Written statement by the Special Rapporteur on the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members, Ms. Alice Cruz, addressed to the distinguished body of the Committee on the Rights of Persons with Disabilities

Excellencies,

Leprosy has been associated with the abuse and violation of countless women, men and children for thousands of years. Religious and traditional harmful beliefs and practices, alongside erroneous misconceptions produced by the late nineteenth-century modern medicine, fuelled pervasive multi-layered discrimination and structural violence.

The Special Rapporteur, through her work as both an academic and an activist, firmly believes that it is labeling and not leprosy itself that is at the root of discrimination on the grounds of leprosy.

The overlapping of harmful stereotypes, wrongful stereotyping and structural iniquities reinforces exclusion, segregation, discrimination and physical, sexual and psychological violence on the grounds of leprosy. Stigmatization against the estimated five million persons affected by leprosy worldwide remains institutionalized at the State’s architecture and functioning: there are more than fifty countries in the world that keep discriminatory laws against persons affected by leprosy in force. Discriminatory practices against persons affected by leprosy at the State’s administration is also an enduring and shameful reality, particularly in health and education services, work opportunities and regulation, and access to disability rights, from which the majority of persons affected by leprosy are excluded due to the lack of their institutional recognition as persons with disabilities.

Lack of substantive equality and pervasive structural disadvantage allocates persons affected by leprosy in the context of intersecting vulnerabilities, multiple discrimination and subordination (understood by the Special Rapporteur as historical devaluation of some groups of people under hierarchical social structures that by producing and reproducing an unequal distribution of power constrain their autonomy and participation) that severely impair access to equal opportunities, as well as outcomes.

Persons affected by leprosy were historically dehumanized under the harmful stereotype of the *leper*. Demands against widespread discriminatory language arouse in the mid-twentieth century with the voices of persons who were forcibly segregated by State policies. However, the outcome of their struggle was still largely in control of the medical community who decided in favour of the expression “persons with leprosy” to replace the ostracizing sign of the *leper*, using it interchangeably with the noun “patient” and conferring, as such, equal meanings to “persons with leprosy” and “patients”. It was only in the late twentieth-century that representatives of already established organizations *of* persons affected by leprosy (and not of organizations *for* persons affected by leprosy) went against the hegemony of biomedicine in classifying groups of persons by diseases and rejected the expression “persons with leprosy”. In their view, such expression continued to put leprosy at the forefront of their identities and concealed the fact that many persons were already cured of the infection, even though they continued to live with physical impairments, discrimination and disabilities. The currently used expression “persons affected by leprosy” was adopted as the first step towards self-identification.

It is the view of the Special Rapporteur and of persons affected by leprosy themselves that the former, but also many of their family members, should be recognized as persons with disabilities (in accordance with articles 1 and 2 of the CRPD), on the grounds of not only physical impairments and the multiple barriers imposed by society to full participation, but also on the grounds of discrimination based upon harmful stereotypes on leprosy itself. Moreover,  the obligation of taking all appropriate measures, including legislation, to modify or abolish existing discriminatory laws, regulations, customs and practices against persons affected by leprosy should be enforced as an immediate State’s obligation under article nº 4 of the CRPD.

The Special Rapporteur requests the honorable members of the committee to kindly consider including reference to the implementation of the Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members in their work with Members States. The Principles and Guidelines provide a roadmap on how to enforce legally binding human rights’ norms in the specific context of systemic and structural violation of persons affected by leprosy and their family members. The Special Rapporteur also requests the honorable members of the committee to kindly consider producing a guideline for the elimination of discrimination on the grounds of leprosy. It is the Special Rapporteur’s aim that the important work of the committee, when addressing persons affected by leprosy, as well as many of their family members who experience the same barriers to full participation on the grounds of wrongful stereotyping, can contribute to preventing ongoing violation of women, men and children affected by leprosy, enforce their rights, and make sure they are not left behind.

Thank you,

Alice Cruz