

OUR COMMUNITY

10

**This module covers
the following information:**

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

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



OUR COMMUNITY

Important: This module can be discussed with caregivers first and then also used to raise awareness in the local community about disability.



Materials

Flipchart paper, pens, copy of the diamond ranking activity (IT'S ABOUT ABILITY: An explanation of the Convention on the Rights of Persons with Disabilities) cut into sections, and information explaining national legislation on the rights of people with disabilities, poster 1.04.



Icebreaker

Tell the following story (Have the drawing of a path and wall on the flipchart ready):

We are starting today with a story with a difference. The story has a beginning and an end, but no middle.

Your task is to fill in the middle of the story:

Imagine you are walking along a path in the countryside. Suddenly you reach a huge wall that blocks you continuing on your path. It's hundreds of metres high and there is no away around it. The only item you have is a small hammer...

... at the end of the story, you have got past the wall. You carry on up the path that you were on, feeling happy about having beaten the obstacle that was in front of you and continue on your journey.



Ask

"What happened in the middle?"

Ask people to discuss ideas in groups of three, then share ideas with the group. Discuss the pros and cons of each solution (examples given below, but there are many more).

There is no right or wrong answer – encourage people to be creative (the more creative the better) about how they got past this obstacle.

Examples include:

You managed to get a lift over by a passing aeroplane (this is great for you but what happens to next person who comes along and still has a wall to overcome).

You hammer at the wall by yourself for months, eventually managing to make a hole in the wall that you can climb through.

A sudden storm breaks away part of the wall and you can climb over. You gather hundreds of people come to help knock down the wall.

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

Today's session is about our community and our rights. We are met with many walls in our life and getting past them, through them, around them or breaking them down is something we will need to face. It is easier to tackle obstacles together and are united, because together we are stronger. Lots of people working together on the wall will be quicker than one.



Explain

By the end of module 10, you will:

1. Understand about disability rights and be able to communicate this to others.
2. Understand your right to health and how to get the most out of your medical visits.
3. Understand more about future education for your child.
4. Have considered where you can go for services within your area and community.

If you are using this module in the community, you may just explain point 1 at the start of the session before moving on to the first activity.

RIGHTS OF PEOPLE WITH DISABILITIES



Ask

Image 10.01 (at the end of module). Cut out the rights on pieces of paper so that groups can receive the text to rank, flipchart paper with diamond drawn on it for each group.

"What do you understand by your own rights?"

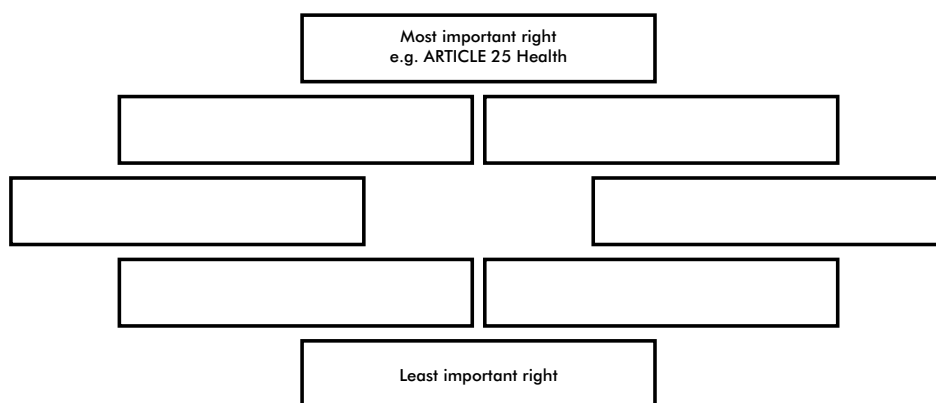


Activity 1

In small groups of 3-4, ask everyone to carry out a Diamond ranking activity (see below, and in facilitator materials) with a selection of Rights taken from the UN Convention on the Rights of Persons with Disabilities. Put a selection of eight rights on pieces of card, and ask the groups to rank which rights they consider are most urgent/ important for them in their lives at the moment.

Equality and Non-Discrimination Everyone has the right to be protected by the law, and the laws of a country should apply to everyone who lives there.
Women With Disabilities Women and girls with disabilities face more discrimination. Their human rights should be protected.
Children With Disabilities Children with disabilities have the same rights as other children. Every child has the right to go to school, to play and be protected from violence.
Awareness Raising Governments should educate everyone about the rights of people with disabilities, their achievements and skills. They will work against stereotypes, stigma and activities that might harm people with disabilities.
Accessibility People with disabilities should be able to live independently and be included in their communities. Any public place must be accessible.
Freedom from Violence and Abuse Children with disabilities should be protected from violence and abuse in the home and outside.
Protecting the Person No one can treat you as less of a person because of your physical and mental abilities. You have the right to be respected by others just as you are!
Personal Mobility Children with disabilities have the right to move about and be independent. Governments must help them do so.
Health and Rehabilitation People with disabilities have the right to the same health care as other people. If you have a disability, you also have the right to health and rehabilitation services.
Adequate Standard of Living and Social Protection The right to food, clean water, clothing and access to housing, without discrimination. The government should help children with disabilities who live in poverty.

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



Ask

Ask each group to share their ranking and what they think the top 3 rights for them are and why. There is no 'right or wrong' answer as some rights will have more relevance to certain people. Link this to information on the National Laws and regulations in the country where you are running the group. Explain that there is no 'right or wrong', all the rights are important, but some will be more important than others to individuals at different times (or something like that).

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) is a global law that protects the rights of people with disabilities. Many countries have signed this and pledged commitments to achieve what is laid out. It is broken down into articles that are designed to protect and ensure the rights of people with disabilities at all ages, such as education, health, personal mobility, accessibility.

Facilitator Tips:

Ideally, if available, invite someone from a local Organisations for Persons with Disabilities (also known as OPD or DPO) to present this information, as they will also be able to detail opportunities for local level advocacy.



Ask

"Where can you go to get help to better understand your rights, or with accessing your rights e.g. your right to a disability grant?"



Explain

There may be many advocates on disability already working within your communities. Disabled People's Organizations from many countries were a major driving force behind the creation of the CRPD and often hold the latest information about disability laws and right in your country.

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

FOCUS ON THE RIGHT TO HEALTH



Ask

"Which health professionals have you seen in relation to your child's condition? Can you tell us what their roles are?"

List the professionals on the flipchart paper.

"What is your experience of going to see healthcare professionals? Can you list some good/bad points?"

Facilitator Tips:

This section aims to bring a discussion on how meetings with healthcare professionals can be better. It is **EXTREMELY** important that you acknowledge that the responsibility does not lie with the caregivers. Much of the time it can be attitudes or time limitations or lack of knowledge on the part of the healthcare provider that can cause a health visit to not go as planned.

There needs to be more training for healthcare workers. Referral services and follow up to health services also needs to be strengthened. While this is outside the scope of this session, it could be something else that the group plan to do at a later stage, recognising its importance.

These sessions are about how families can be more empowered to support their child and this section discusses ways that they may be able to get more from their interactions with healthcare workers.



Explain

Good communication is key to ensuring safe and appropriate care for your child. This is everyone's responsibility. Although communication between multiple health workers can be challenging, it can be helpful to think about strategies that can be used to help things go more smoothly



Activity 2

In groups of three:

"What communication challenges have you experienced in seeking health care for your child? What approaches did you use to deal with these challenges?"

What did you learn? What strategies might help with this in the future?"

Practical tips may include:

- **Learn as much as possible** about your child's health, how it affects your child, local support and health services.
- **Think about your questions** between visits, prioritise and take them with you to health visits.
- You or your family can take a video of your child to show the health care worker what she is like at home.

Ask for:

- Things to be explained in words you understand.
- Information to be repeated when you need it.
- More information or a second opinion if needed.
- **Remember that you are an expert** about your child and an important member of your child's care team.
- **Take a support person** to appointments if you can.
- Think in advance about **what support you will need to get to health facilities** in an emergency (e.g. transport, care for other children). Ask your health worker about any available support for this.
- **Ask health workers to write down information or changes in care plans for your child.** If you have a written record of major changes in treatment, this can help with communication between health workers in different places and at different times. Consider simple strategies, like keeping a communication book, to help with this.



Activity 3

Role play

Ask if 2-3 people will volunteer to present a short role play to the rest of the group about how you can register for a Disability Card. Follow with a question and answer session to clarify the processes.

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

This time of sharing is important for everyone to discuss their difficulties, and as a group talk about what has worked well and share experiences so that we can all learn together.

Facilitator Tips:

If the session is going well, you may want to discuss: Developing a written care plan, especially for emergencies.

Every time you see a health worker, you will need to communicate information about your child's health and developmental needs. This can be challenging especially when the health worker has not met you or your child before, when your child is unwell or the visit is rushed. Ask your child's main health worker if you can get support to write a summary of your child's health needs and plans, especially for emergencies. This might include the information such as:

- Your child's name, date of birth and address.
- Next of kin/emergency family contacts.
- Emergency health contacts: usual doctors/specialists/other health workers.
- Major health problems and how these can present in an emergency (e.g. what seizures look like in your child, choking, chest infections, feeding difficulties).
- Emergency treatment plans (e.g. for seizures, breathing difficulties).
- Communication needs (including how you can tell if your child is in pain or uncomfortable) and usual routines (e.g. feeding, toileting, sleep).
- Medications.
- Allergies.

FOCUS ON THE RIGHT TO EDUCATION



Ask

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

"What types of support do you think schools and teachers in your area might need to allow children with disabilities to go to school? How can they best get this? What might your role and that of your family be to support this?"

Allow time for discussion and raise key points:

- Children with disabilities have just as much right to go to school and have an education as children without disabilities.
- It is good, if possible, for children with disabilities to go to their local school. This allows them to remain part of their local community.
- To enable this, inclusive education needs to take place where schools and teachers are supported to be able to provide education to children with and without disabilities.

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

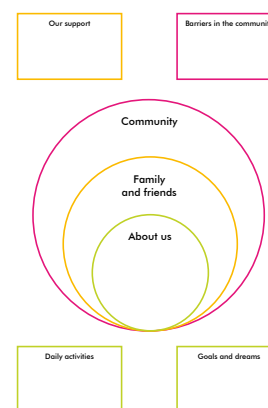
COMMUNITY MAPPING



Activity 4

Complete the outer circle of image 1.04.

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



SHARING COMMUNITY MAPS



Activity 5

Get into groups of three: share your community with two other people. In the barriers section (top right) list some of the main challenges faced in your community. Consider the challenge at different levels.

Prompt everyone to not only think about physical barriers but also attitudinal and institutional/service barriers:

- Within families and extended families.
- Within communities (e.g. school, health services).
- At district level and across the country.



Ask

Ask one person per group to share their poster to the rest of the group. As the group feedback, note barriers down on a flipchart paper.

SHARING COMMUNITY BARRIERS



Activity 6

Link this activity back to the story of the wall. Ask everyone to call out some of their main barriers – these are the ‘bricks’ of the wall. As you talk about each ‘brick’, you can break the wall down.

Attitudinal barriers may include:

- Attitudes from your family.
- Attitudes from people that you do not know.
- Your (caregivers’) own attitudes and fears about taking your child out.

Physical barriers may include:

- Steep hills or steps to get into and out of house.
- Inaccessible roads and buildings – for many children who cannot walk/ have difficulty in walking getting to school or to other services can be difficult inaccessible transport – vehicles, public transports are too crowded, and often refuse to carry disabled people.

Institutional/service barriers:

- Difficulty in getting a disability identity card or a disability allowance.
- Teachers have not had training on how to support children with disabilities.
- Lack of adequate health and rehabilitation services.
- Going to a local health clinic for a routine issue only to be sent to a specialist hospital.

MAPPING OUR COMMUNITIES



Activity 7

In small groups, ask everyone to draw a map of their community, showing the important services and people. Draw where your home is also.

Services might include; health and social services, NGOs, mosques, churches, and schools.

Display the maps, and ask everyone to explain theirs.



Ask

“What makes it difficult to access any of the services?”

“How could you make it easier?”

In Bangladesh, a “community mapping” exercise was done in one of the first sessions. This helped to find local projects that might be helpful. For example, many children were underweight, so it was helpful to connect families to the local nutrition programme.

FINDING COMMUNITY SOLUTIONS



Activity 8

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

Look at each others’ barriers to inclusion and discuss possible ways to address these. Each group should select their favourite solution and act this situation out as a role play back to the others.

Examples:

If transport is a problem for a child getting to school, what could they do?

What can others in the community do? How can other children help? If there are lots of myths about what causes disability how might they address this?

For example, could a religious leader be asked to give a sermon? How could they work as a parent support group to address some of the issues?

What can be done to help these families get a disability identity card and disability allowance (in countries where available).

MONITORING PROGRESS



Ask

Ask everyone to explain one thing they found useful from the session.

"How can you share the lessons that you have learned in this group with your community? Can you work as a group? Who else can work with you and help you? E.g. through community radio, social media, engagement with local faith based organisations."

Take Home Messages:

- Identifying key members of the community is important to help support your child.
- Together we can help find solutions to the challenges experienced by children with disabilities and their families.

SHARING EMOTIONS AND FEELINGS



Ask

"How did this session feel? Did it raise any emotions or feelings that you did not expect? How have you been feeling this week?"

END OF SESSION

The rest of the session is a 'social event' for the invited members of the participants. Introduce them to the programme and show the image 1.01 as an overview.



Ask

Ask everyone to introduce themselves.

You could start with an ice-breaker such as the 'game of life' outlined below.

Explain what everyone has been learning and that today's session has been about how the community can support families of children with developmental disabilities.

Display the participants' posters around the room and ask one or two participants to explain what they have enjoyed/learned from coming. Encourage the community members to ask questions to the caregivers or the facilitators.

Another game to play in the community session is the 'game of life' (found in facilitator resources):

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

1.

Ask for four volunteers from among the group (ideally, two men and two women), willing to stand for about 30 minutes to act as:

- non-disabled men;
- disabled men;
- non-disabled women;
- disabled women.

2.

Assign each volunteer a role. Explain how you'll be telling a life story, from birth to old age. Ask everyone to respond to significant life events as they think their character would react. They'll need to take:

- Two steps forward for a very positive or very successful experience;
- One step forward for a positive or successful experience;
- One step back for a less positive experience;
- Two steps back for a negative experience.

Their response should be based in what they think would happen now, not what they think should happen. Allow time for discussion after each response.

3.

Set the scene for the story in a typical rural village.

"One day, after a wait of nine months, your character is born. How does your family feel when they see who you are? Make your moves."

Note what might happen:

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

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

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

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

"A few years go by. Everyone in your age group is having babies. How much will this be a possibility for you?"

Check if the disabled woman takes two steps back or is told to by the group and ask why. They may say most disabled women cannot have children – a common myth.

Disabled women also often don't have children because society thinks they can't or shouldn't.

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

Ask everyone:

- *"Who is in the best position now? Who is in the worst?"*
- *"Volunteers, how does this make you feel?"*
- *"Does this surprise anyone?"*
- *"Was this a helpful tool for learning how disability affects people's chances of living in poverty?"*
- *"The non-disabled man at the front is seen as living in poverty – what does this suggest for disabled people?"*

Ask:

- *"Who benefits from your development programmes at the moment?"*