BEFORE WE BEGIN

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This module covers the following information:

Chapter 1: About the programme

How the programme works

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Our approach

Chapter 2: Running a session

How to follow the manual

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Monitoring and evaluation

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Guidelines

1. ABOUT THE PROGRAMME

1.1 Aim:

To help families and caregivers of children with developmental disabilities to understand their child and to build support networks that will improve the care and inclusion that their child receives in their local community.

Key objectives:

- To improve the knowledge of caregivers and family members about their child's condition.
- To promote positive attitudes towards having a child with a disability within the family and the community.
- To equip caregivers with skills to care for their child.
- To promote problem solving and peer support amongst caregivers.
- To engage with the wider family and community on how to improve care and support.
- To strengthen linkages and referrals and promote wider inclusion.

1.2 The facilitators

The facilitators deliver the programme and are key to ensuring success of the group. We call them facilitators rather than trainers or teachers, because their role is to 'facilitate' the group to interact with one another, rather than to 'teach' all of the content themselves (known as 'participatory approach', which will be explained later.)

Facilitators can be health workers (e.g. physiotherapists, occupational therapists, nurses) and caregivers of children with developmental disabilities – these are both considered to be 'experts' in the area of raising and supporting a child with a disability: a therapist has been trained in certain skills, techniques and approaches, whilst caregivers bring their own personal experiences of the challenges that can be faced in raising a child with a disability.

We reccomend two facilitators for each session.

The two facilitators need to work well together as equal partners. Some sessions may feel more natural to be led by one person more than the other. This manual gives some suggestions for this.

1.3 Approach

Core to our approach is group work with caregivers, which is driven by adult learning

theory and a participatory approach. Participants are encouraged to share their experience through discussion and reflection. They identify and prioritise problems and choose ways to solve these problems together. This process is built into the modules.

This programme is built on the evidence of the value of self-help groups to improve maternal and child health outcomes. These groups are initially run by an outside 'facilitator', but over time the aim is for the group to become independent and self-organised. How to achieve this needs to be considered during your planning phase.

The caregivers start an empowerment 'journey' over the course of the programme. It is recommended that children and their caregivers participate in these groups as soon as possible after diagnosis.

The programme sessions are the key component of this manual, however, engaging and involving the other family members, including fathers, and the wider community is important. How you do this may vary in different countries and contexts, and needs to be planned for right from the beginning.

The programme is not intended to replace therapy, but to complement it. Children need to be supported in a therapeutic way during all activities of the day, not only during therapy sessions. It is also important that the sessions and your interactions with caregivers do not add to their burden of caregiving.

Local healthcare and education services may need to be strengthened and the quality improved to enable the inclusion of children with disabilities. This will complement the caregiver programme, and strengthen the referral processes. This is not explored in this manual, but you can find ways to offer training to local services.

> *"Work with us, not for us; don't tell us what to do to change our lives but share your knowledge and skills so we can figure out how to do it; you cannot do much for us economically, but help us eradicate the poverty of our ideas and dreams – show us new ways of understanding the world. Help us to be heard by those who don't listen to us. And when we find the path we wish to tread, first walk in front of us; then, when we are stronger, walk beside us; and finally, when we are truly strong, walk behind us, so that if we should stumble and fall, you will there to help us get up and walk again."* **Batliwala, S. (2015). Engaging with Empowerment: An intellectual and experiential journey, Women Unlimited.**

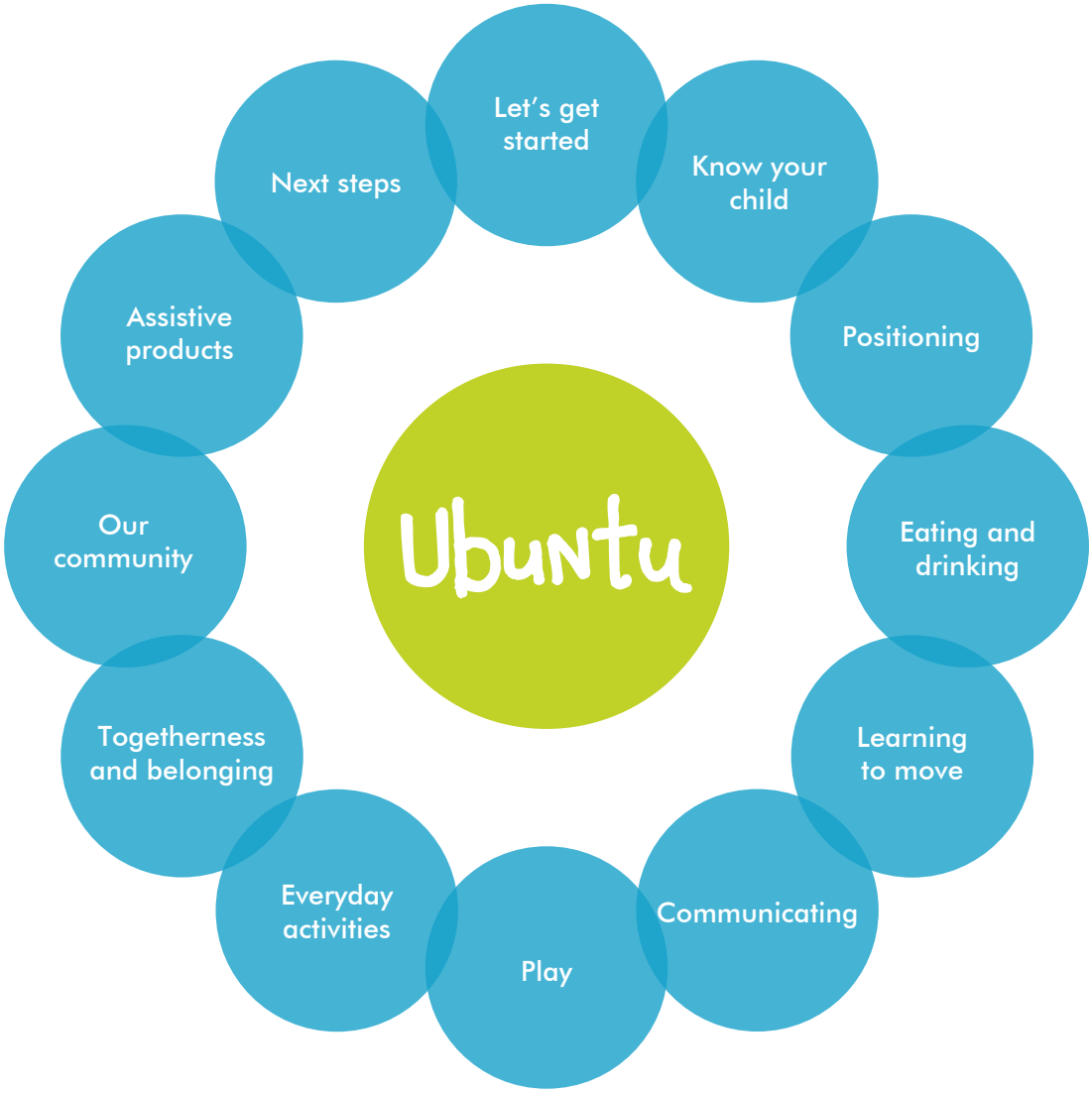
2. FACILITATING A SESSION

2.1 How to follow the manual:

The manual includes:

- 12 modules of activities, including group work and discussion.
- Example images for all modules. These can be found in the facilitator manual, to be printed large or presented on an electronic device eg. iPad.
- Case studies. These are included throughout, but you might want to use information relevant to your local context.

LIST OF MODULES



Module 0: Before you begin	Helps you plan the groups, and provides some useful tools for monitoring and evaluation
Module 1: Let's get started	About the programme Information about developmental disability Personal stories (with posters)
Module 2: Know your child	Introducing close family and friends (with posters) Development milestones for young children Determining each child's progress Managing seizures
Module 3: Positioning	How to position children who need support
Module 4: Eating and drinking	Understanding eating and drinking difficulties Practical skills to address feeding difficulties
Module 5: Learning to move	How to help children learn to move
Module 6: Communicating	Importance of developing communication skills Practicing communication
Module 7: Play	Importance of play for children to develop and learn Early stimulation Making simple toys Inclusion of play in the family and wider community
Module 8: Everyday Activities	How to use everyday activities to help children develop
Module 9: Togetherness and belonging	Starting to address stigma and discrimination at home and in communities

Module 10: Our Community	Identifying our community Discussion about common barriers to inclusion Addressing negative attitudes and exclusion Social Activity – this week contains a chance for caregivers to invite 2-3 members of their community to join in the group for a social discussion and some food/games
Module 11: Assistive Products and Resources	Information on assistive products and available resources in areas with less resources
Module 12: Next steps	Planning for how to continue the group Summing up Endpoint data collection

For each module there are:

Materials

Materials you will need for each session. There is some video material that can be found at www.ubuntu-hub.org and you can make your own short video clips where appropriate to demonstrate issues and help bring the session alive.

Icebreaker

A suggested activity to start the session. This is linked to the topic and should encourage participation, discussion, and fun!

Ask

Suggested questions to ask.

Explain

Notes for the facilitator to explain.

Activity

Suggested tasks and activities to encourage everyone in the group to participate and learn from each other.

Monitoring progress

A check in at the end of each session to see what participants have learned.

Sharing emotions and feelings

A chance for the group to share how they have felt about the topics covered in each session and to reflect together.

The term 'caregiver' is used throughout this manual, sometimes used interchangeably with parent or participant.

Our experiences of other groups are highlighted in GREEN text boxes.
These notes are for the facilitators' reference and are not necessarily used in the session. They can be useful to help you with answering questions.

Facilitator Tips are in BLUE text boxes.
These are Top Tips to assist you with running the sessions.

2.2 Preparing to run a session

How often and how long should sessions be?

- Ask caregivers what is best for them, consider the size of the group, and availability of facilitators. Groups may meet weekly, twice a month or monthly. 6-10 children with their caregivers are ideal.
- Allow enough time in each session to include discussion, questions and a break in the middle, up to 3 hours.
- Some modules may need 2-3 sessions to cover all the material.

Who should you invite?

- Mothers/fathers/caregivers/grandparents of children with developmental disabilities.
- More than one family member can attend sessions (its good if they do).
- Children of any age can join but the earlier you begin the better. If siblings come along, this is a nice opportunity for play.
- 1-2 community volunteers. They can facilitate play with the children. Caregivers will also learn more from seeing how their child can be stimulated through play.

Initial Planning:

- Involve parents in planning and organisation from the beginning, particularly in deciding which venue to use. Consider physical access and transport to the venue, as well as privacy – a quieter area may be preferable.
- Access to water and a toilet is important as some children will have problems with toileting.
- Engage with local stakeholders to explain the importance of the training. They could help find a suitable venue.
- Before starting, read the modules on play and communication as some of the ideas will help with all of the sessions.

Before the session:

- Make sure you are familiar with the content of the session, as well as all instructions for how to present the information.
- Meet with your co facilitator/s to decide on roles for each session
- Teach the community volunteers how to support child with developmental disabilities in play and go through ideas on fun activities they can do with the children. If the children enjoy themselves, the parents are more likely to use the ideas at home.
- Print and prepare all materials, aids and activities in good time.
- Ensure any videos you need are accessible, on your laptop or cell phone.
- Arrive at least 30 minutes before the starting time to prepare your venue and organise your materials.
- Have a flipchart (or similar) and marker pens ready to use.
- Write the outcomes of the session on flipchart.
- Prepare a box of simple developmentally appropriate, locally made toys. Caregivers should be invited and encouraged to interact with their children and use these toys before, during and after the sessions.
- Find some mats (preferably plastic-covered foam) for the children to sit on. Try to also find some simple supportive seats (eg. made from cardboard or other local materials) for the children who cannot sit up unsupported. Mats and seats should be easy to clean.

During the session:

- Provide simple refreshments for the caregivers and children, including thickened fluids for children with swallowing difficulties, if appropriate. This also gives an opportunity to reinforce lessons learned on feeding and drinking.

Facilitator Tips:

- Sit at the same level as the group – you are not a teacher, but a facilitator. Ideally you should sit in a circle and make eye contact with everybody.
- Make sure that the sessions are FUN! Many caregivers work, and have other chores, which they combine with full time caregiving, so taking time out of the day can be a big commitment. Use the icebreakers suggested, and add your own as required. For example, use songs to change the group energy if everyone is looking sleepy – this is popular as well as helping with communication.
- Engaging the children is very important as caregivers often learn more from seeing the difference in how their child is stimulated through play than through lectures.
- Follow the guidelines in the manual – the activities are the core of this programme and should not be left out to save time. Rather add another session if it is taking longer than expected.
- If responses to a question are not as expected, rephrase the question.

- If you don't know the answer to a question, say you will find out – bring the answer next time, or ask for a volunteer to find information to share with the group (if it is not a technical question).
- If a discussion goes off the topic, gently bring the discussion back to the topic, while also allowing time for members to express what they are feeling. If appropriate, place it in a 'parking lot' eg. By saying. "Let's park that for now and come back to it later".
- Recognise caregivers' contributions – draw on their life experiences. Use their stories to illustrate points where possible. Encourage everyone to participate – you may need to speak directly to someone who is very quiet and withdrawn to help them join in.
- Be aware of the influence of your mood on the group – be honest about your feelings and state of mind.
- Be flexible within the modules especially when there are young children in the group – you may need to change the order of the activities or the time of a break to accommodate their needs.
- Use opportunities to model interaction with the children, as well as other things that are being taught where possible.

After the session:

- At the end of each module there are questions and suggestions to help participants reflect on what they have learned - record these to help with future planning.
- Ensure caregivers are aware that they can ask you for time to discuss individual concerns before or after sessions, if they do not feel able to discuss them within the group.
- Ask everyone whether they have suggestions for next time.
- Make sure that you leave the venue tidy and clean.
- Make sure you pack up all your training materials and file them carefully for next time.
- Ask your co facilitators for feedback on how you presented the session, for what went well and what could be done differently next time.
- Reflect yourself on what went well and what needs to be changed.

2.3 Identifying issues and referring

As a facilitator, you are not expected to be an expert in everything. Use your contacts and networks to ensure caregivers get the intervention they need, e.g. a mother needing psychological support or a child who needs nutrition advice.

We know that children with disabilities can be very vulnerable to abuse, and that children with intellectual and communication impairments are particularly vulnerable to abuse. We also know that children with disabilities are often 'missed out' of child protection pathways. Caregivers may be perpetuators of the abuse, but they may also

be vulnerable adults who are abused within the family because of the stigma associated with having a child with a disability.

'Safeguarding' means taking action and having policies to ensure that children and vulnerable adults are safe and to promote their wellbeing. The sessions may bring up some very sensitive discussions. Key messages to promote are: 'Protection is everybody's business!' and 'Children with disabilities and their caregivers have a right to be protected'.

As part of your preparation, check you are familiar with national and local child protection structures or resources that might be able to offer good quality referral services to children. It is important to be clear from the outset of your programme what you will do if faced with child protection concerns. It is important to recognise early signs of violence and abuse and respond in a timely and comprehensive manner. As a team you will need to be clear about your own procedures. We recommend that you ensure that you know what you will do if there are any concerns about the safety of a child or caregiver, which arise from the session. Refer to your own organisation's guidelines on this, so that you know the best process for this.

An example is of a mother attending a parent support meeting with her young daughter Chipo. When she got home her husband was angry and refused to let her in the house because she had talked about Chipo and the social problems they were facing. She was very worried that he would take Chipo to the village and that Chipo may be killed as her husband had not accepted Chipo's condition, and believed that it was caused by evil spirits. The local organisation that was running the training immediately advised the mother to go to the Department of Social Affairs; they quickly convened a meeting with the father. He was ordered not to take Chipo out of the capital city where they lived, and the local organisation is now supporting the family.

2.4 Common mistakes

- Leaving out activities to save time.
- Adding too much extra information and then not being able to complete the materials.
- Forgetting to ask questions and delivering a lecture.
- Focusing eye contact in one part of the group and neglecting others.

2.5 How will I monitor and evaluate?

- Plan how you will measure progress before you begin. You will find suggestions for how to monitor at the end of every module.
- Decide what information you want to collect from your group to learn how to improve future sessions. It is difficult to measure things like empowerment so decide what indicators you will use before you begin.
- If there are older children in the group then it is very important to get their feedback, so ask them what is important for them and how you can improve. If the child finds communication hard, use pictures and work with a familiar caregiver who can translate.

- Check in with parents before or after each session and keep a record of parent feedback.
- Keep a register so you can see who is not attending regularly or who drops out. Follow up with these people to understand their reasons for not being able to attend and see if you can support them any other way..

3. WHY ARE HOME VISITS IMPORTANT?

- Caregivers often need some help applying learning at home.
- Home visits are good opportunities to engage other family members, including siblings who often help with caring duties.

A home visit form is used to keep track of a family's priorities, progress with goals that have been set and the development of the child. A template is provided in Module 2.

Please note:

This is a guide to organising educational group activities for caregivers (parents and families) and children with developmental disabilities.

This manual guides facilitators through the programme, with step by step guidance for each session's activities.

The term **developmental disabilities** covers a range of childhood conditions and is used differently across different settings and cultures. In this manual we define developmental disability as a diverse group of conditions that can impact on the development of children's function (e.g. sensory, cognitive, physical), with a very wide range of effects. Developmental disabilities include cerebral palsy, intellectual disability, sensory impairments, congenital zika syndrome, microcephaly, Down syndrome.