

Research briefing on the Impact of the 2013-2016 Western African Ebola epidemic on people with disabilities

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Background

The Western African Ebola outbreak of 2013 – 2016 was the largest Ebola outbreak in history, infecting almost 30, 000 people and causing over 11, 000 deaths (World Health Organisation, 2020). Particularly impacted were Sierra Leone, Guinea and Liberia, with Liberia suffering the highest proportion of deaths overall. Within the national responses of these countries toward Ebola prevention, care and containment, very little thought was given to addressing the needs of people with disabilities (Berghs, 2016). This is despite the fact that people with disabilities are disproportionately affected by humanitarian crises (Holden et al., 2019), with previous work highlighting that, globally, the majority of people with disabilities directly impacted by such crises are not able to access basic services (e.g., food, shelter, Handicap International, 2015).

Concerning healthcare, people with disabilities have been described as the most marginalized group within any health system (Braathen et al., 2016). During humanitarian crises (as well as more generally), people with disabilities may experience difficulty in accessing healthcare due to inaccessibility of services, lack of accessible health information, and lack of accessible transportation. Moreover, at the point of care, providers commonly do not possess specialized knowledge (e.g., of particular impairments) and people with disabilities routinely encounter stigma and discrimination from healthcare staff (Kuper & Heydt, 2019).

The world is currently in the grip of economic and social disruption caused by COVID-19. Although the crisis is still unfolding, there is a pressing need to understand the impact that the epidemic will have on people with disabilities. We present some research findings from a Department for International Development [DFID]-Economic & Social Research Council [ESRC] funded grant that looked at Ebola and disability in Liberia.

Project Context and Methodology

The project set out to compare living standards between disabled and non-disabled people in Liberia using a mixed methodological approach, comprising both quantitative (survey) and qualitative (interviews) component. Data collection was originally scheduled to begin in 2015, but was delayed until after the conclusion of the Ebola outbreak. To understand the impact that the epidemic had on people with disabilities, the research team adapted the planned survey to include questions on Ebola.

We surveyed households (i.e. families) with a disabled person and neighbouring ‘control’ households (i.e. without a disabled person). Households with a disabled person were identified by random selection from lists provided by the national umbrella Disabled Person’s Organisation (DPO; National Union of Organisations of the Disabled–NUOD). Control households were selected by choosing the next nearest household to households with disabled members that had eligible individuals available to be interviewed. We did not survey every individual in each household, but a selection of individuals that met our criteria (see Carew et al., 2019). Overall, we sampled 2020 individuals from 1023 households across five counties in Liberia (Cape Mount, Lofa, Grand Bassa, Monserrado, and Sinoe).

In total, 560 of the respondents surveyed were in areas that had “many” or “a few” cases of Ebola (assessed via self-reporting). About half (48%) of these respondents lived in a household with someone that was disabled, and a quarter (24%) were disabled themselves.

Key findings

In Ebola affected communities:

- Four fifths of members of disabled households (80%) reported a decreased social life, compared to just over a third of members of non-disabled households (31%).
- Most members of disabled households (91%) listened primarily to community leaders regarding how to stop the spread of Ebola, compared to 38% of members of non-disabled households. In contrast, two-fifths of people living in non-disabled households (40%) listened to government/local authority representatives, while only 2% of people living in disabled households did.
- Lack of food was the primary problem affecting members of disabled (39%) and non-disabled households (36%). The other main issues affecting members of disabled households were lack of information on the Ebola outbreak (20%) and lack of information on health services (15%). For non-disabled households, the other primary problems were lack of information on Ebola (12%), access to Ebola treatment units (11%) and water (11%).
- Access to health services got worse for most disabled (84%) and non-disabled (76%) people. In non-affected communities, almost three quarters (74%) of disabled people reported their access to health services got worse, compared to just over half of non-disabled people (52%).
- While almost four-fifths of non-disabled people (78%) needed some form of medical treatment during the Ebola outbreak, this rose to almost all disabled people (98%). Of these, the majority of non-disabled and disabled individuals self-treated (59% non-disabled; 61% disabled), but more disabled people went to traditional healers (26%) compared to non-disabled people (7%).

In both communities not affected and affected by Ebola:

- Respondents with disabilities reported that people changed their behaviour toward them (84% in affected and 62% in non-affected communities).
- When asked how people's behaviour had changed, respondents with disabilities reported being treated as an outsider and being rejected/shunned. Additionally, in affected communities, almost a fifth of disabled respondents (17%) reported not being allowed to return home.

Implications

We draw out the following implications from these findings that may be relevant for a disability-inclusive COVID response, particularly within Liberia and other similar contexts (e.g., Sierra Leone). During epidemics:

- People with disabilities (and their families) may be at risk of social isolation.
- People with disabilities (and their families) may be less likely to access and follow crucial information (e.g., preventative measures) from government sources, instead relying on a more diverse range of channels.
- Existing barriers in terms of access to healthcare may be exacerbated, and the health of many people with disabilities may get worse.
- People with disabilities who have health needs may self-treat, but also seek healthcare from traditional sources rather than hospitals or health centers.
- People with disabilities may experience stigma and discrimination. This may be particularly acute in communities affected by the epidemic, but also present in communities with lower rates of cases.

Based on our evidence, we would particularly emphasize the following conclusions and associated recommendations made in the recent COVID-19 and Disability Inclusion Helpdesk report (Meaney-Davies et al., 2020). Stakeholders should:

- 1) Provide information on COVID-19 prevention and government response measures in accessible formats, working with DPOs and disability-focused organisations to provide this information if governments fail to do so, and where government guidelines might be less visible, using channels that reach poor and remote areas.
- 2) Identify and remove barriers to safe access to treatment for COVID-19 (e.g., adapted hospitals, accessible testing, signage and information, healthcare worker attitudes).
- 3) Identify and remove access barriers to social support, essential healthcare, & food (e.g., ensure access to medicines, ensure remote social support mechanisms are accessible, ensure food insecurity initiatives are accessible).

References

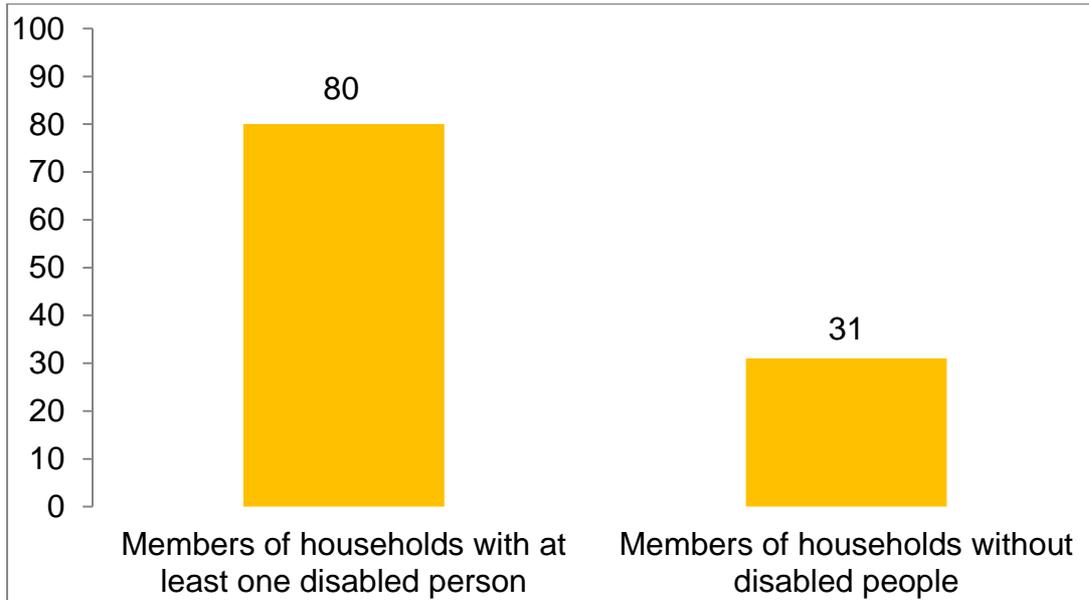
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Acknowledgements

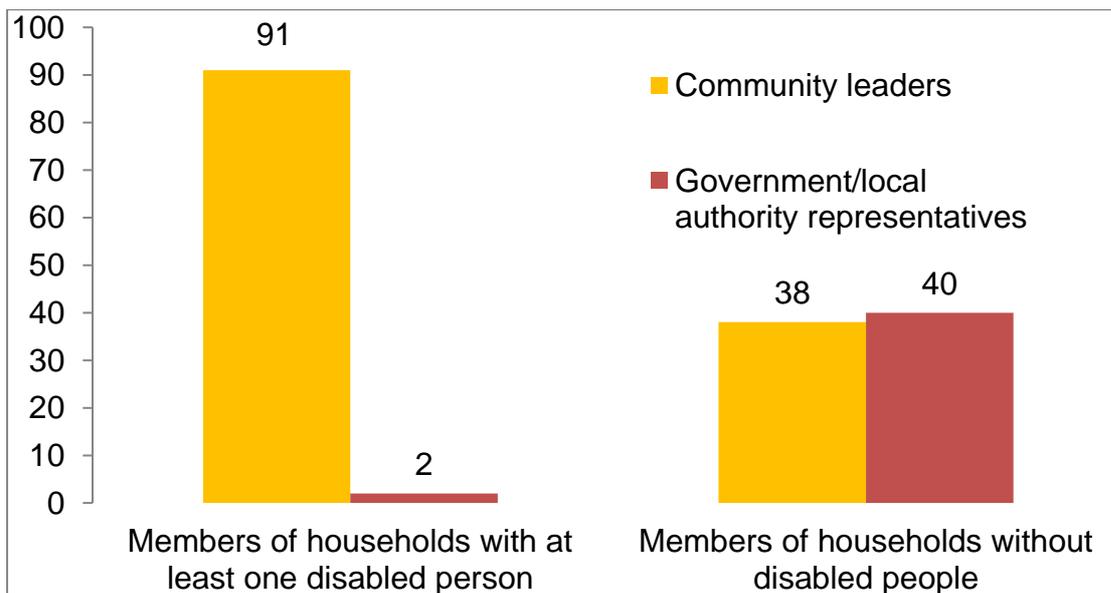
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Graphs of key findings

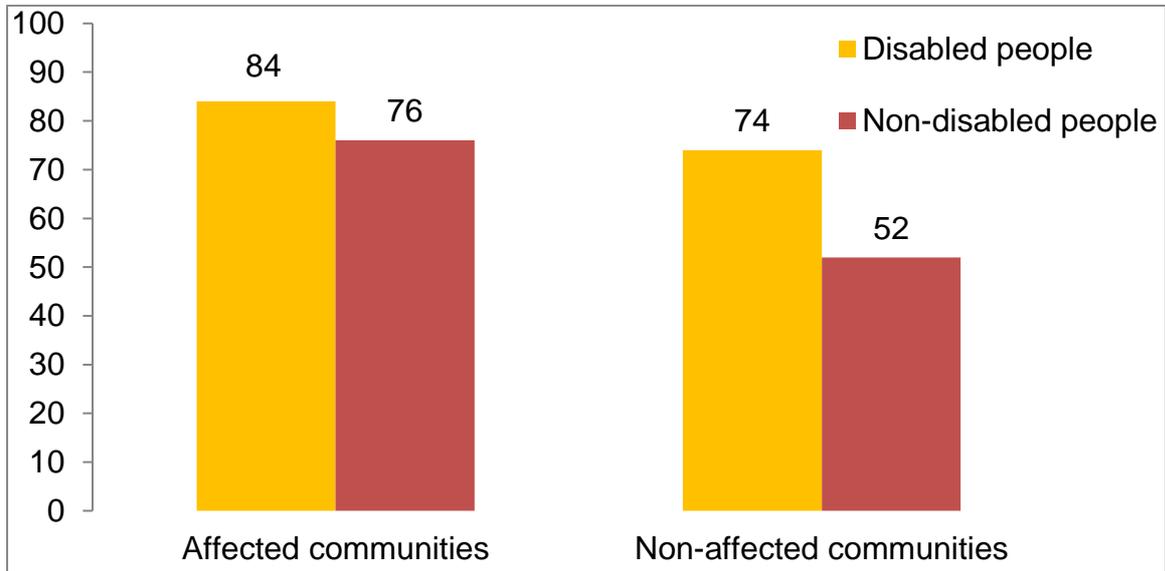
% who reported decreased social life in the community (Ebola-affected communities).



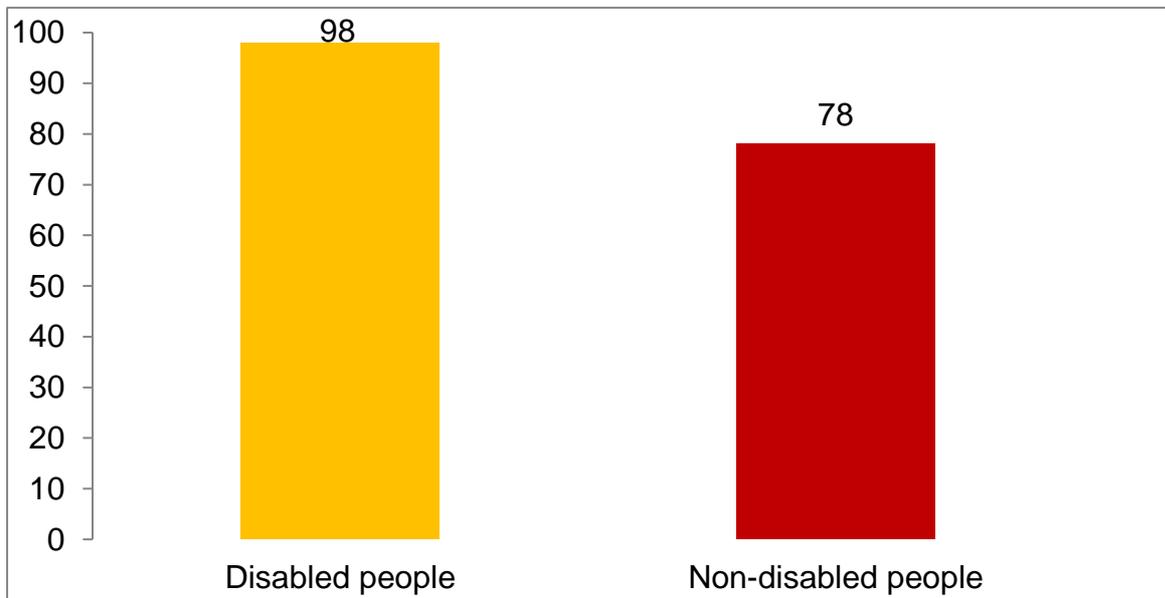
% listened to community leaders and government sources about how to stop the spread of Ebola (Ebola-affected communities).



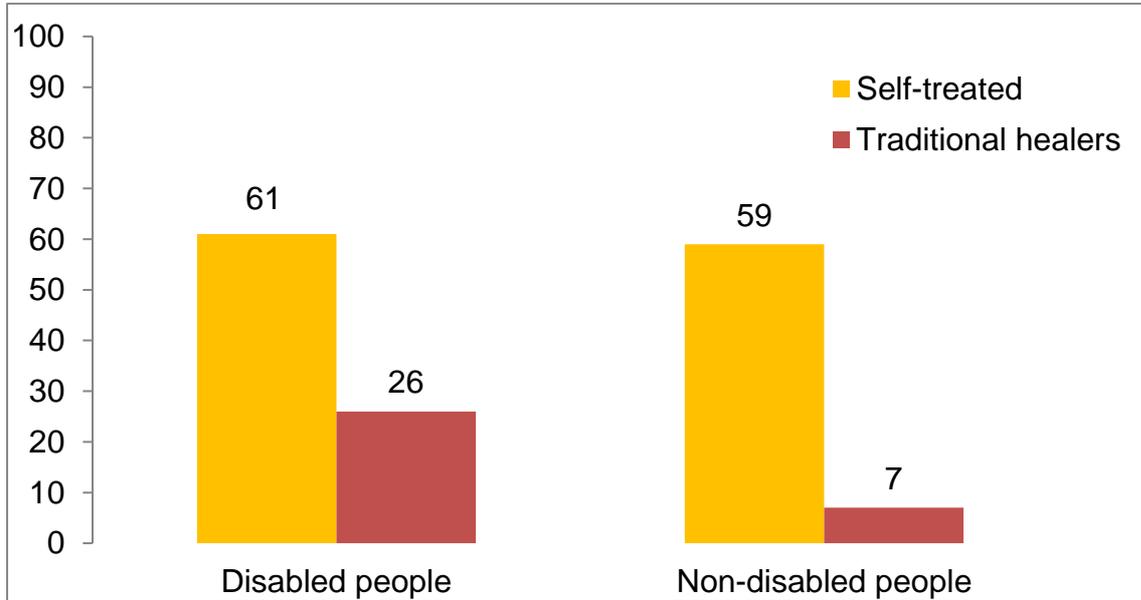
% disabled and non-disabled respondents who reported access to health services got worse (Ebola-affected and non-affected communities).



% who reported needing treatment (Ebola-affected communities).



% who reported self-treating or using traditional healers (Ebola-affected communities).



% disabled respondents reporting being treated differently during the Ebola outbreak (Ebola-affected and non-affected communities)

