BEFORE YOU BEGIN

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1: ABOUT THE PROGRAMME

1.1 Background (how this manual came about)

Juntos is a programme for caregivers of children with congenital Zika syndrome and is built upon 'Getting to Know Cerebral Palsy' (GTKCP), which was adapted in 2014 by the London School of Hygiene & Tropical Medicine from an existing parent training programme (Hambisela) which was developed by the Eastern Cape Branch of Cerebral Palsy Association South Africa.

GTKCP has been used in Asia – Sri Lanka and Bangladesh, and in a number of African countries – Ghana, Uganda, Malawi. In Uganda, a further revision has been developed with a focus on Early Intervention for children with Cerebral Palsy – all of these sources have been drawn on in compiling this manual.

Final project evaluation of the caregiver group programme in Uganda and Malawi showed a positive impact on attitudes in the families, as well as increasing inclusion in communities. Relationships between caregivers and their children improved, as did knowledge in basic care of their children – especially positioning and communication. Many parents found they had a bit of extra time and were able to join in income generation, which was planned as ongoing activities for the parent support groups.

Because congenital Zika syndrome is similar in many ways to Cerebral Palsy and other neurodevelopmental conditions, it was felt that parents of these children could also benefit. In April 2017 a project started to adapt the GTKCP programme for the context in Brazil of Zika.

"This group gave a real change of experiences and also friendship." **Grandmother, Salvador**

"My family has participated much more in the care of my son, we have included him in the practical things that we do."
Mother, Rio de Janeiro

"In reality before this group, I felt alone. I couldn't imagine other parents were passing through things that were worse. When we come to a group like this, we realise each other's difficulties; we can understand it; we can help; and we have the opportunity to interact with other children." **Parent, Salvador**

1.2 Aims and Objectives

The overall aim of this programme is to help families and caregivers of children with congenital Zika syndrome to understand their child and to build support networks that will improve the care that their child receives in the community. This will help children with congenital Zika syndrome to reach their potential.

Key objectives:

- To improve the knowledge of caregivers and family members about their child's condition and specifically in relation to the needs of young children with congenital Zika syndrome.
- To promote positive attitudes towards having a child with a disability within the family.
- 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.

On an emotional level we aim to support families as they deal with uncertainty, not removing hope but maintaining realism.

"I have come know most of the other parents from coming to training. Before training I didn't know them. Now we always talk to each other... Whenever we hear about a child developing we can meet at each other's houses, and try to know something better." **Parent, Sirajganj, Bangladesh (GTKCP)**

1.3 How the programme works

The programme is a multi-session group activity with caregivers – parents and families – of children who are affected by congenial Zika syndrome (CZS), run by two facilitators. This manual helps to guide facilitators through the programme, providing a layout of each session and descriptions of group activities.

1.4 The facilitators

The facilitators deliver the programme and are the key people who ensure whether a group is successful or not. 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. This is called a participatory approach and it will be further explained later.

For the Juntos group, two facilitators with complementary skills and experiences will run the sessions – one therapist (OT, PT, SP) and one mother of a child with CZS. These have been deliberately chosen as they are both 'experts' in the area of raising and supporting a child with a disability: a therapist has been trained in certain skills, techniques and

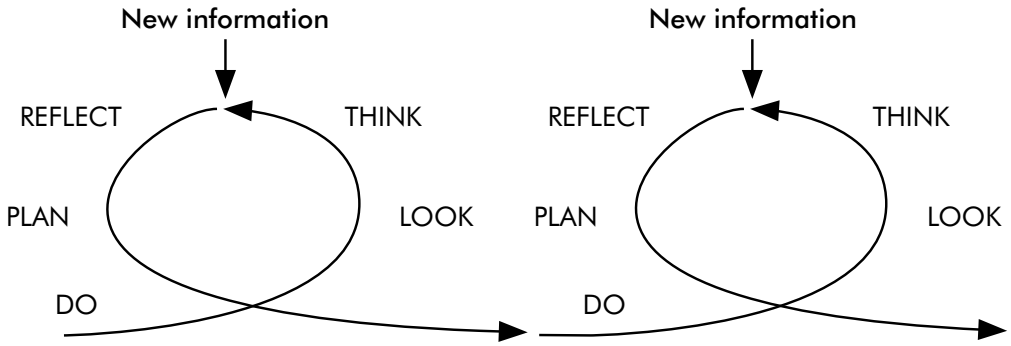
approaches, whilst a mother brings her own personal experiences of the challenges that can be faced in raising a child with a disability.

The two facilitators are **equal partners** in the programme, and need to work well together. Some sessions may feel more natural to be led by one person more than the other. This manual gives some suggestions for this, though these are not compulsory rules to follow.

1.5 Approach

Core to our approach is group work with primary caregivers, which is driven by adult learning theory and a participatory approach. Participants are encouraged to share their experience through discussion and reflection.

Action-Reflection Cycle:



What do we mean by a 'participatory learning and action' approach?

A participatory learning and action cycle approach is one in which group members identify and prioritise problems and choose ways to solve these problems together.

This process is built into the modules, and it is hoped that by the end of the programme that parent support groups will be able to run the groups themselves, and to work together to address problems.

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.

In Ghana, home visits were used as a mechanism for a facilitator to engage with other family members of the household. This was not always effective. 51% of fathers of the children were absent from the home, and many caregivers were women who managed full time caregiving with a range of other household responsibilities.

- It is important throughout the sessions and interactions with primary caregivers, who are predominantly female, that this **does not add to the burden of caregiving.**
- The Juntos programme is not intended to replace therapy, but to complement it. Children need therapeutic management all of the time, not only during therapy sessions.
- Local service provision needs to be strengthened and the quality improved for 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.
- 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.
- The caregivers start an empowerment 'journey' over the course of the programme. For new parent groups it can be the first building blocks for a sustained programme. The issue of sustainability needs to be considered during your planning phase.
- It is recommended that children and their caregivers participate in these groups as soon as possible after diagnosis.

"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: RUNNING A SESSION

2. 1. How to follow the manual

- This manual for group facilitators is divided into 10 modules.
- There is also a separate Display Manual, mainly of photos. This material can be laminated and used for running sessions.

For each module there are:

Materials

Materials you will need for each session. There is some video material and you are encouraged to 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, sometimes used interchangeably with parent or participant.

Our experiences of other groups are highlighted in GREEN text boxes.
These may be from the Juntos group or Getting to Know Cerebral Palsy. These notes are for the facilitators' reference and are not necessarily used in the session. They can be useful to help with answering questions.

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

LIST OF MODULES

Emotions and feelings	Discussion around thoughts and feelings is a theme explored throughout the sessions, using personal posters
Introduction	About the programme Ground rules for the group Information about Zika and Congenital Zika syndrome How to find information Personal stories and start of the posters
Our child	Introducing your close family and friends (posters) Development milestones for young children Determining each child's progress Managing irritability and crying

Positioning and moving	How to position children who need assistance How to assist children to learn to move
Eating and drinking	Feeding challenges Practical skills to address challenges for individual children
Communication	Importance of communication Practical advice to help your child communicate
Play and early stimulation	Importance of play for children to develop and learn Early stimulation Making simple toys and how parents/caregivers can encourage their child to play challenges inclusion in play in the family and broader community
Everyday activities	How to use everyday activities to help your child develop Managing seizures Catch up from previous sessions
Uniting our voices	Understand the context of disability rights Education Communicating with your health team Advocating Thoughts and feelings
Our community	Who is in your community Discussion about common barriers to inclusion Addressing negative attitudes and exclusion Thoughts and feelings Social Activity – this week contains a chance for you to invite 2-3 members of your community to join in the group for a social discussion and some food/games
Next steps	Summing up What have you learned? What haven't you learned? Endline data collection
Home visit	Aims of the visit What to do and say on a home visit

2.2. Preparation to run a session

It is important to involve the parent group in planning for the sessions – e.g. where the programme should be held; length of time and how often to meet.

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.
- Print and prepare all materials, aids and activities in good time.
- Ensure any videos you need are accessible, on your laptop or cell phone.
- Prepare a box of simple developmentally appropriate, locally made toys. Parents should be invited and encouraged to interact with their children and use these toys before, during and after the sessions.
- Have a flipchart and marker pens ready to use.
- Write the outcomes of the session on flipchart.
- Arrive at least 30 minutes before the starting time to prepare your venue and organise your materials.

During the session

- Plastic-covered foam mats for children to sit on can be useful, they are easy to clean.
- 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 learnt on feeding and drinking.
- 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.
- 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 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' and return 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 address some remarks directly to someone who is very quiet and withdrawn.
- 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 or the time of a break to accommodate their needs.
- Use opportunities to model interaction with children and involve them in the session where appropriate.

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[1], 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[2].

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.

Key messages to promote are: 'Protection is everybody's business!' and 'Children with disabilities and their caregivers have a right to be protected'.

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 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.

1. Devries M Karen, Kyegombe Nambusi, Zuurmond Maria, Parkes Jenny, Child C Jennifer, Walakira J Eddy, et al. Violence against primary school children with disabilities in Uganda: a cross-sectional study. BMC Public Health. 2014;14(1017)

2. Banks LM, Kelly SA, Kyegombe N, Kuper H, Devries K. "If he could speak, he would be able to point out who does those things to him": Experiences of violence and access to child protection among children with disabilities in Uganda and Malawi. PLoS one. 2017;12(9):e0183736.

In some contexts, child protection systems may be weak. So you may have to develop a referral network for the purposes of your project, which builds on existing structures and services as much as possible.

You are not expected to be experts on child protection, but you may need to reach out and collaborate with other NGOs, disabled persons' organisations (DPOs) and government bodies.

2.4 After the session

- At the end of each module there are questions and suggestions to help participants reflect on what they have learnt. Record these to help with future planning.
- 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 materials and file them carefully for next time.
- Ask your co facilitators for feedback on how you presented the session and suggestions for improvement in your facilitation techniques.
- Reflect on what went well and what needs to be changed.

2.5 Top tips

- Be well prepared for presenting your session. Know exactly how you will do each section.
- Give enough time for the activities as outlined in the manual.
- Have simple toys available – involve the children and model good interactions with them.
- 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.
- You are a facilitator, not a therapist or expert. Your role is to guide the group to find/share their own solutions.
- After a discussion, briefly summarise what was said – be careful not to repeat too much.
- Make sure that the sessions are FUN!
- Encourage participation of all members.
- Make your own learning active – reflect on how each session went and plan for improvements.

2.6 Common mistakes

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

3: CONDUCTING A HOME VISIT

Useful guidelines for home visits and outreach work.

These guidelines are adapted from Timion, and the original is available from www.timion.org[3]

Some children will receive therapy only once per month, even less, or no 'therapy' at all. 30 minutes of therapy per month is very unlikely to make a difference for the child's development on its own. Positioning and handling of the child during the other 700 hours of the month however can make a big difference – either harmful or helpful. Therefore the time during an outreach or home visit can be used to support the caregiver in how she can position, handle and play with her child daily in a way that helps her child to learn and develop and prevents secondary problems.

The community workers/therapist should use their time to:

Check on activities/any equipment that was given to the caregiver at the previous session.

Find out if there are any particular problems/successes and demonstrate activities again if necessary:

- If the child is **receiving equipment** such as a seating device, sidelyer or standing frame, the community worker/therapist's time is best spent fitting and adjusting the device and teaching the carer how and why to use it. Let them position the child more than once to make sure they are confident in doing it well. Remember: if a child is positioned well every day it will be of much greater benefit than a single session of therapy. Therefore a session spent only on fitting equipment is not wasted.

3. Reproduced and modified with permission of Timion

- Community workers must have an **achievable, realistic, short-term goal** for children who they work with. The parent should also be involved in deciding on this goal and should be clear about it. If the parents have unrealistic expectations, they are likely to become frustrated and discouraged, and may fail to notice small steps of progress.
- It is important to **keep record** of the short term goals, what has been taught to the parent, what works and what does not. It is in a child's best interest that everybody works towards the same goals, that time is not wasted in re-assessing a child by each new therapist, and that conflicting information and instructions are not given, as these discourage the carer.
- It is important to have an idea of **how a child usually spends the day** – Which positions does she sit/lie in? What are the things that the carer does with her daily (e.g. washing, dressing, and holding her on her lap)? HOW does she do it? Changing these positions and the way activities of daily living are carried out can make a much bigger difference than giving a 'home-exercise'. The carer might be too tired or have no time for exercises, but there are certain things that she will do daily and if these can become 'an exercise', her child is getting 'therapy' daily.
- Spend some time **handling children**. It is necessary to find out which positions and key points are helpful to influence a child's muscle tone and help a child to achieve some normal, active, functional movement. All children will not respond the same, so there is no one set of home exercises that can just be given to everybody.
- Choose one activity that worked well. The therapist/community worker should demonstrate and **teach it to the carer**, explaining why it is helpful, pointing out where to place your hands. Let the carer practice it more than once – until she is confident to do it well. Guide her hands if necessary. Give some specific instructions about when and how often to do it. Try to incorporate it into her activities of daily living and daily routine as much as possible.
- **Feeding** is a very big problem for many children. This is something that forms a very important part of a child and caregiver's life and can therefore be a very important goal. It can affect a child's nutritional state and overall health and can require hours of time from the carer. A session spent advising about positioning and techniques for food preparation and feeding are essential if this is identified as a problem. Try to involve and teach volunteers in what the health worker is doing, such as using positioning equipment. If they learn how to do this well, they can spend time helping the caregivers.

Juntos