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Collecting disability data: a case study from Malawi

The Malawi Human Rights Commission (MHRC) published the findings of its research, 'Human Rights Based Research into COVID-19 Related Violations with Focus on Persons with Disabilities', in July 2021.

The MHRC collected specific data assessing the impact of COVID-19 measures on disabled people in Malawi. They then made recommendations to government, healthcare providers and development agencies on actions that must be taken to reduce disadvantage.

Why the MHRC undertook this work

Early in the pandemic, the MHRC were concerned that government measures to contain COVID-19 discriminated against disabled people in a number of ways. Disabled people in Malawi already experience human rights violations in many aspects of life due to attitudinal barriers, economic hardship and limited access to healthcare, employment and education. COVID-19 has compounded these effects, leaving some people who are more susceptible to contracting the virus unable to protect themselves or to access appropriate healthcare.

Up-to-date statistical information about disabled people in the region is extremely limited, and data disaggregated by disability and gender is non-existent. The purpose of the MHRC's research was to assess COVID-19 policy impacts in an intersectional way, taking into account people's disability status, age, gender, sex, health condition, access to basic infrastructure, household composition, access to information and communication technology, employment status and education.

Research methods

This study focused on qualitative research. The MHRC used a combination of inperson, one-to-one interviews with representatives from disabled people's organisations (DPOs) and phone conversations, across the four main administrative districts of Malawi, which contain both urban and rural areas.

The MHRC asked questions to find out:

- Whether disabled people knew about COVID-19, and if so, how they found out about it
- Whether the DPOs were consulted by government officials to plan and implement COVID-19 measures, and whether pandemic-related healthcare was accessible



 How the pandemic has affected disabled people's everyday lives, particularly access to services

What they found out

The research reveals that disabled people's rights to health, economic activity, liberty and movement, employment and access to justice were all negatively impacted by COVID-19 measures.

While awareness of COVID-19 and prevention methods was relatively high across all four districts, many disabled people with communications needs relied on family members and other support providers to pass on information. Accessible formats, such as sign language interpretation on televised news, were not provided.

DPOs reported that they had not been consulted by the government at the planning or implementation stages of policy-making. As a result, disabled people's specific needs have not been taken into account and services aimed at reducing the spread of the COVID-19 are inaccessible.

Blind and visually impaired people who rely on support people to guide them in public were required to socially distance from their support person, effectively stripping them of their personal liberty. Essential services such as handwashing stations were also put in place, but many are inaccessible to those with less mobility.

There are many ongoing court cases regarding attacks against persons with albinism which have been severely delayed. The MHRC is concerned that the quality of evidence may deteriorate over time and affect the outcomes in these cases.

The MHRC has sought to address the impact on disabled people's human rights in their recommendations. They have called for rigorous consultation with disabled people at all stages of policy-making and a total redesign of service delivery to ensure that vaccination, isolation and other healthcare upholds disabled people's right to health.

Read the full report via the CFNHRI website.

