

1 **Development of self-help groups for caregivers of children with disabilities in Kilifi, Kenya:**  
2 **Process evaluation**

3  
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11  
12  
13 **Abstract**

14  
15 **Background:** Caring for a child with disabilities in a resource-poor setting brings many challenges  
16 to the caregiver. We examined the development of self-help groups for caregivers in a rural part  
17 of Kenya.

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19 **Objectives:** To conduct a process evaluation on the development of self-help groups during a 10-  
20 month set-up period, focusing on implementation and mechanisms associated with their functional  
21 status.

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23 **Methods:** Using a realist evaluation project design, we set-up twenty self-help groups for 254  
24 caregivers. A process evaluation was conducted to investigate implementation and mechanisms  
25 of impact. Implementation focused on caregiver registration, community group support and  
26 monitoring visit compliance. Data were collected from group registers, records of meetings and  
27 field notes. Mechanisms of impact employed a framework of Strengths-Weaknesses-  
28 Opportunities-Threats to review the groups at the end of the 10-month set-up period.

29  
30 **Results:** Recruitment resulted in registration of 254 participants to 18 groups - 2 groups disbanded  
31 early. Post-evaluation there were 11 active and 7 inactive groups. Compliance with the monitoring  
32 visits was consistent across the active groups. All groups engaged in 'merry-go-round' activities.  
33 The active groups were characterised by strong leadership and at least one successful income  
34 generation project; the inactive had inconsistent leadership and had dishonest behaviour both  
35 within the group and/or externally in the community. Mediators associated with functional status  
36 included: available literacy and numeracy skills, regular meetings with consistent attendance by  
37 the members, viable income generating projects, geographical proximity of membership and  
38 strong leadership for managing threats.

39  
40 **Conclusion:** Self-help groups have the potential to progress in resource-poor settings. However,  
41 critical to group progression are literacy and numeracy skills amongst the members, their  
42 geographical proximity, regular meetings of the group, viable income generating projects, and  
43 strong leadership.

44  
45 **Keywords:** caregivers; children with disabilities; community-based inclusive development; self-  
46 help groups

## 47 **Introduction**

48

49 Children represent approximately 50% of the general population, 5% of whom are estimated to  
50 have a disability (World Health Organisation: WHO 2011). More recently, about 95% of 52.9  
51 million children below 5 years with developmental disabilities were estimated to reside in low-  
52 middle income countries (LMICs) (Olusanya 2018). Compared to 1990 estimates, the author  
53 concluded there was a lack of significant improvement to the burden of developmental disabilities.  
54

55 The basic needs of the child growing up with a disability, such as shelter, nutrition, clothing,  
56 education, health and emotional well-being, are catered for by the caregiver, usually the mother.  
57 In LMICs, paucity of information concerning the causes of disability, e.g. Kenya (Bunning et al.  
58 2017), limited support services and poor access at community level, make the caregiver's role both  
59 challenging and onerous (Gona et al. 2018 ). Wide variation in rehabilitation services has been  
60 reported across the African continent, including poor coordination of delivery, restricted access to  
61 services at community level and a continuing need for development work (WHO, 2011). Health-  
62 based rehabilitation services that exist tend to be clustered around urban-based institutions with  
63 reports of serious limitations in coverage and capacity (Njelesani, Couto & Cameron 2011; Parnes,  
64 Cameron & Christie 2009).  
65

66 In the circumstance of limited resources (Mitra, Posara & Vick 2011; Peters, Garg & Bloom et  
67 al. 2018) and social isolation, the caregiver and the child with a disability are disenfranchised and  
68 potentially marginalised in their own community (Ambikile & Outwater 2012; Bunning et al.  
69 2017; Trani et al. 2011). The family's finances are impacted by the extra expenses associated with  
70 meeting the child's needs (Ambikile & Outwater 2012; Gona et al. 2016). A report from Sierra  
71 Leone found that families with persons with severe disabilities spent on average 1.3 times more  
72 on healthcare than families where disability was not present (Trani et al. 2011). These challenges  
73 are compounded by a lack of information about the causes of disability and competing  
74 explanations in the community based on cultural superstitions and negative images, e.g. the child's  
75 disability is attributed to curses or evil spirits (Bunning et al. 2017). Furthermore, with an  
76 estimated third of youth (12-14 years) and approximately 60% of those between the ages of 15 and  
77 17 years not attending school in sub-Saharan Africa ([www.uis.unesco.org/en/topic/education-  
78 africa](http://www.uis.unesco.org/en/topic/education-africa)), it is likely that caregivers will lack skills of literacy and numeracy to help advance their  
79 quality of life.  
80

81 Not surprisingly, long-term caregiving in low-income countries has been associated with fatigue  
82 and parenting distress (Gona et al. 2014). Furthermore, children with disabilities are more likely  
83 to have lower school attendance than their non-disabled counterparts with limited support available  
84 generally. Local access to rehabilitation services is cited as a right by the United Nations  
85 Convention on the Rights of People with Disabilities (UN, 2006), although the reality faced by  
86 most people in low-income countries is one of scarce and frequently inaccessible resources.  
87

88 Community-based Inclusive Development (CBID), formerly community-based rehabilitation  
89 (CBR), provides the potential to circumvent existing gaps in available rehabilitation support.  
90 Initiatives based on the WHO CBR Matrix (2010) continue to evolve and grow in more than 90  
91 countries worldwide, focusing on strategies for 'rehabilitation, equalization of opportunities,  
92 poverty reduction, and social inclusion of people with disabilities'. However, published studies

93 have been criticised for the lack of research rigour (Finkenflugel, Wolffers. & Huijsman 2005).  
94 Iemmi et al.'s (2015) systematic review identified modest benefits for people with mental  
95 disabilities and their caregivers, whilst also acknowledging 'methodological constraints' (p.6) in  
96 the cited studies. 'Empowerment' is one of the five domains of the WHO matrix (WHO, 2010),  
97 the others being 'livelihood', 'education', 'health' and 'social'. Seminal studies by Kieffer (1984)  
98 and Zimmerman and Rappaport (1988) supported the idea that psychological empowerment  
99 includes personal control, a sense of competence, a critical awareness of the socio-political  
100 environment, and participation in community organisations and activities. Zimmerman and  
101 colleagues (e.g. Zimmerman & Warschausky 1998; Perkins & Zimmerman 1995; Zimmerman &  
102 Rappaport 1988) identified three key domains: *intrapersonal*, how people think about their  
103 capacity to influence change utilizing critical understanding of context; *interactional*, how people  
104 contribute to transactions with other people and the environment; *behavioural*, how people act to  
105 influence change in the surrounding environment, e.g. through participation in community  
106 organizations and activities. The latter point is relevant to CBID initiatives such as 'self-help  
107 groups' (SHGs), which are identified in the 'empowerment domain' (WHO, 2010) and bring new  
108 opportunities for social connections and support in the community.

109  
110 SHGs are grass root level organisations that build on the traditions of collective savings and shared  
111 livelihood activities. Their purpose is to promote peer assistance and cooperation for the mutual  
112 benefits of the members (Gugerty, Biscaye & Anderson 2019). A variety of models have been  
113 used in LMICs for different purposes including: education for an alternative livelihood in Kenya  
114 (UNESCO 2015); promoting well-being amongst people with mental health needs in Ghana  
115 (Cohen, Raja & Underhill 2012); raising awareness of disability issues in the community in South  
116 Africa (Adams & Galvaan 2016); social support through training for caregivers of children with  
117 disabilities in Ghana (Zuurmond et al. 2018); promoting agricultural practices across remote, rural  
118 regions of sub-Saharan Africa (Self-help Africa) and Asia (Atteraya, Gnawali & Palley, 2016);  
119 and use of microfinance to mitigate the effects of humanitarian crises in Ethiopia (Tearfund 2017).  
120 Few formal evaluations that distinguish independent variables (e.g. interventions) from co-  
121 variables (e.g. environmental factors) have been reported (Gugerty et al. 2019), with the exception  
122 of studies originating in Asia. Atteraya et al. (2016) found that individual capabilities (e.g.  
123 educational experience, home assets, autonomous decision-making) were significantly correlated  
124 with active participation in the SHGs. This finds resonances in Patil & Kokate's (2017) analysis  
125 of factors underpinning participant attitude formation towards SHGs which included 'coping  
126 ability', 'personality traits', 'resource utilisation and building', 'entrepreneurial attributes',  
127 'organisational governance', 'financial inclusion' and 'economic upliftment'. Another study in  
128 India, considered group process characteristics such as commitment and cooperation of members,  
129 absence of conflicts, transparency of communication, to be critical to positive SHG outcomes  
130 (Govindarajan & Padhmanabhan 2013).

131  
132 Regarding impacts, reported outcomes associated with SHG participation include: more positive  
133 attitudes and a reduction in perceived isolation (Zuurmond et al. 2018); and improved financial  
134 and social support (Cohen et al. 2012; Swain & Wallentin 2012). A systematic review of self-help  
135 groups for women in Asia, sub-Saharan Africa and the Caribbean revealed economic gains and  
136 political empowerment (Brody, de Hoop & Vojtkova 2017). Reported challenges to SHG  
137 participation include: competing priorities and time poverty, managing the tensions between  
138 individual and group goals (Adams & Galvaan 2010); differences in community status (e.g. caste  
139 differences in India), disappointment in expected benefits and stigma associated with membership

140 (Brody et al. 2017). However, inadequate documentation of group processes remains a problem in  
141 attributing change to any one model of self-help.

142  
143 In order to understand the functional status of the SHGs at the end of a 10-month set up period,  
144 the current study aimed to carry out a process evaluation. The research question was: What  
145 characteristics and processes define the functional status (active Vs inactive) of SHGs?

## 146 147 **Research Methods and Design**

148  
149 The project adopted a realist evaluation design (Pawson & Tilley, 1997), which recognises that  
150 programmes work in different ways for different people. It was expected that the development of  
151 twenty self-help groups in different geographical locations would be influenced by the  
152 experiences, beliefs and attitudes of the participants, the available opportunities, access to  
153 resources relevant to the context and environmental conditions.

## 154 155 **Setting and Sample**

156  
157 The setting was Kilifi County (area: 12,610Km<sup>2</sup>; poverty level: 71.4% - Kenya Commission  
158 Revenue Allocation). The sample was comprised of caregivers of children with disabilities across  
159 10 sub locations in Kilifi County. The primary caregiver was included if:

- 160 • s/he was 18 years old and above and cares for a child (0-15 years) with a developmental  
161 disability present from birth, noted in first five years of life or considered long-term;
- 162 • parental report identified the child as showing a deficit(s) in one or a combination of the  
163 following areas: seeing, hearing, moving, dribbling, drinking and eating, paying attention,  
164 sitting still, learning, understanding, or experiences epileptic seizures (fits) (derived from  
165 the first section of the Communication Disability Profile: Baker & Hartley, 1999);
- 166 • The child's disability was associated with a primary condition, e.g. cognitive impairment;  
167 deafness; visual impairment; autistic spectrum condition; cerebral palsy; multiple  
168 disabilities.

169  
170 Caregivers were excluded where the child's condition was temporary and possibly associated with  
171 a medical trauma, e.g. fractured limb, and likely to resolve with appropriate treatment, or related  
172 to a need that could be resolved through the provision of corrective devices, e.g. glasses for  
173 myopia.

174  
175 In order to engage the community in each targeted sub-location and to secure the support of the  
176 sub-Chief responsible for community affairs, a field worker, a resident of Kilifi, went to the  
177 designated sub-chief's office to arrange a visit by the project co-ordinator (also a local resident).  
178 At the meeting, project information was provided to the sub-Chief and any questions were fielded.  
179 Caregiver recruitment was carried out by 20 existing community groups (women groups: WG;  
180 community health worker groups: CHW), who had participated in a previous study on disability  
181 awareness training (Gona et al. 2018). Each of two groups per sub-location was asked to identify  
182 around 15 caregivers of children with disabilities who were known to them, making a target  
183 recruitment number of 300 caregivers (see Figure 1. for the location of the SHGs across Kilifi  
184 County). An inaugural meeting was arranged for each SHG development site. Members of the  
185 WGs and CHW groups who had identified caregivers in their own communities, accompanied the

186 caregivers to this first meeting to learn about the project. Informed consent was recorded for those  
187 caregivers who wanted to participate in the development of SHGs, whereby information was read  
188 out, questions were addressed and participation decisions were recorded by signature or  
189 thumbprint.

190

### 191 **Process evaluation**

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193 Process evaluation was carried out during the set-up phase of the project (over 10 months). It  
194 focused on two domains (Moore et al. 2015): (i) Implementation, or the approaches taken to set  
195 up and support the SHGs with a focus on group set-up (caregiver mobilisation and registration,  
196 monitoring visits completed, and adaptations); and (ii) Mechanisms of impact, or group  
197 responses to the development process, with a focus on group activities and membership,  
198 processes and characteristics (internal or external to the group), and their association to group  
199 functional status.

200

201 After the initial meeting for information sharing and recording consent, those who were interested  
202 in taking part were registered individually using a prepared excel spreadsheet addressing the  
203 following fields: sex, age range, marital status, educational level, number of children with and  
204 without disabilities, and quality of life indicators (quality of dwelling, caregiver clothing and  
205 footwear, number of meals served and livestock owned). Each group was encouraged to assign the  
206 roles of Chairperson, Treasurer and Secretary amongst the membership, to agree on a name and to  
207 start up an income generating activity to increase their available resources. Each group was given  
208 a hard-backed exercise book and pen to record their meetings (date and time; members present;  
209 items discussed; income). Post registration, monitoring visits were carried out by the project co-  
210 ordinator, who as a resident of Kilifi was familiar with the culture and conversant in all the local  
211 languages. Each group was visited at once monthly intervals, arranged in advance by mobile phone  
212 communication with the Chairperson. The visits took the form of question-answer interactions  
213 with the group, review of their ledger on member attendance and activities – supplemented by an  
214 oral report, identification of any difficulties experienced with problem-solving as required. Field  
215 notes were recorded *in situ* and later entered into a prepared Excel spreadsheet recording co-  
216 ordinator role assignment, group activities and observations made by the researcher.

217

218 At the end of the set-up period, a comprehensive review of all the groups was conducted by  
219 examining the two domains of: i) implementation; and ii) mechanisms of impact. The former, i)  
220 implementation, focused on caregiver mobilisation by community groups, caregiver registration  
221 data, monitoring visits completed, and adaptations. The latter, ii) mechanisms of impact, focused  
222 on the groups' constitutions, activities, processes and characteristics (internal or external to the  
223 groups). To evaluate implementation of the SHG set up, descriptive statistics were applied to the  
224 data (participant demographics, monitoring visit compliance and any adaptations recorded in the  
225 field notes) according to group functional status (active Vs inactive). To evaluate the mechanisms  
226 of impact, the entire data set was reviewed using a framework of Strengths-Weaknesses-  
227 Opportunities-Threats (SWOT: see Helms & Nixon 2010), with the first two components  
228 addressing factors internal to the group composition, and the latter two addressing external factors.  
229 The SWOT analysis was carried out collaboratively by the first author, a native of the area, who  
230 was responsible for group facilitation and monitoring visits, and the last author, a visitor to Kilifi,  
231 who provided a remote perspective. Each SHG was reviewed in succession and their

232 characteristics recorded on a prepared SWOT matrix initially. This involved review of the  
233 registration characteristics of the caregivers, their quality of life indicators, recorded group  
234 compliance rates with monitoring visits and field notes from visits (identifying group income  
235 generating activities). In addition, the last author asked the first author to describe each group in  
236 his own words using prompts such as: How do the members function as a group? What are their  
237 particular strengths or weaknesses? What difficulties have the group encountered? The research  
238 co-ordinator's responses were added to the appropriate section of the SWOT matrix. A second  
239 iteration involved the last author reviewing each SHG's completed SWOT matrix, comparing them  
240 for commonalities and differences and making adjustments as required. This was then reviewed  
241 with the first author until consensus on the content of each SHG's SWOT matrix was established.  
242 The last stage involved producing two summary SWOT matrices for the active groups and the  
243 inactive groups. Similar items were categorised and assigned a label. These were reviewed and  
244 discussed by the two researchers until agreement was achieved. Finally, a single SWOT matrix  
245 was rendered that combined the two SWOT summary matrices indicating commonalities and  
246 differences according to functional status.

247

## 248 **Ethics**

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250 This study was approved by institute. *(Information removed by the Editorial Office for peer review)*

251

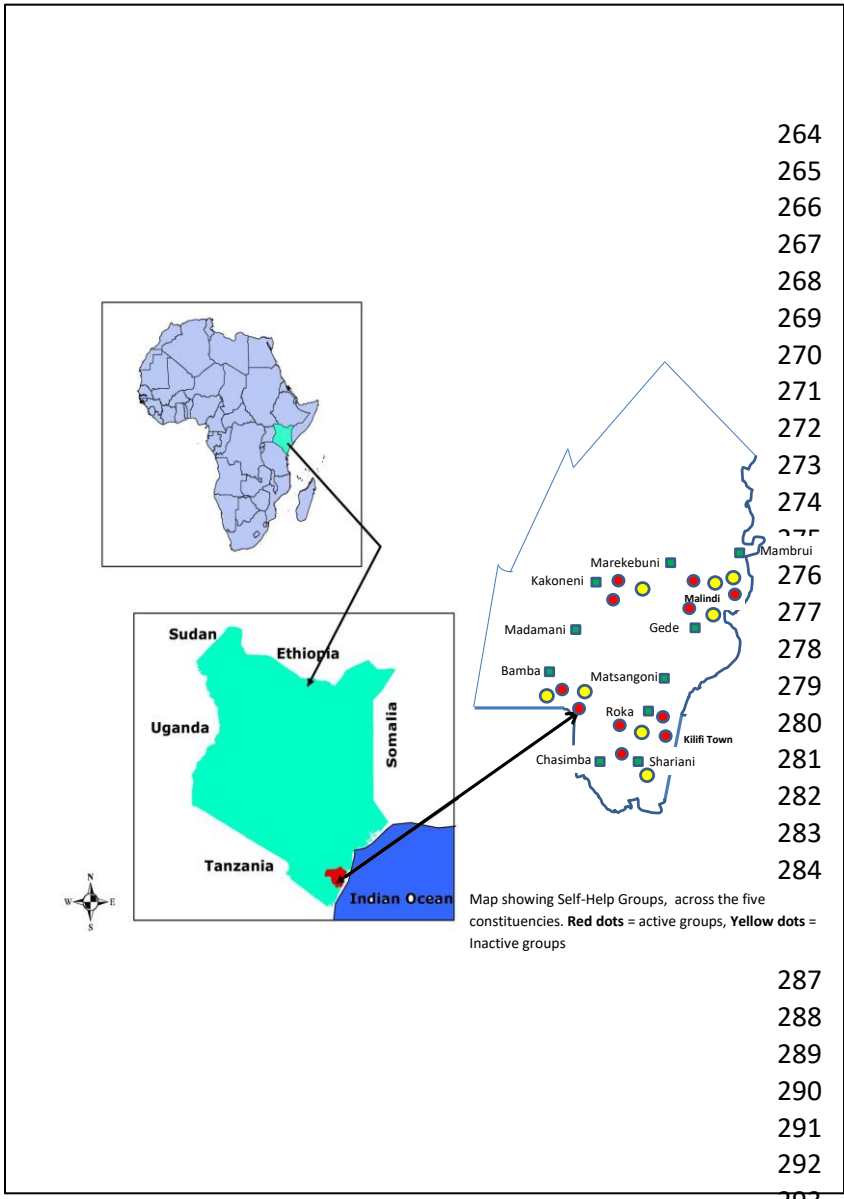
## 252 **Results**

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### 254 *Implementation*

255

256 The community groups (10 CHW; 9 WG) identified around 280 caregivers out of the targeted 300  
257 to start up SHGs. One WG failed to identify and mobilise any caregivers, which left 19 groups  
258 for development as shown in figure 1. However, only 18 groups achieved registration of the  
259 caregivers due to 1 group disbanding shortly after mobilisation. Of the remaining 18 SHGs, the  
260 functional status at the end of the set-up period was as follows: 11 active groups (operational) and  
261 7 inactive groups (disbanded). Figure 1 shows the location and functional status of the 19 groups.  
262 Tables 1 and 2 summarise the characteristics of the registered caregivers according to group  
263 functional status post-set up.



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294 **Figure 1. Map of Kilifi County showing the locations of the SHGs across the five**  
 295 **constituencies: functional status indicated**

296 As shown in table 1, the CHW groups were responsible for bringing caregivers together for 11  
297 SHGs compared to 6 SHGs by the WGs. The amount and frequency of meetings varied across the  
298 SHGs. The active groups met at weekly intervals, which amounted to around 40 meetings over 10  
299 months, each meeting lasting 2-3 hours. Monitoring visits were successful according to the  
300 monthly arrangements made as shown in Table 3. Of the inactive groups, 2 of the 7 came together  
301 as a group for less than a three-month period before disbanding. The remaining 5 groups continued  
302 to meet for between 3 to 5 months. Follow-up visits were arranged when the membership failed to  
303 attend a monitoring visit, by contacting the relevant Chairperson. However, these were largely  
304 unsuccessful (see table 1). The inactive SHGs showed inconsistent attendance and poor  
305 representation of the membership at the visits with as few as 1 or 2 members being present on  
306 occasions.



307 **Table 1. Summary of compliance with implementation across active and inactive groups**  
 308 **post-registration**

<b>SHG</b>		<b>Average Membership</b>				<b>Monitoring visits</b>		<b>No. of SHGs doing activities</b>	
Functional status: sum	Mobilisation - ratio CHW:WG	Members <i>Mdn</i> (range)	M:F	Complete <i>Mdn</i> (range)	Unsuccessful <i>Mdn</i> (range)	Merry-go-round	Other		
Active: 11	6:4	14 (5-20)	2:13	10	0	11	7		
Inactive: 7	5:2	12 (12-20)	1:12	3 (2-5)	3 (2-5)	7	0		

309

310 All the eighteen groups decided on a name and assigned officer roles amongst their membership  
311 (Chairperson; Treasurer; Secretary). In some cases, an additional role was assigned – that of a co-  
312 ordinator who facilitated the work of the other officers. Typically, this role was fulfilled by a  
313 member of the community group who had been involved in the original mobilisation of the  
314 caregivers.

315

### 316 *Mechanisms of impact*

317

318 As shown in table 1, responses to the development process were initially favourable with all  
319 eighteen SHGs embarking on merry-go-round activities, where according to the agreement of the  
320 group, each member contributes either a small sum of money (e.g. around 50Ksh) or food stuffs  
321 (e.g. bag of maize flour, sugar). Once the Treasurer has collected the member contributions, the  
322 collection is divided among 3-4 members who use their allowance to improve the situation at  
323 home, e.g. cooking cakes to sell at profit. In addition, 7 of the SHGs (active) embarked on group  
324 income generating projects (other activities) including, e.g. making and selling liquid soap, makuti  
325 for roofing; rearing livestock (chickens, goats); breaking stones into gravel for building.

326

327 There was minimal difference between the active and inactive groups in terms of caregiver  
328 characteristics (see table 2). As shown in table 2, between 23-25% of the members of both active  
329 and inactive groups had completed primary education. However, a slightly higher percentage of  
330 active group members had attained a secondary level of education (8%) compared to 4% of the  
331 inactive group's membership.

332 **Table 2. Summary of caregiver characteristics registered to 18 SHGs: functional status**  
 333 **indicated**

	<b>Active (n=154)</b>		<b>Inactive (n=100)</b>		<b>Sum (N=254)</b>	
<b>Age Range %</b>						
<20	2	1%	2	2%	4	2%
21-39	79	51%	39	39%	118	46%
40+	74	48%	59	59%	133	52%
<b>Educational Level %</b>						
No formal	68	44%	48	48%	116	46%
Primary – incomplete	36	23%	23	23%	59	23%
Primary – complete	37	24%	25	25%	62	24%
Secondary	13	8%	4	4%	17	7%
<b>Marital status %</b>						
Single	9	6%	4	4%	13	5%
Married	106	69%	73	73%	179	71%
Divorced	16	10%	8	8%	24	9%
Widow	23	15%	15	15%	38	15%
<b>No. of children at home %</b>						
1-2	18	12%	17	17%	35	14%
3-6	90	58%	53	53%	143	56%
7-10	40	26%	25	25%	65	25%
11+	6	4%	6	6%	12	5%
<b>No. of children with disabilities %</b>						
1	146	95%	91	91%	237	93%
2	6	4%	8	8%	14	6%
3	2	1%	1	1%	3	1%

334

335 In terms of demographic characteristics, there was again little difference between the groups  
336 according to their functional status (see table 3). Caregiver clothing, specifically footwear was  
337 much more common amongst the active group members (see table 2). Additionally, 56% of the  
338 inactive group members served two or less meals per day compared to those in the active groups  
339 (46%).

340 **Table 3. Summary of demographic characteristics for caregivers registered to 18 SHGs:**  
 341 **functional status indicated**

	Active (n=154)		Inactive (n=100)		Sum (N=254)	
Caregiver clothing %						
Quality – poor	0	0%	0	0%	0	0%
Quality – good	154	100%	100	100%	254	100%
Footwear – yes	143	93%	6	39%	149	46%
Footwear – no	11	7%	94	59%	105	52%
State of home dwelling %						
Mud & thatch - poor	56	36%	35	35%	91	36%
Mud & thatch - good	29	19%	15	15%	44	13%
Iron roof	37	24%	33	33%	70	26%
Concrete	32	21%	17	17%	49	19%
Meals served per day %						
1	15	10%	12	12%	27	11%
2	55	36%	44	44%	99	39%
3	80	52%	42	42%	122	48%
4	3	2%	2	2%	5	2%
Livestock %						
Chicken	96	62%	62	62%	158	62%
Duck	32	21%	21	21%	53	21%
Goat	68	44%	38	38%	116	46%
Cow	28	18%	23	23%	51	20%
None	39	25%	24	24%	63	25%

342

343 Internal factors were reflected in strengths and weaknesses of all the groups, and external factors  
344 in the opportunities and threats. However, the balance varied between active and inactive groups,  
345 with the former being weighted towards strengths and opportunities, and the latter towards  
346 weaknesses and threats.

347 **Table 4. Summary of SWOT analysis for active and inactive groups: shared characteristics**  
 348 **and processes indicated in italics (separate characteristics are indicated in brackets: active**  
 349 **groups = AG; inactive groups = IG)**

<i>Strengths</i>	<i>Opportunities</i>
<p>Leadership &amp; capacity:</p> <ul style="list-style-type: none"> <li>○ <i>Early allocation of official roles in the group, e.g. chair, secretary, treasurer;</i></li> <li>○ Strong leadership - clear direction for group's endeavours (AG);</li> <li>○ Available literacy and numeracy skills to support activities (AG);</li> <li>○ Managing and contributing to agenda of meetings (AG);</li> <li>○ Maintaining group ledger and basic book-keeping of finances (AG).</li> </ul> <p>Commitment &amp; team process:</p> <ul style="list-style-type: none"> <li>○ Regular attendance of meetings by the members (IG: only 1 SHG showed consistent attendance of meetings in early months);</li> <li>○ Active participation in group discussions, e.g. developing ideas about income generation (AG);</li> <li>○ Prioritisation of group needs over individual needs (AG).</li> </ul>	<p>Capacity-building:</p> <ul style="list-style-type: none"> <li>● Continued support from established community group (e.g. WG or CHW) (AG).</li> </ul> <p>Income generation:</p> <ul style="list-style-type: none"> <li>● <i>Merry-go-round;</i></li> <li>● Making and selling: liquid soap; makuti for thatched roofs, gravel for building (AG);</li> <li>● Livestock rearing: goats, poultry (AG).</li> </ul>
<i>Weaknesses</i>	<i>Threats</i>
<p>Leadership &amp; capacity:</p> <ul style="list-style-type: none"> <li>● <i>Inconsistent attendance by Chairperson;</i></li> <li>● Unreliable and/or uncontactable chairperson (IG);</li> <li>● <i>Dependence on one person with literacy or numeracy skills;</i></li> <li>● Poor book-keeping and financial accounting (IG);</li> <li>● Small membership providing a thinner margin for continuity of activities (AG).</li> </ul> <p>Commitment &amp; team process:</p> <ul style="list-style-type: none"> <li>● <i>Inconsistent attendance of SHG meetings by some members;</i></li> <li>● <i>Passivity of some members who are reluctant to speak up;</i></li> <li>● Individual members requesting financial hand-outs with own needs prioritised over group (IG);</li> </ul>	<p>Environmental conditions:</p> <ul style="list-style-type: none"> <li>● Drought in East Africa affecting home priorities, e.g. need to search for water (IG: 2 SHGs were affected particularly at an early stage);</li> <li>● Distance from homesteads to meeting place (AG: affecting 1 group engaged in farming for income generation);</li> <li>● <i>Pests affecting livestock, e.g. avian flu affecting poultry;</i></li> <li>● <i>Unstable meeting place threatened by weather conditions or competing usage.</i></li> </ul> <p>Interference:</p> <ul style="list-style-type: none"> <li>● <i>Interference from others in the community (IG: WG associated with SHG mobilisation; AG: fraudulent activity by visitors to community, e.g. woman falsely claimed to be from National Council for</i></li> </ul>

<ul style="list-style-type: none"><li>• <i>Generation of non-viable income generation ideas, e.g. poultry, without prior knowledge of care.</i></li><li>• Geographically dispersed membership affecting attendance of meetings (IG);</li><li>• Expectations of an allowance as per other NGOs operating in area (IG).</li></ul>	PWDs took money under false pretences, impostor bankers applied pressure to take group savings).
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351 As summarised in table 4, the majority of the active groups had a strong and consistent leader,  
352 often with the continued support of members of the local CHW or WG. Sometimes a person had  
353 dual membership of both the SHG and a community group, which enabled the sharing of group  
354 experiences and skills. In one group, a CHW continued as a member of the SHG, supporting the  
355 leader by contributing her literacy and numeracy skills for recording group discussions and work  
356 transactions. A stable membership, committed to the group's activities was evident in the regular  
357 attendance of weekly meetings and the commitment of team members. Critical mass appeared to  
358 be important to the development capacity of the groups, with activity success being threatened in  
359 smaller groups by a lack of persons to input their labour. Early identification and management of  
360 threats, e.g. breaking away from a large chaotic group, risk management of income generation  
361 activities, enabled the groups to grow. However, the active groups were not without weaknesses.  
362 Two groups relied on a few caregivers with poor commitment from the rest of the members. Such  
363 vulnerabilities demanded close monitoring and support for those members. Restricted literacy and  
364 numeracy skills amongst members was a problem in one or two groups, affecting management of  
365 group finances and recording decisions. Threats that were identified tended to centre on  
366 interference from external people, e.g. fraudulent activity by people in the community attempting  
367 to take money from the group, individual members demanding hand-outs, and environmental  
368 conditions such as drought – the latter affecting food and water supplies. Notice of such threats  
369 was brought to the attention of the researcher who gave advice that served to mitigate any  
370 potentially disastrous impacts on the group. Lack of a secure meeting place was a minor threat for  
371 a couple of groups, e.g. located under a tree that would be affected by the rainy season; an  
372 incomplete building structure due to be completed for use by the police service.

373  
374 Opportunities for development of key skills, such as chairing a meeting, recording the notes and  
375 the financial transactions were available to all groups. However, income generation was grasped  
376 by the groups with variable success. The 7 groups who started up income generation activities  
377 were all in the active category.

378 The inactive groups demonstrated inherent weaknesses from a very early stage, such as poor and  
379 inconsistent leadership. This made them vulnerable to external threats, even though similar threats  
380 were identified for the active groups. Together with a lack of consistent leadership, a  
381 geographically dispersed membership affected group cohesion. In one area particularly (Bamba)  
382 the effects of drought threatened the setup of groups from the start, as caregivers had to prioritise  
383 the search for water for their families over attendance of SHG meetings. In some cases, the  
384 fraudulent behaviour of others (both within the group and externally) who took money and food  
385 stuffs under false pretences affected the morale of members and their motivations to keep going.

386

## 387 **Discussion**

388

389 Out of twenty targeted SHGs, two groups failed to achieve registration. At the end of the set-up  
390 period, seven groups out of the eighteen registered groups had disbanded. Eleven groups were still  
391 functional. All eighteen groups had decided on a named identity, assigned officer roles in their  
392 group and embarked on merry-go-round activities. However, membership and compliance with  
393 monitoring visits varied across the groups. Characteristics associated with the collapse of the  
394 inactive groups included: poor leadership, inconsistent attendance and failure to comply with  
395 monitoring visit requirements; poor availability of key skills, such as numeracy and literacy;  
396 interference from former members and others outside of the group; harsh environmental conditions  
397 affecting livestock and access to water. In contrast, the active groups appeared to have: greater  
398 commitment amongst the membership and attendance of meetings, with monitoring visits  
399 happening as planned; better access to numeracy and literacy skills amongst the members (with  
400 the exception of one SHG); the means for addressing external threats through timely advice;  
401 capacity to develop start-up projects for income generation.

402

403 Some groups did not progress beyond initial registration due to competing needs in the home  
404 brought about by the extreme drought conditions affecting East Africa. Maslow's motivation  
405 theory based on a hierarchy of need places this at the foundation level: physiological (Kotko-  
406 Revera 2006; Maslow 1943). Without water, the threat to family survival was present. Thus the  
407 search for water was prioritised over participation in the SHG development, which is consistent  
408 with challenges identified by Adams & Galvaan (2010). In addition, caregiver dispersal over a  
409 large geographical area may have been a factor in their coming together for meetings. This was  
410 despite a recruitment strategy via established community groups operating in a defined  
411 geographical area. Transport limitations and a lack of finances would also likely have affected  
412 their attendance (Ambikile & Outwater 2012; Gona et al. 2016). Beyond a 'physiological' level of  
413 need, threats to 'safety' were present in all the groups, active and inactive. The mere act of  
414 registering with a SHG meant identifying themselves as caregivers of a child with disabilities and  
415 possibly opening themselves to aversive responses from the community where stigma was present  
416 (see Bunning et al. 2017). This may have been a factor in the failed registration of caregivers in  
417 one SHG after their initial mobilisation.

418

419 Attaining a level of 'belonging and love' (Maslow's third level) could be seen to be dependent on  
420 the established 'safety' of the group and its members. Individuals asserting their own needs over  
421 those of the membership, brought tensions to some groups, which resonates Adams & Galvaan  
422 (2010) and Brody et al. (2017). However, greater threats were encountered from persons external  
423 to the SHG development. Whilst all the groups encountered threats from dishonest individuals in

424 the community, the inactive SHGs experienced such threats very early on – in the first 2-3 months.  
425 It is possible that the embryonic status of the groups rendered them as vulnerable to disruption. In  
426 contrast, the later threats to the active groups happened at a time when relationships amongst the  
427 caregivers had been established. This corresponds to Maslow’s third level of need: ‘love and  
428 belonging’. There was commitment to the group processes such as the monitoring visits, which  
429 provided opportunities for leveraging help on how to, not only address problems faced by the  
430 group, but to progress their activities. Empowerment theory as defined by Kieffer (1984) and  
431 Zimmerman & Rappaport (1988), would explain this as the growth of control and awareness of  
432 the socio-political context in which the groups were functioning. The merry-go-round activities  
433 were designed to support trust amongst the members, (critical to a sense of belonging) as well as  
434 providing learning opportunities for handling goods and money as a precursor the income  
435 generation projects. However, the inactive groups faltered at this stage and did not progress to  
436 livelihood activities, compared to seven out of the eleven active SHGs. Never-the-less, these  
437 activities were critical components of capacity-building. The members gained important  
438 experiences in the handling of goods and money, leading onto income generation projects, which  
439 reflects Cohen et al’s (2012) findings. In this context attainment of Maslow’s higher levels of  
440 ‘esteem’, where recognition of self contributes to developing agency, and ‘self-actualisation’,  
441 where aspirational potential and the desire to affect change were relevant.

442  
443 The extent to which educational level of achievement amongst the membership was important to  
444 group sustainability has relevance. Limited fulfilment of caregiver education generally was  
445 consistent with recent statistics in sub-Saharan Africa ([www.uis.unesco.org](http://www.uis.unesco.org)). Furthermore, there  
446 was greater representation of caregivers who had completed their secondary education in the active  
447 groups compared to the inactive. This difference in the active and inactive group membership is  
448 consistent with Atteraya et al. (2017) and Patal & Kokate (2016) who asserted the critical  
449 importance of individual capabilities to active participation, which included educational  
450 background. It was the case that the majority of the groups, active and inactive, relied on just two  
451 or three members with the greatest competence in literacy and numeracy, for organising and  
452 recording the group’s activities. Having ties with an already established community group e.g.  
453 CHW or WG, either through affiliation or dual membership of two groups (SHG and CHW/WG)  
454 brought essential capabilities and prior experience, which may have had a positive effect on group  
455 operations. However, the inactive groups had lower access to someone with secondary level  
456 education generally. Whilst officer roles were assigned in all the groups, leadership was a critical  
457 component of the business conducted by the groups. The strong leadership in the active groups,  
458 which was always associated with primary or secondary educational level of achievement,  
459 supported what Zimmerman and colleagues referred to as a critical understanding of context and  
460 how to bring about change (e.g. Zimmerman & Warschausky, 1998; Zimmerman & Rappaport,  
461 1988). Thus the leader may have affected the direction taken by the group in terms of income  
462 generating projects.

463  
464 Strengths & limitations

465  
466 In a context of scarce reporting of development work of this nature, the strengths of the current  
467 study lie in the report of contrasting features of active and inactive groups. However, information

468 on caregiver attendance of group meetings was recorded inconsistently and could not, therefore,  
469 be reported with any accuracy. The SWOT analyses were conducted at the end of the set-up period.  
470 However, a SWOT analysis at the midway point may have yielded further information about the  
471 development process. This would require more extensive resources for the research.

472

### 473 **Conclusions and implications**

474

475 The functional status of SHGs, their active or inactive status at the end of a set-up period, appeared  
476 to be associated with characteristics and processes both within and external to the groups. Threats  
477 to the new enterprise of SHGs were present for all the groups. Motivations to participate in the  
478 groups were undoubtedly affected by drought, particularly for the communities worst affected by  
479 the environmental conditions. Beyond competing physiological needs, the timing of threats in the  
480 group's development process seemed to be important. Early disruptions rendered some groups  
481 vulnerable to dissolution. Of course, the monitoring visits provided opportunities for leveraging  
482 help once a sense of trust and belonging in the group had been established. Thus compliance with  
483 monitoring visits appeared to be critical to group survival and growth in the set-up period. It is  
484 possible that such threats might be countered by early investment in group education, e.g. helping  
485 the groups to identify potential sources of threat to the group's safety from the very start and  
486 putting contingencies in place to support their address, e.g. referring troublesome matters to the  
487 project co-ordinator for advice. Thus group safety is a central consideration in the set-up of SHGs  
488 and crucial to a sense of belonging for progression of activities.

489

490 Capabilities among the membership and strong leadership appeared to be important to group  
491 operations. Effective book-keeping and accounting enabled the active groups to plan and embark  
492 on income generation projects. This might possibly point to a recruitment strategy that purposively  
493 seeks to include sufficient caregivers with achievement at primary or even at secondary level  
494 education, to ensure the smooth organisation of group business. Alternatively, awareness of the  
495 relevance of capabilities and education to the success of a group might trigger early capacity-  
496 building amongst the membership, focusing on processes to support group management and  
497 organisation.

498

499 Finally, the active participation of caregivers in newly formed SHGs is subject to conditions both  
500 external and internal to the group. In order to sustain group development and to achieve growth in  
501 self-help activities, pathways for strategic support and capacity-building need to be in place at the  
502 start of the set-up. In such circumstances the approach to self-help groups has the potential to  
503 contribute to the evidence base on CBID/CBR initiatives development.

504

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