

UPR 4th cycle, 41ST Session

South Africa

THE CURRENT STATE OF PERSONS WITH ALBINISM IN SOUTH AFRICA

NATIONAL ALBINISM TASK TEAM

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Introduction

The United Nation in its endeavour to ensure that the right of persons with Albinism in South Africa is addressed, assisted in the establishment of the National Albinism Task Force on 21 September 2019, in a meeting that was facilitated by the UN Independent Expert Ms Ikpowoswa Ero. The structure serves as a forum for all persons with albinism in SA to consult on how the National Action Plan will be implemented throughout South Africa. This report serves to represent the views of all organisations of persons with Albinism in South Africa.

The following themes will be discussed:

Theme 1: Self-representation

Theme 2: Access to adequate health and healthcare services

Theme 3: Access to inclusive education and training

Theme 4: Access to justice and elimination of harmful practices and killings of persons with albinism

Theme 5: Employment and an adequate standard of living

1.1 Methodology

During the development of the National Action Plan on Albinism, numerous consultation sessions were held with the organisations of persons with albinism to solicit their input. Further inputs were also requested from different experts with albinism e.g. academics, media personalities, lawyers etc. Human Rights organisations were also consulted on the matter. The action plan was then used to develop this report

2. The national context of the UPR

South Africa was under review in 2017. The country received six recommendations about albinism which were all supported by the State. Out of the nine themes discussed in this report four were supported by South Africa.

In 2019, the then UN Independent Expert on Albinism made the following recommendations:

Attacks and killings

- Undertake a situational survey to identify gaps in security and protection measures for persons with albinism, particularly in rural and border towns.
- 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.
- Provide support, including psychosocial and socioeconomic support, to victims of attacks and their family members.
- Reinforce gravesites of persons with albinism to protect against grave robberies.
- Conduct continuous awareness-raising in hotspots.
- Incorporate a gender dimension and an intersectional lens in supporting mothers of children with albinism and women and girls with albinism.

- 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).
- Complete the review of the Witchcraft Suppression Act to protect equally the practitioners concerned, religious freedoms, cultural rights, and the potential victims of abuse of such craft, such as persons with albinism.
- Promote and facilitate the self-regulation of religious bodies and traditional healers.

Right to health

- Ensure that quality sunscreen is accepted, available and accessible in all provinces, paying attention to rural areas.
- Integrate, into the training of health workers, modules on albinism as a disability.
- 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.
- 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.
- Include skin cancer as a priority topic in the national cancer strategy.
- Support and extend the reach of early intervention and detection programmes for skin cancer to all provinces, paying attention to rural and isolated areas.

Education

- 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.
- Immediately improve the security infrastructure at all schools, including special education schools, where children with albinism are placed.
- Incorporate accurate information on albinism in education curricula, and train educators on visual impairments, diversity in disability and health in general.

Other relevant issues

- Regulate, or facilitate self-regulation of, traditional healers and their practices.
- Facilitate self-regulation of religious bodies, particularly independent religious bodies.
- 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.
- Incorporate into ongoing work against harmful practices, those practices that are related to abuse of witchcraft practice

The themes in this report are in line with SDG 3, 4, 5, 8, 10.

At this point, the Albinism Sector has not been consulted to participate in the process of review.

3. Analysis of the implementation

Theme 1: Self-representation

The country has not ratified the African Disability Protocol. The country does not have a disability policy in place. While there is a White Paper on the rights of persons with disability in place, albinism is not mentioned as a disability. This poses a challenge for organisations of persons with albinism to be fully recognised and be included. Currently, the sector is not

represented in any government sphere. Awareness and social cohesion initiatives are difficult to implement due to this lack of self-representation in the sector.

Recommendations

We urge the government to formally recognise the sector and include them in human rights machinery and decision-making structures.

Question

When will government ratify the African Protocol on Disability?

Theme 2: Access to adequate health and healthcare services

The provision is currently in Free visual aids, umbrellas, brim sun hats and sunscreen (SPF 30-50+) and skin cancer screening is currently inconsistent with some provinces able to provide some of these needs but others not able to do so. There are also quality concerns that are further harmful to persons with albinism.

Recommendations

- Set aside a budget to meet the health needs of persons with albinism, such as free access to vision devices, sunscreen and similar dermatological products.
- Standardised guidelines on how these services and products will be provided
- Measure the percentage of persons with albinism receiving free provisions of vision devices, sunscreen and similar dermatological products to understand the impact and identify the gaps.

Theme 3: Access to inclusive education and training

Persons with albinism are not properly included in mainstream schools. The lack of understanding of albinism and support in the form of assistive devices, counselling and prevention of bullying is making it difficult for them to have equal education and force parents to take their children to special schools.

Recommendation\

Inclusive Education policies include the provision of free or subsidised assistive and adaptive technology for access to education for persons with albinism.

Theme 4: Access to justice and elimination of harmful practices and killings of persons with albinism

There is no statistical data to measure how many people with albinism are in this country as a result there is no proper response to the issues they face in terms of health, education, and security. Even after the State assured the Independent Expert on albinism in 2019 that this will be included in the 2022 census, it was not implemented and there has not been any explanation of why it was not included.

It will be difficult for the government to assure protection as required in the last report if this information is not in place. Furthermore, this hampers other areas as mentioned above.

The statistics are also important to conduct targeted awareness and advocacy in the areas where people with albinism are in majority.

Recommendations

- Clear strategies are adopted for the security of persons with albinism.
- Adoption of the National Action Plan for persons with Albinism as developed by the Sector.
- Review of agreed commitment as per the UN Independent Expert report of 2019

Questions

How will government correct the omission of the census to account for persons with albinism?

Theme 5: Employment and an adequate standard of living

The failure to recognise albinism as a disability across all government departments is posing a challenge, first, to access disability grants and other benefits received by people with disability.
Recommendation

The adoption of the National Action Plan will make a public statement by the government in support of albinism as a disability as well as their intent to address the needs of persons with albinism.

4. Useful information

- Report of the Independent Expert on the enjoyment of human rights by persons with albinism

