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EDITORIAL

Leprosy and the Millennium Development Goals

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In September 2000, 189 nations committed to working towards measurable targets to reduce poverty and achieve the basic needs and rights of all.[1] However, the UN's 2010 Millennium Development Goals (MDG) Report[2] recognised that most of the eight MDGs are not on track to be achieved by the proposed 2015 deadline. Ban Ki-Moon, UN Secretary General, stated that '*improvements in the lives of the poor have been unacceptably slow*.'[3]

During the lead up to the MDG Summit in New York in September 2010, NGOs stressed the urgent need for governments to assess why the world's most marginalised are still unreached. For people affected by leprosy, many of whom are also disabled, stigma and social exclusion can lead to lack of livelihood (MDG 1), and an inability to access education (MDG 2) and health care (MDG 4, 5 & 6). They are among the most marginalised, often lack sanitation facilities (MDG 7) and are rarely included in mainstream development programmes. The Leprosy Mission's (TLM) advocacy campaign[4] to improve the impact of the MDGs on people affected by leprosy focused on the fact that over 500 million of the world's poor are disabled and one billion are affected by Neglected Tropical Diseases (NTDs). A failure to specifically mention these two groups in any of the eight MDGs, 21 targets or 60 indicators holds particular significance as to why the most marginalised have not benefited.

So why focus advocacy on the issues of disability and NTDs rather than directly promoting inclusion of people affected by leprosy? The MDGs have become a numbers game. Although 244,796 new cases of leprosy were diagnosed in 2009,[5] leprosy is not seen as a health priority, even in endemic countries. A single disease approach was unlikely to get the attention of the decision makers. It therefore seemed appropriate to follow the WHO's new integrated approach, focusing on 17 diseases that affect one billion of the world's poor.[6] After all, one billion people cannot be ignored. Successful inclusion of NTDs in the 'Keeping the Promise' Summit Outcomes Document also meant inclusion of people affected by leprosy.

Similarly, with disability; approximately 14,000 people report with Grade 2 leprosy-related disability each year, with over three million people worldwide disabled by the disease.

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However, their needs are similar to other disabled people. Thus, disability was targeted as a key issue, since one in five of the world's poor are disabled[7] and disability has already started to be recognised as a cross-cutting issue. The UN Convention on the Rights of Persons with Disabilities (UNCRPD) '*provides an opportunity to invigorate this overlooked issue and aspect of development*.'[8] In February 2010, the UN General Assembly urged member States '*to promote the realisation of Millennium Development Goals for persons with disabilities inter alia through explicitly including persons with disabilities in national plans and tools designed to contribute to the full realisation of the Millennium Development Goals*.'[9]

Since leprosy is so closely entwined with disability and NTDs, their inclusion in the 'Keeping the Promise' document should lead to increased priority and funding. This has the potential to benefit large numbers of people affected by leprosy. After much lobbying, the final document included four notable references:[10]

- *Para 28* notes that policy and actions must focus on the poor, including persons with disabilities, so that they benefit from progress towards achieving the MDGs.
- *Para 70 (d)* promotes the inclusion of persons with disabilities in sustainable development, productive employment and decent work.
- *Para 70 (v)* promotes targeted and effective programming to meeting the nutritional needs of various groups including persons with disabilities.
- *Para 76 (h)* supports a focus on NTDs to accelerate progress to achieve MDG 6.

Prior to the recent Summit, leprosy was said to have been included under MGD 6 – 'Combat HIV, Malaria and Other Diseases'. However, in reality the MDGs led many donors to link their funding to the MDG indicators rather than the goal itself. HIV, Malaria and TB have seen huge investment (e.g. the US$19.3 billion Global Fund[11]). However, since leprosy and the other NTDs are not included within these indicators they have been further neglected. It is hoped that this reference to NTDs in the 'Keeping the Promise' document will raise their profile and that, grouped with similar neglected conditions, leprosy will 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. This is in synergy with the WHO Enhanced Global Strategy for Further Reducing the Disease Burden due to Leprosy (2010–2015)[12] which promotes integrated approaches using general health systems to provide high-quality leprosy services. Now is the time to advocate to those working on other NTDs and donor agencies to ensure that leprosy is an integral part of NTD programmes.

So what of the other MDGs? Effective 'Global Partnerships for Development' (MDG 8) between government national leprosy control programmes, the WHO, leprosy member organisations, ILEP members, the Novartis Foundation (providing free MDT), local NGOs, mission hospitals, researchers and research institutions will be of strategic importance to reduce the leprosy burden and provide specialist services and technical support. However, leprosy organisations also need to explore partnerships with other disability and mainstream development organisations if they are to ensure people affected by leprosy benefit from the MDGs.

As with addressing the disease burden (MDG 6), it may be difficult to access funding to implement MDG programmes solely targeting people affected by leprosy. Leprosy's geographical spread means such programmes are not usually cost effective and they may also

fail to promote social integration. Funding is more likely to be available linked to other NTDs, disability or mainstream development programmes. There is a danger that, if not properly managed, direct implementation of such integrated programmes could lead to a diminishing focus on leprosy on the part of the leprosy NGO. However, integrating leprosy into other NTDs, disability or mainstream development programmes is likely to be more cost effective, particularly if these programmes are directly implemented by mainstream or disability organisations, or at least operated in partnership with them. Thus, it may be advantageous for leprosy organisations to put greater emphasis on developing their advocacy and capacity development role, working in partnership with others.

Are agencies that promote health and gender equity aware that women are at particular risk from leprosy due to their general disadvantaged position in society (MDG 3) which often results in late diagnosis? Are government health departments aware that the immunological changes during and immediately after pregnancy cause deterioration in the condition of women affected by leprosy and their effective treatment needs to be included in 'Maternal Health' strategies (MDG 5)? Do agencies focusing on social and economic empowerment know that leprosy affects marriage prospects, as well as opportunities to generate income (MDG 1) and be involved in community activities (MDG 3)? Are human rights organisations aware of the discrimination and injustice experienced by people affected by leprosy, and the stigma that prevents children affected by leprosy attending school (MDG 2)?

Through raising awareness, advocating for inclusion and building the capacity of disability and mainstream organisations to address leprosy issues, more people will benefit from the MDGs, and leprosy work will have the potential to become increasingly sustainable.

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