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

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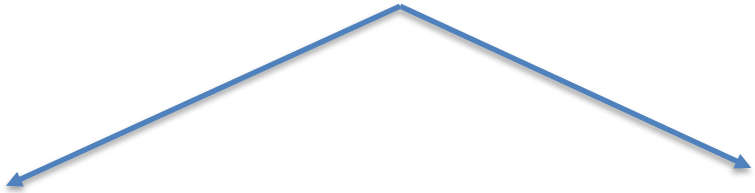
Parenting/Caregiver Programmes



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; 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

People who need them

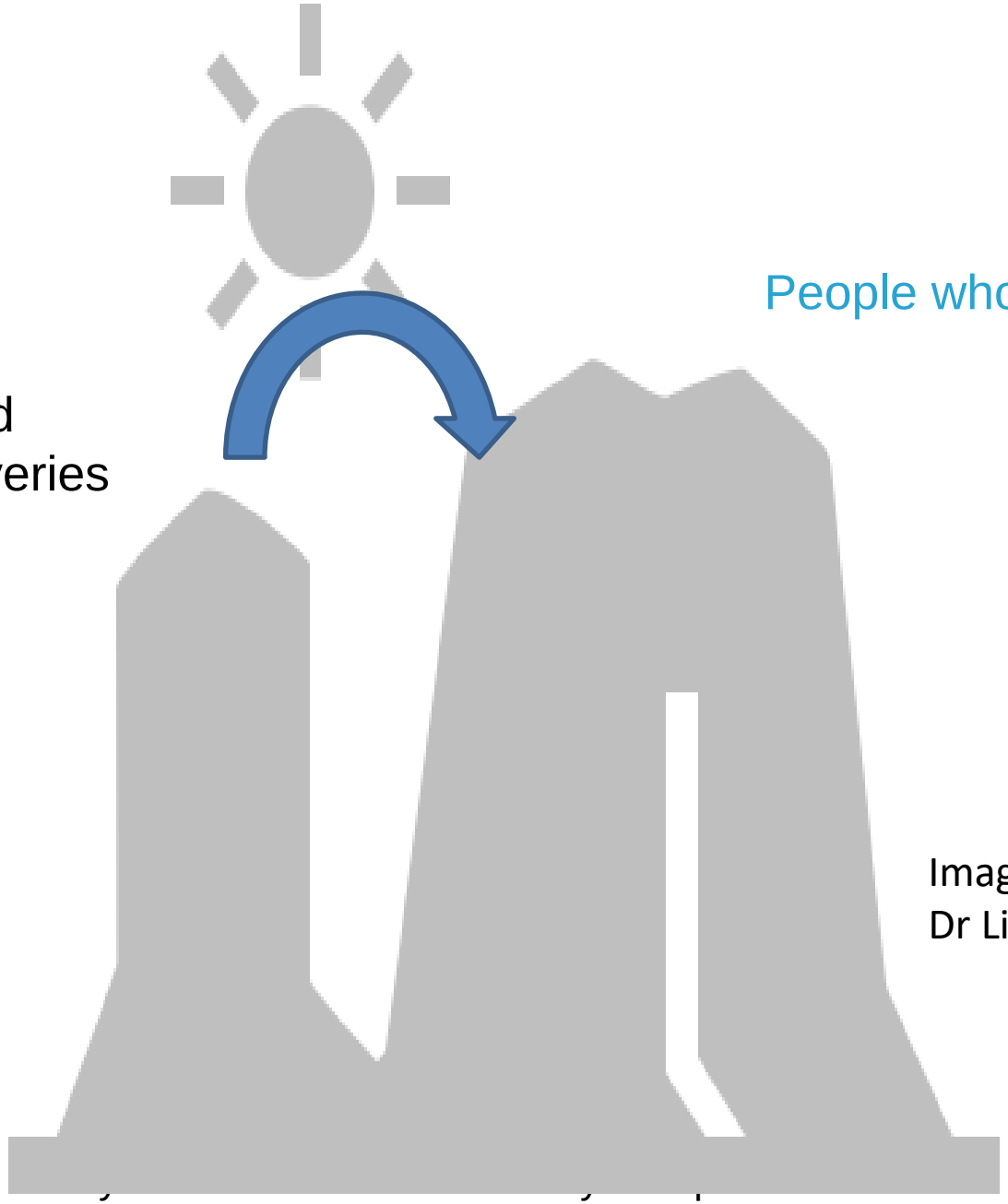


Image courtesy of Dr Liezl Schlebusch

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.

World Health Organization

Slide courtesy of Dr Chiara Servili

Scope of WHO Caregiver Skills Training (CST)

Trainers

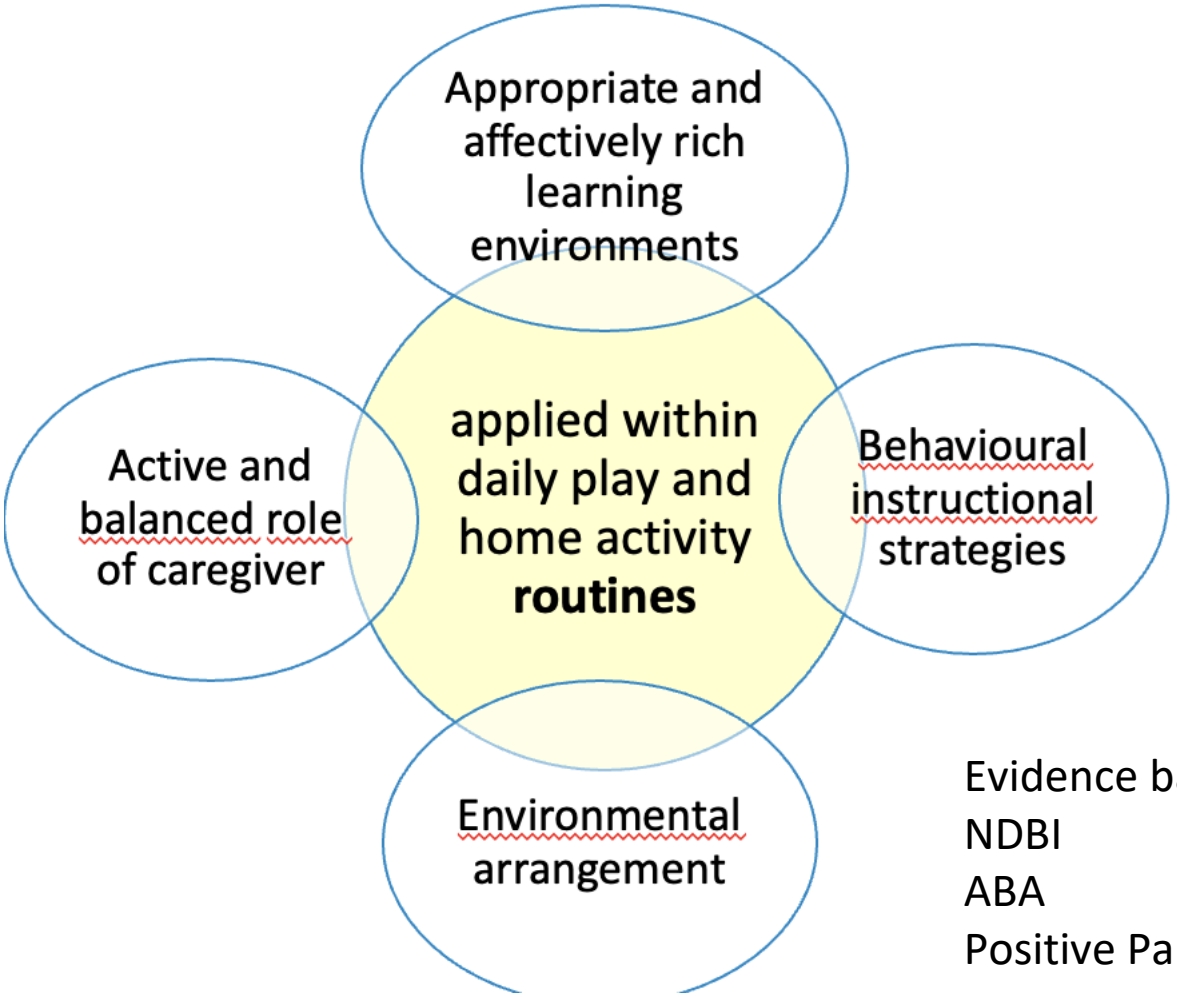
Supervised non-specialists:

- community health workers
- social service workers
- nurses
- ECD facilitators
- teachers
- peer caregivers

World Health Organization

Slide courtesy of Dr Chiara Servili

Evidence-informed CST Strategies

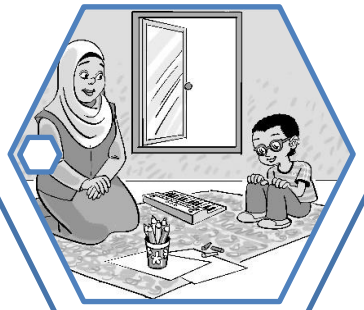


Evidence based on:
NDBI
ABA
Positive Parenting

Slide courtesy of Dr Chiara Servili

Caregiver skills

Involve their child more often in daily activities



Follow their child's lead, interest or choice

Turn-taking to help their child stay enagaged

Respond and expand their child's communication

Respond to child's attempts and effort with praise and attention

World Health Organization

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

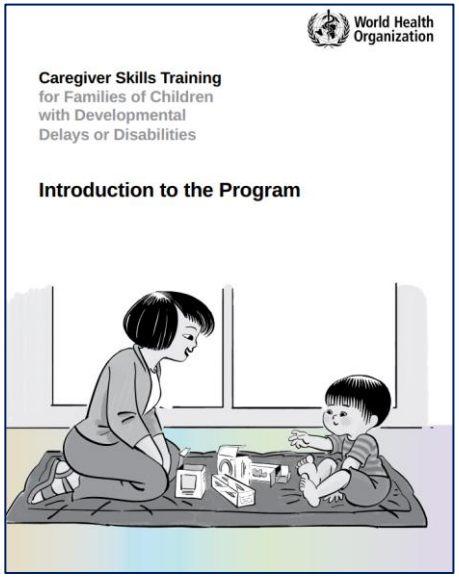
Understanding behaviour and helping the child show more positive behaviour

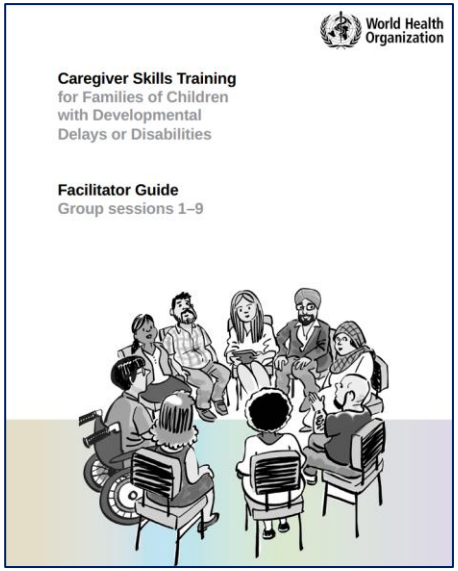
Teaching skills for everyday life

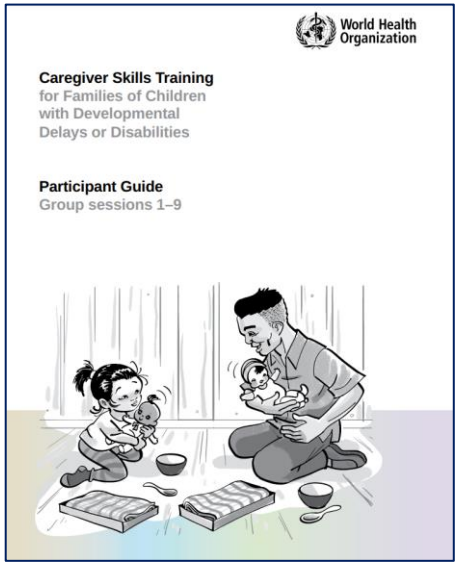
Caregiver wellbeing & problem-solving

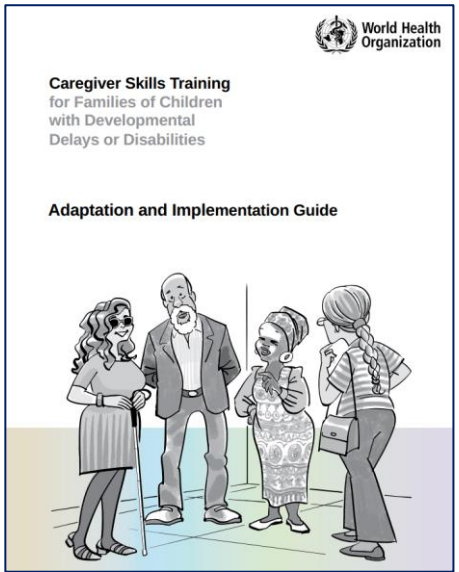
Slide courtesy of Dr Chiara Servili

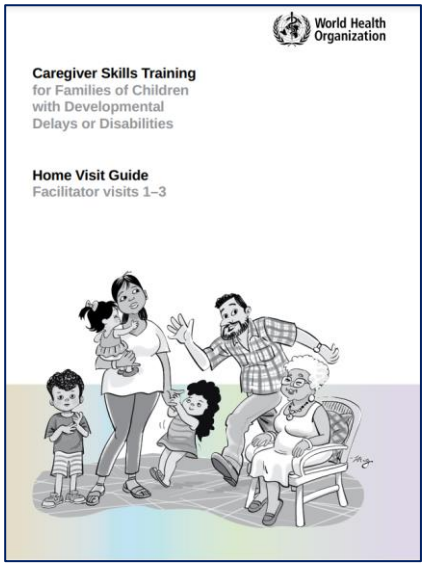
CST ‘Packages’











- ✓ Self-directed eLearning for caregivers
- ✓ Based on WHO CST skills and strategies
- ✓ Total 8 hours, self-paced
- ✓ Low bandwidth required, suitable for mobile 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

social development
Department:
Social Development
REPUBLIC OF SOUTH AFRICA

a;sa
autism south africa

CARA
CENTRE FOR AUTISM RESEARCH IN AFRICA

University of Cape Town • iYunivesithi yaseKapa • Universiteit van Kaapstad
SPES BONA

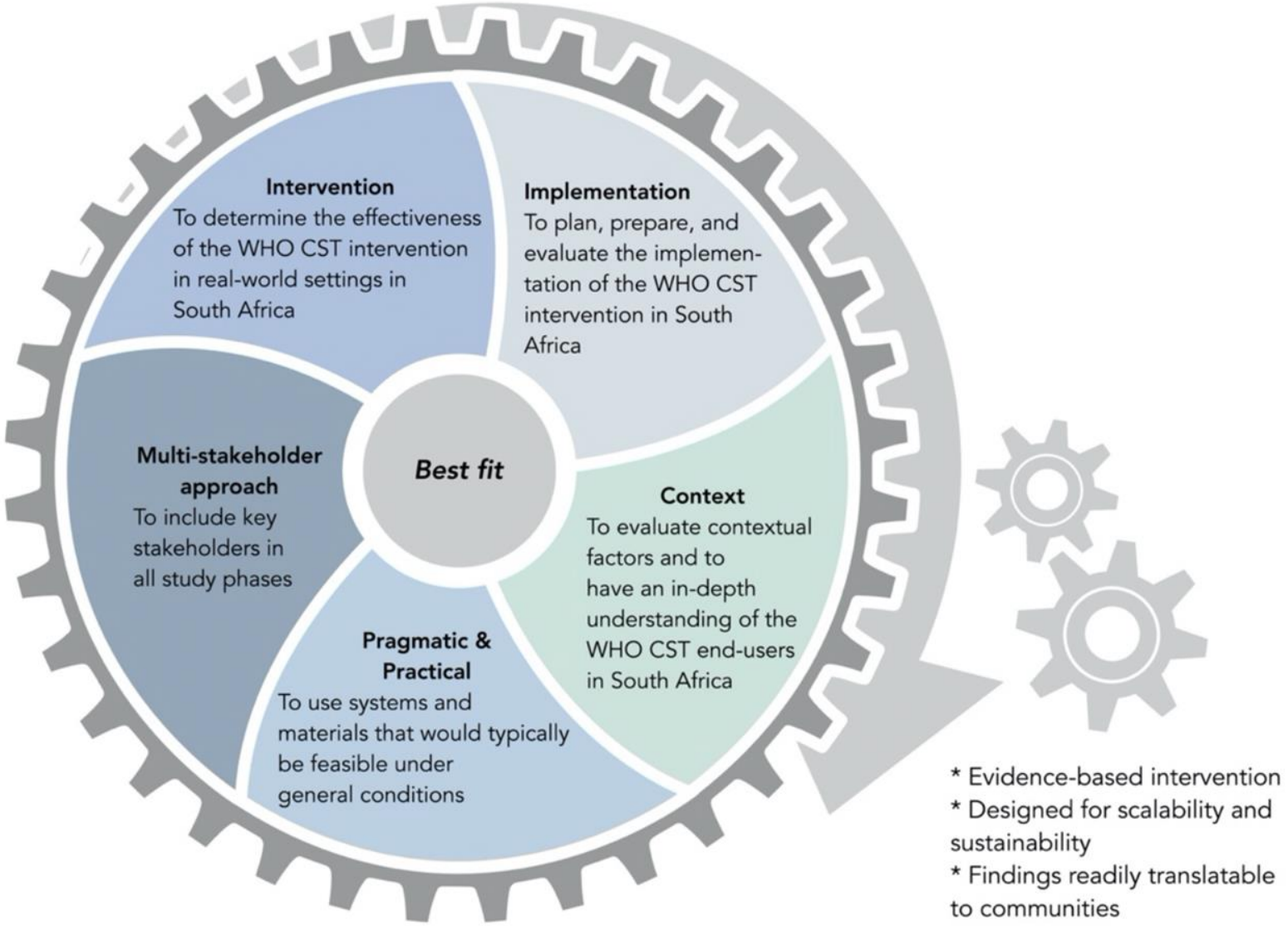


Figure 1. The five goals of the Diamond Families Study

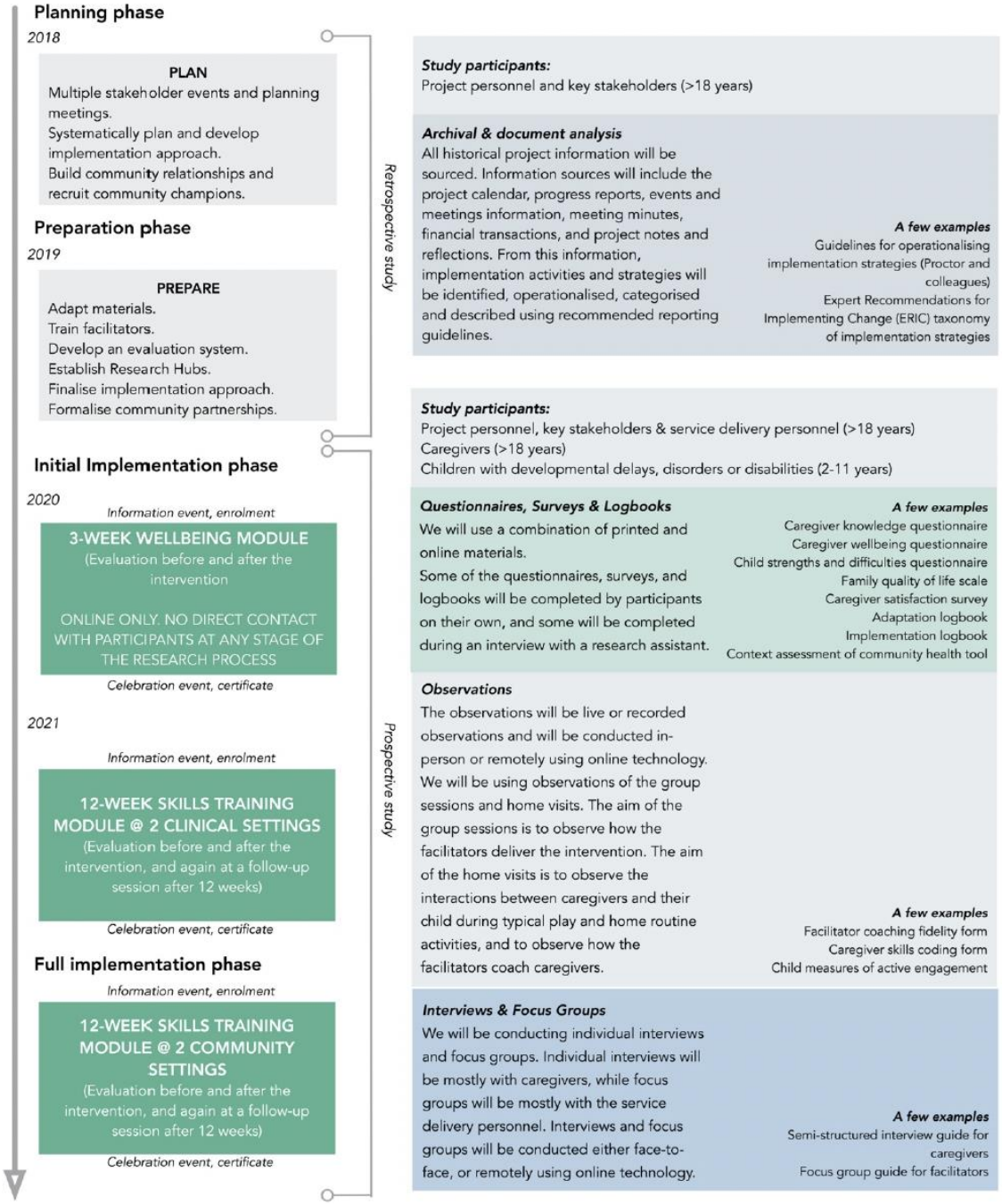


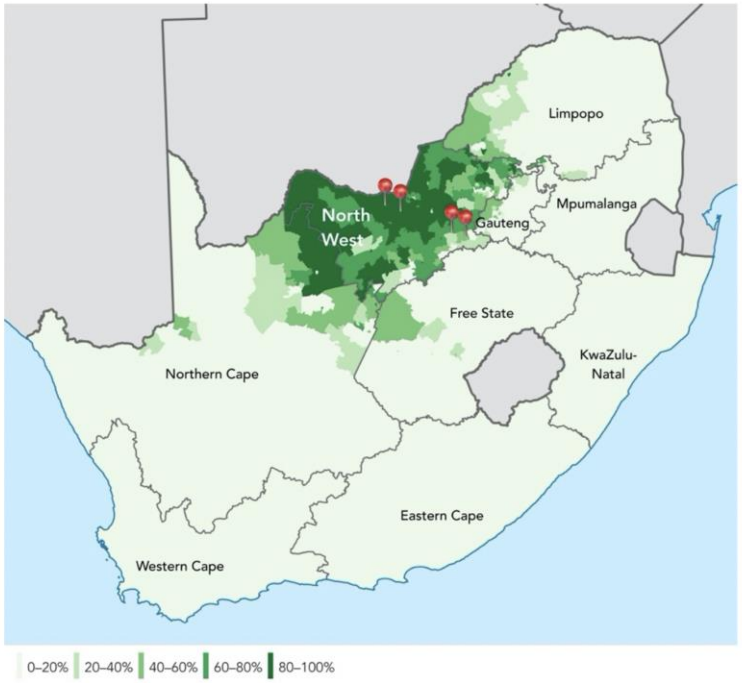
Figure 9. Summary of the data collection procedures

Lessons from South Africa

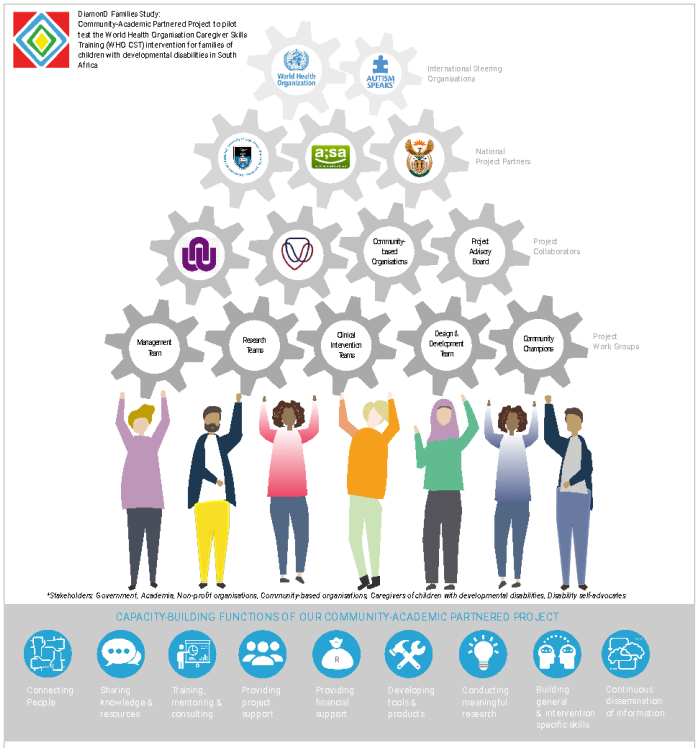
DiamonD Families

Research Project

Creating change for children with **Developmental Disabilities** and their families



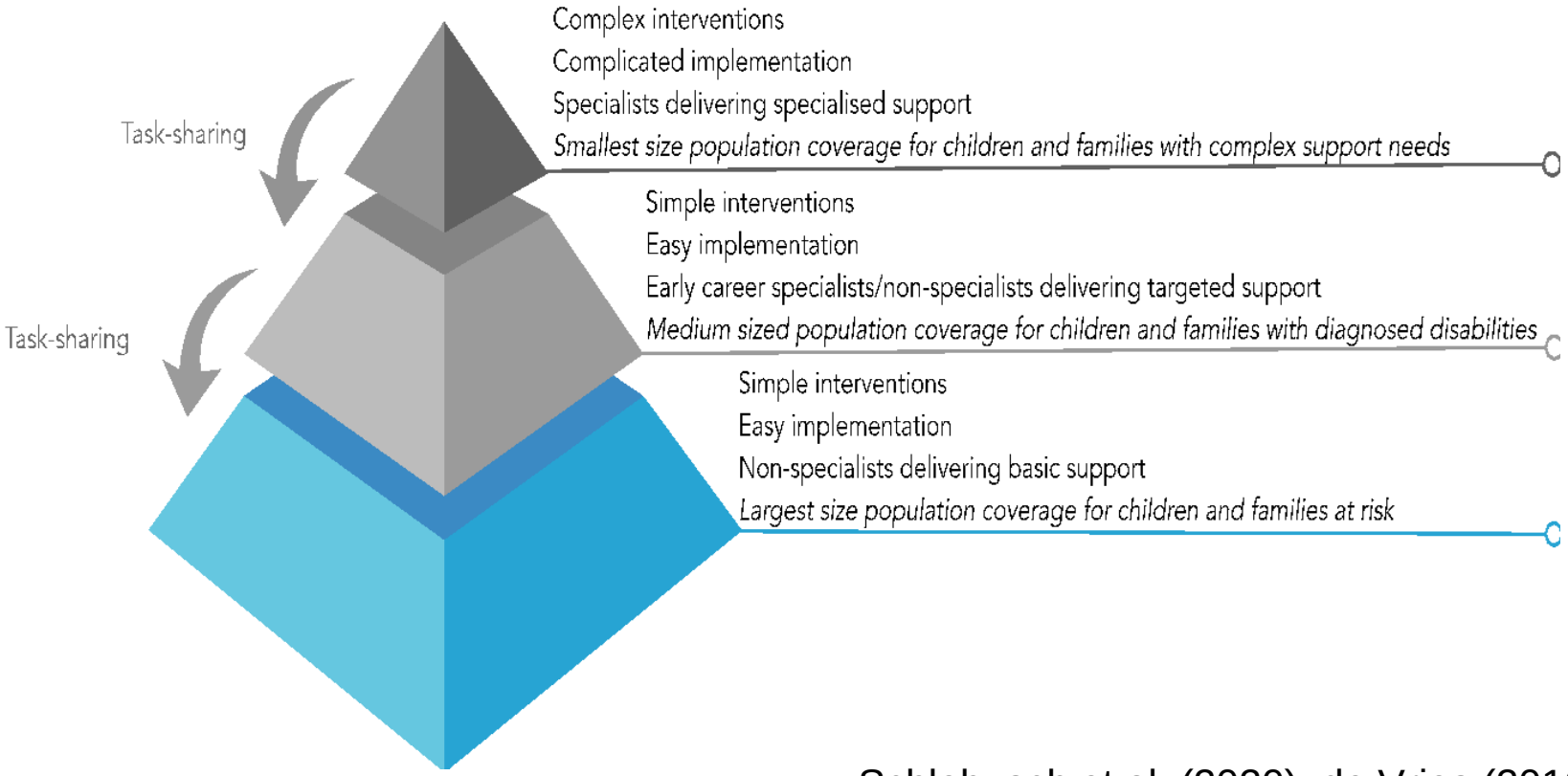
1. Partnerships between academia, non-profit and government sectors can work and is <u>essential</u> for scalability and sustainability of interventions, but…



International WHO Caregiver Skills Training
daptation and Implementation Technical Con
12th-15th December 2017 CHIAN XIAMEN

MAHIKENG

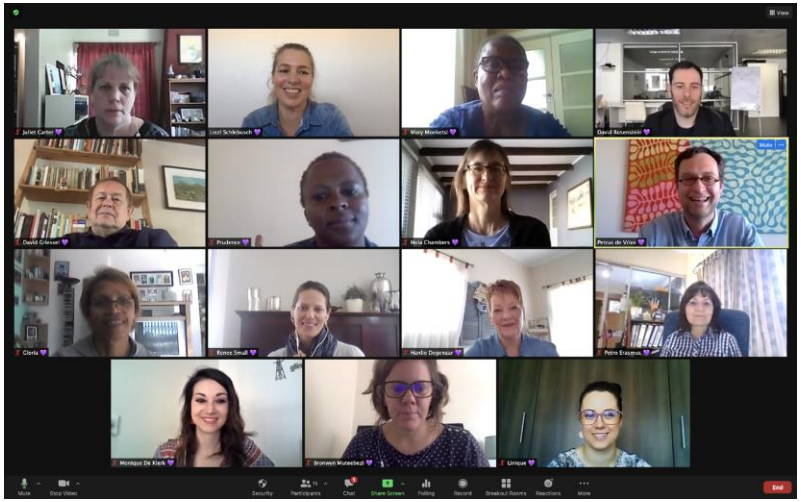
2. Task-sharing with non-specialists is possible, but…

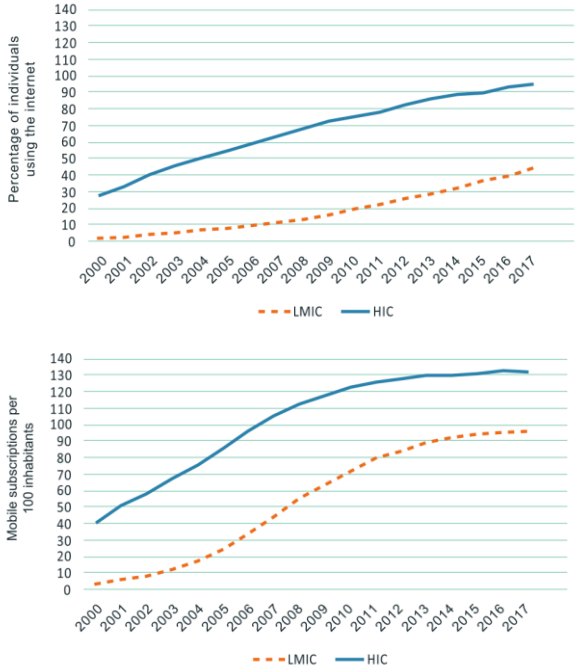


Schlebusch et al. (2020), de Vries (2016)

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)

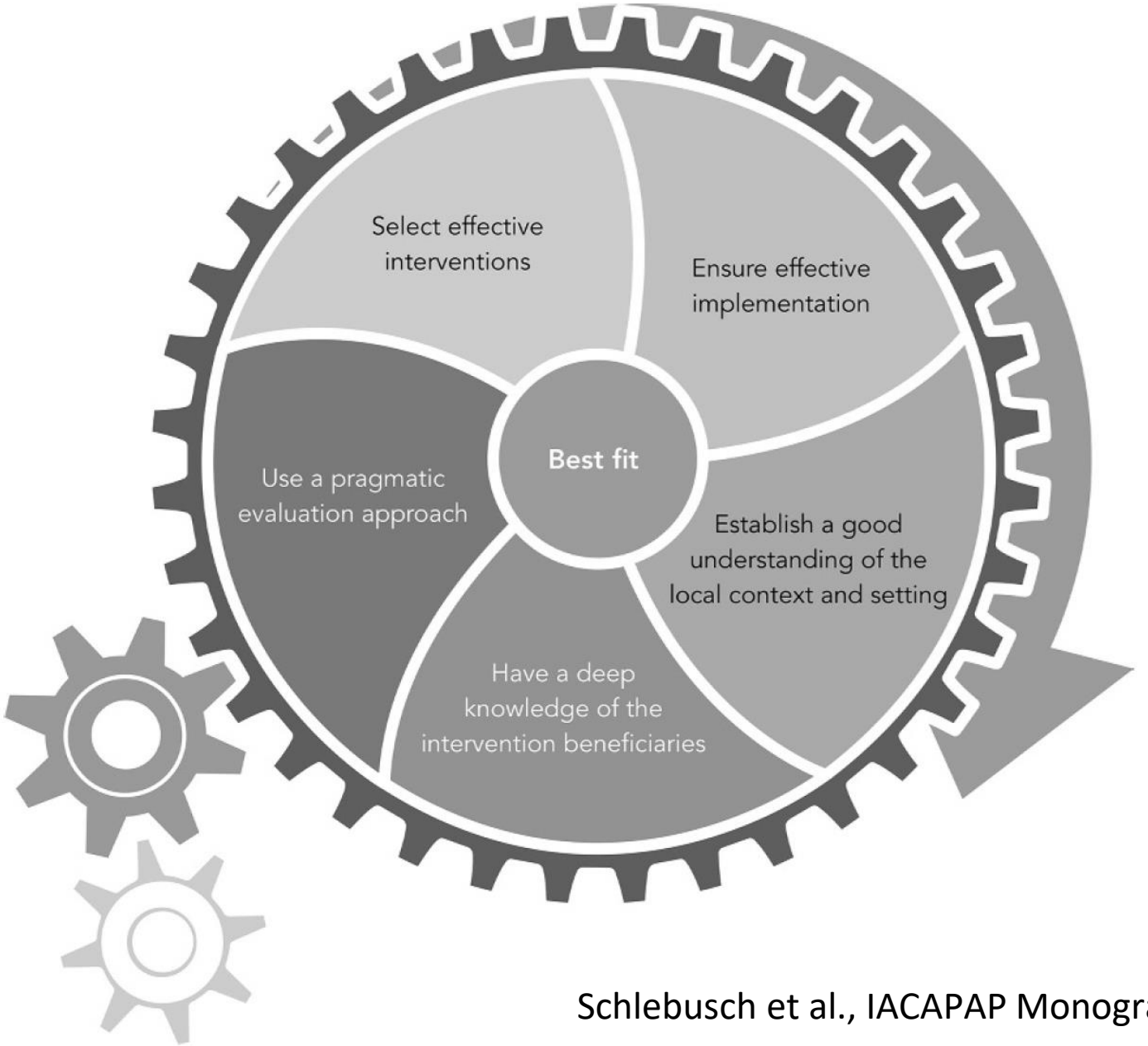
versus

- Caregiver capacity

Image courtesy of Dr Liezl Schlebusch

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

Image courtesy of Dr Liezl Schlebusch



Schlebusch et al., IACAPAP Monograph, 2020

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

Liezl
Petro
Tebs
Agrilla

Thank you!
CARA
Centre for Autism Research in Africa