



# 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

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

Parent/caregiver Education & Training Programmes (PET)

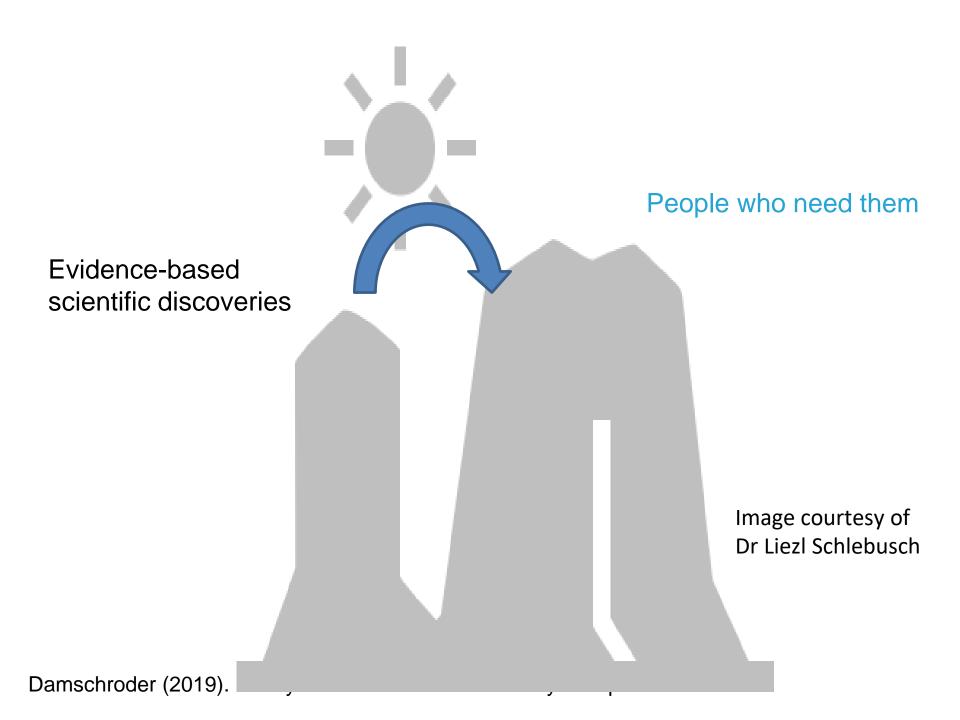
Facilitators and caregivers only

Parent/caregiver mediated Training interventions (PMT)

Facilitator (coach), caregiver and child

### Programmes in CARA

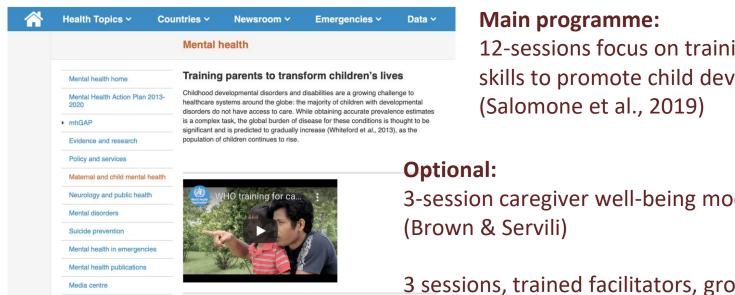
- EarlyBird/EarlyBirdPlus (Autism-specific PET; group-based; UK)
- COMPASS (Autism-specific, group; local)
- Autism Navigator (Autism-specific; webbased; USA)
- Early Start Denver Model (Autism-specific PMT; cascaded task-sharing; local adaptation)
- WHO Caregiver Skills Training (Disability; group;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



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)





12-sessions focus on training caregiver skills to promote child development

3-session caregiver well-being module

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.





## Scope of WHO Caregiver Skills Training (CST)

#### **Trainers**

Supervised non-specialists:

community health workers

social service workers

nurses

**ECD** facilitators

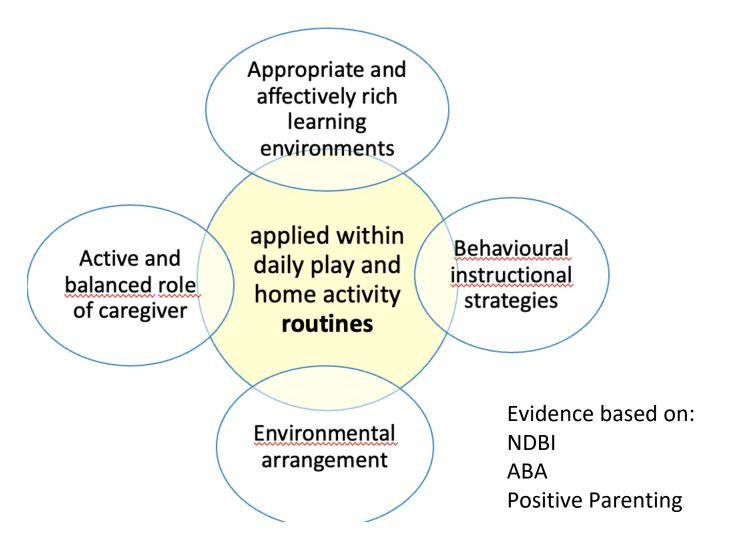
teachers

peer caregivers



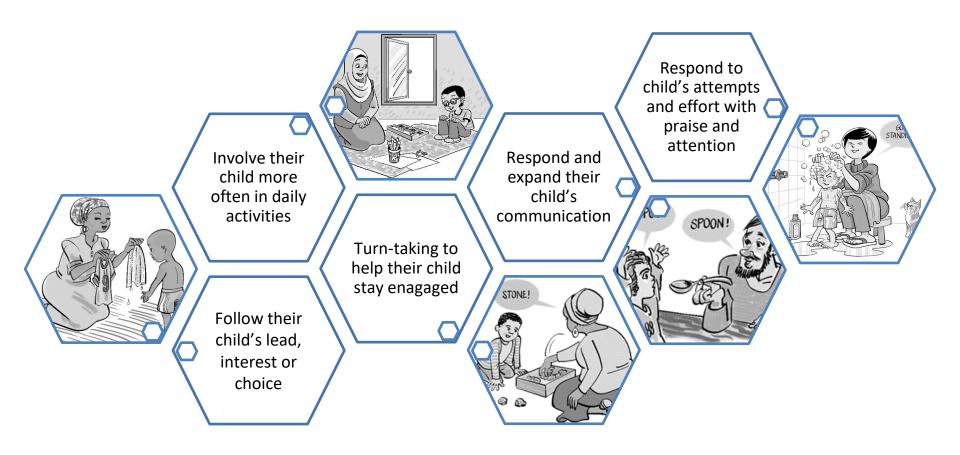


### **Evidence-informed CST Strategies**



Slide courtesy of Dr Chiara Servili

### Caregiver skills





### Structure and contents







Engaging children in everyday activities and games



Understanding and promoting children's communication



Understanding behaviour and helping the child show more positive behaviour

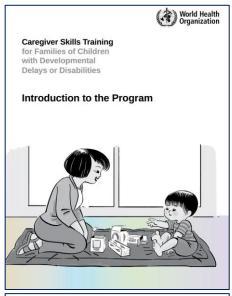


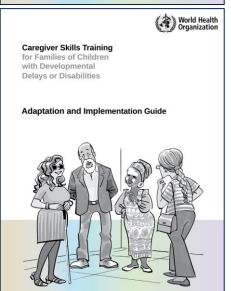
Teaching skills for everyday life

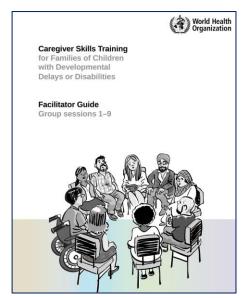


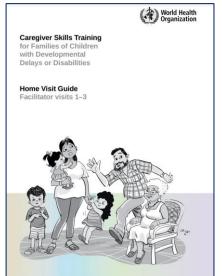
Caregiver wellbeing & problem-solving

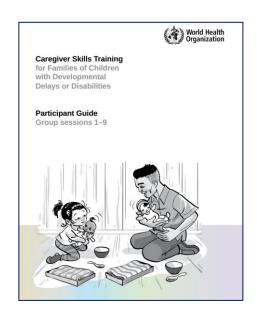
## CST 'Packages'











- ✓ Self-directed eLearning for caregivers
- ✓ Based on WHO CST skills and strategies
- √ Total 8 hours, self-paced
- ✓ Low bandwidth required, suitable for mobile devicesntto
- ✓ Currently being translated in Arabic, Chinese, French, Russian and Spanish
- ✓ It can be used also to support hybrid delivery of CST



## Diamond Families Project: WHO Caregiver Skills Training Programme in South Africa









#### Intervention Implementation To determine the effectiveness To plan, prepare, and of the WHO CST intervention evaluate the implemenin real-world settings in tation of the WHO CST South Africa intervention in South Africa Multi-stakeholder Best fit approach Context To include key To evaluate contextual stakeholders in factors and to all study phases have an in-depth understanding of the Pragmatic & WHO CST end-users Practical in South Africa To use systems and materials that would typically be feasible under \* Evidence-based intervention general conditions \* Designed for scalability and sustainability \* Findings readily translatable

to communities

Figure 1. The five goals of the Diamond Families Study

#### Planning phase

2018

#### PLAN

Multiple stakeholder events and planning meetings.

Systematically plan and develop implementation approach.

Build community relationships and recruit community champions.

#### Preparation phase

2019

#### PREPARE

Adapt materials.
Train facilitators.
Develop an evaluation system.
Establish Research Hubs.
Finalise implementation approach.
Formalise community partnerships.

#### Initial Implementation phase

2020

Information event, enrolment

#### 3-WEEK WELLBEING MODULE

(Evaluation before and after the intervention

ONLINE ONLY. NO DIRECT CONTACT WITH PARTICIPANTS AT ANY STAGE OF THE RESEARCH PROCESS

Celebration event, certificate

2021

Information event, enrolment

#### 12-WEEK SKILLS TRAINING MODULE @ 2 CLINICAL SETTINGS

(Evaluation before and after the intervention, and again at a follow-up session after 12 weeks)

Celebration event, certificate

#### Full implementation phase

Information event, enrolment

#### 12-WEEK SKILLS TRAINING MODULE @ 2 COMMUNITY SETTINGS

(Evaluation before and after the intervention, and again at a follow-up session after 12 weeks)

Celebration event, certificate

#### Study participants:

Project personnel and key stakeholders (>18 years)

#### Archival & document analysis

All historical project information will be sourced. Information sources will include the project calendar, progress reports, events and meetings information, meeting minutes, financial transactions, and project notes and reflections. From this information, implementation activities and strategies will be identified, operationalised, categorised and described using recommended reporting guidelines.

#### A few examples

Guidelines for operationalising implementation strategies (Proctor and colleagues)

Expert Recommendations for Implementing Change (ERIC) taxonomy of implementation strategies

#### Study participants:

Project personnel, key stakeholders & service delivery personnel (>18 years)
Caregivers (>18 years)
Children with developmental delays, disorders or disabilities (2-11 years)

#### Questionnaires, Surveys & Logbooks

We will use a combination of printed and online materials.

Some of the questionnaires, surveys, and logbooks will be completed by participants on their own, and some will be completed during an interview with a research assistant.

#### A few examples

Caregiver knowledge questionnaire
Caregiver wellbeing questionnaire
Child strengths and difficulties questionnaire
Family quality of life scale
Caregiver satisfaction survey
Adaptation logbook
Implementation logbook
Context assessment of community health tool

#### Observations

Prospective

The observations will be live or recorded observations and will be conducted inperson or remotely using online technology. We will be using observations of the group sessions and home visits. The aim of the group sessions is to observe how the facilitators deliver the intervention. The aim of the home visits is to observe the interactions between caregivers and their child during typical play and home routine activities, and to observe how the facilitators coach caregivers.

#### A few examples

Facilitator coaching fidelity form
Caregiver skills coding form
Child measures of active engagement

#### Interviews & Focus Groups

We will be conducting individual interviews and focus groups. Individual interviews will be mostly with caregivers, while focus groups will be mostly with the service delivery personnel. Interviews and focus groups will be conducted either face-to-face, or remotely using online technology.

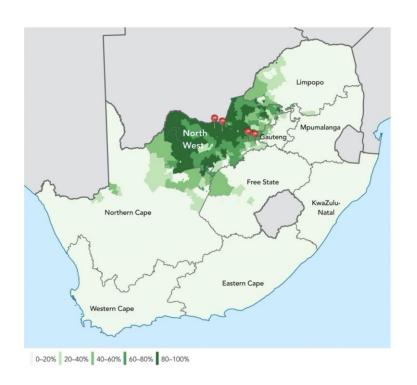
#### A few examples

Semi-structured interview guide for caregivers Focus group guide for facilitators



### Lessons from South Africa



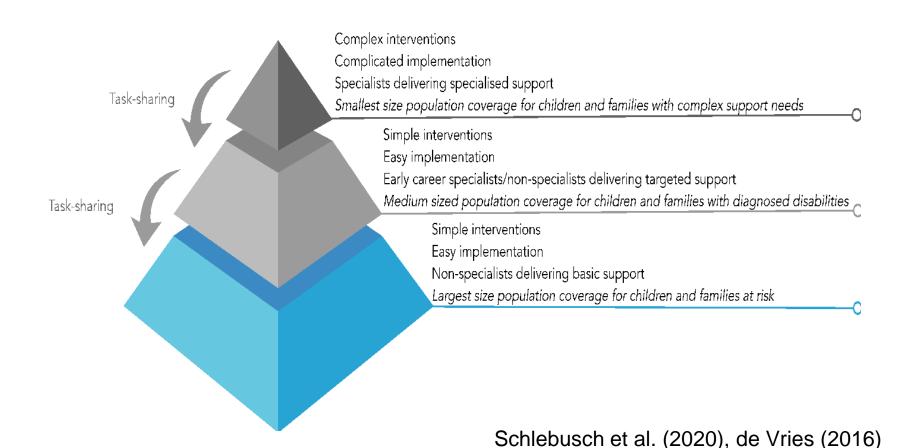


1. Partnerships between academia, non-profit and government sectors can work and is <u>essential</u> for scalability and sustainability of interventions, but...

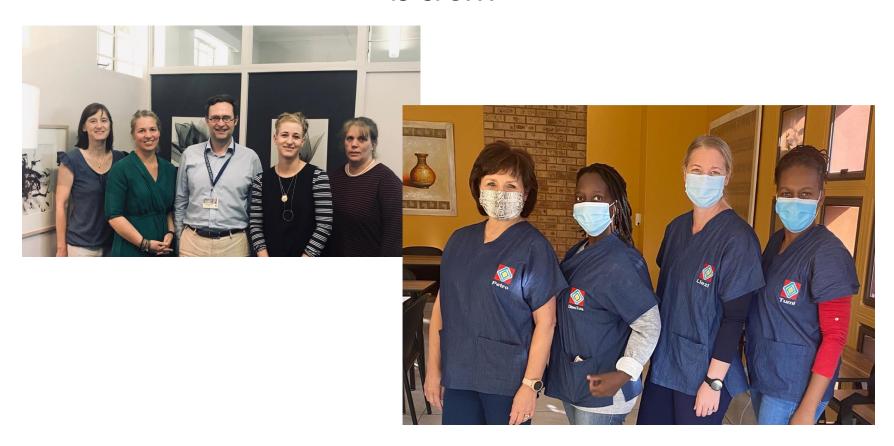




## 2. Task-sharing with non-specialists is possible, but...

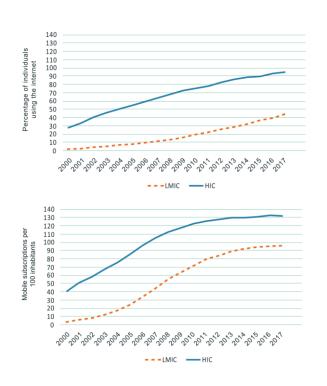


3. The Non-Profit Sector (and other non-governmental sectors) may be powerful implementation partners, but...



## 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



Image courtesy of Dr Liezl Schlebusch

## Findings from the WHO CST Wellbeing Module adapted and delivered via ZOOM



Image courtesy of Dr Liezl Schlebusch

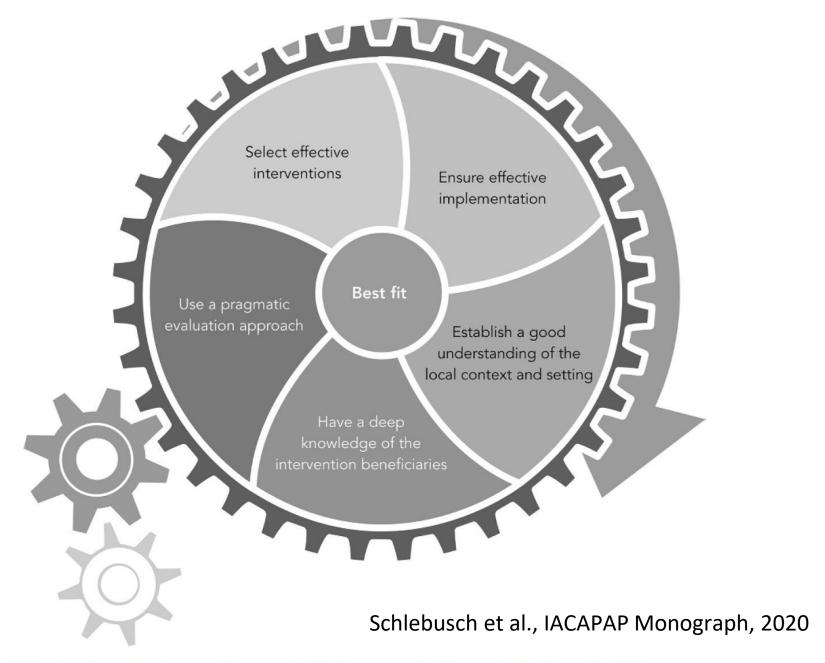


FIG. 2 Key areas to consider for establishing sustainable and scalable early ASD intervention services in resource-limited settings.



