

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 way 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.

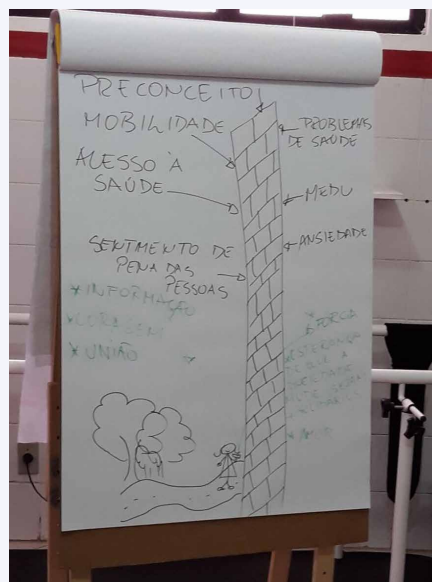


Explain

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.



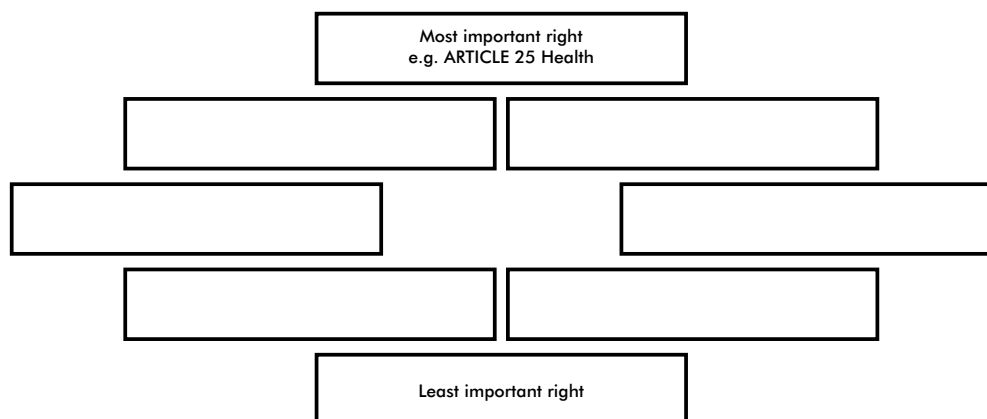
Ask

"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

Flipchart paper

50 minutes



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 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.



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).

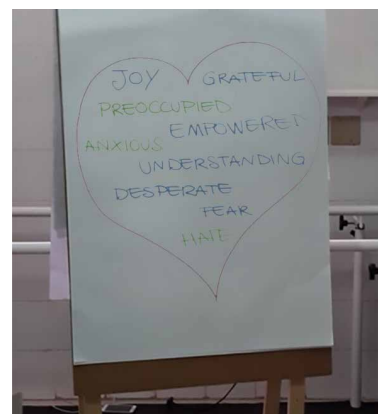


Image 8.01

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.