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

## Visit to Bangladesh

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

#### *Summary*

The Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, submits the present report on her visit to Bangladesh, conducted from 7 to 15 February 2023. In the report, the Special Rapporteur explores issues related to the progress made in eliminating leprosy-related discrimination and stigma in the country and the challenges faced in this regard and offers constructive recommendations on: addressing the social determinants of leprosy and the root causes of systemic discrimination; ensuring the right to independent living of affected persons and their family members; ensuring unrestricted access to justice; the allocation of adequate resources to the national leprosy programme; and the inclusion of leprosy as a prohibited grounds of discrimination in the Anti-Discrimination Bill of 2022.

\* The summary of the present report is being circulated in all official languages. The report itself, which is annexed to the summary, is being circulated in the language of submission only.

\*\* The report was submitted after the deadline in order to include the most recent information.



## Annex

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

#### **I. Introduction**

1. The Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, undertook an official visit to Bangladesh from 7 to 15 February 2023. The purpose of the visit was to identify persistent obstacles faced by persons affected by leprosy (also known as Hansen's disease) and their family members in accessing and enjoying fundamental rights, as well as discriminatory practices that hinder them from gaining access to opportunities on an equal basis with others. During her visit, the Special Rapporteur endeavoured to identify good practices in eliminating leprosy-based discrimination in order to strengthen cooperation between the Government, key stakeholders, civil society organizations and organizations representing persons affected by the disease. In the present report, the Special Rapporteur makes constructive recommendations to the Government on how to eliminate discrimination on the grounds of leprosy. As an expert on the subject, the Special Rapporteur uses the term Hansen's disease instead of leprosy throughout the report.

2. During her visit, the Special Rapporteur met with representatives from the Ministries of Foreign Affairs, Health and Social Welfare. She also met with representatives of the Law Commission, the National Legal Services Organization, the National Human Rights Commission and the National Foundation for the Development of Disabled Persons. In addition, she met with the United Nations resident coordinator and representatives of United Nations agencies working in Bangladesh. The Special Rapporteur also met a large number of stakeholders, including representatives of civil society organizations, health-care workers and persons affected by Hansen's disease living in different districts and had the opportunity to visit health-care facilities and communities of persons affected by the disease in the cities of Bogura and Nilphamari. The Special Rapporteur was deeply impressed by the outstanding work done by organizations of persons affected by Hansen's disease in advocating for the rights of their members and working to improve their lives through practices based on the solidarity economy model. She expresses her deep appreciation to those persons affected by Hansen's disease who shared their experiences and expertise with profound dignity and pride.

3. The Special Rapporteur is grateful to the Government of Bangladesh for its invitation and for the support provided in organizing and facilitating her visit. She also thanks the staff of the office of the United Nations Resident Coordinator for their assistance, the team of the Office of the United Nations High Commissioner for Human Rights for its immeasurable support and the representatives of civil society organizations that provided outstanding support and valuable inputs.

4. The visit of the Special Rapporteur was made subsequent to the issuance by the Committee on the Rights of Persons with Disabilities of its concluding observations on the initial report of Bangladesh.<sup>1</sup> In that report, the Committee made numerous references to persons affected by Hansen's disease, expressly recognizing the discrimination they face in the country, and called upon the Government to duly enforce their disability rights through a comprehensive set of recommendations, including the need to: develop a national strategy to ensure access for persons with Hansen's disease-related disabilities to mainstream community services; eliminate all barriers that hinder the enjoyment and participation of persons with Hansen's disease-related disabilities; and adopt and implement a national strategy on accessible, high-quality health-care services, including accessible hospitals and health-care centres. The Committee also referred to the particular situation of women affected by the disease and to the duty of the State to adopt and implement the necessary measures to address multiple and intersectional forms of discrimination against women and girls with disabilities who are also affected by the disease. Lastly, the Committee called on the State to

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<sup>1</sup> See [CRPD/C/BGD/CO/1](#).

intensify awareness-raising campaigns and initiatives and to adopt a national strategy on awareness-raising to educate the general public and public officials to combat prevailing prejudices, stigma, stereotypes, the use of derogatory language and other forms of discrimination against persons with Hansen's disease-related disabilities.

## II. Epidemiology

5. Based on new case detection, age, gender and disability, Bangladesh is one of 23 countries identified by the World Health Organization (WHO) as being global priority countries for Hansen's disease and has the fifth highest absolute incidence of the disease worldwide, with 3,000 to 3,500 cases detected annually. As in other countries, owing to the coronavirus disease (COVID-19) pandemic, case detection has been sporadic and unreliable, resulting in underreporting, a likely increase in transmission and a higher probability that new cases may have gone undetected, with long-term impairments and disabilities, including in children.

6. In 2021, only 2,872 new cases were detected (a figure that reflects a general decrease in detection during the COVID-19 pandemic): in 156 of those cases the individuals diagnosed had long-term impairments. This is a worrying trend, indicating delayed diagnosis and inadequate treatment. Children under the age of 15 accounted for 8.4 per cent of new leprosy cases in Bangladesh. The rate of new leprosy cases among children was 0.5 per 1 million child population, which is higher than the overall new case detection rate, indicating ongoing transmission. Of the reported cases among children, 12.6 per cent showed long-term impairments, a shamefully high figure. Both figures suggest that there are a considerable number of hidden cases, a suspicion corroborated through active case-finding activities in districts considered to be non-endemic. As a result of the high number of cases of Hansen's disease detected in those districts, their status was changed from non-endemic to highly endemic.

7. There is no official data on how many people living with Hansen's disease suffer from medical complications, impairments and discrimination. The Special Rapporteur is concerned that such people are not only invisible in State statistics but that they are also overlooked by the public health system.

8. Hansen's disease affects people of all ages in Bangladesh although the majority of new cases are detected in people below the age of 35. More men are diagnosed than women, which, aside from epidemiological hypotheses that have yet to be proved, clearly indicates their reduced access to diagnosis and treatment. Moreover, women in Bangladesh are dependent on third-party authorization for access to health care and suffer from particular stigmatization on the grounds of Hansen's disease, which, together with gender-based discrimination, can lead them to hide their symptoms and avoid diagnosis.

9. The fact that the reported incidence of Hansen's disease has been stable for some years, which (considering the epidemiology of Hansen's disease's and its long incubation period) means that unless active case-finding is systematically conducted, it will not be possible to halt transmission in Bangladesh. To achieve that end, proper budget allocation, with clear targets, indicators and benchmarks, is of the essence.

## III. Legal and institutional framework

10. The 1972 Constitution of Bangladesh, the supreme law of the country, expresses the will of the people. Article 7 of the Constitution establishes the authority of the Constitution and its supremacy over all other national laws.

11. The Constitution establishes the duty of the State to endeavour to ensure equality of opportunity to all citizens (art. 19). That duty includes the adoption of efforts to elaborate effective measures to remove social and economic inequality between women and men and to ensure the equitable distribution of wealth among citizens, as well as equality of opportunity and participation of women in all spheres of national life.

12. The equality of all citizens before the law is expressly stated in article 27 of the Constitution and the principle of non-discrimination is enshrined in article 28. The Constitution expressly states that women shall have equal rights to those of men in all spheres

of government and of public life. With regard to non-discrimination in particular, the Constitution states that no citizen shall, on grounds of religion, race, caste, sex or place of birth, be subjected to any disability, liability, restriction or condition with regard to access to any place of public entertainment or resort or admission to any educational institution. Article 28 also allows for the implementation of special measures and affirmative action policies, stating that the Government may make special provisions in favour of women and children and towards the advancement and improvement of any situation of disadvantage affecting citizens.

13. The Government of Bangladesh has a constitutional obligation to provide basic health-care services, as stipulated in article 15 of the Constitution, which also establishes its fundamental responsibility to ensure the basic necessities of life for its citizens, including the right to social security. In 2015, the Government adopted a new national social security strategy and adopted an action plan for its implementation in 2018. The Government has adopted a number of social safety net programmes in the following areas: (a) monetary transfers; (b) micro-credit; (c) food security; and (d) provision of education, health-care facilities and training.<sup>2</sup>

14. Bangladesh, as a signatory party to eight of the nine core human rights treaties,<sup>3</sup> has an obligation to implement them. There is full consistency between the international human rights standards to which the State has agreed and the framework of fundamental rights provided in the Constitution and there is room in the national legal framework for the application of the principles and guidelines for the elimination of discrimination against persons affected by Hansen's disease and their family members.

15. Human rights, with a particular focus on women and children, ethnic minorities, workers and vulnerable groups, have been addressed in different laws that have been passed in Bangladesh in recent years, including, notably, the Persons with Disabilities' Rights and Protection Act of 2013. The Government's long-term vision to address development issues and the rights of the most vulnerable population is reflected in its five-year plans and perspective plans.

16. Since its universal periodic review of 2009, the strong commitment of the Government of Bangladesh to human rights has been expressed through its adoption of a sophisticated set of national plans and policies, including: (a) the national health policy (2011); (b) the population policy (2012); (c) the national policy on older persons (2013); (d) the national women's development policy (2011); (e) the national food and nutrition security policy plan of action (2021–2030); and (f) the national action plan to prevent violence against women and children (2013–2025).

17. In the promotion and enforcement of human rights, the National Human Rights Commission is responsible for monitoring and investigating cases of human rights violations and the Law Commission has the authority to recommend the enactment, amendment or repeal of laws relevant in the context of fundamental rights. When it comes to guaranteeing

<sup>2</sup> See Government of Bangladesh, Ministry of Finance, chapter 12, Ministry of Social Welfare, gender budget, available at [https://mof.gov.bd/site/view/budget\\_mof/%E0%A7%A8%E0%A7%A6%E0%A7%A7%E0%A7%AF-%E0%A7%A8%E0%A7%A6/nolink/Vedio](https://mof.gov.bd/site/view/budget_mof/%E0%A7%A8%E0%A7%A6%E0%A7%A7%E0%A7%AF-%E0%A7%A8%E0%A7%A6/nolink/Vedio).

<sup>3</sup> International Covenant on Civil and Political Rights; International Covenant on Economic, Social and Cultural Rights; Convention on the Elimination of All Forms of Discrimination against Women; Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment; Convention on the Rights of the Child; International Convention on the Elimination of All Forms of Racial Discrimination; International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families; and Convention on the Rights of Persons with Disabilities. Bangladesh also ratified other relevant instruments, including: Optional Protocol to the Convention on the Rights of the Child on the involvement of children in armed conflict; Optional Protocol to the Convention on the Rights of the Child on the sale of children, child prostitution and child pornography; Convention on Consent to Marriage, Minimum Age for Marriage and Registration of Marriages; International Labour Organization (ILO) Convention concerning the Prohibition and Immediate Action for the Elimination of the Worst Forms of Child Labour, 1999 (No. 182); Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women; and Convention on the Political Rights of Women.

access to legal remedies, the National Legal Aid Services Organization has the mandate to develop access to justice strategies for the most vulnerable sectors of the population.

#### **IV. Gaps and challenges in the legal and institutional framework for protecting the of rights of persons affected by Hansen’s disease and their family members**

18. While, in principle, there are a number of laws and policies that should apply to persons affected by Hansen’s disease, in many cases they fail to duly recognize and provide protection for persons affected by the disease, thus hindering their access to and enjoyment of their rights.

19. The Anti-discrimination Bill of 2022, elaborated by the Law Commission and currently under discussion in Parliament, is a noteworthy example of recent human rights legislation. The adoption of such legislation, specifically aimed at anti-discrimination, has been widely anticipated as part of an assertive and comprehensive government strategy to combat the different discriminatory practices and situations in the country. However, the substance of the Bill has raised concerns among experts, civil society organizations and human rights organizations.

20. There are a number of challenges to the Anti-discrimination Bill, including that it: (a) bureaucratizes the treatment of discrimination by creating several layers (including district divisions and national forums) and steps that aggrieved persons must go through in order to obtain remedy in case of violations of their rights; (b) does not ensure the establishment of effective and independent monitoring mechanisms of human rights violations; (c) does not take into account the multidimensional and intersectional aspects of discrimination so as to address the root causes of discrimination or provide effective mechanisms for its prevention; and (d) is not sensitive to gender and intra-religious discrimination.

21. With specific regard to the rights of persons affected by Hansen’s disease and their family members, according to the information received by the Special Rapporteur during her visit, the Anti-discrimination Bill fails to include the disease as a prohibited grounds of discrimination and thus fails to protect the rights of persons affected by the disease in Bangladesh. The Special Rapporteur has urged the Law Commission to consider including discrimination against persons affected by Hansen’s disease in a revision of the law.

22. It is a matter of concern that the State administration and government bodies are failing to ensure that a commitment to the rights of persons affected by Hansen’s disease is duly met. The Special Rapporteur was appalled to discover the widespread lack of knowledge about the disease within the State administration and, in particular, among civil servants at all levels. There is no systematic collection of data about the disease in Bangladesh, other than the number of new cases that are diagnosed annually, which, owing to the reasons mentioned above, is not entirely reliable.

23. Relevant bodies specifically mandated to address discrimination in Bangladesh (such as the National Human Rights Commission) and to enable access to justice and remedies by the more vulnerable members of society (such as the National Legal Aid Services Organization) do not appear to be aware of the persistent challenges faced by persons affected by Hansen’s disease, nor do they collect systematic data about discrimination related to the disease. Furthermore, such bodies do not report information related to discrimination and violations of human rights in a consistent and transparent manner, in accordance with international human rights standards.

##### **National Human Rights Commission**

24. According to the National Human Rights Commission Act of 2009, the National Human Rights Commission is an independent body. The main functions and powers of the Commission include awareness-raising, promoting human rights education and training, conducting research on human rights and monitoring and investigating allegations of human rights violations.

25. During her visit, the Special Rapporteur was surprised to find a lack of knowledge among members of the National Human Rights Commission about the epidemiological

reality of Hansen's disease and recurrent episodes of human rights violations faced by persons affected by the disease and their families in Bangladesh. The Special Rapporteur was particularly concerned by the assertion of the Commission that Hansen's disease-related discrimination no longer exists in the country. Such a statement reflects a more than limited understanding of the disease and its related challenges, and means that relevant bodies and institutions are not fulfilling their duty to serve the entire population of the country.

26. The Special Rapporteur has consistently called attention to the fact that quasi-judicial systems and human rights protection systems in general fail to ensure justiciability, availability, accessibility, good quality, remedies and accountability for affected persons affected by Hansen's disease and their family members. States must recognize and take action to overcome obstacles and constraints that prevent persons affected by Hansen's disease from accessing justice and to safeguard their human rights on the basis of equality.

27. Since persons affected by Hansen's disease face severe and multifaceted forms of discrimination, beginning in the family and extending to interactions with the community and with public and private institutions, it is not uncommon to find that persons affected by the disease avoid claiming their civil rights owing to their fear of discrimination, contempt and public humiliation. The fact that the National Human Rights Commission has listed no complaints of human rights violations on the grounds of Hansen's disease should not be read as an indicator of the absence of such violations but should rather be interpreted as strong evidence that persons affected by Hansen's disease lack access to the institutions responsible for protecting their rights.

28. It is the responsibility of the Government to develop and support the capacity of State bodies and institutions to respond in a sensitive manner to the reality of individuals affected by Hansen's disease and their family members. It is up to the State to enable unrestricted access of this group of people to the justice system and to government bodies and institutions mandated to protect human rights in the country. It is up to the State to empower marginalized groups to achieve *de jure* and *de facto* equality.

#### **National Legal Aid Services Organization**

29. The National Legal Aid Services Organization<sup>4</sup> is a statutory government organization established under the Legal Aid Service Act. The Organization is mandated to provide legal aid to people who are unable to gain access justice owing to their socioeconomic status. The Organization is structured through district legal aid offices staffed by legal aid officers. In addition, there are legal aid committees at the upazila (sub-district) and union levels to provide legal advice and assistance as well as special committees in "chowki" and labour courts.

30. Key functions of the National Legal Aid Services Organization include: (a) ensuring access to justice for economically and socially disadvantaged people according to predefined eligibility criteria; (b) developing projects to expand, improve and promote legal aid programmes; (c) conducting educational and research activities to provide legal aid; (d) ensuring proper training of legal aid officers and staff; and (e) promoting public awareness on legal aid, rights and responsibilities.

31. During her visit, the Special Rapporteur identified a common pattern among government bodies and institutions mandated to protect human rights that reflected an absence of action to protect the rights of persons affected by Hansen's disease.

32. The above government bodies and institutions have failed to address the multiple barriers persons affected by Hansen's disease face in securing access to justice. The absence of complaints noted by the Special Rapporteur points to a failure of the State to promote a culture of awareness of human rights that takes the specific forms of discrimination that hinder access by persons affected by Hansen's disease to public services into consideration. If persons affected by Hansen's disease are not made aware of their human rights, and that the State has an obligation to ensure them, it is unlikely that they will report situations of

<sup>4</sup> Government of Bangladesh, Ministry of Law, Justice and Parliamentary Affairs, "Annual report (2018–2019): National Legal Aid Services Organization". Available at [https://nlaso.portal.gov.bd/sites/default/files/files/nlaso.portal.gov.bd/annual\\_reports-/4264134d\\_fcc9\\_487c\\_906a\\_8531a0539460/0559eb416edf65806136ac1b440b231d.pdf](https://nlaso.portal.gov.bd/sites/default/files/files/nlaso.portal.gov.bd/annual_reports-/4264134d_fcc9_487c_906a_8531a0539460/0559eb416edf65806136ac1b440b231d.pdf).

discrimination or violations of their rights, appeal to public bodies or request the services to which they are entitled.

33. The absence of human rights education and awareness-raising about the mechanisms in place for seeking redress and remedies in the face of discrimination and human rights violations in Bangladesh prevents people from knowing their rights and how to claim them. Affected persons include all those who lack the means to fight against discrimination and whose access to justice is severely limited. This situation is even more common when relevant government bodies and institutions disregard Hansen's disease as grounds of discrimination, as is the case in Bangladesh.

34. Special attention should be given to the situation of women affected by Hansen's disease. Women are subjected to different forms of violence and suffer a higher degree of discrimination due to stereotypes and stigma based on gender and on patriarchal cultural norms. Such discrimination has a direct impact on the ability and opportunity of women affected by Hansen's disease to access public services in order to obtain protections of their rights in the same way as men. Not surprisingly, the scarce data available indicates that legal aid mechanisms are seldom used by women in comparison to their use by men.<sup>5</sup>

35. Among the human rights obligations assumed by the State under the core international human rights treaties is the duty to ensure that people have access to education and information about their rights and the remedies available to ensure them. In the case of persons affected by Hansen's disease, education and information strategies should be especially designed, taking into account the stigmatization they suffer in interpersonal relationships and in their relations with public and private agencies. The Special Rapporteur is in favour of the adoption of an awareness-raising strategy to address social and cultural patterns of conduct that reinforce harmful stereotypes and customary practices that discriminate and stigmatize the rights of persons affected by Hansen's disease, including misconceptions about contagion and beliefs that associate the disease with a curse.

36. Importantly, the right to an effective remedy and reparation, as provided for in article 2 (3) of the International Covenant on Civil and Political Rights and subsequently clarified by the Human Rights Committee in its general comment No. 31 (2004), is a fundamental component of the obligations of States concerning human rights. It is expected that the Government of Bangladesh will develop and implement effective measures to raise awareness and promote education on the rights of affected persons, in close collaboration with communities, civil society organizations and organizations of persons affected persons by Hansen's disease.

### **National leprosy programme**

37. The national leprosy programme is implemented under the prevention of tuberculosis, leprosy, AIDS and sexually transmitted diseases programme, which is supported by eight partner NGOs.<sup>6</sup> The programme, which envisions achieving targets in each endemic district and upazila, also aims to strengthen the identification of cases and treatment, improve surveillance and increase technical and operational capacity in collaboration with partners and other stakeholders.

38. The main targets of the former strategic plan (2016–2020) of the national leprosy programme were to: (a) achieve the long-term goal of a Hansen's disease-free Bangladesh, meaning a country free of morbidity, disabilities and social consequences due to the disease; (b) reduce the number of cases of the disease in each upazila to less than 1 case per 10,000 people by the end of 2020 (point prevalence); (c) achieve zero cases of children (less than 15 years of age) diagnosed with long-term Hansen's disease by 2020; (d) reduce stigma and discrimination, understood as no incidence of refusal of persons affected by the disease at any general hospital and no incidence of separation of husband and wife when either one or both are affected by the disease; (e) strengthen the integration of the services for the disease into general health-care services; (f) introduce web-based surveillance and integrate Hansen's disease into the health management information system under the Directorate

<sup>5</sup> Data from the National Legal Aid Services Organization's annual report (2018–2019) pointed out that in fiscal year 2018/2019 while 7,767 women sought legal advice from the national help line call centre, 25,495 men used this service.

<sup>6</sup> Information shared at an in-person meeting with the Special Rapporteur.



General of Health Services; and (g) strengthen government ownership and coordination among partners (including political commitment, increased funding, coordinated implementation of activities and increased monitoring and evaluation).

39. Regarding the prevalence of Hansen's disease in Bangladesh, as identified in the national leprosy control strategy 2016–2020,<sup>7</sup> the geographical distribution of the disease is not uniform and the integration of the national leprosy programme with general health services is not fully functional owing to operational deficiencies. Other problems highlighted in the strategy included: (a) the shortage of expertise at all levels and limited opportunities for sustaining expertise in the programme; (b) the continuous delay in case detection without a significant change over time; and (c) lack of awareness of the epidemiology of Hansen's disease among service providers. The 2016–2020 strategy also recognized how deeply stigmatizing the disease is, including the profound impact of such stigmatization on women and poorer people, who are more unlikely to seek timely treatment and diagnosis.

40. Experts in the field have already pointed out how that Hansen's disease is gradually being pushed off the public health agenda, which will lead to a deterioration of services for its treatment. Such a deterioration is evident in the loss of technical knowledge and people with the expertise to treat the disease and its complications.<sup>8</sup>

41. When meeting with experts in the country, the Special Rapporteur received reports about challenges related to the coverage of health-care services, which have an impact on ensuring early diagnosis and active case detection. The need for greater integration of Hansen's disease into the work of community health-care workers, especially for detecting new cases, was also mentioned. Experts in the field pointed out that the lack of resources compromises the provision of adequate training for community health-care workers, which, in turn, limits outreach activities at the national level. Historically, the medical care of Hansen's disease patients has been in the hands of non-governmental organizations (NGOs), which have filled significant gaps in care. The Government has yet to ensure adequate provision of medical care for people affected by Hansen's disease.

42. The majority of the hospitals providing medical care for Hansen's disease are managed by NGOs. There are three government hospitals, in Dhaka, Sylhet and Niphamari districts, that specialize in treating persons affected by Hansen's disease. The following medical institutions specializing in Hansen's disease treatment are under the management of NGOs and are funded by donor countries: the Danish Bangladesh Leprosy Mission Hospital in Nilphamari; the Christian Leprosy Centres in Chandraghona, Kaptai and Rangamati; the Missionary Sisters of the Immaculate Tuberculosis and Leprosy Centre in Khulna; the Damien Foundation tuberculosis and leprosy hospitals in Jalchatra, Madhupur and Tangail; the Damien Foundation tuberculosis and leprosy hospitals in Shambuganj and Mymensingh; the Damien Foundation tuberculosis and leprosy hospital in Netrokona; and the Dhanjuri Leprosy Centre in Dinajpur.

43. Bangladesh achieved the elimination status of Hansen's disease as a public health problem in 1998, well before the target year of 2000. After the global elimination of leprosy as a public health problem in 2000 (often misunderstood as eradication, when it actually means prevalence of less than 1 case per 10,000 population), efforts and political will to tackle the disease dramatically decreased worldwide. In Bangladesh, as in many other countries, persons affected by Hansen's disease were forced to turn to charitable organizations to obtain access to health care and to ensure their livelihoods.

44. A decline in the quality of services, equipment and expertise of the health-care workforce were mentioned to the Special Rapporteur during meetings with representatives of civil society and medical experts. The lack of prioritization of the fight against Hansen's disease by the health system has also had a major impact on awareness-raising activities and efforts to eliminate harmful stereotypes about the disease. The Special Rapporteur has received accounts of serious deficits in knowledge of basic information about the disease and its treatment at the community level.

<sup>7</sup> Ibid.

<sup>8</sup> Humayan Kabir and Shaheed Hossain, "Knowledge on leprosy and its management among primary health-care providers in two districts of Bangladesh", *BMC Health Services Research*, vol. 19 (2019), available at <https://doi.org/10.1186/s12913-019-4525-z>.



45. The announcement of the zero leprosy initiative by 2030 by the Prime Minister is a very positive step. In 2019, as part of the national conference on the adoption of such an initiative, the Prime Minister, Sheikh Hasina, committed her Government to ensure adequate treatment for persons affected by Hansen's disease and to overcome discrimination and stigmatization based on the disease.

46. However, after a period of increased public attention to Hansen's disease, structural challenges are still in evidence. Examples of challenges reported to the Special Rapporteur during her visit include: (a) lack of resources for active case detection; (b) difficulties involving the bureaucratic structure of the health services; (c) lack of intersectoral policies; (d) delays in case detection and patient management; (e) lack of communication between government districts; (f) deficit in awareness-raising activities about the disease, (g) lack of a public policy to address the mental health needs of persons affected by Hansen's disease and their family members; (g) lack of assistive devices; and (h) deficiencies in ensuring a continuum of care for persons affected by the disease.

47. Currently, the State administration is failing to ensure that the commitment of the Prime Minister is duly met. The existence of Hansen's disease is hidden below multiple layers of exclusion and systematic discrimination.

## **V. Interpersonal and systemic discrimination: intersections, violence and dehumanization**

48. Having repealed the "Lepers Act of 1898", adopted under British colonial rule, on 24 November 2011, Bangladesh has currently no law that formally discriminates against persons affected by Hansen's disease. However, State obligations to combat discrimination against persons affected by the disease extend to direct and substantive discrimination. In its general comment No. 20 (2009), the Committee on Economic, Social and Cultural Rights states that peoples' actual or perceived state of health cannot be a barrier to the realization of their rights. According to the Committee, the protection of public health cannot be used to restrict the exercise of human rights or to create differential treatment with regard to access, inter alia, to education, employment, health care, travel, social assistance and housing. The Committee also mentions the duty of States to adopt measures to address the problem of widespread stigmatization of people based on their health status. In same general comment, the Committee details systemic discrimination as a pervasive, persistent and deeply entrenched social behaviour, often involving unchallenged or indirect discrimination. Under the provisions of the International Covenant on Economic, Social and Cultural Rights, States must guarantee both formal and substantive equality.<sup>9</sup> In addition to not discriminating and/or expressly prohibiting discrimination in their laws and policies, States must take positive steps to prevent de facto discrimination against any group of people.

49. The duty of the State to eliminate discrimination against persons affected by Hansen's disease and their family members relates to functions and activities for which responsibilities are assumed by public authorities and institutions, such as marriage, divorce, decisions on parental authority, access to public office and employment, access to social welfare benefits, production of identification documents, granting of citizenship, access to public schools and

<sup>9</sup> See Committee on Economic, Social and Cultural Rights, general comment No. 20 (2009), paras. 8 and 10. According to the Committee:

discrimination must be eliminated both formally and substantively: ... Substantive discrimination: Merely addressing formal discrimination will not ensure substantive equality as envisaged and defined by article 2, paragraph 2. The effective enjoyment of Covenant rights is often influenced by whether a person is a member of a group characterized by the prohibited grounds of discrimination. Eliminating discrimination in practice requires paying sufficient attention to groups of individuals which suffer from historical or persistent prejudice instead of merely comparing the formal treatment of individuals in similar situations. States parties must therefore immediately adopt the necessary measures to prevent, diminish and eliminate the conditions and attitudes which cause or perpetuate substantive or de facto discrimination ... Direct discrimination occurs when an individual is treated less favourably than another person in a similar situation for a reason related to a prohibited ground; e.g. where employment in educational or cultural institutions or membership of a trade union is based on the political opinions of applicants or employees. Direct discrimination also includes detrimental acts or omissions on the basis of prohibited grounds where there is no comparable similar situation.

training programmes, access to legal and health services, and the use of discriminatory language by State agencies and documents. The obligation of non-discrimination may also include responsibility to enact and enforce legislation that prohibits discrimination on the basis of the disease and to ensure that private organizations, companies, initiatives, facilities and services eliminate discriminatory practices. It is also the responsibility of the State, through responsible bodies, to take measures to prevent, investigate and punish discrimination and human rights violations and to provide redress.

50. Moreover, and in accordance with general comment No. 6 (2018) of the Committee on the Rights of Persons with Disabilities, States must commit to the elimination of barriers that prevent persons with disabilities from having access to the protections, benefits and advantages provided for all persons under the law. The duty to prohibit all types of discrimination includes recognizing that discrimination can be based on a single characteristic (gender) or on multiple, intersectional characteristics (including, gender, race, disability and poverty). According to the Committee, at least four types of discrimination can occur singly or simultaneously: discrimination, direct discrimination, indirect discrimination, denial of reasonable accommodation and harassment (creating an intimidating, hostile and degrading environment).

51. Neither Hansen's disease nor discrimination on the grounds of the disease have disappeared in Bangladesh. Both the disease and the discrimination attached to it are hidden among multiple layers of poverty, gender, disability, social class and other grounds for discrimination. In meetings with persons affected by Hansen's disease and their representative organizations, the Special Rapporteur realized that the disease remains a cause of great suffering in the country.

52. Hansen's disease intersects with poverty, gender-based discrimination, subordination of children, religious norms and customary practices, leading, among other forms of dehumanization, to: community segregation; divorce and abandonment; loss of marriage opportunities; separation from and within the household; refusal to buy items from persons affected by the disease or to share food with them; abuse and psychological and physical violence (especially against women and children); loss of jobs; exclusion from the education system; denial of medical care; and exclusion from religious settings and participation in religious practices. It appears that there are no frameworks to protect the rights of persons affected by Hansen's disease and their family members or to provide accountability or remedies for such violations in Bangladesh.

53. The Special Rapporteur was deeply concerned by the number of persons affected by Hansen's disease who reported experiences of segregation, discrimination and violence. Testimonies revealed persistent, direct and substantive discrimination, reflected in: (a) out-of-pocket expenses for health care, including for long-distance travel to access health-care services; (b) separation from families and communities in order to obtain medical care far from home; (c) difficulties in locating health-care workers trained to diagnose the disease; (d) degrading treatment by health-care workers who refuse to deliver services owing to baseless fears of transmission; (e) separation within households; (f) job loss as the result of stigmatization; (g) broken marriages or marriage proposals that are broken off when information about the disease is made known; (h) fear and humiliation when seeking public services; (i) lack of access to information that could promote a better understanding of the disease and guarantee inclusion in the community; and (j) lack of opportunities, resources, assistive and support devices, mobility aids, counselling and rehabilitation that could contribute to independent living.

54. The Special Rapporteur was concerned to learn that, owing to a fear of Hansen's disease, some affected individuals reported having been segregated within the penitentiary system and having experienced significant difficulties in obtaining medication. Misappropriation and loss of property and land as a result of having the disease were also reported. Moreover, family members of persons affected by Hansen's disease are also victims of stigmatization and discrimination, particularly at the community level, including in education settings and with regard to marriage prospects.

55. As a result of significant gaps in the public health system, in particular the lack of expertise for the early diagnosis and proper treatment of Hansen's disease, persons affected by Hansen's disease experience a serious deterioration in their health. Almost all of the persons affected by Hansen's disease who met with the Special Rapporteur had visible and long-term impairments of their hands and feet. Such impairments, in combination with a low

educational level, compromise their livelihoods. As a result of the lack of access to education by the poorest sectors of society, affected persons are generally employed in physically demanding labour, which aggravates their impairments, trapping them in a spiralling chain of disadvantage.

56. The Special Rapporteur can testify to the profound effect that Hansen's disease, discrimination on its grounds and the failure of the State to take measures to eliminate harmful stereotypes have on the mental health of affected people, especially women and children. Women and children affected by the disease are often abused, with no means to fight back, and sometimes lack the means to ensure their own survival. The reservations of Bangladesh to articles 2 and 16 (1) (c) of the Convention on the Elimination of All Forms of Discrimination against Women hinder efforts to eliminate such systematic abuses. Counselling services and referrals to mental health-care services for affected persons are manifestly absent.

57. While counselling can be an effective tool in reducing stigmatization on the grounds of Hansen's disease, it should be provided with a clear understanding of the particular context and specificity of each individual case. The Special Rapporteur heard accounts of community efforts to combat stereotypes and discrimination that succeeded in creating an enabling environment, allowing persons affected by Hansen's disease to remain in their communities. In addition, different examples of successful practices implemented by NGOs to restore the self-esteem and dignity of affected individuals through counselling and the formation of self-help groups were provided.

## **VI. Interrelationship between the right to health and disability rights: gaps in the health-care system and disability policies**

58. The Special Rapporteur emphasizes that the suffering caused by Hansen's disease is preventable. It is up to States to enforce and guarantee the right to health of persons affected by the disease, as provided in article 12 of the International Covenant on Economic, Social and Cultural Rights.

59. The health-care system in Bangladesh is largely underfunded. The lack of resources for the control of Hansen's disease and the peripheral place of the disease in the national health agenda is evident from the level of public investment devoted to the disease compared with that devoted to tuberculosis. Although improvements of the national leprosy programme have been identified over the years, in general such advances and increases have been the result of collaborative efforts on the part of NGOs.

60. Studies in the field have pointed to a diversity of problems in the country's public health system, including: lack of adequately trained personnel and supplies; shortage of drugs and equipment; poor prioritization of expenditures; and management and coordination problems.<sup>10</sup> During her meetings with public health experts, the Special Rapporteur realized that, despite the country's accelerated urbanization process, there is still no consolidated health infrastructure in urban areas.

61. The health system in Bangladesh largely fails to ensure that persons affected by Hansen's disease have the right to the highest attainable standard of health, including the availability, accessibility, acceptability and quality of health facilities, goods and services, as stipulated by the Committee on Economic, Social and Cultural Rights in its general comment No. 14 (2000). At present, action by the Government to address the needs of persons affected by Hansen's disease is restricted to providing multidrug therapy.<sup>11</sup> Moreover, the monthly doses of one of the component drugs of the multidrug therapy is only given at the upazila level, which requires out-of-pocket expenses for those people who need to travel to get their medication.

<sup>10</sup> WHO and Asia Pacific Observatory on Health Systems and Policies, "Improving the quality of care in the public health system in Bangladesh: building on new evidence and current policy levers" (2017), available at <https://www.medbox.org/pdf/5e148832db60a2044c2d3c6d>.

<sup>11</sup> The multidrug therapy is distributed by WHO to countries free of charge through an agreement between the pharmaceutical company Novartis and WHO, which began in 2000 and was recently extended to 2025.

62. Despite being curable with multidrug therapy, if not detected early and treated properly, Hansen's disease can become chronic, requiring a continuum of medical and psychosocial care that may include medical treatment for reactions, wound care, rehabilitation and reconstructive surgery, as well as the provision of assistive devices and psychosocial support. Such a continuum of medical and psychosocial care should be fully addressed through effective referral within the national health-care system. During visits to the field, the Special Rapporteur verified that, unfortunately, such a continuum of care is not available for persons affected by Hansen's disease in public health-care settings. Available treatment for reactions to the disease, including wound care, rehabilitation, reconstructive surgery and psychosocial support, is largely dependent on NGOs. Such coverage, however, while welcome, is insufficient since it does not cover the entire country nor does it ensure universal access to medical care.

63. The right to health is interdependent with the realization of other rights, including the right to dignity, equality and non-discrimination. During her visit, the Special Rapporteur was dismayed to hear about the discriminatory treatment of persons affected by Hansen's disease at the hands of staff of health-care services who oftentimes discriminate against them and refuse to provide them with medical care. As stressed by the Committee on Economic, Social and Cultural Rights, in law and in practice, health facilities, goods and services must be accessible to all, without discrimination on any of the prohibited grounds, especially the most vulnerable or marginalized sectors of the population, such as persons affected by Hansen's disease and their families.<sup>12</sup>

64. The State should assume a more central role in carrying out the national leprosy programme and should improve the current service model, which is fragmented into several agencies, both public and private, with different authorities and competencies. The current model should be replaced by a more comprehensive, integrated, multisectoral and comprehensive model, which should address the various dimensions of care, from timely diagnosis to care for complications, wound care, nerve damage and adverse reactions to drug treatment, mental health care and rehabilitation, as well as the provision of mobility aids and assistive devices.

65. It is also necessary to ensure broader access to health information. Health information about Hansen's disease, including its symptoms, treatment and the rights of those affected by it, is very limited. Budget allocation, expertise and the integration of medical care for the disease into general health-care services at all levels, from the primary to the tertiary, including the establishment of an effective referral system, are essential. If such action is not taken, the incidence of around 3,000 new cases annually will remain unchanged, as will the unacceptable suffering of those who fall ill.

66. Responsibility for Hansen's disease is lost within the State administration, with little evidence of coordination among different government bodies. The various entities function under a top-down approach, which hinders communication and leaves each body ignorant of the workings of the others. The lack of interministerial and intraministerial communication, which compromises the quality of health services in general, has a particular effect on the medical services that should be guaranteed to individual affected by Hansen's disease, which cannot be cured without the provision of multisectoral services. The vulnerability of persons affected by Hansen's disease is intensified as a result of the social and economic consequences of the disease. In addition, because of the lack of coverage and the poor quality of available health services, affected people suffer from the most severe and debilitating manifestations of the disease, making them even more vulnerable. While the integration of different government bodies is to be hoped for, the glaring need for cooperation between the health and the disability sectors is urgent.

67. As a result of the lack of proper care at community health-care clinics, the majority of persons with Hansen's disease-related impairments often have to travel away from home to receive treatment at hospitals run by NGOs. In providing such assistance, NGOs are providing an essential service that should, more properly, be provided at government community clinics and under primary health care. Hospitalization for wound care would not be needed if the State could fulfil its obligations under article 12 of the International Covenant

<sup>12</sup> General comment No. 14 (2000), para. 12 (b).

on Economic, Social and Cultural Rights and article 20 of the Convention on the Rights of Persons with Disabilities.

68. Late diagnosis of Hansen's disease comes at great economic losses for the country, in particular when it affects children and young people, and when anti-discriminatory policies and disability rights are not duly enforced. There are important vacuums in both disability-related laws and policies. The Rights and Protection of Persons with Disabilities Act of 2013 does not recognize Hansen's disease as a disability, including the invisible impairments and psychosocial impairments caused by the disease. Furthermore, issues such as accessibility and reasonable accommodation, as well as inclusive education, as provided for in article 24 of the Convention on the Rights of Persons with Disabilities, have yet to be addressed in Bangladesh. The country still implements a "special" (separate) education model for children with disabilities, which goes against the spirit and the provisions of the Convention. The country's disability related legal framework seems to be closer to a charity-based model than to a framework based on human rights.

69. Persons affected by Hansen's disease report many barriers to their access to social protection and disability-related benefits. During her visit, the Special Rapporteur learned about the difficulties faced by persons affected by Hansen's disease in gaining access the national disability card. The problems in obtaining the card generally result from a lack of knowledge about disabilities related to the disease, including among health professionals who conduct the medical examinations required to obtain the card. In this regard, it is important to note that the disability allowance, like other cash transfer benefits, is insufficient to guarantee an adequate standard of living.

70. The barriers faced by persons affected by Hansen's disease in accessing disability rights include complaints about corruption on the part of civil servants with regard to access to disability and other cash transfer social protection schemes, namely old age and widows' allowances, to which affected persons are entitled. Such complaints should be duly investigated by relevant government bodies and punished if proven to be true; accountability mechanisms should be created for this purpose. Procedures for accessing social protection benefits should be transparent and accountability of civil servants should be ensured in order to prevent corrupt practices.

71. The lack of access to quality mobility aids and assistive devices technologies, which are largely unavailable, has a negative effect on the human rights of persons affected by Hansen's disease. It is reported that some hospitals are able to manufacture such devices but do not have the resources to provide them to affected patients. Public health policy for the disease should be sufficiently integrated into other relevant ministries, including the Ministry of Social Welfare, to ensure not only biomedical treatment but also autonomy to affected persons, including the freedom to make their own choices and to independence, as provided in article 3 of the Convention on the Rights of Persons with Disabilities, as well as their right to live independently and to be included in the community, in line with article 19 of the Convention.

72. The social protection system, seen from the viewpoint of the lived experience of persons affected by Hansen's disease, does not seem to be consistent or to be aimed at promoting a transition to active citizenship. There is an evident need for a robust social protection system to ensure an adequate standard of living and the enabling of active citizenship. Policies aiming at the transition of affected persons from the informal economy to the formal economy are needed, given the fact that the majority of affected persons, like many other national citizens, are excluded from the formal work market.

## VII. Conclusions

73. **In 2015, Bangladesh was moved from the World Bank's list of low-income countries to the list of lower-middle-income countries. In 2018, the country met all of the United Nations criteria for graduation from the list of least developed countries. According to the Government's eighth five-year plan, it is expected that Bangladesh will formally graduate from the list of least developed countries in 2024.**

74. **Bangladesh has made consistent progress regarding economic growth and considerable if not yet sufficient improvement in the provision of clean water, sanitation and hygiene, the lack of which contribute to the spread of diseases such as Hansen's**

disease and other neglected diseases endemic in the country. With regard to other socioeconomic determinants of leprosy, there have been positive advances, particularly in women's literacy and education, women's ability to access health care and basic services and an increase in the number of poor women with the opportunity to achieve economic independence through participation in the workforce.<sup>13</sup>

75. The efforts made by the Government in this regard are commendable. However, an in-depth analysis of the intertwining and intersectional dimensions of discrimination in the country raises questions as to whether such progress has been achieved in an equitable manner. The situation of persons affected by Hansen's disease shows that certain groups, who already face serious situations of disadvantage, social inequality and marginalization, remain trapped in poverty and disempowerment. The reality of the lives of such people and communities, which does not reflect indicators of development progress, includes: (a) the persistence of extreme poverty; (b) social exclusion; (c) diverse vulnerabilities; (d) irreducible exposure to indicators of poor health, such as malnutrition; (e) propensity to infectious diseases; and (f) victimization by different forms of violence, extreme events and catastrophes. The human rights situation of persons affected by Hansen's disease provides a clear example of the inequities that need to be overcome so that development in the country may also promote positive change for those who have been left behind.

76. Hansen's disease is classified by WHO as a neglected tropical disease, closely linked to poverty. According to WHO, infectious diseases contribute to lifelong disadvantages, perpetuating a vicious cycle of poverty and infection. As the Special Rapporteur has detailed in previous reports to the Council and to the General Assembly, the disease and its consequences are products of structural violence that is inherently cumulative and reflects systematic restrictions that prevent people who occupy the bottom rungs of society from meeting their basic needs. Structural violence is often invisible, accepted as the natural order of things and perpetrated on a daily basis by dominant institutions.

77. Hansen's disease and the persistence of discrimination against those affected, as well as against their family members, reveal how far the State has to go in terms of ensuring the protection, promotion and fulfilment of human rights, given that people affected by the disease are among those left furthest behind. The condition of persons affected by Hansen's disease is a strong indicator of the overall situation of human rights in a given country and, more particularly, of the achievement of the right to development as framed in the Declaration on the Right to Development adopted by the General Assembly in 1986. As affirmed in the preamble to the Declaration, development is a comprehensive economic, social, cultural and political process, which aims at the constant improvement of the well-being of the entire population and of all individuals on the basis of their active, free and meaningful participation in development and in the fair distribution of benefits resulting therefrom.

78. The situation of persons affected by Hansen's disease and their family members in Bangladesh shows that the country's outstanding economic growth, which has been somewhat compromised by the COVID-19 pandemic, is not reaching the entire population, casting doubt as to whether fundamental principles of the right to development, such as equity, self-determination, participation and justice, are being met. Persons affected by Hansen's disease and their families still do not enjoy the benefits of economic growth nor is discrimination against them being redressed. Moreover, there is no meaningful and free participation of members of marginalized and discriminated groups in public affairs as a means to defend their interests. In addition, given the reports of ongoing corruption, the limited efficiency of oversight institutions and the essentially paternalistic approaches to people living in vulnerable situations, it is evident that the environment in the country is not enabling or inclusive.

79. A human rights-based approach to development requires a bottom-up dynamic, allowing excluded people and groups to break the cycle of disadvantage, isolation and stigmatization through collective action at the grass-roots level. During her visit, the

<sup>13</sup> See Nazneen Akhter, "Enduring response in embracing urgency in community care: a critical perspective on social empowerment of Bangladesh", *Philosophy International Journal*, vol. 5, No. 2 (2022).

Special Rapporteur identified such collective action on the part of grass-roots organizations, with the support of NGOs, to ensure the economic empowerment of the most disadvantaged sectors of society and to enable access to services that are currently available in areas such as self-care and mental health care.

80. Grass-roots organizations make use of popular community-education approaches, offering guidance and supervision to ensure that people affected by Hansen's disease can practise peer counselling and self-care. Such organizations bring together not only persons affected by Hansen's disease but also persons with disabilities and members of other disadvantaged groups. Community education approaches are based on solidarity, rooted in local cultures of the country, which have long been used to overcome socioeconomic inequalities, including: (a) practices based on solidarity economy, such as seed funding and savings, and credit and collective economic activities to build livelihoods; (b) advocacy through political action, especially at the subnational level of government, to defend rights and demand policies; (c) mental care, through mutual help, active supportive listening and peer counselling; and (d) physical care through practical guidance on how to deal with the adverse physical manifestations of Hansen's disease.

81. Interventions at the group level support strong dynamics for the creation of personal and social transformation, based on the lived experience of persons affected by Hansen's disease, to promote empathy, self-recognition, self-esteem, sense of purpose, motivation and trust through mutual support. Such alternative forms of action reveal the effectiveness of collective empowerment to break the cycle of isolation, dependence, chronic poverty and stigmatization.

82. Good practices for the elimination of discrimination on the grounds of Hansen's disease, which are mainly being implemented by civil society organizations, should be scaled up by the Government. The country is in need of a development strategy that places people's autonomy and active citizenship at the centre of decision-making and ensures that the process of development is locally owned through the promotion of active citizenship among those sectors of society that have experienced historical discrimination and have been left furthest behind.

83. In addition, it is essential that the country implement a rights-based development approach that guarantees access to fundamental services on a non-discriminatory basis and ensures the right to participate in development planning both a means and a goal of overall development policies and plans. Development strategies should empower persons who have faced systemic discrimination and both outcomes and processes of development policies should be monitored in a transparent manner to ensure that they are not discriminatory.

## VIII. Recommendations

84. The Special Rapporteur recommends that the Government:

(a) Redress persistent substantive discrimination, in both the social determinants of Hansen's disease and the root causes of systemic discrimination, and target socioeconomic disadvantage through efforts to ensure: redistributive measures to guarantee a minimum standard of living; stigma reduction strategies, through awareness-raising programmes involving persons affected by Hansen's disease and their family members that are sensitive to local languages, gender, age and disability; the autonomous development and independent living of persons affected by Hansen's disease and their family members, including special measures in the fields of education and vocational training, decent work and social protections; multisectoral governance and interministerial cooperation;

(b) Redress persistent direct discrimination against persons affected by Hansen's disease; harmonize the Anti-Discrimination Act of 2022 to include Hansen's disease as a prohibited grounds of discrimination; amend the Rights and Protection of Persons with Disabilities Act of 2013, which does not recognize Hansen's disease as a disability; monitor, investigate and punish perpetrators of discrimination against persons affected by Hansen's disease; and ensure due reparation to persons affected by Hansen's disease for suffering and damage caused;



(c) Ensure unrestricted access to justice and to the bodies responsible for monitoring rights violations by eliminating physical, cultural and economic barriers, as well as discriminatory practices, attitudes and behaviours on the part of civil servants; ensure the training of public officials on Hansen's disease-related issues; implement a human rights education plan, with special focus on increasing access to justice for persons affected by Hansen's disease; establish accessible mechanisms through which persons affected by Hansen's disease may lodge complaints of human rights violations and discrimination; develop an information system, including disaggregated data collection of violations and discrimination; and carry out training on the basic human rights of persons affected by Hansen's disease and their family members;

(d) Provide sufficient resources for the national leprosy programme to sustain expertise on Hansen's disease in the country; ensure high-quality health services; reinforce the role of community health workers; ensure the continuum of care to persons affected by Hansen's disease through the provision of professional counsellors and mental health support in the health system; extend professional counselling and mental health support to include family members of persons affected by Hansen's disease, guarantee access to health care on a non-discriminatory basis through strategies that fight discrimination in health-care settings, ineffective public policies and geographical isolation; guarantee the right to a continuum of medical and psychosocial care that encompasses the full spectrum of prevention, including timely access to multidrug therapy, the proper management of leprosy reactions and complementary care, such as wound care, physiotherapy, rehabilitation and reconstructive surgery, alongside service delivery at the community level; and develop indicators and benchmarks to monitor inequities in the provision of medical care to persons affected by Hansen's disease, including specific targets and monitoring mechanisms;

(e) Recognize persons affected by Hansen's disease as active economic agents, respecting their legal capacity and realizing their rights to equal work opportunities in the open labour market and to equal remuneration; guarantee the right of persons affected by Hansen's disease to education through the creation of an inclusive and enabling education system that is non-discriminatory and that ensures the availability of education services, accessibility at all levels of education and the promotion of life-long training and skills development opportunities, including the provision of reasonable accommodation; foster empowerment, vocational and human rights training; and ensure freedom from want and violence for women affected by Hansen's disease;

(f) Raise awareness among government bodies regarding the provisions of the Convention on the Rights of Persons with Disabilities and the recent country review of the Committee on the Rights of Persons with Disabilities;<sup>14</sup> and develop and distribute informational materials and raise awareness about the United Nations human rights system and the recommendations of the treaty bodies;

(g) Include persons affected by Hansen's disease in public employment programmes; open social dialogue to groups of affected persons working in the informal economy; ensure the right to collective bargaining for persons affected by Hansen's disease working in both the formal and informal economy, including by establishing a defined interface between the institutions and government bodies with which persons affected by Hansen's disease must dialogue; fulfil accessibility and reasonable accommodation rights in all productive sectors and work arrangements; and implement affirmative measures to correct historical and structural disadvantages, encompassing both work and education opportunities, including targets and key performance indicators and effective enforcement mechanisms and remedies, in line with paragraph 11 (i) of International Labour Organization Recommendation No. 168 concerning Vocational Rehabilitation and Employment (Disabled Persons) of 1983 regarding awareness-raising and eligibility criteria, to be defined in consultation with grass-roots organizations, in order to ensure the accessibility of procedures;

<sup>14</sup> CRPD/C/BGD/CO/1.

(h) Address allegations of corruption by public officials in the distribution of social benefits and cash transfer programmes, ensuring prompt and impartial investigations and punishment of those responsible; and develop mechanisms to ensure the transparency of procedures relating to social welfare benefits and to make public officials accountable in decision-making processes, thus ensuring a universal basic income for persons affected by Hansen's disease;

(i) Approve legislation to officially change the name of leprosy to Hansen's disease, in order to eliminate discriminatory language and persistent harmful stereotypes.

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