Juntos

FACILITATOR MANUAL

Working together with caregivers of children with Congenital Zika Syndrome

THE FUNDERS:

wellcome

UKaid
from the British people

WITH THANKS TO:

IFF
INSTITUTO NACIONAL DE SAÚDE DA MULHER, DA CRIANÇA E DO ADOLESCENTE | FERNANDES FIGUEIRA

cbm
together we can do more

Ministério da Saúde
FIOCRUZ
Fundação Oswaldo Cruz

hambisela
Towards Excellence in Therapy for Cerebral Palsy

VIRTUTE SPIRITUS
1808
UFBA | Universidade Federal da Bahia

LSHTM

London School of Hygiene & Tropical Medicine is the United Kingdom's national school of public health, and is one of the foremost postgraduate institutions in the world for research and postgraduate education in global health.
http://www.lshtm.ac.uk

ICED

The International Centre for Evidence in Disability was established in 2010, and is located within the LSHTM. 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

IFF/Fiocruz

O Instituto Nacional de Saúde da Mulher, da Criança e do Adolescente Fernandes Figueira founded in 1924, is a unit of assistance, teaching, research and technological development of the Oswaldo Cruz Foundation (Fiocruz), recognized in 2006 as a hospital de Ensino and in 2010 as a national reference center by the Ministry of Health and the Ministry of Education.

UFBA

Universidade Federal da Bahia is based in the city of Salvador, state of Bahia, where it offers more than 200 courses (undergraduate and postgraduate) with approximately 39,000 registered students. It is a public university, funded by the Brazilian Federal Government. Established in 1946, its Medical School is the oldest centre of higher education in Brazil, founded in 1808. In 2018, UFBA had cooperation agreements with more than 40 countries.

Use and Distribution rights

Published by LSHTM, London, UK
Email: disabilitycentre@lshtm.ac.uk
Available to download at http://disabilitycentre.lshtm.ac.uk

Project team London

London School of Hygiene & Tropical Medicine.
Research Coordinator and Main Editor (manual): Tracey Smythe.
Research Lead: Antony Duttine .
Advisors: Julian Eaton, Kate Milner, Cally Tann, Joerg Weber.
Consultant writers: Mel Adams, Sue Fry, Maria Zuurmond.
Principal Investigator: Hannah Kuper.

Project team Brazil

Project Coordinator: Miriam Calheiros (IFF/Fiocruz) Silvia Ferrite Guimarães (UFBA).
Researchers: Ana Carolina Vieira, Barbara Castro, Mônica Machado de Matos, Julia Reis e Silva.
Facilitators: Fernanda Bertazzoni, Luana Ramalho, Olivia Agostini, Paula Fliess, Lia Bernadeth Araújo de Oliveira, Lais Costa de Oliveira Silva, Karine Jesus Silva, Silvia Leandra de Jesus Pinheiro.
Principal Investigator: Maria Elizabeth Lopes Moreira.

Independent consultants and reviewers

Mila Cabral Mendonça, Maria Antonia Goulart, Liana Ventura.

Acknowledgements

There are a huge number of people to thank for this guide. Key to the work has been input from a multi-disciplinary team: community workers, physiotherapists, occupational therapists, speech and language therapists, educationalists and trainers.

A special thank you to Movimento Zika; CAEE - Centro de Atendimento Educacional Especializado, Abraço, and Instituto Viva a Infância.

We would like to say a particular thanks to CBM, Hambisela and the team that developed “Getting to Know Cerebal Palsy” for their support for our work in Brazil, and allowing us to simplify and modify their training materials. We would like to thank Cressida Evans, Debora Aranha and Adriana Alvarez for translation.

Finally thank you to the Wellcome Trust and DFiD who provided funding for the parent project in Brazil and for the development of this manual.

Logo and manual design

Ellipsis Ltd
www.ellipsis.co.uk

BEFORE YOU BEGIN

0

This module covers the following information:

Chapter 1:

About the programme
Background and history
Aims and objectives of the programme
How the programme works
Who the facilitators are
Approach

Chapter 2:

Running a session
How to follow the manual
Preparation for your session
Identifying issues and referring
Post session reflection
Top tips and common mistakes

Chapter 3:

Conducting a home visit

1: ABOUT THE PROGRAMME

1.1 Background (how this manual came about)

Juntos is a programme for caregivers of children with congenital Zika syndrome and is built upon 'Getting to Know Cerebral Palsy' (GTKCP), which was adapted in 2014 by the London School of Hygiene & Tropical Medicine from an existing parent training programme (Hambisela) which was developed by the Eastern Cape Branch of Cerebral Palsy Association South Africa.

GTKCP has been used in Asia – Sri Lanka and Bangladesh, and in a number of African countries – Ghana, Uganda, Malawi. In Uganda, a further revision has been developed with a focus on Early Intervention for children with Cerebral Palsy – all of these sources have been drawn on in compiling this manual.

Final project evaluation of the caregiver group programme in Uganda and Malawi showed a positive impact on attitudes in the families, as well as increasing inclusion in communities. Relationships between caregivers and their children improved, as did knowledge in basic care of their children – especially positioning and communication. Many parents found they had a bit of extra time and were able to join in income generation, which was planned as ongoing activities for the parent support groups.

Because congenital Zika syndrome is similar in many ways to Cerebral Palsy and other neurodevelopmental conditions, it was felt that parents of these children could also benefit. In April 2017 a project started to adapt the GTKCP programme for the context in Brazil of Zika.

"This group gave a real change of experiences and also friendship." **Grandmother, Salvador**

"My family has participated much more in the care of my son, we have included him in the practical things that we do."
Mother, Rio de Janeiro

"In reality before this group, I felt alone. I couldn't imagine other parents were passing through things that were worse. When we come to a group like this, we realise each other's difficulties; we can understand it; we can help; and we have the opportunity to interact with other children." **Parent, Salvador**

1.2 Aims and Objectives

The overall aim of this programme is to help families and caregivers of children with congenital Zika syndrome to understand their child and to build support networks that will improve the care that their child receives in the community. This will help children with congenital Zika syndrome to reach their potential.

Key objectives:

- To improve the knowledge of caregivers and family members about their child's condition and specifically in relation to the needs of young children with congenital Zika syndrome.
- To promote positive attitudes towards having a child with a disability within the family.
- 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.

On an emotional level we aim to support families as they deal with uncertainty, not removing hope but maintaining realism.

"I have come know most of the other parents from coming to training. Before training I didn't know them. Now we always talk to each other... Whenever we hear about a child developing we can meet at each other's houses, and try to know something better." **Parent, Sirajganj, Bangladesh (GTKCP)**

1.3 How the programme works

The programme is a multi-session group activity with caregivers – parents and families – of children who are affected by congenial Zika syndrome (CZS), run by two facilitators. This manual helps to guide facilitators through the programme, providing a layout of each session and descriptions of group activities.

1.4 The facilitators

The facilitators deliver the programme and are the key people who ensure whether a group is successful or not. 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. This is called a participatory approach and it will be further explained later.

For the Juntos group, two facilitators with complementary skills and experiences will run the sessions – one therapist (OT, PT, SP) and one mother of a child with CZS. These have been deliberately chosen as they are both 'experts' in the area of raising and supporting a child with a disability: a therapist has been trained in certain skills, techniques and

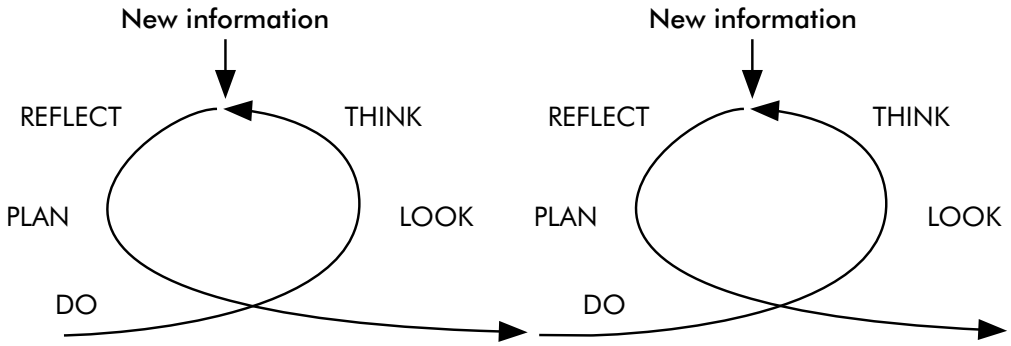
approaches, whilst a mother brings her own personal experiences of the challenges that can be faced in raising a child with a disability.

The two facilitators are **equal partners** in the programme, and need to work well together. Some sessions may feel more natural to be led by one person more than the other. This manual gives some suggestions for this, though these are not compulsory rules to follow.

1.5 Approach

Core to our approach is group work with primary caregivers, which is driven by adult learning theory and a participatory approach. Participants are encouraged to share their experience through discussion and reflection.

Action-Reflection Cycle:



What do we mean by a 'participatory learning and action' approach?

A participatory learning and action cycle approach is one in which group members identify and prioritise problems and choose ways to solve these problems together.

This process is built into the modules, and it is hoped that by the end of the programme that parent support groups will be able to run the groups themselves, and to work together to address problems.

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.

In Ghana, home visits were used as a mechanism for a facilitator to engage with other family members of the household. This was not always effective. 51% of fathers of the children were absent from the home, and many caregivers were women who managed full time caregiving with a range of other household responsibilities.

- It is important throughout the sessions and interactions with primary caregivers, who are predominantly female, that this **does not add to the burden of caregiving.**
- The Juntos programme is not intended to replace therapy, but to complement it. Children need therapeutic management all of the time, not only during therapy sessions.
- Local service provision needs to be strengthened and the quality improved for 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.
- 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.
- The caregivers start an empowerment 'journey' over the course of the programme. For new parent groups it can be the first building blocks for a sustained programme. The issue of sustainability needs to be considered during your planning phase.
- It is recommended that children and their caregivers participate in these groups as soon as possible after diagnosis.

"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: RUNNING A SESSION

2. 1. How to follow the manual

- This manual for group facilitators is divided into 10 modules.
- There is also a separate Display Manual, mainly of photos. This material can be laminated and used for running sessions.

For each module there are:

Materials

Materials you will need for each session. There is some video material and you are encouraged to make your own short video clips where appropriate to demonstrate issues and help bring the 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, sometimes used interchangeably with parent or participant.

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

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

LIST OF MODULES

Emotions and feelings	Discussion around thoughts and feelings is a theme explored throughout the sessions, using personal posters
Introduction	About the programme Ground rules for the group Information about Zika and Congenital Zika syndrome How to find information Personal stories and start of the posters
Our child	Introducing your close family and friends (posters) Development milestones for young children Determining each child's progress Managing irritability and crying

Positioning and moving	How to position children who need assistance How to assist children to learn to move
Eating and drinking	Feeding challenges Practical skills to address challenges for individual children
Communication	Importance of communication Practical advice to help your child communicate
Play and early stimulation	Importance of play for children to develop and learn Early stimulation Making simple toys and how parents/caregivers can encourage their child to play challenges inclusion in play in the family and broader community
Everyday activities	How to use everyday activities to help your child develop Managing seizures Catch up from previous sessions
Uniting our voices	Understand the context of disability rights Education Communicating with your health team Advocating Thoughts and feelings
Our community	Who is in your community Discussion about common barriers to inclusion Addressing negative attitudes and exclusion Thoughts and feelings Social Activity – this week contains a chance for you to invite 2-3 members of your community to join in the group for a social discussion and some food/games
Next steps	Summing up What have you learned? What haven't you learned? Endline data collection
Home visit	Aims of the visit What to do and say on a home visit

2.2. Preparation to run a session

It is important to involve the parent group in planning for the sessions – e.g. where the programme should be held; length of time and how often to meet.

Before the session

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

During the session

- Plastic-covered foam mats for children to sit on can be useful, they are easy to clean.
- 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 learnt on feeding and drinking.
- 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.
- 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 a discussion goes off the topic, gently bring the discussion back to the topic, while also allowing time for members to express what they are feeling. If appropriate, place it in a 'parking lot' and return to it later.
- Recognise caregivers' contributions – draw on their life experiences. Use their stories to illustrate points where possible.
- Encourage everyone to participate – you may need to address some remarks directly to someone who is very quiet and withdrawn.
- Be aware of the influence of your mood on the group – be honest about your feelings and state of mind.
- Be flexible within the modules especially when there are young children in the group – you may need to change the order or the time of a break to accommodate their needs.
- Use opportunities to model interaction with children and involve them in the session where appropriate.

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[1], 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[2].

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.

Key messages to promote are: 'Protection is everybody's business!' and 'Children with disabilities and their caregivers have a right to be protected'.

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 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.

1. Devries M Karen, Kyegombe Nambusi, Zuurmond Maria, Parkes Jenny, Child C Jennifer, Walakira J Eddy, et al. Violence against primary school children with disabilities in Uganda: a cross-sectional study. BMC Public Health. 2014;14(1017)

2. Banks LM, Kelly SA, Kyegombe N, Kuper H, Devries K. "If he could speak, he would be able to point out who does those things to him": Experiences of violence and access to child protection among children with disabilities in Uganda and Malawi. PLoS one. 2017;12(9):e0183736.

In some contexts, child protection systems may be weak. So you may have to develop a referral network for the purposes of your project, which builds on existing structures and services as much as possible.

You are not expected to be experts on child protection, but you may need to reach out and collaborate with other NGOs, disabled persons' organisations (DPOs) and government bodies.

2.4 After the session

- At the end of each module there are questions and suggestions to help participants reflect on what they have learnt. Record these to help with future planning.
- 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 materials and file them carefully for next time.
- Ask your co facilitators for feedback on how you presented the session and suggestions for improvement in your facilitation techniques.
- Reflect on what went well and what needs to be changed.

2.5 Top tips

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

2.6 Common mistakes

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

3: CONDUCTING A HOME VISIT

Useful guidelines for home visits and outreach work.

These guidelines are adapted from Timion, and the original is available from www.timion.org[3]

Some children will receive therapy only once per month, even less, or no 'therapy' at all. 30 minutes of therapy per month is very unlikely to make a difference for the child's development on its own. Positioning and handling of the child during the other 700 hours of the month however can make a big difference – either harmful or helpful. Therefore the time during an outreach or home visit can be used to support the caregiver in how she can position, handle and play with her child daily in a way that helps her child to learn and develop and prevents secondary problems.

The community workers/therapist should use their time to:

Check on activities/any equipment that was given to the caregiver at the previous session.

Find out if there are any particular problems/successes and demonstrate activities again if necessary:

- If the child is **receiving equipment** such as a seating device, sidelyer or standing frame, the community worker/therapist's time is best spent fitting and adjusting the device and teaching the carer how and why to use it. Let them position the child more than once to make sure they are confident in doing it well. Remember: if a child is positioned well every day it will be of much greater benefit than a single session of therapy. Therefore a session spent only on fitting equipment is not wasted.

3. Reproduced and modified with permission of Timion

- Community workers must have an **achievable, realistic, short-term goal** for children who they work with. The parent should also be involved in deciding on this goal and should be clear about it. If the parents have unrealistic expectations, they are likely to become frustrated and discouraged, and may fail to notice small steps of progress.
- It is important to **keep record** of the short term goals, what has been taught to the parent, what works and what does not. It is in a child's best interest that everybody works towards the same goals, that time is not wasted in re-assessing a child by each new therapist, and that conflicting information and instructions are not given, as these discourage the carer.
- It is important to have an idea of **how a child usually spends the day** – Which positions does she sit/lie in? What are the things that the carer does with her daily (e.g. washing, dressing, and holding her on her lap)? HOW does she do it? Changing these positions and the way activities of daily living are carried out can make a much bigger difference than giving a 'home-exercise'. The carer might be too tired or have no time for exercises, but there are certain things that she will do daily and if these can become 'an exercise', her child is getting 'therapy' daily.
- Spend some time **handling children**. It is necessary to find out which positions and key points are helpful to influence a child's muscle tone and help a child to achieve some normal, active, functional movement. All children will not respond the same, so there is no one set of home exercises that can just be given to everybody.
- Choose one activity that worked well. The therapist/community worker should demonstrate and **teach it to the carer**, explaining why it is helpful, pointing out where to place your hands. Let the carer practice it more than once – until she is confident to do it well. Guide her hands if necessary. Give some specific instructions about when and how often to do it. Try to incorporate it into her activities of daily living and daily routine as much as possible.
- **Feeding** is a very big problem for many children. This is something that forms a very important part of a child and caregiver's life and can therefore be a very important goal. It can affect a child's nutritional state and overall health and can require hours of time from the carer. A session spent advising about positioning and techniques for food preparation and feeding are essential if this is identified as a problem. Try to involve and teach volunteers in what the health worker is doing, such as using positioning equipment. If they learn how to do this well, they can spend time helping the caregivers.

Juntos

1 INTRODUCTION

This module covers the following information:

Introduction

Today's session

What is Congenital Zika Syndrome?

What is Zika?

Information sources

Children with Congenital Zika Syndrome

Monitoring progress

INTRODUCTION

Materials — 25 minutes

Flipchart (write up the session objectives and take-home messages before you start), images 1.01-1.06, pens, ball, blank poster template (1 per family), name tags.

Explain

Welcome everyone to the first session!
'During our time together we are going to get to know one another and develop a relationship with each other as a group. We are here to learn from each other and we all have something to teach the rest of the group because we all have experience with children with Congenital Zika Syndrome.'
Ask everyone to write their name on a name tag before you start the icebreaker.

Icebreaker

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

Ask

"What you would like to get out of coming to the group?"
Write everyone's answers on a flipchart. Encourage people to contribute.

Facilitator Tips:

Managing expectations is a very important part of this first session.

Give time to explore expectations and clarify what the programme will and will not cover.

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

It may be useful to write down the expectations of the group and refer to it as the programme progresses. It is important to manage expectations from the beginning.

Clarify what expectations will be met in this group, and what will not:

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.

Image 1.01 which provides an overview of the different sessions.

Clarify what this programme can and cannot cover: through making small changes to everyday activities and how you interact with your child, you can help your child develop.

Explain how long the group sessions will run and how long each session is (3-4 hours).

Coming together in this group and sharing ideas will provide support, learning and encouragement.

Emphasize that this programme does not replace any individual services that caregivers are doing with their child, like physiotherapy, but should complement these.

Sessions are not lectures and are **participatory**. It is about learning from each other's experiences. You will be getting to know more about your children, their unique strengths and their difficulties together. You will also be able to share your experiences of caring for a child with a disability with one another. Comments and questions are always welcome. There is no such thing as a 'silly question'. We're all learning together.

Ask

"Do you think these topics will be useful to meet your expectations?"

Activity

Discuss with the group some simple ground rules for how the groups should run. Write on flipchart paper 'how do we want to work as a group'.

Examples include: encouraging everyone to speak, respect others' opinions, cellphones on silent, what the group would like to do if everyone speaks at once.

TODAY'S SESSION

Explain — 15 minutes

The rest of today's session will focus on what is congenital Zika syndrome and the group getting to know about one another.

Put up the outcomes and go through them with the group (on flipchart):

By the end of the session, you will:

- Introduce yourselves and your child to each other.
- Understand more about the Zika virus and how it can affect children's health, development and well-being.
- Recognise and understand the conditions and challenges for children with CZS and their families.

Information shared in this session can do more than just increase knowledge, it can also build hope and start to challenge negative and stigmatising attitudes. 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, Salvador**

"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, Rio de Janeiro**

WHAT IS CONGENITAL ZIKA SYNDROME?

Facilitator Tips:

During this first session, caregivers will usually want to introduce their child and talk about the impairments 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 1.06. This helps to avoid repetition later in the day and for you to move to discuss day to day activities or hopes and dreams.

Ask — 15 minutes

"Has anyone ever told you why your child has difficulties in their development? What has the doctor or nurse, or traditional doctor told you?"

Explain with materials

Use image 1.02

Congenital Zika Syndrome is the name used to describe the effects that Zika can have among babies and young children who were exposed to the virus before they were born.

Being infected with the Zika virus during pregnancy can affect how the baby develops in the womb. Microcephaly – a condition where a baby has a head size much smaller compared with other babies their age and gender – was one of the first and most commonly reported signs.

There is a wider range of ways Zika can affect children's health and development and not all children with Congenital Zika Syndrome have Microcephaly.

It is not yet understood how Zika causes damage to the developing brain and there is no treatment for Zika infection at this stage.

Baby with Typical Head Size

Baby with Microcephaly

Baby with Severe Microcephaly

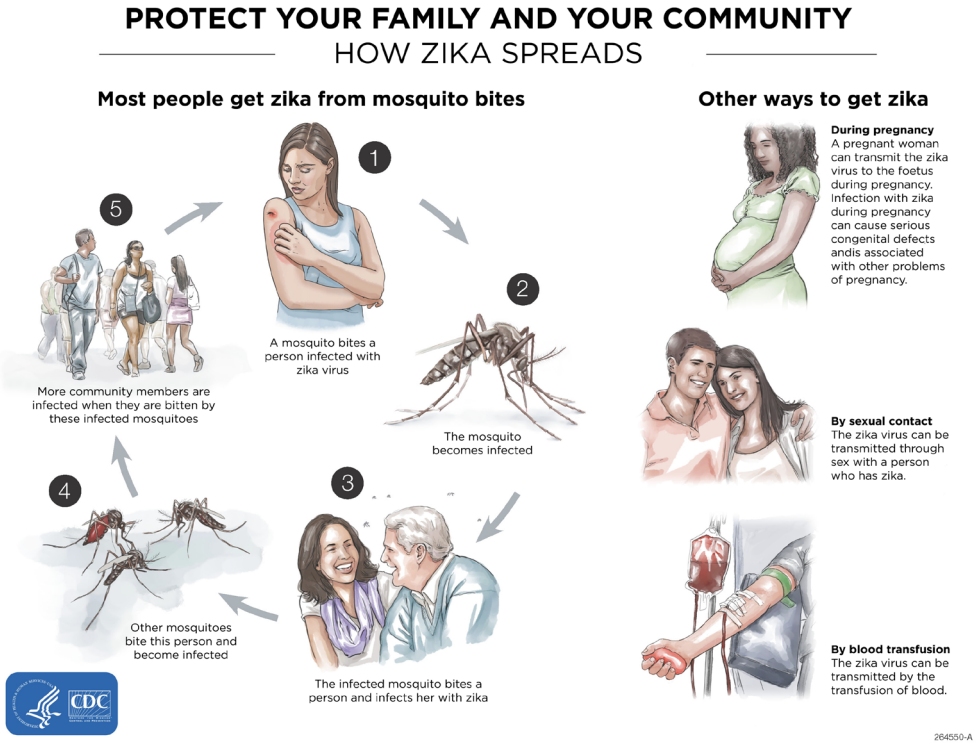
WHAT IS ZIKA?

Ask — 15 minutes

"What do you think causes your child's condition? What do you know about the causes? What have you heard? What do you believe?"

Explain with materials

Ensure the following key points in the discussion.
Use image 1.03 to help explain.



- Zika virus infection is not new, it has been reported in humans since 1952. However, its effects on child development have not been known until recently, when larger outbreaks of Zika in Brazil and other countries have occurred.
- Zika is mostly spread by a particular type of mosquito (the Aedes mosquitos). This is the same type of mosquito that carries other infections such as dengue.
- Zika can also be transmitted sexually and there is also concern that it may be transmitted via blood transfusion.
- Anyone can get Zika. Pregnant women have the same risk of getting Zika as other adults. However, when pregnant women have the Zika virus there is a substantial risk of complications to the unborn child.

- In otherwise healthy adults, Zika usually causes no symptoms. When adults do have symptoms, these are usually mild and short-lived (2-7days). Symptoms may include: fever, skin rash, conjunctivitis (e.g. inflammation of the eyes), muscle and joint pain, headache or a feeling of generally being unwell. Rarely, adults can also develop neurological complications.
- Zika infection during any stage of pregnancy is a substantial risk for CZS but the exact risk is unknown.

INFORMATION SOURCES

Activity: Telephone Game — 20 Minutes

1. **Getting Started.** Ask everyone to sit in a circle. They need to be close enough that whispering is possible, but not so close that someone else can hear the whisper.
2. **Begin the Game.** The first person in the circle whispers a word or phrase into the ear of the person sitting to their right.
3. **The Game Continues.** Everyone whisper the phrase to their neighbour until it reaches the last person.
4. **The Conclusion.** The last person says the word or phrase out loud so everyone can hear how much it has changed from the first whisper at the beginning of the circle.

Rules:

- The word or phrase can only be whispered once, so everyone must pay close attention.
- The word or phrase should not be too familiar; you want to make sure it changes as it is whispered.
- Only one player – the first – should know what the word or phrase is. You may wish to have the original phrase or word written down.

Ask

"Who do you speak to and what resources do you use to access information about Zika? What has been helpful? Which resources have been less helpful? Why?"

Write answers on flipchart paper. Once you have a list, ask everyone to rank the sources from what they feel are the most reliable to the least reliable sources.

Explain

- There are many different sources of information about Zika virus, Congenital Zika Syndrome and childhood disability. Newspapers and the media have reported a lot about Zika and it can be difficult to sort good information from bad.
- It is important that you seek information from sources that are reliable, accurate and up-to-date. If you are unsure about some information, use one or two other sources to see if they confirm the same information.
- This is especially true for Zika and Congenital Zika Syndrome where there are many myths and misconceptions and understanding of the condition is changing all the time, even among expert professionals.
- The telephone game you played shows how small misconceptions can end up making a huge difference.

Facilitator Tips:

We based the information section on several resources produced by the World Health Organization. They regularly update their information on the Zika page on their website: http://www.who.int/topics/Zika/en/

It is in English or Spanish, but they do have some pages/documents in Portuguese which you can find here: http://www.who.int/emergencies/zika-virus/information-in-portuguese/en/

Other reliable resources are:

- The Centre for Disease Control and Prevention (CDC) is an American health agency who collate the latest findings and information in Zika. They have a whole section about Zika on their website in Portuguese: https://portugues.cdc.gov/Zika/index.html
- PAHO is the Pan American Health Organisation and also has some useful information: www.paho.org (search for Zika)
- SUS is the health Ministry for Brazil and has a section on Zika: http://portalsaude.saude.gov.br/index.php/o-ministerio/principal/secretarias/svs/Zika

Ask — 5 minutes

"Can other children catch Congenital Zika Syndrome? Is it contagious?"
Answer: No. It cannot be passed from one child to another directly.

"Can Congenital Zika Syndrome be cured?"
Answer: Congenital Zika Syndrome cannot be cured. However, early support can help children's development.

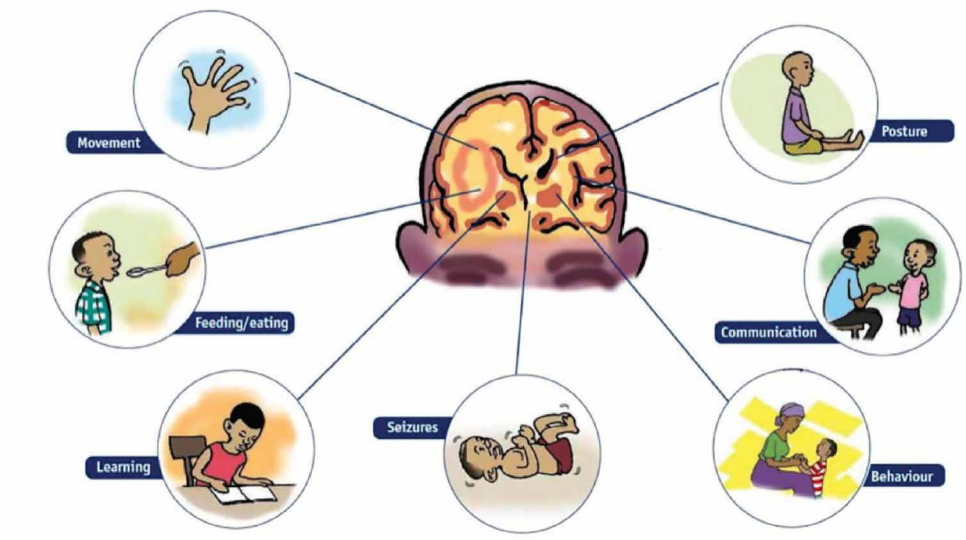
"What are traditional views that some people may have about how CZS is caused?"
Discuss their experiences. Read the example below from other parents in Brazil, and ask how this compares to their experience?

"A mother asked to be far from my son, thinking that Microcephaly is a contagious disease. But it is not. People must have a knowledge before talking about those things, before they open their mouth to judge." **Mother, Salvador**

"This week, at the bus, an evangelic Pastor told me that my husband and I had so many sins in our lives that we were paying for now, and that it would not end, it would get worse". **Mother, Salvador**

Explain

Zika seems to most commonly affect the brain of a developing baby. The brain controls everything we do and so things that affect the brain can cause difficulties throughout the body. We will see how children are different, because areas of the brain may have been affected differently. This diagram shows the characteristics that can be different. Show image 1.04, from CBM International 2012, How can you help your child with cerebral palsy (flipchart) available at http://www.cbm.org/Publications-252011.php.



Go through each picture in the diagram and give an explanation for each. Below are some notes to help discussion. Encourage discussion and ask everyone if their own child shows any of these symptoms.

Behaviour: You may notice that your child has sudden changes of mood from laughing to crying, becoming frightened, angry and other behaviours that are difficult to manage. Many parents say that their children with Congenital Zika Syndrome cry a lot and are restless, irritable and difficult to settle. Their children often have problems with their sleep. We are going to talk more about settling an irritable child in week 2.

Posture and movement: Each child is different and every child has their own abilities and their own difficulties. Some children have tight or stiff muscles and other children can be floppy. Some children cannot control their movements very well. Some can sit on their own and walk, others find

it difficult to lift their head and turn over. Every child has some potential to change and become better at doing some things. We will talk about posture and moving in week 3.

Ask

"Do you feel that your child is more floppy or stiff than other children?"

Feeding/eating: Your child may have difficulties with sucking, chewing and swallowing. She may spill food from her mouth or cough. Even as your child gets bigger, these and other feeding problems may continue. It may be necessary to adapt the food your child eats or ways of feeding to help your child. We are going to talk more about feeding in week 4.

Communication: Your child may not respond to you as other babies do or may be slow in beginning to speak. Your child may develop unclear speech or other difficulties with talking. All children can communicate and we just have to work out how they are trying to do it. We are going to talk more about communication in week 5.

Learning: As children who have been born with CZS grow and develop, we will understand more about how CZS affects their learning and schooling. However, we know that other viruses that affect children from birth can have a broad range of effects on children's learning. Some children may have normal or mild learning difficulties that are barely noticeable. Other children will have more substantial difficulties with everyday tasks and need a lot of support, even if they do not have a physical impairment.
We call this intellectual disability.

Seizures (epilepsy, fits, and convulsions) occur in some children with CZS. Many seizures are treatable and uncontrolled seizures can affect your child's development. It is important to seek advice from a health professional if you are concerned that your child may be having seizures. We will talk about seizures more in week 7.

Hearing and vision: Zika can also affect the eyes and ears as they develop in the womb. This may cause vision and hearing difficulties. We will talk about checking and supporting children's hearing and vision more in week 7.

As we learn more about Congenital Zika Syndrome there may be other issues that come up.

It is important for you to understand how Congenital Zika Syndrome has affected your child so that you can support and care for your child in the best way. Next week we will look more into this.

Ask

"What is your experience with the associated conditions that are shown?"

We will be discussing some of these conditions as we go through different modules as a group.

This may be a good place to have a break for 10mins.

CHILDREN WITH CONGENITAL ZIKA SYNDROME

Materials

Images 1.05 (a-g) in display material (you can add in your own pictures to this set).

Activity

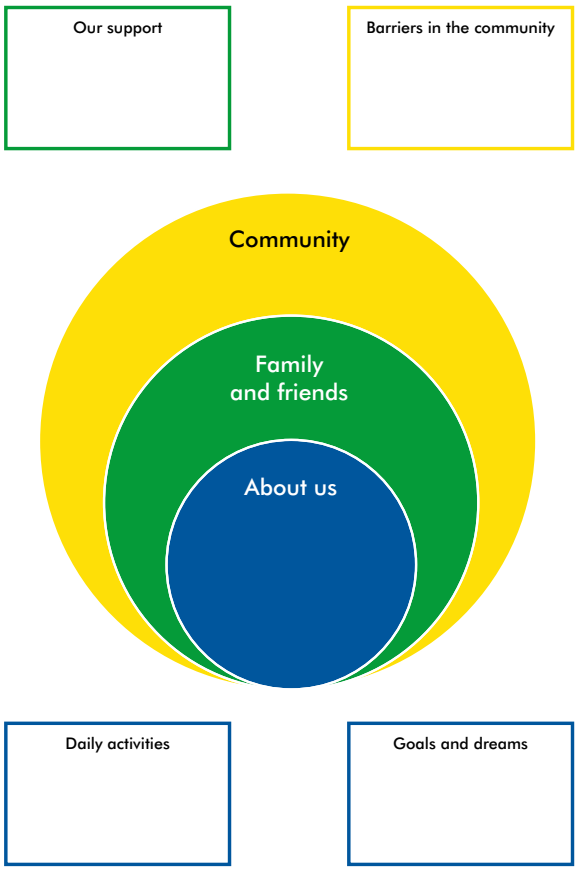
Ask everyone to walk around the room looking at the different pictures of children with CZS. Give them enough time to look at these and to discuss that no two children look the same. Each child is an individual: *"Do the children look the same? Have you seen another child who looks similar to your child?"*

Explain

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

Ask with materials — 50 minutes

Ask everyone to share their story and think about the following questions:
How do you feel about having a child with congenital Zika syndrome? 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.
Give one image 1.06 to each family.



Explain

Explain each week you will fill in a different part of the circle. Today you are going to fill in the centre blue section – about you and your child.

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 green circle). If caregivers prefer not to share their stories at this time that is also fine, as they may feel more comfortable later on, when they know other members of the group.

At the beginning of the Cerebral Palsy programme, the main caregiver reported that they felt isolated, lacked support from others, and that there were problems with talking to others about their child's health.
These sessions therefore offer valuable spaces for sharing and discussing their experiences in caring for their child.

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

Allow plenty of time for this group discussion – it's probably THE MOST IMPORTANT part of this module.

Summarise the time of sharing before moving on. For example, if it has been an emotional experience for some, acknowledge their feelings. 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, Rio de Janeiro**

MONITORING PROGRESS

Explain — 10 Minutes

It is very important that you understand what we discuss for yourself.

It is also just as important that you share what you have learned with the other members of your household, and with your neighbours and your community. You will probably need to practice sharing so that you feel comfortable doing it.

Activity

In pairs ask everyone to tell each other in their own words what Congenital Zika Syndrome is. Encourage everyone to give feedback to each other about their explanations, based on what they have learnt today.

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)?"

Materials

Flipchart with take home messages.

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.

OUR CHILD

2

This module covers the following information:

Our child

Developmental charts

When your child is unsettled or crying

Monitoring progress

Sharing emotions and feelings

OUR CHILD

Materials

Large sweets/toffee, pens, flipchart (outcomes pre-written), copies for each participant of images 2.01-2.03, elasticated silky cloth, image 1.06.

Welcome everyone to the group.

Ask

Ask everyone to list a few things they learned last week. *"Are there any issues from the last session that anyone wants to cover again?"*

Remember that you can use the flip chart as a 'parking lot' for any topics that may be covered at a later date.

Icebreaker — 10 minutes

1. Form a line and ask everyone to hold hands to make a long chain.
2. Explain that when someone has their hand squeezed, they then pass on the squeeze to the next person beside them with their other hand.
3. Choose someone at one end of the line to start. Explain that you will squeeze their hand and then they will begin.
4. Ask everyone to close their eyes.
5. Squeeze the hand of the person at the end of the line that you selected to start.
6. Each person passes on the squeeze once they feel it, so that it passes all along the line to the end.

Invite the group to sit. Discuss how that in order for the last person to feel the squeeze at the end of the line, it had to happen in steps. One hand squeeze led to another hand squeeze and they were passed along the line. We will discuss today steps in your child's development.

Explain — 5 minutes

Outcomes for the module (on flipchart): By the end of this session you will be able to:

1. Understand how children develop.
2. Observe your child and show where she is on the development chart
3. Identify strategies to calm your child when she is distressed/irritable.
4. Talk about your support at home.
5. Understand the importance of talking about your own thoughts, feelings and emotions.

We will share tips for caring for our child and how we can be supported by other family members and our community. These ideas are a way to live our life with our child.

Materials

Image 2.01 (Make 3-4 sets of these cards for your groups.)

Communication	Self-care activities e.g. eating, toileting, dressing
Moving from place to place	Walking (if possible)

Give each group a set of the cards.

Ask

*"Which skills are **MOST** important to you for your child to learn first, then second, third, and fourth?"*

Discuss the sentences and put them in order of priority:
Everyone can then look at how each group has prioritised the issues and discuss altogether how they have come to the decision.

Each person may have a different area that is important to them. One area that is often forgotten is communication.

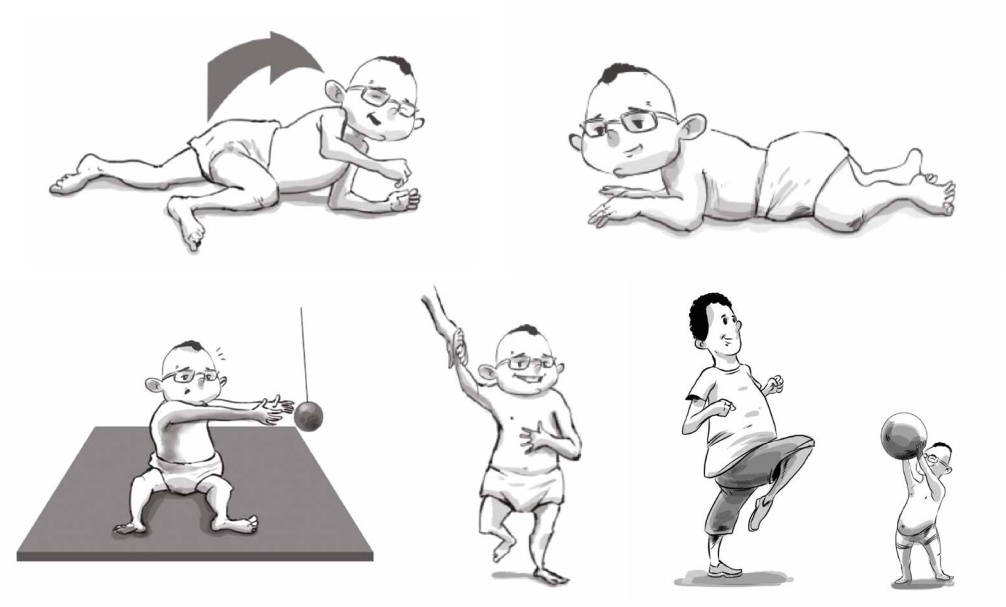
Discuss and ensure that the group covers:
Being able to communicate in some way with others, allows us to build a relationship with them. Additionally, your child can learn to help with her self-care skills even if she is not able to move around from place to place, or walk. Week 5 will focus more on communication.

Activity — 10 minutes

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

Materials:

Images 2.02 (a-e) (enough copies for one set per group)



Activity — 15 minutes

Put up the five pictures below in random order. Discuss the pictures in small groups. Decide on the typical order in which you think most children usually develop.

Explain

Explain that you will now look at the usual order of development for children, and lay the pictures out in the correct order.

Ask — 10 minutes

Ask the groups the following questions: *"Can you think how you have seen your child trying to do things? And what happens? If a child has difficulty moving what do you think she needs to help her to learn to do things?"*

Explain

Children learn by doing the same activity over and over and over again until they get better at it. A child with developmental difficulties has damage to areas in her brain, and therefore **may not be able to move by herself**, or perhaps only with great difficulty.

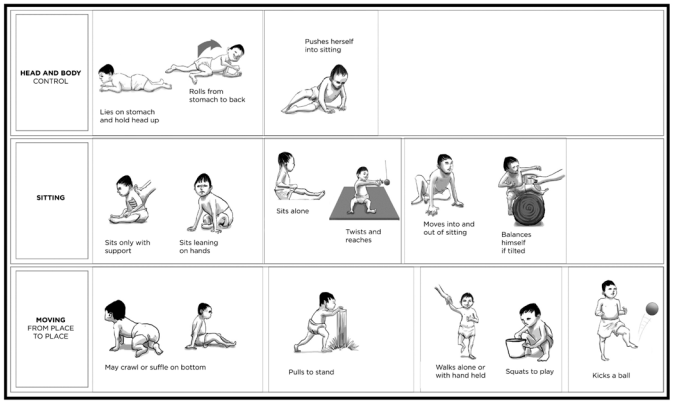
Young children with developmental difficulties do learn and change but they need **extra time** and **extra help** to keep developing. It is important to encourage your child to learn to do things for herself, rather than doing it for her all the time. If you set up the space around her with simple toys/things to look at, this will help her to play and learn more independently. If your child has difficulty doing things on her own, you will have to help her practice, over and over again.

DEVELOPMENTAL CHARTS

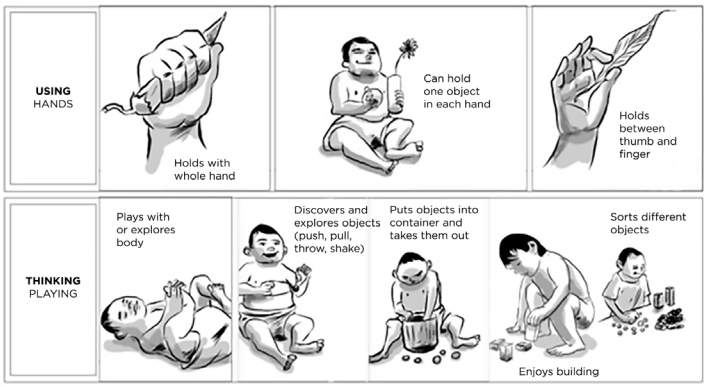
Materials

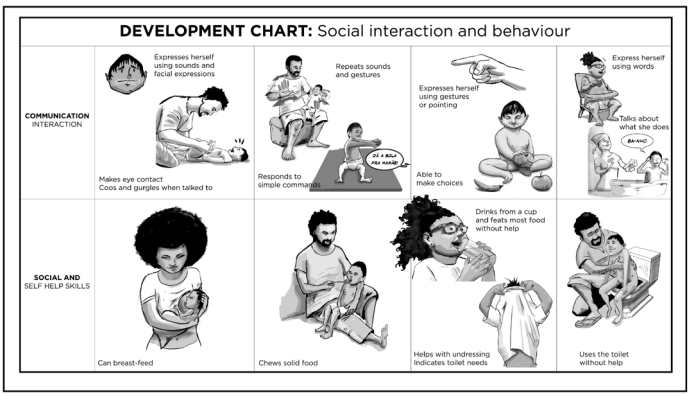
Images 2.03 (a-c). Everyone should have a copy.

DEVELOPMENT CHART: Movement



DEVELOPMENT CHART: Fine motor and thinking/playing





Activity — 20 minutes

Hand out the development charts to each person.
Explain briefly what is happening in each of the pictures.

There are four categories for **Movement**:

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

Plus

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

Working in small groups, ask everyone to mark (in pencil) where their child is on the development charts.

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

Deal with one section at a time, and allow time for lots of discussion and interaction.

Facilitator Tips:

This next part of the session is to encourage caregivers to share strategies amongst themselves for when their child is unsettled or crying. Try to encourage as much interaction as possible.

WHEN YOUR CHILD IS UNSETTLED OR CRYING

Materials

A cup and four pieces of paper with the words ‘stomach pain’, ‘headache’, ‘tired’, ‘emotional’ written on them.

Icebreaker — 20 minutes

Put the pieces of paper into the cup. Break into groups of three. Explain that one person per group will pull out a piece of paper. They must then act out what is written on the paper without using words or pointing.

Explain

Now that we have looked at our children's development, we are going to talk about children's emotions and crying.

All children have a wide range of normal crying, fussing and sleep. It is very common for children to have prolonged crying, fussing or irritability, especially in the first few months of life. This can be very stressful for parents and affect their confidence.

Children with congenital Zika Syndrome are often more irritable than other children.

Materials

Flipchart and pens.

Explain

Many factors can contribute to irritability/prolonged crying and sleep difficulties in children with developmental difficulties.

Ask

"Why do you think some babies are more unsettled than others?"

Key points to include for why some babies may be more unsettled:

- Differences in personality of babies.
- Feeling unwell, such as difficulties with feeding and digestion, seizures, infection, pain in the muscles and joints.
- Feeling hungry, tired or have a dirty nappy.
- Sudden changes in the home environment (e.g. hot or cold, noise), emotional distress.
- Some babies with developmental difficulties may cry because their body can feel quite unusual to them.

Ask

"What strategies have you tried for settling your baby? What has worked best? What hasn't worked?"

Other suggestions for if your baby is not settling:

- Think about some of these reasons and see what solutions can be tried out.
- Many strategies may help to soothe unsettled babies.
- It may take time and extra support to find out what works for your baby.

- All children are different.
- It is important that you comfort your baby if she seems distressed, this will not 'spoil' your baby. (e.g. feeding, use of pacifiers, cuddling, gentle rocking, carrying your baby in a sling, talking/singing/music, bath, gentle massage).

Activity

One example to try is to put your child in a slightly elasticated silky cloth, to make a hammock. Place her in the middle of the cloth in an upright position and two people can rock her gently up and down. She can use her hands to play with a toy when she is settled. (Image 2.04)

What kind of rocking or swinging have you tried before? Have you found anything else with wrapping or swinging your child that has helped?

Ask

"When do you think it is important to seek help and support?"

Key points to include:

- It is important for you and your child that you talk to others if your child has prolonged crying, fussing or irritability.
- If your child has been irritable for a long time or if her crying gets worse, take her to see a health worker or health facility, since there may be a health problem that causes this.
- Health workers may assess your child for many health issues that can make your baby irritable. This can take some time over several visits or sometimes a stay in hospital. Ask your health worker about their recommended next steps.

Break **10 minutes**

Icebreaker — 10 minutes

- Ask 6 people to stand in a circle and face each other, shoulder to shoulder. The remaining people can sit around them.
- Ask everyone to hold hands and remember whose hand they are holding on their right and left.
- Ask everyone to move around and then re-form a circle.
- Everyone then reaches through the circle for the person's hands that they were holding before. Then, they try to untangle the knot of arms without letting go of their hands.
- After 3 minutes ask the remaining people who are sitting for their suggestions or if they have any ideas that may help.

Ask

"How did you start to work as a team? Did you have the same goal? What made untangling easy? What made it hard? What was it like having ideas from outside your circle?"

Discuss that you need to have a team that works together to a common goal. We are going to talk about your team.

Activity with materials — 30 minutes

Use image 1.06. 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 **GREEN** part 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?

Facilitator Tips:

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

MONITORING PROGRESS

Ask

"Can you share something important that you have realized about your child after being here today? What else would you like to know?"

Write up any comments or suggestions that are made.

Materials

Flipchart with take home messages.

Take Home Messages:

- All children have the potential to learn and develop new skills.
- Each child will learn and develop at her own pace and in her own way.
- Sometimes, your child may need help to practice skills or activities.
- There are several reasons why children can cry or be particularly irritable.
- All parents (whether their child has developmental difficulties or not) have a range of emotions and feelings. This is normal.
- Think about who you can reach out to for extra support.

SHARING EMOTIONS AND FEELINGS

Explain — 30 minutes

Each week we are going to have a session at the end that focuses on how you, as caregiver, are. We will talk about 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 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.

Activity

Stand in a circle. Ask everyone to focus on themselves.
"What would you like for your own life?"

It is important to recognize that we all have hopes and dreams. Thank everyone for sharing their wishes for the future. Some people may not be able to think immediately about what they would like for their own life. It can take time to think about what we would like in the future and each person will have their own thoughts for this.

Juntos

POSITIONING AND MOVING

3

This module covers the following information:

POSITIONING AND MOVING

Materials — 10 minutes

Blankets, pillows and towels, carpet on the floor, a doll with floppy limbs that can be positioned (not a hard plastic doll), images 3.01-3.08.

Facilitator Tips:

You can decide if this session should be in one week or spread over two weeks. It is important to explain **the reason why** families and caregivers should use positions and facilitating movement in every day activities at home. We found in the groups in Rio de Janerio and Salvador that many participants did not understand what positions to use at home and why this may be helpful for themselves and their child.

Also, some parents may be afraid to show that they don't know how to use some positions, or of hurting their child.

"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"
Mother, Rio de Janeiro

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

Icebreaker

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

Explain

Outcomes for the module (on flipchart): You will:

1. Understand the importance of correct positioning and how it is the foundation for your child's development.
2. Be more confident to position your child and to be able to show others.
3. Understand ways to help your child learn to move.
4. Be more confident to play with your child to help her to learn to move.

5. Be able to explain to others how they can help your child learn to move.
6. Share some thoughts and feelings about looking after a child with a disability.

GOOD HANDLING AND POSITIONS

Ask — 10 minutes

"We are now in the more practical weeks, why do you think that good handling and positioning is the first discussion?"

Explain

Our body positions are a foundation for life. 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 everyday. The key today is building a foundation to position well and then 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. Parents in Salvador and Rio de Janeiro 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.

POOR HANDLING AND POSITIONS

Materials

20 minutes

Images 3.01 (a-d).

Explain

Positioning your child well is important as it can support development and helps include her in every-day life. Young children with developmental delay may find it difficult to get themselves into good positions. Poor positioning can be uncomfortable and makes it harder for her to learn and be a part of family life.

Activity

Display the pictures to the group. Ask everyone to discuss in pairs.

Ask

"What do you notice about the positions of the children's hips and heads in these pictures?"

3.01a – the boy's hips are far forward on the chair and this means that he slumps backward with his head back.
3.01b – the boy's head is forward and to the side, his hips are crooked.
3.01c – the girl's head is upward and toward the right, she is not looking forward.
3.01d – the boy's head is backward and his hips are far forward.

Discuss

Why the positions are not helpful by asking: Do you think this child will be able to play, communicate, socialise or eat?

Focus on showing difficulties, such as: She can't lift her arms, she can't look around, she can't move, or play.




Explain

If your child is left in one position for a long time or poorly handled, this can:

- Slow your child's development.
- Make it more difficult for you to move and carry your child every day.
- Cause problems such as:

1. Pressure areas
When a person sits or lies for too long without moving, the blood is squeezed away and sores develop. These look dark red or purple and they do not get better quickly as the blood flow is not good. The sores can be painful.

Activity

Press your thumb into your palm and watch it go whiter.

This shows you what it feels like to have the blood stop flow. Imagine if you held it there for several hours.

2. Stiffness
Even if you care for your child really well (such as keeping her clean and dry and feeding her well), if your child is sitting all the time, her body will become stiff and stay in that position. For example, her back can become crooked and twisted, and her hips can move out of place and dislocate.

3. Breathing and swallowing difficulties
Sometimes when your child's neck and back become stiff in a poor position, it is more difficult to breathe and swallow. Feeding can also become more difficult.

Ask

"What advantages do you think good handling and positioning have for us and our children?"

Discuss and ensure that the following issues are covered:

Advantages for us:

- Makes it easier for us to care for our child e.g. in the coming weeks we will discuss how feeding may be quicker and more successful.
- It is part of therapy through the day that we can reinforce at home.

Advantages for our children:

- Helps what she can do and how she develops.
- Helps to make eating, drinking, playing and communicating easier.
- It decreases the risk of food/drink going onto the lungs.
- Helps to prevent positions that lead to our children's bodies becoming too stiff or twisting.
- Is the foundation for all other activities our children need to do.

HOW TO POSITION YOUR CHILD

Explain

Good positions will vary from child to child and not all positions are helpful for all children. Each child is different, so we need to work out how to help your child to stay in a good position.

SITTING WITH A CAREGIVER

Facilitator Tips:
Ensure that the children are with their caregivers at this time so that everyone can practice.

Materials — 25 minutes

Images 3.02 (a-d).

Ask

"Look at the 4 pictures and describe the differences that you see. Which are the better positions and why?"

Poor positions (images 3.02 a-b)

These are poor positions because neither child has their head or hips in the middle:

- His head is hanging backwards, or just leaning against the caregiver.
- He is not sitting on his bottom.
- His hands are not free to do anything.

Good positions (images 3.02 c-d)

These are pictures of good sitting because:

Head and body

- The head is supported.
- The hips are back and give good support.
- She can work her own muscles to move her body and keep it upright.

Legs and feet

- Her hips are bent to keep her back in a good position and stop her from pushing backwards and sliding down.

Shoulders and arms

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

Ask

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

Practice this in pairs. Encourage the pairs 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 write down the one thing that they will change at home. This can be a time to show other people at home how to hold your child. You can take photographs to show the group next week.

SITTING ON A CHAIR OR BUGGY

Materials

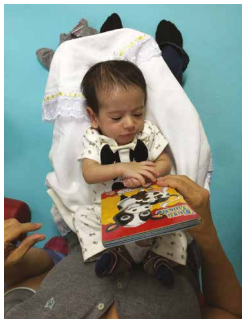
Images 3.03 (a-d).

Ask

"Where your child's hips and head need to be when she is sitting?"

A reminder that her:

- Bottom is all the way to the back of the seat.
- Head is in the middle and supported if needed.
- Arms should be supported slightly forward and in front of her body.

Ask

"How does your child sit in a chair or buggy? What can you and your family use to help support her?"

SITTING ON THE FLOOR

Materials

Images 3.04 (a-d).

Explain

Show everyone the image 3.04a and describe why it is an unhelpful position.

Key points to cover:

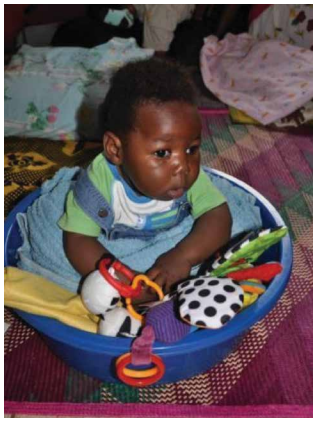
- This position can hurt the knees and hips of the child.
- She does not need much control to sit like this, so she does not need to learn to use her muscles.
- She does not learn to balance in this position and she may find it difficult to sit with good balance in any other sitting position.
- However, if it is the only way that allows her to be independent, do not stop her from sitting but do not let her sit in this position all the time.

Ask

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

Explain

Show images 3.04 (b-d). This is another example of how objects from around your home can be used to help your child to sit.


Demonstrate with a doll

Support your child in a sitting position by holding her around her hips/middle. Place your child somewhere where she can see other people to give her interesting things to look at, to encourage her to hold her head up and look around.

Explain

Trousers that are stuffed will make a good support for your child.

Materials

Images 3.05 (a-b).

Activity

Demonstrate how to make the stuffed trousers and the different ways that they can be used to support children in sitting.




Activity

Practice sitting your child in a chair or buggy, or use a basin and rolled towels.

LYING DOWN

Your child should only be lying down when she is resting, sleeping or playing. It is not helpful for your child to be lying down all day, or to be carried or to sit all day.

Lying down can be a good position for resting, but it does not allow children to engage with other activities.

Materials

Images 3.06 (a-c).

Activity

Ask someone to volunteer to lie on the floor and copy the position of the child in picture 3.06a.

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. Then show images 3.06 (b-c) showing more helpful positions and discuss why.

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

- Head is unsupported.
- Hands and arms are away from her body and so they cannot be used easily.
- Hips and legs are unsupported and cannot relax.

Good position (Images 3.06 b-c)

Head and body

- If she cannot move her head on her own, make sure it is in the middle and comfortable.
- Support on her sides if needed with a rolled up towel to keep her body straight.

Legs and feet

- Bend her hips and support under knees – this helps to relax her back and stiffness in her legs.

- Keep her legs uncrossed – use a pillow between them if needed.
- If her feet point downwards, talk to a therapist about the need for a support for her feet (ankle/foot orthosis).

Shoulders and arms

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

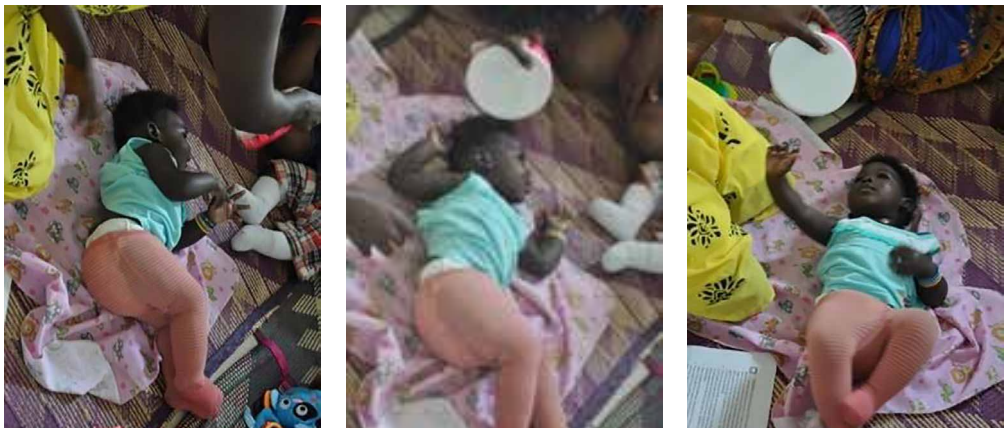
Activity

Split everyone into 2 groups.

Give each group a case study printed on card. Ask them to read through the information about the child, and discuss the questions. 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 (Image 3.07a)



Maria's mother knows that if her daughter lies on her tummy she will develop strength in her head, neck and back, but Maria does not like to spend time in this position. Maria's father knows that rolling over is one of the first movements that she will learn where she uses her whole body. It is the start of her learning to move, but they do not know how to help Maria to learn how to roll.

Can you suggest how Maria can to learn to roll? What have you tried at home?

Someone may show you that they:

- Get down on the floor with their child so that their child can see them.
- Place a toy on the floor in front of their child so that she can look at it or try and reach for it (a toy that rolls away or a mirror is useful in this position).

Move a toy slowly in front of their child, side to side and up and down or in a circle, to encourage them to follow the toy with their eyes and head and slowly roll over.

Facilitator Tips:

If a child tends to push backwards, try to encourage her to look down when she is on her tummy to help change the habit of pushing backwards.

"The best toy that I can have lying next to my son is us or his brother. We are the most interesting." Mother, Salvador

Discussion points:

Children learn to roll, crawl and move by spending time on their front and then pushing up through their arms. Children should be on their tummy several times a day, every day. Time on the floor is a good time for a sibling, also lying on the floor, to play with her.

Helpful lying position includes:

- Head and body in a straight line.
- Her elbows are under her shoulders so that she can lift her body up.
- Her hands are open and she can push down on them.

To roll:

- 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 the hip and knee, and gently turning 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 do as above, encourage her to follow a toy with her eyes and head. Help move the hip if you need to.
- Keep repeating this movement, 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.

Activity

Ask everyone to practice rolling with their child.

Case study 2 (Image 3.07b)

Marco is comfortable on his side because he is stiff. It helps him to get his hands together to play and helps the saliva drain out of his mouth safely. His family uses rolled towels to support him in this position.

What differences do you see between the child that is supported and the child that is not? What things at home could you and your family do with your child in this position? What toys do you have that would be easy and safe for your child to hold in this position?

Discussion points:

The good position is:

- Head supported on a pillow so her chin is level.
- Give good support at his back, from the top of her head to her feet.
- One bent leg and one straight leg helps to relax the stiffness in her legs.
- Support her top leg, bent at her knee, with pillows or blankets so her knee is level with her hip – this is important to help prevent injury to her hip.
- Her shoulder and arm must be forward so they are not trapped underneath her.

Keeping both arms forward will bring her hands together and encourages her to use her hands. Playing a game with her, or putting a toy nearby for her to touch and reach for, are things for family to do.

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

Facilitator Tips:

It is very important to follow up positioning during the home visit, in order to work with the family members and support them in working out which positions are most helpful for their child and to observe how their child spends most of their day.

Explain

Reaching for objects when lying on your back is the most difficult so **work on reaching in side-lying first**.

- Side-lying is a very supported position so your child feels confident and safe to reach forward.
- Use a toy/object that is brightly coloured and that your child likes to get her attention. Hold it close to your child and encourage her to look at it first and then reach for it.
- It is easier to reach for objects and toys when they are put down low in front of you.
- If your child doesn't reach out, you can help guide her arm, from the elbow, towards the object.
- If your child can reach towards the object but can't open her hand to grasp it, help her by gently opening her hand.
- Once they have the toy let them explore it, shake it, move it to their mouth. If they cannot do this alone you can help by gently guiding her hand.
- For holding toys, think about the size and shape to make sure that they can fit easily into small hands.

Activity

Give everyone time to practice getting their child to try and reach and hold using the ideas that were shared earlier.

Break **10 minutes**

STANDING

Materials **10 minutes**

Images 3.08 (a-b).

Icebreaker

This icebreaker helps the group to learn the importance of balance.

- Ask everyone to stand on one leg. Give each person a sheet of paper and ask them to neatly fold and tear it into four equal parts while balancing on one leg.
- Now do the same thing, but let them stand on both legs.

- Compare how easy or fast they could do this activity with a lack of balance and with good balance.
- Now link this to the next pictures, looking at balance and how a lack of balance makes it difficult for a child to do anything with her hands.

Ask

"The girl does not look uncomfortable, but which position of the girl's legs is better? What are the good things that you can see in that position? Can you see a difference in where her mother's hands are?"

In image 3.08b:

- Her hips are facing the front and her mother is helping to keep them in the middle.
- Her feet are firmly on the ground.
- Her head is in the middle.
- She is balanced and will be able to use her hands.

Ask

"Why do you think it is important for your child to stand?"

- To prevent stiffness and tight muscles in the legs.
- To make the bones stronger: a child who never stands has weaker, less dense bones that can more easily break.
- To help to develop the hips.

- To help breathing and blood flow, as well as emptying the bladder and bowels.
- To reduce stiffness and uncontrolled movements in the legs.

Ask

"Can anyone show us how you use your own body to help your child to stand?"

Examples may include:

- Standing on your knee while you hold their body.
- Standing in between your legs while you are seated.
- Leaning your child against your legs either while you are standing or when you are sitting. (This position and the following one need children to be more stable in standing than the first 2 positions.)
- Leaning your child against a stable object – a bed or armchair.

In all these positions:

- Make sure that your child's back and legs are straight and her hips are facing forward when she is standing.
- Make sure that your child's feet and hands are flat on the floor and not turning inwards or curled up/fisted.

Activity

Encourage caregivers to practice the positions with their child if you have time.

MASSAGING AND STRETCHING

Explain

Moving, twisting, massaging and stretching are all ways that we can loosen your child's stiff body. It will be easier for your child to move and for you to handle and care for your child if she is less stiff

1. Good positioning

If you 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

- Play with your child and encourage her to move. These movements help her stretch her muscles.
- Helping your child reach for toys (guiding their hand out or up towards a toy).
- Helping your child open her hand to hold a toy.
- Make sure you are gentle and slow with your stretches otherwise you may hurt your child.

Do not force the joints to move, watch and listen for signs your child is in pain and reduce your effort.

A physiotherapist is the best person to speak to about this, so if you already are seeing a physiotherapist or there is one near to you, it is good to get a programme that is designed specifically for your child.

Ask

"Where/who provides advice and treatment to children with disabilities in the local area? Are there any physiotherapists/occupational therapists in the local area?"

MONITORING PROGRESS

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

Ask **10 minutes**

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

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

Materials

Flipchart with take home messages.

Take Home Messages:

- Good positioning helps make daily activities easier for your child.
- It is not possible to be doing something with your child all the time. You may need to leave her in one position or the other at various times.
- Instead of leaving her in a poor position, guide her into a helpful position and support her in moving herself.

Remind the group that next week is on feeding and drinking

Ask everyone to please prepare and to bring in food that their child likes for the next session. Videoing some moments during the week so that the videos can be seen in the session next week may be helpful.

If a child has a gastrostomy, it is important to make sure that she can have some food by mouth and that her medical team have permitted this.

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.

Juntos

EATING AND DRINKING

4

This module covers the following information:

Eating and drinking

Introduction to solid food

Helping your child to eat and drink enough and safely

1. Environment and hygiene
2. Diet
3. Understanding how your child feeds
4. Positions for feeding
5. Utensils
6. Food textures

Learning to chew and bite

Monitoring progress

Sharing emotions and feelings

EATING AND DRINKING

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 (creating a risk of it going down the wrong way, onto the lungs), and their ability to be able to eat and drink enough (risking malnutrition and dehydration).

It is important to recognise that lack of money and time can make the preparation of special food challenging for many caregivers. Identifying local nutrition programmes is also important, to help you to clarify how the most vulnerable children and families could be linked into their services.

It is important for parents to understand that the notes made by the health team in the child's notebook, especially in the growth and body weight section, allow assessment of the child's risk and vulnerability to low weight.

Important:

If there are children in the group who are fed with a gastrostomy feeding device, it is important to find out if they are allowed to take some food or drink by mouth. If not, you need to make a plan so that they do not feel left out of the group. Groups in Rio de Janeiro used this time for the parents to practice play and positioning with their child and volunteers. This should be planned before the session so that the family knows what to expect and to ensure that you are following the medical guidelines that they have been given. Discussions about nutrition, balanced eating, and positioning for eating are important to everyone, even those who are fed via a gastrostomy.

Materials — 5 minutes

Welcome everyone to the group. Images 4.01-4.04.

For icebreaker: Jug of water and cups.

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

For explanations: Pictures for positioning section.

For practical feeding session: Plastic teaspoons and cut away cups for each caregiver and child. Home-made child food (e.g. bean soup, vegetables, porridge), bananas/soft fruit. Biscuits for the caregivers.

Icebreaker — 10 minutes

This icebreaker is designed to help everyone to understand what it feels like to be fed by someone else, and not fed in a good way.
The caregivers (**NOT** children) work in pairs: ask everyone to take turns to feed one another. Try different positions. The person being fed should be given a sip of water with their head leaning back, and then turned to one side, then flopping forwards.

This activity is important for participants to put themselves in their child's position. One father explained that they often hear the information in a theoretical way so it is not easy to understand.

"All the dynamics today show us how our children feel. We are experiencing the difficulties that our children pass through every day. Because you feed your child every day, it becomes automatic, so some mistakes are involuntary. I am learning more in these practical activities." **Father, Rio de Janeiro**

Ask

"In which position was it easy to swallow? Which position was it difficult to swallow in? How did it feel to be fed?"

Explain

Put up the outcomes (on a flipchart) and go through them with the group.

Today is going to focus on eating, drinking and swallowing. Some children who have difficulties with this may have a feeding tube called a gastrostomy. We won't be covering this today and if there are children in the group with this, explain that is it important to discuss any questions that you may have with your medical team and make plans together.

By the end of the session, you will:

- Know what a balanced diet is and how to maximise your child's nutritional intake to reduce the risk of malnutrition.
- Learn ways for you and your family to feed your child so that you reduce the risk of food/drink going onto the lungs.
- Understand the importance of introducing solid foods to your child at the right time.
- Know ways to encourage your child in independent feeding.

Ask — 5 minutes

"What does your child eat and drink?"

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

INTRODUCTION TO SOLID FOOD

Ask — 15 minutes

"What kinds of difficulties do you have with feeding your child?"
Write up responses and ensure all of the following are discussed.

Difficulty controlling my child's head

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

Difficulty controlling my child's body

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

Difficulty controlling my child's mouth/lips/tongue

- She struggles to close her mouth and food or drink spills out.
- She struggles to chew her food.
- She struggles to swallow/takes a long time before swallowing her food.
- She chokes/coughs a lot when eating.
- She pushes the food out of her mouth with her tongue.

Mood

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

Other problems

- She often vomits after eating.
- She suffers from frequent constipation.
- I feel frustrated when feeding her.

Ask

Discuss in pairs: *"How do you feel about other family members helping your child to eat and drink?"*

Caregivers may be concerned with others helping with eating and drinking.

Recognise:

Your child's different way of eating and drinking puts her at risk of food or drink going onto the lungs.

Your child's muscles may also get tired during the meal and then she can't get enough food and will need to eat more often.

Family members can help your child with eating and drinking because you can start learning together.

A mother spoke of the experience of feeding her daughter who has used the gastrostomy device since 5 months old. Despite being encouraged by her medical team, the mother was afraid that her child would choke on food. She said that she tried to put food in her daughter's mouth so that she can taste food, and at the same time she has physical difficulties with feeding her child. Eating on the street is a challenge and letting other people feed her daughter is too. This was an important moment for this mother, in which she was able to talk and think about her daughter's diet.

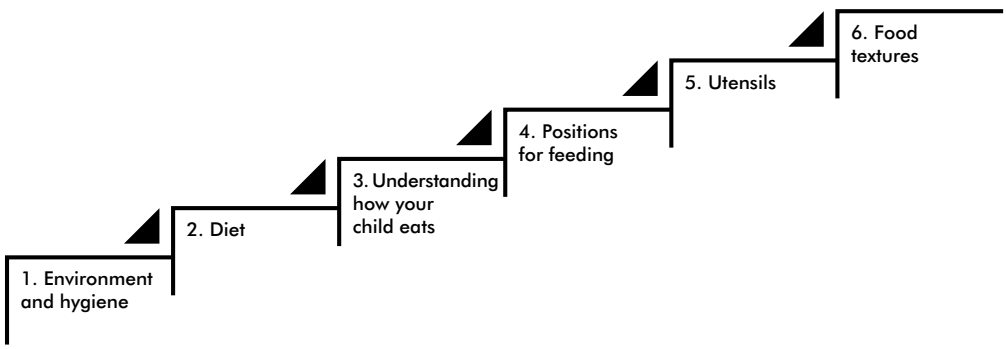
HELPING YOUR CHILD TO EAT AND DRINK ENOUGH AND SAFELY

Materials

Image 4.01.

Explain

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



1. Environment and Hygiene — 5 minutes

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.

"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 include washing both your hands and the hands of your child with soap and water, as well as the utensils.

If your child gets distracted when eating, what is she distracted by? Ask what solutions everyone has found to decreasing distractions.

2. Diet — 20 minutes

Ask

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.

Materials

Images 4.02 (a-b)

Ask

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

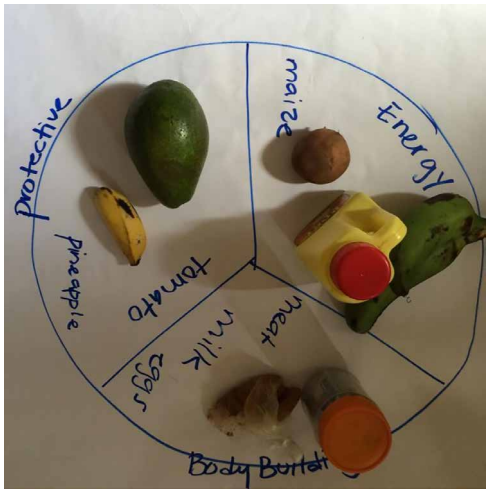
Show the poster and discuss the food groups and that a combination of these will give energy and vitamins, which ALL children need.

Activity

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.



Facilitator Tips:

You can compare these food groups to a tractor:

- Tractor body = formed by food builders
- Lubrication for the gears = fed by the food regulators
- Fuel = energy foods

"I really enjoyed separating food, even when we go to the nutritionist, we do not know everything." **Mother, Salvador**

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 onto 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 congenital zika syndrome 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. Understanding how your child eats 10 minutes

Activity

In groups of three, discuss how you have learned to help your child to eat and drink over the last few months.

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, offer her more milk until she is satisfied.
- Watch your child's reactions to see when she is ready for the next mouthful. Never force feed.
- Start with food – finish with a sip water or milk so that she doesn't fill up on liquid before eating.
- Stop when she indicates that she is tired or has eaten enough.

It is important to give time to all the practical activities. One father in a group said that there are many things that they are just learning now through this group,

"Imagine this, our children have been in treatment with speech therapists and physiotherapists and they are teaching us to feed our children, but here with these practical activities we can put ourselves in our child's position and learn even more."

Facilitator Tips:

If you have a child in the group with a gastrostomy, it may be helpful to have a group discussion about this, so that the caregivers feel supported.

For your information, gastrostomy is nothing more than placing a small flexible tube directly into the stomach to allow feeding in children where the oral route/mouth cannot be used.

In some cases it may be temporary, and you use the gastrostomy until you can eat again, but in others it may be necessary to keep the tube for several years or even for a lifetime.

For children who find eating and drinking very difficult, they may be at risk of taking food and drink into the lungs, which causes pneumonia. Therefore, it is important for caregivers to talk to their child's health team to report coughing or other signs of difficulty, and to better understand when a gastrostomy is needed.

It may be interesting for families to talk to the families of children who already use a gastrostomy. Ask if this is possible.

It is important to be aware of the following guidelines:

Before feeding any child with a gastrostomy tube, place her in a stroller or chair, or with the bed head raised so that the body is semi-upright or upright. The child needs to stay like this for 30 minutes after the feed to avoid reflux (regurgitation). (Image 4.02c).

WASH YOUR HANDS BEFORE AND AFTER ANY HANDLING

4. Positions for feeding 20 minutes

Materials

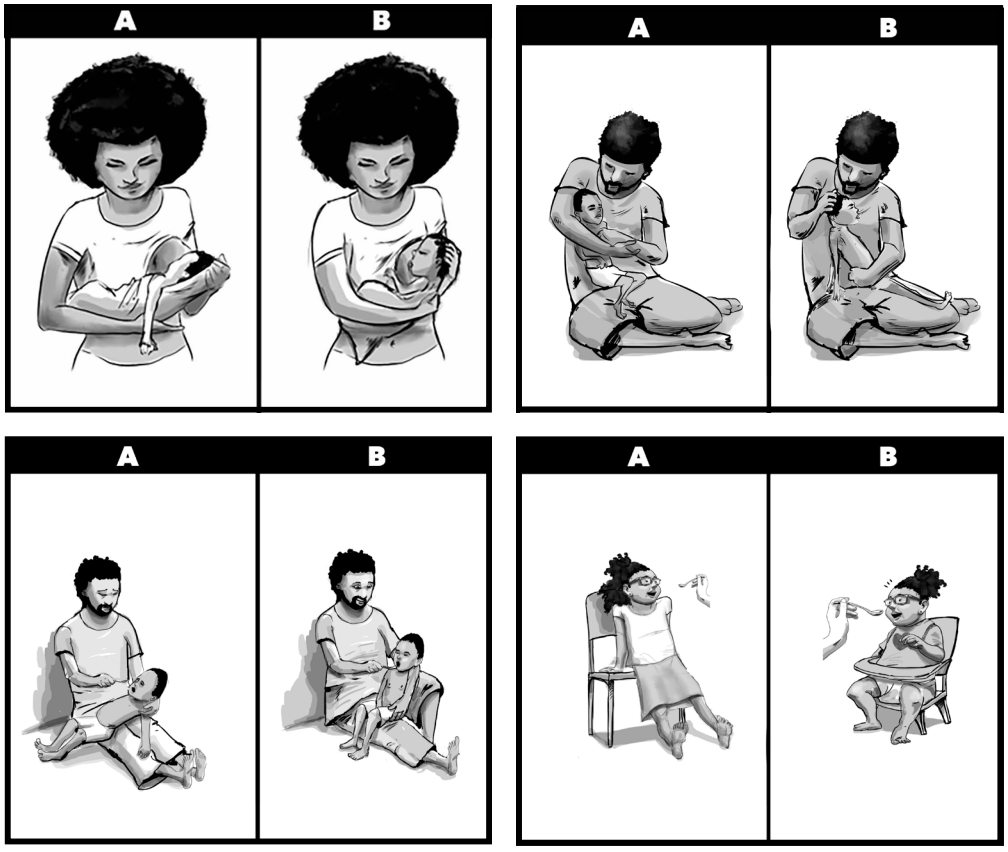
Images 4.03 (a-d). Photocopy 2 sets and cut out.

Facilitator Tips:

This is a good time to reinforce the learning from last week on positioning.

Activity

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 the child and the caregiver need to be positioned well. Children are held in a reclined position when they are breastfed. As they get older and their neck becomes longer, they need to be held more upright to make sure food doesn't go down the wrong way onto their lungs. This 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.

Facilitator Tips:

You will need to be flexible with the timing of activities that involve food and eating. Sometimes children are hungry early and the time for practicing eating will need to be changed. Sometimes caregivers are full after tea and may not wish to participate in activities where they are eating.

You can do the next section during the break. Ask everyone to reserve three foods of their choice, with all three consistencies. Practice using the cup, spoon and solids, provided in this session, with the food chosen. Set aside time for everyone to experiment, discuss and complete.

Activity

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

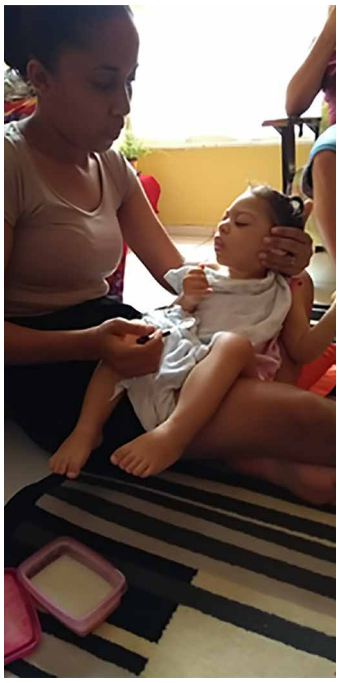
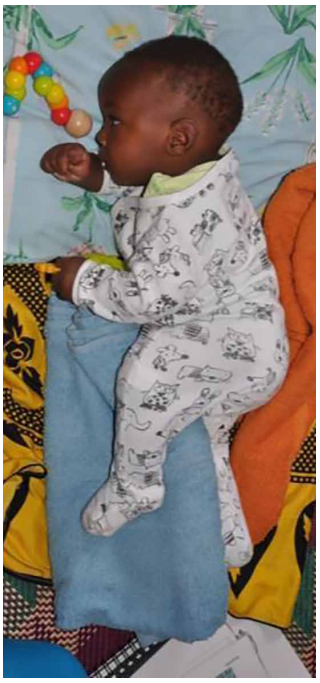
Point out that if you start with the bottom and hips and get them centered and at the back of the chair, it is easier to position the rest of the body.

Demonstrate

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 (next page):

Materials

Images 4.04 (a-c).

If you are sitting on a chair, couch, or bed:

- Make sure that you are comfortable with your back supported.
- Keep your upper arm firmly against the top of her head, and not behind her neck. Make sure you can see your elbow.
- Have your child's bottom firmly between your legs so that she cannot push back.
- If you raise the leg she is sitting on, by putting something under your foot, it will help to make her back straight.
- Bring her arms forward so that her shoulders also come forward.

If you are sitting on the floor:

- Sit with your back against a wall to rest your back.
- Keep your upper arm firmly against the top of your child's head – not behind her neck.
- Make sure you can see your elbow.
- Put a cushion under your raised knee to keep yourself comfortable and to keep her back straight.
- Make sure your child's bottom is well between your legs so that you can keep her hips firmly bent.

Sitting in a supportive chair (for older children)

- Feeding your child on your lap is likely to be difficult if she is bigger or older and it does not support herself well.
- For older children, a supportive seat may be the only way to achieve a good feeding position. As your child grows you need to make sure that the chair still fits. Do not squeeze her into one that she has grown out of.
- Make sure she is correctly seated and positioned by using rolled up towels or cloths if necessary to support her.

Ask

"If you have had difficulty with your child vomiting after feeding, what positions have you found helpful?"

Keeping your child either sitting, upright in a seat or lying on her side on a cushion for 20-30 minutes after meals will reduce vomiting after eating.

Children with developmental difficulties can seem uncomfortable after eating and may vomit because their stomach muscles are weak and let the food come back up either during or after feeds.

Explain

Explain the following summary points for positioning:

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

Activity 30 minutes

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

5. Utensils 20 minutes

Spoon

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

Participants found this part helped them with communication with their child.
"I did not know that you had to show the spoon to the child." **Mother, Salvador**

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. (Image 4.05a).

Activity

In pairs:

- One person is the caregiver and the other is the 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 keep her tongue inside her mouth when she eats and drinks.

When using a spoon to feed your child:

- Give food from the front and straight.
- Give food at her pace.
- 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.
- She will suck on the spoon like she did on the breast/bottle at first.
- Your child should bring her jaw up, but if she doesn't, place your finger under the jaw and give some support.

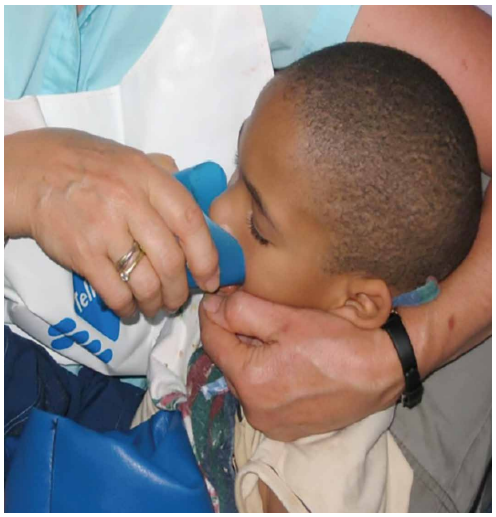
Don't lift the spoon up and drag it against the top gum when taking it out, keep the spoon straight as you take it out of her mouth.

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. (Images 4.05 b-c).



Facilitator Tips:

The cut out section in the cup allows the cup to be tipped upward without having to move the child's neck back in order to finish drinking. The child drinks from the side that is not cut out.

Activity

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 the 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 the 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:

- Child may not wake up.
- Child may not actively swallow.
- Milk may spill from the mouth.
- Child may cough/choke.
- Child might breathe milk into the lungs.
- Child may not control how fast the milk comes out of the cup.

Explain and demonstrate

- Your child needs to be alert and able to suck/sip.
- Position your child upright.
- Present the cup at your child's lips and tilt a little allowing the 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.
- If your child is sucking and swallowing, lower the cup after every 3 sips for a short break.

"Even with my daughter using a gastrostomy I could talk about the difficulties of feeding her." **Mother, Rio de Janeiro**

Bottle Feeding

Ask

Many parents in Brazil use bottles to feed their child.
"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 that the cup will help their child to learn to sip and suck 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

Allow everyone to try out cup feeding.
Observe and advise to ensure correct technique.

6. Food textures — 15 minutes

Facilitator Tips:

This discussion on textures can be included with the activities, they do not have to occur separately.

Materials

Images 4.05 (a-c).



Activity

Show a banana and a biscuit, and other common foods.
Ask the caregivers to discuss if the food items are:

- Hard or soft?
- One type of texture or more?
- Can they be made into smooth puree?
- How can they be made into puree?

Liquids: are runny and can be difficult to control in the mouth. Liquid runs quickly and can go down the wrong way, into the lungs. Liquids should therefore be given very carefully.

Solids: When we introduce solids, children must get used to eating food that's firmer than milk, and feels different in their mouths. Children with developmental difficulties may have problems chewing. This is because they may not have the muscle power or co-ordination, so we need to make solid food moist and soft so that they can manage it. It is important to introduce solid food as this is more nutritious than liquids.

- 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.
- Your child may have difficulty controlling food that has more than one consistency, with both hard bits and liquid, such as bean soup. This is not 'safe' food as it can easily cause choking.
- Banana can be pureed by mashing with a spoon. A biscuit can be moistened with some milk.
- Bean or vegetable soup has hard bits and liquid. This is two textures.

Showing your child the whole food before you mash it up will help her to understand what it is. For example, showing her a banana and then mashing it up in front of her.

If your child has a healthy balanced diet with fresh food cooked and prepared in a way that your child can manage (in terms of texture), this will help her body to be in the best position to be healthy and process the medications that your child is taking.

Ask

"What is one point that change at home and tell you will other members of your family about?"

LEARNING TO CHEW AND BITE

Activity

When a child is able to eat smooth thick consistency foods well, she can be taught to chew soft foods. Ask everyone to eat a biscuit to feel the mouth movements for chewing.

Try to chew and swallow with your mouth open. Do you also need to close your mouth to swallow?

Ask

"What kinds of solid foods have you tried with your child?"

Cooked vegetables such as cassava and potato, biscuits, soft fruits are good for teaching a child to chew. The food should break easily in the mouth and become puree when chewed a few times.

Biting

When your child is able to chew soft foods, e.g., banana, you can help her learn to bite harder foods e.g., biscuits. It is helpful to place a piece of food between the teeth at the side, rather than the front of the mouth.

Ask

Break into two groups.

"What would make you think your child needs help with eating and drink? What would be the reasons that you would take your child to the doctor?"

Answers may include your child:

- Has stopped growing
- Is loosing weight
- Has chest infections
- Is dehydrated
- Vomits during or after meals

These things are different from what you see day to day during meals, these are signs that are good to discuss with your doctor.

MONITORING PROGRESS

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

Ask **10 minutes**

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

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

Materials

Flipchart with take home messages.

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 and chest infections. There is a lot that you and your family can do to help reduce these difficulties.
- If your child has swallowing difficulties, it is important that she is seen by your medical team.

You can:

- 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?"

COMMUNICATION 5

This module covers the following information:

Communication

How do we communicate?

How do communication skills develop?

1. Making eye contact
2. Taking turns
3. Making choices

Monitoring progress

Sharing emotions and feelings

COMMUNICATION

Materials

Flipchart, doll, toys, toffees/sweets (including toys that make a noise e.g. rattles or plastic water bottles with stones/dried beans), images 5.01-5.05.

Icebreaker — 10 minutes

In pairs: One person puts three to four large sweets or toffees in her mouth and tells the other person what she would do if she won the lottery.

How does it feel for the person trying to express themselves? How does it feel for the person trying to understand?

The aim of this activity is to realise how hard it is to communicate with a mouth that does not work properly and how much patience is needed to persevere and listen. It can be frustrating for both people.

Explain — 5 minutes

Outcomes for the module (on a flipchart).

By the end of this session, you will:

1. Understand what communication is and why it is 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.

Activity — 15 – 20 minutes

Ask the group What do you think communication is and what does it involve?

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

Communication is:

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

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

1. My foot is painful.
2. I want to go outside.
3. I am tired.
4. 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.

Material

Use image 5.01 to explain the cycle of communication.

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

Cover the following:

- **Voice:** crying, whining.
- **Facial expression:** smiling, frowning, look of pain, big eyes.
- **Body movement:** nodding head, shrugging shoulders, turning themselves towards or away from someone or something.
- **Gestures**: waving goodbye.
- **Pointing:** using eyes or a finger.

Ask

"Why do we communicate? 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.

HOW DO WE COMMUNICATE?

Materials

Doll

Ask

*"What parts of your body do you use to **EXPRESS** yourself? What parts of your body do you use to **UNDERSTAND** a message?"*

Using a doll ask everyone to point out the different parts of the body which are used in communication, **EXPLAIN** the following:

To EXPRESS yourself you need:

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

To UNDERSTAND a message, you need:

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

Facilitator Tips:

Remember the brain from week 1. If the brain is affected, it can also affect how your child communicates.

Ask

"Which of these communication examples might be difficult for your child?"

In the discussion, caregivers may see some, or all of these things as being difficult, depending on their child.

HOW COMMUNICATION SKILLS DEVELOP

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 her

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.

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.

Break **10 minutes**

Activity — 15 minutes

Ask one person to:

1. Show how to encourage your child to make eye contact (Image 5.02)

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.

Facilitator Tips:

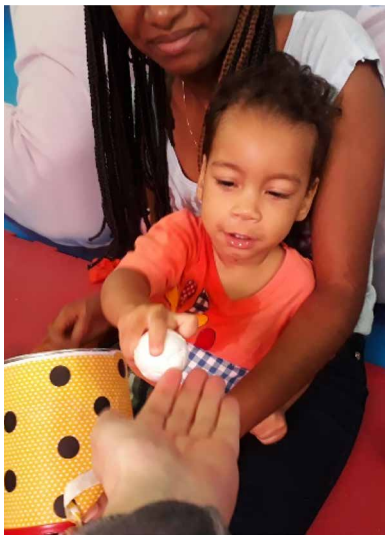
Parents in previous groups have said that they did not know that it was possible for them to stimulate their children to make choices. This is a good time to explore this and how choice making can work for each family. Parents liked having their children in the same room so that they could practice.

2. Show how to encourage your child to take turns (Image 5.03)

Ask

"What did you see the caregiver do? What did you see the child do? What does waiting during play help us to do?"

- When she makes a noise, or uses facial expression, copy her and then try take turns talking. So, for example; child coos/babbles, you coo, you wait for child to coo again, you coo etc.
- Respond immediately to any attempt she uses to initiate communication (noises/eye contact.)
- 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.
- Waiting is very important, children with developmental delay are often slow to respond, so give your child plenty of time.
- Clap your hands and then ask her or help her to clap her hands.



- Roll/throw a ball between you, or build a tower of little blocks together say eg Mummy's turn…your turn etc.

3. Show how to encourage your child to make choices

(Image 5.04)

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 or four choices.
- For example, hold one object in front of the child and name it. Then take it away and show them the other item and name it. Then take that one away. Now show the child both of the items and ask 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 her the object she is looking at or pointing to immediately and say 'you chose the ball by looking at it, so let's play with the ball'.

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.

Activity — 20 minutes

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

Explain

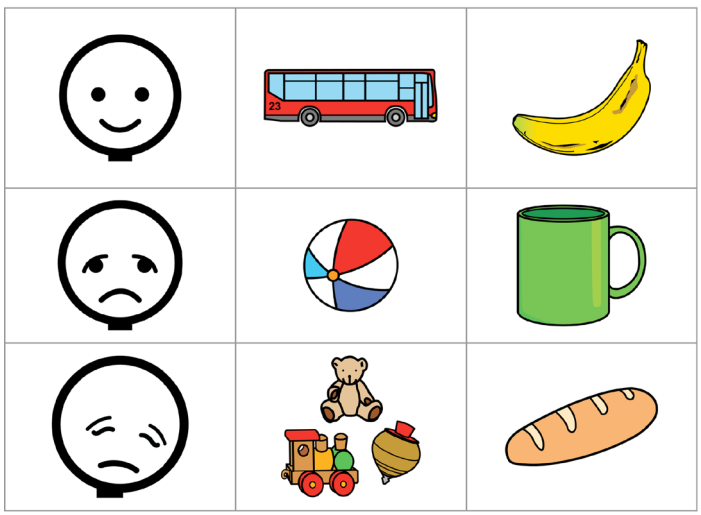
It is not possible to predict the future and no one knows how well your child will communicate when they are older.

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.

Ask

"Has anyone heard of any other things that can help children to communicate?"

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 see but they will still be able to communicate. (Image 5.05)



MONITORING PROGRESS

Ask

"What two things have you learnt today that you will teach to members of your family in order to improve communication with your child?"

Be prepared to come back at the next session and tell us how it went.

Ask

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

"What have you learnt today that would help your child practice these? What are you going?"

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.

SHARING EMOTIONS AND FEELINGS

"There are lots of things to talk about. We learn to express how we feel. We don't have other spaces to do this. It is an opportunity." **Mother, Salvador**

Ask

"How did you feel in this last module about communication? How was it for you to talk about today's subject? Does your child have communication difficulties? How do you feel about that? Did it raise any emotions or feelings that you did not expect? How have you felt this week?"

Allow time for discussion and for everyone to interact with each other.

Facilitator Tips:

Giving feedback to everyone is also very important in these moments.

"What you are saying is important."

"Glad that you can talk about that."

"Do you also feel like this? When do you feel like this?"

These are examples of recognising what caregivers feel.

PLAY AND EARLY STIMULATION

6

This module covers the following information:

Play and early stimulation

Making and adapting suitable toys
- Case study 1
- Case study 2
- Case study 3

Monitoring progress

Sharing emotions and feelings

PLAY AND EARLY STIMULATION

Facilitator Tips:

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.

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

This session can be challenging for caregivers who were not used to playing when they were children, and for caregivers to find the toys and the moments that their children enjoy.

"It is difficult being creative." **Mother, Salvador**

"Playing is a moment of peace, but I do not have time. Joao does not like any toys, he is not very interested. He spends a lot of time sleeping and lying down. If he was more interested in playing, I think he would be more developed. He is just lying down, lying down, lying down and he is happy when he goes in the street."
Mother, Rio de Janeiro

Materials — 10 Minutes

Cup, piece of cloth, container, ball. Materials listed on images 6.01 (a-b) at the end of the module.

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

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 out 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 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.

"I found this interesting. A box of milk can be a lot of fun. We can do that at home and we do not have to spend money." **Grandmother, Rio de Janerio**

Explain

By the end of today's session, 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 may be challenging for a child with developmental difficulties, as she may need support and encouragement to learn to play. It is vital for development and stimulation can be facilitated through play.

This session is an opportunity to reinforce how other family members can be involved, and how everyone brings their own strengths. For example, fathers may be more boisterous in their play, grandmothers may read to their grandchild. Each person can stimulate different senses through play and the variety is important.

Ask

"What is play?"

Use the images 6.02 (a-e) 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.





Explain

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

Ask

"What are our senses?"

In pairs, ask everyone to think of a game and describe what senses would be used during the game.

Ensure that all the senses are discussed:

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

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

Ask

"When should our children start to play?"

Often the words **'Early intervention'** are used. This means doing things as early as possible to work on your child's developmental, health and support needs. Good early intervention will be family focused and will be able to be done through the day at home.

The first years in life are a sensitive period for development of the brain, which affects how a child moves, communicates, and learns to look after herself.

Activity

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

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

Activity

Turn to your neighbour and discuss: What have you found play helps your child to do? Does your child need to play?

Cover the following key points in your discussions:

- **'Play AWAKENS the brain'**– It gives her an opportunity to explore and therefore learn about things in her environment.
- It gives her opportunities to use and develop her senses.
- When she is having fun she will be motivated to move.
- It gives her opportunities to interact with other people and to learn to communicate.
- It gives her the opportunity to think and learn.
- **Play is FUN and fun is what motivated children to move and learn.**

Every child has a right to play.

Ask

"Do children need expensive toys to play? Do they need help to play? What do you see about the experience of children playing during these sessions?"

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

- Almost anything can be used as a toy, if used in a fun and playful way. Favorite toys are most often household items. (pan, wooden spoons, cups etc.)
- Toys that were made this morning may need you to buy something and a community member or father/husband may like to help make them at home.
- It is helpful to think of what the toy is doing and what sense it may stimulate if you are going to buy a toy from the shop.
- Your child may need help to play and interact with the toy.
- How you and other family interact with your child is a key part of play.
- Use the tips learnt in communication about turn taking and waiting for a response while playing with your child.
- Play is more important than toys.

MAKING AND ADAPTING SUITABLE TOYS

Materials — 45 minutes (include break)

Image 6.01 (a-b) and materials listed (at the end of the module).

"I found it interesting, who would have imagined that a coffee capsule could make a toy, and the other, too, like a little bracelet that I can put anywhere, even in his baby crib" Mother, Rio de Janeiro

Activity

Make toys!

Follow the instructions on the sheets. Half the group should make one toy and half of the group the other (each person make a toy, not as a group).

Encourage everyone to ask any siblings and other family members to use the toy and not to just use it themselves.

Break — **10 minutes**

Activity — 25 minutes

Allow 10 mins for discussion, 5 mins each group to feedback.

Split everyone into 3 groups. Give each group a case study. 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 (Image 6.03a)

Theo's arms and legs are very stiff. His hands are always closed so it is difficult for them to hold things. He has poor eyesight but will smile when spoken to.

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

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 them touch and smell the toys around them. This will help her to understand what is around her.

Case study 2 (Image 6.03b)

Samuel is 20 months old. He is unable to hold his head upright or to sit. He spends his days being carried by his mother. Mama finds it difficult to let him play and sit in a chair because she is unsure if this is safe.

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

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

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 neighbors, 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 (Image 6.03c)

Bernadette has 3 children and her husband has left her. As well as full time caring for her son, who has cerebral palsy, she looks after the other two children. Bernadette would like to be able to work again but she is unsure if anyone else can look after her child like she can.

After attending a 'Juntos' group she makes a toy for her son, and explains to the other siblings that 'PLAY awakens the brain'.

She explains clearly to her other children how to use different toys: "I made him this bottle with beans inside to help him hear."

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

Discussion points:

- 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

"How do you make sure that your child is safe when she is playing?"

Answers may include thinking about the surroundings that the child is in (eg decreasing distractions) and the choice of toy (being aware of older siblings putting things in her mouth, choking etc).

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 for a child's development. A child who does not play will not develop as much.
- We can use everyday simple household objects for play. Involve other children in making toys that are suitable for your child to play with.
- We can always find ways to help ensure that play is 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, Rio de Janeiro**

Image 6.01a

CREATING A WRIST RATTLE

Auditory and visual stimulation: colors and sounds.

Materials

- Used expresso cup, yogurt pot, small plastic container.
- Yarn for tying the rattle: string, elastic, wool or other thick thread.
- Bell or large bead.

STEPS

1.Make a hole in the back of the container

2. Thread the string through the bell/bead

3. Thread the string through the hole and knot it

a a1 - To help passing the thread through the hole, wrap tape around the ends of the cord.

a2 - Decorate your cup with paint or stickers to make the object more attractive. Do not forget the contrasting colors to stimulate the child!

b b1 - For child safety, do not use a very thin cord, and make sure the bell or bead is securely tied.

Image 6.01a

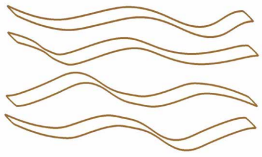
CREATING A RATTLE WITH RIBBONS

Visual and auditory stimulation: colors, sounds and movements.

Materials

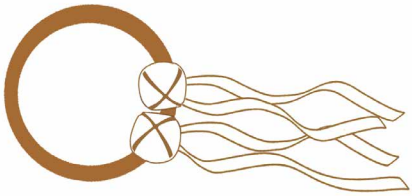
- Curtain ring, bathroom curtain or plastic strap.
- Ribbons with bright colors.
- Bells or large beads.

STEPS

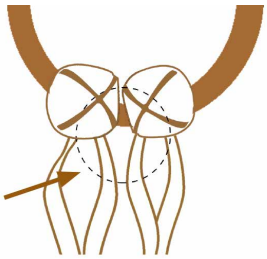


1. Cut 4 coloured ribbons into 40cm each (2 or 4 colors).

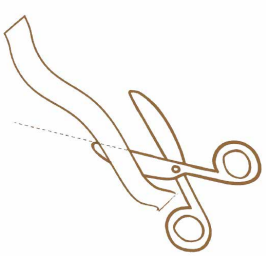
2. Thread the ribbon through the bell/bead to the middle of the tape.



3. Tie the bell on the ring with a double knot. Repeat the procedure with the other ribbons.



5. At the end, tie the ribbons that are next to eachother together.



6. Cut the ends of the ribbons at an angle so that they do not fray.

Juntos

EVERYDAY ACTIVITIES

7

This module covers the following information:

Everyday activities
1. Carrying
2. Face cleaning
3. Brushing teeth
4. Undressing and dressing
5. Toileting
6. Sleeping and resting

Picking up your child

Managing seizures

Monitoring progress

Sharing emotions and feelings

EVERYDAY ACTIVITIES

Facilitator Tips:

This week there is time built in to catch up on any parts of previous sessions that you have not had time to cover or have had to skip.

This module is about helping everyone identify who else in the family can help, such as siblings for play activities or grandmothers for feeding. It explores how to help your child develop while doing the things everyone needs to do and explores practical ways to build in actions that will help children develop through everyday activities.

Materials — 10 Minutes

Basin, doll with floppy limbs that can be positioned, washcloth, paper for each person. Images 7.01-7.05.

Icebreaker

Ask if anyone has 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.

Ask How does the song help your child's development?

Include: singing may help develop communication, encourage eye contact and promote bonding between caregiver and child.

"It is good to interact, to learn new songs. We hear from the facilitators the importance of the songs to stimulate and to motivate our children, and also to have fun." Parent, **Rio de Janeiro**

Explain

Outcomes for the module: By the end of this session, you will:

1. Consider how different family members may be involved in supporting your child's development.
2. Understand how to use everyday activities to help your child to develop.
3. Learn about what to do if your child has a seizure.
4. Recall learning from previous modules.

Activity

Look at the pictures in the image 7.01. Ask everyone to work in pairs and choose one or two of the pictures to discuss using the following questions.

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





Next, show the following pictures. (Images 7.02 a-b).


Ask

"What are the caregivers doing in the photos? How do you think it is helping the child's development?"

"Who can you think of that may help you on this journey of your child's development? How will you work together as a team?"

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 sitting and 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 working.

Explain

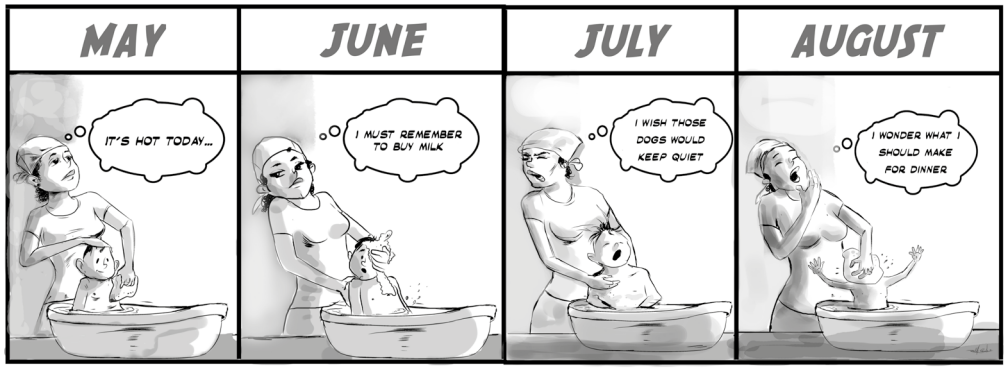
As families, you need to do all these daily things with your child anyway. So if you can do them in such a way that you are stimulating your child **at the same time**, this will help your child **a lot** with her development without taking up any additional time.

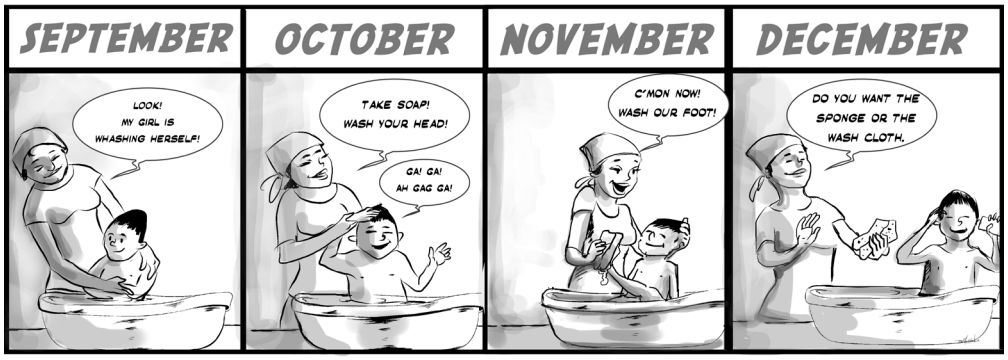
Materials

Doll and basin of water. Cartoon strips (images 7.03 a-b).

Activity

Act out a role play of the two picture strips below, using a doll. Either the facilitators or a few of the caregivers can act out the role play.





Ask

"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.

Facilitator tip:

Having this opportunity to recap and bring together everything learnt during the sessions is valuable for everyone. It is a chance for everyone to demonstrate what they had learnt, consolidate their learning, and reflect on HOW they can build this into everyday activities.

This session includes questions that to ask parents what they will change in the coming week. Encourage everyone to think of just one thing.

1. Carrying

Materials

Images 7.04 (a-c).



Explain

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 parents to recognize 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 he 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

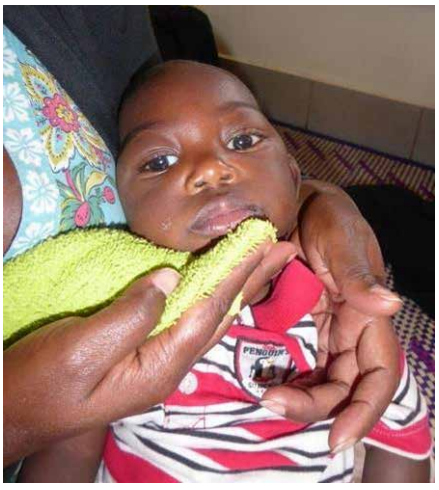
Give everyone the opportunity to discuss in pairs which change they would like to try at home with their child. Then ask them to demonstrate how, with their child or the doll. Encourage everyone to support each other to find the best position for carrying.

2. Face cleaning

Materials

Image 7.05.

Explain and Demonstrate



Some children need to have their faces cleaned often. This can be because they drooling 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

Break into pairs. Take one person from each pair and explain that they will not use any words or tell their partner what they are doing, come from the side and wipe down the face quickly over the eyes and mouth and then from the side quickly as well. It also reinforces the need for good communication with the child. Then practice a good technique.

3. Brushing teeth

Ask

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

Explain

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.

Activity

- 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.

4. Undressing and dressing

Ask

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

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.

Conduct a simple role play/demonstration 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.

5. 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.

6. 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 the knees and hips bent. This encourages them to be less stiff.

Break **10 minutes**

PICKING UP YOUR CHILD

Materials

Images 7.06 (a-b).

Activity

Put up the following two pictures and ask why is it important to take care of your own back?

Which picture shows a good way to take care of your back?

In the discussion, cover the following key points:

- Bending forward with your legs straight will cause small injuries to your back every time you do it.
- Over time you may develop pain.
- Lifting your child puts more strain on your body as she grows bigger and gets heavier.

Activity

Ask everyone to stand in a circle and practice picking up their child:

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

MANAGING SEIZURES

Ask

"What do you understand by a seizure? Do any of your children have seizures? What happens?"

Explain

- Seizures are common in children with congenital Zika Syndrome. Seizures are not caused by evil spirits or from being cursed. They are not contagious or harmful to other children.
- Seizures happen when messages in the brain are mixed up and a child loses control of their 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.

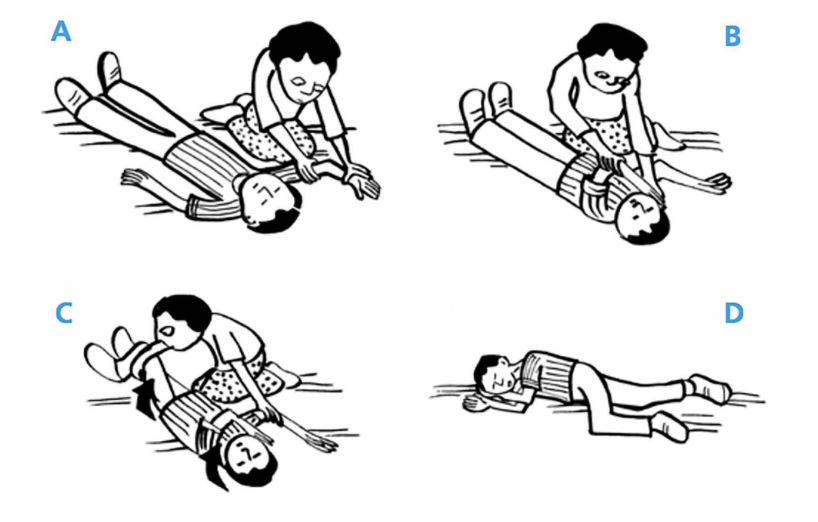
Signs include:

- 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. Someone might just stare into space or have jerking movements in one part of the body.
- When the seizure is over, your child may be very sleepy and may not remember what happened.

Ask

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

Show image 7.07 (Diagram reproduced from WHO mhGAP).



Explain

What to do when a child is having a seizure:

DO:

- Protect your child from injury by making sure she is in a safe place, away from fire or other things that might injure them.
- Put your child on her side when possible, with her head turned to help breathing.
- Make sure she is breathing.
- 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.

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.
- Sometimes the medication makes your child drowsy. If there are any side effects that you are worried about, it is helpful to take a video of your child so that you can 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.

MONITORING PROGRESS

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:

- All children need to be stimulated in order to develop as much as they can, this can be included in any daily routine or activity. It is important to identify helpful positions for everyday activities.
- Every time you do something with your child, help her to be more involved in the activity, and communicate with her.
- All children with developmental difficulties are different, so don't expect the same abilities in each child.
- All children need to be stimulated in order to develop as much as they can, this can be included in any daily routine or activity.

Facilitator Tips:

There is time to discuss questions from the previous weeks or finish sessions that you were unable to complete.

You can use the 'parking lot' questions to guide conversation or list the modules on the flip chart.

Some questions may be difficult to answer or are not able to be covered, the last session is 'where to next?', and it may be helpful to wait to discuss the topic then.

If you have covered all the sessions, you can put up image 1.01 showing all of the modules. Remind everyone of what we have learned so far.

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.

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, Salvador

"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, Salvador

"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, Salvador

UNITING OUR VOICES

8

This module covers the following information:

Uniting our voices

Rights of people with disabilities

Focus on: right to health

Focus on: right to education

Monitoring progress

Sharing emotions and feelings

UNITING OUR VOICES

Materials

Paper, pens.

Icebreaker — 15 minutes

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.

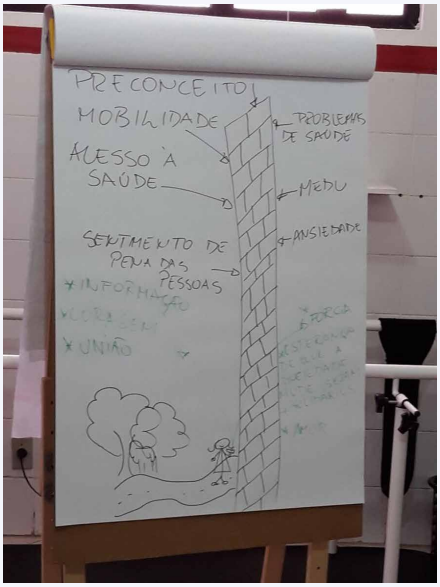
You find the group who built the wall and request them to add a gate.

Explain

Today's session is about rights and raising our voices. 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.

Facilitator Tips:

This is an example of the icebreaker drawn as a story. (Image 8.02)



"I found this realistic. Alone you cannot do anything, you need the support of someone, the presence of someone... with a person helping it becomes easier."
Mother, Rio de Janeiro

Explain — 5 minutes

Outcomes for the module (on flipchart).

By the end of this session, 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.

RIGHT OF PEOPLE WITH DISABILITIES

Materials

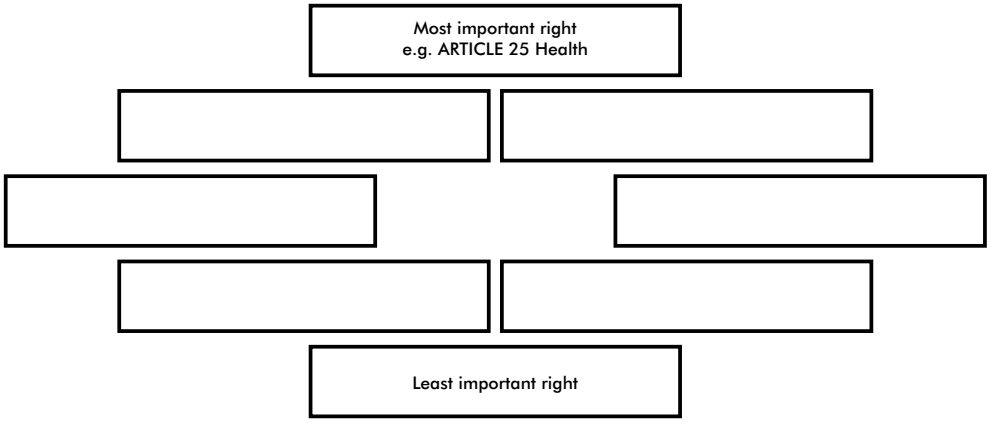
Image 8.01 (at the end of module). Cut out the rights on pieces of paper so that groups can receive the text to rank, flipchart paper with diamond drawn on it for each group.

Ask

"What do you understand by your own rights?"

Activity

In small groups of 3-4, ask everyone to carry out a Diamond ranking activity (see below) with a selection of Rights taken from the UN Convention on the Rights of Persons with Disabilities. Put a selection of 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.



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 'Juntos' group.

Explain

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) is a global law that protects the rights of people with disabilities. Brazil has signed this and pledged commitments to achieve what is laid out.

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

The UNCRPD is broken down into articles that are designed to protect and ensure the rights of people with disabilities at all ages.

Some articles include: education, health, personal mobility, accessibility Brazil has also developed its own national disability law – Inclusion of People with Disabilities Act in 2015.

Facilitator Tips:

If available, you can invite someone from a local Disabled Person's Organisation (also known as DPO) to present this information, as they will also be able to outline opportunities for local level advocacy.

Ask

"Where would you go to find out more information about what is contained within the UNCRPD or the Inclusion of People with Disabilities Act?"

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.

"In reality, there are some laws that we do know exist, but we do not go after them. So we have to do this, we have to act, because there are rights and duties. We have duties. It depends on us too, not only on our politicians." **Father, Salvador**

Today we will focus more on two aspects of the UNCRPD: the right to health and the right to education.

FOCUS ON: RIGHT TO HEALTH

Materials — 50 minutes

Flipchart paper

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.

Ask

"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 alone. 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. However, this is outside the scope of this programme. This programme is 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.

"I heard from doctor that a simple childhood disease was a specific microcephaly problem, so he could not do anything and I must take my son back home. I asked him to please examine my son's ear, and I was right, it was a simple ear inflammation." **Father, Salvador**

Ask

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 facilitie**s 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.

Ask

"While health is a right, how do you get access? We need to access medications, health care workers, hospitals, funds and more. What areas do you have problems with? What has worked for your?"

Activity

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. This role play can then followed by 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.

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: RIGHT TO EDUCATION

Ask **45 minutes**

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

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.

Ask

"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?"

MONITORING PROGRESS

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

Materials

Flipchart with take home messages.

Take Home Messages:

- Children with disabilities have the right to access services including education, health, transport and employment.
- Many different people make up a health team and this can get confusing and tough to navigate. Communication books may help in keeping all the information about your child's health.
- Inclusive education means making sure that children with disabilities go to school. It is best for a child with a disability to be included in their local school which might take some planning or adaptation on the part of the school. It is good to think about this early.

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?"

One example has been to list all the feelings that people have had this week and then to allow time to talk about them. (Image 8.03).

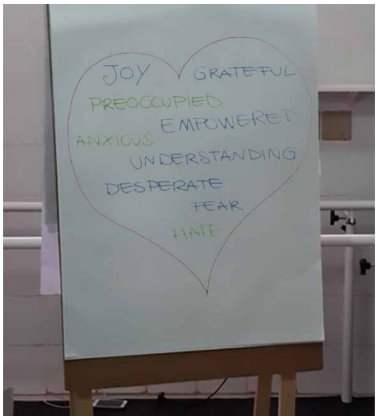


Image 8.01

Education People with disabilities are not excluded from the general education system on the basis of disability and that children with disabilities are not excluded from free and compulsory primary education or secondary education on the basis of disability.
Children with Disabilities Girls and boys with disabilities have the same rights as other children. For example, every child has the right to go to school, play and be protected from violence and to be involved in decisions affecting it.
Awareness Governments should educate all people about the rights and dignity of persons with disabilities and their achievements and skills. They agree to combat stereotypes and activities that are harmful to people with disabilities. For example, schools should promote attitudes of respect towards people with disabilities, even among young children.
Accessibility Governments agree to make it possible for people with disabilities to live independently and participatory in their communities. Any place open to the public, including the building, streets, schools and hospitals, should be accessible to people with disabilities, including children.
Health and Rehabilitation People with disabilities are entitled to the same range and quality of free or affordable health provided to other people. If you have some type of disability, you also have the right to health and rehabilitation services.
Social Protection and Adequate Standard of Living People with disabilities have the right to food, safe drinking water, clothing, and access to housing without discrimination.
Protecting the Person No one can treat you as an inferior person based on your physical and mental abilities. You have the right to be respected by people for who you are!
Freedom from Violence and Abuse Children with disabilities should be protected from violence and abuse. They should not be abused or injured in or out of the home. If you have suffered any type of violence or mistreatment, you have the right to request help in order to stop the situation and to recover.

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

OUR COMMUNITY

9

This module covers the following information:

Our community

Community solutions

Facing exclusion, negative attitudes or discrimination

Monitoring progress

Sharing emotions and feelings

OUR COMMUNITY

Facilitator Tips:

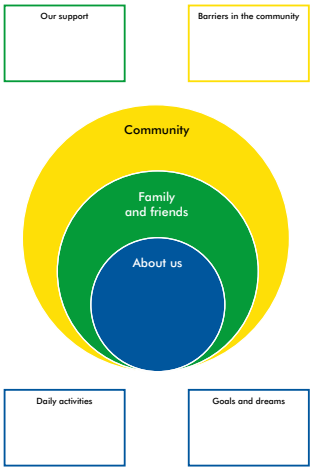
Today is designed with a social event between caregivers and invited members of their community (2-3 per caregiver).

Key community members that may be helpful to invite are community health workers, local religious leaders or other members of the community that the caregivers would like to know better or could interact with more.

The first half of the session is with caregivers only and the remainder with the invited guests.

Materials

Flipchart paper, pens. Image 1.06.



Icebreaker

Tell us who you invited to come today and why. Tell us one thing you hope they will learn from coming today.

Activity: The Game of Life — 20 minutes

Use image 9.01 (at the end of the module) to tell the story.

A summary of the activity is outlined below:

Ask for four volunteers who are willing to stand for about 15 minutes.

Each caregiver is going to represent a character, choose one caregiver to represent:

- A non-disabled man
- A disabled man
- A non-disabled woman
- A disabled woman

Explain that you will now tell a life story, taking the characters on a journey from birth to old age. Your story will reach significant life events. For each life event, the caregiver will respond as they think their community would react to the character that they are representing. You will pause at the life event and the caregiver will make a move. The caregivers move by taking steps.

The steps will be:

1. One step forward for a positive or successful experience.
2. No movement for an experience that is seen as neither positive or negative.
3. One step back for a negative or unsuccessful experience.
4. The steps that they take should be based on what they think is accurate for their community and the situation that their character will be in – not what it ought to be.

After each life stage and step taken, allow time for the others to react and comment.

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

Use image 9.01 to guide people through the story.

At the end of the session, ask the group:

Who is in the best position now? Who is in the worst place? Volunteers, how does this make you feel? Does any of this surprise anyone? What are your thoughts on how disability and social exclusion affects people's abilities to avoid poverty? The non-disabled man at the front of the exercise is regarded as living in poverty – what does this imply for disabled people?

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

Explain — 5 minutes

Outcomes for the module (on flipchart).

By the end of this session, you will:

1. Identify key members of your community and how to engage with them to support your child and your family.
2. Identify some of the main barriers to inclusion of children with disabilities in your community and the ways these might be addressed.
3. Consider attitudes that you may face and how you might address these.

Activity with materials — 15 minutes

Image 1.06

Community mapping:

Complete the outer circle of image 1.06. Tell us a bit more about the community where you live: on your poster, draw the key services and key stakeholders in their community. This can include: health and social services, NGOs, churches, and schools.

Activity — 15 minutes

Get into groups of three: share your community maps 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 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.

Activity

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.

"I went to a doctor that simply didn't get closer and did not even look at my daughter. He looked at me and my husband and told us that he doesn't know how to deal with a child with this condition. He just refused to attend to my daughter. He took a picture and told us that he would send it to a specialist and after he would give us a feedback, but it never happened." **Parents, Salvador**

"I face terrible problems as my child does not sleep at night. If I can't sleep at night, I feel really bad and tired. I don't get any help from anyone apart from my family. A lot of my relatives and neighbours made remarks like 'this is the result of your sins.' "

"Some of the neighbours say 'Why do you need to take care of him? He is mad, leave him like this.' I feel very bad, I feel like committing suicide. A few days ago I put my sister-in-laws child on the chair of my disabled child, and she said very bad things to me: 'you want my child to become disabled like yours, that's why you put him on that chair.' My husband cried for a while after hearing such comments from his own sister." **Mother, Bangladesh**

Physical barriers may include:

- 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.

COMMUNITY SOLUTIONS

Facilitator Tips:

Discussing community solutions is very important and prompts a wider discussion about how the community can promote greater inclusion of children with disabilities.

"We feel alone sometimes. Being here, we feel as normal as the others. We have to be with everybody. We should not be hidden." **Parent, Salvador**

Activity

Go back to your groups of 3. Look at each others' barriers to inclusion, and discuss possible ways to address these. Each group should select their favourite solution and act this situation out as a role play back to the others.

Examples:

If transport is 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).

FACING NEGATIVE ATTITUDES, EXCLUSION OR DISCRIMINATION

Facilitator Tips:

Caregivers report that this section on going outside with their child was really valuable. They have said that they often do not go outside for fun, just for treatment. A supportive discussion on how to deal with exclusion and negative attitudes is key.

Ask

"How do you find the experience of taking your child outside, and to public places? Do you experience any judgements when you go outside? How did you deal with them? How did they address this?"

Discuss within the group about different types of attitudes they have faced. Ask everyone to suggest ways they have addressed these or would address these if they were faced with a similar situation.

Explain

It is important to try and take your child with you wherever you go, for example, to the fields, to the shops. Include the following points:

Talk to your child about what is happening around them, and encourage other people to talk to your child.

It is not your responsibility to do everything on your own! Involve other people, your own family/a neighbour/a church member. They can work with the local community to make it more inclusive of children with disabilities as well.

Ask

How do you include your child's siblings or cousins? How can you involve your child's father more?

Use images in 9.02 (a-b) as a prompt.

Consider ways, either as an individual, or as a group, to help communities become more inclusive of all children with disabilities. What extra help might they need? (E.g. could your church help? Is there a disability 'champion' in your community?).

MONITORING PROGRESS

Ask everyone to explain one thing they found useful from the session and that they will explain to other members of their family and/or community.

How can you share the lessons that you have learned in this group with your community? What would be the best way? E.g. through community radio, social media.

Materials

Flipchart with take home messages.

Take Home Messages:

- Identifying key members of the community is important to help support your child.
- Together we can find local 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 everyone to introduce themselves. You could start with an ice-breaker and ask everyone to make a simple paper hat. Each person then writes what they are called. 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 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.

Material 9.01

'One fine day, after a long wait of nine months, your character is born. How does your society feel when they see who you are? Remember, your characters, one of you is a non-disabled man, a disabled man, a non-disabled woman or a disabled woman. Each character will take the steps as in a 'board game' according to the reaction of society and family to their experiences. Make your moves.'

Note what might happen:

- *Society is very happy (non-disabled son born), one step forward.*
- *Quite happy (disabled son/non-disabled daughter), one step forward.*
- *Not happy (disabled son), stays in same position or moves back.*
- Very unhappy (disabled daughter), one step back.

'Now you are a bit older, and it's time to start thinking about school.
How likely is it that you will be able to attend school? Make your moves.'

'Now you are 20. You'd like to get married, or form a relationship.
How much do you think this will be possible for you? Make your moves.'

'You like to keep busy and want to make some money for your family.
You try to get a job. How easy will it be for you to find one? Make your moves'

'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 one step back, or is instructed to do so by the group. Why did this happen? They may say it's because most disabled women are physically unable to have children – a common myth.

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

Story for facilitators.

Note: words in italics are not to be read out, but are a guide for you.

Juntos

WHAT NEXT? 10

This module covers the following information:

What next?

The value of networking

Linking to other services

Practicalities of running parent support groups

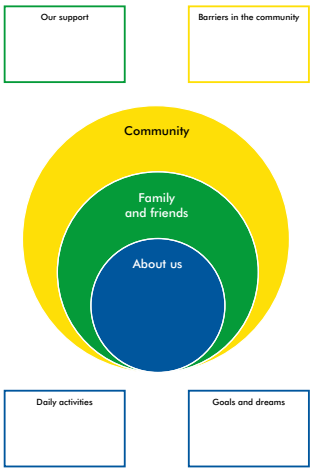
Monitoring progress

Sharing emotions and feelings

WHAT NEXT?

Materials

Flip charts, pens, personalised image 1.06 and image 1.01.



Icebreaker — 15 minutes

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.

Explain — 5 minutes

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).

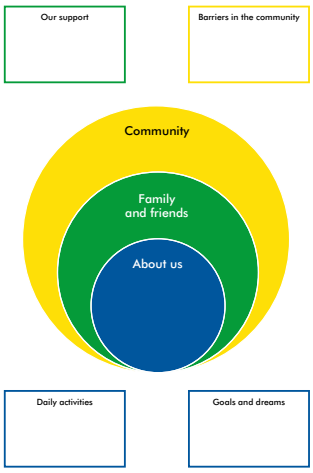
By the end of this session, you will be able to:

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 10 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

Materials

Image 1.06



Activity — 20 minutes

Have a look again at your personal posters. Ask someone who has not presented their poster regularly to present their network. What has changed in your situation since coming? Where do other mothers or parents feature within the posters?

Ask

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

"How do you feel about being networked with other parents/caregivers and other groups?"

"Is it useful? What are the benefits?"

"Do you ever get an opportunity to meet up with any of the other parents outside of the sessions?"

"Is it useful why? Why not?"

"In what ways can you facilitate meeting of parents and gaining support from each other?"

Document suggestions and ways forward for this.

"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, Salvador**

LINKING TO OTHER SERVICES

Ask

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

Activity

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?

Facilitator Tips:

Asking everyone to think of who they can invite e.g. other organisations to come in and give a short talk about their services, may be a useful way to continue the group meetings.

If there is no obvious group that caregivers could join, it might be that they wish to set something up.

PRACTICALITIES OF RUNNING PARENT SUPPORT GROUPS

Ask

Ask everyone to plan how they might run their own parent support group. Emphasise that **there is NO BLUEPRINT** of a perfect group and every group will be different.

Each parent will have a different amount of time to give to this.

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

"What might be some of the challenges for your group? How might you address some of those challenges? What makes a good group leader? How would new people find out about a group?"

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

"I have come to know most of the parents through going to training... before training they were unknown to me. Now, we always talk to each other. Whenever we hear about a child improving, we meet him at their home, and try to find out more."

Parent, Bangladesh, during session on running a support group

Break **10 minutes**

Activity — 40 minutes

Image 1.01 – session overview.

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. (5 minutes per session).

Ask — 20 minutes

"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 devices, gastrostomies, applying for a disability grant, how children with disabilities could go to the local school.

MONITORING PROGRESS

Activity: Most Significant Change stories

Work in groups of four or five.

Looking back over the last 10 sessions, what do you think was the most significant change that you or your family have experienced because of our time together?

Each person tells one story of Most Significant Change as a result of the 'Juntos' group. Ask each group to select one story that they regard as most significant to share with the whole group.

Ask the group to give the reason that they chose this story, this is just as important as the story.

Out of the selected stories, the whole group selects one most significant story of change.

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

1. For themselves as caregivers.
2. For their children.
3. Within the 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. Recongise that everyone may have different feelings about it. Thank everyone for their time and contributions to the sessions.

Juntos


LONDON
SCHOOL of
HYGIENE
&TROPICAL
MEDICINE


International
Centre for Evidence
in Disability