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Promotion and protection of human rights: human rights questions, including alternative approaches for improving the effective enjoyment of human rights and fundamental freedoms

Elimination of discrimination against persons affected by leprosy and their family members

Note by the Secretary-General

The Secretary-General has the honour to transmit to the General Assembly the report of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, submitted in accordance with Human Rights Council resolution [44/6](#).

* [A/77/50](#).



Report of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz

Multiple disabilities and fluid self-identification: disability rights of persons affected by leprosy and their family members and how they challenge national legal frameworks

Summary

In the present report, the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, addresses the disability rights of persons affected by leprosy and their family members, exploring the challenges and the areas for improvement in the relevant national legal frameworks.

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I. Introduction

1. In the present report, submitted pursuant to Human Rights Council resolution 44/6, the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, focuses on national legal protections available for persons affected by leprosy (also known as Hansen's disease) and their family members, along with remaining challenges. More specifically, she discusses how the recognition of persons affected by leprosy and their family members as persons who are entitled to the rights provided for in the Convention on the Rights of Persons with Disabilities is an important step in protecting this group of people, eliminating systemic discrimination against them and fulfilling their human rights. The Special Rapporteur also examines measures taken by States to recognize persons affected by leprosy and their family members as persons who are entitled to disability rights, as well as the barriers that hinder them from gaining access to and enjoying those rights, and offers constructive recommendations in that regard.

2. Since the beginning of her mandate, the Special Rapporteur has endeavoured to mainstream leprosy awareness within the entire human rights system and has focused in particular on raising awareness of discrimination against persons affected by leprosy within the Committee on the Rights of Persons with Disabilities. She has made several submissions to the Committee on the occasion of its reviews of leprosy-endemic countries. She has also contributed to the drafting of the Committee's general comment on article 27 of the Convention, which is in progress.¹ The Special Rapporteur appreciates the increasing inclusion of leprosy-related matters within the system and in the work of the Committee.

3. Only four States actively contributed to the present report, which reflects the extent to which persons affected by leprosy and their family members are neglected by their own Governments, given the fact that, according to the World Health Organization (WHO), at least 23 countries are significantly affected by leprosy. Twenty civil society organizations working in 11 countries, 10 of which are leprosy-endemic countries, submitted key information for the present report. In total, 195 people from 23 countries, the majority being endemic, responded to the Special Rapporteur's online questionnaire. In her work, the Special Rapporteur also relies on two decades of engagement with persons affected by leprosy and their family members and always keeps in mind the words of a woman affected by leprosy, which express the paradox of living with an invisible and unrecognized impairment but still being disabled by discrimination and society's multiple barriers to a dignified life: "I cannot work as a domestic worker, which is what I did before, due to the constant pain I feel, and I cannot hold my baby, because I have no strength in my arms, and yet I am denied social protection because medical doctors say I have no disability." As provided for in the preamble to the Convention on the Rights of Persons with Disabilities, it is the States parties' obligation to recognize further the diversity of persons with disabilities. The present report is intended to contribute precisely to that end.

II. Disabling societies

4. The Special Rapporteur adopts the distinction established by the social model of disability between "impairment" (referring to any loss or difference of physical, mental, intellectual or sensory functioning) and "disability" (referring to the avoidable and imposed restrictions and losses caused by societies' multiple barriers

¹ The Special Rapporteur's oral statement to the Committee in this regard is available at www.ohchr.org/en/events/days-general-discussion-dgd/2021/day-general-discussion-right-persons-disabilities-work-and.

hindering people with impairments and their enjoyment of opportunities on an equal basis with others).

5. It is not impairments, but rather disability, that actively marginalizes, excludes and dehumanizes people who experience any physical, mental, intellectual or sensory loss or difference. Ableism (meaning a system of oppression in which beliefs about disability are in great measure defined by persons without disabilities, reinforcing notions of “normal”, “ideal” or “able” bodies, while at the same time objectifying the lived experiences of persons with disabilities as a deviance from the “normal” and “desirable”),² and its relationship with a capitalist model of social organization and production, is at the root of many of the attitudinal, environmental, legal, institutionalized and systemic barriers that disable people living with impairments. The Special Rapporteur also agrees with feminist scholars and activists who draw attention to the need not to overlook the phenomenological experience of living with impairments, and the present report also reflects that.³

6. Likewise, the Special Rapporteur concurs with scholars and activists from the global South who argue in favour of examining global disabling forces,⁴ such as the enduring effects of colonialism, the devastating consequences of capitalism and the oppression of patriarchy, which have a disproportionate impact on people with impairments living in the global South, including persons affected by leprosy. One of the more important outputs of such a perspective would be to integrate the experiences and views of underrepresented people, such as persons affected by leprosy, into global discussions around disability.

7. Persons affected by leprosy and their family members have been largely excluded from the global conversation about disability, and society’s disabling forces affecting them have been left unexamined. An example of this are the scarce references to leprosy in the profuse set of international policies, guidance documents and papers focusing on disability. In the examination of 115 documents issued by the Food and Agriculture Organization of the United Nations, the International Civil Aviation Organization, the International Labour Organization, the United Nations Educational, Scientific and Cultural Organization, WHO, the World Bank, the United Nations Development Programme, the Joint United Nations Programme on HIV/AIDS, the United Nations Entity for Gender Equality and the Empowerment of Women, and the United Nations Children’s Fund, only 3 were found that mentioned leprosy.⁵ There are several reasons explaining such limited recognition, including the following:

(a) Since its medicalization in the late nineteenth century, leprosy has been under the jurisdiction of the medical professions. According to the reductionist approach of biomedicine, leprosy is a purely biological phenomenon that is immune to culture and politics. Such classification relegated to a secondary role the discrimination associated with the disease in policymaking and also contributed to curtailing the autonomy and self-determination of persons affected by leprosy. The Special Rapporteur also recalls that the discovery of the causative agent of leprosy (*Mycobacterium leprae*) in the late nineteenth century led to a unified response by European experts and Governments in 1879 based upon the idea of contagion, which

² See [A/HRC/43/41](#).

³ Ana Bê, “Feminism and disability: a cartography of multiplicity”, in *Routledge Handbook of Disability Studies*, Nick Watson, Alan Roulstone and Carol Thomas, eds. (London, Routledge, 2012).

⁴ Dan Goodley and Leslie Swartz, “The place of disability”, in *Disability in the Global South: The Critical Handbook*, Shaun Grech and Karen Soldatic, eds. (Springer, 2016).

⁵ WHO, “Improving the health and wellbeing of people living with neglected tropical diseases through rehabilitation and assistive technology”; World Bank, “Disability inclusion in Nigeria: a rapid assessment”; and World Bank, “Poverty reduction strategies: their importance for disability”.

gave rise to the establishment of thousands of leprosariums throughout the world, many of which implemented an official State policy of compulsory internment of persons affected by leprosy. The same policy was applied in 1923 to children of persons affected by leprosy. Many countries continued to implement this policy until quite recently. Subsequent developments in global guidance on addressing leprosy as a health problem continued to deny persons affected by leprosy the right to participate in decision-making processes. In addition, notwithstanding the growing recognition of people's right to participation, the participation of persons affected by leprosy is usually tokenistic in nature;

(b) Historically, services for persons affected by leprosy have been provided by charitable organizations and institutions. Such private organizations and institutions have been filling the substantial and formidable gaps in States' actions regarding the needs of persons affected by leprosy. However, until quite recently, those same organizations and institutions did not engage with a rights-based approach to leprosy, often reproducing paternalistic approaches to persons affected by leprosy. Progress made by some of the private players working in the field is well known, but, at the organization level, the majority of these organizations are still for persons affected by leprosy and not of persons affected by leprosy;

(c) Leprosy is mostly present in countries of the global South, and the global narrative on disability and disability rights is still largely framed by the perspectives coming from the global North. An example of this is the drafting process of the Convention on the Rights of Persons with Disabilities, which resulted from an initiative taken mainly by States from the global South. Resource limitations meant, however, that more organizations from the global North than from the global South were able to engage in the prioritization and framing of the provisions of the Convention.⁶ Notwithstanding the richness of the work done by disability activists and scholars from the global South, the global approach to disability is still dominated by the agenda of the organizations from the global North.

8. Persons affected by leprosy should be fully recognized as persons with disabilities in accordance with articles 1 and 2 of the Convention on the Rights of Persons with Disabilities, not only on the grounds of physical impairments caused by leprosy and the multiple barriers to their full participation imposed by society, but also on the ground of discrimination based on harmful stereotypes about leprosy itself. Furthermore, and as will be shown in the present report, many family members experience psychosocial impairments and disabilities owing to systemic discrimination on the ground of leprosy.

9. Persons affected by leprosy have been systematically subjected to direct and indirect discrimination. Human rights abuses and violations have been perpetrated both in law and in practice. While discrimination in law endures, substantive discrimination, as a result of entrenched and systemic ostracization and marginalization, stands out as a leading cause of the persistent denial of the enjoyment of rights by persons affected by leprosy and their family members on an equal basis with others.⁷

10. The Special Rapporteur has identified a generalized lack of acknowledgement among policymakers of the broad structural causes of ongoing discrimination, as well as gaps in human rights policymaking, with States' actions being limited to the health field. Furthermore, she also identified States' failures to fulfil their obligations to enforce the right to the highest attainable standard of physical and mental health,

⁶ Paul Harpur and Michael Ashley Stein, "The U.N. Convention on the Rights of Persons with Disabilities and the Global South", *Yale Journal of International Law*, vol. 47, No. 1 (2022).

⁷ See the Committee on Economic, Social and Cultural Rights, general comment No. 20 (2009).

which are at the root of the extensive number of persons living with leprosy-related physical impairments.⁸

11. It is labelling based upon harmful stereotypes, and not leprosy itself, that disrupts the social location of a person diagnosed with the disease. However, biomedicine has also played a determining role in framing leprosy as a condition that is antithetical to the modern project, matching it with the structural backwardness that was to be purged from modern nations. Even after being discredited, the biomedical concept that affirmed the need to segregate persons affected by leprosy continued to influence national legal and regulatory frameworks in fields as varied as those concerning freedom of movement, participation in political and social life, family life, work regulations, and immigration and visa regulations. The Special Rapporteur has identified more than 100 laws in place that discriminate against persons affected by leprosy.⁹

III. Medical model

12. Despite being curable, if not detected early and treated leprosy can cause irreversible damage to the skin, nerves, limbs and eyes, leading to disfigurement, blindness, loss of sensation, chronic wounds and neuropathic pain. The main cause of the impairments associated with leprosy is nerve damage, which can occur before and during treatment, as well as after bacteriological cure. A unique feature of the impairments caused by leprosy is their preventable nature, for which access to early diagnosis and treatment are determining factors.

13. The WHO global leprosy strategy¹⁰ contains a grading system for assessing and measuring leprosy-related impairments. Even though such a system uses the term “disability”, it only measures physical impairments, which contributes to misinterpretations of disability associated with leprosy and to misguided policies and practices. The grading system used by WHO consists of grade 0, meaning no impairment, grade 1, meaning loss of sensation in the hand, eye or foot, and grade 2, meaning visible impairment. It is, in essence, a medical and narrow approach that misuses the term “disability”.

14. The long-term vision of the global leprosy strategy includes zero infection and disease, zero disability, and zero stigma and discrimination. One of the global targets for 2030 is a 90 per cent reduction in the rate per million people of new cases with grade 2 disability. Again, such a target is supposed to be met with a strategy that is purely based on a medical approach that fails to acknowledge disability as the result of the interaction between impairments and attitudinal and environmental barriers.

15. The limitations to the medical approach are clear. For example, owing to systemic discrimination, the majority of persons affected by leprosy work in the informal economy and depend on unreliable casual labour with low income and unsafe working conditions. Physically demanding labour, which for many persons affected by leprosy is the daily reality of sustaining a livelihood, can aggravate physical impairments related to nerve damage. The interrelation between physical impairments, discrimination and unequal opportunities for decent work illustrates how the medical approach, by focusing solely on physical impairments, overlooks important socioeconomic factors and generates misinterpretations that negatively influence policymaking, and in so doing, contributes to disabling persons affected by leprosy.

⁸ A/HRC/50/35.

⁹ A/76/148.

¹⁰ WHO, “Towards zero leprosy: global leprosy (Hansen’s disease) strategy 2021–2030”.

16. As the coronavirus disease (COVID-19) pandemic had a huge impact on leprosy case detection,¹¹ data gathered before its outbreak are more reliable. In 2019, a total of 202,256 new cases were detected in 118 countries. In total, 10,816 new cases in 94 countries, including 370 among children, presented irreversible physical impairments at the time of diagnosis – an indication of late diagnosis. The number of affected children is likely to be significantly higher, as some countries did not report data on irreversible physical impairments at the time of diagnosis among children. Also, according to WHO, in the absence of verifiable data it is estimated that between 3 million and 4 million people are living with visible impairments owing to leprosy.¹²

17. WHO global priority countries for action are derived from a composite index using parameters such as prevalence, new case detection, proportions of female children and irreversible physical impairments at the time of diagnosis. The 23 WHO global priority countries are Angola, Bangladesh, Brazil, the Comoros, Côte d'Ivoire, the Democratic Republic of the Congo, Egypt, Ethiopia, Micronesia (Federated States of), India, Indonesia, Kiribati, Madagascar, Mozambique, Myanmar, Nepal, Nigeria, the Philippines, Somalia, South Sudan, Sri Lanka, the Sudan and the United Republic of Tanzania. It is important to note that leprosy also affects countries not among the 23 WHO global priority countries, especially in South America, Africa and Asia.

18. An analysis of the evolution of the number of people diagnosed with already irreversible physical impairments in the 23 WHO global priority countries over the past five years shows that the decrease is manifestly slow. Many people continue to be diagnosed with already irreversible impairments, and efforts to monitor the evolution of impairments after discharge from the health-care services once the bacteriological treatment for the leprosy infection has been completed, together with the provision of rehabilitation, are clearly lacking, as previously documented by the Special Rapporteur.¹³

IV. National legal and regulatory frameworks

19. Apart from South Sudan, the remaining 22 WHO global priority countries for action against leprosy have either ratified or acceded to the Convention on the Rights of Persons with Disabilities. However, a significant number of those States parties have not signed, ratified or acceded to the Optional Protocol, including the Comoros, Egypt, Ethiopia, India, Indonesia, Kiribati, Madagascar, Micronesia (Federated States of), Myanmar, the Philippines, Somalia and Sri Lanka.

20. This situation hinders persons with disabilities from gaining access to their right to an effective remedy and reparation, as provided for in article 2 (3) of the International Covenant on Civil and Political Rights and subsequently clarified by the Human Rights Committee in its general comment No. 31 (2004) on the nature of the general legal obligation imposed on States parties to the Covenant, since the Optional Protocol to the Convention on the Rights of Persons with Disabilities establishes the competence of the Committee on the Rights of Persons with Disabilities to receive individual and collective complaints regarding human rights violations in the countries that are party to the Convention and to undertake relevant investigations.

21. Whether through constitutional norms, national laws or policies, the majority of the WHO global priority countries for action against leprosy that have either ratified or acceded to the Convention on the Rights of Persons with Disabilities recognize the right to equality for persons with disabilities. Nevertheless, while some of these

¹¹ [A/HRC/47/29](#).

¹² WHO, "Towards zero leprosy".

¹³ [A/HRC/50/35](#).

countries have developed legal and regulatory frameworks that are in accordance with the social model of disability and the provisions of the Convention, others continue to draw from a medicalized approach to disability when establishing their provisions. A very small number of countries explicitly mention leprosy as a formally recognized category related to disability in their national legal and regulatory frameworks. The Special Rapporteur urges relevant States that are drafting or enacting new legislation on protecting the rights of persons with disabilities to explicitly refer to persons affected by leprosy as being entitled to those rights. An example is Bangladesh, a country with a significant number of people living with leprosy and leprosy-related disabilities, where efforts to enact an anti-discrimination bill are under way.

22. More detailed information submitted for the purposes of the present report by States and civil society organizations from 15 countries where leprosy is an issue of concern confirms the limited references to leprosy in national legal and regulatory frameworks designed to protect, promote and fulfil the rights of persons with disabilities. Below are a few examples of States where leprosy is an issue of concern and where it is formally recognized as a disability-related category.

23. Brazil, the country with the highest relative incidence of leprosy, has ratified both the Convention on the Rights of Persons with Disabilities and its Optional Protocol. What is notable about Brazil, however, is that it has attributed the value of a constitutional norm to the Convention and its Optional Protocol through Decree No. 6.949. Furthermore, Law No. 13.146/2015, known as the Brazilian Law of Inclusion, integrates the social model of disability that lies at the heart of the Convention. Issues such as accessibility, universal design, assistive technology, communication, reasonable accommodation, independent living and support are fully addressed in the law. Rehabilitation and inclusive labour rights for persons with disabilities are also provided for by Laws No. 8213/1991 and No. 13146/2015. While leprosy is not explicitly referred to in these laws, Brazil has put in place key anti-discriminatory legislation with Law No. 9010/1995, which replaces the term “leprosy” with “Hansen’s disease” (acknowledging the relationship between stereotyping and discrimination, referred to in article 8 of the Convention) and has recognized the damage caused by the State policy of forced isolation of persons affected by leprosy (which had been in place from the 1920s to the 1980s), establishing an administrative programme to provide for material reparation under Law No. 11520/2007.

24. In Colombia, article 47 of the Constitution provides that the State is responsible for implementing a policy of rehabilitation and social integration for persons with physical, sensory and psychological impairments. Several laws have been enacted to protect persons with disabilities, and, in 2013, a national public policy for disability and social inclusion was put in place. Important jurisprudence established a prohibition on using derogatory terms to refer to person with disabilities. Several laws, and more particularly Law No. 380/1997, were also enacted specifically to provide social protection benefits to persons affected by leprosy living in poverty and with physical impairments caused by leprosy.

25. India, the country with the highest absolute incidence of leprosy, has significant legal and regulatory frameworks in place to protect the rights of persons with disabilities, including: the Rights of Persons with Disabilities Act of 2016; the Mental Healthcare Act of 2017; the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act of 2000; the Rehabilitation Council of India Act of 1992; the National Policy for Persons with Disabilities of 2006; and the National Mental Health Policy of India of 2014. Of these, the Rights of Persons with Disabilities Act guarantees: the right to equality and non-discrimination; the right to community life; protection from cruelty and inhuman treatment; protection from abuse, violence and exploitation; equal protection and

safety in situations of risk, armed conflict, humanitarian emergencies and natural disasters; rights related to the home and family; reproductive rights; accessibility in voting; and access to justice. Various types of conditions are also recognized as disabilities in the Act. Persons affected by leprosy are included in the “persons cured of leprosy” category. According to the stipulated definition, persons cured of leprosy are subdivided into persons with three categories of impairments. However, and as the name suggests, only those individuals who have finished bacteriological treatment are recognized. This distinction between the cured and uncured leaves those yet to be diagnosed and those undergoing treatment, who may be equally or more vulnerable to stigmatization and discrimination, completely unprotected under the Act. Another issue of concern is that the Act draws heavily from the medical model when creating a category of persons with benchmark disabilities (whose degree of physical impairment must be 40 per cent or higher), which is decided by designated medical boards in government hospitals. A person who meets this benchmark is entitled to receive a disability certificate, a pension, financial support, a reserved place in educational institutions and workplaces, and other benefits. Others, who do not meet the 40 per cent criteria, are excluded from social protection.

26. Indonesia, which together with India and Brazil accounts for 79 per cent of global leprosy cases, enacted Law No. 8 on persons with disabilities in 2016. This law guarantees a broad range of political, civil, economic, social and cultural rights to persons with disabilities, provides for better access to benefits and other relevant services for persons with disabilities, and promotes government engagement with organizations of persons with disabilities on matters such as policymaking, budgeting, planning and the provision of reasonable accommodation. Leprosy is explicitly mentioned in the law when defining persons with physical disabilities, although the definition contained therein relies heavily on the medical model.

27. Article 18 of the Constitution of Nepal establishes the right to equality as a fundamental right and prohibits any kind of discrimination on the basis of physical condition or disability. The Penal Code also prohibits discrimination against persons with disabilities. The Act relating to Rights of Persons with Disabilities of 2017 provides that persons with disabilities are entitled to fully enjoy the right to non-discrimination, the right to protection, the right to political participation, the right to participation in policymaking, the right to establish representative organizations, the right to access services, the right to justice, and the right to social security, among others. The Act classifies disabilities into 10 categories and expressly recognizes disability that arises as an effect of leprosy.

28. Constitutional norms, legislation, programmes and strategies in force in some countries where leprosy is relevant create favourable conditions for protecting the rights of persons with leprosy-related impairments and disabilities. This situation notwithstanding, information submitted for the purpose of the present report both by organizations of persons affected by leprosy and by organizations for persons affected by leprosy indicate the existence of important challenges regarding the execution and implementation of such frameworks, as well as significant problems with the content of the aforementioned norms, legislation, programmes and strategies.

V. Barriers to disability rights

29. In order to illustrate such difficulties and problems, the Special Rapporteur describes the challenges faced by persons affected by leprosy in gaining access to disability rights specifically in the countries already referred to as having legal and regulatory frameworks that recognize persons affected by leprosy as being entitled to such rights.

30. In Bangladesh, the definition itself of disability constitutes an important barrier hindering persons affected by leprosy from having access to State services and benefits. Invisible physical impairments, as well as psychosocial impairments caused by discrimination on the ground of leprosy, are not recognized as disabilities, thereby excluding an important number of individuals from enjoying social protection and benefits. Civil society organizations also report significant geographical and information barriers, mentioning the limited reach of tertiary health-care facilities and of the provision of rehabilitation and assistive devices, as well as a lack of awareness among public servants and service providers about leprosy-related impairments and disabilities. The same organizations mention enhanced risks to mental health experienced by women affected by leprosy. Many cases of divorce or separation owing to leprosy take place, and these particularly affect women. Stigmatization on the ground of leprosy also hinders people from having access to employment and vocational training opportunities. Responses to the crisis generated by the COVID-19 pandemic, while inclusive of persons with disabilities, left out persons affected by leprosy.

31. In Brazil, access to disability rights and benefits is dependent on a medical evaluation of physical impairments. Most doctors working in the public health system are not prepared to diagnose leprosy-related impairments. This can result in people being denied social protection benefits, while their impairments, whether visible or invisible, may severely limit their activities and ability to work. Difficulties with bureaucratic procedures, which do not provide timely responses to the people who need them, were also reported as barriers to access to disability rights. Reports of stigmatization against persons affected by leprosy perpetrated by the health-care workforce are also common, and such stigmatization acts as a barrier to the recognition that persons affected by leprosy are entitled to disability rights, especially to social protection and benefits, since access is dependent on a medical certificate. Article 4 of Law No. 11520 provides for full rehabilitation and ensures free access to orthotic devices, prostheses and other assistive devices and technologies for the beneficiaries of the special pension provided for in the law. Nevertheless, the relevant article has not yet been regulated, and the aforementioned services, as well as key materials such as assistive devices, lubricating eye drops, thermal gloves, orthotics, prostheses and special shoes, are manifestly lacking for persons affected by leprosy.

32. In Colombia, issues around the intersection of leprosy with deep-rooted harmful stereotypes and wrongful stereotyping, with poverty and with geographical barriers for people living in remote and rural areas stand as the main barriers hindering persons affected by leprosy from enjoying disability-related social protection. The Special Rapporteur has also received worrying reports about bad practices on the part of public servants and service providers with regard to the attribution of disability benefits to persons affected by leprosy that may indicate an abuse of power over people living in vulnerable situations, as well as institutionalized corruption.

33. The same issues around the intersection of leprosy with deep-rooted harmful stereotypes and wrongful stereotyping, with poverty and with geographical barriers for people living in remote and rural areas were raised by civil society organizations working in India. Those organizations also referred to information barriers, especially those faced by people living in rural areas who were deprived of access to their rights and enjoying their entitlements, aggravated by the lack of a viable mechanism to disseminate information within the system of national and subnational governmental bodies. Significant problems with institutional service delivery were also observed, including a lack of knowledge and capacity among public servants and service providers. Bureaucratic and administrative barriers were also reported, especially with regard to access to disability certificates. Concerning the quota system for access to public employment, limited resources are woefully insufficient, resulting in those

more vulnerable being left out. Barriers to access to livelihood loans from government financial institutions, housing schemes and marriage grants were also reported. Another important barrier lies in the definition of disability in national laws. While the Rights of Persons with Disabilities Act of 2016 includes persons affected by leprosy within its purview, there are two major issues with the provisions concerned that hinder the effective guarantee of such rights under the Act for persons affected by leprosy. First, the restriction of a specified disability only to persons who have been cured of leprosy excludes a large proportion of persons who may live with leprosy-related impairments but who have not yet been cured of leprosy. Second, the manner in which disability percentages are calculated (only disabilities of 40 per cent or more give access to disability-related benefits) does not give sufficient weight to the loss of sensation and other important invisible impairments, which often leads to the denial of disability certificates to persons affected by leprosy. The scoring grade misses out on the important aspect of nerve damage, which causes partial or complete loss of sensation and has the potential to cause dynamic changes resulting in further, visible impairments. There are more than 100 discriminatory laws against persons affected by leprosy in the country – an issue that has already been addressed by the Special Rapporteur.¹⁴ Lastly, there is a significant problem with the non-discrimination clause set out in section 3 (3) of the Rights of Persons with Disabilities Act, which reads as follows: “No person with disability shall be discriminated on the ground of disability, unless it is shown that the impugned act or omission is a proportionate means of achieving a legitimate aim.” Neither the law nor its implementing regulations define what constitutes a “legitimate aim” or “proportionate means”, and the reality of the negative attitudes towards and perceptions of leprosy disability, coupled with a lack of awareness, will form the basis of the decisions that people make regarding what constitutes a legitimate purpose. This subsection nullifies the objective of protection from discrimination under the Rights of Persons with Disabilities Act in its entirety, rather than providing for the same in unambiguous terms. It is therefore essential to repeal section 3 (3) of the Act and insert a non-discrimination subsection that is in line with the dispositions on special and affirmative measures as detailed by the Committee on the Elimination of Discrimination against Women in its general recommendations No. 32 (2014) on the gender-related dimensions of refugee status, asylum, nationality and statelessness of women and No. 25 (2004) on temporary special measures and by the Committee on Economic, Social and Cultural Rights in its general comment No. 20 (2009) on non-discrimination in economic, social and cultural rights.

34. Issues around the intersection of leprosy with deep-rooted harmful stereotypes and wrongful stereotyping, with poverty and with geographical barriers for people living in remote and rural areas are also referred to by civil society organizations as outstanding barriers hindering persons affected by leprosy from having access to disability rights in Indonesia. According to these organizations, the enjoyment of disability-related protection and benefits by persons affected by leprosy remains very limited, and stigmatization against persons affected by leprosy is a major barrier that calls for leprosy-specific affirmative measures. Examples provided by the organizations include access to employment, especially in the area of food production and services, which is restricted for persons affected by leprosy but open to persons with disabilities as a very common income generation opportunity in Indonesia. Persons affected by leprosy are regarded as leprosy patients in the health-care services and are treated in a separate leprosy room, often located at the back of the health-care centre, even if their current illness is not leprosy-related. Reasonable accommodation is provided to people with visual impairments, hearing impairments and mobility impairments, but not for the special needs of persons affected by leprosy. These

¹⁴ [A/76/148](#).

special needs are often caused by stigmatization. For example, persons affected by leprosy are reluctant to go to a district general hospital owing to previous experiences of discrimination on the part of health-care workers. They felt accepted and well treated in the former leprosy hospitals but not in the general hospitals. Therefore, since currently they only have the option of being treated in general district hospitals, they need support in admission, and it must be ensured that the hospitals accept them and have the right capacities to treat them. Statutory health insurance companies should also offer special help addressing the needs of persons affected by leprosy. The health insurance companies argue that the wounds of persons affected by leprosy are no different from diabetic wounds, but, unlike people with diabetic wounds, persons affected by leprosy cannot go to local wound services because they are not accepted there. When they are told to treat their wounds at home, they often cannot do so because they live in poverty and have to work. Civil society organizations also call attention to the preventable nature of physical impairments caused by leprosy and demand the right to an effective remedy for those people whose right to the highest attainable standard of physical and mental health, including early diagnosis and prompt treatment of leprosy, has not been guaranteed, leading to irreversible physical impairments.

35. In Nepal, the definition of persons with disabilities set out in the Disability Act of 2017 is comprehensive in nature, but in practice persons with sensory impairments face many difficulties in gaining access to disability cards. Furthermore, psychosocial impairments and disabilities resulting from stigmatization on the ground of leprosy are not recognized *de facto*. Information barriers, with a lack of awareness among persons affected by leprosy about their rights and how to claim them, was also reported. An important gap in the country concerns the collection of data on leprosy-related disabilities. According to the civil society organizations that submitted information for the purpose of the present report, during the preparation of a population census conducted in 2021, several disability groups were included in the discussion, and their inputs were sought before and after the census. However, representatives of organizations of persons affected by leprosy were not invited to participate, and their specific situation was thus not duly taken into account. Overall, the participation of persons affected by leprosy and their representative organizations in policymaking remains low when compared with that of other organizations of persons with disabilities. Lastly, Nepal has not yet abolished discriminatory norms against persons affected by leprosy under its Civil Code.

36. Importantly, the difficulties and problems described herein are not particular to these countries, but rather reflect a common pattern of non-recognition and exclusion that is shared by people living in other countries and that calls for reviewing legal and regulatory frameworks, as well as administrative procedures for their implementation. While the majority of countries in which leprosy is relevant have legal and regulatory frameworks in place that, in principle, recognize visible impairments caused by leprosy, issues around the assessment and recognition of invisible impairments and psychosocial impairments, disability as the interaction between impairments and society's restrictions, effective access to disability-related benefits, the right to an effective remedy and reparation, the elimination of discriminatory legal and regulatory frameworks, the elimination of harmful stereotypes, and measures to protect the rights of people living in former leprosy colonies, among others, remain unaddressed. In essence, disability rights seem to be restricted to social protection, and decisions on who is or is not entitled to such protection remain largely in the hands of the medical professions.

37. The situations described above, taken together, echo the paternalistic approach to persons with disabilities and to persons affected by leprosy that international human rights law was set to transform through provisions aimed at promoting an

active citizenship and creating enabling environments that embrace diversity. Importantly, it is clarified in the Convention on the Rights of Persons with Disabilities that States' obligations include not only non-discrimination but also taking all the steps necessary to eliminate barriers and promote enabling environments that guarantee the right of persons with disabilities to enjoy opportunities on an equal basis with others. Undoubtedly, systemic change requires more than what is provided for in existing national legal and regulatory frameworks.

38. Another issue of concern is that few countries have established mechanisms for monitoring the implementation of the Convention and of disability-related national legal and regulatory frameworks. Monitoring mechanisms, together with proper budget allocation and transparent accountability procedures, are essential to the enforcement of international and national human rights law. The same is true of the enforcement of participation rights, especially for historically marginalized groups who have been structurally denied the opportunity to engage in public affairs and to defend their own interests in the democratic construction of free societies.

VI. Why inclusive participation matters

39. At the heart of the Convention on the Rights of Persons with Disabilities lies the right to participation. This right is implicit in the preamble to the Convention, which contains recognition of the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities and of the importance for persons with disabilities of their individual autonomy and independence, including their freedom to make their own choices. By the same token, it is stated in the preamble that the Convention will make a significant contribution to redressing the profound social disadvantage of persons with disabilities and promote their participation in the civil, political, economic, social and cultural spheres with equal opportunities, in both developing and developed countries. The right to participation is mentioned in article 3 (c), which provides for the full and effective participation and inclusion of persons with disabilities in society; in article 4 (3), which provides that persons with disabilities and their representative organizations shall be involved in the development and implementation of legislation and policies to implement the Convention and in other decision-making processes concerning issues relating to them; and in articles 29 and 30, where it is further elaborated.

40. In the Convention, it is acknowledged that persons with disabilities are not homogenous, and their diversity is recognized, which is essential to guiding States towards ensuring the participation of all groups of persons with disabilities in the development and implementation of legislation and policies and in decision-making processes that concern them. Only those with the experience of specific impairments and disabilities are best positioned to identify the exact barriers and risks affecting them, vocalize their needs and contribute to solutions. Communities have an accumulated and action-oriented knowledge about their territory and people, which can only enhance the efficiency of States' responses to their problems. This notwithstanding, participation is often used in discourse and seldom put into practice. In order for participation to be meaningful and not merely tokenistic, issues around recognition and access, as well as the barriers that hinder both, need to be prioritized in States' frameworks for implementing the Convention.

41. Several civil society organizations report that limited participation is enjoyed by persons affected by leprosy and their representative organizations in institutional matters relating to them, as well as in umbrella organizations for persons with disabilities. Unarguably, there are numerous systemic barriers to the full and

meaningful participation of persons affected by leprosy and their family members. Such barriers include: institutionalized discrimination; illiteracy and low educational qualifications; legal impediments; inaccessibility of administrative procedures and requirements; inaccessibility and unintelligibility of the information being provided; physical and environmental barriers; and a lack of support mechanisms for overcoming structural disadvantages reflected in unequal and unfair socioeconomic and education status.

42. Under the Convention, States are obliged to actively promote enabling environments, ensuring equality, guarantees to free expression, accessibility, accommodation in procedures and support. Accessibility as an indispensable condition for the fulfilment of the right to participation relates to information, communication, infrastructure and transport. In order to promote the participation of persons affected by leprosy and their family members, States are required to identify and remove any legal barrier and any institutionalized discriminatory practice. Adopting temporary special measures to guarantee de facto equality in participation in public affairs, as endorsed by the Committee on the Elimination of Discrimination against Women in its general recommendation No. 23 (1997) on women in political and public life, may also be needed.

43. The Special Rapporteur, in line with her working methods, has consulted persons affected by leprosy and their family members on issues such as self-identification and disability when preparing the present report. Their experience and needs show the limitations of existing legal and regulatory frameworks for protecting the rights of persons with disabilities and, accordingly, the value of ensuring their right to participation in the development and implementation of legislation and policies and in decision-making processes that concern them.

44. A total of 195 people from 23 countries (Bolivia (Plurinational State of), Brazil, Colombia, Ghana, India, Indonesia, Iran (Islamic Republic of), Kenya, Morocco, Myanmar, Nepal, Nigeria, Papua New Guinea, Paraguay, Peru, the Philippines, Portugal, Senegal, Solomon Islands, Timor-Leste, the United Kingdom of Great Britain and Northern Ireland, the United States of America and Zambia), the majority being leprosy-endemic countries, responded to the online questionnaire designed for the present report. A total of 43 per cent of the respondents were women affected by leprosy, 27 per cent were men affected by leprosy, 10 per cent were female family members of persons affected by leprosy, 6 per cent were male family members of persons affected by leprosy and 14 per cent were categorized as “other” (of which 60 per cent were members of organizations of persons affected by leprosy or organization of persons with disabilities and 40 per cent were health-care professionals). Of the 195 respondents, 58 per cent were members of organizations of persons affected by leprosy or organizations of persons with disabilities.

45. When asked whether they self-identified as a person with disabilities, 74 per cent of the specific group of persons affected by leprosy responding to the questionnaire answered in the affirmative, as did 30 per cent of the family members of persons affected by leprosy. A total of 23 per cent of the persons affected by leprosy who self-identified as persons with disabilities mentioned living with impairments on their feet, 23 per cent mentioned living with impairments on their hands, 19 per cent described numbness of their limbs and skin, 11 per cent described visible impairments, 8 per cent referred to mobility impairments, 7 per cent referred to visual impairments, 6 per cent referred to loss of sensation and 3 per cent referred to the amputation of limbs. Importantly, 43 per cent of the family members of the persons affected by leprosy mentioned living with mental illnesses.

46. It is worthwhile to note that, while the majority of persons affected by leprosy identify as persons with disabilities (74 per cent), others do not. Discussion about the

recognition of persons affected by leprosy and their family members as persons with disabilities challenges any fixed definition of disability, as well as dichotomic frontiers between “disabled” and “non-disabled”. Acknowledgement of fluid, complex and evolving identities is key not only to avoiding any exclusion but also to preventing any labelling that goes against people’s right to self-identification.

47. As recognized in the Convention on the Rights of Persons with Disabilities, persons with disabilities are not a homogeneous group, but rather a very internally diverse one, as is the case with persons affected by leprosy and their family members. Fluidity is at the heart of the preamble to the Convention, in which it is affirmed that disability is an evolving concept. However, binary definitions of “disabled” and “non-disabled” that do not recognize disability as a dynamic and evolving experience in people’s lives are largely dominant.

48. It is affirmed in article 1 of the Convention that persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others, thereby not restricting coverage to any person. Such definition accommodates family members of persons affected by leprosy who self-identify as persons with psychosocial disabilities owing to stigmatization and discrimination on the ground of leprosy.

49. When asked what daily activities were more challenging in people’s lives, 26 per cent of the specific group of persons affected by leprosy who responded to the questionnaire referred to mobility issues; 19 per cent referred to personal daily activities such as bathing and changing clothes; 18 per cent referred to kitchen work; 14 per cent referred to difficulties in getting to work, performing heavy work and working; 11 per cent referred to holding and picking up objects; and 12 per cent referred to housekeeping activities. Nevertheless, 54 per cent did not receive any support or State benefits, nor did 73 per cent of family members of persons affected by leprosy.

50. A total of 36 per cent of persons affected by leprosy mentioned not being recognized as a person with disabilities by doctors as a barrier to disability-related protection, while 32 per cent said that they did not know about any possible benefits and another 32 per cent complained about the absence of any benefit. Medical jurisdiction over the assessment of disability and a lack of information seem to be the major barriers at work with regard to access to disability-related social protection.

51. In total, 61 per cent of persons affected by leprosy reported having been discriminated against on the ground of their impairments, as did 57 per cent of family members of persons affected by leprosy. The Special Rapporteur has extensively documented discrimination on the ground of leprosy, which ranges from interpersonal to structural and institutionalized violence, and has also detailed the specific patterns of discrimination perpetrated against women and children affected by leprosy.¹⁵

52. The Special Rapporteur believes that it is important to signal in the present report that not only are persons with disabilities a diverse group of people, but that their problems and needs may also differ from those of other persons with disabilities, which emphasizes the importance of recognizing diversity and consulting all groups of persons with disabilities. Specific examples involving issues such as reasonable accommodation, deinstitutionalization and the disabling effects of institutionalized and structural discrimination and violence in family members follow:

(a) As previously mentioned, the majority of persons affected by leprosy have been pushed out of the formal economy and into poverty and extreme poverty. The

¹⁵ A/HRC/41/47.

majority work in the informal economy and have been systematically denied the rights to decent work and social protection, and they have also been voiceless in social dialogue and other decision-making processes. Their sector of activity is mostly petty trade, agriculture, fishing and other manual activities. While reasonable accommodation, as described in article 2 of the Convention on the Rights of Persons with Disabilities, and as provided for in article 27 of the Convention regarding the workplace, may not be an obligation of the State unless it relates to public employment, but rather of the 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 for many persons who have experienced leprosy. The latter face several barriers to their enjoyment of the right to education, and this pushes them into performing manual labour, which, owing to nerve damage caused by leprosy, can aggravate physical impairments and chronic pain. Importantly, women, who bear the brunt of unpaid care and household work, often lack rest periods, self-care and assistive devices that are essential to their well-being. The right to reasonable accommodation should, as such, be mainstreamed into relevant government programmes, such as those related to gender, agriculture and the rural population. 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;

(b) The majority of people who were forcibly segregated into what have become globally known as leprosy colonies (there are nearly 2,000 such colonies active in the world) and their descendants do not enjoy property rights over the land where they were once confined, and this situation aggravates poverty. Notably, these places have become, for many people, their home and their descendants' home. As such, article 19 of the Convention on the Rights of Persons with Disabilities should be interpreted in the light of guideline 5 of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members. It is affirmed in the guideline that States should promote the enjoyment of the same rights for persons affected by leprosy and their family members as for everyone else, allowing their full inclusion and participation in the community, but also that States should allow any persons affected by leprosy and their family members who were once forcibly isolated by State policies to continue to live in the places that have become their homes, if they so desire. States should also improve living conditions in those places. The Special Rapporteur has received worrying reports of cases of forced eviction from former leprosy colonies. Such colonies should come under the protection of housing rights, as provided for in article 11 of the International Covenant on Economic, Social and Cultural Rights, and land and property should be regulated in order to guarantee ownership of property and land to persons affected by leprosy and their descendants, if they so desire;

(c) For many family members of persons affected by leprosy, discrimination on the ground of leprosy has a severe impact on their enjoyment of opportunities on an equal basis with others, and stigmatization also affects their mental health and well-being. In the case of some family members, moreover, human rights violations have been equally perpetrated against them on the ground of leprosy. This is the case for the children and family members who experienced separation from their parents and segregation from society. In Brazil, it is reported that approximately 16,000 children were separated from their parents as a result of the segregation policy; they were sent to institutions known as preventoriums between the 1920s and the 1980s.

There are also reports of illegal adoptions and even executions.¹⁶ As a result of these violations, many of these people currently do not have access to an adequate standard of living and economic autonomy, and many suffer from psychosocial disorders and disabilities that impair their rehabilitation and inclusion in society. In accordance, they should be guaranteed remedies and reparation for the damages they have suffered owing to the compulsory isolation of their biological parents and the abuse and violence that they suffered within State facilities.

VII. Terminology

53. An important element of enjoying dignity, which is a core human rights principle, relates to people's power to choose how they are identified and referred to. 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" (which came to be employed by the Human Rights Council in its resolution 35/9) to refer to individuals currently under treatment for leprosy and individuals who had been cured of leprosy. That expression was adopted by representatives of the people's organizations as an important step towards self-identification. Nevertheless, recent developments are leading to an increasing use of the alternative terminology "persons who have experienced leprosy" by the people's organizations and to a rejection of the term "leprosy" altogether in favour of the term "Hansen's disease". The Special Rapporteur included in her questionnaire two questions on issues of terminology, to be answered only by persons affected by leprosy. In total, 82 per cent of the respondents preferred terms such as "Hansen's disease", while 66 per cent would rather use the expression "persons affected by Hansen's disease", compared with 34 per cent who preferred to use "persons who have experienced Hansen's disease". While no definite conclusions can be drawn from these results, they certainly point to a large majority of people preferring "Hansen's disease" over "leprosy", and to the need for a wider discussion at the national level, but also within WHO, on terminology.

VIII. Conclusions and recommendations

54. While progress made in the elaboration of norms at the national level that recognize equality for persons with disabilities is well known, States must do more to effectively implement the provisions of the Convention on the Rights of Persons with Disabilities, given the fact that, in practice, the implementation of such norms reproduces paternalistic approaches that largely fail to promote systemic change. By the same token, recognition of the diversity of persons with disabilities is limited, and more marginalized groups of persons with disabilities, such as persons affected by leprosy and their family members, are overlooked in national policymaking. Issues that demand much more attention from policymakers include those surrounding the definition and assessment of disability, the removal of institutionalized and extra-institutional barriers hindering access to rights, the relationship between poverty and disability, the provision of remedies and reparation, and the establishment of specific measures with proper budget allocations that can promote active and participatory citizenship.

¹⁶ Pedro Pulzatto Peruzzo and others, "Contribuição para o relatório temático da relatora especial das Nações Unidas para a eliminação da discriminação contra as pessoas atingidas pela hanseníase e seus familiares ao Conselho de Direitos Humanos da ONU", *Revista de Direitos Humanos e Desenvolvimento Social*, vol. 2 (2021).

55. In order for States to develop and implement leprosy-inclusive disability laws and policies, the Special Rapporteur recommends that they adopt and implement the measures set out below.

56. In general, States should:

(a) Ratify both the Convention on the Rights of Persons with Disabilities and its Optional Protocol, if they have not already done so;

(b) Establish a framework to promote and monitor the implementation of the Convention that recognizes persons affected by leprosy and their family members as persons with multiple disabilities and that duly takes guidance from the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members as a road map that clarifies the normative content of legally binding international human rights instruments in the specific context of the systemic and structural violation of the human rights of persons affected by leprosy and their family members;

(c) Make use of a concept of disability that is in line with the Convention and guarantee that recognition of rights holders is not dependent on medical criteria and assessment, but rather is based on encompassing standards that acknowledge the disabling effect of discrimination, integrate self-identification and accommodate the complexity and fluidity of people's experiences and identities; review administrative procedures for gaining access to disability rights and benefits and guarantee their accessibility; and ensure that persons affected by leprosy, their family members and representative organizations are fully involved in such a reform.

57. With regard to equality and non-discrimination, States should:

(a) Review, amend, repeal or abolish all laws, regulations, ordinances, resolutions and policies that discriminate against persons affected by leprosy and deny them the enjoyment of rights on an equal basis with others at both the national and subnational levels of government;

(b) Duly ensure civil and political rights for persons affected by leprosy and their family members, including owning national identity cards, voting and standing in elections and holding public office; develop and enact comprehensive affirmative measures as a means of correcting historical and structural disadvantage, in line with general recommendation No. 25 (2004) of the Committee on the Elimination of Discrimination against Women, in which the Committee 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; ensure that affirmative measures are defined in consultation with persons affected by leprosy, their family members and representative organizations; and ensure that affirmative measures come with targets and key performance indicators, as well as effective enforcement mechanisms and remedies;

(c) Strengthen the protection of persons affected by leprosy and their family members against violence and abuse by prohibiting discrimination on the ground of leprosy and extending that prohibition to the private and public spheres, as well as by establishing inclusive and accessible victim support services;

(d) Recognize and enforce housing and property rights for persons affected by leprosy who were forcibly segregated into leprosy colonies, and ensure the same rights for second-generation and third-generation family members.

58. With regard to awareness-raising and access to information, States should:

(a) Increase knowledge in all parts of society, including among State officials and public servants working in different areas of the State Administration, particularly in health care, education, labour and justice, as well as in the private sector, about updated scientific evidence on leprosy and on the rights to non-discrimination and equality for persons affected by leprosy and their family members;

(b) Implement awareness-raising programmes that are sensitive to culture, language, gender, age and disability and that are developed in close collaboration with organizations of persons affected by leprosy, in order to ensure both accessibility and efficacy; address barriers created by the digital divide and invest in community media in order to reach as many people as possible; raise awareness among community leaders, traditional leaders and healers, religious leaders, local pharmacists, and schoolteachers with regard to leprosy and engage them in further awareness-raising; and reinforce the positive image of persons affected by leprosy and their family members as rights holders;

(c) Translate the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, as well as the Convention on the Rights of Persons with Disabilities and its Optional Protocol, together with national legal and regulatory frameworks designed to implement those instruments, into the local languages, and disseminate them widely in accessible formats.

59. With regard to health and rehabilitation, States should:

(a) Strengthen universal health coverage, ensuring the universality of access in both rural and urban areas, through public services, which should be culturally appropriate, gender-sensitive, age-friendly and disability-friendly; and build the capacity of the health-care workforce on the human rights model of disability, as well as on the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members;

(b) Guarantee habilitation and rehabilitation programmes for persons affected by leprosy and their family members; guarantee to persons affected by leprosy and their family members access to mental health-care services on the basis of a recovery-based paradigm and through services that are ethical, respectful, culturally appropriate, gender-sensitive and empowering to individuals; provide, free of charge, assistive devices for protection and assistive devices for the facilitation of activities of daily life; partner with organizations of persons affected by leprosy to strengthen peer-to-peer counselling and family-based counselling; and extend counselling and support to family members of persons affected by leprosy.

60. With regard to decent work and employment, States should: prevent and address discrimination against persons affected by leprosy and their family members at the workplace; implement a gender approach to article 27 of the Convention on the Rights of Persons with Disabilities that fights the intersection of gender with disability and affirms the rights of women with disabilities to an inclusive education, vocational training, decent work and equal remuneration; guarantee the transition of persons affected by leprosy and their family members from the informal economy to the formal economy, and open social dialogue to organized groups of persons with disabilities, including persons affected by leprosy, working in the informal economy; fulfil accessibility and reasonable accommodation rights in all productive sectors and work arrangements, including agriculture, husbandry and fishing; and recognize visible physical

impairments related to leprosy for the provision of reasonable accommodation, as well as invisible ones such as pain or loss of sensation, and psychosocial disabilities related to stigmatization.

61. With regard to social protection, States should: review the qualification requirements for social protection to ensure access for persons with invisible and psychosocial impairments, as well as for persons with disabilities living in poverty, recognizing the additional costs of disability; and ensure a universal basic income for persons affected by leprosy.

62. With regard to guaranteeing the right to access to justice and the right to an effective remedy, States should: ensure that accessible mechanisms are in place for filing complaints of rights violations and that legal procedures include gender-sensitive and age-appropriate accommodations for persons with disabilities, including persons with invisible and psychosocial impairments; provide training and awareness-raising for public officers and the judiciary on leprosy-related discrimination and to organizations of persons affected by leprosy on how to bring complaints and access justice; put in place an independent mechanism in line with the principles relating to the status of national institutions for the promotion and protection of human rights (the Paris Principles) to monitor the implementation of the Convention on the Rights of Persons with Disabilities, together with a consultative mechanism for systematic consultations with persons with disabilities that is inclusive of persons affected by leprosy, their family members and their representative organizations.

63. With regard to data collection, States should: ensure the full recognition of persons affected by leprosy and their family members in disability-related data collection, which should also include disaggregation not only by demographic, environmental, socioeconomic and cultural variables, but also by the various grounds of discrimination recognized in international human rights law, and respect for the principles of participation and privacy; and guarantee analysis and dissemination of disaggregated data across all sectors, in close cooperation with organizations of persons affected by leprosy.

64. The Special Rapporteur also recommends that intergovernmental agencies use leprosy as a case study to fill the evidence gap on the relationship between disability and poverty; review the definition of leprosy-related disabilities in line with the human rights model; recognize the diversity of persons with disabilities; and ensure leprosy inclusiveness in intergovernmental agencies and human rights monitoring mechanisms when addressing disability-related issues.