

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).

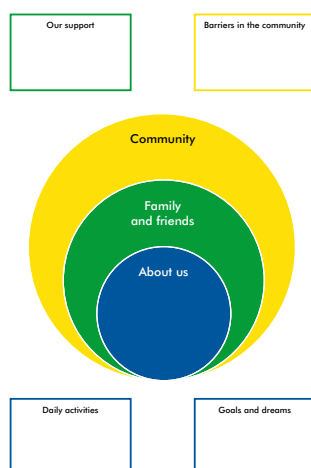
Key community members that may be helpful to invite are community health workers, local religious leaders or other members of the community that the caregivers would like to know better or could interact with more.

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.

