

**Identifying a Research Agenda for NTD-related Stigma and Mental Health Care**

**Session Date:** Friday, November 3

**Session Time:** 1:00pm – 4:00pm

**Session Location:** Sassafras

**Session Description:** This session will build upon the documented link between NTDs, stigma and mental health problems, focusing on identifying research gaps in stigma reduction and mental health care provision. Presentations will cover joint measurement tools, existing community-level mental health care programs and interventions addressing stigma reduction, the perspectives of affected persons, and integration of NTD, stigma and mental health programs into state systems.

**Session Chairs:** Gail Davey, Brighton and Sussex Medical School  
Dean Sienko, The Carter Center  
Wim van Brakel, Netherlands Leprosy Relief

**Session Rapporteur:** Liesbeth Mieras

**KEY DISCUSSION POINTS**

The burden of the stigma associated with disease and the mental health consequences will remain after elimination. Public health elimination is not complete if the mental health problem is still there.

There is a need to measure stigma and mental health consequences to inform relevant stakeholders (e.g. donors and policy makers) and to assess the effect of interventions.

During the recent NNN meeting in September 2017 in Senegal a Mental Wellbeing and Stigma Task Group was established. (NNN= Neglected tropical diseases NGO Network)

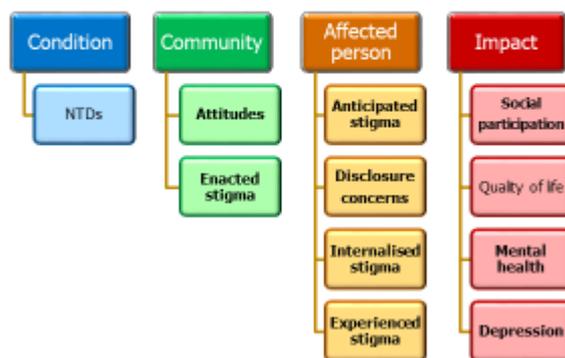
Donors often consider mental health-associated disease management, disability and inclusion (DMDI) as a black hole; for example, they feel that financial support does not lead to clear results. This is not true as effective measures are available. Impact can be shown. Tools for measurements are available but not widely used.

**KNOWLEDGE GAPS IDENTIFIED**

Available services are often concerned with physical impairments, but mental well-being should also be addressed.

Stigma and mental well-being can be visualized using the assessment framework for stigma. A toolbox is under development with measurement tools for all elements in the framework.

## Assessment framework for stigma



Adapted from Rensen et al, 2010

In Ethiopia, India, Nepal, South Africa and Uganda, the PRIME: PProgramme for Improving Mental health care is being implemented. The aim of the programme is to develop evidence on the best approaches for integrating mental health care into primary health care.

Questions to answer:

- What kind of organizational interventions are needed?
- What kind of capacity strengthening is needed?
- What are the best approaches to improving accessibility?

Mr. Jidda Muhammad Assakin, from rural northern Nigeria, born in 1959 was interviewed. He worked for the Nigerian customs but was forced to retire prematurely because of elephantiasis. He tried traditional treatments as well as modern medicine. Debulking surgery was performed on one leg and his scrotum. He was a senior officer and enjoyed his work. His retirement was unexpected. As a result of his forced retirement, he became depressed. Mr. Assakin: *“People in Africa do not know what causes the disease. Researchers should assist us and put us on the right track.”*

### RECOMMENDED NEXT STEPS

#### Priority areas, and specific research required

##### A. Strengthening understanding of links between mental health, stigma and NTDs

- Generate baseline data related to prevalence of mental disorders among people affected by different NTDs.
- Delineate putative mechanisms for associations between individual NTDs, mental health outcomes & stigma.

##### B. Understanding the impact on the lives of people affected, communities in which they live, and on efforts to control NTDs

- Quantify and explore social and economic impact on people affected, and caregivers’ wellbeing and family finances.
- Modelling of above to inform GBD estimates and generate economic burden figures.
- Understand the impact of poor mental health on key NTD goals, for example those specified by the London Declaration and Sustainable Development Goals.
- Synthesize, develop and validate appropriate instruments to measure mental health, wellbeing and stigma in the context of NTD programmes

C. Crafting the response.

- Quantify the impact of good physical treatment for NTDs on mental health outcomes
- Quantify the impact of good psychosocial support and access to mental health care on use of NTD services, access to MDA and NTD physical outcomes
- Develop and evaluate models of integration of mental health care into NTD programmes (who to engage, at what level; training, support and supervision; demand creation; holistic rehabilitation)
- Policy work on effective integration of mental health into basic care packages for NTDs, ultimately to ensure formal recognition as standard component. E.g., Develop and evaluate practicality of inclusion of access to mental health care as a required component of WHO national dossier on elimination of lymphatic filariasis as a public health problem.