

Supporting Families of Children with Developmental Disabilities in Kenya

Summary

In Kenya, most children with developmental disabilities (DD) remain undiagnosed and receive little or no formal help. These children and their families experience multiple challenges, which include stigma, care burden, social isolation, limited access to essential services, and are often left out of programmes and government services.

To address some of these challenges, the World Health Organization (WHO) developed a Caregiver Skills Training (CST)¹ programme that teaches caregivers strategies to help them support their child with developmental disabilities. In collaboration with local stakeholders, our team at the KEMRI-Wellcome Trust Research Programme in Kilifi, the African Population and Health Research Centre (APHRC) Nairobi, and the University of Oxford (UK), adapted and pilot tested the WHO CST programme in Nairobi's urban informal settlements and rural Kilifi, in 2018. Findings indicated that the CST addresses behavioural and communication challenges in children with DD, enhances caregivers' quality of life and their attitudes towards capabilities of their children, and is highly acceptable and feasible to be implemented in Kenya.

In the new **SPARK project**, our team is working with key stakeholders and researchers in Kenya and Ethiopia 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 multi-sectoral 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 the 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 and learn with other families with similar experiences and get individualised support during home visits.

¹Salomone, E., Pacione, L., Shire, S., Brown, F. L., Reichow, B., & Servili, C. (2019). Development of the WHO Caregiver Skills Training Program for Developmental Disorders or Delays. *Frontiers in Psychiatry*, 10, 769. <https://doi.org/10.3389/fpsy.2019.00769>

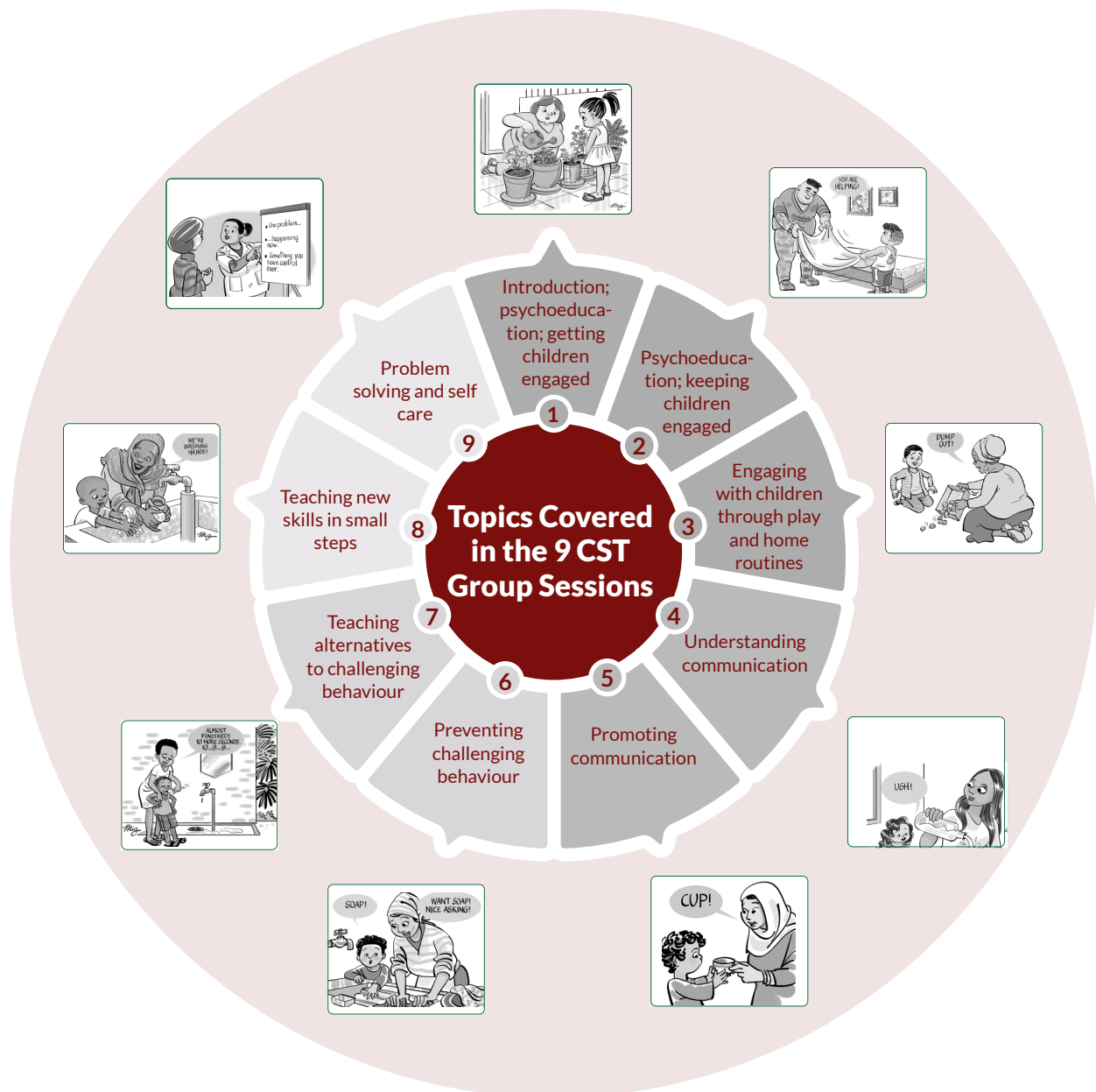


Figure 1: Overview of the WHO CST Programme Group Sessions

What did we do?

Adapting the Caregiver Skills Training programme for Kenya

This was led by a team of researchers and clinicians at the KEMRI-Wellcome Trust Programme (Kilifi) and the African Population and Health Research Centre (APHRC) Nairobi. We first conducted an extensive consultation and review, asking Kenyan caregivers, and other stakeholders: 1) their views on the draft CST materials; and 2) potential barriers and challenges to implementing a caregiver-based intervention in rural and urban informal settlements in Kenya. Based on this feedback, the materials were adapted to fit the Kenyan context and then translated to Swahili. Facilitators of the programme (research assistants, clinical officers, and health workers) conducted competency training of the weekly CST programme sessions with two groups of caregivers (literate and non-literate) in Kenya.

Pilot testing

We pilot-tested the CST programme in urban and rural Kenya with a total of 80 caregivers with a child with disability.

Post study evaluation

We organised group discussions with caregivers who took part in the CST programme to learn about their programme experiences and lived experiences of raising a child with disability.



What did we find?

- » CST programme is acceptable and feasible to implement in different socio-cultural settings.
- » CST programme showed improvements in caregiver and child outcomes as shown in Figure 2.
- » CST positively transformed caregivers' attitudes and beliefs about their child's capabilities and finding better ways to engage them in daily tasks and care.
- » Participating in the CST programme made caregivers feel less stressed during childcare, improved caregivers' understanding of their child's communication needs, increased caregiver confidence in teaching peers of children with DD and enhanced their knowledge on developmental disabilities.
- » Delivering CST in a "peer-group" format was highly appreciated; it enabled caregivers learn from other's experiences, encourage each other, and cope with life stressors.
- » CST programme could easily be followed by literate and illiterate caregivers.
- » All CST session content were deemed relevant and relatable to living situations. Applicability of CST content by caregivers depended on the child's specific needs and type of disability.
- » Finding alternative childcare for the child while the caregiver took part in the CST sessions, and caregivers' working schedule were some of the barriers to participating in the CST programme.

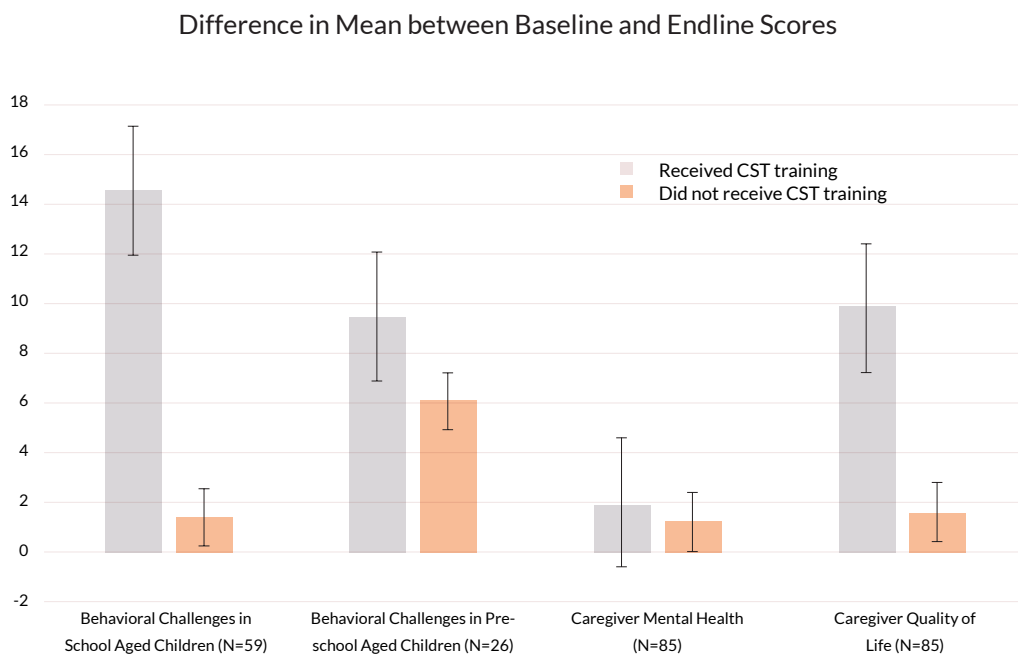


Figure 2: CST programme impact on caregiver and child outcomes

Intervention impact

NGO representative
Nairobi

“Of course! They will find [CST] useful and parents love their children! ... People think that the parents that probably lock their children in the house, leaving their children at home, [that] they don't like them...they protect them.”

“

Yes, it [CST] has great benefits because it will make the child achieve milestones...

”

Mother
Nairobi



CST delivery and programme experience

Mother
Kilifi

“
It is good when you are in a group setting because you will find that ... there are some things you may not know, and your colleague will remind you, and you will be attentive if you are at the same level [following the sessions] with others.
”

“
... the [CST] helped me because I used to think that a child with disability, cannot do anything, I used to do everything for them. Bathing... like almost everything. But when I was taught, I knew that a person with disability can help themselves.
”

Mother
Kilifi

Barriers/challenges

Mother
Kilifi

“
...the problems were about... who would I leave the child behind with? Because most of them [family members] do not want to be left with a child who is like her...”
”

“
... others may have very many household responsibilities, at times the spouse may not allow them to leave because they are required to do certain things.
”

Special needs teacher
Kilifi

Next Steps

Our team in Kenya (the Institute for Human Development, Aga Khan University Nairobi, and the KEMRI/Wellcome Trust Research Programme Kilifi) is currently working with researchers in Addis Ababa University, Ethiopia and the King's College London and University of Oxford, in the United Kingdom to develop and evaluate a context-specific training package to raise community awareness and reduce stigma against children with developmental disabilities. The new study SPARK, funded by the National Institute for Health and Care Research (NIHR) will involve working collaboratively with caregivers of children with disabilities and various stakeholders (national and county government; private sector partners; civil society and others) to develop a multi-sectoral 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, including cost effectiveness.

Implications and recommendations

- » In keeping with the UN convention on the rights of persons with disabilities (UNCPRDs) (Article 8), it is important to prioritize activities aimed at raising community awareness about developmental disabilities to decrease misconceptions and tackle stigma.
- » We need to scale up community-based support for children with developmental disabilities to address the urgent needs of families, including inclusivity and responsiveness to caregivers' life situations.

Prof. Amina Abubakar, in country principal investigator for Kenya
amina.abubakar@aku.edu
SPARK research team: EMwangome@kemri-wellcome.org

The CST pilot research in Kenya was funded by the Medical Research Council [MR/NO22157/1], and the new SPARK study funded by the National Institute for Health and Care Research (NIHR200842) using UK aid from the UK Government to support global health research. The views expressed in this publication are those of the authors. The funders had no role in the design and conduct of the study.