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Author

Moses, Kawikizi, Kasang, Christa, Hirsch, Ernst, Kawuma, Joseph, Kuipers, Pim

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SHORT REPORT

Engaging with disability organisations in Uganda

KAWIKIZI MOSES*, CHRISTA KASANG**,
ERNST HIRSCH**, JOSEPH KAWUMA* &
PIM KUIPERS***

**German Tuberculosis and Leprosy Relief Association,
Kampala, Uganda*

***DAHW Deutsche Lepra- und Tuberkulosehilfe, Würzburg,
Germany*

****ILEP, Geneva, Switzerland and Menzies Health Institute,
Queensland, Griffith University, Queensland, Australia*

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Summary In Uganda, disabled peoples' organizations (DPOs), disability unions and the national disability council have the systems and a mandate to respond to the needs of people with disabilities. This short report presents aspects of a survey conducted in 2015 which explored the extent to which people affected by leprosy engage with, and benefit from these generic disability organisations.

Structured interviews were conducted with 144 people affected by leprosy, 102 people with other disabilities as well as with 86 service providers and workers in disability organisations. The survey showed evidence of the exclusion of people affected by leprosy from the disabled people's organizations. The survey identified key reasons for such exclusion, from the perspective of service providers as well as from the perspective of people with leprosy-related and other forms of disability. Suggestions for addressing this concern are noted.

Introduction

On the basis of Uganda GLRA office estimates, there are well over 2000 people living with leprosy-related impairments in the country.¹ With an additional 250 new cases per year (of which there are about 56 with visible impairments),² the number of people with leprosy-related disabilities is substantial.

In Uganda there is also a strong network of disability related civil service organisations, most of which come under the National Union of Disabled Persons of Uganda (NUDIPU).³ Recognising that in the 2014 Ugandan census, 12.5 % of people noted at least one form of

Correspondence to: Pim Kuipers, Menzies Health Institute, Queensland, Griffith University, Queensland, Australia (e-mail: p.kuipers@griffith.edu.au)

disability, these organisations have a key role to play. They provide a number of vital social and livelihood services for people with disabilities (including health education, providing medicines and mosquito nets, and support for income generation and savings and credit schemes).⁴ In parallel, the Ugandan government is actively partnering with these organisations to include people with disabilities in their policies and programmes. The importance of ensuring that people affected by leprosy are engaged in this network is self-evident, however anecdotal accounts indicate that they are not included in (or possibly actively excluded from) such disability organisations.

This study sought to investigate the extent to which people affected by leprosy are excluded from disability organisations.

Methods

Structured interviews were conducted with a total of 246 people with disabilities, comprising 144 people affected by leprosy and 102 people with disabilities not caused by leprosy. All had visible impairments, with all of the people affected by leprosy having completed MDT at least 2 years prior to interview. In addition, a related series of structured interviews were conducted with 86 service providers and workers in disability organisations across four study sites in East, Central, North and West Uganda. Data were collected by trained research assistants using a structured questionnaire.

In order to ensure consistent ethical practice, all research assistants were trained about leprosy and research practices by the first author. Verbal consent was obtained from all participants after the goals of the project were outlined. Confidentiality was assured through careful data storage and ensuring no personal or identifying details were presented in any outputs or reports. Findings were presented to key stakeholders through feedback sessions.

Results and Discussion

In overview, only 57% of people affected by leprosy said they had been included in the register of members of general disability organisations. When asked further, it appeared that their involvement was quite marginal, with only 52% of those registered saying they derived any benefit from visits of community representatives/workers.

While 64% of community workers/representatives maintained that they occasionally visited people affected by leprosy in their homes, very few recalled doing so in the weeks leading up to the survey. Approximately half of the service providers surveyed admitted that people affected by leprosy were sometimes not included in the organisational register. They stated that the main reasons for this were: self-exclusion by people affected by leprosy (40%) or exclusion by others due to fear of infection (33%). Other reasons noted were that people affected by leprosy were constrained by their disability, that there are now very few people affected by leprosy in the community, or that they were unable to afford the membership fees.

In comparison, when people affected by leprosy were asked about their reasons for not being engaged, they noted: not having information about who were the relevant representatives/workers (36%), indeed a quarter of respondents said they did not have information about the sorts of services these organisations provide. Other reasons given by people with leprosy-related disabilities included feeling discriminated against, lack of transport and lack of trust in the community workers.

A key dimension of the survey was to explore the views of people affected by leprosy as to why their perspectives were not included in the planning processes of community disability groups. While 10% said they had chosen not to participate, 55% said they were never consulted, with the remaining 35% saying they were isolated from the process, since the workers did not believe they could contribute or offer meaningful ideas.

As noted above, the government of Uganda has a strong legal framework pertaining to disability, with consistent laws, acts and bye-laws. However only about 10% of people affected by leprosy surveyed indicated that they understood this framework. Almost three quarters of leprosy-affected respondents said they lacked information about disability rights and freedoms, or even of available disability and development programmes.

While historical factors, such as the longer term consequences of living in separate communities or leproseries may contribute to this exclusion, external factors including myth, stigma and discrimination are also evident. Regardless of the causes, it is clear that there is a need for substantial efforts to ensure that people affected by leprosy can engage in these organisations to draw vital disability services, as well as financial, health, community and social benefits. As the role of local and national community disability groups and organisations becomes more prominent in the emergence of community-based disability-inclusive development globally⁵ ensuring their inclusion is further underlined. Suggestions for such actions from respondents included greater sensitisation of communities, providing relevant information for disabled person's organisations, and specifically targeting sensitisation efforts and anti-discrimination messages towards their key stakeholders, service providers and community volunteers.

Conclusion

Brief structured interviews were conducted with 332 people on the topic of engagement of people affected by leprosy in community disability organisations in Uganda. The survey showed evidence of the exclusion of people affected by leprosy from the disabled people's organisations. Many were not registered with the relevant disability organisations, and few were included in or even consulted for any local or organisational planning. The risk of people affected by leprosy also being 'organisationally marginalised' is a serious concern in the context of local and national disability organisations gaining prominence in emerging models of community-based disability-inclusive development.

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