

## **Submission of The Leprosy Mission on implementation of Principles and Guidelines to eliminate discrimination against persons affected by leprosy and their families in Nigeria**

### **1. Background**

According to WHO around 214,783 new cases of leprosy were reported from 118 countries in the year 2016 and 95 percent of the new cases were reported from 14 countries which includes Nigeria<sup>1</sup>. However many millions are thought to go unreported<sup>2</sup>. An estimated 20-25% of persons affected by leprosy experience disability. <sup>3</sup> Evidence- based studies indicate that children constitute 10 percent of the new cases diagnosed<sup>4</sup>. This means that every 30 minutes, one child is diagnosed with leprosy. Acute stigma attached to this ancient disease has prevented early detection and prompt treatment of the disease leading to disability. While some estimates suggest that over 3 million people are living with leprosy related disability, the actual figures could be much more than what is being estimated as often leprosy affected persons refuse to be identified due to the fear of stigma and disability stakeholders often exclude persons with leprosy related disabilities in their policies and programmes leading to further exacerbation of the exclusion experienced by them.

Since historical times, leprosy has been feared and misunderstood. One of the major reasons for the stigma and discrimination directed against persons affected by leprosy and their family members is the deep rooted myths and misconceptions that revolve around the understanding of leprosy as a disease both in the past and even in the present times. Although leprosy is not highly contagious, it is often perceived by different societies, socio-religious beliefs and cultural practices as being highly contagious, hereditary and received as a divine punishment<sup>5</sup>.

This situation has not changed much today. Persons affected by leprosy are often discriminated in educational institutions, transport services, restaurants, religious places and within the family.<sup>6</sup> There are still instances where persons with leprosy related disabilities are addressed using denigrated terms such as 'Lepers' which reinforces existing stigma against them.

### **2. Situation of human rights of persons affected by leprosy in Nigeria**

According to the National TB and Leprosy Control Programme, Nigeria continues to be one of the leprosy high endemic countries and reporting around 3000 new cases annually. Persons affected by leprosy and their families continue to face discrimination on account of stigma which is often resulting in late detection leading to deformities. Prevailing myths and superstition has led to erroneous perception that the disease is highly infectious leading to exclusion and discriminatory practices against persons affected by leprosy and their families. There are instances where persons affected by

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<sup>1</sup> [http://www.who.int/gho/neglected\\_diseases/leprosy/en/](http://www.who.int/gho/neglected_diseases/leprosy/en/)

<sup>2</sup> <http://journals.plos.org/plosntds/article?id=10.1371/journal.pntd.0003658>

<sup>3</sup> ILEP technical guide. Facilitating the integration process: a guide to the integration of leprosy services within the general health system. London: ILEP; 2003. [30 March 2010]. [www.ilep.org.uk/library-resources/ilep-publications/english/](http://www.ilep.org.uk/library-resources/ilep-publications/english/)

<sup>4</sup> NLEP- ' Progress Report for the year 2013-14 ending on 31st March 2014', Central Leprosy Division, Directorate General of Health Services, New Delhi

<sup>5</sup> Progress report on the implementation of the principles and guidelines: A/HRC/AC/17/CRP.1/29<sup>th</sup> July 2016

<sup>6</sup> Progress report on the implementation of the principles and guidelines: A/HRC/AC/17/CRP.1/29<sup>th</sup> July 2016.

leprosy have lost their homes and their lands grabbed by their relatives leading to loss of livelihoods due to stigma<sup>7</sup>.

Exclusion of persons affected by leprosy and their family members often compel them to live in poverty and there are three out of four states in Nigeria with intense transmission of leprosy in North West geo political zone which also has the highest relative poverty rate in the country<sup>8</sup>

### **3. Principles and Guidelines on elimination of discrimination against persons affected by leprosy and their families.**

The concern shown by the UN Human Rights Council towards discrimination of persons affected by leprosy and their families led to the formulation of Principles and Guidelines which have been adopted by the General Assembly and the Human Rights Council. These principles and guidelines clearly emphasizes the role that the national governments have to play in eliminating discrimination against persons affected by leprosy and their families. It makes us realize that global commitment to promote and protect human rights of individuals cannot be fulfilled as long as persons with leprosy related disabilities face discrimination and their rights not being respected.

Despite adoption of the resolution on principles and guidelines by the Human Rights Council and its endorsement by the UN General Assembly, persons affected by leprosy and their families continue to be discriminated in many ways. The Principles and Guidelines complements many rights recognized by human rights treaties to which Nigeria is a state-party such as ICCPR, ICESCR, CRC, CRPD and CEDAW.

### **4. Recommendations**

The Principles and Guidelines unanimously adopted by the UN General Assembly on the recommendation of the Human Rights Council has been a significant step forward to eliminate discrimination and stigma against persons affected by leprosy and their families. Nigeria is yet to take affirmative action though being one of the high endemic countries to implement the human rights framework.

a) The Nigerian government may please be urged to raise awareness through campaigns about the Principles and Guidelines within the relevant national and sub-national level government agencies and through state sponsored media. In all such awareness –raising actions, persons affected by leprosy and their family members should be consulted and given a pivotal role.

b) The Nigerian government may be encouraged to identify discriminatory laws that are in force and take action to repeal such laws. The government should also consider framing appropriate policies and legislations in line with the Principles and Guidelines to end discriminatory practices against persons affected by leprosy and their families.

c) Action taken to address discrimination and promote the human rights of persons affected by leprosy and their families should become part of the national reports that are prepared for submission under various human rights treaties such as ICCPR, ICESCR CRC, CEDAW and CRPD

d) The national government may be urged to identify either the National Human Rights Commission or the National Leprosy Elimination /Control agency as a national committee with representation of

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<sup>7</sup> <https://www.reuters.com/article/us-nigeria-health-leprosy/leprosy-neglected-in-nigeria-as-health-spotlight-turns-away-idUSKBN1CW0SD>

<sup>8</sup> NBS. Nigerian Poverty Profile 2010. Abuja; 2012. Available from: <http://nigerianstat.gov.ng/>

persons affected by leprosy to monitor and follow-up on the effective implementation of the principles and Guidelines.

e) Appropriate training may be provided to various government agencies entrusted with the responsibility of promoting and protecting the human rights of Nigerian citizens about the discriminatory practices against persons affected by leprosy and their families and to address them accordingly.

f) The Nigerian judicial and quasi- judicial authorities under various Ombudsman mechanisms addressing human rights violations should specifically be asked to be proactive in identifying cases of discriminatory practices against persons affected by leprosy and to redress them expeditiously.

g) As significant number of persons affected by leprosy experience disability, the national government may be encouraged to include persons with leprosy related disabilities within the broader definition of persons with disabilities within the national disability law /legislations / commissions and to take appropriate steps to combat stigma and discrimination against them.

h) Last but not the least , Sustainable Development goals are all about leaving no one behind, let us ensure that persons affected by leprosy and their families are not left behind on account of the stigma and discrimination they face on a daily basis in their communities today.