



Implementing training in the home post COVID-19

The WHO Caregiver Skills Training
Programme for Families of
Children with Developmental
Disorders or Delays

Pamela Dixon, PhD, LP

Autism Speaks

pamela.dixon@autismspeaks.org





Common *Experiences* of Parents

- ***Denial***
 - “...his father would say...that is not my son, in our family we do not give birth to children like that”
- ***Guilt***
 - “we got married and we were expectant, and this is the baby we got. Sometimes I regret, I ask myself whether I did something wrong...”
- ***Disappointment***
 - “..they say I got an epileptic child and I will never benefit from her”
- ***Fear***
 - “I didn’t understand all of it because I was so scared”
- ***Stigma***
 - Someone used to shout at my son, Zolo! Do not play with my children...”
- ***Religious beliefs***
 - I still go to the pastors...even if I bring my son to hospital...they tell me he has demons...
 - “...my husband’s relatives have said a lot...they say I did something and I should know the cause of my son’s problem”





Comprehensive *mental health* action plan 2013–2020

SIXTY-SIXTH WORLD
HEALTH ASSEMBLY Agenda
item 13.3

WHA66.8 27 May 2013

- The vision of the action plan is a world in which mental health is valued and promoted and where persons affected by mental health disorders are able to exercise the full range of human rights and to access high-quality, culturally-appropriate health and social care in a timely way.
- Goal: to promote mental well-being, prevent mental disorders, provide care, enhance recovery, promote human rights and reduce the mortality, morbidity and disability for persons with mental disorders

Guiding principles:

- 1) Universal health coverage
- 2) Human rights
- 3) Evidence-based practice
- 4) Multisectoral approach;
- 5) Life-course approach;
- 6) Empowerment of persons with mental disorders.





Sixty-Seventh World Health Assembly

Agenda Item 13.4

WHA67.8 24 May 2014

Resolution on “Comprehensive and coordinated efforts for the *management of autism* spectrum disorders





mhGAP: Scaling up care



Mental Health Gap Action Programme

- Integrated packages of key evidence-based interventions
- Collaborative network of community-based services
- Promotes a life course approach
- Empowerment of users and families





mhGAP Intervention Guide

for mental, neurological and substance use disorders
in non-specialized health settings

Version 2.0






CMH 2 » Management

PROTOCOL

1


Developmental Delay/Disorder

- » Provide guidance on child/adolescent well-being. (2.1)
- » Provide psychoeducation to person and carers and parenting advice. Provide guidance on developmental disorders. (2.2 and 2.3) 
- » Provide carer support. (2.6)
- » Liaise with teachers and other school staff. (2.7)
- » Link with other available resources in the community such as Community-Based Rehabilitation.
- » Offer Parent Skills Training, when available. (2.8)
- » Refer children with developmental disorders to specialist for further assessment, advice on management plan and family planning. 
- » Ensure appropriate follow-up every three months or more, if needed. 

PROTOCOL

2

Problems with Behaviour

- » Provide guidance on child/adolescent well-being. (2.1)
- » Provide guidance on improving behaviour. (2.3)
- » Assess for and manage stressors, reduce stress and strengthen social supports.
- » Liaise with teachers and other school staff. (2.7)
- » Link with other available resources in the community.
- » Offer follow-up. 

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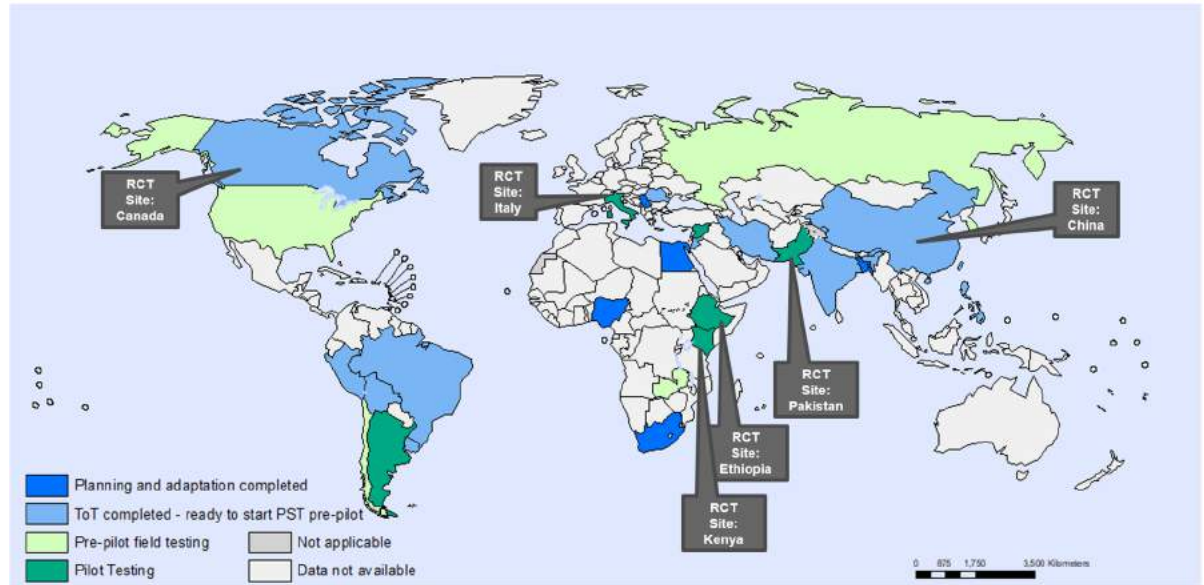
“Offer Parent Skills Training, when available”



Sites in Africa: Kenya, Ethiopia,
Zambia, Egypt, South Africa, Uganda

Field trials and *implementation* sites/2020 N=30

Field trials and implementation sites



The boundaries and names shown and the designations used on this map do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate border lines for which there may not yet be full agreement.

Data Source: World Health Organization
Map Production: Information Evidence and Research (IER)
World Health Organization



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CST Target *population*

- Caregivers of children 2–9 years of age with a developmental delay or developmental disorder
 - *A diagnosis is not required*
 - *Age range can be slightly adapted in settings*
- Referred by primary health care providers, community health workers or specialists





Characteristics of the *Programme*

- Can be delivered by non-specialists
 - Contributes to capacity building
- Can be adapted for use in low resource settings
- Effective
 - Based on evidence based practices
 - 6 RCT sites
- Freely available
- Integrated into existing services





Format and *setting*

- 9 Group sessions at health facility level, community level, or in schools (2 -2.5 hours each, weekly or biweekly) OR via telehealth

AND

- 3 Individual sessions in caregivers' homes, (90 minutes each)





Programme content

- Behavioural approaches for promoting shared engagement and communication e.g.:
 - JASPER (Joint Attention Symbolic Play Engagement Regulation)
 - PRT (Pivotal Response Treatment) – behavioural intervention
 - DTT (Discrete Trial Training) – method of teaching in simplified and structured steps
- Positive parenting approaches for promoting positive child behaviour/management of challenging behaviour
- Problem solving
- Promotion of caregiver well-being





Group Sessions & Home Visits

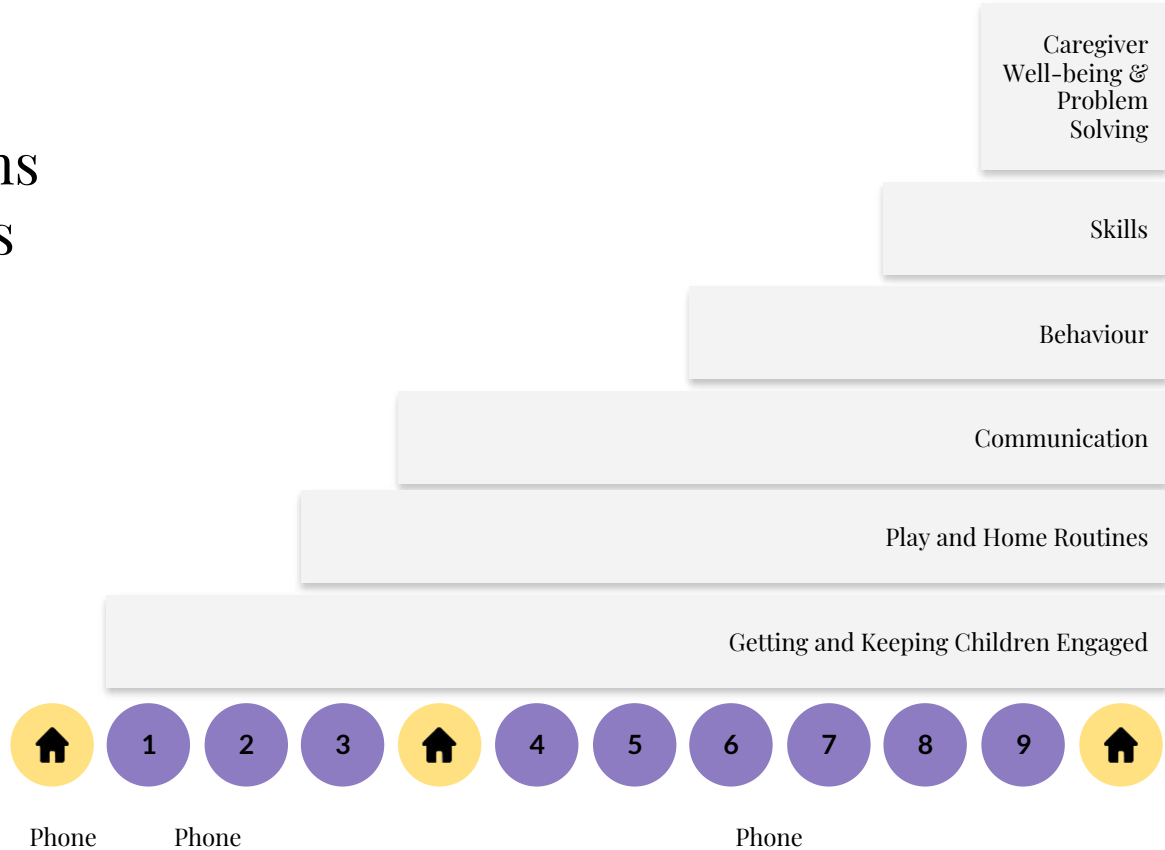


Home visit



Group session

Home visit 2 can be done
between Session 3
and Session 4 or 5





Expected *Outcomes*

- Progress toward caregiver's goals for their child
- Improved child joint engagement, communication and behaviours
- Improved caregivers' wellbeing and improved family functioning
- We expect the program will contribute to reducing stigma in communities



Session *booklet*

Key Message #1

Children communicate using words, behaviour without words, and challenging behaviour

Children may use challenging behaviour to communicate when other ways of communicating are difficult

These are ways children communicate:



WORDS: Clear words, unclear words or something that sounds similar to a word, like "ca" for "cat"



ODD WORDS: Repetitive sounds words or phrases, echoed words, repetition of words and phrases heard from videos or books



SOUNDS Crying, yelling, whining, sounds that means "yes" or "no", etc.



Training Structure

Training of Master
Trainers and
Supervisors

Training of
Facilitators

CST programme

WHO/AS Trainers

Master Trainers

Facilitators

Caregivers





Selection criteria for *master trainers* and *supervisors*

- Suggested minimum education requirement is formal training in child development or mental health at the post-secondary level or equivalent
 - Trained non-specialist primary health care providers e.g. general doctors, nurses
 - Specialized health care providers e.g. paediatricians, psychiatrists, psychologists, mental health nurses
- Clinical or simply past personal experience with children with developmental disorders.
- They are considered ‘specialists’.





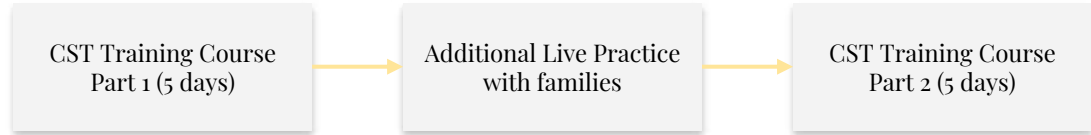
Selection criteria for *facilitators*

- Previous experience with children with developmental disorders, and possibly experience with early childhood development programmes and mhGAP.
- The programme can be delivered by teams with diverse set of skills and educational backgrounds (nurses, teachers, social workers, community health workers and peer caregivers)
- Teams should be well recognized and accepted by the community.





Training of *Master* Trainers



- 2 5-day training sessions or 1 5-day training session + online coaching
- Overview of key programme content and strategies
- Practice core strategies with child and caregiver participants
- Practice delivering programme content and coaching other trainees





Programme *Implementation* Toolkit

Facilitator guides

Participant booklets

Adaptation and Implementation guide

Monitoring & Evaluation framework

Training and supervision materials

Planning guide

New eLearning version





Parent Comments about *CST*

being together with your friends is nice because in situations where you tell yourself, “I am really suffering with this child”, when you get there your friends have more complications than yours or your situation is more complicated, but because of the others you will know that you are not alone, there are others, and that encourages you...

also for me the training helped me because I used to think that a child with a disability, cannot do anything, I used to do everything for them. Bathing... like almost everything. But when I was taught I knew that a person with disability can help themselves to do so many things...Training really helped. I am grateful.

we know that it is not witchcraft, it's God's plan... so we are happy about the skills and we would like that because there are many out there in marginalised areas who are suffering that they are also able to access the education.





Thank you

CST Team

Chiara Servili
(servilic@who.int)

Laura Pacione

Erica Salomone

Andy Shih

Stephanie Shire

Jilly Chang

Cecilia Montiel-Nava

Pamela Dixon
(pamela.dixon@autismspeaks.org)

WHO Regional Offices



+ teams in 30 countries

With support from Autism Speaks

