# 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

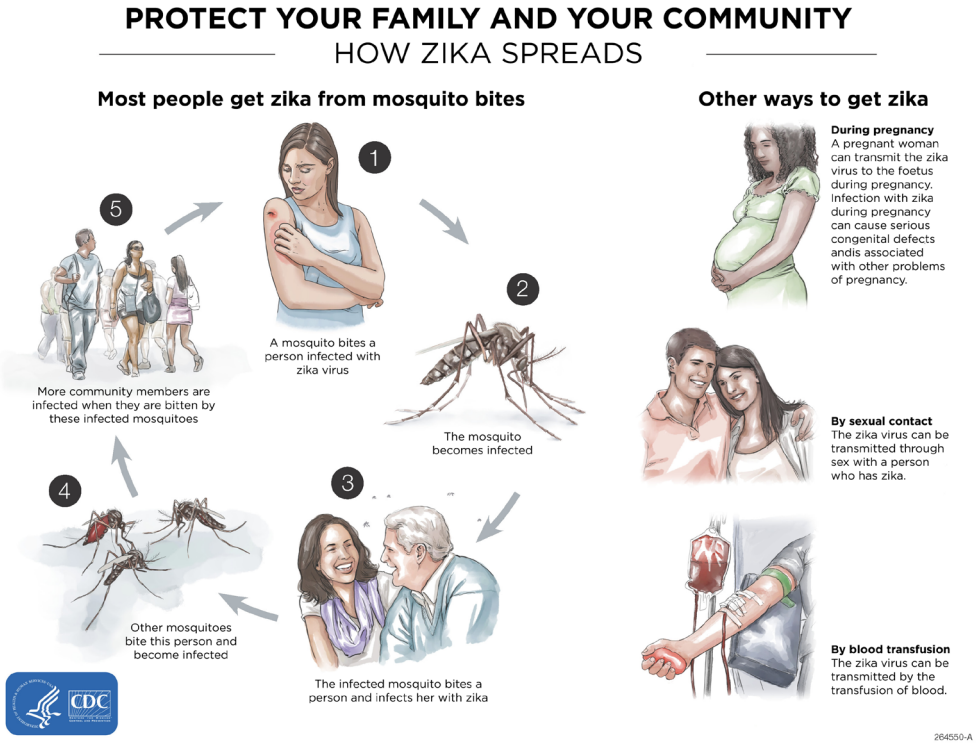
# WHAT IS ZIKA?

## 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.

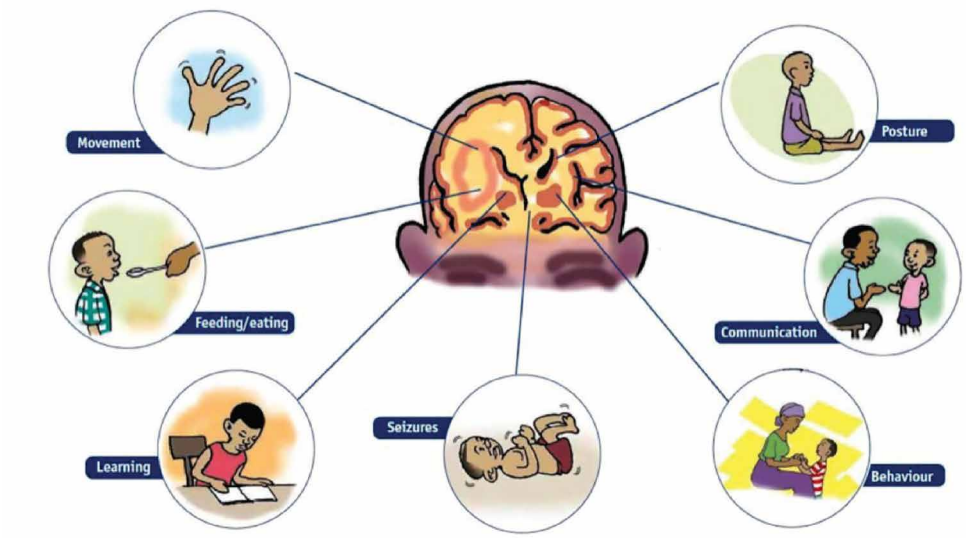
*"What are traditional views that some people may have about how CZS is caused?"*
Discuss their experiences. Read the example below from other parents in Brazil, and ask how this compares to their experience?

*"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

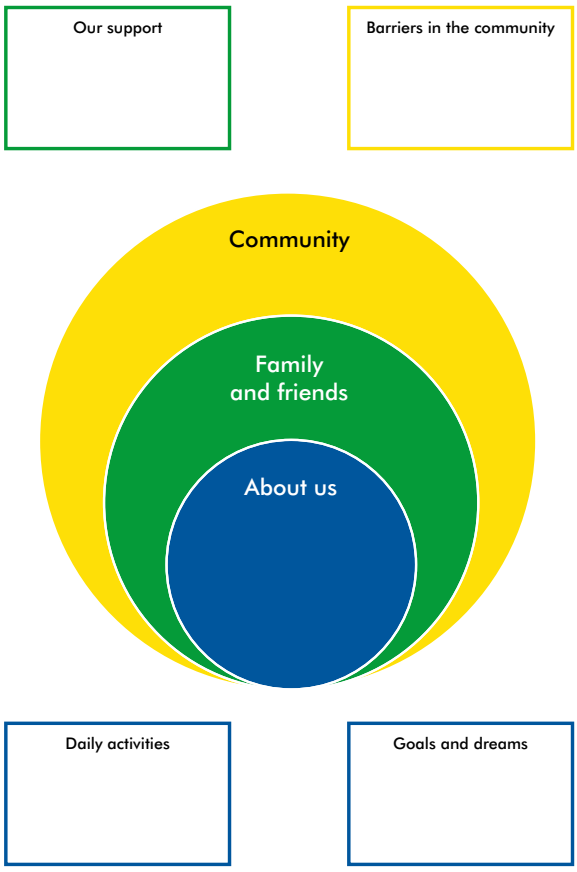
Ask everyone to walk around the room looking at the different pictures of children with CZS. Give them enough time to look at these and to discuss that no two children look the same. Each child is an individual: *"Do the children look the same? Have you seen another child who looks similar to your child?"*

## 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.