

Impact case study (REF3)

Institution: University of East Anglia		
Unit of Assessment: 3 - Allied Health Professions, Dentistry, Nursing and Pharmacy		
Title of case study: Community-based inclusive development: empowering caregivers of children with developmental disabilities in rural Kenya		
Period when the underpinning research was undertaken: 2012 - 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Dr Karen Bunning	Reader in Developmental Disabilities	2003 – to present
Period when the claimed impact occurred: 2015 - 2020		
Is this case study continued from a case study submitted in 2014? Yes		
1. Summary of the impact		
<p>Caregivers and their children with developmental disabilities are one of the most marginalised groups in sub-Saharan Africa. In partnership with the Kenya Medical Research Institute (KEMRI), UEA Researchers have built on a previous collaboration with the World Health Organisation (WHO) to establish new principles for community-based inclusive development (CBID, formerly community-based rehabilitation: CBR). The partnership established 19 self-help groups to address the economic poverty, disenfranchisement and alienation affecting such individuals in rural Kenya. Demonstrating resilience to successive droughts and the COVID-19 pandemic, the caregivers have an enhanced role and their voices are heard. Group livelihood activities are registered with the Kenyan Government Ministry and have become a vital, local source of entrepreneurship, employment, skills development and caregiver empowerment, with visible benefits for their communities. Peer support and self-advocacy have helped to address long-held prejudices against children with disabilities. This work has informed a model that is being adopted in other African countries.</p>		
2. Underpinning research		
<p>Since 2008, UEA and KEMRI have partnered to investigate challenges faced by caregivers and their children with developmental disabilities in Kilifi County, Kenya, addressing gaps in pre-existing knowledge and establishing culturally relevant and sustainable interventions. A situation analysis [Grant A] revealed workforce deficiencies in health and educational provision, suboptimal rehabilitation practice and poor community-level access [3.1]. This led to a focus on caregivers as agents for change in the lives of their children [Grant B]. Caregivers were successfully engaged in delivering a home-based intervention to address their children's complex communication needs. After the intervention caregivers reported a greater sense of well-being, a perception that their child's disability was less severe, and observed an increase in the child's community participation [3.2].</p> <p>Sustainability of approach and reach of impact remained important concerns despite these positive outcomes. Therefore, the team changed focus beyond the home to the wider community [Grant C] and adopted CBID, a composite strategy to meet the needs of persons with disabilities (WHO, 2010). Firstly, the team investigated cultural understanding of disability and the associated challenges for caregivers. This revealed misconceptions about disability causation, discriminatory attitudes and aversive responses, some of which related to superstitious beliefs [3.3]. Secondly, to raise awareness and to shape community responses to persons with disability, 4 local experts-by-experience (people living with disabilities) intervened by telling their personal stories to 20 formally constituted community groups (health worker and women's groups). This led to a shift in group attitudes to persons with a disability - from 'burden' to 'agency', and 'sub-human' to 'human' [3.4]. As a result, the community groups called for further action to help such families.</p> <p>Having created a more enabling environment at the local level, the team refocused on the caregivers and their children with disabilities. Using the 'empowerment' domain of the original CBR matrix (WHO, 2010) [Grant D, SEEK], attention was given to the development of self-help groups</p>		

(SHGs). Adoption of a realist evaluation research design enabled a focus on the primary beneficiaries and the setting conditions. The SEEK project mobilised the caregivers (N=254) from the 20 community groups from the previous study to form SHGs. Despite the challenges of drought affecting water supplies, destruction to livestock through infections, limited education amongst caregivers, and in-group conflicts, 11 out of 19 SHGs (154 caregivers) were successful, demonstrating resilience and capacity for growth [3.5]. At baseline the burden of caregiving, (characterised by *aloneness, challenges, stigma and discrimination*) was evidenced. Post-intervention, caregiver agency emerged emphatically (defined by *togetherness, capacity-building, acceptance and well-being*). There were significant gains in the caregiver's social support networks; they viewed their child's disability as less severe, and their caregiving role as less problematic. Mechanisms of 'handling goods and money' and 'social ties and support' underpinned the outcomes [3.6].

This programme has brought benefits to caregivers and children with disabilities, and contributed to the evidence on CBID/CBR [3.4-3.6]. Currently, a follow-up study is underway in collaboration with a Kenyan-based, non-government funded organisation: Kuhenza for the Children Foundation [Grant E, SEEK-2] that focuses on the upscaling of SHGs and the adoption of the model by CBID/CBR sites across countries in the Africa network (Afri-CAN). More recently, this includes monitoring impacts associated with the Covid-19 pandemic which has had differential effects on caregivers and their children with developmental disabilities.

3. References to the research

- [3.1] Survey of rehabilitation support for children 0–15 years in a rural part of Kenya.
Bunning, K., Gona, J.K., Odera-Mung'ala, V., Newton, C., Geere, J., Hong, C.S., Hartley, S. (2014). *Disability & Rehabilitation* 36(12),1033–1041.
 DOI: 10.3109/09638288.2013.829524.
- [3.2] Caregiver perceptions of children who have complex communication needs following a home-based intervention using augmentative and alternative communication in rural Kenya: An intervention note.
Bunning, K., Gona, J.K., Newton, C.R., Hartley, S. (2014). *Augmentative & Alternative Communication* 30(4), 344-356. DOI: 10.3109/07434618.2014.970294.
- [3.3] The perception of disability by community groups: Stories of local understanding, beliefs and challenges in a rural part of Kenya.
Bunning, K., Gona, J., Newton, C., Hartley, S. (2017). *PLoS ONE*, 12(8), e0182214.
 DOI: 10.1371/journal.pone.0182214
- [3.4] Person with disabilities as experts-by-experience: using personal narratives to affect community attitudes in Kilifi Kenya.
 Gona, J., Newton, C., **Hartley, S., Bunning, K. (2018).** *BMC International Health & Human Rights* 18(18),1-12; DOI: 10.1186/s12914-018-0158-2.
- [3.5] Development of self-help groups for caregivers of children with disabilities in Kilifi, Kenya: Process evaluation.
 Gona, J.K., Newton, C.R., **Hartley, S., Bunning, K. (2020).** *African Journal of Disability* 9 (0), a650. DOI: 10.4102/ajod.v9i0.650.
- [3.6] Empowering self-help groups for caregivers of children with disabilities in Kilifi, Kenya: Impacts and their underlying mechanisms.
Bunning, K., Gona, J.K., Newton, C.R., Andrews, F., Blazey, C., Ruddock, H., Henery, J., Hartley, S. (2020).
PLoS ONE 15(3): e0229851. DOI: 10.1371/journal.pone.0229851.

Grant Details

- [A] PI: Bunning, K. *et al.* Project: *Disability to Rehabilitation*.
 Funder: CP Trust. Value: GBP105,250. Dates: 2008-2010.
- [B] PI: Bunning, K. *et al.* Project: *Communication for ALL Pilot (CALL)*.
 Funder: CP Trust. Value: GBP30,281. Dates: 2010-2013
- [C] PI: Bunning, K. *et al.* Project: *Disability awareness in the community: Preparation for Communication for ALL*. Funder: CP Trust. Value: GBP42,381. Dates: 2014-2015.

- [D]** PI: Bunning, K. *et al.* Project: *Empowering community-based SElf-hElp groups for children (0-15 years) with disabilities and their families in rural Kenya (SEEK)*. Funder: CP Trust. Value: GBP120,163. Dates: 2015-2018
- [E]** PI: Bunning, K. *et al.* Project: *Empowering community-based SElf-hElp groups for children (0-15 years) with disabilities and their families in rural Kenya: Follow up (SEEK-2)*. Funder: CP Trust. Value: GBP90,059. Dates: 2018-2021

4. Details of the impact

Globally, the development potential of children growing up with disabilities continues to be neglected. This is particularly evident in sub-Saharan Africa where caregivers bear the responsibility for the burden of care. In rural Kenya, a combination of superstition, stigma and discrimination marginalises these families. Not only can these children be excluded from education, employment and contact with other villagers; the level of stigma is such that the caregiver's shame may lead them to deny their existence. This creates social isolation with a burden of care that is unrelenting for many: *"the mother is experiencing a lot of trouble because when she wants to go somewhere... she cannot carry the child and cannot leave her at home also."* **[Source of quote: 3.3].**

Working with local collaborators, the team developed a culturally-relevant and sustainable CBID programme that brought about lasting change to the self-value and socioeconomic status of caregivers of children with developmental disabilities.

Attitude and behaviour change

The deployment of experts-by-experience in a disability sensitisation programme **[3.4]** and the establishment of self-help groups (SHGs) across Kilifi County **[3.5, 3.6]** produced a fundamental attitudinal shift away from deeply held prejudices. Structured multi-dimensional partnerships with caregivers provided opportunities for local communities to reflect upon, and then adjust, their views on disability. They began to recognise the person before the disability: *"...we are all human beings..."*; recognition of children's potential for learning: *"...regardless of the disability, people with disabilities can learn in school."*; and contribution to the community more widely: *"They know how to work. When they ask for a job, don't look at his disability. Look at his abilities; look at what he can do."* **[Source of quote: 3.4].**

Greater community spirit is evident: in one village when a caregivers' house was burnt down by her disabled child, the SHG group provided clothing and food and then rebuilt their house. Previous experience of isolation was replaced with a mutually supportive social network, which came out of the SEEK project. **[5.1].**

The importance of changing attitudes is illustrated by the fact that 75 caregivers rated their child's disability as significantly less severe after participating in SHGs even though no intervention had been directed at the children themselves **[3.6]**. Children from households participating in SHGs now attend school unless prevented by distance to school, impaired mobility, or lack of transport **[5.5]**. The care, food and clothing needs of children with disabilities were catered for and their participation was encouraged by many caregivers: *"I make sure that I involve my child in house chores. We should not hide them and making them be seen by people around us"* **[5.2].**

Capacity-building

Growing competence: Despite their limited education, 33 individual female members demonstrated growing competence and confidence in their SHG officer roles (e.g. Chairperson, Secretary, Treasurer), leading weekly meetings, recording attendance and managing financial transactions). One group reported diversification of their livelihood activities to help the membership and their children with disabilities **[5.5]**.

Developing community activism: Despite limited structures to support activism, funding and official recognition of these families, each SHG has written its own formal constitution and has secured funding for the group's registration fee with the Ministry of East African Community, Labour and Social Protection, enabling them to apply for official support. Ten groups achieved SHG certification with linked bank accounts, and one as a community-based organisation legitimising their business over a larger geographical area **[5.3]**.

Building influence: Groups are acting to influence various stakeholder groups: “...our chairperson who has a disability has been used by organisations to talk about his experiences of living with a disability. People listen to him and get the message he gives” [5.2]. One group established links to a thriving national women’s organisation. Another invested in plastic chairs, which are hired out to a local Chief for community functions and another meets outside the local Chief’s Office, with his permission, thus raising its local status [5.1].

Advancing Kenyan research excellence: Completion rates for postgraduate studies are low in Kenya. Our main local collaborator Joseph K. Gona (KEMRI) completed his PhD in this area, published 7 first-authored peer-reviewed journal articles as lead author [e.g. 3.4; 3.5], and presented at an international conference [5.8].

Experts-by-experience: Adults with disabilities are assuming new roles as leaders and educators within their SHGs. Four individuals conducted disability sensitisation training initiatives in 20 community groups in 2014-5 [3.4]. When they leave school, young people with disabilities are now supported to set up their own small businesses [5.5]. One SHG Chair with cerebral palsy was nominated to co-present a workshop for the World CBR Congress in Uganda, July 2020.

Economic development, growing resilience and well-being

Kilifi County is one of the poorest areas in Kenya, with 71.4% poverty. Most residents live in 1-2 room mud construction dwellings without power or running water. Largely dependent on subsistence farming, the average income for a family (parents and six children) is KES1000 per month – less than USD13 (Kenya National Bureau of Statistics). The economic benefits of SHG livelihood projects are evident. SHG testimonials at 1-year follow-up speak of their savings and the extra resources for their children with disabilities, e.g. food, skin oil and well-being [3.6]. One caregiver told us: “I’m happy because my child with disability cannot cry for anything now. I can provide for him with what I get from this group. It has brought us together. We all have phones and we can communicate with each other in case there is need”. [5.2] One SHG outlined their business plan to purchase a tuk-tuk for running a taxi business [5.5].

In 2016, Kilifi County’s food security was classified as ‘stressed’ due to three consecutive below-average rainfalls and near total failure for crop staples such as maize, cowpeas and cassava. However, despite extreme environmental conditions, most (n=11) SHGs were active throughout the crisis, continuing to grow, buy, and sell crops, and rear livestock [5.1].

Some SHGs have expanded using microfinance loans. By early 2019, they generate proposals, articulate business goals and managed repayment schedules [5.5]. One SHG told us: “This group has a big projection. When it comes to saving money, we have saved over KSH80,000. After our collection today, we will have a bit over KSH100,000. Circulating money does not give us enough profits. But when we give it to individual members to run individual projects that gives a lot of profit”. [5.2] Cognisant of the devastating impacts of drought, SHGs now consider alternatives to farming to raise money. “We are thinking of buying plates and sufurias (large cooking pots) for hire...it does not depend on the rains”. [5.2]. Just before COVID-19 lockdown (01.02.20), the caregivers expressed high satisfaction in their roles in relation to their children with disabilities, with a positive sense of self-value and personal growth. Money worries and a lack of carer support were still present; however, there was new confidence in their ability to manage [5.2].

Resilience in Covid-19 pandemic

Structured interviews were administered with an official (e.g. Chairperson, treasurer) from the SHGs and recorded in fieldnotes. The supportive structures of the SHGs have helped to mitigate the worst effects of Covid-19 on the caregivers and their children with disabilities (April-December 2019). Despite the difficulties imposed by the pandemic affecting SHG meetings, the continuity of livelihood activities and attendance of schools, contact amongst the membership has been maintained, in most cases, via brief socially-distanced meetings and mobile phone communications. The groups have been active in identifying and advocating for the needs of their most vulnerable members at the local Chief’s office for food relief. One group said they were not in urgent need of food and preferred it should go to others with a greater need. Two groups managed to repay their microfinance loans during this period. One SHG planned to expand their successful flour selling business by applying for microfinance and another group planned a poultry

project. Despite the departure of most of its members during the COVID-19 crisis, the two remaining members of an SHG are motivated to rebuild and are looking for new members [5.6].

Network development

County: Recent easing of lockdown allowed for six socially-distanced interviews with officials from the locality Chief's offices, and health and education sectors in Kilifi County. Fieldnotes recorded in situ capture the Chiefs recognition of the role of SHGs in helping caregivers to 'manage' and 'transform' the lives of children with disabilities; headteachers confirmed the attendance of children with disabilities at their schools recognising the facilitating role of the SHGs; health practitioners commented that children with disabilities are brought to the health centres, demonstrating how SHGs have encouraged other caregivers to seek medical help for their children [5.7].

Pan-Africa: In 2018, the SHG work was recognised as an important strategy by the Africa Network and the SEEK project team was invited to contribute to their Summary Report of the 6th CBR/CBID Africa conference [5.8]. The conference, attended by five hundred CBID workers from 24 African countries, resulted in 37 sites across 10 countries, signing up to trial the SEEK guidelines. Proposals included: SHGs for parents at primary schools (Malawi); capacity-building for disabled persons organisations (Zambia); enhancement of existing caregiver support programmes (Ethiopia; DRC). Implementation has been impacted by the global pandemic. However, early feedback included: "*strengthening the parents support groups to become self-sustaining*"; empowering "*children to learn how to make door mats, sew bags and string beads into necklaces and bracelets*" (Zambia) with reported impacts of mutual support, growth in confidence and vocational planning for children with disabilities [5.9]. A new partnership between Kenya and Cameroon was established to co-author a chapter for a new edition of an Africa Network publication, capturing this community development work for dissemination to its membership across Africa [5.10].

Global: Whilst SEEK's work builds on an earlier collaboration with the WHO, the current pandemic prevents further responses at this time. The Honorary President of the Global CBR Network has endorsed the work on SHGS for the "*very human*" process that has established "*connectivity...to the social and geographical context*" with "*easy to use guideline for possible use in the community*" [5.4].

5. Sources to corroborate the impact

- [5.1] Project SEEK: (a) SHG pilot guidelines, 2015; (b) SHG in Africa Newsletters: (b.1) October 2019; (b.2) December 2019; (b.3) March 2020.
- [5.2] Transcriptions of 3 SHG focus group discussions at 1-year follow-up (January/February 2020).
- [5.3] Certificates of registration, Ministry of East African Community, Labour and Social Protection, Kenya (2018-20).
- [5.4] Letter from the Honorary President of the Global CBR Network (20.1.21).
- [5.5] Transcript of SHG focus group discussion (February 2020).
- [5.6] Questionnaire responses from SHG's answering questions relating to the Covid-19 pandemic (April – December 2020).
- [5.7] Feedback from strategic partners in Kilifi County health and educational sectors including handwritten fieldnotes taken during brief, socially distanced interviews (2020).
- [5.8] Congress report from 6th CBR Africa Network Conference, Zambia (7-11 May 2018), p.29.
- [5.9] (a) CBR Africa Network registration forms for trialling SHGs (May 2018); (b) e-mailed feedback from CBR Africa Network sites (2019-20); (c) SEEK self-help guidelines pilot evaluation form.
- [5.10] Commissioned chapter on self-help groups for Africa publication (March 2020).