

## MODULE 8:

# Disability in Your Local Community

**Facilitator note:** This module is developed for a session with caregivers, but can also be used in the community. Ideally you would run it with the caregivers first, and then in the local community. Although this is the 8th module many of the activities can be slotted in anywhere during the training programme. Ideally you might plan some of this work earlier in the training programme, to allow time for follow up and linkages with other organisations. If your training programme is embedded within an existing CBR project then many of the issues may already have been covered.

This module has some overlap with Module 9, Running Your Own Parent Support Group, which also looks at disability and rights.



### Materials

Flipchart paper, pens. Copy of *IT'S ABOUT ABILITY: An explanation of the Convention on the Rights of Persons with Disabilities* (see Resources), and material about national legislation on the rights of persons with disabilities (this will vary between countries).



### Icebreaker

**For caregivers:** Ask them to walk around the room and find someone that they do not know or don't know very well, and ask them to *Share the funniest thing that's happened to you as a parent of a child with a disability*. Ask for a selection of funny stories to be fed back to the group.

**For a session with the community:** Get each person to turn to a person next to them and *Tell your partner a story about one disabled person that you know (in your family, work place, community), and highlight what surprised you when getting to know that person*.



## Explain

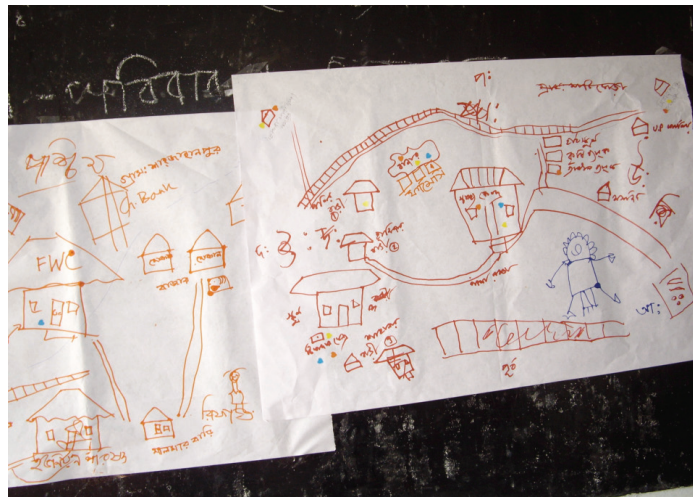
Outcomes for the module (on flipchart).

As a caregiver you will:

1. Identify some of the main barriers to inclusion of children with disabilities in your community and the ways these might be addressed.
2. Understand the basics about the UN Convention on the Rights of the Persons with Disabilities (UNCRPD), and of national legislation on disability, and be able to communicate this to others.



**Activity Community mapping:** In small groups ask parents from the same village to map out, on a large piece of flipchart paper, the key services and key stakeholders in their community. This can include: health and social services, NGOs, mosques, churches, and schools. Ask parents to mark their own homes, as well as the services which they access. Put up the different community maps around the room and ask parents to explain their maps. During the plenary consider what, if any, are the barriers to accessing some of the services that they have mapped. Discuss what could be done to make access to these services easier for them and their families.



Photos: Mothers mapping out their village and key services in Bangladesh

In Bangladesh a “community mapping” exercise was undertaken early on in the training programme. This helped to identify key NGOs and government projects working in the project area, and identified linkages that could be made with the training project. For example, a number of children in the groups were severely malnourished and there was a need to identify opportunities for connecting families to the government nutrition programme, and for linking families with existing livelihoods programmes.



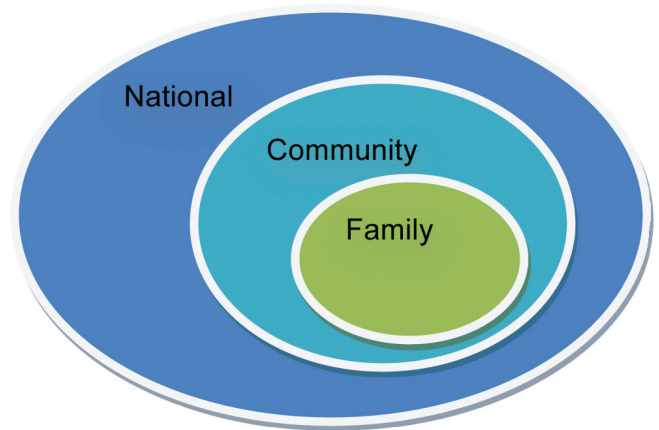
**Activity** An alternative activity for a session with the community is the ‘Game of Life’ activity. Full details are available from the World Vision resource ‘Travelling Together’ (see Resources for a summary).



**Activity** Barriers faced in your community. In small groups refer to the community maps, and ask participants to brainstorm what they think are some of the main challenges faced by families of children with disabilities in their community. Consider the challenge at different levels. Prompt them not to only think about physical barriers:

- Within families and extended families
- Within community (e.g. school, health services)
- At district level and national level

Note these down on a flipchart paper, and then get each group to provide feedback.



In Bangladesh research highlighted a number of barriers to the uptake of referrals and services by families.[1-2]

Physical or environmental barriers to participation and inclusion are often easiest for the community to identify as barriers, for example steps or uneven pathways, not being able to walk to school, and not able to access the toilet independently. It was important to not only focus only on these issues, but also to unpack some of the attitudinal barriers which they faced with their family and community.



**Explain** during the plenary some of the key barriers under the following headings. You can use some of the case study examples below prompt further discussion – are these stories familiar to them?

**Attitudinal barriers may include:**

- Stigma and discrimination within the family and community
- Parents themselves don't consider taking their child to school
- Other family members can stigmatise the child

*"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 their 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:

- Inaccessible/cramped home environment which make it impossible or difficult to perform activities of daily living
- Inaccessible roads and public 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

### Voices of Children

In all the children's interviews, being able to go to school was the most important priority for them. Not being able to attend school was a key reason given for feeling sad. One of the main barriers to access was transport – they were often dependent upon members of the family carrying them to school. How could you address this at community level?

*"My mother can't take me to the school regularly anymore because she is sick. If I was healthy, then my mother would not have to take me to school. When I see the pain of my mother, I feel like leaving school. It's really painful for me to go to school. ....I walk on a stick and I rest every now and then. Sometimes when I really want to go to the school, but my mother can't take me, I cry."*

**Girl, 12yrs, Attending Grade 1 primary school, Bangladesh**

### Institutional/service barriers:

- It can be a difficult process for families to get a disability identity card, and even harder to get a disability allowance
- Difficulty in getting admission to school
- Educational institutions lack appropriately trained staff to meet the needs of certain students with disabilities
- Lack of adequate of health and rehabilitation services in rural areas

Discussing community solutions was a really important component of the session which prompted a wider discussion at the community level about how the community can promote greater inclusion of children with disabilities.



**Activity Finding community solutions:** In small groups ask the participants to look at each of the barriers to inclusion, and ask them to discuss possible ways to address them. You can also ask groups to prepare a short role play to illustrate how some of the issues might be addressed. For example:

- 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)?





Photo: Role Play to illustrate how to get a disability card, Bangladesh

In Bangladesh only 11 of 153 families were registered for the government disability card at the start of the project, and by the end of the training all had been supported to register. Most families had heard of the card but did not have the relevant information about the registration process. A key part of the training was a role play activity by the community workers, where they acted out how to approach the local leaders and the necessary steps to be taken to access the disability card. This was very amusing and made everybody laugh! After the session many parents immediately acted to register the birth of their child at the Union office.

Participants were really keen to know more about their rights and there was a lot of discussion about the Bangladesh Persons with Disability Welfare Act 2001. For the full details of the Welfare Act and the disability card application process, check out the appendices of this module.

## RIGHTS OF PEOPLE WITH DISABILITIES



### Materials

Copy of *IT'S ABOUT ABILITY: An explanation of the Convention on the Rights of Persons with Disabilities* (see Resources), and material about national legislation on the rights of persons with disabilities (this will vary between countries).



**Ask** the groups what they have heard about the rights of persons with disabilities.



**Explain** briefly the key points from the UN Charter on the Rights of Persons with Disabilities (UNCRPD), and nationally relevant legislation related to people with disabilities. Where possible, 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.

# PLANNING FOR A SESSION IN THE COMMUNITY

Ask them to think about running for a session on disability in their own community; what would be the key points that they would want to get across? Who do they think it is important to invite? There would need to be separate planning time for running a session in the community. Parents and other caregivers should be at the heart of any community session if they feel confident with this. They may require some support.

In Bangladesh sessions were run for parents first, and then for local community leaders, including Union members, teachers<sup>1</sup>, health personnel, etc. At the start of the community session basic information was covered about “what is a disability?” and more specific details about cerebral palsy. There are a lot of myths about the causes of disability, and it was useful to spend time on challenging some of those myths. Module 1 of this training programme was used to explain some of the basics about cerebral palsy.



## 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:

1. Children with disabilities have the right to access services including education, health, transport and employment.
2. Together we can find local solutions to the challenges experienced by the children with disabilities and their families.

## References

1. Nesbitt, R., et al., *Predictors of referral uptake in children with disabilities in Bangladesh-Exploring barriers as a first step to improving referral provision*. Disability and Rehabilitation, 2011(00): p. 1-7.
2. Bedford, J., et al., *Reasons for non-uptake of referral: children with disabilities identified through the Key Informant Method in Bangladesh*. Disability & Rehabilitation, 2013(0): p. 1-7.

<sup>1</sup> Union Councils are the smallest rural administrative and local government units in Bangladesh.

# RESOURCES

Check out Module 9 'Running your own parent support group' which has additional material on Rights of Persons with Disabilities.

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](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.

Coe, S. and L. Wapling (2012). *Travelling together*, Milton Keynes, World Vision. Available at <http://www.worldvision.org.uk/what-we-do/advocacy/disability/travelling-together-publication/>. This training material aims to boost disability inclusion in development programmes, and is developed primarily for programming staff who have not considered disability inclusion before.



**Activity** The 'Game of Life' (Coe, S. and L. Wapling (2012). p.25) can be used as a stand alone activity for training in the community. A summary of the activity is outlined below:

1. Ask for four volunteers from among the group (ideally, two men and two women), willing to stand for about 30 minutes to represent the following groups: • 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, taking the characters on a journey from birth to old age. As you reach each significant life event, you'll ask them to respond as they think their character (or their family) 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 not-so-positive or not-so-successful experience;
  - two steps back for a negative or unsuccessful experience.

Also, their response should be based on what they think is currently accurate for their culture and situation – not what it ought to be. After each life stage and volunteers' responses, allow time for the others to react and comment. If there's disagreement, the group should decide by consensus and the volunteer may be asked to alter their move.

3. Set the scene for the story. Since you want to emphasise links between disability and poverty, consider placing the story in a typical village.

‘One fine day, after a long 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? 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?’

‘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 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.

Two steps back may well be an accurate response for a different reason – disabled women often don’t have children because society thinks they can’t or shouldn’t.

‘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?’

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?
- Is it helpful as a tool for reminding us that disability and social exclusion seriously 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 rural location where general levels of poverty are quite high. Even though the non-disabled characters are well ahead of the disabled ones, they’re by no means wealthy. Ask the group – who benefits from your development programmes at the moment?



## Bangladesh – A Step by step guide to obtaining a Disability Identity Card in Bangladesh

- ✓ Collect birth certificate from the Union Parish office,
- ✓ Collect nationality certificate from the Union Parish office,
- ✓ Determine blood group and obtain a certificate from a nearby government or non government hospital or clinic/diagnostic centre.
- ✓ Collect a certificate from the Thana Health Officer (THO) about the type of disability. Please note that THO usually do this verification only on specific days of the week.
- ✓ Complete the application form at the social welfare office and get it signed by the respected union field officer.
- ✓ Attach two passport size and two stamp size photographs of the applicant and the certificates with the application.
- ✓ Submit the complete application pack to the sub-district social welfare department office and get it signed by the authority. Sub-district social welfare office shall forward your application to the district social welfare office. Please note that applicant (CP children) may have to be present at the both sub-district and the district offices of the social welfare department for inspection by the social welfare officer. If the office accepts your application they will give you a date (usually one week later) to collect the disability identity card.

## Bangladesh Persons with Disability Welfare Act 2001

- ✓ As a human being and a citizen of Bangladesh persons with disabilities have all fundamental rights and state parties shall take all necessary measures to ensure there effective enjoyment on an equal basis with others.
- ✓ A person or children with disabilities have the rights of accessing **health and disability rehabilitation services**. Government shall ensure adequate supply of medical utilities for treatment of the PWDs and arrange training of physicians/health professionals attending the PWDs.
- ✓ **Education** of the PWDs: State parties shall establish specialised education institutions to cater the special needs of the children with disabilities, to design and develop specialised curriculum and write special text books and to introduce special arrangement for examination if needed by a disabled student.
- ✓ Create opportunities for free education to all children with disabilities below 18 years of age and provide them with books and equipments free of cost or at low-cost.
- ✓ Endeavour to create opportunities for integration of students with disabilities in the usual class-set-up of regular normal schools wherever possible.
- ✓ **Rehabilitation and Employment** of the Persons with Disability: Identification of appropriate job/employment areas for the PWDs and arrange employment opportunities thereto. Ensure equity of opportunities for employment while recruiting employees in the Government Departments, Statutory Bodies and Local Authorities for suitably qualified persons with disabilities.
- ✓ **Accessibility and Transport Facilities:** To set up appropriate facilities at all buildings and establishments and transports belonging to the Government, Statutory Bodies and private organisations to facilitate easy movements and communications for the PWD.

