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Elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members

Note by the Secretary-General

The Secretary-General has the honour to transmit to the General Assembly the report of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members, Beatriz Miranda-Galarza, in accordance with Human Rights Council resolution 44/6.

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Report of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members, Beatriz Miranda-Galarza

Care and support for persons affected by leprosy (Hansen's disease) and their family members from a human rights perspective

Summary

In the present report, the Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members, Beatriz Miranda-Galarza, examines care and support for persons affected by leprosy and their families through a human rights lens. In her report, the Special Rapporteur presents the first-hand experiences of those affected by leprosy and offers guidance to States on ensuring rights-based care and support, emphasizing people's participation. The report also contains an overview of the activities undertaken by the Special Rapporteur since her appointment in October 2023.

In her report, the Special Rapporteur highlights the urgency of integrating leprosy into global discussions on human rights-based care and support aligned with the Sustainable Development Goals and underscores the significant workload borne by persons and families in caring for affected relatives. She calls for the shared responsibility of families, communities, States and the private sector to be recognized.

The Special Rapporteur identifies a persistent gap in the representation of caregivers and receivers of care and support in the development and implementation of laws, policies and programmes related to care and support, partly stemming from historical misconceptions of leprosy care and support as merely charitable. In addition, valuable insights from the leprosy field on self-care are often overlooked due to the limited participation of affected persons in decision-making processes.

The Special Rapporteur expresses her gratitude for the support and feedback received from persons affected by leprosy, disability rights activists, the Special Procedures Branch of the Office of the United Nations High Commissioner for Human Rights, and various United Nations agencies actively engaged in advancing a human rights-based approach to care and support for persons affected by leprosy.

Contents

I. Introduction

1. In accordance with Human Rights Council resolution 35/9, the Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members reports annually to the Council, and to the General Assembly. In the present report, the Special Rapporteur sets out the urgency of implementing a human rights-based care and support system for persons affected by leprosy, identifying key definitions, challenges and opportunities for persons, families, communities and governments. The report includes some key elements to rethink leprosy care and support from a human rights perspective. It concludes with a brief overview of the activities carried out by the Special Rapporteur, as well as some conclusions and recommendations.

2. The present report is based on insights gathered from group interviews organized by the Special Rapporteur, engaging persons affected by leprosy from countries including Brazil, Colombia, the Democratic Republic of the Congo, India, Indonesia, Kenya, Liberia, Myanmar, Nepal, Peru, Senegal, Sierra Leone and Timor-Leste. Consultations were also held with United Nations experts, disability advocates, academic scholars specializing in the field, and representatives from international leprosy organizations. A comprehensive questionnaire was distributed to Member States, national human rights institutions, United Nations agencies, civil society groups, and organizations representing persons affected by leprosy. The report synthesizes the findings of a literature review encompassing journal articles and reports on leprosy, disability and related topics, such as gender, children, care and support for older persons, and social protection. It also integrates insights from previous reports of other special procedures mandate holders covering the themes of disability, health, poverty and older persons.

3. The present thematic report addresses the needs of persons affected by leprosy regarding access to care and support. Untreated leprosy can cause impairments, and even after eliminating the bacteria, chronic pain, impairments and long-term conditions may persist due to treatment reactions. These issues are worsened by inadequate medical support, poor diet, insufficient rest, emotional conditions and underlying health issues, all of which are exacerbated by poverty and inequality. Care and support are therefore crucial at all stages of the disease: diagnosis, treatment and post-treatment.

4. The centuries-long reduction of leprosy to solely a medical condition has limited discussions about care and support to health-related care and support and provision issues. During dialogues with persons affected by leprosy, the Special Rapporteur identified the need to shift the focus to include leprosy in the broader agenda of care and support that has also been envisioned in the mandates of the Special Rapporteur on the rights of persons with disabilities, the Independent Expert on the enjoyment of all human rights by older persons, the Working Group on discrimination against women and girls, and the Special Rapporteur on human rights and extreme poverty, all aligned with the Sustainable Development Goals.

5. Discrimination based on false information, myths and lack of awareness on the part of communities, professionals and authorities end up limiting the access of persons affected by leprosy and their families to various sectors and services, including health care, social security, education, work, water and sanitation, electricity, accessible and adequate household arrangements, leisure and independent living, all of which are components of the care and support agenda.

6. The Special Rapporteur also considered a life course approach. Given that children, young people, adults and older persons can face leprosy and its effects throughout their lives, a life course approach helps to identify the specific needs of

each generational group, as well as commonalities across them. A life course approach also helps to visualize an integral understanding of the impact of the disease, which is often lifelong, even for persons without an impairment, and to address the multifaceted and evolving needs of persons affected by leprosy, through the provision of policies and tailored interventions during the different stages of their lives.

7. In her report, the Special Rapporteur employs a gender transformative approach to discuss the situation of women and girls as both caregivers and receivers of care and support. Cultural practices and social inequalities have often impeded discussions about redistributing care and support responsibilities within families. In many countries, care is historically viewed as a natural skill that women and, in many places, children possess and are obliged to perform within their families and communities.

8. Issues about children and older persons with leprosy-related disabilities are not dismissed in the report. It is evident that one of the questions regarding care and support in current times is related to the fact that by 2050, the proportion of the world's population aged 60 and above will nearly double, with profound consequences for care and support systems.[1]

9. In her report, the Special Rapporteur takes into consideration the current century's crisis in care and support that societies are experiencing due to issues such as increased poverty, the breakdown of health systems, the impact of climate change, conflicts and wars, and migration, particularly among poor populations. These issues contribute to and, in some cases, are exacerbated by the rising number of people facing mental health conditions, as well as the long-term effects of coronavirus disease (COVID-19). Such challenges are familiar to persons dealing with various health conditions, disabilities and, of course, leprosy. The COVID-19 pandemic has exacerbated the unequal distribution of care and support responsibilities, burdening families and particularly women in the global South. Often, women affected by leprosy also serve as primary caregivers under unjust and unpaid conditions. This aggravates their already difficult situations and negatively impacts overall family conditions.

10. Feminist movements and their allies worldwide, such as civil society, together with representatives of organizations of populations that have historically been marginalized, have driven the discussion about policies and social and economic programmes that address integral and inclusive care and support with a human rights perspective. These actions have resonated with other social movements, such as the disability rights movement, and within various United Nations entities and governing bodies, as well as regional mechanisms such as the European Commission.[2]

11. The Special Rapporteur welcomes the resolution on promoting care and support systems for social development[3] approved in February 2024 by the Commission for Social Development of the Economic and Social Council. In it, the Council urges States "to ensure the creation of enabling environments for promoting care and support systems for social development and implement all measures necessary to ensure the well-being and rights of care recipients and caregivers, to recognize and redistribute care work among individuals, as well as families, communities, the

[1] World Health Organization, "Aging and health", fact sheet, 1 October 2022. Available at www.who.int/news-room/fact-sheets/detail/ageing-and-health.

[2] International Labour Organization, United Nations Entity for Gender Equality and the Empowerment of Women (UN-Women), Office of the United Nations High Commissioner for Human Rights, United Nations Children's Fund, World Health Organization, United Nations Development Programme, General Assembly of the United Nations, Economic and Social Council, Human Rights Council and International Labour Conference.

[3] E/CN.5/2024/L.5.

private sector and States, and to contribute to the achievement of gender equality and the empowerment of all women and girls".

12. Other important highlights are Human Rights Council resolution 54/6 on the centrality of care and support from a human rights perspective, adopted in October 2023, and General Assembly resolution 77/317 establishing the International Day of Care and Support, to be commemorated annually on 29 October. In resolution 77/317, the Assembly emphasizes the critical role of both paid and unpaid care work and stresses the need for substantial investments and policy improvements in the care and support system.

13. In the present report, the Special Rapporteur invites Member States, civil society organizations, international donors and the private sector to implement strategies that ensure the participation of persons affected by leprosy in the consultation, design and implementation of inclusive and integral policies and social programmes addressing care and support. The Special Rapporteur also calls on United Nations agencies, bodies and international organizations to rethink the definition of care and support, taking into consideration the demands, needs and experiences of persons affected by leprosy and their families. The progress they have made in areas such as self-care offers valuable lessons for other fields and human rights movements.

II. Care and support: semantics, definitions and normativity

14. To understand the significance of care and support in the field of leprosy and the need to rethink care and support from a human rights perspective, it is necessary to consider the basic aspects of leprosy and review data that can help connect the realities of persons affected by leprosy and their families with current discussions about care and support systems.[4]

15. Leprosy, also known as Hansen's disease, is a chronic infectious disease caused by the bacterium Mycobacterium leprae. It primarily affects the skin, peripheral nerves, mucosa of the upper respiratory tract and eyes. It is known for causing skin lesions, nerve damage and deformities, which lead to visible and invisible impairments, especially in untreated cases. It is not highly contagious but can be spread through respiratory droplets from an infected person, although prolonged close contact is usually required for transmission. With appropriate diagnosis and treatment using multidrug therapy, it is curable. Diagnosis and treatment is also crucial in preventing and minimizing long-term complications and reducing transmission of the disease.

16. In 2019, leprosy data reported by 161 countries to the World Health Organization (WHO) showed that 202,256 new cases were detected in 118 countries. Of those, 96 per cent were reported by the 23 global priority countries, including 79 per cent in India, Brazil and Indonesia. In total, 10,816 new cases in 94 countries, including 370 children, presented with grade 2 disabilities at the time of diagnosis. Of the new cases, 38.9 per cent were female, and 7.4 per cent were children. The number of children is likely to be significantly higher, as some countries did not report data on grade 2 disabilities in children. Detection of cases in children is considered an indicator of recent transmission of infection in the community. Globally, the new case detection rate for those aged 0 to 14 years was 7.9 per million children.

17. Persons affected by leprosy can experience a variety of reactions both during and after treatment. These reactions are important to recognize and manage because they can significantly impact the patient's health, causing impairment and lifelong

[4] The data presented in the present report have been taken from World Health Organization, *Towards zero leprosy. Global Leprosy (Hansen's disease) Strategy 2021–2030* (New Delhi, 2017).

illness that will necessarily have an effect on quality of life. According to WHO, in the absence of verifiable data, it is estimated that 3–4 million people are living with visible impairments or deformities due to leprosy. Leprosy-related disabilities can negatively affect a family's daily income due to job losses and increased family expenses for medical and rehabilitation costs, intensifying other challenges faced by families affected by leprosy.

18. Myths, false information, misunderstandings and lack of reliable data not only affect the detection and treatment of persons affected by leprosy, but also hinder the prevention and identification of new cases, as well as the treatment of those who are aware of being infected, especially within families that already have a relative affected by the disease. In 2019, 56 countries (35 per cent) reported the availability of counselling services, which is significant given the mental health consequences of leprosy diagnosis, disability, discrimination and social exclusion. The workload carried by both caregivers and receivers of care due to limited support from States and communities also contributes to critical mental health conditions experienced at individual, family and community levels. The physical, social, mental, emotional, cultural, political and economic aspects of leprosy have historically been viewed as disassociated and unconnected. This has led to a fragmented understanding of care and support, often excluding considerations of gender, class, ethnicity and race, religion, age and geographical background.

19. Against this background, the Special Rapporteur proposes rethinking the understanding of care and support that has predominated in the field of leprosy and influenced political, social and economic spaces. Considering care and support from a human rights perspective requires reimagining the conditions of persons affected by leprosy as human rights holders whose lives are affected by issues such as income generation, gender inequality, age, and social class disparities.

A. What is care?

20. The issue of care raises important questions regarding its definition, the social actors involved, and its implementation. While the answers to these questions may vary based on context and historical circumstances, it is clear that care is fundamental to any proposal addressing human development. In the words of the Executive Director of the United Nations Entity for Gender Equality and the Empowerment of Women (UN-Women), Sima Bahous, "care is the thread that weaves across our societies and underpins all aspects of our daily lives and well-being".[5]

21. The notion of care has become central to the analysis and research of social protection policies and programmes aimed at marginalized populations, such as women and children, persons with disabilities, older persons and those with chronic diseases. Issues of citizenship and rights within the private and public spheres where care takes place are crucial when proposing a care and support system in any society, especially when aiming for a consensual concept of care. These discussions began to take shape in the academic and feminist sectors during the 1960s and have been reactivated, particularly in the light of the COVID-19 pandemic and its social and economic effects.

22. Care could be defined as "an ethical framework that emphasizes responsibility, attentiveness, and responsiveness to the needs of others".[6] This approach prioritizes

[5] Closing remarks delivered at the inaugural commemoration of the International Day of Care and Support at the Headquarters of the United Nations on 31 October 2023. Available at www.unwomen.org/en/news-stories/speech/2023/10/speech-international-day-of-care-and-support-2023.

[6] J. C. Tronto, "An ethic of care", *Generations*, vol. 22, No. 3 (1998).

empathy and the nurturing of relationships over abstract principles and rules. According to Joan Tronto, a political theorist who has contributed to the development of care ethics, there are five interconnected phases of care:

(a) Caring about: recognizing the need for care;

(b) Caring for: taking responsibility to meet the need;

(c) Caregiving: directly meeting the needs, often involving physical labour;

(d) Care receiving: the response of the person receiving care, which provides feedback on the effectiveness and adequacy of care and support;

(e) Caring with: this involves collective responsibility, and the recognition that caring for others demands justice, solidarity and mutual and reciprocal care.[7]

23. At a more institutional level, care is seen as "an indispensable social function for the sustainability of life that encompasses the activities that daily and generationally regenerate the physical and emotional well-being of persons, including everyday tasks related to the management and sustenance of life, such as the maintenance of domestic spaces and goods, and the education and development of persons, among other aspects".[8]

24. Although in democratic societies, care should generally involve a balanced relationship between families, communities, organizations, the State and the private sector, its practice has been relegated to families, especially to women and girls, in lower and middle-income countries, promoting and deepening inequalities. This effect has highlighted the public nature of care and support and underscored that it cannot be discussed solely as a private issue. It has also brought to the forefront elements that are transversal and often overlooked, such as ableism and discrimination based on gender, race, social class, age and place of residence.

25. The interplay between the private and public spheres has been a key factor in shaping a paradox, where the division of time, efforts, responsibilities and resources has also implied inequality and discrimination, particularly against women and even children. The paradox of care refers to the distinction between its legal and economic dimensions and its moral and emotional ones. Historically understood as a selfless act between human beings (and, lately, towards other species), care has essentially been exercised between family members, friends and close relatives and been unpaid. However, it has also involved economic compensation when provided by persons external to the families and as a labour action.

26. In this sense, current discussions on integral and inclusive care and support systems consider various aspects to be incorporated in their design and implementation. Such aspects include the regulation and supervision of services, working conditions of caregivers, and time policies; the creation and expansion of services; the training of caregivers; information and knowledge management; the participation of receivers of care and support; and communication to promote cultural change.[9] Furthermore, the discussions have also highlighted the need to ensure that specific groups in vulnerable conditions, such as older persons, persons with disabilities, children, and persons with chronic diseases, are considered as partners in the design and structuring of care and support systems. Such systems must incorporate

[7] J. Tronto, "Democratic caring and global responsibilities for care", paper presented at the annual meeting of the Western Political Science Association, Hollywood, United States of America, March 2013.

[8] EU-LAC Foundation and others, *Hacia políticas y sistemas integrales de cuidados con las personas en el centro: diálogos entre América Latina, el Caribe y la Unión Europea* (2023).

[9] Ibid.

the participation of those identified as receivers of care and support, who, in different situations, could also be playing the role of caregivers.

B. What is support?

27. In the present section, the Special Rapporteur builds on the work of previous Special Rapporteurs on the rights of persons with disabilities, who have also addressed the issue of care and support in alignment with the Convention on the Rights of Persons with Disabilities, as discussed in her previous report (A/HRC/56/59). The Special Rapporteur also draws on a number of resolutions adopted by the Human Rights Council related to support and care,[10] as well as the report of the Office of the United Nations High Commissioner for Human Rights on good practices of support systems enabling community inclusion of persons with disabilities (A/HRC/55/34). In each case, support has been presented from a human rights perspective and as a demand that is integral to persons' experiences and responsive to cultural and contextual elements.

28. Support refers to "the act of providing help or assistance to someone who requires it to carry out daily activities and participate in society. Support is a practice, deeply embedded in all cultures and communities, that is at the basis of all our social networks".[11] Like care, support has been historically undervalued and medicalized, leading to its importance being overlooked when addressing matters of rights. The disability rights movement has made significant progress in discussions, particularly regarding the support needed to ensure the participation of persons with disabilities in society and politics. It has also raised concerns that the required support for persons with long-term conditions, impairments, chronic pain and terminal diseases is often seen as irrelevant, and their support needs frequently neglected. Support encompasses considerations of material, emotional and mental assistance needed in everyday life, which vary across cultures, contexts and different stages of a person's life. It involves both formal and informal interventions, including live assistance, mobility aids and assistive devices, personal assistance, decision-making support, communication support, mobility support, services for securing housing and household help, and community services. In addition, it includes the necessary support for persons to access and use general services such as health, education and justice.[12]

29. Considering support systems as a set of resources and strategies aimed at promoting the development, interests, quality of life and autonomy of persons, they are undoubtedly an essential factor for reducing poverty, isolation, and preventable impairments and deaths among socially, economically and geographically at-risk groups. The discussion about access to support and care from a human rights perspective is now more urgent than ever, given the new challenges societies face regarding climate change, displacement, conflict and war, natural disasters, migration, and potential future pandemics.

C. Care and support systems: normative frameworks

30. Care and support for persons with chronic illnesses and disabilities are explicitly recognized and protected under several international human rights instruments and treaties. Such documents provide a framework for ensuring that persons with chronic illnesses and disabilities receive appropriate care, support and protection to live with dignity and full participation in society. The Special Rapporteur considers it relevant

[10] Human Rights Council resolutions 28/4, 40/14, 43/13, 47/15 and 54/6.
[11] A/HRC/34/58.
[12] A/HRC/34/58 and A/HRC/56/59.

to examine these key instruments so that governments, international organizations and grassroots organizations can use them to support their work. They also serve as a reference for the movement of persons affected by leprosy to claim their rights.

31. The Universal Declaration of Human Rights recognizes, in its article 25 (1), the right to an adequate standard of living, including food, clothing, housing, medical care and necessary social services. Article 25 (2) emphasizes the right of mothers and children to special care and assistance.

32. The International Covenant on Economic, Social and Cultural Rights recognizes the right of everyone to social security (article 9), to an adequate standard of living (article 11), and to the enjoyment of the highest attainable standard of physical and mental health (article 12).

33. The Convention on the Rights of Persons with Disabilities, in its article 19, on living independently and being included in the community, recognizes the right of persons with disabilities to have access to in-home, residential and other community support services. Article 25 recognizes the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. Article 26 mandates that States Parties shall provide comprehensive rehabilitation services and programmes in the areas of health, employment, education and social services. Article 28 recognizes the right of persons with disabilities to an adequate standard of living and to social protection.

34. The Convention on the Elimination of All Forms of Discrimination Against Women protects the right to social security, particularly in cases of retirement, unemployment, sickness, invalidity and old age (article 11 (1) (e)), and access to health-care services, including those related to family planning (article 12).

35. The Convention on the Rights of the Child recognizes the right of every child to the enjoyment of the highest attainable standard of health and access to health-care services (article 24), to benefit from social security (article 26), and to a standard of living adequate for the child's physical, mental, spiritual, moral and social development (article 27).

36. The International Labour Organization (ILO) Vocational Rehabilitation and Employment Convention, 1983 (No. 159) promotes the provision of vocational rehabilitation and employment opportunities for persons with disabilities. The ILO Social Protection Floors Recommendation, 2012 (No. 202) encourages the establishment of social protection floors that provide access to essential health care and income security, especially for those unable to earn sufficient income due to chronic illness or disability.

37. There are also regional instruments that must be taken into consideration, such as the European Social Charter, which guarantees the right to social and medical assistance, social security, protection of health, and social welfare services. The African Charter on Human and Peoples' Rights recognizes the right to health and social security. The American Convention on Human Rights protects economic, social and cultural rights, including the right to health and social security.

38. The 2030 Agenda for Sustainable Development adopted in 2015 includes goals that refer directly to care and support. Sustainable Development Goal 3, on ensuring healthy lives and promoting well-being for all at all ages, includes targets related to universal health coverage and access to quality health-care services. Goal 10, on reducing inequality within and among countries, emphasizes the social, economic and political inclusion of all, including persons with disabilities. Goal 11, on making cities and human settlements inclusive, safe, resilient and sustainable, promotes access to safe and affordable housing and basic services.

39. The Human Rights Council has adopted several resolutions related to support and care, including resolution 54/6, which highlights the centrality of care and support from a human rights perspective. In it, the Council calls for the recognition of care work, the promotion of care and support systems, and the implementation of measures to ensure the well-being and rights of both caregivers and care recipients. The Council also underscores the importance of creating gender-responsive and inclusive care and support systems.

40. The Special Rapporteur also considers it important to mention the World Health Organization (WHO) guidelines for strengthening participation of persons affected by leprosy in leprosy services. The guidelines recognize the crucial role that persons affected by leprosy and their families play in transforming health and care and support services with a person-centred approach. Including persons affected by leprosy in decisions about the care and support they need results in their empowerment and fosters community development.

41. The United Nations principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members are also relevant and must be considered within the debate about care and support from a human rights approach. They provide a framework to ensure the rights and dignity of persons affected by leprosy. Key aspects related to care include access to services and support without discrimination, comprehensive care, promotion of community-based rehabilitation programmes, health education, training of service providers and legal protection.

III. Lived experience of care and support of persons affected by leprosy and their families

42. For the following section, the Special Rapporteur collected information from persons affected by leprosy, grass-roots organizations and representatives of donor organizations through online workshops and interviews. In total, 80 persons from different parts of the world participated in these dialogues. The questions focused on the issues of daily care and the support that affected persons and their families receive from communities and governments. Information has also been collected continuously through informal channels, such as WhatsApp groups, which have been established by the Special Rapporteur to facilitate direct dialogue with people.

43. Participants in the dialogues described care as “the opportunity to access a normal life through inclusion in regular systems such as health, education, employment, leisure, social, and community life”. Generally, care and support were seen in relation to strategies implemented by governments and communities to assist persons affected by leprosy in improving their health. These categories were also linked to social and economic advancement. Specifically, support was referred to as access to medication, treatment, rehabilitation and financial assistance, particularly for individuals experiencing permanent impairments or long-term chronic conditions. According to one interviewee, the fact that care and support for affected persons are primarily related to medical and financial aspects reflects the historical approach to “caring for” persons affected by leprosy, which often excluded their involvement in decision-making, presenting care and support as a disease-centred issue instead of a person-centred one.

A. From an institutional perspective to a human rights approach of care and support

44. In her previous report,[13] the Special Rapporteur highlighted that modern care and support for leprosy has often been institutionalized, neglecting the rights of affected persons. Settlements and hospitals have treated these persons as dependents rather than rights holders. Despite this, many patients appreciated the accurate medical treatment in dedicated leprosy hospitals. Consequently, the concept of care and support has been undervalued and misrepresented in the field of leprosy.

45. The Special Rapporteur notes that this issue is common in various health fields, including disability and mental health. Before the nineteenth century, care for leprosy in some cultures could have been seen as segregation rather than abandonment. Recent archaeological studies in England[14] reveal that medieval shelters treated leprosy patients communally rather than as segregated persons, although care varied by social class. With the establishment of leprosaria and hospitals, care was often provided by religious orders and sometimes by laypeople.[15] The quality of care varied significantly based on location, resources and attitudes towards leprosy.[16] It is important to underline the role that patients themselves played as caregivers for others, due to neglect from official caregivers. Testimonies collected from persons affected by leprosy who lived in colonies, leprosaria and, later, hospitals reveal how they played an important role as caregivers and self-carers.[17] Shared experiences, community bonds and the need to survive led patients to provide essential care and support to one another in the absence of adequate external support.[18] This was also possible as patients often learned caregiving skills through experience and observation. They organized themselves to manage daily life aspects, ensuring that everyone's needs were met despite being secluded. Unfortunately, patients were also often obliged to ensure that no one left the facility due to societal fears and misconceptions about the contagious nature of the disease.[19] Methods included physical barriers, surveillance, strict internal regulations, and self-policing among patients. This could be due to a sense of community responsibility or fear of collective punishment.

46. Many leprosaria, colonies and specialized leprosy hospitals began to close from the mid-twentieth century onwards, with the process accelerating after the introduction of multidrug therapy in the 1980s.[20] Maintaining these institutions was expensive, and there was a shift towards community-based health services to provide more comprehensive and less stigmatizing care and support. This transition shifted

[13] A/HRC/56/59.

[14] Simon Roffey, "Medieval leper hospitals in England: an archaeological perspective", *Medieval Archaeology*, vol. 56, No. 1 (November 2012), pp. 203–233.

[15] Kathleen Vongsathorn, "Gnawing pains, festering ulcers and nightmare suffering: selling leprosy as a humanitarian cause in the British empire, c. 1890–1960", *The Journal of Imperial and Commonwealth History*, vol. 40, No. 5 (December 2012), pp. 863–878.

[16] Z. Gussow and G. S. Tracy, "Stigma and the leprosy phenomenon: the social history of a disease in the nineteenth and twentieth centuries", *Bulletin of the History of Medicine*, vol. 44, No. 5 (1970), pp. 425–449.

[17] James L. Flexner, "An institution that was a village: archaeology and social life in the Hansen's disease settlement at Kalawao, Moloka'i, Hawaii", *International Journal of Historical Archaeology*, vol. 16, No. 1 (March 2012), pp. 135–163.

[18] Chryssi Bourbou, "The leprosarium of Spinalonga (1903–1957) in eastern Crete (Greece)", *Eres. Arqueología/Bioantropología*, vol. 14 (2006), pp. 121–136.

[19] Susan L. Burns, "From 'Leper Villages' to Leprosaria: Public Health, Nationalism and the Culture of Exclusion in Japan", in *Isolation*, Alison Bashford and Carolyn Strange, eds. (London, Routledge, 2003).

[20] Dorothy McMenamin, "Out of Sight and Out of Mind: The Ongoing Problem of Treating Leprosy", *The Journal of Pacific History*, vol. 52, No. 3 (2017), pp. 343–359.

care for leprosy patients to the community and families.[21] Health-care systems were often not equipped to provide specialized care and support for leprosy. Many countries lacked the resources for comprehensive care and support systems, placing the financial and caregiving workload on families and communities.[22] Cultural factors need to be considered here too, as in many cultures, there is a strong expectation that families will take care of and support their ill, impaired or older members.[23] Women bear a significant workload of care due to gender stereotypes of caregiving as a female characteristic, which in many cultures gives them recognition and a role within the family and community. In addition to household responsibilities, economic hardships, navigating the health-care system, and mental health struggles, women must also balance their roles in both public and private spheres.

47. The movement advocating for the rights of persons affected by leprosy offers an opportunity to improve care and support systems. A human rights-based approach emphasizes the agency and autonomy of affected persons, contrasting with traditional, disease-based care and support models. However, to build this approach, it is important to listen to the experiences and demands of persons affected by leprosy, their families, and the sectors involved in leprosy care.

B. Access to medical and rehabilitation services is essential for understanding leprosy care and support

48. Persons affected by leprosy emphasize the need to understand the disease's multifactorial nature, its treatments, and complications. As one person stated, "if people do not understand what we go through physically and mentally, they will never understand why we need support". Historically, persons affected by leprosy have been stereotyped with disfigured faces, hands and feet, perpetuating myths about the disease. However, the physical and mental health challenges they face have multifactorial causes.

49. Interviewees described various physical conditions caused by leprosy: (a) skin lesions and nerve damage, which manifest as nodules and patches, leading to loss of sensation in hands, feet and face, increasing injury risk; (b) muscle weakness and paralysis, especially in hands and feet, causing deformities such as claw hand and foot drop; (c) eye problems, including loss of blinking reflex, dry eyes, corneal ulcers and potential blindness; (d) ulcers and infections from unnoticed injuries, possibly leading to amputations; (e) disfigurement and deformities, such as loss of eyebrows, nasal collapse and other facial changes; and (f) mobility issues due to deformities and muscle weakness, hindering daily activities and independence.

50. People affected by leprosy also experience secondary health issues, such as malnutrition, respiratory problems and general poor health. These issues can arise during treatment and are classified into two types. Type 1 reactions involve acute inflammation of skin lesions, new lesions, neuritis, swelling, redness and pain, caused by the immune system reacting to remaining bacteria. This can happen before, during or after treatment. Corticosteroids are used to reduce inflammation and nerve damage,

[21] Jing Jing Lim and Yong Long Lim, "The dawn of humane leprosy segregation: transforming leprosarium into home", *International Journal of Built Environment and Sustainability*, vol. 4, No. 1 (2017).

[22] Annisa Ika Putri and others, "Understanding leprosy reactions and the impact on the lives of people affected: An exploration in two leprosy endemic countries", *PLOS Neglected Tropical Diseases*, vol. 16 (No. 6) (June 2022).

[23] A. Kleinman, L. Eisenberg and B. Good, "Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research", *Annals of Internal Medicine*, vol. 88, No. 2 (1978), pp. 251–258.

and timely treatment is essential to prevent permanent disability. Type 2 reactions (erythema nodosum leprosum) are characterized by painful red nodules, fever, joint pain, general malaise, neuritis, and sometimes internal organ involvement. Common in patients with multibacillary leprosy, these immune complex-mediated reactions can recur during treatment. Treatment includes thalidomide (in some countries), corticosteroids, and non-steroidal anti-inflammatory drugs (NSAIDs). Proper management is crucial to control symptoms and prevent complications.

51. According to WHO, type 1 reactions occur in about 30 per cent of borderline leprosy cases, while type 2 reactions occur in 10–50 per cent of lepromatous and borderline lepromatous cases. Despite the proclaimed elimination of leprosy, effective treatment for these reactions remains inadequate. Persons affected by leprosy can also experience a relapse, the symptoms of which are the reappearance of new skin lesions and possibly new nerve involvement. Relapse can be caused by inadequate treatment or resistance to multidrug therapy. It can also be due to a dormant bacilli resurgence. In this case, it requires re-evaluation and possibly a new course of multidrug therapy, sometimes with additional drugs if resistance is suspected. There can also be late reactions post-treatment, with symptoms similar to type 1 and type 2 reactions; such reactions can occur years after completing treatment. They are caused by late immune responses to remaining bacterial antigens. The management is the same as for acute reactions, often involving corticosteroids or other immunosuppressive treatments. In 2019, only 47 countries reported treatment completion rates above 85 per cent. Furthermore, 3,897 relapses were reported by 54 countries, 44 per cent of them in Brazil. The increase in relapses may be attributable to better reporting, although there are still weaknesses in diagnosing relapse. The overall relapse rate in leprosy appears low at around 1 per cent over 5–10 years. As there is limited availability of second-line drugs for leprosy, vigilance is needed to avert amplification of drug resistance.

52. Leprosy, its complications, and relapses are influenced by multiple factors, with bacterial activity and immune response being just one aspect. The institutional and bureaucratic barriers within medical services are significant challenges for affected persons. Access to specialized health care and trained professionals is increasingly problematic, unlike in the past, when dedicated hospitals provided extensive training for managing leprosy. In addition, since leprosy is often considered an eliminated disease, medical schools only cover it as a rare occurrence.

53. Persons living in marginalized and rural areas complain about distance and transportation issues, especially in leprosy-endemic countries where major health facilities are centralized in main cities and capitals. This makes it difficult to receive timely and regular treatment. In addition, in countries with few cases of leprosy, there is a shortage of professionals trained to treat the disease, which also presents a significant barrier to accessing care and support. Delayed diagnosis and treatment can result in more severe complications and disabilities. This is linked to the factors mentioned above, but social stigma can also have an impact on seeking care and support behaviour among persons, families, communities, health workers and professionals.

54. Although it is established that leprosy treatment should be completely free, persons in some countries report having to pay for it. Financial constraints also make transportation and rehabilitation services prohibitive for many patients, leading to delays or avoidance of care and support. This situation is aggravated by the fact that, even when the treatment is free, persons must pay for medication, medical appointments and other expenses during reactions and relapses. In addition, misdiagnoses can result in incorrect treatment, further complicating the issue. There were also complaints about shortages of medications used to control reactions and relapses. For example, in certain countries, including Indonesia, the use of

thalidomide is restricted, and in most cases, it is not authorized for patients affected by leprosy. Thalidomide is used in cases of severe erythema nodosum leprosum or when patients do not respond adequately to other treatments, such as corticosteroids or NSAIDs, as well as in chronic or refractory erythema nodosum leprosum. Without the appropriate medication, the outcome can be fatal.

55. Another issue is lack of awareness and information. There is often insufficient information about the disease, its treatment options, and available services, both among patients and within the health-care and support system. In addition, rehabilitation services, including physiotherapy, occupational therapy and reconstructive surgery, are often inadequate, insufficient or unavailable, affecting the quality of life and recovery of patients.

56. There is an ambiguous sentiment regarding the universal practice of inclusive health services, particularly concerning the conversion of leprosy-specialized hospitals into general hospitals. While the practice of inclusion has pushed communities and authorities to recognize that persons affected by leprosy have the right to access any service, it has also resulted in a reduction in the number of professionals knowledgeable about the disease and a decrease in support from medical staff.

57. High-quality and respectful treatment appears to hinge not solely on the enforcement of laws and regulations, but also on the commitment and dedication of authorities, professionals and health workers. Some participants noted varying levels of support across different regions of their countries; while some areas receive adequate support, particularly from health workers, in others, persons affected by leprosy experience stigma and rejection. The sustainability of effective practices often relies more on individual authority and commitment rather than strict adherence to legal frameworks.

58. One of the primary concerns relates to the limited, and sometimes non-existent, mental health support provided by public services. Such support is crucial at every stage of the disease and often remains necessary for years after treatment has ended. Some interviewees reported that mental health issues are stigmatized in their communities. Consequently, they may avoid seeking help, fearing judgment or discrimination. This reluctance to seek help also diminishes accountability for public services that should be provided.

C. Discrimination versus social and economic support: the role of the State and families

59. Social discrimination poses a significant barrier that hinders the rights of persons affected by leprosy to access support and care. Participants expressed frustration that many governments, particularly in leprosy-endemic countries, lack laws and enforcement against discrimination of leprosy-affected persons. This includes anti-discrimination laws, equal opportunity policies and specific regulations to protect their rights. While disability discrimination laws are more prevalent, not all persons affected by leprosy are classified as persons with disabilities, yet the majority have faced discrimination at some point in their lives.

60. Participants noted that some countries offer State-sponsored social welfare programmes providing financial assistance, vocational training and cash transfers to help persons affected by leprosy. Cash benefits, typically $30–$50 a month, support persons with disabilities, older persons and those below the poverty line. However, bureaucratic barriers and lack of information often prevent access. Despite being

small amounts, these benefits can cover basic necessities such as food. Economic benefits provided during the COVID-19 pandemic have now been discontinued.

61. In countries where disability benefits have been implemented, persons affected by leprosy often find it difficult to become beneficiaries because their impairments are frequently considered not severe or are invisible. Disability identity cards, where the grade of disability is registered, are required to access such benefits. Many persons affected by leprosy are rejected because they are not considered "legally disabled". There have also been cases where persons have been rejected because their impairment has been linked to leprosy. Social pensions that are generally offered to employed persons are typically inaccessible for persons affected by leprosy who have impairments, especially women. In many low- and middle-income countries, most persons affected by leprosy are either unemployed or engaged in informal work, which prevents them from making formal contributions to social security schemes.

62. Governments have overlooked the importance of accurate data and proactive identification of persons affected by leprosy to assess their specific support and care needs. Those living in remote areas often remain unregistered for social schemes and lack information about their rights and entitlements. While some measures have improved, interviewees believe that governments need to take more initiative in raising awareness about leprosy, dispelling myths, reducing stigma through education and media campaigns, and informing persons affected by leprosy about their rights as citizens.

63. Regarding the situation of families, interviewees said that, fortunately, things had changed compared with decades ago, when families used to expel persons affected by leprosy from their homes. Nowadays, some families still hesitate to accept a member affected by leprosy due to lack of information, fear of community exclusion, and cultural and religious beliefs, among other reasons. However, as the responsibility for care and support falls primarily on families, especially women, they often find ways to accept and support the affected relative within their close family circle.

64. Burnout resulting from fatigue, economic challenges, illness and other difficulties can inadvertently lead families to harm relatives affected by leprosy. When caregiving responsibilities fall primarily on women and girls, it adds significant stress to both caregivers and receivers of care. Despite the need for respite and self-care, cultural norms often fail to recognize this necessity, perpetuating stereotypes that women are inherently responsible for continuous care and support and protection.

65. Women affected by leprosy in Latin American countries highlighted the overwhelming workload they bear as caregivers without any payment. They not only manage their own illness, but also care for and support other ill relatives or family members with disabilities without receiving financial recognition. One interviewee said, "Being a caregiver is not just about the physical tasks at home; it involves navigating complex processes such as accessing benefits, monitoring medications and managing finances, often with limited or no resources. Being sick is a job itself, but being a sick caregiver is a double full-time job without any payment."

66. In many cases, families must provide financial support to persons affected by leprosy. In her previous report,[24] the Special Rapporteur underlined the fact that there is limited data on the economic burden borne by the families of persons affected by leprosy. A study implemented in rural India[25] demonstrated that the impact of severe leprosy reactions on households predominantly took the form of indirect costs (reduction in household productivity resulting from the interruption of normal or

[24] A/HRC/56/59.

[25] David J. Chandler and others, "Household costs of leprosy reactions (ENL) in rural India", *PLOS Neglected Tropical Diseases*, vol. 9, No. 1 (2015).

preferred activities of household members), which accounted for 65 per cent of total household costs.

67. A similar study carried out among migrant and resident patient populations in Guangdong Province, China, concluded that the median yearly total expense after diagnosis amounted to 15 per cent of migrant and 38 per cent of resident patients' annual income. Among migrant patients, the median cost before diagnosis was $131.60, the median yearly cost of leprosy treatment after diagnosis was $300.60, and the median yearly cost of leprosy complications was $69.50. By comparison, among residents, the median yearly costs were $152.40 pre-diagnosis, $309.70 after diagnosis and $91.90 for leprosy complications.[26]

68. Men also voiced concerns about cultural gender stereotypes that often place them as the primary providers for their families. However, when men develop impairments or chronic conditions, it can significantly reduce their ability to work, placing additional pressure on women to become primary earners. One female interviewee pointed out that "The division of labour between men and women affects women doubly. When men cannot work and support the family, women often have to take on that role. They also face increased domestic violence due to the mental health challenges their husbands, fathers or brothers experience."

69. It was emphasized that in countries with families, especially older persons, still living in former leper colonies, governments and communities must address the issue of abandonment, which affects them across multiple dimensions: health, social, economic, legal and psychological. Many individuals in these areas face legal uncertainties regarding land and housing rights. Others live without social protection and rely solely on community members for care and support, often passing away with their generation's history, overlooked by States and authorities, who may erase their historical memory from national narratives.

D. Community engagement, advocacy and awareness as part of the care and support system

70. Several persons affected by leprosy emphasized the importance of advocacy and awareness within care and support systems. They highlighted issues of stigma and discrimination exacerbated by insufficient government and community support for awareness campaigns and dissemination of reliable information. They also stressed the need for confidential channels where affected individuals and their relatives can address concerns about leprosy and treatment within their families and communities. In some countries, self-care groups, initially established for medical or rehabilitation purposes, have transformed into platforms for political awareness. Such groups have enabled persons affected by leprosy and their families to unite, understand their rights and participate actively in community decision-making. However, achieving these goals requires sustained efforts to combat social discrimination and alleviate fears of societal judgment, which is a gradual process.

71. Fear and ignorance leading to negative reactions within communities often stem from deeply rooted religious beliefs and practices passed down through generations. The importance of dialogue between religious and spiritual leaders, activists and representatives of organizations of persons affected by leprosy was emphasized as a strategy to shift perspectives on care and support. Given their role in pastoral care,

[26] Mingzhou Xiong and others, "Evaluation of the economic burden of leprosy among migrant and resident patients in Guangdong Province, China", *BMC Infectious Diseases*, vol. 17, No. 1 (December 2017).

religious figures play a crucial role in disseminating accurate information, underscoring the need to elevate their involvement more significantly.

72. Many of the successful practices in care and support are documented by grass-roots organizations in countries including Brazil, Colombia, Ethiopia, Indonesia, India, Nepal and Senegal. Representatives from these organizations attribute their success to innovative projects and programmes that involve persons affected by leprosy in every stage, from inception to evaluation. Financially sustainable community projects and youth-led awareness campaigns are actively promoted. In addition, knowledge exchange and leadership training programmes between Indonesia and Colombia are under way. In Brazil and Nepal, legal support initiatives include training persons affected by leprosy in legal matters, facilitated in collaboration with legal firms and local lawyers.

73. In Latin America, countries have made significant advances in care and support policies. For instance, discussions on legislation about inclusive health systems are actively ongoing in Brazil and Colombia. Persons affected by leprosy in Brazil have played a proactive role in advocating for their experiences and demands to be included in such discussions.

IV. Rethinking care and support for persons affected by leprosy and their families from a human rights perspective

74. Considering the perspectives of persons affected by leprosy and their organizations, the Special Rapporteur emphasizes that for governments to implement and protect care and support from a human rights perspective, specific key measures must be established. These include creating inclusive, human-rights based support and care systems that are responsive to age, disability and gender. Such systems should be built on contextual and culturally sensitive foundations, respecting local concepts of care and support intertwined with cultural and religious understandings. They should ensure appropriate access to services while upholding the rights of both caregivers and receivers of care.

75. Care and support from a human rights perspective challenges the gender stereotypes regarding caregiving and advocates for the redistribution of responsibilities between families, communities, organizations, the private sector and States. Such an approach includes the recognition of informal support, such as unpaid care and support work, primarily from families and personal networks; and formal support, provided through support services and support workers, such as professional personal assistants, domestic care and support workers, and communication facilitators, or through assistive and technological devices.[27]

76. Reclaiming rights within the care and support agenda – specifically the right to provide care, receive care and engage in self-care – is crucial,[28] particularly for persons affected by leprosy. Historically, self-care has played a pivotal role in their lives and families. Defined by WHO as “the ability to promote and maintain health, prevent disease, and cope with illness”,[29] self-care should empower persons affected

[27] Report of the Office of the United Nations High Commissioner for Human Rights on good practices of support systems enabling community inclusion of persons with disabilities (A/HRC/55/34).

[28] Laura Pautassi, “The right to care. From recognition to its effective exercise” (Mexico City, Friedrich Ebert Stiftung, 2023).

[29] WHO guideline on self-care interventions for health and well-being, 2022 revision (Geneva, 2022).

by leprosy to assert control over their health needs while advocating for their rightful place in the care and support system from a human rights perspective.

77. With these insights in mind, the Special Rapporteur revisits the key principles outlined in the report of the Office of the United Nations High Commissioner for Human Rights on good practices of support systems enabling community inclusion of persons with disabilities (A/HRC/55/34), which serve as essential guidelines for Member States aiming to implement inclusive, rights-based care and support systems. The Special Rapporteur has added one more principle that involves ethics and compassion.

A. Good governance

78. Good governance involves offering adequate and participatory legal, policy, institutional and administrative frameworks. It includes careful needs and demands assessments for support and care, as well as the meaningful involvement of persons affected by leprosy, their families and their allies in the design, implementation, monitoring and evaluation of support and care systems. The key principles of good governance should include accountability, transparency, participation, equality and sustainability.

79. Good governance implies an inclusive approach, considering the broader context in which persons live, including their living environment, social support networks, and access to community resources. Awareness of evidence-based practices is crucial for implementing and evaluating good governance.

B. Accurate assessment of support and care needs

80. Persons affected by leprosy often struggle to access inclusive services due to inadequate data and professional knowledge about their condition and treatment. Effective assessment of their care and support needs requires improved information management and data collection efforts, as well as a multisectoral and multidisciplinary approach. Therefore, assessments and evaluations should involve professionals from diverse fields and sectors, as well as caregivers and receivers of care.

81. An accurate assessment entails a participatory evaluation involving both caregivers and receivers of care to ensure an individualized approach that addresses each person’s unique needs. This approach must consider their medical condition, psychosocial and economic circumstances, cultural factors influencing care and support needs, and personal preferences. Respect for the person’s autonomy and choices is crucial, while ensuring their safety and well-being.

C. Development of comprehensive social protection systems

82. Integral social protection addresses extra costs, including direct expenses, related to impairment, long-term consequences and chronic conditions associated with leprosy. The economic impact of leprosy on the lives of affected individuals and their families is variable and multilayer, and includes, for example, the purchase of assistive technology, paying for accessible transport and housing, and indirect costs arising from reduced earning capacity owing to limited access to education and employment opportunities.

83. Integral social protection ensures that care and support services are accessible to all individuals, especially those in vulnerable situations, by reducing financial

barriers and promoting social and economic inclusion. It also promotes the delivery of high-quality care and support services that meet standards of effectiveness, safety and patient-centeredness.

84. Integral social protection provides financial assistance and benefits to cover the costs associated with care and support, alleviating economic burdens on individuals and families. To achieve this, it establishes sustainable funding mechanisms and policies to ensure the continuity and effectiveness of care and support systems over time, adapting to demographic changes and evolving societal needs.

D. Cultivating a skilled and diverse support and care workforce

85. This principle highlights the need for high-quality support services, emphasizing that knowledge and reliable information are essential for those providing care and support, even on an unpaid basis. This ensures that expertise, up-to-date knowledge and good practices are available to individuals affected by leprosy and their families.

86. It also ensures that patients and those seeking support will find reliable references, effectively addressing their doubts and needs, preventing the aggravation of situations, and potentially saving lives. It also guarantees that skilled and ethically trained professionals and front-line workers will recognize and utilize the knowledge that patients and their families possess to enhance their care and support.

E. Increasing human rights-based investment

87. This principle involves prioritizing funding and resources for support and care services in a manner that respects and upholds human rights principles. It ensures that care and support services are accessible, equitable, and respect the dignity and rights of all individuals, particularly the most vulnerable populations. To do this, States need to allocate sufficient funding to care and support services, which includes investing in infrastructure, training, and support for care providers.

88. Funding mechanisms should be multisectoral, including taxation, public and private insurance schemes, and direct subsidies to service providers and users. In this context, the involvement of the private and public sectors, communities, and international cooperation is vital to sustain development with equality and justice. This principle also takes into account gender inequality issues, recognizing the status of those who are caregivers, especially women and girls, as rights holders. In a similar line, the principle recognizes persons who are receivers of care as rights holders.

F. Implementing ethical and compassionate policies and programmes

89. Integrating an ethical and compassionate approach into care and support systems is an acknowledgement of the diversity of contexts and cultures in which these services operate. This approach underlines the importance of viewing care and support through a lens of compassion, which entails recognizing every person as an essential and unique agent in the human development process, deserving of freedom from suffering and unjust treatment.

V. Annual activities report of the Special Rapporteur

90. The Special Rapporteur has participated in various meetings, particularly with United Nations agencies focusing on care and support issues, such as the United Nations Children’s Fund, UN-Women and WHO. She has also engaged with

universities in the United Kingdom and Australia to explore potential collaborations on religious and spiritual aspects related to leprosy. In addition, she has met with representatives of international organizations, including Enablement in the Netherlands. She has also been in constant contact with organizations of persons affected by leprosy, as well as with international donor organizations.

91. The Special Rapporteur has attended multiple conferences on health, leprosy, disability and family issues. She has been invited to speak about her mandate's role in the lives of persons affected by leprosy at universities in the United Kingdom, Canada and Mexico. She has conducted interviews with media outlets in countries including Denmark, the United States of America and Turkey to discuss the situation of persons affected by leprosy worldwide. She continues to advocate for the rights of persons affected by leprosy through radio programmes and editorial platforms. She also utilizes digital social media platforms such as X and Facebook to connect with organizations and individuals affected by leprosy.

92. Communications expressing her interest in visiting certain countries have been sent to missions in Geneva. During her visit to Geneva in June 2024, she held meetings with representatives from Indonesia and Nigeria to discuss potential country visits.

VI. Conclusions and recommendations

93. **There is an urgent need to create and implement care and support systems from a human rights perspective for persons affected by leprosy and their families. In addition, it is essential to include leprosy in the broader debate about care and support. Introducing this approach and raising awareness at the national and international levels will facilitate a transition from a disease-centred model to a person-centred model rooted in human rights and compassion. Such discussions must be promoted within the leprosy rights movement and supported by different social movements, civil society and academics.**

94. **States and governments must ensure equitable access and design systems that will uphold the dignity and respect that persons affected by leprosy deserve. This involves combating any kind of discrimination and stigmatization.**

95. **Robust rights-base care and support systems have robust legal frameworks that guarantee just access to services and social protection. In this connection, ethical monitoring and evaluation mechanisms with a human rights perspective must be incorporated.**

96. **Sustainability is a crucial aspect of care and support systems. The State must ensure that policies and laws supporting their creation are backed by reliable funding mechanisms. It is important to emphasize the alliance of the public and private sectors, civil society, and international cooperation in this effort.**

97. **Care and support systems must be comprehensive, extending beyond health care to address daily life conditions, especially for those with severe and chronic effects of leprosy. These systems should also address gender inequality and the disparity between paid and unpaid caregivers. States must implement interdisciplinary research to have more information and data regarding these issues.**

98. **These systems shall incorporate an approach that considers cultural perspectives on care, acknowledging both positive aspects and those that cause**

harm. Strategies must be implemented to facilitate dialogue and motivate positive changes.

99. **The Special Rapporteur argues that without implementing a human rights approach alongside compassionate and ethical care, care and support systems will fail to adequately meet the needs and demands of persons affected by leprosy.**

100. **Overall, the participation and agency of persons affected by leprosy and their families must guide the processes of design, implementation, monitoring and evaluation.**