

Supporting Families of Children with Developmental Disabilities in Ethiopia

Summary

In Ethiopia most children with developmental disabilities including autism and intellectual disability remain undiagnosed and receive little or no formal help. These children and their families experience multiple challenges, including stigma, social isolation, poverty, and lack of educational opportunities.

To address some of these challenges the World Health Organization (WHO) has developed a Caregiver Skills Training (CST) programme that teaches caregivers strategies to help them support their child. In collaboration with local stakeholders, our team at Addis Ababa University and King's College London has adapted and pilot tested the WHO CST in urban and rural Ethiopia. Findings from the pilot studies indicate that the WHO CST addresses a local need and is highly acceptable and feasible to be implemented in Ethiopia.

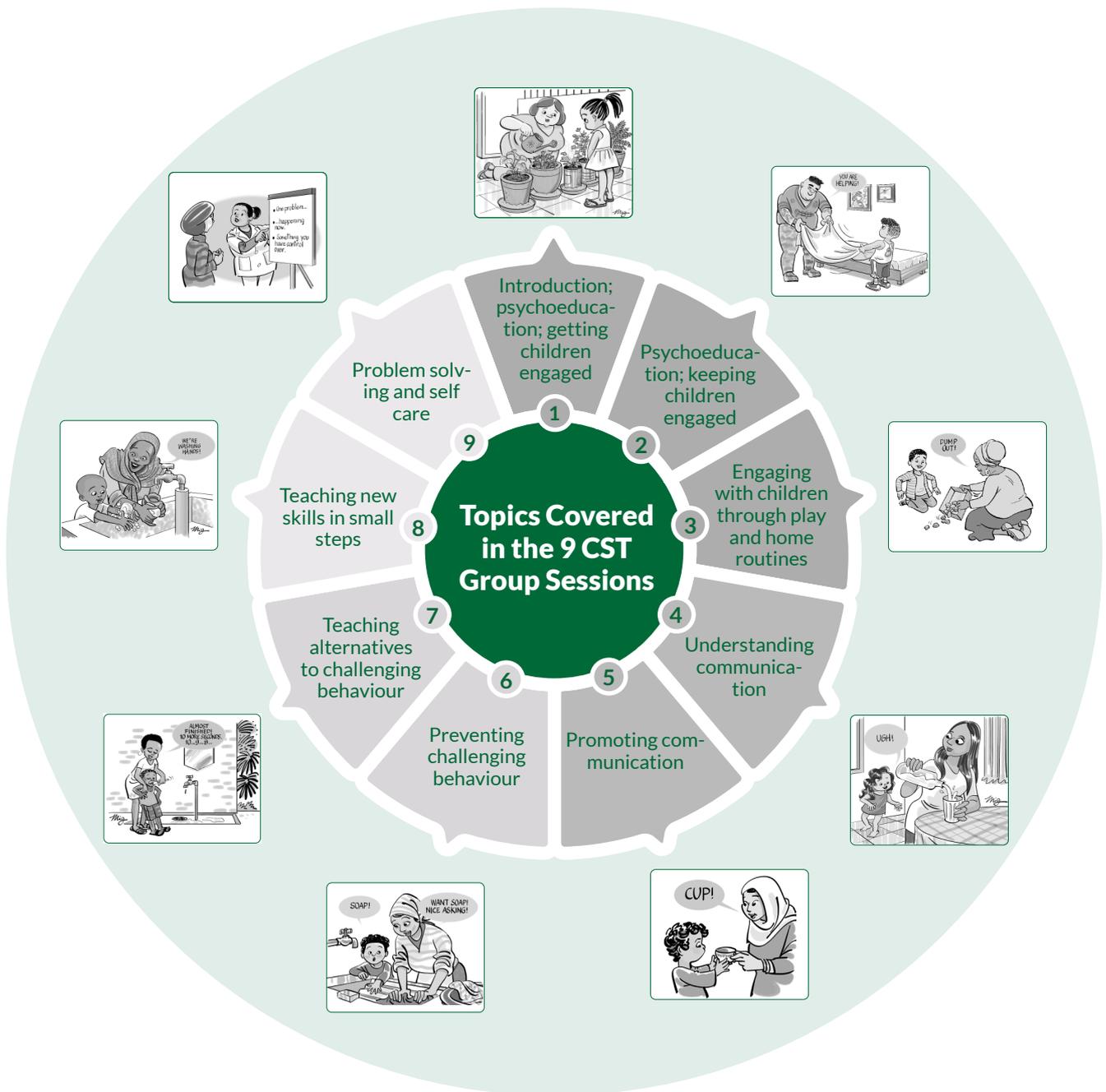
However, our research also identified urgent unmet needs, such as stigma and access to education, of families with children with developmental disabilities. In the new **SPARK project**, our team is working with key stakeholders and researchers in Ethiopia and Kenya to:

- » Develop and evaluate a context-specific toolkit to raise community awareness to improve identification of children with developmental disabilities in the community and reduce stigma.
- » Develop a multisectoral care model for children and their families, to improve their health and education and to promote inclusion.
- » Conduct a large trial of the CST to test its effectiveness, including cost effectiveness.

Background

In line with Sustainable Development Goals 3 (ensure healthy lives and promote wellbeing) and 4 (quality education), there is an urgent need for community-based care that increases identification of children with developmental disabilities and provides community-based support for both children and caregivers.

The World Health Organization (WHO) Caregiver Skills Training (CST) programme teaches caregivers strategies to help them support their child's development, address challenging behaviours, and reduce caregiver stress. The programme is taught in groups, so caregivers meet other families.



What did we do?

Adapting the Caregiver Skills Training programme for Ethiopia

Adaptation of CST was led by a team of researchers and clinicians at Addis Ababa University, Yekatit 12 and St Paul's Millennium Medical College hospitals and King's College London. We first conducted an extensive consultation and review, asking Ethiopian caregivers, professionals, and other stakeholders their views on the draft CST materials. Based on this feedback the materials were adapted to fit the Ethiopian context and then translated to Amharic.

Pilot testing

We pilot-tested the programme in urban and rural Ethiopia with a total of 95 caregivers. Facilitators of the programme were health workers, community rehabilitation workers, or teachers. and they were trained for 10 days.

We also conducted interviews and group discussions with the caregivers who took part in the CST programme to gauge their views of the programme, and to explore their lived experiences, unmet needs, and stigma experiences.



What did we find?

The experiences of children with developmental disabilities and their families

- » Most caregivers reported high levels of stigma and described the negative impact of stigma on the lives of their child with developmental disabilities, siblings, and themselves.
- » Lack of knowledge and understanding about developmental disabilities contributed to people's negative attitudes and responses towards children with developmental disabilities and their caregivers.
- » Many caregivers experienced multiple challenges such as lack of services, financial difficulties, and stigma, but single mothers were affected the most.
- » Lack of appropriate education was one of the most pressing needs expressed by caregivers.

A mother from
Addis Ababa

The awareness level of the community is very low, and a lot needs to be done. ... They talk about you behind your back and because of that, you will be forced to exclude yourself from them. ... They believe in the curse and they give different explanations. Due to this and to protect your mind you will exclude yourself. It has a huge impact. It is very difficult.

...It would have been nice if something can be done for our children. For example, it might be a school or a place for them to stay and to develop their mind...it might be some kind of school...I went to two or three places, but they said, "we will call you when we have free space" ... But what if there is no space? Am I supposed to keep my child at home?

A father from
Addis Ababa

Experience of the CST programme

- » High attendance and completion rates showed that the CST programme is highly acceptable to caregivers.
- » Caregivers who took part in the CST programme reported improved knowledge and skills in how to support their child.
- » The CST programme also enabled caregivers to meet other families, reducing their social isolation and parental stress.

A mother from
Addis Ababa

I didn't expect that they [the CST team] will know what we were feeling deep down, and they would present it to us in the lessons. I didn't know that they knew [what we were feeling inside] ... when I took one class, I saw a lot of the things that were in my life. All the problems I had at home were written down in this book [CST participant booklet] ...

I used to be the one that fed him, now, however, after the training, he has gotten used to eating by himself. This itself is a big change, at first, he did not dress himself either, but now, he started dressing himself

A mother from
Butajira

A father from Addis
Ababa

It's a big deal to be able to share with people about your experience. When you can share the things that you didn't even share with your family you become very happy...



Implications and recommendations

- » In keeping with the UN convention on the rights of persons with disabilities (UNCPRDs) (Article 8), increasing the awareness of the community about developmental disabilities to decrease misconceptions and tackle stigma is crucial.
- » In line with the Ethiopian National Mental Health Strategy, scaling up community-based support for children with developmental disabilities is a priority. The CST addresses many of the families' urgent needs.
- » Interventions to support caregivers of children with developmental disabilities should consider the wellbeing of the whole family unit rather than focus on individuals alone and also consider the vulnerable position of single mothers raising a child with developmental disabilities.
- » A prominent remaining unmet need is access to appropriate education for children with developmental disabilities.

Next Steps

Our team in Ethiopia is currently working with researchers in Kenya to develop and evaluate a context-specific training package to raise community awareness and reduce stigma against children with developmental disabilities. The new SPARK study aims to work with local and federal government to develop a multisectoral care model for children and their families, to improve their health and education and to promote inclusion. We are also going to do a large trial of the CST to test its effectiveness and cost effectiveness.

References

Tekola, B., *et al.* (2019). Adapting and pre-testing the World Health Organization's Caregiver Skills Training programme for autism and other developmental disorders in a very low-resource setting: Findings from Ethiopia. *Autism*, 24(1), 51-63. <https://doi.org/10.1177/1362361319848532>

Tilahun, D., *et al.* (2016). Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: across-sectional facility-based survey. *BMC Health Services Research*, 16, 1-12. [152]. <https://doi.org/10.1186/s12913-016-1383-9>

Tekola, B., *et al.* (2020). Perceptions and experiences of stigma among parents of children with developmental disorders in Ethiopia: A qualitative study. *Social Science & Medicine*, 256, 113034. <https://doi.org/10.1016/j.socscimed.2020.113034>

Tekola, B., Kinfu, M., Girma, F., Hanlon, C., & Hoekstra, R. A. The experiences of parents raising a child with developmental disabilities in Ethiopia. Under review.

Resources

Amharic language training videos on developmental disabilities:

<https://www.open.edu/openlearncreate/mod/oucontent/view.php?id=127693>

A pocket guide on mental health for community health workers:

In English: <https://www.open.edu/openlearncreate/course/view.php?id=2714>

In Amharic: <https://tinyurl.com/AmharicPocketGuide>

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