



TOGETHERNESS AND BELONGING

Tackling stigma and discrimination
at home and in the community

November 2019

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Learning outcomes for caregivers. By the end of this session you will:

- Understand that a range of activities at home and in your community is required to promote inclusion.
- Have ideas on activities or actions you can take and have identified what others (we will call them allies) can do.
- Understand that you and your child have rights, including the right to be treated with dignity. Caregivers, families, and communities also have a responsibility to achieve their rights.



INTRODUCTION



Materials

Paper, pens, flipchart, Materials 0.1 – 3.6.

Facilitator Tips:

- ‘Togetherness and Belonging’ is intended as a very flexible module. It can be included as part of the GTKCP, Early Intervention and Juntos programmes, or used as a module on its own. There is no ‘one size fits all’ for addressing stigma and discrimination experienced by children with disabilities and their caregivers. There will be important differences across countries and contexts.
- There can also be differences between urban and rural settings, so you will need to tailor this module to your community.
- We provide a variety of stories that you can use. We strongly recommend that you add or replace with 1-2 examples from your own context. Be aware of safeguarding issues, so that you don’t put any child/caregiver at risk. We suggest you do not use real names and photos.
- We also encourage you to include some examples from other countries, as it is useful for people to understand that ‘they are not alone’ and that facing stigma and discrimination occurs everywhere.
- This module can be run in 3-4 hours but can also take much longer. In Burkina Faso they ran the session over 2 days!
- The main approaches we use are low cost. However, if you have additional resources, you might be able to do some of the suggested extras. E.g. making a participatory video.
- Although this module is focussed on caregivers, service providers will often have low levels of knowledge and awareness. We strongly recommend that some training is provided to service providers as part of a more comprehensive programme.
- This module may bring up some very sensitive discussions. 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.

‘Safeguarding’ means taking action and having policies to ensure that children and vulnerable adults are safe and to promote their wellbeing. Research shows that these children, and mothers, are commonly more vulnerable to abuse. As a team you will need to be clear about your own procedures.

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. The mother was very worried that he would take Chipo to the village and that she would 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 BOTH the mother and the child and monitoring the situation closely.

REFLECTION ON CHANGING YOUR INDIVIDUAL BELIEFS



Materials

Flipchart. Material 0.1:
Image of a plate
with ingredients for
a delicious meal.





Icebreaker

Draw/create a line from one end of the room to the other. Explain that one end of the room is 'Strongly Agree', and the other end of the room is 'Strongly Disagree'. Read the following statement and then ask everyone to move to a part of the line that reflects how they feel. Emphasise there is no right or wrong. Give everyone time to reflect, and then ask the group to put themselves somewhere on the line from Agree to Disagree.

"I have changed how I feel about being a caregiver of a child with a disability over time."

Ask for 2-3 volunteers to explain what changes there have been and what brought about this change in their individual beliefs and feelings. *"What do you think have been important 'ingredients' in making this change?"*

Show the group material 0.1. Just like important ingredients are used to create a delicious meal, there are important 'ingredients' that can bring about change in people's attitudes, beliefs and feelings. Draw a picture of a plate on a flipchart and add the ingredients as people speak about them.



Ask

"What 'ingredients' make a delicious 'togetherness and belonging' meal?"

Ensure the following points are emphasised:

1. Learning new information – this addresses myths and fears.
2. Making contact with other families/caregivers who have a disability.
3. Being more visible in your community.
4. Understanding that you and your children have rights, which include the right to be treated with dignity. BUT you, your family, and your community, also have a responsibility to help achieve those rights.

Facilitator Tips:

Keep this picture of the plate on the wall throughout the session and as more ideas come up, add them to the picture. Encourage everyone to think about ingredients in togetherness and belonging more broadly in their community through the session.

FAMILY AND COMMUNITY INCLUSION

Facilitator Tips:

- We are looking to transform society's view of disability. We understand from learning from others that this can take a long time.
- Do not expect caregivers to be responsible for challenging stigma and discrimination on their own. Encourage ways to include 'allies' (friends, 'disability champions') who can help with this change. For example, encourage your group to think of people in their community who can help them 'champion' the rights of people with disabilities.
- Be as creative as possible, build on the strengths of your group, and your local community. You could involve art, local craft skills, drama, film, and music to deliver key messages within their community.



Materials

Video of James the Investor (7-minute film from Uganda, translated into English), or photo-story Materials 1.1 – 1.6.



You are welcome to translate this film into your local language or find a suitable alternative that shows positive examples of inclusion. If you cannot show a film, use the 'photo-story'.

- https://www.youtube.com/watch?time_continue=2&v=nZ2VlrqWzM
- <https://www.ugent.be/pp/orthopedagogiek/en/news-events/news/obuntubulamu.htm>



Activity: “James the Investor” video

Show the film, or pictures from the photo story around the group.

After watching ask the following questions and discuss in the whole group. As people describe things that helped a more inclusive experience, add the ideas to the meal on the flipchart.

This module is all about inclusion.

Inclusion is being a part of what everyone else is, being welcomed and embraced as someone who belongs. Inclusion means that everyone can use their own abilities as member of their community (www.kidstogether.org).

Inclusion is the process whereby every person who wishes to, can access and participate fully in all aspects of an activity or service in the same way as any other member of the community (CBM Barriers to Inclusion 2013).



Ask

“How does this relate to your experience in your community?”

Encourage everyone to talk about similarities and differences.

“What do you think helped James to be included?”

“Often mothers are the main caregivers and play an important role. In this case, we can see a father being involved. What can we learn from this?”

“What do you think of James? If you showed this film to people in your family or community, what do you think they will think of James?”

Explain that James is a great role model, and that we know that is important to help change people opinions.

“What are the lessons we can learn about promoting a more inclusive school environment?”

Ask everyone to consider teachers, friends or peers, environment.

“Overall, what are the most important lessons we can learn for your situation from this film about promoting more ‘Togetherness and Belonging’ in your family and community, and school?”

Facilitator Tips:

- In many cases caregivers may not feel that they have that power (yet!) to challenge views, and that this is a journey you are taking them on.
 - Understand that through giving people education, you can provide them with better knowledge (we can call this ‘information for the head’).
 - It is also important sometimes to make people feel differently (we can call this ‘information for the heart’).
 - Contact, direct (e.g. encouraging positive interactions between the people in the community and people with disabilities) or indirect (e.g. through a film or radio), allows us to engage with others, and we know this can be an important way to break down myths and change social and cultural norms.
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Materials

Materials 2.1 – 2.9: Stories.



Togetherness and belonging within the family

Example story: Steven



Togetherness and belonging at the community level

Example story: John



Togetherness and belonging in the health and education services

Example story: Blessing



Activity: Our stories

Divide into 3 groups and provide each group with one set of stories (we sometimes call these case studies).

Each set contains at least:

- A story from families
- A story from the community
- A story from health and education services



Ask

Ask everyone to discuss in their small groups:

“What do you think of the story? Has something similar happened in your family/community? If so, do you want to share?”

“Are the child and parent being treated with respect and dignity? What helped improve the situation in stories that were positive?”

“What advice would you give to improve the situation in stories that were less positive? What other people could or should be involved?”

“Do you think this could work in your community?”

Facilitator Tips:

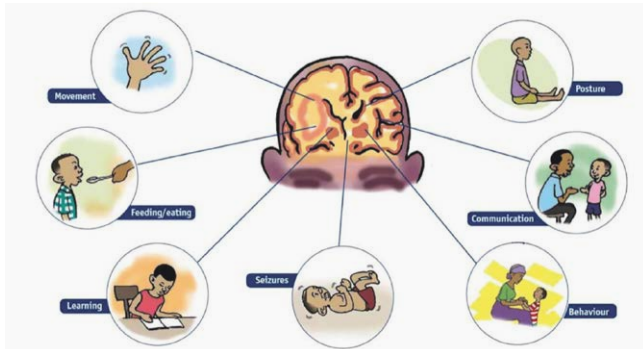
Stay in groups of three for this activity to encourage everyone to voice their thoughts and discuss together in smaller groups. This can be less intimidating than discussing all together in a large group and gives an opportunity for those who are quieter to speak.



Materials

Materials 3.1 – 3.6 images.

Make enough copies so that everyone can take 1-2 pictures home.



The brain and how it works
Courtesy of CBM

Boy who is drooling
*Courtesy of Lenie Hoegen
Dijkhof, Groupe ACCES*



Playing with father and mother
Courtesy of Rachel Lassman, KCDC

Playing with siblings
*Courtesy of Rachel
Lassman, KCDC*



Child helps with bathing
Courtesy of CBM

Learning together at school
Courtesy of Obuntu Bulamu



Activity: Role Play

In groups of three, ask everyone to choose one image (from the selection above) that they could take home and share with someone in the family.

Conduct a short role play about what you would say to the family member.

One person acts as the caregiver, one person is the family member, and a third person is a friend and/or someone they would identify can help them with the discussion.

Here are some questions to think about in preparing your role play:

*“What do you want to be able to say to some of your family members?
Who could help you with this discussion? As the father or mother-in-law,
what do you think about what you have been told? ”*

Facilitator Tips:

Support the groups in the role play. These may bring up some difficult issues, so also encourage some humour and fun in the acting out the role play. We know that humour can play an important role in helping to talk about difficult issues.



Ask

*“Who are **the key ‘gatekeepers’** in your family and in your community?”*

These are people who have influence; they can make obstacles but can also be people who can help you.

*“Is there anyone in your family or community who can be **a useful ally** (friend who is a good champion for disability) and can help with some of these discussions?”*

Some examples might include: a health worker, a teacher, a special needs teacher, the head of a local woman’s group, someone you can trust, someone who can help your group, someone who has power in your community, someone who is listened to.

Record some of these ideas on a flipchart – and come back to them when you make the Action Plan (at the end of this session).

What causes the negative attitudes that the other people have? What are the triggers to negative attitudes in your own context?

Discuss possible solutions to address this. If your group does not come up with some feasible ideas, here are some ideas from other groups around the world that have aimed to ‘transform’ views on disability. You can discuss how suitable these ideas would be in your context.

- Invite family/community members for a ‘Celebration day’ and/or a social activity with your group.
- Conduct some awareness raising with local traditional healers, including faith leaders.

- Plan a celebration for Father’s Day/International Day of the Child /special day in your community.
- Look at different ways of engaging with siblings, and fathers.
- Share educational resources with the family.
- Engage with local community radio to tell your stories.
- Link into traditional ceremonies in your community where you can promote more awareness raising. For example, families organising a coffee ceremony for community members in Ethiopia, or Durbar meetings (traditional community meetings) in Ghana.
- Reach out to a local DPO and find ways to work together. Often a united voice on promoting inclusion has more power. We can call this ‘advocacy’.
- There are a wide range of other resources on how to promote inclusion e.g. inclusion in education. This module is just a starting point.

INCLUSION IN SERVICES (EDUCATION, HEALTH AND SOCIAL)

Facilitator Tips:

- This activity is called ‘hot seating’. The idea is that after a group acts out a short role play, they get advice and support from the rest of the group.
- Questions are asked to someone sitting in a chair - the ‘hot-seat’ - and then others can give advice, and ideas of what could be said or done differently to improve the situation.



Activity: ‘Hot seating’ - Treating each other with dignity

In groups of 2 or 3, briefly reflect on past experiences when receiving health, rehabilitation or education services with your child or social services e.g. to get a disability card.

Ask one group to act out a short role play which reflects this experience.

Ask the person who acted as the health worker/teacher to sit in the 'hot seat' (they can sit on a chair or one a mat in the middle of the group) and to stay in their role.

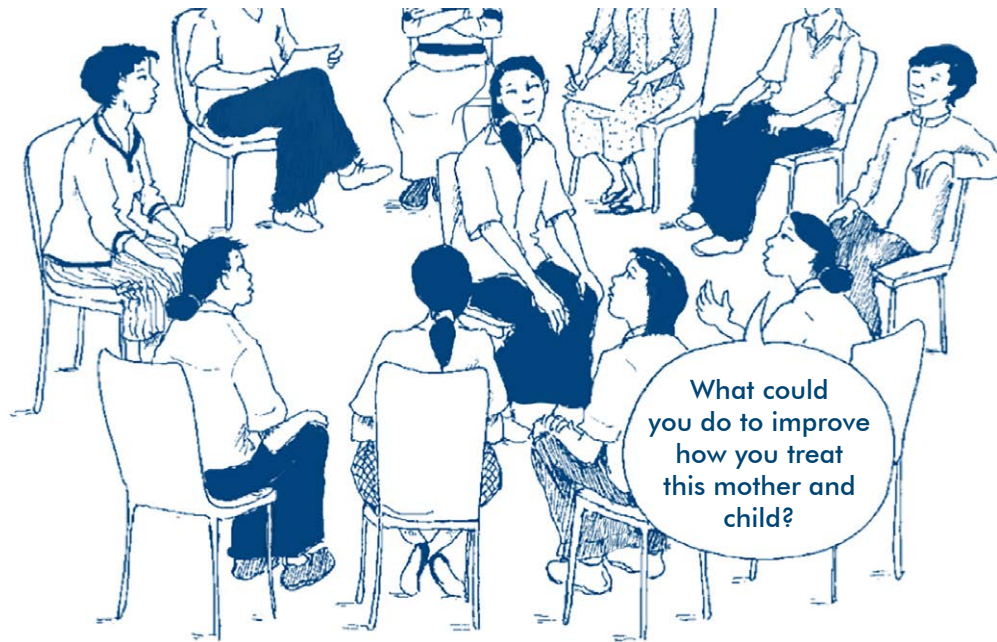


Image adapted from illustration by Petra Röhr-Rouendaal, International HIV/AIDS Alliance (2006)

Encourage the group to ask her questions about why she treated the caregiver in a certain way.

"What could she have done differently in order to treat the family with more dignity? Why did you talk to the mother like that?"

"What could you have done differently? How do you think the mother felt?"

Then ask the caregiver to take the 'hot seat' and ask the rest of the group to ask questions and give some ideas about what she could do or say differently, as well as ideas of who could help her.

"How did you feel when you were meeting the nurse? What would have helped you?"

From the discussion draw up a list of how children with disabilities and their caregivers should ideally be treated to improve their experience of inclusion, and ideas of what could be done to improve the inclusion in these contexts. These ideas could be added as 'ingredients' to the 'meal'.

Possible ideas and solutions to include which have been drawn from other experiences:

- Ask another parent or friend to accompany you to a health or education service for the first time.
- Invite community health workers/teachers to a training and use ideas from this session.
- Involve local community health workers as soon as possible in planning care for your child.



Activity: Group action plan



Ask

“What will your community look like when you are included and belong? What will it be like to live there?”

Facilitator Tips:

Starting the action plan with this question will help the group to have a vision for change. Write down key words or draw picture on a flipchart. Refer back to the delicious ‘meal of inclusion’. Ask everyone to look at the ingredients of what is needed.



Ask

“What activities can you carry out as a group to improve the ‘togetherness and belonging’ of your children and their families?”

Discuss ideas and help to ensure that practical activities are suggested.

“What is the most feasible action to start with and what is the one thing that you will plan to do for the next month?”

“What will help you to do this? Who are people who could help you? What materials (resources) will you need?”

Encourage the group to decide together about one action that they can work on together in the coming month.

Put in a simple table, such as like the one below:

Activities that we can carry out as a group:	What will help us to do this – People who could help us? Any materials we need?	Who can be responsible for what?	Timings – When will we do this?
Offer to speak on the radio		E.g. who would be happy to speak, who would be willing to go to the radio station?	
Invite family/ community members for a ‘Celebration day’ and/or a social activity with our group			



Ask each person

"What is one thing that you found useful from the session and how do you think that you can contribute to the action plan?"



Materials

Flipchart with take home messages.

Take Home Messages:

- Children with disabilities and their caregivers have rights.
- Families and community members have a responsibility to help them fulfil those rights, and to challenge stigma and discrimination.
- It is important to find 'allies' in the community and family to help facilitate change.
- It is important to provide people with information, but you also need to have contact with people e.g. take your child outside of the house, be willing to talk with others about your experience. Ask for other people's help with this.

SHARING EMOTIONS AND FEELINGS



Ask

"How did you feel in this session about togetherness and belonging? How was it for you to talk about today's subject?"

"Did it raise any emotions and feelings that you did or did not expect?"

"How have you felt this week? What did this week bring you?"

"Did anything change for you?"

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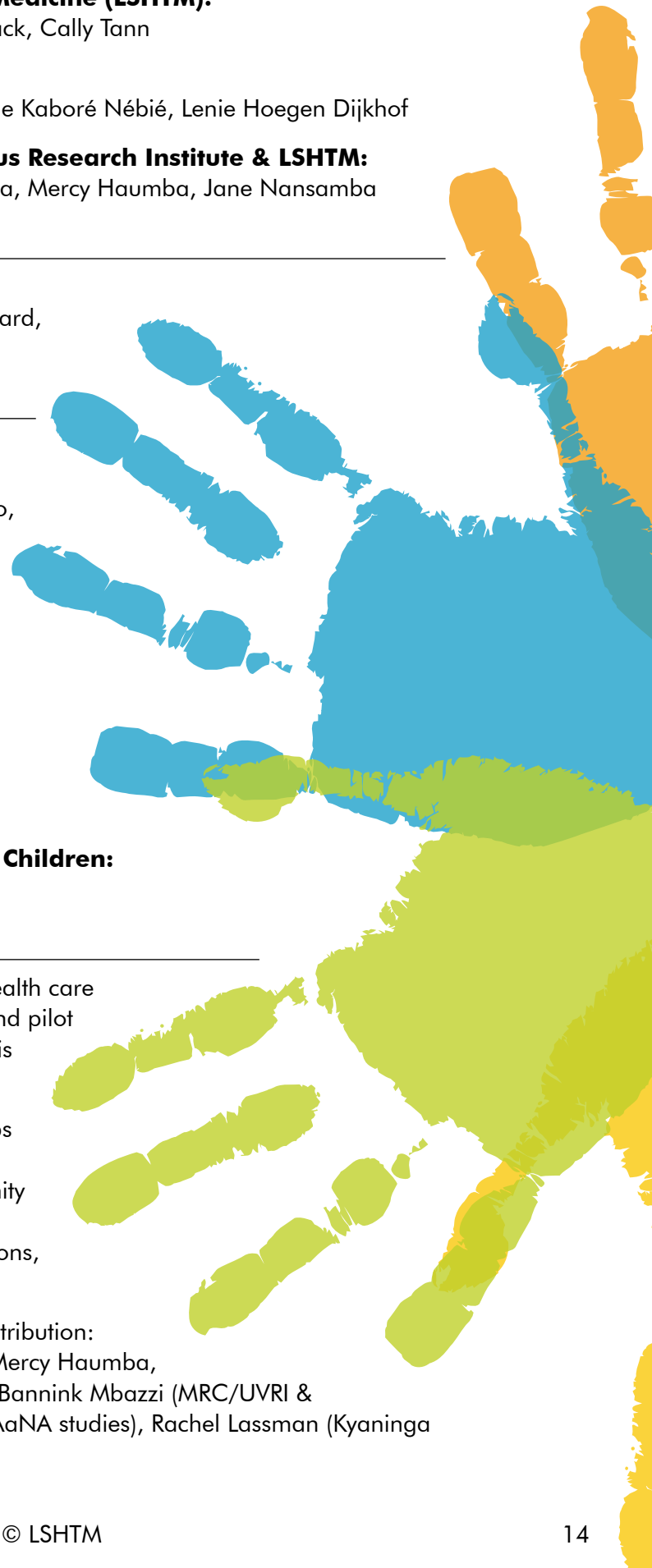
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