**To the honorable members of the Committee on the Rights of Persons with Disabilities**

**From the Special Rapporteur on the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members, Alice Cruz**

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**Introduction**

Persons with leprosy have been systematically subjected to dehumanization in distinct historical periods and cultural backdrops. Harmful stereotypes have been at the root of human rights abuses and violations against them. As part of their struggle against dehumanization, people who were stigmatized on the basis of leprosy rejected both discriminatory and medical terminology, preferring the expression “persons affected by leprosy” (that came to be employed by the Human Rights Council resolution 35/9) to refer to individuals currently under treatment for leprosy and individuals who had been cured of leprosy. Such expression was adopted by representatives of the people’s organizations as one important step towards self-identification. Notwithstanding, recent developments are leading to an increasing use of the alternative terminology “persons who have experienced leprosy” by the people’s organizations. The Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, acknowledges such development and in full respect of their autonomous choices will hereafter adopt the expressions “persons who have experienced leprosy”.

**1. Persons who have experienced leprosy as persons with disabilities**

Persons who have experienced leprosy should be recognized as persons with disabilities in accordance with articles 1 and 2 of the Convention on the Rights of Persons with Disabilities (CRPD), on the grounds of not only physical impairments and the multiple barriers imposed by society to their full participation, but also on the grounds of discrimination based upon harmful stereotypes on leprosy itself.

Persons who have experienced leprosy have been systematically subjected to direct and indirect discrimination. Human rights abuses and violations have been perpetrated both in law and in practice. The Special Rapporteur has identified an outstanding lack of acknowledgement among policymakers of the broad structural causes of ongoing discrimination, as well as gaps in human rights policy-making with State’s action being limited to the health field.[[1]](#footnote-1)

Such gaps are the result of historical and enduring paternalistic approaches that hinder the enforcement of *de facto* equality for persons who have experienced leprosy. Actions is still restricted to the medical and charity fields. With the aim of contributing to a much-needed paradigmatic shift, the Special Rapporteur has developed a policy framework for rights-based action plans[[2]](#footnote-2) that draws on the provisions of CRPD, among other relevant international human rights instruments and standards.

While discrimination in law endures, substantive discrimination stands out as a leading cause of persistent marginalization. [[3]](#footnote-3) General Comment No 6 of the CRPD provides for a substantive and inclusive model of equality that is of great relevance to address inequalities and stigmatization related to leprosy, as well as to guarantee the promotion of dignity, full and effective participation and accommodation of differences for persons who have experienced leprosy.

**3. Consultations with the People’s Organizations**

At the start of her second term in November, 2020, the Special Rapporteur consulted the people’s organizations, in order to develop a participatory work plan for the next three years of her mandate that embodies the views of experts by experience. The barriers to the right to work and rights at work were systematically pointed out by the people’s organizations as being simultaneously the result and one of the causes of ongoing discrimination.

Importantly, many people’s organizations reported on similar and correlated barriers to the access to social protection and, more specifically, to disability related social protections benefits. If the global work scenario for persons with disabilities is worrying (with persons with disabilities less likely to be in employment or to enjoy decent employment conditions than persons without disabilities while also not being adequately covered by social protection rights), persons who have experienced leprosy are among those pushed furthest behind and amount to the 80% percent of people with severe disabilities that do not have access to disability related social protection schemes in low and middle income countries.[[4]](#footnote-4)

**4. Report to the 47th Regular Session of the Human Rights Council**

Notably, as the Special Rapporteur monitored the impact of the COVID-19 pandemic on persons who have experienced leprosy and their family members, she quickly realized the close relation between the historical and systematic exclusion of persons who have experienced leprosy from the open labour market and the disproportionate impact of the COVID-19 pandemic on the right to life of persons who have experienced leprosy. For such reason, the Special Rapporteur discusses the right to work, among other economic, social and cultural rights, in her forthcoming report to the Human Rights Council, which is dedicated to the disproportionate impact of the pandemic on persons who have experienced leprosy and their family members. On her report, the Special Rapporteur discusses the right to work for persons who have experienced leprosy based on a great number of contributions from persons who have experienced leprosy and their representative organizations, both written contributions and oral contributions provided to the Special Rapporteur during the calls she has been having with the people’s organizations since March, 2020.

**5. General Comment on Article 27 of the CRPD**

The Special Rapporteur concurs with the Committee on the great necessity for a general comment that can detail article 27 of the CRPD and deeply appreciates such timely and key initiative, more so in the face of the vital need to ensure an inclusive recovery from the COVID-19 pandemic that addresses with determination the multiple divides that keep pushing a significant part of the world’s furthest behind, including persons who have experienced leprosy.

**6. Barriers to the right to work**

Unreliable casual labour with low income, unsafe working conditions and without entitlements to social protection or participation in social dialogue defines livelihoods for the majority of persons who have experienced leprosy. The former amount to the 2 billion people that ILO estimates work in the informal economy[[5]](#footnote-5) and who are denied the rights to work, at work, social protection, as well as to enjoy income security. Not only persons who have experienced leprosy have been systematically denied the rights to decent work and social protection, but they have also been voiceless in social dialogue and other decision-making processes.

Persons who have experienced leprosy face formidable, intersecting and multiple barriers to freely choose their work and to enjoy rights at work. The testimony of one individual from XX (country) [[6]](#footnote-6) captures all too well how leprosy related discrimination simultaneously operates at different levels of social live and is at the root of rights’ violations that deny economic autonomy to persons who have experienced leprosy: while working as a public servant he was dismissed from his job after being diagnosed with leprosy; he then went back to work as a farmer in a community land, but he was also dismissed by the village committee that administered such land due to leprosy; resorting to growing vegetables in his backyard, he could not sell those at the local market because people were afraid to buy vegetables from him. This testimony represents a shared pattern of denial of equality of opportunities to persons who have experienced leprosy, as well as of denial of equality of treatment denial, both of which violate ILO Convention No 111.

Some of the barriers that have systematically hindered persons who have experienced leprosy to work at the formal economy are as follows: a) the more than one century State’s policy that forcibly segregated persons with leprosy and that aimed at the elimination of leprosy through the elimination of those who carried the disease in their bodies[[7]](#footnote-7) – such policy still reverberates in the public mindset, reinforcing structural discrimination, and shapes the more than 100 discriminatory laws against persons who have experienced leprosy and that are still in force worldwide;[[8]](#footnote-8) b) the fact that the majority of people who were forcibly segregated into what has become globally known as leprosy colonies (there are up to two thousand leprosy colonies active in the world), and their descendants, do not have enjoy property rights over the land where they were confined, which aggravates poverty; c) the fact that in some countries, customary law denies land and inheritance rights to persons who have experienced leprosy, especially to women, which aggravates the feminization of leprosy related poverty; d) the already aforementioned discrimination in law that, in some countries, also regards employment; e) institutionalized discrimination in what concerns hiring policies for public jobs; f) discrimination at school, which has pushed too many persons who have experienced leprosy out of education; g) interpersonal discrimination in both public and private employment settings.

These barriers have systematically pushed persons who have experienced leprosy into poverty and extreme poverty, forcing many of them to resort to begging. The majority of the work performed by persons who have experienced leprosy is characterized as follows: a) insufficient and unregular income, many times dependent on begging and/or assistance from families, religious institutions and NGOs; b) employment status as small scale, own-account, casual, and domestic; c) sector of activity mostly being petty trade, agriculture, fishing, and other manual activities; d) no written contracts, job cards, payment through bank accounts, grievance and appeal mechanisms, as well as no social security contributions or employment protection. Such profile is not accidental. Such profile is the result of intentional and systemic exclusion of persons who have experienced leprosy, together with what the Special Rapporteur on extreme poverty and human rights[[9]](#footnote-9) has called the series of deliberate and conscious decisions of main actors, who have chosen to prioritize other goals than fighting extreme poverty. Notably, the structural barriers to the full inclusion of persons who have experienced leprosy in the open labor market and enjoyment of work and social protection rights are deep rooted and endure due to the generalized lack of a specific intervention model based on comprehensive and rights-based legal and regulatory frameworks.

**7. The vital importance of General Comment on article 27 of the CRPD for persons who have experienced leprosy**

For the reasons mentioned above, the Special Rapporteur requests the honorable members of the Committee to kindly consider including an explicit reference to leprosy as a prohibited ground of discrimination, as well as to persons who have experienced leprosy as being entitled to the rights provided by the CRPD, and more specifically the provisions of article 27, as a means to contribute to a much-needed paradigmatic shift towards the recognition of persons who have experienced leprosy as right holders and as person with disabilities in national legal and regulatory frameworks.

**8. Contributions from the experience of discrimination on the grounds of leprosy to the draft general comment on article 27 of the CRPD**

1. **A gender approach to the overall general comment that fights the intersection of gender with disability and affirms women with disabilities’ rights to an inclusive education, vocational training, decent work and equal remuneration.** The following testimony of a woman who has experienced leprosy shows how the denial of inclusive education, furthered by denial of opportunities that can ensure economic autonomy to women with leprosy and leprosy related disabilities, makes women more vulnerable to poverty, denial of autonomy, and physical, psychological and sexual violence:[[10]](#footnote-10) “As a woman with disability, I am more disadvantaged, the society outcasts me, even if I am allowed to live within the household, I am like dead, not getting involved and no opinions are asked to me. I got the disease in childhood, I was denied education, it was like a predestination because of the disease. I became dependent of my family, providing support within the household. But the household activities can be quite challenging, things like fetching water can be very difficult, because of my disability. I have been hiding inside the house, but men within the household take advantage of me, they intimidate me and they also sexually abuse me, they think that people like me must accept that. Other female members of our organization say that once they got the disease, their husbands blamed them and started beating them.” Moreover, women bear the brunt of unpaid care work. The draft general comment on article 27 should guide States to recognize unpaid care work and include carers with disabilities in social protection schemes.
2. **Assertion of the transition of persons with disabilities from the informal economy to the formal economy as part of the State’s obligations with regard to the enforcement of the right to work for persons with disabilities.** Recommendations on a whole government approach that can simultaneously mainstream person with disabilities in macro policies aimed at the transition from informality to formality and develop specific intervention models that are fit to the specific characteristics of different groups of person with disabilities working in the informal economy, would be of high value. State policies should aim at change in systems and at promoting an inclusive structural transformation, with strategic objectives and key performance indicators. Furthermore, social and solidarity economy should be properly recognized by relevant government bodies and institutions.
3. **Social dialogue needs to be open to organized groups of persons with disabilities, including persons who have experienced leprosy, working in the informal economy.** Social dialogue must be undertaken in strict respect and fulfillment of article 29 of the CRPD, ensuring a barrier-free participation by addressing not only physical barriers, but also those related to illiteracy, poor education, culture, gender and the digital divide. Not only States should abstain from interfering with the freedom of association, but should also enable the right to collective bargaining for person with disabilities, including persons who have experienced leprosy, working both in the formal and informal economy. A defined interface with those with whom the organizations need to dialogue should be made available and people’s organizations, either working in the formal or informal economy, should be involved in formal institutions for tripartite and bipartite social dialogue.
4. **While reasonable accommodation may not be an obligation of the State (unless it relates to public employment), but of the actual employer, it is still the responsibility of the State to create the conditions for reasonable accommodation to be provided in all productive sectors and work arrangements.** In this sense, States should be obliged to create mechanisms that can ensure reasonable accommodation to own-account workers and to people working in agriculture, husbandry, fishing, and other physical labour, as is the case of many persons who have experienced leprosy. The former face several barriers to enjoy the right to education that pushes them into performing manual labour, which due to nerve damage caused by leprosy, can aggravate physical impairments and chronic pain. Importantly, and again, women who bear the brunt of unpaid care and household work, many times lack rest periods, self-care and assistive devises that are essential for their well-being. The right to reasonable accommodation should, as such, be mainstreamed into relevant government programmes, such as the ones related to gender, agriculture, rural population, among others. By the same token, accessible mechanisms to receive information, complaints, and to provide remedies, should be put in place. Furthermore, the provision of reasonable accommodation should take into consideration not only visible physical impairments related to leprosy, but also invisible ones, such as pain or loss of sensation, as well as psychosocial disabilities related to stigmatization.
5. **On affirmative measures.** The former, being highly necessary as a means to correct historical and structural disadvantage, should draw inspiration from General Recommendation No 25 of CEDAW, which affirms that the duration of a temporary special measure should be determined by its functional result in response to a concrete problem and not by a predetermined passage of time. Affirmative measures may need to be of a permanent character. Affirmative measures must not only ensure that related procedures are accessible, but also that eligibility criteria do not rely on a narrow medical assessment, nor that it excludes specific groups. For such reason, affirmative measures should be defined in consultation with all groups of persons with disabilities, including persons who have experienced leprosy. Affirmative measures should come with targets and key performance indicators, as well as effective enforcement mechanisms and remedies. Affirmative measures should also follow ILO Recommendation No. 168 on awareness raising.
6. **The principle of progressive realization should be applied in a reasonable manner that recognizes poverty as a human rights violation**. Such principle should comply with existing jurisprudence that determines that, if the steps taken to progressively realize economic, social and culture rights fail to take into account the needs of the most vulnerable, that means that those do not meet the test of reasonableness. Concomitantly, looking at the establishment of minimum core obligations from the experience of discrimination on the grounds of leprosy, however controversial those may be and difficult to define, such minimum core obligations seem necessary to guarantee basic essential levels of rights’ enjoyment to extremely marginalized groups who have been historically trapped in a cycle of discrimination and poverty that needs to be braked.

**9. Relevant norms**

Importantly, General Comment No 18 of CESCR acknowledges the right to work as being essential for realizing other human rights and forms an inseparable and inherent part of human dignity. CESCR also connects the right to work to the right to life, speaking of the survival of the individual and that of his/her family, by the one hand, and to the right to development, insofar as work is freely chosen or accepted, by the other. Concomitantly, ILO Convention No 122 affirms that productive employment and decent work are prerequisites for raising living standards and alleviating poverty. Hence, articles 6 and 7 of the ICESCR and others closely interrelated, such as articles 11 of the ICESCR and 19, 26, 28 of the CRPD are of key importance. ILO Convention No 111 and No 204 are also key for guaranteeing non-discrimination and providing practical steps to ensure the right to work for persons who have experienced leprosy. Article 4 of the CRPD is of fundamental value to abolish discriminatory laws against persons who have experienced leprosy, as well as CRPD’s General Comment No 6.

1. A/HRC/41/47 [↑](#footnote-ref-1)
2. A/HRC/44/46 [↑](#footnote-ref-2)
3. *Ibid* [↑](#footnote-ref-3)
4. 2020, ILO, *COVID-19 and the World of Work: Ensuring the inclusion of persons with disabilities at all stages of the response* [↑](#footnote-ref-4)
5. 2020, ILO, *The global deal for decent work and inclusive growth flagship report – social dialogue, skills and COVID-19*  [↑](#footnote-ref-5)
6. In order to protect people who shared their testimonies, the Special Rapporteur does not discloses their identities. [↑](#footnote-ref-6)
7. A/HRC/38/42 [↑](#footnote-ref-7)
8. The Special Rapporteur will dedicate her forthcoming report to the General Assembly to the issue of discrimination in law. [↑](#footnote-ref-8)
9. A/69/297 [↑](#footnote-ref-9)
10. See the Special Rapporteur’s report A/HRC/41/47. [↑](#footnote-ref-10)