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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 Brazil

Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero*

Summary

In her report, the Independent Expert on the enjoyment of human rights by persons with albinism presents her findings on her official visit to Brazil, which she conducted from 28 October to 8 November 2019. They include existing challenges regarding stigma and discrimination, the right to life and the rights to health, education, employment, an adequate standard of living and access to justice. While recognizing the commendable steps taken by the Government since her visit, she recommends further specific steps that the authorities and relevant stakeholders can take to ensure a sustainable and effective approach to protecting and promoting the human rights of persons with albinism in Brazil.

* The summary of the 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.



Annex

Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, on her visit to Brazil

I. Introduction

1. Pursuant to Human Rights Council resolution 37/5, the Government extended an invitation to the Independent Expert on the enjoyment of human rights by persons with albinism to visit Brazil. The Independent Expert carried out an official visit to Brazil from 28 October to 8 November 2019.

2. The Independent Expert held meetings in Brasília in the Federal District, in Maceió in the State of Alagoas, in Salvador and Ilha de Maré in the State of Bahia and in São Paulo in the State of São Paulo. She met with Brazilian authorities including at the Ministries of Foreign Affairs, of Women, Family and Human Rights, of Citizenship, of Health, of Education, Justice and Public Security and of Economy at the national and state levels. She also met with staff of the Office of the Federal Public Defender, the Human Rights Commissions of both the House of Representatives and the Federal Senate, and the National Human Rights Council.

3. In addition, she held consultations with staff of United Nations agencies, funds and programmes, civil society representatives, academics, social workers, medical professionals and influencers promoting positive exposure for persons with albinism, such as fashion models. She also had the opportunity to meet persons with albinism from the States of Alagoas, Bahia, Minas Gerais, Rio de Janeiro and São Paulo, both individually and as members of representative groups, including the Association of Persons Living with Albinism in Bahia State (Associação das Pessoas com Albinismo na Bahia (APALBA)),¹ the Association of Albinos in Alagoas State (Associação dos Albinos de Alagoas (ALBINAL)) and the Pro-Albino Programme at the Santa Casa de Misericórdia hospital in São Paulo.

II. Background

4. Approximately 305 groups in Brazil self-identify as indigenous peoples, speaking over 274 different languages. While representing only 0.43 per cent of the population, they are present in 80 per cent of Brazilian municipalities (A/HRC/33/42/Add.1, para. 9).

5. During the transatlantic slave trade, Brazil is estimated to have received millions of enslaved Africans. In 1888, it became the last country in the region to abolish that form of slavery. The country was proclaimed a republic in 1889 and a federal and decentralized system was adopted. While the non-white population could not afford a high level of economic development, immigration policies to “whiten” the population were adopted in the early twentieth century. The population of Brazil is currently estimated at 209.5 million persons.²

6. At the federal level, the executive is headed by the President. The bicameral National Congress, consisting of the Federal Senate and the House of Representatives, exercises legislative power. State governments have three branches: the executive, represented by a governor and an appointed cabinet, the legislative, constituted by a unicameral congress, and a judiciary. States are divided into municipalities, which are governed by mayors.

7. The Federal Constitution of 1988 is the main political and legal instrument. It sets out the decentralized governance system: 26 autonomous states, each with its own constitution, and a Federal District. Each municipality has its own organic law.

¹ See <https://abong.org.br/associadas/apalba/>.

² See <http://hdr.undp.org/en/countries/profiles/BRA>.

8. In 2018, the economy of Brazil was ranked the world's ninth largest.³ In the wake of a strong recession, economic activity has been undergoing a depression. The growth rate has slowed in recent years, from 4.5 per cent between 2006 and 2010 to 2.4 per cent between 2011 and 2014. Economic activity contracted significantly in 2015 and 2016, with gross domestic product (GDP) dropping by 3.8 per cent and 3.6 per cent respectively.⁴

9. A recent study by the Brazilian Institute of Geography and Statistics showed that inequality was on the rise. For instance, in 2018, black or brown Brazilians had a per capita monthly household income of 934 reais, almost half of that of white Brazilians.⁵ According to the 2018 Human Development Index of the United Nations Development Programme (UNDP), Brazil ranked 79 out of 189 countries.⁶ States in Brazil have varying levels of development. For instance, the North-East region, which has the largest percentage of Brazilians of African descent, includes some of the poorest and least developed States. Brazil continues to be characterized by institutional racism, with racial hierarchies culturally accepted as natural (A/HRC/27/68/Add.1, para. 6).

10. In 2016, to manage public debt, the Government enacted Constitutional Amendment No. 95/2016, an austerity measure restricting public spending to 4.1 per cent of GDP until 2026. In February 2019, a social security reform was sent to Congress and was approved by the lower house in August 2019. The reform is expected to generate accumulated savings of 9 per cent of GDP until 2030. The fiscal adjustment and social security reform should stabilize the Government's gross debt at around 81.7 per cent of GDP by 2023.

11. During her visit, the Independent Expert observed that those fiscal reforms inadvertently exacerbated inequalities, affecting some of the most vulnerable and marginalized individuals, including persons with albinism.

III. Legislative and policy framework

A. International and regional standards and normative framework

12. Brazil has signed and ratified eight of the nine core international human rights treaties.⁷ It has signed and, in some cases, ratified all the optional protocols to those treaties, except for one.⁸

13. Brazil was one of the 21 founders of the Organization of American States.⁹ Brazil is signatory to a wide range of treaties, conventions and inter-American instruments, such as the American Declaration of the Rights and Duties of Man (1948), the American Convention on Human Rights (1969) and its protocols, the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities (1999) and the Inter-American Convention against Racism, Racial Discrimination and Related Forms of Intolerance (2013).

B. National legal framework

14. At the national level, the Federal Constitution expressly provides that equality and dignity are principles of the rule of law in the country. In addition, it stipulates the building of a free and fair society, the eradication of poverty and the reduction of social and regional

³ See www.weforum.org/agenda/2018/04/the-worlds-biggest-economies-in-2018/.

⁴ See <http://documents1.worldbank.org/curated/en/148141498229092629/pdf/20170619-Brazil-CPF-draft-for-Board-with-CLR-Acknowledgement-Box-06202017.pdf>, para. 11.

⁵ See <https://agenciadenoticias.ibge.gov.br/en/agencia-news/2184-news-agency/news/25895-extreme-poverty-affects-13-5-million-persons-and-hits-highest-level-in-seven-years>.

⁶ See http://hdr.undp.org/sites/all/themes/hdr_theme/country-notes/BRA.pdf.

⁷ Brazil has not signed or ratified the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families.

⁸ Brazil has not signed or ratified the Optional Protocol to the International Covenant on Economic, Social and Cultural Rights.

⁹ Having signed the Charter in 1948.

inequalities and the promotion of equality without distinction on the basis of race, sex, colour, age or any other form of discrimination. It also enshrines education, health, food, employment, housing, transport, leisure, safety and social security, among others, as social rights.

15. Law No. 13146/2015 is in line with the Convention on the Rights of Persons with Disabilities and establishes a rights-based framework, including with regard to accessibility, education, political participation and legal capacity, among other fundamental rights. To ensure that persons with disabilities can exercise their rights, the law includes provisions on legal capacity, accessibility, political participation and inclusive education.

16. Decree-Law No. 5452 of 1 May 1943 adheres to the principle of non-discrimination by consolidating all laws that regulate labour relationships in Brazil. Furthermore, Law No. 9029/95 on combating discrimination in employment relationships prohibits the adoption of discriminatory practices on the basis of sex, origin, race, colour, marital status, family status or age.

17. Law No. 12288/2012 establishes standards and objectives to ensure the realization of equality of opportunities for the black population, while Law No. 7716/89 defines crimes of prejudice based on race or colour.

18. Bill No. 7762/2014 provides for a national policy on the protection of the rights of persons with albinism. It is currently pending adoption by Congress.¹⁰ Article 2 of the bill provides for:

- (a) Developing and implementing a national registry;
- (b) Developing the range of health-care products and encouraging the practice of self-care;
- (c) Organizing the flow of health care;
- (d) Defining the epidemiological profile;
- (e) Training and building capacity among staff in the Unified Health System so that they can address the various aspects of health care of persons with albinism;
- (f) Improving integrated health care for persons with albinism.

Article 3 provides that persons with albinism have the right to access dermatological care, including sunscreen and essential medicines, in addition to non-pharmacological treatment, cryotherapy and photodynamic therapy; and to access specialized eye care, special lenses and the other assistive devices – optical and non-optical equipment – necessary for the treatment of low vision and photophobia.

19. At the regional level, the municipality of Maceió has two laws concerning persons with albinism. Law No. 6605 provides for the distribution of sunscreen free of charge and Law No. 6627 establishes that 13 June is the municipal day for persons with albinism.¹¹

C. National policy framework

20. The Unified Health System was created pursuant to the Federal Constitution of 1988. It provides for universal, comprehensive access to health, the promotion of equity, decentralized management and social participation. Management of the system is shared by the three levels of government: the Ministry of Health at the federal level, the state health secretariats and the municipal health secretariats. The system is funded by taxes and contributions at the federal, state and municipal levels. According to the Brazilian Institute

¹⁰ See www.camara.leg.br/proposicoesWeb/prop_mostrarintegra?codteor=1263631&filename=PL+7762/2014.

¹¹ See General Assembly resolution 69/170.

of Geography and Statistics, total health spending in 2017 amounted to 9.2 per cent of the country's GDP,¹² and 3.9 per cent of public spending.¹³

21. Launched in 2009, the National Comprehensive Health Policy for the Black Population aims to promote equity in the Unified Health System, including by tackling racism and discrimination in the system's institutions and services.

22. Pursuant to Ordinance 199/2014, the Policy on Comprehensive Health Care for Persons with Rare Diseases was integrated into the Unified Health System. The Ordinance aims at ensuring the universality, completeness and equity of health care for persons with rare diseases in order to reduce morbidity and mortality, to establish care plans at all levels of the health-care system, to ensure comprehensive health care for persons with rare diseases in the health-care network, and to ensure that persons with rare diseases have timely access to diagnostic and therapeutic resources.

23. The Popular Pharmacy Programme was created by the Federal Government in 2004 to ensure that individuals with low incomes have access to medication for some of the more common medical conditions, such as asthma, high blood pressure and diabetes. Under the programme, which establishes partnerships with private pharmacies and drugstores, some specific medicines are free while others are heavily subsidized, with the Government covering up to 90 per cent of the price of other medicines (Federal Law No. 10858/2004).

24. The Unified Social Assistance System has its origins in the Constitution (arts. 196–200). It enshrines the State's obligation to provide social security, health and social assistance, with universal coverage; to protect families, pregnant women, children, adolescents and older persons; to integrate people into the labour market; to provide rehabilitation services for persons with disabilities; and to guarantee a monthly minimum income for persons with disabilities and older persons who do not have sufficient means for themselves and their families.

25. The Unified Social Assistance System is organized in the form of a non-contributory, decentralized and participatory public system. It is coordinated by the Ministry of Citizenship and composed of public authorities and civil society, which jointly participate in the decision-making process. All procedures, including the allocation of resources, are monitored and approved by the National Council for Social Assistance and the State and Municipal Councils for Social Assistance.¹⁴

26. The Continuous Welfare Benefit for the Elderly and Persons with Disabilities is part of the Basic Social Protection provided under the Unified Social Assistance System. It is a non-contributory, individual social assistance welfare benefit that is not for life and is non-transferable. It consists of the payment of a monthly minimum wage to persons aged 65 years or above, and persons with disabilities, regardless of age, due to long-term physical, mental, intellectual or sensory impairments, who can prove that they do not have the means to provide for their own subsistence or who are dependent on a family whose income per person is less than a quarter of the monthly minimum wage.¹⁵

27. The Bolsa Familia programme provides a conditional direct cash transfer, aiming to improve the lives of about 14.1 million extremely poor Brazilian families. It has been lauded for reducing the levels of inequality in the country and for lifting many families out of poverty. It reduced poverty in Brazil by 28 per cent between 1992 and 2012 and greatly reduced the number of people going hungry from 22.8 million in 1992 to 13.6 million in 2012.¹⁶

28. In 2016, the Federal Government launched the new National Health Plan, 2016–2019. Its central objective is the timely expansion and improved quality of universal access, aimed

¹² Data released on 20 December 2019.

¹³ See <https://agenciadenoticias.ibge.gov.br/agencia-noticias/2012-agencia-de-noticias/noticias/26444-despesas-com-saude-ficam-em-9-2-do-pib-e-somam-r-608-3-bilhoes-em-2017>.

¹⁴ Information on public policies for citizenship and international cooperation received from the Ministry of Citizenship in the form of a programme briefing (2019).

¹⁵ Ibid.

¹⁶ See www.centreforpublicimpact.org/case-study/bolsa-familia-in-brazil/.

at improving health conditions, promoting equity and improving the quality of life of Brazilians.¹⁷ During her visit, the Independent Expert was not able to receive concrete information on a health plan beyond 2019.

29. The National Education Plan (2014–2024) includes 20 goals and targets, together with strategies that can be implemented and defined by states and municipalities. Brazil has also made an effort to increase funding for education.¹⁸ Inclusive education was introduced in 2008 under the National Policy on Special Education and aims to ensure that children and young people with disabilities are integrated into classes in mainstream schools.

30. With regard to the right to employment, Federal Law No. 8213/91 established quotas to ensure that between 2 and 5 per cent of staff hired are persons with disabilities in all public and private enterprises with over 100 staff.

D. National institutions

31. The Federal Public Defender offers free legal, judicial and out-of-court support to citizens who require assistance and who can prove that they lack sufficient means to acquire such support privately. The Public Defender's Office is present in all Brazilian states and in most large cities.

32. In 1988, several thousand local councils were created in Brazil spanning the areas of health, social assistance and urban planning. The councils include public officers and members of civil society groups representing their constituencies. They rely on the participation of representatives from diverse sectors of society who are subject area specialists, in addition to members of relevant government ministries and bodies. The councils are responsible for proposing guidelines, taking policy decisions and overseeing the administration of government programmes.

33. The National Human Rights Council is a collegiate body of the Ministry of Women, Family and Human Rights. Its purpose is to promote and defend human rights by taking preventive, protective and remedial action in situations where there is a threat of a human rights violation or an actual violation, pursuant to the Constitution and the international treaties Brazil has ratified. The Council is responsible for overseeing and monitoring human rights policies and the national human rights programme and can suggest and recommend guidelines for its implementation.

34. The National Council for the Rights of Persons with Disabilities is composed of representatives of Government and civil society, with an advisory and deliberative capacity. It also forms part of the structure of the National Secretariat for the Rights of Persons with Disabilities. The National Council discusses guidelines on the rights of persons with disabilities in the context of the Convention on the Rights of Persons with Disabilities. Councils are established at the municipal, state and Federal District levels and include representatives of civil society organizations that work in the area.

35. On 11 April 2019, the Federal Government published Decree No. 9759 aimed at reducing the number of collegiate bodies such as councils, committees and working groups from 700, as mandated under the National Social Participation Policy and System, to less than 50.

36. The National Cancer Institute plays multiple roles in all areas of cancer prevention and control in Brazil. As a technical branch of the Federal Government, under the direct administration of the Ministry of Health, the Institute delivers cancer care within the Integrated Public Health System. The Independent Expert regrets having been unable to secure a meeting with representatives of the National Cancer Institute and the National Council for the Rights of Persons with Disabilities.

¹⁷ See www.paho.org/salud-en-las-americanas-2017/?p=4246.

¹⁸ See <http://pne.mec.gov.br/>.

IV. Main findings

A. Persons with albinism

37. Albinism is a relatively rare, non-contagious, genetically inherited group of conditions that affects people worldwide, regardless of ethnicity or gender. It is the result of a significant deficit in the production of melanin and is characterized by the partial or complete absence of pigment in any or all of the skin, hair or eyes. Persons with albinism often appear pale in comparison to members of their family and their community. In order for a person to be affected by albinism, both parents must carry the gene and, in such a case, there is a 25 per cent chance that a child will be born with albinism at each pregnancy. The prevalence of albinism varies by geographic region worldwide.

38. The most common and visible type of albinism is oculocutaneous albinism, which affects all of the skin, hair and eyes. Nearly all human rights issues relating to albinism reported to date have been linked to the oculocutaneous form of albinism. A key physiological consequence of albinism includes vision impairment in the majority of cases. The severity of impairment varies from person to person. The other key physiological consequence is vulnerability to skin cancer, which is fatal when left untreated. Skin cancer accounts for a significant number of early deaths of persons with albinism, particularly in sunny climates.

39. Persons with albinism are commonly recognized as persons with disabilities. They have also been recognized as persons who face racial discrimination on the ground of colour by the Committee on the Elimination of Racial Discrimination (CERD/C/ZAF/CO/4-8, para. 20). Racial discrimination can occur on the basis of colour even among those within the same race and of the same descent and national and ethnic origin as those who discriminate against them.

1. Positive and exemplary initiatives

40. At the national level, the Independent Expert had the opportunity to discuss bill No. 7762/2014 with several of her interlocutors. At the time of her visit, the bill was pending final adoption by Congress. Its adoption would significantly benefit persons with albinism nationwide because it addresses their fundamental right to health. It does so, *inter alia*, by establishing that sunscreen is an essential medicine, developing a range of health-care products for persons with albinism, providing for a national registry of persons with albinism and guaranteeing the training of health workers to adequately respond to the issues faced by persons with albinism.

41. The Independent Expert urges Congress to promptly adopt the bill, as she stressed in a letter she sent to the Government on 20 June 2018.¹⁹ Following her visit, she sent another letter, on 29 November 2019, with further suggestions aimed at strengthening the provisions of the bill and again urging Congress to adopt it.²⁰

42. The Independent Expert commends the municipality of Maceió for adopting two laws (Nos. 6605 and 6627) that aim to significantly improve the lives of persons with albinism. They provide for the distribution of sunscreen free of charge to persons with albinism and promote International Albinism Awareness Day to demystify and destigmatize the condition. She also notes that the Municipality of Salvador has been distributing sunscreen free of charge to persons with albinism since 2006.

43. Furthermore, the Independent Expert was impressed by the tireless efforts of members of associations such as the Association of Persons Living with Albinism in Bahía State and the Association of Albinos in Alagoas State, and the staff of the Santa Casa de Misericórdia Pro-Albino Programme, which provides free ophthalmological and dermatological services

¹⁹ See <https://spcommreports.ohchr.org/TMResultsBase/DownloadPublicCommunicationFile?gId=23916>.

²⁰ See <https://spcommreports.ohchr.org/TMResultsBase/DownloadPublicCommunicationFile?gId=24983>.

to persons with albinism in São Paulo and also outside São Paulo State. She was pleased to learn that since her visit, it has been decided that the programme will receive support from the State Health Secretariat and will, in that format, be piloted at Santa Casa de Misericórdia hospital and subsequently replicated throughout the country.

2. Data and statistics

44. The Independent Expert observed that the absence of concrete data and statistics relating to persons with albinism posed a major challenge in Brazil, as such data would facilitate a thorough assessment of the enjoyment of their human rights.

45. The Ministry of Health estimates the prevalence of albinism in Brazil to be 1 in 17,000 on average.²¹ The prevalence of albinism in the North and Northeast of the country is reportedly higher than elsewhere. In Salvador, in the State of Bahia, unofficial data shared with the Independent Expert put prevalence rates around 2 in 10,000.²² She was also informed that in the State of Bahia in certain *quilombos* (historical settlements of escaped slaves), the prevalence is estimated to be as high as 6 in 1,000 persons, likely owing in part to consanguineous marriages. The national total of persons with albinism is purported to be around 10,000 persons, although that number cannot be verified owing to the lack of reliable data.²³

46. The Independent Expert was informed that the questionnaire for the national census of 2020 had already been prepared and could no longer include a question on albinism. However, she notes that the authorities have come up with alternative ideas for data collection on persons with albinism, such as through national health surveys, intake processes of primary health-care workers, by developing the rare conditions field at the Ministry of Health, by including a question on albinism during registration for the Unified Health System, or more concretely, through points of service delivery, for instance, once the Government begins the system-wide distribution of sunscreen as an essential medicine, as contemplated in Bill No. 7762/2014. Data may also be gathered through health policies targeting black and indigenous persons, as albinism rates are estimated to be relatively higher among those communities.

3. Stigma and discrimination

47. Stigma and discrimination against persons with albinism have reportedly decreased in recent decades. Nevertheless, name-calling using terms such as “gringo”, “white rat”, “monkey”, “shrimp”, “panda” and “peeled cockroach” reportedly still occurs.

48. Social avoidance and exclusion were the most widely reported forms of stigma, closely followed by bullying of school-age children and cyberbullying in the case of adults. Several interlocutors pointed out that the lack of information on the condition manifests as experiences of stigma in some public spaces. People fear the colouring and appearance of persons with albinism, particularly when they have visible sun damage, such as skin lesions. They also suffer from exclusion based on the belief that the condition is contagious.

49. Stigma, prejudice and social isolation can result in mental health issues among persons with albinism, including depression and low self-esteem, which are often overlooked in public health responses and pose major barriers to self-advocacy. Stigma and social exclusion

²¹ Presentation made to the Independent Expert by the Specialized Health Care team.

²² A single work, published in 2015 with the support of the Association of Persons Living with Albinism in Bahia State in a non-indexed journal, is held in Bahia. It contains details of research into the prevalence of persons with albinism in the city of Salvador and the relationship with persons of African descent. A register of residents with albinism was found in 44 per cent of the total of 163 neighbourhoods and localities. In 17 per cent of the neighbourhoods and localities, there was a high prevalence of albinism (greater than or equal to 1 in 10,000 persons) and in 8.5 per cent, the prevalence was greater than or equal to 2 in 10,000 persons. In the districts with the highest rates of albinism, a higher prevalence of African ethnicity was observed. One specific region, Ilha de Maré, had a very high prevalence of 1 in 1,000 persons.

²³ See www.sbd.org.br/dermatologia/pele/doencas-e-problemas/albinismo/24/.

further impact the ability to participate in public life, access education and employment. The extent of that problem is more evident in rural areas.

50. Gendered stigma was also reported concerning mothers of children with albinism, including abandonment by the father of the child based on the question of paternity. That problem is aggravated in communities of persons of African or mixed descent, likely owing to the contrast in colouring between parent and child. The Independent Expert also received reports of women with albinism enduring abusive relationships owing to their very low self-esteem and a related fear of the inability to find a new spouse or partner.

51. Several interlocutors with albinism, particularly in the North-East region of the country, prioritized immediate intervention for their visual impairment and vulnerability to skin cancer over the stigma they faced both within and outside their communities. Their reasoning was often that, because they had “fallen painfully through policy cracks”, they lacked the luxury of asking for more than one thing at a time. Consequently, several associations and persons with albinism are looking forward to the adoption of Bill No. 7762/2014. Many of them believe that it will give them legal visibility and social standing in the pursuit of the full enjoyment of their human rights.

B. Right to health

52. The right to the enjoyment of the highest attainable standard of physical and mental health has been recognized in instruments such as the Universal Declaration of Human Rights and the International Covenant on Economic, Social and Cultural Rights. The right encompasses specific entitlements, including the right to an adequate system of health protection, the right to care in the prevention and treatment of illnesses, the right to access essential medicines and the provision of health-related education and information, as well as the participation of those concerned in health-related decisions. While Brazil has not ratified the Covenant, those entitlements are also enshrined in regional instruments to which Brazil is party.

53. The Independent Expert is grateful to the Ministry of Health and its secretaries at the state and municipal levels for their readiness to engage in discussions regarding measures to improve access to health for persons with albinism, including through data collection and measures aimed at improving prevention and treatment of skin cancer.

54. According to the information received, 93 million persons are registered in the Unified Health System. The proportion of people who consulted a doctor in the 12 months running up to the collection of the data was, however, lower among black and brown Brazilians, 69.5 per cent and 67.8 per cent respectively, whereas the national average was 71.2 per cent. Among the black or brown adult populations, 37.8 per cent rated their health as between regular and very poor. Only 29.7 per cent of white Brazilians rated their health as between regular and very poor.²⁴

55. The Independent Expert commends the provision of primary health care in the country through the Unified Health System. However, available evidence indicates that the majority of persons with albinism in the country come from low socioeconomic backgrounds and face significant barriers to access to primary and specialized health care. Persons from rural areas find access particularly challenging, as most health centres are concentrated in urban areas. Travelling to the city centre by bus could cost close to a quarter of their monthly income and could take up to 10 hours. A human rights-based approach to health requires that health policy and programmes prioritize the needs of those left furthest behind and bring them towards greater health equity.

56. The Independent Expert was informed about the void left by the departure of several thousand Cuban doctors who had been stationed in remote and socioeconomically disadvantaged areas under the More Doctors programme. She urges the Government to fill those vacancies as a matter of priority in order to ensure continuous access to primary health-care services.

²⁴ Information shared by the Ministry of Health in a presentation by the Primary Health Care Secretariat.

57. Against a background of racial inequalities and at the intersection of health and socioeconomic development, the Independent Expert commends the Primary Health Care Secretariat on its efforts to promote equal access to all groups that have specific needs. Among some of the measures presented to her are information systems of the Ministry of Health (pursuant to Ordinance No. 344/2017) that can build an epidemiological profile by race or colour of Unified Health System users and can map the interaction of multiple factors, including several social determinants of health, to ultimately guide the adoption of specific interventions.²⁵ The Independent Expert was also pleased to hear from the Ministry of Health about the possibility of adding “albinism” as a self-classification to contribute to specific lines of care in the Primary Health Care System.

58. Furthermore, she was pleased to hear about the development of a nationwide policy focusing on rare diseases. The national rare disease survey planned for 2020 should include a question on albinism. The National Policy for Comprehensive Health Care for Persons with Rare Diseases defines rare diseases as those affecting up to 65 out of 100,000 people. While the Independent Expert welcomes the idea of channelling the needs of persons with albinism through that Policy, she is concerned that priority support is given only to those with the most extensive needs without addressing those with relatively fewer health-care needs, such as persons with albinism.

1. Right to life

59. Some of the most pressing health issues faced by persons with albinism in Brazil revolve around varying degrees of visual impairment and high susceptibility to ultraviolet-induced skin damage, particularly skin cancer. Actinic damage and skin cancer occur early and have a high incidence in persons with albinism, often leading to premature death. The Independent Expert was informed that life expectancy among persons with albinism could be as low as 33 years of age owing to an absence of timely and quality preventive and curative care for skin cancer. Based on recent research, the prevalence of skin cancer in patients enrolled in studies of the Pro-Albino Programme was 26 per cent, which is similar to that found in persons with albinism by researchers in Tanzania (25 per cent) and South Africa (23 per cent).²⁶ The same research indicated that persons with albinism in Brazil tend to face similar prejudice and stigma to those experienced by their counterparts in African countries.

60. Brazil has a high incidence of solar radiation during the year nationwide, including in winter and outside the periods of critically high solar radiation. According to the ultraviolet index scale of the World Health Organization (WHO), the country has very high (8–10) to extremely high (11+) ultraviolet rays. Daily doses of radiation are higher in the North and North-East regions, even in winter reaching 20 times the daily dose recommended by WHO. Critical levels of over 15 times the daily recommended dose are also recorded in the South-East region of the country in summer.²⁷ The Independent Expert met persons with albinism, including babies as young as 8 months old, who had been burned indoors as a result of exposure to harsh ultraviolet rays in inadequate housing conditions and a lack of protection devices such as sunscreen.

61. There are several effective and easy ways to prevent skin cancer, including the lifetime use of sun protection lotions and sun protective clothing and ensuring that individuals have adequate and relevant health information. Such basic needs should be provided in a reliable manner, in line with the principles of quality, availability, accessibility and acceptability. Sun protection lotion should be included in the list of essential medicines and not treated as a cosmetic product in the context of protection against skin cancer. It should be available free of charge and distributed regularly to all communities, using mechanisms such as health surveillance assistants and the Popular Pharmacy Programme.

62. However, sunscreen is currently distributed free of charge only in the municipalities of Maceió and Salvador. The Independent Expert was informed that a bottle of sunscreen

²⁵ Information shared by the Ministry of Health in a presentation by the Primary Health Care Secretariat.

²⁶ Carolina Reato Marçon and Marcus Maia, “Albinism: epidemiology, genetics, cutaneous characterization, psychosocial factors”, *Anais Brasileiros de Dermatologia*, vol. 94, No. 5 (September–October 2019).

²⁷ Information shared by the Ministry of Health in a presentation by the Primary Health Care Secretariat.

with sun protection factor 70 costs around 150 reais (about \$34) and is thus unaffordable to the majority of those who need it.

63. The Independent Expert considers it extremely important and non-negotiable that persons with albinism have access to comprehensive sun-protection measures and curative measures once cancer or precancerous lesions develop. Unfortunately, access to such health protection, especially against skin cancer and disfiguring precancerous lesions, is not available to many persons with albinism in Brazil.

64. The Independent Expert is concerned about the lack of information on albinism in the primary health-care system, which may lead to misinformation and a lack of preventative measures and early treatment. She strongly encourages the training of all health-care professionals in the primary health-care system, including midwives, nurses and doctors, on albinism, and the provision of information to persons with albinism themselves.

65. Multiple generations of persons with albinism in Brazil lack information on their condition and on the measures required to prevent sun damage and skin cancer. Over half of the persons with albinism who the Independent Expert encountered had visible sun damage and disfiguring premature ageing that was aggravating the discrimination they already face.

66. In that regard, the Independent Expert was encouraged by pledges from authorities at the national and state levels to include the distribution of sunscreen as part of respective national or state policies. She encourages the initiatives at the Ministry of Health that aim to distribute sunscreen free of charge to the consumer through the Popular Pharmacy Programme, and urges the authorities to ensure the immediate launch of that initiative.

2. Specialized health service care

67. The Independent Expert found that access to specialized doctors, such as ophthalmologists, dermatologists, paediatricians, oncologists and psychologists, was particularly challenging as they tend to be concentrated in city centres. Moreover, some of them reportedly have a serious backlog of patients.

68. An interlocutor from the Ministry of Health mentioned the possibility of using telemedicine through telephone applications, whereby photographs of lesions or skin deformations would be sent remotely to dermatologists for consultation. In the absence of sufficient and accessible specialists, the Independent Expert strongly encourages the use and development of digital technology and the implementation of such initiatives, which have proved successful in Tanzania for persons with albinism.

69. The lack of melanin in the eyes of persons with albinism results in high sensitivity to bright light and significant vision impairment. Vision impairment varies in severity from one person with albinism to another, often but not necessarily in proportion to the level of residual pigment in the individual. In the absence of early intervention, vision impairment in persons with albinism can deteriorate significantly. Therefore, it is particularly important to ensure that persons with albinism have access to ophthalmologists and that prescription glasses and low-vision devices are made available to them at little or no cost. Such optical devices are fundamental to upholding the right to education of persons with albinism. Without them, persons with albinism risk having little to no schooling and are consequently at risk of unemployment and poverty. Poverty drives some to work outdoors, exposing them to a high risk of skin cancer and early death.

70. The Independent Expert was informed that access to ophthalmologists was particularly challenging in Brazil, and most were not trained in low vision. She urges the Government to ensure that ophthalmologists who are trained in low vision are accessible and available in sufficient numbers to care for all the persons with albinism in the country. She recommends that monocular lenses, magnifying glasses, prescription glasses and contact lenses are made available as part of the reasonable accommodation for persons with disabilities, including persons with albinism. Nearly all the persons she consulted had purchased such devices at their own expense. The Independent Expert commends the Ministry of Health, which put forward the idea that, when persons with albinism collect their sunscreen, they could be given a voucher to cover the cost of a consultation with an ophthalmologist. She encourages the immediate implementation of that initiative.

71. In the face of barriers to access specialist doctors, associations of persons with albinism have sometimes entered into partnerships with private health providers. Nearly all cases of success in access to health care seemed to depend on the personal efforts of medical professionals, social workers and associations representing persons with albinism as opposed to the implementation of laws or policy.

72. Bill No. 7762/2014, if fully implemented and if sufficient resources are allocated to that end, would alleviate many of the challenges identified above. In particular, the provision of a range of health-care products, the definition of the epidemiological profile, the training of health-care personnel, the provision of access to dermatological and ophthalmological specialized care, the inclusion of sunscreen as an essential medicine and the provision of assistive devices would address many of the challenges currently faced by persons with albinism in Brazil. The Independent Expert was pleased to hear from various senior officials at the Ministry of Health that the cost of implementing the Bill could be readily absorbed into the current budget.

73. Pending the adoption of the bill, the Independent Expert recommends that a specialized range of health-care products for persons with albinism be developed and included in the primary health-care system, such as through training of health personnel in the context of wider training on disability, rare diseases and policies governing health conditions particular to persons of African descent and indigenous persons. Such training provides an opportunity to raise awareness about the genetics of albinism and its link to consanguineous procreation in some of those communities. However, it is important that such information is communicated in a manner that does not reduce albinism to a mere disease to be eliminated, but rather presents it as a condition affecting persons who should be able to enjoy all their human rights. Hence it is important that such training and awareness-raising be conducted, where possible, with the participation of organizations of persons with albinism.

3. Efforts at the state and municipal levels

74. The governments of the states and cities that the Independent Expert visited work closely with associations representing persons with albinism and actively consult them on the needs of persons with albinism. The Association of Persons Living with Albinism in Bahía State in Salvador de Bahía is part of the State Health Council, the State Council for the Rights of the Persons with Disabilities and the State Council for Promotion and Collaboration.

75. Since 2006, the municipality of Salvador has been making sunscreen available free of charge for persons with albinism who are registered in health centres in their municipality. The Independent Expert's interlocutors also mentioned that transport to the health centres was sometimes provided. Others, however, travelled long hours in the sun to reach the health centres.

76. According to some accounts, upon arrival at health centres, there is no sunscreen or any services available and persons with albinism often have to face complex bureaucracy that is difficult to navigate. Those barriers discourage further efforts and put them at a higher risk of developing skin cancer. The Independent Expert observes that such services need to be continuous, as disruptions in sunscreen provision can have serious health consequences. Moreover, basic technology can facilitate the sharing of information on availability.

77. The Independent Expert was also informed that often, the process of registration with the municipality, requiring an examination from a dermatologist, was too tiresome and complicated to navigate. Many of her interlocutors reported routinely sharing their sunscreen lotion with those who had none, or they used free samples distributed at times by dermatologists or the Association of Persons Living with Albinism in Bahía State. The Independent Expert recommends that more effort be made to ensure that sunscreen is accessible to those who need it.

78. During her meeting with the State Health Secretary, the Independent Expert was pleased to hear that as of 2020, the Bahía State Health Secretariat will purchase and distribute sunscreen, as well as offer screening services in ophthalmology and dermatology in all regional health clinics.

79. The Independent Expert is particularly encouraged by the efforts she observed in Maceió, the capital city of Alagoas State, where at municipal level, Law No. 6605 guarantees sunscreen distribution free of charge. She was informed that distribution takes place once a month and that the State's health plan provides for the distribution of clothing that protects against ultraviolet radiation.

80. Nevertheless, the Independent Expert was also informed that sunscreen had to be collected in the city centre. In that regard, many of her interlocutors with albinism in the State of Alagoas described serious challenges when trying to use public transportation, as bus numbers were difficult for them to read. That is a result of the fact that most of them do not possess any specialized glasses, monocular lenses or any other adaptive or assistive reading devices that would make public transportation more accessible to them.

81. The Independent Expert encourages the Maceió Municipal Secretariat of Health to conduct a consultation or survey with regard to the enjoyment of the right to health by persons with albinism. That would allow the municipality to evaluate the effects of its policy in order to identify and eliminate remaining barriers to the full enjoyment of the right to health.

4. Mental health

82. The mental health of persons with albinism was raised regularly in the course of discussions during the Independent Expert's visit in relation to frequent humiliation and discrimination within the family, the immediate community, from society at large and particularly in schools. The cumulative effect of social exclusion can take a toll on persons with albinism and lead to low self-esteem and depression.

83. Information on albinism should be incorporated into all curricula for training of health and education practitioners throughout the country. Medical professionals should provide parents of children with albinism, from the moment the children are born, with accurate information on the condition. Mothers of children with albinism and family members of persons with albinism may need psychosocial support and counselling, as they often encounter stigma relating to albinism. Associations representing persons with albinism play a crucial role in providing psychosocial support and should be assisted in that endeavour.

(a) Right to education

84. The Independent Expert identified some major challenges to access to education for persons with albinism. The main barrier is a lack of reasonable accommodation, which is the necessary and appropriate modification and adjustments needed in a particular case to ensure that persons with disabilities can enjoy or exercise all their human rights and freedoms on an equal basis with others.²⁸

85. Reasonable accommodation for persons with albinism in schools may include the provision of adaptive and assistive devices, such as monocular lenses and reading glasses, allowing persons with albinism to sit at the front of the class, adjustment to uniforms so that they become sun-protective, permission to wear wide-brimmed hats, accommodation in sporting activities, extra time on tests and examinations and distribution of learning documents in large print format. Based on the Independent Expert's findings, the adjustments are often based on the individual teacher's willingness and ability to accommodate and seem, in the experience of many persons with albinism, to lack the proactivity needed to identify and remove barriers to access education.²⁹

86. While reasonable accommodation measures are not totally absent, they appear to be unevenly implemented across the country, depending on the individual teacher's level of understanding of the impairment and willingness or capacity to accommodate it. Often, family members or friends assist the learners, which is empathetic but not sustainable.

87. The Independent Expert was informed that since 2014, various assistive devices have no longer been distributed to municipalities and as a result, magnifying glasses and

²⁸ Convention on the Rights of Persons with Disabilities, art. 2.

²⁹ Information from the United Nations Educational, Scientific and Cultural Organization (UNESCO) Office in Brazil. Available at <https://en.unesco.org/fieldoffice/brasil/expertise/inclusive-education>.

monocular lenses have not been made available to learners with albinism. She encourages the Ministry of Education to ensure that schools and municipalities receive the necessary resources or material to provide the assistive and adaptive devices required by learners with disabilities, including those with albinism. She reminds the Government of the need to fulfil its obligations and guarantee that all students have access to quality education that responds to all the basic learning needs to enrich young people's lives, as stipulated in international human rights treaties and Brazilian law.

88. Education professionals need to be trained on how to respond to learners with albinism, including how to protect them from bullying. In the absence of such measures and reasonable accommodation, persons with albinism have dropped out of school, which seriously impacts their ability to acquire skilled labour indoors, forcing them to work outdoors, which exposes them to skin cancer and confines them to poverty.

89. Learners with albinism in very poor regions and communities face additional challenges. For instance, it can take up to two hours of walking or travelling in the sun to access a school in *quilombola* communities. Often, the roofs of schools do not provide adequate sun protection and some activities take place in the open air. Both can leave pupils with serious burns. The level of school dropout is reportedly higher in such rural communities.

90. The Independent Expert was told about the Continuous Cash Benefit programme for schools, which seeks to promote social inclusion for persons with disabilities from 0 to 18 years of age. The aim of the programme is to identify and overcome barriers that hinder access to school.³⁰ While the Independent Expert met with various children who were benefiting from the programme, they seemed to be unaware of the programme's existence. The Independent Expert encourages the Government to ensure that information on the programme reaches potential beneficiaries, particularly through organizations representing persons with disabilities and persons with albinism.

(b) Right to employment and to an adequate standard of living

(i) Access to employment

91. The population of Brazil is diverse; the cultural, social and economic levels of its inhabitants vary significantly. According to official statistics, poverty rates among the population of African descent are twice as high as the average in the rest of the population and women and young people are also disproportionately affected by poverty.³¹ Extreme poverty affects mainly black or brown Brazilians, who constitute 72.7 per cent of the poor, or 38.1 million people.³² Around 12.6 million Brazilians are unemployed, while 11.7 million work in the informal sector.³³

92. The majority of persons with albinism in Brazil are reportedly indigenous or of African descent. They are therefore exposed to similar levels of discrimination and poverty rates as their ethnic constituencies. Moreover, their colouring and appearance and their visual impairment and sensitive skin lead to multiple and intersecting marginalization. The Independent Expert was informed about the structural inequalities faced by people of African descent and indigenous persons, who suffer socioeconomic exclusion, are often employed solely in the informal sector and face barriers in access to social services and social security benefits.

93. Given that broader context, the Independent Expert is particularly concerned about recent setbacks in terms of legislation, public policies and civil society participation, which have tended to reduce the protection afforded to historically marginalized groups.

³⁰ 2019 programme briefing delivered by the Ministry of Citizenship on public policies for citizenship and international cooperation.

³¹ See <https://biblioteca.ibge.gov.br/visualizacao/livros/liv101629.pdf>.

³² See <https://agenciadenoticias.ibge.gov.br/en/agencia-news/2184-news-agency/news/25895-extreme-poverty-affects-13-5-million-persons-and-hits-highest-level-in-seven-years>.

³³ See <https://agenciadenoticias.ibge.gov.br/en/agencia-news/2184-news-agency/news/25318-unemployment-falls-to-11-8-but-12-6-million-are-still-searching-for-work>.

94. The Independent Expert was informed that only 10 per cent of persons with albinism are reportedly employed in the formal sector and 18 per cent in the informal sector. The situation for those living in rural areas and *quilombos* is worse still, as sources of income in those areas are often limited to fishing and farming. Persons with albinism are thus exposed to the harsh sun, leaving them extremely vulnerable to skin cancer.

95. Persons with albinism, like other persons with disabilities, face extensive discrimination and marginalization when it comes to accessing employment opportunities. Despite the fact that Federal Law No. 8213/91 establishes quotas to ensure that between 2 and 5 per cent of staff hired are persons with disabilities in any public or private enterprise with over 100 staff, the State and the private sector are still encountering difficulties in achieving the 2 per cent minimum quota. When persons with disabilities are hired, there is a tendency to relegate them to low-ranking jobs, sometimes outdoors. The lack of willingness to provide reasonable accommodation in the public and the private sectors is also a serious barrier to inclusion.

96. In the case of persons with albinism, non-compliance with Law No. 8213/91 also relates to discrimination based on appearance or colour. The compounded issue of a commonly repulsed or racialized appearance combined with visual impairment, which requires reasonable accommodation, tend to influence the ways in which employers and co-workers regard people with albinism.

97. The Independent Expert was informed about the Continuous Cash Benefit programme for employment, which aims to promote access to vocational training and work for beneficiaries aged between 16 and 45, and to give them access to work experience without losing the benefit.³⁴ She strongly supports such initiatives, noting nonetheless that none of her interlocutors seem to have benefited thus far from that programme.

(ii) *Access to an adequate standard of living*

98. The Independent Expert observed a wide discrepancy in the level of employment and socioeconomic opportunities between persons with albinism living in cities, such as São Paulo and Salvador, and those living in rural areas and *quilombos*. The level of unemployment of persons with albinism living in rural areas or *quilombos* is reported to be much higher, due to early dropout from school and the lack of opportunities for work indoors. That means that they often face compounded marginalization, which seriously impedes the realization of their socioeconomic rights.

99. Owing to prejudice and barriers in accessing employment, most persons with albinism tend to depend on public social security benefits, such as the Continuous Cash Benefit or the Bolsa Familia programmes. However, several reports indicate that persons with albinism are often denied that essential support – even when they meet the requirements – and many have to wait several years before they are enrolled. Navigating the enrolment process requires funding and rights awareness, in addition to self-esteem and self-advocacy skills, most of which are often lacking among persons with albinism who are poor.

100. Persons with albinism are often denied access to the Continuous Cash Benefit programme as a result of both the unclear criteria for determining the requisite impairment levels and the ongoing debate about whether the person with albinism has a disability. That debate is likely fuelled by a very narrow perception of disability, often referred to as the “medical approach”. Furthermore, it reduces albinism to a vision impairment and, given the variation in vision impairment from person to person, that approach effectively excludes many people with albinism from the benefit. As a result, persons with albinism have had to resort to the court system to defend their rights to that essential social security net.

101. The Independent Expert concludes that it is important that the Continuous Cash Benefit be granted to persons with albinism, taking into account disability emanating from barriers experienced from either vision impairment or skin impairment, or both. That is

³⁴ Information shared by the Ministry of Citizenship from a 2019 programme briefing on public policies for citizenship and international cooperation.

particularly important given the strong link between skin impairment and the ability to work outdoors, particularly in rural communities.

102. The Independent Expert was informed that while waiting to be enrolled in the Continuous Cash Benefit programme, most persons with albinism depend on the support of family members, which can have an extremely negative impact on their self-esteem and aggravate the burden of care on an often already poor family. The Independent Expert was told that, in some cases where children receive the benefit, an entire family lives on that amount alone.

C. Access to justice

103. The Independent Expert noted that many persons with albinism lack knowledge of their human rights, including international and national norms and standards. They often also lack information about and access to recourse where violations have occurred. The absence of such knowledge is a major barrier to access to justice.

104. The Independent Expert received reports of several cases in which the Continuous Cash Benefit programme had been granted only when the concerned parties had appealed before the courts against the decision of the National Social Security Institute to deny them the benefit. One well-publicized case concerns the mother of a 9-year-old with albinism in the State of Goiás, where the judge ruled in her favour. The decision has been interpreted as an extremely significant development in the enjoyment of human rights by persons with albinism, particularly in terms of access to social security or welfare benefits for a basic standard of living.³⁵

105. While the Independent Expert commends the existence of the Public Defender's Office, which is able to provide legal assistance for persons who cannot afford it, she is concerned at the serious lack of capacity of the Office to provide that service, given that at least 6,000 posts are vacant. The Independent Expert urges the Government to fill as many of those posts as possible as a matter of priority.

106. The Independent Expert was informed about the Office of the General Ombudsman of the Unified Health System, which includes 2,100 ombudspersons evenly distributed among the states. The ombudspersons can receive complaints and suggestions from citizens about the services provided by the Unified Health System. However, none of the Independent Expert's interlocutors with albinism or their family members had ever had recourse to the Unified Health System ombudspersons. Support for organizations representing persons with albinism would no doubt improve access to justice for persons with albinism.

D. Representation and participation

107. In order to contribute effectively to the implementation of the rights of persons with albinism, meaningful consultation with persons with albinism on all measures, including legislative initiatives, programmes and policies, is necessary. The Government and all other stakeholders should uphold the principle of "nothing about us without us" and involve organizations of persons with albinism at every step, where the process cannot be led directly by them.

108. The Independent Expert was impressed by the efforts of associations representing persons with albinism, individuals with albinism, social workers, health-care workers and others, who work tirelessly to raise awareness on the particular needs of persons with albinism and to distribute information and goods to persons with albinism and their family members. However, the Independent Expert notes that owing to several factors, including the immense size and diversity of Brazil, coupled with the current absence of a national initiative on the matter (pending the adoption of Bill No. 7762/2014), those efforts remain ad hoc and fragmented.

³⁵ See www.lex.com.br/doutrina_27706466 (case No. 389916-50.2014.8.09.0132).

109. The Independent Expert notes that government and relevant non-governmental entities need to be protagonists for groups that have been particularly marginalized or those who have “fallen through the cracks”, as they also tend to include people with very low self-esteem, limited self-awareness and knowledge about their human rights and the human rights-based approach in general. She wishes to highlight the initiative launched at the Federal District level aiming to bring the Secretariat of Justice closer to the citizen, which includes guidelines on programmes and services for populations in vulnerable situations.³⁶ She urges others to replicate that model with associations that defend the rights of persons with albinism and their family members.

110. The Independent Expert urges international organizations, including the United Nations, to collaborate with civil society organizations representing persons with albinism to strengthen their capacities. Those groups are in dire need of support, have great passion for the work they do, and are crucial to the lives of the members of their communities.

111. The Independent Expert regrets not having been able to meet with the National Council for the Rights of Persons with Disabilities, which is composed of government representatives and civil society. She issues a strong call for a public hearing between the National Council and civil society organization representatives who defend the human rights of persons with albinism.

112. The Independent Expert also calls for positive representation of persons with albinism, which helps to overcome exclusion and stigma. She was pleased to hear about and meet influential persons in the Brazilian entertainment industry, including two fashion models with albinism, whose aim is to bring about positive change in society.

113. The Independent Expert encourages the entertainment industry and in particular, the media, to engage in responsible narratives by consulting widely in the development of shows broadcast on the television and the radio, among other media, and to include persons with albinism in a variety of ordinary roles that highlight the positive contributions they make to society, like any other person in Brazil.

V. Conclusions and recommendations

114. **The Independent Expert notes that, despite several commendable efforts that Brazil has taken to ensure the enjoyment of human rights by persons with albinism, further steps need to be taken nationwide to promote equality and non-discrimination.**

115. **Many people with albinism are some of the most marginalized persons in the country, enduring multiple and intersecting discrimination within their immediate community and in society at large. Measures to ensure that they are not left behind should include both specific action, such as the adoption and implementation of Bill No. 7762/2014, and the active integration of the issue into wider contexts relating to the rights to life and to health, relating to disability, and through support and awareness-raising, both generally and through policies focusing on Brazilians of African descent and indigenous Brazilians. In that regard and through the implementation of the measures listed below, Brazil can chart a course for other countries in the region in their response to the rights of persons with albinism.**

116. **With regard to data, the Independent Expert recommends that Brazil:**

(a) **Ensure the systematic collection of disaggregated data and include albinism as a category in national health surveys, surveys on rare conditions and other relevant data-collection efforts, with reference to the work of the Washington Group on Disability Statistics;**

(b) **Undertake a situational survey to better understand the human rights challenges faced by persons with albinism, particularly in rural areas and among the**

³⁶ See www.sejus.df.gov.br/sejus-mais-perto-do-cidadao-sera-um-programa-permanente-anuncia-secretario-gustavo-rocha/.

socioeconomically disadvantaged communities in the North-East, in *quilombos* and among indigenous communities;

(c) Collect disaggregated data on the level of employment of persons with disabilities, including persons with albinism, to assess and rectify issues relating to the effective implementation of Law No. 8213/91.

117. With regard to awareness-raising, the Independent Expert recommends that Brazil:

(a) Carry out awareness-raising programmes on albinism throughout the country, particularly at the local and rural community levels. Those initiatives should include intracommunity initiatives and involve organizations representing persons with albinism and their family members at all stages of the planning and implementation process;

(b) In collaboration with United Nations agencies, funds and programmes, use events such as International Albinism Awareness Day on 13 June and other relevant days, such as Human Rights Day on 10 December and the International Day of Persons with Disabilities on 3 December, to highlight and give visibility to the rights of persons with albinism and their family members;

(c) Effectively address discrimination and stigma through widespread awareness-raising and training programmes on albinism and on the specific needs of persons with albinism, in coordination with all stakeholders at all levels.

118. With regard to health, the Independent Expert recommends that Brazil:

(a) Adopt Bill No. 7762/2014, which would immediately provide for concrete health interventions for the enjoyment of the right to health for persons with albinism;

(b) Complement Bill No. 7762/2014, once adopted, with the following health-related recommendations:

(i) Ensure that sunscreen is included on the list of essential medicines that are available and accessible;

(ii) Replicate the Pro-Albino Programme in the Northeast region wherever the prevalence of the condition is relatively high;

(iii) Make quality health services available, affordable and accessible, including through specialized doctors such as ophthalmologists trained in low vision, dermatologists, oncologists, paediatricians and psychologists in sufficient numbers and in rural areas, among Brazilians of African descent and indigenous Brazilians;

(iv) Incorporate in training courses for health-care professionals modules on persons with albinism, particularly in the fields of low vision, skin cancer prevention and treatment, and psychosocial support for persons with albinism and their family members;

(v) Ensure community outreach activities, including measures for the purpose of early intervention and prevention of skin cancer among persons with albinism in local communities, particularly in rural areas and remote areas;

(vi) Ensure sustainable and continuous support for all the above-mentioned services.

119. With regard to education, the Independent Expert recommends that Brazil:

(a) Integrate a response for learners with albinism into special needs education and inclusive education programmes to ensure that learners with albinism are well integrated in mainstream schools, particularly through the provision of reasonable accommodation and of relevant training for educators;

(b) Undertake, as part of the situational survey recommended in paragraph 116 (b) above, a comprehensive mapping exercise of the experience of learners with

albinism, including those who have dropped out of school, and take the necessary measures to ensure their reintegration in the formal school system;

(c) Ensure that all schools in the country are provided with appropriate adaptive and assistive devices, such as monocular lenses, in order to accommodate the educational needs of all students with disabilities, including those with albinism;

(d) Integrate into the existing teacher training modules on health and disability additional modules to raise awareness about albinism and about specific educational methods and interventions that can effectively address the educational needs of persons with albinism. In doing so, ensure that teachers address stigma, prejudice and bullying, including cyberbullying, and encourage measures to prevent those phenomena.

120. With regard to employment and standard of living, the Independent Expert recommends that Brazil:

(a) Review and standardize the criteria for accessing disability grants, such as the Continuous Cash Benefit programme, to ensure that persons with albinism have access to them;

(b) Ensure that persons with albinism are provided with adaptive and assistive devices to facilitate their access to public transportation and employment;

(c) Facilitate access to skills development programmes and entrepreneurship development for persons with disabilities, including persons with albinism;

(d) Take the necessary measures to reach employment quotas on the hiring of persons with disabilities, including by conduct widespread training on reasonable accommodation in the public and the private sectors, including for persons with albinism;

(e) In coordination with the Unified Social Assistance System, the National Council for the Rights of Persons with Disabilities, civil society organizations and international partners, expand and further develop vocational training and orientation programmes for persons with disabilities, including persons with albinism, and facilitate their access to employment.

121. With regard to participation and representation, the Independent Expert recommends that Brazil:

(a) Support the inclusion of persons with albinism and their representative organizations in relevant decision-making processes that affect them, at all levels of government, including in public debates and the development of legislation, policy and programmes;

(b) Provide support to initiatives and programmes on albinism organized by civil society organizations. In particular, support the expansion and sustainability of the Pro-Albino Programme at the Santa Casa de Misericórdia hospital, and organizations representing persons with albinism, such as the Association of Persons Living with Albinism in Bahía State, and engage them as specialized government partners to provide direct services and carry out awareness-raising programmes.

122. With regard to cross-cutting issues, the Independent Expert recommends that Brazil:

(a) Strengthen public institutions responsible for formulating, implementing and assessing public policies from a human rights perspective, especially those seeking to protect the rights of the most marginalized groups and those in vulnerable situations;

(b) Create an enabling environment for civil society organizations, including by ensuring their continued participation in the various councils and participatory bodies of the executive branch;

(c) Facilitate the creation of an independent national human rights institution in accordance with the principles relating to the status of national institutions for the promotion and protection of human rights (the Paris Principles);

(d) **Ensure that all states have a sufficient number of public defenders' offices, and that they have adequate human, technical and financial resources to carry out their work;**

(e) **Implement all the relevant recommendations made by the treaty bodies, particularly the recommendation of the Committee on the Rights of Persons with Disabilities to implement policies to address the multiple forms of discrimination against indigenous people and people of African descent with disabilities (CRPD/C/BRA/CO/1, para. 13);**

(f) **Implement the pending recommendations made by the treaty bodies and during the universal periodic review relating to poverty, children, education, persons of African descent, indigenous persons, persons with disabilities and other minorities, particularly those in poor and remote communities.**

123. **With regard to the United Nations and other international organizations, the Independent Expert recommends that Brazil:**

(a) **Encourage and contribute to the development of research programmes and activities on albinism, in close coordination with local and international partners;**

(b) **In line with the central pledge of the 2030 Agenda for Sustainable Development – to leave no one behind, reaching the furthest behind first – fully integrate the responses to issues faced by persons with albinism into United Nations programming through coordination with its various agencies and programmes;**

(c) **Report on the enjoyment of human rights by persons with albinism in future State party reports to the treaty bodies and for the universal periodic review.**
