



## 人权理事会

## 第四十三届会议

2020年2月24日至3月20日

## 议程项目3

促进和保护所有人权——公民权利、政治权利、  
经济、社会和文化权利，包括发展权

## 对南非的访问

## 白化病患者享有人权问题独立专家的报告\* \*\*

## 概要

在本报告中，白化病患者享有人权问题独立专家称赞南非政府采取的积极和模范举措。独立专家着重指出了生命权、人身安全权、污名和歧视、卫生、教育、就业和代表权方面的现有挑战。她建议南非政府和相关利益攸关方可以采取哪些具体措施来维持已经取得的成就，包括保护和预防措施、消除污名和歧视的措施以及消除白化病患者享有人权的其他所有已知障碍的措施。

\* 因提交方无法控制的情况，经协议，本报告迟于标准发布日期发布。

\*\* 报告概要以所有正式语文分发。报告本身载于概要附件，仅以原文印发。



## **Annex**

# **Report of the Independent Expert on the enjoyment of human rights by persons with albinism on her visit to South Africa**

## **I. Introduction**

1. The Independent Expert on the enjoyment of human rights by persons with albinism undertook a visit to South Africa from 16 to 26 September 2019. The visit was carried out at the invitation of the Government and pursuant to Human Rights Council resolution 37/5, which mandates the Independent Expert to undertake country visits to assess the human rights situation of persons with albinism.

2. The Independent Expert held meetings in Johannesburg, Pretoria, Richards Bay and Durban, in the provinces of Gauteng and KwaZulu-Natal. She met with government officials representing the Department of International Relations and Cooperation, the Department for Women, Youth and Persons with Disabilities, the Department of Social Development, the Department of Justice and Constitutional Development, the Department of Basic Education, the Department of Higher Education and Training, the Department of Health, the Department of Sports, Arts and Culture, the Department of Planning, Monitoring and Evaluation, the Department of Public Service and Administration, the Department of Home Affairs, the Department of Cooperative Governance and Traditional Affairs, the Department of Correctional Services, Statistics South Africa, the South African Police Service, the National Prosecuting Authority, the State Security Agency and the South African National Defence Force. She also met with the Law Reform Commission, and with “chapter 9” institutions – specifically with representatives of the South African Human Rights Commission, the Commission for the Promotion and Protection of the Rights of Cultural, Religious and Linguistic Communities, and the Commission for Gender Equality.

3. The Independent Expert held a consultation with over 40 leaders of civil society organizations serving persons with albinism, from six provinces, nearly all of whom were persons with albinism. Through that consultation,<sup>1</sup> she obtained first-hand knowledge about challenges faced by persons with albinism in South Africa. She provided technical support for the process of developing a national action plan on the promotion and protection of human rights for persons with albinism in South Africa.

4. She also met with offenders convicted of crimes against persons with albinism, representatives of faith-based organizations, traditional healers, academics and researchers. She visited Prinshof School, for persons with visual impairments, and also met with around 50 young learners with albinism from various parts of the country at a mentorship workshop held in Durban.

5. The Independent Expert sincerely thanks each person and entity that made time to meet with her and share their experiences. She extends her utmost gratitude to the Government of South Africa for its excellent cooperation. She also thanks colleagues at the Office of the United Nations High Commissioner for Human Rights (OHCHR) Regional Office for Southern Africa, in Pretoria, for their excellent support and efforts in making her visit a productive one.

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<sup>1</sup> Organized with the help of the University of Pretoria and the Office of the United Nations High Commissioner for Human Rights (OHCHR).

## II. Background

6. South Africa is the largest country in southern Africa, with a population of around 57.73 million.<sup>2</sup> The country comprises nine provinces: Eastern Cape, Free State, Gauteng, KwaZulu-Natal, Limpopo, Mpumalanga, Northern Cape, North West, and Western Cape. Around 51 per cent of the population are women, and about 29 per cent of the population are aged 15 years or less, while 8.5 per cent are aged 60 and above.

7. South Africa is a multi-ethnic society which encompasses a variety of cultures, languages and religions. It has 11 official languages: nine African languages, and Afrikaans and English. According to Statistics South Africa, around 80.9 per cent of the population identify as black African, 8.8 per cent as coloured, 2.5 per cent as Indian or Asian, and 7.8 per cent as white. South Africa is often known as the “rainbow nation”, on account of its diverse ethnic groups.

8. The economy of South Africa is the second-largest in Africa and the thirty-third-largest in the world.<sup>3</sup> In recent years, slow economic growth has increased the poverty rate, from 16.8 per cent to 18.8 per cent.<sup>4</sup> Unemployment remains a key challenge, standing at 27.6 per cent in the first quarter of 2019; the rate is even higher among youths, at around 55.2 per cent. South Africa has one of the highest inequality rates in the world. As at 2015, the richest 10 per cent of the population held around 71 per cent of net wealth, while the bottom 60 per cent of the population held 7 per cent of net wealth.<sup>5</sup> Furthermore, inequalities appear to be endemic and passed down from generation to generation, with little change over time.

9. South Africa has had a turbulent history marred by the scourges of racial discrimination, marginalization and inequality as a result of the apartheid era, which ended in 1994. The consequences of this era are still tangible in South African society.

## III. Persons with albinism

10. Albinism is a relatively rare, non-contagious, genetically inherited group of conditions 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 any or all of the skin, hair or eyes. Persons with albinism often appear pale in comparison to members of their family and their community. In order for a person to be affected by albinism, both parents must carry the gene and, in that case, there is a 25 per cent chance that a child will be born with albinism at each pregnancy. The frequency of albinism varies by geographic region, worldwide.

11. The most common and visible type is oculocutaneous albinism, which affects all of the skin, hair and eyes. Nearly all human rights issues relating to albinism reported to date have been linked to the oculocutaneous form of albinism. A key physiological consequence of albinism is visual impairment, in nearly all cases. The severity of impairment varies from person to person. The other key physiological consequence is vulnerability to skin cancer, which is fatal when left untreated. Skin cancer accounts for a significant number of deaths of persons with albinism, particularly in sunny climates such as in most of the African region. Persons with albinism are commonly recognized as persons with disabilities. They have also been recognized by the Committee on the Elimination of Racial Discrimination as persons facing racial discrimination on the ground of colour.<sup>6</sup> Racial discrimination can occur on the basis of colour, even among those of the same race, descent, and national and ethnic origin as those who persecute them.

<sup>2</sup> See [www.statssa.gov.za/publications/P0302/P03022018.pdf](http://www.statssa.gov.za/publications/P0302/P03022018.pdf).

<sup>3</sup> See <https://www.cia.gov/library/publications/the-world-factbook/geos/sf.html>.

<sup>4</sup> See [www.worldbank.org/en/country/southafrica/overview](http://www.worldbank.org/en/country/southafrica/overview).

<sup>5</sup> Ibid.

<sup>6</sup> See CERD/C/ZAF/CO/4-8.

12. In sub-Saharan Africa, the reported frequency of albinism ranges from 1 in 5,000 to 1 in 15,000, with prevalence rates of 1 in 832 to 1 in 1,000 for selected populations in the southern Africa region. It should be noted that these figures are outdated. New data is necessary to reflect disaggregation by gender, age, and type of albinism.

13. The Independent Expert's visit took place at an opportune time. It was national albinism awareness month. During the visit, the Government faced challenges on several fronts, which included pockets of unrest and protests erupting in the country, as well as large-scale problems around gender-based violence, femicide and xenophobia. In this context, the President, Cyril Ramaphosa, held a dialogue on gender-based violence, in which he specifically referenced the killing of persons with albinism as an added challenge for the Government. The Independent Expert welcomed the statement by the President, as well as past and ongoing initiatives that have brought the plight of persons with albinism to the fore in South Africa.

#### **IV. Legal and institutional framework**

14. In spite of the fractured history of the apartheid era, South Africa has progressed significantly in terms of commitments to human rights law and standards. It has ratified a number of core human rights treaties, including the International Covenant on Civil and Political Rights, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of the Child. It has also ratified the Convention on the Rights of Persons with Disabilities.

15. In April 2019, South Africa signed the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, aiming to ratify it at the end of 2019. The Protocol particularly mentions persons with albinism and includes reference to harmful practices, covering the various forms of harmful practices faced by persons with albinism in the region.

16. At the national level, South Africa has adopted an impressive array of legislation concerning the rights of persons with albinism. These include the Constitution, of 1996, which is one of the most progressive in the world, with its wide-ranging Bill of Rights that prohibits discrimination on several grounds, including race, colour, sexual orientation, disability and culture. The Promotion of Equality and Prevention of Unfair Discrimination Act 2000 and the Employment Equality Act 1998 are both aimed at promoting equality and eliminating discrimination, including for persons with disabilities, which includes persons with albinism. The Employment Equality Act gives recognition to affirmative action measures to redress past inequalities and inequities. High courts and magistrates' courts are designated as equality courts to hear cases of unfair discrimination, harassment and hate speech.

17. The White Paper on the Rights of Persons with Disabilities, of 2015, was approved by the Cabinet, as the first step towards incorporating the Convention on the Rights of Persons with Disabilities into national legislation.<sup>7</sup>

18. Regarding the violence and transborder elements of ritual killings of persons with albinism, the Criminal Procedure Act (Act No. 51 of 1977), the Legal Aid South Africa Act (Act No. 39 of 2014) and the Prevention and Combating of Trafficking in Persons Act (Act No. 7 of 2013) are generally adequate. The latter has a broad definition of trafficking and sets out trafficking-related offences, with harsh penalties. The Independent Expert is particularly pleased to note that the Prevention and Combating of Trafficking in Persons Act covers the trafficking of body parts, and not just trafficking of persons and organs. This is an important provision in the context of the type of ritual attacks faced by persons with albinism.

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<sup>7</sup> The White Paper builds on the objectives of the Integrated National Disability Strategy of 1997.

19. Moreover, there is a National Intersectoral Committee on Trafficking in Persons – comprised of numerous representatives from various departments, including the Department of Justice and Constitutional Development, the Department of Health, the Department of Home Affairs, the Department of International Relations and Cooperation, the South African Police Service and the National Prosecuting Authority, among others – which leads the implementation and administration of the Act. The National Policy Framework on Trafficking in Persons was passed in 2019 to guide an integrated approach to combating trafficking in persons and related matters. Provincial task forces on trafficking in persons are also operating throughout the country.

20. Regarding inclusive education, there are several legislative and policy instruments in place. These include the South African Schools Act (Act No. 84 of 1996); Education White Paper 6: Special Needs Education – Building an Inclusive Education and Training System; the Protocol for the Management and Reporting of Sexual Abuse and Harassment in Schools; and the Policy on Screening, Identification, Assessment and Support, of 2014, within the Department of Basic Education.

21. The National Action Plan to Combat Racism, Racial Discrimination, Xenophobia and Related Tolerance, of 2019, and the National Social Cohesion Strategy, of 2012, provide crucial frameworks within which the rights of persons with albinism can be fully realized.

22. The Constitution provides, in its chapter 9, for various institutions to strengthen constitutional democracy. These bodies are independent, impartial, and accountable to the National Assembly, where they have to report on their activities and performance annually. The “chapter 9” institutions, along with an independent judiciary, contribute to a normative framework under which compliance with international human standards and constitutional imperatives is mandatory.

## V. National Development Plan

23. The overarching framework on development and human rights issues is the country’s National Development Plan, with its vision of eliminating poverty and reducing inequality by 2030. The Plan, adopted in 2013, aligns with the Sustainable Development Goals, on which the Independent Expert bases her thematic and country reports. It focuses on development and human rights, and entails, for the Government, consecutive five-year plans as part of the Medium-term Strategic Framework. Currently, there are 14 broad priority areas in the Medium-term Strategic Framework, which are related to education, health, safety and security, economic growth and employment, skills development, infrastructure, rural development, human settlements, local government, the environment, international relations, the public sector, social protection, and nation-building and social cohesion. Updates and progress on these areas are required monthly, quarterly or annually, and there are budgetary allocations for implementation.

24. The Independent Expert’s findings and recommendations in the present report should be read through the lens of the Sustainable Development Goals, with their central pledge to leave no one behind, which also underpins the goals of the National Development Plan. The Independent Expert emphasizes that development initiatives require that specific attention be paid to groups that have been left the furthest behind in the gains made over the past 25 years.<sup>8</sup>

<sup>8</sup> See A/73/181.

## A. Main findings

### Positive and exemplary initiatives

25. The Independent Expert notes a myriad of positive initiatives undertaken by South Africa. In addition to comprehensive legislative frameworks, the adoption of the Ekurhuleni Declaration on the Rights of Persons with Albinism, of 2013, was a key achievement. The Ekurhuleni Declaration was the product of the first national conference on albinism, through which the Government brought together over 250 delegates with albinism, including 90 children from all nine provinces, to focus on the elimination of discrimination against persons with albinism. The Ekurhuleni Declaration consists of 40 articles which call for equality for persons with albinism, children's rights in education, and the correction of erroneous beliefs, myths and superstitions. It reiterates the standards of the Convention on the Rights of Persons with Disabilities and of national laws protecting persons with disabilities. It calls for self-representation, positive language, reducing the costs of living for persons with albinism, improving access to health care, providing reasonable accommodation such as adaptive devices, and strengthening the protection of persons with albinism against killings and attacks. The conference participants included government representatives, members of civil society organizations representing persons with albinism, academics, artists and poets, among others. The Ekurhuleni Declaration prompted much-needed dialogue and awareness in the country and laid the groundwork for subsequent government and civil society engagement on the issue. This included a round table on albinism in 2018, and support for programmatic initiatives on albinism at the provincial level, although many of these have been ad hoc.

26. The departments taking the lead on initiatives on albinism are the Department for Women, Youth and Persons with Disabilities and the Department of Social Development. They work with other crucial agencies including the Department of Justice and Constitutional Development, the South African Police Service, the vulnerable groups unit at the Department of International Relations and Cooperation, and others overseeing health, education, sports, the arts and culture. The Independent Expert noted that the close collaboration between the Department of Social Development, the Department for Women, Youth and Persons with Disabilities and civil society organizations working for the human rights of persons with albinism, particularly the Albinism Society of South Africa, had a positive impact on the awareness at the national level of issues related to persons with albinism. However, she notes that the interdepartmental work on issues related to disabilities and albinism needs to be coordinated in a consistent manner, with clear focal points who can ensure the integration and sustainability of engagement on issues related to persons with albinism.

27. The Government's designation of September as Albinism Awareness Month is also positive. Additionally, the national commemoration of International Albinism Awareness Day, on June 13, and various undertakings to highlight albinism through sports, arts and culture, are commendable, as these have been instrumental in educating and raising public awareness about albinism.

28. Additionally, numerous awareness-raising events have been held, including through public funding initiatives of the Albinism Society of South Africa. Albinism awareness has been supported through the arts and culture, such as the play *Mama, I Want To Be the Black That You Are*, mentorship programmes, and soap operas with characters with albinism on State-owned television, among other things. Representation at government round tables has also been accorded to individuals with albinism, including models, actors and other public figures.

29. A bill on preventing and combating hate crimes and hate speech is currently before Parliament, and specifically criminalizes hate speech against persons with albinism. The incorporation of the Convention on the Rights of Persons with Disabilities into national legislation is also promising.

30. In terms of violence and attacks, prevention measures have been championed by the South African Police Service, associations of traditional healers, religious leaders, and a dynamic array of civil society organizations representing persons with albinism. The police

and the Albinism Society of South Africa have a memorandum of understanding to protect the gravesites of persons with albinism from desecration and robbery of remains. In terms of judicial remedies and access to justice in cases of attacks against persons with albinism, South Africa has been exemplary as compared to several other countries in the region that have records of attacks against persons with albinism.<sup>9</sup> Court officials and prosecutors have been exposed to harrowing cases, with little or no trauma counselling, with most expressing personal commitment to ensuring justice for victims and their family members. Case proceedings have been publicly shared, as a form of deterrence, with the police embarking on awareness-raising programmes in communities where attacks have occurred. The court judgments from these cases have been detailed in the findings of fact.<sup>10</sup> Such facts have informed the Independent Expert as well as prosecutors across the region about the patterns of these attacks, in a manner that, in turn, informs the advocacy and protection measures in the Regional Action Plan on Albinism in Africa.<sup>11</sup>

31. While these positive initiatives are commendable, challenges and obstacles to the enjoyment of human rights remain for persons with albinism. However, the Government has identified many of these challenges, and steps have been initiated to address some of these. The Independent Expert promotes a “twin-track” approach to the situation of persons with albinism. The general approach is active integration of the issue into relevant sectors, such as disability, health, education, gender, and migrants, among others. The specific approach is the carrying out of particular concrete measures to address pressing issues including security. In this regard, general and specific measures are outlined in the recommendations, and can form part of the compendium of measures that can be included in a national action plan on albinism. Most of these measures are relatively inexpensive, yet will be life-saving for persons with albinism in South Africa, thus making the pledge to “leave no one behind” in the Sustainable Development Goals and the National Development Plan a reality for them.

## B. Challenges

### (a) Data and statistics

32. A major challenge is the absence of concrete data and statistics relating to persons with albinism. Around 85 per cent of births are registered in South Africa, according to World Bank data in 2012.<sup>12</sup> During the presentation made by South Africa for its third universal periodic review, concerns were raised about obstacles to birth registration for persons with albinism.<sup>13</sup>

33. At the time of the Independent Expert’s visit, there were no official disaggregated data on disability and thus no such data on persons with albinism. Academic surveys estimate a prevalence of around 1 in 3,900 to 1 in 4,000 persons, with certain ethnic groups and communities in South Africa having as high a prevalence as 1 in 832 persons with the condition. Various genetic and epidemiological surveys report a higher prevalence than reported averages of albinism in southern Africa as whole.<sup>14</sup>

34. In its concluding observations on South Africa issued in 2018, the Committee on the Rights of Persons with Disabilities expressed its concerns about the lack of accurate and comprehensive data on persons with disabilities in all sectors, and on the non-inclusion of disability concerns in the monitoring indicators for the implementation of the Sustainable

<sup>9</sup> “United Nations rights expert welcomes conviction of mastermind in murder of woman with albinism”, available at [www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=21284&LangID=E](http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=21284&LangID=E).

<sup>10</sup> *L. v. Mandla Lucky Mabuza and Lindokuhle Sisifo Khumalo, S. v. Siyabonga Sikhulile Gwala and S. v. Bhekukufa Lindeni Gumede*.

<sup>11</sup> See [www.ohchr.org/EN/Issues/Albinism/Pages/AlbinismInAfrica.aspx](http://www.ohchr.org/EN/Issues/Albinism/Pages/AlbinismInAfrica.aspx).

<sup>12</sup> See <https://data.worldbank.org/indicator/sp.reg.brth.zs>.

<sup>13</sup> See A/HRC/36/16.

<sup>14</sup> See [www.firah.org/upload/l-appel-a-projets/projets-laureats/2018/albinisme/rl-en-albinisme.pdf](http://www.firah.org/upload/l-appel-a-projets/projets-laureats/2018/albinisme/rl-en-albinisme.pdf).

Development Goals. The absence of statistical data and of its dissemination to persons with disabilities in all accessible formats<sup>15</sup> is worrying. The Independent Expert learned that Statistics South Africa is currently in the process of harmonizing indicators or measures on disability across all government departments, in order to improve data.

35. The Independent Expert was unable to obtain specific data on the overall number of cases involving crimes against persons with albinism. However, she noted that a database created by the police was aimed, among other objectives, at noting cases involving persons with disabilities, and had the potential to indicate the type of disability or impairment concerned, including albinism. The Independent Expert hopes that the database will be operational soon, as it will be crucial for recording cases of violence against persons with albinism, and for protection measures including identifying locations and cases where persons with albinism are at risk of violence.

36. South Africa has the opportunity to alleviate the problems related to lack of data on persons with albinism, in the forthcoming census in 2021. The Independent Expert recommends the inclusion of a question on persons with albinism using the format proposed by the Washington Group on Disability Statistics,<sup>16</sup> as was done in the recent census in Kenya. Such data should be used securely and be safeguarded against misuse, in light of the vulnerability of persons with albinism to harmful practices including attacks, killings, trafficking and grave robberies.

**(b) Attacks and killings**

37. The Independent Expert was informed of a number of cases of attacks and extreme human rights violations against persons with albinism, most of which had occurred in the past five years. These included the murder of Gabisile Shabani,<sup>17</sup> a 13-year-old girl with albinism, and her 1-year-old nephew, in Mpumalanga. In June 2016, a 12-year-old boy survived trafficking and attempted sale in eManguzi, KwaZulu-Natal, before being found some kilometres away from the border of Mozambique. The woman who had attempted to sell the boy to a traditional healer was arrested. Also in 2016, a 4-year-old boy, Maneliswa Ntombela (Mlungu), was kidnapped in Richards Bay and is yet to be found.<sup>18</sup>

38. The Independent Expert also received the case files for Thandazile Mpunzi,<sup>19</sup> brutally murdered by a church bishop, who was also a traditional healer, with the help of three young men, one of whom was courting her as a ruse to kill her for ritual purposes – also known as a *muthi* killing.<sup>20</sup>

39. To date, civil society organizations representing persons with albinism have reported 11 cases, of murder or attack, in South Africa, the majority of which have occurred over the last few years. Although these cases seem few compared to in neighbouring countries, the Independent Expert stresses that, given the small number of persons with albinism, and their minority status in quantitative terms, an attack against one person is a significant threat to all.

40. Moreover, the absence of data should not be interpreted as an absence of cases. There are no organizations that systematically monitor or record cases. Nearly all civil

<sup>15</sup> See CRPD/C/ZAF/CO/1.

<sup>16</sup> See [www.washingtongroup-disability.com/people-albinism-included-washington-group-questions](http://www.washingtongroup-disability.com/people-albinism-included-washington-group-questions).

<sup>17</sup> This case was the subject of discussions with the Government and other stakeholders. It is known in the public arena, due to wide media coverage and ongoing investigations.

<sup>18</sup> See <https://actiononalbinism.org/assets/1558461982635eqw12oo66t.pdf>.

<sup>19</sup> The Independent Expert had sent a joint allegation letter to the Government of South Africa on 3 September 2015 concerning this case (ZAF 2/2015), which is available at <https://spcommreports.ohchr.org/TMResultsBase/DownloadPublicCommunicationFile?gId=18721>.

<sup>20</sup> *Muthi* means traditional African medicine or magical charms. The phrase “*muthi* killings” is generally used to refer to the use of body parts for medicine or charms in southern Africa. See [www.underthesamesun.com/sites/default/files/Albino%20Killings%20are%20Muti%20Killings%20-%20English.pdf](http://www.underthesamesun.com/sites/default/files/Albino%20Killings%20are%20Muti%20Killings%20-%20English.pdf).



society organizations representing persons with albinism are volunteer-driven, with no operational funding. While some of these groups, particularly in KwaZulu-Natal, reported further cases to the Independent Expert during the visit, the absence of sufficient information means these are only anecdotal reports. However, such reports are indicative of wider problems which require an investigative analysis into the security situation for persons with albinism in the country – particularly in rural areas and border provinces – in order to better gauge the reality.<sup>21</sup> Studies on wider national challenges, such as gender-based violence and xenophobia, should factor in the compounded vulnerability to violence of women with albinism and of persons with albinism who are foreign nationals in the country, as they have not been spared from these systemic issues.

41. The right to life and security is a fundamental right of persons with albinism. Yet the reality for many persons with albinism is a life of fear and insecurity. The duty to protect the right to life requires States to take special measures of protection for persons in a situation of vulnerability whose lives have been placed at particular risk because of specific threats or pre-existing patterns of violence. This includes persons with albinism.<sup>22</sup> Many persons with albinism have reported that they continue to live in fear of attacks and harassment, regardless of where they reside in the country. However, the killings documented in the country have mainly been in Limpopo, Mpumalanga and KwaZulu-Natal. These “hotspots” are border provinces, leading many to believe that these attacks, most of which are spurred by manifestations of belief in “witchcraft”, are a foreign phenomenon imported and perpetrated by nationals of neighbouring countries. In the context of challenges around xenophobia in the country, the Independent Expert notes that the majority of apprehended and convicted perpetrators of these crimes are South African.

42. The cross-border element to these crimes, and the higher prevalence of albinism in the region, requires dedicated attention and action by the Southern African Development Community (SADC) as well as in the meetings of regional police chiefs. The Independent Expert urges the adoption of the SADC declaration on persons with albinism and calls for South Africa to assume leadership in this regard.

**(c) Discrimination and stigma**

43. Discrimination and stigma experienced by persons with albinism is best summarized by the names used for them in several official languages. The fact that many use these without a second thought and take them for granted is telling. Names such as *isishawa*, meaning a curse, and *inkawu*, meaning monkey, are some of the popular names for people with albinism. As one interlocutor commented: “If you are being referred to as a monkey, then your rights will not be easily protected since animals cannot have human rights. These names need to be eliminated as quickly as the word *kaffir* was for black South Africans.”

44. Civil society organizations representing persons with albinism can help in replacing these names with more dignified, humane and neutral variants for the official languages. The Independent Expert urged the Commission for the Promotion and Protection of the Rights of Cultural, Religious and Linguistic Communities to support this process. The Hate Speech Bill also provides an important avenue to humanize and effectively protect persons with albinism.

45. Discrimination also entails myths that persons with albinism are for *muthi*, or medicine, and that their body parts can be used in witchcraft-related rituals to generate wealth and fortune. There is a prevailing myth that persons with albinism do not die but disappear. Discrimination against persons with albinism also includes daily taunting, stares and harassment. While the intensity of this experience varies by community and region, it is not uncommon in South Africa for people to spit on the chest of a person with albinism, upon seeing such a person, as a way of protecting themselves from having a future child with albinism. Family members and intimate partners of persons with albinism sometimes

<sup>21</sup> See [www.ohchr.org/Documents/Countries/MW/StudyInvestigationsProsecutionCasesMarch2018.pdf](http://www.ohchr.org/Documents/Countries/MW/StudyInvestigationsProsecutionCasesMarch2018.pdf).

<sup>22</sup> See Human Rights Committee, general comment No. 36 (2018) on the right to life.

face public ridicule, and persons with albinism are often socially excluded from various aspects of community life. Many persons with albinism find it difficult to have normal, healthy and sustained personal and romantic relationships, due to discrimination. Often, pressure from family members makes such relationships untenable. Given the importance of social relationships for health and well-being, it is unsurprising that the Independent Expert received many reports describing psychosocial issues faced by persons with albinism.

46. Discrimination has a damaging cumulative effect on the psychosocial health and self-esteem of many persons with albinism, some of whom reported a fear of going out in public because of mockery, rejection and discrimination. This fear is further compounded by ongoing personal safety and security issues.

47. To entrench dignified names for persons with albinism, and to speed up changes to mindsets and to misbeliefs about persons with albinism, sensitization is crucial, which needs to include mass awareness-raising efforts at the grass-roots level for a minimum period of two years. This is based on best practices. Such sensitization should be wide in scope, and continuous – not ad hoc. It should also target sectors such as education and health, use local languages, and involve persons with albinism.

**(d) Health**

48. Persons with albinism are highly vulnerable to skin cancer, which is a primary cause of early death in most persons with albinism. Though South Africa has a national cancer strategy, skin cancer is not one of its area of focus. However, it is laudable that the Government has added sunscreen lotions to its list of essential medicines, making the product available and free of charge to persons with albinism. Nonetheless, persons with albinism are concerned about consistency in availability, and about accessibility – particularly in rural areas and where people have to travel distances to reach supply points. There were also reports about the quality of these products. Based on best practices, particularly practices in Kenya, persons with albinism should choose the sunscreen that works best for them through consultations and focus groups that are familiar with the diverse climate conditions in the country. The generally accepted sunscreen could be procured, or produced locally through a social enterprise employing persons with albinism and/or other disabilities.<sup>23</sup>

49. In rural areas, medical specialists such as dermatologists do not have enough training about albinism, and some have been biased against clients with albinism. Accessing the right optical device is also problematic, as there are often some that are not available in the country. There is also a lack of specialists in ophthalmology and optometry who are trained in low vision.

50. Some persons with albinism reported having access to “care packs”, which included sun-protective clothing and sunglasses, among other health-related items. This is a positive initiative, which should be evaluated, and scaled up with the help of civil society, especially to poorer communities which have systemic barriers to accessing goods and services.

51. The psychosocial health of persons with albinism was regularly raised, in relation to frequent humiliation and discrimination – from society at large, from health workers, at schools, at churches and in nearly all other spheres of society. As was aptly put in one study that remains relevant: “It is very difficult to nurture social relationships despite a non-normative body and to construct a viable and life-sustaining sense of self while constantly being rejected by others.”<sup>24</sup> This is particularly the case for conditions such as albinism, which are misunderstood.

<sup>23</sup> See A/HRC/37/57/Add.1.

<sup>24</sup> C. Baker, Patricia Lund, Julie Taylor and Richard Nyathi, “The myths surrounding people with albinism in South Africa and Zimbabwe”, *Journal of African Cultural Studies*, vol. 22, No. 2 (2010), pp. 169–181.

52. The cumulative effect of social exclusion takes a toll on persons with albinism and leads to suicidal tendencies and drug abuse. Medical professionals should equip the parents of children with albinism – right from birth – with accurate knowledge about the condition. Information on albinism should be incorporated into all curricula for the training of health and education practitioners, across the country. Mothers of children with albinism should also be trained about albinism, as they often do not get this information from the health system. They too need psychosocial support and counselling, as they often encounter stigma related to albinism.

53. Civil society organizations that support persons with albinism should be empowered and supported to carry out most of these measures to disseminate knowledge on albinism both to the public and to medical professionals. Entry points include training modules on disabilities, on rare conditions and diseases and on skin conditions, and primary health-care services. Inclusion in team sports at the primary education level is also important in supporting persons with albinism in their development of healthy social relationships, a positive self-image and self-acceptance – all of which are jettisoned when facilities restrict equal competition and contribute to psychosocial and mental health issues.

**(e) Education**

54. A major challenge to access to education for persons with albinism is a lack of reasonable accommodation, that is, necessary adjustments, needed in a particular case, to ensure to persons with disabilities the exercise of their human rights and freedoms on an equal basis with others.<sup>25</sup> Reasonable accommodation measures in schools, for persons with albinism, include the provision of adaptive as well as assistive devices, the placing of persons with albinism at the front of the class, adjustments to uniforms so that they are sun-protective, permission to wear wide-brimmed hats, accommodation in sporting activities, and extra time on tests and exams, among other measures. These are often lacking in mainstream schools, although there are some positive reports on this matter. It seems that such measures of reasonable accommodation are implemented unevenly across the country and are thus unreliable. Consequently, some persons with albinism opt to attend special schools for persons with visual impairments. However, at special schools, resources, assistive devices and teacher awareness about how to provide reasonable accommodation are not always available, especially in poorer communities.

55. According to the Department of Basic Education, there were 279 learners with albinism enrolled in special schools in Gauteng, 153 in KwaZulu-Natal, 138 in Limpopo, 4 in Mpumalanga, 3 in Northern Cape and 67 in Western Cape. As regards learners with albinism enrolled in mainstream schools, there were 216 in KwaZulu-Natal, 182 in Limpopo, 32 in Mpumalanga and 11 in Northern Cape, with no data available for Gauteng or Western Cape. There appeared to be no real discrepancy between the number of learners with albinism in special schools and the number in mainstream schools.

56. Avoidance of long walks in the sun, and security, were often cited as other key reasons why persons with albinism attend special schools, which are often boarding schools. These schools tend to have gated perimeters with dedicated security personnel, among other protection measures. However, some who need these schools, such as those living in the midlands of KwaZulu-Natal, a province where attacks have been reported, are not in close proximity to them. Security arrangements at some of these schools are not sufficient, and one of the best special education schools, Prinshof School, for persons with visual impairments, is situated in a highly insecure part of Pretoria. Security is a non-negotiable measure for children, especially those with disabilities, who are at risk of various forms of attack.

57. Bullying of learners with albinism was reported both in integrated, or mainstream, schools (known in South Africa as “ordinary” schools), and in special schools. It appears to be worse in ordinary schools, and learners often opt to attend special schools in order to escape bullying. Children of mothers with albinism have also been subjected to bullying in

<sup>25</sup> See the Convention on the Rights of Persons with Disabilities, art. 2.

schools. It is important not to normalize bullying as “what children do”, as the effects on learners with albinism are compounded. The discrimination they face is often not confined to one environment, but permeates nearly every sphere of society. Introducing the topic of albinism and persons with the condition into school subjects, through courses on life skills, diversity, human rights and civic responsibility, from an early age, will likely reorient learners away from the cultural mystification of albinism and can mitigate bullying.

58. Some parents stated that they did not send their children with albinism to school as they believed, mistakenly, that they were less intellectually capable, and unable to compete favourably with other children. In addition, children with albinism are more isolated from activities that stimulate cognitive and perceptual motor development, because they are often unable to take part in outdoor activities and tasks. At school, poor vision, skin problems, social exclusion and lack of appropriate accommodation impede their progress.

59. South Africa has, however, made considerable progress in enhancing access to education. The Government announced fully subsidized post-school education and training for students from low-income families over a five-year period.<sup>26</sup> Nevertheless, profound inequalities continue to undermine economic, social and cultural rights.<sup>27</sup> In 2016, 20 per cent of the national budget was allocated to education.<sup>28</sup> However in 2018, budget cuts were made,<sup>29</sup> which may further worsen inequalities and increase dropout rates among schoolchildren.

60. There are also disparities in terms of access to quality education and educational resources by all ethnic groups. The current educational programmes have been gradual in eliminating racial and xenophobic tensions and barriers.<sup>30</sup> As the prevalence of albinism is usually higher within some ethnic groups and indigenous groups, some children with albinism may face intersecting discrimination in their access to education. The Committee on the Rights of the Child has also noted persistent wide disparities in access to quality education, according to economic status, race and geography.

61. By 2018, the Government had not implemented key aspects of the 2001 national policy to provide inclusive education for all children with disabilities, nor had it adopted legislation to guarantee the right to inclusive education. However, it continued to implement the Screening, Identification, Assessment and Support Policy designed to ensure that children with disabilities were provided with full support when accessing education. The majority of the Government’s limited budget for learners with disabilities continued to be allocated to special schools rather than inclusive education.<sup>31</sup>

62. In October 2018, the Government said it would declare special schools for children with disabilities as no-fee schools, which the Independent Expert commends. However, many learners with disabilities have to study far from their families and communities, in schools that are isolated and lack properly trained staff.<sup>32</sup>

63. In a workshop for over 50 learners with albinism from various provinces, the Independent Expert heard of challenges faced by learners wanting to attend mainstream schools but forced to attend special schools. There is an ongoing debate about the value of specialized schools vis-à-vis mainstream schools for learners with albinism. This debate is not only a reflection of pre-existing differences between both forms of education, but is also due to issues of security, namely reported attacks against persons with albinism. The Independent Expert notes that in light of the security situation faced by learners with

<sup>26</sup> See E/C.12/ZAF/CO/1.

<sup>27</sup> Amnesty International Annual Report 2017/18, available from [www.amnesty.org/en/latest/research/2018/02/annual-report-201718/](http://www.amnesty.org/en/latest/research/2018/02/annual-report-201718/).

<sup>28</sup> See CERD/C/ZAF/CO/4-8.

<sup>29</sup> Human Rights Watch, “South Africa: events of 2018”, available at [www.hrw.org/world-report/2019/country-chapters/south-africa](http://www.hrw.org/world-report/2019/country-chapters/south-africa).

<sup>30</sup> See E/C.12/ZAF/CO/1.

<sup>31</sup> Amnesty International Annual Report 2017/18.

<sup>32</sup> See CRPD/C/ZAF/CO/1.

albinism and their family members, the decision is to be left to parents and children to choose what is in the best interests of the child. Equally important is the need to properly equip and resource both types of environments to adequately respond to persons with albinism, so that there is a real choice for the learner. The majority of persons with albinism who met with the Independent Expert appeared to favour ordinary schools, which better prepared them for university and “the real world”. Some stated that special schools tended to isolate learners who may already be experiencing difficulty with social exclusion, and may not provide the necessary curricula that learners with albinism require.

64. The above-mentioned workshop was part of the #ICanBe campaign – a partnership between the Department of Social Development and the Albinism Advocacy for Access Foundation which brings together learners and mentors with albinism. The Independent Expert commends these programmes and encourages similar workshops in all provinces.

65. Education support at higher education or tertiary institutions, provided by disability units, was often reported as a positive experience by persons with albinism. These units could benefit from more resources and more consistency in their delivery of services and support.

**(f) Employment and adequate standard of living**

66. Persons with albinism, in common with other persons with disabilities, face extensive discrimination and marginalization when it comes to accessing employment opportunities. The State has had difficulty in achieving the 2 per cent employment target for persons with disabilities. The private sector has experienced similar difficulties in achieving its self-set employment equity targets. When persons with disabilities have been hired, there has been a tendency to relegate them to low-ranking jobs; this has sometimes included outdoor jobs, with exposure to the sun, thereby increasing the risk of skin cancer. The lack of understanding about reasonable accommodation, in both the public and private sectors, has been a serious barrier to inclusion; the South African Human Rights Commission aims to change this, with its Toolkit for Employers. For persons with albinism, the situation is exacerbated by there being little accurate knowledge about the condition, and widespread myths. The compounded issue of aversion on the grounds of appearance and/or race, combined with visual impairment, influences the ways in which employers and co-workers regard persons with albinism.

67. The disability grant, provided to all persons within a particular (low-) income bracket who qualify through a means test as well as an impairment test based on a medical model, exists to mitigate poverty for persons with disabilities. Persons with albinism reported that they had been disqualified from that grant for failure to meet the requirements of the impairment test. Due to the variation in levels of vision impairment among persons with albinism on the one hand, and to lack of knowledge of the condition on the other, the grants have been issued to persons with albinism across the country in a non-uniform way. The Independent Expert urges the Government to move away from the medical approach to disability that is entrenched in the grant-issuing processes and to standardize provision of the grant to all persons with albinism.

68. As a result of the challenges in accessing adequate education, persons with albinism face significant difficulties in getting employment indoors which could provide them with protection from skin cancer and with an adequate living. This cycle often ends up in poverty and early death.

**(g) Access to justice**

69. While South Africa has been exemplary in its response to reported cases of attack in recent years, some challenges to access to justice for victims remain. Sensitization of law enforcement officers within the country, and at the borders, on issues concerning the insecurity faced by persons with albinism, and on how to respond to persons with disabilities, is necessary. Long delays in DNA analysis have reportedly threatened the rapid determination of these cases. Lack of public knowledge about legal procedures in communities affected by attacks has prompted, and led to threats of, mob violence against

accused persons, who should be protected from extrajudicial attacks and need to be prosecuted in a court of law.

70. The Independent Expert noted that many persons with albinism lacked knowledge of their human rights and the relevant international and national legislation, that they could have recourse to where violations had occurred. The absence of such knowledge and capacity is worrying and is a major barrier to accessing justice. The round table and meeting of the task force, hosted by the Department of Social Development, in addition to other initiatives such as annual training at the Centre for Human Rights at the University of Pretoria, have strong potential to remove this barrier.

71. South African authorities face difficulties in identifying and apprehending perpetrators of attacks, notably when these are related to the cross-border trade in body parts of persons with albinism. Although the Trafficking Act exists, the Independent Expert is not aware of how many albinism cases have been prosecuted under this Act, despite the likelihood that the black market for ritual killings is continuing. Its implementation needs to be evaluated. In the case of Gabisile Shabani, for instance, the mutilated child with albinism was found in a shallow grave with several body parts missing, which are reportedly in Eswatini. A traditional healer from Eswatini was implicated in the crime, and to date the case is stalled – reportedly for technical reasons – and family members have not been able to bury the victim with dignity.

#### (h) Representation

72. Representation is crucial for social inclusion. In all relevant public processes and discourses – on disabilities, health and education, among others – it is important to make efforts to reach out not only to persons with disabilities, but also to those who have rarely been represented in such arenas. The Independent Expert notes that the Government has made commendable strides in this area.

73. Throughout the visit, the Independent Expert was very concerned at the inaccurate portrayal of persons with albinism in public discourse. These misrepresentations feed into the stigma and discrimination that persons with albinism experience on a daily basis. The Independent Expert urges the creative arts industry and the media to engage in responsible narratives by consulting widely in developing shows that are on television and radio, among other media, and to include persons with albinism in ordinary roles that highlight the positive contributions that they make to society as any other person in South Africa does. She also calls on all media personalities, particularly journalists who report on crimes against persons with albinism, to report on these cases sensitively and responsibly. This includes avoiding the use of dehumanizing names, and sensational reporting, and leaving out the alleged prices of body parts, which could incentivize perpetrators of attacks.

74. Some good practices to further enhance representation include appointing champions for albinism. This should include various persons with albinism of various ethnicities. It should also involve influencers with albinism using their platforms to raise awareness about the condition and to debunk myths and misbeliefs. The Independent Expert was pleased to watch a performance by persons with albinism, supported by the Department of Sports, Arts and Culture, entitled *Mama, I Want To Be the Black That You Are*, which gave a holistic portrayal of the struggles and pains experienced by persons with albinism. Renowned public influencers such as artists and models with albinism also met with the Independent Expert and provided insight on how they raise awareness by sharing widely their personal journeys.

75. Cultural events, and popular platforms showcasing the beauty of albinism as a part of diversity, help raise awareness in popular forums. These help to mitigate the “us versus them” narratives that are inadvertently produced through awareness-raising activities. They also help depict the lives of persons with albinism as “ordinary”, and to debunk myths, misbeliefs, prejudice or negative stereotypes about them.

76. The Independent Expert held a consultation with over 40 civil society organizations representing persons with albinism from six provinces including Eastern Cape, Gauteng, KwaZulu-Natal, Limpopo, Northern Cape and North West. From the consultation, a task force was formed to facilitate collective decision-making and advocacy. The task force,

with the help of government and other stakeholders, will develop a time-bound national action plan of concrete measures together with an implementation strategy to promote the enjoyment of human rights for persons with albinism. This is a best practice that is employed in neighbouring countries, as it unifies persons with albinism, and provides an avenue for government to concretely intervene in areas that persons with albinism themselves have identified as priorities.

77. The Independent Expert urges the Government not only to support the development of this national action plan, but also to fund its processes and, at the least, some of the priorities identified in it, as has been done in other countries in the region such as Kenya and Malawi. All current funding for civil society organizations representing persons with albinism should be revisited and equitably distributed to diverse national civil society groups serving persons with albinism, or reallocated to implement the strategies that will be proposed by the national action plan task force. This is crucial both to mitigate any fracture within the movement and to respond to priorities identified by *all* civil society serving persons with albinism.

78. The national action plan is linked to the Regional Action Plan on Albinism in Africa adopted by the African Union,<sup>33</sup> calling for measures to, inter alia, counter discrimination and combat attacks against persons with albinism. Though legislation and policies are positive initiatives, the Independent Expert sees the value of the national action plan as a compendium of concrete steps that are achievable in the short, medium and long term. The national action plan also helps to identify key stakeholders – including government and international organizations – that can work together with the albinism community in achieving the objectives set out in the plan.

79. The Independent Expert is pleased to note that the task force created during her visit has begun meeting and its members have begun consulting with one another. The Department for Women, Youth and Persons with Disabilities has hosted a meeting with the task force, and further meetings, possibly involving the Independent Expert, are planned for 2020. The Independent Expert is grateful for the government partnerships that have enabled these initiatives, and for the support received from the Centre for Human Rights.<sup>34</sup> She hopes that such partnerships can contribute to future implementation of the national action plan.

**(i) Other relevant issues**

*Harmful practices related to manifestations of belief in witchcraft*

80. As stated earlier, erroneous myths about albinism are common in South Africa, particularly in rural areas. The Independent Expert notes that any attempt to tackle harmful practices nationwide should also recognize – or at least discuss – harmful practices that are *muthi* killings or attacks related to belief in so-called witchcraft. Though “witchcraft” is not defined appropriately in national legislation, acts related to witchcraft are criminalized by the Witchcraft Suppression Act 1957. The Act has been under review by the South African Law Reform Commission for about 10 years.<sup>35</sup> The review process has been delayed, in part because of extant ambiguities around the term “witchcraft” and difficulties arising from the use of the term as a descriptor for harm arising from what is deemed as misuse of the craft of indigenous religions, traditional healers, and neopagan and Wiccan witchcraft practices. The Independent Expert notes that in several official languages that are not English, there are clear nuances in the terminology used to distinguish witchcraft from indigenous religions and traditional medicine, for which the English language provides no equivalent. Moreover, the polemics around what is “good” or “bad” witchcraft, often raised by neopagans, continue to highlight the need to delve into this issue with a focus on

<sup>33</sup> Endorsed in 2017 by the African Commission on Human and Peoples’ Rights and adopted in 2019 as official policy by the African Union Commission.

<sup>34</sup> At the University of Pretoria.

<sup>35</sup> See [www.justice.gov.za/salrc/ipapers/ip29-prj135-Witchcraft-2014.pdf](http://www.justice.gov.za/salrc/ipapers/ip29-prj135-Witchcraft-2014.pdf).

whether practices are harmful, where that harm exists, and how these harms should be criminalized or deterred. Considerations should not only be oriented to practitioners of so-called witchcraft and to their religious liberties and cultural rights, among other rights, but also to the rights of victims and those vulnerable to these types of attack, such as persons with albinism.

#### *Traditional healers*

81. Traditional healers have been both blamed and convicted in cases of attack against persons with albinism in South Africa. The Independent Expert was informed that these are not “real” traditional healers but charlatans and frauds who exploit the vulnerabilities of persons with albinism, and who use their craft as a source of income. The question, therefore, seems to be one of separating “wheat from chaff”, given the important role that traditional healers play in the South African cultural and spiritual landscape.

82. Traditional healers are an important part of South African history and culture. An estimated 200,000 healers are reportedly used by 80 per cent of the general population<sup>36</sup> – larger than the number of (allopathic) doctors. The Traditional Healers Organization reportedly has 78,000 members, who provide services to 27 million people in the country.

83. The Traditional Health Practitioners Act 2007 regulates the work of traditional healers. Pursuant to the Act, traditional healers need to be registered, to have attained a minimum level of qualifications and to be under the oversight of the Interim Council of Healers. A traditional healer could be a diviner (*sangoma*) or a person who calls on ancestral spirits, a herbalist (*inyanga*), a surgeon or a childbirth attendant. While the Act is meant to streamline the activities of healers, it is not effective in determining who is a genuine healer, from among the frauds and charlatans who are often linked to ritual attacks and killings of persons with albinism. The dilemma here is identifying who is who, and the Independent Expert raised this matter in her dialogue with over 50 traditional healers from the Traditional Healers Organization. While recognizing and protecting the inherent value of traditional healing, the Council still has the challenge of vetting healers and ensuring that bona fide practitioners are registered.

84. The secretive nature of the work of traditional healers makes this more difficult. Healers are required by law to be South African nationals, and it is reported that many who are not nationals are also practising. The lucrative nature of traditional healing generally, and with regard to harmful practices perpetrated against persons with albinism, facilitates monetization of the criminal acts of rogue and dangerous healers who are not detected by the authorities nor by their peers. The Independent Expert noted that some persons with albinism were also healers, and some modern doctors also served as traditional healers.

85. The Independent Expert notes the need to better monitor and oversee the work carried out in this sector through collaboration with healers’ associations to ensure that threatening activities are reported and that there is oversight over all healers, beginning with self-regulation, as suggested by the Traditional Healers Organization, or under a licence regime akin to that of other professionals offering a public health service who must be regulated to protect the public.

86. Much like traditional healers, the proliferation of religious actors in the country also includes charlatans and dangerous personalities who have manipulated their followers into engaging in ritual killings and attacks. The principal offender in the case of Thandazile Mpunzi<sup>37</sup> was a church leader, of the Zion Church, with hundreds of congregants. He was also a traditional healer who promised R25,000 to three young men for the body parts of the victim. Church leaders who make false claims and lead their congregants astray have also perpetuated dangerous myths about persons with albinism. It is important that self-

<sup>36</sup> “South Africa’s health: traditional healers in South Africa: a parallel health-care system”, available from [www.bmj.com/content/310/6988/1182.abstract](http://www.bmj.com/content/310/6988/1182.abstract).

<sup>37</sup> See the case files of *L. v. Mandla Lucky Mabuza and Lindokuhle Sisifo Khumalo, S. v. Siyabonga Sikhulile Gwala* and *S. v. Bhelukufa Lindeni Gumede* regarding the convictions of the perpetrators.



regulation be promoted for all faith-based leaders, whether traditional, hierarchical or independent, for more effective oversight of the services they offer to the public. As churches are required to register as not-for-profit organizations, penalties should be meted out, including revocation of not-for-profit status, public warnings, and prosecutions, among other measures, to protect the public from leaders who are a threat to congregants, and to vulnerable groups, including persons with albinism.

**(j) Gender-based violence and infanticide**

87. South Africa has a widespread issue of sexual and gender-based violence, with more than 40,000 cases of rape reported every year, and femicide rates five times higher than the global average. Much of this violence is underreported.<sup>38</sup> Women and girls with albinism are at particular risk of sexual and gender-based violence, due to a belief that having sexual intercourse with a person with albinism can cure HIV/AIDS. Women with albinism are more likely to fall prey to sexual violence than men.

88. Many children with albinism are brought up by single mothers, because the father of the child often leaves when the woman gives birth to a child with albinism. The single parent and the child often lead a life of poverty and exclusion, which can lead to tragic consequences such as infanticide.<sup>39</sup>

89. In rural areas of South Africa there is still a very strong suspicion, based on anecdotal reports, that babies with albinism are strangled at birth or left to die.

**(k) Migrants, refugees and asylum seekers**

90. The Independent Expert was informed of persons with albinism who had been forced to flee to South Africa, from conflicts and attacks in neighbouring countries. The relative safety of persons with albinism in South Africa has been adversely affected by discrimination.<sup>40</sup> In the context of challenges related to racism and xenophobia, migrant persons with albinism are at a heightened risk of being targeted, both for being a foreigner and for albinism. They are also likely to be living without basic social services, including proper housing. Around 30 per cent of undocumented migrant, refugee and asylum-seeking children are not enrolled in formal education.<sup>41</sup>

## VI. Conclusions and recommendations

91. The Independent Expert notes that in the spectrum of priorities that South Africa has under the Sustainable Development Goals, persons with albinism are some of the most marginalized people in the country, who bear the brunt of social and economic inequalities. Progress can be accomplished by implementing concrete measures, both in the form of specific interventions focused on the albinism community alone, for example providing relief and rehabilitation and putting an end to attacks and other extreme forms of human rights violations, and by integrating measures to support persons with albinism into broader measures for the fulfilment of human rights in long-term development initiatives.

92. In order to ensure that the gains to date are sustained and that their situation is not neglected by reason of the gaps identified above, the following recommendations should be implemented by the Government:

<sup>38</sup> Human Rights Watch, "South Africa: events of 2018".

<sup>39</sup> See [www.underthesamesun.com/sites/default/files/Waiting-to-disappear-International-and-Regional-Standards-for-the-Protection-and-Promotion-of-the-Human-Rights-of-Persons-with-Albinism-June2017.pdf](http://www.underthesamesun.com/sites/default/files/Waiting-to-disappear-International-and-Regional-Standards-for-the-Protection-and-Promotion-of-the-Human-Rights-of-Persons-with-Albinism-June2017.pdf).

<sup>40</sup> "'We thought we will be safe here': narratives of Tanzanian albinos in Kenya and South Africa", available at <https://pdfs.semanticscholar.org/7209/4034159376d1ba65f8a0f01da7bae73e6dad.pdf>.

<sup>41</sup> See E/C.12/ZAF/CO/1.

## A. Data and statistics

93. Include a question on albinism, with reference to the comment of the Washington Group on Disability Statistics on albinism, in the forthcoming census, in 2021, in order to securely compile disaggregated data.
94. Conduct a situational analysis to assess the situation of persons with albinism in the country, in both rural and urban areas, and include audits of current services.
95. Highlight the diversity within disability in all training modules, with particular reference to persons with albinism.

## B. Attacks and killings

96. Undertake a situational survey to identify gaps in security and protection measures for persons with albinism, particularly in rural and border towns.
97. Strengthen targeted measures to protect the rights of persons with albinism, particularly in rural areas, using the exemplary national action plans from Kenya and Malawi.
98. Provide support, including psychosocial and socioeconomic support, to victims of attacks and their family members.
99. Reinforce gravesites of persons with albinism to protect against grave robberies.
100. Conduct continuous awareness-raising in hotspots.
101. Incorporate a gender dimension and an intersectional lens in supporting mothers of children with albinism and women and girls with albinism.
102. Work with remorseful and willing convicted offenders in demystifying albinism and harmful practices linked to abuse of witchcraft and traditional practices (with consent from victims and their family members).
103. Complete the review of the Witchcraft Suppression Act with a goal of protecting equally the practitioners concerned, religious freedoms, cultural rights, and the potential victims of abuse of such craft, such as persons with albinism.
104. Promote and facilitate the self-regulation of religious bodies and traditional healers.
105. The South African Human Rights Commission should undertake investigative studies and research into the incidence of human rights violations against persons with albinism, including infanticide and human trafficking.
106. The police services database should be operational and should include data on cases relating to albinism.
107. Empower civil society organizations representing – and working for the enjoyment of human rights by – persons with albinism to monitor, document and report human rights violations perpetrated against persons with albinism.
108. Expedite the passage of the hate speech bill.
109. Advocate for a SADC protocol that can address cross-border issues such as the trafficking of body parts of persons as a consequence of *muthi*, or ritual, attacks.
110. Adopt the SADC declaration on persons with albinism.

## C. Right to health

111. Ensure that quality sunscreen is accepted, available and accessible in all provinces, paying attention to rural areas.
112. Integrate, into the training of health workers, modules on albinism as a disability.

113. Facilitate training for relevant specialists such as ophthalmologists and dermatologists, which should include modules on persons with albinism – particularly on the subjects of low vision and skin cancer prevention and treatment.

114. Consistently provide free specialized clinical assessments, particularly dermatological and ophthalmological services, to persons with albinism, including in rural areas, as well as providing glasses, adaptive and assistive devices.

115. Include skin cancer as a priority topic in the national cancer strategy.

116. Support and extend the reach of early intervention and detection programmes for skin cancer to all provinces, paying attention to rural and isolated areas.

#### **D. Education**

117. Consistently implement inclusive education by increasing resources at “ordinary” and special schools to support reasonable accommodation, and train educators on the practical implementation of reasonable accommodation and provide assistive and adaptive devices at all schools.

118. Immediately improve the security infrastructure at all schools, including special education schools, where children with albinism are placed.

119. Incorporate accurate information on albinism in education curricula, and train educators on visual impairments, on diversity in disability and on health in general.

#### **E. Employment and adequate standard of living**

120. Review and standardize the criteria for persons with albinism to access disability grants so that they meet the impairment test based on albinism per se.

121. Provide barrier-free access to skills development and entrepreneurship development programmes for persons with disabilities, including persons with albinism.

122. Supplement employment quotas on the hiring of persons with disabilities with wide-reaching training on the provision of reasonable accommodation in the public and private sectors.

123. Involve disability rights activists, including leaders of groups representing persons with albinism, in strategic initiatives on disability mainstreaming within the public sector and promote reasonable accommodation to dismantle the – often misguided – fears about hiring persons with disabilities.

#### **F. Representation**

124. Include persons with albinism in decision-making that affects them, at all levels of government and in all programming for public consumption, including in the arts and culture.

125. Support organizations representing persons with albinism, particularly through funding for operations, and through training to develop their capacity to represent themselves in all relevant public arenas and particularly with regard to decisions that affect them.

126. Executive authorities in the public service, the arts and culture should be encouraged to continue to champion the inclusion of persons with albinism at the sectoral and programmatic level.

127. Train media outlets on humanizing the terminology in reference to persons with albinism, and to promote narratives that normalize persons with albinism, debunk myths and misbeliefs about them and enhance their inclusion in society.

## **G. Destigmatization and awareness-raising**

128. In consultation with civil society organizations representing persons with albinism, work on developing rights-based language to describe persons with albinism in all official languages, replacing dehumanizing terminology with humanizing and neutral terms that serve to explain the condition and highlight their dignity as persons.

129. Continue awareness-raising about albinism across the country, particularly at the local and rural community levels, with a particular emphasis in border towns; persons with albinism should be involved in this at all stages of the planning, development and implementation.

130. Incorporate the human rights of persons with albinism in situations relating to gender-based violence, and in combating racial discrimination and xenophobia.

## **H. Regional and national action plans**

131. Adopt and implement the Regional Action Plan on Albinism in Africa.

132. Adopt and fund a national action plan on albinism, based on the Ekurhuleni Declaration and the Regional Action Plan on Albinism in Africa, in concert with the task force.

133. Support the task force in developing the national action plan, and fund the priorities identified therein.

## **I. Other relevant issues**

134. Regulate, or facilitate self-regulation of, traditional healers and their practices.

135. Facilitate self-regulation of religious bodies, particularly independent religious bodies.

136. Complete the process of review of the Witchcraft Suppression Act, with a view to protecting all rights involved, including those of practitioners as well as those of the potential victims of harmful practices perpetrated by those who practise the craft.

137. Incorporate into ongoing work against harmful practice, those practices that are related to abuse of witchcraft practice.

## **J. International cooperation**

138. Implement all recommendations made by treaty bodies, particularly the Committee on the Rights of Persons with Disabilities and the Committee on the Elimination of Racial Discrimination, which have made recommendations on the situation of persons with albinism during their reviews of South Africa.

139. Include persons with albinism in future State party reports to treaty bodies and in the universal periodic review.

140. Support civil society groups representing persons with albinism in human rights training and capacity development.

141. Implement the national action plan, once commissioned.