Reflections on the new WHO leprosy indicator: The rate of new cases with grade 2 disabilities per 100,000 population per year

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WHO adopted its ‘Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy (Plan Period: 2011–2015)’ in 2009. This Strategy was adopted after much in-depth discussion, first by mail through exchanges between experts, then during a formal meeting in New Delhi in April 2009 which was attended by over 100 participants, including leprosy control programme managers. A new global target was adopted, based on ‘reducing the rate of new cases with Grade 2 disabilities per 100,000 population by at least 35% by the end of 2015, compared to the baseline at the end of 2010’. This new indicator, with the target date of 2015, had been the object of very long, and sometimes hot, discussions, but was finally accepted. The objective of this paper is not to question the appropriateness of this indicator and the target, but to review the advantages and possible limitations of the indicator, to make the best use of it, and to avoid drawing invalid conclusions from the data that will be collected.

Let us first remember why this indicator was chosen:

- For the national programme managers, it was extremely important that a target for leprosy control be defined for the future. Leprosy elimination defined as had been reached in many countries, and it was feared that, without a specific target, leprosy would not receive the due attention from the authorities in the Health Ministries. The target should be simple, and thus preferably based on one indicator only.
- The prevalence of registered cases was not acceptable as an indicator: it had been used for the Elimination strategy, but had been criticised because of its dependence on operational factors, in particular the duration of treatment.
- Incidence is not easily measurable and its proxy indicator, case detection, is also influenced by operational factors.
The rate of new cases with Grade 2 disabilities per 100,000 population is probably less influenced by operational factors; it focuses attention on prevention of disabilities and stimulates early detection; it is probably a robust marker of the level of the occurrence of the disease in the community.

Grade 2 disabilities are easy to recognise and have been reported by programmes in different ways for years, so minimal extra training will be required.

As a consequence, as stated by WHO, ‘Reduction in new cases with Grade 2 disabilities is expected to reflect a reduction in the total number of new cases’.

The new indicator undoubtedly has advantages. In particular, prevention of disabilities, at least through early detection, should now receive due attention. However, it also has some limitations:

- This single indicator is a global target to influence the direction of the programme, but, as stated by WHO, it should ‘be used in conjunction with a series of indicators for the purpose of monitoring and evaluation’. If I translate this sentence as saying: ‘use this indicator for lobbying, but do not rely on it alone to monitor your programme’.
- It is also influenced by operational factors, particularly the level or intensity of case detection, and can vary from one year to the next. In addition, in some countries, there are only a few patients with disabilities, so relatively small variations in these numbers can have a disproportionate effect on the rate. Comparing only two years’ data can be misleading. Observing trends based on data collected over several years would be more valid.
- Grade 2 disabilities are theoretically easy to recognise. Experience shows however, that mistakes are still made in evaluating individual patients in the field. Consequently, good and regular supervision and continued capacity building remain essential to ensure reliability of the data reported.
- Consistency of population data over time can be a problem, and introduces bias in the calculation of the indicator.
- Disability can also develop during and after treatment. This is not taken into account at all by this indicator and the danger exists that prevention of disabilities after diagnosis might receive very little attention.
- In most countries this rate is less than one case per 100,000 population per year. It might not be so easy to use such low rates to convince policy makers that leprosy remains a problem.
- It is likely that this target of reducing the rate of new cases with Grade 2 disabilities per 100,000 population by at least 35% by 2015 compared to 2010, adopted at national level, will be transposed at local level. This becomes less and less appropriate when the number of patients involved becomes smaller and smaller, and the danger exists that some people could feel forced to meet this target by any means and could be tempted to ‘play’ with the data.
- An examination of recent trends in the new indicator suggests that findings over the next 5 years may be different in different countries – some countries seem to be on course to meet the target easily, while in others it will be much more difficult.

To conclude, I would say that the choice of this indicator certainly has the advantage of focusing attention on the prevention of disabilities, particularly in stimulating early detection.
However, when the time comes to try and interpret the data, it will be important to keep a critical mind, before jumping to conclusions. Moreover, one must be conscious that, for monitoring purposes, one cannot be satisfied with one indicator only, and that the other indicators recommended by WHO remain important.

Reference