

# REPORT ON THE PUBLIC HEARINGS ON *discrimination and other challenges faced by* **PERSONS WITH ALBINISM IN NAMIBIA**



OFFICE OF THE OMBUDSMAN



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OFFICE OF THE OMBUDSMAN  
2022



THIS REPORT WAS COMPILED IN PARTNERSHIP WITH



Directorate: Law Reform,  
Ministry of Justice

With thanks to the following stakeholders for their assistance with the public hearings on discrimination and other challenges faced by persons with albinism in Namibia.

The Namibia Albino  
Association



Our special thanks to all who participated in the public hearings, including parents, family members, friends, service providers, children and persons with albinism.





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# 1

## INTRODUCTION

**ALBINISM IS A GENETIC CONDITION** that affects the production of melanin in the body. It is a lifelong condition which is present at birth. Persons with albinism have reduced melanin, or none at all, which causes them to have little or no pigmentation in their eyes, hair and skin.

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*Globally, persons with albinism face numerous challenges...*”

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Globally, persons with albinism face numerous challenges, including health issues, discrimination, abduction, trafficking, and even murder for ritual purposes. The challenges faced by persons with albinism in Namibia vary in severity and type, depending on the area.

To better understand the situation of persons with albinism in Namibia and the discrimination they face, formal hearings were conducted by the Office of the Ombudsman, with the assistance of the Directorate: Law Reform, Ministry of Justice via its Disability Law Project.<sup>1</sup> The Ombudsman also welcomed proposals from the public on how issues could be addressed, whether through law reform or other means.

The decision to conduct these hearings stemmed from the constitutional requirement in Article 1(2), which states: “All power shall vest in the people of Namibia who shall exercise their sovereignty through the democratic institutions of the State”. This can be read with Article 95(k) of the Namibian Constitution, which requires that the State actively promotes and maintains the welfare of the people by adopting, among other things, policies aimed at the encouragement of the masses of the population through education and other activities to influence government policy by debating its decisions.

This report outlines how the public hearings were conducted, their purpose, and their outcomes. It further investigates discrimination against people with albinism, customary practices and myths, violence and other challenges. Recommendations and possible solutions are also included.

Through these consultations, the following sentiments were frequently voiced:

- Persons with albinism are not seen as similar or equal to people with pigment.
- Persons with albinism are not readily accepted by their families or communities.
- Society does not understand albinism; therefore, outdated cultural beliefs and dehumanising name-calling are still practised.
- Service providers, especially those in the education, health, insurance and employment sectors, do not understand albinism nor accommodate people with the condition.

<sup>1</sup> The Disability Law Project works closely with Disability Affairs, Organisations of Persons with Disabilities (OPDs) and other stakeholders to ensure that disability rights are put at the forefront. The Law Reform and Development Commission (LRDC) provides its expertise in research and experiences in disability law and its linkages to other areas of law and human rights on different platforms.

## 1.1 Albinism and disability

Namibia has no laws or policies that specifically list albinism as a disability. However, albinism seems to be treated as a disability in practice due to the health care needs of this vulnerable group, which include:

- **Visual impairment:** Melanin is required for optical nerve development. Therefore, persons with albinism often have vision problems which include crossed eyes, sensitivity to light, involuntary rapid eye movements, impaired vision or blindness, or astigmatism.
- **Skincare:** Due to the lack of melanin in their skin, persons with albinism are prone to sunburn and more likely to develop skin cancer.<sup>2</sup>

Viewing albinism as a disability protects people with this condition under the national disability legal framework.

Aside from the health challenges mentioned above, persons with albinism in Africa face stigma, discrimination, abuse, dehumanisation and sometimes brutal murder for rituals.

In Namibia, two non-governmental organisations cater for the needs of persons with albinism, namely the National Albinism Association and the Support in Namibia of Albinism Suffers Requiring Assistance (SINASRA-Albino Care). These two organisations share the prime objectives of protecting and promoting the rights of persons with albinism, particularly the right to education and health, and protection from discrimination, poverty, stigmatisation and psychological trauma. These organisations also advocate for the rights of persons with albinism in collaboration with government agencies and other stakeholders through sensitisation campaigns.

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with this condition...”

The available statistics on albinism in Namibia are outdated and may not be accurate. According to the Namibia 2011 National Census: Disability Report, a total of 1,153 persons with albinism were recorded in the country. The National Statistics Agency gathered this data through the following questions:<sup>3</sup>

- *Does (name) have any type of long-term disability or limitation?*
- *Because of disability does (name) have any difficulties engaging in any learning and/or economic activity?*

These questions have been deemed insufficient as the data captured did not accurately depict the situation of persons with albinism in Namibia. To correct this, albinism-specific questions will be included in the next census, in line with Article 31 of the Convention on the Rights of Persons with Disabilities, by modifying the Washington Group Short Set questions.<sup>4</sup>

2 See Annexure A: Correspondence by the then Minister of Health and Social Services, Dr Libertina Amathila, in which she recognises that persons with albinism require special care and pledges the addition of sunscreen to the national medicine emergency list.

3 Namibia Statistics Agency, 2016. *Namibia 2011 Census: Disability Report*. Available at [https://cms.my.na/assets/documents/Namibia\\_2011\\_Disability\\_Report.pdf](https://cms.my.na/assets/documents/Namibia_2011_Disability_Report.pdf). Accessed on 22 May 2020. p14.

4 Mont, D. *Are People With Albinism Included In The Washington Group Questions?* Available at <https://www.washingtongroup-disability.com/wg-blog/are-people-with-albinism-included-in-the-washington-group-questions-119/>. Accessed on 13 February 2021.

# 2

## THE INQUIRY

### 2.1 The need for a national inquiry

The Ombudsman of Namibia is established under Article 89(1), Chapter 10 of the Namibian Constitution, and the Ombudsman Act, 1990 (Act No. 7 of 1990). The Ombudsman is an independent<sup>5</sup> multifunctional office which maintains the traditional ombudsman function with additional directives. The Ombudsman is mandated to receive and investigate complaints relating to maladministration in government, violation of human rights and freedoms in the public and private sphere, misappropriation of public monies and misuse of property by public officials, and the protection of the environment.<sup>6</sup>

The Ombudsman launched this national inquiry to determine the extent of human rights violations, discrimination and violence against persons with albinism, customary practices and myths associated with persons with albinism and other challenges faced by them.

The need for this inquiry stemmed from the following factors:

- Persons with albinism in southern Africa face human rights violations daily, and the State needs to determine the extent to which such violations occur within Namibian borders in order to ensure adequate planning for the protection of the rights of this group of persons.
- The State's responsibility to respect, protect and fulfil the rights contained in international, regional and sub-regional human rights instruments to which Namibia is a party.
- The Ombudsman's responsibilities under the National Human Rights Action Plan 2015-2019 with regard to the right not to be discriminated against.

In conducting this inquiry, the Ombudsman invoked the following powers conferred on him in terms of Section 3–4 of the Ombudsman Act 7 of 1990:

- *Enquire into and investigate complaints concerning alleged or apparent or threatened instances or matters of violations or infringement of fundamental rights and freedoms;*
- *call any person to appear before him in relation to the inquiry;*
- *ask such person who appears before him to give evidence or to make submissions; and*
- *question such person who appears before him in connection with any matter which the Ombudsman may deem necessary in connection with the inquiry.*

<sup>5</sup> Article 89(2) of the Namibian Constitution provides that the Ombudsman shall be independent and subject only to this constitution and the law. Article 89(3) of the constitution further provides that no cabinet or legislature member or any other person shall interfere with the Ombudsman's exercising of his functions and all organs of the State shall assist him as needed for the protection of the independence, dignity and effectiveness of the Ombudsman.

<sup>6</sup> Section 3 of the Ombudsman Act, 1990 (Act No. of 1990).

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*... to determine the extent of human rights violations...*

”

## 2.2 The purpose of the inquiry

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The national inquiry, implemented through public hearings, was conducted to understand the human rights challenges faced by persons with albinism in Namibia. These in-depth interviews focused on the social aspect of the past and present lives of persons with albinism and how they address daily positive and negative experiences.

The inquiry, therefore, aimed to:

- Assess the State's compliance with its obligations under various international, regional and sub-regional human rights instruments and the extent to which it has implemented the recommendations made by the monitoring committees established under these instruments.
- Conduct public hearings to assess the extent to which the violation of the rights of persons with albinism is prevalent in Namibia.
- Determine the Namibian public's understanding of albinism and human rights, and solicit views addressing the prevention and elimination of these violations.
- Compile a report with findings and recommendations for legal and regulatory reform that will protect the rights of persons with albinism.

## 2.3 Methodology

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A multifaceted methodological approach was employed for the successful completion of this project, which included:

### **Desk research**

The Ombudsman and the staff of the Directorate: Law Reform, as part of the public hearing panel, critically analysed legislation, policies, publications, case law, as well as relevant international, regional and sub-regional human rights instruments, and the concluding observations and recommendations made by monitoring committees and treaty bodies established under these instruments.

### **Media campaign**

The then Ombudsman Advocate John Walters was interviewed by several media houses, such as the Namibia Broadcasting Corporation National Radio and Setswana Radio, to discuss the plight of persons with albinism and to invite the public to participate in the national inquiry. Advertisements explaining the project and encouraging public participation appeared in all major daily newspapers.<sup>7</sup>

### **Cooperation with organisations for persons with albinism, service providers and international human rights partners**

The public was further notified of the inquiry via the welfare organisations for persons with albinism, including the SINASRA-Albino Care, the National Albinism Association and relevant service providers. SINASRA-Albino Care and the National Albinism Association donated sunscreen, hats, umbrellas and

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<sup>7</sup> See Annexure B.

long-sleeved clothes for persons with albinism attending the public hearings. Amnesty International assisted with the transport and accommodation costs of the two panel members from the Directorate: Law Reform. United Nations Educational, Scientific and Cultural Organization (UNESCO) contributed 70 hats and funding to assist with the printing of this report, in partnership with the African Albinism Network.<sup>8</sup>

## Public hearings

To select the most appropriate locations for the public enquiries, the following was considered:

1. **Demographics:** These figures showed that although there are persons with albinism throughout Namibia, there is a higher concentration in the central and northern regions.
  - Ohangwena Region (16.1%)
  - Omusati Region (14.1%)
  - Oshikoto Region (13.9%)
  - Kavango Region (12.7%)
  - Khomas Region (13.4%)<sup>9</sup>
2. **Budget:** Due to financial constraints, the Ombudsman could not conduct a substantive nationwide survey of public opinion or consult individuals and communities in all regions.

Taking the above into account, it was decided to host the initial public inquiries as follows:

Date	Place	Time
29/07/2019	Oshakati State Hospital	09h00–13h00
30/07/2019	Eenhana State Hospital	09h00–13h00
31/07/2019	Okongo District Hospital	09h00–13h00
01/08/2019	Rundu State Hospital	09h00–13h00
05/08/2019	Windhoek Disability Resource Centre, Okuryangava, Katutura	09h00–16h00

These initial hearings were presided over by a panel consisting of the Ombudsman Advocate John Walters; two Chief Legal Officers from the Directorate: Law Reform, Ms Ruusa Ntinda and Mr Charles Uuwanga; Ms Marianne Muvangua, a mother of a person with albinism; Mr Werner Valde Kambambi, President of the Namibian Albinism Association; and Mr Joseph Ndinomupya, Vice President of the Namibian Albinism Association.

To ensure full inclusive participation, written submissions via email, post, or hand delivered to the Ombudsman's Offices in Oshakati, Katima Mulilo and Keetmanshoop were encouraged.

Further public meetings in other parts of the country were, however, requested by persons with albinism and the National Albinism Association, for a more comprehensive view of the situation.

<sup>8</sup> Africa Albinism Network is a consortium of non-governmental organisations working to promote the dignity and welfare of persons with albinism and their family members through human rights advocacy. See <https://actiononalbinism.org/en/page/s3e6cfhxqxie7v46ridjnstt9>. Accessed 25 February 2022.

<sup>9</sup> Namibia 2011 Census Disability Report. Available at [https://cms.my.na/assets/documents/Namibia\\_2011\\_Disability\\_Report.pdf](https://cms.my.na/assets/documents/Namibia_2011_Disability_Report.pdf). Accessed on 22 May 2020. p14.

The following hearings were conducted with the Ombudsman and the National Albinism Association as panel members.

Date	Place	Time
17/08/2021	Opuwo Hospital	09h00–13h00
18/08/2021	Outapi Hospital	09h00–13h00
19/08/2021	Okahao Hospital	09h00–13h00
21/08/2021	Tsumeb Hospital	10h00–13h00
23/08/2021	Katima Mulilo Hospital	09h00–12h00
26/08/2021	Otjiwarongo Ministry of Education	09h00–13h00
28/08/2021	Swakopmund Ombudsman Regional Office	09h00–12h30

The public hearings created an avenue to collect information from affected persons as a first step in understanding and synthesising the bigger picture. The hearings started a conversation about concerns and views on issues surrounding albinism by urban and rural participants from all walks of life. It is hoped that this process will lead to change and result in a more just society where everyone with albinism has a sense of validation and dignity.

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## 2.4 Compilation of report

Relevant allegations, responses and points of law and fact were considered during the compilation of this report. All the information and desk research results were thoroughly analysed before making observations and recommendations. This report will be submitted to the minister responsible for disability in the hope that the recommendations contained herein will be implemented.



Photograph taken at a public hearing

# 3

## LEGAL OVERVIEW

**ALBINISM, WHEN VIEWED AS A DISABILITY,** is covered under the domestic disability legal and normative framework. This protection is strengthened by international, regional and sub-regional laws and human rights instruments, which provide for the rights of persons with disabilities and require the State to take all necessary measures to prevent, combat and eliminate discrimination to ensure equal enjoyment of the rights guaranteed in such instruments.

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*Namibia has several disability-related laws and policies...*

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### 3.1 The domestic legal framework

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Namibia has several disability-related laws and policies that protect the rights of persons with albinism. A handful of such laws are mentioned below, with the majority discussed in the appropriate sections of this report.

#### THE CONSTITUTION OF THE REPUBLIC OF NAMIBIA

The Namibian Constitution is the supreme law of the land<sup>10</sup> based on the rule of law, justice and respect for fundamental human rights.<sup>11</sup> Shivute, CJ in *Osbert Mwenyi Likanyi v the State*,<sup>12</sup> stated, “The importance of the State adhering to the rule of law and the values enshrined in the Constitution cannot be over emphasised”. The preamble to the Namibian Constitution proclaims equal and inalienable rights of all members of the human family as enshrined in the Bill of Rights in Chapter 3 of the constitution.

Article 5 of the constitution provides:

*Fundamental rights and freedoms enshrined in this Chapter shall be respected and upheld by the Executive, Legislature and Judiciary and all organs of Government and its agencies and where applicable to them, by natural and legal persons in Namibia, and shall be enforceable by the Courts in the manner hereinafter prescribed.*

This provision calls for an interpretation that accepts that the rights enshrined in Chapter 3 have both vertical application between the State and the individual; and horizontal application between two individuals. According to this interpretation, both the state and individuals have a duty to respect and uphold the human rights of all persons.

Article 10 on equality does not list disability as a prohibited ground for discrimination. It appears to be a closed list as it does not contain the words ‘or any other status’. However, the jurisprudence on

<sup>10</sup> Article 1(6) of the Constitution of the Republic of Namibia 1990.

<sup>11</sup> The Preamble of the Constitution of the Republic of Namibia 1990.

<sup>12</sup> SCR 2/2016 at 10.

Article 10(2) indicates that value judgment is sometimes used in the broad or narrow interpretation of Article 10.<sup>13</sup> Furthermore, when this article is read with Article 23(2) on affirmative action, the terms ‘persons’ or ‘every person’ in Article 10 include persons with disabilities.

Chapter 10 establishes the Ombudsman as an independent body with the mandate, in Article 91 thereof, to protect and promote human rights.<sup>14</sup> This protection and promotion extend to persons with disabilities. Article 131 provides that the rights under Chapter 3 cannot be amended or repealed in any manner which diminishes the rights contained under that Chapter and effectively can only be amended in a way that enhances the human rights under Chapter 3. The rights can only be strengthened and not discarded. This is further supported by Article 25, which provides that:

- 1) *...the parliament and executive shall not make any law or take any action which abolishes or abridges the fundamental rights and freedoms conferred by this chapter...;*
- 2) *An aggrieved person who claim that a fundamental right or freedom...has been infringed or threatened shall be entitled to approach a competent court to enforce and protect such a right...*

As the supreme law of the land, the constitution sets the tone for the protection and promotion of disability rights in Namibia. The Principles of State Policy, as captured in Article 95, provide an opportunity for the justiciability of socio-economic rights not explicitly provided for under Chapter 3, such as the right to health. Article 101 further provides that the principles of state policy shall not of and by themselves be legally enforceable by any court but shall nevertheless guide the government in making and applying laws to give effect to the fundamental objectives of the said principles. In addition, under Article 131, courts are entitled to regard the principles of state policy in interpreting any laws based on them.

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sets the tone... ”

### THE ELECTORAL ACT, 2014 (ACT NO. 5 OF 2014)

To facilitate the taking of a poll in any election, Section 89(2)(g), as read with Section 91(1) of this Act, requires the Electoral Commission to establish polling stations at convenient places for accessibility for people with disabilities. Section 103 further provides that the polling officers may assist persons with disabilities in the manner of voting when so requested. It is unclear, however, if this also includes provision for persons with albinism to not stand in long queues to limit exposure to the sun.

### THE NATIONAL YOUTH COUNCIL ACT, 2009 (ACT NO. 3 OF 2009)

Amongst the powers and functions conferred on the National Youth Council, Section 3(i), in particular, states that the council must “advocate for the rights and opportunities of youth with disabilities”.

<sup>13</sup> Hubbard, D. *The paradigm of equality in the Namibian Constitution: Concept, contours and concerns*. Available at [https://www.kas.de/c/document\\_library/get\\_file?uuid=8c2963a8-71cc-d64d-e9da-360175ed9aa8&groupId=252038](https://www.kas.de/c/document_library/get_file?uuid=8c2963a8-71cc-d64d-e9da-360175ed9aa8&groupId=252038). Accessed on 22 February 2021.

<sup>14</sup> In terms of *Principles relating to the Status of National Institutions (The Paris Principles)*. Adopted by General Assembly Resolution 48/134 of 20 December 1993. Available at <https://www.ohchr.org/EN/ProfessionalInterest/Pages/StatusOfNationalInstitutions.aspx>. Accessed on 22 February 2021.

## NATIONAL DISABILITY COUNCIL ACT, 2004 (ACT NO. 26 OF 2004) AND THE NATIONAL POLICY ON DISABILITY, 1997

This Act establishes the National Disability Council as a body<sup>15</sup> which:<sup>16</sup>

*Represents any person with a disability before any organ of state, or provide or procure legal assistance for such persons if the matter relates to the rights of, or the integration of persons with disabilities in society.*

Further, the National Disability Council “recommend to the Cabinet necessary steps to facilitate compliance with the National Policy on Disability and the amendment of any law.”<sup>17</sup>

The National Disability Policy is a schedule to the 2004 Act. This policy is based on the principles of participation, integration and equalisation of opportunities as defined by the United Nations in the World Programme of Action Concerning Disabled Persons and the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. It acts as a guide to promote and provide for the needs of persons with disabilities for the government and other institutions.

“  
It acts as a guide to promote  
... the needs of persons with  
disabilities...”

### 3.2 The international human rights framework

Article 144 of the Namibian Constitution states:

*Unless otherwise provided by this Constitution or an Act of Parliament, the general rules of public international law and international agreements binding upon Namibia under this Constitution shall form part of the law of Namibia.*

This Article sanctions the use of international human rights instruments to which Namibia is party to ensure the protection of the rights of persons with disabilities, including those of persons with albinism.

The following international human rights instruments have a bearing on the rights of persons with albinism.

### SOUTHERN AFRICAN DEVELOPMENT COMMUNITY (SADC) PROTOCOL ON HEALTH (1999)

The SADC Protocol on Health defines disability as “any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being”<sup>18</sup> and emphasises the need for health systems research<sup>19</sup> and good quality health data.<sup>20</sup> In addition, sanctions are imposed as a punishment on States that fail to fulfil their obligations without good cause.<sup>21</sup>

<sup>15</sup> Section 2 of the National Disability Council Act, 2004 (Act No. 26 of 2004).

<sup>16</sup> *Ibid.* at Section 4(c).

<sup>17</sup> *Ibid.* at Section 4(d).

<sup>18</sup> Article 1 of the SADC Protocol on Health (1999).

<sup>19</sup> *Ibid.* at Article 6.

<sup>20</sup> *Ibid.* at Article 7.

<sup>21</sup> *Ibid.* at Article 31.

### AFRICAN CHARTER ON HUMAN AND PEOPLES' RIGHTS (ACHPR)<sup>22</sup>

The ACHPR provides for non-discrimination under Article 2 but does not list disability as a ground for non-discrimination. Persons with disability, including albinism, may, however, fall under the category of 'other status' as provided for in the charter. This can be understood in the context of Article 18(4), which provides that "the aged and the disabled shall also have the right to special measures of protection in keeping with their physical or moral needs".

### AFRICAN CHARTER ON THE RIGHTS AND WELFARE OF THE CHILD (ACRWC) (1990)<sup>23</sup>

The ACRWC, under Article 3, provides for non-discrimination. As with the case of the ACHPR, persons with albinism would fall under the category of 'other status' as disability is not a listed ground for non-discrimination. The charter makes special provision for 'handicapped children' under Article 13 as follows:

1. *Every child who is mentally or physically disabled shall have the right to special measures of protection in keeping with his/her physical and moral needs and under conditions which ensure his/her dignity, promote his/herself-reliance and active participation in the community.*
2. *State Parties to the present Charter shall ensure, subject to available resources, to a disabled child and to those responsible for his/her care, assistance for which application is made and which is appropriate to the child's condition and in particular shall ensure that the disabled child has effective access to training, preparation for employment and recreation opportunities in a manner conducive to the child achieving the fullest possible social integration, individual development and his/her cultural and moral development.*
3. *The State Parties to the present Charter shall use their available resources with a view to achieving progressively the full convenience of the mentally and physically disabled person to movement and access to public highway buildings and other places to which the disabled may legitimately want to have access to.*

### THE AFRICAN PROTOCOL ON THE RIGHTS OF WOMEN AND THE AFRICAN YOUTH CHARTER<sup>24</sup>

The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa<sup>25</sup> and the African Youth Charter<sup>26</sup> are worded in the same way as the African Charter on the Rights and Welfare of the Child.

22 Organization of African Unity. *African Charter on Human and Peoples' Rights (Banjul Charter)*, 27 June 1981, CAB/LEG/67/3rev.5, 21 L.M. 58 (1982). Available at <https://www.refworld.org/docid/3ae6b3630.html>. Accessed on 11 February 2021.

23 Organization of African Unity. *African Charter on the Rights and Welfare of the Child*. 11 July 1990, CAB/LEG/24.9/49 (1990). Available at <https://www.refworld.org/docid/3ae6b38c18.html>. Accessed on 11 February 2021.

24 African Union. *Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa*. 11 July 2003. Available at <https://www.refworld.org/docid/3f4b139d4.html>. Accessed on 11 February 2021.

25 The Protocol on Women's Rights of 2005, Article 23.

26 The African Youth Charter of 2000, Article 24.

## RESOLUTION 263 ON THE PREVENTION OF ATTACKS AND DISCRIMINATION AGAINST PERSONS WITH ALBINISM<sup>27</sup>

This resolution requires States to implement measures to ensure the provision, promotion and protection of the rights of persons with albinism and to encourage international cooperation among African States. Due to their shared historical, cultural, socio-economic, colonial, political and regional institutions, it is felt that African states possess the ability to implement Resolution 263 effectively.<sup>28</sup>

### THE REGIONAL ALBINISM PLAN OF ACTION (2017-2021)

This plan was put together by UN Independent Experts using recommendations from relevant resolutions of the UN and the African Union and consultation with persons with albinism on the continent. Content was also obtained from recommendations of treaty bodies, by the universal periodic review mechanism and from national responses, such as the multi-sectoral action plans for Malawi. The plan aimed to eradicate discrimination and violence against persons with albinism in Sub-Saharan Africa and to monitor the true impact of efforts to protect and integrate persons with albinism by multiple stakeholders across Africa. It consists of specific measures to realise the enjoyment of peace and human rights by persons with albinism. The objectives were divided into four pillars: prevention, protection, accountability and equality, and non-discrimination.<sup>29</sup> The plan was replaced by the African Union Plan of Action (2021-2031).<sup>30</sup>

### AFRICAN UNION PLAN OF ACTION (2021-2031)

In July 2019, the Executive Council of the African Union (AU) decided to adopt a Plan of Action on Ending Attacks and Discrimination against People with Albinism (Plan of Action), making it a continent-wide strategy. The AU also decided that a Special Envoy on Albinism would be appointed to ensure the implementation of the Plan of Action. The Plan of Action establishes baselines and targets that are measurable, can be tracked, and monitored. Monitoring requires rigorous data collection for Member States to correctly reflect statistics on persons with albinism. The targets of the Plan of Action for 2031 are loosely based on available baseline information from the Report on the African Decade of Persons with Disabilities (2010– 2019).

This matrix has been informed by the Report on the Regional Action Plan, and a two-day consultation in 2020 with organisations representing persons with albinism, as well as representatives from national human rights institutions and the United Nations: The Office of the High Commissioner for Human Rights and the United Nations Educational, Scientific and Cultural Organization. A group of elected representatives further met several times in 2021 to finalise the Plan of Action based on input from participants in the November 2020 consultation.

The AU Plan of Action sets out the activities necessary to achieve the goals of the Plan of Action in the timeframe of 2021–2031. It identifies who the responsible entities are, in the first place, Member States,

27 The African Commission on Human and Peoples' Rights, meeting at its 54th Ordinary Session held from 22 October to 5 November 2013 in Banjul, The Gambia.

28 Dugard J. 2012. 4th edition. *International law: A South African perspective*. Juta. p342.

29 African Albinism Network. African Union Plan of Action (2021-2031). Available at <https://actiononalbinism.org/page/sfj6gs7s8kjd5f6c6zyhw7b9#:~:text=In%20particular%2C%20the%20plan%20consisted,and%20equality%20and%20non%2Ddiscrimination>. Accessed on 4 March 2022.

30 African Union. *Implementation Matrix of the Plan of Action to end Attacks and other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031)*. Available at [https://actiononalbinism.org/uploaded\\_documents/16270537974156ddw0tvbef7.pdf](https://actiononalbinism.org/uploaded_documents/16270537974156ddw0tvbef7.pdf). Accessed on 4 March 2022.

ministries, partner organisations and other stakeholders, which may differ from country to country. It also includes indicators and possible data sources to achieve the strategic outcomes. It is believed that in illuminating the different components of action in this manner, policy planners and implementers will be assisted in adapting the Plan of Action to the specific context, country, or region. The results-based

management approach used in the AU Plan of Action will foster the participation of all actors and stakeholders in the implementation of the Plan of Action and promote accountability at national level. As the Plan of Action is an imperative tool for Member States to advance the human rights of persons with albinism effectively, it is essential that persons with albinism be consulted with and participate in its implementation.

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*Extends the rights to families and caregivers of persons with disabilities...*”

”

### PROTOCOL TO THE AFRICAN CHARTER ON HUMAN AND PEOPLES' RIGHTS ON THE RIGHTS OF PERSONS WITH DISABILITIES IN AFRICA

Although Namibia is not a signatory to this protocol, it is worth mentioning for possible exploration of whether or not Namibia should become a signatory. The protocol addresses continued exclusion, harmful practices, and discrimination of persons with disabilities. It draws its essential content from the Convention on the Rights of Persons with Disabilities and attempts to address additional issues specific to Africa. It was adopted during the 19<sup>th</sup> Extraordinary Session on the African Charter on Human and Peoples' Rights. It guarantees the equal protection of economic, social, cultural, civil, and political rights to individuals with “physical, mental, intellectual, developmental or sensory impairments”. It requires State parties to implement affirmative actions to advance their equality.<sup>31</sup>

The protocol requires that Member States ensure that persons with disabilities enjoy equality. Articles 4–21 emphasise the rights of persons with disabilities to life, liberty, security of person, be free from harmful practices, protection in situations of risk, equal recognition before the law, access to justice, to live in the community, accessibility, education, health, rehabilitation, work, an adequate standard of living, social protection, participation in political and public life, self-representation, freedom of expression and opinion, participation in recreation and culture, and family. Articles 22–25 recognise the particular vulnerabilities and rights of women, children, youth, and older persons with disabilities. Article 3 extends the rights to families and caregivers of persons with disabilities who might otherwise be subject to discrimination due to their association. Article 7 makes specific provision for the protective needs of persons with disabilities in periods of armed conflict or other humanitarian situations. States are required to take necessary steps to promote equality and to provide reasonable accommodations to enable access to basic economic and social spheres, such as employment under just and favourable conditions, education, and health care and conditions of health,<sup>32</sup> and to participate in politics and governance, liberty and humane treatment, free speech and expression, and access to justice,<sup>33</sup> in accordance to Article 3 of the Protocol.

31 Draft Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (adopted 25 February 2016), Article 1(g).

32 See Articles 12, 13, and 15 of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa.

33 *Ibid.* Articles 5, 9, 17, 19.

### UNIVERSAL DECLARATION ON HUMAN RIGHTS<sup>34</sup>

Article 2 of the Universal Declaration on Human Rights (UDHR) provides that everyone is entitled to all the rights and freedoms outlined in this declaration, without distinction of any kind, such as “race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status”. Persons with albinism may fall under the category ‘other status’.

### INTERNATIONAL COVENANT ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS

Article 2 of the International Covenant on Economic, Social and Cultural Rights (ICESR) requires States to guarantee the rights enunciated in the covenant without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

### INTERNATIONAL COVENANT ON CIVIL AND POLITICAL RIGHTS

Article 2 of the International Covenant on Civil and Political Rights (ICCPR) requires States to respect and ensure the rights recognised in the covenant, to all individuals within its territory and subject to its jurisdiction, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

### CONVENTION ON THE ELIMINATION OF ALL FORMS OF DISCRIMINATION AGAINST WOMEN

Article 1 of the Convention of the Elimination of all forms of Discrimination Against Women (CEDAW) defines ‘discrimination against women’ as:

*Any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.*

It requires States to condemn discrimination against women in all forms and agree to pursue, by all appropriate means and without delay, a policy of eliminating discrimination against women.

<sup>34</sup> Universal Declaration on Human Rights (1948), adopted by Namibia when it became a member of the UN on 23 April 1990.



Photograph taken at a public hearing

## CONVENTION ON THE RIGHTS OF THE CHILD

This convention deals comprehensively with the human rights of children, and specifically provides for the rights of children with disabilities. Article 2 provides for non-discrimination, and disability, in addition to 'other status', is listed as a ground for non-discrimination. The convention further provides for the child's best interests, respect for the views of the child and the needs of all children, including those with disabilities.

## CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The Convention on the Rights of Persons with Disabilities (CRPD) promotes and protects the rights of persons with disabilities. The CRPD moves towards viewing persons with disabilities as 'subjects' with rights capable of claiming their agency, making decisions for their lives based on their free and informed consent, and being active members of society. The CRPD does not precisely define disability in Article 1 to make it more applicable to different people. It goes on to define reasonable accommodation and other key principles as the cornerstones of the CRPD in Article 2 as follows:

- **Discrimination on the basis of disability** means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.
- **Reasonable accommodation** means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.
- **Universal design** means designing products, environments, programmes and services to be usable by all people, to the greatest extent possible, without needing adaptation or specialised design. 'Universal design' shall not exclude assistive devices for particular groups of persons with disabilities where this is required.
- The CRPD fails to define **accessibility** as a principle in Article 9 and Article 3(f). Accessibility is further emphasised in individual rights as an underlying element for access to justice, participation, education, health, rehabilitation, employment, social protection, and participation in political, social, sports and cultural life, amongst others in Articles 10-30. This is because all the rights provided for in the CRPD are interlinked, and persons with disabilities cannot enjoy them without adequate accessibility provisions. This requires the state to remove all the physical, environmental, transportation, infrastructure, institutional, educational, and informational barriers that may hinder the enjoyment and fulfilment of persons with disabilities, enabling accessibility in all aspects of society and human development.

Article 3 provides for the principles upon which the convention is founded. These principles consist of:

*Inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference of persons with disabilities as part of human diversity and humanity; equality of opportunity; accessibility; equality between men and women and respect*

*for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.*

The general obligation in Article 4 requires States to take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities. It also requires States to consider protecting and promoting the human rights of persons with disabilities in all policies and programs. States should further refrain from engaging in any act or practice inconsistent with the present Convention and ensure that public authorities and institutions conform. Articles 10–30 provide for specific human rights and freedoms, while Articles 3–9 provide for general applications.

### CRPD OPTIONAL PROTOCOL

The Optional Protocol makes provisions for individual complaints to the Committee on the Rights of Persons with Disabilities. Its decisions should be viewed and used as an improvement tool to implement the CRPD effectively. The committee was established in terms of Article 34 to monitor the implementation of the CRPD through periodic reports by States and communications from civil society. Furthermore, victims of violation of the CRPD will be able to make formal complaints to the committee if their States have ratified the Optional Protocol, like Namibia has done.

### UNITED NATION'S RESOLUTIONS 23/13 AND 24/33

Resolution 23/13 requires UN State parties to adopt effective measures to ensure the safety and protection of persons with albinism from attacks and discrimination.<sup>35</sup> In addition, the UN Resolution 24/33 calls for States to put practical steps in place to fight and eradicate attacks, torture and ill-treatment against persons with albinism to ensure the protection of their right to life and security through technical cooperation among States.<sup>36</sup>

The above legal instruments can be read with other laws and regulations that may indirectly provide for persons with disabilities and, as such, also indirectly provide for persons with albinism.

35 The United Nation's Resolution 23/13. *Attacks and discrimination against persons with albinism*. Human Rights Council Twenty-third Session Agenda item 3: 20 June 2013. Available at <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G13/150/42/PDF/G1315042.pdf>.

36 United Nation's Resolution 24/33. *Technical cooperation for the prevention of attacks against persons with albinism*. Human Rights Council Twenty-fourth Session Agenda item 10 Technical assistance and capacity-building 8 October 2013.

# 4

## PUBLIC/COMMUNITY HEARINGS

**DURING THE PUBLIC HEARINGS**, persons with albinism, parents of children with albinism, guardians and service providers raised their concerns and disappointment. In the following discussions, some sentiments are quoted verbatim to capture the essence of what was said. These direct quotations help to reflect the gravity of the concerns and bring messages across in the way they were expressed.

“

*... persons with albinism face discrimination in various areas of life...*

”

Although participants of the hearings were asked to sign attendance registers, some did not use their real names or contact details. This implies that they felt unsafe or believed their views might lead to further discrimination and stigmatisation. Therefore, the identities of the participants whose views are captured within this report have not been disclosed.

### 4.1 Discrimination

Worldwide, persons with albinism face discrimination in various areas of life.<sup>37</sup> Namibia is no different; therefore, this part of the report focuses on discrimination in general, reserving discussions on specific types of discrimination under the appropriate headings that follow.

#### SUMMARY OF SUBMISSIONS

A commonly-shared sentiment shared by participants throughout the hearings was that society views persons with albinism as a disgrace or an abomination. To avoid discriminatory treatment, persons with albinism often exclude themselves from many facets of society, including education, employment and from using public transport. Due to this, many persons with albinism suffer from low self-esteem. During the public hearing in Oshakati, a participant admitted that he often found it difficult to express himself or share common interests with others because of the discrimination he was subjected to. During a closed session in Okongo, a 24-year-old woman stated that she had started hating herself and still does not understand why she is different. She has questioned God about this on numerous occasions and is unsure of what she or her ancestors did for her to receive such a punishment. This sentiment was echoed by a participant in Eenhana, who said, “You can only imagine what happened when I looked at myself as I walked past shop windows, in the rear-view mirror; when I looked down even for a moment, and see glimpses of ghostly white, and it didn’t fit with who I want to be. Why me?”

Throughout the hearings, participants stressed that discrimination against persons with albinism is widespread and perpetrated by many, including service providers, teachers, families, prospective in-laws and community members.

<sup>37</sup> *People with albinism face multiple forms of discrimination worldwide.* Available at <https://albinism.ohchr.org/human-rights-dimension-of-albinism.html>. Accessed on 11 August 2021.

The range of discrimination faced by persons with albinism is wide and includes:

- being called names, spat at, mocked and avoided by their peers;
- being treated differently based on the colour of their skin (this is common in a predominantly black African nation with an apartheid history based on colour);
- abuse and violence, such as being beaten or cut to see if their blood is as different as their skin; and
- misconceptions and beliefs make people unwilling to share their food and clothing with persons with albinism. If persons with albinism touch someone or their belongings, they are often beaten or insulted.

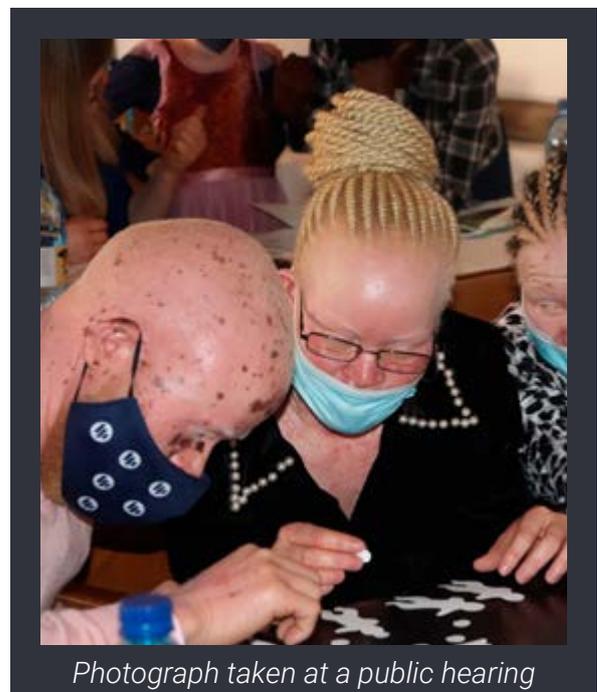
As a result of the above, most persons with albinism are hidden and excluded from society, either by personal choice or by their families. This was clearly illustrated by a 34-year-old woman, who informed the panel in Rundu that her family had hidden her for 22 years. “People stayed away from our house and avoided visiting my family because of the albino baby in the house,” she narrated.

### CONCLUDING OBSERVATIONS

Namibia provides for equality and freedom from discrimination under Article 10 of the Namibian Constitution. Article 10(1) states, “All persons shall be equal before the law”. The approach to legal analysis under Article 10(1) was set out in the 1995 *Mwellie* case,<sup>38</sup> which held that Article 10(1) permits “reasonable classifications” which are “rationally connected to a legitimate object”.<sup>39</sup> The Namibian Supreme Court, however, also noted that Article 10(1) had been interpreted “not to mean absolute equality but equality between persons equally placed”.<sup>40</sup>

With such discrimination, participants felt that they were not equally placed. So how one interprets the Supreme Court’s “equality between persons equally placed” may be difficult for this group of persons. Perhaps, the *Mwellie* test, as summarised in the *Müller* case, that “the questioned legislation or action would be unconstitutional if it allows for differentiation between people or categories of people and that differentiation is not based on a rational connection to a legitimate purpose”<sup>41</sup> may offer more protection.

In addition, Namibia, as a State with a colonial past of apartheid which was solely based on colour, can also be deemed to indirectly protect persons with albinism against discrimination based on colour in Article 10(2) of the Namibian Constitution, which lists colour as a ground for non-discrimination.



Photograph taken at a public hearing

38 *Mwellie v Minister of Works, Transport and Communication and Another* 1995 (9) BCLR 1118 (NmH).

39 *Mwellie* at 1132E-H.

40 *Government of the Republic of Namibia & Others v Mwilima & all other accused in the Caprivi treason trial* 2002 NR 235 (SC) at p30, citing *Müller v President of the Republic of Namibia* 1999 NR 190 (SC).

41 See *Hiskia & Another v Body Corporate of Urban Space & Others* 2018 (4) NR 1067 (HC) at paragraph 50, which notes that the approach set out in the *Mwellie* case has been consistently applied by the High Court and the Supreme Court whenever it has considered Article 10(1).

This can be supported by Article 5 of the CRPD<sup>42</sup> read with Section 2 of the Racial Discrimination Prohibition Amendment Act 26 of 1991, which provides that:

*No person shall in respect of any public amenity apply any practice or policy whereby any facility or service available at such public amenity is provided to members of the public on a segregated basis according to colour, race, nationality or ethnic or national origin.*

It should further be understood by the Namibian people that:<sup>43</sup>

*Any discrimination against a member of the society is discrimination against all. Any discrimination against a minority or class of people is discrimination against the majority. Plurality, diversity, inclusivity and tolerance are quadrants of a mature and an enlightened democratic society.*

## RECOMMENDATIONS

Irrespective of the legal measures in place, discrimination against persons with albinism continues due to lack of knowledge, misguided misconceptions and societal attitudes. Participants pointed out that much needs to be done to address this. Sensitisation campaigns for protecting and promoting the rights of persons with albinism must be strengthened to ensure that Namibians understand the condition. Albinism must not only be seen as a medical condition because, in addition to medical challenges, social challenges such as prejudice and discrimination prevent them from fully participating in society. Hence, this condition's medical and social elements must both be understood. Persons with albinism are encouraged to report any incidents to the police, and any occurrence of discrimination or violation of their rights to the office of the Ombudsman and the National Disability Council.

### 4.2 Myths and Stereotypes

Misconceptions caused by cultural myths and stereotypes fuel the violation of the rights of persons with albinism, dehumanising them and placing individuals with this condition in a vulnerable position.

## SUMMARY OF SUBMISSIONS

Several myths and stereotypes about persons with albinism stood out at the public hearings. These include but are not limited to:

- Participants in Rundu stated that some people believe that albinism is contagious and can be spread by direct or indirect contact with a person with albinism.
- It is believed that persons with albinism have a specific smell, and if you associate with them, you start to smell like them.
- There are several beliefs regarding the birth of a child with albinism. Some believe this results from adultery or racial mixing, conception during the menstrual period, or punishment from God.

<sup>42</sup> Article 5 of the CRPD provides that:

1. *State Parties recognise that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.*
2. *States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.*
3. *In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.*
4. *Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.*

<sup>43</sup> See *Letsweletse Motshidiemang v Attorney General and Others* MAHGB-000591-16, 11 June 2019, paragraph 158, quoting *Attorney General v Dow* [1992] BLR 119 (CA) where the Court emphasised the universality of human rights.

Participants in Rundu stated that some consider such a child as the punishment for a woman who mocked or insulted a mother of a child with albinism.

- Some believe having sex with a woman with albinism cures HIV/AIDS; others believe this ensures wealth and prosperity.
- There is a belief that if a pregnant woman has friends with albinism, she will bear a child with albinism.
- Another belief is that persons with albinism are not people but ghosts who do not die but simply disappear. "I am still waiting to disappear one day. It is scary," said a young woman.

The media and film industry's stereotypical portrayal of persons with albinism as evil reinforces pre-existing misconceptions, creating and re-creating unbalanced relations with this group of people.

The above illustrates that the public is largely ignorant of what albinism is, and this harmful behaviour results in persons with albinism feeling shame, self-blame and worthlessness.

## CONCLUDING OBSERVATIONS

The origin of many myths and stereotypes is deeply rooted in cultural beliefs, norms and taboos. It could be argued that such cultural beliefs are a manifestation of the right to culture protected in Article 19 of the Namibian Constitution that:

*Every person shall be entitled to enjoy, practice, profess, maintain and promote any culture, language, tradition or religion subject to the terms of this Constitution and further subject to the condition that the rights protected by this Article do not impinge upon the rights of others or the national interest.*

This is further supported by Article 66 on *Customary and Common Law* that:

- 1) *Both the customary law and the common law of Namibia in force on the date of Independence shall remain valid to the extent to which such customary or common law does not conflict with this Constitution or any other statutory law.*
- 2) *Subject to the terms of this Constitution, any part of such common law or customary law may be repealed or modified by Act of Parliament, and the application thereof may be confined to particular parts of Namibia or to particular periods.*

Article 140 of the Namibian Constitution on existing laws before independence, read with the Traditional Authorities Act 25 of No. 2000, the Community Courts Act No. 10 of 2003 and Article 15(1)(a) of the International Covenant on Economic, Social and Cultural Rights (ICESCR), recognises the right of everyone to take part in cultural life.

A right to culture can be construed to mean freedom akin to freedom of expression by performing or practising arts and sciences. Culture denotes a people's entire store of knowledge and artefacts, their language and their belief system. However, various aspects of cultural beliefs, such as those listed above, have been identified as outdated or contrary to human rights and need to be challenged and changed.<sup>44</sup>

<sup>44</sup> Ntinda, R. *Customary practices and children with albinism in Namibia: A constitutional challenge?* Available at [https://www.kas.de/c/document\\_library/get\\_file?uuid=b6dc0797-15b0-962e-f1bc-46a19ab239f7&groupId=252038](https://www.kas.de/c/document_library/get_file?uuid=b6dc0797-15b0-962e-f1bc-46a19ab239f7&groupId=252038). Accessed on 28 May 2020. p247.

All over Africa, it is believed that the body parts of persons with albinism have various purposes when used in rituals.<sup>45</sup> Although no such cases have been recorded in Namibia, the Combating of Trafficking in Persons Act 1 of 2018 aims to combat ritual killings and trading in body parts of persons with albinism by defining and criminalising the 'removal of organs or body parts'. This is further supported by the Witness Protection Act, 2017: Act No 11 of 2017, which seeks to ensure the protection of whistleblowers and witnesses that may come forward and Act No.10 of 2017, which provides for the establishment of a whistleblower protection office as well as procedures for disclosing improper conduct. The Act also provides for the investigation of disclosure of improper conduct and protection of whistleblowers, investigation of complaints of detrimental action, the review of certain decisions, remedies for persons against whom detrimental action is taken and incidental matters. Under these acts, protection is also offered specifically for witnesses of ritual killings and the removal of organs or body parts of persons with albinism.

## RECOMMENDATIONS

It may be difficult to dispel these beliefs or change mindsets. Vigorous awareness raising and public education is therefore encouraged.

Regarding the belief that having sex with a woman with albinism cures HIV/AIDS or ensures wealth and prosperity, it is difficult to determine if this belief has led to rape, as rape statistics are not segregated by disability. It is therefore recommended that the Namibian Police and the Gender and Child Abuse Centre should add a new category to their statistics to ensure a more detailed picture of violence and crime against persons with disabilities.

“  
It may be difficult to dispel  
these beliefs or change  
mindsets.”

## 4.3 Derogatory Expressions and Slurs

The practice of derogatory expressions, name-calling and slurs against persons with albinism is widespread in Namibia. This highly offensive behaviour humiliates and violates a person's right to dignity and equality. Such utterances amount to abuse. Perpetrators of this offence are often fuelled by prejudice passed on from previous generations.

## SUMMARY OF SUBMISSIONS

Name-calling and insults are among the most common forms of discrimination that persons with albinism are subjected to daily.

These take many forms and include, but are not limited to:

- Persons with albinism are called *Ethithi*, *Ekishi*, *Nambalakata* among the Ovambo; *Ekihi* among the Ovaherero; *Otjihenyange* among the Zemba, *Wit vleis* (white meat) in Afrikaans; and *Sindangwaleza* among the Lozi people of the Zambezi Region. Although the meaning of some of these terms is unknown, they are all used in a derogative manner.

<sup>45</sup> Baker, C. *The trade in body parts of people with albinism is driven by myth and international inaction*. <https://theconversation.com/the-trade-in-body-parts-of-people-with-albinism-is-driven-by-myth-and-international-inaction-84135>. Accessed on 21 November 2020.

- Some community members call persons with albinism *Nakale* or *Whity-Dewet*, after local musicians with albinism.
- In the Ovambo communities, parents threaten misbehaving children by saying, “*Neyo lile* (long tooth) will eat you.” This implies that persons with albinism are monsters who eat misbehaving children. Due to this learned attitude, children grow up fearing persons with albinism, and thus these discriminatory practices continue.
- A participant in Rundu explained that persons with albinism are often called *Etokatoka* (white thing) in the Rukwangali language. She further stated that phrases such as: “Look at that albino”; “You’re an abomination”; “You should have been killed at birth”; “You are not one of us” and “You do not belong here” are constantly said to persons with albinism.
- A participant in Swakopmund said that it was painful to be constantly told, “You are not a full human being, or you are different and do not belong.”
- Other offensive insults include white elephant, white coconut, white bread, stupid albino, it, and that thing.

Although some names may not necessarily be derogatory, as the meaning or origin of most could not be determined, they are used to hurt, humiliate and degrade persons with albinism. The offensive slurs cause persons with albinism to become highly defensive and anti-social as a way to protect themselves and fearful of associating with pigmented persons. If people with albinism react to the provocations and insults, they are labelled rude, bitter, and arrogant.

## CONCLUDING OBSERVATIONS

Derogatory expressions, name-calling or slurs of persons with albinism violate their right to dignity. Dignity is part of the foundation of the Namibian Constitution, which, in the first paragraph of the Preamble, acknowledges the “*recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is indispensable for freedom, justice and peace*”.

Article 8 of the Namibian Constitution expressly provides for the right to dignity:

- 1) *The dignity of all persons shall be inviolable.*
- 2) a) *In any judicial proceedings or in other proceedings before any organ of the State, and during the enforcement of a penalty, respect for human dignity shall be guaranteed.*
- b) *No persons shall be subject to torture or to cruel, inhuman or degrading treatment or punishment.*

According to the 2006 *Afshani* case, dignity is a core constitutional value of the Namibian people because:

*Article 8(1) demands respect for human dignity and entrenches that right in peremptory language: The dignity of all persons shall be inviolable. One only has to refer to the articulation of this value in the first paragraph of the Preamble to the Constitution to understand why human dignity is a core value, not only entrenched as a fundamental right and freedom in chapter 3, but also permeating all other values reflected therein.*<sup>46</sup>

<sup>46</sup> *Afshani and Another v Vaatz* 2006 (1) NR 35 (HC). p.48, paragraph 28.

McCrudden's theory,<sup>47</sup> which considers, among other things, that consensus on the meaning of the concept of human dignity exists, emphasises three elements:

- That every human being possesses an intrinsic worth merely by being human.
- That this intrinsic worth should be recognised and respected by others.
- That the intrinsic worth of the individual requires that the state should be seen to exist for the sake of the individual human being and not vice versa.

The relationship between one's worthiness in oneself as a person and dignity was also captured by the court in the case of the *National Coalition for Gay and Lesbian Equality and Another v Minister of Justice and Others*.<sup>48</sup> The court held that "dignity is a difficult concept to capture in precise terms" but found that it requires acknowledgement of "the value and worth of all individuals as members of our society".<sup>49</sup> The Supreme Court's interpretation of Article 8 on dignity in *Ex Parte: Attorney-General, In Re: Corporal Punishment by Organs of State*<sup>50</sup> further held that:

“  
...dignity is a difficult  
concept to capture in  
precise terms...”

*The relevant words in Article 8 have to be read disjunctively. Such a reading means that Article 8 protects the citizen against six different violations: torture; cruel treatment; inhuman treatment; inhuman punishment; degrading treatment; and degrading punishment.*

The court added that all the rights under Article 8(2)(b) are non-derogable and that the State's obligation is absolute and unqualified. All that is therefore required to establish a violation of Article 8 is a finding that the particular practice falls within one or other of the seven permutations of Article 8(2)(b).<sup>51</sup> In determining the implications of Article 8, *McNab and Others v Minister of Home Affairs NO and Others*<sup>52</sup> referred to the English definition of the words 'inhuman' and 'degrading'.<sup>53</sup> According to the Oxford English Dictionary, 'inhuman' is defined as "Brutal, lacking the human qualities of kindness, pity, etc." and to degrade or degrading means "to reduce to a lower rank; to bring into dishonour or contempt;" and "humiliating; lowering one's self-respect."<sup>54</sup>

Barnett further stated that the word 'inhuman' is limited to action that is, by its very nature, barbarous, brutal or cruel and not merely such treatment as results from want of pity or human feeling, whereas 'degrading' connotes treatment which is calculated to, or in all probability will, destroy the human qualities and character of the recipient.<sup>55</sup> This is further supported by Article 15<sup>56</sup> and Article 17<sup>57</sup> of the

47 McCrudden, C. *Human Dignity and Judicial Interpretation of Human Rights*. 2008. 19 European J Intl L 655, 679.

48 *National Coalition for Gay and Lesbian Equality and Another v Minister of Justice and Others* 1999 (1) SA 6 (CC).

49 *Ibid.* at paragraph 28.

50 *Ex Parte: Attorney-General, In Re: Corporal Punishment by Organs of State* (SA 14/90) [1991] NASC 2; 1991 (3) SA 76 (NmSc) (5 April 1991).

51 *Engelbrecht v Minister of Prisons and Correctional Services* 2000 NR 230 (HC) at 232.

52 *McNab and Others v Minister of Home Affairs NO and Others* 2007 (2) NR 531 (HC)

53 *Ibid.* at page 548.

54 *Ibid.* at page 219.

55 Barnett, L.G., 1977. *The constitutional law of Jamaica*. Oxford [etc.]: Oxford University Press for the London School of Economics and Political Science.

56 Article 15 of the CRPD provides that:

1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.
2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

57 Article 17 of the CRPD provides that: "Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others."

CRPD, read with paragraph 3.12 of the National Disability Policy of 1997, under which family life and personal integrity is provided for. This can also be read with Chapter 3 of the Namibian Constitution, which guarantees all Namibian citizens their fundamental human rights and freedoms. Every person, including anyone with disabilities, has a right to respect for their physical and mental integrity on an equal basis with others.

## RECOMMENDATIONS

There is an urgent need to unlearn derogatory language and dismantle fixed misconceptions through radical change. Changing entrenched behaviour patterns may be challenging, but it is not insurmountable; old ways of conduct must be replaced by new behaviour patterns. As Namibians, we should ask ourselves, where does change start, or where can it begin? Meaningful change should start with oneself. Unfortunately, verbal abuse is a constant occurrence in the lives of many persons with albinism, and victims need to learn to deal with it constructively.

*The right to live with dignity has been recognised as a human right on the international front, and by number of precedents of the Namibian Courts and, therefore, Namibia must strive to protect the dignity of every individual, for, without the right to dignity, every other right would be rendered meaningless. Dignity is an inseparable facet of every individual that invites reciprocatively respect from others to every aspect of an individual which he/she perceives as an essential attribute of his/her individuality.<sup>58</sup>*

### 4.4 Access to land, housing and services

Access to land, housing and services were issues raised during the public hearings as being of significant concern.

## SUMMARY OF SUBMISSIONS

The public hearing panel was informed by some participants that:

- Many persons with albinism lack adequate shelter due to cost or discrimination based on gender or skin colour. A participant at Oshakati stated that her deceased parent's land was given to her brother by the family elders. She wanted a portion to cultivate mahangu and get something for her family. However, the family decided that only a male could inherit the land. She believes that she would have gotten some land if she were male. Other participants confirmed the land and housing issue, claiming their requests for communal land around their communities had also been refused. During the one-on-one sessions in Eenhana, a man alleged that when he was looking for land to create his mahangu field, some community members said, "He will disappear soon anyway; what will he do with the land?"
- It was further alleged that some government officials refuse to assist persons with albinism. They are also mistreated when using public transport because people don't want to sit close or allow them in their cars. Persons with albinism often cannot get driver's licences due to Namibian Traffic Information System (NATIS) rejections. This refusal is usually due to the results of eyesight testing

<sup>58</sup> *Navtej Singh Johar & Ors v Union of India*, Supreme Court, Writ Petition (Criminal) No. 76 of 2016 (6 September 2018) (available at [www.humandignitytrust.org/wp-content/uploads/resources/2018.09.06-Johar-v-India-judgment-Indian-SC.pdf](http://www.humandignitytrust.org/wp-content/uploads/resources/2018.09.06-Johar-v-India-judgment-Indian-SC.pdf)). Paragraph 126.

on the applicants. During the Eenhana public hearings, one participant expressed dissatisfaction with how these eyesight tests are conducted. He added that NATIS should develop a standard for testing persons with albinism and reasonably accommodate them to acquire driving licenses.

- During the Windhoek public hearings, it was alleged that when persons with albinism apply for insurance, certain contracts stipulate that the insurance will not cover death or further disability due to their condition. This amounts to discrimination since albinism is a genetic condition prevalent at birth and forms part of who they are.
- A woman from Shambyu village stated that she faced difficulties registering the birth of her child with albinism due to the refusal of the child's father to provide his identity documents. She further noted that this is a common practice amongst men whose partners give birth to children with albinism.
- A participant in Katima Mulilo stated that it takes months to register a child with albinism for a disability grant. Doctors may also refuse to register the child for a disability because they do not believe that albinism is a disability or that the child may need assistance. Persons with albinism are usually assessed for disability grants based on visual impairments, which vary from person to person.
- Participants in all sessions agreed that the disability grant provided by the State is not enough to cater for their needs.



*Photograph taken at a public hearing*

## CONCLUDING OBSERVATIONS

There are legal provisions which can assist with addressing some of the challenges faced by persons with albinism in accessing land, housing and services. This report proposes alternative recommendations in certain instances where the law is silent. The key observations based on the issues raised at the inquiry include the following:

### **Access to land and housing:**

Chapter 5 of the Namibia 2011 Census Disability Report (Namibia Statistics Agency 2016) focuses on characteristics of housing units occupied by households with persons with disabilities, specifically

information on the type of tenure, type of housing unit, the material used for construction, source of energy for cooking and lighting, water supply and sanitation. The report shows that 69.9% of households with persons with disabilities owned the housing units that they occupied without a mortgage. This was more common in rural areas with 80.4% of households, as most dwelling units are traditional houses with no title deeds and cannot be mortgaged. In addition, about 19% of households consisting of persons with disabilities in urban areas consist of rented housing units.<sup>59</sup> This may be attributed to the fact that persons with disabilities have difficulties engaging in learning and economic activities.<sup>60</sup>

There are measures in place to assist persons with albinism as part of the general disability group in accessing land and housing. These include:

- Regulations 23C and 23G of the Communal Land Reform Act, 2002 (Act No. 5 of 2002) provide that persons with disabilities should be given a higher score when applying for, and being allocated, leaseholds. Regulation 23C(4) lists the factors to be considered during the evaluation process with a point scoring system for infrastructure development support, specifying that members of recognised marginalised groups, such as people with disabilities, score two points. Regulation 23G(3) requires Traditional Authorities to use these factors and the associated point scoring system when evaluating and recommending applications for persons with disabilities.
- The National Policy on Disability makes provision for Social Welfare and Housing in paragraph 3.8.4. It requires the State to plan and develop public housing schemes to ensure the provision of, and access to, housing for persons with disabilities. In paragraph 4.1, the policy provides that the needs of persons with disabilities should be incorporated in all existing and new legislation dealing with education, employment, building codes, sport and recreation, housing, transportation, telecom/communication and all other sectors serving the public. Regional Planning Advisory Committees under paragraph 4.3.7 include persons with disabilities or their representatives so their needs can be included in development planning. When developing new, and upgrading existing, service extensions in towns, villages and settlement areas, Local Authorities are required to do so based on a comprehensive needs survey. This survey should include the different needs of persons with disabilities and their families.
- The Build Together Programme (BTP) is a self-help programme initiated in 1992/1993 to house low and ultra-low-income households. The programme is an umbrella body of four sub-programmes, namely: urban/rural individual housing loans; social housing for persons with disabilities, pensioners and the destitute; single-quarters transformations; and the informal settlement upgrading programme. Although this programme has a specific social housing component, all Namibians, including persons with disabilities, have access to the other sub-programmes mentioned. With the formulation of the Decentralisation Policy, the programme was transferred to Regional Councils and Local Authorities in 1998.<sup>61</sup>
- The Mass Housing Development Programme was initiated in 2013 to address the housing backlog in Namibia. The Social/Housing Subsidy component of this programme aims at providing housing to low and ultra-low-income groups, and indigent/welfare cases such as persons with disabilities and the unemployed.

59 Namibia 2011 Census Disability Report (Namibia Statistics Agency 2016). p62.

60 *Ibid.* p70.

61 Responses on adequate housing: *Report on the right to housing of persons with disabilities*. Available at <https://www.ohchr.org/en/calls-for-input/report-right-housing-persons-disabilities>. Accessed 20 May 2021.

- These are further supported by:
  - The Namibia Housing Policy, adopted in 1991 and revised in 2009, reiterates the declaration of housing as one of the government's development priorities. Therefore, the government's role is to ensure that the housing development process is inclusive for all and that those households excluded from the market and conventional housing development mechanism can access land, housing and services and create an enabling environment for a vibrant housing market. The policy also contains several strategies relating to housing provision, one of which is the provision of subsidies and grants by government and development partners to support social housing.
  - The National Housing Development Act (Act No. 28 of 2000) provides for the establishment of a National Housing Advisory Committee, which advises the relevant minister on any aspect of national housing, including the formulation and implementation of specific policies and programmes relating to low-cost residential accommodation. The Act also makes provision for Housing Revolving Funds by Regional Councils and Local Authorities.
  - The Local Authorities Act (Act No. 23 of 1992 as amended).
  - The Regional Councils Act (Act No. 22 of 1992).
  - Harambee Prosperity Plan – Pillar 3 (Social Progression) sets clear goals, desired outcomes, and measures to address the country's housing and urban land delivery.
  - The 2012 National Rural Development Policy and Strategy focuses on improving the living conditions of rural communities by creating conditions to address poverty, food security, unemployment and underdevelopment of rural areas.
  - The Flexible Land Tenure Act No. 4 of 2012 provides for implementing the Flexible Land Tenure System, which is already being piloted in some local authorities before its full rollout.
  - The Ordinances of 1954 and 1963.
- It should also be noted that the court took cognisance of the right to housing for all in Namibia by declaring itself in *Petrus Shaanika and 10 others v The Windhoek City Police and 3 others*.<sup>62</sup> The court held that subsection 4(1)<sup>63</sup> and (3)<sup>64</sup> of the Squatters Proclamation, No. 21 of 1984, are inconsistent with the constitution, invalid, and of no force and effect.

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*The Act also makes provision for Housing Revolving Funds...* ”

62 Case No. SA 35/2010.

63 Section 4(1) provided that:

Notwithstanding anything to the contrary in any law contained and without the authority of an order of court or prior notice of whatever nature to any person -

- a) the owner of land may demolish and remove together with its contents any building or structure intended for human habitation or occupied by human beings which has been erected or is occupied without his consent on such land;
- b) any building or structure intended for human habitation or occupied by human beings which has been erected on land within the area of jurisdiction of any local authority, without the prior approval of that or any former local authority of any plan or description of such building or structure required by law, may at the expense of the owner of the land be demolished and removed together with its contents by the local authority or the Secretary or any officer employed in his department and authorized thereto by him.

64 Section 4(3) provided that:

Unless a person first satisfies the court on a preponderance of probabilities

- a) that he is lawfully entitled to occupy the land on which any building or structure has been erected; and
- b) in the case of any person whose right of occupation is based on the consent of any person other than the owner of such land, that such other person is lawfully entitled to allow other persons to occupy such land, such first-mentioned person shall not have recourse to any court of law in any civil proceedings founded on the demolition or removal or intended demolition or removal of such building or structure under this section and it shall not be competent for any court of law to grant any relief in any such proceedings to such last-mentioned person.

## Obtaining a driver's license

Section 34(1)(vi) of the Road Traffic and Transport, 1999 (Act No. 22 of 1999) disqualifies a person from obtaining a license if they suffer from defective vision. This is ascertained following a prescribed standard for public safety. NATIS reasonably accommodates persons with visual disabilities by allowing them to seek assistance from qualified optometrists or ophthalmologists/eye specialists of their choice, at their own cost, to assist with testing. The test determines whether a person is visually fit to drive a vehicle or whether a person requires assistive devices such as glasses or any corrective treatment or surgery. A proposed recommendation is that relevant stakeholders investigate the possibility of assisting persons with albinism with the costs associated with the eye test, assistive devices or corrective treatment where appropriate.

## Discrimination by insurance companies

This issue is relevant and has also been dealt with by the courts. In *Gibbs v. Battlefords and Dist. Co-operative Ltd*,<sup>65</sup> the Supreme Court rejected an appeal and found that:

*It is not fatal to a finding of discrimination that not all persons in the group bearing the relevant characteristic have been discriminated against. Discrimination against a sub-set of the group, in this case, those with a mental disability (persons with albinism), can be considered discrimination against persons with disabilities.*

Article 12(5) of the CRPD would require Namibia to take “appropriate and effective measures to ensure the equal rights of persons with disabilities to have equal access to other forms of financial credit”, including insurance services. In Namibia, Section 13(1)(b)(i) of the Long-term Insurance Act, 1998 (Act No. 5 of 1998) makes provision for the disability insurance business as a class of long-term insurance. This class of insurance is in the business of providing or undertaking to provide policy benefits under disability policies which should be accessible to persons with albinism. A prohibition on unfair discrimination does not preclude an insurer from considering someone’s health status per se but prohibits unfair discrimination on that basis.

## Disability grants

The government provides disability grants to assist disadvantaged persons with disabilities as part of its social welfare measures. It is unclear why doctors consider visual impairment to be the main criteria or why the lack of melanin in the skin is not considered when diagnosing a patient as disabled.

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...unclear why doctors  
consider visual impairment to  
be the main criteria...”

The Aged Person’s Act, 1967 (Act No. 81 of 1967)<sup>66</sup> primarily aims to secure the welfare and social amenities of people of old age and debilitating conditions. In this context, old age and debilitation are defined to insinuate a disability. In other words, although caused by age, these conditions suggest certain limitations and that these people cannot care for themselves.

<sup>65</sup> *Gibbs v. Battlefords and Dist. Co-operative Ltd* (1996), 27 C.H.R.R. D/87 (S.C.C.).

<sup>66</sup> Act of 1967, a number of amendments were effected to this Act.

The following measures further support the Aged Person's Act:

- Article 95(f) of the Namibian Constitution provides that the State should ensure that senior citizens are entitled to and receive a regular pension adequate for maintaining a decent standard of living and enjoying social and cultural opportunities.
- The National Policy on Orphans and Vulnerable Children (2004), launched in 2005, provides a national social grant of monetary value to vulnerable children. This policy equally applies to children with disabilities even if their parents are still alive.
- The National Policy Options for Marginalised Children (1998) identified children with disabilities, street children, children in remote areas, children in squatter camps and over-aged children as children in urgent need of intervention to ensure access to formal education.
- The National Disability Policy provides in paragraph 3.9 that to develop personal autonomy and economic independence, persons with disabilities shall have the right to receive social security and a decent standard of living. It goes on to state that the exercise of fundamental legal rights of such persons shall be protected, including being free from discrimination. In addition, cases where people with disabilities are partially or totally unable to administer their own property, they shall be provided with legal protection in the form of a guardian or legal assistant.
- Section 241 of the Child Care and Protection Act, 2015 (Act No. 3 of 2015) provides a national disability grant to benefit any child with disabilities. It could be argued that the amount currently provided by the State for social grants may be influenced by various financial, developmental and economic factors. Where children are concerned, it could perhaps be argued that the duty to maintain a child rests on the parents in terms of Section 3(1) of the Maintenance Act No. 9 of 2003, which states that "subject to Section 26 and to the law relating the duty of a parent to maintain a child who is unable to support himself or herself, both parents of a child are liable to maintain that child". The State only plays a supporting role. However, this is debatable as unemployment and other factors may affect a parent's ability to maintain their child.
- Finally, no Namibian law prevents a mother from registering their child's birth under her family name should a father refuse to acknowledge or take responsibility for the child. Section 10(3) of the Births, Marriages and Deaths Registration Act No. 81 of 1963 provides that a child born out of lawful wedlock shall be registered under the surname of (a) their mother; or (b) their father, provided the latter has made the acknowledgement referred to in subsection (2) and the mother has consented.

## RECOMMENDATIONS

Service providers are advised to serve all persons equally, regardless of personal opinions and beliefs. Service should be provided equally for all without discrimination in line with the procedures of that service industry, which should not conflict with the constitution. Persons with albinism should understand that being classified under disability and receiving a disability grant should not make them feel less of a person. The State is aware that disability does not mean inability; the funding is provided as a social protection measure, not a means to undermine a person's ability. Further sensitisation and awareness campaigns are strongly suggested.

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*Service providers are advised to serve all persons equally...*

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## 4.5 Employment

The high unemployment rate in Namibia among persons with albinism remains a serious concern. The unemployment rate for persons with disabilities is 39.0%, which is higher for females (43.5%) than males (34.7%).<sup>67</sup> The Namibian Constitution and other legislation provide directly and indirectly for the advancement of persons who have been socially, economically or educationally disadvantaged by past discriminatory laws or practices or for the implementation of policies and programmes aimed at redressing social, economic or educational imbalances in Namibia, arising from discriminatory laws or practices.

### SUMMARY OF SUBMISSIONS

Persons with albinism have difficulties getting jobs due to their physical appearance, poor eyesight, lack of sufficient skills, educational background and limited work experience. Overall the rate is higher for females than males across all disability types. Females with albinism account for the highest unemployment rate among persons with disabilities at over 50%.<sup>68</sup>

The following employment issues were raised during the public hearings:

- Participants narrated the forms of discrimination they faced, which included unfair labour practices, stigmatisation and name-calling within the workplace.
- Most employment adverts in Namibia encourage persons with disabilities to apply, but no reasonable accommodation is provided during the interviews.
- Persons with disabilities often avoid indicating their disabilities and reasonable accommodation needs in job applications, which is often used to disqualify them.
- Lack of education, relevant skills and work experience continue to be stumbling blocks. For instance, during the Windhoek public hearings, a young woman with albinism stated that she was trained as an electrician at the Namibian Institute of Mining and Technology (NIMT) but could not find a job. She further said that a potential employer once told her that she was weak and could not work due to her sight.
- A participant in Windhoek pointed out that when they ask potential employers if they have a vacancy, they are immediately told there is no vacancy. However, they later learn they were discriminated against due to their condition.
- A female employee in the Kavango lamented that some workplaces have unfair labour practices where persons with albinism are paid less than other employees of the same rank.

### CONCLUDING OBSERVATIONS

The Namibian Government has adopted several measures to ensure fair and equal opportunities for all in the labour market, such as:

- Article 9 of the Namibian Constitution protects all persons from slavery and forced labour. Article 21 makes provision for all persons to practice any profession, occupation, trade or business, to

<sup>67</sup> Namibia 2011 Census Disability Report. p40.

<sup>68</sup> *Ibid.*

withhold their labour without being exposed to criminal penalties, and the freedom of association, which includes freedom to form and join associations or unions, including trade unions.

- The Namibian Constitution, under Article 23, further provides for affirmative action as follows:
  - 1) *The practice of racial discrimination and the practice and ideology of apartheid from which the majority of the people of Namibia have suffered for so long shall be prohibited and by Act of Parliament such practices, and the propagation of such practices, may be rendered criminally punishable by the ordinary Courts by means of such punishment as Parliament deems necessary for the purposes of expressing the revulsion of the Namibian people at such practices.*
  - 2) *Nothing contained in Article 10 hereof shall prevent Parliament from enacting legislation providing directly or indirectly for the advancement of persons within Namibia who have been socially, economically or educationally disadvantaged by past discriminatory laws or practices, or for the implementation of policies and programmes aimed at redressing social, economic or educational imbalances in the Namibian society arising out of past discriminatory laws or practices, or for achieving a balanced structuring of the public service, the defence force, the police force, and the correctional service.*
  - 3) *In the enactment of legislation and the application of any policies and practices contemplated by Sub-Article (2) hereof, it shall be permissible to have regard to the fact that women in Namibia have traditionally suffered special discrimination and that they need to be encouraged and enabled to play a full, equal and effective role in the political, social, economic and cultural life of the nation.*

This can be read with the Affirmative Action (Employment) Act, 1998 (Act No. 29 of 1998), which addresses the injustices of the past to place previously disadvantaged groups on equal footing with other groups in society for the full realisation of their rights. Section 17–19 of the Act guides employers to eliminate barriers against persons in designated groups to ensure that no person shall be denied an employment opportunity for reasons unrelated to ability.<sup>69</sup> Section 17(1), read with Section 17(2) (b), provides that an affirmative action measure includes “making reasonable efforts in the workplace to accommodate persons with disabilities”. Section 18(c) lists persons with disabilities as one of the designated groups requiring affirmative action. Furthermore, Section 19 provides for preferential treatment of such designated groups by a relevant employer in filling positions of employment by suitably qualified persons of these designated groups.

In addition, in Article 95 of the constitution, the State promises to enact legislation to ensure equality of opportunity and the implementation of the principle of non-discrimination in remuneration, provides for maternity and related benefits for women;<sup>70</sup> actively encourages the formation of independent trade unions to protect workers’ rights and interests, and promotes sound labour relations and fair employment practices<sup>71</sup> in adherence to and action following the international Conventions and Recommendations of the ILO.<sup>72</sup>

The article also stipulates that workers are paid a living wage adequate for maintaining a decent standard of living and enjoying social and cultural opportunities.<sup>73</sup>

69 See Section 17-19 of the Affirmative Action Act of 1998.

70 See Namibian Constitution Article 95(1)(a).

71 See Namibian Constitution Article 95(1)(c).

72 See Namibian Constitution Article 95(1)(d).

73 See Namibian Constitution Article 95(1)(i).



*Photograph taken at a public hearing*

- Section 5 of the Labour Act, 2007,<sup>74</sup> defines a person with disability and prohibits direct or indirect discrimination based on any degree of physical or mental disability in employment. The section further provides that it is not discriminatory to take any affirmative action measure to ensure that racially disadvantaged persons, women, and persons with disabilities enjoy employment opportunities at all levels of employment that is at least equal to those enjoyed by other employees of the same employer; and are equitably represented in the workforce of an employer. This is further echoed by Section 26(1)(a)(v) of the Employment Service Act, 2011 (Act No. 8 of 2011), which prohibits private employment agencies from discrimination in vacancy advertisements on the grounds of physical or mental disability.
- Paragraph 3.7 of the National Disability Policy of 1997 provides that employment policies shall be based on the principle of equal opportunity for all citizens and ensure that persons with disabilities have equal opportunities for productive and gainful employment in the labour market. The policy provides sheltered employment for people who, because of their disability or special needs, cannot obtain, keep, or cope with the demands of a job in a competitive labour market. This will take the form of sheltered workshops and/or work centres and prepare them, as far as possible, for employment in the open labour market.
- The Covenant on Economic, Social and Cultural Rights, which forms part of the domestic law in terms of Article 144 of the constitution, recognises the right to work and the right of everyone to the enjoyment of just and favourable conditions of work which ensures fair wages and remuneration for work of equal value without distinction of any kind; equal opportunities for everyone to be promoted in their employment to an appropriate higher level, subject to no consideration other than those of seniority and competency.
- Article 27 of the CRPD goes further to set out that State Parties shall:
  1. *Recognise the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities.*

<sup>74</sup> Labour Act No. 11 of 2007.

*State Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:*

- a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;*
- b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;*
- c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;*
- d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;*
- e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;*
- f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;*
- g) Employ persons with disabilities in the public sector;*
- h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;*
- i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;*
- j) Promote the acquisition by persons with disabilities of work experience in the open labour market;*
- k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.*

*2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.*

## RECOMMENDATIONS

- The State should ensure the implementation of the existing rich employment legal framework.
- Employers are encouraged to provide reasonable accommodation in consultation with persons with albinism to ensure their needs are adequately met.
- Persons with albinism are encouraged to report any form of discrimination within the employment sector to the Labour Commission, the Employment Equity Commission, the Disability Council and the Office of the Ombudsman.

- Finally, the Labour Commission plays a crucial role in implementing policies and laws to combat discrimination in employment. Therefore, the Labour Commission should:
  - create awareness among employers and employees of the prohibition of discrimination in employment<sup>75</sup> and the remedies available to victims of such discrimination;<sup>76</sup>
  - develop and disseminate programmes and strategies to eliminate disability-based discrimination in employment;
  - provide support for victims of discrimination; and
  - timeously resolve disputes relating to disability-based discrimination in employment through mediation, arbitration, and conciliation. Should these fail, assist employees who wish to enforce their rights through the courts to apply for legal aid.

## 4.6 Education

The right to education is a fundamental right. It enables persons to express and defend their other human rights. According to the Namibia 2011 Census Disability Report, the overall highest literacy rate for persons with disabilities was recorded among those with albinism at 85.1%. However, all persons aged 15 years and above were only asked whether they could read and write in any language with understanding; no test was done to determine their literacy level.<sup>77</sup>

*“The right to education is a fundamental right.”*

### SUMMARY OF SUBMISSIONS

Persons with albinism are often denied the enjoyment of their right to education due to discrimination, poor eyesight, the cost of medical care and the lack of reasonable accommodation within the education sector. Access to quality education for persons with albinism was a significant concern among the parents of children with albinism at the public hearings. The following challenges were noted:

- Some parents consider sending children with albinism to school a waste of time because “Nothing good can come from an albino”. This was especially noted during the public hearing in Rundu.
- Children with albinism are often not accepted in school, forced to change schools or drop out and abandon school due to mistreatment by teachers, and name-calling and bullying by other learners.
- During the Windhoek public hearings, it was alleged that a child with albinism was refused admission because other children threatened to leave the school if he was admitted. This was echoed by another participant who stated that a particular school discriminated against her child. She informed the panel that she had registered her child for Grade 1, and the child was admitted; however, on the first day of school, the teachers told her they did not know the child had albinism and based on that, they refused the child admission in the school.
- A participant in Okongo complained that school is a long distance from home, and hostel/boarding facilities are unavailable. Therefore, he must walk the long distance to and from school, continuously exposing himself to the sun.

<sup>75</sup> Section 5(2) of the Labour Act.

<sup>76</sup> Section 7 of the Labour Act.

<sup>77</sup> Namibia 2011 Census Disability Report. p36.

- Most public hearing participants complained about the lack of awareness about albinism in schools. They encouraged awareness programs to educate society on how to live in harmony with persons with albinism.
- Often, no reasonable accommodation is provided to assist children with albinism who have poor sight or to accommodate them to stay out of the sun during physical education.
- Some participants expressed disappointment with the free, universal and inclusive primary and secondary education system. They indicated that, since its introduction, schools have sent out long lists of school and cleaning materials that parents must buy. Most parents cannot afford to buy all the schools require and wonder what amounts to Namibia's free, universal and inclusive primary and secondary education.
- Some schools allow children with albinism to sit near the board. However, participants pointed out that this doesn't always help, especially if the board is not adequately cleaned or if red, yellow or green chalk is used. Sitting in front was reported to increase teasing. In addition, it is alleged that teachers frequently get annoyed by the number of times children with albinism ask for clarification because they cannot see what is written on the board clearly.

## CONCLUDING OBSERVATIONS

The right to education is guaranteed in Article 20 of the Namibian Constitution, read with the Basic Education Act, 2020 (Act No. 3 of 2020), which provides for free and compulsory basic education through accessible, equitable, qualitative and democratic education services and lifelong learning. It defines 'inclusive education', 'Socio-economically disadvantaged learner', and 'Special education needs'. It provides for the right to education for children with disabilities under Section 6(2)(c) and lists disability as a ground for non-discrimination under Section 7(1)(b). It goes on to provide for the special needs of learners with disabilities in Section 12 and the need to include disability-friendly and gender-sensitive or responsive infrastructure in Section 34(4)(i). Another feature of the Act is the assessment of the implementation and effectiveness, and efficiency of any programme of education which has been devised in respect of individual learners with disabilities or special educational needs.

In Section 87(2)(a), the Act further provides that a parent may apply for homeschooling in a situation where health or disability exists that prevents the learner from attending or fully benefiting from regular school attendance. For each region, the Minister is required to establish a regional education forum, for which the National Disability Council must nominate three persons to represent persons with disabilities.<sup>78</sup> The Education Board should consist of not less than 20 and not more than 30 members, including all regional directors and other members appointed by the Minister and one person representing persons with disabilities.<sup>79</sup> Finally, Section 114(1) states that in teachers' recruitment, promotion, transfer and employment termination, a person may not directly or indirectly discriminate against another person based on disability amongst other statuses.

Other educational policies and laws include:

- The Sector Policy on Inclusive Education 2013 directs the education sector to adopt flexible and holistic approaches to budgeting, programme planning and development and to monitor and evaluate purposefully to create an inclusive education system.

<sup>78</sup> Section 96(4)(p) of the Basic Education Act, 2002.

<sup>79</sup> *Ibid.* Section 99(1)(m) subject to subsection (5).

- The National Policy on Disability (1997) stresses that the government shall ensure that children and youth with disabilities have the same right to education as children and youth without disabilities.
- The National Policy on Special Needs and Inclusive Education (2008) ensures that the regular school system meets the diverse educational needs of all children and increases the opportunities available to students with disabilities.
- The National Integrated Early Childhood Development Policy of 2007 was supported by the National Policy on School Health of 2008.
- The National Agenda for Children.
- The Educational Sector Policy on Orphans and Vulnerable Children.
- The Educational Sector Policy for the Prevention and Management of Learner Pregnancy aims to promote the continued education of pregnant learners, inclusive of both girls and boys.
- Regulations derived from Section 14 of the Namibian Qualifications Authority Act, 1, 1996 (Act No. 29 of 1996) require that the accreditation of institutions and organisations, learning facilities, resources and contexts, and all buildings and facilities be capable of accommodating the needs of persons with disabilities.<sup>80</sup>
- Free, inclusive primary education (from 2013) and secondary education (from 2016).
- Other measures include mobile schools (to provide for children from nomadic communities), school feeding programmes, and financial assistance for learners from the San Community.

The above laws and policies align with Article 17 of the African Charter on Human and Peoples' Rights and Article 11 of the African Charter on the Rights and Welfare of the Child. Article 13 of the United Nations International Covenant on Economic, Social and Cultural Rights also recognises the right to education.

Furthermore, learners with disabilities who manage to proceed to institutions of higher learning are also beneficiaries of the government's student financial assistance through the Namibia Student Financial Assistance Fund (NSFAF).

It should be noted that the State faces challenges in providing visual aids for children with albinism due to numerous factors such as costs and technical understanding of how to fully provide for their specific visual needs. It is therefore recommended that:

- Ministries of both Basic and Higher Education should be more accommodating, especially during examinations, by providing increased writing time or a bigger font size, especially for graphs, maps and math diagrams that are usually unclear.
- Any reasonable accommodation measures should be done in consultation with the specific child or persons with albinism, as their needs may differ.

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*...the State faces challenges in providing visual aids for children with albinism due to numerous factors...*

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<sup>80</sup> Section 2(f) of the Regulations for the Accreditation of Persons, Institutions or Organisations promulgated under Government Notice 124 of 2006.

- Parents of children with albinism and persons with albinism themselves are encouraged to report all discrimination issues within the education sector to their specific regional educational offices, the Disability Council and the Office of the Ombudsman.

## RECOMMENDATIONS

Albinism is an inherited and manageable condition. If progress in learning seems slow, it might be due to factors raised above, which can act as barriers to learning and development. Schools can provide inclusive education by overcoming such obstacles to learning through raising awareness among teachers and learners on medical conditions, disabilities and associated prejudices, and with a few classroom adaptations. Any mainstream school can accommodate and support learners with albinism to participate fully.<sup>81</sup> Principals and teachers must:

- *Be aware that learners with albinism may try to remain invisible to counter their highly visible condition. They may remain silent about their needs so as not to draw attention to themselves. With this understanding and sensitivity, it is important for teachers to open up conversations with learners with albinism to gain insight into their real and particular difficulties. This approach may open-up the possibility of trusting relationships being built between teachers and the learners.*
- *Ensure that learners with albinism are not made to feel different from other learners. Most learners experience some type of difficulty and barrier to learning.*
- *Adjust the lighting in the classroom. Learners with albinism need to avoid glare from the sunlight coming in through the side windows and overhead lighting. If the classroom has two fluorescent lights, learners should sit in between them to avoid casting shadows on their books.*
- *Ensure that learners with albinism do not sit near the window in direct sunlight. Encourage learners to wear large-brimmed hats or garments with hoods that can be pulled over the head to help reduce the glare.*
- *Write in big, clear handwriting on the board using white chalk, which is easiest to read against a green or black background. Avoid using different coloured chalks because they are less visible.*
- *Ensure that learners with albinism sit in the front of the classroom, in the position where they best see their teacher and the writing on the board. Allow learners to walk up to the board to copy notes without obscuring any learner's view.*
- *Make sure that a learner with big, easy-to-read handwriting sits next to a learner with albinism. Allow extra time for note taking because learners with albinism may take more time to copy notes. Encourage note sharing.*
- *When resources like books are shared, learners with albinism should be given their own copy so they can hold it close to their eyes.*
- *When notes are presented on an overhead projector or power-point, prepare separate large-font handouts for learners with albinism who may struggle to see the information on an overhead projector because it is light based.*

81 *Understanding Albinism: An inherited and manageable condition and disability*; Human Rights Media Centre Cape Town, 2014, 57-63.

- *Apply for extra time for tests and examinations for learners in primary and high school at the Ministry of Education if needed.*
- *Apply for large-font question papers from the Ministry of Education when learners write national assessments in primary and high school.*
- *Maximise interactive teaching methods and group work that foster inclusivity through participation and teamwork.*
- *Plan lessons carefully and think creatively about how best to relay information to partially sighted learners. Reflect on methods used and improve on them.*
- *Encourage a 'no hat no play' policy in the school generally. Encourage learners with albinism and their friends to play in the shade during break times, alternatively, indoors, especially during hot summer months.*
- *Ensure learners with albinism wear long-sleeved shirts and long pants, i.e. the winter school uniform, throughout the year. Learners should also be encouraged to wear a large-brimmed hat or 'hoodies' when outdoors, garments with hoods, to provide protection to the head, neck and ears. Bear in mind that peer image is important; learners are unlikely to wear protective clothing they consider unfashionable or conspicuous.*
- *Set a good example. Be aware that teachers are role models inside and outside the classroom. Teachers should examine their own prejudices honestly.*
- *Challenge discriminatory attitudes and behaviours displayed in the classroom and school grounds. Outlaw name-calling on school grounds. Outlaw name-calling and bullying; neither should be tolerated.*
- *Encourage parents or guardians of learners with albinism to be involved in school activities and meetings. Stay in regular contact to listen and share suggestions helpful to learner's progress.*
- *Initiate school projects to sensitise and inform everyone about albinism.<sup>82</sup>*

## 4.7 Health

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The lack of melanin in the skin and poor eyesight makes persons with albinism highly dependent on the health sector. The absence of melanin renders persons with albinism highly vulnerable to the sun's harmful ultraviolet (UV) rays and can result in skin cancer. UV radiation is a natural energy produced by the sun, two types of which are proven to contribute to skin cancer risk. The longer wavelength Ultraviolet A is associated with skin ageing, while the shorter wavelength Ultraviolet B is associated with skin burning. The two UV rays damage the DNA in skin cells resulting in genetic defects and mutations which cause skin cancer, premature ageing, cataracts and eyelid cancers.<sup>83</sup>

82 *Understanding Albinism: An inherited and manageable condition and disability*; Human Rights Media Centre Cape Town, 2014. pp57-63.

83 *UV Radiation & Your Skin. The Facts. The Risks. How They Affect You.* Available at <https://www.skincancer.org/risk-factors/uv-radiation/>. Accessed 13 May 2021.

## SUMMARY OF SUBMISSIONS

Several issues were raised during the public hearings that affect persons with albinism's full enjoyment of their right to health. These issues have been captured as follows:

### Continuous exposure to the sun:

- This damages the skin of persons with albinism, creating boils and sores. Numerous participants stated that if such sores and boils are not treated, they worsen and produce a foul smell. This often leads to abandonment and neglect by friends and family members.
- Leads to skin cancer which is painful, life-threatening and costly to treat. According to Dr Emvula,<sup>84</sup> many children with albinism currently have skin cancer, especially in Rundu. A small number of them are sent to Windhoek for treatment, but often too late. Some children often do not go back to the hospital for their follow-ups, which makes it difficult for them to get better treatment. Persons with albinism become ill because of a lack of proper health care and lack of sunscreen lotion. Nurses at clinics and hospitals often take too long to attend to them and refer the patient for appropriate treatment at the cancer centre. Dr Emvula added that most persons only seek help when their cancer has already spread. The oncologist further stated that some health workers keep dressing wounds of persons with albinism which may have become cancerous, without referring them for further examination and testing.

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...which may have become cancerous. without referring them for further examination and testing.”

### Treatment by health care workers:

- Participants in most public hearings complained of the long distances they must travel to get their sunscreen lotion from hospitals. Some clinics sent persons with albinism to other health care centres due to a lack of sunscreen stock, which adds to travel distance and costs.
- During the Windhoek public hearings, a parent stated that after she gave birth to her child with albinism, nurses mistreated her and made negative comments about her child's condition. This was also echoed by a young mother in Swakopmund, who shared how nurses mistreated her from the day she went into labour. They gossiped about her in Damara>Nama, a language she understood, and talked among themselves about her discharge being abnormal and that they had never seen anything like that. The young mother was frightened, and no explanation was provided. Upon giving birth to her baby boy, the nurse kept asking her, “What is this? What are you doing smiling at that thing?” The nurse humiliated her, and she was traumatised. Two days later, a social worker was called to assist, but the nurses continued to call her all sorts of names and referred to her baby as ‘that thing’. Some family members also made her feel terrible. An aunt who visited her in the ward asked her, “Owadala ekishi hano?” (Oh, you give birth to an albino.) The child's father also asked her, “What is this?” He refused to accept the child. Her mother was her light. She prayed for her and motivated her by stating that there was nothing wrong with the child. She explained that the child's skin was just a bit sensitive. She also talked to the baby's paternal grandparents, who accepted the child.
- In Opuwo, it was further mentioned that poor service at health care facilities, as well as mistreatment and humiliation by healthcare providers, deters persons with albinism from seeking medical

84 Oncologist at the Cancer Centre, Windhoek Central Hospital.

assistance. Most participants also believed this might be one of the main reasons most children with albinism die young.

Most people still do not believe albinism can be manageable with the necessary care and support.

## CONCLUDING OBSERVATIONS

The right to health is not explicitly provided under Chapter 3 of the Namibian Constitution. It falls under the Principles of State Policy in Article 95 of the Namibian Constitution, which requires that government policies focus on every citizen's right to "fair and reasonable access to public facilities and services", "an acceptable level of nutrition and standard of living of the Namibian people" and that there must be efforts made to "improve public health". The following measures support this:

- The National Health Policy Framework 2010–2020.
- The National Guidelines for Adolescents Living with HIV.
- The policy on the Prevention Management of Learner Pregnancy.
- Educational Sector Policy on HIV.
- Adolescent Friendly Healthcare Guidelines and National School Health Policy.
- Hospitals and Health Facilities Act, 1994 (Act No. 36 of 1994) empowers a health inspector, in terms of Section 10(2)(ii), to enter the premises of a health facility to ascertain whether such facility is adequately equipped, adequately staffed and is conducted in a manner conducive to the physical, mental and moral welfare of its patients and staff.
- National Health Act, 2015 (Act No. 2 of 2015) provides the framework for Namibia's structured uniform health system. Section 53 establishes a Fund for persons who may need special medical treatment. Section 47(2) of the Act further provides that a guardian or curator should classify persons with disability, and Section 63 provides research into diseases, mental illnesses and other medical conditions.
- Public health services are provided through 30 district hospitals, 44 health centres, 269 clinics, about 1,150 mobile outreach points, three intermediate hospitals and one national referral hospital.<sup>85</sup>
- The Namibia Household Income and Expenditure Survey of 2015/2016 indicate that 33.1% of households in Namibia travel less than one kilometre to the nearest hospital or clinic, while 32% travel between two and five kilometres. 13.3% of households travel between 11 to 40 kilometres to the nearest health facility, while 4.6% are more than 40 kilometres away from the nearest health facility. Urban households travel shorter distances compared to those in rural areas.<sup>86</sup>
- Free medical care for persons with disabilities in all State health facilities.
- Sexual reproductive and family planning care.
- Skincare, sunscreen and moisturising cream.
- Dermatologists and cryotherapy services at designated State hospitals.

85 Demographic and Health Survey 2013. <https://dhsprogram.com/pubs/pdf/fr298/fr298.pdf>. Accessed 23 May 2021. p3.

86 Namibia Household Income and Expenditure Survey (NHIES) 2015/2016 Report. Available at <https://nsa.org.na/microdata1/index.php/catalog/28/related-materials>. Accessed 22 October 2020. p64.

- Free skin cancer treatment and care at the Dr Bernard May Cancer Centre at the Windhoek State Hospital. Private cancer care is also provided at private oncology centres at their own expense for those who prefer private care.
- Free eye care is provided at State eye clinics. Private eye care providers are available at their own expense.

The above measures are further supported by various international conventions and covenants, which in terms of Article 144 of the constitution, are part of our domestic law. These include:

- Article 25 of the CRPD provides that *States Parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:*
  - a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;*
  - b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons;*
  - c) Provide these health services as close as possible to people's own communities, including in rural areas;*
  - d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care; [emphasis added].*



Photograph taken at a public hearing

e) *Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;*

f) *Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability. Requires healthcare services to make provision for the care of the same quality to persons with disabilities as it does to everyone else based on free and informed consent.*

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*... everyone has the right to the highest attainable standard of physical and mental health...*”

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- Article 12 of the United Nations International Covenant on Economic, Social and Cultural Rights (ICESCR) provides that everyone has the right to the highest attainable standard of physical and mental health and that each country that has ratified the covenant must take steps toward achieving the full realisation of these rights. Article 12 can be read with the Committee on Economic, Social and Cultural Rights General Comment No. 5<sup>87</sup> and General Comment No. 14,<sup>88</sup> which recognise the application of ICESCR concerning persons with disabilities. It also affirms that the right to health extends to timely and appropriate health care and the underlying determinants of health. General Comment No. 14 confirms that the right to health is not just a right to be ‘healthy’ but rather a right to facilities, goods, services and conditions conducive to realising the highest attainable physical and mental health standards.

## RECOMMENDATIONS

Concerns raised by participants indicate possible shortcomings of the Namibian health systems for persons with albinism. It is therefore recommended that:

- Persons with albinism are referred for biopsies as soon as possible so that, if detected, cancer can be treated as early as possible.
- Health providers should raise awareness and educate health workers to ensure persons with albinism are treated with respect and dignity.
- Health providers must be educated on counselling or assisting mothers who give birth to children with albinism.
- Educational information booklets and posters should be readily available at health facilities, especially in maternity wards, to educate expecting mothers on albinism and how to care for children with albinism.
- Sunscreen should be distributed to all levels of the health care system, including mobile clinics, to reduce travel distance and costs.
- Finally, parents are encouraged to take extra care of their children with albinism from birth and encourage such children to wear sun protective clothing and sunscreen at all times.

87 CESCR General Comment No. 5: Persons with Disabilities Adopted at the Eleventh Session of the Committee on Economic, Social and Cultural Rights, on 9 December 1994 (Contained in Document E/1995/22). Available at <https://www.refworld.org/pdfid/4538838f0.pdf>. Accessed 16 August 2020.

88 CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12). Adopted at the Twenty-second Session of the Committee on Economic, Social and Cultural Rights, on 11 August 2000 (Contained in Document E/C.12/2000/4) <https://www.refworld.org/pdfid/4538838d0.pdf>. Accessed 16 December 2020.

## 4.8 Women and Children with Albinism

Due to cultural practices, myths, stereotypes and a lack of understanding of their rights, women and children with albinism face numerous challenges, including abuse, abandonment, displacement and loss of inheritance.

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*Children with albinism are often abandoned by their families.*

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### SUMMARY OF SUBMISSIONS

The challenges faced by women and children with albinism noted during the public hearings included the following:

#### Children with albinism

- Children with albinism are often abandoned by their families.
- They are often not adequately cared for when they are sick. During the Okongo public hearing, a participant alleged that some parents do not see the need to spend money on the medical needs of children with albinism, as such expenses are endless.
- It was alleged during the public hearings in Rundu that, in the olden days, children with albinism were killed at birth. A young man in Eenhana stated that his mother wanted to kill him, but his grandmother protected him. Other family members discriminated against him, calling him names and refusing to share utensils with him. An elderly midwife from Eenhana informed the panel that she believes that such killings may still be happening in remote areas. She assisted a family from the San community in her area by delivering two healthy children on different occasions. Both children had some form of albinism or skin issue. When she visited the new mother for follow-ups, she was told that the children had died. She has no proof but believes that they were murdered. She added that when the couple had a third child with a similar condition, she took the child into her care without being granted guardianship or fostering by the necessary authorities, as she feared for the child's life. She is aware that she may be committing a crime by keeping the child, but she does not know how else to assist.
- The public hearings highlighted that women are often ill-treated and blamed for bearing a child with albinism. This leads them to be divorced or abandoned by their partners. A participant from Walvis Bay stated that she had to endure blame from her in-laws for bearing a child with albinism. She added that the treatment from society was so bad and hurtful. She was ridiculed and called names even by close friends and relatives. However, despite the discrimination and taunting she receives, she loves her child. This story is similar to that of other mothers who attended the sessions. A woman narrated that after she had given birth, a friend told her that she was “very strong” because after giving birth to a child with albinism, she still managed to smile. “She made it seem as if my child was a burden.”
- Some children with albinism do not have official identity documents such as birth certificates and IDs, as fathers often refuse responsibility for a child with albinism. Mothers struggle to register their children as the fathers refuse to provide their identity documents.

### Women with albinism

- It is believed that having sex with a woman with albinism (regardless of whether or not you are married to them) brings good luck.
- It was alleged that the right to family is often denied as families often refuse potential spouses who have albinism or those with a child or family member with albinism.
- Some persons with albinism are forced into relationships and marriages against their will, as it is believed that they will not find a suitable partner.

## CONCLUDING OBSERVATIONS

The concluding observations by the panel on challenges faced by children and women with albinism are as follows:

### Children with albinism

- Article 15 of the Namibian Constitution provides for the rights of children as follows:
  - 1) *Children shall have the right from birth to a name,<sup>89</sup> the right to acquire a nationality<sup>90</sup> and, subject to legislation enacted in the best interests of children, as far as possible, the right to know and be cared for by their parents.*
  - 2) *Children are entitled to be protected from economic exploitation and shall not be employed in or required to perform work that is likely to be hazardous or to interfere with their education, or to be harmful to their health or physical, mental, spiritual, moral or social development. For the purposes of this Sub Article children shall be persons under the age of sixteen (16) years.*
  - 3) *No children under the age of fourteen (14) years shall be employed to work in any factory or mine, save under conditions and circumstances regulated by Act of Parliament. Nothing in this Sub-Article shall be construed as derogating in any way from Sub-Article (2) hereof.*
  - 4) *Any arrangement or scheme employed on any farm or other undertaking, the object or effect of which is to compel the minor children of an employee to work for or in the interest of the employer of such employee, shall for the purposes of Article 9 hereof be deemed to constitute an arrangement or scheme to compel the performance of forced labour.*
  - 5) *No law authorising preventive detention permits children under sixteen (16) years to be detained.*
- Paragraph 2.5.2 of the National Disability Policy (Children with Disabilities) states that:
 

*Parents of children with disabilities shall be provided with information about services available so that they can make informed decisions about the needs of their children in cases where these children cannot do so themselves. Early intervention, such as early stimulation and education shall be provided to children as early as possible in order to prevent developmental disabilities. The State shall ensure that children with disabilities have equal opportunities and equal access to education, sports and recreation and all other services in the community such as health care. Boys and girls shall have equal rights.*

89 See Section 10(3) of the Births, Marriages and Deaths Registration Act No. 81 of 1963 that allows a mother to register a child's birth under her family name.

90 See also Article 4 of the Constitution of the Republic of Namibia.

- The Maintenance Act of 2003 places a duty on both parents to maintain a child. Section 16(4) of the Act lists factors the courts must consider where a beneficiary under the Act has disabilities. These factors include the extent of the disability, the life expectancy of the beneficiary, the period that the beneficiary would in all likelihood require maintenance and the costs of medical and other care incurred by the beneficiary as a result of the disability. Even if the current age of majority is 18 in terms of Section 10 of the Child Care and Protection Act of 2015, subsection 9 emphasises that the section does not affect the liability of any person to pay maintenance under any agreement or order which is in force before the commencement of this section. However, the Ombudsman pointed out that the start of this section does not affect a person's liability to pay maintenance if the person being maintained is still a dependent, e.g. still in school.
- In Section 2(1)(j) of the Child Care and Protection Act, the special needs of children with disabilities are recognised. Section 5(2)(d)(i) of the Act protects all children from direct and indirect discrimination, which is further supported by Section 5(2)(f), which ensures that all proceedings, actions, or decisions in matters concerning a child must respond to any special needs that the child may have as a result of a disability. Section 9 of the Act makes specific provisions for children with disabilities, ensuring prevention and early intervention services and catering for children's special needs. The Act provides a Children's Advocate in the Ombudsman's office<sup>91</sup> to look after children's rights and related issues. The Children's Advocate is mandated with receiving and investigating complaints concerning children, monitoring the implementation of international child laws binding on Namibia, taking child-related matters to court and monitoring childcare facilities.<sup>92</sup> In addition, the Act prohibits harmful practices that affect girls' rights, such as child marriage, early sexual activities and childbearing. It further enables a child aged 14 years or older to consent to medical intervention and surgical operation under Section 220.
- The above measures are further supported by Article 7 of the CRPD, which states that:

*State Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration. State Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right.*
- The CRPD further provides in Article 23 (2)–(5) that in cases where the immediate family is unable to care for a child with a disability, governments are required to:

  2. *Ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties*

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... the Act prohibits  
harmful practices that  
affect girls' rights... ”

91 Ms. Ingrid Husselmann was appointed as Child Advocate and the Deputy Chief. She is the head of the Human Rights and Legal Services Division in the Office of the Ombudsman effective 1 November 2018.

92 See the Ombudsman Annual Report 2017 p18-22.

*shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.*

3. *State Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realising these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, State Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.*
  4. *State Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.*
  5. *State Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.*
- Finally, Article 23 of the Convention on the Rights of the Child provides that:
    1. *State Parties recognise that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.*
    2. *State Parties recognise the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.*
    3. *Recognising the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.*
    4. *State Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling State Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.*

#### **Women with albinism**

- Article 4 of the Namibian Constitution provides that all Namibians are entitled to have birth certificates, marriage certificates, identity documents, passports, citizenship, and to be given a name and nationality.

- Article 14 of the Namibian Constitution provides that men and women of full age, without any limitation due to race, colour, ethnic origin, nationality, religion, creed or social or economic status, shall have the right to marry and found a family. Article 14, read with the Married Persons Equality Act, 1996 (Act No. 1 of 1996), provides for equal rights to marriage, during marriage and at its dissolution, and this applies to all persons.
- The National Disability Policy of 1997, under paragraph 3.12, provides for family life and personal integrity and holds that the State shall promote the full participation of persons with disabilities in family life. The Policy dictates that the State shall promote the right to personal integrity and ensure that the laws do not discriminate against persons with disabilities concerning their sexuality, marriage, and parenthood. Persons with disabilities are particularly vulnerable to abuse and violence within the family, community, and institutions. The State must ensure that measures are taken to prevent abuse and violence against them. Adequate counselling and support services are to be provided for those who become victims of violence or abuse.
- Other gender-sensitive procedures in place for women include the 15 specialised Gender Based Violence Investigation Units in 14 regions supported by the National Gender Policy (2010-2020); the National Plan of Action on Gender-Based Violence; the Combating of Rape Act, 2000 (Act No. 8 of 2000) and the Combating of Domestic Violence Act, 2003 (Act No. 4 of 2003).
- Article 6 of the CRPD requires:
  1. *State Parties recognise that women and girls with disabilities are subject to multiple discrimination and, in this regard, shall take measures to ensure their full and equal enjoyment of all human rights and fundamental freedoms.*
  2. *State Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women to guarantee the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.*

In addition, Article 23 of the CRPD read with Article 16 of the Convention on the Elimination of All Forms of Discrimination against Women and Article 6 of the Protocol to the African Charter on Human and People's Rights on the Rights of Women in Africa also provides that:

*State Parties shall take effective and appropriate measures to eliminate discrimination against women with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others.*

## RECOMMENDATIONS

- Parties interested in taking any child into their care should ensure that they follow the correct procedures. They can approach the nearest magistrate's office or the Ministry for Gender Equality and Child Welfare.
- Nothing in the law prevents a parent from registering the birth of a child. Specifically, nothing in the Births, Marriages and Deaths Registration Act 81 of 1963 prevents a parent from registering the birth of a child. Mothers can register the child in their name, and the space for the father's details can be left blank. The birth certificate can be altered later to include the father's details if he so wishes.

# 5

## GENERAL RECOMMENDATIONS

**THE MANDATE OF THE OMBUDSMAN** to receive public complaints on human rights violations enables the Ombudsman to be the watchdog for the people and to hold the government accountable for its actions. The Ombudsman will submit this report to appeal to the government of Namibia to implement proactive measures to ensure that the rights of persons with albinism are protected, respected and upheld. The Ombudsman remains available to work with the government to build capacity and develop policies and practical measures to fill societal gaps, including developing important educational tools to denounce and correct social myths and cultural practices. In addition, the following avenues are also available should persons with albinism seek redress for any grievances:

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*The Ombudsman will submit this report to appeal to the government of Namibia...*

”

- The courts: Article 25(2)–(4) of the constitution provides that:

*(2) Aggrieved persons who claim that a fundamental right or freedom guaranteed by this Constitution has been infringed or threatened shall be entitled to approach a competent Court to enforce or protect such a right or freedom, and may approach the Ombudsman to provide them with such legal assistance or advice as they require, and the Ombudsman shall have the discretion in response thereto to provide such legal or other assistance as he or she may consider expedient.*

*(3) Subject to the provisions of this Constitution, the Court referred to in Sub-Article (2) hereof shall have the power to make all such orders as shall be necessary and appropriate to secure such applicants the enjoyment of the rights and freedoms conferred on them under the provisions of this Constitution, should the Court come to the conclusion that such rights or freedoms have been unlawfully denied or violated, or that grounds exist for the protection of such rights or freedoms by interdict.*

*(4) The power of the Court shall include the power to award monetary compensation in respect of any damage suffered by the aggrieved persons in consequence of such unlawful denial or violation of their fundamental rights and freedoms, where it considers such an award to be appropriate in the circumstances of particular cases.*

- The National Disability Council can make representations on behalf of any person with a disability before any organ of the state, or provide or procure legal assistance for any persons with disabilities, if the matter in question relates to the rights of, or the integration of, persons with disabilities in society under Section 4(1)(c) of the National Disability Council Act (Act No. 26 of 2004). Section 17 of the Act further calls upon every Executive Director of any ministry, within 90 days after the end of each financial year, to submit or cause to be submitted to the National Disability Council a report on the implementation of the National Policy on Disability in their ministry.

- The State, in terms of the Legal Aid Act, 1990 (Act No. 29 of 1990) in line with Articles 12–13 of the CRPD, provides for legal aid in civil and criminal matters to persons (including persons with disabilities) whose means are inadequate to enable them to engage legal practitioners to assist and represent them.
- The Labour Commission and the Employment Equity Commission can address workplace discrimination complaints, including discrimination based on disability.
- Community Courts.
- The Namibian Police.

Finally, the Ombudsman further recommends the following general recommendations:

- The ministry responsible for disability affairs should publicly recognise and announce in writing that persons with albinism require assistance and are to be provided for in terms of the general disability framework.
- Likewise, this ministry should design and promote programmes for raising public awareness and changing public attitudes towards persons with albinism.
- The Ministry of Health and Social Services should provide programme-based training on albinism for its entire staff, especially those in clinics, casualty and maternity wards.

# 6

## CONCLUSION

**PERSONS WITH ALBINISM IN NAMIBIA** continue to face numerous challenges and discrimination. Therefore, continuous protection and more awareness campaigns for the public and service providers are needed. Government agencies responsible for disability issues must include, in their following budget motivation, a request for financial allocation to conduct extensive nationwide education campaigns on the rights of persons with disabilities in general, with a special focus on persons with albinism. There has been an increase in discrimination cases experienced by persons with albinism across the regions, which needs to be addressed as part of the government's implementation of its obligations under the CRPD. As seen from the discussions in this report, persons with albinism lack the minimum adequate means to live a quality and dignified life.

“

*There has been an increase in discrimination cases experienced by persons with albinism...*”

”

In conclusion, a person's dignity and value as a human being are manifested in the realm of a person's rights. Therefore, the constitution must be interpreted to afford persons with albinism the full measure of protection of the rights set out in the Bill of Rights.<sup>1</sup> Concerning equality, the Court in *McCoskar v The State* noted:

*Equality based on the premise of acceptance focuses on creating symmetry in the lived-out experiences of all members of society by eliminating the unequal consequences arising from difference... It affirms that difference should not be the basis for exclusion, marginalization, stigma...<sup>2</sup>*

Although the Namibian Constitution guarantees that all persons in Namibia be treated equally and free from discrimination, the reality faced by persons with albinism diminishes their entrenched human rights. It is therefore essential for the government to collaborate with organisations for persons with albinism/disabilities and international organisations to take cognisance of this report, and devise proper policy and social responses to the challenges faced by persons with albinism.

<sup>1</sup> *Alexander v Minister of Justice and Others* 2010 (1) NR 328 (SC) pp. 359-360.

<sup>2</sup> *McCoskar v The State* [2005] FJHC 500; HAA00 85 & 86.2005. Available at [www.humandignitytrust.org/wp-content/uploads/resources/Nadan\\_McCoskar\\_v\\_State.pdf](http://www.humandignitytrust.org/wp-content/uploads/resources/Nadan_McCoskar_v_State.pdf). Accessed 21 February 2021.

# ANNEXURE A



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## REPUBLIC OF NAMIBIA

### Ministry of Health and Social Services

Private Bag 13366  
Windhoek  
Namibia  
Enquiries: Mr. J. Haaeseb

Ministerial Building  
Harvey Street  
Windhoek  
Ref. No. :

Telephone: (061) 203 2350  
Telefax: (061) 203 2349  
International: 264 - 61 -  
Date: 28 April 2004

PEGGY EMYULA  
THE SECRETARY  
SINASRA  
P.O. BOX 1739  
WINDHOEK

#### **RE: PROVISION OF SUNBLOCK BY THE MINISTRY OF HEALTH AND SOCIAL SERVICES**

Thank you for your letter on the above-mentioned subject matter.

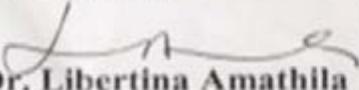
I would like to inform you that my Ministry is as concerned of albinism suffers as your organization is. In recognition of their plight we have added, in our latest edition of the Namibia Essential Medicines List (NEMLIST), **Mexenone cream** (a sunscreen cream) to be widely available.

In the past we did not make provision for such a cream and that is why, as rightly pointed out in your letter, clinics and health centers did not have stock of any sunscreen products. However this is a thing of the past as the Mexenone cream is now available at the lowest level of the primary health care chain, i.e. the clinics.

Let me make use of this opportunity to show our appreciation of the important role played by organizations, such as yours, in complementing my Ministry to achieve the objective of "Health for all Namibians".

Thank you for your understanding.

Yours Sincerely

  
**Dr. Libertina Amathila**  
Minister of Health and Social Services



*Forward with Health for all Namibians by the Year 2005!*



# ANNEXURE B

## **PUBLIC HEARINGS ON DISCRIMINATION AND OTHER CHALLENGES FACED BY PERSONS WITH ALBINISM**

The Ombudsman will be conducting formal hearings on discrimination against persons with albinism, customary practices and myths associated with persons with albinism, violence against persons with albinism and other challenges faced by them. The Ombudsman also invites proposals on how the issues could be addressed, either in new legislation or amending existing legislation or through any other appropriate means.

The public is herewith requested to participate in this important venture by making written presentations on the matter and submit it to the Ombudsman, through any of the following means:

- email to: [office@ombudsman.org.na](mailto:office@ombudsman.org.na)
- post to Private Bag 13211, Windhoek
- deliver in person to Office of the Ombudsman, cnr of Feld and Lossen Streets, Ausspannplatz, Windhoek
- Or to attend the public hearings at the following places and make oral submissions:

<b>DATE</b>	<b>VENUE</b>	<b>TIME</b>
29 July 2019:	Oshakati State Hospital	09h00-13h00
30 July 2019:	Eenhana State Hospital	09h00-13h00
31 August 2019:	Okongo District Hospital	09h00-13h00
1 August 2019:	Rundu State Hospital	09h00-13h00
5 August 2019:	Windhoek – Disability Resource Centre Okuryangava, Katutura	09h00-16h00

**For more information please visit our website: [www.ombudsman.org.na](http://www.ombudsman.org.na),  
find us on Facebook at Ombudsman Namibia or contact us on 20732111.**