

Briefing Paper

The Worldwide Leprosy Burden – Priorities for Action

Leprosy – What is it? Leprosy is a chronic infectious disease, caused by the bacillus *Mycobacterium leprae*. It is believed to be transmitted via droplets from the nose and mouth, through close contact with a person affected by the disease who has not received treatment. In leprosy endemic areas most people who encounter the bacteria develop protective immunity. The bacillus multiplies slowly and it can take up to 20 years before symptoms appear. Leprosy primarily affects the skin and peripheral nerves, the upper respiratory tract and the eyes. Delayed treatment can result in physical and sensory disability, including damage to fingers and toes, contractures, inability to close the eyelids and blindness, which often lead to social exclusion. Approximately three million people are disabled by the disease.

Diagnosis and Treatment - Diagnosis of leprosy is based on three signs: anaesthetic skin patches, enlarged peripheral nerves and finding the mycobacterium on a slit-skin smear. Leprosy can be treated effectively with multi-drug therapy (MDT), a combination of antibiotics (rifampicin, clofazimine and dapsones). Only a minority of patients are infectious before starting treatment. Early diagnosis and treatment, combined with effective self-care, mean permanent disabilities can be avoided. Late detection and leprosy reaction (which can occur before, during and up to a few years after treatment) are the major causes of disability. Poverty, poor healthcare infrastructure, stigma, false beliefs and a lack of understanding about the disease by the affected person, family, community and health providers, increase the likelihood of leprosy resulting in disability and of social exclusion.

The Burden of Leprosy can be viewed in different ways.

1) Incidence – The latest WHO epidemiological indicators for leprosy¹ show the number of reported new cases reduced by 2% from 249,007 in 2008 to 244,796 in 2009. Over half of these (133,717) were in India. Other countries with pockets of high endemicity include Bangladesh, Brazil, China, DR Congo, Ethiopia, Indonesia, Madagascar, Mozambique, Myanmar, Nepal, Nigeria, Philippines, Sri Lanka, Sudan, Tanzania and Timor Leste. For many years the new case detection rate remained consistently above 600,000 new cases per year. There has been a sharp drop in new cases reported between 2002 and 2005, associated with the integration of leprosy diagnosis and treatment into general healthcare services, combined with the WHO target of elimination of leprosy as a public health problem (i.e. a prevalence of < 1 in 10,000). However, lack of awareness about the disease, the stigma of coming forward for diagnosis, a move from active case finding to voluntary reporting, lack of skills of general health staff in leprosy diagnosis and lack of inclusion of cases from private practice within leprosy control statistics, mean the real number of people affected by the disease is likely to be far higher than statistics suggest. It is also claimed that since countries could only achieve the elimination target by declaring fewer cases, there was an incentive for under-reporting².

Even so, in 2009 there were still 16 countries reporting more than 1,000 new cases, covering 93% of the global total; new case detection rates show that between 1985 and 2008 nearly 15 million people have been cured of leprosy³. The number of new cases with Grade-2 disability (visible complication of nerve, skin or eye involvement) at the time of diagnosis has remained stable for the last five years at around 14,000 per year. In an attempt to move away from elimination targets to give a better picture of the leprosy burden, Grade-2 disability has now replaced prevalence rates as the WHO measure for leprosy³.

According to national leprosy control programmes' statistics, and in line with The Leprosy Mission's (TLM's) understanding of the disease, changes in incidence take place slowly over decades and are related to factors such as BCG immunisation, economic development and effective leprosy control practices. E.g. despite more than a decade of hard work in leprosy control in China, the number of annual newly detected cases has not dropped below 1,500 for the last 15 years.⁴

¹ WHO Weekly epidemiological record 27 August 2010, <http://www.who.int/wer/2010/wer8535.pdf>

² Kumar, A & Girdhar, B.K. (2006) Is increasing MB ratio a positive indicator of declining leprosy? http://ismocd.org/jcd/38_1/s4.pdf

³ WHO Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy (2011-2015) http://www.searo.who.int/LinkFiles/GLP_SEA-GLP-2009_3.pdf

⁴ Shen, J. et al (2010) A big challenge in case finding at low endemic situation: Analysis on 1462 new leprosy patients detected in China in 2007, *Lepr Rev* (2010) 81, 176–183 <http://www.leprahealthinaction.org/lr/Sept10/1421.pdf>

2) Health Services - The burden on health services has declined considerably because of changes in the duration of treatment and a reduction in new case detection rates. Before MDT became available, patients needed to take medication daily for the rest of their life; with MDT the duration of treatment reduced to six months or a year, depending on the load of bacilli. However, primary healthcare staff are often unable to diagnose and treat leprosy, or provide specialist care in the absence of a good referral system. Proper wound care, the treatment of reactions, and reconstructive surgery are often not available. Even when services are available, barriers such as lack of transportation, money, family and livelihood commitments, and discrimination by health staff prevent people taking up referrals. Innovative approaches for stimulating self-reporting and accessing referrals are needed to reduce the delay in diagnosis and Grade-2 disability.

3) Disability and social exclusion - The 'burden of leprosy' does not end on completion of MDT. It is estimated that more than three million people worldwide are living with disability due to leprosy. Fear of the disease is deeply rooted in folklore and religious beliefs. In many communities, leprosy leads to social rejection, mental suffering and a denial of human rights. People affected by the disease and their family members are often discriminated against, denied opportunities for education, income generation and community participation. These are often life-long burdens leading to increased vulnerability and poverty. Even amongst those cured before a disability occurs, a considerable number still battle with stigma-related consequences.

Enhanced Global Strategy for Further Reducing the Disease Burden Due to Leprosy (2011–15)³

There are many challenges to reduce the leprosy burden including: loss of clinical skills in recognising and managing leprosy and its complications, young doctors not attracted to specialising in leprosy, lack of research, no political commitment, and leprosy not being firmly imbedded in health systems. A consequence of the decline in reported cases is that for governments and healthcare staff of endemic countries, leprosy is no longer a priority. Many governments are now reducing investment in leprosy services, and professional expertise and knowledge of the disease is declining. This, accompanied by the long incubation period of the bacillus, may result in the re-emergence of new leprosy cases in the future.

Working towards a '*world without leprosy*', WHO, along with partners like TLM, have designed a new strategy to address the burden of leprosy. Major efforts are needed to build and maintain capacity of primary healthcare staff to diagnose and treat leprosy. In addition, in many countries general health referral systems also need to be equipped to address the complications and consequences of the disease.

Emphasis needs to be placed on maintaining knowledge about leprosy, including scientific research on its social and medical implications. WHO outlines research priorities³ that address issues of integration, equity, quality and sustainability within the three domains of epidemiological, operational and patient management. This includes research to:

- Develop tools to detect infection and patterns of transmission
- Explore the use of anti-leprosy drugs in preventing the occurrence of new cases among household contacts
- Remove barriers to accessing and using services and explore how to empower people affected by leprosy to participate in decision-making
- Ensure early recognition, prevention and timely management of nerve-function impairment and reactions, and improve chemotherapy
- Develop and improve diagnostics to identify individuals at high risk of developing leprosy
- Develop new drugs and regimens for use in situations when rifampicin is contraindicated for reasons of resistance or toxicity
- Improve the quality and quantity of the tools and procedures available for leprosy control

TLM would also add the need for more research into addressing stigma and social exclusion.

Since leprosy is not just a medical but also a human rights issue, the strategy also emphasises the need for community-based rehabilitation (CBR), with a particular focus on addressing stigma and discrimination against people affected by leprosy and their family members. A recent WHO meeting in Manila advocated for involvement of people affected by leprosy in all aspects of leprosy programmes⁵. Many INGOs/NGOs which support health, education, social services and respond to emergency situations have little understanding of

⁵ Develop Guidelines to Strengthen Participation of Persons Affected by Leprosy in Leprosy Services, WHO Report of the Meeting 9-10 June 2010, Manila, Philippines

leprosy and rarely include people affected by the disease in their programmes. As a result, people affected by leprosy are one of the most vulnerable and impoverished groups in society. Extensive lobbying is needed at all levels of government and with NGOs to keep leprosy on the agenda and promote inclusion.

The Wider Context - Millennium Development Goal (MDG) 6 aims to reduce the burden of disease. Now regarded as a Neglected Tropical Disease (NTD), it is hoped that grouped with similar neglected conditions leprosy will continue to receive due attention. It is anticipated that programmes will be developed in endemic countries that cluster NTDs, to train staff in health and other services to address their causes and consequences. Effective partnerships (MDG 8) between government national leprosy control programmes, WHO, leprosy member organisations, anti-leprosy INGOs (making up ILEP, the International Federation of Anti Leprosy Associations), the Novartis Foundation (providing free MDT), local NGOs, Mission Hospitals, researchers and research institutions will still be required to reduce the leprosy burden.

Women are at particular risk from leprosy, due to their general disadvantaged position in society which often results in late diagnosis and also the immunological changes during and immediately after pregnancy, causing deterioration in their condition. Maternal health strategies (MDG 5) need to include reference to women affected by leprosy and appropriate treatment of their condition. Leprosy also affects women's marriage prospects, as well as opportunities to generate income (MDG 1) and be involved in community activities (MDG 3); programmes need to be gender sensitive and include women affected by leprosy. Children affected by leprosy have less opportunity for education (MDG 2) because of the stigma and discrimination associated with the disease. Stigma reduction programmes that promote inclusive education are essential.

The current WHO Global Strategy for Leprosy has adopted a specific target in reduction in disability by 2015. However, it is of prime concern that disability is not explicitly included in the MDGs. The UN recognises that, *'The lack of a disability perspective is undermining the objective of the Goals, which is to measure human development benchmarks on the way to more inclusive and equitable global development.'*⁶ If the MDGs are to benefit people affected by leprosy, implementation of the UN General Assembly recommendation that Member States *'promote the realization of the MDGs for persons with disabilities, inter alia, through explicitly including persons with disabilities in national plans and tools designed to contribute to the full realization of the Millennium Development Goals'*⁷ is vital.

Leprosy thrives in poverty; it also leads to poverty because the stigma that accompanies it limits social inclusion, and its progressive and permanent damage to nerves results in disability which affects job opportunities. To ensure people affected by leprosy benefit from the MDGs, stigma and discrimination must be addressed and people affected by leprosy included in mainstream development programmes.

Priorities for Action:

- Ensure NTDs are addressed under MDG 6, and that leprosy is included within funding criteria for programme implementation and research for NTDs
- Encourage governments of endemic countries to ensure knowledge and expertise on leprosy is preserved, and early detection and referral systems are given greater priority
- Recognise that leprosy is a human rights issue as well as a medical issue, and provide funding for programmes that support people affected by leprosy to access their rights and entitlements
- Support the approval of the Principles and Guidelines for Governments for the Elimination of Discrimination Against People Affected by Leprosy and their Family Members (UN Resolution 8/13)⁸ and lobby for governments to implement these guidelines
- Encourage governments and INGOs integrate people affected by leprosy into mainstream development programmes
- Ensure the needs of pregnant women affected by leprosy are addressed in maternal health programmes (MDG 5) and that health staff are able to provide appropriate treatment.

⁶ Fifth quinquennial review and appraisal of the World Programme of Action concerning Disabled Persons <http://eprints.ucl.ac.uk/15695/>

⁷ Realizing the MDGs for Persons with Disabilities, RES/64/131, 2 <http://www.un.org/esa/socdev/unga-resolutions.html>

⁸ UN Principles and Guidelines to Eliminate Discrimination Against People Affected by Leprosy and their Family Members <http://bit.ly/c1dBJN>



The Leprosy Mission England and Wales (TLMEW) is an international Christian development organisation, transforming the lives of people affected by leprosy. Its goal is to eradicate the causes and consequences of leprosy, one of the 'neglected tropical diseases' (NTDs). It supports individuals, families and communities affected by leprosy, other disabilities and causes of stigma that result in social exclusion and poverty. TLMEW's holistic approach meets the physical, social, economic and emotional needs of individuals and communities, generating confidence and self-esteem to participate in society.

TLMEW is affiliated to The Leprosy Mission International (TLMI), which currently has programmes in 28 countries across Africa, South Asia and South East Asia. The primary beneficiaries are people affected by leprosy and people with disabilities. Programmes include: advocacy for the rights of people affected by leprosy/disability; community-based rehabilitation (e.g. education, vocational training and housing); micro-enterprise; leprosy treatment and general healthcare; research; training health staff to diagnose leprosy and prevent disability; surgery and physiotherapy. In the UK, TLMEW is supported by over 34,400 individuals and 3,885 churches and groups. TLMEW engages with these supporters to increase their knowledge and commitment to development through a network of speakers, publications and new media.

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