

Training caregivers to transform children's lives

Erica Salomone

*Research Fellow,
University of Turin, Turin,
Italy*

Brian Reichow

*Associate Professor,
University of Florida,
Gainesville FL, USA*

Laura Pacione

*Lecturer, University of
Toronto, Toronto, Canada*

Stephanie Shire

*Assistant Professor,
University of Oregon,
Eugene OR, USA*

Andy Shih

*Senior Vice President,
Public Health and
Inclusion, Autism Speaks,
New York, USA*

Chiara Servili

*Medical Officer, World
Health Organization,
Geneva, Switzerland¹*

Childhood developmental disorders and disabilities are a growing challenge to healthcare systems around the globe: the majority of children with developmental disorders do not have access to care. While obtaining accurate prevalence estimates is a complex task, the global burden of disease for these conditions is thought to be significant and is predicted to gradually increase (Whiteford *et al.*, 2013), as the population of children continues to rise.

The World Health Organization's (WHO) Global Strategy for Women's, Children's and Adolescents' Health calls for the provision of nurturing care to all children. This means a stable, protective and emotionally supportive environment set up by parents and other caregivers that promotes the child's good health and learning. Given the additional challenges that they experience, parents of children with developmental disorders or delays should be specifically supported in providing nurturing care within a 'whole family' approach.

There is now convincing evidence that parents can learn skills to promote their children's development; hence comprehensive caregiver skills training is being recommended for families of children with developmental delays by the WHO in the *mhGAP Intervention Guide* (WHO, 2016). Given that no existing training programme was freely available and feasible in low-resource settings, the WHO, along with international partners, began the development of a novel, open-access programme for families of children with developmental disorders or delays, which could be implemented in low-resource settings by non-specialists.

Developing the WHO Caregiver Skills Training programme

To inform the development of the Caregiver Skills Training (CST) programme, evidence reviews, meta-analyses and expert consultations were conducted. The systematic review was designed to allow the identification of the 'active ingredients' of successful interventions, and used statistical analyses to identify common elements of effective programmes (Reichow *et al.*, 2013; Reichow *et al.*, 2014).

It showed that caregiver-mediated interventions can be effectively delivered by non-specialists in community settings, and even low-intensity programmes lead to improved child developmental and behavioural outcomes as well as improved family well-being. It also emerged that programmes that included behaviour

¹ Disclaimer: The authors alone are responsible for the views expressed in this article and these views do not necessarily represent the decisions, policy, or views of the universities with which the authors are associated, the World Health Organization, or any of the funders.

management techniques and instruction on the use of cognitive intervention strategies to improve caregiver coping were more effective than programmes without this content. Additionally, programmes that used a combined delivery format of group and individual sessions showed a greater impact in the reduction of problem behaviour.

Experts from diverse professional and cultural backgrounds, including caregivers of children with developmental delays and disorders, were consulted in a meeting, hosted by the WHO and remotely, in order to define the content and structure of the intervention and identify capacity-building strategies. Issues discussed included the selection of inclusion and exclusion criteria for children and families who would receive the intervention, programme content, delivery methods (for example, individual or group delivery), and the optimal intensity of the programme in terms of the number and duration of sessions. A flexible, individualised approach suitable for the heterogeneous needs of families that builds on a family's strengths and promotes the involvement of other family members was chosen to increase retention and reduce drop-out.

Design of the WHO CST programme

Based on the evidence reviewed and experts' guidance, a programme was developed comprising intervention manuals, participant booklets, adaptation, capacity building and monitoring and evaluation tools and methods.²

² For further information on the WHO CST programme and children's mental health issues please visit: http://www.who.int/mental_health/maternal-child/PST/en/



△ Illustration: Miguel Mendes

'Parents of children with developmental disorders or delays should be specifically supported in providing nurturing care within a "whole family" approach.'

The programme uses a family-centred approach that is designed to be delivered as part of a network of health and social services for children and families. The programme structure and content have been designed to be adapted and it has the flexibility to incorporate the characteristics of local health and educational systems and in different cultural settings.

The engagement of families and communities was considered paramount to make caregivers' attendance and participation in the programme feasible. It was proposed that the programme should be organised in a modular way, with 'core' individual and group sessions followed by additional optional sessions, according to specific needs and availability of resources. The WHO CST programme addresses the challenge of the heterogeneous needs of children and families first by defining individualised intervention targets, taking into account the child's developmental level and the family's priorities. Secondly, one-to-one tailored coaching is provided to the caregivers during group sessions and home visits. Lastly, optional modules and add-ons to the core sessions are available to ensure that additional medical conditions and other co-occurring needs are addressed. Considering the complex nature of such tasks, continuous support and supervision were included to effectively support the implementation of CST by non-specialist providers.

The WHO CST intervention was designed to target:

- the **child's functioning**, by developing communication, social and adaptive skills and reducing disruptive and challenging behaviour
- the **caregiver's role and functioning**, by promoting self-confidence, parenting skills and knowledge as well as coping skills and psychological well-being
- the **caregiver-child relationship**
- the **caregiver and child's participation and inclusion** in community events.

The WHO CST consists of nine group sessions and three individual home visits, focused on training the caregiver on how to use everyday play and home activities and routines as opportunities for learning and development. The sessions specifically address communication, engagement, daily living skills, challenging behaviour and caregiver coping strategies. Additional, booster modules on caregiver well-being and for minimally verbal children are available. During the group sessions, facilitators illustrate evidence-based psycho-educational strategies derived by principles of applied behaviour analysis, developmental science, social communication interventions, positive parenting and self-care methods through group discussions, demonstrations and guided role play. One-to-one facilitator-to-caregiver coaching is provided during the home visits (prior to the first group session, midway and at the end of the programme), with the purpose of tailoring the intervention to the families' individual environments, goals and needs.

In order to be scalable and sustainable, the WHO CST was designed to be implemented by a range of non-specialist providers (such as nurses, community

health workers, peer caregivers) at health facility level, at community level, or in schools. It should be delivered as part of a network of community-based services, within a stepped-care model. A cascade model, for training specialist Master Trainers responsible for the training and supervision of facilitators, was developed and in December 2015 the programme was made available for field testing for the first time.

Field testing and the way forward

The WHO CST programme is currently undergoing field testing in more than 30 countries in regions throughout the world, including high-, low- and middle-income countries. Two randomised controlled trials are underway in Pakistan and Italy, and future trials are planned in China, Ethiopia and Kenya; the WHO CST is being tested using a variety of delivery approaches, including the use of peer facilitators and tablet-based support. In December 2017 an International Technical Consultation with researchers and representatives of governments and civil society organisations from 14 countries was hosted in China, with the goal of facilitating knowledge exchange on the adaptation and implementation of CST among sites at different stages of field testing.

With previous research highlighting the effectiveness of caregiver-mediated interventions and preliminary evidence of good acceptability and feasibility of the WHO CST programme in communities worldwide, the programme is working towards the goal of closing the gap in access to care for children with developmental disorders and delays, ultimately aiming to help them reach their optimal developmental potential.

Acknowledgment

The development of CST materials and the coordination of CST field testing are being supported by Autism Speaks.

References

- Reichow, B., Kogan, C., Barbui, C., Smith, I., Yasamy, M. T. and Servili, C. (2014). Parent skills training for parents of children or adults with developmental disorders: systematic review and meta-analysis protocol. *BMJ Open* 4(8): e005799.
- Reichow, B., Servili, C., Yasamy, M. T., Barbui, C. and Saxena, S. (2013). Non-specialist psychosocial interventions for children and adolescents with intellectual disability or lower-functioning autism spectrum disorders: a systematic review. *PLoS Med*, 10(12): e1001572.
- Whiteford, H.A., Degenhardt, L., Rehm, J., Baxter, A.J., Ferrari, A.J., Erskine *et al.* (2013). Global burden of disease attributable to mental and substance use disorders: findings from the Global Burden of Disease Study 2010. *The Lancet* 382(9904): 1575–86.
- World Health Organization. (2016). *mhGAP Intervention Guide for Mental, Neurological and Substance Use Disorders in Non-specialized Health Settings*. Geneva: WHO.