Non-specialist delivery of the WHO Caregiver Skills Training Programme for children with neurodevelopmental disorders: stakeholder perspectives about acceptability and feasibility in rural Ethiopia

By Tigist Zerihun Kebede

KBDTIG001

SUBMITTED TO THE UNIVERSITY OF CAPE TOWN

In partial fulfilment of the requirements for the degree

Master of Philosophy (M.Phil) in Child and Adolescent Psychiatry

Department of Psychiatry and Mental Health

Faculty of Health Sciences

UNIVERSITY OF CAPE TOWN

February 2022

Primary Supervisor:

Prof Petrus J de Vries, University of Cape Town, South Africa

Co-supervisors:

Dr Charlotte Hanlon, King's College London, UK & Addis Ababa University, Ethiopia

Dr Rosa Hoekstra, King's College London, United Kingdom

Contents

Declaration

I, Tigist Zerihun Kebede, hereby declare that this thesis is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature: Signed by candidate Date:14/02/2022

Abstract

Background: Autism and other neurodevelopmental disorders (NDD) are common in low- and middle-income countries (LMIC). However, services to address the needs of this group in LMIC are almost non-existent. The World Health Organization (WHO) developed the Caregiver Skills Training (CST) programme to be suitable for delivery in diverse global contexts. Ethiopia, the country of focus in this study, has a largely rural population and a lack of specialist service providers. Additional contextual challenges, including poverty, low literacy, limited access to healthcare and a lack of specialist child mental health services, may undermine the delivery of CST in this setting. This thesis, therefore, seeks to explore the acceptability and feasibility of non-specialist delivery of the WHO-CST from the perspective of providers and caregivers in rural Ethiopia.

Methods: In Chapter one, a general literature review of neurodevelopmental disability and caregiver skills training is presented, with a focus on sub-Saharan Africa, to help contextualise the main qualitative study, outlined in chapter two. In-depth interviews were conducted with caregivers (n=19) who were all participants in two rural pilot studies of the WHO-CST programme. In addition, three focus group interviews were conducted with non-specialist facilitators (n=8), who facilitated the CST programme in two rural pilot tests. Data were analysed using the framework approach.

Results: Findings were mapped onto the three framework themes created for this analysis: 1) Programme content: caregivers and facilitators uniformly indicated that the adapted programme addressed a need and was relevant for their context; caregivers emphasised how the programme helped them understand their child's problems and improve their skills to support their children; facilitators highlighted having acquired new knowledge and skills relating to NDD; 2) Programme facilitation: caregiver responses suggested that programme facilitation by non-specialists was acceptable; non-specialist facilitators emphasised the importance of support and supervision for the facilitators and simplification and modification of some concepts, such as the concept of play, and 3) CST training approach and delivery: participants indicated that the training modalities, including home visits and group training, were acceptable and feasible in the local context.

Conclusions: This study suggested that, with some contextually appropriate modifications of programme content and delivery and continuing supervision of facilitators, the WHO-CST programme facilitated by non-specialists would be acceptable and feasible in rural Ethiopia.

Results from this study may be useful to fine-tune the implementation of non-specialist delivery of the CST programme in Ethiopia, as well as other LMIC.

Key Words: Caregivers, non-specialist facilitators, World Health Organization Caregiver Skills Training, neurodevelopmental disorders.

Acknowledgements and Contributions

Acknowledgements

This research is based on data gathered during the primary Ethiopian WHO CST study programme set out to test the feasibility, acceptability and fidelity of the WHO CST programme in the local context of Ethiopia. I am very grateful for the contribution of caregivers and non-specialist facilitators for participation in this study. The primary study was funded by Autism Speaks (#9817) and joint funding from the Medical Research Council (MRC) (United Kingdom), Department for International Development (DFID), Wellcome Trust and National Institute for Health Research (NIHR) (#MR/P020844/1).

Furthermore, I would like to acknowledge the Ethiopian WHO study team, WHO CST team members, and Autism Speaks, for technical support for the primary study.

I should like to thank Dr John-Joe Dawson-Squibb for proofreading the final thesis.

I must also thank Mr Wondwosen Tensou for study area graphics.

My deepest gratitude goes to my supervisors for their mentorship and dedication.

Finally, I would like to thank Prof Markos Tesfay, Dr Wolfgang Krahl, Prof Senait Fisseha and St Paul's Hospital Millennium Medical College, Addis Ababa, Ethiopia for their special support during my training.

Authors' contributions

TZ - Conceptualised the idea, led protocol development, Data analysis and interpretation, drafting the manuscript, review and editing.

CH - Conception and design of the study; Contribution to the protocol development, contribution to data analysis and reviewing and editing the draft; funding acquisition.

PJdV - Contribution to the protocol development, data analysis and reviewing and editing the draft

RH - Conception and design of the study; Contribution to the protocol development, contribution to data analysis and reviewing and editing the draft; funding acquisition.

List of Tables

List of Figures

List of Abbreviations

ADHD	Attention Deficit Hyperactivity Disorders
ASD	Autism Spectrum Disorder
CST	Caregivers’ Skill Training
DD	Developmental Disabilities
GBD	Global Burden of Disease
HIC	High Income Country
HREC	Human Research and Ethics Committee
ID	Intellectual Disabilities
LMIC	Low- and Middle-Income Countries
NDD	Neurodevelopmental Disorder
PET	Parent Education and Training
RCT	Randomized Controlled Trials
SSA	Sub-Saharan Africa
WHO	World Health Organization

Chapter One

Introduction and Literature Review

Introduction to the thesis

Autism and other neurodevelopmental disorders (NDD) are common in low- and middle-income countries (LMIC). Children with NDD typically need services that address behavioural and developmental challenges. However, services to address the needs of this group in resource-scarce contexts are almost non-existent (de Vries, 2016; Franz et al., 2017). Building on the growing evidence that caregivers can learn skills to support their children, the World Health Organization (WHO) and other collaborators developed an open-access skills training programme to strengthen caregiving skills for families of children with NDD (Salomone et al., 2019). The broader aim of the WHO Caregiver Skills Training (CST) programme is to scale up freely available, evidence-based interventions for children with NDD (WHO, 2008). The CST is a low-intensity training programme for caregivers of children with NDD between the ages of two and nine years and was designed to be feasible in low-resource contexts. To date, the WHO CST programme has been undergoing field testing in more than 30 countries involved in different levels and stages of adaptation, piloting and implementation (Salomone et al., 2019). Ethiopia was one of the early research sites to adapt and pilot the programme.

A study from Ethiopia found promising results of CST in the urban clinical setting, with mental health specialists as facilitators (Tekola et al., 2020a). This study found that the adapted WHO-CST programme was feasible and acceptable for implementation in an urban setting in Ethiopia from the perspectives of caregivers and facilitators. Additionally, this study reflected the demand for this kind of service in a context where no other services are available for caregivers of children with NDD (Tekola et al., 2020a). However, while there is limited evidence of acceptability and feasibility of psychosocial interventions delivered by non-specialists in LMIC (Mendenhall et al., 2014), delivery of the WHO CST by non-specialist providers has not yet been tested in Ethiopia.

This thesis commences with a literature review to provide an overview of the scope of the problem of NDD in children and adolescents in sub-Saharan Africa (SSA). The review is followed by a description of interventions available for children and adolescents with NDD and their caregivers, with specific attention given to parent education and training programmes for caregivers of children with NDD. The literature review concludes with the justification of the research study. The publication-ready research findings are presented in Chapter Two.

Literature Review

Purpose

The purpose of this literature review is to provide context for the research findings presented in Chapter Two by examining all relevant literature on NDD and parent or caregiver skills training programmes by non-specialists, i.e., the two main themes of interest in this study. While the primary focus was on SSA and other LMIC settings, evidence from high-income countries (HICs) was also explored, where it had potential relevance.

Objectives

The objectives of the literature review can be summarised as follows:

1. To describe neurodevelopmental disorders (NDD)
2. To describe the burden of NDD globally and in low and middle-income countries
3. To review evidence on CST programmes for children with NDD and
4. To explore non-specialist delivered CST programmes for children with NDD

Search strategy on NDD and CST programmes for children with NDD

Search method

An electronic database search of PubMed, Medline, Google Scholar and PsycINFO was conducted for published, peer-reviewed journal articles. The following Medical Subject Headings (MeSH) terms were used:

(1) "Neurodevelopmental disorder" OR "developmental delays" OR "Autism" OR "Intellectual disabilities" OR "Mental retardation" OR "learning disability") AND ("Prevalence" OR "Burden");

(2) ("Neurodevelopmental disorder" OR "Developmental delays") AND ("Caregivers skill training programme" OR "parent skill training programme" OR "Parent mediated programme" OR "Parent training education programme");

(3) ("Caregiver skill training") OR ("parent skill training programme")
AND ("non-specialists" OR "A lay health worker" OR "task-sharing" OR "task-shifting" OR "primary health worker"); and
(4) ("acceptability") OR ("feasibility") AND ("caregiver skills training programme").

It should also be noted that the search term "sub-Saharan Africa" was used in a secondary search to identify articles relevant to the continent.

Search results

The database search identified 204 articles, all published in English. Four additional records were retrieved by searching other sources, such as WHO websites. From the total of 208 published articles, 111 duplicate articles were removed, leaving 97 studies for review. Following the screening of the abstracts, 49 articles were excluded for the following reasons:

- The full text or the abstract did not match with inclusion criteria (n = 42)
- They consisted of reports from the same study (n = 2)
- The title and abstract did not match inclusion criteria (n = 5) or
- The training programmes did not involve parents or caregivers (n = 1)

Finally, a total of 48 eligible studies met the inclusion criteria for full-text review and were included in the final review (Fig 1.1).

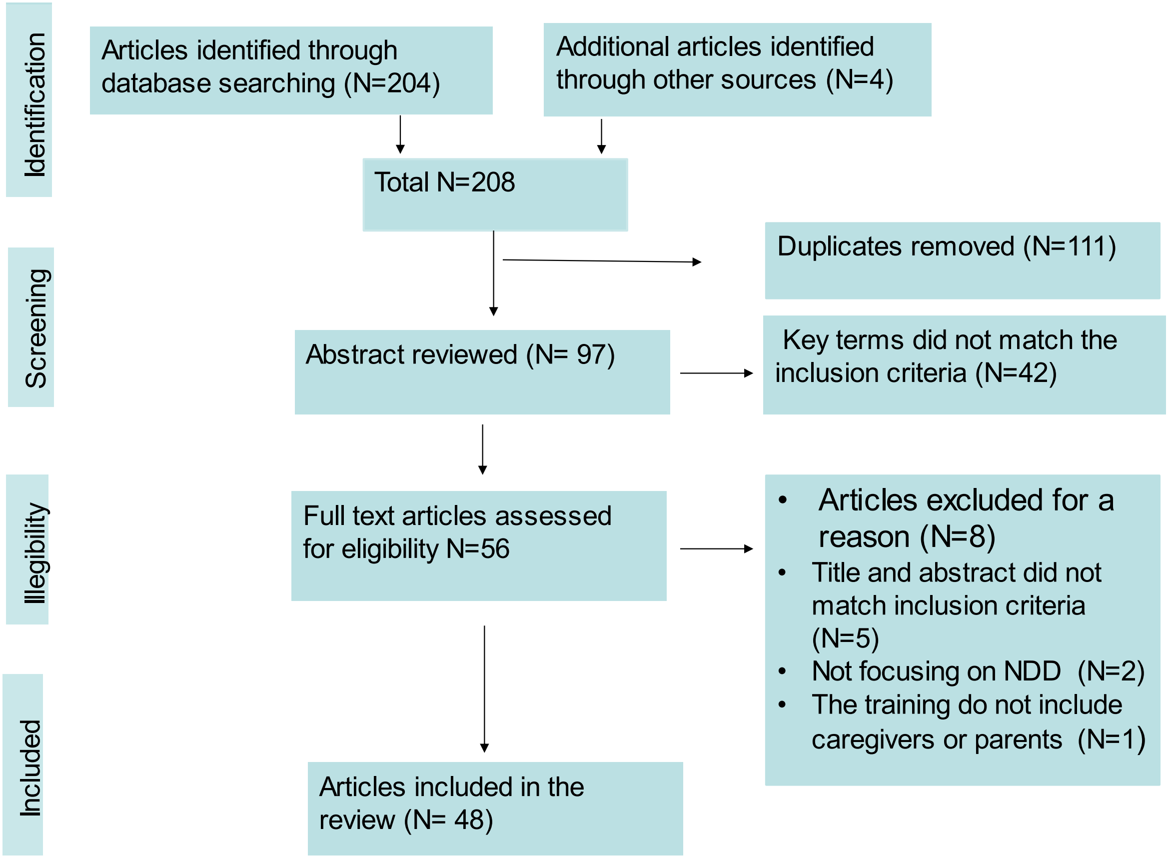


Figure 1.1: PRISMA flow diagram demonstrating study selection process

Neurodevelopmental disorders

Neurodevelopmental disorders are early onset disorders that tend to occur during the developmental years. They cause significant challenges in the acquisition and achievement of intellectual, motor, language or social functions and usually persist into adulthood (APA, 2013; WHO, 2019). By definition, these disorders are neurodevelopmental in the sense that they occur during the developmental phase, such as during the periods of intrauterine life, ante-natal or post-natal periods, infancy, and in early childhood (Bakare et al., 2014). Both the International Classification of Diseases 11th edition (ICD-11) and Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) include a number of NDDs, such as intellectual disabilities (ID), autism spectrum disorder (ASD), communication disorders, attention deficit hyperactivity disorders (ADHD), specific learning disorder, motor disorders, and 'other' NDDs (APA, 2013; WHO, 2019). NDDs are typically conceptualised as multifactorial in origin (APA, 2013; WHO, 2018), stemming from genetic or metabolic aetiologies and traumatic or congenital brain injuries, but also include conditions such as cerebral palsy and similar prenatal exposures (De Felice et al., 2015).

Prevalence of neurodevelopmental disorders in sub-Saharan African countries

Autism and other NDD are common globally and associated with a considerable burden. The available reports detailing autism and NDD prevalence are from HICs or the global burden of disease (GBD) reviews (Olusanya et al., 2018). An analysis based on 2016 GBD data estimated that 8.4% of children globally had a developmental disability, including NDD and sensory disabilities (Olusanya et al., 2018). Furthermore, 95% of people with developmental disabilities live in LMIC, primarily in South Asia and SSA (Olusanya et al., 2020). There are few epidemiological studies into the prevalence and burden of NDD in SSA or other LMIC regions, and most studies were of just one specific NDD condition (Bakare et al., 2014; Bitta et al., 2017). For instance, a systematic review of research in SSA found only one epidemiological study on ASD in SSA (Abubakar et al., 2016). The prevalence of NDD is likely to be underestimated, given that key risk factors for NDD, such as poverty, stunting and poor obstetric care, are more abundant in LMIC (Damiano & Forssberg, 2019).

Olusanya and colleagues reported that the prevalence of NDD has increased by 71% in SSA in the last 25 years in the GBD report (Olusanya et al., 2018). The same systematic review of the global burden of diseases documented that on the African continent, Nigeria, Ethiopia and Congo were among the top ten countries with the highest number of children with any developmental disability (Salomone et al., 2018). Another systematic review and meta-analysis of 51 population-based studies measuring the prevalence or incidence of any NDD from LMIC found the pooled overall prevalence of all NDD (per 1000) and their corresponding 95% CI (Confidence interval) to be 4.4 (4.2–4.6) in Africa. In this study, the authors found that the specific pooled prevalence (per 1000) for ADHD was 62.5 (35.4–101.0), and for learning disability, 80 (68.6–92.7) (Bitta et al., 2017). Generally, there is a paucity of reports of epidemiological studies in SSA. This lack of evidence quantifying the burden of NDD in SSA adversely affects healthcare planning and policy development (Bakare et al., 2022; Lord et al., 2021).

Services for children with neurodevelopmental disorder

Children with NDD typically need services that address behavioural, developmental and educational challenges. Even though most children and adults with NDD live in LMIC, access and availability of services to support their needs are very limited. This is also the case in SSA (de Vries, 2016). SSA has an extreme shortage of resources for treating NDD, as well as a shortfall of mental health services generally, resulting in huge unmet needs (Galvin & Byansi, 2020). For instance, a study from Ethiopia showed that among caregivers of children with autism and other NDD, 47% lacked access to health care; 27.5% had unmet needs for professional support, and 22.5% lacked adequate information (Tilahun et al., 2016). Even though the 'support gap' is variable across LMIC, most studies identified a significant need for educational services, health service provision, support for social activities, and access to information (Ambikile & Outwater, 2012; Brown et al., 2012). Even if effective programmes have been identified for children with NDD, the provision of these interventions requires significant health care resources, such as specialist human resources and infrastructure — which represents another layer of challenge for SSA (de Vries, 2016; Gona et al., 2015).

A systematic review of many studies, mostly conducted in high-income settings, suggested that interventions involving the training of caregivers to deliver different strategies to support children with NDD can be effective (Reichow et al., 2013). In a review from HICs, children and families were found to benefit from these interventions, even if they were brief and low intensity (Oono et al., 2013). Additionally, it is recommended that the majority of interventions for NDD should be ultra-low or low intensity, with delivery by non-specialist facilitators (de Vries, 2016).

Parent education training programmes for children with neurodevelopmental disorders in Sub-Saharan Africa

Many studies, mostly conducted in high-income settings, suggest that interventions that train caregivers to deliver various strategies supporting children with NDD can be effective (Reichow et al., 2013). Dawson-Squibb and colleagues defined parent education and training (PET) programmes as providing the transmission of information and skills using different modalities (didactic, role play, discussions) and with the direct participation of parents or caregivers and trained facilitators without the direct participation of children (Dawson-Squibb et al., 2019).

In resource scarce contexts, PET programmes could address the needs of children with NDD and their families (Bearss et al., 2015; Dawson-Squibb et al., 2019; Dawson-Squibb & de Vries, 2020). A systematic review of 23 studies from LMIC in South Asia reported that PET programmes were cost-effective and improved access to care for children with NDD (Koly et al., 2021). However, given the importance of PET, existing studies on PET interventions cannot adequately inform implementation in resource-limited settings like SSA. The handful of studies that had been performed in SSA suggested demonstrated the feasibility and acceptability of this kind of intervention in resource-limited settings (Bello-Mojeed et al., 2016).

Non-specialist delivered interventions for children with neurodevelopmental disorders

There will never be a sufficient number of specialist healthcare providers in LMIC to deliver services to all those with NDD who need them. Task-shifting to non-specialists has therefore emerged as an important implementation strategy. A task-shifting approach is an approach that aims to improve the delivery of mental health care by utilising non-expert providers (McInnis & Merajver, 2011). For example, a study from Ethiopia found that training and using the existing non-specialist health personnel to scale up adult mental health care services was able to improve overall access to care (Hanlon et al., 2017). Similarly, a study from South Africa suggested that integrating mental health services into primary care with task-shifting represented an integral part of improving access and filling the care gap (Marais & Petersen, 2015). Another systematic review found that task-shifting was a valuable tool for increasing access to mental health in LMIC, particularly in SSA, where the number of specialist human resources are severely limited (Galvin & Byansi, 2020). Community-based psycho-social interventions delivered by non-specialist care providers (e.g., teachers, community health workers, and primary health care workers), therefore represent a potentially viable strategy to scale-up support for families of children with NDD (de Vries, 2016; Divan et al., 2019; Patel et al., 2013).

A study conducted in 24 Ethiopian public primary schools reported that task-shifting enabled teachers to detect and refer childhood mental health conditions more effectively (Desta et al., 2017). Similarly, task-shifting approaches in which local non-specialist providers were trained to deliver ASD interventions were also successfully implemented in India (Divan et al., 2019). Finally, a systematic review of studies, mostly conducted in HICs, found that training non-specialists to implement PET for people with ASD was an effective way to address the care gap (Rispoli et al., 2011).

Acceptability and feasibility of non-specialist delivered PET for children with neurodevelopmental disorders

Even though PET interventions have been shown to be effective in HICs, there is little evidence indicating how they need to be adapted to be acceptable and feasible in low-resource settings (Hastings et al., 2012). For instance, a review of PET programmes from countries outside of the United States found only a few publications from LMIC and only one from Africa (Dawson-Squibb & de Vries, 2020). The authors of the recent *Lancet Commission* on the future of care and clinical research in autism, commented that adaptations of interventions delivered by specialists in HICs could potentially be delivered using non-specialists with no prior experience of autism but with the same degree of fidelity (Lord et al., 2021). The few existing studies in LMIC reported the acceptability and fidelity of non-specialist delivered interventions. However, one study from South Africa suggested that such programmes may face many barriers, such as poverty, to reach the people in need, as well as a need for ongoing supervision (Makombe, 2019). Therefore, implementing this kind of intervention needs a thorough assessment of acceptability and feasibility to inform reasonable recommendations for a resource-limited context. Different authors defined feasibility and acceptability in different ways for our study, we used Proctor and his colleague’s definition. Proctor and colleagues define ‘acceptability’ as the perception of the intervention being agreeable, palatable, or satisfactory to all stakeholders, and ‘feasibility’ as the extent of the practicality of it to be successful when used in a given context or context-intervention interaction (Proctor et al., 2011).

The World Health Organization Caregivers Skills Training Programme

The World Health Organization (WHO) Caregiver Skills Training (CST) programme is an evidence-informed, open-access programme developed by the WHO to reduce the treatment gap for families of children with NDD and minimise delays within the mental health treatment pipeline (Reichow et al., 2014; Reichow et al., 2013; Salomone et al., 2019; Saxena, 2016).

Based on the available evidence showing the benefits of PET interventions delivered by non-specialist providers (Reichow et al., 2013), the WHO-CST aims to support caregivers, both by tapping into their existing competencies and by helping them to develop new skills that can foster their child's learning, social communication, and adaptive behaviours. The programme was designed to be implemented by trained non-specialists and adopted a caregiver-centred approach that fits within a stepped care model for caregivers of children with developmental delays (including, but not limited to, autism). The WHO-CST programme has been adapted and translated for field testing in more than 30 countries (Salomone et al., 2019), with feasibility and acceptability reported from Ethiopia (Tekola et al., 2020a) and Italy (Salomone et al., 2021). All countries that piloted the WHO-CST programme are culturally, economically, and linguistically diverse (e.g., Argentina, Ethiopia, Italy, Russia, South Africa and the USA). Therefore, as different countries adopt, implement, and evaluate the preliminary impact and feasibility of the WHO-CST programme, it is essential to examine the lessons learned across regions, as this will highlight the unique cultural and context-specific feasibility challenges.

Even though there were promising findings from the specialist-delivered WHO-CST programme in an urban clinical setting (Tekola et al., 2020), the key unanswered question for scale-up in an Ethiopian context is to determine whether non-specialist delivery of the programme in a rural setting (where there is lower literacy, lower access to health and educational resources, and higher poverty rates), may be acceptable and feasible. Robust evaluation is therefore required to gauge the success of this intervention, including its fidelity and implementation outcomes in the local setting.

Limitations of the available literature

This literature review did not identify any epidemiological studies about NDD in SSA. The limited number of identified studies from SSA were focused on specific conditions such as ASD or ID and their interventions. The exact prevalence of NDD in Africa therefore remains unknown. In addition, only one article in our literature search described the feasibility and acceptability of the WHO-CST programme in SSA. In that study, the intervention was delivered by specialist facilitators in an urban setting in Ethiopia. No literature to date has examined the feasibility and acceptability of non-specialist delivery of CST or of delivery in a *rural* sub-Saharan African context.

Conclusions

This brief literature review sought to examine NDD and the feasibility and acceptability of low-level interventions such as CST in SSA. It highlighted the scarcity of studies focusing on NDD and services for children with NDD and their caregivers in SSA. The few available studies suggest a high prevalence of NDD, as well as a huge service gap for children with NDD and their caregivers in SSA. The existing literature suggests that the WHO-CST programme may be able to address the need for support in managing NDD in resource-limited settings such as SSA. The task-shifting model for training and supervision to bring accessible interventions for children with NDD and caregivers is a potential way to reach communities in need. The literature review, therefore, provided a clear motivation for the proposed project to focus on CST in an LMIC setting such as SSA. Furthermore, the study was designed to assess the acceptability and feasibility of the WHO-CST programme delivered by non-specialist facilitators. To determine this, we elected to examine the perspectives of caregivers and non-specialist facilitators who participated in the programme in a rural Ethiopian setting.

References

Ambikile, J. S., & Outwater, A. (2012). Challenges of caring for children with mental disorders: Experiences and views of caregivers attending the outpatient clinic at Muhimbili National Hospital, Dar es Salaam-Tanzania. *Child and Adolescent Psychiatry and Mental Health, 6*(1), 16.

American Psychiatric Association(2013) Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition. Arlington, VA, American Psychiatric Association.

Bakare, M., Onu, J., Bello-Mojeed, M., Okidegbe, N., Onu, N., & Munir, K. (2022). Picture of Autism Spectrum Disorder (ASD) Research in West Africa—A Scoping Review. *Research in Autism Spectrum Disorders, 90*, 101888.

Bakare, M. O., Munir, K. M., & Bello-Mojeed, M. A. (2014). Public health and research funding for childhood neurodevelopmental disorders in Sub-Saharan Africa: a time to balance priorities. *Health Care in Low-Resource Settings, 2*(1).

Barlow, J., & Stewart-Brown, S. (2001). Understanding parenting programmes: parents' views. *Primary Health Care Research & Development, 2*(2), 117-130.

Bearss, K., Johnson, C., Smith, T., Lecavalier, L., Swiezy, N., Aman, M., et al. (2015). Effect of parent training vs parent education on behavioral problems in children with autism spectrum disorder: a randomized clinical trial. *JAMA, 313*(15), 1524-1533.

Bello-Mojeed, M., Ani, C., Lagunju, I., & Omigbodun, O. (2016). Feasibility of parent-mediated behavioural intervention for behavioural problems in children with Autism Spectrum Disorder in Nigeria: a pilot study. *Child And Adolescent Psychiatry And Mental Health, 10*(1), 1-8.

Berhanu, G. (2006). Parenting (parental attitude), child development, and modalities of parent-child interactions: sayings, proverbs, and maxims of Ethiopian Jews in Israel. *Journal of Cognitive Education and Psychology, 5*(3), 266-287.

Bitta, M., Kariuki, S. M., Abubakar, A., & Newton, C. R. J. C. (2017). Burden of neurodevelopmental disorders in low and middle-income countries: A systematic review and meta-analysis. *Wellcome Open Research*, *2*, 121-121.

Black, M. M., Walker, S. P., Fernald, L. C., Andersen, C. T., DiGirolamo, A. M., Lu, C., ... & Fink, G. (2017). Advancing Early Childhood Development: from Science to Scale 1 Early childhood development coming of age: science through the life course. *Lancet*, *389*, 77-90.

Brown, H. K., Ouellette-Kuntz, H., Hunter, D., Kelley, E., & Cobigo, V. (2012). Unmet needs of families of school-aged children with an autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities, 25*(6), 497-508.

Bryman, A., & Burgess, R. G. (1994). *Analyzing Qualitative Data* (Vol. 11): Routledge London.

Cutress, A. L., & Muncer, S. J. (2014). Parents' views of the national autistic society's earlybird plus programme. *Autism, 18*(6), 651-657.

Damiano, D., & Forssberg, H. (2019). Poor data produce poor models: children with developmental disabilities deserve better. *The Lancet Global Health, 7*(2), e188.

Dawson-Squibb, J.J., Davids, E. L., & de Vries, P. J. (2019). Scoping the evidence for EarlyBird and EarlyBird Plus, two United Kingdom-developed parent education training programmes for autism spectrum disorder. *Autism, 23*(3), 542-555.

Dawson-Squibb, J.J., Davids, E. L., Harrison, A. J., Molony, M. A., & de Vries, P. J. (2020). Parent Education and Training for autism spectrum disorders: Scoping the evidence. *Autism, 24*(1), 7-25.

Dawson-Squibb, J.J., & de Vries, P. J. (2020). A comparative feasibility study of two parent education and training programmes for autism spectrum disorder in a low-resource South African setting. *Autism, 24*(8), 2269-2284.

De Felice, A., Ricceri, L., Venerosi, A., Chiarotti, F., & Calamandrei, G. (2015). Multifactorial origin of neurodevelopmental disorders: approaches to understanding complex etiologies. *Toxics, 3*(1), 89-129.

de Vries, P. J. (2016). Thinking globally to meet local needs: autism spectrum disorders in Africa and other low-resource environments. *Current Opinion in Neurology, 29*(2), 130-136.

Dendir, Z., & Simane, B. (2019). Livelihood vulnerability to climate variability and change in different agroecological zones of Gurage Administrative zone, Ethiopia. *Progress in Disaster Science, 3*, 100035-100035.

Desta, M., Deyessa, N., Fish, I., Maxwell, B., Zerihun, T., Levine, S., et al. (2017). Empowering preschool teachers to identify mental health problems: a task-sharing intervention in Ethiopia. *Mind, Brain, and Education, 11*(1), 32-42.

Divan, G., Vajaratkar, V., Cardozo, P., Huzurbazar, S., Verma, M., Howarth, E., et al. (2019). The feasibility and effectiveness of PASS Plus, a lay health worker delivered comprehensive intervention for autism spectrum disorders: pilot RCT in a rural low and middle income country setting. *Autism Research, 12*(2), 328-339.

Esponda, G. M., Hartman, S., Qureshi, O., Sadler, E., Cohen, A., & Kakuma, R. (2020). Barriers and facilitators of mental health programmes in primary care in low-income and middle-income countries. *The Lancet Psychiatry, 7*(1), 78-92.

Franz, L., Chambers, N., von Isenburg, M., & de Vries, P. (2017). Autism spectrum disorder in sub-saharan africa: A comprehensive scoping review. *Autism Research, 10*(5), 723-749.

Galvin, M., & Byansi, W. (2020). A systematic review of task shifting for mental health in sub-Saharan Africa. *International Journal of Mental Health*, *49*(4), 336-360.

Gona, J. K., Newton, C. R., Rimba, K., Mapenzi, R., Kihara, M., Van de Vijver, F. J., et al. (2015). Parents' and professionals' perceptions on causes and treatment options for autism spectrum disorders (ASD) in a multicultural context on the Kenyan coast. *PLOS one, 10*(8), e0132729-e0132729.

Hanlon, C., Eshetu, T., Alemayehu, D., Fekadu, A., Semrau, M., Thornicroft, G., et al. (2017). Health system governance to support scale up of mental health care in Ethiopia: a qualitative study. *International Journal of Mental Health Systems, 11*(1), 1-16.

Hastings, R. P., Robertson, J., & Yasamy, M. (2012). Interventions for children with pervasive developmental disorders in low and middle income countries. *Journal of Applied Research In Intellectual Disabilities, 25*(2), 119-134.

Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child And Family Psychology Review, 15*(3), 247-277.

Koerting, J., Smith, E., Knowles, M., Latter, S., Elsey, H., McCann, D., et al. (2013). Barriers to, and facilitators of, parenting programmes for childhood behaviour problems: a qualitative synthesis of studies of parents' and professionals' perceptions. *European Child & Adolescent Psychiatry, 22*(11), 653-670.

Koly, K. N., Martin-Herz, S. P., Islam, M. S., Sharmin, N., Blencowe, H., & Naheed, A. (2021). Parent mediated intervention programmes for children and adolescents with neurodevelopmental disorders in South Asia: A systematic review. *PLOS one, 16*(3), e0247432-e0247432.

Lord, C., Charman, T., Havdahl, A., Carbone, P., Anagnostou, E., Boyd, B., ... & McCauley, J. B. (2022). The Lancet Commission on the future of care and clinical research in autism. *The Lancet*, *399*(10321), 271-334.

Makombe, C. B. T., Shabalala, N., Viljoen, M., Seris, N., de Vries, P. J., & Franz, L. (2020). Sustainable implementation of early intervention for autism spectrum disorder through caregiver coaching: South African perspectives on barriers and facilitators. *Pediatric Medicine*, *2*, 39-39.

Marais, D. L., & Petersen, I. (2015). Health system governance to support integrated mental health care in South Africa: challenges and opportunities. *International Journal Of Mental Health Systems, 9*(1), 1-21.

McInnis, M. G., & Merajver, S. D. (2011). Global mental health: Global strengths and strategies: Task-shifting in a shifting health economy. *Asian Journal of Psychiatry, 4*(3), 165-171.

Mendenhall, E., De Silva, M. J., Hanlon, C., Petersen, I., Shidhaye, R., Jordans, M., et al. (2014). Acceptability and feasibility of using non-specialist health workers to deliver mental health care: stakeholder perceptions from the PRIME district sites in Ethiopia, India, Nepal, South Africa, and Uganda. *Social Science & Medicine, 118*, 33-42.

Metaferia, B. K., Futo, J., & Takacs, Z. K. (2021). Parents' Views on Play and the Goal of Early Childhood Education in Relation to Children's Home Activity and Executive Functions: A Cross-Cultural Investigation. *Frontiers in Psychology*, *12*, 646074-646074.

Mytton, J., Ingram, J., Manns, S., & Thomas, J. (2014). Facilitators and barriers to engagement in parenting programs: a qualitative systematic review. *Health Education & Behavior, 41*(2), 127-137.

O'Donovan, K. L., Armitage, S., Featherstone, J., McQuillin, L., Longley, S., & Pollard, N. (2019). Group-based parent training interventions for parents of children with autism Spectrum disorders: A literature review. *Review Journal of Autism and Developmental Disorders, 6*(1), 85-95.

Olusanya, B. O., Davis, A. C., Wertlieb, D., Boo, N.-Y., Nair, M., Halpern, R., et al. (2018). Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Global Health, 6*(10), e1100-e1121.

Olusanya, B. O., Wright, S. M., Nair, M. K. C., Boo, N.-Y., Halpern, R., Kuper, H., et al. (2020). Global Burden of Childhood Epilepsy, Intellectual Disability, and Sensory Impairments. *Pediatrics, 146*(1), e20192623-e20192623.

Oono, I. P., Honey, E. J., & McConachie, H. (2013). Parent-mediated early intervention for young children with autism spectrum disorders (ASD). *Evidence-Based Child Health: A Cochrane Review Journal, 8*(6), 2380-2479.

Patel, V., Kieling, C., Maulik, P. K., & Divan, G. (2013). Improving access to care for children with mental disorders: a global perspective. *Archives Of Disease In Childhood, 98*(5), 323-327.

Pickard, K., Rowless, S., & Ingersoll, B. (2019). Understanding the impact of adaptations to a parent-mediated intervention on parents' ratings of perceived barriers, program attributes, and intent to use. *Autism, 23*(2), 338-349.

QSR International. (2018). NVivo (Version 12). Retrieved from https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home on January 12 2022

Reichow, B., Barton, E. E., Boyd, B. A., & Hume, K. (2014). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD): A systematic review. *Campbell Systematic Reviews, 10*(1), 1-116.

Reichow, B., Servili, C., Yasamy, M. T., Barbui, C., & Saxena, S. (2013). Non-specialist psychosocial interventions for children and adolescents with intellectual disability or lower-functioning autism spectrum disorders: a systematic review. *PLOS Medicine, 10*(12), e1001572.

Rispoli, M., Neely, L., Lang, R., & Ganz, J. (2011). Training paraprofessionals to implement interventions for people autism spectrum disorders: A systematic review. *Developmental Neurorehabilitation, 14*(6), 378-388.

Salomone, E., Ferrante, C., Salandin, A., Ferrara, F., Torchio, E., Foletti, G., ... & Servili, C. (2021). Acceptability and feasibility of the World Health Organization's caregiver skills training implemented in the Italian national health system. *Autism*, *26*(4), 859-874.

Salomone, 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*, 769-769.

Salomone, E., Reichow, B., Pacione, L., Shire, S., Shih, A., & Servili, C. (2018). Training caregivers to transform children's lives. *Early Childhood Matters, 127*, 74-77.

Saxena, S. (2016). Challenges and opportunities in global mental health: a perspective from WHO. *Epidemiology and Psychiatric Sciences, 25*(6), 495-498.

Sengupta, K., Shah, H., Ghosh, S., Sanghvi, D., Mahadik, S., Dani, A., ... & Servili, C. (2021). World Health Organisation-Caregiver Skills Training (WHO-CST) Program: feasibility of delivery by non-specialist providers in real-world urban settings in India. *Journal of Autism and Developmental Disorders*, 1-18.

Stewart-Brown, S., Patterson, J., Mockford, C., Barlow, J., Klimes, I., & Pyper, C. (2004). Impact of a general practice based group parenting programme: quantitative and qualitative results from a controlled trial at 12 months. *Archives of Disease in Childhood, 89*(6), 519-525.

Straiton, D., Groom, B., & Ingersoll, B. (2021). A mixed methods exploration of community providers' perceived barriers and facilitators to the use of parent training with Medicaid-enrolled clients with autism. *Autism*, *25*(5), 1368-1381.

Tekola, B., Girma, F., Kinfe, M., Abdurahman, R., Tesfaye, M., Yenus, Z., et al. (2020a). 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.

Tekola, B., Kinfe, M., Girma, F., Hanlon, C., & Hoekstra, R. A. (2020b). Perceptions and experiences of stigma among parents of children with developmental disorders in Ethiopia: A qualitative study. *Social Science & Medicine, 256*, 113034-113034.

Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y., & Hoekstra, R. A. (2016). Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey. *BMC Health Services Research, 16*(1), 1-12.

Todd, S., Bromley, J., Ioannou, K., Harrison, J., Mellor, C., Taylor, E., et al. (2010). Using group-based parent training interventions with parents of children with disabilities: A description of process, content and outcomes in clinical practice. *Child and Adolescent Mental Health, 15*(3), 171-175.

Toure, D. M., Wani, R. J., Do, K., & Su, D. (2020). Exploring African American and Latino populations perceptions of parenting education programs: A qualitative assessment of enablers and barriers. *Journal of Social Service Research, 46*(2), 256-263.

United Nations Population Fund. (2020, October 2020). World Population Dashboard :Ethiopia Retrieved from https://www.unfpa.org/data/world-population/ET on Decemebr 1 2022

World Health Organization. (2008). *mhGAP: Mental Health Gap Action Programme: scaling up care for mental, neurological and substance use disorders*: Geneva: World Health Organization.

World Health Organization.. (2017). World Health Organization World mental health atlas 2017 member state profile: ETHIOPIA. Retrieved from https://www.who.int/mental_health/evidence/atlas/mental_health_atlas_2017/en/ on January 12 2022

World Health Organization.. (2018). Training parents to transform children's lives. Retrieved from https://www.who.int/mental_health/maternal-child/PST/en/ on January 12 2022

World Health Organization.. (2019). *ICD-11 International Statistical Classification of Diseases and Related Health Problems* World Health Organization.

Chapter Two

Publication-Ready Manuscript

Non-specialist delivery of the WHO Caregiver Skills Training Programme for children with neurodevelopmental disorders: Stakeholder perspectives about acceptability and feasibility in rural Ethiopia

Tigist Zerihun[1,2], Petrus J de Vries[1], Charlotte Hanlon[3,4], Rosa A. Hoekstra[3]

[1]Centre for Autism Research in Africa, Division of Child & Adolescent Psychiatry, University of Cape Town, Cape Town, South Africa
[2]Saint Paul's Hospital Millennium Medical College, Ethiopia
[3]King's College London, UK
[4]Addis Ababa University, Ethiopia

Corresponding Author:

Dr Tigist Zerihun
Division of Child & Adolescent Psychiatry, University of Cape Town, South Africa
Email: KBDTIG001@myuct.ac.za/tigistzerihunk@gmail.com

Abstract

Autism and other neurodevelopmental disorders (NDD) are common in low- and middle-income countries (LMIC). The World Health Organization (WHO) developed the Caregiver Skills Training (CST) programme for NDD to address the service needs of people with NDD globally. Ethiopia, the focus of this study, has numerous contextual factors that may affect the delivery of CST. Therefore, this study explored the acceptability and feasibility of non-specialist delivery of CST in rural Ethiopia. A qualitative study design was used. In-depth interviews with caregivers (n=19) and focus groups with non-specialist facilitators (n=8) were conducted in two rural pilot tests of the CST programme. Data were analysed using the framework approach. Results suggested that participants described the adapted programme as acceptable and relevant for their context. Caregivers described that the facilitation by non-specialists was acceptable and facilitators emphasised the importance of supervision in the programme. Participants indicated that the training modalities, including home visits and group training, were acceptable and feasible. However, some barriers to attending the sessions were reported, such as transportation, and the difficulty of explaining some concepts by non-specialist facilitators to caregivers. Caregivers highlighted how the programme helped them understand their child's problems and improve their skills to support their child. These findings may have relevance to non-specialist delivery of the CST in other LMIC.

Lay abstract

Children with neurodevelopmental disorders, including autism, have limited access to care in low- and middle-income countries. The World Health Organization developed the Caregivers Skills Training programme for children with neurodevelopmental disorders that aims to train caregivers to better support their children’s development. In Ethiopia, there are many cultural and contextual elements that may affect the success of the programme. We implemented the programme with non-specialist care providers in rural Ethiopia and examined whether it was acceptable and feasible by conducting interviews and group discussions with caregivers and providers. Findings revealed that the Caregiver Skills Training was considered feasible and acceptable in rural Ethiopia. Caregivers emphasised how the programme helped them understand their child's problems and improve their skills to support their child. However, some barriers to attending the sessions were reported, such as transportation. Facilitators also emphasised the importance of supervision in the programme.

Key Words: Caregivers, non-specialist facilitators, World Health Organization Caregiver Skills Training, neurodevelopmental disorders, neurodevelopmental disabilities.

Introduction

Autism and other neurodevelopmental disorders (NDD) are priority conditions for intervention efforts around the globe, particularly in low- and middle-income countries (LMIC). Almost 95% of people with NDD live in LMIC, predominantly in South Asia and sub-Saharan Africa (SSA) (Olusanya et al., 2018; Olusanya et al., 2020). The prevalence of NDD is likely to be underestimated in these settings, given that key risk factors for NDD, such as poverty, stunting and poor obstetric and neonatal care, are more abundant in LMIC (Black et al., 2017; Damiano & Forssberg, 2019). The prevalence of NDD has increased by 71% in SSA in the last 25 years, and Ethiopia is one of the top ten SSA countries in terms of NDD burden and estimated prevalence (Olusanya et al., 2018).

Children with NDD typically need services that address behavioural, developmental and educational challenges. However, access to, and the availability of, services to support their needs is highly limited in SSA (de Vries, 2016; Franz et al., 2017; Lord et al., 2021). Moreover, SSA countries have a limited capacity for managing NDD and an extreme shortage of resources for treating mental health in general (Galvin & Byansi, 2020). For instance, Ethiopia has just one child psychiatrist for a population of 115 million (UNPF, 2020), and no other cadres of professionals who are specialised in child mental health (WHO, 2017). To address this service gap in LMIC and other low-resource contexts, the WHO and collaborators developed an open-access training programme to strengthen caregiving skills for families of children with NDD (Salomone et al., 2019; WHO, 2018). This programme is referred to as the WHO Caregiver Skills Training (CST) programme. CST is a manualised, relatively low-intensity training programme for caregivers of children with NDD between the ages of two and nine years that was designed to be feasible for wide-scale implementation (Salomone et al., 2018). It consists of twelve sessions in total: nine sessions delivered to groups of caregivers plus three home visits to individual family homes. The CST programme targets caregivers' skills to enhance communication, increase shared engagement, improve adaptive behavioural skills, and reduce and prevent challenging behaviour in their children. The first home visit aims to understanding the main problems of the child and to set goals for the training. The second and third home visits are intended to coach the caregiver in the naturalistic environment to evaluate progress and identify any additional needs and problems (Salomone et al., 2018).

In Ethiopia, the CST programme underwent an initial contextual adaptation and was tested in a pre-pilot conducted with mental health specialists as facilitators in an urban clinical setting. Stakeholders in that study reported that the CST programme was feasible and acceptable (Tekola et al., 2020a). Additionally, this study identified the clear need for this kind of service in a context where no other services were available for caregivers of children with a NDD (Tekola et al., 2020a).

Even though these were encouraging findings, most people in Ethiopia live in rural communities and cannot access centralised services run by specialists. Therefore, there was a need to investigate the potential of non-specialist delivery of CST in a rural Ethiopian setting. However, there is limited evidence of acceptability and feasibility of non-specialist delivery of CST or similar programmes in any LMIC (Esponda et al., 2020; Mendenhall et al., 2014) and non-specialist delivery of the CST programme has not yet been evaluated in Ethiopia.

This study therefore aimed to assess the acceptability and feasibility of the CST programme delivered by non-specialist facilitators in a rural Ethiopian setting from the perspectives of both caregivers and facilitators.

Methods

Study design

The study used a qualitative design comprising in-depth interviews and focus group discussions nested within a pre-pilot study and a pilot randomised controlled trial (RCT) of the CST programme with non-specialists.

Setting

The study was conducted in two rural areas in the Gurage zone, in the Southern Nations, Nationalities and People's Region of Ethiopia. Butajira and Sodo are predominantly rural districts in the Gurage zone located 135km and 99km, respectively, south of the capital city, Addis Ababa. Both districts have populations with low socioeconomic status and livelihoods that rely mainly on agriculture. Infrastructure such as schools, health facilities and roads are underdeveloped in the towns and surrounding villages (Dendir & Simane, 2019) (Figure 2.1).

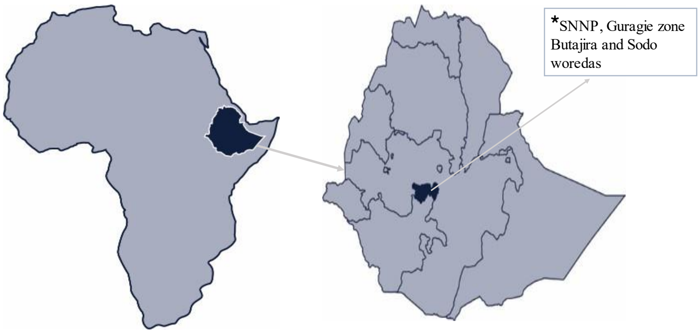


Figure 2.1: Map of the study area

Participants

The study included two participant groups from the pre-pilot study and pilot RCT of CST: a) caregivers of children with NDD, and b) non-specialist CST facilitators. Table 2.1 shows details of the two datasets, participants and samples included in the study.

Table 2.1: Datasets and sample size

Data Set	Description	Participants
Dataset I	Pre-pilot in a community setting in rural Sodo district involving 20 families	- In-depth interviews with caregivers (N=9) - Focus group discussion with non-specialist facilitators (N=7)
Dataset II	Pilot randomised wait-list controlled field trial study in rural Sodo and Butajira involving 66 families	- In-depth interviews with caregivers (N=10) - Focus group discussion with non-specialist facilitators (N=8)

Caregivers

The CST programme included a total of 86 caregivers as participants pre-pilot (N=20) and pilot RCT (N=66). The criteria for inclusion of caregivers included the following:

1) Having a long-term caring responsibility for a child aged 2–9 years with a NDD, preferably as the primary carer;
2) Living within easy travelling distance of a training site;
3) Being able to attend the full number of training sessions;
4) Having sufficient contact time during the week with the child with the NDD (seeing the child at least five days a week on average) to do homework exercises;
5) Having the ability to speak Amharic, the official language in the study site;
6) Being 18 years of age or older, and
7) Being willing to provide written informed consent to participate in the study.

For this nested qualitative study, caregivers were purposively selected in terms of religious or educational background, child diagnosis and the marital status of the caregiver.

Non-specialist facilitators

All non-specialist facilitators were selected from the district they were working in and comprised community health workers (health extension workers), primary health care workers (nurses and health officers) or teachers. All non-specialist facilitators received intensive training on WHO CST before commencement of the delivery of the programme to the caregivers.

Non-specialist facilitators received four days of initial training focusing on CST sessions 1–5 and home visit 1 and then assisted the delivery of these sessions in practice. Master trainers (Mental health specialist who trained in CST as a trainer) reviewed a video recording of the home visits and goal setting sheets and provided comprehensive feedback to the facilitators to improve goal-setting and facilitator skills. A further three days of training focused on CST sessions 6–9 and home visits 2 and 3. This was followed by the completion of assisting with the delivery of the full CST programme by the non-specialists under the supervision of the master trainers. Finally, the non-specialists completed 2 further days of training focusing on troubleshooting, a review of the complete programme, and roleplays conducted to practice skills that focused on leading rather than assisting the facilitation of the programme (See figure 2.2).

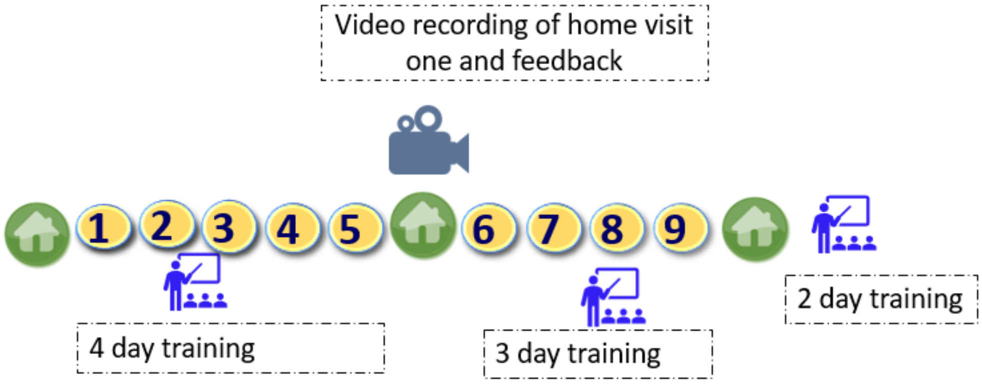


Figure 2.2: Non-specialist facilitators training on WHO-CST in Ethiopia

Supervision and support

Facilitators received ongoing supervision and support from CST master trainers throughout the programme. Supervisory meetings took place 30 minutes to an hour before each session to discuss any challenges encountered by non-specialists during preparation. In addition, brief feedback sessions were arranged for the facilitators after they completed the delivery of each CST group session.

During the pre-pilot, supervisors attended all nine weekly CST group sessions, whereas in the pilot RCT, supervisors attended only six out of nine weekly CST sessions (sessions 1, 2, 3, 6, 8 and 9), with the same pre-session supervisory and post-session feedback meetings. Two facilitators led the group sessions: one lead (who facilitated the training session) and one assistant (who assisted the lead facilitator with role plays, demonstrations, and timekeeping). Figure 2.3 summarises this process.

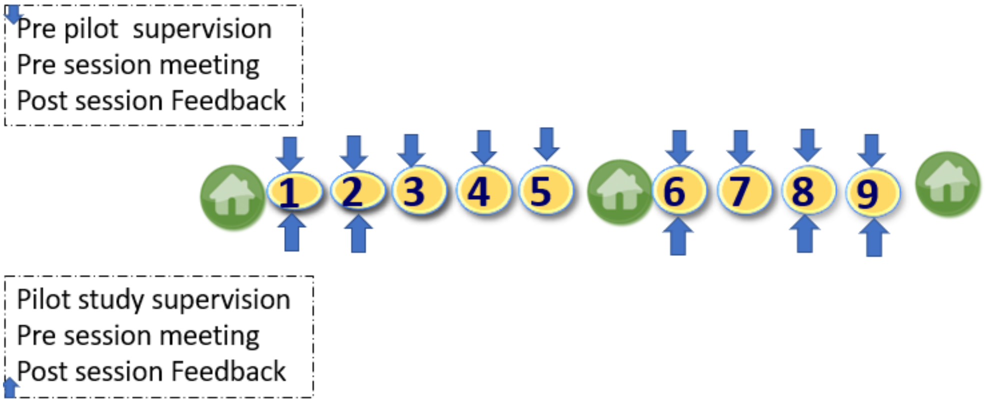


Figure 2.3: Non-specialist facilitators supervision and support by specialists

Datasets

The study used two datasets (see Table 2.1). In the pre-pilot phase of the Ethiopian study, dataset I was collected following the completion of CST group sessions. In-depth interviews were conducted with nine caregivers. Dataset II was collected after completion of all 9 CST group sessions of the pilot RCT and constituted ten purposively sampled caregivers offering their perspectives about the suitability of the CST programme for the families of the children with NDD.

Research procedures and data collection

In-depth interviews (see Table 2.2) and focus group discussions (see Table 2.3) were conducted with caregivers and facilitators, respectively. Demographic data were collected on age, gender, marital status, employment and educational level. The topic guides focused on programme content, experience and remaining needs from both the caregivers and facilitators' perspective (see Tables 2.2 and 2.3). All non-specialist facilitators who facilitated pre-pilot and RCT pilot studies were invited to participate in focus group discussions. All qualitative interviews and focus group discussions were conducted in Amharic (the official language of

Ethiopia) by an independent researcher who did not have any role in the CST delivery or implementation. All interviews were audio-recorded.

Table 2.2: Summary of the interview guide for caregivers

- Tell me about your experience of CST participation
- What did you think of the facilitators who delivered the CST programme?
- What is your experience with meeting parents who have children who develop similarly to your child?
- Following the programme you attended, how is your child doing?
- Is there something that has changed since you took part in the intervention? If so, can you give examples?
- Are there areas where you think the programme could have helped more?

Table 2.3: Summary of the interview guide for non-specialist facilitators

- Can you tell me about your experiences with the programme?
- What do you think these families need the most?
- How do you think these needs can be best met?
- In the CST materials, there may be concepts introduced that are unfamiliar to the caregivers. Did you come across such a situation?
- How do you see the techniques in CST?
- Can you tell me about your experience with the facilitator training?

Data analysis

Audio recordings were transcribed verbatim in Amharic and translated into English by bilingual Amharic/English researchers from Addis Ababa University. The transcripts were checked against the audio files by the first author, who led the analysis. The datasets were analysed together, with an effort made to compare the caregiver and facilitator perspectives. The framework approach was used for analysis (Gale et al., 2013). According to Bryman and Burgess (1994), this approach encompasses five interconnected stages: 1) familiarisation, 2) identifying a thematic framework, 3) indexing, 4) charting, reviewing themes, and 5) mapping and interpretation.

For the analysis, the research team developed a specific framework (see Table 2.4) that was informed by a thorough review the relevant literature and previous research experience in this context, including the urban pilot study of CST (Tekola et al., 2020a) and the broader experience of co-investigators in implementing mental health interventions in the study site. Sample interviews were coded using the framework, and discussions were held on sample coding. The framework was then revised for further data coding. After the final review of the framework, all the data were coded using the framework by the primary author of this study.

The data from the pre-pilot study were independently coded by another researcher and the codes from the pilot study coded by the PI were reviewed by the researcher who coded the pre-pilot data. Finally, the PI and the second coder sat together and went through all the codings to ensure a high level of consistency.

During the coding, the researcher was cognisant that the participants were from different datasets collected from different study phases (dataset I after session 6, and dataset II after completing all nine sessions). The research team also considered differences in facilitator levels of exposure to CST (the facilitators had had more experience delivering the CST in the pilot RCT phase than in the pre-pilot studies). NVivo (Version 12) software was used to facilitate the analysis (QSR, 2018).

Table 2.4: Analysis framework for this study

Major themes	Sub-themes
Programme content	Acceptability and relevance Complexity of concepts Contextual appropriateness Overall programme perception
Programme facilitation	Acceptability of non-specialist facilitators to caregivers Support and supervision
CST training approach and delivery	Feasibility of CST in the local context Programme delivery structure

Positionality

We acknowledge our local positionality and potential contextual biases as researchers based in an LMIC context. The primary author who performed the analysis was a CST master trainer and supervisor of the non-specialist facilitators with first-hand experience of the context; a factor that might affect the interpretation of the data. Furthermore, she worked in child and adolescent mental health services as a psychiatrist in a resource-limited setting with two other co-authors. All the authors have worked in, and conducted research in, low-resource settings and subscribe to the principle of developing initiatives to scale up mental health services to reach as many people as possible given the limited resources available, using task-sharing as an example. Thus, we tend to gravitate toward a model that uses non-specialists and may be tolerant of the potential disadvantages of task-sharing. This perspective is distinct from a specialist working in a high-income context with relatively better resources.

Ethical approval

This study was approved by the Institutional Review Board of the College of Health Sciences of Addis Ababa University (#062/16/Psy), the Psychiatry, Nursing and Midwifery subcommittee of King's College London's College Research Ethics Committee (#RESCM-17/18-3489) and by the Health Research Ethics committee of the Faculty of Health Sciences, University of Cape Town (HREC 476/2021). The feasibility RCT was also registered (Trial Number: PACTR201812802696820).

Community involvement

This study benefited from the long-term involvement of a project advisory board that was comprised of the following: a group of stakeholders in Addis Ababa (including parents of children with NDD); the founders of special schools for children with NDD; representatives of local and international non-governmental organisations (NGOs); and experts in child mental health and education. This project advisory board advised the research team on important research questions, methods and measures, and directly informed the adaptation of the CST programme, as previously outlined in Tekola et al. (2020a). This study was unable to solicit the views of Ethiopian people with autism or other NDD themselves. In Ethiopia, autism tends to only be identified and diagnosed in children who also have intellectual disability and are typically minimally verbal.

Results

Demographic information

Caregivers

As shown in Table 2.4, a total of (N=19) in-depth interviews were conducted with caregivers from the two rural pilot tests of the CST programme. Participants had an age range of 30 to 70 years, and the majority (15/19) were women. More than half of the participants (10/19) could not read or write and only one caregiver had education beyond high school.

Non-specialist facilitators

Eight facilitators (four male and four female), participated in the focus group. Seven facilitators were interviewed twice; once after the pre-pilot and once after the pilot RCT of Ethiopian CST study. Four were primary or junior high school teachers, and four were primary health care workers.

Table 2.4: Demographic information of caregivers and children

Caregiver Study Code	Main diagnosis of child	Child age (years)	Sex	Caregiver relationship to the child	Caregiver educational level
C01*	Autism + ID	4	Male	Father	Secondary
C02*	ID	9	Male	Mother	Primary
C03*	ID	7	Male	Mother	Primary
C04*	Autism	7	Male	Mother	No education
C05*	Autism + ID	9	Male	Mother	No education
C06*	ID	8	Female	Father	Tertiary
C07*	ID	6	Female	Mother	Basic literacy
C08*	Autism	5	Male	Mother	Secondary
C09*	ID	7	Female	Mother	Secondary
C10	GDD	3	Male	Mother	No education
C11	ID	2	Female	Mother	No education
C12	ID	4	Male	Mother	No education
C13	GDD	3	Male	Mother	No education
C14	ID	5	Female	Mother	Secondary
C15	ID	3	Female	Mother	Secondary
C16	ID	5	Female	Mother	No education
C17	ID	10	Male	Mother	No education
C18	ASD	6	Male	Father	No education
C19	ID + CP	12	Female	Father	No education

Note: ID = intellectual disability, CP = Cerebral Palsy, ASD = Autism Spectrum Disorder, GDD=Global developmental delay, *Participants from the pre-pilot study

Framework analysis findings

In this section, the findings are presented under the three themes identified for framework analysis: 1) programme content; 2) programme facilitation, and 3) CST training approach and delivery. Illustrative quotes are marked as C (for caregivers), LF (for lead facilitators) and AF (for assistant facilitators).

Table 2.5: Framework finding presentation

Themes	Sub-themes	Codes
1. Programme content	i. Acceptability and relevance	
	ii. Complexity of concepts	
	iii. Contextual appropriateness	a. Clarity of illustrations b. Availability of toys c. Homework
	iv. Overall programme perception	
2. Programme facilitation	i. Acceptability of non-specialist facilitators to caregivers ii. Support and Supervision	
3. CST training approach and delivery	i. Feasibility of CST in the local context	
	ii. Programme delivery structure	a. Group sessions b. Home visits

Programme content

The programme content theme included four sub-themes. These sub-themes were as follows:

- Acceptability and relevance of CST for the context
- Complexity of concepts
- Contextual appropriateness, and
- Overall programme perception

Acceptability and relevance

Several caregivers described the programme as relevant for their circumstances because it helped them address their children's needs. They reported that the programme dealt with issues specifically caused by their child's problem, such as challenging behaviour and poor caregiver wellbeing. Caregivers often noted that they found the CST relevant for their children and themselves, as captured below:

> "In all sincerity, CST is very valuable not because I was compensated [for transport costs], but I left all my work to come here at that time so that I wouldn't miss it." (C03)

Another participant also emphasised that she had wished it was available in her area before joining the CST programme:

> "It [CST] was something that I had always wanted; it is just something that is available in larger cities only." (C01)

Facilitators also described the programme as relevant to the community and themselves, even for those with physical comorbidities:

> "The programme is excellent. It has even shown me things clearly on problems I did not know before as a professional." (AF-02)

> "The training is also relevant for those with physical disabilities. Although the physical disability cannot be reversed, the cognitive delay can be improved by this training. We witnessed that." (AF-06)

Participants further remarked that the programme was acceptable and appropriate for their culture. Caregivers specifically mentioned that the content was highly relevant to their lives. They could not identify any aspect that was redundant or not applicable to their needs:

> "I cried after I learned about the stories [in the booklet]. Like in one of the stories in the booklet [the booklet participants receive as part of each group session], my son cries every day in the afternoon. It is the same." (C18)

> "The feeling, the stress, crying, fear in the story [in the training], all are related to me." (C16)

Facilitators also emphasised that the training content was acceptable overall. However, in addition, they commented on the hesitation of certain caregivers to accept some content or activities, such as playing with the children. The concept of a caregiver playing with their child, rather than children playing amongst themselves, was unfamiliar for many caregivers. For instance, one lead facilitator said:

> "Sitting on the floor and playing with the child took them a long time to accept and practise." (LF-01)

Participants demonstrated a positive attitude regarding the programme and its potential benefits. For example, one participant highlighted the way his family members were happy about it and offered the following comments:

> "I am very happy. My wife and her mother are also happy with this programme. My wife and I both read the manual after I went home from this training. We will do the five-minute practice together and later at night she will do it again; this is a big step for us. We have enjoyed the programme." (C06)

Participants also indicated their interest in future use. Caregivers indicated that they would like to continue the programme and recommended follow-up training for the sustainability of benefits. Facilitators also expressed interest in participating in a similar programme in the future:

> "It is beneficial, I have enjoyed it a lot, and I wish this could continue in the future." (C06)
> "Since I have seen good outcomes while doing this job, I would like to continue this programme and help them." (LF-01)

Complexity of concepts

Caregivers indicated that most of the concepts in the training manual were clear to them:

> "For me the lessons are very clear, there isn't a part that you would hate or want to take out; I think it is easy to understand." (C02)

In contrast to the caregiver reports, however, non-specialist facilitators indicated that some concepts and techniques were difficult to understand and to explain to caregivers and required extra practice and time. For example, the concept that children may engage in different levels of play, from simple play to advanced pretend play, was difficult for both facilitators and caregivers:

> "It is difficult for them to identify and increase the level of their children's play. Some of the parents do not even know their children's level of play." (LF-02)

Facilitators commented that despite the apparent interest in practising the home routine activities in the training manual, some parents struggled to understand how to set small clear steps in their daily routines:

> "Sometimes activities [home routines] like setting teachable small steps of washing the dishes is complex for the participant." (AF-02)

Facilitators found the need to tailor some content to meet the participants' different literacy levels. They reported that the concepts were time-consuming to explain to parents and for themselves to understand:

> "We were working in a community where most of them are not educated. Due to the individual illiteracy, they were not able to understand easily what we try to train them." (AF-01)

Contextual appropriateness

Under this sub-theme, findings regarding the clarity of the illustrations, availability of toys, and homework practice are discussed.

Clarity of illustrations

Firstly, facilitators emphasised the overall value of the illustrations in the caregiver manual and how they helped them to train caregivers with no education:

> "Most of the time, caregivers understand the illustrations. I think a caregivers' booklet should have illustrations that account for more than 75 per cent of its content." (AF-08)

Additionally, the illustrations helped the facilitators to elaborate when the caregivers experienced difficulty understanding the discussion. However, the facilitators also commented that some illustrations from the participant booklet were unclear and incompatible with a rural setting. For example:

> "The illustrations did not represent the context. Most people do not have tap water access, and in the manual, it says "by opening the water tap". It would have been nice if that could have been substituted with a "water jug". Therefore, I think the illustrations should be modified so that they reflect the actual living conditions of society." (AF-01)

Availability of toys

Facilitators indicated that some toys or materials listed in the booklet were unavailable to families. For instance, the facilitators were fond of demonstrating particular care principals by using a toy cup for the child and the family. However, caregivers did not have the toys to practice and were afraid to practise with an actual cup in case it got broken:

> "The child shows an interest in playing, but the materials are unavailable. The families might not have any toys for the child to play with. This problem was seen in many households." (AF-07).

Another facilitator gave an example of how challenging it was for caregivers to get toys:

> "For example, one of the activities we showed them can be performed with puppets ordered on the shelf, but caregivers won't get them." (AF-06)

> "In some cases, the children cried or refused to return the demonstration toy. The caregivers don't have any animal toys to give." (AF-07)

Homework

Caregivers reported that the homework allowed them to understand the material and gave them the opportunity to practice with other family members. However, despite these reported benefits, there were some challenges. For instance, one complaint was that there was a lack of time to complete homework and a lack of family support:

> "I could not practise [the homework] as we planned. We have a high workload which never ends." (C19)

Facilitators also described how difficult it was for caregivers to complete their homework practice between sessions due to busy home schedules:

> "When they [caregivers] were asked as to why they did not do it [homework] they said we were busy." (AF-02)

Overall programme perception

Caregivers emphasised how the programme helped them to understand their child's problems and improve their skills to support their child. Facilitators highlighted having acquired new knowledge and skills relating to developmental disabilities.

Caregivers also commented on specific behavioural changes in their children that were based on the CST strategies, such as their child's increased capacity to communicate and help themselves; their increased engagement; and an increased capacity to control their own behaviour:

> "My son couldn't ask for water and food before the training. Based on my training, I taught him how to ask for what he needs. It helped both my son and myself." (C15)

Another participant said:

> "During the training, every single thing was new to me. I had no idea what I was doing, and I gained a lot of new knowledge and skills." (C19)

Facilitators also described how their understanding improved after taking part in CST, and how they benefited:

> "The training taught me more about neurodevelopmental disorder and delay than I had learned while at university." (AF-03)

Programme facilitation

The programme facilitation theme included two sub-themes:

- Addressing the acceptability of having non-specialists facilitate the programme, and
- The ongoing support and supervision of facilitators by master trainers.

Acceptability of non-specialist facilitators to caregivers

Caregivers described that facilitation by non-specialists as acceptable. Indeed, they expressed that using local non-specialists was essential to ensure that caregivers who were more comfortable speaking local languages could participate. Caregivers described the facilitators as being knowledgeable about the content, skills and resources needed to support their children. Several participants described facilitators as "excellent" [እጅግ በጣም ጥሩ] and reported that they made the training enjoyable. They also appreciated the facilitators' patience, compassion, and the way they interacted with the caregivers and family:

> "There is nothing difficult to understand and even for those who can't read they are teaching us very well." (C06)

Another caregiver described how the facilitators took time to explain the content:

> "The trainers were excellent. I don't even have words to explain. There were different behaviours [in the booklet] [and] they took the time to explain to us. They made us feel free to tell what was on our minds." (C16)

One of the caregivers also stated that she was happy with how the non-specialist facilitators handled difficult issues during CST group sessions:

> "The facilitators are extremely patient; there are some participants who don't understand things easily, and they ask unrelated questions. Trainers explain things in more detail and gently encourage caregivers to return to the topic of discussion. That is very good behaviour of the trainers, and I look at it with much respect." (C14)

Support and supervision

The facilitators emphasised the importance of supervision in the programme. They particularly valued feedback received from the supervisors and highlighted the need for discussion with the supervisor at the end of each session. Having a supervisor with whom they could consult, together with additional teaching from the supervisor in response to their emerging needs, was viewed as essential by the non-specialist facilitators:

> "It is very important that we have people who supervise us. For instance, if there is something we are unclear about, we talk to them at the end when they asked if there were any challenges we encountered while delivering the training. Therefore, it is essential to have those who supervise us." (LF-02)

Generally, facilitators identified that they struggled to comprehend some of the CST concepts in their early days of training, but their understanding improved after further practice and training. One of the facilitators said they were well equipped for the second round of CST groups after participating in the pre pilot:

> "Due to the fact that the challenges we faced during the first round of training did not exist during the second round and that we were more familiar with the training materials allowed for more time to prepare for the training." (LF-01)

CST training approach and delivery

Results under this theme focused on two sub-themes:

- The feasibility of CST in the local context, including perspectives on training modalities, and
- The structure of programme delivery, including training.

Feasibility of CST in the local context

Participants indicated that the training modalities, including the three individual home visits and nine sessions delivered to groups of caregivers, were acceptable and feasible in the local context:

> "Both sections, the support they have given us during the home visit and the programme here is very helpful and convenient; it is not something that has any problem." (C05)

However, some caregivers reported barriers to attending the group sessions on time, including transportation, family responsibilities and childcare:

> "I arrived late, I was sweaty, I have walked to the hospital, which is far from my home on foot. Since there is no *bajaj* [a three-wheel motorbike], the moment I arrive here, I am sweaty, and I miss the section about behaviour." (C01)

Despite some challenges, the facilitators also agreed that CST was doable in their context. For example, one lead facilitator said:

> "Most of the time, or I should say all of the time, we did not experience difficulty. We were able to conduct the training without any problems." (LF-02)

Programme delivery structure

Group sessions

All caregivers described the group setting as beneficial and stated that they enjoyed the social support. Multiple caregivers highlighted one particular benefit of the group sessions:

> "Having met other caregivers made me realise that I'm not the only one dealing with this issue." (C07)

Despite this benefit, one caregiver said she had difficulty adjusting to being in a group in the early training days. She indicated that the non-specialist facilitators helped her cope with it:

> "I was scared of learning with others and talking about things in front of people. They [the facilitators] helped me to be able to sit in the group setting while I took the training." (C15)

Facilitators also emphasised the benefits of the group sessions. An assistant facilitator said:

> "By participating in the group, they had an opportunity to share their experiences." (AF-06)

Home visits

Caregivers described that the home visits helped them to understand what they could do for their child and allowed demonstration of CST strategies in the natural environment of the child and caregivers:

> "I have learned a lot from the lesson they gave us by coming to our home. I am happy about the home visit. I have observed several changes in my child because of their lesson by coming up to our home.'' (C07)

Another caregiver raised the issue of timing of visits and her distress when her facilitator arrived for the home visit much earlier than she expected:

> "It was once the case that they came earlier than I expected them to, in the time we scheduled. I should prepare myself in the time we agreed to; if you just drop by at any time, I may not be able to express myself clearly." (C01)

Generally, facilitators described that the home visit was acceptable, helpful and that caregivers were accommodating. The facilitators observed that the caregivers felt more comfortable expressing themselves in their homes compared to in group settings:

> "Parents might have questions they were not comfortable asking during group sessions. When we visit their home, we will give them the chance to ask those questions and also review for them some of the topics they had difficulty understanding." (LF-02)

Despite the general positive perception of home visits by facilitators, they did raise the challenge of travelling long distances to families' homes and the absence of caregivers during the visits despite the scheduled appointment:

> "In this town, the houses are scattered and far from each other, so we have to walk long distances to do home visits." (AF-01)

Discussion

This study explored the acceptability and feasibility of non-specialist delivery of the WHO-CST programme in rural Ethiopia from the perspectives of caregivers and non-specialist facilitators. The findings show that the adapted and non-specialist delivered CST programme was valuable and perceived to be both relevant and useful by caregivers and facilitators. Furthermore, the programme was found to be culturally acceptable and largely feasible but needed several contextual adaptations to be appropriate for a rural Ethiopian context.

All participants reported that the training gave them new insights, with caregivers reporting that CST helped to increase their understanding of their child's condition and improved their capacity to manage. This gave caregivers hope and encouragement to implement the strategies they were learning during the programme. Facilitators also commented on how caregivers noticed a positive change in their children throughout their participation in the training. Caregivers likewise commented on specific behavioural changes in their children based on the CST strategies, such as their children’s increased capacity to communicate, help themselves, be more engaged and control their behaviour. These descriptions of perceived benefits are in line with reports from participants in CST when delivered by specialists in a clinical setting in Addis Ababa (Tekola et al., 2020a). Similarly, a study from an Indian urban setting reported the acceptability and feasibility of non-specialist delivered the WHO-CST programme (Sengupta et al., 2021). Other existing reports have also noted the benefits of parenting programmes in improving parental knowledge and skills (Dawson-Squibb et al., 2020); understanding and managing challenging behaviour in children (Karst & Van Hecke, 2012); managing caregiver stress (Stewart-Brown et al., 2004), and reducing social isolation (Barlow & Stewart-Brown, 2001). Tekola and colleagues also found that WHO-CST had a positive effect and helped the caregivers to look after their psychological wellbeing in urban Ethiopian context (Tekola,2020). Several studies indicated that exchanging ideas with others and feeling safe to talk was important for parenting programme participants (Cutress & Muncer, 2014; O'Donovan et al., 2019; Todd et al., 2010; Toure et al., 2020). Adding to the insights of these previous investigations, this study indicated that some caregivers in a rural Ethiopian context may need extra encouragement and support to feel comfortable in group sessions.

In general, home visits and group sessions were deemed to be acceptable and feasible in rural Ethiopia, but with some practical challenges reported by participants (such as travel time and the busy schedule of caregivers). These findings speak to the challenges and barriers to implementation of the WHO CST programme and are consistent with previous CST studies in Ethiopia and Italy (Salomone et al., 2021; Tekola et al., 2020a). Other studies of alternative parenting programmes have also identified similar barriers (Koerting et al., 2013; Mytton et al., 2014; Pickard et al., 2019; Straiton et al., 2021; Tekola et al., 2020a). Interestingly, our finding that caregivers struggled to fit in the time to practise at home contrasted with findings in Italy where participation in home practice was good. In that study, the authors found that the ability to keep the child engaged was aided by additional support, which helped caregivers to adhere to home practice regimes (Salomone et al., 2021).

Some of the challenges reported in this study were partially reported by the previous Ethiopian CST study and not at all by studies from other settings, such as the lack of toys in homes (Salomone et al., 2021; Tekola et al., 2020a). It is worth noting that Ethiopian children tend to play with ordinary objects found within their household environment (Berhanu, 2006), rather than with 'toys'. The initial adaptation of the WHO-CST to an Ethiopian context (outlined in Tekola et al., 2020) already included more emphasis on household items and items in the natural environment (such as sticks and leaves) than the original WHO-CST materials. The present study suggests that these adaptations are even more important in the rural Ethiopian context, where resources are scarce and children are very unlikely to have toys per se.

A more fundamental challenge was the culturally alien concept of a caregiver playing with a child. In Ethiopia, play between parent and child is uncommon and not typically thought of as an opportunity for parent-child interaction or learning (Metaferia et al., 2021). There are a number of sayings and proverbs that illustrate this cultural norm, such as, "ከልጅ አትጫወት ይወጋሃል በእንጨት" ["Do not play with children, otherwise they will pierce you with a stick"]. The findings of this study are in line with those of the WHO-CST in Italy, where the cultural beliefs of traditional parent-child interaction do not facilitate application of the concept of teaching children through play (Salomone et al., 2021). In the current study, the facilitators reported that caregivers did try to play, even when initially hesitant, but a more culturally consonant approach may be to adapt CST to focus on the daily routines where caregiver and child naturally interact rather than imposing the requirement to play.

Participants made various suggestions to improve the programme, and most of these were similar to findings identified in earlier CST studies (Salomone et al., 2021; Tekola et al., 2020a). Facilitators also recommended ways to improve CST, such as making illustrations more contextually meaningful, including more illustrations in caregiver manuals, and simplifying roleplays and concepts. Facilitators also emphasised the importance of ongoing support and supervision.

Delivering the CST programme in a setting with low literacy, low awareness, no other child mental health services, high levels of stigma (Tekola et al., 2020b), common beliefs that a child with a NDD is unable to learn, and high expectations of a cure, brings extra challenges (Tekola et al., 2020a). In the present study, fewer than half of the participants were literate, and only one caregiver had been educated beyond high school. This is reflective of the rural context in which the study was conducted and is representative for much of Ethiopia outside the urban areas. In these contexts, CST programmes require an increased focus on psychoeducation and the simplification of participant booklets, including more illustrations and discussing concepts orally rather than in writing. This finding can serve as a model for future sustainable and scalable services for children with developmental disabilities in rural LMIC contexts.

Limitations and strengths of the study

We acknowledge various limitations affecting the scope and breadth of the current study and the analysis of the findings. First, the possibility of socially desirable responses is a real challenge in most low-resource contexts, including in Ethiopia. We acknowledge that participants may have been more likely to evaluate any programme positively when no other services were available. However, to reduce this possibility, we included strategies, such as employing an experienced qualitative study researcher independent of the CST facilitating team, who established a good rapport and encouraged participants to give their honest opinions about the programme.

Secondly, caregivers were interviewed at different stages of completion of the CST, i.e., after CST group session six in pre-pilot study and after completing the full nine programme sessions in the pilot RCT. This was considered during the analysis but may have affected some of their responses. The facilitators were interviewed at two different time points as care givers this helps to get their perspective after more work experience in facilitating the CST for the second time. This could also be considered a strength, as this study was able to capture their perspectives during different points in their training journey.

Finally, the primary author of this research who analysed the data was also the supervisor and the master trainer of the programme. This may therefore have biased her interpretation of the data. To mitigate against this potential bias in the data analysis, all data were collected by an independent researcher and we included a researcher who had not participated in programme adaptation and implementation in the analysis as a second coder. All themes were discussed and agreed upon with the second coder, and continuous dialogue between all authors was maintained throughout the process.

A strength of this study is the unique perspective provided on implementing an intervention for families with children with NDD in rural very low-income contexts, where the majority of caregivers have low-levels of literacy. Autism intervention research is heavily skewed towards Western, HICs (de Vries, 2016; Durkin et al., 2015), with over-representation of parents with higher socio-economic status and education. However, the majority of the global population of children with autism and other NDD live in LMIC (Olusanya et al., 2018), and many of the caregivers caring for these children have limited levels of education. This study provides unique insights in how to support families in these contexts of very high unmet need.

Conclusions

In this study, we found that the adapted and non-specialist delivered WHO-CST programme was of great value in a rural Ethiopian context, as it was perceived to be relevant and useful, culturally acceptable, and generally feasible. However, the adapted CST did require several contextual adaptations, as well as a simplification of programme content and delivery in order to be made more appropriate. A key insight was that the regular supervision of non-specialist providers was an essential ingredient when rolling out the WHO-CST in rural East Africa. These findings suggest that the CST programme has the potential to be scaled up for families of children with NDD in Ethiopia and in other similar LMIC. Additional studies evaluating effectiveness, alternative delivery and supervision models, and integration of CST into existing health care systems will also be important.

We hope that these results may be useful for informing the implementation of non-specialist delivery of the CST programme, with special consideration for the regional and cultural diversity of LMIC.

Acknowledgements

The authors are very grateful for the contribution of caregivers and non-specialist facilitators for participation in this study. Additionally, we would like to acknowledge members of the WHO-CST team and Autism Speaks for technical support.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the primary research, The Ethiopian WHO CST study was funded by Autism Speaks (#9817) and joint funding from the Medical Research Council (MRC) (United Kingdom), Department for International Development (DFID), Wellcome Trust and National Institute for Health Research (NIHR) (#MR/P020844/1). There was no direct funding of this secondary study.

References

Barlow, J., & Stewart-Brown, S. (2001). Understanding parenting programmes: parents' views. *Primary Health Care Research & Development, 2*(2), 117-130.

Berhanu, G. (2006). Parenting (parental attitude), child development, and modalities of parent-child interactions: sayings, proverbs, and maxims of Ethiopian Jews in Israel. *Journal of Cognitive Education and Psychology, 5*(3), 266-287.

Black, M. M., Walker, S. P., Fernald, L. C., Andersen, C. T., DiGirolamo, A. M., Lu, C., ... & Fink, G. (2017). Advancing Early Childhood Development: from Science to Scale 1 Early childhood development coming of age: science through the life course. *Lancet*, *389*, 77-90.

Bryman, A., & Burgess, R. G. (1994). *Analyzing Qualitative Data* (Vol. 11): Routledge London.

Cutress, A. L., & Muncer, S. J. (2014). Parents' views of the national autistic society's earlybird plus programme. *Autism, 18*(6), 651-657.

Damiano, D., & Forssberg, H. (2019). Poor data produce poor models: children with developmental disabilities deserve better. *The Lancet Global Health, 7*(2), e188-e188.

Dawson-Squibb, J.-J., Davids, E. L., Harrison, A. J., Molony, M. A., & de Vries, P. J. (2020). Parent Education and Training for autism spectrum disorders: Scoping the evidence. *Autism, 24*(1), 7-25.

de Vries, P. J. (2016). Thinking globally to meet local needs: autism spectrum disorders in Africa and other low-resource environments. *Current Opinion in Neurology, 29*(2), 130-136.

Dendir, Z., & Simane, B. (2019). Livelihood vulnerability to climate variability and change in different agroecological zones of Gurage Administrative zone, Ethiopia. *Progress in Disaster Science, 3*, 100035-100035.

Esponda, G. M., Hartman, S., Qureshi, O., Sadler, E., Cohen, A., & Kakuma, R. (2020). Barriers and facilitators of mental health programmes in primary care in low-income and middle-income countries. *The Lancet Psychiatry, 7*(1), 78-92.

Franz, L., Chambers, N., von Isenburg, M., & de Vries, P. (2017). Autism spectrum disorder in sub-saharan africa: A comprehensive scoping review. *Autism Research, 10*(5), 723-749.

Galvin, M., & Byansi, W. (2020). A Systematic Review of Task Shifting for Mental Health in Sub-Saharan Africa. *International Journal of Mental Health*, 1-25.

Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child And Family Psychology Review, 15*(3), 247-277.

Koerting, J., Smith, E., Knowles, M., Latter, S., Elsey, H., McCann, D., et al. (2013). Barriers to, and facilitators of, parenting programmes for childhood behaviour problems: a qualitative synthesis of studies of parents' and professionals' perceptions. *European Child & Adolescent Psychiatry, 22*(11), 653-670.

Lord, C., Charman, T., Havdahl, A., Carbone, P., Anagnostou, E., Boyd, B., et al. (2021). The Lancet Commission on the future of care and clinical research in autism. *The Lancet*.

Mendenhall, E., De Silva, M. J., Hanlon, C., Petersen, I., Shidhaye, R., Jordans, M., et al. (2014). Acceptability and feasibility of using non-specialist health workers to deliver mental health care: stakeholder perceptions from the PRIME district sites in Ethiopia, India, Nepal, South Africa, and Uganda. *Social Science & Medicine, 118*, 33-42.

Metaferia, B. K., Futo, J., & Takacs, Z. K. (2021). Parents' Views on Play and the Goal of Early Childhood Education in Relation to Children's Home Activity and Executive Functions: A Cross-Cultural Investigation. *Frontiers in Psychology, 12*.

Mytton, J., Ingram, J., Manns, S., & Thomas, J. (2014). Facilitators and barriers to engagement in parenting programs: a qualitative systematic review. *Health Education & Behavior, 41*(2), 127-137.

O'Donovan, K. L., Armitage, S., Featherstone, J., McQuillin, L., Longley, S., & Pollard, N. (2019). Group-based parent training interventions for parents of children with autism Spectrum disorders: A literature review. *Review Journal of Autism and Developmental Disorders, 6*(1), 85-95.

Olusanya, B. O., Davis, A. C., Wertlieb, D., Boo, N.-Y., Nair, M., Halpern, R., et al. (2018). Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Global Health, 6*(10), e1100-e1121.

Olusanya, B. O., Wright, S. M., Nair, M. K. C., Boo, N.-Y., Halpern, R., Kuper, H., et al. (2020). Global Burden of Childhood Epilepsy, Intellectual Disability, and Sensory Impairments. *Pediatrics, 146*(1), e20192623-e20192623.

Pickard, K., Rowless, S., & Ingersoll, B. (2019). Understanding the impact of adaptations to a parent-mediated intervention on parents' ratings of perceived barriers, program attributes, and intent to use. *Autism, 23*(2), 338-349.

QSR. (2018). NVivo (Version 12). Retrieved from https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home on January 2 2022

Salomone, E., Ferrante, C., Salandin, A., Ferrara, F., Torchio, E., Foletti, G., ... & Servili, C. (2021). Acceptability and feasibility of the World Health Organization's caregiver skills training implemented in the Italian national health system. *Autism*, *26*(4), 859-874.

Salomone, 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*, 769-769.

Salomone, E., Reichow, B., Pacione, L., Shire, S., Shih, A., & Servili, C. (2018). Training caregivers to transform children's lives. *Early Childhood Matters, 127*, 74-77.

Sengupta, K., Shah, H., Ghosh, S., Sanghvi, D., Mahadik, S., Dani, A., et al. (2021). World Health Organisation-Caregiver Skills Training (WHO-CST) Program: Feasibility of Delivery by Non-Specialist Providers in Real-world Urban Settings in India. *Journal of Autism and Developmental Disorders*, 1-18.

Stewart-Brown, S., Patterson, J., Mockford, C., Barlow, J., Klimes, I., & Pyper, C. (2004). Impact of a general practice based group parenting programme: quantitative and qualitative results from a controlled trial at 12 months. *Archives of Disease in Childhood, 89*(6), 519-525.

Straiton, D., Groom, B., & Ingersoll, B. (2021). A mixed methods exploration of community providers' perceived barriers and facilitators to the use of parent training with Medicaid-enrolled clients with autism. *Autism*, *25*(5), 1368-1381.

Tekola, B., Girma, F., Kinfe, M., Abdurahman, R., Tesfaye, M., Yenus, Z., et al. (2020a). 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.

Tekola, B., Kinfe, M., Girma, F., Hanlon, C., & Hoekstra, R. A. (2020b). Perceptions and experiences of stigma among parents of children with developmental disorders in Ethiopia: A qualitative study. *Social Science & Medicine, 256*, 113034-113034.

Todd, S., Bromley, J., Ioannou, K., Harrison, J., Mellor, C., Taylor, E., et al. (2010). Using group-based parent training interventions with parents of children with disabilities: A description of process, content and outcomes in clinical practice. *Child and Adolescent Mental Health, 15*(3), 171-175.

Toure, D. M., Wani, R. J., Do, K., & Su, D. (2020). Exploring African American and Latino populations perceptions of parenting education programs: A qualitative assessment of enablers and barriers. *Journal of Social Service Research, 46*(2), 256-263.

United Nations Population Fund. (2020, October 2020). World Population Dashboard :Ethiopia Retrieved from https://www.unfpa.org/data/world-population/ET

World Helath Organization. (2017). World Health Organization World mental health atlas 2017 member state profile: ETHIOPIA. Retrieved from https://www.who.int/mental_health/evidence/atlas/mental_health_atlas_2017/en/ on on Decemebr 22 2022

World Health Organization . (2018). Training parents to transform children's lives. Retrieved from https://www.who.int/mental_health/maternal-child/PST/en/ December 22 2022

Appendices

Appendix 1 Information sheet

Testing skills training for caregivers of a child who develops slowly

We would like to invite you to participate in our research project. This study is a collaboration between researchers from Addis Ababa University (Drs Abebaw Fekadu, Charlotte Hanlon, Fikirte Girma and Henrikje Klasen) and 'King's College London in the United Kingdom (Drs Rosa Hoekstra and Bethlehem Tekola). You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is essential for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully or have the information read out to you and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the research project?

The World Health Organization recently developed a training package for caregivers of a child who develops slowly. The training aims to help caregivers to understand their ' 'child's problems better and to teach caregivers skills to support their child in their development. The training was developed by an international group of experts and has not yet been used in Ethiopia.

We want to test the training programme in Ethiopia, to find out whether the training is suitable for the Ethiopian setting and meets the needs of local families. Based on the study findings, the programme may be adapted to suit the needs of Ethiopian families. The results from this study will also be feedback to the World Health Organization so that it can inform the adaptation and implementation of the programme in other countries.

Why have I been invited to take part in this study?

We are inviting a group of caregivers, whom each has a child who is developing slowly, to take part in this project.

Do I have to take part?

Participation is voluntary. You do not have to take part. You should read this information sheet and if you have any questions, you should ask the research team.

What will happen if I agree to take part?

If you decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. You will be invited to attend nine training sessions at the health centre in Sodo. The sessions will be led by local experts (explicitly trained to lead this programme) and will be attended by a group of 6-10 caregivers whom all have a child with problems developing slowly. The sessions will be held weekly, and each session will last approximately 2-3 hours. During these group sessions, you will learn more about the condition of your child. There is no cure for your ' 'child's condition. But in this training, you will learn skills to help you support your child in their communication, learning and development and to address behavioural difficulties. The sessions also provide an opportunity to exchange experiences with other caregivers if you wish to do so. You are asked to come to each session by yourself, without your child if possible. You will be reimbursed for the costs of travelling to the health centre. Throughout the training, you will be given exercises to try out at home with your child. In order to get the most out of the training, you will be asked to spend some time during the week to try out these exercises with your child.

In addition to the group sessions one of the trainers will visit you and your child three times: once before the first group session, once before the fifth group session, and once after the final group session. It is probably easiest for these visits to take place in your home, but we can also agree on another location convenient to you. The first home visit is made so that the trainer has a good understanding of the main problems and needs facing you, your child and your family, and to set training goals specific to your 'family's needs. The second and third home visit are intended to evaluate progress and to identify any additional needs and problems.

During the nine group sessions and the three home visits you will be asked for your feedback: what did you think of the quality of the training session, and how relevant was the session to you and your family? Throughout the programme we would also like to ask you more detailed questions about yourself, your child and your experiences with the programme. A data collector will meet you at a location and time convenient to you four times during the programme: once before the programme starts, once midway the programme, once after the final session and once 2 months after the last sessions. These interviews are conducted by an independent data collector (not one of the programme facilitators), so that you can speak freely about your thoughts of the programme. There are no right or wrong answers to any of the questions asked. All questions will be asked through an interview. The data collector will record your answers on a record sheet. The data collector will also ask your permission to make a video recording of you and your child while you are doing an activity together. We would like to use the video recording in our research to study the impact of the training. However, if you are not agreeable to the video being recorded then you are free to say so, this will not affect your eligibility to take part in the programme. During one of the interviews the interviewer will ask you more detailed feedback about the programme. During this interview we will ask for your permission for the interview to be recorded with a tape recorder so that the interviewer can remember all of the information. However, if you prefer the interview not to be audio recorded, then you are free to say so.

Will other people be able to identify me from the information I give you?

All the feedback that you give us and the information you provide about yourself and your child during interviews will be regarded as strictly confidential and will be held securely and only accessed by the researchers working on this project. We will write down your feedback notes using a code number instead of your name so that only the research team will know that this information comes from you. The code and your name will be kept in a separate, locked cupboard. We will make sure that the audio and videotapes do not include your name. The tapes will be kept in a locked cupboard. Once the interview audiotapes have been written down, and the data has been analysed, the audiotapes will be cleared. The videotapes will include footage of you and your child, so will identify you and your child. We will make sure these data are kept confidential, by ensuring that the videotape data is encrypted and password protected and does not include any further personal information from you (e.g. your name or where you live).

During the training sessions with other caregivers of children who develop slowly, you may wish to exchange experiences about your lives. We ask everyone who takes part in the group sessions not to share any of the stories told by caregivers to anyone outside the group.

What are the possible benefits and risks of taking part?

We hope that taking part in the training programme will be helpful to you. The programme was developed to support caregivers like you, to equip you with confidence and skills to support your child and help you to better understand your child.

A disadvantage for you is that participation in the programme will take time: around 2-3 hours each week to attend the group sessions, a further hour during each of the three home visits, and up to an hour and a half each time you meet with the data collector. Moreover, it will take some time to practise what you learned during the training at home with your child.

We also recognise that you may find it distressing at times to discuss your ' 'child's difficulties. The aim of the programme is to provide you with support, both from the expert who leads the programme sessions, as well as mutual support provided by other caregivers, who may experience similar difficulties. However, should you wish to withdraw from the programme then you are free to do so at any time.

What happens if I decide not to take part in this study?

Your participation in this study is entirely voluntary. Choosing not to take part in this study will not disadvantage you in any way.

Even after the training programme has started, you are free to stop taking part at any time, without providing us with an explanation. If you wish to withdraw from the study, please contact the researchers as described below. We can destroy the data you have provided us with if you instruct us to do so. You can withdraw from the study up until the data are analysed (up to March 31, 2018).

What will happen to the results of the study?

The results of this study will provide us with necessary information on the suitability of the training for Ethiopian caregivers of a child who develops slowly. Based on your feedback, the programme may be adapted further to suit the needs of Ethiopian families. The results from this study will also be fed back to the World Health Organization so that it can inform the adaptation and implementation of the programme in other countries.

We will also present our findings to other researchers. All results will be presented without giving any personal details about you, so other researchers will not be able to identify you.

Who has reviewed the study?

The ethics protocol of this study has been reviewed and approved by the Institutional Review Board of the College of Health Sciences of Addis Ababa University and by the Psychiatry, Nursing and Midwifery (PNM) Research Ethics Subcommittee (RESC) at King's College London.

How is the study being funded?

This research is funded by Autism Speaks, a charity and advocacy organisation from the USA.

I have some more questions about the research. Whom can I speak to?

Please contact [researcher name] on [telephone number] or email [email address].

If you would like to talk to someone else about this project, or you wish to make a complaint about the conduct of the study, you can contact the Institutional Review Board of the College of Health Sciences of Addis Ababa University [telephone number].

If this study has harmed, you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information:

The Chair, Psychiatry, Nursing and Midwifery (PNM) Research Ethics Subcommittee (RESC) at King's College London, rec@kcl.ac.uk.

Thank you for reading this.

Appendix 2: consent form for participants in research studies

Study phase 1: Consent form for participants in interview study potential beneficiaries ' 'WHO's Parent Skills Training (caregivers of a child with a developmental disorder)

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: Developing a training programme for caregivers of a child who develops slowly: An interview study

'King's College Research Ethics Committee Ref:(RESCM-18/19-34)

Addis Ababa University IRB Ref:(062/16/ Psy)

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialling each box I am consenting to this element of the study. ☐

I understand that it will be assumed that unticked/initialled boxes mean that I DO NOT consent to that part of the study.☐

I understand that by not giving consent for any one element I may be deemed ineligible for the study.☐

I confirm that I have read and understood the information sheet dated [INSERT DATE AND VERSION NUMBER] for the above study. I have had the opportunity to consider the information and asked questions which have been answered satisfactorily.☐

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. Furthermore, I understand that I will be able to withdraw my data up to December 31, 2016.☐

I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 1998 and Ethiopian data protection rules.☐

I understand that my information may be subject to review by responsible individuals from Addis Ababa University or 'King's College London for monitoring and audit purposes. ☐

I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications. ☐

I agree to be contacted in the future by Addis Ababa University or 'King's College London researchers who would like to invite me to participate in follow up studies to this project, or in future studies of a similar nature. ☐

I agree that the research team may use my data for future research and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. (In such cases, as with this project, data would not be identifiable in any report). ☐

I agree that the information that I provide can be used for educational or primary/ secondary research purposes, including publication. In these publications, my confidentiality and anonymity will be maintained and it will not be possible to

identify me. ☐

I consent to my interview being audio recorded and transcribed. ☐

I understand that if I have any questions, I can contact the study researchers at the telephone number 021 406 6338 ☐

___________________ __________________ ____________

Name of Participant Date Signature

Witness Statement (in event that participant is not literate):

I ____

agree that the research project named above has been explained to

_______________________________ (participant) to his/her satisfaction and that s/he agrees to take part in the study. Both the notes written above and the Information Sheet about the project have been read to him/her, and s/he understands what the research study involves.

___________________ ___________________

Date Signature

Appendix 3 Information sheet for CST Non-specialist facilitators

Your experiences delivering a training programme for caregivers of a child who develops slowly: An interview study

We would like to invite you to participate in our research project. This study is a collaboration between researchers from Addis Ababa University (Drs Abebaw Fekadu, Charlotte Hanlon, Fikirte Girma and Henrikje Klasen) and King's College London in the United Kingdom (Drs Rosa Hoekstra and Bethlehem Tekola). You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully or have the information read out to you, and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the research project?

We would like to learn about your experiences delivering the parent skills training programme for caregivers of children who develop slowly. We would like to hear from you which parts of the programme worked well in your opinion and which parts could be improved. We would also like to hear if you experienced any challenges in delivering the programme and would be grateful for any suggested revisions you may have.

The results from this study will inform the further adaptation of the training programme, to tailor it to the needs of the Ethiopian setting. The results from this study will also be fed back to the World Health Organization, so that it can inform the adaptation and implementation of the programme in other countries.

Why have I been invited to take part in this study?

We are inviting all facilitators and observers of the parent skills training programme to learn about their experiences delivering the training.

Do I have to take part?

Participation is voluntary. You do not have to take part. You should read this information sheet and if you have any questions, you should ask the research team.

What will happen if I agree to take part?

If you decide to take part you will be given this information sheet to keep and will be asked to sign a consent form. The study interviewer will then discuss the interview procedure with you and will arrange for the interview to take place in a quiet place so that you can speak freely. The interviewer will ask you a range of questions, including some brief questions about your background, and then more detailed questions about your experiences delivering the parent skills training. There are no right or wrong answers to any of the questions asked. We are genuinely interested in your thoughts on the programme and welcome any comments you may have. Please feel free to share your concerns or less positive experiences, as these will help us to improve the programme.

The interview will take approximately one hour. While the interview takes place, we will be recording what is said with a tape recorder so that we can remember all of the information. We will later write down what is on the tape.

Will other people be able to identify me from the information I give you?

What is said during the interview will be regarded as strictly confidential and will be held securely. We will make sure that the audio tapes do not include your name or identifying information. The tapes will be kept in a locked cupboard. Once the interview tapes have been written down, and the data has been analysed, the tapes will be cleared. On the written material we will use a code number instead of your name so that only the research team will know that this information comes from you. The code and your name will be kept in a separate, locked cupboard.

When we write up the results of this study we will endeavour that quotes are not identifyable. However, given that this is a small study there is a possibility for a person to work out who is likely to have given a particular quote. By default, all results will be presented without giving any personal details about you, so other people will not be able to identify you. However, if you wish you can give your consent to be identified. If you do so we can explicitly attribute your contributions to you when we write up the results of this study. It is your choice whether you prefer to remain anonymous or be identified; you can indicate your preference on the consent form.

What are the possible benefits and risks of taking part?

The information we receive form participants in this study will help us in adapting the training package developed by the World Health Organization, so that the training is appropriate for Ethiopian families and feasible to conduct in the Ethiopian setting.

There are no foreseeable risks in participating in this study.

The main disadvantage for you is that it will take around an hour of your time to take part. You will be recompensed for any travel costs associated with participating in this interview.

What happens if I decide not to take part in this interview?

Your participation in this study is entirely voluntary. Choosing not to take part in this interview will not disadvantage you in any way. Even after the interview has started, you are free to stop taking part at any time, without providing us with an explanation. If you wish to withdraw from the study, please contact the researchers as described below. We can destroy the data you have provided us with if you instruct us to do so. You can withdraw from the study up until the data are analysed (up to 31 October 2017 / 31 March 2018*).

What will happen to the results of the study?

Based on the information that you and other programme facilitators give us, we will adapt the original training package developed by the World Health Organization further. We will also present our findings to other researchers.

Who has reviewed the study?

The ethics protocol of this study has been reviewed and approved by the Institutional Review Board of the College of Health Sciences of Addis Ababa University and by the Psychiatry, Nursing and Midwifery (PNM) Research Ethics Subcommittee (RESC) at King's College London.

How is the study being funded?

This research is funded by Autism Speaks, a charity and advocacy organisation from the USA.

I have some more questions about the research. Who can I speak to?

Please contact [researcher name] on [telephone number] or email [email address].

If you would like to talk to someone else about this project, or you wish to make a complaint about the conduct of the study, you can contact the Institutional Review Board of the College of Health Sciences of Addis Ababa University [telephone number].

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information:

The Chair, Psychiatry, Nursing and Midwifery (PNM) Research Ethics Subcommittee (RESC) at King's College London, rec@kcl.ac.uk.

Thank you for reading this.

*31 October 2017 for interviews in phase 3, 31 March 2018 for interviews in phase 4.

Appendix 4 Consent form for CST Non-Specialist facilitators

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: Your experiences delivering a training programme for caregivers of a child who develops slowly: An interview study

'King's College Research Ethics Committee Ref: (RESCM-18/19-34)

Addis Ababa University IRB Ref: (062/16/ Psy)

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialling each box I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element I may be deemed ineligible for the study.

☐I confirm that I have read and understood the information sheet dated [INSERT DATE AND VERSION NUMBER] for the above study. I have had the opportunity to consider the information and asked questions which have been answered satisfactorily.

☐I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. Furthermore, I understand that I will be able to withdraw my data up to 31 October 2017/31 March 2018.

☐I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 1998 and Ethiopian data protection rules.

*31 October 2017 for interviews in phase 3, 31 March 2018 for interviews in phase 4.

☐I understand that my information may be subject to review by responsible individuals from Addis Ababa University or King's College London for monitoring and audit purposes.

Anonymity is optional for this research. Please select from the following 3 options:

I agree to be fully identified ☐

I agree to be partially identified ☐

I wish to remain anonymous ☐

I agree to be contacted in the future by Addis Ababa University or King's College London researchers who would like to invite me to participate in follow up studies to this project, or in future studies of a similar nature.

I agree that the research team may use my data for future research and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. (In such cases, as with this project, data would only be identifiable in any report if I consent to be identified under point 5 abo☐

I agree that the information that I provide can be used for educational or research purposes, including publication. In these publications, my confidentiality and anonymity will be maintained and it will not be possible to identify me.☐

I consent to my interview being audio recorded.☐

I understand that if I have any questions, I can contact the study researchers at the telephone number [xx] ☐

____________________	_______________	___________________
Name of Participant	Date	Signature

Appendix 5 Interview guides

Interview guides for Caregivers

Introduction to the interview: I am a psychologist from Addis Ababa, and I heard about the 'Caregiver's Skills Training programme. The colleagues from Butajira/Soddo told me that you have already participated in the programme and I would be very interested in knowing how it is, what was good and what 'didn't work well.

Warm-up questions

' 'Let's first talk about your daily life here. Can you briefly introduce your family: who is living with you?

Can you talk about the community you are living in?

Can you tell me about one of your days, for example yesterday? What did you do and how was it?

Perceptions of the child

You recently took part in the CST programme. Can you tell me about your child? What are his or her strength and difficulties?

Before joining the CST programme, how did you live with your child? What did you try to do to help your child?

Can you tell me about your other children, how do they see your child developing slowly?

Can you tell me about other family members, how do they see your child developing slowly?

During intervention

' 'Let's talk a bit about how the intervention took place. What did you expect from a programme like CST?

You recently took part in the CST programme. Can you tell me what happened during the programme?

Was there something in the programme that you had known before or had been doing before?

Was there something particularly interesting or surprising during the intervention?

Was there something you had not heard about before?

Was there something that you felt was not relevant to you or to your child? Something that was not useful?

What did you think of the facilitators who delivered the CST programme? What was your interaction like with him or her?

Were there any times when you felt upset or distressed by the groups? What was the reason for that? Were there times when you felt tired or bored?

What is your experience with meeting parents who have kids who develop similarly to your kid?

Do you continue to meet any of the other caregivers now that the CST programme has ended? If so, how do you keep in contact?

Following the intervention

Following the programme, you attended, how do you see your child?

Is there something that has changed since you took part in the intervention? If so, can you give examples?

Is there something you have started doing differently since the intervention?

Is there something you are doing differently from what the intervention suggested? Where did you get the idea for this? In what ways has this different approach helped?

Are there areas where you think the programme could have helped more?

Further needs

What else do you think you would need to help your child developing slowly?

What are your main concerns at the moment? What are your main concerns about your child now?

Who do you talk to about your child? What are these discussions about?

Are there any people outside of the intervention who you think could help you in some way? In what way could they help?

Focus group discussion guide for non-specialist Facilitators

A. Introduction

Focus group moderator to say his/her name and where they are from.

We are here to learn about your thoughts and experiences regarding the parent skills training programme for caregivers of children who develop slowly. This is the first time the programme was tested in rural villages in Ethiopia. We are keen to learn what went well and what we can further improve to better support families and help you in your role as facilitator.

While we are talking, we are recording what is said with this tape recorder so that we can remember all of the information. Everything we learn from our group discussion, as well as from the participating caregivers, will be put together so that we get a broad overview of the views and experiences, and this will inform the revisions we will make to the programme.

Group discussion rules:

- It is important that only one person speaks at a time.
- There are no right or wrong answers
- You do not have to speak in any particular order
- When you do have something to say, please do so.

- You do not have to agree with the views of other people in the group
- When speaking, please try use the number you have been assigned instead of using names, so that the audio recording does not include names.

B Introductory question

I am just going to give you a couple of minutes to think about your experiences delivering the parent skills training programme for caregivers of children who develop slowly. Is anyone happy to share his or her experience?

C Guiding questions

Can you tell me about your experiences with the programme? Were there any aspects that you found particularly good or aspects that did not work well?

[Prompt about difficult experiences with engaging participants, conducting home visits, facilitating any activity, making the programme relevant to the group of caregivers, how confident/competent they felt, time burden, emotional burden, handling expectations/requests (e.g., for money) of the caregivers]

I would like to ask you some more questions about the families who took part in your CST group sessions. What do you think these families need the most? How do you know?

How do you think these needs can be best met?

- To what extent do you think the CST helps meeting these needs?
- Are there other ways you think these needs could be met?

Let's now talk a bit about whether or not the programme was relevant to families. What is your experience with this? [prompt if not raised spontaneously: Were there occasions where you felt the programme was not relevant to a family? Are there other types of professionals you think could help meeting these needs?]

In the CST materials, there may be concepts introduced that are unfamiliar to the caregivers. Did you come across such a situation? If so, what was your experience?

Were there any concepts that caregivers found difficult to understand? Did you find any solutions to this?

Did you find any techniques that worked particularly well explaining new concepts to caregivers? Did you find any techniques that proved to be unhelpful?

Were there any tasks or activities during the programme that the caregivers found difficult to follow? Were there occasions where they didn't understand what they were supposed to do? Did you find any solutions to this?

What was your experience with setting homework activities for caregivers, and reviewing the homework in the next group session? Were any homework activities difficult for caregivers? How did you find reviewing the homework in the next session?

I would like to ask you some specific questions about the home visits.

- What do you think was most useful about the home visits?

- From all home visits you made, can you give an example of what you found most difficult? How did you deal with these?

Did you meet any children that had physical health problems in addition to their problems with developing slowly? [e.g., malnourished children, children with physical disabilities, children with epilepsy, etc].

– How did you respond to this? [e.g., referral, recommended caregiver to take child to health centre, etc, discuss case with supervisor, etc]

– For families of children with these additional physical health needs, what did you think of the relevance of the CST programme to them?

– What do you think about the CST programme in relation to the wider health system in your community? Do you have suggestions how to improve referral of children or parents with needs to health professionals?

You were part of the first group that has been trained as facilitators.

Can you tell me about your experience with the facilitator training? Do you have recommendations in how the training can be improved?

How did you find the supervision sessions with your supervisor?

A) [for FGD with lead facilitators only]:

- How did you find leading the CST group sessions?
- What did you find particularly challenging?
- How can future facilitator training help in supporting you in these challenges?
- If the CST were implemented in your community, would you consider continuing the role as facilitator? What would be your considerations in taking on this job?

B) [for FGD with assistant facilitators only]:

- How did you find assisting the CST group sessions?
- How did you find the collaboration with the lead facilitator?
- What should any future facilitator training focus on to help you in this role?
- If the CST were implemented in your community, would you consider continuing the role as facilitator? What would be your considerations in taking on this job?

Is there anything else you would like to share?

Thank you for participating

Appendix 6 Demographic Questionnaire

Demographic and service history information sheet

Family ID________________ Participant ID: ____________________

Date: ______________[Ethiopian calendar]

We would now like to ask you some questions about you and your child who develops slowly. This information will be shared with the facilitators who will be leading your training, so that they have a good understanding of your personal circumstances and the difficulties that you might face.

What is your gender? Male/Female

What age are you now? _________ years

Date of Birth (if known) [ ]

How much formal education have you received?

No formal education [ ] Completed grade [ ] [ ]

What is your marital status?

Married [ ] Single [ ]

Divorced[ ] Widowed [ ]

Do you live in a rural or urban area?

Rural [ ] Urban [ ]

Do you practise a religion?

No religion [ ] Orthodox Christian [ ]

Catholic [ ] Protestant [ ]

Muslim [ ] Other (please specify):_______________

What is your occupation?

Housewife [ ] Government employee [ ]

Student [ ] Private employee [ ]

Unemployed [ ] Trader [ ]

Farmer [ ] Other (please specify):_______________

What is your relationship to the child who has problems with development we will be talking about today?

Mother [ ] Grandmother [ ]

Father [ ] Grandfather [ ]

Brother [ ] Aunt [ ]

Sister [ ] Uncle [ ]

Other (please specify): _____________________________________

Do you live with the child? Yes [ ]

No [ ]

How old is the child with problems with development?

________years ___________months

Is this child a boy or a girl? Boy [ ]

Girl [ ]

What is the main language spoken in the home of the child?

Amharic	[ ]	Tigrinya	[ ]
Oromo	[ ]	English	[ ]

Other (please specify):____________________

How many children do you have? [ ]

Do any of your other children have developmental problems? Yes [ ]

No [ ]

If yes, please give details about their problems:

Please describe the main difficulties of your child

____

____

Does your child have a formal diagnosis? If so, what is the diagnosis? [tick all that apply]

Intellectual disability	[ ]	ADHD	[ ]
Autism	[ ]	conduct disorder	[ ]

Other (please specify): ___________________

How old was your child when you first noticed that she/he may have some difficulties?

_____________years ___________months

If child has a formal diagnosis:

How old was your child when the formal diagnosis was made?

_____________years ___________months

Has your child ever received support and/or medication from a health professional?

Please give details [on medication and who prescribed medication]

____

____

Has your child ever received support or treatment from anyone else?

[probe: behavioural support, education support, traditional treatments]

Please give details [on treatment and provider]

____

____

What do you think is the most likely cause of your ' 'child's problems with slow development? [caregiver can list as many causes as they feel are relevant]

1. _______________________________________

2. ____

Topic guide for focus group discussion with assistant or lead CST facilitators in RCT pilot

Background information

[To be completed for each of the focus group discussion participants before the focus group discussion begins]

What is your gender? Male/Female

What age are you now? __________ years

Date of Birth (if known) [ ]

Today’s date [ ]

What are your educational qualifications?

____

What is your current profession? _______________________

How long have you been working in your current job role?

________months ___________years

What was your role during CST implementation?

Lead facilitator [ ]

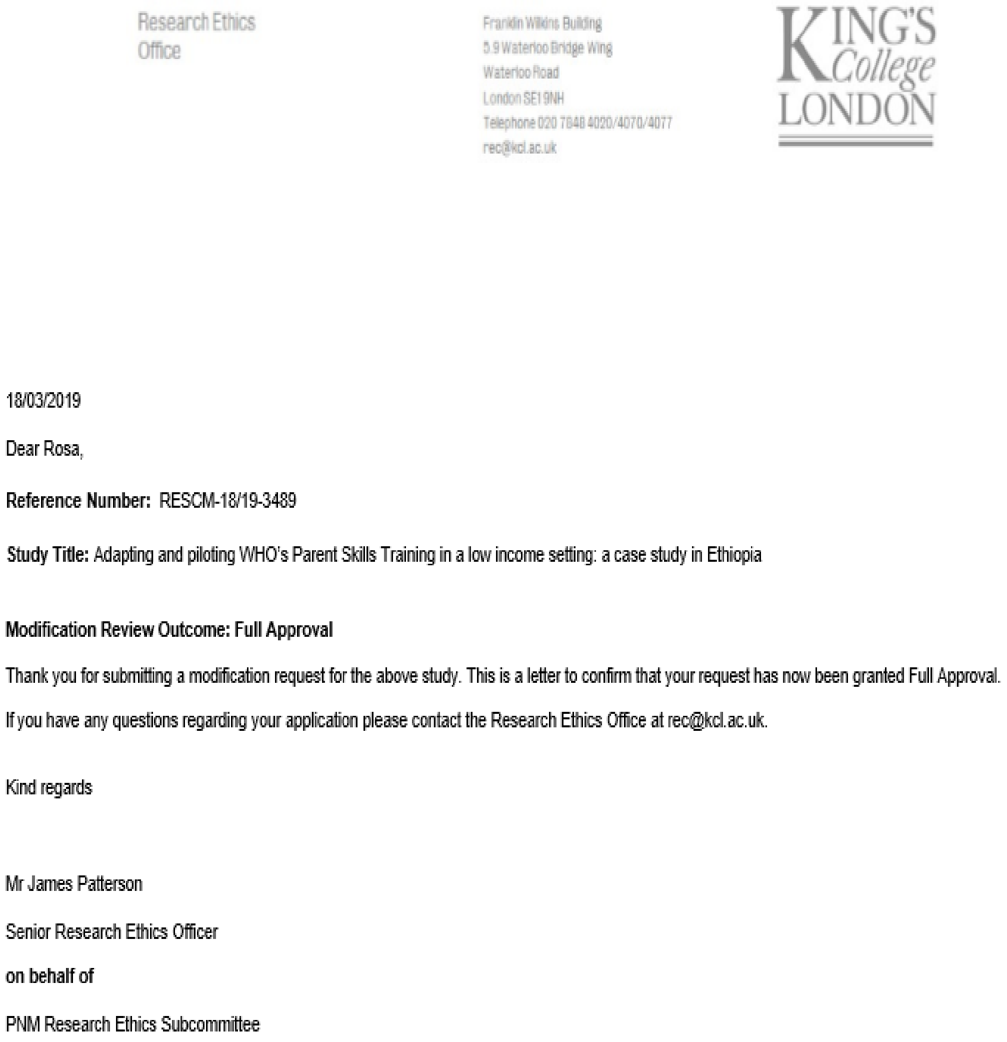
Assistant facilitator [ ]

Observer [ ]

Do you practise a religion?

No religion	[ ]	Orthodox Christian	[ ]
Catholic	[ ]	Protestant	[ ]
Muslim	[ ]	Other	__________

Appendix 7 ‘King's College Ethics Approval letter



Research Ethics
Office

Franklin Wilkins Building
5.9 Waterloo Bridge Wing
Waterloo Road
London SE1 9NH
Telephone 020 7848 4020/4070/4077
rec@kcl.ac.uk

18/03/2019

Dear Rosa,

Reference Number: RESCM-18/19-3489

Study Title: Adapting and piloting WHO's Parent Skills Training in a low income setting: a case study in Ethiopia

Modification Review Outcome: Full Approval

Thank you for submitting a modification request for the above study. This is a letter to confirm that your request has now been granted Full Approval.

If you have any questions regarding your application please contact the Research Ethics Office at rec@kcl.ac.uk.

Kind regards

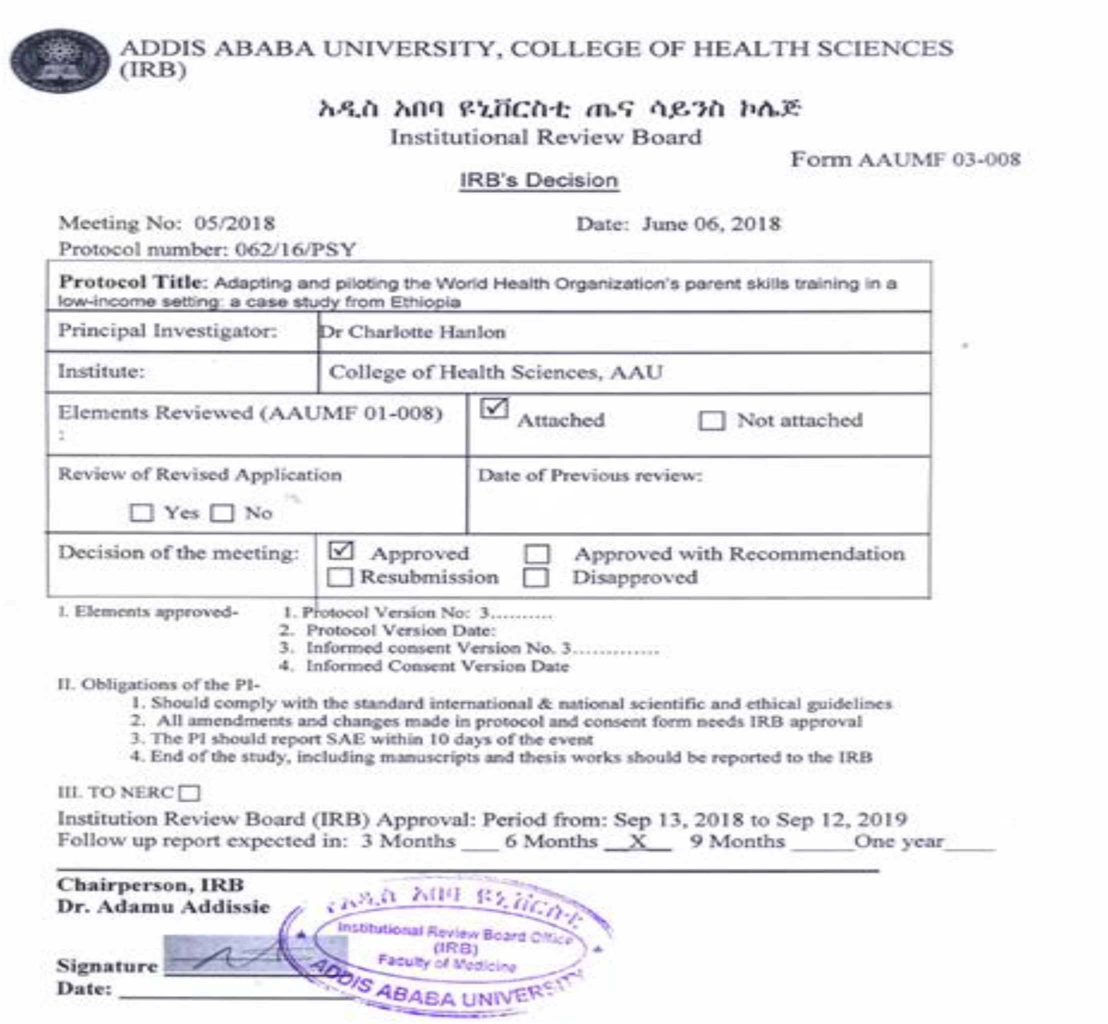
Mr James Patterson

Senior Research Ethics Officer

on behalf of

PNM Research Ethics Subcommittee

Appendix 8 Addis Ababa University Ethics Approval letter



ADDIS ABABA UNIVERSITY, COLLEGE OF HEALTH SCIENCES
(IRB)

አዲስ አበባ ዩኒቨርስቲ ጤና ሳይንስ ኮሌጅ
Institutional Review Board

Form AAUMF 03-008

IRB's Decision

Meeting No: 05/2018 Date: June 06, 2018
Protocol number: 062/16/PSY

Protocol Title: Adapting and piloting the World Health Organization's parent skills training in a low-income setting: a case study from Ethiopia	
Principal Investigator:	Dr Charlotte Hanlon
Institute:	College of Health Sciences, AAU
Elements Reviewed (AAUMF 01-008) :	☑ Attached ☐ Not attached
Review of Revised Application ☐ Yes ☐ No	Date of Previous review:
Decision of the meeting:	☑ Approved ☐ Approved with Recommendation ☐ Resubmission ☐ Disapproved

I. Elements approved-
1. Protocol Version No: 3..........
2. Protocol Version Date:
3. Informed consent Version No. 3.............
4. Informed Consent Version Date

II. Obligations of the PI-
1. Should comply with the standard international & national scientific and ethical guidelines
2. All amendments and changes made in protocol and consent form needs IRB approval
3. The PI should report SAE within 10 days of the event
4. End of the study, including manuscripts and thesis works should be reported to the IRB

III. TO NERC ☐

Institution Review Board (IRB) Approval: Period from: Sep 13, 2018 to Sep 12, 2019
Follow up report expected in: 3 Months ___ 6 Months __X__ 9 Months _____One year____

Chairperson, IRB
Dr. Adamu Addissie

Signature __________
Date: __________

Institutional Review Board Office
(IRB)
Faculty of Medicine

Appendix 9 University of Cape Town Ethics Approval

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room G50- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-enquiries@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

10 September 2021

HREC REF: 476/2021

Prof P de Vries
Division of Adolescent Psychiatry
Red Cross War Memorial Children's Hospital
Email: petrus.devires@uct.ac.za
Student: KBDTIG001@myuct.ac.za

Dear Prof de Vries

PROJECT TITLE: **STAKEHOLDER PERSPECTIVES ON THE ACCEPTABILITY AND FEASIBILITY OF THE WHO CAREGIVER SKILLS TRAINING PROGRAMME FOR NEURODEVELOPMENTAL DISORDERS WHEN DELIVERED BY NON-SPECIALISTS IN RURAL ETHIOPIA - A QUALITATIVE STUDY (MPHIL DEGREE – DR TIGIST ZERIHUN KEBEDE)**

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC) for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020: 06 July 2020 & 01 July 2021.

Approval is granted for one year until the 30 September 2022.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledge that the student: -Dr Tigist Kebede will also be involved in this study

Please quote the HREC REF 476/2021 in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

HREC/REF 476/2021sa

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Appendix 7 Letter of permission from the principal investigator of Ethiopia WHO CST programme (The primary study)

Research Ethics
Office

Franklin Wilkins Building
5.9 Waterloo Bridge Wing
Waterloo Road
London SE1 9NH
Telephone 020 7848 4020/4070/4077
rec@kcl.ac.uk

KING'S
College
LONDON

27/06/2019

Dear Rosa,

Reference Number: RESCM-18/19-3489

Study Title: Adapting and piloting WHO's Parent Skills Training in a low income setting: a case study in Ethiopia

Modification Review Outcome: Full Approval

Thank you for submitting a modification request for the above study. This is a letter to confirm that your request has now been granted Full Approval.

If you have any questions regarding your application please contact the Research Ethics Office at rec@kcl.ac.uk.

Kind regards

Mr James Patterson

Senior Research Ethics Officer

on behalf of

PNM Research Ethics Subcommittee

Manuscript Submission Guidelines: Autism: SAGE Journals

This Journal is a member of the Committee on Publication Ethics

Please read the guidelines below then visit the Journal's submission site http://mc.manuscriptcentral.com/autism to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of Autism will be reviewed.

There are no fees payable to submit or publish in this journal.

As part of the submission process, you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Autism, please ensure you have read the Aims & Scope.

1.2 Article Types

The Journal considers the following kinds of article for publication:

1. Research Reports. Full papers describing new empirical findings;
2. Review Articles

    (a) general reviews that provide a synthesis of an area of autism research;

    (b) critiques - focused and provocative reviews that may be followed by a number of invited commentaries, with a concluding reply from the main author.

Both full Research Reports and Review Articles are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract [**200 words maximum**], notes, tables, text), but excluding references. Editors may ask authors to make certain cuts before sending the article out for review.

3. Short Reports. Brief papers restricted to a maximum of 2,000 words with no more than two tables and 15 references. Short reports could include other approaches like discussions, new or controversial ideas, comments, perspectives, critiques, or preliminary findings. The title should begin with 'Short Report'.
4. Letters to the Editors. Readers' letters should address issues raised by published articles. The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 800 words, with no tables and a maximum of 5 references.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

Back to top

2. Editorial policies

2.1 Peer review policy

Autism operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard policy practice is for both identities to remain concealed. Each new submission is carefully read by one of the Editors to decide whether it has a reasonable chance of getting published. If the Editor thinks it does not have this chance, at least one other Editor will be consulted before finally deciding whether or not to send the manuscript out for review. *Autism* strives to do this within two weeks after submission, so that authors do not have to wait long for a rejection. Feedback is also provided on how to improve the manuscript, or what other journal would be more suitable. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within (e.g.) 6-8 weeks of submission.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

2.3.1 Third party submissions

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

-
- Disclose this type of editorial assistance – including the individual's name, company and level of input
- • Identify any entities that paid for this assistance
  • Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g., conflicting interests, funding, etc.

Where appropriate, SAGE reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

2.4 Funding

Autism requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Important note: If you have any concerns that the provision of this information may compromise your anonymity, you should withhold this information until you submit your final accepted manuscript.

2.4.1 National Institutes of Health (NIH) funded articles

If you have received NIH funding for your research, please state this in your submission and if your paper is accepted by *Autism* an electronic version of the paper will automatically be sent to be indexed with the National Library of Medicine's PubMed Central as stipulated in the NIH policy.

2.5 Declaration of conflicting interests

Autism encourages authors to include a declaration of any conflicting interests and recommends you review the good practice guidelines on the SAGE Journal Author Gateway. In particular, for working reporting on the development or evaluation of interventions the ICJME Conflict of Interest form provides an excellent template for considering a range of potential sources of conflict, and this can be uploaded and submitted with your manuscript if relevant.

Where an Editor of Autism is a lead or contributing author to a paper submitted to publication, the paper is always handled through the peer review process by another member of the Editor team and three reviews are obtained in each case. A statement is also published on each article where this occurs.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants

2.7 Clinical trials

Autism conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines

2.8.1 Transparent reporting of trials

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed CONSORT flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed PRISMA flow chart as a cited figure and the completed PRISMA checklist should be uploaded with your submission as a supplementary file. The EQUATOR wizard can help you identify the appropriate guideline.

The What Works Clearinghouse (WWC) guidelines should be followed when submitting in single-case design (SCD) and meet the standards outlined for internal validity of the SCD.

Other resources can be found at NLM’s Research Reporting Guidelines and Initiatives

2.8.2 Sample selection and demographic characteristics

Autism now requires authors to report the following information for all Research Reports (including systematic reviews):

i. procedures for sample selection and recruitment; and

ii. major demographic characteristics, including age, gender, race/ethnicity and socioeconomic status.

Including this information will provide greater clarity regarding sample characteristics and generalisability of the findings, even when such characteristics are not used in the analysis (although we encourage investigation of subgroup differences, where possible). It should also encourage researchers to consider the way in which context and culture contribute to their findings.

If authors are unable to report some or all of this information, its absence must be acknowledged with a clear statement of explanation (e.g., “specific data on socioeconomic status and educational attainment levels were not recorded”). Manuscripts that contain neither the required information nor an appropriate statement will be returned prior to consideration by the editors.

2.8.3 Community involvement

Autism encourages research that is actively carried out ‘with’ or ‘by’ members of the Autistic and autism communities (rather than ‘to’, ‘about’, or ‘for’ them), often referred to as ‘co-production’, ‘participatory research’, ‘patient and public involvement’ or ‘integrated knowledge translation’.

We therefore now require authors to include a community involvement statement at the end of the Methods section for Research Reports, outlining whether autistic people or family members, community providers, policy makers, agency leaders or other community stakeholders were involved in developing the research question, study design, measures, implementation, or interpretation and dissemination of the findings. Community members should be duly acknowledged – as authors or in the acknowledgements section – depending on the extent and nature of their contribution. We recommend that authors follow the BMJ’s editorial guidelines for documenting how community stakeholders were involved in their research.

If community members were not involved in the study, authors should state this.

For more details about the reasoning behind this journal requirement, and editorial expectations of authors, please download this FAQs document.

.

2.9 Data Policy Statement

Autism supports open research practices and FAIR principles. As such encourages authors to share their data wherever possible and submit their data (or a link to it) and where applicable, their syntax/command files for the analyses presented in the contribution. Authors can make data available through a third-party data repository or on the journal website as a supplementary data file.

If cited data is restricted (e.g., classified, require confidentiality protections, were obtained under a non-disclosure agreement, or have inherent logistical constraints), authors should notify the editor at the time of submission. The editor shall have full discretion to follow their journal's policy on restricted data, including declining to review the manuscript or granting an exemption with or without conditions. The editor shall inform the author of this decision prior to review.

Where data is sensitive and cannot be shared in an open forum, authors are encouraged to share metadata and provide a contact for requesting access if the raw data itself cannot be made available.

Data can be submitted with your article and hosted on the SAGE *Autism* website where we work with Figshare to host data content. Authors can use a recognised third-party data repository service to host their data such as Open Science framework. Authors may use their institution's data sharing repository.

Autism also encourages authors to delineate clearly the analytic procedures upon which their published claims rely, and where possible provide access to all relevant analytic materials. If such materials are not published with the article, we encourage authors to share to the greatest extent possible through a digital repository (above).

Autism encourages authors to use data citation practices that identify a dataset's author(s), title, date, version, and a persistent identifier. In sum, data should be referenced and cited, where possible, as an intellectual product of value.

Back to top

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International

Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

Autism and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor’s Publishing Agreement. SAGE’s Journal Contributor’s Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information, please visit the SAGE Author Gateway.

3.3 Open access and author archiving

Autism offers optional open access publishing via the SAGE Choice programme. For more information on Open Access publishing options at SAGE please visit SAGE Open Access. For information on funding body compliance, and depositing your article in repositories, please visit SAGE's Author Archiving and Re-Use Guidelines and Publishing Policies.

Back to top

4. Preparing your manuscript for submission

4.1 Formatting

Autism asks that authors use the APA style for formatting. The APA Guide for New Authors can be found on the APA website, as can more general advice for authors.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g., datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information, please refer to our guidelines on submitting supplementary files.

4.4 Terminology

4.4.1 Terminology about autism and autistic people

Autism has researched and produced its own guidance on terminology and language used in autism research. Please consult the guide here: autism terminology guidelines.

4.4.2 Language used to discuss race and ethnicity

Likewise, *Autism* has also produced the following guidance to be considered when writing about race and ethnicity. Please consult the guide here: race and ethnicity language guidelines.

4.5 Reference style

Autism adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

Back to top

5. Submitting your manuscript

Autism is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts.
Visit http://mc.manuscriptcentral.com/autism to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID iD to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID iD please follow this link to create one or visit our ORCID homepage to learn more.

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage, please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

5.3 Lay Abstracts

As part of your submission, you will be asked to provide a lay abstract of your article. Lay abstracts are a brief (max 250 words) description of the paper that is easily understandable. These abstracts will be made widely available (to the general public, and particularly to autistic people and their families). As such, lay abstracts should avoid both technical terminology and the reporting of statistics. Examples of lay abstracts are provided in recent issues of the journal.

Authors may consider the following questions when composing their lay abstract.

a. What is already known about the topic?
b. What this paper adds?
c. Implications for practice, research or policy

Authors may also find the following resources helpful on this topic:

- How to write a summary paragraph
- Self Advocacy Resource and Technical Assistance Center (SARTAC): Plain Language
- Center for Plain Language: **Error! Hyperlink reference not valid.**

5.4 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway

Back to top

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

6.3 Access to your published article

SAGE provides authors with online access to their final article.

6.4 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the Promote Your Article page on the Gateway for tips and advice.

Back to top

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Autism editorial office as follows:

Katie Maras
Department of Psychology
University of Bath, UK
Email: katiemaras.autism@gmail.com

\