

Self-help groups for caregivers of children with developmental disabilities in Kenya: pathway to empowerment

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THE SETTING:

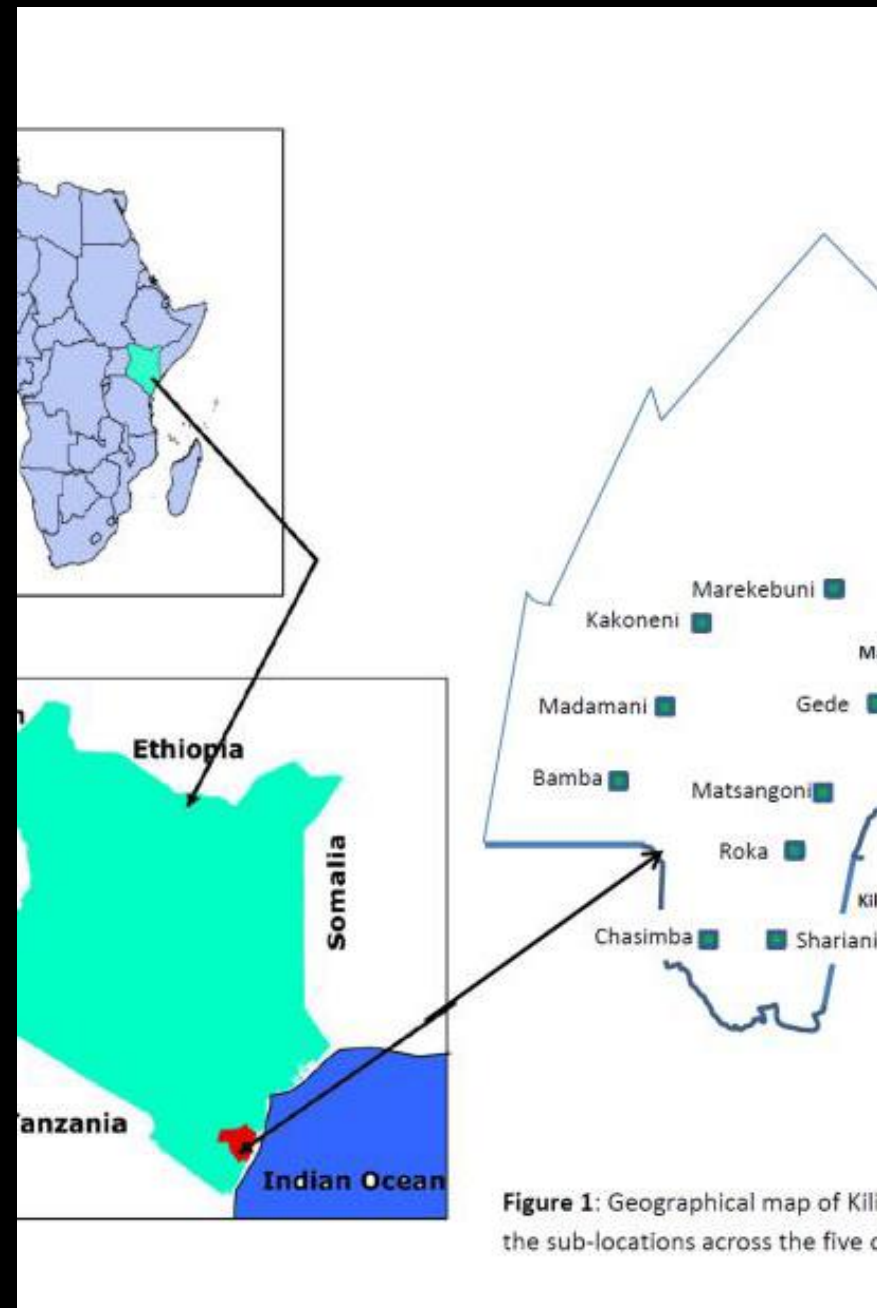
Kilifi County, Kenya

Location: Indian ocean - coastal & rural communities

Culture & language: Mijikenda: Swahili, Giriama & Chonyi; c70% Christian, 20% traditional, 10% Muslim

Poverty level: Among poorest areas in Kenya; subsistence farming

Dwellings: Typically of mud construction, 1 or 2 rooms, & no power supply or running water



Developing self-help groups

- ❖ Target - 20 groups of c300 caregivers
- ❖ Caregiver empowerment
- ❖ Capacity-building over professional input
- ❖ Meaningful & sustainable change for the better
- ❖ Contribute evidence CBR/CBID (WHO, 2010)



Research Questions

1. What changes are associated with empowering self-help groups for caregivers of children with disabilities?
2. If there are changes associated with the self-help group process, how does it do so?



Study Design & Recruitment

Realist evaluation design (Pawson & Tilley, 1997)

- ❖ Context
- ❖ Mechanisms
- ❖ Outcomes

Recruitment

- ❖ Snowballing
- ❖ Support from Women & Community Health Worker Groups
- ❖ Informed consent



Phase 1. Set-up (10m)

- ❖ Election of officials (chair, secretary, treasurer)
- ❖ Regular meetings
- ❖ Relationships
- ❖ Income generation (Merry-go-round; subscriptions; small projects)
- ❖ Monitoring visits






End of Set-up

- ❖ 11 SHGs remained (154 caregivers)
- ❖ Challenges of low education, poverty & stigma in community
- ❖ In group conflicts
- ❖ Fraudulent activity in community
- ❖ Extreme environmental conditions, e.g. drought, avian flu

Caregiver characteristics		n	%
Age range	<20	4	2%
	21-39	118	46%
	40+	133	52%
Education	No formal	116	46%
	Primary - incomplete	59	23%
	Primary - complete	62	24%
	Secondary	17	7%
Children at home	1-2	35	14%
	3-6	143	56%
	7-10	65	25%
	11+	12	5%
Children with disabilities	1	237	93%
	2	14	6%
	3+	3	1%

Caregiver characteristics		n	%
Caregiver clothing	Quality - poor	0	0%
	Quality - good	254	100%
	Footwear - yes	149	46%
Dwelling	Mud & thatch - poor	91	36%
	Mud & thatch - good	44	13%
	Iron roof	70	26%
	Concrete	49	19%
Meals per day	1	27	11%
	2	99	39%
	3+	127	50%
Livestock	Chicken	158	62%
	Duck	53	21%
	Goat	116	46%
	Cow	51	20%
	None	63	25%

Characteristics of CwDs		n	%
Gender	Male	51	59
	Female	35	41
Age range	0-3	9	11
	4-6	14	16
	7-10	26	30
	11-15	37	43
Area of difficulty identified (body function & structure)*	Vision	4	5
	Hearing	12	15
	Physical 	45	54
	Drooling	2	2
	Attention	14	17
	Communicating	22	27
	Seizures	10	12
Disability aids	Wheelchair 	0	0
	Other	3	4
School registered*	Yes	35	42
	No 	48	58

Phase 2. Facilitated Intervention (7m)

Topic review & discussion:

- ❖ Economic empowerment**
- ❖ Personal situation
- ❖ Peer support
- ❖ Community inclusion
- ❖ Access to health
- ❖ Access to education

** micro-finance





Farming



Poultry



Buying & selling food stuffs

Evaluation

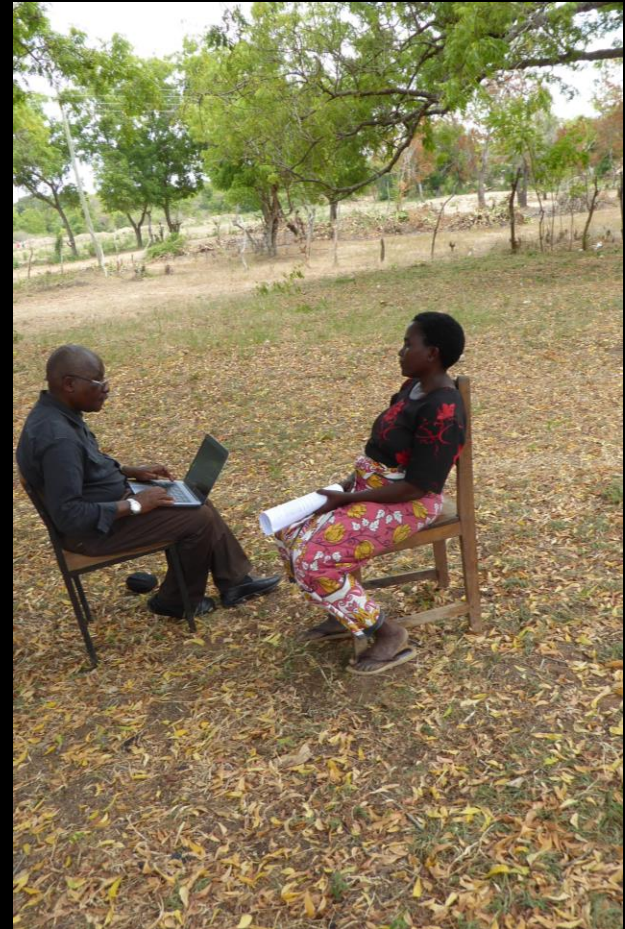
Questionnaires:

- ❖ Multi-dimensional Scale of Perceived Social Support (MSPSS: 75)
- ❖ Sections of Communication Disability Profile: caregiver severity rating of child's disability; extrinsic factors affecting role

Interviews:

- ❖ Caregiver interviews (36)

Triangulation



Results (1)

Measure	N	Mdn (pre- post)	Inter- quartile ranges (pre-post)	P value	Effect size (r)
Communication Disability Profile	75				
Section 1. Perceived severity of child's disability		68-72	24-17	<.00	-.87
Section 3. Perceptions of extrinsic factors affecting caregiver		19-29	7-3	<.00	-.867
Multi-dimensional Scale of Perceived Social Support	75	39-84	23-6	<.00	-.84

Results (2)

Burden ←————→ Agency

Aloneness & Challenges

Care demands

Socio-economic challenges

Sorrow & pain

Togetherness & Capacity-building

Group cohesion

Business

Self-determination

EMPOWERMENT

Stigma & Discrimination

Blamed

Discounted

Acceptance & Well-being

Benefits to child & family

Community recognition

Contentment & hope

Burden	Agency
<i>Challenges & Aloneness</i>	<i>Togetherness & Capacity-building</i>
<p>‘... availability of food, sometimes I get, sometimes I miss to get the food. I have to struggle to get. There are also clothes.’ [CG229-1]</p>	<p>‘... we sat together and found ways and means of how we could help each other... we use mobile phones... my child has this and this. We call each other and visitWe discuss what we could do.’ [CG150-2]</p>
<p>‘I felt my heart was burning. I was not feeling good.’ [CG023-1]</p>	<p>‘When we sit we plan our business, how is it progressing; if certain items are finished, we plan and then get more items for sale.’ [CG112-2]</p>

Burden	Agency
<i>Stigma & Discrimination</i>	<i>Acceptance & Well-being</i>
<p>‘when you get a child of this nature, people think it is a curse, others think it is witchcraft, so you are rejected.’ [CG100-1]</p>	<p>‘My child used to be left alone, could not mix with other children. This project has made my child in school mix with other children.’ [CG119-2]</p>
<p>‘I just saw people gathering at my house...village leader said these people are here because of this child of yours. They are claiming that such children prevent rain from coming.’ [CG051]</p>	<p>‘I see how things are moving, I think they will produce benefits which will benefit my child.’ [CG112-2]</p>

Burden	Agency
<i>Challenges & Aloneness</i>	<i>Acceptance & Well-being</i>
<p>‘If it is eating, I have to feed her, if it is toileting, I have to help her. I have to carry her. I have to do everything for her.’ [CG100-1]</p>	<p>‘This child has given me hope. Even I have observed changes in the father towards the child.’ [CG119-2]</p>
<p>‘...even if I want to take her for exercises, it becomes a big problem because I do not have even the fare to the hospital.’ [CG051-1]</p>	<p>‘I prepare good breakfast for her..... I buy soap for her. Even clothes I do buy for her.’ [CG074-2]</p>

Burden	Agency
<i>Stigma & Discrimination</i>	<i>Togetherness & Capacity-building</i>
<p>‘People at home or even my co-wives when they see him they close their doors, or even chase him away saying, ‘Go to your mother.’ He comes back or sits at the door...’ [CG081-1]</p>	<p>‘What has kept us together is communication. What are we going to do, what are the best ways to follow, then we do together. We understand each other, otherwise you would not have seen us together.’ [CG121-2]</p>
<p>‘...they say they will not treat a child who is already dying....’ [CG081-1]</p>	<p>‘The secret is that we identify the problems our children have and try to solve them ourselves.’ [CG155-2]</p>

Underlying Mechanisms

- ❖ Mechanism 1.
handling goods
& money
- ❖ Mechanism 2.
social ties &
support

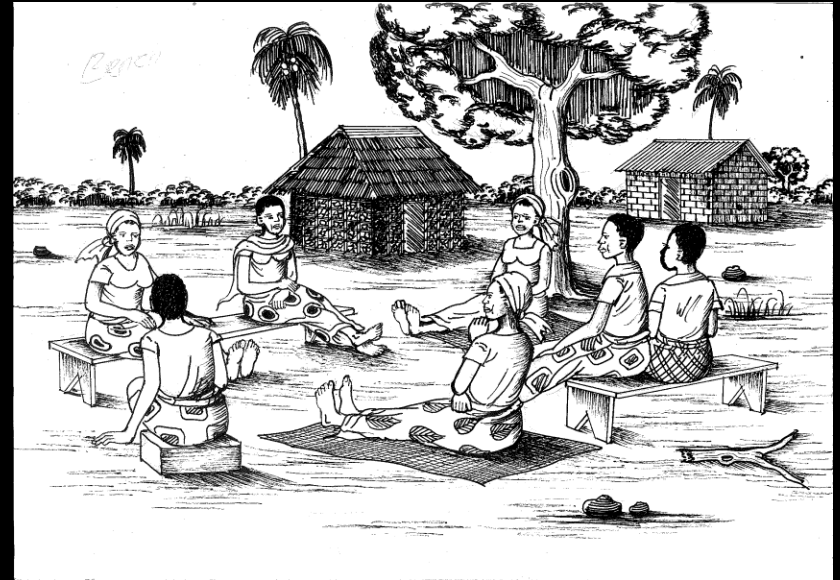


Conclusions

- ❖ **Proof of concept**
- ❖ **Contributes to evidence on community-based inclusive development (formerly CBR)**
- ❖ **An approach that is both meaningful & sustainable**

Associated Impacts

- ❖ Registration with government dept.
- ❖ Bank accounts
- ❖ Attendance of health facilities
- ❖ Engagement with education
- ❖ Food on the table
- ❖ Caregiver control
- ❖ New partnerships



Beyond Kenya

- ❖ Follow up study started 2018-21
- ❖ Guidelines on empowering SHGs
- ❖ Pilot sites in Africa (e.g. Zambia, Malawi, DRC, Togo, Madagascar, Ethiopia, Burkino Faso)



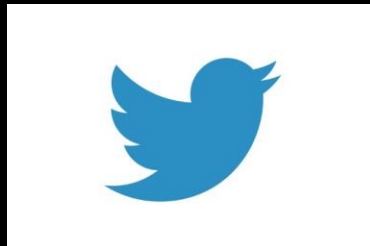
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Publications

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