

WHAT IS THE IMPACT OF HARMFUL AND WRONGFUL STEREOTYPES ON THE LIVES OF PERSONS AFFECTED BY LEPROSY AND THEIR FAMILY MEMBERS?

Stereotypes are labels that deprive people of their identity. The overlapping of harmful stereotypes, wrongful stereotyping and structural iniquities strengthens exclusion, discrimination and violence on the grounds of leprosy and compromises the enjoyment of fundamental rights, such as dignity, equality and non-discrimination, by millions of persons affected by leprosy worldwide, as well as by many of their family members. Stigmatization of persons affected by leprosy remains institutionalized in the State's architecture and functioning: more than 50 countries in the world keep hundreds of discriminatory laws against persons affected by leprosy in force, while discriminatory practices at the State's administration services endure.

HOW DO STEREOTYPING AND STIGMATIZATION WORK AS A TOOL FOR DEHUMANIZATION OF PERSONS AFFECTED BY LEPROSY?

Extreme dehumanization becomes possible when the target group can readily be identified as a separate category of persons who are stereotyped and stigmatized as inferior, dangerous or uncivilized. Harmful stereotypes about leprosy, for example, can lead to informal segregation and widespread exclusion by treating individuals as untouchable; segregating individuals within the household and also prohibiting them from leaving the house; divorce on the grounds of leprosy and prohibiting marriage with an affected person or any of his/her family members; barring individuals from participating in religious and community activities as well as in economic transactions; dismissing individuals from their jobs; pushing individuals into begging; and banishing individuals from the community.

HOW HAS THE REPORT ADDRESSED THE SITUATION OF DISCRIMINATION OF WOMEN AND CHILDREN?

In order to assess discrimination from below, the Special Rapporteur strived at giving voice to people living in extreme vulnerable conditions. The Special Rapporteur undertook an online and individual consultation with persons affected by leprosy, their family members, health workers and non-governmental organization (NGO) personnel. A total of 575 responses were received from the following eight high-burden countries: Angola, Brazil, Ethiopia, India, Indonesia, Nepal, Myanmar, Nigeria and the Philippines. Responses were also received from Benin, Cabo Verde, China, Colombia, France, Japan, Mexico, the Netherlands, New Zealand, Paraguay, Switzerland, Timor-Leste, Trinidad and Tobago, the United Kingdom of Great Britain and Northern Ireland, the United States of America and Venezuela.

WHAT IS THE SITUATION OF WOMEN AFFECTED BY LEPROSY?

Women are at the higher risk to developing leprosy-related physical impairments and disability. Some of the institutional barriers to diagnosis and prevention of physical impairments in women result from institutional mediating factors, such as discriminatory legal frames; underfinancing of health care and poorly implemented policies for prevention, care and rehabilitation; status of leprosy services integration into primary care; the reach of health services; and the gender of the health-care workforce in primary care services. However, non-addressed social barriers are also a leading cause of deficient access by women to the highest attainable standard of health, for example: harmful traditional beliefs and practices; the low status assigned to women, which is at the root of women's widespread self-concealment of the disease; dependency of women's access to health services on third-party authorization; women's limited mobility; illiteracy; and poor knowledge of leprosy. Driving out from the

household without financial resources to ensure survival; psychological, physical and sexual abuse and violence within the household; and lack of resources to fight against discrimination, including lack of access to justice are examples of the adverse impacts of stigmatization, harmful stereotyping and traditional beliefs in women affected lives.

WHAT IS THE SITUATION OF CHILDREN AFFECTED BY LEPROSY?

About 8 per cent of the total of new cases reported by 150 countries to WHO in 2017 were children under 15 years of age, a shamefully high figure. Enduring underdetection of new cases of leprosy in children and late diagnosis are causal factors of physical and psychosocial impairments and disabilities. Physical impairments can worsen over time without proper care requiring follow-up studies, the absence of which hinders a clear understanding of the real conditions faced by children affected by leprosy in the medium and long term. Treatment dropout rates in children range from 10 to 20 per cent in some programmes, the main cause being the child's refusal to cooperate in swallowing tablets and the long duration of the treatment. However, no paediatric formulations are on the horizon, given the overall lack of funds for leprosy. Reports point out attempted suicide among adults who were diagnosed with leprosy in childhood and who experienced multilayered stigmatization from a very early age.

HOW CAN THE INTERNATIONAL FRAMEWORK OF HUMAN RIGHTS PROTECTION HELP PERSONS AFFECTED AND THEIR FAMILY MEMBERS?

International human rights norms prohibit inhuman and degrading treatment, as well as arbitrary detention. The principles and guidelines (P & G) for the elimination of discrimination against persons affected by leprosy and their family members recognize the massive violation of the human rights

of persons affected by leprosy and their family members through the enactment of discriminatory policies and institutionalized practices. The P & G underpin the normative integration of several international human rights instruments, interpreting and translating legally binding norms in close connection with the conditions and needs of the particular group of persons affected by leprosy and their family members. They provide States with a road map for monitoring the situation of persons affected by leprosy and their family members and for implementing measures that, by enforcing international human rights law, can guarantee formal and substantive equality.

WHAT ARE THE STEPS TO TACKLE THE SITUATION OF WOMEN AND CHILDREN COMING FROM THE REPORT?

The Special Rapporteur recommends general and specific measures that States, national human rights institutions and civil society organizations can take in order to implement a human rights based approach to the reality of women and children affected by leprosy, such as: (a) inclusion of women affected by leprosy in national plans for gender equality, gender violence prevention and empowering women through measures that can ensure economic independence and women's access to justice; (b) research into the risk factors that may perpetuate violence against children affected by leprosy, alongside the formation of integrated partnerships of experts, parents, teachers and young people that can respond effectively to such violence; (c) ensuring children with leprosy-related disabilities participation on an equal basis with others in education services, recreational, leisure and sporting activities; and (d) systematically approaching, consulting and involving in decision-making processes that directly affect their lives persons affected by leprosy and their representative organizations, with the guarantee of all measures for ensuring the participation of women and children and all persons with leprosy-related disabilities.