

*EDITORIAL*

## **Leprosy and human rights**

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On the 18th June the United Nations Human Rights Council unanimously adopted a resolution (A/HRC/8/L.18) on ‘The elimination of discrimination against persons affected by leprosy and their family members.’<sup>1</sup> This historic resolution was sponsored by 59 member states and made specific reference to key earlier documents, namely the Universal Declaration of Human Rights (1948) and the International Covenant on Economic, Social and Cultural Rights (1966).

The Council called upon Governments to take effective measures to eliminate any type of discrimination against persons affected by leprosy and their family members and requested the Office of the High Commissioner for Human Rights to collect information on the measures that Governments take to eliminate discrimination against persons affected by leprosy and their family members and to submit a report to the Council. It further requested the Human Rights Council Advisory Committee to formulate a draft set of principles and guidelines to eliminate discrimination against persons affected by leprosy and their family members, and to submit it to the Council for its consideration by September 2009.

This resolution is very important and all should be encouraged to pursue its follow-up and implementation. However, leprosy has traditionally been seen as a disease apart and there are parallel arguments that rights-based approaches to health and development should be pursued for the benefit of *all* people, including those affected by leprosy.

Since people affected by leprosy should have the same human rights as all people, it is appropriate to make greater use of the International Covenant on Economic, Social and Cultural Rights (1966).<sup>2</sup> Almost all the articles of this Covenant can be seen to remain unfulfilled and unrespected for people who have been affected by leprosy. Its articles cover self determination, economic and social and cultural rights, right to work and fair remuneration, protection of the family, adequate living standards, physical and mental health, education, participation in cultural life, and access to the benefits of scientific progress.

In 2008 the UN Convention on the Rights of People with Disabilities entered into force following its adoption and ratification by the requisite number of member states.<sup>3</sup> This Convention too, represents a major new international legal instrument, and with its greater focus on inclusivity in development, is of critical importance in pursuing the rights of all persons with disabilities, including those affected by leprosy.

The WHO Global Strategy on Leprosy highlights the importance of social justice and equity and stresses that this must be integral to all leprosy work including approaches to preventing disability, stigma and discrimination.<sup>4</sup>

Specific practical strategies are therefore needed to ensure States meet their obligations to respect, protect, fulfill and promote the rights enshrined in these various Conventions and Covenants including the latest UNHRC resolution to end leprosy-related discrimination.

The 17th International Leprosy Congress in Hyderabad in 2008 highlighted the increasing importance being attached to the issue of leprosy and human rights with workshops, presentations and plenary sessions on the topic. And yet, stigma and discrimination remain widespread for people affected, their families, and communities. Negative attitudes are perpetuated through ignorance, fear, laws, the media and social exclusion. Health workers, in spite of their knowledge, may often be the worst offenders. In many countries laws remain citing leprosy as grounds for divorce, non inheritance or travel restrictions.

## Practical Approaches

### EDUCATION

Educating people affected by leprosy and their communities about their rights, facilitating social mobilisation and enabling communities to advocate for legislation in their countries are some practical activities that can be undertaken. The Brazilian Ministry of Health for example has recently produced an excellent booklet on Hansen's Disease and Human Rights for people affected.<sup>5</sup>

### BETTER USE OF MEDIA AND LANGUAGE

The media in all its forms is still not used enough to promote and reinforce positive attitudes. Indeed, in many instances it can still be found guilty of perpetuating negative and disempowering attitudes. Vigilance and persistence are required to promote more inclusive terminology and appropriate language. Much has been achieved already in the case of HIV/AIDS, so why not in leprosy? We need to continuously challenge the unacceptable and stigmatising labels which persist.

### LEGISLATIVE REFORM

Attitudinal change often comes about only when society has been forced by law to respect certain basic human rights. In the case of leprosy, collation of data on existing legislation, both good and bad, might give a focus for future campaigns for change. In theory, rights and justice are reflected in laws and conventions but the most enlightened of these are worthless unless in practice they are reflected in the way we relate to each other. The concept of dignity for the person goes hand in hand with rights.

### WORKING TOGETHER

Traditionally, those affected by leprosy were isolated, ostracised and segregated. But all people who are marginalised, disabled or oppressed, *including* those affected by leprosy, need to engage more broadly with each other in order to promote the rights of all. Initiatives focusing *only* on the human rights of those affected by leprosy may risk failure and their advocates may themselves continue to be marginalised and excluded from the development process unless a more inclusive and universal rights-based approach is taken. Within the

disability movement and even among the organisations of people affected by leprosy and their advocates, there has often been a tendency to pursue and promote exclusive approaches.

Integration of leprosy treatment into the general primary health services and integration of leprosy rehabilitation and prevention of disability programmes into broader community-based rehabilitation programmes are prerequisites for sustainable leprosy control. Likewise, work to uphold the human rights and dignity of people affected by leprosy needs to be integrated into the growing efforts, both globally and locally, to pursue integrated and inclusive rights-based approaches to health and development for all.

## References

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- <sup>3</sup> United Nations. *Convention on the Rights of Persons with Disabilities*, UN Dept. of Economic and Social Affairs, 2007; <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- <sup>4</sup> World Health Organization. *Global strategy for further reducing the burden of leprosy and sustaining leprosy control activities (plan period 2006–2010)*, 2005; [http://www.ilep.org.uk/fileadmin/uploads/Documents/WHO\\_Publications/gstrat130605.pdf](http://www.ilep.org.uk/fileadmin/uploads/Documents/WHO_Publications/gstrat130605.pdf)
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