

Self-help groups empower caregivers of children with disabilities

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Caregivers in low-income settings will be able to respond to the challenges of bringing up children with disabilities, thanks to a new model created by the University of East Anglia (UEA) and the Kenya Medical Research Institute (KEMRI).

Caregivers experience multiple deprivations, including inadequate resources, lack of support, negative responses from others in the community, and poverty. Not surprisingly, many caregivers experience fatigue, distress and isolation.

The aim of the UEA-KEMRI three-year project was to empower the caregivers so they could take control of their lives and bring about positive changes to their existing situations. Caregivers were brought together to run their own meetings and self-help activities, which included shared livelihood projects, talking to each other about the difficulties of caregiving, sharing their ideas for improving the lives of their children with disabilities, and advocating for change in their local communities.

The researchers carried out monthly monitoring

visits to the groups, facilitated group discussions and helped with activity planning.

Dr. Karen Bunning, a reader in speech and language therapy in UEA's School of Health Sciences, led the project.

Dr. Bunning said: "At the start of the project, caregivers spoke of their aloneness, the challenges and stigma and discrimination experienced in the community.

"At the end of the <u>project</u>, the caregivers had a greater sense of their own agency and talked of friendships with other members of the group, the development of new skills, acceptance of their child's disability and their own sense of well-being.

"In addition, there was significant growth in the <u>social support</u> around the <u>caregiver</u> and, despite the fact that the children with disabilities had received no targeted intervention, the caregivers rated their child's disability as less severe with fewer problems affecting their ability to provide care."

The model, including a set of practical guidelines, can be applied in other low-income settings and is currently being piloted across sub-Saharan Africa.

"Empowering self-help groups for caregivers of <u>children</u> with <u>disabilities</u> in Kilifi, Kenya: Impacts and their underlying mechanisms," is published March 9, 2020 in *PLOS ONE*.

More information: Karen Bunning et al. Empowering self-help groups for caregivers of children with disabilities in Kilifi, Kenya: Impacts and their underlying mechanisms, *PLOS ONE* (2020). DOI: 10.1371/journal.pone.0229851

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