what is around her.

Case study 2 discussion points:

- This case study brings up the issue of negative attitudes and discrimination – what ways could you and other members of your community begin to address that?
- Share what you learn from this session 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 for 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 discussion points:

- This case study asks us to think about how 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 them about one of the games we have discussed in this session. Show them how to play it with your child, and explain how and why it is important to your child's development.

Ask

Ask everyone to think of ways more children can be included in play, such as:

- Share information with friends so they can help care for your child.
- Explain to siblings and other children which activities your child can do, and adapt toys and activities so she can play along with them.
- Ask a teacher to talk to local children about how to include children with disabilities. They could set up a 'buddying' system for non-disabled children to help children with disabilities.
- Set up a parent support group, and invite everyone to bring their children so they can meet. The group could run a session on disability in your community.
- Make local play areas accessible to children with disabilities.

MONITORING PROGRESS

Ask

Ask everyone to share one activity that they plan to try at home with their children.

"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?"

Take Home Messages:

- Play is very important, and will help your child develop more.
- Use everyday objects for play, and involve other children in making toys your child can play with.
- We can find ways to make play inclusive for all children.

SHARING EMOTIONS AND FEELINGS

Ask

"How have these sessions influenced your relationship with your child? And with your family? Did it raise any emotions or feelings that you did not expect? How have you been feeling this week?"

> *"It is very useful, we stop to analyse the week and everything that happened, what was lacking. It is a moment when we can think and reflect, it is very good. Sometimes we do not have support at home, from father, mother or husband, then when you enter a place that can do that, it is very good. I feel very taken care of here."* **Mother, Ghana**

EVERYDAY ACTIVITIES

8

This module covers the following information:

Everyday activities
Introducing everyday activities
Role play
Practicing together
Carrying
Washing and bathing
Brushing teeth
Undressing and dressing
Toileting
Sleeping and resting
Monitoring progress
Sharing emotions and feelings

EVERYDAY ACTIVITIES

Materials

Flipchart, pens, buttons/bottle tops (different sizes and colours), everyday household objects such as plastic cups, cutlery etc., flip chart and pictures 8.01-8.06, doll, basin of water.

Icebreaker

"Does anyone have a song they like to sing with their child that they can share with the group?"

Encourage everyone to take part and sing with their child.

Explain

By the end of Module 8, you will:

1. Understand how to use everyday activities to help your child develop.
2. Be able to explain this to your family.
3. Consider how different family members may be involved in supporting your child's development.

INTRODUCING EVERYDAY ACTIVITIES

Activity 1

Display picture 8.01.

Ask

"What activities are shown in the pictures?"

"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 pictures?"

Explain

- **If** you stimulate your child **during everyday things**, this will help her **develop** without taking up extra time.
- Talk to your child about the things happening around her
- Show her what you are talking about, and get her to look at and feel objects.
- Offer choices (e.g. what shall we wash next, your arms or your legs?).

You are the most important caregiver for your child, and you may already be feeling very busy and stressed. How worried are you about finding more time and energy to help your child learn and develop?

Bring up some of these issues in the discussion:

- Think about how you and your family position your child while you are all busy. Choose a position that maximizes their development rather than simply leaving them on their back. For example, sit your child in a basin or a corner safely nearby while you work rather than carrying them, this way your child can be learning to hold her head up or using her hands to play with a toy.
- Think about leaving toys in close reach of your child to encourage her to use her hands.
- Think about the value of talking to your child while carrying them and and doing daily activities.

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

Facilitator Tips:

Caregivers often talk about feeling tired, or not having enough time to care for their child on top of other responsibilities. They are often more stressed, tired, anxious, and feel less supported than parents without a disabled child. Using everyday activities for 'treatment' helps caring feel more manageable and it will be important to explain this.

ROLE PLAY

Activity 2

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

"What do you think about the different ways that these two caregivers bathe their child?"

In the feedback from the group, summarise the following main points (also covered in the module on communication). The story/role play demonstrates how to communicate with your child in an everyday situation:

- Talk to your child about the things happening around her.
- Show her what you are talking about, and get her to look at and feel the objects.
- Offer 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 mother in the second bathing role play/ picture strip also helping her child to develop other skills?"

"Does it always need to be the mother who bathes the child?"

Discuss the following:

Movement and Balance

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

- To sit by holding her in a helpful position (ie. supported) so that she can make choices and use eye contact.
- By encouraging her to balance. (In the top row, the caregiver always holds onto her child, so her child has not been given the opportunity to learn some balancing for herself).

Using her Hands

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

Social and Emotional

- Your child is learning a self-help skill, bathing. Over the months she has just the amount of help and encouragement she needs to learn about bathing.

Thinking and Playing

- Your child is playing and having fun while learning.
- You can involve your child by communicating what you are doing and then helping her to do this with you. You can let your child do more by herself as she learns.

Summary

A helpful (comfortable, supported and stable) position:

- Makes it easier for a child to be more involved with everyday activities.
- Allows her to look around and watch what is happening in the room and communicate more easily with others.
- Allows her to use her arms more easily during activities.

Remember that children with developmental delay can be different from each other and every child has their own abilities and their own difficulties. However, all children have the potential to change and families and communities can support them 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.

PRACTICING TOGETHER

Ask

Ask a volunteer to sit in a poor position and stack bricks.

"How do you feel?"

"Now sit in a good position and do the same activity?"

"Is this easier?"

Explain

Look back to the positioning and handling module and remember the main features of good positioning and handling.

Head and Body

- Your head is upright and facing forwards.
- Your body is upright and facing forwards.

Legs and feet

- Your hips are level, centred and bent at a right angle.
- Your legs are slightly open.

Shoulders and arms

- Your shoulders are not too far back or too far forward.
- Your arms are close to the body and forward, with open hands

CARRYING

Activity 3

As a revision from the positioning session, good carrying positions allow your child to practice using her head and neck muscles. 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. She can free her arms for playing and keeping her hips and knees supported will allow her to control her body.

Ask

Look at the photos that show poor and good ways of carrying your child.

"Can you show us one thing that you will change this week when you carry your child and explain why?"

Facilitator Tips:

This activity will help everyone to recognise a good and poor position in a photograph and then to identify one change that they will make this week when they go home. You can encourage this by asking them to take photos or videos of the change that they make during the week.

Ask

In pairs, demonstrate how you carry your child.

Ask each partner to feedback on the good points, and then suggest one thing further that may help correct the positioning.

Give everyone the opportunity to discuss in pairs which change they would like to try at home with their child. Then ask them to demonstrate how, with their child or the doll. Encourage everyone to support each other to find the best position for carrying.

WASHING AND BATHING

Activity 4

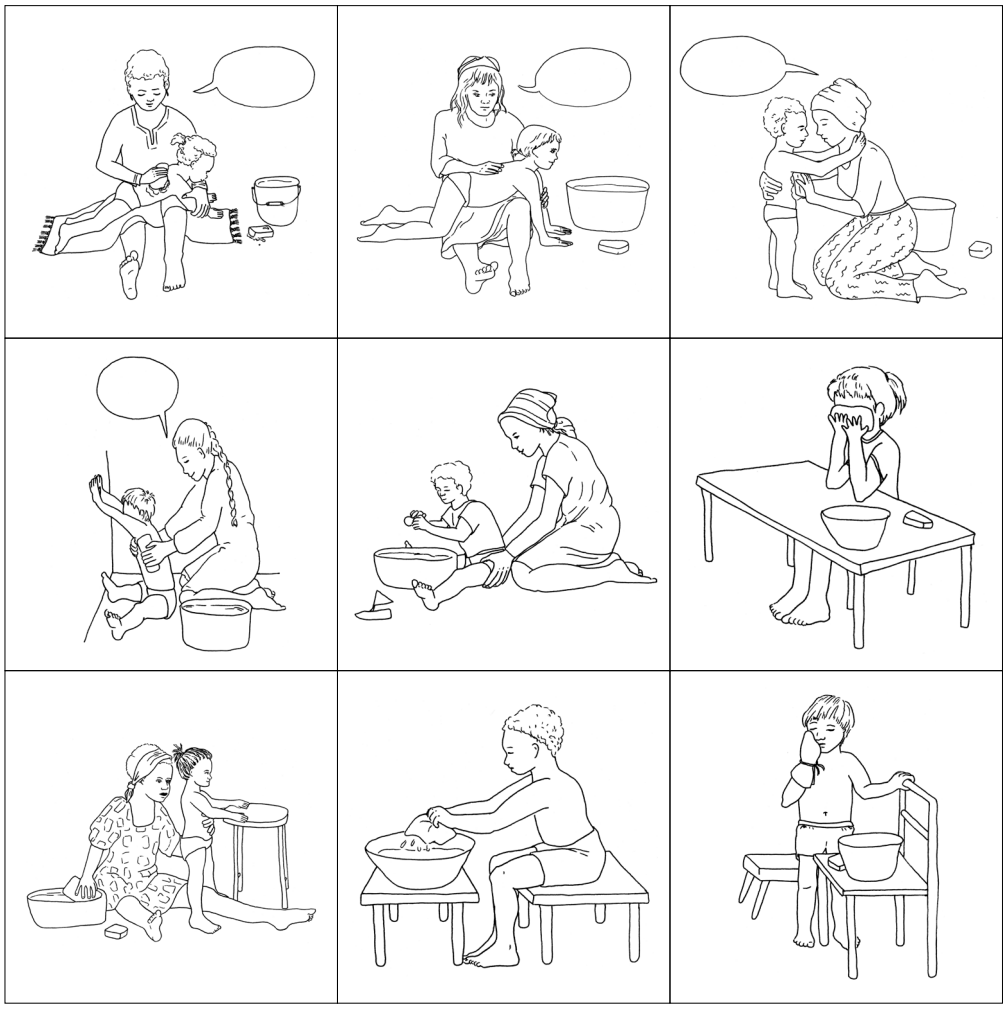
In groups of 2-3, look at picture 8.04.

Ask

"What is happening in the pictures? Which things is your child able to do?"

"How can you use bath time to stimulate your child's development?"

- Make sure your child is always in a good position. Change her position regularly.
- Talk to her about what you are doing, and help her join in.
- In 8.04 the last two positions are good for children who move a lot.



Explain

Some children need to have their faces cleaned often. This can be because they drool or food spills out when they eat.

Your child can learn to close her lips, if cleaning her face 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 small pushing movement with a cloth – do not use a wiping or sweeping motion.
- Always push the cloth towards the mouth, as if you are helping to close the lips.
- Push the cloth toward 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.

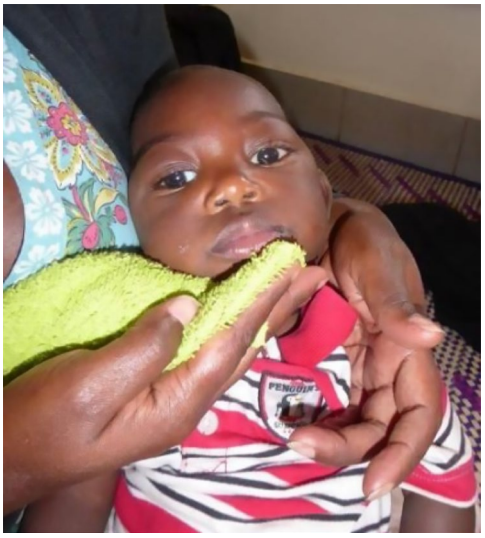
Activity 5

Break into pairs. Take one person from each pair and give them a cloth.

Explain that without using words or telling their partner what they are doing, they will wipe their partners face from the side quickly over the nose and mouth.

After this, ask the person who had their face wiped how they are feeling.

This activity is designed to reinforce how good communication is important to your child during every day activities.



Once this has been explained, help the group to practice a good technique.

BRUSHING TEETH

Ask

"Why do you think it is especially important to clean the teeth and mouth of your child?"

Children who don't clean their teeth regularly may develop problems with their gums and mouth, which can then cause pain or make eating more difficult

Discuss in the group and ensure the following points are covered:

- We all use our tongues all day long to clean our teeth, however if children have 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 she has swallowing problems.

Therefore:

- **You should start cleaning your child's mouth even before they have teeth, once they are eating/drinking more than breastmilk then their mouths need cleaning.**
- You should clean your child's teeth carefully after every meal and especially after sugary snacks and drinks!
- Some children with developmental difficulties have very sensitive mouths that can make it difficult to clean their teeth well, so extra care is needed. A flannel or washcloth can be used as an alternative to a toothbrush for children with sensitive mouths.

Activity 6

Ask everyone to position their child and practice: 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 her head and neck.

- Brush gently in a circle motion.
- Rinsing can be very difficult. You may have to bring her 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.

UNDRESSING AND DRESSING

Ask

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

In groups of 2-3, look at picture 8.05.

Ask

"What is happening in the pictures? Which things is your child able to do? "

"How can you use dressing and undressing to stimulate your child's development?"

- Make sure your child is always in a good position. Change her position regularly.
- Talk to her about what you are doing, and help her join in.

Explain

Dressing can be fun for your child. If your child is lying down she cannot see and cannot help. Supporting her in sitting will help her to see her body and help a little.

Role play or demonstrate using a doll or ask a parent to volunteer with their child.

- Physically support your child to make her feel safe while she is being undressed or dressed.
- Encourage her to look at you, by calling her name and playing with her. This will also help develop her eye contact and head control.
- Talk about what is happening. This helps your child to anticipate what is coming next, for example, ask "Where is your arm?" "Where is your vest?" Help develop their communication skills.
- Pause for your child to look at her arm or move it up. Help her learn to reach out and use her hands.
- You can use some supported standing in dressing too, to help make your child's body strong.
- Smile and praise her when she communicates or helps a little.

Ask

In pairs, discuss one thing that you will share with a family member about dressing and undressing your child. Write down the one thing that you will share and change this week when you dress and undress your child.

TOILETING

Ask

"What do you think about teaching your child to know when she needs to go to the toilet? What have people told you? What is your experience of nappy change time and your child's awareness that she has a wet or soiled nappy"

Explain

Your child may progress at a different speed, each child has their strengths and activities that they find difficult.

Nappy change time gives good opportunities for your child to develop:

- **Eye contact:** this is an ideal time for gaining eye contact, playing and talking.
- **Communication skills:** use your facial expression and a soft voice.
- **Learn to sit:** As your child learns to sit up with help, this can prepare for

toileting using a potty or small bowl. Hold her on each side of the hips.

- **Movement:** you could also use it as a time to practice a few stretches to help keep your child moving well.

> In Bangladesh, toileting was a priority for many parents. Communicating about needing the toilet, and becoming independent in toileting were both issues. Some parents did not have time to help their children with toileting so they were left in their own urine for hours.
>
> *"I do pottery all day long, and I have to cook food three times a day. My father-in-law is ill and I have to take care of him. During sharecropping, when the crops arrive at our house, I have to work on that and I have to look after my disabled child all the time."*
>
> *"My husband... does not help me in any work with our child... I never get the chance to relax. That's why I always feel weak. My daughter urinates and defecates lying down and it gets on her body, and I find it difficult to clean her up."* **Mother, Bangladesh**

SLEEPING AND RESTING

Ask

"How do you position your child when she sleeps?"

Include the following points in the discussion:

- 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, position her into different positions from time to time, using cushions and rolled up towels to support her to lie with knees and hips bent. This encourages them to be less stiff.

MONITORING PROGRESS

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?"

Take Home Messages:

- Identify helpful positions for everyday activities.
- Communicate with your child as you do things.
- Every child is different, so your child may have different abilities.
- Your child should be stimulated to help her develop as much as possible.

"What two things have you learned today that you will share with someone else at home?

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?"

Allow time for discussion and interaction with each other. This should be aguided session between everyone with only short prompting from facilitators.

Parents have spoken about how their friends distance themselves and they often feel alone:

"I got tougher with people and with feelings after my son was born." **Mother, Brazil**

"I like very much to talk about my granddaughter, to talk about her development, to talk about how good it is to be here with you. I really love this. Everywhere I go I talk about this group and tell them that is being very good to me." **Grandmother, Ghana**

"In reality, before this group I felt alone in this world, thinking that this problem was only mine. I couldn't imagine that some parents were passing through things like I was. So when we come to a group like this, we can recognize each other's difficulties; we can understand it; we can take some things like they were our own, we can help and we have the opportunity to interact with other children." **Parent, Colombia**

TOGETHERNESS AND BELONGING

9

This module covers the following information:

Togetherness and belonging

Reflection on changing your individual beliefs

Family and community inclusion

Inclusion in Services

Group action plan

Sharing emotions and feelings

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=nZ2VlrqnWzM
- https://www.ugent.be/pp/orthopedagogiek/en/news-events/news/obuntubulamu.htm

Facilitator Tips:

- '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 Tips:

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 Tips:

- 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 Tips:

- 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. though 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?"

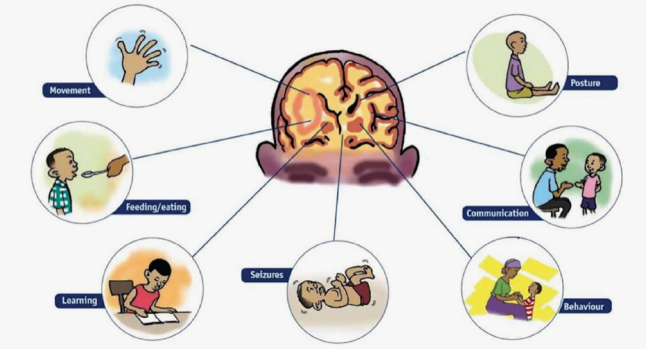
"Are the child and parent being treated with respect and dignity? What helped improve the situation in stories that were positive?"

"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 Tips:

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 and 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 Tips:

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 Tips:

- 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.

Image adapted from illustration by Petra Röhr-Rouendaal, International HIV/AIDS Alliance (2006)

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 Tips:

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.

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

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?"

Take Home Messages:

- 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?"

"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?"

"Did anything change for you?"

OUR COMMUNITY 10

This module covers the following information:

Our community
Rights of people with disabilities
Focus on the right to health
Focus on the right to education
Community mapping
Sharing community maps
Sharing common barriers
Mapping our communities
Finding community solutions
Monitoring progress
Sharing emotions and feelings
End of session

Important: This is a long module that can be split over 2-3 sessions.

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, poster 1.04.

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 out 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.

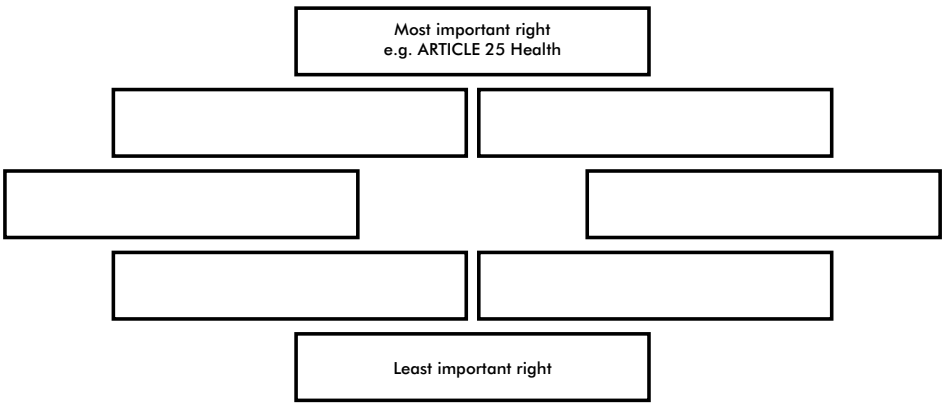
"What do you understand by your own rights?"

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.

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



Ask

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 Tips:

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

"Which 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 Tips:

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 you can register for a Disability Card. Follow with a question and answer session to clarify the processes.

Involve caregivers who have already been successful in registering for a card. Alternatively, in countries where there is no disability registration process, the role play can illustrate how families are eligible for other benefits, for example social protection programmes.

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 Tips:

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).
- Emergency treatment plans (e.g. for seizures, breathing difficulties).
- Communication needs (including how you can tell if your child is in pain or uncomfortable) and usual routines (e.g. feeding, toileting, sleep).
- Medications.
- Allergies.

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.

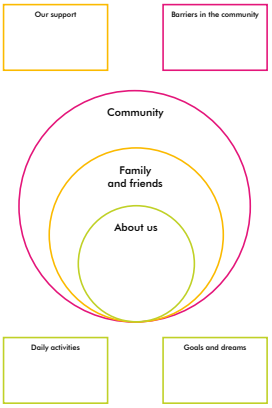
Much of what this programme has focused on has been the individual steps.

COMMUNITY MAPPING

Activity 4

Complete the outer circle of image 1.04.

Tell us a bit more about the community where you live.



SHARING COMMUNITY MAPS

Activity 5

Get into groups of three: share your community with two other people. In the barriers section (top right) 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 their poster to the rest of the group. As the group feedback, note barriers down on a flipchart paper.

SHARING COMMUNITY BARRIERS

Activity 6

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 7

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?"

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.

FINDING COMMUNITY SOLUTIONS

Activity 8

Go back to your groups of 3. List your support in the top left of the poster.

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).

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."

Take Home Messages:

- 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.

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.

Display the participants' posters around the room and 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' (found in facilitator resources):

The 'Game of Life' (from Coe, S. and L. Wapling (2012). p.25)
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:

- Gamily is very happy (non-disabled son born), two steps forward.
- Quite happy (disabled son/non-disabled daughter), one step forward.
- Not happy (disabled son), one step back.

Very unhappy (disabled daughter), two steps back.*"Now you are a bit older, and it's time to start thinking about school. How likely is it that you will be able to attend school?"*

"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?"*

ASSISTIVE PRODUCTS AND RESOURCES

11

This module covers the following information:

Assistive products and resources

What are assistive products?

Benefits of assistive products

- Supportive seating
- Wheelchairs
- Glasses
- Adapted cutlery
- Communication boards

Monitoring progress

Sharing emotions and feelings

ASSISTIVE PRODUCTS AND RESOURCES

Important: This module can be run alone or at the same time as positioning. You can use this module to advise on assistive products when there are less rehabilitation services available.

Materials

One A4 piece of paper for each participant to make a hat from for the ice-breaker, flipchart, pens, pictures of children with different types of assistive products.

Icebreaker

Ask everyone to make a simple paper hat from their sheet of paper. Each person then writes what they are called on the hat. This can be 'parent' or 'job description' or 'nickname' etc. In pairs, everyone can then describe the names that they have on their hat.

Explain that over the past sessions we have learned together about ourselves, our children, families and communities.

Explain

By the end of module 11, you will:

1. Understand what assistive products are.
2. Understand how assistive products can increase your child's participation in every day life.
3. Know how assistive products can be made and provided.

WHAT ARE ASSISTIVE PRODUCTS?

Ask

"What are assistive products?"

Explain

Explain anything that helps your child do everyday activities on her own is an 'assistive product'. This helps her be independent and take part in society. There are many kinds of assistive products.

Can you name some assistive products?

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

Facilitator Tips:

- Assistive products are often not used properly because parents don't understand why they are important. Sometimes they are also not shown how to use them. Home environments may also limit use: a paper chair is not suitable in a home where it might get wet, and a large wheelchair will not be helpful if there is not enough space to move around in it. During your home visit, or this session, ask participants to demonstrate to each other how the assistive product is used. This will help you to identify their understanding, and reasons for why it is or is not used.
- Manage expectations from the beginning!
  Explain: **not ALL CHILDREN will benefit from assistive products** like an expensive wheelchair.
- In the community mapping exercise, local carpenters may have been identified. Encourage the group to identify how they can form a good relationship with a local carpenter who can make low cost devices such as corner chairs. Decide together how to ensure that they are of good quality. Locally made devices can also be fixed locally if needed.

Put up the pictures of assistive products, and children using assistive products:

Photo by: The International Committee of the Red Cross

Photo by: Motivation

Photo by: CECHE Foundation

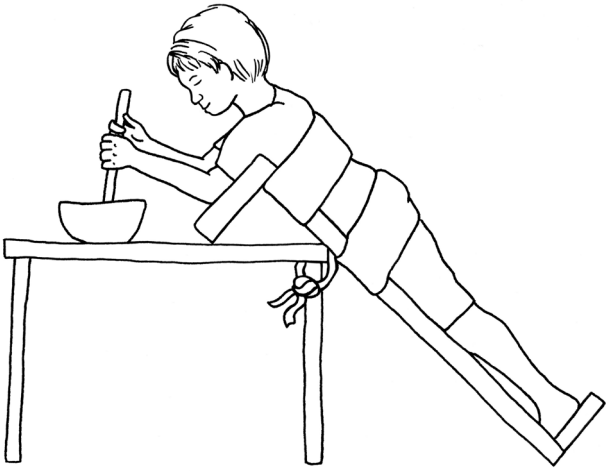


Photo by: The International Committee of the Red Cross

Photo by: CECHE Foundation

Ask

"What is happening in the picture? What are the devices made from? Why do some children have certain devices and not others? Are any made locally of low cost materials? Are there any children without 'assistive products'? Why?"

Discuss:

- Some children won't need an 'assistive product'.
- Find out what your child needs to see whether having one would help her become independent.
- Each child's abilities are different, so different assistive products should be used.

BENEFITS OF ASSISTIVE PRODUCTS

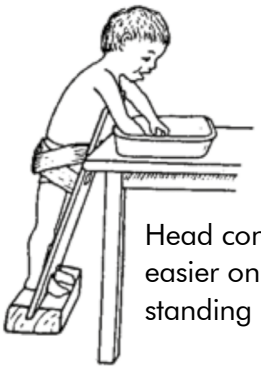
Ask

"How can a standing frame help?"

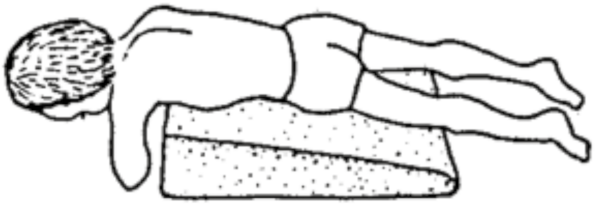
Explain

- Standing frames support your child when standing.
- Standing is an important position for your child to learn.
- Many children who can't stand lie down a lot. In a standing frame your child can see what is going on around her, play and interact with others. This will help her development.
- A prone stander supports children who find it hard to hold their body up by making it easier to lift the head. Your child leans forward on the device, which also leans forward.

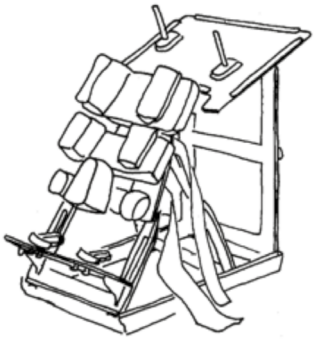
Discuss the 'good' and 'poor' positions in the diagrams below.



Head control easier on prone standing board

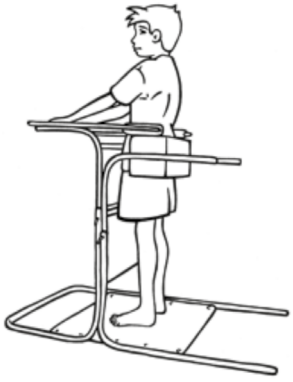


Child is unable to lift head up in prone



Prone stander

Child standing badly in an upright standing frame



Child standing well in a standing frame

Supportive Seating

Ask

"How can your child benefit from a supportive seat?"

- Sitting upright helps your child stay healthy by helping her digestion and blood circulation.
- Stops your child from getting injuries that disable her more, and can help her bones to grow strong.
- Your child is able to make eye contact with people around her, which helps her communicate.
- Supporting your child while sitting can help her control her head, hands and concentrate for longer. This will help her develop self-care (eating, toileting, dressing), playing, learning.

A corner seat gives less support so should be used for children with more ability. They are good for children up to 5 yrs old for floor activities.

Pelvis: upright

Hip joints: 90 degrees, knees slightly apart

Knees and ankles: 90 degrees

Back: straight

Shoulders: relaxed with arms free to move

Head: upright in the middle, chin tucked in

Side view: Ear, shoulder, hip – in line

From the front: Eyes, shoulders, hips, knees are all level

Wheelchairs

Ask

"How can your child benefit from using a wheelchair?"

- Helps a child who cannot walk or move alone be independent.
- Can help a child get to school and into the community to play with other children.

However, not all children who find movement hard will benefit from a wheelchair.

To check if a wheelchair is right for your child, the World Health Organisation (WHO) says a wheelchair should:

- Meet the wheelchair user's needs.
- Be usable in their home environment.
- Fit well and be supportive.
- Be safe and last well.
- Be available and can be maintained at an affordable cost.

There are many different kinds of wheelchairs. They always need to be fitted to your child by someone trained, so you should ask your therapist on a home visit. If the wheelchair does not fit your child properly, she can become more disabled.

Walking Frames

Ask

"How can a walking frame help your child?"

A walking frame will help if your child can stand on her own but finds it hard to walk. It will help her move around and be active in your community.

Glasses

Photo by: Priya Morjaria

In Bangladesh 180 children with cerebral palsy were tested for visual impairment. Around 32% had poor vision and 18% needed glasses.

Adapted cutlery

Ask

"When would you use adapted cutlery?"

You can make a spoon or fork easier to hold by making the handle bigger. You can also hold your child's hand in place with a scarf.

Photo by: Enablement

Communication boards

Ask

"How can a communication board help your child?"

- If your child finds speech difficult, a communication board helps her express her needs with pictures.
- This helps your child communicate with other children and adults, and be included in your community.

Photo by: Enablement

Photo by: Enablement

Activity 1

Ask each participant to demonstrate how they help their child to use their assistive products. Ask each person to explain what they are doing, and how the assistive product helps their child to participate in everyday life.

MONITORING PROGRESS

Think back to session 4 where you looked at positioning and moving.

Take Home Messages:

- Identify helpful devices that make positions for everyday activities easier.
- Every child is different, so your child may have different abilities.

Ask

"What two things have you learned today that you will share with someone else at home? "

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"

Allow time for discussion and interaction with each other. This should be a guided session between everyone with only short prompting from facilitators.

NEXT STEPS

12

This module covers the following information:

Next steps

The value of networking

Finding other services

Practicalities of running parent support groups

Session overview

Most significant change

Sharing emotions and feelings

NEXT STEPS

Materials

Flip charts, pens, Poster 1.04.

Icebreaker

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

Ask

"Today is the last session of our programme. For some of you it might feel quite sad to be finishing and for others you might feel relieved to be done!"

The biggest question we often get asked is what happened next, so todays session is going to think about that: Outcomes for the module (on flipchart).

Explain

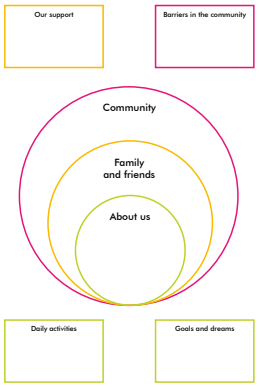
By the end of this session, you will be able to:

1. Understand some benefits to networking with other caregivers and parent groups.
2. Identify which support groups already exist and how you may be able to connect with those.
3. Identify good practice for running and organising 'self-help parent groups'.
4. Reflect on what you have learned over the past sessions and how it has impacted on you, your family and your child.
5. List a number of subjects that we have not covered and considered how you might find out more about those.

THE VALUE OF NETWORKING

Activity 1

Have a look again at your personal posters.
Ask someone who has not presented their poster regularly to present.



Ask

"What has changed in your situation since coming to this group? Where do other parents and families now feature within your posters?"

Use image 6.01 to explain the cycle of communication.

Ask

"How do you feel about meeting members of Organisations for Persons with Disabilities? How do you feel about meeting other community members who are interested in disability rights? Is it helpful? Why?"

"Do you ever meet up with other parents outside of the sessions? Is this useful? why? How can you help more parents meet and support each other?"

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

"During this group I had a lot of discussions with my husband, we talked about how important it was to be accompanying and participating in the activities, and today it seems that he is more aware of things and participates without complaining." **Mother, Salvador**

"We also change psychologically, it is important to be with other parents." **Parent, Colombia**

FINDING OTHER SERVICES

Activity 2

Invite local organisations to give short talks about their services.

Explain

Explain that a parent support group can help parents access services, like a disability registration card.

In small groups, read the leaflet on local services;

- Which services did you know about?
- Have you used them?
- Were they good?

Ask

Which other groups for parents/families do you know in the area? Do you already go to any of them?

Activity 3

Discuss in your groups the services that you are aware of, whether you have accessed them, and your experience of using the service.

List the names of organizations on flipchart paper and the activities that you do. How can people join or find out more about these groups?

PRACTICALITIES OF RUNNING PARENT SUPPORT GROUPS

Activity 4

Ask everyone to stand in a line.

The order should be from the person who had longest journey today, to the person who had the shortest journey.

Ask

Ask everyone to say:

- How you got to the meeting?
- Was it an easy journey?
- Was it difficult traveling with your child?
- How could we make transport more accessible?

Ask

"What would a good parent support group be like?"

It might be:

- Welcoming.
- Meet regularly.
- A safe space to talk about feelings.
- Somewhere you can learn information and share ideas.
- Confidential.

Ask

"What makes a good group leader?"

They might be:

- A good listener.
- Someone you can trust.
- Someone who knows about local services.

Ask

"How would you run a parent support group?"

There is no one 'right' way of doing this. Think about:

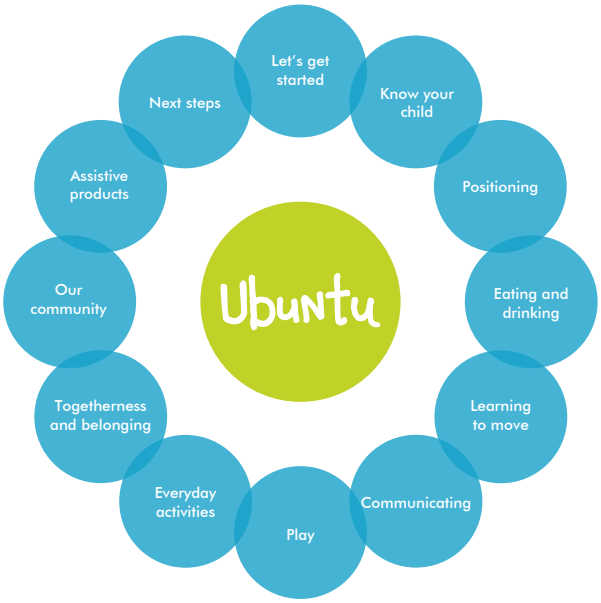
- Would the group meet regularly? When? Where?
- Is there something you would like the group to help change? How?
- How will you communicate with each other about meetings?
- How can you find out what other services would be helpful? For example, group savings schemes.
- What might be some challenges? How might you address them?

> In Bangladesh, two parents from each of the 14 groups were chosen as leaders and this module was run with them. Carers had the chance to meet parents from other groups, and everyone shared information.
>
> *"I have come to know most of the parents through going to training before training they were unknown to me. Now, we always talk to each other Whenever we hear about a child improving, we meet him at their home, and try to find out more."* **Parent, Bangladesh**

SESSION OVERVIEW

Activity 5

Guide everyone through each of the sessions that they have covered. Ask them to remember two or three points from each session that they learned.



Ask

"What subjects do you feel we have not discussed that you would like to know more about? How do you think you can find out more about these? Could this be something organized as a group activity?"

List the issues on a flipchart paper and make a plan for each.

Points to raise:

- Some issues may be specific to just one person or child and so this may be something you try to find out for yourself.
- Other issues may be shared by several parents and asking someone to come to present to you as a group might be useful.
- Ideas include: assistive products, gastrostomies, applying for a disability grant, how children with disabilities could go to the local school.

MOST SIGNIFICANT CHANGE

Activity 6

Work in groups of four or five.

Facilitator Tips:

This activity will involve participants sharing their view and describing a story of their most significant change since participating in these sessions. They will discuss in small groups and then together decide one story that is the most significant story to represent the group.

The first question to start the conversation would be:

"Looking back over the last month/since you started with this group, what do you think was the most significant change for yourself/for your children/within your family?"

You can ask:

"From among all these significant changes, what do you think was the most significant change of all?'"

This is a good way to identify unexpected changes. It can also build a rich picture of what is happening, rather than an overly simplified picture where organisational, social and economic developments are reduced to a single number.

Ask

Ask each person tell one story of Most Significant Change as a result of participating in this group. Ask each group to select one story that they regard as most significant to share with the whole group.

Ask

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

Ask everyone to consider 'Most Significant Changes' at different levels:

1. For themselves as caregivers.
2. For their children.
3. Within the family.

Some 'Most Significant Changes' from Bangladesh:

- Having stronger networks with other caregivers in the community and being able to support each other.
- Knowing more about their child and how to care for her.
- Feeling more confident with sharing information.
- Noticing their child's abilities improving, meaning she can play with other children.
- Parents having more free time because their child is more independent.
- More positive attitudes towards their child and family.

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? How are you feeling about the end of the sessions?"

This is the end of the facilitated group sessions. Recognise that everyone may have different feelings about it. Thank everyone for their time and contributions to the sessions.

THE FUNDERS:

cbm
together we can do more

WITH THANKS TO:

hambisela
Towards Excellence in Therapy for Cerebral Palsy

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