

Stigma, discrimination and exclusion are the constant, daily life and experience of millions of persons disabled by leprosy, worldwide. When we ask people for examples of stigma and discrimination, they look at us blankly and say 'Don't you understand? This is my daily life, and I am excluded and stigmatised constantly in the small, small daily events. No matter what I do, and how I behave, this does not change'.

I want to put this into a longer picture. Leprosy is a very ancient disease, and it is still very prevalent today. Around 220,000 people are diagnosed with leprosy, or Hansen's Disease, each year in 120 countries, though the true incidence of the disease is thought to be larger. 95% of the cases of leprosy occur in just 23 countries of which the leading ones are India, Brazil and Indonesia. Early treatment usually means a complete cure. But because leprosy attacks the nerves, a delay in diagnosis or treatment often results in physical impairment – damage to hands, feet and eyes. This can occur before diagnosis, or during treatment, or in the lifetime after treatment for people who lose feeling in hands or feet. Estimates say there are over 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 a result, the label of leprosy has been associated with the abuse and violation of countless women, men and children. And that is true whether these people had visible impairments or not. So the barriers, the exclusion, the dehumanising attitudes of society are not just about visible impairments or even about a disease which is so easily cured: they are in the label and this long, long history of discrimination at all levels.

How has this been practised? Through segregation.

For more than 3,000 years, there was no cure. Cultural practice forced people with leprosy to live outside the town or city so they could not contaminate others. In medieval Europe, people needed to carry bells or clappers to warn people to keep away. From the late 19th century, on medical advice, national laws were established to force people with a history of leprosy to live apart. They were dehumanized under the harmful stereotype of the *leper*. Many countries with coastlines found convenient islands to banish them onto. Where that was not possible, leprosaria or leprosy homes – some of them holding up to 2,000 people – were established. Even after a treatment was found in the 1950s, people diagnosed with leprosy didn't go home, they went to leprosy colonies which sprang up sometimes just across the wall from leprosy hospitals, or to leprosy villages. Hundreds of these still exist. In some cases they are evolving into ordinary villages, but in many cases, the leprosy stigma is being passed to a new generation who never had the disease.

In our supposedly more enlightened age, the public is repeatedly told that that leprosy is a curable disease. Nevertheless, women, men and children affected by leprosy – whether they have physical impairments or not – are still being segregated by the daily actions of people around them. Not touched. Not welcome in the shop. Not traded with. Barred from school or, if not barred, the object of hatred or violence from fellow pupils. 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, all too often leading to despair, and sometimes to suicide.

This is the daily, damaging, brutal reality for millions affected by leprosy today. And not only at community level. Stigmatization remains institutionalized at the State's architecture and functioning. More than fifty countries in the world keep discriminatory laws in force against persons affected by

leprosy. India, as you have heard, has more than 100. Even in nations with legislation guaranteeing disability rights, the majority of persons affected by leprosy have no access due to the lack of their institutional recognition as persons with disabilities.

There are some slow changes. Some laws are repealed. Persons affected by leprosy build confidence by connecting with one another and are gaining a voice. Organisations like ILEP, which have always worked *for* people affected by leprosy, now seek actively to work *with* them especially on human rights issues, and to support the development of organisations *of* persons affected. In 2008 – the year of the CRPD – the Human Rights Council recognized that tens of millions of people and their family members still suffer from leprosy not only as a disease but also from political, legal, economic or social discrimination and ostracization, a clear violation of human rights. So in 2010 it 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 norms in the specific context of violation of rights experienced by 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 at state and community level, the same segregating patterns persist.

So, honourable members, I request four things of you.

First, that in your deliberations, you recognise persons affected by leprosy as persons with disabilities under Articles 1 and 2, on the grounds that – whether they have impairments or not – they suffer exclusion, stigmatisation and the barriers imposed by society to full participation as a result of harmful stereotypes on leprosy itself.

Second, that under Article 5 you take all appropriate measures to ensure that States accept the obligation to modify or repeal existing discriminatory laws, regulations, customs and practices against persons affected by leprosy.

Third, that you are attentive in each of the submissions you receive to the loss of rights chronically, daily, being experienced by persons affected by leprosy contrary to Article 19.

And fourth, in keeping with Human Rights Council resolution 29/5 from 2015, that in your work with Member States, that you routinely urge them to take their responsibility as States 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, in these ways, for helping to prevent ongoing violation of women, men and children affected by leprosy, enforce their rights, and make sure they are not left behind.

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