

People are neglected, not diseases: the relationship between disability and neglected tropical diseases

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People with disabilities and the neglected tropical diseases (NTDs) are separately receiving increased focus. In light of this positive development, and the similarities and intersections between the negative impacts experienced by both people with disabilities and people with NTDs, we believe now is the right time to focus attention on the overlap between the two. Both people with NTDs and people with disabilities experience a myriad of overlapping negative health, financial and socio-cultural consequences. Despite this, we believe that disability is not yet properly prioritised on the development agenda, and that there are multiple opportunities to make NTD programming more inclusive, to the benefit of those at this neglected intersection and beyond. There are both opportunities and need to scale up, integrate, and invest in inclusive, health system-focused NTD programming. Realisation of the Sustainable Development Goals, Universal Health Coverage, and the control and elimination of NTDs all rely on ensuring people with disabilities are not left behind.

Keywords: development, disability, mental health, equity, neglected tropical diseases, NTDs

Neglected tropical diseases and disability

For the frequently overlooked intersection between disability and neglected tropical diseases (NTDs), the past year has signalled an increased focus on this important domain. In 2018, the first Global Disability Summit took place in the UK, as well as an All-Party Parliamentary Group meeting on the intersection between NTDs and disability. Internationally, disability-focused sessions were presented at the NTD NGO Network (NNN) and Coalition on Operational Research for NTDs (COR-NTD) meetings. Alongside these events, mental health and NTD-focused blogs, news articles and opinion pieces surrounding these events each emphasize the growing attention this important issue is getting. However, despite this increased focus, the current reality is that people with disabilities continue to be excluded from the development mainstream.

At the 2018 Global Disability Summit, the World Health Organization (WHO) committed to develop guidance and to support countries to address the negative attitudes and practises towards people with psychosocial, cognitive and intellectual disabilities. The WHO further committed to implementation of mental health-related policies, plans, laws and services that are compliant with the United Nations Convention on the Rights

of People with Disabilities (CRPD) and in line with the comprehensive mental health action plan for 2013–2020. One such high-level plan will soon result from the collaboration between the Mental Wellbeing and Stigma Task Group of the NNN and the WHO, which are working together to create a joint mental health intervention manual for NTDs.¹ The summit thus saw commitments that if implemented could be a significant step towards mainstreaming disability inclusion and ensuring that 'no one is left behind' on the path towards achieving the Sustainable Development Goals (SDGs).

Significant progress towards achieving the SDGs can also be made by tackling NTDs. The affect of NTDs can contribute to poverty, illness, mental health^{2–6} and psychosocial, cognitive, intellectual and physical impairments, all of which can, in turn, result in disability through a multifaceted process upon which many other factors impinge. It is this complex and non-linear relationship between disability and NTDs that forms the basis of this review.

Similarities and intersections

Globally, more than 1.5 billion people are affected by at least one NTD.⁷ NTDs are a group of primarily infectious diseases that

also include some exposure-related conditions such as snake-bite and podoconiosis. Despite their different causes, all NTDs are common in low-income regions of the tropics. Individuals and communities living in impoverished conditions, lacking proper water and sanitation and in close proximity with disease-carrying insects and animals are the most vulnerable to these diseases and worst affected by them. In the worst cases, NTDs can kill affected individuals, although more often NTDs cause a variety of impairments and morbidity that are frequently chronic and irreversible. In turn, this erodes the capacity for economic activity and gives rise to significant health care costs for those already at the lowest income levels, with other effects related to mental health and social well-being. Beyond the affected individual, NTDs are far reaching in their impacts, causing long-lasting impoverishment and impairment for whole households and communities,^{8–12} who have little support to provide care and assistance to those with permanent NTD sequelae. Reflecting this, some NTDs, lymphatic filariasis (LF), for example, have been suggested as indicators of poverty.^{13,14}

One in five of the world's poorest people has a disability¹⁵ and the majority of this same population group are infected with or at risk from an NTD.¹⁶ Like NTDs, there is a strong association between living with a disability and poverty; lack of water and sanitation, inadequate nutrition and substandard living conditions not only increase the risk of exposure to NTDs, but also of impairments and the impact of the exclusion of persons with disabilities.¹⁷

In recognition of the myriad of health, financial and sociocultural impacts of NTDs on the world's poorest and most vulnerable, significant investments and commitments have been made to combat this group of diseases, including the WHO NTD roadmap,¹⁸ the London Declaration on NTDs,¹⁹ doubling of the UK government's support for NTDs through the Department of International Development,²⁰ the renewed commitments by the US government²¹ and the Reaching the Last Mile Fund,²² among others. The European Union, US Agency for International Development and the Bill and Melinda Gates Foundation all fund significant NTD research and/or control programmes. The NTDs are also prominent in the SDGs, with specific targets relating to their control, as well as broad recognition of the contribution NTD control and elimination could bring to so many different health, wealth and development targets.

Thankfully then, the diseases grouped together under the umbrella of NTDs are beginning to leave behind some of the 'neglect' that they have suffered in the past, having been subject to a period of sustained focus and attention. However, the importance and impact of the intersection between NTDs and disability is frequently overlooked in efforts to strengthen health systems, combat NTDs and achieve universal health coverage (UHC). The interrelationship between NTDs and disability can still be considered a neglected aspect of both the drive to control and eliminate NTDs and more generally the lack of attention paid to mainstreaming inclusive health programming to achieve UHC. Current NTD control is not fully comprehensive, it contributes towards the preventative and curative strands of UHC, but, as discussed below, the rehabilitative and palliative aspects of NTDs, and more so those at the intersection between NTDs and disability, are not well prioritized.

UHC is defined by the WHO as all people and communities being able to use the promotive, preventive, curative,

rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.²³ UHC means that essential health services need to be integrated into a strong and responsive health system. Investment in primary health care is seen as key to achieving UHC. In communities at risk of contracting NTDs, or where individuals experience chronic disease and disabilities as a consequence, service providers need to work towards the integration and sustainability of the full range of NTD services. The goal should be integration within the formal health system at the primary care level close to the community. Because of the disproportionate burden of NTDs on the poorest and most marginalized communities, coverage of NTD services has been proposed as a good indicator for equity in UHC.²⁴

Additionally, while great progress has been made in the NTDs, moving away from the neglect of the past, they cannot yet be considered as beacons for inclusion. Often the drive and enthusiasm to eliminate transmission of NTDs through preventative chemotherapy (PC) leads to the neglect of long-term morbidity management and a lack of measures to improve the mental health and well-being of those impacted by NTD-related morbidity or disability. The PC NTDs have benefited from increased attention because of the existence of a broad, relatively simple strategy to combat these diseases, that is, mass drug administration (MDA). The situation for including people with disabilities in NTD programmes and health system structures is inherently more nuanced, but no less important. While there are several emerging examples of good practice and inclusive programming within the NTD sector, these tend to be derived from diseases such as LF and trachoma, where elimination dossiers require evidence of morbidity management. Embedding of morbidity management for the verification of elimination of certain NTDs does promote disability inclusion to a certain extent, however, active morbidity management does not automatically fully encompass the intersection between NTDs and disability. More broadly speaking, especially where morbidity-related indicators are not common practise, the intersection between NTDs and disability is poorly prioritized in national NTD programmes, health systems and research and funding agendas. The lack of prominence that disability receives on NTD and global health agendas indicates that there is more to be done to increase both understanding and awareness for successful control and elimination of NTDs while achieving UHC in an equitable way.

Highlighting the intersection between NTDs and disability

The long-term symptoms and chronic outcomes for many NTDs can lead to permanent impairment and disability, with physical, mental, social and economic impacts, as summarized in Table 1. Lymphoedema caused by LF or podoconiosis is debilitating, demobilizing and stigmatizing, giving rise to social isolation, emotional and mental distress, depression and loss of income.^{25–28} Hydrocele for men and breast lymphoedema for women are particularly distressing and stigmatizing. Leprosy has been linked with depression, generalized anxiety disorder and alcohol/drug misuse,²⁹ and there are more than 3 million people with irreversible physical impairments due to leprosy.³⁰ Trachoma and onchocerciasis cause visual loss and blindness,

Table 1. Physical, mental, social and economic consequences of chronic NTD infection

NTD	Physical affects	Mental and social affects	Economic affects
Onchocerciasis	Blindness ³⁴ Visual impairment ³⁴ Severe painful skin itching ³⁴ Nodules ³⁴ Atrophy of skin ³⁴ Leopard skin ³⁴ Onchodermatitis ³⁴	Mental distress ^{25,27,33} Unhappiness ^{27,33} Stigma ^{11,19,25,27,33,40,42} Discrimination ^{25,42} Rejection ^{25,40,42} Depression ^{25,27,33} Despair ²⁶ Feelings of isolation ^{26,32} Low self-esteem, ^{27,32,40,41} Shame ^{11,32,40-42} Sleeplessness ^{32,41} Inability to participate in community activities ³¹ Withdrawal from community and family activities ³¹ Reduced marriage prospects/ marital problems ^{11,25,31,32,41,42} Reduced community standing ^{25,31,42}	Reduced productivity ^{11,28,39,40} Reduced earnings ^{9,28,39} Loss of earning capacity for patient ^{12,25,39} Loss of earning opportunity for caregivers ³⁹ Out of pocket treatment costs ^{9,12,32,39,40} Out of pocket caregiver costs ³⁹ Out of pocket costs for travel to treatment ²⁷ Loss of education opportunity for caregivers ^{9,39,40} Loss of education opportunity for patient ^{9,39,40} Cost to health system of treatment ³⁹ Cost to health system of assessment and management ³⁹ Loss of access to health and community services that are not accessible to all abilities ³⁹
Trachoma	Blindness ³⁵ Visual impairment ³⁵ Eye pain ³⁵ Light sensitivity ³⁵ Swelling of eyelids ³⁵ Eye itching and inflammation ³⁵		
Schistosomiasis (heavy infection)	Anaemia ³⁶ Malnutrition ³⁶ Stunting ³⁶ Liver, bladder or intestine damage ³⁶		
Soil transmitted helminths (heavy infection)	Abdominal pain ³⁷ Diarrhoea ³⁷ Anaemia ³⁷ Cognitive delay or impairment ³⁷ Stunting ³⁷ Malnutrition ³⁷		
Lymphatic filariasis	Acute fever ³⁸ Skin exfoliation ³⁸ Lymphoedema ³⁸ Elephantiasis ³⁸ Hydrocele ³⁸ Secondary ³⁸ infections ³⁸		

with additional stigmatizing impacts caused by onchodermatitis skin lesions.³¹ Onchocerciasis has been linked to low self-esteem, exclusion and sleeplessness in a number of studies.^{31,32}

As a result, there is growing appreciation that these chronic health outcomes frequently garner stigma, poor mental well-being and social exclusion. Not only are the direct impacts of NTD-related disability on the individual still neglected in existing programmes, the indirect, yet significant, impacts on caregivers, families and communities are often completely overlooked.³³ Ongoing NTD control and elimination activities mean a new generation is increasingly free of the risk of new infections and their stigmatizing outcomes. However, those already affected are affected for life, and in our drive to eliminate 'infection' or 'transmission', we must not overlook those for whom the benefit of such achievements will be tangential at best.

Emerging and established best practice

Opportunities exist to build on existing prevention-oriented MDA platforms to address the needs of individuals with chronic,

lifelong NTD manifestations, disabilities and poor mental well-being. Strengthening the capacity of community health workers, community volunteers and tertiary health systems to support and include people with disabilities is a key pillar of Article 25 of the CRPD, which states that 'persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability'.⁴³

In general, the evidence base on how best to make NTD programmes more inclusive of people with disabilities is still developing. However, there are numerous examples of small-scale community-based interventions supporting the management of impairment or disease and promoting inclusion and accessibility for individuals with disabilities. Encouraging and enabling individuals to form self-care groups to advocate more effectively for their own needs has worked extremely well in some settings. For leprosy, the benefits of patient-led self-care groups are well established^{44,45} and community-based peer counselling to reduce leprosy-related stigma has also been proven effective in an Indonesian setting.⁴⁶ Integration of LF and leprosy self-care

groups has been assessed as feasible in Nepal.⁴⁷ In Haiti, self-care ‘hope clubs’ have been established to provide information on symptom management, psychological empowerment and emotional support for LF.^{48,49} Sightsavers’ UK Aid Match-funded programmes in regions of Nigeria, Uganda, the Democratic Republic of Congo and Guinea Bissau have been working to implement LF-related community-based patient care activities. In addition to the inclusion of the WHO-recommended minimum package of care, the programmes aim to address mental health aspects of NTDs. Examples include revised LF messaging in Uganda aimed in part at reducing stigma and its consequent negative impact on mental health following a knowledge, attitudes and practices survey and the promotion of self-help groups for persons with LF-related lymphoedema in Kogi state, Nigeria. The programmes are ongoing and looking to evaluate such interventions as they continue.

A new toolkit to address the stigma caused by leprosy was released, with the authors highlighting the modular structure of the kit, which makes adaptation to other diseases or a set of diseases achievable.⁵⁰ Important first steps are being taken towards developing and validating a cross-NTD morbidity and disability assessment toolkit, initially trialled in the Brazilian context.⁵¹ Additionally, there is detailed guidance available to assist the implementation of community mental health care,⁵² elements of which could be incorporated in dual NTD and disability approaches. A systematic review of validated screening tools for mental health disorders in low- and middle-income countries has yielded recommendations on the best tools to accurately assess mental health burden,⁵³ which could be adapted for use in an NTD and disability-focused mental well-being assessment. The multistate implementation of a community-based mental health service in Nigeria in which volunteer community health workers are trained to advocate for mental health and challenge misconceptions that could give rise to stigma can inform similar programmes elsewhere.⁵⁴

We know what works and how we can support individuals and communities affected by NTDs at the local level. But questions remain regarding how to integrate or synergize the above approaches and techniques with health systems and community-based MDA delivery frameworks, particularly the community-based drug distributors who are trained to implement MDA; how to implement such approaches at scale and how to ensure such activities have maximal synergy with the efforts to eliminate certain NTDs, such as onchocerciasis and LF, while strengthening the health system.

Opportunities for creating synergy between disability and NTDs

The most readily realizable opportunities to create synergistic benefit through disability-inclusive approaches to NTD programmes are fourfold.

First, invest both financially and programmatically in strengthening NTD programme focus on the morbidity management aspects of control and elimination. Drawing lessons from what works for the disease programmes with a longer history of managing disability and mental health aspects (e.g. leprosy) and interrogating successes and failures in developing strategies

will enable NTD programmes to continue to effectively meet the needs of their most neglected beneficiaries after elimination targets related to transmission have been met. It is vitally important to note that communities themselves may not see NTDs as eliminated if morbidity and disability related to NTDs remain after treatment has stopped.⁵⁵

Secondly, scale up of integrated case management and psychosocial services is needed within all levels of existing health care systems and by NGO implementation partners, as part of the drive to scale up morbidity management for NTD control and elimination. This maximises the impact of the funds and resource prioritisation NTDs are currently benefitting from.

Third, ensure that NTD control and elimination programmes are accessible to persons with disabilities, with a particular focus on public health activities such as MDA. Although data are scarce in this area, current approaches targeting a set proportion of the general population with interventions to interrupt transmission could inadvertently exclude or have poor reach in specific marginalized population groups, including persons with disabilities. By extension, this could increase the risk that treatment, and thus elimination targets, are not met in such settings. If there is not greater effort to ensure NTD programmes are accessible to individuals with disabilities, which constitutes 15% of the general population, then it is can be assumed that a higher proportion of less-marginalized population groups (without some form of disability) will need to be reached to meet the overall population coverage targets. Where existing data show people with disabilities are well included in programmes, strategies and learning should be highlighted to make sure this is the norm everywhere. Inclusive, accessible programming is beneficial for all members of society.

Fourth, focus where the evidence base of the interplay between NTDs, impairment and disability is strongest. There is a strong literature base for some NTDs that are particularly prone to give rise to long-term health impacts, stigma and discrimination, including leprosy, trachoma, onchocerciasis, podoconiosis and LF. While these are not the only NTDs to have such impacts, they provide an informed starting point to work with persons with disabilities to understand and address the issues arising from NTD-related health impacts and beyond. While this evidence is patchy in terms of the number of diseases and countries where context-specific evidence exists, it is clear that the dual impacts of disability and NTDs are broad and wide reaching. Therefore, addressing these impacts holistically, using combined approaches that focus on the people who are affected, could yield massive benefits for physical and mental health and well-being.

This focus could contribute to a far stronger evidence base on what works in inclusive health programming and has the potential for insightful lessons to be transferred and scaled up to other NTDs and embedded within wider health systems.

The way forward

The Global Disability Summit placed the need to mainstream inclusive, innovative health care approaches into NTD programmes and beyond into sharp relief. Disability is a long-standing, well-known outcome of the interaction between the

chronic health conditions caused by many NTDs and discriminatory economic, health system and general social environments. Long-term chronic conditions caused by NTDs and impairments in general have disproportionate negative impacts in low- and middle-income countries. Although it has been long understood that disability and NTDs give rise to stigma, low self-esteem and decreased mental well-being, the intentional programming to address the overlap of the two is less understood. We need to invest in accelerating the move beyond simplistic prevention and focus on disability inclusion as a key strand in all health, education and other mainstream development activities. Part of the 'neglect' NTDs were previously subject to came from their lack of inclusion in health systems generally, therefore increased integration of the currently somewhat vertical, highly successful, MDA approaches is key to ending this neglect for good. Vertical programmes have been a catalyst in progressing towards elimination. Now that fewer people are in need of MDA, there is a need to transition from mass treatment to the integration of services into the existing health system. This will ensure the sustainability of case detection and continued opportunities for disease management focused on the needs of the patient.

Because of the influence that water, sanitation and hygiene activities have on NTD prevention and morbidity management for diseases such as LF, podoconiosis and leprosy, these linkages should be further strengthened. There is also a need to integrate mental health and well-being in development planning, focusing on reinforcing the rights of people with mental health issues.⁵⁶ The tools and strategies to deliver disability-focused, patient-centric NTD care and management strategies are being developed⁴ and opportunities for upscaling and collaboration abound. The global health community must do all it can to ensure UHC includes people with disabilities, NTDs and mental well-being through a continuum-of-care approach. While there is much room for improving the synergy and overlap between NTDs and disability, particularly with regards to mental well-being, there is also cause for optimism. Opportunities exist to build on existing prevention-oriented MDA platforms to address the needs of people already affected by these health issues. Community links and referral pathways built by NTD programmes can be strengthened and used to help support those impacted by NTDs, disability or mental health problems. There are many parallel strands being developed to assess and address the burden experienced by those at the intersection of disability and NTDs. Now is the time to start doing this in an integrated way at scale. The current lack of crosstalk between the disability and NTD communities means it is not the diseases that are neglected, but the people at this intersection. With the global and well-publicized efforts to combat NTDs and to ensure mainstream development is inclusive of people with disabilities, there is a huge opportunity to ensure neither are left behind.

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