Empowering families who live with disabilities in Africa – South African experience with the WHO Caregiver Skills Training Programme (WHO CST)

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Parenting/Caregiver Programmes

Typically developing children and their families

Parent/caregiver Education & Training Programmes (PET)
Facilitators and caregivers only

Children with specific needs e.g. those with developmental delays, disorders, mental health problems

Parent/caregiver mediated Training interventions (PMT)
Facilitator (coach), caregiver and child
Programmes in CARA

- **EarlyBird/EarlyBirdPlus** (Autism-specific PET; group-based; UK)
- **COMPASS** (Autism-specific, group; local)
- **Autism Navigator** (Autism-specific; web-based; USA)
- **Early Start Denver Model** (Autism-specific PMT; cascaded task-sharing; local adaptation)
- **WHO Caregiver Skills Training** (Disability; group; global)

Schlebusch et al., IACAPAP Monograph, 2020
Evidence-based scientific discoveries lead to people who need them.

Image courtesy of Dr Liezl Schlebusch

Damschroder (2019).
Cultural, linguistic diversity
Stigma
Beliefs about disability
Child-rearing practices
Play
Help-seeking behaviour
Limited/broken systems of care
WHO Caregiver Skills Training Programme (WHO-CST Programme)

**Main programme:**
12-sessions focus on training caregiver skills to promote child development (Salomone et al., 2019)

**Optional:**
3-session caregiver well-being module (Brown & Servili)

3 sessions, trained facilitators, group of caregivers, once a week for three weeks (2-3 hours)
Scope of WHO Caregiver Skills Training (CST)

For whom
Caregivers of children aged 2–9 years who have developmental delays or disabilities
Specific focus on caregivers of children with delays or impairments in social and communication domains

Aims
• Increase caregivers’ skills to promote their children’s development and well-being through joint engagement in play and home routines.

Slide courtesy of Dr Chiara Servili
Scope of WHO Caregiver Skills Training (CST)

**Trainers**

Supervised non-specialists:
- community health workers
- social service workers
- nurses
- ECD facilitators
- teachers
- peer caregivers

Slide courtesy of Dr Chiara Servili
Evidence-informed CST Strategies

- Appropriate and affectively rich learning environments
- Active and balanced role of caregiver
- Environmental arrangement
- Behavioural instructional strategies

Evidence based on:
- NDBI
- ABA
- Positive Parenting

Slide courtesy of Dr Chiara Servili
Caregiver skills

- Follow their child’s lead, interest or choice
- Involve their child more often in daily activities
- Turn-taking to help their child stay engaged
- Respond to child’s attempts and effort with praise and attention
- Respond and expand their child’s communication
- Slide courtesy of Dr Chiara Servili
Structure and contents

9 Group sessions

3 Home visits

Engaging children in everyday activities and games

Understanding and promoting children’s communication

Understanding behaviour and helping the child show more positive behaviour

Teaching skills for everyday life

Caregiver wellbeing & problem-solving

Slide courtesy of Dr Chiara Servili
CST ‘Packages’

- Self-directed eLearning for caregivers
- Based on WHO CST skills and strategies
- Total 8 hours, self-paced
- Low bandwidth required, suitable for mobile devices
- Currently being translated in Arabic, Chinese, French, Russian and Spanish
- It can be used also to support hybrid delivery of CST
Figure 1. The five goals of the Diamond Families Study

- **Intervention**: To determine the effectiveness of the WHO CST intervention in real-world settings in South Africa
- **Implementation**: To plan, prepare, and evaluate the implementation of the WHO CST intervention in South Africa
- **Context**: To evaluate contextual factors and to have an in-depth understanding of the WHO CST end-users in South Africa
- **Multi-stakeholder approach**: To include key stakeholders in all study phases
- **Pragmatic & Practical**: To use systems and materials that would typically be feasible under general conditions

* Evidence-based intervention
* Designed for scalability and sustainability
* Findings readily translatable to communities
Figure 9. Summary of the data collection procedures
Lessons from South Africa
1. Partnerships between academia, non-profit and government sectors can work and is essential for scalability and sustainability of interventions, but...
2. Task-sharing with non-specialists is possible, but...

Schlebusch et al. (2020), de Vries (2016)
3. The Non-Profit Sector (and other non-governmental sectors) may be powerful implementation partners, but...
4. We can train and supervise online, even in Africa, but...

Kumm, Viljoen & de Vries, 2021
5. It is not all about caregiver knowledge and skills...

- Caregiver competencies (knowledge and skills)

versus

- Caregiver capacity
Findings from the WHO CST Wellbeing Module adapted and delivered via ZOOM

Image courtesy of Dr Liezl Schlebusch
FIG. 2  Key areas to consider for establishing sustainable and scalable early ASD intervention services in resource-limited settings.
Thank you!