

Presentation to opening meeting of 22nd CRPD session by Geoff Warne, CEO of International Federation of Anti-Leprosy Associations (ILEP). ILEP is a federation of 13 member associations working in leprosy-related activities in 69 countries. Its goal is zero leprosy, including zero stigma and discrimination against persons affected by leprosy and their family members.
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Excellencies,

In this address I talk about persons affected by leprosy. Some of you dislike this term. I use it because it is the term preferred by the people themselves. For hundreds of years they were ostracised as 'lepers'. Let us never hear that term here. In the 20th century doctors decided on the term 'persons with leprosy' and used it to mean the same as 'patient'. Late last century, organizations of persons affected by leprosy rejected the expression 'persons with leprosy' because it concealed the fact that many of them were already cured of the infection, though they continued to live with physical impairments and discrimination. The expression 'persons affected by leprosy' was adopted as the first step towards self-identification.

Because leprosy attacks the nerves, it often results in damage to hands, feet and eyes. This can occur before diagnosis, or during treatment, or in the lifetime after drug treatment. Estimates say there are 3-4 million people living with visible impairments from the disease. But this is only part of the story. For thousands of years, as a result of traditional beliefs and practices and some religious teachings, the word leprosy has brought feelings of fear and revulsion. As Michelle Bachelet's spokesman said recently, there is no medical justification for this fear and prejudice: it is a social invention. But it is real. This label of leprosy is associated with the abuse and violation of countless women, men and children – around 5 million of them alive today.

So I appreciate the willingness of this committee to recognise persons affected by leprosy as persons with disabilities under Articles 1 and 2. That's because – whether they have visible impairments or not – they suffer exclusion and stigmatisation based on harmful stereotypes on leprosy.

How is this stigma, discrimination, denial of rights practised today? It is through segregation.

For more than 3,000 years, cultural practices, and then national laws, forced people with a history of leprosy to live apart. They were banished onto islands or forced into leprosaria or leprosy homes. Even after a treatment was found in the 1950s, people cured of leprosy didn't go home, because they knew they would not be welcome. Instead they went to leprosy colonies or leprosy villages. Hundreds of these still exist. Some are evolving into ordinary villages, but in many cases, the leprosy stigma is being passed to a new generation who never had the disease.

These days the public is repeatedly told that that leprosy is curable and is not to be feared. Nevertheless, women, men and children affected by leprosy – whether they have physical impairments or not – are still facing segregation by the daily actions of people around them. Sure, most do not live in leprosy colonies or villages anymore. But here is the daily reality of social segregation: Not touched. Not welcome in the shop. Not traded with. Barred from school or else the object of hatred or violence from fellow pupils or teachers. Not offered a job. Shut out from health facilities unless they are specifically for leprosy. Not invited to events or to meals. Not welcome in the temple, church or mosque. Never considered as some who could marry a son or daughter. Told to leave the family home and find somewhere else to live. Results: poverty, dehumanisation, mental torture, despair, sometimes suicide.

This is the daily, brutal reality for millions affected by leprosy today. And not only at community level. Stigmatization remains institutionalized. More than fifty countries keep discriminatory laws in

force against persons affected by leprosy. Even in countries whose legislation guarantees disability rights, most persons affected by leprosy have no access because they are not officially recognised as persons with disabilities.

In 2010 the Human Rights Council adopted Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members. These form an excellent roadmap on how to enforce legally binding human rights of persons affected by leprosy and their family members. Many of the sections closely match the Articles of the CRPD, which is hardly surprising as the issues are so similar. But the Principles and Guidelines are non-mandatory and have largely been ignored, and so the same segregating patterns persist.

At this 22nd session and the 12th pre-session, you will see submissions on denial of rights to persons affected by leprosy in India, Myanmar, Mexico, Lao, Venezuela and Singapore. Each submission refers to the reality in that country, but there is a repeated thread running through all of them.

Honourable members, I urge you to call upon States to do seven things:

1. First, to ensure that persons affected by leprosy are never denied access to general health care or health services on the basis of having experienced leprosy. In some countries, sadly, stigma is at its worst in the health services.
2. Second, to ensure that persons affected by leprosy have ready access to whatever rehabilitation services may exist – especially community based – and that these programs focus not just on physical aspects but on the broader issues of social inclusion.
3. Third, to ensure that the children of parents affected by leprosy – children who have never had leprosy themselves – face no obstacles to participating in schools. The same, of course, for children who themselves have experience of leprosy.
4. Fourth, to repeal or amend all discriminatory laws. This is critically important for India, which at times has undertaken to repeal its 100+ discriminatory laws, but has not done so.
5. Fifth, to combat the daily segregation I have talked about here, by ensuring that these persons have access to social protection, with strong affirmative action and massive public education programs to build awareness and change attitudes. These programs should have a particular focus on women and girls, who often face the worst of discrimination.
6. Sixth, to ensure that persons affected by leprosy have access to Government assistance on the same basis as other persons with disabilities.
7. And finally, in keeping with Human Rights Council resolution 29/5 of 2015, that you routinely urge Member states to take their responsibility to implement the Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members. Effective implementation of the Principles and Guidelines will go a long way in enabling persons with leprosy related disabilities to live with dignity.

Thank you.