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

The right to education for persons with albinism

**Report of the Independent Expert on the enjoyment of human rights by
persons with albinism, Muluka-Anne Miti-Drummond**

Summary

The present report is submitted in accordance with Human Rights Council resolutions
28/6 and 46/12



I. Introduction

1. The present report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond,¹ is submitted pursuant to Human Rights Council resolutions 28/6 and 46/12. The report focuses on the right to education for persons with albinism and their experiences in different regions.

2. In preparing the report, a call for inputs was sent to various stakeholders, including Member States, civil society organizations and persons with albinism. Submissions were received from the Bolivarian Republic of Venezuela, Chile, El Salvador, Italy, Malaysia, South Africa and Zimbabwe. Responses were also received from civil society organizations, covering 14 countries.² The United Nations Children’s Fund (UNICEF) Eastern and Southern Africa regional office also provided inputs covering eight countries.³ In addition, two interviews were conducted and a virtual consultation was held with focus groups from Africa, Europe, North and South America, the Asia-Pacific and Australia. An online survey received responses from 28 countries.⁴ The report was further supplemented by a survey on albinism carried out in the United Kingdom of Great Britain and Northern Ireland, to which 18 people responded, and the outcome of a round-table discussion on albinism in the United Kingdom, held on 9 June 2023, chaired by the Independent Expert in dialogue with persons with albinism, their families and relevant civil society organizations.

3. Albinism is a rare, non-contagious, genetically inherited condition that occurs at varying frequencies in populations all over the world, regardless of race or ethnicity.⁵ The most common form of albinism, oculocutaneous albinism, is characterized by the lack of melanin pigment in the hair, skin and the eyes, causing susceptibility and vulnerability to skin damage from exposure to the sun, including skin cancer. Moreover, lack of melanin in the eyes also contributes to visual impairments, including photophobia, strabismus, nystagmus, low visual acuity and refractive error. Prevalence figures for oculocutaneous albinism vary from region to region: Africa has the highest incidence, with an average rate of approximately 1 case in 4,000, whereas in Europe there is an estimated rate that is three times lower, with an average of approximately 1 case in 13,000.⁶

II. Normative and policy framework

A. Relevant international human rights laws and standards

4. The right to education is a fundamental human right and has a solid basis in international human rights law. Key international human rights instruments affirm and protect the right to education, including the Universal Declaration of Human Rights (article 26), the International Covenant on Economic, Social and Cultural Rights (article 13), the Convention on the Rights of the Child (article 28), the Convention on the Elimination of All Forms of Discrimination against Women (article 10), the Convention on the Elimination

¹ The development of the tools for the conduct of the interviews, data analysis and the drafting of the report was carried out by Paul Lynch, Senior Lecturer in Inclusive Education, School of Education, University of Glasgow, United Kingdom of Great Britain and Northern Ireland.

² Benin, Burkina Faso, Brazil, Czechia, France, Kenya, Nigeria, Rwanda, Sierra Leone, South Africa, Togo, Uganda, United Republic of Tanzania and Zambia.

³ Angola, Comoros, Kenya, Lesotho, Madagascar, Malawi, Mozambique, Namibia, Rwanda, Uganda, United Republic of Tanzania, Zambia and Zimbabwe.

⁴ Argentina, Australia, Austria, Brazil, Canada, Chile, Côte d’Ivoire, Czechia, Dominican Republic, Ecuador, Finland, Germany, Ghana, Guatemala, India, Japan, Malaysia, Mali, Mexico, Philippines, Rwanda, Spain, Togo, Türkiye, Uganda, United Kingdom of Great Britain and Northern Ireland, United Republic of Tanzania and United States of America.

⁵ Jennifer G.R. Kromberg, “Epidemiology of albinism”, in Jennifer G.R. Kromberg and Prashiela Manga, eds., *Albinism in Africa: Historical, Geographical, Medical, Genetic, and Psychosocial Aspects* (San Diego, Elsevier, Academic Press, 2018), pp. 57–79.

⁶ Jennifer G.R. Kromberg et al., “Determining a worldwide prevalence of oculocutaneous albinism: a systematic review”, *Investigative Ophthalmology & Visual Science*, vol. 64, No. 14 (July 2023).

of All Forms of Racial Discrimination (article 5) and the Convention on the Rights of Persons with Disabilities (article 24).

5. Of particular relevance to persons with albinism are the articles of the Convention on the Rights of Persons with Disabilities, which highlight, *inter alia*, that States parties should recognize the right of persons with disabilities to education without discrimination and should ensure an inclusive education system at all levels of lifelong learning. As also set out in the above-mentioned treaties, children with disabilities should not be excluded from free and compulsory primary education or from secondary education on the basis of disability. The Convention also provides crucial reference to reasonable accommodation, including access to assistive devices on the basis of individual requirements, and sets out that learners should receive the required support to ensure the effectiveness of their education within the general education system. Support measures should be provided in environments that maximize academic and social development, with full inclusion as the goal.

6. The Committee on Economic, Social and Cultural Rights has also provided a framework through which the right to education should be understood, comprising the essential 4A features: availability; accessibility; adaptability; and acceptability. The four indicators encapsulate the obligation of States parties to enforce the right to education. In that context, learners with disabilities, including persons with albinism, should receive an education that, *inter alia*, incorporates an expanded core curriculum,⁷ including instructions and guidelines specifically tailored to their needs.

7. In terms of regional human rights standards, the right to education is also affirmed, *inter alia*, in the African Charter on Human and Peoples' Rights; the Association of Southeast Asian Nations (ASEAN) Human Rights Declaration; the resolution of the European Parliament of 2021 on the European Educational Area: a shared holistic approach; the Arab Charter of Human Rights; and the Charter of the Organization of American States. Although not yet in force, article 16 of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa also provides important provisions on the right to education.

8. Sustainable Development Goal 4 of the 2030 Agenda for Sustainable Development and the Education 2030 Framework for Action further demonstrate the commitment of States to the right to education. The right to education is universally recognized in that it has been assessed to be a norm of international customary law.⁸

B. National laws and policies

9. National laws and policies for learners in general also apply to learners with albinism. Some countries, including Guinea (law No. 0016/AN of 2021) and Panama (law No. 210 of 2021), have adopted specific legislation on the rights of persons with albinism, which also cover the right to education.

10. Albinism, because of its attendant visual impairment and vulnerability to skin damage from the sun, including skin cancer, falls within the framework of disability legislation and policies. Some countries have made explicit references to the inclusion of learners with albinism in mainstream schools in their disability laws. For example, in Ghana, the law on persons with disabilities specifically recognizes persons with albinism as falling within the remit of the law. It calls for inclusive education of persons with disabilities, non-discrimination and reasonable accommodation in inclusive schools.⁹ In Uganda, the Persons with Disabilities Act, 2020 also specifically recognizes persons with albinism as persons with disabilities and calls for inclusive education, as well as the provision of reasonable accommodation and assistive devices for all learners with disabilities.

⁷ The expanded core curriculum comprises independent living skills, including self-determination skills (self-advocacy skills, decision-making skills and understanding accessibility rights), orientation and mobility skills and assistive technology skills, see www.prcvi.org/resources/the-expanded-core-curriculum.

⁸ A/HRC/53/27, para. 8.

⁹ Ghana, Persons with Disability Amendment Bill, 2020, sect. 18.

11. In many countries, however, albinism is not specifically referenced under disability laws. Some laws do not define disability but provide criteria to be met in order for persons to qualify as having a disability and needing educational support. In terms of those laws, learners meeting specific criteria can access educational support plans tailored to their needs. For example, in the United States of America, the Individuals with Disabilities Education Act and section 504 of the Rehabilitation Act provide for the provision of individualized education plans to support the specific needs of learners with disabilities. In the United Kingdom, part 3 of the Children and Families Act 2014 sets out the process of obtaining an education, health and care plan through which children with albinism, if they qualify, can be provided with needed support. Similar laws and policies provide for access to a personalized schooling plan in France.¹⁰

12. Even where disability laws may not specifically refer to albinism, a small number of countries have made explicit reference to albinism in their inclusion policies or other official documents. In Togo, the Government has adopted a circular note calling for reasonable accommodation for learners with albinism.¹¹ In Kenya, a sector policy for learners and trainees with disability, adopted in 2018, recognizes albinism as a category of disability, including the need to provide learners with albinism with appropriate accommodation. Nigeria has a national policy on albinism,¹² which explicitly recognizes the right to education. In some countries, particularly in Africa, including Angola, Malawi, Mozambique and Uganda, national action plans on albinism also cover the provision of specific needs for learners with albinism.

III. Barriers to enjoyment of the right to education

A. Stigma and discrimination

13. In Africa and parts of Asia, there is still a belief that albinism is a supernatural phenomenon that manifests itself in the form of a ghost figure who has supernatural powers that can be harmful to others in the same community. In some African countries, there is also a belief that albinism is contagious and that if you sit next to a child with albinism you will catch the condition. There are other superstitions, including the belief that the body parts of persons with albinism can provide some form of wealth or fortune if used in ritual practices. The multitude of superstitions and myths, as well as the lack of understanding of albinism, have led to widespread discrimination against persons with albinism.

14. In the context of the right to education, submissions to the Independent Expert highlighted that bullying and name-calling were the most evident forms of stigma and discrimination against persons with albinism. Exclusion from sport and other activities, as well as failure to provide specific forms of support, also ranked high as forms of discrimination experienced by persons with albinism in places of learning.

B. Bullying

15. From information received, there is overwhelming evidence that learners with albinism have experienced and are still experiencing different degrees of bullying and/or name-calling at schools worldwide. Bullying was identified as a barrier to accessing education for persons with albinism in almost 65 per cent of the responses to the call for inputs.¹³ Further, close to 85 per cent of respondents in the global survey highlighted bullying

¹⁰ France, Law No. 2005-102, Circular No. 2016-117, Circular No. 2015-129 and Circular No. 2016-186.

¹¹ See Circular No. 078/MEPSTA/CAB/SG.

¹² National Policy on Albinism in Nigeria; see also the Discrimination against Persons with Disabilities (Prohibition) Act 2018.

¹³ Submissions from Angola, Benin, Brazil, Czechia, France, Kenya, Mozambique, Nigeria, Rwanda, Sierra Leone, South Africa, Uganda, United Republic of Tanzania and Zambia.

and name-calling as a concern.¹⁴ Many submissions stated that there are existing anti-bullying or anti-discrimination policies, but that they have not proven to be effective. In other opinions, such policies were seen as only moderately effective in curbing bullying and name-calling against learners with albinism.

16. Bullying tends to be at a peer-to-peer level, but teachers may also make inappropriate comments or mock a learner's vision or a learner requiring more help. Various submissions referred to cases where learners who asked for help were made fun of by teachers and peers alike in Brazil, France, Germany, Malawi, the Philippines, the United Kingdom and Zambia. The Independent Expert also heard anecdotes from different countries about learners being mocked by teachers, including being called a "pirate", in reference to a learner who used a monocular. In a submission from Angola it was stated that some teachers refused to be in a classroom with a child with albinism.¹⁵

17. Bullying can be specifically about the hair, skin colour or eye movements of persons with albinism. At the round-table discussion held in the United Kingdom, a participant narrated how other students had burned the back of her neck with cigarettes because they said she had "devil eyes". In another submission, from the Philippines, it was stated that persons with albinism are also victimized because of their nystagmus or squint. A person with albinism had surgery to reduce the movement of their eyes in order to avoid further bullying. In submissions from Japan¹⁶ and Malaysia,¹⁷ it was reported that students with albinism have been bullied about their blonde hair as the majority of the population has black hair. To avoid name-calling, young persons with albinism often try to hide the colour of their hair by dyeing it or using fake tanning products.

18. In Germany, learners have transferred to special schools for the visually impaired because of peer bullying and a lack of understanding from the teachers. Similarly, students in Fiji have been forced either to change schools, sometimes more than once, or to drop out of school completely.¹⁸

19. Bullying has also been linked to the provision of reasonable accommodation. A submission from Denmark referred to a case of a student being bullied as the result of being placed at the front of the class, making the learner a target of mockery by others.

20. Even in Guna Yala, Panama, where persons with albinism are said to be "blessed", there are incidents of bullying at school. During her country visit to Panama in September 2023, the Independent Expert spoke to a number of parents of children with albinism who narrated stories of their children being bullied, including having their hair cut by peers, their shoes soaked in water and embarrassing videos of them being posted and shared. Some children were so severely traumatized that they were unable to talk about their experiences at school.

21. Bullying and name-calling can lead to long term psychological issues, including depression, self-isolation and anxiety, which can impact young children with albinism throughout their school years and beyond. In Zambia, learners with albinism oftentimes give up their education as a result of discrimination and the feeling that the learning environment is an unwelcome place.¹⁹

22. These challenges are further amplified by community-level stigma and discrimination. Children with albinism often face mockery, bullying and exclusion, not only from their peers but also from the wider community. In some cases, parents discourage their children from interactions with children with albinism. Such prevailing attitudes create an environment where children with albinism are marginalized, not only in educational settings but also in broader social interactions, perpetuating a cycle of disadvantage and exclusion.

¹⁴ Submissions from Australia, Brazil, Canada, Chile, Côte d'Ivoire, Czechia, Finland, Germany, Ghana, Japan, Malawi, Rwanda, Togo, Türkiye, United Republic of Tanzania and United States.

¹⁵ United Nations Children's Fund (UNICEF) East and Southern Africa Regional Office.

¹⁶ Japanese Albinism Network.

¹⁷ Kuala Lumpur and Selangor Albinism Association.

¹⁸ See [A/HRC/40/62/Add.1](#).

¹⁹ Albinism Foundation of Zambia.

23. There are also different efforts by non-governmental organizations to challenge bullying at school, including by speaking to teachers, other students and school administrations, as well as through the provision of awareness-raising materials. In Malawi, a civil society organization working on albinism has reported a reduction in name-calling and bullying across the country although this is difficult to confirm. Civil society organizations working on albinism in Mali and Senegal cited financial constraints that restrict their capacity to counter bullying and highlighted the importance of working with Governments in this regard.²⁰

C. Exclusion from school curricula, sports and higher education

24. The stigma and discrimination against children with albinism extends to their exclusion from certain courses and activities at places of learning owing, inter alia, to the belief that their impaired vision will prevent them from engaging with certain materials or participating in certain activities. This is often the case for subjects pertaining to science, technology, engineering and mathematics and for sports activities. However, with appropriate accommodation, learners with albinism can be included in such activities.

25. There are reports of persons with albinism being excluded from learning institutions altogether. Community attitudes put into question the value of educating children with albinism, with some viewing it as a futile investment. As one respondent stated, “I was once asked ‘you barely see, why are you going to school?’”²¹ Another respondent from Burkina Faso stated that many children with albinism are not enrolled in school because of prejudices that they are unfit for education. Consequently, some parents may not send their children with albinism to school.

26. There have also been a few cases where institutions have reportedly refused to admit children with albinism. In Malaysia, students have been refused admittance to degree courses because they ticked a box declaring that they had a disability. This was the case of one student with albinism who applied to a university and was rejected. The student’s mother immediately contacted a local albinism association, which went to the Ministry of Education, together with civil society leaders, to complain about the university’s decision. As a result of the complaint, the Government prohibited universities from excluding learners with disabilities from studying at their institutions.²² The Independent Expert was also informed of cases of learners being turned away from a private school in Pinga State in Malaysia, apparently due to a lack of teachers’ understanding of how to support students with albinism. It appears that discrimination is less of an issue in State schools.

D. Lack of understanding of albinism

27. A lack of understanding of albinism and the specific needs of learners with albinism is prevalent in nearly all countries. Based on information received, as a general trend, few teachers have received information or training on how to accommodate learners with albinism in mainstream schools. Overall, teachers appear to have little understanding about how albinism affects learners’ vision or how they can adapt their teaching practice and classrooms to be more inclusive of learners with albinism. As stated in one submission, some teachers do not understand that children with albinism cannot see normally, despite wearing glasses; this misunderstanding on the part of teachers is detrimental to children’s education.²³ In general, teachers do not receive specific training or information on albinism either as part of initial teacher development courses or as part of their continuous professional development. The exceptions seem to be Australia, the United Kingdom and the United States, where training about albinism is included in specific courses on visual impairment, in particular for

²⁰ Salif Keita Global Foundation.

²¹ Africa Albinism Network.

²² Kuala Lumpur and Selangor Albinism Association.

²³ Genespoir.

teachers who are responsible for teaching the expanded core curriculum. The content of the courses is not, however, comprehensive.

28. Lack of basic knowledge about the impact of albinism on learners' vision means that some learners are still being forced to learn braille rather than print. In some countries, including Zambia, many learners with albinism are enrolled in schools for the visually impaired where they are taught braille. As a result of this lack of understanding, even the simplest accommodation to aid learners' vision may be denied, making it increasingly difficult for learners to see study materials in the classroom. In the United Kingdom, for example, a teacher insisted that a learner with albinism remove her photochromic glasses when entering the classroom from outside. As a result, she often spent the first moments in class unable to see the board.

29. Lack of understanding of albinism also has an impact on needs related to the vulnerability of individuals to skin damage. In many countries, including Chile and El Salvador, only visual impairment, not albinism, is recognized as a disability. As highlighted by a respondent from Czechia, the perception of albinism as a vision impairment creates barriers to the right to education for persons with albinism. Some learning institutions are still unaware of the need for learners with albinism to use sunscreen. In some cases, learning settings may be willing to provide sunscreen as a reasonable accommodation, although neither the students nor the teachers are necessarily aware of such a need. During a meeting with an academic institution in South Africa, for example, the disability unit mentioned that they provided support and products required by the students at the students' request. The unit had not, however, been asked for sunscreen by a student with albinism. The staff of the unit admitted that they had not known about the importance of sunscreen. A former student of the institution stated that she had not known of the importance of sunscreen nor that she could request it while she was a student at the institution.

30. Almost half of those who responded to the global survey had no knowledge of government-provided guidelines for teachers of learners with albinism. The task of educating teachers on the needs of learners with albinism is therefore often left to organizations of persons with albinism and parents of learners, or left up to the learners themselves to self-advocate. In Mali, a civil society organization stated that during its visits to schools it often had to speak to the same teachers multiple times to ensure that they understood what they needed to do to help facilitate access to learning for children with albinism. The organization currently had no materials on inclusive education for distribution to teachers, as a result of which, after its visits, learners must continue to advocate for themselves, which is not an easy task, given that they may be subjected to name-calling or even bullying.

E. Reasonable accommodation for visual impairment

31. Common accommodations related to the visual challenges of persons with albinism include: the placement of children in the middle of the first row, not too close to the window if there is too much light in the classroom; large print documents and textbooks; suitable arrangements enabling them to copy notes from colleagues in class; teaching assistant/learning support persons; and extra time to complete exams. In France, a table with a slanted top is available to minimize the risk of back pain for learners who need to bend low to read their books. However, the extra time allowance to complete exams is not always seen as fair by other learners who think learners with albinism are being given an unfair advantage. It is important to explain the reasons why some learners require extra support and are given extra time to complete exams.

32. Despite the ease of providing some of the above accommodations, some countries do not provide any accommodations for learners with albinism. One respondent stated that teachers were not always trained to adapt their lessons to the needs of visually impaired students and that some professors did not provide suitable documents, despite requests. Although help was available, learners still needed to know about it and to find an interlocutor. However, if the few teachers who did not want to comply with requests for accommodations persisted in their refusal, nothing could be done. Some teachers refused to make adaptations on the pretext that students must be prepared to take an exam without any accommodation in

the event that it was refused.²⁴ Further, large print examination papers were not always made available.²⁵

33. In a significant number of submissions, the issue of lack of consultation with parents or caregivers was raised, in particular about individual requirements for children as contributing to a lack of reasonable accommodations. This has led to instances where children, particularly those without assistive devices, have not been able to follow lessons on the blackboard, see books being shown during storytime or answer test or exam questions from the board in class. This was raised as a concern by several people, including respondents from Argentina, Malaysia, Panama and the Philippines.

34. Some parents acknowledged that their own limited knowledge about their children's condition would have made it difficult for them to advise schools, even had they been consulted. This was the case in Brazil, Mali and Senegal, for example. There were countless examples where children were more aware of their own reasonable accommodation requirements. From information received, it became clear that students in primary and high school are rarely consulted.

F. Lack of reasonable accommodation for mobility around school

35. According to 75 per cent of respondents to the global survey, schools do not fully provide for the mobility needs of learners with albinism. Adjustments could include making clear signs, with good colour contrast; placing yellow tape on steps; and including texture contrast on pathways. An experienced orientation and mobility professional in the United States emphasized the need to improve the school experiences of learners by providing relevant orientation and mobility skills training to both learners and teachers in schools. Orientation and mobility training is an area that is not always included in training of learners with low vision and is mainly included only for learners who are blind or have severe low vision. Further, such training is not sufficiently covered in teacher training programmes.

G. Inappropriate “accommodations”

36. Concerns were raised about the appropriateness of so-called reasonable accommodations in certain cases and the application of “one-size-fits-all” measures to all learners with albinism. Reasonable accommodations of individuals' requirements are not always made, as specified in the Convention on the Rights of Persons with Disabilities (article 24 (2) (c)). A respondent from Denmark raised a concern about the fact that, even though learners with albinism have access to appropriate assistive devices, they are often seated alone in front of the class, with the teacher's desk in between them and the rest of the class, which isolates them from the other students in the class and may result in bullying. In some cases, the accommodation provided for learners with albinism is to allow them to copy notes from other students. Those notes, however, may not always be accurate and could cause further problems in learning the subject, or cause learners with albinism to fall behind.

37. Similar concerns have been raised by persons with albinism who were forced to learn braille in primary and high school. While some persons with albinism may have very low visual acuity and require braille, many can read large print documents with appropriate fonts. In the majority of submissions, it was noted that persons with albinism use print to access school curriculum and that a few are also able to use braille. One university student with albinism in Zambia lamented that being forced to learn in braille meant that he had automatically been excluded from science, technology, engineering and mathematics subjects in schools.

²⁴ Genespoir.

²⁵ Joint submission from the Disability Rights Fund/Disability Rights Advocacy Fund and others.

H. Provision of assistive devices

38. Thanks to a surge in new low vision optical devices, magnification applications and the Internet, increasing choices of distance and near-vision devices are available, although matching individuals to the right device takes time and requires high-quality professional advice. Furthermore, in many countries such devices are not available. Respondents also highlighted the challenges in accessing such devices, even in countries where they are available.

I. Unavailability of assistive technology for learners

39. There are stark differences in the provision of assistive devices from country to country, with higher income countries, such as Canada, the United Kingdom and the United States, being able to supply appropriate and sometimes multiple devices that can be used both at home and in school. In those countries, devices such as powered handheld magnifiers, monocular telescopes and tablets may be provided by State institutions or through specific rehabilitation centres or eye clinics run by the Government. Conversely, few devices are provided to learners with albinism in low- and middle-income-countries. Most recent research suggests that in low- and middle-income-countries only 5 per cent to 15 per cent of those who need assistive technology are able to obtain it.²⁶ In the area of educational technology, fundamental issues of equity and support of effective inclusion for all must be addressed.

40. From information received, it was evident that primary schools tend to receive more resources than early childhood education centres and secondary schools. Throughout the world, large print books are the most frequently provided materials to accommodate visual impairment, in particular in the early years and primary school levels. In addition, low vision clinics and private optometry centres can prescribe low vision devices for learners with albinism. However, families are often expected to bear the burden for purchasing low vision devices and other essential equipment for their children, particularly in countries in Africa and Latin America. Such purchases are beyond the financial reach of many families. In some cases, this kind of equipment may be donated by overseas benefactors or non-governmental organizations. In Zambia, for example, some, although not all, learners with albinism receive support from Sightsavers²⁷ in the form of spectacles and assistive devices. In Burkina Faso, Mali and Senegal respondents reported receiving mainly small hand-held magnifiers from donations.

J. Accessing timely and appropriate assistive devices

41. While learners with albinism in higher income countries have greater access to free or subsidized devices, not all are able to receive them for a variety of reasons. For example, most respondents to the United Kingdom survey stated that they had some access to reasonable accommodations, although not all did. Further, certain accommodations are only available through education, health and care plans, but less than 18 per cent of respondents stated that they had such plans. Furthermore, over 58 per cent of those in higher education stated that they had not been able to receive a disabled students' allowance. Participants at the round table in the United Kingdom also highlighted difficulties in obtaining assistive devices, citing lack of knowledge of educators about their specific needs and lack of budget from the authorities for assistive devices, and pointed out cases where support services had requested medical proof to support their claims. Participants also stressed that access to assistive devices was a "postcode lottery", stating that it was often dependent on one's address. Similar concerns were brought up by parents of persons with albinism in the United States, who said that it all depended on which school district you lived in. In some rural districts, access was only available to a reduced range of assistive devices, whereas

²⁶ See UNICEF, *Annual Report 2015* (New York, 2016), available at https://www.unicef.org/media/50046/file/UNICEF_Annual_Report_2015_ENG.pdf.

²⁷ See www.sightsavers.org/programmes/zambia-inclusive-education-project.

some larger more urban districts had access to more professionals and might even have fully equipped assistive technology departments. Even within the same location, whether city or town, some learners may not receive assistive devices because they live in school districts with fewer resources. In Japan, there is a comprehensive legal system that represents persons with low vision. Each district education committee in Japan has to secure a budget to take care of educational services for learners with low vision in order to provide minimum support at school and access to assistive devices thus depends on the size of the district budget.

42. Concerns have also been raised about the timeliness of funding and purchasing of devices for learners with albinism. In the submission from France, it was stated that, as a result of administrative delays, adaptations can take a long time to put in place and children can find themselves without adaptation for several months or even years. Adaptations can be made inconsistently, depending on who is responsible for providing the materials. For example, children may be given a camera to see what is written on the board, but the screen may not be provided until the following year, rendering the camera useless. As a result, parents are forced to buy some of the equipment, which not all families can do. Similar concerns have been raised in other countries. A mother of a learner with albinism in the United Kingdom narrated how her daughter had to pull out of A-level biology because of delays by the school in ordering an adapted microscope for her. The learner had to drop the subject as she did not receive the needed device in time.

43. In addition, concerns have been raised about the provision of the required technical support at schools for assistive devices. In some cases, while smart boards or other closed circuit-enabled devices may be provided for learners, they are not connected in such a way as to enable students to benefit from them. In other cases, they are connected, but educators do not receive the right training on how to effectively use them. For example, a participant at the United Kingdom round table narrated how her teacher would “pin” a computer window to an interactive blackboard for the class to work from, but continue with her own work on a different non-shared window. However, because the teacher’s laptop and hers had a direct connection, their screens would be mirrored and she would see the teacher’s private screen rather than the exercise like the rest of the class. The effective use of technology requires the teaching of specialist skills and ongoing assessment of needs, including aspects such as positioning and handling of devices as set out in the universal design for learning.²⁸

K. Lack of accommodation to minimize exposure to the sun

44. As persons with albinism fall within the framework of the Convention on the Rights of Persons with Disabilities, owing both to visual impairment and lack of melanin, reasonable accommodation needs to be made in relation to sun exposure. Information received highlighted verandas, outside school building, window shutters, protective clothing and sunscreen as important forms of reasonable accommodation for the protection of the skin of persons with albinism. These accommodations were evident in countries that have high levels of ultraviolet rays throughout the year, including Australia, Brazil, Canada, Côte d’Ivoire, India, Japan, Malawi, the Philippines, Spain, Togo and the United Republic of Tanzania. Moving sporting activities to cooler times of the day or having indoor sports facilities can also help reduce exposure to the sun.

45. Climate change also has a direct impact on education of children with albinism.²⁹ Harsh or prolonged sun exposure means that the eyes of children with albinism are more exposed to glare and consequently they have greater difficulty seeing classroom content and concentrating on their learning. At the same time, more frequent extreme sun exposure at school and on the way to school poses a grave health risk of skin cancer for children with albinism. Other health consequences, such as sunburn, are also very painful and disruptive to their education and learning.

46. Participating in outdoor play and sports activities can be dangerous for learners with albinism if schools have not taken sufficient steps to ensure that they will not be adversely

²⁸ See <https://udlguidelines.cast.org>.

²⁹ See A/78/167.

affected by ultraviolet light while playing sports. There are clear instructions for schools in Australia and the United States with regard to wearing protective clothing, sunscreen and sunglasses whenever there are sports activities in the playground and sports fields. In Africa, learners with albinism tend to be included in sporting activities, but suitable accommodations are not always made to minimize their exposure to the sun.

47. Organizations of persons with albinism around the world provide practical advice on how to protect children's skin using long-sleeved shirts, hats, umbrellas and sunscreen. In Australia, Canada, Denmark, the United Kingdom and the United States, this includes regular updates on ultraviolet rays, particularly during the summer months, using the ultraviolet index, which is available on weather applications on smart phones. However, sunscreen, hats and protective clothing and gear do not appear to be provided through schools. In some cases, learners receive such equipment through organizations of persons with albinism or, where they exist, through government schemes³⁰ that make sunscreen and sometimes protective gear available to all persons with albinism, regardless of whether they are learners or not. In Mali, Senegal and the United Republic of Tanzania, even when sunscreen is available for persons with albinism, it is often not distributed across all parts of a country, leaving rural populations with albinism without any form of protection. The Independent Expert has also received concerns that sunscreen is not always consistently distributed, with gaps in distribution, and that it may sometimes be delivered when it is already out of date. In addition, frustrations have been raised about the process for accessing social support for sunscreen in some countries. For example, the national disability law in Argentina (1981) requires that an individual register in order to receive a certification of disability. The certificate gives access to some forms of support, but these are not always forthcoming, in spite of parent pressure for quality health care, including sunscreen lotion.

L. Challenges in commuting to school

48. Although specific challenges may differ, travelling to school for learners with albinism was raised as a concern by survey respondents in almost all countries. Broadly speaking, the challenges identified related to exposure to the sun in Africa, Asia and Latin America, in particular for those travelling from remote areas; fear of attacks in Africa; and the accessibility of public transport systems, bearing in mind the low vision of persons with albinism, in high-income countries, as well as Latin America.

M. Exposure to the sun

49. Commuting to school increases the exposure of people with albinism to the sun. This is aggravated by the cost or lack of public transport, lack of sunscreen and protective gear, long distances from homes to schools and/or the high ultraviolet ray index in some countries. Learners travelling to school are particularly susceptible to repeated sunburn and can develop scaly tough skin on their necks (solar elastosis), with red, burned skin and an attendant high risk of skin cancer, which can attract unwanted attention from other people in their community.³¹ During her visit to Panama, the Independent Expert noted that for children from the islands in the Guna Yala region, an area with a high prevalence of albinism, the risk of sunburn and skin damage is increased by the reflection of ultraviolet rays off water as they travel by boat to schools on other islands.

N. Risk of attack

50. The risk of attack was a particular concern for respondents in Africa, who raised the major challenge of exposure to verbal and physical attacks on the way to or from school,

³⁰ Such as the Albinism Support Programme, administered by the National Council for Persons with Disabilities in Kenya.

³¹ Paul Lynch, Patricia Lund and Bonface Massah, "Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi", *International Journal of Educational Development*, vol. 39 (2014), pp. 216–224.

including name-calling, abductions and mutilations. In Malawi, children were warned by their families to take special precautions when walking alone or through maize fields when the crop is fully grown, as this is a potential hiding place for abductors. In Mozambique some parents prohibit their children with albinism from attending school for fear of abductions, in particular during the harvest time. Many parents in the United Republic of Tanzania have reportedly stopped their children from going to school owing to fear of attack.³²

51. A representative of an international civil society organization working in Malawi stated that it has working with victims of such attacks, including children who were abducted, to see if they had returned to school. Around 10 children who were specifically targeted or were victims of attacks have returned to school. There is a positive movement of parents encouraging their children to go back to school. This process is not happening in the southern region of the country, where districts border Mozambique. There are parents who still fear being attacked again and who still consider it unsafe for their children to go back to school. It is important to note that the region was hit by a cyclone in 2022, which led to a lot of destruction of buildings, including schools, as well as being affected by other economic factors that are particular to that region.

52. In some countries, the risk of attacks along the way to school has contributed to the practice of placing learners with albinism in boarding schools. This was the case in the United Republic of Tanzania, and in Malawi learners with albinism are still being placed in resource centres with boarding facilities. In response to the wave of attacks against children with albinism in Madagascar, parents have also started placing their children with albinism in boarding schools. However, there are also concerns about the adequate care of learners with albinism in those facilities. One respondent stated that a recent case of attempted abduction of a learner with albinism in Zambia, which reportedly included a teacher and carers at the school, illustrates that learners are not necessarily safe at such facilities either.

O. Accessibility of public transport systems

53. Over 73 per cent of the respondents to the global survey identified the challenges of identifying and using public transport as a significant barrier to accessing education. Respondents also gave a high ranking to the lack of reliable transport to school as one of the reasons for school dropouts by persons with albinism.

54. In countries where public transport systems are available, concerns were raised about their accessibility as oftentimes, with little accommodation for disability, it was difficult for learners to travel independently to school like their peers. It can be a challenge for learners with albinism to identify their bus in time in order to indicate their intention to board. As a result, bus drivers may unknowingly leave them behind, while learners, who have to stop every bus coming, only not to board, suffer from embarrassment. One interviewee from Brazil said she was able to overcome this problem when she learned to recognize the shape of the bus.

55. Digital signage boards for trains can also be inaccessible for persons with albinism, with low colour contrast and quickly changing information, making it difficult for them to access relevant information for their journey, for example, platforms, arrival times and destinations. In big cities with complex public transportation systems, bus terminals and train stations may also be inaccessible with tripping hazards and inaccessible signage to platforms or relevant stops, thus making independent travel for learners with albinism challenging.

IV. Impact of the COVID-19 pandemic on learning

56. Challenges in accessing education for students with albinism were exacerbated during the coronavirus disease (COVID-19) pandemic because of the inaccessibility of teaching methods. In April 2020, the pandemic caused more than 180 countries to mandate temporary

³² UNICEF.

school closures, leaving approximately 1.6 billion children out of school.³³ Familiar, inclusive teaching methods, which centred on all learners being in same room, with an adult (the teacher) leading the lesson, disappeared and a whole range of online and remote teaching modalities were introduced, with varying degrees of success. Online learning was used in many countries, with low and middle-income countries also opting for learning programmes through the use of television and radio. However, for learners with disabilities, who had an additional barrier of inaccessible learning content, the digital divide exacerbated the learning divide related to accessing equipment, electricity and the Internet.³⁴ In some cases, persons with albinism, who are generally among the poorest in society, particularly in low and middle-income countries, were not served by the introduction of online learning as oftentimes their families did not have such devices. Further, those learners with albinism who had access to laptops or a television struggled to follow due to low vision. For example, one respondent from a civil society organization in Nigeria stated that many online applications that were used during the pandemic did not have features such as bold fonts to make learning inclusive.³⁵ In addition, a key informant from the Philippines attested that many learners with low vision experienced challenges in staring at a screen for hours each day with little accommodation for their individual needs. In many countries, learners were expected to log on between 8 a.m. and 3 p.m., or longer, Monday to Friday. Consequently, for a year they were required to spend most of the day in front of a screen in order to receive their schooling; the long hours at the screen affected both their eyesight and their mental health. In Uganda, some schools sent out hard copies of exercises for students, although no accommodation was made to provide large print materials for students with albinism.

57. Furthermore, during the pandemic, reports emerged of persons with albinism being labelled as “corona”, generating fear and anxiety among them and ostracism within their communities.³⁶ As schools reopened, children with albinism were concerned about being discriminated against and isolated. In addition, stricter hygiene requirements, upon return to school, left some students with albinism exposed to the sun in long queues for handwashing, particularly in warmer climates.

58. More research is needed in order to fully understand how online learning at home has affected the learning, assessment outcomes and psychosocial and emotional outcomes of learners with albinism across the globe.

V. Good practices

59. While there are still many concerns regarding the realization of the right to education for learners with albinism, some promising practices have emerged. A few of these are from States, sometimes in partnership with civil society organizations and non-governmental organizations. However, most of the promising practices appear to have been put in place by associations of persons with albinism, who have stepped in to fill the gap in the provision of reasonable accommodations by the authorities. Many of the initiatives have also sought to tackle concerns related to stigma and discrimination, as well as the marked lack of understanding of albinism, which tends to be the leading cause for the failure to ensure reasonable accommodations.

³³ UNICEF, “Responding to COVID-19: UNICEF’s 2020 key achievements”, available at www.unicef.org/reports/responding-to-covid-19.

³⁴ World Bank, *Pivoting to Inclusion: Leveraging Lessons from COVID-19 Crisis for Learners with Disabilities* (Washington, D.C., International Bank for Reconstruction and Development/The World Bank, 2020), see www.worldbank.org/en/topic/disability/publication/pivoting-to-inclusion-leveraging-lessons-from-the-c-ovid-19-crisis-for-learners-with-disabilities.

³⁵ Disability Rights Fund.

³⁶ See A/76/166.

A. Practices instituted by States

1. Increasing teacher awareness of the needs of persons with albinism

60. In Australia, the United Kingdom and the United States, training about albinism is included in specific courses on visual impairment, although the content varies between countries. Training tends to cover topics such as how to personalize learning based on visual impairment, ways to provide reasonable accommodation within the classroom and ways to create a safe school environment. Other themes include providing information on the different types of assistive device that can enhance access to learning materials and information on how the different eye conditions can affect a learners' vision.

61. In the United Republic of Tanzania, throughout 2022, the non-governmental organization Standing Voice and the Government of Malawi partnered with 15 schools across four regions of the country to provide specialist training for 167 teachers. Tasked with monitoring and promoting the welfare of students with albinism, the teachers acted as "Vision Ambassadors" to create a culture of respect, solidarity and mutual accountability in safeguarding the rights of learners with albinism in their schools. They also functioned as an important referral link with the main clinical service, reporting to Standing Voice on the ongoing vision needs of the students and ensuring the correct use and maintenance of prescribed assistive devices. The reciprocity between teachers' training and clinical care was strengthened by the increasingly prominent role of eye health specialists who travelled to schools with the Standing Voice team to support the delivery of teacher training and provide follow-up care to learners.

62. In South Africa, several policies on persons with disabilities have been adopted and recognition has been given to persons with albinism, particularly through the work of the national task force and stakeholders. The draft policy on persons with disabilities included the participation of persons with albinism, including children, through a series of public hearings aimed at accelerating access to social services.

63. Data, which is crucial for raising awareness about learners with albinism, is rarely available. The Independent Expert was pleased to receive information from the Government of Zimbabwe indicating the specific number of learners with albinism under the Ministry of Primary and Secondary Education.

2. Ensuring access to assistive devices

64. A number of States, particularly high-income countries, have developed policies and practices to enable learners with visual impairments to access educational support, including assistive technologies. Learners with low vision, who qualify, can access a wide range of assistive technologies and support through a personalized plan known as the education, health and care plan in the United Kingdom, the personalized schooling project in France and the individualized education plan in the United States. These plans are also available to learners with albinism. For example, in Denmark, learners with low vision have access to an eyesight adviser. In addition, there is a standard kit that is available to persons with albinism, including a laptop, a hand-held magnifier, video magnifiers and sunscreen. The contents of the backpack are tailored, on a case-by-case basis, to the individual and the level of provision varies. In Canada, provinces loan laptops, screen-magnification software, devices including video magnifiers to improve access to reading. Learners can use the devices throughout their entire education cycle.

65. In Malawi, Standing Voice has partnered with the State to establish low vision and skin screening clinics for learners with albinism. The programme involves eye screening and the fabrication of appropriate glasses for learners with albinism. So far, over 1,000 learners with albinism have been reached with ophthalmology services.

3. Minimizing the risk of skin cancer

66. Australians, possibly more than any other nationality, understand the risks connected to overexposure to the ultraviolet rays of the sun. To minimize the risk of skin cancer, Australia has put awareness raising campaigns in place, aimed at encouraging skin cancer

reduction behaviour. There is a “no-hat no-play” policy in most schools, targeting all children, while simultaneously encouraging teachers to support learners. The Cancer Council’s “Slip, Slop, Slap” campaign, launched in 1981, known to most Australians, helps to explain the diligence of most Australians in protecting their skin against the sun. This has been extended to its current “Slip, slop, slap, seek and slide” wording, which is even more relevant. The slogan “slip” on a long-sleeved top, “slop” on some SPF lotion, “slap” on a hat, “seek” shade (for example, use an umbrella) and “slide” on some sunglasses³⁷ is aimed at all children in Australia.

67. Programmes have been put in place by some States to ensure access to sunscreen, lip care, after-sun and/or protective clothing for persons with albinism, which are also available to learners with albinism. The albinism support programme implemented by the National Council for Persons with Disabilities in Kenya operates in a similar manner. Low vision and skin screening clinics in Malawi offer education on skin cancer prevention strategies, skin assessments and appropriate sunscreen lotion to clients and also treat and refer suspected cases for surgery in tertiary health facilities.

68. Some States have partnered with non-governmental organizations to produce and distribute sunscreen locally. In the United Republic of Tanzania, the regional dermatology training centre has been producing “Kilisun”, an SPF 30+ UVA/UVB lotion and supplying it to skin clinics within the country. The local production of sunscreen has reduced reliance on importing lotion from overseas, which was often more expensive and not always easy to source. Much of the success of the initiative is thanks to an initiative with two non-governmental organizations, Standing Voice and Beyond Suncare. The sunscreen is regularly distributed to around 6,000 people with albinism across 21 regions of the United Republic of Tanzania.³⁸ Beyond Suncare also locally produces and distributes sunscreen in Malawi, Rwanda and Uganda. In addition, the Pierre Fabre Foundation collaborates with States on skin cancer prevention programmes in Burkina Faso, Côte d’Ivoire, Mauritania, Nigeria and Togo.

4. Financial support

69. Given the additional cost of education for learners with albinism, and bearing in mind that persons with albinism tend to be among the poorest members of society, some States offer financial assistance and bursaries for learners. The Albinism Support Programme, organized by the National Council for Persons with Disabilities in Kenya, offers education assistance at primary, high school and mid-level colleges in the form of bursaries. The National Council also partners with the corporate sector to provide scholarships. Although not yet implemented, the Law on Persons with Disabilities in Panama also provides for education grants for learners with albinism. In South Africa, the National Student Financial Aid Scheme has special provisions to support students with disabilities.

B. Practices instituted by civil society organizations working on albinism

1. Guidelines and support for schools for full inclusion of learners with albinism

70. A number of albinism associations have developed documents with information to share with educators. In Argentina, the civil society organization *Simplemente Amigos – Fundación Nacional de Albinismo* has prepared protocols (or guidelines), written in collaboration with persons with albinism, knowledgeable teachers, lawyers and psychologists, targeted at administrators of kindergartens, primary schools, secondary schools and universities. The protocols are simple to follow and provide low-cost solutions to protect learners’ skin and vision. Similar guidelines have been developed in Malawi, Sierra Leone, the United Republic of Tanzania and Zambia.³⁹ However, there appears to have been limited amount of dissemination of many of the publications. There are also issues around the cost

³⁷ Australia, Cancer Council, available at www.cancer.org.au.

³⁸ Kilimanjaro Sunscreen, available at www.standingvoice.org/programmes/kilisun.

³⁹ [People with Albinism: Not Ghosts but Human Beings](http://www.pwaweb.org/).

of producing and distributing them, which are often left up to Ministries of Education.⁴⁰ Organizations such as the Albinism Fellowship in Australia, Under the Same Voice, Standing Voice and the National Organization for Albinism and Hypopigmentation in the United States have also published practical guidelines for teachers on their websites.

71. In addition, the Australian Albinism Fellowship⁴¹ has developed a template letter, which is available for download, to use and personalize for children starting school. The letter is addressed to the pre-school teacher from the new student. It sets out some useful information that teachers will need to know about accommodating a child with albinism in relation to their vision and skin health. Parents can personalize the letter by adding their children's favourite toys and books and provide their contact details so that the teacher can contact them to ask for more information.

2. Civil society organizations' training for teachers on albinism

72. According to the Disability Rights Fund, a pilot training programme for teachers on supporting students with albinism was undertaken across five districts in Uganda. The training, a joint initiative by non-governmental organizations, targeted teachers from pre-primary, primary and secondary schools. The programme was aimed at raising awareness about albinism among teachers, including by addressing myths and misconceptions about albinism and learners with albinism, the challenges they face at school and how teachers can support them in the classroom so that they realize their full learning potential.

73. Associations of persons with albinism also carry out capacity-building activities for teachers, although not always in the form of a training. Associations such as the Japanese Albinism Network and Kuala Lumpur and Selangor Albinism Association offer support to families who need help discussing their children's needs at school. They normally give advice to parents on what they should tell teachers on their child's first day in school. They also speak to teachers, as well as students, as some of the children do not like to draw attention to their differences for fear it may result in them being bullied by their peers. Many other associations throughout the globe carry out similar interactions.

3. Conferences and summer camps for families of persons with albinism

74. In the United States, the National Organization for Albinism and Hypopigmentation⁴² organizes conferences for families of children with albinism and invites key experts on low vision, orientation and mobility skills, as well as counselling (self-advocacy) and skin specialists, to share new practices, changes in legal practices. The organization also holds an annual summer family camp, which provides children with albinism and their families with an opportunity to share a fun-filled outdoor vacation with others with similar conditions.⁴³ The conferences and camps have been seen as a lifeline to many young people who are experiencing isolation, in particular those who have moved away from their families to study at college or university.⁴⁴ Similar gatherings, although at a smaller scale, are also organized by the Albinism Fellowship in the United Kingdom.

4. Scholarships for learners with albinism in the United Republic of Tanzania

75. Scholarships provided by the organization Under the Same Sun to learners with albinism at all levels of education have had a positive impact on the ability of young persons to advocate for their own needs. Some individuals who received scholarships are entering employment opportunities, including one person who is working as an accountant in a hotel. These students are raising awareness of their needs to a broader population across the United Republic of Tanzania. Increased numbers of persons with albinism who are educated are more vocal and know their rights.

⁴⁰ Malawi, United Republic of Tanzania and Zambia.

⁴¹ See <https://albinismaustralia.org/about/albinism-skin>.

⁴² National Organization for Albinism and Hypopigmentation, see <https://albinism.org>.

⁴³ In 2023, the Summer Camp, called Camp Abilities, focused on adaptive sports and social events, music, cooking and self-advocacy.

⁴⁴ Albinism Fellowship in the United Kingdom organizes an annual one-day conference.

5. Use of social media for persons with albinism

76. Persons with albinism in Argentina, Brazil, Colombia and Panama are able to connect on either a closed group on Facebook or through a WhatsApp group. The groups are effective in bringing families and young persons with albinism together, allowing them to share their experiences and information about their rights, including the rights of children at school. There are reports that persons with albinism are also connecting with Facebook groups from countries where there is little presence of organizations for persons with albinism.

77. In some cases, restricted access Facebook groups have been set up. These have the advantages of not requiring much administration and can provide young persons in their teens an opportunity to talk about issues that may concern them at school, such as bullying and name-calling, in a closed, relatively safe space. Creating a Facebook group or a simple website targeted at persons with albinism can also increase the profile of associations, increase membership and give a voice to those who feel isolated or marginalized in their communities.

6. Support for learners with albinism during the COVID-19 pandemic

78. In some countries, good initiatives were reported to accommodate learners with albinism during the COVID-19 pandemic. For example, in Uganda, organizations provided solar panels for power as well as radios so that children could keep tuning in to their lessons. Some organizations also reprinted hard copy exercises in large print, enabling students with albinism to read and complete their schoolwork.

VI. Conclusion and recommendations

79. **The present report provides a synopsis of the challenges and barriers that persons with albinism have experienced in 28 countries, in the realization of the right to education. From the research and information received by the Independent Expert, the low vision of learners with albinism continues to be highlighted as the main challenge to accessing an adequate education for many persons with albinism. However, there is also a weakness or a failure in the support provided by certain States in removing the numerous barriers to the full enjoyment of the right to education. In terms of wide-spread discrimination and misunderstanding of persons with albinism, the Independent Expert did not receive information on any country that has effectively dealt with the problem of bullying and name-calling.**

80. **In addition, there has been a lack of effective action taken to enhance and increase the understanding of educators on how to provide the required accommodations for learners with albinism to ensure their access to a full school curriculum. These accommodations can range from simple adjustments, such as placing learners as near to the board as possible, and providing sunscreen, as well as appropriate assistive technology devices (for example, magnifying glasses), to more complex solutions, such as setting up personalized screen magnification systems on learners' laptops so that they can see the board clearly from their seats.**

81. **From the information received, it is clear that even though laws and policy state that learners with disabilities, including albinism, should receive appropriate adaptations and accommodations for their learning needs, that is not always the case. In high-income countries, much appears to be dependent on how well funded a district or educational authority is within the same city or country. In lower- and middle-income countries, the lack of adaptations and accommodations tends to be more of a macro, national issue, with little or no budget cited as the cause for lack of sunscreen, available assistive technologies or the provision of large print books.**

82. **The limited provision of information for persons with albinism and their families about the condition and how to protect the skin and maximize visual acuity for those with albinism is of great concern. Having access to the right information at the time of birth could prevent unnecessary instances where both parents and pre-school teachers**

do not know where to position children in the classroom or how to protect them from ultraviolet light when playing outside during recreation breaks or sporting activities.

83. There still remains little published evidence or information concerning the educational experiences of learners with albinism and there is a dearth of research on the educational, psychological and parental experiences of having a child with albinism. A research agenda needs to be developed for persons with albinism, incorporating the priorities of the albinism community.

84. On a positive note, there are various initiatives aimed at assisting persons with albinism to realize their right to education, including sponsorship schemes, which are slowly making changes to the lives of persons with albinism, particularly in Africa. Having more persons with albinism with exemplary educational backgrounds in influential positions can further help to change public opinion and misbeliefs about persons with albinism. It is hoped that, with time, more attitudinal changes towards albinism will be seen, although this will require concerted efforts at all levels from all relevant stakeholders. Significant resources have already been invested in the education of the younger generation over the past five years although more still needs to be done to ensure that learners with albinism can enjoy the same educational rights as others across the globe.

85. It should be highlighted that the role of States and non-governmental stakeholders are both imperative. The particular role of civil society organizations working with persons with albinism in developing promising practices for ensuring the full enjoyment of the right to education cannot be overstated. The advocacy of parents and self-advocacy of learners with albinism has been instrumental in increasing the knowledge of their specific requirements. It is therefore essential that States include those voices in the development of new policies and practices to support learners with albinism.

86. With regard to education, the Independent Expert recommends that States:

(a) Establish and implement policy guidelines for educators, through a consultative process with learners with albinism, their guardians and representative organizations, to ensure access to appropriate and timely reasonable accommodations at places of learning for both the visual and skincare requirements of learners with albinism;

(b) Ensure, at the very minimum, that learners with albinism receive the necessary support, including being placed near the front of the class setting and have access to large print notes and magnifiers and, where possible, enable them to use personal technology to access and enlarge information on the board at the child's learning post;

(c) Introduce frequent monitoring and evaluation to measure how effectively reasonable accommodations and assistive devices are being accepted and implemented in classrooms;

(d) Implement guidelines and protocols for educators, focusing on supporting learners with albinism, to ensure they are available through as many services as possible, including through governmental departments, as well as associations representing the rights of persons with albinism;

(e) Put in place reasonable accommodations to ensure mobility for persons with albinism around places of learning, such as clear signs, with good colour contrast, yellow tape on steps and texture contrast on pathways;

(f) Ensure that infrastructure in places of learning take into account the need to minimize exposure to the sun, including through having verandas and shaded areas around the school, appropriate covered walkways between buildings and shutters on windows that can be used to redirect sunlight in learning spaces;

(g) Implement measures to reduce the challenges of commuting to school for learners with albinism, including by ensuring accessible public transport systems, subsidies for travel costs and measures to reduce risk of attacks on the way to school;

(h) Establish programmes to promote school attendance by students with albinism, including social protection schemes for families, which can be used to alleviate the added financial costs for parents of children with albinism;

(i) Collect data, including across schools, on students enrolment, completion and dropout rates, disaggregated by age, gender and disability, including the grouping of albinism, to better inform policy formulation and resource allocation;

(j) Take appropriate steps to mobilize resources, including international cooperation, to ensure access to appropriate and timely assistive devices for learners with albinism, including sunscreen and protective gear;

(k) Provide free sunscreen to learners with albinism in school settings, in particular in countries with tropical climates, and ensure that sunscreen is listed in the national essential list of medicines, given its criticality for the health and life of learners with albinism.

87. The Independent Expert recommends that States, the international community and development partners:

(a) Provide capacity-building, assistance and training to educators and persons with albinism on the factors conducive to the effective realization of the right to education;

(b) Ensure the inclusion of persons with albinism in development or human rights-related activities in relation to the right to education;

(c) Provide financial support, to persons with albinism to eliminate barriers to the right to education;

(d) Provide support and assistance to strengthen the work of civil society organizations working to support persons with albinism, in particular in the context of the right to education.
