

People, power and participation: strategic directions for integrated person-centred care for NTDs and mental health

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Received 9 January 2024; revised 10 January 2024; editorial decision 11 January 2024; accepted 11 January 2024

Introduction

In this second editorial for the *International Health* supplement on mental health, stigma and neglected tropical diseases (NTDs), we reflect on how we can capitalise on the positive shift toward global normative frameworks of person-centred care, highlighted by Eaton in this supplement,¹ to shape positive change for persons affected by NTDs. The World Health Organization (WHO) presents five interdependent strategic directions that can support shaping the development of integrated people-centred health systems: empowering and engaging people, strengthening governance and accountability, reorienting models of care, co-ordinating services and creating an enabling environment.² These strategic directions are designed to generate a set of actions that can support transforming health systems to enable service delivery that is both integrated and people-centred. Here we consider each of these strategic areas in relation to the articles within this supplement, which we hope will enable a collective journey that is guided by the needs and values of the persons affected and that promote positive mental well-being for all.

Empowering and engaging people: recognising people as assets and building social networks

Social collectives/networks of people affected by NTDs are expanding globally, as emphasised by Zaizay et al.³ and Duck.⁴ However, as illustrated by Molyneux⁵ and Duck,⁴ people affected by NTDs are frequently excluded from the production of scientific knowledge, policy processes and in defining future research and program priorities. This is particularly true for the majority of persons affected by NTDs who live in remote rural areas and may not have the opportunity, skills and/or resources to be able to communicate their needs and priorities in ways that international (e.g. WHO) and national (e.g.

Ministry of Health) agenda-setting bodies are able/willing to engage with. Many within the NTD disease management, disability and inclusion (DMDI) community value the role of people affected by NTDs as assets in the co-production of knowledge, health and social care priorities, supporting them to become owners of health services and healthy environments that can support positive shifts in mental well-being through the attainment of person-centred care.² We have upheld this value within the production of this supplement.

However, in this supplement we deliberately invited people with lived experience to contribute articles, and the consequence has been important insights into the engrained power imbalances that hinder efforts to address complex social and structural causes of morbidity and disability associated with NTDs. Stigmatising experiences that are catalysing the mental health-NTD nexus are described within several articles in this supplement.^{6–9} The different ways in which gender, stigma and physical morbidity interact at the micro/individual level to shape mental health outcomes, access to health services and inclusion within community interventions are clearly illustrated. Until now, few studies in the field of mental health, stigma and NTDs have taken a gendered or intersectional approach to understanding disease burdens, and fewer still have considered how these differences may require tailoring of emerging interventions to enable gender transformative and inclusive approaches across health system levels.¹⁰ Thus, further engagement and prioritisation of people affected by NTDs to understand how community norms and values shape illness experience are critical to attainment of people-centred responses to mental health and NTDs, ensuring interventions are adaptive to the contextualised experiences of suffering at the community, household and individual level.

To date, the movement related to NTDs, mental well-being and stigma has largely focused on skin NTDs as a consequence of their profound physical and social impact. Within this supplement, Pedeboy⁶ and Masong⁹ remind us not to forget other NTDs in our work, emphasising the negative impact female

genital schistosomiasis can have on mental well-being, largely driven by gendered social and structural inequities. Harnessing support from persons affected by NTDs and capitalising on the power of local communities is clearly essential in advocating for the rights of people affected by chronic morbidity, disability and mental ill health as a result of NTDs. Patient advocates and support groups are highlighted across this supplement as an essential resource for the NTD community and health systems globally^{11,12}; e.g. such groups and individuals could be engaged to provide feedback on national and subnational policies and plans³ (see Creating an enabling environment).

Strengthening governance and accountability

Good governance within the design and delivery of people-centred health systems promotes transparency in decision making and ensures that all voices are heard and consensus is achieved.^{2,13} By integrating service delivery, people-centred health systems seek to bring together disparate strategies and priorities of varying donor agencies and vertical programs (e.g. NTD and mental health) to tackle specific health issues within overall systems strengthening.² Within their commentary, Ojo et al.¹⁴ reflect on their experiences of integrating NTDs and mental health services in Nigeria resulting from a shared vision across programs that capitalised on a window of opportunity for policy change. Policy change in Nigeria has also been informed by the generation of new context-specific evidence (some of which is presented in this special issue) that emphasises integration of locally designed services that support mental health of people with NTDs is possible at the primary care level.^{8,15-17} However, as highlighted by Eaton et al.,¹⁵ weak health system infrastructure and minimal investment are barriers to the sustainability and potential effectiveness of such approaches.

Health system governance, decision making and resource allocation is often driven by the availability of data and burden estimates. Many articles within this supplement emphasise the high burden of common mental health conditions (e.g. depression and anxiety) among people affected by NTDs,^{7,18,19} representing further progress in this area. However, across these articles, key challenges in ensuring the accuracy of epidemiological estimates are highlighted: literature on burden estimates is still relatively sparse, concentrated in sub-Saharan Africa and India, and focused on skin NTDs (mainly leprosy)¹⁹; despite commonality in the tools used (e.g. nine-item Patient Health Questionnaire and seven-item Generalized Anxiety Disorder questionnaire) across contexts, tools need further validation and testing for psychometric equivalence among NTD populations^{7,19} mental health measurements through time and disease trajectory are required,¹⁹ mental health conditions that may be more relevant to some NTDs (e.g. post-traumatic stress disorder following snakebite is less prioritised)¹⁹ and evaluation of the economic costs of including mental health burden in disability-adjusted life year estimates linked to NTDs is still required.⁵ Responding to these challenges to generate more reliable data is an essential foundation for further progress as a research and implementation community.

Across many countries, the current participation deficit of civil society and inclusion of people affected by NTDs in current

decision-making processes continues to limit external social accountability of the health system.¹³ This further compromises the sustainability of locally designed primary care interventions for mental health and NTDs, largely due to the reliance on communities to be active participants in care delivery (see Coordinating services). Thus, alongside the strengthening of burden estimates, we must continue to create equitable partnerships and democratic checks and balances between government actors, civil society organisations and community members to ensure strong governance and accountability processes. As highlighted by Nganda et al.,¹¹ participatory action-based learning approaches to research and intervention design have great potential in strengthening social accountability processes for mental health and NTD service delivery.

Reorienting the model of care

Person-centred systems require a reorientation of care models to embody a more holistic understanding of health while prioritising primary and community-level intervention.² This is not to completely substitute other levels of care, but rather, effective coordination of services between levels should be established.² As emphasised within this supplement and showcased across multiple contexts (Democratic Republic of the Congo, Nigeria, Haiti, Malawi and India), models of care for NTDs and mental health must prioritise a life-course approach and give attention to case finding for the assessment of risk factors, detection of early disease and identification of risk status; disability limitation and rehabilitation; involving and enabling the affected person in managing the condition; provision of psychosocial support for affected persons and provision of long-term follow-up with regular monitoring to promote adherence to pharmacological and psychological interventions.^{8,11,12,15,16,18} Several models of the ways in which life course approaches that promote positive mental well-being of people affected by NTDs can be embedded within health systems are presented in the supplement. For example, Barrett et al.¹⁸ present an 'enhanced package of self-care' within post-elimination service delivery for lymphatic filariasis in Malawi and Sadiq et al.¹² emphasise the potential of embedding a 'chronic disease self-management programme' within Hope Clubs in Haiti.

Coordinating services

The articles in this supplement illustrate that NTDs create a profound disruption in the lives of people affected. Broader social and structural drivers of the relationship between NTDs and mental health are apparent, yet consideration of these macro-level political factors is still emerging and an area for further consideration. Illness experiences often relate to a collection of challenges that can produce, exacerbate and maintain insurmountable disadvantage and exacerbate poor mental well-being. These challenges are often underpinned as a result of complex historical colonial and neo-colonial approaches, as emphasised by Mora et al.²⁰ in their commentary highlighting the intergenerational impacts of leprosy stigma in Colombia. Thus service coordination and intersectoral collaboration are essential to tackle sociopolitical drivers of stigma and its consequences to ensure an effective continuum of care for people affected by NTDs.²¹

A reduction of mental health stigma and provision of psychosocial support has been shown to be most effective when interventions prioritise social contact.^{22,23} Learning from the studies presented within this supplement suggests that the decentralisation of mental health services that engage communities is essential in achieving sustained contact in the provision of longitudinal psychosocial support. For example, Argawal et al.²⁴ and Mol et al.²⁵ showcase promising practice through the training of peer supporters in the use of a basic package of psychosocial support for NTDs. Engagement of persons affected by mental health conditions and their families and caregivers has also been identified as critical when considering the best approaches to expanding access to integrated primary healthcare services and is essential to the development of people-centred responses.

Creating an enabling environment

Reorienting health services becomes a political act that challenges existing interests.² Justice and a focus on people—not diseases—are key reasons cited for the increased prioritisation of person-centred care for NTDs within recent global policy shifts. This includes the launch of WHO's NTD Roadmap 2021–2030, WHO's guidance document on 'Mental health of people with NTDs—towards a person-centred approach' and development of an essential care package for mental health and stigma. These shifts have undoubtedly supported the creation of a more enabling environment for systems change and the integration of mental health and NTDs. Collective action between multiple actors, including national NTD programs, donors, non-governmental development organization partners, community health cadres, persons affected and researchers, is a welcome development, and one that should continue to be nurtured if this creative alliance for change is to flourish.

This supplement provides policymakers, future donors and collaborating partners with a snapshot of existing evidence that we hope can be used to continue to shape and support decision making that creates an enabling environment for policy, program and system reform. We have emphasised that the needs and values of affected persons and health system actors must be at the fore, which alongside country ownership can enable system reform that has good outcomes, strengthens social accountability processes, responds to national priorities and reflects the values, needs and experiences of people affected by NTDs, their households and communities. In this way, we can see progress toward DMDI strategies that are truly person-centred and address unnecessary, avoidable, unfair and unjust differences in health outcomes for the most vulnerable.

Authors' contributions: LD conceived and wrote the manuscript. JE reviewed and approved the text.

Acknowledgements: None.

Funding: None.

Competing interests: LD and JE are guest editors on this supplement but had no role in the review of this manuscript.

Ethical approval: Not required.

Data availability: The data are available in the article.

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