Persons with disabilities must not bear the brunt of COVID-19 aftermath: lessons from Ebola in Liberia

Dr Mark Carew, Senior Researcher at leading disability charity Leonard Cheshire, explores the importance of ensuring persons with disabilities are not excluded as part of COVID-19 responses.

It is no secret that persons with disabilities are disproportionally affected by humanitarian crises. In everyday life, persons with disabilities are already one of the most marginalised groups in society, a situation that’s further exacerbated by global events like the COVID-19 pandemic.

Globally we know there are gaps between persons with and without disabilities, from education, to employment, to social integration and healthcare. That’s why organisations must act now to ensure persons with disabilities are considered at the forefront of government responses to COVID-19. Otherwise, these gaps will likely widen, and work that’s already been done to try and address them may unravel.

To put this into perspective we can look at a research briefing, based on findings from research funded by ESRC-DFID and awarded to Leonard Cheshire (Principal investigator: Dr Maria Kett) between 2014-2017, in partnership with University College London, University of Liberia and National Union of Organizations of the Disabled in Liberia following the Western Africa Ebola outbreak, the largest of its kind in history. Sadly, when we examine the national responses to prevention, care and containment, it is obvious that very little thought was given to addressing the needs of persons with disabilities.

Combining surveys and interviews with people from households with a disabled person as well as those without, the research included responses from 560 persons living in areas that had ‘many’ or ‘few’ cases of Ebola. About half of these respondents lived in a household with someone that was disabled and a quarter were disabled themselves.

Through any crisis, access to information is crucial in order to understand developments. As we know with COVID-19, advice and plans are constantly changing so having accessible, reliable information is key. In Liberia, this wasn’t the case. Nine in ten respondents in households with a disabled member received information on Ebola from local leaders in the community. Only 2% of these respondents got their information from official sources like the government or local authority. In contrast, two-fifths of respondents in non-disabled households reported getting information from government or local authority sources.
While access to healthcare may have been an existing issue in Liberia, the research also showed that this was exacerbated by the Ebola crisis. Almost all (98%) persons with disabilities needed some form of medical treatment during the Ebola outbreak. Yet the majority of respondents, both disabled and non-disabled, reported access to healthcare got worse in both affected and non-affected areas. This is cause for concern, as lack of access to quality healthcare can have devastating effects.

Perhaps one of the most striking differences between the two groups was the social impact. Four-fifths of disabled households reported a decreased social life following the Ebola outbreak, compared to a third of non-disabled households. The research also suggested that persons with disabilities experienced stigma and discrimination. Respondents with disabilities reported that people had changed their behaviour towards them and that they were being treated like outsiders and rejected or shunned from their communities. Sadly, in affected communities almost a fifth of disabled respondents said they were not allowed to return home.

From this research, and other evidence emerging in the sector on disability and coronavirus, there are a number of considerations governments should think about when mapping out their COVID-19 responses to ensure persons with disabilities are not left behind:

• Any information on COVID-19 must be accessible and governments should work with organisations, like Disabled People’s Organisations (DPOs), to ensure information is relayed effectively to all communities, particularly in remote areas
• Any barriers to healthcare must be identified and removed as quickly as possible to ensure everyone has access to the treatment they need
• Barriers to social support and basic needs must be identified and good support measures put in place

The Liberia research provides a snapshot of the challenges persons with disabilities may face following a health crisis and further analyses are underway to understand the full implications of these findings. Another general point to highlight is the importance of disability data collection. Quality disability measures, like the Washington Group Questions, will allow us to fully understand the impact of COVID-19 on persons with disabilities and identify and mitigate any barriers that may arise. As we know, without robust data it can be hard to advocate for change, but it is also crucial for monitoring when sufficient progress toward inclusion has occurred. If we do not equip ourselves with good quality disability data, we cannot begin to accurately understand the extent of the challenges, exclusion and stigma that persons with disabilities may face in communities around the world as COVID-19 continues to impact our lives.

We already know that this pandemic will have a long-lasting impact, but we must not allow persons with disabilities to bear the brunt of this. We must act now to get the data we need to move forward. Otherwise, hopes of creating more disability inclusive societies as part of the 2030 Sustainable Development Goals may be further compromised.
**Dr Mark Carew** is Senior Researcher in Disability Data and Inclusive Policies at Leonard Cheshire. A psychologist by training, Mark’s expertise within the disability sector spans stigma and discrimination, access to healthcare, and disability data collection. To date, Mark has published over 20 peer-reviewed articles and book chapters in these areas, including the co-authored book *Disability and Sexual Health: A Critical Exploration of Key Issues*. He was named in the 2019 edition of the Power 100 list, which recognises the top one hundred most influential people with disabilities in the UK.

We welcome constructive feedback on this blog and are keen to collaborate with organisations that share our values and our commitment to ensuring no one is left behind as part of the COVID-19 response. If you would like to share feedback or explore opportunities for collaboration, please email harri.lee@sddirect.org.uk.