

## Commentary

### Leprosy remains an important public health challenge in India

In the year 2011 a total of 219,075 new leprosy cases were registered in the world, of whom 127,295 were in India<sup>1</sup>. Among the new cases detected in India, approximately 3 per cent have grade 2 disability, referring to the presence of visible (and often permanent) deformity. It has been estimated that in 2015 there will be nearly 500,000 people living in India with grade 2 disability due to leprosy<sup>2</sup>. Leprosy affects the peripheral nervous system and in the absence of timely treatment this will lead to irreversible neuropathy in a large proportion of cases. This in turn leads to secondary impairments, such as wounds caused by burns or pressure on the sole of the foot, contractures of fingers and toes and visual impairment. These impairments can finally lead to limitations in activities of daily living and/or restrictions in social participation<sup>3</sup>. Leprosy is thereby a leading cause of preventable disability in India and poses a major public health challenge for the country.

Although we have some grasp of the extent of the leprosy disability problem in India in terms of individuals affected, it is very difficult to establish the burden of this problem accurately. This is partly due to the inherent difficulty of measuring phenomena such as impairment, activities of daily living, stigma, social participation and quality of life. Such information is essential for planning services for prevention of disability and rehabilitation. Leprosy control worldwide has relied basically on the WHO Disability Grading system for measuring and reporting the disability burden in leprosy<sup>4</sup>. This is a leprosy-specific measure of severity of impairment of eyes, hands and feet, which can be established easily in field conditions. It has proven useful as a proxy indicator for the success of leprosy control in general. In leprosy control, early diagnosis and treatment are essential in preventing ongoing transmission of *Mycobacterium leprae*,

the causative agent of leprosy, as well as preventing the occurrence of permanent nerve damage. A low proportion of newly detected leprosy cases with grade 2 disability is, therefore, an indicator of a successful control programme (new patients are apparently found in time), but does not provide much information on actual health burden, both at the individual and population levels. More recently, instruments have been developed for persons affected by leprosy to measure level of activity (*e.g.* the SALSA Scale<sup>5</sup>) and participation (*e.g.* the Participation Scale<sup>6</sup>). These newer approaches and tools for measuring disability in low and middle-income countries have been described comprehensively by Van Brakel & Officer<sup>7</sup> and represent important improvements in establishing the disability burden in people affected by leprosy and comparable diseases causing disability.

For measuring disease burden at population level, a standard unit has been developed, namely the disability-adjusted life years (DALY). This measure is useful for establishing (cost) effectiveness of interventions for preventing illness or alleviating disease burden. This measure has been widely used, also for estimating the burden of neglected tropical diseases, a category including leprosy<sup>8</sup>. DALY is the sum of years of life lost (YLL) plus years lost due to disability (YLD). Mortality in leprosy is not an important issue; a few people die from leprosy<sup>9</sup>. Therefore, the DALY in leprosy is derived primarily from YLD, which is the number of incident cases times disability weight times the average duration of the case until remission or death (in years). The average disability weight attributed to leprosy WHO Disability Grades 1 and 2 is 0.152<sup>8</sup>. In comparison, the disability weight for blindness is 0.600. It is however, very difficult to measure disability caused by leprosy and its duration accurately. Disability often starts insidiously at a relatively early age and can

develop gradually over time. DALY is, therefore, a problematic indicator to describe the burden of leprosy disease.

Rao and colleagues in their article in this issue<sup>10</sup> are commended for developing an alternative indicator to measure the leprosy burden; the disability adjusted working life years (DAWLY). It takes into account loss of (anticipated) productive work years, a meaningful economic indicator for both the individual and society. They showed a reduction of 13.4 years from the ideal productive working life period of 42 years. As the authors state correctly, the DAWLY as indicator needs refinement and further validation, but the concept is appealing because it is practical and easy to understand. In order to face the public health challenge of disability burden due to leprosy in India, it is essential to have suitable indicators and measurement tools to establish the burden of disability accurately in all its aspects, including physical impairments, activity limitation, and participation restriction. Knowledge of these factors will help developing effective preventive and support programmes and evaluating progress of these activities at individual and population levels. The DAWLY is an innovative contribution towards these ends.

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