

# CBM UK Project Evidence Brief #6

A person-centred approach to support the mental health and wellbeing of people affected by Neglected Tropical Diseases (NTDs)

The Neglected Mind - Skin Link (MSL) project, Nigeria



Photo: Anas is a participant in our CiSKuLA Holistic and Inclusive NTD project in Nigeria, a follow on project that has applied lessons from the Neglected Mind Skin Link research

Consortia partners:



Funder:



This research is supported by the Coalition for Operational Research on NTDs (COR-NTD) [grant number NTD-SC #214D} through support from the UK Foreign, Commonwealth and Development Office (FCDO)

## Overview

High levels of community stigma surround Neglected Tropical Diseases (NTDs) such as Leprosy and Lymphatic Filariasis (LF). This stigma considerably impacts the wellbeing of those affected by these visible skin conditions. Access to Leprosy and LF treatment is difficult due to barriers such as distance and transportation costs. Affected people report having poor mental health, particularly depression and anxiety.

Mental health support for persons affected by NTDs can be improved through promoting access to basic mental health care, and by building the competencies of NTD service providers to identify, treat, and refer people with mental health needs. Self-help groups are helpful in not only providing practical support and livelihood opportunities, but also in providing peer support for wellbeing. NTD-affected people receiving these services reported improvements in their physical and mental health status, with wider emotional and wellbeing benefits being felt by their families and caregivers.

## Introduction

Skin NTDs affect the poorest communities in low-income countries and cause physical impairments due to nerve damage (Leprosy), abnormal swelling of limbs (LF), skin ulcers (Leprosy, LF, Buruli ulcer), and itching (onchocerciasis). People affected often experience rejection, stigma and discrimination. The resulting emotional consequences can lead to psychiatric comorbidities, particularly depression and anxiety, exacerbating the physical effects of the conditions.<sup>1</sup>

Despite this, people with NTDs often lack access to the mental health care they need as services tend to concentrate in urban areas, often far from the rural communities where affected people live. Mental health care providers also often lack skills and experience of working with people with NTDs and perpetuate stigmatising beliefs and exclusionary behaviours towards them.

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<sup>1</sup> Litt et al., 2012; Obindo et al., 2017

**Title:** Neglected Mind-Skin Link (MSL)

**Location:** Benue State, Nigeria

**Timeframe:** July 2020 – Jan 2022

**Partnership between:** CBM Global, The Leprosy Mission Nigeria and the University of Jos

The Neglected MSL research project conducted a feasibility assessment of the [World Health Organization's \(WHO's\) 2020 toolkit](#) for supporting the mental health needs of people affected by neglected tropical diseases (NTDs).

This person-centred WHO model recognised and prioritised the mental health needs of people affected by NTDs. A combination of psychosocial, pharmacological and educational interventions was then proposed as a package of basic mental health support to people affected by NTDs.

The Neglected MSL research project piloted the WHO approach in Benue State, Nigeria, with people affected by Leprosy and Lymphatic Filariasis (LF). The team adapted the WHO modelled Theory of Change (ToC) for operationalisation in Nigeria, in a participatory way with local, national and international stakeholders. This guided the implementation of culturally and locally appropriate interventions to identify and address mental health, anti-stigma and wellbeing needs of people with NTDs and their wider families.

## Methodology

The Neglected MSL project (see Red box) brought researchers alongside Benue State health care personnel (mental health and NTD services), people with lived experience of LF and Leprosy, and health service policymakers. Together, they developed a Theory of Change (ToC) based on international guidelines and local contextual knowledge, to guide the implementation of culturally and locally appropriate interventions to identify and address mental health, anti-stigma and wellbeing needs of people with NTDs and their wider families. These interventions included training health care professionals in Psychological First Aid and NTDs, integration of mental health into primary health care, and peer support groups.

This brief summarises the findings of an evaluation of the feasibility and acceptability of the intervention using different research methods: A Mental Health prevalence survey with 141 people living with leprosy and LF, and matched control populations, was conducted in Benue State, Nigeria. Those who screened positive for depression or anxiety were interviewed to understand their experiences, and their priorities for services and support. Focus group discussions (FGDs) were held with service users and their carers, often family members. Key informant interviews were conducted with frontline health providers and health care leaders in both NTD and mental health services.

## What the evidence tells us

### **1. Mental wellbeing is negatively affected among people with Leprosy and Lymphatic Filariasis (LF), with increased prevalence of conditions like depression and anxiety**

We found high rates of depression, anxiety, and reduced wellbeing among people with NTDs in Benue State. The prevalence of depression was 60.3% among people with NTDs compared to 31.2% among those without.

Compared to people with similar age, level of education, employment status, family history of mental illness etc, people with LF were 9.5 times more likely to have depression and people with leprosy were 2.69 times more likely.

### **2. There are high levels of community stigma reported by people affected by Leprosy and LF, which is possibly a major factor leading to negative impacts on their mental health**

**“For some of us we avoid even to mingle with people because you are different from others.”**

**MSL Focus Group participant, with NTD**

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**“This disease has separated me from people, I used to attend gatherings of all sorts and have fun but now not possible, and so disheartening.”**

**MSL Focus Group participant, with NTD**

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**“Our community members lack pleasure and joy to associate with us”.**

**MSL focus group participant, with NTD**

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People with Leprosy and LF experienced high levels of community stigma, resulting in social exclusion and discrimination, impacting negatively on individuals' sense of self (self-stigma) and their place in society. People reported impacts on their social lives, ability to find a partner, and other forms of isolation.

**"It has affected me because the ladies that I wanted to marry decided to cut off from me because of this condition."**

**MSL Focus Group participant, with NTD**

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### **3. Barriers to health care limit NTD treatment for Leprosy and LF affected people.**

Despite primary health services being available locally, physical distance to the secondary health clinics was a barrier to access and use of the integrated mental health and NTD services. Associated costs of treatment and transport were major barriers. NTD affected people highly valued medical access but pointed to their low income, exacerbated by their health conditions, as a barrier. Solutions to enable people with NTDs to better manage their conditions included providing affected people with additional finance, as well as free treatment and self-care products through local, primary health facilities.

### **4. Mental health support can be provided through promoting access to mental health care in primary health services, and by building competencies among providers of NTD services to identify, treat, and refer people with mental health needs.**

The MSL pilot improved access to free medication and better health outcomes for NTD affected people in terms of both their physical and mental health. Training NTD clinic staff in mental health care resulted in services that both users and their carers expressed satisfaction. Training reinforced the importance of primary health care providers speaking to, and treating NTD patients respectfully and without stigmatising them, as well as knowing when to refer them on. In turn, health care providers also felt the pilot was sustainable as a result of the enhanced collaboration between government and non-governmental organisations strengthened through this new people-centred approach.

### **5. Self-help groups provide an important platform for providing support for people with Leprosy and LF, including peer support, mental health support, and community advocacy.**

The facilitation of self-help groups, for example through capacity-building activities and awareness raising on the linkages between mental health and NTDs, alongside some Psychological First Aid (PFA) training, underscored the success in wellbeing improvements. Self-help groups enabled NTD-affected communities to self-advocate at the community level (e.g. developing key messages on NTDs and stigma and using these messages for community awareness and reestablishing relationships), with consequent positive impacts on personal resilience and wellbeing.

## 5 Key Lessons

1. **Mental health services are essential for people with Leprosy and Lymphatic Filariasis.**
2. **Promoting access to mental health care in primary health services, and building competencies in those who provide NTD services to identify, treat, and refer people with mental health needs are two practical strategies to improve the reach of mental health service.**
3. **Access to NTD care and medication for Leprosy and LF has to be improved in terms of meeting costs and overcoming transportation challenges for affected people.**
4. **High levels of community stigma have to be addressed in order to reduce negative impacts on the mental health of people with Leprosy and LF.**
5. **Self-help groups are an important platform for providing support to people with Leprosy and LF. They work well to promote peer support for mental health, facilitate livelihoods, and to engage in community advocacy.**

## Recommendations

- **For national policy makers and healthcare institutions:**
  - Design NTD policy and planning investments in a more person-centred way, with reference to the WHO NTD Roadmap and pilot models.
  - Major system components (e.g. information systems and drug availability), as well as community and professional stigma reduction, require policy-led longer-term interventions and evaluation.
- **For healthcare institutions:**
  - Equip frontline staff with the skills to recognise mental health concerns in patients and understand crucial next steps for referral.
  - Consider developing lay and peer counselling services, to provide individual or group-based, low intensity, transdiagnostic psychosocial interventions.
  - Look to provide treatment for depression and anxiety within primary care services (i.e. via nurses using mhGAP skills).
  - Ensure clear referral pathways and maintain access to specialist services through:
    - Ongoing links to mainstream mental health services (through primary care to access to specialist support where needed).
    - Clear referral pathways between NTD services, primary health care and specialist care.
    - Improved liaison between the State NTD Programmes and mental health services.
- **For national policy makers and Non-Governmental Organisations (NGOs):**
  - For both professionals and general communities, anti-stigma interventions require a comprehensive approach. Consider use of direct contact interventions with stigmatised

- people for targeting specific attitudes (relevant to both mental illness and NTD-related stigma).
- Provide basic stigma training and materials to carry out awareness raising. Two good resources include: (1) [The International Federation of Anti-Leprosy Associations \(ILEP\) Guidelines on Health-Related Stigma](#); and (2) [CBM Good Practice Guide: Mental wellbeing and stigma in NTDs](#)
- Recognise the importance of including NTD affected people in wider social programmes (such as livelihoods support and social welfare).
- Support knowledge and skills in existing peer networks, self-help groups and Organisations of Persons with Disabilities on the links between mental health and NTDs.

## Conclusions

The evidence points to the importance of recognising and addressing mental health and wellbeing needs of people affected by NTDs. These highly stigmatised conditions require efforts to increase community awareness alongside access to mental health services for people affected by NTDs. Interventions to promote access to mental health care include building competencies among primary health service providers to better identify, treat, and refer people with mental health needs. Self-help is also a powerful intervention channel, with peer groups proving an important and ongoing support channel. People with NTDs reported improvements in their physical and mental health status, with wider emotional and wellbeing benefits also felt by their families and caregivers.

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## **Acknowledgements**

This evidence brief is produced by CBM UK, with reference to the reports written by the project team of the Neglected Mind-Skin Link project, in Nigeria. We would like to express our gratitude to all the researchers, participants and authors and reviewers of these project outputs. We are particularly grateful to the people with lived experiences of Leprosy and Lymphatic Filariasis, as well as staff of the health system in Benue State, who so generously shared their experiences and insights with the Neglected Mind-Skin Link project partners.

Sincere thanks are due to CBM Global, the Leprosy Mission Nigeria and the University of Jos for their invaluable contributions to this research project. The support of state authorities and local organisations of people with Leprosy and LF as close collaborators in this project is highly appreciated, and we thank them for sharing their perspectives and experiences.

Lastly, we would like to thank the Coalition for Operational Research on NTDs (COR-NTD) [grant number NTD-SC #214D] for funding our project through a grant from the UK Foreign, Commonwealth and Development Office.

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