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

Disproportionate impact of the coronavirus disease (COVID-19) pandemic on persons affected by leprosy and their family members: root causes, consequences and the way to recovery

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, addresses the disproportionate impact of the coronavirus disease (COVID-19) pandemic on persons affected by leprosy and their family members, exploring the underlying causes and offering constructive recommendations for an inclusive recovery.



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I. Introduction

1. The Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, submits the present report pursuant to Human Rights Council resolution 44/6. In the report, she explains how the coronavirus disease (COVID-19) pandemic has had a disproportionate impact on persons affected by leprosy¹ and their family members, discussing the underlying causes of such an impact and offering constructive recommendations for an inclusive recovery.
2. In November 2020, the Special Rapporteur consulted with grass-roots organizations,² in order to develop a participatory work plan for the following three years that embodied the views of experts through experience. The Special Rapporteur also consulted with key stakeholders in the field of leprosy, the World Health Organization (WHO) and relevant human rights mechanisms, with the aim of aligning her efforts with those of the wider health and human rights community.
3. In her second term, the Special Rapporteur plans to build on the work developed during the previous three years and support the implementation of the global health policies for tackling leprosy in the next decade, to which she has contributed in the context of her mandate,³ but she also seeks to integrate into her work responses to the global challenges arising from the COVID-19 pandemic.
4. There is much to learn from the history of leprosy that can be applied to the current global crisis. Since the beginning of 2020, the world has been experiencing the disruption of social ties and livelihoods, discovering the impacts on mental health of separation from family members, friends and social environments, acknowledging long-existing hidden epidemics, such as domestic violence against women and children, and realizing how people are stigmatized on the basis of their health status, as well as the fact that inequalities can kill and institutional neglect can impair lives. All this has been known for centuries by persons affected by leprosy.
5. While examining the disproportionate impact of the COVID-19 pandemic on the lives of persons affected by leprosy and their family members, another lesson came to light: there is no building back better if States fail to put those who have been systematically pushed further behind at the centre of recovery efforts. In the present report, the Special Rapporteur, drawing on the lived experiences of members of a marginalized and dehumanized group, calls for a recovery paradigm that begins building back better by enforcing the rights of those who have been systematically pushed into the margins and denied not only fundamental rights and freedoms, but also the right to claim rights. If one thing became clear during the pandemic, it is that “other people’s problems” are everyone’s problems.
6. In March 2020, the Special Rapporteur began monitoring the impact of the COVID-19 outbreak on persons affected by leprosy and their family members. She joined forces with 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, as well as with Federation members and grass-roots organizations, providing guidance and supporting the production of documents and reports. She issued an open letter on COVID-19 and leprosy to States. For the present report, she received information from 13 States (Algeria, Bolivia, Brazil, Costa Rica, Denmark, Guatemala, India, Japan,

¹ A discussion among persons with a personal experience of leprosy and their representative organizations about terminology regarding the disease and the people who experience it is ongoing, with some segments of the community preferring the terms “Hansen’s disease” and “persons who have experienced Hansen’s disease”. The Special Rapporteur appreciates such a discussion, but given that there is still no consensus, in the present report, she employs the terminology used by the Human Rights Council in its resolution 44/6.

² The Special Rapporteur thanks the Sasakawa Health Foundation, the Leprosy Mission International and the International Association for Integration, Dignity and Economic Advancement for their support in the consultation process.

³ See www.ohchr.org/Documents/Issues/Leprosy/AliceCruz-April2019.pdf; and www.ohchr.org/Documents/Issues/Leprosy/STM_WHO_consultation.pdf.

Kyrgyzstan, Maldives, Mauritius, Morocco and Mozambique) and 32 civil society organizations, including non-governmental organizations and grass-roots organizations.⁴ The webinar, entitled “Zero leprosy for whom in the post-COVID world?”,⁵ organized by the Sasakawa Leprosy (Hansen’s Disease) Initiative, which gave voice to grass-roots organizations, was also a relevant source of information. The present report is aimed at providing a clear portrait of the lived experience of historically dehumanized groups under the current global health and socioeconomic crises and at elaborating specific steps for an inclusive recovery.

II. Access to livelihoods

A. Exclusion from the formal economy

7. Unreliable casual labour with low income, unsafe working conditions and without entitlements to social protection or participation in social dialogue defines the livelihoods of the majority of persons affected by leprosy. The former make up part of the 2 billion people that the International Labour Organization (ILO) estimates work in the informal economy;⁶ they are denied rights to decent work and, at work, to social protection and income security. ILO estimates that 1.6 billion informal economy workers are experiencing significant effects from the current crisis,⁷ with women affected more greatly than men, while also facing other COVID-19-related impacts, such as increased unpaid care work and gender-based domestic violence.⁸ Informal economy workers are also largely excluded from social dialogue, an activity which is key for a sustainable economic recovery.⁹

8. The majority of persons affected by leprosy 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. Furthermore, as with so many people, the pandemic imposed upon them the immoral dilemma of having to choose between dying from hunger or from the virus. If before the pandemic this marginalized group was already struggling with what one organization’s representative referred to as the “pre-pandemic crisis”, the pandemic became one additional basis for discrimination, aggravating structural violence and rights violations.

B. Barriers to the right to decent work

9. Persons affected by leprosy face formidable, intersecting and multiple barriers to freely choosing their work and to enjoying their rights at work. The testimony of one individual captures all too well how leprosy-related discrimination simultaneously operates at different levels of social life and is at the root of rights violations. While working as a public servant, he was dismissed from his job after being diagnosed with leprosy; he then went back to work as a farmer on community land, but he was also dismissed by the village committee that administered the land. Resorting to growing vegetables in his backyard, he

⁴ The Special Rapporteur is extremely grateful for the contributions provided by States and civil society organizations for the present report. The submissions will be available on the webpage of the Special Rapporteur (www.ohchr.org/EN/Issues/Leprosy/Pages/LeprosyIndex.aspx).

⁵ See www.shf.or.jp/information/10426?lang=en.

⁶ In its recommendation No. 204, the General Conference of the International Labour Organization (ILO) defines the informal economy as encompassing all economic activities undertaken by workers and economic units that are, in law or in practice, not covered or insufficiently covered by formal arrangements, apart from illicit activities. Importantly, ILO distinguishes the informal economy from the shadow economy. The informal economy is also heterogeneous. See also *Transition to Formality and Structural Transformation: Challenges and Policy Options*, Iyanatul Islam and Frédéric Lapeyre (eds.) (Geneva, ILO, 2020).

⁷ ILO, *Global Wage Report 2020/21: Wages and minimum wages in the time of COVID-19* (Geneva, ILO, 2020).

⁸ ILO, “The global deal for decent work and inclusive growth flagship report: social dialogue, skills and COVID-19” (April 2020).

⁹ Ibid.

could not sell them at the local market because people were afraid to buy vegetables from him. His testimony represents a shared pattern of denial of equality of opportunity, as well as of denial of equality of treatment, both of which are in violation of the ILO Discrimination (Employment and Occupation) Convention, 1958 (No. 111).

10. Some of the barriers that have systematically hindered persons affected by leprosy from working in the formal economy are as follows:

(a) The State policy that for more than a century forcibly segregated persons with leprosy and that was aimed at the elimination of leprosy through the elimination of those who carried the disease in their bodies;¹⁰ such a policy still reverberates in the public mindset, reinforcing structural discrimination, and shapes the more than 100 discriminatory laws that are still in force worldwide;¹¹

(b) The fact that the majority of people who were forcibly segregated into what has become globally known as leprosy colonies (there are nearly 2,000 leprosy colonies active in the world) and their descendants do not enjoy property rights over the land where they were once confined, which aggravates poverty;

(c) The fact that, in some countries, customary law denies land and inheritance rights to persons affected by leprosy, especially to women, which aggravates the feminization of leprosy-related poverty;

(d) The aforementioned discrimination in law that, in some countries, also applies in the context of employment;

(e) Institutionalized discrimination in hiring policies for public jobs;

(f) Discrimination at school, which has pushed too many people out of education;

(g) Interpersonal discrimination in both public and private employment settings.

11. Such barriers have systematically pushed people into poverty and extreme poverty, forcing many of them to resort to begging. Their work is characterized as follows: (a) insufficient and irregular income, in many cases dependent on begging and/or assistance from families, religious institutions and non-governmental organizations; (b) employment as small-scale, own-account, casual and domestic workers; (c) sector of activity mostly being petty trade, agriculture, fishing and other manual activities; (d) no written contracts, job cards, payment through bank accounts or grievance or appeal mechanisms, as well as no social security or employment protection. Such a profile is not accidental. It is the result of intentional and systemic exclusion.

12. The rights protected by articles 6 and 7 of the International Covenant on Economic, Social and Cultural Rights, but also article 27 of the Convention on the Rights of Persons with Disabilities, and other closely interrelated articles, such as article 11 of the Covenant and article 19 of the Convention, have been systematically and grossly violated with regard to persons affected by leprosy. As the Committee on Economic, Social and Cultural Rights has acknowledged in its general comment No. 18 (2005), the right to work is essential for realizing other human rights and forms an inseparable and inherent part of human dignity. The Committee also connects the right to work with the right to life, speaking of the survival of the individual and that of his or her family, on the one hand, and to the right to development, insofar as work is freely chosen or accepted, on the other. Work is recognized by ILO as being crucial to ensuring dignity, well-being and development. Concomitantly, the ILO Employment Policy Convention, 1964 (No. 122) affirms that productive employment and decent work are prerequisites for raising living standards and alleviating poverty.

13. Only India reported on the existence of reservations for persons with disabilities in government jobs and in government or government-aided higher education institutions, to which persons affected by leprosy are eligible.

14. Civil society organizations, including non-governmental organizations and grass-roots organizations, undertake various projects in the areas of socioeconomic and vocational

¹⁰ See A/HRC/38/42.

¹¹ See <https://ilepfederation.org/discriminatory-laws>.

rehabilitation. In their submissions, non-governmental organizations described socioeconomic and vocational rehabilitation projects that were disability-inclusive, many starting with self-care and self-help groups. Skills development is applied in the areas of gastronomy, handicrafts, agriculture, animal husbandry, health-care facilitation and entrepreneurship. Support is also provided to the children of persons affected by leprosy so that they may pursue their education. Microcredit loans and seed funding are provided to support people in starting their own businesses. Capacity-building is provided in the areas of entrepreneurship and leadership, but also in terms of access to government schemes. Social and economic solidarity is also stimulated by cooperatives and savings groups.

C. Barriers to the right to social security

15. The “pre-pandemic crisis” in which persons affected by leprosy were trapped pushed them to work as daily laborers and left them more vulnerable to economic hazards. In addition, if the global work scenario for persons with disabilities is worrying – with persons with disabilities less likely to be in employment or to enjoy decent employment conditions than persons without disabilities, while also not being adequately covered by social protection rights – persons affected by leprosy are further behind within the heterogeneous population with disabilities and are among the 80 per cent of people with severe disabilities who do not have access to disability-related social protection schemes in low- and middle-income countries.¹² Moreover, the fact that leprosy-related physical impairments have nerve damage as a main cause, and that physical labour can severely aggravate it, leads to too many persons affected by leprosy experiencing the deterioration of their health and well-being as a result of the need to perform manual labour in the face of structural exclusion from education opportunities.

D. Impact of the COVID-19 pandemic

16. With the COVID-19 outbreak and the lockdown and containment measures, social distancing regulations, mobility restrictions and public transportation restrictions and prohibitions that followed, persons affected by leprosy, who were already outside the formal economy and denied employment protection, faced the loss of jobs, income-generating activities and safety nets. People who, before the pandemic, had depended on begging, their families, charity institutions and non-governmental organizations could no longer rely on that support. Regarding family support, the Special Rapporteur received many reports of persons with leprosy-related disabilities who were experiencing discrimination within their own families due to the economic blow. People working as daily labourers in informal and unreliable activities, such as petty trade, agriculture or fishing, are not bringing in any income, due to the disruption in supply chains, restrictions on movement and limited market access. Importantly, women are the hardest-hit among those engaged in business and agriculture activities. Furthermore, people working in agriculture usually do not own the land on which they work, which adds an additional barrier to ensuring their livelihoods in the context of the pandemic. Children with leprosy or those with affected parents lack access to the technology necessary to move to online learning, and many have dropped out of school.

17. Notably, many people had no savings available to help them to endure lockdown measures and their effects, given the lack of income security in pre-pandemic times, which also compromised their ability to recover from the present crisis. The widespread denial of social protection to persons affected by leprosy aggravates those worsening scenarios and prospects. Social protection would have guaranteed a safety net in times of economic crisis,¹³ and it is acknowledged to be essential for preventing crises, enabling recovery and building resilience.¹⁴

¹² ILO, “COVID-19 and the world of work: Ensuring the inclusion of persons with disabilities at all stages of the response”, policy brief, June 2020.

¹³ ILO, *Rules of the Game: An Introduction to the Standards-related Work of the International Labour Organization* (Geneva, ILO, 2019).

¹⁴ ILO, “Employment and decent work for peace and resilience recommendation, 2017 (No. 205)”.

18. However, social protection floors are still far from where they should be,¹⁵ and persons affected by leprosy are still not recognized in existing social protection schemes, poverty reduction measures and in many disability-related social protection schemes. As the Special Rapporteur has heard repeatedly from grass-roots organizations, widespread barriers to access to disability benefits as a result of eligibility criteria based on a limited medical assessment, alongside the non-recognition of invisible impairments, such as loss of sensitivity and chronic pain, as well as mental health disorders caused by stigmatization on the grounds of leprosy, continue to be in violation of the provisions of the Convention on the Rights of Persons with Disabilities.

III. Access to fundamental goods and life-saving information

A. Social determinants of health and illness

19. Recommendations made and measures taken by governments to contain COVID-19 disclosed the unequal distribution of fundamental goods worldwide. Containment measures based on isolation, social distancing outside and within the household, frequent hand washing, space cleaning and the use of masks can only be implemented if individuals enjoy decent housing, access to clean water and soap and the income security with which to ensure subsistence during lockdown measures and to purchase masks and other personal protective equipment. Such measures are inaccessible to a large share of the world's population, in which persons affected by leprosy are included.

20. As previously noted by the Special Rapporteur, social determinants play a crucial role in the incidence of leprosy,¹⁶ in particular household crowding, inadequate nutrient intake, poor hygiene and lack of access to clean water. The social determinants of leprosy shape the socioeconomic conditions in which affected people live. The same social determinants augment vulnerability to COVID-19 and feed back into the disproportionate impact of the pandemic on such vulnerable populations. Gaps in access to water, sanitation and hygiene and in poverty reduction policies are unmistakably at the root of the incidence of leprosy, but also of vulnerability to COVID-19.

B. Food emergency

21. The current global recession – the worst in nearly a century – has pushed an estimated 70 to 100 million more people into extreme poverty.¹⁷ Model-based simulations suggest an even greater number of around 90 million to 150 million people.¹⁸ Considering the fact that the poorest households spend around 70 per cent of their incomes on food, the pandemic is generating a global food crisis.¹⁹

22. Recognized as a human right in article 11 of the International Covenant on Economic, Social and Cultural Rights, the right to food is explicitly referred to by the Committee on Economic, Social and Cultural Rights in its general comment No. 12 (1999) as being inseparable from social justice. The aforementioned barriers to the enjoyment of the right to decent work have also made persons affected by leprosy food insecure and particularly

¹⁵ ILO, “Financing gaps in social protection: global estimates and strategies for developing countries in light of the COVID-19 crisis and beyond”, working paper No. 14, October 2020.

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

¹⁷ United Nations, “United Nations comprehensive response to COVID-19: saving lives, protecting societies, recovering better”, September 2020.

¹⁸ David Laborde and others, “COVID-19 risks to global food security”, *Science*, vol. 369 No. 6503.

¹⁹ *Ibid.*

vulnerable to food crises. Independent studies have shown the relation between leprosy and malnutrition, which lowers immunity and therefore makes people more prone to infection.²⁰

23. Since March 2020, the Special Rapporteur has been receiving reports from all leprosy-endemic countries about a food emergency among affected persons. A food emergency is defined as an extraordinary situation in which people are unable to meet their basic survival needs or there are serious and immediate threats to human life and well-being.²¹ As daily workers, the majority of persons affected by leprosy depend on their daily income to buy food. Together with the generalized increase in food prices, this has generated a food emergency. As one contributor to the present report expressed: “It is tough to see members [of the organization] dying from lack of food and other COVID-19 issues.”

24. The right to food is closely related to other rights, such as health, water, adequate housing and education. Access to fundamental and life-saving goods other than food, such as energy for cooking, clean water, soap, masks and personal protective equipment, has also been missing for the majority of affected people and their families.

C. Housing

25. According to the Committee on Economic, Social and Cultural Rights, the seven components of the right to an adequate housing are: legal security of tenure, availability of services, materials, facilities and infrastructure, affordability, habitability, accessibility, location and cultural adequacy.²² Forced eviction is considered a prima facie violation of the International Covenant on Economic, Social and Cultural Rights. The Committee also acknowledged the close connection between adequate housing and the right to health.

26. The Special Rapporteur has received reports of a lack of adequate housing, clean water, sanitation and electricity, as well as of housing deprivation due to loss of income, the specific risks faced by refugees affected by leprosy and cases of forced eviction in one former leprosy colony in Brazil.²³ Widespread institutional neglect leading to lack of food, clean water and personal protective equipment in the nearly 2,000 leprosy colonies that are still active in the world today has also been reported.

D. Access to information

27. Key information for COVID-19 prevention has, to a large extent, not been accessible to a considerable number of persons affected by leprosy, especially those living in rural areas, those who cannot read and those without access to technology. Lack of information, misinformation and low levels of awareness of how COVID-19 spreads, as well as of protection mechanisms, has been frequently reported.

28. In the face of the absence of medical technologies to stop the spread of COVID-19, its containment largely depends on individual and community engagement in preventive behaviour. The Joint United Nations Programme on HIV/AIDS (UNAIDS) has recommended a community-centred response to the pandemic, with the prioritization of the most vulnerable.²⁴ Experience has shown that health education, in order to be effective and empowering to people, should be cognizant of the varying levels of comprehension and not

²⁰ Sharika Mahato and others, “Inequities towards leprosy-affected people: a challenge during COVID-19 pandemic”, *PLoS Neglected Tropical Diseases*, vol. 14; K.N. Rao and others, “Undernutrition in lepromatous leprosy, Part I. Is it associated with poverty or with disease?” *Leprosy Review*, vol. 57 (1986); S.G. Feenstra and others “Recent food shortage is associated with leprosy disease in Bangladesh: a case-control study”. *PLoS Neglected Tropical Diseases*, vol. 5; and Julia Moreira Pescarini and others, “Socioeconomic risk markers of leprosy in high-burden countries: a systematic review and meta-analysis”, *PLoS Neglected Tropical Diseases*, vol. 12.

²¹ United Nations, “The impact of COVID-19 on food security and nutrition”, policy brief, June 2020.

²² Committee on Economic, Social and Cultural Rights, general comment No. 4 (1991).

²³ See <https://g1.globo.com/sp/mogi-das-cruzes-suzano/noticia/2021/03/13/familias-que-moram-no-10-leproario-do-brasil-recebem-notificacoes-de-despejo-durante-a-pandemia.ghtml> (in Portuguese).

²⁴ Joint United Nations Programme on HIV/AIDS (UNAIDS), “Rights in the time of COVID-19: lessons from HIV for an effective, community-led response”, 2020.

be too technical, complex, hasty or delivered in a language, manner or context that people do not understand.

29. Low-literacy populations require additional efforts to facilitate comprehension of technical concepts. The same is true for specific groups, such as children. Health education must be gender-sensitive, accessible for persons with disabilities and culturally appropriate. Furthermore, it is critical to address barriers created by the digital divide. Communication should also be reciprocal and channels for receiving the feedback from the community be made available. The right to access to information is provided for under article 19 of the International Covenant on Civil and Political Rights. Taking into consideration the risks to life associated with the lack of information about COVID-19, the Special Rapporteur considers such information to be fundamental to guaranteeing the right to life in the context of the pandemic and the lack of effective measures taken by governments to make it accessible to all people, especially those who are the most vulnerable, to be a human rights violation.

IV. Access to health care and essential medicines

A. Continuum of care

30. 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.²⁵ 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.

31. One of the greatest challenges in the medical care of leprosy is 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, sometimes for several years.²⁶ 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. Drugs used for treating leprosy reactions are immunosuppressive and are likely to increase susceptibility to COVID-19, which means that a high percentage of persons affected by leprosy are especially vulnerable to COVID-19.²⁷

32. Despite being curable with multidrug therapy, if not detected early and treated, leprosy can become a 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 referral within national health-care systems. While assessing the impact of COVID-19 on medical care, the continuum of care must be properly taken into consideration.

B. Barriers to the right to health

33. During the first months of the pandemic, specifically from early March to late July 2020, the Special Rapporteur received many reports pointing to a generalized pattern of multiple barriers to access to health care, such as the following:

²⁵ WHO, “Guidelines for the diagnosis, treatment and prevention of leprosy”, 2017.

²⁶ Diana N.J. Lockwood and others, “Three drugs are unnecessary for treating paucibacillary leprosy: a critique of the WHO guidelines”, *PLoS Neglected Tropical Diseases*, viewpoints, 31 October 2019.

²⁷ See www.who.int/docs/default-source/searo/thailand/advice-about-leprosy-and-covid-19.pdf?sfvrsn=6171bfc0_0.

- (a) The loss of financial and human resources from national leprosy programmes with the redirection of leprosy funds and staff to the fight against COVID-19, which caused a substantive reduction in leprosy-related initiatives;
- (b) The interruption of key activities for early diagnosis and the concomitant prevention of physical impairments, such as active case detection and post-exposure prophylaxis with single dose rifampicin;
- (c) The non-availability of leprosy care among health-care services, which in some cases even refused to attend to people suspected of having leprosy;
- (d) Sporadic difficulties in the provision of multidrug therapy;
- (e) Generalized difficulties in the treatment and clinical management of leprosy reactions, aggravated by the lack of monitoring necessary for the treatment of a highly complex health problem;
- (f) Lack of drugs for treating leprosy reactions;
- (g) The deferral of complementary care that was essential for the prevention of physical and psychosocial disabilities, such as wound care, protective footwear and other assistive devices or self-care and self-help groups;
- (h) A reduction in and the interruption of disability prevention and rehabilitation;
- (i) A reduction in and the interruption of community-based rehabilitation;
- (j) Self-diagnosed cases not receiving a diagnosis or treatment at health-care facilities;
- (k) The lack of effective national systems in place to monitor COVID-19 infection among immunocompromised persons affected by leprosy;
- (l) Older people living in former leprosy colonies being at greater risk of contracting COVID-19, with some public administrations turning parts of those former colonies into field hospitals for COVID-19;
- (m) The unavailability of health care in former leprosy colonies, due to lockdown and mobility restrictions;
- (n) Specific cases in which persons affected by leprosy could not receive health care, due to recently adopted procedures that excluded persons such as themselves, who do not possess citizenship cards, health insurance or the financial means to buy COVID-19 tests;
- (o) The lack of income to buy means of transportation to gain access to health-care services;
- (p) Political instability, with forced displacement in some countries, with no measures in place to ensure leprosy treatment.

As the Special Rapporteur wrote in her open letter to governments,²⁸ the first months of the pandemic pointed to a serious threat to the continuum of care for persons affected by leprosy, as well as to the high probability of setbacks in the interruption of transmission and early diagnosis in the near future. During the second half of 2020, not only have those concerns been proven to be well-founded, but they have also increased.

C. Barriers to access to essential medicines

34. Shortages in multidrug therapy have been reported since August 2020. The first reports came from Brazil, with complaints of what was soon revealed to be a serious problem of a national scale, with a high number of people going without treatment. In the second half of 2020, the Special Rapporteur received news from more leprosy-endemic countries facing

²⁸ See www.ohchr.org/Documents/Issues/Leprosy/SR_leprosy_Open_letter_22May2020.pdf.

multidrug therapy shortages.²⁹ According to the sources consulted by the Special Rapporteur, including Novartis, WHO and a number of national leprosy programmes, the problem was the result of distinct issues affecting the overall supply chain at various times, with the pandemic playing an important role, especially in terms of distribution and delivery to patients.

35. Reportedly, three issues affected access for leprosy patients to essential medicines: (a) shortages in one of the multidrug therapy drugs, namely, dapsone, at the end of 2019; (b) problems in the shipment of multidrug therapy after the outbreak of the pandemic; and (c) the discovery of impurities in one of the three multidrug therapy drugs, namely, of nitrosamines in rifampicin, in the second half of 2020. Importantly, multidrug therapy is not available to be bought at local pharmacies, and access for leprosy patients to it depends on donations to countries and in-country distribution.

36. In December 2020, the International Federation of Anti-Leprosy Associations mapped the shortage of multidrug therapy drugs in countries in which its members operate and identified at least five leprosy-endemic countries whose patients were not receiving multidrug therapy and four countries that had run out of stocks for multidrug therapy treatment for children. According to the Federation, many other countries were expected to run out of multidrug therapy stocks in the months that followed. The Special Rapporteur received non-official and official complaints about the shortage of multidrug therapy drugs in more than the five countries mapped by the Federation, bringing to 10 the number of countries identified by the Special Rapporteur with multidrug therapy drug shortages during the period from mid-2020 through the beginning of 2021.

37. Being the cornerstone of leprosy control, multidrug therapy gaps increase transmission, transmission within households, including to children, neuropathic pain, physical impairments and mental health problems as a result of the extreme physical, mental and social suffering caused by leprosy.

38. In its general comment No. 14 (2000), the Committee on Economic, Social and Cultural Rights explicitly mentioned the provision of essential drugs as part of the right to health. The Committee also noted that, in the face of disaster, the international community bore the duty to contribute to relief and humanitarian assistance by providing medical supplies as a matter of priority. The Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health has elaborated further on those obligations, affirming that the requirement of human rights accountability extended to both the public and the private sectors and that it was not confined to national bodies, but encompassed international actors working on health-related issues.³⁰ Importantly, in the Doha Declaration on the Agreement on Trade-Related Aspects of Intellectual Property Rights and Public Health, the members of the World Trade Organization affirmed that the agreement should be interpreted and implemented in a manner that promoted access to medicines for all.

39. Principle 11.3 of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members provides for the obligation of all States to ensure that persons affected by leprosy have access to free medication for leprosy, as well as appropriate health care, reflecting articles 25 and 27 of the Universal Declaration of Human Rights and article 12 of the International Covenant on Economic, Social and Cultural Rights.

D. Double standards

40. The multidrug therapy crisis revealed double standards at play in terms of the protection of the right to health in the context of the pandemic. The Special Rapporteur has been calling attention to those double standards since mid-2020 at several stakeholders'

²⁹ In order to protect the sources, the Special Rapporteur will only disclose information about Brazil in the present report, given that such information is publicly available. See BRA 10/2020. Available from <https://spcommreports.ohchr.org/Tmsearch/TMDocuments>.

³⁰ See A/63/263.

meetings and through the mandate holder's regular working methods.³¹ The Special Rapporteur notes that global action to ensure supply channels for delivering essential medicines and goods did not reach persons affected by leprosy, nor did the definition of priority groups for COVID-19 vaccinations include them, despite the fact that many such persons are immunocompromised.

41. No official information has been released about the causes of the multidrug therapy crisis, nor about problem-solving activities or estimates of the resumption of delivery. The Special Rapporteur appreciates the difficulties of communicating information in uncertain scenarios, in addition to that fact that multidrug therapy delivery is conveyed through a complex chain of shared responsibilities, but she calls attention to the negative consequences of the failure to proactively communicate gaps and what is being done to fill them. Such a failure leads to the loss of trust and hinders people from being empowered with key information about matters that have a direct impact on their lives.

42. The multidrug therapy crisis revealed the following gaps in need of an immediate response: (a) lack of international and national contingency plans for emergency situations, such as the one created by the COVID-19 crisis; (b) lack of multidrug therapy buffer stocks; (c) lack of guarantees of the right of the concerned people to access to information; and (d) lack of accountability mechanisms and remedies for failures in the overall multidrug therapy supply chain.

43. The year 2021 began with the confirmation of the worst estimates regarding leprosy control and the fear that leprosy would continue to be kept furthest behind, as health resources and health-care personnel continued to be directed towards the fight against COVID-19 and were now also being directed towards COVID-19 vaccination campaigns. According to the WHO global leprosy programme,³² the impact of the pandemic on leprosy control is currently characterized as follows:

- (a) Delays in multidrug therapy provision and stock-outs;
- (b) Significant reductions in case detection in many countries;
- (c) Delays in case detection;
- (d) Increases in the number of hidden cases;
- (e) Increases in the development of irreversible physical impairments;
- (f) Slowdowns in the reduction in the incidence of leprosy.

44. The Special Rapporteur received reports from civil society organizations working in various countries that pointed in that direction, more specifically to a 50 per cent decrease in the diagnosis of new cases, with concerns over an increase in transmission rates and new cases among children, who may also be more likely to be diagnosed with already irreversible physical impairments. Official data from Brazil, the country with the highest relative incidence of leprosy worldwide, indicates that the number of new cases diagnosed in 2020 was less than half that of the new cases diagnosed in the same period in the year before the pandemic, which denotes a dangerous increase in transmission and disability in the near future.³³ No strategies have been reported for tackling the situation, nor for ensuring the priority vaccination of immunocompromised leprosy patients. Again, double standards seem to be at play.

V. Women and children

45. Women and children are more vulnerable to discrimination on the grounds of leprosy.³⁴ While monitoring the adverse effects of the pandemic, the Special Rapporteur, realizing how women and children faced multiple barriers which amplified the challenges

³¹ See www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=26697&LangID=E.

³² Personal communication.

³³ See www.aids.gov.br/pt-br/pub/2021/boletim-epidemiologico-hanseniose-2021 (in Portuguese).

³⁴ See A/HRC/41/47.

they faced, made special efforts to listen to them. Such an endeavour was more successful in amplifying the voices of women than of children. In fact, it was with great concern that the Special Rapporteur learned, especially from female representatives of grass-roots organizations, that the counselling strategies in place to respond to leprosy-related discrimination were not age-sensitive and failed to effectively provide support to children and teenagers, whose needs went mostly unmet.

46. The following testimony of a woman affected by leprosy shows how the denial of inclusive education, furthered by the denial of opportunities that can ensure economic security, makes women who have experienced leprosy more vulnerable to poverty, denial of autonomy and physical, psychological and sexual violence within the household: “As a woman with [a] disability, I am more disadvantaged. The society outcasts me; even if I am allowed to live within the household, I am like dead, not getting involved and no opinions are asked [of] me. I got the disease in childhood. I was denied education; it was like a predestination, because of the disease. I became dependent [on] my family, providing support within the household. But the household activities can be quite challenging; things like fetching water can be very difficult, because of my disability. I have been hiding inside the house, but men within the household take advantage of me, they intimidate me and they also sexually abuse me. They think that people like me must accept that. Other members of our organization say that, once they got the disease, their husbands blamed them and started beating them.”

47. The general pattern of institutionalized, structural and interpersonal violence against women affected by leprosy has worsened with the pandemic and lockdown measures, while no institutional attempt to map the disproportionate impact of the pandemic on women and children has been reported. If the COVID-19-related health and socioeconomic crises hit women harder than men, for women affected by leprosy, the following root causes have aggravated their vulnerability to the adverse effects of the pandemic:

(a) In some countries, customary law denies, on the grounds of leprosy, land and inheritance rights, which affects women more than men;

(b) Discrimination in law on the grounds of leprosy disproportionately affects women;

(c) Women bear the brunt of unpaid care and household work, which, together with the denial of the continuum of care in the context of the pandemic, causes the severe deterioration of their mental and physical health;

(d) Women have been the hardest hit among those engaged in business and agriculture activities, and initiatives for economic empowerment, such as cooperatives and other social and solidarity economy endeavours, have been put on hold due to the pandemic;

(e) Household isolation during lockdown measures, which further restricted the already limited autonomy of women affected by leprosy, including with regard to health, sexual and reproductive rights, has left them more vulnerable to domestic violence; the multidrug therapy crisis has aggravated that situation.

VI. Responses to the crisis

A. Social protection and COVID-19-related mitigation measures

48. The pandemic disclosed serious gaps in social protection coverage. According to ILO, at the time of the COVID-19 outbreak, only 45 per cent of the world’s population had access to at least one social protection benefit and less than one third was fully covered, while half of the global population lacked access to health-care services.³⁵ As the crisis unfolded, many countries responded with mitigation measures and, by the end of 2020, around 1,600 social

³⁵ ILO, “Financing gaps in social protection”.

protection measures had either been announced or implemented.³⁶ Despite such a remarkable number, the majority of those measures have been defined as short-term, reactive and inaccessible for many, especially for those most in need.³⁷ The resources employed were only a fraction of what was needed to fill the social protection gaps in developing countries.³⁸ Once again, the lived experience of persons affected by leprosy, as reported to the Special Rapporteur, confirm the existence of such gaps.

49. In mid-2020, a survey about the global public and private responses to the adverse effects of the crisis on persons affected by leprosy showed that, out of 24 countries³⁹ (10 of which were among the 23 leprosy-affected countries identified by WHO as a priority), 18 had put into place protection measures from which persons affected by leprosy could benefit. Only one of the countries on that list, Myanmar, had implemented a specific measure to protect persons affected by leprosy. Most of the measures comprised short-term food aid and were discontinued after the first months of the outbreak.⁴⁰

50. By the end of 2020, 14 Governments (of which only 3 were leprosy-affected countries identified by WHO as a priority), had provided information on the general and specific social protection measures from which persons affected by leprosy could benefit in the context of the pandemic. Regarding pre-existing and regular social protection schemes, persons affected by leprosy are eligible to enjoy either disability, old age-related or poverty-related benefits in some of those 14 countries.

51. In India, the Rights of Persons with Disabilities Act is applicable to persons cured of leprosy⁴¹ who have valid disability certificates. The Act mandates the appropriate administrative and government bodies to develop schemes and programmes in the areas of social security, health, rehabilitation and skills development. In order to apply online for the aforementioned certificate and receive it in digital form, the government implemented the Unique Disability Identity Card, from which 17,973 persons cured of leprosy have registered to date. Under the Department of Empowerment of Persons with Disabilities, several initiatives to support persons with disabilities have been put into motion, among which is the project for the rehabilitation of persons cured of leprosy, with a grant being provided to non-governmental organizations working in the field. In Brazil, persons affected by leprosy are eligible for a continuing instalment benefit, under Law No. 13.982/2020, that provides a monthly minimum wage to people with disabilities or to people over 65 years of age. Also in Brazil, Law No. 11.520/2007 provides for special lifelong, monthly, non-transferable pensions to persons affected by leprosy who were subjected to compulsory isolation up to 31 December 1986. In Maldives, persons affected by leprosy are eligible for the Senior Citizen Allowance. In Mauritius, the Ministry of Social Integration and Economic Empowerment targets its efforts at the inclusion of vulnerable groups, providing free gender-sensitive and culturally sensitive education and benefits to vulnerable families and support to persons living in extreme poverty.

52. With regard to COVID-19-related mitigation measures, only the delivery of multidrug therapy, where available, seems to have been the object of specific leprosy-related measures, as part of countries' responses aimed at enhancing effective access to health care in the context of the pandemic. The majority of the measures reported are of a general type. General health-care protection measures range from increasing the capacity of the health-care system, such as was done in Costa Rica, to the simplification of occupational medicine procedures, as well as benefits, for persons with chronic diseases and disabilities, as was done in Algeria.

³⁶ ILO, "Towards solid social protection floors? The role of non-contributory provision during the COVID-19 crisis and beyond", January 2021.

³⁷ See www.ohchr.org/EN/Issues/Poverty/Pages/Covid19.aspx.

³⁸ ILO, "Financing gaps in social protection".

³⁹ Brazil, Cambodia, Chad, Colombia, the Democratic Republic of the Congo, Ecuador, Gabon, Ghana, India, Indonesia, Mexico, Mozambique, Myanmar, Nepal, Nigeria, Pakistan, Papua New Guinea, the Philippines, Senegal, Sierra Leone, South Sudan, Togo, Venezuela (Bolivarian Republic of) and Yemen.

⁴⁰ See <https://zeroleprosy.org/covid-data/?fbclid=IwAR0xCWKzEBAHyClZYc0ojWdcKnoZGFvbrPnaK1jaAiJg0IkPUNneeuQqZvc>.

⁴¹ It has been brought to the attention of the Special Rapporteur that such terminology could exclude people under medical treatment.

Measures aimed at ensuring the proper delivery of multidrug therapy were implemented in Bolivia, Guatemala, Maldives and Morocco. In India, guidelines to ensure the supply of multidrug therapy, the sustenance of disability prevention activities and new case detection were issued by the central Government. In Mozambique, COVID-19-related health awareness-raising materials, hygiene items and masks were distributed among leprosy-affected communities. Socioeconomic measures were enacted in Brazil, where a cash transfer benefit has been provided to informal and self-employed workers, as well as to unemployed persons. Similar measures were implemented in Maldives. In Japan, the Ministry of Health, Labour and Welfare held a consultation in October 2020, in order to assess the needs of persons affected by leprosy and their families due to COVID-19, and implemented special prevention measures against COVID-19 at leprosy sanatoriums, with accompanying budgetary measures.

B. Issues of access and gaps

53. Social protection systems have not only proved to be essential in responding to the crisis, but are also economic and social stabilizers that can play an important role in recovery.⁴² Social protection systems should, in principle, extend security to all, throughout the life cycle, underpinning universality and linking basic income security to dignity.⁴³ The Special Rapporteur received a considerable number of reports that pointed to multiple and intersecting barriers to access for persons affected by leprosy to social protection benefits before and during the pandemic. As regards disability-related benefits, eligibility criteria based on a limited medical assessment, together with administrative services and bureaucratic procedures that are not accessible to illiterate or poorly educated populations or to populations living in remote or peripheral areas, are widespread and exclude, in practice, a large number of persons affected by leprosy. Moreover, the shutdown of public administration, in addition to transportation restrictions, acted as barriers to social protection measures during lockdown measures. A considerable number of people also reported being discriminated against on the grounds of leprosy when seeking access to social protection services. Notably, ILO identified geographical and financial accessibility to essential services, such as water, sanitation, health and education, as an integral part of comprehensive social protection systems,⁴⁴ and the ILO Social Protection Floors Recommendation, 2012 (No. 202) explicitly indicates that States should identify barriers to protection.

54. With regard to COVID-19-related mitigation measures, barriers, such as eligibility criteria, lack of recognition of the additional costs of disability, inaccessible administrative services or bureaucratic procedures, lack of access to the Internet and digital illiteracy, in addition to civil and political rights violations on the grounds of leprosy, which have resulted in the denial of the right to own identity cards and to be integrated into cities and municipalities' databases in some countries, amount to a widespread denial of protection. Furthermore, emergency measures were mostly one-off and indisputably insufficient. Concomitantly, persons affected by leprosy are reportedly not being taken into consideration in national recovery plans.

55. Temporary measures enacted during the pandemic should act as building blocks for founding national social protection floors.⁴⁵ With such an aim in view, the Special Rapporteur considers that significant improvement is indispensable and recommends the fulfilment of one gap in particular. Apart from Japan, no other country provided information on attempts to guarantee the participation of persons affected by leprosy and of their representative organizations in the formulation and implementation of social protection measures in response to the crisis.

56. Participation is a fundamental principle of human rights and community engagement a well-documented key strategy for simultaneously preventing and responding to outbreaks

⁴² ILO, "Financing gaps in social protection".

⁴³ ILO Social Protection Floors Recommendation, 2012 (No. 202).

⁴⁴ ILO, "Towards the right to work: innovations in public employment programmes", employment working paper No. 69, 23 June 2010.

⁴⁵ ILO, "Towards solid social protection floors?".

in an equitable, appropriate and efficient manner.⁴⁶ A very limited number of WHO member States report having included community engagement in COVID-19-related plans.⁴⁷ Policymakers must guarantee that citizens' voices are being heard⁴⁸ on a non-discriminatory basis that enables marginalized groups to have a voice and a choice in problem-solving endeavours, even more so because they possess key knowledge, which is many times absent from official monitoring systems, and can easily identify both additional needs and solutions. As the world starts rolling out COVID-19 vaccines, and while the socioeconomic crisis expands, ensuring the participation of those who have been systematically pushed furthest behind is a sine qua non for ensuring equity in recovery.

C. Filling the gaps

57. Once the health crisis and food emergency became evident, many non-governmental organizations working in the field of leprosy transferred resources from field activities to humanitarian aid. In October 2020, non-governmental organizations were providing emergency relief to persons affected by leprosy in at least 16 countries.⁴⁹ In the beginning of 2021, 23 leprosy-related non-governmental organizations informed the Special Rapporteur that they were engaging in humanitarian activities in 19 countries, 12 of which are leprosy-affected countries identified by WHO as a priority. Leprosy-related non-governmental organizations usually cooperate with central and local governments, filling the gaps, especially at the community level.

58. During lockdown measures, non-governmental organizations reached out to isolated communities of persons affected by leprosy, filling the gaps concerning health care, health promotion and food relief. The general provision of health care by non-governmental organizations in the context of the pandemic encompassed the continuum of care, from the delivery of essential medicines, including multidrug therapy and drugs for treating leprosy reactions, to wound dressing kits for ulcers, protective footwear and self-care kits. Telemedicine, mobile clinics and home-based care services were part of a set of strategies developed to reach people under lockdown measures, alongside the provision of key support to local health systems, especially to community health-care workers and front-line health-care workers. Health promotion was also targeted, with the distribution of hygiene and sanitation supplies, masks and information about COVID-19 prevention. Food relief has also been frequent and widespread, with the delivery of food, cash transfers and cooked meals by community kitchens at leprosy hospitals.

D. Good practices

59. The Special Rapporteur considers good practices to be the set of strategies put in place through collaborative work with persons affected by leprosy and their representative organizations, respecting autonomy, enhancing local capacities and linking relief to development.⁵⁰

60. Coproduction of health⁵¹ through participatory strategies that engage persons affected by leprosy and their representative organizations as agents, and not just as passive beneficiaries, has been at the core of the work of a more limited number of non-governmental

⁴⁶ Brynne Gilmore and others, "Community engagement for COVID-19 prevention and control: a rapid evidence synthesis", *BMJ Global Health*, vol. 5, No. 10.

⁴⁷ Ibid.

⁴⁸ Cicely Marston and others, "Community participation is crucial in a pandemic", *The Lancet*, vol. 395, No. 10238.

⁴⁹ See <https://zeroleprosy.org/covid-data/?fbclid=IwAR0xCWKzEBAHyClZYc0ojWdcKnoZGFvbrPnaK1jaAiJg0IkPUNneeuQqZvc>.

⁵⁰ Active Learning Network for Accountability and Performance in Humanitarian Action, "Participation by crisis-affected populations in humanitarian action: a handbook for practitioners", (London, Overseas Development Institute, 2003).

⁵¹ Cicely Marston and others, "Community participation is crucial in a pandemic".

organizations. Some of the good practices that they have developed in the context of the pandemic are as follows:

- (a) In Brazil, NHR Brazil has provided support to persons affected by leprosy for moving the sale of their products online;
- (b) In India, the Karuna project of the Stepping Stone Charitable Society, with the support of the Leprosy Mission England and Wales, supported trainee tailors in stitching washable face masks, which were then distributed among various communities;
- (c) In India, the LEPRA Society office in Odisha implemented a resilience project that enhanced the local capacity of extremely marginalized families to fend for themselves against the adverse effects of the pandemic;
- (d) In India, the Leprosy Mission Trust India developed accessible COVID-19 awareness-raising materials that also included information on mental well-being and care at home under lockdown measures, within a participatory and intercultural framework;
- (e) In Nepal, the Nepal Leprosy Trust of the Lalgadh Hospital and Leprosy Services Centre partnered with persons affected by leprosy to enable them to advocate for the protection of their human rights in the context of the pandemic at the local government level;
- (f) In Nepal, the Leprosy Mission Nepal produced accessible and intercultural materials based on the WHO guidelines;
- (g) In Papua New Guinea, the Leprosy Mission Papua New Guinea used locally available materials to produce clean water for the use of communities;
- (h) In Myanmar, the Leprosy Mission Myanmar facilitated the process for persons affected by leprosy to apply for cash transfers and supported the Myanmar Association of Persons Affected by Leprosy to advocate for their rights;
- (i) The Sasakawa Leprosy (Hansen's Disease) Initiative provided funds and technical support to 22 organizations of persons affected by leprosy from 14 countries in order for them to provide emergency relief to their communities, through a grant based on four pillars, namely, emergency relief, advocacy for rights enforcement, communication and building sustainability, the core objective of which is respect for the autonomy of the organizations and increasing their capacity.

61. Grass-roots organizations, such as the Advancing Leprosy and Disadvantaged Peoples' Opportunities Society, the Movement of Reintegration of Persons Affected by Hansen's Disease (MORHAN), the Federación de Asociaciones de Personas Afectadas por Lepra (FELEHANSEN), the Organization of People Affected by Leprosy in Congo (OPALCO), the Ethiopian National Association of Persons Affected by Leprosy (ENAPAL), the Saksham Kushthanteya Swabhimani Sanstha, the Independent Leprosy Association (PerMaTa) and the Tanzania Leprosy Association, as well as many others that the Special Rapporteur will not refer to in the present report so as to safeguard confidentiality, have been at the forefront of responding to and mitigating the disproportionate impact of the pandemic on their peers and communities.

62. Such organizations were in fact the first ones to sound the alarm about the disproportionate impact of the COVID-19 pandemic on persons affected by leprosy and to mobilize resources to ensure their survival amid the health and socioeconomic crises. In the face of an absence of data collection about persons affected by leprosy in national COVID-19 monitoring systems, grass-roots organizations produced data and introduced bottom-up, contextualized and effective solutions to problems. In the context of the pandemic, those organizations proved to be experts through experience in the area, as well as in the areas of health and equality data. By the same token, not only did they fill the gaps, they also devised innovative strategies for mapping problems, solving them, providing emergency aid and mainstreaming health education and counselling under lockdown measures. Only grass-roots organizations seemed to have effected strategies that were gender-sensitive, age-sensitive and disability-sensitive. Advocacy for rights enforcement for all, and not just the few within the reach of civil society organizations, is at the core of the work of grass-roots organizations, as is networking with partners outside the leprosy community, such as organizations working

on the right to clean and safe water and access to water, sanitation and hygiene. Notably, all of that was done with scarce support from governments.

VII. Conclusions and recommendations

63. The lived experiences of persons affected by leprosy and their family members in the context of the COVID-19 pandemic acutely illustrate the relevance of the content of general comment No. 36 (2018) of the Human Rights Committee. While recognizing the linkage between the right to life and the enjoyment of a life with dignity, as well as affirming the protection of vulnerable groups and the fight against health-related and disability-related stigmatization as part of the duty of States parties to the International Covenant on Civil and Political Rights to protect the right to life, the Committee also called for measures to ensure adequate general conditions that included the fulfilment of fundamental economic and social rights. The Committee on Economic, Social and Cultural Rights⁵² has identified the undermining of health-care systems in the past decades, the inadequacy of social programmes to respond to poverty and the increase in discrimination, stigmatization and inequality as determining factors for the current health, social and economic crises that disproportionately affect those who are more vulnerable. Discrimination in law and in practice, together with substantive discrimination with regard to access to social and economic rights, has left persons affected by leprosy in a situation of extreme vulnerability to COVID-19 and to the crisis that has unfolded, compromising their right to life and unveiling, in practice, the indivisibility, interdependence and interrelation of human rights. The principle of universality of human rights as provided for in the Universal Declaration of Human Rights has hardly been fulfilled, and the pandemic disclosed the multiple divides that persist and result in the denial of the enjoyment of substantive equality for a significant part of the world population, including persons affected by leprosy. Over the course of the pandemic, the enjoyment of social and economic rights has been compromised not only by structural material deprivation, but also by the intersections of the latter with gender, race, age, disability status and sexual orientation, among other historically oppressed social categories. Such a fact calls for legal and policy frameworks that can ensure de facto universal access to economic, social and cultural rights for the most vulnerable. The principle of progressivity should be applied in a reasonable manner that firmly recognizes poverty as a human rights violation and that guarantees minimum core obligations in a way that is proportional to the needs of vulnerable groups and groups that have been discriminated against. Such is the core principle for building back better by placing those who have systematically been pushed furthest behind at the centre of an inclusive recovery.

64. **The Special Rapporteur recommends that States put those who are furthest behind at the centre of an inclusive recovery by eliminating double standards in the response to the current crisis, ensuring non-discrimination and the right to participation for the most marginalized. States should establish minimum core obligations of social and economic rights with regard to vulnerable groups as a matter of priority, with the necessary accompanying institutional arrangements and allocation of resources within national budgets. In accordance with articles 4 and 6 of the Declaration on the Right to Development, it is crucial to mitigate the adverse effects of the pandemic on vulnerable groups and to enable comprehensive and human-centred development policies in low- and middle-income countries. Grass-roots organizations should be placed at the centre of emergency aid, coproduction of health and policymaking for systemic change and be recognized as experts through experience, in accordance with the spirit of the 2030 Agenda for Sustainable Development, in which it was affirmed that development must go beyond transforming the material conditions of people in disadvantaged circumstances to actually enabling them to have a voice and a choice. States should systematically collect and analyse data in a way that includes disaggregation not only by demographic, environmental, socioeconomic and cultural variables, but also by the various grounds of discrimination recognized in international**

⁵² See E/C.12/2020/1.

human rights law, such as gender, age and disability status, with full respect for the principles of participation and privacy.

65. The Special Rapporteur recommends that States fulfil the right to the highest attainable standard of physical and mental health for persons affected by leprosy as follows:

(a) Health systems should be strengthened and the efforts of national leprosy-related programmes sustained;

(b) The WHO road map for neglected tropical diseases, 2021–2030, should guide action taken by leprosy-endemic countries, which must be accompanied by proper budget allocations at the national and subnational levels;

(c) A rights-based strategy for leprosy within health-care systems must be people-centred, having as a priority the well-being of persons, communities and populations, and should ensure the availability, as well as physical and economic accessibility, of health-care services;

(d) Access to health care should be guaranteed on a non-discriminatory basis through strategies that fight discrimination in health-care settings, ineffective public policies and geographical isolation;

(e) The scope of national leprosy-related programmes should be expanded to include targeted action on the social determinants of leprosy, which should be based on a comprehensive multisectoral policy with coordinated interventions between the different sectors of government;

(f) The right to a continuum of medical and psychosocial care that encompasses the full spectrum of prevention, timely access to multidrug therapy, the proper management of leprosy reactions and complementary care, such as wound care, physiotherapy, rehabilitation and reconstructive surgery, should be guaranteed, alongside service delivery at the community level, and access to essential medicines should be ensured through national and international efforts, while also guaranteeing the right to access to information;

(g) National leprosy programmes should endeavour to ensure the right of persons affected by leprosy to the highest attainable standard of mental health, with an approach that is ethically respectful, culturally appropriate, gender-sensitive and empowering to individuals and that makes use of peer support as an integral part of recovery-based services;

(h) Short-term mitigation action and long-term systemic change should be developed with the full participation of persons affected by leprosy and their representative organizations in the design, implementation and evaluation stages, with proper institutional arrangements that enable the transparent sharing of information, ownership and joint decision-making;

(i) Accessible mechanisms for filing complaints of rights violations should be made available and the health-care workforce should be trained in not only clinical, but also structural, competencies that can foster in-depth understanding of the root causes of discrimination and emotional distress experienced by users in the context of their culture and life;

(j) Persons affected by leprosy must be recognized as a vulnerable group with regard to COVID-19, given that many of them are immunocompromised, and leprosy should be recognized as grounds for priority in COVID-19 testing, COVID-19 vaccinations and access to health care.

66. The Special Rapporteur recommends that States protect the right to work of persons affected by leprosy as follows:

(a) Abolishing discriminatory laws that hinder persons affected by leprosy from enjoying the right to work and enjoying their rights at work;

(b) Recognizing persons affected by leprosy as active economic agents, respecting their legal capacity and realizing their rights to equal work opportunities in the open labour market and to equal remuneration;

(c) Guaranteeing the right to education through the creation of an inclusive and enabling education system that is non-discriminatory and that ensures the availability of education services, accessibility at all levels of education and the promotion of life-long training and skills development opportunities, as well as the provision of reasonable accommodation;

(d) Implementing gender-inclusive approaches to ensuring the right to work and ensuring rights at work that fight the intersection of gender with leprosy-related harmful stereotypes and disability and which affirm women's rights to inclusive education, vocational training, decent work and equal remuneration, and properly recognizing unpaid care work in social protection schemes;

(e) Implementing a whole-of-government approach that mainstreams persons affected by leprosy into macro-level policies aimed at the transition from the informal economy to the formal economy, as well as develops specific intervention models adapted to the reality of persons affected by leprosy working in the informal economy, including strategic objectives and key performance indicators;

(f) Formally recognizing the social and solidarity economy, as well as its tangible economic benefits and intangible social benefits;

(g) Including persons affected by leprosy in public employment programmes;

(h) Opening social dialogue to organized groups of persons affected by leprosy working in the informal economy and guaranteeing barrier-free participation by addressing both physical barriers and those related to illiteracy, poor education, culture, gender and the digital divide;

(i) Enabling the right to collective bargaining for persons affected by leprosy, working both in the formal and informal economy, including by making available a defined interface with the institutions and government bodies with which the organizations must dialogue;

(j) Fulfilling accessibility and reasonable accommodation rights in all productive sectors and work arrangements, including agriculture, husbandry and fishing; and recognizing 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;

(k) Implementing affirmative measures as a means to correct historical and structural disadvantage, which should encompass both work and education opportunities and come with targets and key performance indicators, as well as with effective enforcement mechanisms and remedies, while also following paragraph 11 (i) of ILO recommendation No. 168 concerning vocational rehabilitation and employment with regard to awareness-raising, and the eligibility criteria for which should be defined in consultation with grass-roots organizations and should ensure the accessibility of procedures.

67. The Special Rapporteur recommends that States fulfil the right to social protection of persons affected by leprosy. Social protection measures to respond to the current crisis should act as building blocks for founding national social protection floors and contribute to the realization of universal health coverage and to universal social protection schemes, while also fulfilling urgent needs regarding health care, basic income security and access to food and to personal protective equipment. Given the interlinkages between leprosy and poverty, the rights to an adequate standard of living and to independent living cannot be realized without the prior granting of social benefits under a rights-based, comprehensive social protection policy, which must be implemented through administrative services and bureaucratic procedures that can guarantee full accessibility to illiterate or poorly educated populations, as well as to populations living in remote areas. Such a comprehensive social protection policy

should also target active citizenship by promoting training opportunities and formal employment, while guaranteeing support as needed. In the design of social benefits, such as unconditional cash transfers, the real needs of the target population, including the additional costs of disability, should be taken into consideration. Specific measures for short-term action regarding the adverse effects of the pandemic include broadening social protection to persons affected by leprosy and simplifying both eligibility criteria and administrative requirements, providing cash and in-kind benefits, supporting people who provide long-term care for older persons affected by leprosy, supporting the special needs and responding to the specific challenges faced by women, children, teenagers and older persons affected by leprosy, ensuring a universal basic income for persons affected by leprosy and ensuring security, access to health care and fundamental goods to people living in former leprosy colonies.
