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**Promotion and protection of all human rights, civil,
political, economic, social and cultural rights,
including the right to development****Policy framework for rights-based action plans****Report of the Special Rapporteur on the elimination of discrimination
against persons affected by leprosy and their family members****Summary*

In the present report, the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, sets out a policy framework for rights-based action plans aimed at the enforcement of de facto equality for persons affected by leprosy and their family members, with specific recommendations in four main areas: adequate standard of living and economic autonomy; non-discrimination, independent living and inclusion in the community; elimination of stereotypes and the right to truth and memory; and empowerment, with a focus on vulnerable groups.

* The annex to the present report is being issued without formal editing, in the language of submission only.



I. Introduction

1. Pursuant to Human Rights Council resolution 35/9, in which the Council affirmed the need to intensify efforts to eliminate all forms of discrimination against persons affected by leprosy and their family members, and stressed the importance of implementing the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, the Special Rapporteur, Alice Cruz, has set out a policy framework with the aim of assisting States in the development of rights-based national and regional action plans. The Special Rapporteur hopes to contribute to a much-needed paradigmatic shift, from traditional medical and charity-based approaches to the enforcement of de facto equality for persons affected and their family members. Concomitantly, the Special Rapporteur aims to foster the recognition and inclusion of persons affected and their families, who have systematically been left behind and might continue to be the furthest behind, if no positive action is taken, in the global implementation of the Sustainable Development Goals.
2. The principles and guidelines underpin the normative integration of several international human rights instruments, interpreting and translating legally binding norms in close connection with the conditions required by and the needs of persons affected by leprosy and their family members. The need for a rights-based policy framework is put forward in the principles and guidelines, when identifying development, implementation and follow-up activities, within a participatory arrangement, as the obligations of States. Having identified substantive discrimination as a leading cause of systemic marginalization, the Special Rapporteur agrees with the Special Rapporteur on extreme poverty and human rights, who has raised the matter of the insufficiency of anti-discrimination policies for bringing people who have been subjected to discrimination and poverty into mainstream society groups (see A/72/502). Guaranteeing equal opportunities to people living in poverty may be nothing more than a well-intentioned discourse. A comprehensive multisectoral policy is therefore key for achieving the goal of eliminating discrimination against persons affected by leprosy and their family members.
3. The Special Rapporteur considers a policy to be any means through which States define and implement action within a comprehensive framework that puts into practice the principles of the indivisibility, interdependence and universality of rights through coordinated interventions between the different aspects of governmentality. In accordance with standardized practice for developing a policy framework, the present report is set out as a continuation of the previous report (A/HRC/41/47), in which the Special Rapporteur recognized the problematic situation with resource to a comprehensive description of the situation of persons affected and their family members that identified root causes of discrimination through a bottom-up approach firmly anchored in the experience of affected persons, their families and key stakeholders in the field of leprosy.
4. In the previous report, the Special Rapporteur identified a lack of acknowledgement among policymakers of the broad structural causes of ongoing discrimination and the limited number of interventions outside the health field. Such gaps call for a rights-based policy framework structured on the following four main axes: (a) adequate standard of living and economic autonomy, which includes social protection, work and training opportunities and access to health systems; (b) non-discrimination, independent living and inclusion in the community, which includes anti-discrimination principles, accessibility and independent living; (c) elimination of stereotypes and the right to truth and memory, which includes awareness-raising and capacity-building, reparation and the preservation of history; (d) empowerment, with a focus on vulnerable groups, which includes education, participation and access to justice.
5. The Special Rapporteur acknowledges the epidemiological, social, cultural and political heterogeneity of the expression of leprosy worldwide and, for that reason, has strived to develop a policy framework that simultaneously safeguards universal basic human rights principles and norms and leaves room for the specificities of national and local contexts. Importantly, the policy framework is suitable for implementation within already existing national human rights policies and programmes. However, such integration cannot jeopardize an efficient response to the needs of the target population, for which it

may be necessary, in some contexts, to elaborate specific policies and/or programmes within a multisectoral approach.

6. Methodologically, the Special Rapporteur conducted extensive bibliographical research and analysis of international standards (see annex) and of the work of the human rights mechanisms, such as the treaty bodies and the special procedures, and the relevant United Nations agencies and organizations. Good and best practices regarding leprosy and those from adjacent human rights fields were also examined. Governments and civil society organizations¹ were consulted in order to learn from their positive experiences. Responses to a call for input were received from Brazil, Cambodia, Chad, Cyprus, the Dominican Republic, Ecuador, India, Japan, Lebanon, Mauritius, Mexico, Mozambique, Myanmar, Nepal, the Philippines, Romania, Senegal and Uganda. The Special Rapporteur also made use of her extensive experience in the field of leprosy and, in particular, of her permanent dialogue and interactions with persons affected worldwide and their representative organizations. The goals, outline and content of the present report were thoroughly discussed in focus groups, meetings and interviews with representatives of grass-roots organizations of persons affected, at the Global Forum of People's Organizations on Hansen's Disease,² organized by the Sasakawa Health Foundation, in order to deliver a policy framework that responded to the needs and aspirations of persons affected and their families from various regions, cultural contexts and lived experiences.

II. Adequate standard of living and economic autonomy

7. Leprosy is classified as a neglected tropical disease closely linked to poverty by the World Health Organization (WHO).³ According to WHO, infectious diseases contribute to lifelong disadvantages, perpetuating the vicious cycle of poverty and infection. Limited enjoyment of substantive equality among persons affected and their families has an impact on the overall course of leprosy, from transmission, to health care and social rehabilitation and inclusion after persons affected are cured. The socioeconomic and environmental root causes of leprosy are widely acknowledged, although its mechanisms remain unclear. That fact notwithstanding, neither person-to-person transmission nor genetic predisposition are sufficient to explain the incidence or distribution of leprosy.

8. Independent research points to the following socioeconomic and environmental risk factors for the incidence of leprosy: poverty and inequality; household crowding; inadequate nutrient intake; poor hygiene; lack of access to clean water (*Mycobacterium leprae* can survive in some aquatic plants); low education levels; low income; and geographical areas with deficient infrastructure and hindered access to goods and services. Independent research also points to the protective effects of welfare measures on incidence, adherence to treatment and cure.

9. However, lack of targeted action on the social determinants of leprosy is a major gap in global and national policies for the control of leprosy. The promotion of material equality through redistributive policies that can guarantee a minimum standard of living to persons affected and their family members, alongside equitable access to public goods and services, is manifestly lacking. Strategies that can guarantee persons affected and their families freedom from want, as well as their right to personal development and economic autonomy, are broadly seen as secondary to public health goals, which continue to be disease-centred, in opposition to being people-centred.

10. In accordance with article 11 of the International Covenant on Economic, Social and Cultural Rights, the Special Rapporteur considers progressive realization thereof to be the standard and acknowledges the need to be sensitive to national specificities, in line with

¹ The Special Rapporteur wishes to thank Fondation CIOMAL, IDEA, Lepra, the Leprosy Mission, Netherlands Leprosy Relief and the National Alliance Against Leprosy Uganda for their important contributions to the present report.

² The Special Rapporteur wishes to thank Sasakawa Health Foundation for facilitating her in-depth discussions with participants at the Global Forum of People's Organizations on Hansen's Disease.

³ See www.who.int/neglected_diseases/diseases/en.

general comment No. 3 (1990) on the nature of States parties' obligations of the Committee on Economic, Social and Cultural Rights, the Special Rapporteur recalls that, while being a flexibility device, the concept of progressive realization obligates States to move as expeditiously and effectively as possible towards the realization of the goals of the Covenant. Moreover, and in accordance with the Convention on the Rights of Persons with Disabilities, an adequate standard of living is only effective to the degree that individuals can live a dignified life and participate on equal terms in society at large. The principles and guidelines state that the fulfilment of the right to an adequate standard of living for persons affected and their families entails access to goods, services and infrastructure, but also poverty reduction measures, as well as education and work opportunities, linking an adequate standard of living to autonomy and personal development.

A. Social protection

11. Persons affected by leprosy and their families continue to bear the impact of systemic and multilayered discrimination and marginalization, which have positioned them as the furthest behind. Such structural disadvantage calls for protective measures to be implemented, irrespective of contributory scheme or employment status. National policies should establish minimum standards of social protection and benchmarks for persons affected and their family members.

12. According to the Social Protection Floors Recommendation, 2012 (No. 202), of the International Labour Organization (ILO), States should establish national social protection floors that can ensure income security and universal access to essential health care. In line with article 9 of the International Covenant on Economic, Social and Cultural Rights and general comment No. 19 (2007) on the right to social security of the Committee on Economic, Social and Cultural Rights, the principles and guidelines state that financial measures that can guarantee the right to an adequate standard of living, such as benefits for those who cannot work due to age, illness or incapacity, or financial assistance for housing and health care to persons living in poverty, should be made available. According to the Committee, the right to social security may be mandatory for the realization of other social, economic and cultural rights. The Committee therefore recommends that States guarantee access to social security schemes for enabling individuals and families to acquire essential health care, basic shelter and housing, water and sanitation, food and the most basic forms of education. Such access should be non-discriminatory and should take into consideration the special needs of marginalized individuals and groups. An important point made by the Special Rapporteur on the rights of persons with disabilities was that the Convention on the Rights of Persons with Disabilities was paving the way towards an inclusive conceptualization of social protection that could promote active citizenship, social inclusion and participation, in opposition to paternalistic approaches that reinforced dependence and segregation (see A/70/297).

13. Given the interlinkage of leprosy and poverty, the right to an adequate standard of living may not be accomplished without the prior granting of social benefits under a rights-based comprehensive social protection policy. Such a policy must be implemented through administrative services and bureaucratic procedures that can guarantee full accessibility to illiterate or poorly educated populations, as well as to populations living in remote or peripheral areas. Furthermore, social benefits, such as unconditional cash transfers, should take into consideration the real needs of the target population, including the additional costs of disability. Such a comprehensive social protection policy should sensitively ponder mainstream and specific programmes and target active citizenship by bridging guarantees to basic income security to policies that promote training opportunities and formal employment

B. Work and training opportunities

14. Multilayered discrimination has pushed many persons affected by leprosy and their family members out of formal employment opportunities. A significant number of individuals are left to engage in unreliable casual labour, with low wages, in unsafe and

degrading working conditions, outside the formal economy and without an entitlement to social security benefits.

15. According to ILO, the deficit of decent work has a disproportionate impact on already disadvantaged groups. As a consequence, the main policy for increasing productive inclusion of the poorest is providing them with greater human capital. The principles and guidelines recommend measures for the public and private sectors, such as employment inducements in the regular employment market, support for cooperative work, entrepreneurship and vocational education and training, reflecting provisions of the International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of Persons with Disabilities.

16. Article 7 of the International Covenant on Economic, Social and Cultural Rights states that it is both the right of everyone to the enjoyment of just and favourable working conditions and to a decent living. In its general comment No. 23 (2016) on the right to just and favourable conditions of work, the Committee on Economic, Social and Cultural Rights called for States to raise awareness in the private sector and act affirmatively to mitigate the disadvantaged positioning of some groups. According to the Committee, States should put into place measures enabling education, information and awareness-raising, with a view to ensuring equal work opportunities in both the private and public sectors. The Special Rapporteur notes that such measures should be sensitive to gender, age, disability, illiteracy and low education levels. The Committee also emphasized the responsibility of States to establish non-contributory social security programmes for people working in the informal sector, in order to guarantee them protection from hazards.

17. Basic guidelines established by the Committee on the Rights of Persons with Disabilities to promote job opportunities for persons with disabilities comprise non-discrimination, accessibility, reasonable accommodation and affirmative measures. Article 27 of the Convention on the Rights of Persons with Disabilities guides the public sector, in collaboration with the private sector, to guarantee job opportunities, equal salaries, equality in working conditions, career counselling opportunities and professional education, entrepreneurship opportunities and vocational and professional rehabilitation programmes to assist in returning to work. States are obligated to take measures to guarantee fully accessible workplaces, removing any physical, behavioural, informational, communication or transport barrier. Both the public and private sectors are expected to provide for reasonable accommodation to workers who need it.⁴ Affirmative measures are to be taken by the public sector and promoted in the private sector in order to increase the employability of persons with disabilities.

18. The guarantee of equal work opportunities for persons affected by leprosy and their family members should be grounded on the guidelines provided by ILO and the provisions set out in the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of Persons with Disabilities and the Convention on the Elimination of All Forms of Discrimination against Women. States should aim at an inclusive economy that can ensure economic autonomy to persons affected and their family members, encompassing the intersectionality of leprosy with age, gender and disability, through training and formal employment opportunities. Guaranteeing equal work opportunities can be ensured within mainstream and/or disability and programmes, as long as due recognition is given to specific leprosy-related needs and the multiple barriers to inclusion. Affirmative measures may be required in some contexts, in order to avoid this specific population being left furthest behind in mainstream and disability programmes. Affirmative measures should be temporary in principle, but in some cases, they may need to be of a permanent nature. Reasonable accommodation, including workplace access adaptation, adjustment of machines and equipment, but also of work content, time and work organization, as well as availability of assistive devices, must always give due consideration not only to visible physical impairments related to leprosy, but also invisible ones, such as pain or loss of sensation, as well as psychosocial disabilities related to

⁴ Whereas accessibility is related to collectivities, reasonable accommodation is called for in relation to individuals in inaccessible environments. Both concepts will be considered further below.

stigmatization. Guarantees of equal opportunities must be context-grounded; they can only be properly enforced with the full participation of affected individuals and their representative organizations.

C. Health systems

19. The principles and guidelines set forth an approach to the right of persons affected by leprosy and their family members to the highest attainable standard of physical and mental health that emphasizes the State's responsibility in guaranteeing free or affordable medical assistance and treatment, access to free essential drugs and psychological and social counselling. In addition, the Special Rapporteur considers the lack of substantive equality, discrimination, the inaccessibility and inadequacy of health-care services, the lack of clinical and structural competence of the health-care workforce, the inaccessibility of public goods and services, the lack of community services and the lack of participation, accountability and transparency mechanisms as social determinants of leprosy that should be addressed within health-care systems. The Special Rapporteur's conceptualization of the right to the highest standard of physical and mental health by persons affected and their family members is grounded in the provisions set out in the Universal Declaration of Human Rights and the International Covenant on Economic, Social and Cultural Rights and in the work of the treaty bodies. She situates the enforcement of such a right on a continuum of medical and psychosocial care that encompasses the full spectrum of prevention, treatment⁵ and rehabilitation and that should be fully addressed by effective referral within national health-care systems.

20. Article 12 of the International Covenant on Economic, Social and Cultural Rights defines the steps that States should take to progressively realize, to the maximum of their available resources, the highest achievable standards of health. Article 26 of the Convention on the Rights of Persons with Disabilities establishes as measures to be adopted by States the provision of quality and standard disability-sensitive health care on a non-discriminatory basis, the guarantee of service delivery at the community level and the full respect of autonomy, dignity, informed consent and the needs of persons with disabilities by the health-care workforce. In its general comment No. 14 (2000) on the right to the highest attainable standard of health, the Committee on Economic, Social and Cultural Rights interpreted the right to health as interdependent with the realization of other economic, social and cultural rights, emphasizing that its proper implementation goes beyond a medicalized view. The general comment is key to understanding how a healthy life is dependent upon a complex set of socioeconomic conditions, binding the right to health with the right to an adequate standard of living.

21. The Committee on Economic, Social and Cultural Rights has established the following obligations of the State: access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups; access to the

⁵ According to Dr. Claudio Guedes Salgado at Pará Federal University, Brazil, and President of the Brazilian Society of Hansen's Disease, the treatment of leprosy should be multidisciplinary, with the use of drugs, physiotherapy, occupational therapy, individual therapy and group therapy, surgery, orthotics and prosthetics and wound care. The drugs used are categorized into two groups, namely, antibiotics, which is the most well-known treatment, called multidrug therapy, and other substitute antibiotics, which can be used when a problem with multidrug therapy arises. Unfortunately, there is no drug to treat neurodegeneration, a major problem of leprosy, which continues to progress in many cases, even after the completion of treatment with antibiotics. Physiotherapy is aimed at preventing the progression of muscle loss and the maintenance of functions in the affected limbs and face; through occupational therapy, patients with physical impairments are taught new skills; and psychology addresses the emotional condition involved with leprosy, be it individual or familial. Surgery may be used to prevent the neurodegenerative process. The orthotics and prosthetics can be prepared in home mode, with simple material, to prevent burns, for example, or in orthopedic workshops, to return the loss of skills or movements, with the addition of the production of prostheses for amputees. Wound care should be done carefully and technically, with the use of materials that can prevent the evolution of the wound, and even promote its closure, avoiding major physical impairments.

minimum essential food, which is nutritionally adequate and safe, to ensure freedom from hunger; access to basic shelter, housing and sanitation and an adequate supply of safe and potable water; provision of essential drugs; equitable distribution of all health-care facilities, goods and services; adoption of a national public health strategy and plan of action seated on epidemiological evidence that is to be devised and periodically reviewed on the basis of a participatory and transparent process; provision of education and access to information; and appropriate training for health-care personnel, including education on human rights.

22. The Special Rapporteur emphasizes the importance of non-discrimination and preventative interventions on the social determinants of health, health education, rehabilitation and the human rights education of the health-care workforce, as well as the provision of health-care at the community level, which is essential for people living in remote areas or peripheral areas, together with outreach services. Focus on primary care must not lead to the loss of medical expertise in diagnosing and properly treating a highly complex disease, nor to the absence of secondary and tertiary services able to address the multiple medical challenges posed by leprosy. The provision of health care to children affected should ensure, in cooperation with social, child protection, education and other relevant services, a continuum of care for children that effectively uses psychoeducational and psychosocial methods for interventions that enhance emotional health and social development. The Special Rapporteur also emphasizes the importance of health-care systems empowering community engagement and participation, including social support, increased patient-provider communication that should fully acknowledge the experience of affected persons as valid knowledge, psychosocial individual and family counselling, self-care and self-help groups, peer support and peer health promoters and outreach activities within partnerships between health services and persons affected as integral parts of health-care services.

23. A rights-based strategy for leprosy within health-care systems must be people-centred, having as its priority the well-being of persons, communities and populations, and must ensure: availability, as well as physical and economic accessibility of health-care services; quality of health-care facilities, goods and services; active and informed participation of users; gender-sensitive and culturally sensitive strategies, as well as child-friendly services; accountability of the health-care workforce, with indicators that facilitate monitoring; non-discriminatory treatment; and provision of high-quality medical care. The strategy must take a holistic approach that includes a rights-based approach to mental health, which should be ethically respectful, culturally appropriate, gender-sensitive and empowering to individuals, making use of peer support as an integral part of recovery-based services.

D. In practice

24. In Brazil, the conditional cash transfer programme Family Allowance and the benefit of continuous instalments for older persons and persons with disabilities have been guaranteeing financial aid to persons affected who are eligible under the established criteria for both benefits, even though difficulties in access have been reported. Private-public partnerships between the Ministry of Health and the Movement of Reintegration of Persons Affected by Hansen's Disease (MORHAN), Novartis Brazil, DAHW Brazil, the Sasakawa Health Foundation and the Pan American Health Organization are examples of groundbreaking initiatives in the fields of health care and active case detection, awareness-raising, the training of health-care workers, outreach activities and community engagement. In India, the pension for persons with disabilities has been benefiting persons affected by leprosy that fit into the established criteria of disability, but difficulties in access have been reported, as well as the insufficiency of the pension amount to meet basic needs. Civil society has been taking the lead in the training of affected persons for inclusion in the labour market and the creation of job opportunities, an important example being the vocational training centres in India. Microcredit loans, training through partnerships with non-governmental organizations, including initiatives in areas such agriculture and/or livestock rearing, have been reported in Mozambique, the Niger and Nigeria. The existence

in some countries of food security programmes also contributes to the improvement of the standards of living of persons affected, such as the case of the food security system established by the Government of India. In Senegal, existing programmes, such as the national, community-based rehabilitation programme, the programme for equality opportunity card for persons with disabilities and the national programme for family security, may be of benefit to persons affected and their families. In countries such as Brazil, India, Japan, Mozambique, Nepal and Nigeria, the existence of self-help and self-care groups have proved to be an effective strategy for fostering recovery, survival and inclusion. Community partnerships between civil society organizations and traditional leaders and healers, as well as religious leaders, have been reported in Brazil, Ghana and Nigeria, with positive effects on rights enforcement.

III. Non-discrimination, independent living and inclusion in the community

25. Pervasive structural disadvantage, harmful stereotypes and wrongful stereotyping place persons affected by leprosy and their families in the context of intersecting vulnerabilities, multilayered discrimination and subordination, perpetuating informal segregation from community life and denial of fundamental human rights. Stigmatization remains institutionalized in State architecture and its functioning. According to the International Federation of Anti-Leprosy Associations, there are more than 50 countries in the world that keep discriminatory laws against persons affected by leprosy in force. Discriminatory practices in State administration services is also an enduring reality, in particular in health-care and education services, work opportunities and regulation and access to disability rights. With regard to the former, a substantive number of persons affected by leprosy are excluded, due to the lack of institutional awareness and/or inadequate eligibility criteria. Specific and targeted measures are mandatory for ensuring de facto non-discrimination and equality. The Special Rapporteur makes use of disability as a core concept for achieving a barrier-free society, emphasizing the need for leprosy-sensitive policies that should go hand in hand with capacity-building on the rights of the target population among State workers, persons affected and their families.

A. Non-discrimination

26. The principles and guidelines are based on legally binding provisions of international human rights instruments that prohibit discrimination, i.e., any distinction, exclusion, restriction or preference based on a specific condition or status. Both the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights prohibit all forms of discrimination on any grounds. For cases of multiple discrimination, in which a person affected or a family member is subjected to intersectional exclusion on the basis of gender, age, disability or race, provisions from the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child, the Convention on the Rights of Persons with Disabilities and the International Convention on the Elimination of All Forms of Racial Discrimination also apply.

27. The enforcement of equality and the prohibition of discrimination are provided in article 2 of the International Covenant on Civil and Political Rights and article 2 of the International Covenant on Economic, Social and Cultural Rights. Whereas the full enjoyment of economic, social and cultural rights is a progressive obligation, the prohibition of discrimination is an immediate obligation. Furthermore, under the Convention on the Rights of Persons with Disabilities States are obligated to take all appropriate measures to modify or abolish existing discriminatory laws, regulations, customs and practices and to eliminate discrimination on the grounds of disability by any person, organization or private company.

28. States must abstain from any interference in the enjoyment and exercise of civil, political, economic, social and cultural rights by persons affected and their family members,

whether through direct or indirect discrimination. Such an obligation includes taking immediate measures to abolish or repeal discriminatory laws. Likewise, States must ensure that every public body, institution and service eliminates leprosy-related discriminatory practices. States are accountable for the cases in which any public authority perpetrates discriminatory acts against persons affected or their family members.

29. The principles and guidelines reflect the tenets of general comment No. 20 (2009) on non-discrimination in economic, social and cultural rights, in which the Committee on Economic, Social and Cultural Rights established that a person's actual or perceived health status could not be a barrier to the realization of rights and that the protection of public health used as grounds for restricting the rights of any individual is a clear violation of the Covenant. The Committee also pointed out the duty of the State to adopt the measures necessary to address stigmatization on the grounds of actual or perceived health status. The principles and guidelines set out concrete situations in which States are obligated to prevent persons affected and their family members from being discriminated against. States also have a positive obligation to fight discrimination in the private sphere. States should undertake research on the root causes of discrimination, with systematic collection of data and thorough analysis of risk factors. Such research should be supported by lay experts. Through effective policies, States should establish positive measures to prevent discrimination and investigate, punish and repair any abuse. Such an obligation includes monitoring the private sector and the fields of education, work and health.

30. In the light of systemic discrimination and marginalization, discrimination on the grounds of leprosy must be tackled through an inclusive equality policy, as put forward by the Committee on the Rights of Persons with Disabilities. According to its general comment No. 6 (2018) on equality and non-discrimination, inclusive equality embraces a substantive model of equality based on redistribution to address inequalities, elimination of stigmatization and promotion of dignity, full and effective participation and accommodation of differences. A comprehensive anti-discrimination policy also entails the need for creating mechanisms to receive and provide quick and effective responses to complaints of discriminatory events, both in the administrative sphere and the judicial sphere. Such mechanisms should be implemented within an accessibility framework and in full respect of the legal capacity of persons affected and their family members.

B. Accessibility and independent living

31. Persons affected and their families continue to experience informal segregation from community life, as well as multiple barriers to access to fundamental rights. The widespread lack of reparation measures and the limited reach of awareness-raising to redress the iatrogenic stigma created by the prophylactic segregation practiced in the past by States are some of the root causes of persistent informal segregation. Persons affected by leprosy and many of their family members are entitled to the rights provided under the Convention on the Rights of Persons with Disabilities on the basis of not only physical and psychosocial impairments, but also of the impairing effects of leprosy-related stigmatization.

32. The Committee on the Rights of Persons with Disabilities elaborates thoroughly on the multiple barriers to equal participation, which can occur in isolation or simultaneously, result from direct or indirect discrimination, be grounded on one actual or perceived characteristic or on the intersection between several ones and take multiple forms, namely, institutional, extra-institutional, physical, socioeconomic, attitudinal, environmental, informational, educational and cultural, among others. Persons affected, and also their families, are faced with many of the aforementioned barriers to participate on an equal basis in society with others.

33. According to article 5 of the Convention on the Rights of Persons with Disabilities, interpreted in relation to articles 1, 3 and 4, and general comment No. 6 of the Committee on the Rights of Persons with Disabilities, in order to enforce the rights of persons with disabilities, States should guarantee accessibility, reasonable accommodation and individual support. In the light of its general comment No. 2 (2014) on accessibility, the

Committee has noted that accessibility is a precondition for independent living and for full participation in community life. Its implementation encompasses physical environments, transportation, information and communication and public and private goods, products and services. States must elaborate accessibility standards to guide service providers and all relevant stakeholders.

34. According to article 5 of the Convention on the Rights of Persons with Disabilities, reasonable accommodation should be provided when any individual is faced with an inaccessible situation or environment. Although accessibility should be included in systems and collective processes, reasonable accommodation should be ensured for individualized situations. Examples of reasonable accommodation include: making existing facilities and information accessible; adapting equipment; reorganizing activities; rearranging tasks; adjusting programmes, learning materials and teaching strategies; adjusting medical procedures; and guaranteeing access to support staff without disproportional or undue costs.

35. The principles and guidelines also link the exercise of the right to actively participate in public affairs with the enjoyment of autonomy. With that in mind, the Special Rapporteur recalls the provisions of article 19 of the Convention on the Rights of Persons with Disabilities that are aimed at overcoming any structural barrier that hinders living an independent life and fully participating in the community, and according to which, the State should, to the maximum of its available resources, create supporting environments that enable independent living, through habilitation and rehabilitation services, community-based support services and arrangements, including personal assistance, assisted living arrangements, mobility aids and assistive devices and technologies. The aforementioned measures must be implemented in full respect of the right to privacy and must be available, accessible, affordable, acceptable, gender-sensitive and culturally sensitive. The same applies to psychosocial disabilities related to leprosy. Access to the highest attainable standard of mental health not only implies the right to community-based services, but also support for the full enjoyment of the rights to live independently and to legal capacity.

36. Autonomy and independent living should also be guaranteed in old age. An approach that can address the psychosocial effects of multiple discrimination and violations throughout life, as well as the physical impairments related both to leprosy and to ageing, should be implemented to guarantee a dignified life. Older people affected by leprosy should never be denied the right to legal capacity because of their age and/or mental health status. Older people affected by leprosy have the right to personal autonomy in making decisions, in particular life decisions. For the enjoyment of that right, support services may be required. By the same token, palliative care provided within ethical and deontological standards should be ensured.

C. In practice

37. Among constitutional democracies, some nations present sophisticated tools for defending equality and prohibiting discrimination in their constitutional texts. However, there are still more than 50 countries in the world with discriminatory laws against persons affected by leprosy. In India, the country with the most discriminatory laws in place against person affected, positive steps are currently being taken. The Government has adopted a policy of adopting zero discriminatory laws, which may contribute to the abolishment of remaining discriminatory laws. Public interest litigation cases in the Supreme Court of India have been contributing to progress in that regard, which evinces the key role played by civil society in the defence of the rights of persons affected. It is equally important to highlight the actions of civil society in India, undertaken through campaigns and advocacy, against discriminatory laws and practices. In Nepal, IDEA conducts legal advocacy workshops for raising awareness of the rights of persons affected. In Brazil, the National Observatory on Human Rights and Hansen's Disease has been created as result of a partnership between the Office of the Public Defender of the State of Maranhão, MORHAN and the Sasakawa Health Foundation. The Observatory receives and monitors report of human rights violations of persons affected, with the mission to fight institutionalized discriminatory practices.

IV. Elimination of stereotypes and the right to truth and memory

38. Persons affected by leprosy and their family members continue to experience the violating effects of unwritten social norms, values and beliefs. Together with the ripple effect of historical State segregation policies, the remaining discriminatory laws and persistent harmful stereotypes sustain the dehumanization of persons affected and their family members, with a damaging and sweeping impact on their autonomy and self-esteem. The internalization of stigmatization is an extreme form of dehumanization that compromises the right to the highest attainable standard of mental health and the overall enjoyment of fundamental freedoms.

39. The persistence of harmful stereotypes and wrongful stereotyping calls for fine-grained strategies aimed at both raising awareness among the general public and building capacity among persons affected and their families on their rights and how to claim them. Remedies, compensation and reparation for violations on the grounds of leprosy suffered both by persons affected and their family members are justice measures able to produce positive spillover effects, through general acknowledgment of the unfairness of violations and of the legal obligation of States to take the violation of rights seriously.

A. Awareness-raising and capacity-building

40. The relationship between stereotypes about leprosy and the dehumanization of affected individuals has been documented by the Special Rapporteur. The Committee on the Elimination of Discrimination against Women has expounded thoroughly on how gender stereotypes are root causes of human rights violations, also pointing out the limited awareness of stereotypes as mechanisms that breach the principles of equality and non-discrimination and undermine human dignity. Article 2 of the Convention on the Elimination of All Forms of Discrimination against Women establishes the duty of the State to take all appropriate measures to modify or abolish existing discriminatory laws, regulations, customs and practices. Article 7 of the International Convention on the Elimination of All Forms of Racial Discrimination affirms the obligation of the State to adopt measures for fighting prejudices that spur racial discrimination. In its general recommendation No. 35 (2013) on combating racist hate speech, the Committee on the Elimination of Racial Discrimination called for ethical conduct among the media and high-level public authorities, with a view to promoting a culture of tolerance and respect. Article 8 of the Convention on the Rights of Persons with Disabilities directly addresses the problem of harmful stereotypes, referring to the obligation of the State to adopt immediate, effective and appropriate measures to combat stereotypes, prejudices and related harmful practices in all areas of life. The principles and guidelines prohibit any discriminatory language against persons affected by leprosy and their family members, acknowledging the interlinkage between language and stigmatization, which should also include the use of images.

41. In joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child (2019) on harmful practices, the Committees called for a holistic approach to addressing stereotypes that acknowledged the interconnection between different social norms and the need of a comprehensive framework for addressing any harmful practice. The limitations of an approach targeting individual behaviours were also stressed, and a community-based approach aimed at systemic change through the collective adoption of new social rules was put forward. Participation of the victims is a key component of the strategy, which links protection to empowerment.

42. Strategies aimed at transforming social norms and customs about leprosy should be grounded in a holistic framework, community-based, empower affected individuals and have as primary focus the prevention of discrimination. Capacity-building of persons affected and their families on their human rights will promote active citizenship, accountability and strategic use of access to justice. Strategies should target awareness-raising and capacity-building of non-official authorities, such as community and traditional leaders and healers, as well as relevant professional groups, such as health-care workers,

educators and social workers. Training health-care workers to overcome personal and institutional discriminatory attitudes should be implemented as a priority, alongside the monitoring of health-care services and health-care delivery.

43. Collection, analysis and dissemination of data, disaggregated by indicators of equality, should be a priority for delivering evidence-based policies, which should be designed, implemented and monitored in close collaboration with persons affected and their family members. Good practices implemented in the HIV/AIDS field should be followed. That field of action shows the importance of empowering individuals and communities to address and respond to discrimination, having developed an outstanding good practice for collecting data on stigmatization and assessing the levels of human rights enjoyment that involved persons living with HIV as primary stakeholders and executors, called the people living with HIV stigma index. Promotion of rights education for affected individuals, as well as the delivery of legal advice, together with the enactment of protective laws and policies and accountability in courts and tribunals, is strongly recommended.

44. Awareness-raising as a structural pillar of any leprosy-related policy framework should be grounded in evidence and give due consideration to local perspectives. Awareness-raising strategies should also be designed and implemented in close consultation with persons affected and communities in order to prevent any backlash against affected individuals. Strategies cannot rely on medical knowledge and information alone, nor be delivered under an individual-centred framework, but must employ accessible, intercultural and gender-, age- and disability-sensitive language and formats. Personal testimonies on the obstacles to living a full and dignified life, but also on how people survive discrimination, are the most effective instruments for achieving systemic change in mindsets. To that end, sharing positive experiences and the promotion of role models and leadership skills should also be employed as effective strategies. Different dissemination channels should be used, such as community-based and mainstream media, the Internet and social media, as well as artistic expressions and performances.

B. Reparation and memorialization

45. Health and illness are not just biological phenomena. Accumulated knowledge in the field of medical anthropology has proved the difference between illness, meaning the bodily process itself, and disease, meaning the nosology produced by a given medical system, which is always culturally grounded. Diseases are biosocial constructs and, as the history of epidemics show, explanatory models of diseases can produce labelling and even spur institutionalized and structural stigmatization, of which the modern history of leprosy is a paradigmatic example. There was never scientific evidence to support the prophylactic segregation of persons affected by leprosy, and yet such segregation was widespread from the late nineteenth century until the late twentieth century – almost half a century after the discovery of a cure. There are still up to 2,000 leprosy colonies and villages active in the world today.

46. Segregation was very often accompanied by public campaigns aimed at educating the public on the dangers of interacting with persons affected by leprosy. The eradication of the disease from the public space was pursued at the expense of the rights of those affected by it. In many countries, marriage between persons affected was prohibited and, in some countries, forced sterilization was a standard practice. Stigma was the *dolus* behind this State policy, which continues to impact the lives of persons affected and their family members, therefore comprising a continuous violation. Due recognizing of that systemic and massive violation calls for reparation measures that not only redress harm at the individual level and recognize victims as rights holders, but also promote social integration. Such measures may be urgent for many persons affected, but also for their descendants, given their age. Second and third generations living in leprosy settlements should also be beneficiaries of complex reparation programmes.

47. The legal basis of the right to reparation is anchored in the provisions of international human rights instruments (Universal Declaration of Human Rights, article 8; International Covenant on Civil and Political Rights, article 2; International Convention on

the Elimination of All Forms of Racial Discrimination, article 6; Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, article 14; Convention on the Rights of the Child, article 39). The General Assembly adopted the Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law, in 2005, according to which reparation comprises restitution, compensation, rehabilitation, satisfaction and guarantees of non-repetition. The Human Rights Committee has also affirmed the State's obligation, under article 2 of the International Covenant on Civil and Political Rights, to promote changes in laws, official procedures and practices as part of reparation. The principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members calls for the reunification of families separated as a result of leprosy-related policies and practices, in full accordance with article 23 of the Convention on the Rights of Persons with Disabilities.

48. The Special Rapporteur on the promotion of truth, justice, reparation and guarantees of non-recurrence elaborates thoroughly on reparation measures, putting forward the idea that reparation programmes should ideally be of a complex nature that allows for benefits to fully acknowledge the complexity of the harm (see A/69/518). Reparation programmes should therefore comprise both material and symbolic reparations. Rehabilitation should be a core measure of reparation programmes, given that victims of serious human rights violations usually need specialized health-care services. By aiming at systemic change and non-recurrence, States should implement a comprehensive prevention structure that makes use of education, arts and culture, archives and documentation, linking reparation programmes with memorialization processes.

49. The principles and guidelines call for attention to be paid to the current situation of leprosy settlements and enumerate the rights of those inhabiting them. Such guidance is in accordance with general comment No. 4 (1991) on the right to adequate housing, in which the Committee on Economic, Social and Cultural Rights defined seven components of the right to housing: juridical security; availability of services, materials, installations and infrastructure; accessibility of costs; habitability; accessibility of space; localization; and cultural adequacy. The Committee emphasized the universality of the right to housing and its interdependency with other rights.. The principles and guidelines also reflect article 19 of the Convention on the Rights of Persons with Disabilities, on the right to make autonomous and free choices about one's place of living.

50. Reparation programmes for persons affected and their family members who have been forcibly segregated and separated should be of a complex nature, encompassing material measures aimed at redressing structural disadvantages and symbolic measures aimed at systemic change, and including rehabilitation, a memorialization process and the enforcement of housing rights. Housing and property rights should also be given to second and third generation family members living in leprosy settlements. Even in the contexts in which segregation was not implemented as an official government policy, it was nevertheless the result of systemic stigmatization, and people who have been subjected to it should also be eligible for reparation programmes.

51. Given the deeply ingrained social representation of leprosy as a symbol for everything that should be kept apart, leprosy is particularly fitting to be used as a powerful example in general human rights education. As an historical epitome of dehumanization, leprosy holds a powerful aptitude to illustrate the importance of human rights for the building of a free and just society.

C. In practice

52. Reparation measures for forced segregation have been implemented in Brazil and Japan. Japan has also enacted legislation to provide for reparation to family members, and the state of Minas Gerais in Brazil has granted reparations to persons who were separated from their parents due to the official policy, although only applicable in the state of Minas Gerais, and the remaining population remains to receive reparation. In Brazil, the regulation

of lands and property has resulted in the handing over of the usufruct and ownership of property of houses to persons affected and their family members in the states of Acre, Rio de Janeiro and Minas Gerais. In Japan, pioneering memorialization initiatives stand out, such as the creation of museums and the preservation and study of the artistic production of persons affected who were forcibly segregated. In Brazil and Japan, there are innovative experiences of participatory health-care management and health-care provision in former leprosy colonies. In Taiwan Province of China, strategies are put into place by civil society to ensure that older people affected who are still living in segregated communities are able to live in a dignified manner. In Ghana and Togo, civil society organizations have reunited families living in segregated facilities by assisting them in their return home, if desirable and possible.

V. Empowerment, with a focus on vulnerable groups

53. As documented by the Special Rapporteur, leprosy-related discrimination is multilayered – it frequently intersects with discrimination against other marginalized groups. Furthermore, the impact of stigmatization on the grounds of leprosy on the lives of persons affected is proportional to their vulnerability and resilience. She recognizes that the call for special attention to be paid to, and for the protection of, groups that are more vulnerable to leprosy-related discrimination, as set out in the principles and guidelines, identifies women and children as priority target groups. In order to prevent paternalistic approaches to vulnerability, the Special Rapporteur underscores three critical safeguards: vulnerability is not an ontological feature of a group of persons; vulnerability is often coupled with subordination, understood by the Special Rapporteur as the historical devaluation of some groups of people under hierarchical social structures that, by producing and reproducing an unequal distribution of power, severely constrain their autonomy and participation; and vulnerability reduction policies must focus on building the autonomy of target populations by promoting their empowerment.

54. Although eradicating vulnerability might not be feasible, diminishing it through policymaking and institutional arrangements is viable. Reinforcing the principle of autonomy implies not only recognizing the independence of individual viewpoints, choices, values and beliefs, but also creating conditions that can enable individuals to act autonomously. A human rights-based approach to vulnerability includes making groups in vulnerable situations the preferential beneficiaries of public policies in order to guarantee their full enjoyment of fundamental rights and freedoms. Vulnerability is at the core of the elaboration of norms, when factors such as disability, age, migration status, deprivation of liberty, refugee status or ethnicity are considered in human rights standards. Furthermore, international human rights law has come to recognize the specificity of the economic, social and political conditions of certain groups, responding to their struggles with specific instruments for protecting their rights, including the Convention on the Elimination of All Forms of Discrimination against Women, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Rights of the Child and the ILO Indigenous and Tribal Peoples Convention, 1989 (No. 169).

55. The obligation of the State to protect, promote and fulfil human rights is, for people living in vulnerable situations, inextricably linked to taking all measures necessary to empower them. Through empowerment, marginalized persons or persons in disadvantaged situations achieve greater control over their lives, furthering their democratic engagement with enhanced critical understanding about their own settings and their relation to power relations and hegemonic social structures. Common elements to the various definitions of empowerment are that it is a process, has a dimension of collective involvement, and involves active participation, critical reflection, awareness-raising, understanding, and access and control over important decisions and resources. The 2030 Agenda for Sustainable Development is built upon the recognition that development is not only transforming the material conditions of people in disadvantaged circumstances, but also implies providing them with a voice and choice. The empowerment of individuals and groups can contribute to transforming laws, policies, practices, norms and power relations.

56. Empowerment is, therefore, a multidimensional concept that highlights the need for States not only to safeguard civil and political rights, but also to duly implement economic, social and cultural rights. Its implementation is twofold: it requires enabling people to claim their rights and actively contribute to shaping decisions, policies and practices; and it entails creating conditions for overcoming any obstacle to personal and collective development. To empower individuals affected and their families, the Special Rapporteur calls upon States to develop research that can identify the groups that are more vulnerable to leprosy-related discrimination and to invest in the education, participation and access to justice for those groups.

A. Education

57. Education is both a human right and a means to fulfil other rights. Education promotes peace, reduces poverty and empowers disadvantaged groups. Article 26 of the Universal Declaration of Human Rights establishes that one of the goals of the right to education, whether public or private, formal or non-formal, is ensuring both the full development of individuals and generalized respect for human rights and fundamental freedoms. Those goals are furthered in article 13 of the International Covenant on Economic, Social and Cultural Rights, which reinforces the role of education for the full development of the human personality and for enabling all persons to participate in a free society built upon common understanding among different social groups. Education is key for materializing the rights to dignity and equality in social relations.

58. The principles and guidelines affirm the right to equal access to education opportunities and progress at school by persons affected and their family members, prohibiting the denial of admission or expulsion from school or training programmes on the grounds of having or having had leprosy. It is recommended that States also implement measures that can encourage increasing access for affected persons to educational opportunities. Provisions in the Convention on the Rights of the Child, the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of Persons with Disabilities are key for its implementation.

59. In its general comment No. 1 (2001) on the aims of education, the Committee on the Rights of the Child, recalled article 29 of the Convention on the Rights of the Child and underscored the far-reaching importance of education. Education should be child-centred, child-friendly and empowering. The Convention is clear in stating that the child's right to education is not only a matter of access, but also of content. The Committee on the Elimination of Discrimination against Women and the Committee on the Rights of Persons with Disabilities have called attention to how education systems can produce and reproduce exclusion, outlining guidelines for States to overcome exclusion. In its general recommendation No. 36 (2017) on the right of girls and women to education, the Committee on the Elimination of Discrimination against Women noted that equality and non-discrimination as part of the right to education involved three aspects: equal access to education; equal rights within the education system; and equal rights by means of education. Importantly, the Committee drew attention to the need to materialize equality in the way in which education was provided and to direct education for the transformation of disadvantaged social positioning and move forward the structurally disadvantaged positioning of women in society. Article 24 of the Convention on the Rights of Persons with Disabilities calls for inclusive education. In its general comment No. 4 (2016) on the right to inclusive education, the Committee on the Rights of Persons with Disabilities identified hindering factors to the right to education, at all levels and for all students, and enumerated the main features of inclusive education, some of which were: taking a whole-person approach; establishing a learning-friendly environment; and ensuring reasonable accommodation when necessary.

60. Access to education by persons affected and their family members is therefore not independent of the creation of an inclusive and enabling environment in which the system succeeds in diagnosing and correcting shortcomings related to educational progress. Similarly, education is expected to become an instrument for critical discussion, recognition and dissemination of the human rights of affected persons. States should promote

cooperation between the health-care, welfare and education systems, in order to prevent discriminatory attitudes within the education system. The involvement of parents or caregivers and the community and the participation of children affected and the children of persons affected, in accordance with their evolving capacities, should also be guaranteed for the creation of an inclusive and enabling environment.

61. The enforcement of the right to education by persons affected and their family members should be grounded in the elimination of discrimination, the availability of education services, the accessibility of all levels of education, the promotion of training and skills development opportunities and reasonable accommodation. To that end, strategies grounded in the specific context and needs must be developed in close consultation with persons affected and their families and should consider: ensuring that children affected by leprosy participate on an equal basis with other children in education services and recreational, leisure and sporting activities; increasing the enrolment and retention rates of affected children in the education system; enhancing the empowering effects of education by equipping students with the capacity to claim and exercise their rights; training teachers to adopt constructivist strategies that stimulate self-worth and confidence among students; eradicating illiteracy among affected persons; providing for continued and life-long learning, as well as technical and vocational education, as part of both the right to education and the right to work; ensuring the availability of counselling services, psychoeducational methods and medical care within education establishments; guaranteeing reasonable accommodation and support to students when needed; using the education system as an opportunity for raising awareness of leprosy and the human rights of persons affected; fostering the rights to freedom of speech and the participation of children affected in any decision-making process involving their lives, in accordance with their evolving capacities and in respect of their own choices of how to express themselves, including in non-written and/or non-verbal forms; targeting schools as a primary locus for education on leprosy and on the human rights of persons affected; using leprosy as a paradigmatic example in human rights education; and, in line with the recommendation of the Committee on the Elimination of Discrimination against Women to ensure equal rights within the system, medical schools should ensure that their curricula properly include leprosy and in such a way that fully respects the voice and choice of persons affected with regard to dignified health care and their right to the highest standard of physical and mental health.

B. Participation

62. Participation is multidimensional, including the elements of representative democracy, participatory democracy, non-governmental organizations and communities and epistemic communities, as well as the family sphere. Participation can simultaneously play a role in empowering persons affected and their family members and enable them to become agents of change. Participation in decision-making is not only a right, it is also pivotal for the production of more effective responses to problems. The Special Rapporteur has previously called attention to persons affected as being lay experts and called for the inclusion of situated knowledge in scientific research related to leprosy and in data collection and policymaking (see A/HRC/38/42). Moreover, the involvement of persons affected and their representative organizations and non-governmental organizations, as well as research and training institutions, should be a fundamental part of the formulation, implementation, monitoring and evaluation of all leprosy-related policies, which should ensure transparency and the democratization of information and create the mechanisms for holding policymakers, but also the private sector, accountable.

63. International conventions and treaties, especially the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of Persons with Disabilities, recognize the right of everyone to political participation and representation in public office. The opportunity of everyone to take part on an equal basis in public affairs and to have access to inclusive representation is key for the exercise of democracy and of the right to self-determination. For underrepresented groups, exercising the right to participation in public office and politics may require additional

efforts, such as affirmative measures, as indicated in the Committee on the Elimination of All Forms of Discrimination against Women. Participation in public life is fundamental for eliminating stereotypes, prejudice and exclusion. The exclusion or underrepresentation of certain groups in decision-making processes contributes to segregated societies and limits the possibilities of disadvantaged groups to protect their own interests. The principles and guidelines uphold the right of persons affected and their family members to take part in political and public life through the fulfilment of the general principle of equality and the prohibition of discrimination.

64. One critical aspect for the promotion of participation by persons affected and their family members is indicated in the Convention on the Rights of Persons with Disabilities. Unarguably, there are several systemic barriers to the full and meaningful participation of marginalized groups, which persons affected and their families often face. Such barriers include: illiteracy and low educational qualifications; legal impediments; inaccessibility of administrative procedures and requirements; inaccessibility and unintelligibility of the information being provided; physical and environmental barriers; and lack of support mechanisms for overcoming structural disadvantages reflected in unequal and unfair socioeconomic and education status. Article 29 of the Convention, by fully acknowledging those multiple barriers, affirms the obligation of the State to actively promote enabling environments, ensuring equality, guarantees to free expression, accessibility, accommodation of procedures and support. Accessibility as an indispensable condition for the fulfilment of the right to participation relates to information, communication, infrastructure and transport.

65. In order to promote the participation of persons affected and their family members, States are required to identify and remove any legal barrier, as well as any institutionalized discriminatory practice. Adopting temporary special measures to guarantee *de facto* equality in participation in public affairs, as endorsed by the Committee on the Elimination of Discrimination against Women in its general recommendation No. 23 (1997) on women in political and public life, may also be needed. The implementation of all measures aimed at barrier-free participation, as indicated in the Convention on the Rights of Persons with Disabilities is an indispensable condition. Participation goes hand in hand with the active promotion of empowerment.

C. Access to justice

66. Access to justice is one of the main instruments for protecting civil, political, economic, social and cultural rights. It is through the equal and effective guarantee of access to justice that people may stand up in defence of their rights, objecting to situations of discrimination and violation and holding policymakers accountable. In the declaration of the high-level meeting of the General Assembly on the rule of law at the national and international levels, Member States emphasized the importance of equal access to justice for all and of capacity-building concerning legal rights, committing themselves to taking all steps necessary to provide fair, transparent, effective, non-discriminatory and accountable services that promote access to justice, including legal aid. A comprehensive approach to ensuring access to justice must take into consideration the plurality of justice systems and address formal courts, specialized agencies, quasi-judicial mechanisms and traditional justice systems.

67. The Special Rapporteur on extreme poverty and human rights identified the main obstacles that people in vulnerable conditions must overcome to fully and equally exercise the right to access justice, which included: social and cultural barriers; legal and normative barriers; institutional and structural obstacles in the justice chain; non-existent or inadequate legal assistance; and structural problems of the judicial processes, encompassing formalism and differences in language and culture (see A/67/278). In its general recommendation No. 33 (2015) on women's access to justice, the Committee on the Elimination of Discrimination against Women highlighted a set of obstacles experienced by women and girls regarding access to justice, many of which are shared by persons affected, and especially women affected, by leprosy, such as stereotyping, discriminatory laws, intersecting forms of discrimination, procedural and evidentiary requirements and practices

and a failure to systematically ensure that judicial mechanisms were physically, economically, socially and culturally accessible.

68. Persons affected and their families are among those left furthest behind with regard to access to justice as a means to fight back against discrimination and defend their rights. On the one hand, systemic segregation, marginalization, violation, discriminatory legal frames and institutionalized practices, together with subordination and vulnerability, have made it almost impossible for persons affected to acquire access to justice. On the other hand, the centralization of courts and quasi-judicial bodies in urban centres, the cost and length of time of transportation to those places, as well as the non-accessibility of procedures, information and documentation, the non-availability of legal aid, the many deficiencies of the judicial system and the lack of knowledge among public defenders and judicial staff, have curtailed their right to justice.

69. In order to enforce the right to justice and the human rights literacy of a population that struggles with financial, physical and knowledge restrictions, States should take all measures necessary to: remove economic barriers, with the provision of legal aid; remove linguistic and cultural barriers, with the provision of translation and interpretation services, assistance to illiterate individuals and intercultural interpretation; develop partnerships with traditional justice systems for ensuring a rights-based approach to leprosy is taken in contexts of juridical pluralism; systematically record discrimination for supporting research, analysis of risk factors and providing quick, adequate, holistic, efficient and proportional remedies, with easy-to-access mechanisms for making complaints of discrimination; train judicial staff on issues related to leprosy; and build capacity on core human rights of those affected and their families.

D. In practice

70. In some countries, like Brazil and Nepal, persons affected have been participating in collegiate bodies, officially instituted working groups and committees. In countries such as Brazil, India and Japan, the existence of and action plans for protecting vulnerable groups, such as inclusion of persons with disabilities, elimination of violence against women and protection of the rights of children and older persons, may benefit persons affected by leprosy and their family members. However, it is necessary to pinpoint affected persons as the main target group of such policies and to monitor their impact and results. The work of some civil society groups deserves to be equally highlighted, including the work of MORHAN in Brazil and the Leprosy Mission and the Leprosy Society in India, in promoting and supporting affected women to take on leadership positions in their organizations and also in forums for institutional participation.

VI. Conclusion and recommendations

71. **Recommendations for implementing the policy framework presented in the present report are already integrated into the four main areas of the aforementioned policy. The Special Rapporteur calls attention to basic operational principles for the implementation of a rights-based policy for eliminating discrimination and promoting inclusion of persons affected by leprosy and their family members comprising the following tenets:**

- (a) Due recognition of persons affected by leprosy and their family members as rights holders;**
- (b) Substantive equality and inclusive governance as core paradigms of anti-discrimination policies;**
- (c) Adjustment or creation of adequate institutional arrangements and schemes;**
- (d) Meaningful participation of the target group, recognized as lay experts, in policymaking, monitoring and evaluation;**

- (e) **Elaboration of special temporary affirmative measures when needed;**
- (f) **Systematic data collection that includes disaggregation not only by demographic, environmental, socioeconomic and cultural variables, but also by the various grounds of discrimination recognized in international human rights law, and respect for the principles of participation and privacy;**
- (g) **Monitoring and accountability mechanisms with transparent sharing of information;**
- (h) **Provision of accessible mechanisms for filing complaints on the violation of rights;**
- (i) **Proper budget allocation at the national and subnational levels, with targets, indicators and benchmarks;**
- (j) **International cooperation, which is key to supporting the promotion of human rights policies for persons affected and their families in low-income countries.**

72. Considering the global prevalence of leprosy, necessary resources from Member States would be modest, whereas the return on the investment would be of great value for the promotion of the human rights of extremely vulnerable groups, especially within the context of the realization of the 2030 Agenda for Sustainable Development.

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