Distr.: General 19 June 2023 Arabic

Original: English



مجلس حقوق الإنسان الدورة الثالثة والخمسون 19 حزيران/يونيه – 14 تموز/يوليه 2023 البند 3 من جدول الأعمال تعزيز وحماية جميع حقوق الإنسان، المدنية والسياسية والاقتصادية والاجتماعية والثقافية، بما في ذلك الحق في التنمية

## زيارة إلى أنغولا

تقرير المقررة الخاصة المعنية بالقضاء على التمييز ضد الأشخاص ذوي الجذام (داء هانسن) وأفراد أسرهم، أليس كروز \* \*\*

موجز

تبحث المقررة الخاصة المعنية بالقضاء على التمييز ضد الأشخاص ذوي الجذام (داء هانسن) وأفراد أسرهم، أليس كروز، في هذا التقرير عن زيارتها إلى أنغولا، التي أُجريت في الفترة من 28 نيسان/أبريل إلى 10 أيار/مايو 2022، المسائل المتعلقة بالتقدم المُحرز في أنغولا في القضاء على التمييز والوصم المتصلَين بالجذام والتحديات المائلة في هذا الصدد. وتقدم المقررة الخاصة أيضاً توصيات بنّاءة في عدد من المجالات ذات الصلة، بما في ذلك السياسات الوطنية لمكافحة التمييز، وتخصيص الموارد، وجمع البيانات، وإمكانية اللجوء إلى العدالة، وحقوق الأشخاص ذوي الإعاقة، إلى جانب توصيات بشائر الحاجة إلى تعزيز نظام الرعاية الصحية الوطني والتعاون الدولي من أجل مواصلة الجهود وتحقيق تغيير نُظمي.



<sup>\*</sup> \_\_\_\_ يُعمَّم موجز هذا التقرير بجميع اللغات الرسمية. أما التقرير نفسه، الوارد في مرفق هذا الموجز، فيُعمَّم باللغة التي قُدَّم بها فقط.

<sup>\*\*</sup> تأخّر تقديم هذا التقرير عن الموعد المقرر له لتضمينه أحدث المعلومات.

## Annex

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

## I. Introduction

1. The Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, undertook an official visit to Angola from 28 April to 10 May 2022.

2. In accordance with Human Rights Council resolution 44/6, during her visit the Special Rapporteur assessed both progress and challenges regarding the implementation of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members. In its resolution 65/215, the General Assembly took note with appreciation of the principles and guidelines.

3. More specifically, the Special Rapporteur investigated the multidimensional aspects of living with leprosy in Angola, a country which, on the basis of statistical data regarding new case detection, age, gender and disability, is listed by the World Health Organization (WHO) as one of 23 global priority countries for the disease. In the present report, the Special Rapporteur sets out constructive recommendations to improve the human rights situation of individuals affected by the disease. As an expert on the subject, the Special Rapporteur has used the scientific name Hansen's disease instead of leprosy, the name it is commonly known by, throughout the report.

4. During her visit, the Special Rapporteur met with representatives of central, provincial and municipal governments in the cities of Benguela and Luanda, as well as with representatives of the Office of the Ombudsman. She also met with the United Nations resident coordinator, the United Nations country team, as well as with representatives of United Nations agencies working in Angola, including the WHO representative and the WHO focal point for neglected tropical diseases, the United Nations Children's Fund (UNICEF) and the United Nations Development Programme. In addition, she consulted with prominent scholars and experts in the fields of public health, history and social sciences in a meeting organized with the support of scholars from the Catholic University of Angola; law and health-care experts; members of civil society organizations; and representatives of doctors and nurses' unions. She listened carefully to the testimony of members of the Association for the Reintegration of People Affected by Leprosy, the Evangelical Solidarity Association and churches engaged in fighting Hansen's disease and supporting individuals affected by it. In addition, the Special Rapporteur visited the Funda health centre (a former leprosarium) and the tuberculosis and leprosy dispensary in Luanda Province and the Calossobekua health centre and the Alto Esperança health centre in Benguela Province. During field visits, she met with representatives of central and provincial governments, health-care workers and persons affected by Hansen's disease and their family members. The majority of persons affected by Hansen's disease that the Special Rapporteur met were undergoing medical treatment for it. The Special Rapporteur made every effort to assess the intersectional dimensions of the problems and challenges identified by persons affected by the disease and to ensure that all stakeholders had a voice. She also endeavoured to make her visit an opportunity for interdisciplinary dialogue and the exchange of knowledge, aiming at building bridges between different stakeholders and fostering a more effective responses to health disparities and discrimination.

5. The Special Rapporteur expresses her appreciation to the Government of Angola for the invitation to visit and assess the situation of persons affected by Hansen's disease in the country. Her visit marked the first visit of a special procedure mandate holder of the Human Rights Council to Angola since the visit of the Special Rapporteur on the human rights of migrants in 2016. The Special Rapporteur appreciates the willingness of the Government to interact with the United Nations human rights system. She also thanks the office of the United Nations Resident Coordinator for its assistance and, in particular, the team of the Office of the United Nations High Commissioner for Human Rights for its outstanding support. She is particularly grateful to persons affected by Hansen's disease and the organizations supporting them for their extremely valuable inputs. The Special Rapporteur listened to the testimony of persons affected by the disease with great respect for the challenges they face and the suffering they endure and with profound admiration for their resilience and will to survive and support their peers.

## II. Epidemiology

6. In 2005, Angola reached the milestone set by the World Health Assembly in 1991<sup>1</sup> for the elimination of Hansen's disease by achieving a national rate of less than 1 case per 10,000 population. This was accomplished through a successful campaign to distribute medical treatment in all provinces of the country, largely implemented with the assistance of external funding. Nevertheless, the disease remains a matter of great concern in Angola. As mentioned above, the country is listed by WHO as one of 23 global priority countries for the disease.<sup>2</sup>

7. The achievement of the target set by WHO for the elimination of Hansen's disease as a public health problem, which is frequently thought to mean its actual eradication, often results in negative consequences for those sectors of the population that remain exposed to transmission and suffer from the cumulative impacts of the disease, in particular the disability and discrimination associated with it. In the case of Angola, the negative results of achieving the WHO target for the elimination of the disease include a decrease in the political will to fight the disease; a decline in expertise to properly diagnose and treat the disease; and a loss of international funding to tackle the disease. Moreover, the loss of international funding has had a profound impact on the work of civil society organizations to raise awareness and fight harmful stereotypes about the disease.

8. According to WHO data, the current detection rate in Angola is around 600 to 800 cases per year. In 2021, 797 new cases were registered. As noted by the Special Rapporteur in her report on the disproportionate impact of the coronavirus disease (COVID-19) pandemic,<sup>3</sup> there has been a significant reduction in the detection of Hansen's disease in many countries. In 2020, official WHO data recorded only 422 cases in Angola.

9. In the light of underreporting and late diagnosis, both of which are manifestly evident in Angola, official epidemiological data must be read with caution. Data collected by the national leprosy control programme suggest that the number of existing cases is probably much higher than the number of registered cases. The number of registered cases has remained constant, at about 1,000, for the past 20 years: Benguela, Bié, Cuando Cubango, Huambo, Huíla, Kwanza Sul, Luanda, Malange and Moxico are the most affected provinces.

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Population	32 097 671
New cases	797
New cases in children	93
New cases in women	197
New cases with grade 2 disabilities	115
Grade 2 disabilities in children	93
Grade 2 disabilities in women	54
New cases (multibacillary)	681
New cases (paucibacillary)	116

#### Epidemiological data: 2022

<sup>&</sup>lt;sup>1</sup> World Health Assembly, resolution WHA44.9 (1991).

<sup>&</sup>lt;sup>2</sup> See WHO, "Global leprosy (Hansen's disease) update, 2021: moving towards interruption of transmission" (2022).

<sup>&</sup>lt;sup>3</sup> See A/HRC/47/29.

	Total	1 785
Cured		437
Dropouts		202
Re-entries		146

Source: National leprosy control programme.

10. According to WHO, in 2021 the proportion of children (under age 15) among new cases of Hansen's disease was 11.7 per cent, a share that is not only very high but also deplorable.<sup>4</sup> Moreover, new cases among children are an important indicator of ongoing transmission. In 2021, the number of new cases of people living with Hansen's disease who had irreversible physical impairments at the time of diagnosis was 187. In almost 25 per cent of new cases, diagnosis was made after a person had already developed long-term physical impairments. New cases with irreversible physical impairments at the time of diagnosis are not only an indicator of late diagnosis but also a sign of ongoing transmission at the community level. Over the long term, the significant number of undetected cases may very well lead to an increase in both transmission and disability. In 2021 alone, according to data provided by WHO (which must be read with caution, given the impact of the COVID-19 pandemic on new case detection), 72 children were diagnosed when they were already suffering with impairments of their hands, feet and/or eyes.<sup>5</sup>

11. The Special Rapporteur has called attention to the limitations of the medicalized approach of the WHO grading system for assessing and measuring impairments related to Hansen's disease. The system misuses the concept of disability (as provided in the Convention on the Rights of Persons with Disabilities), while measuring only physical impairments.<sup>6</sup> Furthermore, not only visible but also invisible and psychosocial impairments, as well as discrimination itself, can be deeply disabling. Specifically in Angola, persons affected by Hansen's disease, owing to general barriers in accessing education, are often obliged to perform physically demanding labour to sustain their livelihoods. Over time, such work can aggravate invisible physical impairments to the point where they become not only visible but also irreversible.

## III. Legal and institutional framework

#### A. General

12. The Special Rapporteur welcomes the efforts of the Government of Angola to enact a comprehensive legal framework for the advancement of human rights in the country. Important constitutional norms, legislation, programmes and strategies dedicated to the core principles of equality, non-discrimination and human dignity are in force in Angola. While the domestic legal framework is favourable to the effective implementation of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, important challenges regarding the execution and implementation of the legal framework have yet to be addressed.

13. The principle of non-discrimination is established in the Constitution of Angola (2010) and the same principle is the basis for the fundamental rights established in the country's legal framework. Articles 22 and 23 of the Constitution recognize the principles of universality and equality in relation to the enjoyment of fundamental rights and freedoms. Article 23 specifically provides that no one may be discriminated against, privileged, deprived of any right or exempted from any duty on the basis of origin, sex, race, ethnic identity, colour, disability, place of birth, religion, political, ideological or philosophical

<sup>&</sup>lt;sup>4</sup> WHO, "Number of new leprosy cases among children (less than 15 years of age): 2021", Leprosy database. Available at https://apps.who.int/neglected\_diseases/ntddata/leprosy/leprosy.html.

<sup>&</sup>lt;sup>5</sup> Ibid.

<sup>&</sup>lt;sup>6</sup> See A/77/139.

beliefs, educational level or economic, social or professional status.<sup>7</sup> Importantly, the Penal Code (2020) includes discrimination as a relevant circumstance for the determination of criminal sentences in article 71 and of penalties for the crime of threat in article 170 and criminalizes and punishes discrimination on a number of grounds (including illness and disability) in article 212.

14. In addition, article 12 of the Constitution guarantees respect for and application of the principles contained in the Charter of the United Nations and the Charter of the Organization of African Unity in Angola and article 13 establishes that international law, once ratified, is part of domestic law. Article 13 of the Constitution clarifies the obligation of Angola to enforce international law and norms contained in the international treaties it has ratified, many of which are also embodied in the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members.

15. Angola is a State party to seven core international human rights treaties: (a) the International Covenant on Civil and Political Rights; (b) the International Covenant on Economic, Social and Cultural Rights; (c) the Convention on the Elimination of All Forms of Discrimination against Women; (d) the Convention on the Rights of the Child; (e) the Convention on the Rights of Persons with Disabilities; (f) the Convention against Torture and Other Cruel Inhuman or Degrading Treatment or Punishment; and (g) the International Convention on the Elimination of All Forms of Racial Discrimination.

16. The establishment, by Presidential Decree No. 100/20, of the national human rights strategy was an important landmark in the development of human rights protections in Angola. Equality and non-discrimination form the basis of the national strategy and its action plan. One of the main goals of the strategy is to support the implementation of actions to promote respect for people belonging to vulnerable groups. The strategy is also aimed at strengthening human rights mechanisms at the local level, including through the establishment of provincial committees in all 18 provinces, 163 municipal committees and more than 50 communal committees. The committees are responsible for organizing actions to promote and protect human rights.

17. The Government's medium-term strategic framework on human rights is designed to ensure the autonomy of the State to identify, punish and remedy human rights violations. The Office of the Ombudsman has national jurisdiction and legal authority to pursue people's claims against abuses or violations committed by public officials or institutions.

18. Progress has also been made regarding the protection of groups of people living in vulnerable situations who are structurally discriminated against, including through: (a) the national policy for gender equality and equity established by Presidential Decree No. 222/13; (b) the law for the protection and integral development of the child, enacted in 2021; and (c) Law No. 10/2016, which established general rules to promote accessibility for persons with disabilities. Subsequent presidential decrees introduced: (d) a reservation of vacancies and procedures for the hiring of persons with disabilities, with 4 per cent of vacancies in the public sector and 2 per cent in the private sector; (e) an intervention strategy for the social inclusion of children with disabilities; and (f) grants for students with disabilities and a policy for persons with disabilities and Decree No. 6-E/1991 established the National Rehabilitation Institute, whose mission is to develop a national policy for the rehabilitation of persons with disabilities.

19. The right to health and social protection is guaranteed in the Constitution, which states that it is the duty of the State to promote and guarantee measures ensuring that everyone has the right to medical and health care, as well as the right to social assistance in childhood, maternity, disability, old age and in any situation of inability to work (article 77). The country also has a basic law on the national health system (Law No. 21-B/92 of 1992), a national

<sup>&</sup>lt;sup>7</sup> As noted by the Committee on the Elimination of Discrimination against Women, the definitions of equal rights and non-discrimination in articles 21 (h), 22 (3) (b) and 23 of the Constitution of the State party do not comprise a comprehensive definition of discrimination in line with article 1 of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW/C/AGO/CO/7, para. 11 (b)).

health policy (Presidential Decree No. 262/10) and a national programme for the municipalization of the health system. Solidarity, equity, ethics, cultural identity and gender equality are the core values of the national health policy. Universality, quality, humanization, freedom of choice, accountability and an intersectoral approach are the basic principles for health interventions. The Office of Ethics and Humanization, which is responsible for the ethical and humane quality of health care, is linked to the Ministry of Health. The national policy on traditional and complementary medicine as a practice that may be incorporated into the national health system was approved by Presidential Decree No. 253/20.

20. The basic law on social protection (Law No. 7/04 of 2004), which sets out a system for social protection, has not yet succeeded in integrating people who are excluded from the formal work market, an important gap in a country where the majority of the population works in the informal economy. Nevertheless, several non-contributory programmes are in place, although they appear to be dependent on external donors. One such programme is a cash transfer scheme called "Kwenda", which is aimed at supporting families living in vulnerable situations. Another, called "APROSOC", is a cash transfer scheme for the benefit of families with children under age 5.

21. While it appears that a forceful legal and institutional framework is in place, there are still significant barriers that hinder the effective enjoyment of human rights by all. The gap between law in books and law in practice is, without a doubt, a major challenge for the country as a whole, and it is also one that has a severely negative impact on the enjoyment of fundamental rights by persons affected by Hansen's disease and their families.

#### B. Institutional framework for fighting Hansen's disease in Angola

22. Angola has a national leprosy control programme, under the Ministry of Health, which is decentralized and implemented in all 18 provinces of the country. The programme's activities are planned and coordinated at the central level and its health information database is periodically updated, ensuring that epidemiological statistics on the disease are current. The programme is based on four strategic pillars established by WHO: (a) implementing integrated interventions, especially in endemic areas; (b) scaling up disease prevention, together with integrated active case detection; (c) managing the disease and its complications and preventing disabilities; and (d) combating stigma and ensuring that the human rights of affected persons are respected. Multi-drug therapy is provided free of charge from WHO and distributed to patients free of charge through the public health-care system.

23. During the course of the Special Rapporteur's visit, she was able to assess the national leprosy control programme from the perspective of both the Ministry of Health and of persons affected by Hansen's disease. One of the negative consequences of Angola having reached the WHO target of eliminating Hansen's disease as a public health problem has been a reduction in the pace and investment in the implementation of the national leprosy control programme. As a result, the transmission of the disease has intensified and the number of people, including children, with Hansen's disease-related impairments and disabilities has increased.

24. Other challenges faced by the national leprosy control programme include: (a) low coverage provided by the health-care system, which heightens out-of-pocket expenses for those persons affected by the disease who need to travel long distances to access both diagnosis and treatment; (b) inefficiencies at the primary level of health care in detecting new cases in a timely manner; (c) scarcity of health-care workers with the expertise to diagnose and properly treat the disease; (d) lack of referral services to manage complications and Hansen's disease reactions and to guarantee mental health care and rehabilitation; (e) high dropout rate from treatment; and (f) lack of networking and collaborative work with civil society organizations, especially in the area of outreach and awareness-raising activities.

## IV. Remaining challenges: Hansen's disease mirrors the gap between law in books and law in action

## A. National health-care system and universal health coverage

25. According to the national Strategic Plan for Neglected Tropical Diseases 2017–2021, the percentage of the population exposed to the risk of such diseases, including children below the age of 14, is 47.3 per cent, an alarming statistic.

26. The epidemiology of Hansen's disease in Angola reveals important gaps in the national health-care system. During her visit, the Special Rapporteur observed that, owing to late diagnosis, a substantial number of people experience the worst forms of the disease and its consequences. By meeting with persons affected by Hansen's disease, the Special Rapporteur gained a first-hand understanding of how difficult and gruelling it can be to obtain a proper diagnosis of Hansen's disease; people are often misdiagnosed, or undiagnosed, for too long before being recognized as having the disease.

27. The lived experience of persons affected by Hansen's disease demonstrates that health information about the disease, including its symptoms, treatment and the rights of those affected by it, is limited. The Special Rapporteur witnessed with concern that, oftentimes, in order to be properly diagnosed, individuals must visit a number of health-care units, as a majority of the health-care workers lack both the expertise and the means to make and to corroborate an accurate diagnosis of the disease.

28. Testimonies indicate that frequently there is a prolonged waiting period, during which time individuals are reduced to self-diagnosing and self-medicating in order to deal with what are initially mild symptoms that later evolve into more severe manifestations of Hansen's disease. In many cases, persons affected by the disease obtain a correct diagnosis only if they have been able to locate health-care workers with the adequate expertise. Once diagnosed, they face another struggle in order to secure access to continuing treatment, while dealing with Hansen's disease reactions, ulcers, impairments and discrimination resulting from the disease, including economic consequences.

29. Late diagnosis of Hansen's disease is a matter of great concern in Angola.<sup>8</sup> Late diagnosis represents a failure of the State party to fulfil its duty under article 12 of the International Covenant on Economic, Social and Cultural Rights and points to important deficiencies in the health-care system, in particular with regard to primary care and health-care coverage. In addition, late diagnosis comes at a great economic loss for Angola, especially since it affects children and young people. Furthermore, late diagnosis may occur when anti-discriminatory policies and disability rights are not enforced.

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 Hansen's disease. Multi-drug therapy is provided free of charge to all patients detected with the disease, in accordance with WHO recommendations, through an agreement between the pharmaceutical company Novartis and WHO that began in 2000 and was recently extended to 2025. The company produces the multi-drug therapy components in India and WHO manages distribution to Angola and to other countries. However, the drugs are only sent when countries report on new case detection and the quantity of medicine sent depends on number of new cases detected in the previous year. If data collection fails at the country level, problems in supply are to be expected.

31. Hansen's disease reactions, which may occur before, during and after antibacterial treatment, causing great physical and mental suffering, represent significant challenges in the medical treatment of the disease and are often associated with nerve damage, which is the main cause of physical impairment. Hansen's disease reactions may require prolonged

<sup>&</sup>lt;sup>8</sup> Even the limited data officially collected in the country about the experience of Hansen's disease, such as the survey on inclusion, participation and stigmatization in Benguela and Luanda, undertaken as part of the national leprosy control programme in 2017, corroborate the serious consequences of late diagnosis in Angola.

treatment, sometimes for several years. Unlike multi-drug therapy, most of the drugs used for treating Hansen's disease reactions are not provided to countries free of charge. These drugs include steroids and thalidomide, the latter being well known for its teratogenic effects and its effects on sexual and reproductive health. Despite being curable with multi-drug therapy, if not detected and treated at an early stage, the disease can become chronic, demanding a continuum of medical and psychosocial care, including rehabilitation, reconstructive surgery, the provision of assistive devices and psychosocial support. Such a continuum of medical and psychosocial care needs to be fully addressed by effective referral within the national health-care system.

32. During her visit, the Special Rapporteur was concerned to discover that the healthcare system in Angola is not adequately prepared to treat Hansen's disease reactions and that steroids are oftentimes not available free of charge to people who need them. Many people suffering from Hansen's disease reactions are only provided with guidance on self-care and wound care; lacking proper medical care, nerve damage is common in the country.

33. Rehabilitation, reconstructive surgery, the provision of assistive devices for protection and assistive devices for the facilitation of activities of daily life, as well as psychosocial support, are major gaps in the national health-care system. In her visits to specialized healthcare units, the Special Rapporteur witnessed the lack of resources and of qualified personnel to guarantee rehabilitation and psychosocial support. The supply of adapted shoes, orthoses, prostheses and other protective and assistive devices for patients was in short supply, and the provision of such devices was dependent on external donations.

34. Evidence showing that the health-care system in Angola is not adequately prepared to diagnose or properly treat Hansen's disease and Hansen's disease reactions deserves attention. The health-care workforce seems to be both insufficient and to lack the training to properly diagnose and treat the disease. There are great disparities in health-care coverage throughout the country, which, at present, is more advanced in urban areas. In general, the urban population has greater geographical proximity to health-care services, while the rural population must seek health-care services at a significant distance from home. Transportation is key to guaranteeing that health care is accessible in the country.

35. The national health system provides health services free of charge through a pyramidal system comprising three levels of care: at the primary level, services are provided by health centres and units, municipal hospitals, infirmaries and doctor's offices; at the secondary level, general and single hospitals provide such services; and at the tertiary care level, central hospitals and specialized hospitals provide health care.

36. During her meetings with doctors and experts in the field of public health, the Special Rapporteur was informed that the delivery of health-care services by the national health system is still precarious and that the caseloads of health-care workers are usually overloaded. Major challenges in the health-care system at the municipal level were also noted, with significant barriers for rural and peripheral populations in gaining access to health care.

37. The significant efforts of the Government to decentralize the administration of the national health system are commendable, although there are concerns with regard to the administration of the health-care budget, which does not always prioritize the pressing problems faced by local populations. Furthermore, decision-making on public expenditure does not always seem to be aligned with central planning and there are concerns about transparency in local budgeting. Experts in the field point to the need to improve mechanisms for the social control of health policies, transparency in the management of resources and access to information in order to ensure accountability in policymaking and budget management.

38. At present, health coverage in Angola is clearly far from being sufficient in all areas. A more significant effort in terms of budget allocation, including guarantees of community participation and accountability, is required. Such an effort is all the more necessary in order to tackle diseases related to poverty, including Hansen's disease and other neglected tropical diseases. In a country that is still affected by transmissible diseases, primary health-care services, supported by an efficient infrastructure and adequate human resources, are essential and should be a priority. The need to increase public funding to build a sustainable path to achieving universal health coverage, as well as the strengthening of primary health care and the better distribution of health-care workers, has also been identified by WHO, including through the monitoring of results already achieved in this regard.<sup>9</sup> It is alarming that resources allocation for public health programmes, such as Hansen's disease and other neglected tropical diseases, may not meet the international commitments made by the Government of Angola at the African Summit on HIV/AIDS, Tuberculosis and Other Related Infectious Diseases, held in Abuja in 2001.<sup>10</sup>

39. The Special Rapporteur is concerned that the lack of a strategic vision for the development of outreach activities, in particular the promotion of health literacy, and the consequent lack of investment and allocation of resources in health care has worsened the already limited options of the population in gaining access to early diagnosis and treatment of Hansen's disease. As a result, detection and service delivery efforts have been taken over by civil society organizations, including through the humanitarian work carried out by churches. Such efforts, however, while praiseworthy, are hardly sufficient to ensure universal access. Difficulties in carrying out the work of early detection, health education and the dissemination of health information about Hansen's disease in the country have been reported by representatives of civil society organizations and churches. Responsibility for community mobilization has largely been passed on to civil society organizations and churches; however, they lack the resources and infrastructure to ensure a large-scale intervention in this area,

40. It is important to emphasize the role that community health and development workers could play in expanding outreach activities in order to reinforce and multiply prevention activities, active case detection and health education. Although not directly involved in the provision of health services, community health and development workers can play a significant role through health promotion activities, as well as by encouraging good practices and reinforcing multisectoral and intersectoral approaches, with attention to the specific situations of women, children and persons with disabilities.

41. At meetings and during discussions held during the Special Rapporteur's visit, it was pointed out that the role of community health and development workers in strengthening the bridge between health-care services and communities has yet to be explored and enhanced. This work, however, can only be done through a strategic vision, greater investment in the integration and coordination of actions between the State, civil society and communities, proper budget allocation, training and decent working conditions. The work being carried out by traditional doctors in Angola is also noteworthy. The conditions for greater integration between biomedicine and traditional medicine in Angola are promising, including the enactment of Presidential Decree No. 253/20, which recognized the importance of the role of traditional medicine. The integration of care for persons affected by Hansen's disease, as well as to active case detection and the enabling of timely treatment of the disease within a multidisciplinary health-care perspective.

42. According to the Committee on Economic, Social and Cultural Rights, all health facilities, goods and services must be respectful of medical ethics and be culturally appropriate, that is, respectful of the culture of individuals, minorities, peoples and communities.<sup>11</sup> In addition, the Committee recognized that health-care services should take traditional preventive care, healing practices and medicines into account and that the health-care workforce should be properly trained to recognize and respond to the specific needs of vulnerable and marginalized groups.<sup>12</sup> Hansen's disease requires continuous self-care practices and the provision of key health information. Accessibility and acceptability of

<sup>&</sup>lt;sup>9</sup> See WHO, "Contribuindo para a melhoria da saúde em Angola: relatório bianual 2018–2019" (in Portuguese only). Available at https://www.afro.who.int/sites/default/files/countries/Angola/Relat%C3%B3rio%20Bianual%20da%2 0OMS%20em%20Angola%202018-2019.pdf.

<sup>&</sup>lt;sup>10</sup> See Organization of African Unity, Abuja Declaration on HIV/AIDS, Tuberculosis and Other Related Infectious Diseases, OAU/SPS/ABUJA/3. Available at https://au.int/sites/default/files/pages/32894file-2001-abuja-declaration.pdf.

<sup>&</sup>lt;sup>11</sup> General comment No. 14 (2000) on the right to the highest attainable standard of health, para. 12 (c).

<sup>&</sup>lt;sup>12</sup> Ibid., paras. 27 and 37.

health-care services are crucial, especially in a country such as Angola. It is the role of the Government to ensure that health-care services are suited to the cultural diversity of the country. Health-care workers should be prepared to respond to different groups and communities, taking linguistic diversity into account. During her visit, the Special Rapporteur came to understand that the requirement to use Portuguese as an official language in health-care facilities constitutes a significant barrier to the access of individuals from diverse cultural groups to the national health system.

43. Hansen's disease is part of a set of diseases that seriously compromise not only the development of the most vulnerable people but also of the population of the country as a whole. Additional efforts are needed in order to guarantee the inclusion of vulnerable populations in the country's development goals. In this regard, better coordination between the different levels of governmental administration and the establishment of priorities that accurately reflect the needs of local populations are fundamental. Overcoming the multiple obstacles and barriers to guaranteeing the highest possible standard of physical and mental health for the people who need it most is an essential condition for the full compliance of the Angolan health system with the principles established by the Committee on Economic, Social and Cultural Rights in its general comment No. 14 (2000), namely, availability, accessibility, acceptability and quality of health services.<sup>13</sup>

#### B. Formal, institutionalized and interpersonal discrimination

44. There is no formal discrimination, that is, no laws and/or regulations in force, against persons affected by Hansen's disease in Angola. Nevertheless, incidents of discrimination resulting from the application of laws that appear neutral at face value against persons affected by Hansen's disease reported to the Special Rapporteur during her visit should be duly monitored. Situations of indirect discrimination or institutionalized discrimination in the administration of the State or in State services, including health care, social protection and the justice system, should also be properly monitored and addressed.

45. In general, institutionalized discrimination is inseparable from ongoing interpersonal discrimination. Social isolation, exposure to insults, rejection within the family and in marital relationships, denial of the right to have a proper burial and difficulties in accessing public services and education and in keeping jobs or being accepted for new jobs are common situations faced by persons affected by Hansen's disease and their family members. Restrictions regarding adequate and non-discriminatory care in health-care facilities should be highlighted as they negatively affect the therapeutic processes and self-esteem of individuals, including their health and well-being. Discrimination in health-care services, which is often the reason that persons affected by Hansen's disease drop out of treatment, contributes to the internalization of stigmatization and to self-isolation.

46. During her visit, the Special Rapporteur received reports of various forms of discrimination faced by persons affected by Hansen's disease, including: (a) children being excluded from school as a result of bullying by their peers; (b) discriminatory practices by school teachers owing to lack of information about the disease; (c) abandonment by the family, spousal rejection and neglect of children affected by the disease; (d) children forced to interrupt school activities due to Hansen's disease reactions, and lack of reasonable accommodation in schools; (e) refusal of health workers to admit or to treat affected persons at health facilities because they have the disease; and (f) loss of employment, denial of employment opportunities or inability to perform work because of adverse reactions to drugs, complications of the disease or lack of assistive and protective devices and rehabilitation services.

47. Women, whether themselves affected by Hansen's disease or as family members of persons affected by the disease, suffer from intersections between the disease-related stigma and gender-based discrimination and oppression. In addition to facing severe forms of rejection and discrimination within the household and the family and at the community level, women who are family members of affected individuals also suffer from the consequences

<sup>&</sup>lt;sup>13</sup> Ibid., para. 12.

of discrimination. Furthermore, as family members of persons affected by the disease, women bear the burden of caregiving tasks, including the responsibility for the social and economic costs of the disease. They also suffer from the same rejection and isolation experienced by their family members, especially when the individuals affected by the disease are either their husbands or their children.

48. A harsh, punitive isolation falls upon individuals affected by Hansen's disease, especially women. As one woman affected by the disease living in the Funda health centre explained to the Special Rapporteur:

As soon as the disease contaminated my whole body, neighbours started saying "It contaminates. You don't deserve to stay here in the neighbourhood, you have to stay away." When I was at my family home, I was isolated and they pushed a plate on the floor with a stick to give me food. Since I went to seek medical treatment, I haven't seen my family members, until this day.

49. Persons affected by Hansen's disease suffer from nerve damage that can cause impairments in the hands, as a result of which they face difficulties in providing fingerprints for their national identity cards. Lacking such identification, they are unable to enjoy all of the rights provided for in the International Covenant on Civil and Political Rights. Civil registration services have other official forms of identification, in addition to fingerprints, that can be used by persons affected by the disease, including photos and signatures, and in law and in practice they must guarantee an environment that is free of discrimination and is culturally accommodating. However, the systematic discrimination often faced by individuals affected by the disease makes them fearful of facing intimidation and/or contempt from public officials.

50. During her visit, the Special Rapporteur witnessed a lack of adaptability in health-care services and facilities, as well as a persistence of harmful stereotypes among public servants. On a number of occasions, the Special Rapporteur heard public servants referring to persons affected by Hansen's disease as "lepers", in violation of guideline 9 of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, which prohibits discriminatory language, including the derogatory use of the term "leper" or its equivalent in any language or dialect.

51. Harmful stereotypes about Hansen's disease, which are still widely believed, lead to discriminatory practices. There are, at a minimum, two harmful stereotypes about leprosy: one is the idea that the disease is a curse related to sorcery and/or a person's ancestors and that it is a condition that no traditional healer can heal; the other has its origins in biblical misconceptions, which, in combination with incomplete biomedical information, spurs a fear of contagion and leads to the separation and segregation of people who suffer from the disease.

52. It is worth noting that the introduction of the biomedical notion of contagion, lacking accompanying comprehensive information and education clarifying that Hansen's disease is not easily transmitted, that not all forms of the disease are contagious and that once people begin medical treatment they can no longer transmit the disease, has contributed to increased discrimination against individuals affected by the disease. In the course of her visit, the Special Rapporteur heard interesting reports about people who had not experienced discrimination at the community level and the provision of safety nets by families, based on traditional values of solidarity. In some communities, traditional explanatory models about Hansen's disease were fully included in community life. However, the introduction of the biomedical explanatory model in a fragmented manner, which focused on the idea of transmission, spurred fears about the disease in those same communities.

53. While the provision of family safety nets could be a good practice for eliminating discrimination on the grounds of Hansen's disease, it has unfortunately been suppressed by biomedical conceptions. Without being accompanied by proper health education, biomedical conceptions and practices have enhanced stigmatization and harmful stereotypes about the disease as being dangerous and highly contagious, which could not be further from the truth.

54. The absence of strategies to promote equality and inclusion of persons affected by the disease in relevant government programmes and policies in Angola is a significant gap that contributed in practice to the reproduction and persistence of harmful stereotypes about leprosy and discrimination against this group of people. The elimination of harmful stereotypes about Hansen's disease, which is a key area for action, calls for the integration of civil society organizations and groups, especially groups of persons affected by the disease, into health education and promotion activities. Accountability and engagement in public affairs, which are fundamental and essential for people living in vulnerable situations (whose needs are frequently overlooked), enabling them to defend their interests, are manifestly lacking.

55. Several norms of international human rights law provide that non-discrimination is an immediate and cross-cutting obligation. Both the Committee on Economic, Social and Cultural Rights, in its general comment No. 20 (2009), and the Committee on the Rights of Persons with Disabilities, in its general comment No. 6 (2018), clarify that tackling discrimination is not subject to progressive realization. Guideline 1.1 of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members affirms that States should take all appropriate legislative, administrative and other measures to modify, repeal or abolish existing laws, regulations, policies, customs and practices that discriminate directly or indirectly against persons affected by Hansen's disease and their family members.

56. The Government of Angola should double its efforts to effectively prevent, monitor, investigate, punish and remedy discrimination and human rights violations against persons affected by Hansen's disease and their families. Although Angola has a legal and institutional framework for punishing discrimination and for monitoring and mediating situations of rights violations and abuses, it is worth noting that there are no official records of cases of discrimination in the courts or other types of complaints filed by persons affected by Hansen's disease or by their families with the Office of the Ombudsman or other relevant bodies.

57. Ensuring access to justice for persons affected by Hansen's disease and their families will not be effective if the Government does not act proactively. The existence of harmful stereotypes about the disease and other stigmatizing and discriminatory practices, attitudes and behaviours at the family level, in the community and in State institutions denies persons affected by the disease their rights as citizens, as well as their enjoyment of opportunities on an equal basis with others. The lack of a proactive policy in Angola to promote the human rights of persons affected by Hansen's disease and their families, including strategies ensuring access to information and awareness-raising activities aimed at educating both the general public and public officials and servants, is a significant gap that needs to be addressed.

58. At present, judicial and other State mechanisms with the legal authority to defend and promote human rights are not physically, economically, socially or culturally accessible to persons affected by Hansen's disease and their families. From evidence gathered, it appears that provincial human rights committees do not guarantee accessibility to persons affected by Hansen's disease, nor do they effectively promote human rights education. Human rights education in general, including as part of the national human rights strategy, needs to be enhanced. Efforts to ensure access to justice for persons affected by Hansen's disease must also be considered within the context of legal pluralism in the country.

59. While epidemiological data on Hansen's disease may not be entirely reliable, disaggregated data (not only by demographic, environmental, socioeconomic and cultural variables, but also by the various grounds of discrimination recognized in international human rights law) are manifestly lacking. There is no systematic data on discrimination, human rights violations or standards of living with regard to persons affected by Hansen's disease and their family members. It is a matter of concern that data on incidents of discrimination and human rights violations of persons affected by Hansen's disease are not collected and analysed by the State in a systematic way.

60. Efforts to produce updated and disaggregated demographic and socioeconomic data must be intensified. It should be noted that the last census in Angola was carried out in 2014. At present, there is no integrated information management system upon which to build a

database of relevant demographic, socioeconomic and cultural variables in order to promote an understanding of the situation of persons affected by Hansen's disease. Such a database could be used to support and strengthen public policies aimed at ensuring an adequate standard of living for those affected by the disease.

61. The interest expressed by the Office of the Ombudsman in integrating the promotion and defence of the rights of persons affected by Hansen's disease into its overall work presents a valuable opportunity to establish good practices to fill the data gap, to inform evidenced-based policies and to strengthen accountability.

#### C. Discrimination and substantive equality

62. In its general comment No. 20 (2009) on non-discrimination in economic, social, and cultural rights, the Committee on Economic, Social and Cultural Rights acknowledges that economic growth has not, in itself, led to sustainable development and that individuals and groups of individuals often continue to face socioeconomic inequality because of entrenched historical and contemporary forms of discrimination. The Committee determines that, in order for States parties to guarantee that the rights under the International Covenant on Economic, Social and Cultural Rights are exercised without discrimination of any kind, discrimination must be eliminated both formally and substantively.

63. World Bank data indicate that, in 2018, almost half of the Angolan population lived on less than \$1.90 per day per person, which is below the Bank's extreme poverty line.<sup>14</sup> According to the Multidimensional Poverty Index, which considers four dimensions (health, education, employment and quality of life), 54 per cent of the Angolan population lived in multidimensional poverty during the biennium 2015–2016.<sup>15</sup> Angola ranks 149 out of 182 countries on the human development index; has a score of 0.36 on the human capital index, one of the lowest in the world; and has a Gini coefficient of 0.51, one of the highest in Africa.<sup>16</sup>

64. Structural inequality contributes to the dehumanization <sup>17</sup> of persons affected by Hansen's disease, since discrimination against them clearly intersects with a limited enjoyment of economic and social rights, including an adequate standard of living, decent work, education and social protection.

65. Limited enjoyment of economic and social rights is one of the social determinants of Hansen's disease, as well as other neglected tropical diseases, in particular in the provision of access to clean water, sanitation and hygiene. Data on the evolution of anti-poverty policies and the progress achieved in ensuring clean water and sanitation in the country are not up to date and require greater attention.

66. Based on household surveys in Angola carried out under the WHO and UNICEF Joint Monitoring Programme for Water Supply, Sanitation and Hygiene, overall access to improved water sources increased from 36 per cent in 1990 to 50 per cent in 2008 (38 per cent in rural areas). With respect to sanitation, it is estimated that progress in access to sanitation between 1990 and 2008 increased from 25 per cent to 57 per cent (18 per cent in rural areas).<sup>18</sup> Key aspects of health promotion are related to poverty reduction and ensuring a minimally adequate standard of living, as established in the International Covenant on Economic, Social and Cultural Rights, which has been ratified by Angola.

67. While the vast majority of persons affected by Hansen's disease live in poverty and extreme poverty, the disease brings with it a silent worsening of general living conditions, leading to job losses, denial of decent education and work opportunities and the disruption

<sup>&</sup>lt;sup>14</sup> World Bank, Macro Poverty Outlook: Sub-Saharan Africa (Washington, D.C., 2021).

<sup>&</sup>lt;sup>15</sup> See Government of Angola, *Voluntary National Review on the Implementation of the 2030 Agenda for Sustainable Development* (2021).

<sup>&</sup>lt;sup>16</sup> World Bank, Angola Poverty Assessment (2020), Washington, D.C. Available at https://openknowledge.worldbank.org/server/api/core/bitstreams/ff4600f9-e62d-545c-9f86-1fc07b3a3581/content.

<sup>&</sup>lt;sup>17</sup> On the concept of dehumanization, see A/HRC/41/47.

<sup>&</sup>lt;sup>18</sup> See Government of Angola, *Voluntary National Review*.

of family, community and social ties. The worsening of health conditions also leads to additional costs, including transportation costs related to treatment, expenses for medication to treat Hansen's disease reactions, ulcers and other complications and expenses associated with impairments and disabilities caused by the disease.

68. In testimonies collected during the Special Rapporteur's visit, it was emphasized that the disease results in the perpetuation of economic and social disadvantages, compounded by disease-specific discrimination and stigmatization. The Special Rapporteur witnessed how people under treatment for Hansen's disease invariably lacked the means and resources to cope in a way that would ensure their autonomy. The lack of social protection from the State places people affected by the disease in a dependent position, reliant on their families or on charitable organizations. This situation goes against the provisions of article 19 of the Convention on the Rights of Persons with Disabilities, on living independently and being included in the community.

69. In situations where the disease has resulted in the rupture of community and family ties, the condition of isolation faced by individuals affected by Hansen's disease is even more serious. The Special Rapporteur witnessed how, as a result of discrimination, many persons affected by Hansen's disease, and sometimes their family members, ended up living isolated from their families and communities, often inside or near former sanatoriums for the disease, without enjoying access to basic services or to a minimum standard of living.

70. Importantly, guideline 5.1 of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members affirms that States should identify persons affected by Hansen's disease and their family members living in isolation or segregated from their communities because of their disease and should give them social support. Guideline 5.4 further asserts that States should consult with people affected by the disease on matters regarding their reintegration into the community, in case they prefer to remain living in the leprosariums and hospitals that have become their homes, and should strive to improve living conditions in such places.

71. Persons affected by Hansen's disease are right to call for a more active role of the State in ensuring a minimum standard of living, beyond the provision of pharmaceutical treatment. As stated by one individual affected by the disease:

The first thing we need is treatment; the second thing we need is food. In the state we are in, we really need help because our families have already abandoned us. Regarding treatment, they treat us very well, but what we really need is food because we are in a very bad situation here at the health centre.

72. The enforcement of disability rights is essential for the promotion of substantive equality for persons affected by Hansen's disease in Angola. The fundamental rights enshrined in the Convention on the Rights of Persons with Disabilities are still not duly enforced in the country, despite the fact that the Convention was ratified by Angola and that several laws to protect persons with disabilities have been enacted. Persons affected by Hansen's disease do not enjoy accessibility, rehabilitation services, reasonable accommodation or support, which compromises their right to live independently and to be included in the community. Furthermore, they do not enjoy the social protection benefits that could support their active citizenship and their participation in the formal work market.

73. Decisions, policies and programmes aimed at recognizing and guaranteeing the human rights of affected persons and their family members must be based on the principle of human dignity. It is up to the State to ensure an enabling environment for persons affected by Hansen's disease and their family members so that they can develop their full potential, enjoy the highest degree of protection and have their role as powerful agents of social change recognized, as stated in principle 8 of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members.

# **D.** Shrunken civic space and lack of options for promoting active citizenship

74. Civil society organizations have been developing their intervention strategies in a restricted civic space. The Government of Angola has not yet fostered a politically stimulating environment for the inclusion of critical and dissident voices. The same can be said about participation rights and the oversight of government actions by civil society. As a result, most organizations and activists avoid issues of governance, transparency and democracy, including oversight and accountability of public institutions and civil servants.<sup>19</sup>

75. The Government of Angola accommodates a diversity of interests and agents in a multifaceted structure, which is fragmented into several layers of authority, within which it is difficult to identify clear responsibilities. The structure of the State makes it difficult for civil society organizations to find avenues to make their demands heard, as well as to call for transparency and accountability in public management. In an extremely unequal country, where the lack of substantive equality is a pressing problem, such a limited civic space creates ever more restrictions on the civic and political participation of people living in vulnerable situations. Groups that experience structural discrimination, such as persons affected by Hansen's disease and their families, who already face multiple barriers to obtaining minimal standards in their enjoyment of human rights, must struggle harder to find the means for the exercise of their active rights as citizens and their participation in public affairs, as well as in all other matters that impact their lives.

76. In addition to the limited civic space, there are no strategies in place to enhance greater synergy and cooperation between the actions of the State and the work of civil society organizations dedicated to supporting persons affected by Hansen's disease. This reality is further compromised by the significant lack of action to promote the civic participation, engagement and active citizenship of persons affected by the disease. An active civil society, with the meaningful participation of persons affected by the disease and their family members, is a key element for the achievement of the strategic goals to stop the transmission of the disease in the country and to guarantee human rights to those affected.

## V. Conclusions and recommendations

## A. Conclusions

77. Within the normative and institutional framework in place in the country, the Government of Angola has the capacity to protect, promote and fulfil the rights of persons affected by Hansen's disease and their family members. De facto discrimination against affected persons and their family members persists in harmful attitudes, practices and behaviours. The persistence of harmful stereotypes that are not systematically tackled by the State contributes to the continuation of discriminatory practices that contaminate the performance of institutions and the behaviour of State officials. Structural barriers blocking the access of persons affected by Hansen's disease and their family members to economic, social and cultural rights act as powerful social determinants for the continued existence of the disease in the country. Pressing issues that need to be addressed with urgency include: (a) data collection to inform evidencebased policies and enable accountability; (b) monitoring and evaluation mechanisms; (c) proper budget allocation at the national and subnational levels, with targets, indicators and benchmarks; and (d) guarantees of the right to participation. Mechanisms that can ensure accountability, transparency and access to information, as well as physically, culturally and economically accessible channels for filing complaints and referring them to the relevant authorities, as well as for ensuring effective access to justice and remedies, are critical in order to ensure equality for persons affected by Hansen's disease, including equitable access to State services and to an adequate

<sup>&</sup>lt;sup>19</sup> See Inge Amundsen and Cesaltina Abreu, *Civil Society in Angola: Inroads, Space and Accountability* (Bergen, Norway, Chr. Michelsen Institute (2006)).

standard of living. Gender, age and disability intersect with Hansen's disease-related discrimination, producing specific restrictions for women, children, older persons and persons with disabilities with regard to their enjoyment of the rights to nondiscrimination, equality, dignity, health, education, work, accessibility, reasonable accommodation and support, independent living and inclusion in the community, as well as for overcoming poverty and violence. These groups need targeted interventions in terms of empowerment, capacity-building and safety net generation. Such strategies require that policymaking be supported by a qualified collection of disaggregated data, taking demographic, environmental, socioeconomic and cultural variables into account. In addition, policymaking must always include meaningful consultation with persons affected by Hansen's disease, their family members and representative organizations.

#### **B.** Recommendations

78. The Special Rapporteur recommends that the Government:

(a) Make every effort to combat pervasive substantive discrimination, considering both the social determinants of Hansen's disease and the systemic roots of discrimination and develop policies that include redistributive measures aimed at ensuring a minimum standard of living and stigma-reduction strategies, including guarantees for the autonomous development and independent living of persons affected by Hansen's disease and their family members, with special measures in the areas of education and vocational training, decent work and social protection;

(b) Duly recognize persons affected by Hansen's disease and their family members as rights holders rather than recipients of charity and ensure their participation in relevant policymaking processes; civic space should be respected and the work of the organizations of persons affected by Hansen's disease duly enabled;

(c) Ensure that sufficient public resources are mobilized, allocated and effectively utilized to fully implement the human rights of persons affected by Hansen's disease and their family members, consider the intersectional dimension of discrimination, including the implementation of special measures to address the situation of women, children, older persons and persons with disabilities, and guarantee sufficient resources to sustain expertise on Hansen's disease in the country and to ensure high-quality research and teaching at medical schools on the disease;

(d) Enhance the systematic collection of data that are disaggregated not only by demographic, environmental, socioeconomic and cultural variables but also by the various grounds of discrimination recognized in international human rights law, with full respect for the principles of participation and privacy; such data should be made transparent and people's right of access to information should be fully guaranteed;

(e) Approve legislation to officially change the name of the disease to Hansen's disease in order to prohibit discriminatory language and to fight against persisting harmful stereotypes;

(f) Enforce access to justice and human rights literacy for persons affected by Hansen's disease and their family members, make existing complaints mechanisms accessible to persons affected by the disease or establish complaints mechanisms within primary health-care services and at former sanatoriums and/or communities; provide information through primary health-care services on the rights of users, the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members and the WHO guidelines for strengthening the participation of persons affected by leprosy in leprosy services and put in place a robust human rights education strategy, in close cooperation with civil society, traditional leaders and healers and, in particular, with women;

(g) Duly enforce the rights enshrined in the Convention on the Rights of Persons with Disabilities and develop, as part of the national human rights strategy, a national plan for the implementation of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, in close consultation with persons affected by Hansen's disease, their family members and their representative organizations;

(h) Ensure that the health system is capable of guaranteeing, for all persons affected by Hansen's disease and their family members in all regions of the country: access to good quality health services; accessibility without discrimination; physical and economic accessibility; accessibility of health information; active and informed participation of individuals and groups of persons affected by Hansen's disease in decision-making processes about health policies and programmes; monitoring and accountability mechanisms on the performance at all levels of the administration of effective, transparent and accessible health programmes designed to ensure early diagnosis of Hansen's disease, prevention of impairment and sustainable reduction of new cases among children; and education of the health workforce on the rights of persons affected by Hansen's disease and their family members;

(i) Give special attention to strengthening the health-care system and universal health-care coverage, giving priority to primary health care, and implement the four pillars of the WHO Global Leprosy Strategy (2021–2030), with proper budget allocation at the national and subnational levels, including targets, indicators and benchmarks enabling monitoring, evaluation and accountability;

(j) Prioritize primary prevention through multisectoral policymaking and action and, to that end, fight poverty and diseases of poverty, including Hansen's disease, through redistributive policies and the establishment of 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, and provide a universal basic income for persons affected by Hansen's disease, including those living in former Hansen's disease hospitals;

(k) Involve communities as co-producers of health and partner with persons affected by Hansen's disease in order to strengthen peer-to-peer counselling, as well as family-based counselling, and promote mental health care for persons affected by Hansen's disease and for their family members under a recovery-based paradigm and through services that are ethical, respectful, culturally appropriate, gender-sensitive and empowering to individuals;

(1) Ensure continuity and enhance cooperation with the special procedures of the Human Rights Council in order to advance progress in key areas of concern in the country, especially those related to substantive discrimination, and use its leadership in international forums, such as the African Union and the Community of Portuguesespeaking Countries, to eliminate discrimination based on Hansen's disease through joint action.