

How can we address intersectional stigma for people living with disability and chronic infectious diseases?

The question and the problem

People living with disability are at a higher risk of contracting chronic infectious diseases such as human immunodeficiency virus (HIV) compared to those without disabilities. Furthermore, those with HIV are at higher risk of developing a disability as a result of their condition. Infectious diseases such as HIV, tuberculosis (TB), neglected tropical diseases (NTDs), etc can, like disability, be very stigmatising. Stigma is founded in inequality, power, and systems of domination. It can be intra-personal, such as self-stigmatisation, interpersonal, such as social stigma, and structural, such as institutional stigma. Intersectionality looks at the way different forms of discrimination combine in the experiences of marginalised groups, such as people with disabilities living with chronic infectious diseases. Consequently, this group can face additional societal barriers in their day-to-day lives compared to people with disabilities that don't have chronic infectious diseases or those that have a chronic infectious disease without a disability. This evidence brief summarises how intersectional stigma for this particularly vulnerable group can be addressed.

Recommendations

- **Recommendation #1:** Inclusion and participation of people with disabilities in the development and implementation of national strategies for infectious diseases.
- **Recommendation #2:** Establish peer-led or peer-supported outreach for people with disabilities focused on chronic infectious diseases.
- **Recommendation #3:** Provide health workers in infectious disease control services with disability training.
- **Recommendation #4:** Offer nutritional and social grant support to people with disabilities and/or chronic infectious diseases.

“We, the blind, we have challenge – most of our guides do not want to guide us to the areas where the services are offered simply because they fear the community associating them with the HIV/AIDS.”

[A 58-year-old visually impaired man in Zambia, Tun *et al* (2016) – taken from Akpu Philip *et al* (2022)]

Challenges

Challenge #1: Internalised stigma and a lack of privacy discourages people living with disability from seeking care at infectious disease control services.

- Fear of being identified as someone with a chronic infectious disease can prevent many from seeking preventive services. This concern is further compounded for people with disabilities who may not have the privilege of keeping their health status private due to it being involuntarily disclosed to those who assist them in accessing these health services.
- Internalised stigma resulting from negative stereotypes associated with both their disease and disability can negatively impact self-esteem for people with disabilities, preventing them from seeking care or resulting in treatment withdrawal.

Challenge #2: Pervasive negative stereotypes prevent people living with disability from accessing infectious disease control services.

- Stigma from chronic infectious diseases, such as lymphatic filariasis and HIV, have been reported to adversely affect all aspects of life for people with disabilities, including their roles within families, school, health systems and within the broader community. How men and women with disability living with chronic infectious diseases experience marginalisation and access barriers can differ – with research indicating that women can experience more barriers due to sociocultural norms.
- Institutional stigma within educational and health systems, such as stigmatising beliefs amongst staff or fear of contagion, can prevent people with disabilities from receiving information about and access to preventive and treatment services for chronic infectious diseases.

Challenge #3: Lack of rights and obligations for people living with disability in national strategic plans for infectious diseases.

- There is frequently a lack of rights and obligations for people living with disability in national strategic plans for infectious diseases in LMICs. For sexually transmitted diseases this can be due in part to the mistaken assumption that people with disabilities are not a high-risk group for infection because they are not sexually active, are not sexually exploited, and do not take drugs. Prevalence studies for HIV, for example, in people with disabilities in sub-Saharan Africa are rare. However, HIV prevalence estimates among people with disabilities tend to be higher than the national average. This has meant that this vulnerable group has been ignored in the design and deployment of services, and consequently their needs for accessing and using these services have not been addressed.
- When people living with disability are included in national strategic plans and policies, this rarely translates into actual change on the ground. Furthermore, there is limited information, as well as services and support, to enable people with disabilities to have legal recourse when their rights are violated.

Challenge #4: Disability, poverty, and infectious diseases all intersect and contribute to health inequities.

- Disability and chronic infectious diseases can both act as barriers to employment, consequently people with disability living with a chronic infectious disease can find it hard to attain work causing financial hardship to both themselves and their households. Studies show that poverty impedes the ability to seek and access care, and accessing infectious disease services may be de-prioritised in place of other essentials, like food. Even when free treatment is provided, the cost of travel can prevent people with disabilities from accessing services – particularly when they face additional costs from transport providers as a result of their disability.

How did we find answers

We conducted a review of reviews, examining systematic, narrative, and other types of review evidence on the topic of intersectional stigma for people living with disability and chronic infectious diseases. Three databases were searched, including MEDLINE, Embase, and Web of Science. This evidence brief is based on the findings of 5 reviews from low- and middle-income countries, and 3 reviews which covered literature from a range of low, middle, and high-income settings. The 3 reviews that focused on all income settings were included as their recommendations were still deemed transferable, relevant, and feasible to low- and middle-income settings. The literature predominantly focused on HIV/AIDS, with one review on lymphatic filariasis and another review which looked at leprosy and tuberculosis, in addition to HIV/AIDS.

Evidence-informed Recommendations and Actions

Key Recommendations	Actions
Inclusion and participation of people with disabilities in the development and implementation of national strategies for infectious diseases.	<i>Disabled people's organisations (DPOs) should be engaged and consulted in the development and implementation of national strategies for infectious diseases, which should be guided by the principles of universal design. This should extend to the inclusion of disability in any proposed research, as well as in monitoring and surveillance strategies.</i>
Establish peer-led or peer-supported outreach for people with disabilities focused on chronic infectious diseases.	<i>Develop accessible health education materials (pamphlets, videos, and home visits) that provide health information on the prevention and management of chronic infectious diseases for people with disabilities, as well as information on their legal rights. These can be used to raise awareness through peer-led or peer-supported outreach, for example through DPOs, or community-based rehabilitation programmes. Support groups can also help address the psychosocial needs of people with disability living with chronic infectious diseases.</i>
Provide health workers in infectious disease control services with disability training	<i>All health workers responsible for the provision of infectious disease control services should receive training on the rights of people with disability, the risks and vulnerability of people with disability in acquiring different infectious diseases, how to meet the needs of people with disabilities when delivering health services, and how to ensure patient confidentiality when providing care for people with disability.</i>
Offer nutritional and social grant support to people with disabilities and/or chronic infectious diseases.	<i>Stigma from disability and chronic infectious diseases can both act as barriers to employment, causing poverty and poor nutrition, which can also reduce the effectiveness of medications for diseases like HIV. Nutritional and social grant support should ideally be enacted through legislation and allocation of the government budget. However, where this is not possible, bottom-up approaches whereby community-based organisations (CBOs) empower people with disabilities living with chronic infectious diseases with skills to provide for themselves can be an alternative option.</i>

Policy priorities

Access to infectious disease control services should be 'universally designed' so that they meet the needs of people with all types of disabilities, including physical, intellectual, sensory, and mental. Departments responsible for the control of infectious diseases in Ministries of Health should actively engage and include people with disabilities during the development and implementation of national strategic plans, and ensure a budget is available to fund the accessible delivery of their services. In particular, infectious disease control services delivered through community health workers could strategically engage with community-based rehabilitation programmes for people with disabilities. The inclusion of people with disabilities within the delivery of infectious disease control services should be routinely monitored and key indicators disaggregated by disability status. Furthermore, legal frameworks in-country should ensure adequate provision of accessibility, mobility, access to justice, and protection from violence for people with disabilities. The introduction of social protection for people with disabilities and those with chronic infectious diseases, such as HIV, could also reduce marginalisation and vulnerability to HIV and disability respectively.

GAPS & RESEARCH NEEDS

This brief is predominantly based on reviews that looked at intersectional stigma between disability and HIV, and to a lesser extent NTDs. Further research is needed on intersectional stigma of people with disabilities with other chronic infectious diseases, such as hepatitis, TB, and long COVID.

Much of the evidence was looking at interpersonal stigma, whereas there was little research on structural stigma. There was also limited information regarding the effectiveness of interventions to address intersectional stigma. Consequently, more research is needed in this area.

Conclusion

People with disability living with a chronic infectious disease face significant stigmatisation at personal, social, and structural levels. How these stigmas intersect and are experienced varies and is highly context driven. There is limited evidence of what works in terms of addressing intersectional stigma for this group. However, approaches that aim to address this type of intersectional stigma must be developed and implemented in close coordination with people living with disability, disabled people's organisations (DPOs), as well as those living with chronic infectious disease.

Acknowledgements

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Included sources

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