

MODULE 9:

Running Your Own Parent Support Group

Facilitator note: If you are running a number of caregiver training groups then you may want to identify 'parent leaders' to represent each group. Invite key staff from local organisations (e.g. social services, micro-credit, health care, DPOs etc.) who can present information to the group about what services or support they can offer. Prepare additional background information on national-level legislation about rights. As one of the last modules in the training package, this is also a useful opportunity to undertake more in-depth evaluation of the training. See Resources for additional links on M&E.



Materials

Flip charts, pens, map of the locality, copies of the *Convention on the Rights of Persons with Disabilities* (See Resources) and information on national legislation regarding the disability rights.



Icebreaker

Welcome the parents. Check on their expectations for attendance. If they are representing different parent groups then ask each participant to introduce themselves, the village that they are from, as well as the parent group they are representing. Ask them to mark their village/group on the map.

Review together the map of all the different villages, and using a marker pen, join up the groups. Explain that the purpose of the training is also about sharing experiences across the different groups.



Photo: Parent presentations, Bangladesh



In Bangladesh two parents from each of the 14 parent groups were identified as leaders and this module was run with them. This provided an important opportunity to meet parents from other groups, and encouraged a wider exchange of information.

"I have come to know most of the parents through going to training before training they were unknown to me. Now, we always talk to each other Whenever we hear about a child improving, we meet him at their home, and try to find out more."

Parent, Bangladesh, during session on running a support group



Explain

Outcomes for the module (on flipchart).
As a caregiver you will:

1. Identify good practice for running and organising self-help parent groups.
2. Explore some of the benefits of wider networking with other parent groups.
3. Understand basic information in relation to rights of persons with disabilities, and have a basic understanding of the role of advocacy in their local community.

DISABILITY AND RIGHTS



Materials

Cards for diamond ranking activity (see Resources)



Explain

that this session repeats some of the material on rights covered in the *Disability in Your Community* session. Check what they remember from this session, and what they found most useful. Remind them that the CRPD (Convention on the Rights of Persons with Disabilities) is a convention which explains different rights that people with disabilities have.



Activity In small groups ask them 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 nine rights on pieces of card, and ask the groups to rank which they consider are most urgent/important for them in their lives at the moment.

Most Important Right e.g. ARTICLE 25 Health		
Least Important Right		

In plenary ask each group to share their ranking and what they think are the top 3 rights for them and why. There is no 'right or wrong' 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 training.



Ask the group how they, as parent leaders, can best share this information on rights with other members of their community. Document some of the ideas on a flipchart.

DISABILITY RIGHTS IN YOUR COMMUNITY

One concrete aspect of realising rights can be registering for a disability card. In many countries there is some form of registration for a disability card, although the nature of the registration process will vary widely. The disability registration can bring a number of benefits, including a disability allowance in some cases. This activity may need to be modified in different settings.



Activity Ask if 2-3 members of the group 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 is then followed by a question and answer session to clarify the processes. Involve parents who have already been successful in registering for a card. Alternatively, in countries where there is no disability registration process, conduct a role play to illustrate how families are eligible for other benefits, for example social protection programmes.

In Bangladesh this Rights Activity prompted lots of discussion and interest. Participants were very keen to understand the Bangladesh 2001 Disability Welfare Act. One of the most popular activities was the short role play about how to register for a Disability Card, followed by a question and answer session. At the beginning of our training only 11 families had registered for a card, and by the end of the training programme all 153 families had registered for a card, or were in the process of registering for one.



Photo: Disability Registration Cards, Bangladesh

THE VALUE OF NETWORKING



Materials

Two different coloured marker pens and flipchart.



Activity

Social network mapping. This activity can serve two purposes. It can highlight how well linked up with other parents they have become, and at the same time can be a useful monitoring activity. Give each participant ONE coloured pen and ask them to draw a circle in the centre of the paper with a picture of themselves and their child. At the top of the sheet write the name of their village. Ask them to mark outside the circle – like the spokes of a bicycle – how many other mothers/families they knew who had a child with a disability **BEFORE** they started the training. Use the same coloured pen. Give them a **DIFFERENT COLOURED MARKER PEN**, and ask them to mark how many new parents they know as a result

of the training (prompt them to think about how many are coming to their group). As an extension to this activity, participants can map out (in a different colour) the other services locally, and organisations they have been linked to as a result of the training.

Put up the posters so that everyone can see how many caregivers are now linked up through the training, and the wider linkages.



Photo: Bangladesh – mapping social networks which result from training



Ask the group the following questions and allow plenty of time for discussion.

- *How do you feel about being networked with other parents/caregivers and other groups?*
- *Is it useful? What are the benefits?*
- *Do they ever get an opportunity to meet up with any of the other parents outside of the training sessions?*
- *Is it useful why? Why not?*
- *In what ways can you facilitate meeting of parents and gaining support from each other? Document suggestions and ways forward for steps.*

“There are many physically disabled children in our village. I did not know them before this time, and we also were not aware of those who arrive from other villages. As a result of coming to the training we know each other.”

Parent, Bangladesh

Recent research in Bangladesh highlighted the important role of networking of self-help groups in promoting greater social inclusion for disabled adults and children [1].

PRACTICALITIES OF RUNNING PARENT SUPPORT GROUPS



Icebreaker

Ask everyone to stand in a line in the following order: from the person who had the longest journey to get to the workshop today through to the one who had the shortest journey. Briefly ask each person to say how they got to the meeting, whether it was an easy journey or difficult journey? Was it more difficult if they were bringing their child with them? We know that transport for children with disabilities is often one of major barriers to accessing services. Ask what suggestions they have for improving transport and access issues.



Ask Imagine a parent support group in your village. *What would a **GOOD** group be like? What would be important qualities?* Brainstorm the ideas.

Possible ideas for a good Parent Support Group might include:

- A welcoming group
- A group that meets regularly
- A place where you can feel safe to discuss your problems
- A space where you can share ideas and access more information
- Importance of confidentiality in the group



Ask Brainstorm ideas for *What makes a good facilitator/coordinator of the group?*
Possible suggestions might include:

- A good listener
- Someone you can trust and maintains confidentiality
- Able to 'signpost' to different services available locally



Ask them to plan how they might run their own parent support group. Emphasise that **there is NO BLUEPRINT** of a perfect group and every group will be different. Each parent will have a different amount of time to give to this. Some questions to think about:

- *Would it be a group that meets regularly? How often or not at all?*
- *Is there something that is important for your group that you want to work together to change? How might you do this? Is there anything you could do as a group?*
- *Could you meet at someone's house? Could you rotate and meet at different people's houses?*
- *How will you communicate with each other about the meetings?*
- *How can you find out what other opportunities there may be for your group to access services? For example, group savings schemes.*
- *What might be some of the challenges for your group? How might you address some of those challenges?*

SIGNPOSTING TO OTHER SERVICES

Ideally invite other organisations to come in and give a short talk about their services.



Materials

Leaflet detailing local organisations and services (You will need to develop this for your context)



Explain that one purpose of a parent support group is to help refer other parents to available services. For example, how to get hold of the disability registration card, how to find out if they are eligible for any social protection programmes etc.



Activity Work in small groups to look at the leaflet detailing local services. Discuss in their groups the services which they are aware of, whether they have accessed them, and their experience of using the service.



MONITORING AND EVALUATING PROGRESS



Activity Most Significant Change stories: Work in groups of four or five. Each person is asked to tell one story of Most Significant Change (MSC) as a result of the training. Each sub-group selects one story that they regard as most significant to share with the whole group. As important as the stories themselves are the reasons given for the selection – ask the parent groups why they consider them to be the Most Significant Change Story? Out of the selected stories, the whole group selects one most significant story of change. Ask parents to consider “Most Significant Changes” at different levels: a) for themselves as parents/mothers/caregivers, b) for their children, and C) within the family.

For more information on MSC tools check out the Resources section.

Some of the Most Significant Changes identified by parents in Bangladesh included:

- Having stronger networks with other caregivers of disabled children in their own community. As a result, being able to better support each other.
- Increased knowledge about their child’s condition, and confidence in caring for their children.
- Increased confidence in sharing this information with others in the wider community.
- Improvements in the functioning of their child, and increased opportunities for their child to participate with other children.
- The parent having more free time because of the improvement in their child’s development.
- A change in the attitude in their family and community towards their child, and towards the family as a whole.

References

1. Miles, S., et al., *Education for diversity: the role of networking in resisting disabled people’s marginalisation in Bangladesh*. Compare: A journal of Comparative and International Education, 2012. **42**(2): p. 283-302.

RESOURCES

Know your Rights Activity

A selection of information extracted from UNICEF 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.

Background: The Convention makes many promises. Its 50 articles clearly explain what these promises are. The principles (main beliefs) of this Convention are:

- (a) Respect for everyone's inherent dignity, freedom to make their own choices and independence.
- (b) Non-discrimination (treating everyone fairly).
- (c) Full participation and inclusion in society (being included in your community).
- (d) Respect for differences and accepting people with disabilities as part of human diversity.
- (e) Equal opportunity.
- (f) Accessibility (having access to transportation, places and information, and not being refused access because you have a disability).
- (g) Equality between men and women (having the same opportunities whether you are a girl or a boy).
- (h) Respect for the evolving capacity of children with disabilities and their right to preserve their identity (being respected for your abilities and proud).

Diamond Ranking Activity Cards Activity

- Cut out on separate pieces of card (enough for each group to have a copy of all articles).
- A selection of rights given below. You can choose a different selection of rights if you prefer.

Article 5: Equality and Non-Discrimination

Governments recognise that all people have the right to be protected by the law, and that the laws of a country apply to everyone who lives there.

Article 6: Women With Disabilities

Governments know that women and girls with disabilities face many different types of discrimination. They agree to protect their human rights and freedoms.

Article 7: Children With Disabilities

Boys and girls with disabilities have the same rights as all children. For example, every child has the right to go to school, to play and be protected from violence, and to be involved in decisions that affect him or her.

Article 8: Awareness Raising

Governments should educate everyone about the rights and dignity of persons with disabilities and their achievements and skills. They agree to combat stereotypes, prejudice and activities that might harm people with disabilities. Your school, for example, should promote an attitude of respect towards people with disabilities, even among very young children.

Article 9: Accessibility

Governments agree to make it possible for people with disabilities to live independently and participate in their communities. Any place that is open to the public, including buildings, roads, schools and hospitals, must be accessible by persons with disabilities, including children.

Article 16: Freedom from Violence and Abuse

Children with disabilities should be protected from violence and abuse. They should not be mistreated or harmed in their home or outside. If you have faced violence or maltreatment, you have the right to get help to stop the abuse and recover.

Article 17: 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!

Article 20: Personal Mobility

Children with disabilities have the right to move about and be independent. Governments must help them do so.

Articles 25 and 26: Health and Rehabilitation

People with disabilities have the right to the same range and quality of free or affordable health care as provided to other people. If you have a disability, you also have the right to health and rehabilitation services.

Article 28: Adequate Standard of Living and Social Protection

People with disabilities have a right to food, clean water, clothing and access to housing, without discrimination. The government should help children with disabilities who live in poverty.

