Community Mental Health Good Practice Guide:

Mental Wellbeing and Stigma in Neglected Tropical Diseases

CBM Global Disability Inclusion

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Introduction

CBM Global wants to see a world where people with mental health conditions and/or psychosocial disabilities:

- Participate meaningfully and authentically in their communities
- Have a good quality of life and wellbeing
- Have access to dignified quality care and supports to address individual needs

Promoting the mental wellbeing of people with Neglected Tropical Diseases (NTDs), including providing mental health support while addressing stigma, can help achieve these aims.

The purpose of this document is to provide:

- An overview of the existing evidence linking mental wellbeing, stigma and NTDs
- A summary of recognised good practice and evidence to improve mental health support for people with NTDs and to address community stigma through the presentation of a framework for action

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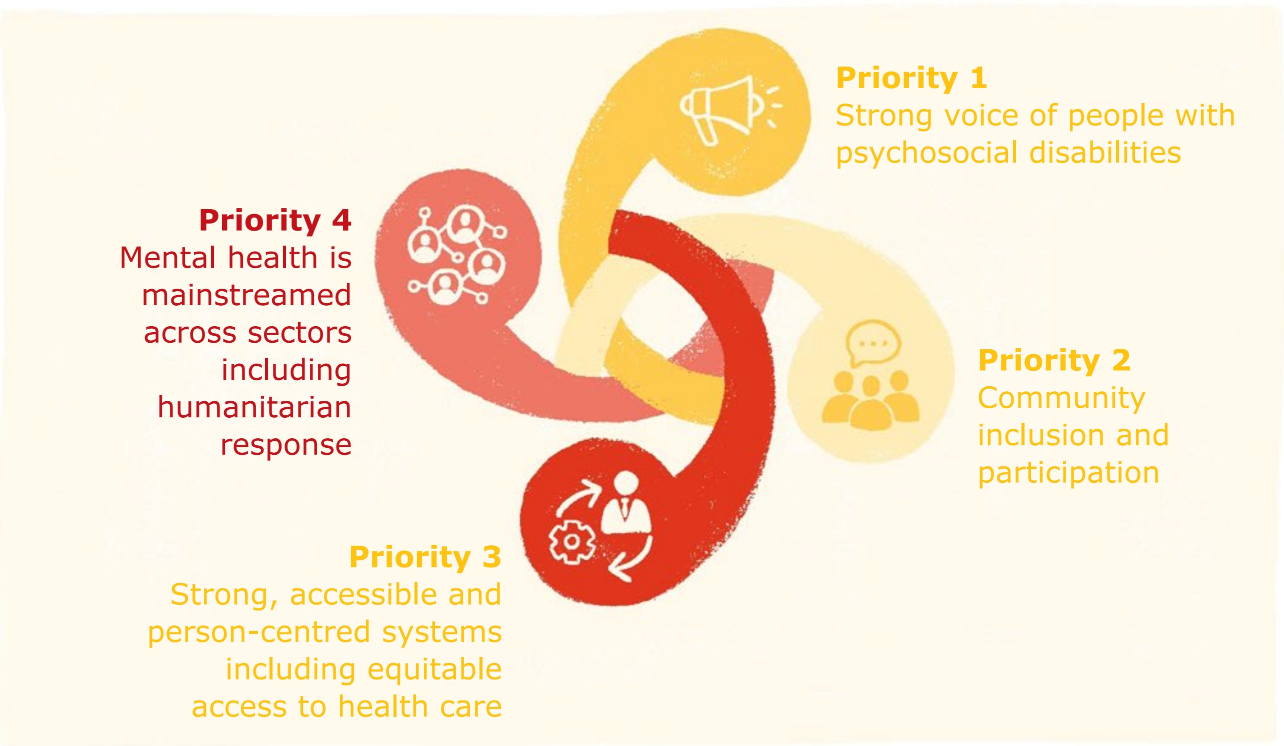
CBM's Community Mental Health Plan & Neglected Tropical Diseases

In 2019 CBM launched a Community Mental Health (CMH) Plan. The purpose of the CMH Plan was to bring focus and scale to the work that CBM does in order to have a greater impact on this area, both for people with mental health conditions and/or psychosocial disabilities, as well as the wider communities where we focus our work, and people with other disabilities, who are often at increased risk of mental health problems.

The CMH Plans has 4 key priorities:



Priority 4 in CBM's CMH plan is to **mainstream mental health across sectors including humanitarian response.** This includes mainstreaming mental health into NTD care, strengthening mental health support and stigma reduction for people with NTDs in countries where CBM works.

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Mental Wellbeing and Stigma in Neglected Tropical Diseases

What are Neglected Tropical Diseases?

Neglected Tropical Diseases (NTDs) are a group of communicable and non-communicable diseases categorised together due to their geographical spread, and neglected status which is determined by under-funding relative to other conditions of equal prevalence[5,6]. The World Health Organisation (WHO) categorise 20 diseases or neglected conditions as NTDs.

NTDs affect more than one billion people globally, many of whom are some of the world's poorest and most marginalised people. People at risk of infection are those without adequate access to water, sanitation and health services as well as those in close contact with insects or animals that carry infections[1]. Some NTDs are short illnesses that are reversible if the correct healthcare is available and social conditions are addressed. However, many NTDs have a chronic course, are physically disabling and/or are associated with stigmatisation[5]. Impacts of this long-term course can include inability to work, reduced employment or livelihoods, catastrophic health expenditure (when medical costs exceed 40% of household income), and reduced societal roles and participation due to stigma, all of which have significant emotional burden and can lead to distress, and in some cases impact on ability to function and participate in important aspects of life. When mental health problems lead to such limitations, this is called psychosocial disability[7].

What is Stigma?

Stigma, discrimination and social exclusion, are common experiences for people affected by NTDs, particularly when they show significant physical disfigurement. Stigma operates at a personal and structural level for people affected by NTDs and is also shaped by individual characteristics such as age, gender, or wealth to impact overall health and wellbeing[8]. At an institutional or structural level, stigma can mean that policies and processes restrict opportunities for people affected, which may result in: a lack of allocated resources; reduced access to health and social services; lack of educational opportunities; and exclusion from income generation activities[1]. At a personal level, stigma can lead to; experiences of abuse or violence, exclusion from community or familial activity such as meal times, divorce or abandonment by a spouse or partner, and concealment or hiding[8]. (See CBM's *Community Mental Health Good Practice Guide: Anti-Stigma and Awareness-Raising* for more information on stigma and ways to address it).

What is Mental Health and what are Mental Health Conditions?

Mental wellbeing, temporary distress and long-term severely disabling mental health conditions operate on a continuum[1]. Mental health conditions (mental, neurological and substance use disorders, suicide risk and associated psychosocial, cognitive and intellectual disabilities) affect 1.1 billion people worldwide, a number which is increasing[1]. NTDs can be significant drivers of mental ill-health in the people they affect as well as their families and caregivers.

A Mental Health Continuum
(adapted from[1])

Mental Wellbeing
A state of well-being in which the individual realises their own ability, can manage the daily stressors of life, can work productively and fruitfully, and are able to make contribution to the community.

Psychological Distress
Comprises of the worry, fear, sadness and insecurity often experienced by people with an NTD and the associated stigma. Can lead to reduced social functioning and self-isolation.

Mental Health Condition
Characterised by changes in thoughts, perceptions, emotions or behaviour that affect relationships and ability to perform expected social roles. Can cause significant functional impairment. For example, depression, anxiety, harmful use of alcohol.

Psychosocial Disability
Interaction between impairment caused by mental health conditions and barriers to participation in society experienced by many people with these conditions.

What is the Link between Mental Health and NTDs and why does it Matter?

The interconnections between mental health conditions, NTDs and disability are increasingly recognised[5,9]. They share many common social and structural causal factors.

- People with NTDs are at higher risk for mental health conditions,
- People with mental health conditions are at higher risk of an NTD[5,9].

Considering people experiencing psychological distress, mental health conditions and/or psychosocial disability at all points on the NTD continuum of care is essential. This can support the prevention of life-long illness and associated disability related to NTDs for the majority, whilst also ensuring the establishment of person-centred disease management, disability and inclusion programmes for those who would benefit from long-term support. Both of these elements are critical to ensuring the elimination of NTDs and in improving the quality of life for people with NTDs and mental health conditions.

Multiple social and structural factors pre-dispose people with NTDs to poor mental health including:

- poverty,
- precarious livelihoods,
- poor employment opportunities and/or loss of earnings,
- health care costs,
- chronic pain, discomfort (like itching),
- reduced functioning, restrictions in exercising their rights, and social isolation.

Personal and structural stigma acts to shape how each of these factors affects a person at the individual, household, community and societal level. Consequently, studies have shown higher rates of depressive disorders in populations affected by NTDs, including people with NTDs, their caregivers and communities. Chronic NTDs (e.g. with symptoms like lower leg swelling/lymphoedema) are also associated with higher rates of common mental health conditions than other common chronic disease(s)[5,9].

70% people with lymphoedema in a study in Togo found to be at risk of depression[3].

20% of people with lymphatic filariasis in a study in Plateau State, Nigeria experience depression[4].

68.5% of people with lower leg lymphoedema in a study in Rwanda reported depressive symptoms[2]

There is also a direct pathological impact of NTDs on brain health, resulting in some NTDs leading to neurological consequences.

Neurological consequences may be due to: ‘direct infection of neurons (e.g. rabies), direct infection of brain tissue with provocation of local symptoms due to mass effect and local inflammatory reaction (e.g. leishmaniasis), a systemic inflammatory response to the pathogen at the time of infection or treatment (e.g. filariasis), an increased risk of cerebrovascular disease (e.g. Chagas disease) or immune-mediated nerve damage (e.g. leprosy)’[1,p4].

Sleeping sickness (Human African Trypanosomiasis) is another example of a disease that directly affects the brain.

For people affected by NTDs, mental health is frequently cited as a priority. Consequently, programmes have begun to act to mainstream the consideration of mental health within NTD programmes and to increase links with mental health services.

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Box 1

CBM and Partners Have Contributed to Two Important and Complementary WHO Resources:

Health workers and community volunteers who work with people with NTDs, mental health conditions and/or psychosocial disability, may experience stigma and discrimination as a result of their job role. It is important to consider this in the design of any action or intervention. Health workers themselves may need support to manage stigma and discrimination and/or associated psychological distress.

Conversely, some health workers may also be perpetrators of stigmatisation or discrimination toward people with NTDs, mental health conditions and/or psychosocial disability. Working with health workers to understand the reasoning behind stigmatisation of affected persons is a necessary action in the development of better quality and person-centred care. The NTD NGO Network (NNN) and International Federation of Anti-Leprosy Associations (ILEP) recently produced a set of stigma guides (www.stigmaguides.org); guide 3 is particularly useful in identifying strategies and techniques for addressing stigma within the health workforce, for example through the use of participatory activities to understand the root causes of stigma so that actions to address misconceptions can be identified.

Mr Jidda from Nigeria, who is affected by lymphatic filariasis (elephantiasis), participated in an international conference, contributing his expert experience about how research could best improve quality of life of people affected by NTDs

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Case Study:

The Mind-Skin-Link Project

(CBM, The Leprosy Mission Nigeria, and the University of Jos)

CBM recently collaborated with WHO to produce the guidance document 'Mental Health of people with neglected tropical disease, towards a person-centred approach'[1]. This document provides guidance for policy makers, funders, NTD programme managers and health service providers to support the mainstreaming of mental health within NTD services. CBM's Mind-Skin-Link Project, in Benue State, Nigeria, is piloting the approach set out in the document by working toward developing a model intervention based on a step care approach and better link communities with mental health services. This intervention will be designed in partnership with communities and health service providers to improve feasibility and accessibility and will involve:

- Training of community health workers or volunteers to screen people with NTDs for visible signs of depression and to refer where needed
- Support for people to access mental health services at the primary health care centre
- Supervision of community health workers or volunteers from trained personnel

A Framework for Action

Over the past decade, CBM has worked with a range of partners to encourage the mainstreaming of mental health considerations within NTD programming and health systems more generally. This work has informed the development of multiple guidance documents that shape best practice regarding the integration of care for mental, neurological, and substance use disorders, some of which are NTD specific. These guidance documents should be considered as key information sources when planning for programme adaptation.
Inclusive health systems should be designed to respond to national priorities and reflect the values, needs and experiences of people with NTDs, their households and communities. In this way, disease management, disability and inclusion strategies can be truly person-centred and address unnecessary, avoidable, unfair and unjust differences in health outcomes for the most vulnerable. Cross-sectoral and integrated approaches are the most appropriate, evidence based, effective way of achieving this[1], because people with NTDs and mental health problems have needs beyond just health services.

Such systems reform relies on change at multiple levels that is often context specific. Change is needed in relation to:

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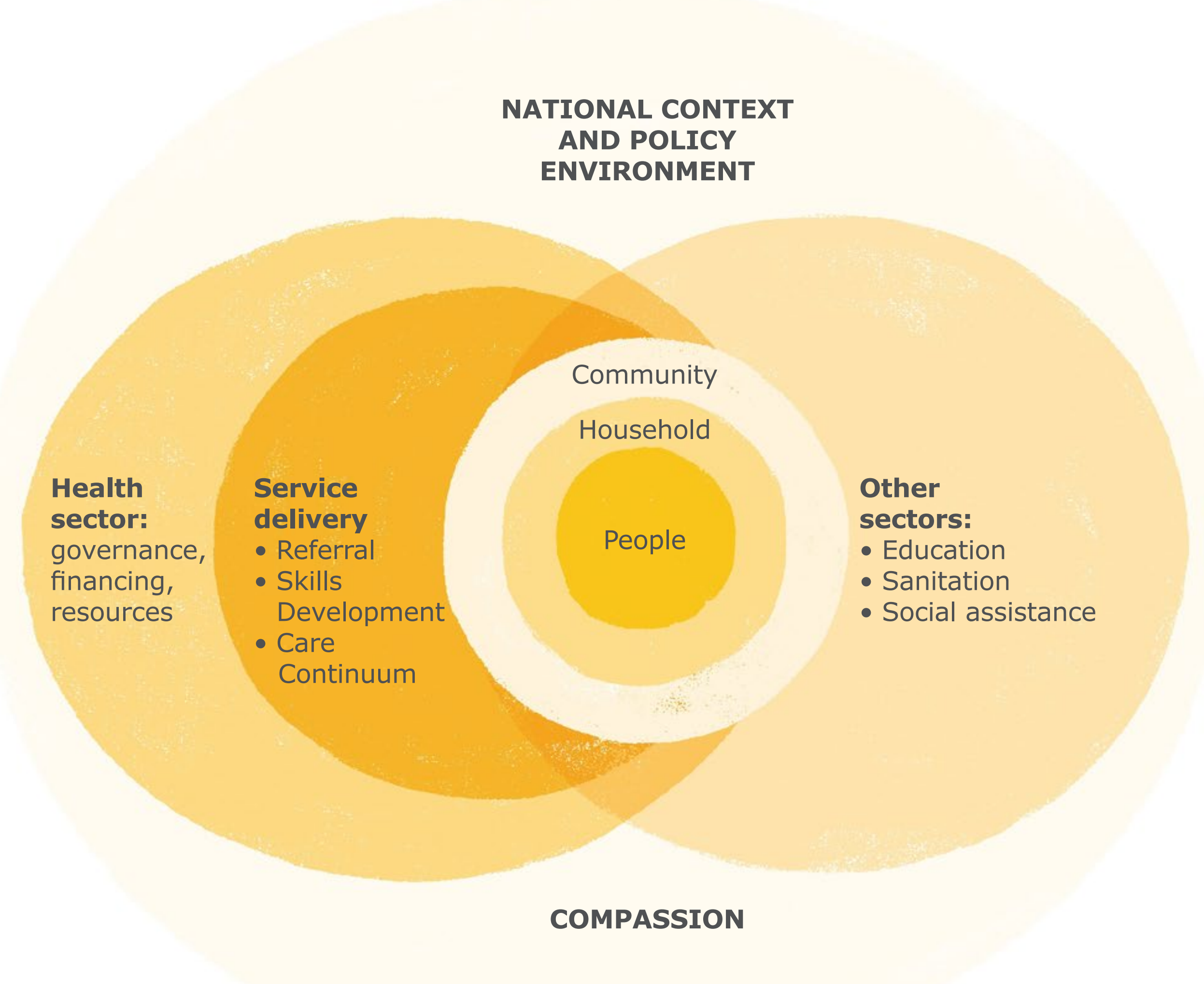
- health sector governance, financing and resources;
- service delivery processes, including skills strengthening and support for the health workforce and system wide referral processes that better link health services to communities;
- and increased collaboration with other sectors such as education, sanitation and social assistance.

The goal of any form of intervention or treatment must be to prioritise the whole person, their household and community and the prioritisation of **compassion** within service design becomes essential to maintaining quality healthcare.



WHO present five interdependent strategic directions that can support in shaping the development of integrated people centred health systems[10]. These strategic directions are designed to generate a set of actions that can support in transforming health systems to enable service delivery that is both integrated and people-centred.

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Empowering and Engaging People

Individuals and communities have the opportunity, skills and resources they need to be able to make effective decisions about their own health, ultimately becoming co-producers of health services and healthy environments.

Strengthening Governance and Accountability

Promoting transparency in decision making and collective transparency of health providers and health systems managers through aligning governance and accountability incentives.

Re-orientating the Model of Care

Efficient and effective care is purchased and provided through models of care that prioritise primary and community care services and co-production of health. Focus on holistic care delivery and a shift to outpatient care and efficient and effective referral systems. Intersectoral collaboration at the community level becomes critical in shaping how social determinants of health are addressed.

Co-ordinating Services

Care should be co-ordinated around the needs of people at every level as well as including other sectors in an attempt to overcome the fragmentation of care delivery.

Creating an Enabling Environment

Need to bring together different stakeholders to enable transformational change.

Within the subsequent table, a series of actions are presented that are based on existing evidence to support the mainstreaming of mental health services within NTD programmes and aligned to WHO's strategic directions for the delivery of person-centred care. The actions presented are not intended to be an exhaustive list. Rather, they are presented as recommendations to enable a step in the right direction toward facilitating integrated person-centred disease management, disability and inclusive with a strong focus on psychosocial support for people with NTDs, their families and communities.

People with NTDs and mental health conditions and/or psychosocial disability face disadvantage because of social and structural causal factors. Acting to address these factors is essential to the development of inclusive health systems and in minimising the burden of ill-health. Together, the actions presented below have the potential to address barriers to inclusion in ways that reflect the needs, values and realities of the most marginalised, and support the realisation and practical opportunities for participation.

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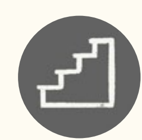
National Programme Managers

Collaborate	Create a policy framework to ensure collaboration between mental health services and NTD programmes Ensure that people with NTDs are present in all policy development meetings and work with them to listen to and respond to their experiences Establish multi-sectoral working groups (e.g. WASH, education, rehabilitation) to identify opportunities for integrated care, with a focus on prevention and management Ensure that health policies and plans are consistent with international human rights conventions and standards (such as the Convention on Rights of Persons with Disabilities)
Monitor, Evaluate and Adapt	Collate disaggregated data by gender, age, and disability through global best practice approaches e.g. Washington Group Questions. Review this data regularly and make adaptations to the programme as necessary.
Promote Early Case Detection	Ensure mass drug administration continues for people affected by acute NTDs Use mass drug administration platforms for the identification of suspected and new long-term NTD cases Pilot the use of clinical identification or diagnostic tools within primary healthcare settings (e.g. Recognising Neglected Tropical Disease Through Changes in the Skin)
 **Establish a stepped care approach**	Identify endemic NTDs in your setting that present with chronic sequelae (e.g. lower leg lymphoedema, scaring) and/or high levels of stigmatisation (e.g. leprosy) where resources should be targeted Agree on the use of a culturally sensitive psychological measurement tool (see Stigma Guides 4) and a process for screening for alcohol and substance use disorders (e.g. ASSIST or AUDIT) that are practical for large scale use in your setting through non-expert administration. Create a training, supervision and referral cascade from community to tertiary level to ensure evidence based psychological care for people with long-term NTDs (see Mental health of people with neglected tropical disease, Towards people-centred approach)

National and International NGOs		
	Support National Ownership	Provide flexible funding for integrated programme activities Strengthen the capacity of national actors in governance and decision making to support adaptation of international agendas to local context
	Promote an Environment of Learning and Change	Develop a structured programme of operational research that responds to context specific challenges Lobby for increased investment in integrated mental health, NTD and stigma reduction programmes with national government and NGDO partners
	Facilitate Medicine and Resource Availability	Conduct supply chain assessments to ensure access to essential psychotropic medications as well as those for physical needs Support the provision of self-care packages for those who need it, including bandaging, foot hygiene and eye care

Health Service Providers		
	Strengthen Service Delivery and Community Connections	Conduct community wide sensitisation focused on the risks of people with NTDs developing mental health conditions and links with psychosocial distress Ensure that all health workers (including close to community providers e.g. CHWs) are trained in basic knowledge communication skills, awareness and identification of mental health concerns Establish a system of basic first line care, for example, through the identification of community-based counsellors or befrienders who are trained in psychological first aid or other low intensity psychosocial interventions. Ensure supervision for these cadres Engage with village health committees and service-users' organisations to gain feedback on services provided. Adjust where necessary. Establish dialogue with other health providers (e.g. traditional or faith healers) to support collaboration and referral of complex cases.

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Peer Support Groups		
	Facilitate Contact Based Interventions	Consider people with NTDs in support group organisation Connect people through the use of social media where possible Support peer advocates to share health information messaging and take messages to communities around them (a key anti-stigma intervention) Establish connections and referral links to livelihood support programmes for people with NTDs at the local level See the CBM guide in this series on peer support

Box 2

Moving Forward with Mental Wellbeing and Stigma in Neglected Tropical Diseases

The following will support the scale-up of initiatives that support the mental health and reduce stigma of people with NTDs in low and middle income countries (LMICs):

- **Research:** The majority of NTD research does not take into consideration mental health, however there is a growing body of evidence that highlights the need for further research.
- **QualityRights:** All NTD related activities should take an approach that promotes human rights and access to quality mental health care.
- **Central to Community Mental Health (CMH) Work:** All community-based models of mental health should be inclusive of people with NTDs and vice versa.
- **Full and Meaningful Participation of People with Lived Experience:** People with lived experience should fully participate in the design, development, implementation and evaluation of all CMH interventions.
- **Emphasis on Lived Experience in Advocacy:** CMH and NTD practitioners and organisations must ensure that advocacy is carried out with and by people with disabilities and/or NTDs – ‘nothing about us without us’.

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For further information on CBM's Community Mental Health work:

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CBM Global Disability Inclusion

CBM Global Disability Inclusion works alongside people with disabilities in the world's poorest places to transform lives and build inclusive communities where everyone can enjoy their human rights and achieve their full potential.

Community Mental Health Thematic Area in CBM Global

Mental health conditions are a major cause of disability and ill-health worldwide. Those living in poverty are at greatest risk and least likely to access treatment or support. Many people experiencing mental health conditions and/or psychosocial disabilities face stigma, discrimination, even abuse. With decades of experience in the field of global mental health, CBM Global recognises the central role of mental health in wellbeing and works to promote good mental health, challenge the exclusion of people with mental health and/or psychosocial disabilities, and strengthen mental health systems, so that mental health needs are recognised and addressed.

This is one of a number of guides that CBM Global will be producing to share our work and experience in community mental health.

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List of Resource Materials

- Neglected Tropical Diseases and Mental Health: Progress Partnerships and Integration https://www.who.int/publications/i/item/9789241548052

Mental Health

- mhGAP intervention guide and Community Toolkit https://www.who.int/publications/i/item/mhgap-intervention-guide---version-2.0
- WHO Quality Rights Toolkit https://www.who.int/mental_health/publications/QualityRights_toolkit/en/

Stigma Reduction

- ILEP/NNN Stigma Guides https://www.infontd.org/toolkits/stigma-guides/stigmaguides
- Stepping Stones Resources and Community of Practice https://steppingstonesfeedback.org/resources/

Peer Support and Community Based Rehabilitation

- The experience of self-care groups with people affected by Leprosy: ALERT, Ethopia https://pubmed.ncbi.nlm.nih.gov/11715277/
- Community Involvement in the Care of Persons Affected by Podoconiosis https://www.mdpi.com/2414-6366/3/3/87

Neglected Tropical Disease Policy and Guidance

- Ending the Neglect to Attain the Sustainable Development Goals. A roadmap for neglected tropical disease 2021-2030 https://www.who.int/neglected_diseases/Revised-Draft-NTD-Roadmap-23Apr2020.pdf?ua=1
- NLR Skin App https://nlrinternational.org/what-we-do/projects/skinapp/

Promoting Equity and Inclusion

- Disability and Gender Analysis Toolkit https://www.cbmuk.org.uk/wp-content/uploads/2020/03/CBM_disability_and_gender_analysis_toolkit_accessible.pdf
- Disability Inclusive Health Services Toolkit https://iris.wpro.who.int/bitstream/handle/10665.1/14639/9789290618928-eng.pdf

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