

LET'S GET STARTED

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**This module covers
the following information:**

Let's get started
What are developmental disabilities?
Our children
Our family and support
Monitoring progress



LET'S GET STARTED



Materials

Flipchart, ball, Diagrams 1.01 – 1.04, pens.



Icebreaker

Welcome everyone and introduce yourself.

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

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



Ask

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

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



Explain

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



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



Explain

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

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



Explain

Explain what we will learn together today.

In Module 1 you will:

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

Facilitator Tips:

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



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

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

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

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



WHAT ARE DEVELOPMENTAL DISABILITIES?



Ask

Ask the following questions and discuss as a group.

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

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

Discuss experiences.



Ask

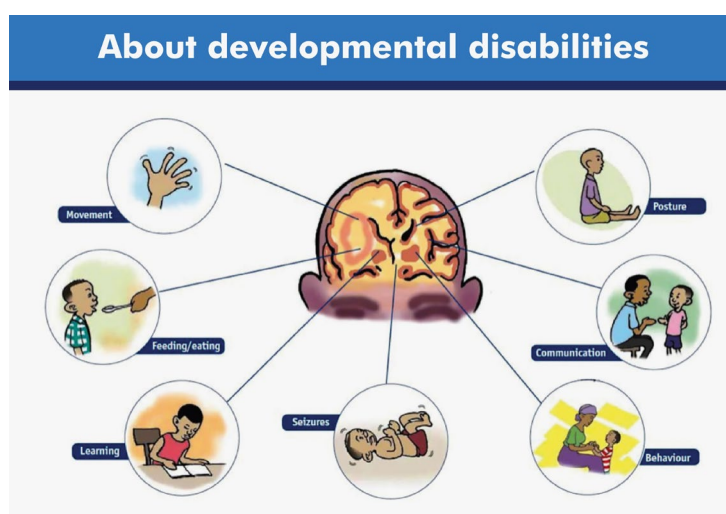
Have you ever heard the words developmental disability? What do you think causes your child's condition?



Explain

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

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



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

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

Present diagram 1.02.

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

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

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

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

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

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

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



Ask

Can other children catch developmental disabilities? Is it contagious?

No. It cannot be passed from one child to another.

Can developmental disabilities be cured?

No, but early help, therapy and learning together in this group can help a child's development and it can help their participation in the family and community.

OUR CHILDREN



Activity 1

Display photos 1.03 a-d.



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



Ask

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

Describe the physical symptoms shown in the pictures.

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

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

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

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



In Bangladesh caregivers really valued looking at the pictures of children with cerebral palsy. This was the first time most of them had seen pictures of other children with a developmental disability, and many had never met other parents of children with disabilities before. This activity stimulated valuable discussion and encouraged story sharing.

"Initially, I thought my child may be cured by a doctor or traditional doctor. Then I saw that he wasn't cured... I understand more about the condition [cerebral palsy] by participating in the training and as a result of this my child has been developing. Now I feel less physical and mental pain."

Parent, Bangladesh



Explain

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

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



Ask

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

OUR FAMILY AND SUPPORT

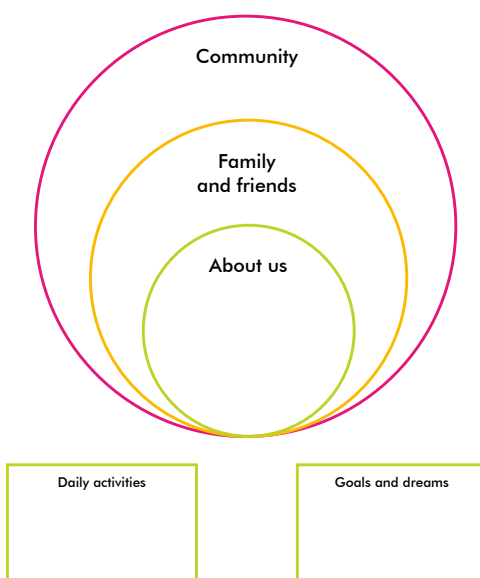


Activity 2

Give one image 1.04 to each family

Our support

Barriers in the community



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



Explain

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

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



Ask

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

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

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

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

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Caregivers of a child with a disability are more likely to report feeling isolated and that they lack support than parents of children without disabilities. These sessions offer valuable spaces for discussion, support and connection.

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

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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.

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Discussing similarities between their stories is valued by caregivers and the activity with pictures of other children creates a lot of discussion and sharing of stories in the group.

“I see the power of this group, this is one of the most important things, it is good to know that there are others who have the same situation as you, that gives you a greater strength” **Father, Brazil**

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MONITORING PROGRESS



Take Home Messages:

- Through our sessions we can make a big difference to the quality of life of our children.
- Share what you are learning with the other people who are part of your child's life – family, friends, and neighbours.
- The earlier you start to help your child to learn, the more she can develop.

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

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



Ask

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

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

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