



## **NTD Report 2016**

Neglected Tropical Diseases

**Disability Inclusive  
Development in action**

DRC: Vincent Mutoke whose right  
eye was saved due to Mectizan®  
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**CBM supports neglected tropical disease (NTD) programmes in areas where these diseases are identified as a public health problem. Working within a disability-inclusive development (DID) approach, CBM aims to provide a continuum of care from prevention to treatment of NTDs.**

Neglected tropical diseases represent a largely hidden health burden, affecting the most marginalised and voiceless communities. These diseases disproportionately affect children, women and people with disabilities. They flourish where there is poor housing and sanitation, unsafe water, and limited access to basic health services – particularly in conflict zones.

In 2015, the United Nations (UN) identified 17 sustainable development goals (SDGs) in its global pledge to 'leave no one behind'. If NTDs are not addressed, we will not achieve targets related to universal health coverage (SDG 3.8), poverty (SDG 1), hunger (SDG 2) and quality education (SDG 4). Other goals – such as water and sanitation (SDG 6), climate

change (SDG 13) and global partnership (SDG 17) – are also closely linked to success in eliminating NTDs.

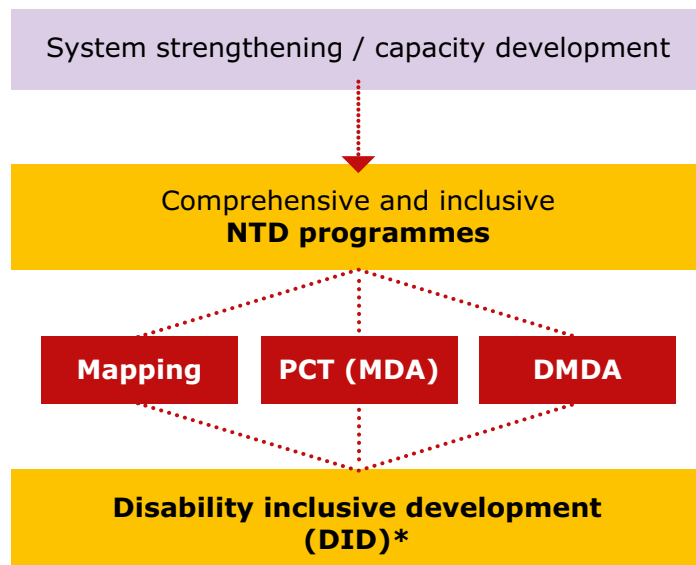
For these reasons, NTDs have now been included in a specific target under SDG 3 which aims to end the epidemic of NTDs by 2030.

The World Health Organization (WHO) and other key stakeholders have suggested that NTDs have a distinct 'targeting' function. This allows NTD-endemic areas to be prioritised and investments focused on the most marginalised people. NTDs also have a 'tracer' function: they help to monitor progress on a number of SDGs and on achieving greater equity.

## CBM aims to implement NTD programmes that are comprehensive and inclusive, integrated into national programmes, and that build inter-sectoral collaboration.

CBM works through alliances and networks, for example it is a member of the Disease Management, Disability and Inclusion (DMDI) working group of the NTD non-governmental development organisations (NGDO) Network (NNN). It participates in the development of tools for disease and disability mapping, with the aim of developing fully-inclusive NTD programmes, and also promotes operational research. In the area of mental health, CBM is collaborating in a pilot project to address NTD-related stigma and depression.

With experience in inclusive eye health, community-based rehabilitation, mental health, self-help groups and the effects of NTDs on patients' livelihoods, CBM and its partners are uniquely placed to promote DID, and ensure the rights of people with disabilities are recognised and upheld.



**NTD** = neglected tropical diseases

**PCT** = preventive chemotherapy and transmission control

**MDA** = mass drug administration

**DMDI** = disease management, disability and inclusion (including mental health)

\*See: <http://www.cbm.org/CBM-publishes-its-DID-Toolkit-480240.php>

# NTDs and mental health – CBM study in Nigeria

Over the last three decades, mass drug administration (MDA) for preventing NTDs has been a great success. For a continuum of care approach, however, the needs of those already disabled by NTDs should be addressed; in particular, the many barriers they must overcome to be accepted in society.

CBM supported a study in Nigeria that investigated mental health problems among people affected by lymphatic filariasis (LF). The study explored the attitudes and underlying reasons for exclusion from society.

The study showed that stigma, discrimination and exclusion are a common experience in people affected by LF, being similar to those documented for leprosy and resulting in high levels of depression and anxiety.

While stigma and discrimination were reported

by many respondents, it was their lack of expectations and limited social engagement – a process often called self-stigma – that had the most damaging effect on their quality of life.

**“I have a disease which means that I can’t walk and people avoid me. I get worried and feel so sad because I wish to be able to work like others, and be able to feed myself – but I cannot.”**

**Female affected with LF in Nigeria**

The study highlighted that mental health needs to be included in a comprehensive package of NTD services.

However, health systems in countries with endemic NTDs are often weak, especially at grass-roots level. NTD programmes can serve

as an effective platform for strengthening systems and integrating mental health services, for example by:

- 1.** Training NTD programme field staff to recognise and respond to mental health problems (using WHO's Mental Health Gap Action Programme [mhGAP] materials).
- 2.** Collaborating with experts for training, supervision and referral purposes.
- 3.** Establishing and upholding peer groups for mutual support (social, economic and therapeutic).
- 4.** Promoting social inclusion by raising awareness about NTDs, and challenging negative beliefs and stigma.

Based on the findings of the study, CBM and its local partner are planning a pilot

community mental health project for people affected by NTDs in northern Nigeria.

**Lymphatic filariasis (LF)** is a chronic, disabling and often disfiguring condition caused by a filarial parasite transmitted through the bite of infected mosquitoes.

LF is a major cause of physical disability and affects more than one billion people in Africa, Asia, Latin America and the Pacific Islands.

# Trachoma

Worldwide, 200 million people live in areas in which trachoma is known to be endemic. As the **leading infectious cause of blindness**, trachoma is estimated to be responsible for visual impairment in around 2.2 million people, of whom 1.2 million are irreversibly blind.

CBM increased its efforts to scale up SAFE\* interventions in 2015: more than 34,000 trichiasis surgeries, benefiting over 25,000 patients, were performed primarily in Ethiopia, Nigeria and Uganda; over 430,000 people were treated with azithromycin; 68 surgeons were trained in surgery for trachomatous trichiasis (TT); and 201 community and health workers were trained in the 'F' and 'E' components (F&E) of the strategy.

## \*The SAFE strategy:

Surgery for trichiasis

Antibiotics

Facial cleanliness

Environmental improvement

## The Queen Elizabeth Diamond Jubilee Trust Trachoma Initiative

Launched in 2014, the Initiative aims to tackle blinding trachoma in 12 Commonwealth countries by 2019, with CBM as an implementing partner in Uganda, Kenya and Malawi.

In Uganda, where CBM supports trichiasis (TT) surgery in the Busoga and Karamoja sub-regions, it is expected that targets will be reached by the end of 2016. The Trust has now approved an extension of the project to the remaining 23 endemic districts. CBM

will support surgery in seven districts of the Acholi sub-region and thereby contribute to the goal of eliminating trachoma in Uganda. The programme will build on experience from previous years, especially regarding the role of 'TT case finders' who have substantially increased the number of patients reporting to the surgical camps. This is of particular importance since, as the programme progresses, the number of patients declines and remaining cases are more difficult to find.

### **Trachoma mapping in Pakistan**

Researchers, donors and implementers have long acknowledged the importance of mapping the prevalence of trachoma to help target interventions to areas of greatest need.

The Global Trachoma Mapping Project (GTMP) is the most ambitious disease mapping project ever undertaken. During a period of over three years it has screened a total of 2.6 million people in 29 countries. In Pakistan, 15 districts with endemic trachoma were

mapped under GTMP in 2015, with CBM being the implementing partner for the Punjab and AJK provinces. Based on these findings (and previous survey results), CBM and partners presented a Trachoma Action Plan for Pakistan in March 2016.

### **New Trachoma project in Chad**

Building on previous work in Chad, CBM has been supporting a new trachoma project aiming at eliminating the disease in four regions of the country. The project will benefit over 2 million people and is being implemented by a CBM partner organisation in collaboration with the Chadian government so as to ensure alignment with the Trachoma National Plan. The project concentrates on the 'S' component of the SAFE strategy, and collaborates with water, sanitation and hygiene (WASH) NGOs for F&E. So far, training for TT surgeons has been completed and TT surgery has started. Zithromax distribution will be coordinated by the government.

# The Amhara Trachoma Control Programme (ATCP) in Ethiopia, 2014–2017

Amhara Regional State in Ethiopia has one of the highest trachoma rates in the world.

Although the government and its NGO partners have been implementing trachoma control in the region for the last 10 years, elimination has not yet been achieved – weak F&E is believed to have been a major factor. The Ethiopian ‘One-Wash’ programme was introduced to strengthen F&E activities, and CBM’s Amhara Trachoma Control Programme (ATCP) builds on this. ATCP is delivered through a multi-sectoral and multi-partnership framework and is funded by the Italian government. It includes the S&A components of SAFE, but specifically focuses on improving community awareness of F&E and behaviour change through significant investments in:

1. Village health educators (VEHs) and health extension workers (HEWs)

2. WASH committees (WASHCOs)
3. Anti-trachoma school clubs (ATSCs)
4. Construction of community water supply schemes
5. Hydrological analysis and water point selection

CBM systematically works with WASH partners to ensure inclusion of F&E principles.

A mid-term evaluation in 2016 revealed that increasing awareness of SAFE had resulted in strong community participation in the construction of latrines and water wells and behaviour change. Education on appropriate animal husbandry had also been successful in reducing local fly populations.

Key to the success of the programme was



the adoption of an approach that ensured ownership at the community level. In addition to the inclusion of local government partners and other stakeholders in all stages of the planning and execution of the programme, local community members (of all genders and ages) also were closely involved in planning and decision making, and were active in implementing the programme.

The ATCP also leveraged in-kind contributions for water sources and sanitation from other partners. This resulted in a more efficient use of the budget, and better results than would have otherwise been possible.

**“There will be behavioural changes and it’s those changes that will have long-term impact in the community and help eliminate trachoma.”**  
**Birhan Desalegn, Health Office, Raya Kobo**



ATCP stakeholder meeting ©CBM

# Comprehensive NTD programmes

## The UNITED programme in Nigeria

Under the UK Department for International Development (DfID)-funded UNITED programme, CBM supports MDA for onchocerciasis, LF, schistosomiasis, soil transmitted helminths (STH) and trachoma in communities in Kano state, northern Nigeria. The programme builds on CBM's onchocerciasis work in Nigeria that has been ongoing for over 20 years, despite security challenges.

The programme started with drug distribution in 2014. It receives continuous support from the Ministry of Health in Kano state through teams that mobilise and raise awareness of NTD among communities.

In 2015, CBM's partner organisation through this programme alone reached over 11 million people through MDA, and trained or re-trained

over 25,000 community members in drug distribution.

## NTD programmes in DRC

In partnership with the Ministry of Health and the Liverpool School of Tropical Medicine (UK), and with funding from the UK DfID LF elimination programme, LF mapping was completed in DRC in 2015. In addition, trachoma mapping was conducted with funding from the US Agency for International Development's (USAID's) ENVISION programme.

CBM provides ongoing financial management and technical assistance to the Ministry of Health for planning and monitoring of NTD activities. Ten provinces are now targeted for integrated MDA for LF, onchocerciasis, schistosomiasis and STH.

**“I’m a lucky man,” says Vincent Mutoke (pictured on the front cover) and smiles: “Yes, I lost the vision in my left eye due to river blindness, but my right eye was saved – I’m not blind!”**

Vincent is a peasant farmer who lives with his wife and his six children in a remote village in Kasai Province, DRC.

When he was a young man, Vincent was infected with onchocerciasis. He was digging for diamonds near a fast flowing river – an ideal breeding place for the blackflies that transmit the disease.

“I got those nodules under my skin, my skin was itching severely. I got headaches and my eyes started watering. All that came progressively, over a long time,” Vincent explains.

Unfortunately, at a time when Mectizan® could have saved both of Vincent’s eyes, there was no efficient distribution programme in place in the mining fields. It was only because he hadn’t found diamonds and was starving, that after many years he returned to his village. By

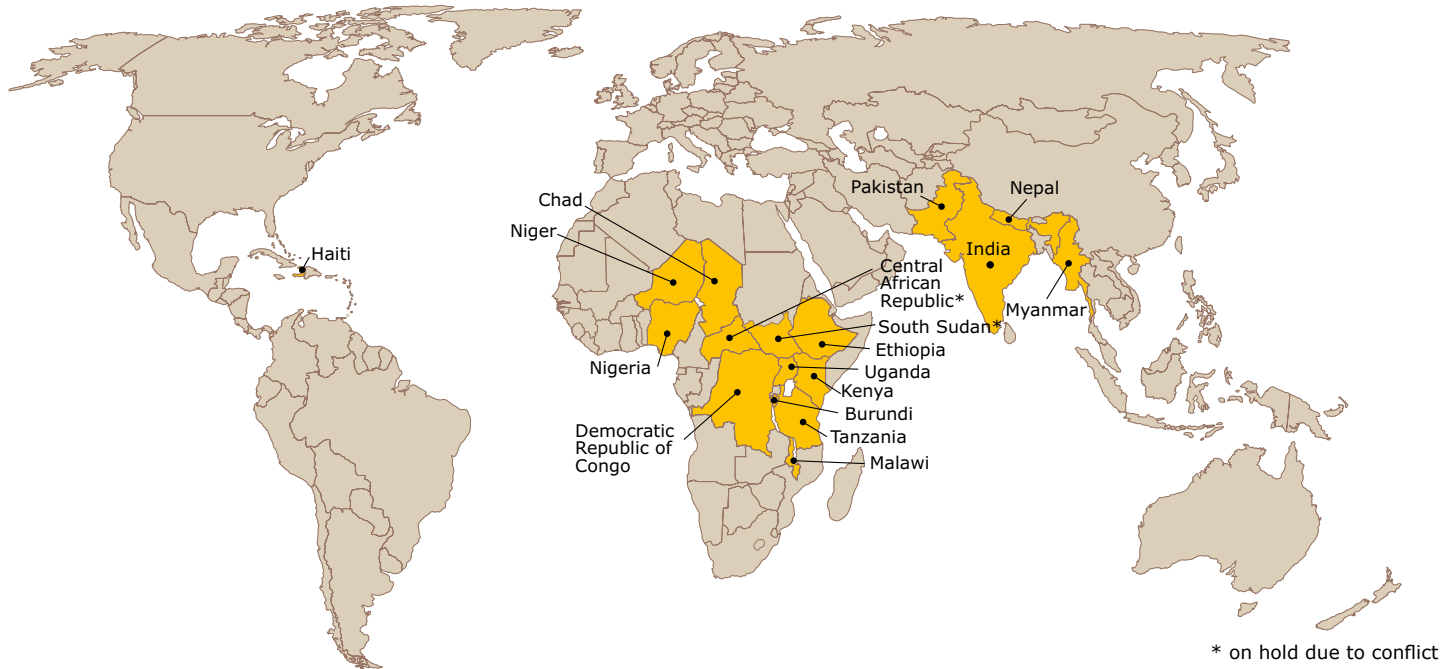
then, Mectizan® was distributed – just in time to save his right eye and to ensure that his wife and children will never get the disease.

CBM is a major contributor to the national programme for onchocerciasis elimination in DRC. The success of the programme means that hardly any new cases of the disease are now observed in CBM supported regions.



Vincent with three of his children  
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## CBM supports work with NTDs in 17 countries



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