



General Assembly

Distr.: General
12 April 2022

Original: English

Human Rights Council

Fiftieth session

13 June–8 July 2022

Agenda item 3

**Promotion and protection of all human rights, civil,
political, economic, social and cultural rights,
including the right to development**

Right to the highest attainable standard of physical and mental health for persons affected by leprosy and their family members

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

Summary

In the present report, the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, discusses the right to health, in order to detail the content and application of this right for persons affected by leprosy and their family members, as well as for persons who experience neglected tropical diseases other than leprosy.



I. Introduction: the right to health for subordinated groups

1. In the present report, developed in accordance with 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, addresses the right to the highest attainable standard of physical and mental health for persons affected by leprosy, also known as Hansen's disease, and their family members. With the report, the Special Rapporteur hopes to provide people-centred and action-oriented elements that can help to detail, in practical and pragmatic terms, both the content and the application of the right to the highest attainable standard of physical and mental health for persons affected by leprosy and their family members, and also for persons who experience neglected tropical diseases other than leprosy.

2. Few human rights have such intricate, controversial and uncertain features as the right to health.¹ While there has been undeniable progress towards the generalized recognition of health as a human right, as well as in regard to the specification of its normative content, debates about the right to health are still rather fragmented and sprawl over diverse theoretical and practical fields, each with its own, and many times competing, agenda. Such uncertainty is coupled with difficulties in defining health.

3. Health is far from being a univocal concept. Contending visions about the human body and what it means to enjoy a good life fills this concept with controversy. Notwithstanding the rich cultural diversity around the concept, most of international and national policymaking adopts one hegemonic narrative about health and the adequate means to foster it. The narrative is anchored on biomedicine's explanatory models and technologies and on the State's regulation of human bodies within a capitalist model that aims to maximize their productivity, as well as on the consumer market.

4. In its Constitution, the World Health Organization (WHO) defines health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, whereas article 25 of the Universal Declaration of Human Rights presents a more overarching concept that connects health and well-being to the guarantees to a dignified and secure standard of living, encompassing access not only to food, clothing and housing, but also to medical care and social security. Yet the majority of global and national health narratives and strategies continue to be dominated by the biomedical narrative on human suffering, which narrows diseases to mere biological phenomena, and thus remain disease-centred. Although they include recommendations on ensuring universal and affordable access to water, sanitation and hygiene in order to tackle diseases related to poverty, global health policies do not address the structural violence that is at the root of many of such diseases (as is the case of leprosy and other neglected tropical diseases) and much of the human suffering and economic loss they cause.

5. Biomedical practices are usually structured upon unequal power relations, which are exacerbated in the cases of groups and populations historically subjected to structural violence, as a woman affected by leprosy sharply pointed out to the Special Rapporteur:

I need to persuade the health professional that I really need assistance, like I didn't have the right to the service. Often, they don't even bother listening. Their answer is already ready: "Let's wait and see what happens and if you don't improve by next month, we'll see what to do." Who suffers from pain shouldn't have to wait. But that's what we've been doing. We're getting used to the pain, the prejudice, the lack of rights, because it's very tiring, having to fight every day for something you are entitled to.

6. Unequal power relations convert people into passive beneficiaries without the means to overcome the unintentional harm that misguided policies and practices may, and often do, cause. Significantly, while leprosy is mostly endemic in countries of the global South, the global North continues to lead decision-making, without sufficiently taking into account the immense expertise consistently being produced by the global South. As some authors point

¹ Jennifer Ruger, "Toward a theory of a right to health: capability and incompletely theorized agreements", *Yale Journal of Law & the Humanities*, vol. 18 (2006).

out, imbalances in power can predispose programme implementers to important blind spots.² The reductionist approach, together with unbalanced power relations between decision makers, health practitioners and persons affected by leprosy, often engenders misconceptions and bottlenecks that end up producing and reproducing discrimination, as the present report will demonstrate.

A. Goals and methodology: a bottom-up narrative about the right to health

7. In a historical moment marked by a pandemic that has had devastating consequences at the global level, which were exacerbated by an economic crisis that led, in many contexts, to a regression in terms of people's enjoyment of social and economic rights, it seems more relevant than ever to detail the content of the right to the highest attainable standard of physical and mental health, particularly from a people-centred and action-oriented perspective. Furthermore, and as the Special Rapporteur has already mapped and reported on, the disproportionate impact of the coronavirus disease (COVID-19) pandemic on persons affected by leprosy has jeopardized not only the individuals' right to health, but also the efforts made over decades. Estimates shared by the Special Rapporteur regarding a significant drop in new case detection rates³ were recently confirmed by WHO.⁴

8. The COVID-19 pandemic has simultaneously unveiled and deepened structural gaps regarding the enjoyment of the right to the highest attainable standard of physical and mental health by persons affected by leprosy. In the view of the Special Rapporteur, some of these gaps relate to the priority that has been given over the years to only one of the three components of the overarching goal of zero leprosy, namely, to zero infection and disease (meaning stopping transmission and eliminating leprosy), over zero disabilities (prevention of impairments and rehabilitation) and zero discrimination (elimination of both formal and substantive discrimination), which reflects the hegemony of the reductionist interpretation in biomedicine of health and human suffering.

9. Moreover, and as the prevalence of leprosy has declined (even though incidence has proved to be much harder to reduce), the tendency for leprosy to lose priority at the government level has increased. And so has the historical underfunding of basic, clinical and operational research on leprosy, leaving key questions about leprosy and how to mitigate the suffering it causes unanswered. Additionally, the dramatic loss of expertise to diagnose and treat leprosy is decried by many leprosy experts as a major cause of the systematic denial of the right to health of persons affected by leprosy. Such structural dynamics, which encompass all levels of health production, from the global to the local, lie at the root of the pain expressed to the Special Rapporteur by one woman affected by leprosy: "Stop saying that this disease is curable! It is not! One cannot ever go back to living a normal life."

10. Such complaints are common. Many persons affected by leprosy claim that, even though health-care workers say they are cured, they do not feel healed. Such complaints are commonly dismissed by health-care workers and experts as being the result of a limited understanding by lay people of this highly specialized area of biomedicine, since, officially, a cure for leprosy has existed for seven decades. The Special Rapporteur strongly disagrees with this reading and affirms that such complaints are not the result of ignorance, but are instead a valuable source of knowledge to be used for the evaluation of existing public health policies, as well as an enlightening statement about diverse but interrelated subjects, such as: the classification of diseases, namely, the boundary between the normal and the pathologic; public health strategies; the continuum of care; the quality of health-care systems; the reach of universal health coverage; and the barriers people face in accessing health care.

² David G. Addiss and Joseph J. Amon, "Apology and unintended harm in global health", *Health and Human Rights Journal*, vol. 21, No. 1 (June 2019).

³ See [A/HRC/47/29](#).

⁴ According to WHO, the proportion of new cases in many countries was significantly lower than in 2019 (31.1 per cent on average.), which may reflect the impact of the COVID-19 pandemic. WHO, *Weekly Epidemiological Record* No. 36 (2021), pp. 421–444.

11. What this woman is saying is that health is not a purely biological, individual and/or technical issue, as it is portrayed in a reductionist approach, but rather a deeply political matter, which is very much in line with what Rudolph Virchow, the father of social medicine stated in the late nineteenth century. His famous saying – that medicine is a social science and politics is nothing but medicine at a larger scale – was rarely taken into account in the subsequent development of the field of traditional top-down public health (with important exceptions, such as in the case of Latin American collective health), which relegated to a secondary status the social medicine perspective that defended the view that ill health resulted from social deprivation and poor living conditions.⁵ His words nonetheless reflect the fact that the human body always tells a story about society. In the case of leprosy, that story speaks of endemic social injustice.

12. Over the past years, the Special Rapporteur has always made herself available to cooperate with intergovernmental agencies and their leprosy-related programmes, such as WHO, in particular its Control of Neglected Tropical Diseases department and Global Leprosy Programme, but also with other stakeholders that work hard to fight leprosy and its consequences, such as the WHO Goodwill Ambassador for Leprosy Elimination, the Global Partnership for Zero Leprosy (a coalition that includes WHO, the Novartis Foundation, the International Federation of Anti-Leprosy Associations, the Sasakawa Health Foundation and the International Association for Integration, Dignity and Economic Advancement) and the International Federation of Anti-Leprosy Associations and its members.

13. The Special Rapporteur acknowledges the comprehensive nature of the guidelines recommended and the practices implemented by some of these key stakeholders. She regrets the difficulties of implementation of the same guidelines at the national and subnational levels, which often result from budget limitations, but also from the low awareness of decision makers as to the human suffering and economic losses caused by leprosy. The Special Rapporteur thus believes that a new narrative about the right to the highest attainable standard of physical and mental health for persons affected by leprosy and their family members is of the essence.

14. Such a narrative must be drawn from the expertise of the community of persons affected by leprosy and their own interpretation of their right to health, but also from evidence that is alternative and complementary to official epidemiology. Why is alternative and complementary evidence necessary? Because in the field of global health, metrics, as technologies of counting, are standardized and uniformized in order to enable global conversation,⁶ many times making invisible local knowledge that might be key for meeting agreed-upon targets. In the present report, the Special Rapporteur aims to posit people-centred elements that can encourage States, intergovernmental agencies and international, national and local stakeholders to produce knowledge that places people's experience at the centre of the analysis.

15. In order to prepare the present report, the Special Rapporteur undertook several consultations, in line with her usual working methods. She consulted States and civil society organizations about national policies and practices. She also developed an online questionnaire to try to reach as many persons affected by leprosy as possible, while being very much aware that the majority of the target population does not have access to the Internet and struggles with multiple barriers to participation.⁷ This means that the responses to the online questionnaire reflect a very specific layer of the target population, one that already enjoys a higher degree of inclusion, which is not the harsh reality of the great majority of persons affected by leprosy and their family members.

16. For the report, the Special Rapporteur also draws on her continuous collaboration with the key stakeholders mentioned above, and others, such as the International Leprosy

⁵ See Abadía-Barrero and Ardila-Sierra, "The right to health under capitalism".

⁶ See Vincanne Adams, ed., *Metrics: What Counts in Global Health* (Durham, Duke University Press, 2016).

⁷ The Special Rapporteur thanks the Sasakawa Health Foundation, the International Association for Integration, Dignity and Economic Advancement and The Leprosy Mission International, but also individuals such as Deepa Palaniappan, for their support in the preparation and dissemination of the online questionnaire.

Association, alongside which she has learned greatly over the years.⁸ She particularly relied on her permanent dialogue with persons affected by leprosy and their representative organizations. As usual, through her work, the Special Rapporteur aims to identify the particular patterns of discrimination experienced by women affected by leprosy. In this sense, she was privileged to participate in three international meetings organized by the women's policy department of Movimento de Reintegração das Pessoas Atingidas pela Hanseníase, a non-profit organization in Brazil, with the goal of listening to girls and women affected by leprosy, as well as female family members of persons affected by the disease. The meetings were held in three sessions (Africa, the Americas and Asia) between November and December 2021. An important source of data concerning young people affected by leprosy were the webinars on human and youth rights organized by the Sasakawa Leprosy (Hansen's Disease) Initiative.⁹ Lastly, the report is also informed by two decades of intense work by the Special Rapporteur with persons affected by leprosy and their family members in relation to their right to the highest attainable standard of physical and mental health.

B. Right to be healthy versus the right to health care

17. From the nineteenth century onwards, the global health agenda has put greater emphasis on the right to health care to the detriment of the right to be healthy. Likewise, subsequent scholarly work on the right to health has been dedicated mainly to clarifying States' obligations on ensuring access to health care. The right to health, although supported by a body of international law, is usually referred to as being too vague, barely enforceable and as an inaccessible standard in itself. Services, freedoms, resources, opportunities and goods seem more adequate variables for monitoring the enforcement of the right to health than health itself.

18. Provisions in international norms about the right to health reflect this biased reasoning and sectarian approach, by putting greater emphasis on individual access to health care to the detriment of the promotion of the collective conditions that can allow groups and populations to experience healthy living. Notably, the right to health was codified in a time of utter trust in the lineal progress of science and in biomedicine as the decisive tool for fighting the burden of diseases. Such ideas shaped the architecture and goals of contemporary institutions. Those institutions match the right to health with the individual right to receive medical treatment, encourage the expansion of the medical and pharmaceutical industries, and sideline approaches targeting the underlying social determinants of health.¹⁰ In this context, health has become one of the more profitable industries of our time, with shameful discriminatory effects.

19. The right to health, as provided for in international human rights law, and particularly in article 12 of the International Covenant on Economic, Social and Cultural Rights, faces important restrictions. One such limitation is that the right to health is inherently resource dependent.¹¹ Progressive realization, meaning that States are only obliged to progressively realize, to the maximum of their available resources, the highest achievable standards of health, hinders agreement over a theoretical framework that can objectively evaluate the cost-effectiveness of States' health expenditures.¹² In practice, States can simultaneously not implement and not violate the right to health. Another limitation concerns accountability. As the experience of persons affected by leprosy demonstrates, it is almost unfeasible for individuals who have been left behind by health-care policies to successfully find the means

⁸ The Special Rapporteur thanks Mauricio Lisboa Nobre, leprologist and specialist in tropical medicine, for his support in clinical matters related to leprosy.

⁹ See <https://sasakawaleprosyinitiative.org/latest-updates/initiative-news/1062/>.

¹⁰ Benjamin Mason Meier and Ashley M. Fox, (2008) "Development as health: employing the collective right to development to achieve the goals of the individual right to health", *Human Rights Quarterly*, vol. 30 (2008).

¹¹ Benjamin Mason Meier and Larisa M. Mori, "The highest attainable standard: advancing a collective human right to public health", *Columbia Human Rights Law Review*, vol. 37 (2005); and Philip Alston and Gerard Quinn, "The nature and scope of States Parties' obligations under the International Covenant on Economic, Social and Cultural Rights", *Human Rights Quarterly*, vol. 9 (1987), p. 177.

¹² Meier and Fox, "Development as health".

to legally hold States accountable under international human rights mechanisms. If States can evade accountability, underfunded health-care systems will hardly meet the needs of groups and populations living in vulnerable situations, as is the case for persons affected by leprosy and other neglected tropical diseases.

20. Global health, a movement very much aligned with the business interests of the global North, has encouraged solutions to health problems that support the commodification of health and the privatization of health care,¹³ which, together with States' discretion to progressively realize economic, social and cultural rights, have favoured the individualistic model of health, as well as sectarian approaches to it. Contrarily to the wide consensus that technocratic approaches are temporary and do not provoke substantial shifts, international and national decision makers have largely opted for such approaches to problem-solving. And with that, the dependency of the global South on external aid and technology transfers remained an obstacle to the enjoyment of health and well-being by many people around the world, as the unequal access to vaccination against COVID-19 has gloomily shown. Furthermore, the privatization of health care undermines implicit values of health as a right, as its outcomes are unfair health systems that provide unequal health care dependent on the income of each person.

21. The market model applied to health stimulates biases and diverts the attention from primary prevention and collective action. Global-health, disease-control and prevention programmes – generally seen as apolitical ways of providing medication and technologies to the poorest – are, in fact, highly political, since they often operate from the outside and impose devices and solutions that are many times unrelated to the reality and knowledge developed at the local level.

22. These are strategies that favour the accumulation of power and benefits in the hands of already powerful actors, while transferring the responsibility for the disease to the diseased. By blaming the victim, collective and structural issues of societies as a whole are seen as mere individual problems. Explanations of disease incidence based on individual behaviour spare the whole society, as well as those who are more privileged, from committing themselves to structural changes and engaging in collective actions. Victim blaming triggers data about individual refusal to engage in treatment or other forms of disease prevention and control. It may even criminalize victims, as has happened with leprosy and as is still the case with the more than 100 legal frameworks that discriminate against persons affected by leprosy worldwide.¹⁴

C. Commodification of health and neglected tropical diseases

23. Leprosy is one of the 20 diseases classified by WHO as a neglected tropical disease. Neglected tropical diseases disproportionately affect populations living in poverty, predominantly in Africa, the Americas and Asia, and have a devastating social and economic effect on over 1 billion people,¹⁵ in particular in low-income countries and the most disadvantaged communities in middle-income countries.¹⁶ Neglected tropical diseases are formally recognized as targets for global action in target 3.3 of the Sustainable Development Goals, and WHO developed a road map for tackling these diseases throughout the current decade.

24. Neglected tropical diseases are classified as such because of the low priority they are given in the context of global health, which, together with the limited resources of middle- and low-income countries, leads to gaps in health systems and coverage that severely affect groups of people that already struggle with multiple barriers to access fundamental rights. Neglected tropical diseases share one same pattern of deprivation, structural disadvantage,

¹³ See Audrey R. Chapman, *Global Health, Human Rights and the Challenge of Neoliberal Policies* (Cambridge University Press, 2016).

¹⁴ See [A/76/148](#).

¹⁵ WHO, *Ending the Neglect to Attain the Sustainable Development Goals: A Roadmap for Neglected Tropical Diseases 2021–2030* (2020).

¹⁶ Dirk Engels and Xiao-Nong Zhou, "Neglected tropical diseases: an effective global response to local poverty-related disease priorities", *Infectious Diseases of Poverty*, vol. 9, art. No. 10 (2020).

stigmatization, poor access to State services, disability and diminished participation in decision-making.

25. Because they mainly affect the poorest, neglected tropical diseases present no market opportunities, hence the pharmaceutical industry does not invest in products to address them. Governments, through tax incentives and patent protection, contribute to these market-driven choices,¹⁷ leaving the poorest with few or no treatment options. While the majority of neglected tropical diseases disable more than they kill, the burden they cause to individuals and their families, and also to economies and societies, is significant. Such diseases can also have a “hidden burden” in wealthy countries, where they may go unnoticed by Governments, in particular health monitoring mechanisms.

26. While there has been an important paradigmatic shift in the past decade towards multi-disease service integration and the recognition of the importance of partnerships,¹⁸ in practice public-health strategies continue to be disease-centred, as they maintain focus on the individual body and sideline knowledge that is able to address both the psychosocial dimension of the human being and the collective dimension of health and illness. The knowledge that seems to count for policymaking is the kind that reaffirms top-down analysis and the pharmaceuticalization of public health, that is, the emphasis that is put on the distribution of medicines. Two concrete examples follow.

27. First, calls to act on the underlying social determinants of health are restricted to universal and affordable access to water, sanitation and hygiene, when the right to work, the right to education and the right to social protection are equally important for preventing diseases and poor health outcomes. Moreover, hardly any strategies are effectively put into place to promote access to water, sanitation and hygiene by people living in vulnerable situations as part of public health programmes. Second, stigmatization and discrimination, while increasingly acknowledged as being interrelated with physical and mental health, are still analytically narrowed to the micro level of social interaction and regarded from the perspective of a functionalist understanding of stigmatization that describes it as a natural consequence of the disease and that fails to address the socioeconomic and political factors that produce and reproduce stigmatizing identities and discriminatory practices. Moreover, emphasis is put on the profoundly discriminatory expression of “self-stigmatization” and on how this “self-stigmatization” leads people to avoid diagnosis and treatment. Such a narrow understanding of stigmatization and discrimination does no more than blame the victim.

D. Health industry, and gaps in leprosy care

28. According to WHO, early diagnosis and complete antibacterial treatment with multidrug therapy – a combination of rifampicin, clofazimine and dapsone – remain the most effective strategies for tackling leprosy.¹⁹ Multidrug therapy is provided free of charge to all detected leprosy patients in accordance with WHO recommendations and through an agreement between the pharmaceutical company Novartis and WHO, which began in 2000 and was recently extended to 2025. The company produces the multidrug-therapy components in India, and WHO manages its distribution to national leprosy programmes. During 2020, problems in production and in the supply chain left several countries with multidrug-therapy shortages, with devastating consequences for individuals and the transmission of leprosy.²⁰ The Special Rapporteur notes that at that time, the right of access to information was denied to persons affected by leprosy and that the lack of accountability mechanisms and remedies for failures in the overall multidrug-therapy supply chain was made manifest, evincing double standards at play in terms of the protection of the right to health for persons affected by leprosy.

29. Multidrug therapy was created by WHO in the 1980s, with the combination of three drugs to avoid drug resistance. These drugs were also cheap, which seemed to be a positive

¹⁷ Gavin Yamey and Els Torrelee (2002). “The world’s most neglected diseases”, *BMJ*, 325 (July 2002).

¹⁸ Lucinda Claire Fuller, Kingsley B. Asiedu and Roderick J. Hay, “Integration of management strategies for skin-related neglected tropical diseases”, *Dermatologic Clinics*, vol. 39, No. 1 (2021).

¹⁹ WHO, *Guidelines for the Diagnosis, Treatment and Prevention of Leprosy* (2017).

²⁰ See [A/HRC/47/29](#).

factor for ensuring massive distribution.²¹ However, the drugs included in multidrug therapy have significant side effects that compromise people's physical, mental and social well-being. For example, clofazimine causes darkening of the skin and often leads to stigmatization and poor mental health. Dapsone can cause severe to lethal anaemia. Drugs for treating leprosy are old and the pharmaceutical industry is not interested in paying for research that could prove the safety and efficacy of other and better drugs, nor in developing new drugs that could be administered for a shorter period of time and thus improve the quality of life of people under medical care.

30. One of the greatest challenges in the medical care of leprosy are leprosy reactions, which cause great physical and mental suffering. Leprosy reactions frequently occur during and after antibacterial treatment. They are also associated with nerve damage, which is the main cause of physical impairments. Leprosy reactions may require prolonged treatment,²² sometimes for several years. Mechanisms of reactions are poorly understood and treatment is largely empirical. In addition, some of the drugs used impair the immune system of the patients. Unlike multidrug therapy, most of the drugs used for treating leprosy reactions are not provided to countries free of charge. They include steroids and thalidomide – the latter being well-known for its teratogenic effects and risks to sexual and reproductive health. Both steroids and thalidomide cause insufferable side effects. Thalidomide, if used during pregnancy, can harm the fetus and cause malformation of the limbs. Steroids can cause dependence and radical body changes. While sharing common clinical features, progress in the medical treatment of inflammatory diseases does not seem to have extended to the care of leprosy reactions.

31. Both antibacterial treatment and reactions management rely on obsolete and cheap drugs that can cause major side effects. The commodification of health and the lack of interest of the pharmaceutical industry in neglected tropical diseases, together with the low priority Governments give to leprosy, explain why persons affected by leprosy are offered such low-quality medical treatment.

32. Despite being curable with multidrug therapy, if not detected and treated early, leprosy can become a disabling and chronic disease that demands a continuum of medical and psychosocial care, which includes rehabilitation, reconstructive surgery, the provision of assistive devices and psychosocial support. Such a continuum of medical and psychosocial care should be fully addressed by effective referrals within national health-care systems. However, the harsh reality of health care for persons affected by leprosy is the progressive dismantlement of leprosy services and of key infrastructure, such as laboratories, and loss of expertise,²³ which aggravate the systemic barriers to access to diagnosis and treatment widely faced by persons affected by leprosy in both endemic and non-endemic countries. Another issue of great concern is that access to quality health-care services after bacteriological cure is extremely limited for persons affected by leprosy, although it is critical for preventing physical impairments. As some leprosy experts say, such a gap is a clear manifestation of stigmatization against discharged leprosy patients among health workers.²⁴

E. International guidance and national action for fighting leprosy

33. In its Global Leprosy (Hansen's Disease) Strategy 2021–2030: Towards Zero Leprosy,²⁵ WHO reports a total of 202,256 new cases detected in 118 countries in 2019, of which 96 per cent were reported by the 23 global priority countries, including 79 per cent in

²¹ World Health Organization, "Chemotherapy of leprosy for control programmes: report of a WHO study group" (Geneva, 1982).

²² Diana N.J. Lockwood and others, "Three drugs are unnecessary for treating paucibacillary leprosy – a critique of the WHO guidelines", *PLoS Neglected Tropical Diseases* (October 2019).

²³ Letícia Gomes Costa and others, "Factors associated with the worsening of the disability grade during leprosy treatment in Brazil", *Leprosy Review*, vol. 86, No. 3 (September 2015); and Liliana Müller Larocca and Maria Marta Nolasco Chaves, "Multiple dimensions of healthcare management of leprosy and challenges to its elimination", *Revista da Escola de Enfermagem da USP* (2020).

²⁴ Maria Rita de Cassia Oliveira Cury and others, "Spatial analysis of leprosy incidence and associated socioeconomic factors", *Revista de Saúde Pública*, vol. 46 (2012).

²⁵ See <https://www.who.int/publications/i/item/9789290228509>.

Brazil, India and Indonesia. In total, 10,816 new cases in 94 countries, including 370 children, presented irreversible physical impairments at the time of diagnosis in 2019, an indication of late diagnosis. The number of children diagnosed with irreversible physical impairments is likely to be significantly higher, as some countries did not report such data. It is estimated that 3 million to 4 million people are living with visible physical impairments due to leprosy. The new strategy is focused on interrupting transmission and achieving zero autochthonous cases. It encourages high-burden countries to accelerate activities, and compels low-burden countries to reach zero autochthonous cases. It is based upon four strategic pillars.

34. In practice, and as indicated by the information the Special Rapporteur received for the present report and previous reports, most of the national programmes focus on multidrug therapy, which, as explained, is distributed free of charge to countries. With regard to the questionnaire, only nine States²⁶ responded to questions about national strategies for addressing leprosy; the implementation of such strategies within the national health-care system; leprosy services at the primary, secondary and tertiary levels of health care; the continuum of medical and psychosocial care; capacity-building of the health-care workforce in the clinical, socioeconomic and cultural aspects of leprosy; and the implementation of the WHO guidelines for strengthening participation of persons affected by leprosy in leprosy services. The Special Rapporteur regrets the lack of cooperation from high-endemic countries, while she appreciates the collaboration from non-endemic ones.

35. All responding States mentioned the existence of national leprosy programmes and/or strategies as part of their epidemiological or infectious disease control departments. As a rule, the treatment of leprosy is ensured within the primary level of health care, while secondary and tertiary levels of health care largely fail to address leprosy complications. Furthermore, few States mentioned measures taken to ensure psychosocial care for persons affected by leprosy. Some States recognized important bottlenecks that required significant improvement. The Plurinational State of Bolivia acknowledged that the psychosocial approach to leprosy was a neglected area that should be prioritized. Peru and Paraguay explicitly reported the lack of measures aimed at guaranteeing occupational therapy. Peru also highlighted the lack of group therapy, as well as the need to strengthen physiotherapy and rehabilitation services. Japan mentioned the need for improvement in the care provided to elderly persons affected by leprosy that remained in former sanatoriums. While the majority of States reported on the existence of periodic training of health-care personnel, especially on up-to-date procedures for leprosy diagnosis, control and treatment, some also mentioned the difficulties that the constant rotation of health-care workers within the system posed to early diagnosis and active case finding. Some States also mentioned the negative impact of their dependency on external funding for fighting leprosy in the country. Mentions of measures to promote the participation of persons affected by leprosy in health services, as recommended by WHO, were conspicuously absent in State responses. Only Nigeria mentioned the participation of persons affected by leprosy in all leprosy-related activities.

36. Such data is in line with submissions from civil society organizations provided for the preparation of the present report and for previous reports. Information provided by civil society organizations operating in endemic countries²⁷ points to the existence of national programmes aimed at fighting leprosy in such countries. In some of the countries (Brazil, India, Indonesia, Nepal, the Niger and Papua New Guinea), there are specific national leprosy programmes, while in others (Burundi, Cameroon, the Congo, Liberia, Senegal and Togo), leprosy programmes are integrated into tuberculosis or neglected tropical disease programmes. As a rule, leprosy services are provided at the primary level of care, with activities aimed mainly at diagnosing and treating leprosy. A considerable number of civil society organizations highlighted the fact that health-care workers showed limited skills with regard to diagnosing and managing leprosy reactions and that training for health-care workers

²⁶ Bolivia (Plurinational State of), Côte d'Ivoire, Japan, Jordan, Mali, Nigeria, Paraguay, Peru and Portugal. Submissions from States that have authorized their statements to be made public will be available on the web page of the mandate of the Special Rapporteur: <https://www.ohchr.org/en/special-procedures/sr-leprosy>.

²⁷ Submissions from civil society organizations that have authorized their statements to be made public will be available on the web page of the mandate of the Special Rapporteur: <https://www.ohchr.org/en/special-procedures/sr-leprosy>.

was sporadic, limited to specialized hospitals and focused mainly on the clinical aspects of the disease. Treatment of adverse reactions, wound care, reconstructive surgery and rehabilitation are restricted and often inaccessible for persons living in remote areas. Secondary and tertiary health-care services are, generally speaking, dependent on private donations and/or non-governmental organizations programmes and services. Another important gap is the limited awareness of persons affected by leprosy about insurance schemes, owing to the unavailability of such information through health-care services, which diminishes their chances of accessing comprehensive and quality care. Regarding the participation of persons affected by leprosy in health services, information provided by civil society organizations points to a lack of policies that can foster meaningful participation. The engagement of one national organization of persons affected by leprosy in the national leprosy programme in Senegal was the only example of such participation identified, and the limited participation of persons affected by leprosy at the decentralized level was also mentioned.

37. In summary, State strategies to ensure the highest attainable standard of physical and mental health are, in most cases, restricted to guaranteeing access to free medicine for treating infection, whereas the other elements of the continuum of care, which include reaction management, psychological care, physiotherapy, occupational therapy, group therapy, wound care, surgery, provision of assistive devices and rehabilitation, and also the right to participation, are largely unattended to. Dependency on external private funding also has an impact on national budgets for leprosy and their reach. And while it is true that civil society organizations and non-governmental organizations fill many of the existing gaps, it is also true that they are far from reaching everyone. Hence, their action is not enough to ensure that everyone affected by leprosy can access his or her right to health. Such universal access can be guaranteed only by the State itself. While partnerships between the public and the private sectors can improve national responses to leprosy, Governments still have the primary responsibility for fulfilling their obligations under national constitutions and international human rights law.

F. Victims of a disease or of a system that overlooks people's needs and suffering?

38. One of the topics consistently pointed out to the Special Rapporteur by persons affected by leprosy and their representative organizations as being of the utmost importance to them are the unsatisfactory results of medical technologies and practices for treating leprosy, which are too often experienced by persons affected by leprosy as discriminatory and disabling. Centring her analysis on people's experience, the Special Rapporteur begins and ends the present section with two individual stories. Both stories speak less about leprosy as a disease and more about the gaps in political action to fight it. None of the cases presented in the report are isolated events, but rather examples of a pattern of violations suffered by persons affected by leprosy worldwide.

39. The first story is about João.²⁸ In 2021, when he was only 15 years old, João died due to leprosy complications in a city in the interior of Brazil. João's story is told by one of the leaders of the Brazilian national movement of persons affected by Hansen's disease, Faustino Pinto:²⁹

My first encounter with João dazed me, he was 14 years old, but he looked like he was 8 years old: undernourished, swollen belly and face due to the excessive use of steroids for controlling leprosy reactions, with a distant and sad look. We began to visit João monthly. On one of those visits, his grandmother told me that other children bullied him. One day I met João and his grandmother at a public health-care service. There, his medical doctor told me that João had developed Cushing's syndrome due to the prolonged use of steroids; days later I received the news that João had been hospitalized with Lucio's phenomenon (a rare reactional leprosy state). João spent 40 days hospitalized. He turned 15 on top of a hospital bed, both of his legs were

²⁸ In order to protect the child and his family, the Special Rapporteur has used a pseudonym.

²⁹ The individual is identified in the present report with his full authorization.

amputated, his organs began to fail and he died. João is just another victim of negligence from the government, of structural invisibility, of the lack of coverage of primary health care, of the lack of public policies for leprosy, of the lack of early diagnosis, of the lack of a multidisciplinary treatment for leprosy, and of the lack of empathy.

40. Perhaps medical and leprosy experts will say that this is an isolated case. And perhaps they will have such a view because of the gap between people working on the ground and those making decisions from a geographically and epistemologically distant place. In the extensive experience of the Special Rapporteur, feedback from health-care practitioners working on the ground is usually very different from that coming from those working at the government level and those at the international level of decision-making. The Special Rapporteur recalls the words of one medical doctor with decades of experience treating people in one of the top three priority countries for leprosy:

It's one thing for the doctor who works with the patient, and another for the manager who works behind a desk at the Ministry of Health's headquarters. Those people are concerned with numbers, with statistics. They are not concerned with people. So, what's their concern? Lowering the incidence; lowering the prevalence. How is this done? Treating faster. The faster you treat, the faster you discharge. If you take a person and discharge that person, it's over. That person is no longer a numerical problem. That person is going to be a problem for me. Why? Because I'm going to discharge that person and in three months he or she will come back. That person is no longer part of the statistics, but is still part of my problem.

41. Or as one representative from an organization of persons affected by leprosy in a priority country for leprosy in Africa told the Special Rapporteur: "It really depends on whether or not you go into the field. Public health managers are bureaucrats, they know much from top to bottom, but they know very little from bottom to up."

42. In order to promote bottom-up knowledge, the Special Rapporteur developed an online questionnaire with 52 questions on the right to the highest attainable standard of physical and mental health for persons affected by leprosy; 174 people from and living in Afghanistan, Bolivia (Plurinational State of), Brazil, Colombia, the Dominican Republic, Ecuador, Ethiopia, France, Germany, Ghana, India, Indonesia, Kenya, Malaysia, Mozambique, Myanmar, Nepal, the Niger, Papua New Guinea, Paraguay, the Philippines, Portugal, Peru, Sierra Leone, Spain (Santander), Switzerland, Timor-Leste, the United States of America, the United Kingdom of Great Britain and Northern Ireland, Zambia and Zimbabwe responded.

43. Of the people who responded, 41 per cent were women affected by leprosy and 37 per cent were men affected by leprosy; 8 per cent were female family members, 6 per cent were male family members and 4 per cent were health-care workers, all responding on behalf of persons affected by leprosy. Of the respondents, 67 per cent were part of a leprosy organization, with more than half participating in organizations of persons affected by leprosy. A total of 70 per cent lived in an urban area, which indicates difficulties in reaching out to people living in rural and remote areas. Most of the respondents were between 29 and 59 years old.

44. A total of 40 per cent of the persons affected by leprosy had been between the ages of 11 to 21 at the time of their leprosy diagnosis; 35 per cent had been between the ages of 21 and 31. The majority of the persons affected by leprosy (55 people) were diagnosed 1 year after their first symptoms appeared, 21 persons were diagnosed after 2 years, 19 persons after three years, 13 persons after five years, and 10 persons were diagnosed only 10 to 15 years after symptoms appeared, demonstrating the difficulties in getting an early diagnosis for leprosy. A total of 68 per cent of the diagnoses were given in public health-care services. Information people received through health-care services at the time of diagnosis was mainly about treatment, and half of the respondents stated that such information was not enough, with 30 per cent demanding more information on rights, 20 per cent demanding more information on leprosy reactions and 11 per cent demanding more information on self-care.

45. With regard to the type of care received for leprosy, 38 per cent of the respondents, which included persons affected by leprosy and people responding on their behalf, referred

to drugs, 19 per cent to physiotherapy, 14 per cent to wound care, 12 per cent to surgery and only 5 per cent to orthotics and prosthetics, which proves the emphasis leprosy services place on treating the disease with multidrug therapy, and reveals existing gaps in complementary care. When asked if there was any specific care that was seen as needed but was not provided by health-care services, 51 per cent said yes, and the majority of respondents mentioned unfulfilled needs regarding psychological support, information about the disease, physiotherapy, supplementary medicines and wound care.

46. While 90 per cent of the persons affected by leprosy did not pay for multidrug therapy, 77 per cent did not pay for drugs to manage leprosy reactions and 75 per cent were treated through public health-care services, out-of-pocket expenses were considerable, with 76 per cent of respondents paying for transportation to health-care services. About 59 per cent of people under treatment were not able to continue working during the course of treatment and 48 per cent could not afford all of the medical treatment and additional expenses. The majority of the persons affected by leprosy were not aware of any alternative sources of financial assistance for meeting leprosy-related health needs. A total of 71 per cent of the persons affected by leprosy did not have access to financial support from the government during the course of treatment, while 59 per cent did not have access to disability benefits. About 50 per cent of the respondents claimed that difficulties in access to disability benefits were due mainly to the lack of medical expertise to identify leprosy-related impairments.

47. A total of 88 per cent of the persons affected by leprosy had experienced leprosy reactions, pain, psychological distress and stigmatization. About 71 per cent had required additional care after being cured for leprosy, and only 45 per cent indicated that they had access to it. A total of 75 per cent had developed physical, mental and social impairments and disabilities, with 67 per cent referring to physical impairments on their upper and lower limbs, as well as to a loss of sensitivity. About 46 per cent needed to be hospitalized during the course of treatment, and 32 per cent required assistive devices, 59 per cent of whom did not have access to such devices when they needed them.

48. Discrimination in health-care services was reported by 37 per cent of the respondents. About 50 per cent referred to important gaps in knowledge about leprosy in the health-care workforce, which in 20 per cent of the cases had led to diagnosis errors. A total of 24 per cent of the respondents mentioned violations of the patients' rights to privacy, speaking about inhumane and humiliating treatment and breaches of professional secrecy.

49. About 83 per cent of the persons affected by leprosy stated that leprosy, its complications and the associated stigma affected their feelings, self-esteem and well-being, with 16 per cent mentioning sadness, 15 per cent fear; 13 per cent anxiety; 13 per cent loneliness; 10 per cent depression, 9 per cent exhaustion, 8 per cent insomnia, 6 per cent aggressivity, 6 per cent suicidal thoughts and 4 per cent mental confusion. A total of 44 per cent did not feel cured.

50. Such data is in line with the picture provided over the years to the Special Rapporteur by organizations of persons affected by leprosy from 15 endemic countries. Their feedback with regard to health issues emphasizes neglect as a shared pattern among countries.³⁰ All of the organizations concurred that the global elimination of leprosy as a public health problem in 2000,³¹ as well as progressive multi-disease service integration, while positive, had also raised considerable barriers to the access of persons affected by leprosy to high quality health care. In the words of representatives of one organization of persons affected by leprosy from an Asian endemic country:

Until a few years ago there were special Hansen's disease hospitals at provincial or district levels in which all persons affected with reactions, wounds or rehabilitation needs were admitted. These have now all been converted into general hospitals. District hospitals are now generally responsible for treating complications, but this is not always possible due to stigmatization. The health insurance system has also changed and makes no distinction between persons affected and other patients, which

³⁰ Health issues are connected to disability issues. However, the Special Rapporteur does not address disability issues in the present report, as she plans to dedicate a report to them.

³¹ See www.who.int/en/news-room/fact-sheets/detail/leprosy.

is good in principle, but persons affected often remain untreated in this system. Since the transformation of special Hansen's disease hospitals into general hospitals, there are almost no medical rehabilitation services for persons affected. Severe reactions and repeated reactions occur in people living in remote areas and they receive no decent treatment.

51. Other issues on which the views of these organizations converge include the following:

(a) The biomedical classification of leprosy fails to respond to the reality of radically different experiences that call for distinct approaches to health care. An emphasis on infection seems to lead to neglect of individual case management and care after bacteriological cure. However, for many people the more serious issues they experience are leprosy reactions, neuropathic pain, nerve damage and physical and psychosocial impairments and disabilities that may appear during treatment and/or after bacteriological cure;

(b) An emphasis on delivering multidrug therapy leads to shortages of drugs to treat reactions, but also of other supplementary medicines. The limited availability of psychosocial and mental health care, diagnosis and treatment of leprosy reactions, information on self-care, rehabilitation and reconstructive surgery, and limited prevention of impairments and provision of assistive devices, together with persisting discriminatory practices perpetrated by the health-care workforce, violate people's rights;

(c) Deficient health coverage in remote areas, together with limited budgets for leprosy at the national and subnational levels, as well as misappropriation of funds allocated for leprosy by subnational administrators, maintain transmission and may be causing a hidden epidemic of leprosy;

(d) There is a lack of awareness-raising activities, and a lack of acknowledgement of the limitations of traditional approaches to health education that do not recognize local cultures and knowledge, communities as co-producers of health, traditional healers and leaders as key players, women as key agents of health education, and community media, such as radio, which are much more effective than traditional and/or social media in vulnerable communities that face issues of access;

(e) Socioeconomic empowerment and rehabilitation, rarely promoted by government policies, are essential to restoring people's right to a healthy standard of living and to promoting their physical, mental and social well-being; they are also key to stopping leprosy's transmission within families and communities.

52. While most global and national policies and strategies are based on metrics that do not disaggregate data by demographic, environmental, socioeconomic and cultural variables, or the various grounds of discrimination recognized in international human rights law, the data underlying bottom-up knowledge produced by organizations of persons affected by leprosy frequently is disaggregated by such variables. The Special Rapporteur has already addressed intersections of leprosy with age and gender in a previous report, but she recalls some of the key issues affecting women affected by leprosy's right to the highest attainable standard of physical and mental health, as well as their fundamental role in protecting and promoting health, which require policies that specifically involve women as co-producers of health and are aimed at guaranteeing their physical, mental and social well-being. Those key issues include the following:

(a) Due to multiple and intersecting barriers, women experience longer delays than men do in diagnosis and frequently have a higher risk of developing leprosy-related physical impairments and disability;

(b) A generalized lack of gender-sensitive health-care services, including women health-care workers, leads to late diagnosis and treatment, especially in contexts characterized by deep patriarchal values. Many women are also dependent on third-party authorization, especially from husbands and fathers, to seek health care;

(c) Power imbalances between health-care workers and patients mainly affects women, whose suffering is frequently dismissed by health-care workers, especially in the case of neuropathic and chronic pain caused by leprosy;

(d) The use of drugs to treat leprosy reactions usually leads to bodily changes that have an impact on women's mental health and their relationships, often leading to discrimination within the household and divorces entailing significant economic losses for women and separation from their children;

(e) Many women affected by leprosy experience acute psychological stress and depression and report having suicidal thoughts due to discrimination within the household and in work environments that do not accommodate the physical impairments caused by leprosy;

(f) As the Special Rapporteur has already reported, there is a pattern of psychological, physical and sexual violence experienced by women affected by leprosy, especially within the household.

53. Intersection between stigmatization on the grounds of leprosy and gender-based discrimination can even threaten women's right to life, as the next case, told to the Special Rapporteur by representatives of persons affected by leprosy from one of the top three priority countries, dramatically demonstrates:

A lady who left home because her husband didn't accept her anymore due to leprosy had to stay in a place like a small house on the street. She then looked for the help of her family, but her family also rejected her and made her a small house outside. Complications due to the disease appeared and we contacted health professionals, but they said they could not come to take her to the hospital as there was no budget for that. The lady eventually died.

54. Leprosy, or gaps in the system, can also have a brutal impact on women's sexual and reproductive rights. It has already been explained that one of the drugs for treating leprosy reactions is thalidomide, which if used during pregnancy can severely harm the fetus. As recently as 2019, a child born with thalidomide syndrome was detected in Brazil, while others have been mapped over the years.³² This child, born with congenital anomalies in her upper and lower limbs, is currently under medical review, which means she may have other health problems (heart, ears and eyes) due to the use of thalidomide by her mother during pregnancy. When reporting on this to the Special Rapporteur, the geneticist³³ who has been monitoring this child spoke of a cascading effect of late diagnosis, deficient communication between health-care workers and patients and vulnerable socioeconomic conditions of patients. Undoubtedly, the health system shamefully failed both this mother and her child, but no one is being held accountable for a child that was born in 2019 with a syndrome identified back in the 1960s.

55. Family members also experience deterioration of their mental health. The Special Rapporteur was struck by comments from representatives of persons affected by leprosy during the webinars on human and youth rights organized by the Sasakawa Leprosy (Hansen's Disease) Initiative that many young family members chose not to develop their full potential in life and to hide themselves because they were fearful of the consequences if their community, co-workers or employers discovered their family's history with leprosy.

56. The Special Rapporteur was informed that the leader who had shared with her the case of João, described above, had recently discovered that he was, after three decades of being considered cured, again ill with Hansen's disease.³⁴ His diagnosis is of lepromatous

³² Thayne Woycinck Kowalski and others, "Thalidomide embryopathy: follow-up of cases born between 1959 and 2010", *Birth Defects Research – Part A, Clinical and Molecular Teratology*, vol. 103, No. 9 (2015); F. Sales Luiz Vianna and others, "The impact of thalidomide use in birth defects in Brazil", *European Journal of Medical Genetics* (2016).

³³ Lavínia Schüler-Faccini, professor at the department of genetics at the Federal University of Rio Grande do Sul, and chief of the medical genetics service at the Hospital de Clínicas de Porto Alegre. The individual is identified in the present report with her full authorization.

³⁴ The individual in question denounces the use of the word leprosy as one of the root causes of

leprosy. Given the lack of annual vigilance by the health-care system, remaining bacilli within his nerves have thus been able to multiply over the years, which led to a relapse. His nerves are damaged beyond any possibility of recovery.

57. Much of the human suffering described in the present section is preventable. States are called to acknowledge such human suffering and take action to prevent and mitigate it. As one organization's representative told the Special Rapporteur: "For leprosy affected persons, services from [non-governmental organizations] are very much limited and not what we would expect as citizens. What we want is for the Government to take responsibility. But this should not be a process which we have to ask for. These should be regular entitlements." Furthermore, people and reality are far more complex than the projections of experts can account for, making it imperative for decision-making to be open to those who bear the consequences of such decisions.

II. Conclusion: what people create, people can change

58. As data presented in the present report show, leprosy and its consequences are the product of structural violence. Structural violence, which is inherently cumulative, reflects the systematic restrictions that prevent people who occupy the bottom rungs of societies from meeting their basic needs. It is often invisible, accepted as the natural order of things and perpetrated on a daily basis by dominant institutions. A growing body of evidence has shown that disadvantaged people are more prone to illness, distress and disability and also die younger. That is why reducing diseases to mere pathological entities is like telling a story without telling its beginning and its end. Metrics employed by global health and national health programmes tell us little about structural violence as a cause, and human suffering as a consequence, of leprosy. In order to fulfil the right to the highest attainable standard of physical and mental health for the most disadvantaged, diseases must be acknowledged as political issues and action to tackle them must be subjected to accountability mechanisms at all levels of human agency – from the global to the local.

59. While scholars dwell on attempts to define the content of the right to health, persons affected by leprosy who endure extreme physical, mental and social suffering, and whose right to life is threatened by such suffering, interpret the right to health from the perspective not of written law, but of what it means to enjoy equal opportunities in life on an equal basis with others without discrimination and violence. Furthermore, persons affected by leprosy demand to be recognized as people who are entitled to self-determination over their bodies, as well as people whose special needs, such as accessibility, accommodation and support, must be guaranteed. Lastly, their narrative about the right to health calls for very practical but fundamental steps, as well as for a shift of the place where planning starts.

III. Recommendations

60. The Special Rapporteur urges States, especially those where leprosy is endemic, to develop a country-owned political agenda for fighting leprosy and protecting, promoting and fulfilling the right to the highest attainable standard of physical and mental health for persons affected by leprosy and their family members, and recommends that they:

- (a) Put people at the centre of health production, and to that end:
 - (i) Implement guideline 14.1 of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, which affirms that States should create a committee to address activities relating to the human rights of persons affected by leprosy and their

persistent stigmatization against affected individuals, a subject to which the Special Rapporteur will come back in a following report, but that does not fall within the scope of the present report.

family members, which should include individuals affected by leprosy and their family members and representatives of organizations of persons affected by leprosy;

(ii) Ensure that planning starts with a needs assessment and that persons affected by leprosy and their family members own the process of policy design, monitoring and evaluation;

(b) Start with the community and strengthen community-based support systems, and to that end:

(i) Involve communities as co-producers of health; identify relevant communities through spatial analysis that can map clusters of leprosy; and implement community diagnosis in such contexts, reflecting a participatory and bottom-up method for attaining a quantitative and qualitative description of the health of citizens and the factors that influence their health, identifying problems, proposing areas for improvement and stimulating action;

(ii) In contexts where leprosy is more dispersed, ensure that primary health-care services are settings where, through the promotion of self-care and self-help groups with a focus on building advocacy skills, people can engage in diagnoses of problems and in solutions;

(iii) Promote systematic data collection through the primary health-care services that includes disaggregation of leprosy not only by demographic, environmental, socioeconomic and cultural variables, but also by the various grounds of discrimination recognized in international human rights law, and with full respect for the principles of participation and privacy; and use such data to identify groups that are more vulnerable to leprosy, leprosy-related impairments and discrimination, such as women and children, and develop special measures to protect them;

(c) Invest in health education and guarantee people's right to access to information, and to that end:

(i) Identify communities affected by diseases with shared root causes, such as diseases of poverty, and implement integrated multi-disease awareness-raising programmes that are sensitive to culture, language, gender, age and disability and that are developed in close collaboration with local communities 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 school teachers with regard to leprosy and engage them in further awareness-raising; and support women to enable them to engage in health promotion activities;

(ii) Guarantee people's right to access to information at all stages of health care and leprosy prevention, as well as their right to privacy, making informed consent an indispensable procedure for any intervention – from post-exposure prophylaxis with single-dose rifampicin to the examination of contacts and medical care of persons affected by leprosy; and ensure that the information being provided is focused on reducing stigma;

(iii) Provide information through primary health-care services on the rights of users, on the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, and on the WHO guidelines for strengthening participation of persons affected by leprosy in leprosy services;

(iv) Strengthen the structural competency of the primary health-care workforce by building their capacity on the socioeconomic and cultural aspects of leprosy and on user-involved design, and train them to mitigate stigmatization in all their activities;

(d) Prioritize primary prevention through multisectoral policymaking and action, and to that end:

- (i) Mainstream leprosy into poverty reduction programmes;**
- (ii) Recognize that key aspects of health promotion match the rights set out in the International Covenant on Economic, Social and Cultural Rights, but also others contained in treaties created to protect groups that face discrimination; frame such issues as rights and develop country-owned theoretical frameworks for evaluating the cost-effectiveness of States' expenditures on enforcing them; and identify responsibilities within the government and enable accountability mechanisms.**

(e) Bet on multiservice integration without discriminating against leprosy, and to that end:

- (i) Strengthen universal health coverage and integrate leprosy into primary health care, ensuring universality of access through public services, which should be culturally appropriate and gender-sensitive, age-friendly and disability-friendly;**
- (ii) Sustain and strengthen the efforts of national leprosy-related programmes and implement the four pillars of the Global Leprosy (Hansen's Disease) Strategy 2021–2030, with proper budget allocations at the national and subnational levels, as well as targets, indicators and benchmarks;**
- (iii) Include leprosy in medical schools' curriculums and build the capacity of the primary health-care workforce on the clinical aspects of leprosy; prioritize action that supports early detection of leprosy and prevention of both its transmission and associated impairments and disabilities; and partner with organizations of persons affected by leprosy to undertake active case-finding and the examination of contacts;**
- (iv) Ensure the continuum of care (prevention, treatment and rehabilitation) without discrimination; sustain monitoring of nerve damage during medical treatment and after bacteriological cure as part of primary health-care services; and guarantee people's access to secondary and tertiary care when needed;**
- (v) Provide, free of charge, assistive devices for protection and assistive devices for the facilitation of activities of daily life;**
- (vi) Invest in mitigating suffering caused by neuropathic pain and stigmatization through high quality pain management and effective referral within national health-care systems for mental health care, under a recovery-based paradigm and through services that are ethical, respectful, culturally appropriate, gender-sensitive and empowering to individuals; and ensure access by family members of persons affected by leprosy to mental health care;**
- (vii) Partner with organizations of persons affected by leprosy to strengthen peer-to-peer counselling, as well as family-based counselling, and extend counselling to family members of persons affected by leprosy;**
- (viii) Promote peer-to-peer cooperation between national leprosy programmes of endemic countries to share good practices and foster progress;**
- (f) Guarantee social protection and, to that end:**
 - (i) Ensure food security and cash transfers for people under medical treatment for leprosy;**
 - (ii) Guarantee disability rights to people under medical treatment and after bacteriological cure;**
 - (iii) Target active citizenship by promoting training opportunities and formal employment, while guaranteeing support as needed;**

- (iv) **Partner with non-governmental organizations to provide socioeconomic and vocational empowerment and rehabilitation;**
- (v) **Empower women affected by leprosy through income-generation programmes, creation of cooperatives and continued education;**
- (g) **Ensure democratic engagement and, to that end:**
 - (i) **Provide legal aid and accessible mechanisms for filing complaints of rights violations at primary health-care services;**
 - (ii) **Enforce the right of access to justice and guarantee the accessibility of procedures and infrastructure;**
 - (iii) **Provide monitoring and accountability mechanisms with transparent sharing of information.**

61. The Special Rapporteur also recommends that non-endemic States fulfil their international cooperation obligations, in particular with regard to target 3.3 of the Sustainable Development Goals. She urges States to accept responsibility for drug development, taking it into the public sector, and facilitating access by the world's poorest to high-quality medicines. She also makes an appeal to the health industry to comply with the Doha Declaration on the Agreement on Trade-Related Aspects of Intellectual Property Rights and Public Health, in particular when it affirms that the agreement should be interpreted and implemented in a manner that promotes access to medicines for all.
