

Developing SElf-hElp groups for caregivers of children with disabilities in rural Kenya (SEEK)

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Outline

- ❑ Set-Up Phase

- ❑ Intervention Phase

- ❑ Associated Impacts

Objective of Project SEEK

To generate **new knowledge** on the **development process** of **community-based, self-help groups** for **caregivers** of children with disabilities and their families in **rural Kenya** and to establish any **associated impacts**.

Study design

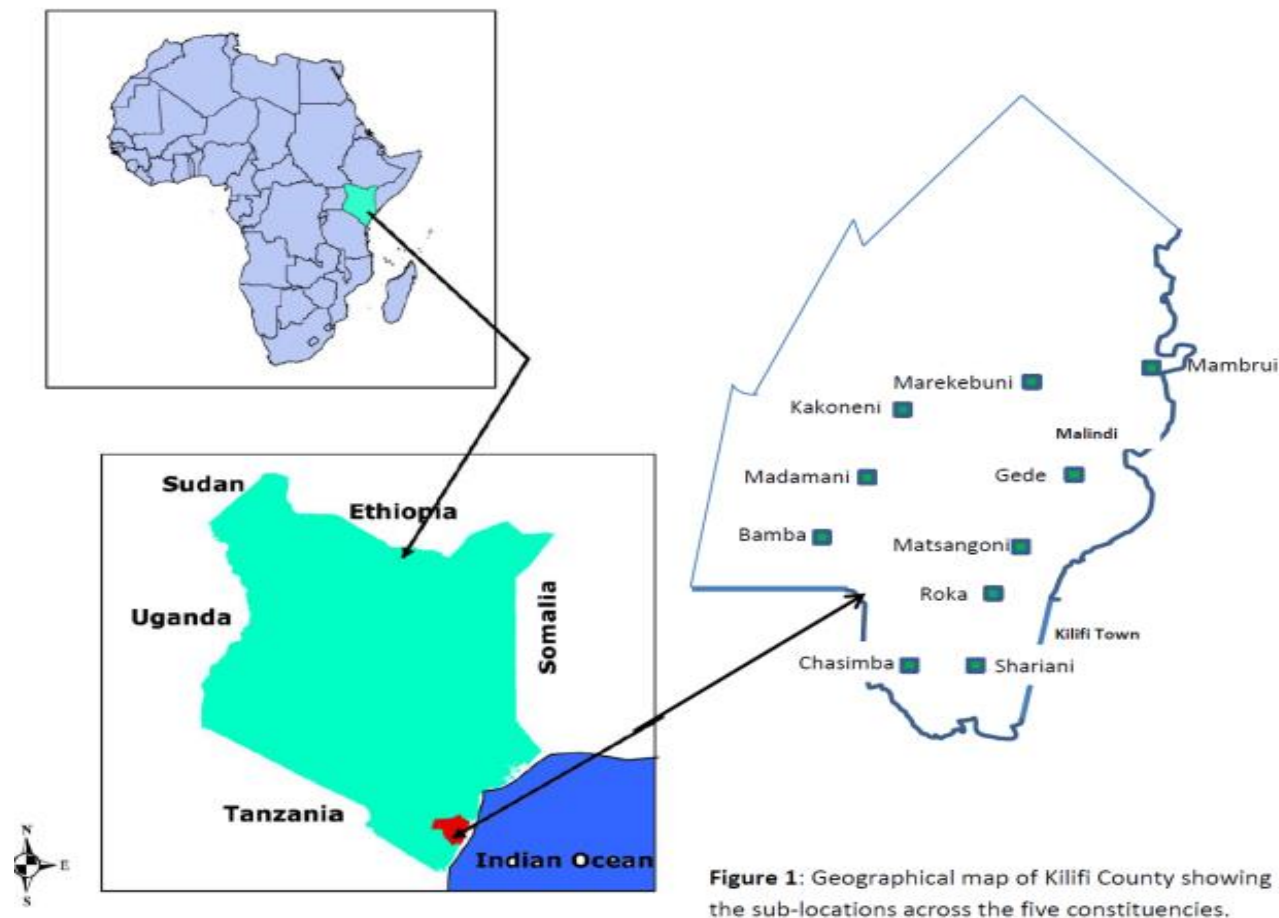
Realist evaluation design (Pawson and Tilley, 1997) focusing on:

- **C**ontext (contextual factors that did or did not support self-help group development)
- **M**echanisms (practices that were considered critical to the successes or failures of the groups)
- **O**utcomes (evidence in support of the above)
(CMO)

The Set-up Phase

- Set up lasted about 12 months
- The caregivers were recruited and brought together for:
 - Regular meetings
 - Building relationships with each other
 - Income generation projects
- Planning meetings were held to:
 - Elect a leader
 - Make decisions on size of membership, frequency and location of meetings, group identity and name

Study Site



Study participants

- We aimed to establish 20 self-help groups for caregivers across Kilifi County
- 20 community groups (10 CHWs & 10 WGs) involved in a previous project on disability awareness training, identified the caregivers (paper in press)
- Two groups of caregivers mobilised in each of 10 sub-locations across Kilifi County

Recruitment procedure

Identification of caregivers used snowballing techniques, e.g. CHW and WGs spoke to people they knew or were aware of in their local communities and followed up others as identified.

Inclusion criteria:

- having a child with known disability
- willingness to participate
- availability to attend meetings



All recruited caregivers signed an informed consent form

Officials

- Meetings were held to choose officials
 - the chair and vice chair
 - the secretary and vice secretary
 - the treasurer



Requirements from groups

- Registration with Ministry of Labour, Social Security and Services
- Opening of bank account
- Regular meetings (at least once in a week)

Meeting procedures

- CBR guidelines (WHO, 2010) used to lend structure and purpose to the group proceedings
 - welcoming new members
 - opening each meeting with introductions
 - agreeing on the rules of confidentiality
 - carrying out targeted activities
 - taking notes (topics discussed and decision made; recording attendance and planning next meeting)
 - closing the meeting

Capacity building

- Facilitation from the research team with regular monitoring visits
- Group leaders given contacts to trigger visits at any time
- Inter-connections encouraged between groups to facilitate sharing of experiences, ideas worked solutions and resources

Sharing experiences

- A member telling his story



Sharing foodstuff

Sharing sugar



Sharing wheat flour



Start-up projects

Making 'makuti'



Soap making



Start-up projects (cont'd)

Poultry keeping



Merry-go-round



The Intervention Phase

The Facilitated Intervention

- 6 key topics addressed in 1 monthly meetings with each group

Topic	Purpose
1: Economic empowerment	Establish or strengthen micro-finance system of the group
2: Sharing of personal situation	To promote confidence and self-actualization of caregivers
3: Peer support	To raise caregiver awareness of similar experiences of others
4: Community inclusion	To increase levels of participation, inclusion and belonging
5: Access to health	To improve and maintain the health of both CWD and caregiver
6: Access to education	To raise awareness on the value of education to CWD

Associated impacts

Peer support



The house before it was burnt



Rebuilt with contributions from the group

Access to services



Assessment for educational placement and other referrals



A physiotherapist giving advice to caregivers

Opportunities for micro-finance



Farming- growing maize



Business-selling fuel to bodabodas

Business-selling of foodstuff



Evidence: pre- to post-intervention

- Multi-dimensional scale of perceived social support (Zimet et al. 1988) applied of convenience sample (n=75)
 - Significant change in caregiver perceptions of increased social support
- Sub-sections of: Body Structure/Function and Community Participation - derived from the adapted Communication Disability Profile (Baker & Hartley, 1999) applied to convenience sample (n=75)
 - Significant change in caregiver perceptions with child's disability seen as less severe and participation increased
- Semi-structured interviews with random sample (n=18):
 - Analysis is ongoing – to reported later

Guidelines

Guidelines in booklet form

Get one from this CBR conference

Acknowledgement

- CP Trust Fund, UK
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- The caregivers of children with disabilities

THANKS



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