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## Совет по правам человека

### Сороковая сессия

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**Поощрение и защита всех прав человека,  
гражданских, политических, экономических,  
социальных и культурных прав,  
включая право на развитие**

## Посещение Фиджи

### Доклад Независимого эксперта по вопросу об осуществлении прав человека лицами с альбинизмом\*

#### *Резюме*

В своем докладе о посещении Фиджи 27 ноября – 7 декабря 2017 года Независимый эксперт дает оценку положения в области прав человека лиц с альбинизмом в стране, уделяя особое внимание мерам, которые необходимо укрепить для обеспечения равенства и недискриминации. Она также дает оценку осуществления права на наивысший уровень физического и психического здоровья лиц с альбинизмом, включая создание адекватных систем защиты, профилактики и лечения. Она особо указывает, что право на образование и обеспечение разумного приспособления для достижения этого права, а также право на достаточный уровень жизни имеют исключительно важное значение для лиц с альбинизмом в Фиджи, которые сталкиваются с серьезными проблемами в этих областях. Она представляет различным заинтересованным сторонам рекомендации по решению этих проблем.

\* Резюме доклада распространяется на всех официальных языках. Сам доклад, содержащийся в приложении к резюме, распространяется только на том языке, на котором он был представлен.



**Annex****Report of the Independent Expert on the enjoyment of  
human rights by persons with albinism on her visit to Fiji****Contents**

	<i>Page</i>
I. Introduction .....	3
II. Background .....	3
A. General overview .....	3
B. Persons with albinism in the Pacific and in Fiji .....	4
III. Legal and institutional framework .....	5
A. Legal framework .....	5
B. Institutional framework .....	7
IV. Main findings and challenges .....	8
A. Invisibility and stigma .....	8
B. Education .....	9
C. Access to health care and adequate medical treatment .....	11
D. Social inclusion and adequate standard of living .....	13
E. Participation and representation .....	15
V. Conclusions and recommendations .....	16

## I. Introduction

1. In accordance with the mandate set out in Human Rights Council resolution 28/6 and at the invitation of the Government, the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, conducted an official visit to Fiji from 27 November to 7 December 2017. The objective of the visit was to assess the human rights situation of persons with albinism throughout the country. Particular attention was given to issues concerning equality and non-discrimination and the promotion of special measures; effective participation in cultural and public life; the right to the highest standard of physical and mental health, including adequate protection, prevention and treatment systems; the right to education and the provision of reasonable accommodation; and the right to an adequate standard of living.
2. During her visit, the Independent Expert travelled to the capital city of Suva and to the districts of Nadi and Rakiraki. She met with several senior government representatives, including the Attorney-General and high-level officials from the Ministry of Health and Medical Services, the Ministry of Education, Heritage and Arts, the Ministry of Local Government, Housing and Environment, and the Ministry of Employment, Productivity and Industrial Relations. She also held meetings with the Director of Public Prosecutions, the Speaker of Parliament, members of the parliamentary Standing Committee on Justice, Law and Human Rights and of the parliamentary Standing Committee on Social Affairs, and representatives of the Fijian police force, the Human Rights and Anti-Discrimination Commission, and the National Council for Persons with Disabilities.
3. The Independent Expert met with academic, religious, faith-based and civil society organizations, including those representing persons with albinism. She also visited medical and educational institutions providing assistance to persons with albinism in Nadi, Suva and Rakiraki. There, she observed the provision of health-care and educational services to persons with albinism and had exchanges with health-care professionals, teachers and community leaders. Most importantly, the Independent Expert visited numerous persons with albinism to hear from them about the enjoyment of their human rights.
4. The Independent Expert expresses her sincere gratitude to the Government for its invitation and full cooperation. She is also grateful to all other interlocutors, especially the persons with albinism who kindly shared their collective experiences and their individual perspectives with her. The Independent Expert looks forward to a fruitful and continued dialogue with the Government and other stakeholders on the implementation of the recommendations contained in the present report.
5. The Independent Expert thanks the United Nations country team and particularly the Office of the United Nations High Commissioner for Human Rights for their valuable assistance. She also thanks the representatives at the Permanent Mission of Fiji to the United Nations Office and other international organizations in Geneva and the Office of the Attorney-General in Suva for coordinating official meetings.

## II. Background

### A. General overview

6. Fiji is an archipelagic country with more than 330 islands and more than 520 smaller islets in the South Pacific. A total population of 884,887 persons was recorded in the 2017 Population and Housing Census.<sup>1</sup> Its closest neighbours are New Caledonia, Tonga, Tuvalu, Vanuatu and Wallis and Futuna Islands. Its two largest islands, Viti Levu and Vanua Levu, are home to over 80 per cent of the total population. Viti Levu is the largest island and the demographic and economic centre of the country. It is also where the capital, Suva, is located, along with other urban centres such as Lautoka and Nadi.

<sup>1</sup> See [www.statsfiji.gov.fj/](http://www.statsfiji.gov.fj/).

7. Fiji is a multi-ethnic and multicultural state. The population is 56.8 per cent iTaukei – an ethnic indigenous group native to Fiji, who are predominantly Melanesian with a Polynesian admixture. Those of Indian descent make up around 37.5 per cent of the population; 1.2 per cent are Rotumans, a recognized minority living mainly on the island of Rotuma; and 4.5 per cent are composed of other ethnic groups, including other Pacific islanders and people of Chinese and European descent. Around 65 per cent of Fijians are Christians (with more than half of them identifying as Methodists), 28 per cent identify as Hindu, 6.3 per cent as Muslim and less than 1 per cent identify as Sikh and other beliefs. Fiji recognizes three official languages: English, Fijian and Hindi.

8. At the time of the visit of the Independent Expert, Fiji ranked 91 in the human development index.<sup>2</sup> The average life expectancy was 70 years and more than 43 per cent of the population belonged to the age group of 0 to 24 years old. Its gross domestic product per capita was around US\$ 5,300 and it was estimated that more than 30 per cent of the population lived below the national poverty line. Fiji is described as an upper-middle-income country and one of the most developed and connected of the Pacific island economies. The economy draws its strength from the forests, minerals and fish resources in Fiji. It also relies heavily on tourism and the sugar trade – the latter remains a significant industry despite the damage caused by Cyclone Winston in 2016.

9. The current Constitution of Fiji was promulgated in 2013. It drew many of its provisions from the previous Constitutions of 1990 and 1997. It defines Fiji as a secular State, recognizes that all citizens of Fiji should be known as Fijians and reaffirms the status of the Human Rights and Anti-Discrimination Commission, which was established under the 2009 Human Rights Commission Decree. The most recent general elections prior to the visit were held in Fiji on 17 September 2014. Subsequent to the visit, general elections were held in November 2018.

## **B. Persons with albinism in the Pacific and in Fiji**

10. Albinism is a relatively rare, non-contagious, genetically inherited condition that affects people worldwide regardless of ethnicity or gender. It results from a significant deficit in the production of melanin and is characterized by the partial or complete absence of pigment in the skin, hair and eyes. In order for a person to be affected by albinism, both parents must carry the gene, resulting in a 25 per cent chance that a child will be born with albinism at each pregnancy. Some key implications of albinism include vision impairment, which varies in each person with albinism, and a high vulnerability to skin cancer, including potential fatality, due to extensive sun exposure without protection.

11. Persons with albinism are entitled to the same rights and standards enjoyed by persons with disabilities, owing to their visual impairment and susceptibility to skin cancer. They are discriminated against on the basis of their colour, which exacerbates the consequences of their disabilities, in particular when there is a high degree of contrast between the colouring of persons with albinism and that of the dominant population. Discrimination against persons with albinism should be understood as a specific situation stemming from the intersection of both disability and colour (A/HRC/37/57, paras. 29 and 30).

12. The prevalence of albinism varies worldwide. In Europe and North America, it is reportedly 1 in 17,000. In sub-Saharan Africa, reported estimates are 1 in 5,000 to 1 in 15,000, with multiple communities reporting a higher prevalence of 1 in 1,000. Some aboriginal communities in North and South America have reported a prevalence of 1 in 125.

13. Preliminary research on albinism in the Pacific region has indicated that the estimated prevalence in certain parts of the region is approximately 1 in 700. This implies that the prevalence of albinism in the region is potentially one of the highest in the world, despite the fact that there are no official statistics, and the number of persons with albinism is not

<sup>2</sup> See <http://hdr.undp.org/en/composite/HDI>.

reflected in population censuses and other surveys.<sup>3</sup> A study on oculocutaneous albinism type 2 in Tuvalu, with data collected both experimentally and defined in family trees genealogically, showed a relatively high prevalence of 1 in 669 among its population, which is based on a common mutation that has been present for many generations and has been repeated throughout the entire Pacific region as a result of migration flows across the Pacific.<sup>4</sup>

14. In Fiji, research and fieldwork conducted by civil society groups, such as the Fiji Albinism Project, concluded that Fiji is no exception to the general rule with regard to the high prevalence in the region. Apart from the possible historic environmental origins of the condition, one hypothesis that has been put forward to explain the high prevalence in Fiji relates to socialization patterns within small communities in the country, which increase the chances of marriage between persons from the same original gene pool or consanguineous marriages.<sup>5</sup>

15. Awareness about albinism, its prevalence and its impact on the daily lives of persons with albinism is relatively new in Fiji. The Independent Expert commends the Government for its openness and the commitment it has made to strengthening its focus on persons with albinism, who are a particularly vulnerable group in society. She wishes to particularly highlight its efforts in developing, in coordination with stakeholders at the national, regional and international levels, measures to effectively respond to the needs of persons with albinism and ensure their full inclusion in society.

16. Some of those measures were the outcome of a first workshop on the situation of persons with albinism, organized in Suva in November 2014, which included the participation of health-care workers, teachers and persons with albinism. In August 2015, the first multisectoral Albinism Awareness Symposium was organized in Suva with the support of the Ministry of Health and Medical Services. There were 200 participants from the mainland and nearby outer islands. The Symposium led to the formulation of recommendations on education and training, provision of resources, strengthening coordination between governmental and non-governmental sectors, reforms in the health and education sectors, and enhanced advocacy targeting the general public. It also gave significant momentum to raising awareness about albinism in Fiji. In 2016 and 2017, with the support of the Fiji Albinism Project, the leading civil society group, International Albinism Awareness Day was celebrated with the involvement of government and international stakeholders.

17. In this context, the Independent Expert is convinced that Fiji has the opportunity to put in practice the central pledge of the 2030 Agenda for Sustainable Development, which is to leave no one behind, reaching the furthest behind first. It can do so by adopting priority and fast-track specific measures to address the ongoing effects of the historical invisibility of persons with albinism within and outside of the communities of persons with disabilities, and by ensuring that their needs and voices are taken into account in the design and implementation of inclusive policies in all areas affecting them (see A/73/181).

### III. Legal and institutional framework

#### A. Legal framework

##### International human rights instruments

18. Fiji is party to the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Rights of the Child, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention against Torture and Other

<sup>3</sup> Helene C. Johanson and others, "Inheritance of a novel mutated allele of the OCA2 gene associated with high incidence of oculocutaneous albinism in a Polynesian community", *Journal of Human Genetics*, vol. 55, No. 2 (February 2010), pp. 103–111.

<sup>4</sup> Ibid.

<sup>5</sup> Interview with Dr. Margot Whitfield, Backyard Films and Video, "Coming out of the shadows – Albinism in Fiji", documentary film, 2016.

Cruel, Inhuman or Degrading Treatment or Punishment, the Convention on the Rights of Persons with Disabilities, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. Fiji is also party to the Discrimination (Employment and Occupation) Convention, 1958 (No. 111) of the International Labour Organization.

### **National framework**

19. Article 1 of the Constitution of 2013 stipulates that the core values on which Fiji is founded are, inter alia, common and equal citizenry and national unity; respect for human rights, freedom and the rule of law; equality for all and care for the less fortunate; human dignity, respect for the individual, personal integrity and responsibility, civic involvement and mutual support; and transparency and accountability. Article 5 provides that all Fijians have equal status and identity, and are entitled to all the rights, privileges and benefits of citizenship.

20. The Constitution guarantees every person's right to life (art. 8); right to personal liberty (art. 9); freedom from slavery, servitude, forced labour and human trafficking (art. 10); freedom from torture of any kind, whether physical, mental or emotional, and from other cruel, inhumane and degrading or disproportionately severe treatment or punishment (art. 11); right to a fair trial before a court of law (art. 15); freedom of speech, expression, thought, opinion and publication with their limitations with regard to, inter alia, incitement to hatred and violence and to subversion of the constitutional order (art. 17); freedom of assembly and association (arts. 18 and 19); right to work and to fair employment practices, including humane treatment and proper working conditions (arts. 20 and 33); freedom of movement (art. 21); participation in public life (art. 23); right to education (art. 31); right to full and free participation in economic life (art. 32); and right to health (art. 38).

21. The main anti-discrimination provision of the Constitution is article 26, which stipulates that every person is equal before the law and therefore entitled to equal protection, treatment and benefit of the law. It prohibits direct and indirect discrimination on the grounds of actual or supposed personal characteristics or circumstances, including race, culture, ethnic or social origin, colour, place of origin, sex, gender, sexual orientation, gender identity and expression, birth, primary language, economic or social or health status, disability, age, religion, conscience, marital status or pregnancy, and opinions or beliefs, the latter as long as they do not cause harm to others or infringe upon others' rights and freedoms. Under article 26, every person is guaranteed the right of access, membership or admission, without discrimination, to shops, hotels, lodging houses, public restaurants, places of public entertainment, clubs, education institutions, public transportation services, taxis and public places. Private owners of such places or services should ensure reasonable access for persons with disabilities.

22. The Independent Expert notes that the Constitution includes a separate section on the rights of persons with disabilities. Under article 42, persons with disabilities are guaranteed reasonable access to places, services, information, materials, substances and devices relating to their disability. They are also guaranteed the right to reasonable adaption of buildings, infrastructure, vehicles, working arrangements, rules, practices and procedures to enable their full participation in society and to ensure the full realization of their human rights.

23. In 2016, the Rights of Persons with Disabilities Bill (Bill No. 12) was tabled before the Parliament of Fiji. During her visit, the Independent Expert met with members of the parliamentary Standing Committee on Justice, Law and Human Rights and the parliamentary Standing Committee on Social Affairs to discuss the status of the parliamentary consultations on the draft text and to provide her input, particularly with regard to the issue of reasonable accommodation and the alignment of the text's wording with specific provisions of the Convention on the Rights of Persons with Disabilities.

24. The Independent Expert commends the Government for the adoption of the Rights of Persons with Disabilities Act in March 2018, which reflects its international commitment to protect and promote the human rights of persons with disabilities. Although the Government had issued a public call for submissions and input regarding the text of the Bill, the Independent Expert received complaints during her visit that the consultation process could

have been more transparent. She encourages the Government to ensure active and effective participation of all stakeholders, including persons with albinism, in the design and implementation of legislative and policy initiatives that affect them.

25. In accordance with the provisions of the Convention on the Rights of Persons with Disabilities, in article 27 of the Act, discrimination on the basis of disability is defined as any distinction, exclusion or restriction that has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It is explicitly stated that denial of reasonable accommodation is a form of discrimination. Furthermore, the Act includes sections on accessibility (art. 29); the rights of children with disabilities (art. 30); the right to reasonable accommodation in the context of natural disasters, armed conflict and humanitarian emergencies (art. 31); equality before the law, access to justice, and protection from exploitation, violence and abuse (arts. 32, 33 and 35); personal mobility, which guarantees access to quality mobility aids, devices, assistive technologies and forms of assistance at an affordable cost (art. 39); the right to education, the inclusion of persons with disabilities in the general education system, including tertiary education, and the provision of reasonable accommodation (art. 43); the right to health, including the right to special health care, early identification and intervention, ensuring free and informed consent and protecting personal autonomy (art. 44); the right to work (art. 45); the right to an adequate standard of living and social protection (art. 46); and the right to participate in public, political, and cultural life (arts. 47 and 48).

26. Comprehensive anti-discrimination provisions are also included in other national legal instruments, such as the Employment Relations Act of 2007 (sects. 6 and 75). The Act includes specific provisions with regard to disability and establishes specific quotas for persons with disabilities in the area of employment.

## **B. Institutional framework**

27. An important institutional outcome of the Rights of Persons with Disabilities Act was the creation of the National Council for Persons with Disabilities, which, according to articles 4 and 5, is mandated to act as a coordinating body for all organizations dealing with the care and rehabilitation of persons with disabilities, to raise awareness and to foster respect for the rights of persons with disabilities, to advise ministers on relevant matters and to establish a national policy to ensure that persons with disabilities are provided with services. This new body has replaced the former Fiji National Council for Disabled Persons, established in 1994, whose work led to the adoption by Cabinet of the National Disability Policy 2008–2018, the realization of a national baseline survey in 14 provinces and the ratification of the Convention on the Rights of Persons with Disabilities in 2017. The Rights of Persons with Disabilities Act provides for the establishment of more advisory committees under the Department of Social Welfare and strengthens the operational autonomy of the Council, including with regard to the allocation of resources.

28. The institutional human rights framework in Fiji includes the Human Rights and Anti-Discrimination Commission, established in 2009. The Commission has a broad human rights mandate. However, it does not have any particular focus on persons with albinism. In addition, there have been concerns expressed about the capacity of the Commission to discharge its mandate in line with the principles relating to the status of national institutions for the promotion and protection of human rights (the Paris Principles).<sup>6</sup>

<sup>6</sup> See, for example, CEDAW/C/FJI/CO/5, paras. 19 and 20.

## IV. Main findings and challenges

### A. Invisibility and stigma

29. Persons with albinism and their particular needs tend to be “invisible” in Fiji. The absence of data has prevented the development and implementation of targeted policies and initiatives that could have ensured reasonable accommodation and the protection and promotion of the human rights of persons with albinism. This has further augmented their vulnerability.

30. Barriers to the full enjoyment of human rights faced by persons with albinism are both structural and attitudinal. With regard to structural barriers, the absence of data is a recurring issue. During the visit, the majority of interlocutors, both governmental and non-governmental, acknowledged that more efforts were needed in the area of data collection, including with regard to discrimination and other human rights violations against persons with albinism. There is also a need to build and maintain disaggregated databases, which would enable Fiji to design and implement effective policies and programmes in all areas affecting all Fijians without discrimination.

31. Fiji concluded its most recent national census in 2017, which incorporated the set of questions on disability by the Washington Group on Disability Statistics.<sup>7</sup> However, the data collected on disability were not fully disaggregated by type of disability and albinism was not listed as a specific indicator. Similarly, in the survey conducted by the Fiji National Council for Disabled Persons in 2010,<sup>8</sup> persons with albinism were not recorded among the estimated 11,400 persons with disabilities registered in Fiji.

32. At the same time, incidents of discrimination and violence against persons with albinism have rarely been recorded by the Fijian police or by the Office of the Director of Public Prosecutions, including domestic violence, and discrimination in employment and education and in access to health care and other services. Societal pressure within communities, including pressure on victims to withdraw complaints, the absence of human rights training for law enforcement officers and the judiciary, and the lack of registration of cases or their registration under other generic categories of offence, may explain the absence of reported cases of discrimination and violence against persons with albinism.

33. Discrimination and stigma against persons with albinism also has a strong attitudinal dimension. It emanates from a lack of knowledge and widespread misconceptions about the condition of albinism and the issues faced by persons with albinism, including the belief that it is a communicable disease. Such misconceptions are fuelled by the hypervisibility of persons with albinism due to their colouring and appearance compared with the majority of the population who are more pigmented. As a result, persons with albinism are subject to intersecting grounds of discrimination at the juncture of disability and colour, and this is often aggravated by additional factors such as gender and age.

34. During her visit, the Independent Expert received accounts of discrimination in access to and maintenance of employment, disregard for the needs of pupils with albinism in school settings, leading to early school dropouts, discrimination in access to social welfare, and abandonment of children and cases of divorce as a result of the birth of children with albinism. She talked to a number of persons with albinism from various districts in Fiji who shared their experience that society was not embracing them and that they had to look out for themselves. In a bid to survive with their own condition and the associated societal pressures, they often isolated themselves from society, and consequently, their invisibility was further entrenched, creating the false impression that they intentionally “distanced themselves” from the rest of society. For some of them, basic acts such as walking around their communities

<sup>7</sup> The Washington Group Short Set of Questions on Disability is often included in surveys or censuses, and is designed to identify people with a disability. The questions are formulated in a way that identifies people who have difficulty performing basic universal activities such as walking, seeing, hearing, cognition, self-care and communication. See [www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/](http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/).

<sup>8</sup> Fiji, National Council for Disabled Persons, *Making Women with Disabilities Visible* (2010).



and participating in social activities could be a particularly difficult endeavour due to frequent and commonly accepted taunts. For some of those living in rural areas and villages, even wearing hats and sunglasses as sun protection measures was seen as inappropriate social behaviour.

35. Several interlocutors, both governmental and non-governmental, highlighted the widespread lack of knowledge about the suffering of persons with albinism in Fiji and the fact that their well-being had not yet been considered as a priority. Almost all of them could attest that in their immediate family or broader social environment, they had been in contact and had sometimes developed relationships with one or more persons with albinism.

36. The lack of awareness about and attention to the particular needs of persons with albinism appears to be driven also by the general perception that persons with albinism are not to be treated differently, but rather they ought to be treated in the same way as any other Fijian as a matter of equality. This conception of “sameness” fails to take into account the concept of equity and substantive equality, which recognizes the reality that sometimes equality also means treating people differently to bring them to true and substantive equality. This general principle of “sameness” has often led to persons with albinism being treated in a generic way without due regard to the social suffering and exclusion arising out of both their colouring and disabilities. In order to ensure the right to equality and non-discrimination of persons with albinism, specific measures and reasonable accommodation are required. These are necessary in order for them to enjoy their human rights without discrimination and for Fijian society to achieve substantive equality.

## **B. Education**

37. Persons with albinism often face multiple and intersecting forms of discrimination that have an impact on the realization of their right to education. Discrimination, social stigma, superstitions and myths surrounding their physical condition, violence and verbal abuse owing to their distinctive colouring and appearance, poverty, and the lack of appropriate infrastructure, reasonable accommodation, learning materials, and sufficiently trained personnel, all constitute factors that may explain general patterns of low school attendance and high school dropout rates of persons with albinism.

38. In 2016, the Government reviewed the Policy on Special and Inclusive Education, which focuses on a number of specific areas, namely: (a) enhanced support to the Special and Inclusive Education Unit for effective service delivery; (b) screening of students in all schools to identify disabilities and to develop intervention programmes to maximize learning outcomes; (c) enhanced support to all schools to enable adequate staffing, teaching and learning resources, and adequate infrastructure to support students with disabilities; (d) strengthening of early intervention programmes in special schools and early childhood centres; (e) further development of pre-service and in-service teacher training and education; and (f) enhanced support to vocational training programmes in special schools and vocational training centres. An implementation plan for the period 2017–2020 has been developed on the basis of this adopted revised policy.

39. According to an internal database developed by the Ministry of Education, Heritage and Arts, there were 1,289 students with disabilities in the school system at the time of the visit. However, this database was not disaggregated by type of disability and it did not record students with albinism. The Ministry recognizes the significant challenges that are faced by persons with disabilities in accessing special education. There are only 17 special education institutions in Fiji and they are situated in the main urban areas, which, given the wide geographical distribution of Fijians, poses significant accessibility challenges to persons living in rural and remote areas. In addition, the Policy on Special and Inclusive Education makes specific reference to the lack of appropriate infrastructure for rendering school premises accessible to persons with disabilities, including adequately equipped classrooms, walkways, and water and sanitation facilities. For this reason, the Ministry intends to further strengthen the integration of persons with disabilities in the mainstream educational system through, inter alia, the implementation of inclusive education programmes in the mainstream

educational institutions throughout the country. This policy will apply to all primary schools, secondary schools and tertiary educational institutions in Fiji.<sup>9</sup>

40. One good practice in the area of education for persons with disabilities concerns the financial support provided by the Government to all schools that have enrolled children with disabilities. This public subsidy is annual and amounts to approximately F\$ 680 for each student with a disability. The Ministry is responsible for monitoring the procurement by each school of adequate materials to support the learning needs of enrolled students with disabilities.

41. However, these funds are not focused on the purchase of adaptive devices, such as monoculars and magnifiers, and protective measures, such as wide-brimmed hats, sunglasses and sunscreen, all of which are significantly important for the educational performance and well-being of students with albinism.

42. The Independent Expert visited the Fiji School for the Blind in Vatuwaqa, Suva, to which pupils with albinism are often referred. She thanks the school's management and staff, the pupils and their parents for making themselves available for the visit and for sharing information about the school, their impressions and experiences. The school was established in 1982 and offers primary education, typing and computer training, and skills training for visually impaired students. It receives funding from the Government, members of the diplomatic corps and the private sector. However, the Independent Expert noted with concern that financial support from the Government covered only the salaries of the teachers and it was not extended to the purchase of equipment, including the appropriate protective and assistive devices for children with albinism. Such equipment was highly dependent on private donations, which posed significant challenges and risks with regard to the sustainability of the support needed by the students. For example, all the special materials and equipment for pupils with albinism, including a batch of sunscreen, protective clothing and sunglasses, had been provided as a one-off donation by St. Vincent's Hospital in Australia. Moreover, the quality of the sunscreen was a concern considering that sunscreen has an expiration date, and at the time of the visit, the school was using the same batch it had received in 2014.

43. The Independent Expert also observed that pupils with albinism, who have low vision, were being taught Braille in this school. Normally persons with albinism can use their vision with the aid of devices such as monoculars, which can significantly enhance their visual capabilities and thus their educational performance. These devices can also facilitate their transition to and integration into mainstream secondary education. The teaching of Braille to pupils with albinism may be explained by an unfounded perception that the visual impairment of persons with albinism can evolve into blindness, and therefore there is a perception of equality of treatment at a school where most learners use Braille. It could also be the consequence of the belief that Braille is the best available alternative in the absence of adequate adaptive devices in the Fijian school system in general.

44. The Fiji School for the Blind is the only school of this kind in Fiji and it is considered a transition point from special education to the mainstream educational system. Some pupils coming out of this school have successfully pursued their secondary education studies. Nevertheless, secondary education dropout rates for pupils with disabilities remain high, mainly due to a lack of reasonable accommodation and assistive devices.

45. The Independent Expert met with a support group of mothers of children with albinism who had been previously or were currently enrolled at the Fiji School for the Blind. The interviews with them shed light on the strength, eagerness and determination of those children to pursue their studies at the school despite the numerous challenges, such as the lack of adaptive devices, and discrimination or even taunting both in school and in their neighbourhood, including against their families by association. The Independent Expert cannot stress enough the strength and commitment of those women in their efforts to ensure that their children were receiving education, and their engagement with the school and

<sup>9</sup> At the time of the visit, there were 736 primary schools, 167 secondary schools and 30 tertiary educational institutions in Fiji.

community to raise awareness about albinism and the educational needs of children with albinism.

46. Furthermore, in her visits to Nadi and Rakiraki, the Independent Expert met with a number of persons with albinism who shared their school experiences. Exchanges with them suggested that there was no specific approach for dealing with students with albinism and for addressing their educational needs, but instead their experiences were highly contingent upon the school environment and the level of understanding shown by the teaching personnel and the community. Some of the testimonies from pupils and their parents highlighted constant bullying and taunting in school, including the use of pejorative local words such as “rea”, and their experience of physical aggression and difficulty keeping up with learning. As a direct consequence, most of these pupils had been forced either to change schools, sometimes more than once, or to drop out completely. Other testimonies described a school approach that was inclusive and sensitive to pupils with albinism, for example by ensuring that they were placed in the front of the class in order to be closer to the board, or by assigning fellow students as support during classes.

47. Nonetheless, in certain school settings in Fiji, there seems to have been a gradual improvement in the understanding of the condition and the need to address both the disability and the vulnerability to colour-based stigmatization. School management and teachers have tried to adapt to the educational needs of persons with albinism, despite the absence of appropriate infrastructure and equipment. Strengthening awareness about albinism and persons with albinism in the area of education has been one of the key activities of the Fiji Albinism Project, in coordination with the Ministry of Health and Medical Services, the Ministry of Education, Heritage and Arts, the Ministry of iTaukei Affairs, the Fiji Society for the Blind, St. Vincent’s Hospital in Australia, and the Rotary Club of Suva. A key output of this multi-stakeholder engagement has been the publication of an information booklet to educate children with albinism about their condition and how to live with it,<sup>10</sup> and an information pamphlet on albinism aimed at schoolteachers.<sup>11</sup> The pamphlet for teachers has already been distributed to schools in Ba, Nadi, Ori and Tavua, and at the time of the visit, those involved in the Fiji Albinism Project were also in discussion with the Ministry of Education, Heritage and Arts to expand the distribution to other regions. Other initiatives include advocacy work by medical personnel of the PJ Twomey Hospital, in collaboration with the Ministry of Education Heritage and Arts, to raise awareness about techniques to prevent skin damage in school settings. Such initiatives and programmes need further support from the Government in order to become sustainable. Furthermore, they should be coupled with investments in adaptive devices and training and educational programmes for schoolteachers, staff, parents and students.

### **C. Access to health care and adequate medical treatment**

48. The most pressing health issues faced by persons with albinism are visual impairment to varying degrees and a high susceptibility to ultraviolet-induced skin damage, in particular skin cancer. A number of exogenous health determinants can explain the significant obstacles that persons with albinism face in the enjoyment of their right to health, including misconceptions about their specific health needs, discrimination and stigma, the absence of specialized medical services or their lack of affordability when they are available, the lack of trained health personnel and the absence of support programmes to enable persons with albinism from remote areas to access medical treatment, including transport and other subsidies.

49. Based on consultations with the Ministry of Health and Medical Services and with health-care providers, the Independent Expert noted with concern the absence of information and data about the number of persons with albinism who had access to therapeutic treatment, in particular with regard to their skin and eye conditions. The Ministry was planning to further develop community outreach programmes to identify persons with albinism and to ensure that they were provided with the necessary medical and therapeutic services in order to, inter

<sup>10</sup> Fiji Albinism Project, “Living with albinism in Fiji: information for children and young people”.

<sup>11</sup> Fiji Albinism Project, “Albinism: information pamphlet for teachers”.

alia, prevent precancerous skin lesions and skin cancer. At the same time, during the visit, the Ministry recognized the importance of including sunscreen on its list of essential medicines in order to reduce the significant financial burden for persons with albinism. This was a concrete and welcome step arising from the visit of the Independent Expert.

50. At the time of the visit, specialized dermatological assessments and skin treatment for persons with albinism were provided monthly at the PJ Twomey Hospital in Tamavua, Suva, through a clinical programme supported by the Fiji Albinism Project. There was only one specialized dermatologist working in collaboration with the medical personnel of that hospital to perform therapeutic interventions. The clinic also provided sunscreen and informed patients and their families about techniques for preventing skin cancer. According to the Ministry of Health and Medical Services, the most serious dermatological cases were often referred to health-care centres abroad, with a number of them being referred to clinics in India. Beginning from 2018, to increase the number of dermatologists capable of responding to the needs of persons with albinism, the Ministry of Health and Medical Services was planning to organize a series of training activities for dermatologists in Fiji with Fiji National University, in collaboration with St. Vincent's Hospital and Dr. Margot Whitfeld, the founder of the Fiji Albinism Project.

51. The Independent Expert visited the PJ Twomey Hospital in Tamavua and had first-hand experience of the preventive and curative dermatological care offered to persons with albinism, and held conversations with the specialized dermatologist and the medical personnel. The hospital had 3 doctors, 12 nurses and 2 team leaders working on leprosy and dermatology. The specialized dermatologist provided prevention advice to the patients, checked their skin condition and intervened with cryotherapy, the application of liquid nitrogen to burn out precancerous lesions, to essentially prevent the advancement of skin cancer.

52. The Independent Expert noted with concern the absence of programmes and investment initiatives led by the Government to ensure the availability of liquid nitrogen, which is fundamental for the prevention of skin cancer. Furthermore, there was no investment in liquid nitrogen dispensers, which administer cryotherapy to patients through a pressure pump. The liquid nitrogen was being imported by the clinic at a relatively low price, whereas the dispensers were part of a one-off donation by St. Vincent's Hospital, Australia. In addition, St. Vincent's Hospital had donated a total of 3,000 bottles of sunscreen in the previous two years, some of which appeared to have expired.

53. Checks and treatment regarding the skin condition of persons with albinism took place almost exclusively at PJ Twomey Hospital in Tamavua, with limited and mostly donated resources. However, during discussions with the specialist dermatologist, the Independent Expert became aware of efforts to reach out to local communities through mobile clinics, in particular in the northern district of Bua on Vanua Levu, and, according to the information received, some other regions such as Kadavu, Navosa, Rewa and Savusavu, which might have a higher prevalence of albinism. However, there were currently no specific outreach activities taking place in those regions and some of the persons with albinism in those areas were forced to travel to Suva to receive life-saving treatment at the PJ Twomey Hospital in Tamavua, at their own expense. Various reports indicated that the cost of transportation was a barrier to access to clinical services for persons with albinism at the PJ Twomey Hospital in Tamavua.

54. Some of the persons with albinism who were patients at the skin clinic at the hospital confirmed the vital importance of such a clinic with its committed health professionals. Their testimonies showcased the importance of the clinic as some of them, who could personally cover transportation costs, presented themselves there once a month from as far as, for example, Koro Island, approximately 140 kilometres from Suva, in order to meet with the medical personnel and have their skin checked and treated. Visitors to the clinic also receive support and advice on how to cope with the challenges they face due to their condition. Persons with albinism see the PJ Twomey Hospital in Tamavua not only as a centre for medical treatment, but also as a place of care and accompaniment, which is fundamental for their well-being.

55. Information about the availability of services offered by the skin clinic at PJ Twomey Hospital in Tamavua did not reach a large number of persons with albinism in the various regions of Fiji. Most of the persons with albinism that the Independent Expert met in Nadi and Rakiraki were not aware of the skin clinic and were often left with no choice but to purchase the necessary products for themselves, which is particularly expensive because a 50 ml bottle of sunscreen only lasts for around one month. Those who knew about the clinic came to know it either through referrals from their doctors, but also by chance, such as listening to a radio programme or through limited community outreach activities undertaken by the Fiji Albinism Project.

56. The Independent Expert also visited the low vision clinic at the Pacific Eye Institute in Suva, which was offering services to approximately 50 persons with albinism once a year, including eye checks and prescriptions for glasses. Referrals to the Pacific Eye Institute were mainly made by the Fiji Albinism Project and the Fijian Society for the Blind, and there were cross-referrals between the skin clinic at the PJ Twomey Hospital in Tamavua and the low vision clinic of the Pacific Eye Institute. Discussions with medical personnel at the Pacific Eye Institute revealed the continued efforts to extend the activities and services of the Institute to districts and regions outside Suva through mobile clinics in Ba, Lautoka, Nadi, Navua, Rakiraki, Sigatoka, Tavua, Wainibokasi and Yaqara, and the development of eye treatment services at the divisional health-care centres in Labasa and Lautoka. The Independent Expert was informed of the importance of early intervention in improving the residual vision of persons with albinism in general. She was also informed of the significantly high price of prescription glasses, a cost ranging between F\$ 200 and 300, which was not covered by health insurance.

57. The Independent Expert also visited the divisional health-care centre in Rakiraki and the subdivisonal hospital in Nadi. Both centres had received a number of patients with albinism but they had not registered them in their databases as persons with albinism. There had been no recorded number of patients with albinism who had been admitted during the previous three to four years. The medical personnel indicated that there was a scarcity of dermatological clinics in Fiji and that there were no specific government programmes addressing the dermatological needs of persons with albinism. Furthermore, the pharmacies attached to those health-care centres did not have sunscreen for preventive treatment.

58. Further information shared by medical personnel was that the divisional health-care centre in Lautoka received more serious dermatological cases, although, to date, there had been only one case of melanoma in a person with albinism that had been referred to that divisional health-care centre. This was an unusually low number, considering that the tropical climate generally accelerates the development of melanoma in persons with albinism. While it is possible that persons with albinism in Fiji were not developing melanoma as quickly as others in similar climates, it is equally possible that such serious cases were not being reported to the hospital due to a lack of awareness among all stakeholders, including persons with albinism themselves.

59. A good practice was shared in Nadi with regard to identifying and gathering information on persons with albinism. A total of 32 public health professionals were conducting regular outreach interventions and “zone visits” to local communities. Those professionals could eventually be trained to gather specific information on persons with albinism and their state of health.

60. Finally, the challenge of being a person with albinism, coupled with a difficult socioeconomic situation and accumulated experiences of discrimination and stigma, may take a toll on the life of persons with albinism in Fiji. The Independent Expert was concerned by the absence of specialized psychosocial support aimed at providing a space for expression, building self-confidence and empowerment.

#### **D. Social inclusion and adequate standard of living**

61. In November 2017, the Government published its National Development Plan for 2017–2021 and for 2017–2036, in which specific reference is made to social inclusion programmes for persons with disabilities. There is also reference made to the effective

implementation, monitoring and review of legislation relating to the principles and provisions of the Convention on the Rights of Persons with Disabilities, and to improved data gathering on persons with disabilities.<sup>12</sup>

62. The right to adequate housing is guaranteed in article 35 of the Constitution, which stipulates that the State must take reasonable measures within its available resources to achieve the progressive realization of the right of every person to accessible and adequate housing. In 2011, the Government adopted the National Housing Policy, which, due to rapid urban growth between 2002 and 2008, focuses particularly on addressing housing needs in urban areas and the economic discrepancies between rural and urban areas of the country.

63. The Independent Expert notes with concern that the 2011 National Housing Policy does not include specific sections and policies on the housing needs of persons with disabilities, including persons with albinism, with regard to the required standards of building construction and maintenance, or to programmes for the development of accessible and adequate housing. However, at the time of the visit, the Government was implementing a policy of financial support of F\$ 10,000 to any household below an annual income of F\$ 50,000, for the purchase of a house or apartment. This was important for the independence of persons with albinism living in poverty or those dependent on relatives who reportedly, in some cases, abused and mistreated them. The Ministry of Local Government, Housing and Environment was also implementing programmes for urban development that took into consideration the needs of persons with disabilities, and it was involved in partially writing off loans for persons with disabilities in a dire financial situation. Following the ratification of the Convention on the Rights of Persons with Disabilities in 2017, the Government is expected to revise its National Housing Policy to ensure that the housing needs of persons with disabilities, and of persons with albinism, will be included as a priority.

64. In terms of access to employment, section 6 of the Employment Relations Act of 2007 includes disability as a prohibited ground of discrimination with respect to “recruitment, training, promotion, terms and conditions of employment, termination of employment or other matters arising out of the employment relationship”. Section 84 (4) provides that businesses that employ at least 50 workers may employ persons with disabilities on a ratio of at least 2 per cent of the total number of their workers.

65. In addition, during consultations with representatives from the Ministry of Employment, Productivity and Industrial Relations, the Independent Expert was informed about a specific tax deduction programme, called the Employment Taxation Scheme, for businesses that employ persons with disabilities. It encourages Fijian businesses to support the employment of school leavers, tertiary students and persons with disabilities. Under the scheme, since 2016, the Government has implemented a tax deduction over three years, which includes a 300 per cent deduction on the amount of wages and salaries paid to an employee with a physical disability, whereas in the case of an unfair dismissal of an employee with a physical disability, the employer is to be taxed on the amount of incentive allowed as a deduction. However, the Ministry of Employment, Productivity and Industrial Relations does not collect data on the number of businesses that hire persons with disabilities, or on the total number of persons with disabilities employed in the public and private sectors.

66. Further positive developments in the area of employment include the creation in 2010 of national employment centres,<sup>13</sup> which aim to provide professional advice and facilitate employment orientation. According to information provided by the Ministry of Employment, Productivity and Industrial Relations, at the time of the visit, a total of 108 persons with disabilities were registered in these centres. In addition, the Ministry is in close cooperation with the Fiji National Council for Disabled Persons to implement vocational training programmes for persons with disabilities and to grant them special scholarships. Nevertheless, there are no data on the number of registered persons with albinism in the national employment centres, or on the number of persons with albinism who have access to vocational training and are supported financially through State grants. Furthermore, despite

<sup>12</sup> Fiji, Ministry of Economy, *5-year and 20-year National Development Plan: Transforming Fiji* (November 2017).

<sup>13</sup> As a result of the adoption in 2009 of the National Employment Centre Decree, which was amended in 2017.

the complaint mechanism for cases of discrimination and sexual harassment provided for in sections 109–114 of the Employment Relations Act of 2007, there are no disaggregated data on the number of complaints filed for cases of discrimination on the grounds of disability.

67. Exchanges with persons with albinism and their family members brought forward both examples of social exclusion and discrimination in employment, and also of inclusion and professional success. The Independent Expert learned that factors such as family support, awareness and understanding at the local level, the socioeconomic situation of the family, and more importantly, gender, might determine the social experiences of persons with albinism and their socioeconomic integration in their communities. Persons with albinism, in particular women, who have been neglected by their families and their local communities, who are without support or strong social ties, find themselves in a particularly vulnerable situation, fighting prejudice and the challenges of their health condition, and trying to financially provide for themselves.

## **E. Participation and representation**

68. At the time of the visit, and in the three years prior to it, the Fiji Albinism Project was the only platform through which persons with albinism could voice some of their concerns, be informed about their health condition and receive ad hoc therapeutic treatment for their skin and eyes, mostly funded by private donations. The project actively engaged government agencies and medical personnel and reached out to local communities through awareness-raising activities and material support to clinics and schools.

69. However, the geographic scope of the project is limited and it lacks resources due to the absence of institutional support. At the time of the visit, it employed one full-time and two part-time officers, and the Government funded salaries but not programmes or activities. However, the project had been provided with an office space in a government building. It is important that the Government embrace this pioneering initiative and provide it with sufficient support in order to ensure its expansion and sustainability as a key specialized partner of governmental agencies.

70. The Independent Expert also met with the Pacific Disability Forum, the main civil society organization working and advocating for the rights of persons with disabilities. Established in 2004, the forum is the main body that works in partnership with organizations for persons with disabilities in the Pacific region with the purpose of building their capacity and improving their standard of living. At the time of the visit, it maintained a network of 65 regional partners and coordinated with the Ministry of Health and Medical Services and the Fiji National Council for Disabled Persons with regard to policies and legislative measures, such as the Rights of Persons with Disabilities Bill. Representatives of the forum reported that persons with albinism in Fiji were likely facing serious barriers to the enjoyment of their human rights. However, at the time of the visit, the forum had paid particular attention to issues faced by persons with albinism. They were not represented in the working groups of the forum, although its members stated their openness to including them in the future. In addition, the forum appeared to lack financial support from the Government and relied mainly on other sources of funding, including foreign donations.

71. Existing coordination platforms between the Government and civil society groups, such as the Fiji National Council for Disabled Persons and existing consultation forums at the local government level, can also play an important role in facilitating dialogue and contributing to the development of research programmes, policy and other activities related to albinism. Nevertheless, there is a need to strengthen the representation and participation of persons with albinism.

72. One positive example of an ad hoc activity to strengthen the participation of persons with albinism was the establishment of a support group for parents of children with albinism, which functions as a platform for information and advice. During discussions with some members of the group, the Independent Expert observed the empowering effect of the initiative, not only for mothers, but most importantly for their children with albinism. Formal registration as an association or a non-governmental organization would give such groups

the institutional framework and backing to operate and to seek support, thus increasing their capacity to reach out to other families who are affected by albinism.

73. Finally, based on the information she received, the Independent Expert is of the view that more must be done to strengthen the representation of persons with albinism in the public service sector and at the different levels of government. Neither the colouring of persons with albinism nor their disabilities should be a disqualifying factor or a reason for exclusion and discrimination.

## V. Conclusions and recommendations

74. In the four years prior to the visit, the promotion and protection of the human rights of persons with albinism had progressively gained attention in Fiji as an issue for further consideration and action. This was mainly thanks to governmental efforts and committed advocacy and intervention by civil society groups with experience in the area of health care. The Independent Expert observed genuine interest among all interlocutors, governmental and non-governmental, in learning about the condition, the barriers to enjoyment of human rights faced by persons with albinism, and the significant challenges they face in their everyday lives as a result of the intersecting characteristics of the condition.

75. Moreover, the Independent Expert wishes to commend the Government for its constructive engagement through its different ministries and departments. She also commends its commitment to raise awareness about albinism and the lives of persons with albinism, to design and implement specific programmes and initiatives, including in the areas of education and health care, and to ensure sustainable financial support for those programmes and initiatives.

76. The Independent Expert particularly appreciates the exchanges she had with local communities and persons with albinism and their families. She was impressed by their strength and spirit in the face of numerous challenges, and their generosity in sharing personal stories and experiences, both positive and negative. Although the lived experience of persons with albinism is determined by a multitude of factors, notably the stigma and lack of understanding of their particular needs, the absence of information, data and specific measures and strategies on albinism are the main reason for their continued invisibility and marginalization.

77. It is time to step up efforts in order to provide the necessary initiatives, institutional support and resources in order to ensure that albinism is an integral part of relevant policies and programmes. The ratification of the Convention on the Rights of Persons with Disabilities in 2017 and the adoption of the Rights of Persons with Disabilities Act in 2018 created ample opportunities for further dialogue and specific measures for persons with albinism.

78. In this regard, and in the twin spirit of constructive dialogue and the core pledge of the Sustainable Development Goals to leave no one behind, reaching the furthest behind first, including persons with albinism, the Independent Expert makes the following recommendations.

### Human rights framework

79. The Independent Expert recommends that Fiji:

(a) In the context of the ratification and incorporation of the Convention on the Rights of Persons with Disabilities in 2017, include specific measures for persons with albinism in its legislative, institutional and policy measures, including any future national strategy on persons with disabilities, and ensure wide consultation with and participation of persons with albinism;



(b) Consider including persons with albinism in future measures to implement the International Convention on the Elimination of All Forms of Racial Discrimination, taking into consideration the expressed position of the Committee on the Elimination of Racial Discrimination on the discrimination and stigmatization faced by persons with albinism on the basis of their colour;

(c) Effectively address discrimination and stigma through wide-scale awareness-raising and training programmes on albinism and on the specific needs of persons with albinism, in coordination with all stakeholders at all levels, including local chiefs and religious representatives, whose role in promoting empathy and respect for difference is crucial;

(d) Further strengthen the national human rights institutional framework, including through an independent and well-resourced Human Rights and Anti-Discrimination Commission, in line with the Paris Principles.

## **Education**

80. The Independent Expert recommends that Fiji:

(a) Pay particular attention to the design and implementation of education policies and programmes with a view to ensuring that persons with albinism, including children, are well integrated in mainstream schools, particularly through the provision of reasonable accommodation; in addition, undertake a comprehensive mapping of pupils with albinism;

(b) Step up efforts to ensure that all schools in the country are provided with appropriate infrastructure and materials in order to accommodate the educational needs of all students, including those living with albinism;

(c) Design and implement training and community outreach programmes in order to effectively address any barriers, including misconceptions and bullying, that constitute impediments to the full realization of the right to education by persons with albinism;

(d) Further expand financial support to all schools that enrol persons with disabilities, including persons with albinism, and establish institutional mechanisms to monitor and assess the way this financial support is invested by those schools, particularly with regard to the purchasing of appropriate adaptive devices and other support materials;

(e) Integrate modules into training programmes for schoolteachers and staff members to raise awareness about albinism and about specific educational methods and interventions in order to effectively address the educational needs of persons with albinism. In doing so, enhance coordination with other relevant groups, including international organizations, the National Human Rights and Anti-Discrimination Commission, civil society organizations and persons with albinism. One such example of an awareness-raising project in an educational setting is the information pamphlet on albinism for schoolteachers, produced by the Fiji Albinism Project. The Government should support such initiatives, strengthen their visibility and ensure that any materials produced are widely disseminated.

## **Data**

81. The Independent Expert recommends that Fiji:

(a) Ensure the systematic collection of data on disabilities that follows the methodology of the Washington Group on Disability Statistics, and include albinism as a category in that methodology and in population censuses and other surveys. In the short term, and with the support of the National Council on Persons with Disabilities, promptly undertake a specific survey on the situation of persons with albinism, as the most recent census did not include albinism as a category;

(b) Alongside censuses and surveys, source disaggregated data on persons with albinism from existing institutional frameworks, including through outreach

activities in local communities carried out by health and education professionals and through the research and activities of the National Council for Persons with Disabilities;

(c) Design and implement training programmes for health-care personnel and parents on the importance of registering newborns with albinism.

#### **Health care**

82. The Independent Expert recommends that Fiji:

(a) Further develop health-care measures, including services specifically dedicated to skin and eye treatment for persons with albinism, and ensure sustainable financial support for those services, including through international cooperation. In doing so, systematically provide training on the condition of albinism through international partnerships and in close collaboration with stakeholders, including academic institutions, medical centres with a focus on dermatologists and ophthalmologists, civil society groups and the private sector;

(b) Implement specific psychosocial support programmes aimed at effectively addressing the accumulated experiences of discrimination and stigma faced by persons with albinism, with a view to providing a space for expression, building self-confidence and empowerment;

(c) Create specific or general focal points within existing health-care centres to provide medical evaluations and treatment for persons with albinism for both their skin and eye conditions and to ensure the availability of adequate financial and human resources for that purpose;

(d) Expand and further strengthen the community outreach activities currently carried out by health-care professionals for the purpose of early intervention and prevention of skin cancer among persons with albinism in local communities, in particular in rural areas and remote islands;

(e) Ensure the sustainable provision of protective and adaptive materials and treatment equipment for skin care in educational institutions and health-care centres, particularly by ensuring that sunscreen is included on the list of essential medicines in Fiji;

(f) Consider the local production of sunscreen, including through international partnerships, with a view to making it accessible to all persons in need, and ensure that the costs of prescribed glasses are covered by government subsidies.

#### **Participation and representation**

83. The Independent Expert recommends that Fiji:

(a) Provide support to initiatives and programmes on albinism organized by civil society organizations. In particular, ensure the expansion and sustainability of the Fiji Albinism Project as a key, specialized government partner in providing direct services and carrying out awareness-raising programmes;

(b) Facilitate the registration of and provide support to associations representing persons with albinism and their families, and to civil society organizations working on the promotion of human rights and inclusion of persons with albinism;

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

(d) In coordination with the National Council for 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;

(e) In line with the central pledge of the 2030 Agenda for Sustainable Development, which is to leave no one behind, reaching the furthest behind first, fully integrate the responses to issues faced by persons with albinism in Fiji into United Nations programming through coordination with its various agencies and programmes. The aim should be to proactively reach out to persons with albinism and to design and implement support and awareness-raising programmes to draw them away from the margins and into social visibility, ultimately leading to the enjoyment of their human rights.

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