

“When a child with a disability is born, everything stops.”

“We say it takes a village to raise a child, but when the child has a disability it is you alone.”

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- Core strategies:
 - Child development (including parents)
 - Enabling environments
- Supporting strategies:
 - Strengthening local partner organisations
 - Lobby & advocacy
 - Capacity building

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open the world
for a child
with a disability

- ✦ Equal opportunities and participation
- ✦ Children, youth, young adults
- ✦ Enjoy highest quality of life

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Lead

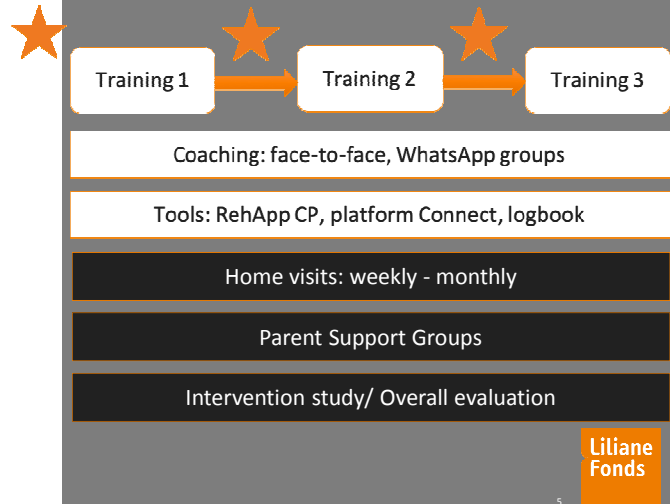
- Evaluation outcomes (Cornielje & Veltman, Holle et al., 2013, Laagland, 2016)
 - improvement quality of care
 - increase knowledge and skills local partners and fieldworkers
 - no clear curriculum/opportunities for fieldworkers
- Mortality rate
- Health

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STEP

- Intervention package
- Neurological disorder
- 1 year pilot project
- 4 African countries
- 160 families
- 4 SPOs, 16 POs ★
- Informed by needs
- Caregivers as training participants



Content training

- Role of fieldworker
- Rehab cycle steps
- Psychosocial support & Coaching strategies
- Basic functional (re)habilitation services
- ABC of actions
- Existing training programs in South
- "Getting to know Cerebral Palsy"
- MAITS community worker manual



Research questions

What are the outcomes of the STEP pilot on the lives of children with neurological disorder, their caregivers and fieldworkers involved in the family.

- Increased skills child
- Change knowledge, attitude, skills caregiver
- Change knowledge, attitude, skills fieldworker



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Methods

- Intervention study
- Pre-post test
- Experimental design
- Qualitative & Quantitative
 - COPM
 - survey
 - questionnaires
 - interviews
 - Logbooks
- N= 10 families, 3 fieldworkers

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Results: child

- “Because it is not enough. I see the difference, I see the change.”
- “He’s still dependent on anything. You have to do things for him.”
- “What I want for her, she has not achieved yet what I want her to achieve: walking, talking (...).”
- “Now he is able to sit outside in his chair, other children come and play with him and I am free to do other things during the day.”

CHILD

Increased skills

Assistive devices

Emphasizing care

Amaanyi

Coaching
difficulties

Perception of
change

Results: caregiver

- “My life stopped, I had to stop working, she killed my life. I really got frustrated but I had to get used to the situation.”
- “I don’t understand how he will progress.”
- “When the fieldworker came, she gave me courage, ‘Amaanyi’, and now I see that he has a future.”
- “The group has been important because when you go there, you see other children and from talking to those parents and observing other parents, you also learn from their situation. It always makes me, when I see other parent, it makes me stronger (...).”
- “If you see the book now, you see where D was at and you see the record of change in the book.”

CAREGIVER

Courage

Confidence

Parent Support
Group

Future questions

Ladder of life

Home environment

Grieving process

Scoring

Satisfaction

Results: fieldworker

- “Even if you don’t know that child before, you go through the logbook and RPS process, assess them, set goals, make plans – step by step. Before we didn’t really know – you go to visit, but you don’t do very much, just there to check on them.”
- “I feel I can apply this now with other children also”
- “How to generate ideas?”
- “What to do on the kids like [...]? What can I do for severe level? What if you finish the wheelchair, then what?”

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FIELDWORKER

Expectation
management

Confidence

Trust vs Knowledge

Generating ideas

Pressure

Motivation

Training needs

Coaching needs

Status

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Conclusions

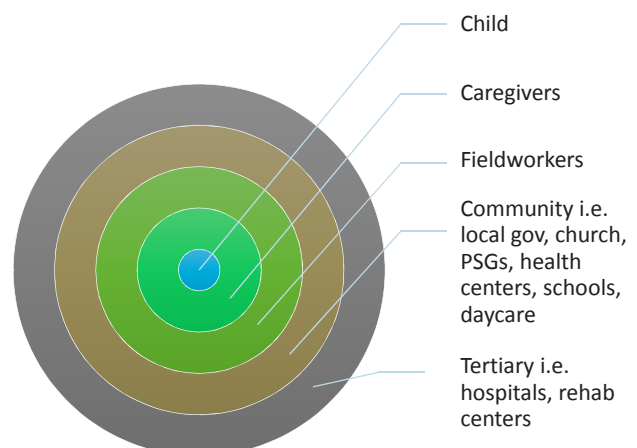
- Increased daily life skills child
- Increased interaction child – caregiver
- Increased knowledge, skills, confidence
- Connections are crucial: CBR/CBID
- Amaanyi
- Someone to keep track of progress: proof
- Interaction package elements
- Understanding child's condition
- Assistive devices: burden, feeding, social participation

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What's next?

- Discuss with SPOs and POs
- Support local decision making & planning
- Upscaling with local master trainers
- Embed in CBR/CBID
- Connect with colleague organisations
- Invest in multi-level skills and support networks
- Resources for fieldworkers
- Assistive devices: local manufacture/repair
- Fieldworker role



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open de wereld
voor een kind
met een handicap

Message Kenneth



- All families
- Fieldworkers
- SPOs & POs
- Kenneth Nangai
- Léa Guignard
- Kees van der Broek
- Kate Sherry
- Lyndal Alexander
- Adri Vermeer
- Huib Cornielje

dioraphte

Rising Above Disability
Katalemwa Cheshire Home
for rehabilitation Services
Uganda



Cheshire Disability Services Kenya



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Thank you!



Enablement

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