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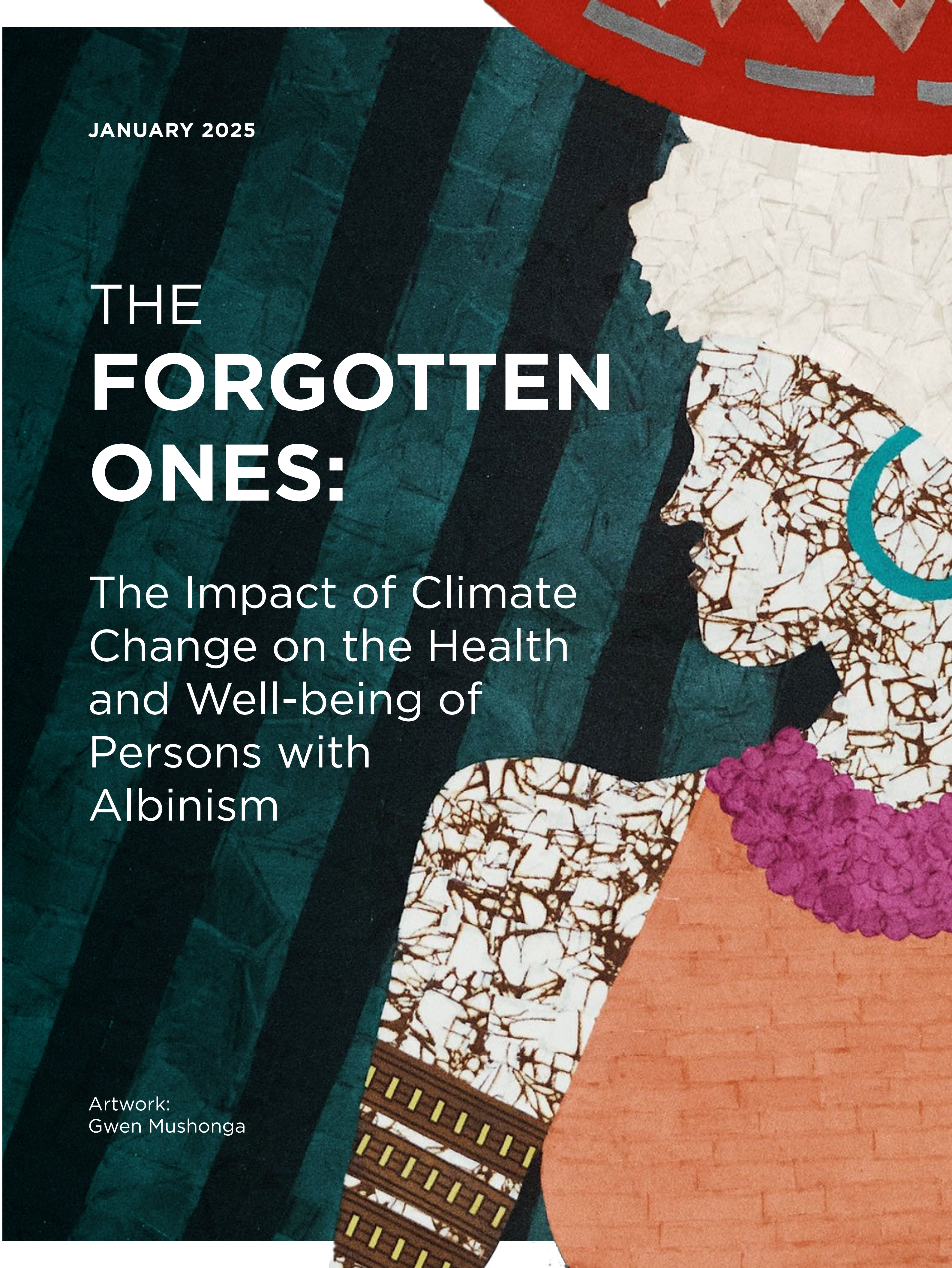
THE FORGOTTEN ONES:

The Impact of Climate Change on the Health and Well-being of Persons with Albinism



Artwork:
Gwen Mushonga

Acknowledgments

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Many thanks to artist Gwen Mushonga whose artwork transforms discarded African fabrics into evocative works that celebrate strength and identity. As a woman with albinism, Gwen reimagines these materials into powerful portraits and soulful creations, each telling a story of overcoming adversity and embracing one's true self.

> ***Most importantly we are deeply appreciative to everyone who trusted us with their stories.***

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We are grateful to Nadia Mutisi for her research support.

> **“[Persons] with disabilities form part of different sub-groups of marginalized and vulnerable populations, have different challenges to adapt to climate-induced disasters, and are not recognized in the sustainability research agenda.”[1]**

SUMMARY

Albinism is a rare genetic condition characterized by a lack of melanin, which results in severe sensitivity to ultraviolet (UV) radiation. For the almost 70,000 individuals with albinism in Zimbabwe,[2] climate change raises a number of challenges in their daily lives, impacting their enjoyment of basic human rights, such as the right to health, education, and work. Due to the unique color of their skin, persons with albinism are often ostracized in society and face pronounced levels of stigma and discrimination that harm their mental health. Climate change magnifies the human rights deprivations persons with albinism face.

The effects of climate change are increasing human exposure to ultraviolet radiation, and persons with albinism are at a disproportionate risk of the consequences. Workshop participants reported that climate change increased the risk of sunburn, a precursor to skin cancer, and highlighted the challenge of irregular access to sun protectants, such as sunscreen lotion, which was too expensive for many persons with albinism.

This report documents the findings from storytelling workshops held with 73 individuals comprising persons with albinism, and caregivers and guardians of children with albinism in Zimbabwe. The myriad of challenges persons with albinism face include climate-related health shocks, lack of adequate inclusive health care services, lack of access to inclusive education, and a heavy economic reliance on the informal sector, which increases their vulnerability to the impacts of climate change on health. Many individuals with albinism work as vendors or farmers, often in outdoor environments with limited access to shade and other protection. The need to work for economic survival conflicts with the risk of severe health consequences from environmental exposure.

Mothers who give birth to children with albinism are often abandoned by the fathers of their children. This abandonment leads to a disproportionate burden of care work for female-headed households. There is a disproportionate burden of care for female-headed households. The heightened demands of care work and the risk of abandonment can impact the mental health of both mothers and their children.

Discrimination based on skin color is a dominant experience for all persons with albinism regardless of age or any other status — negatively impacting their mental health and, in some cases, affecting both their health-seeking behavior and their ability to access quality health care services.[3] Persons with albinism reported facing persistent discrimination and stigma, both in social settings and within health care systems. They stated that health care providers often lack training on albinism and sometimes provide incorrect or dismissive care. In extreme cases, persons with albinism reported health discrimination, where health care professionals even refused to treat individuals with albinism due to misconceptions about the condition. The lack of inclusive health care services compounds the impact of climate change, making it even more difficult for individuals with albinism to access the care they need.

Women with albinism also face nuanced sexualized gender-based discrimination fueled by harmful myths and traditional beliefs. Mothers of children with albinism also suffer under the burden of the discrimination their children face, including ostracization from paternal relatives and rejection by their intimate partners.

Addressing these issues requires urgent action — a comprehensive, intersectional approach to health care and climate resilience, one that recognizes the unique vulnerabilities of persons with albinism.

To fulfill its national and international obligations, the government of Zimbabwe should consider implementing additional policy and legal measures to ensure that persons with albinism receive adequate care in health facilities, including accurate health information from health care providers and free access to skin cancer, screening, treatment and prevention measures, such as free access to sunscreen lotion. To address the disproportionate burden in the care economy and precarious work in the informal economy, the government must put in place social protection measures to support female-headed households of mothers of children with albinism to improve the welfare of women and children.

Climate change is a real and present threat to the well-being, health, and dignity of persons with albinism, and it is critical to create climate change-resilient health systems and policies to enable the enjoyment of the full range of human rights.

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Methodology

This report describes the impact of climate change on the human rights of persons with albinism, with a focus on Zimbabwe, which is ranked high on the Global Climate Risk Index[4] and is home to one of the largest populations of persons with albinism in the world.[5]

In June 2024, 20 leaders from nine nongovernmental organizations (NGOs) and trusts ("the collective"), all dedicated to supporting persons with albinism, and health lawyers from the O'Neill Institute for National and Global Health Law convened meetings to address the difficulties that persons with albinism experience and to deliberate about how climate change exacerbates these challenges.

The collective mobilized its members for storytelling workshops that enabled individuals with albinism and caregivers of children with albinism to share their experiences with climate change. The discussions were facilitated and led by the collective in both English and Shona, with interpretation provided as necessary. Discussions were semi-structured and covered topics related to living as a person with albinism in Zimbabwe, including issues related to discrimination, health, work, education, and the impact of climate change.

The discussions were held in a safe and private location with counselors from the collective on hand to provide moral support as participants shared their lived experiences. All participants were informed about the purpose of the discussions, how their stories would be used, and their participation was voluntary.

In total, the collective held six storytelling sessions and met with 73 participants, consisting of persons with albinism and caregivers of children with albinism. The goal was to hear the perspectives of people from different socioeconomic backgrounds, including age, gender, geography, and primary sources of livelihood. The collective had raised the importance of conducting workshops with individuals living in rural Zimbabwe. As such, workshops were held with participants from two urban communities (Epworth and Chitungwiza) and three rural areas (Zvishavane, Goromonzi, and Concession). The collective also convened one "women-only session" with students from the University of Zimbabwe and other early-career women.

While this report is based on conversations from the discussions with the collective and workshops with persons with albinism and parents of children with albinism in Zimbabwe, the needs, challenges, and recommendations that are discussed are relevant to persons with albinism across the African continent.

Background

Understanding Albinism

Albinism is a relatively rare, non-contagious genetic condition that affects people around the world, regardless of gender, race, or ethnicity. As a recessively inherited condition, anyone can carry the gene that causes albinism. If both parents carry the gene for albinism, there is a 25% chance their child will inherit the condition, regardless of whether the parents have albinism themselves.[6]

Albinism is characterized by a deficit in melanin, a photo-protective pigment that protects humans from the harmful effects of ultraviolet (UV) radiation.[7] The deficit of melanin production consequently results in a lack of pigmentation in the hair, skin, and/or eyes.

The lack of melanin in the eyes contributes to vision impairments ranging from mild to severe cases due to the presentation of hypoplastic fovea, photophobia, hyperopia, strabismus, nystagmus, and/or loss of stereoscopic perception.[8] As a result, many persons with albinism are extremely sensitive to bright light and have difficulty reading small text. While the impairments are permanent, eyeglasses, visual aids, and other adaptive devices can help with sight overall.

Persons with albinism are also vulnerable to sun exposure and face a higher risk of developing skin rashes, burns, and other skin malignancies,[9] including skin cancer, which can be a life-threatening condition.[10]

Because of the associated visual impairments and serious health implications due to vulnerability to skin cancer, persons with albinism are classified as persons with disabilities.[11] Under international law, disability is defined as "long-term physical, mental, intellectual, or sensory impairments which, in interaction with various barriers may hinder … full and effective participation in society on an equal basis with others."[12]

Africa, especially Southern Africa, has the highest prevalence of albinism, ranging from 1 for every 15,000 people to 1 for every 5,000 people.[13] Detailed epidemiological studies and disaggregated data are limited. However, it is known that the percentage of persons with albinism in Zimbabwe is one of the highest globally. It is estimated to be between 1 in every 2,000-4,000 people[14] and can reach 1 in 1,000 people in some communities across the country.[15]

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An Overview of Climate Change and Albinism

Climate change is increasing human exposure to UV radiation from the sun.[16] Ozone depletion and reduced cloud cover allows more radiation to reach the Earth's surface, and higher daily temperatures are believed to amplify the effects of this radiation on the skin.[17]

Daily human behavior also changes as people spend more time outdoors to make the most out of work opportunities due to reduced rainfall and economic disruptions — ultimately leading to greater exposure to UV radiation.[18]

Zimbabwe is highly vulnerable to climate change globally and ranks in the top three countries of Southern Africa on the Global Climate Risk Index.[19] The average annual temperature in the country is projected to increase by 1 to 1.5° by 2040,[20] with warming projected to increase through 2080.[21] Zimbabwe's geographical location makes it vulnerable to erratic rainfall, droughts, and vector-borne diseases.[22] Zimbabwe has been subject to El Niño events since 1982, which have been associated with prolonged dry spells, reduced rainfall, and increased temperatures, resulting in crop failures and significant health challenges.[23] Urgent action is needed to safeguard the most vulnerable groups, which include persons with albinism.

Climate change risks compound the range of human rights violations that persons with albinism already face throughout their lives, particularly breaches of the right to health. Exposure to UV radiation from the sun can cause damage to the skin, such as blisters, solar elastosis, and actinic keratosis. Additionally, they are at constant risk of developing skin cancer due to UV sun exposure.[24] Over time, the damage accumulates, leading cells to grow out of control and form tumors. Damage in this form can be permanent and ultimately lead to skin cancer.[25]

Compared to the general population, persons with albinism globally are much more likely to develop skin cancer from UV radiation exposure, with squamous cell carcinoma of the head and neck being the most prevalent.[26] Studies show that persons with albinism across Africa are up to 1,000 times more likely to develop skin cancer than the general population.[27] Furthermore, researchers estimate that 98% of persons with albinism do not live beyond the age of 40 due to sun exposure, with skin cancer being the primary cause of death.[28]

Legal & Policy Frameworks
Albinism Rights in Zimbabwe

Zimbabwe has taken important steps to safeguard the rights and dignity of persons with albinism through legislative and policy initiatives. However, there is room for further reform.

CONSTITUTION OF ZIMBABWE

Section 22 of Zimbabwe's Constitution mandates government ministries at all levels to recognize the rights of persons with physical or mental disabilities, in particular, their right to be treated with respect and dignity,[29] and to ensure that assistance is provided to enable members of the community to achieve their full potential and to minimize the disadvantages suffered by them.[30] In addition to ensuring all buildings and facilities are accessible to persons with disabilities, the Constitution requires ministries to mainstream the requirements of persons with disabilities in its development plans.[31]

Additionally, the Constitution guarantees the enjoyment of the following human rights based on the principles of non-discrimination,[32] respect for human dignity,[33] the right to life,[34] the right to work,[35] and the right to health,[36] among others.

DOMESTIC MEASURES IN ZIMBABWE

Zimbabwe has a National Disability Policy (NDP) that was launched in June 2021[37] to improve the well-being of persons with disabilities and their families in both rural and urban areas. The NDP also endeavors to strengthen the right to decent work, protect labor rights, and promote access to housing and health care, among others, for persons with disabilities.

In 2024, Zimbabwe launched the National Assistive Technology Strategy and Assistive Products Priority List for persons with disabilities.[38] Modeled after the World Health Organization's (WHO) priority list of assistive devices, the Zimbabwean priority list has pledged to support access to spectacles and magnifiers to address the vision needs of persons with albinism. The government has also classified sunscreen lotion as an assistive device, which is critical given the existing tax exemption for assistive technologies in the country[39] and may improve affordability.

Furthermore, new legislation related to provide disability protections is also under consideration. The Persons with Disabilities Bill (H.B. 2 of 2023)[40] has already undergone public consultations, and persons with albinism were able to make submissions for their recognition. Currently, section 35 (1) of the bill mentions the importance of protecting the right to health and providing support for persons with albinism.

REGIONAL HUMAN RIGHTS FRAMEWORKS ON RIGHTS OF PERSONS WITH ALBINISM

Within the regional human rights framework, Zimbabwe has ratified relevant treaties related to the rights of persons with albinism, including the African Charter on Human and Peoples Rights and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa ("Maputo Protocol").[41] In May 2024, the government of Zimbabwe ratified the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa ("African Disability Protocol").[42] The African Disability Protocol obligates states parties to mainstream disability in all spheres of life[43] and to provide assistance and support to enable persons with disabilities to realize their human rights.[44]

Additionally, at the Southern Africa Development Community (SADC) level, a declaration on the Protection of Persons with Albinism was issued in Harare, Zimbabwe, in August 2024 during a summit between heads of state and government.[45] Championed by activists advocating for albinism rights in Africa and globally, the declaration places a responsibility on SADC heads of state and governments to prioritize actions, including (i) conducting education and awareness-raising campaigns to address discrimination against persons with albinism, (ii) addressing issues relevant to the health and human rights of persons with albinism, and (iii) ensuring that sunscreen lotion is added to all essential medicines list and is available to all persons with albinism, including in the remotest regions.[46]

UNITED NATIONS AND INTERNATIONAL FRAMEWORKS PROTECTING THE RIGHTS OF PERSONS WITH ALBINISM

Persons with albinism are protected by all existing human rights treaties that guarantee human rights for all persons, including the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. Zimbabwe has also ratified treaties that afford protections to specific groups of persons, such as the Convention on the Rights of Persons with Disabilities (CRPD), the Convention on the Rights of the Child, and the International Convention on the Elimination of All Forms of Racial Discrimination.[47]

Persons with albinism have specific protections under the CRPD, which recognizes albinism as a disability.[48] As a state party to the CRPD, Zimbabwe must guarantee the right to the enjoyment of all human rights by persons with disabilities in the country, including the right to the highest attainable standard of physical and mental health, the right to inclusive education, to protect the family, the right to work, the right to life, and the right to equality and non-discrimination.

Zimbabwe is also a state party to the United Nations Framework Convention on Climate Change[49] (UNFCCC), a primary instrument to address climate change and its impacts globally. As such, Zimbabwe is obligated to create policies and measures to mitigate the adverse effects of climate change on human health and welfare. These policies and measures must also respect human rights, including the right to health for persons with disabilities and people in vulnerable situations.[50]

DATA ON PERSONS WITH ALBINISM IN ZIMBABWE

In addition to robust legal and policy frameworks, reliable and comprehensive data is important to support the protection and fulfillment of the human rights of persons with albinism. In 2022, Zimbabwe's Statistical Office ("ZimSTAT") included a question on albinism in the national census in a bid to improve its disaggregated data collection methods.[51] Before this change, persons with albinism were counted as a part of one homogenous group and designated as persons with disabilities, without capturing the nuances and diversity of the community. While this is a positive development, the government of Zimbabwe should continue to disaggregate data to understand the diversity of other disabilities, not just albinism, in Zimbabwe to improve access to services for all. The UN has noted that a growing number of African countries are beginning to include persons with albinism in their national censuses, which is a welcome development.[52]

Life as a Person with Albinism in Zimbabwe

Workshop participants reported facing high levels of discrimination rooted in cultural myths, such as the belief that persons with albinism are a curse from God or ancestral spirits and are not human beings, but "unfinished creatures."[53] Reportedly, women who give birth to children with albinism were blamed for the occurrence and accused of sin, adultery, or some other form of evil.

> **When I gave birth to my son, people in the community said I had sinned and that is why I gave birth to a child with albinism. People in my church would continually ask me, How do you accept the birth of such a child? People told me there was a curse on my family for giving birth to such a child and that I should confess my sins because this was not normal. People told me, "Do not let your child pass near my house.**

— Mother of a child with albinism from rural Zimbabwe

Stigma and discriminatory attitudes and behaviors permeate every facet of society — church, family, work, schools, and the general public. The dehumanization of persons with albinism is complex and ambiguous.[54] While they are discriminated against and shunned in society, they are also viewed as "lucky charms" that can bring wealth and good fortune. Some Zimbabweans view albinism as associated with *manjuzu* (water spirits/mermaids) known to bring blessings, such as good health and financial or material wealth. This has led to the abuse of persons with albinism in rituals intended to harness the powers of these "spirits."[55] Participants recounted experiences in their daily lives that affirmed the continued strength of the prevailing attitudes of both otherworldly reverence and loathing.

> **People believe that persons with albinism are supernatural beings that bring luck, or that if you make them happy, it brings you good fortune. A random vendor selling their wares in the city once asked me to touch or pray over their goods.**

— Young female university student with albinism

During the workshops, participants with albinism also reported being mocked or laughed at while walking in public or being touched without their consent by strangers. One young woman with albinism shared that growing up she was called *chidhoma* (an evil mythical being) or *chidhori* (a derogatory reference to cheap Caucasian plastic dolls commonly sold in Zimbabwe) and that other children lifted her dress to check for batteries. These experiences result in immense mental anguish, which in some cases can lead to self-discrimination.[56]

> **When I walk in public, people are always name-calling. I remember once wishing that God would change my skin color. But I decided that instead of looking down on myself, I would be the best and most successful version of myself.**

— Young female university student with albinism

Parents of children with albinism also reported discrimination against infants and young children by members of the public and, in some cases, by other children. Parents reported that they heard neighbors discourage their children from playing with a child with albinism or encountered name-calling of their child with the derogatory term *musope* — the correct designation is *munhu aneruvara*. The mental toll of bullying impacts both the children and caregivers.

> **When my child with albinism was born, I accepted her because my family has a history of persons with albinism. In fact, one of my brothers had a child with albinism, and my father-in-law is a man with albinism. My wife was worried that I would not accept my child, but I did. The biggest challenge I have faced is discrimination from our neighbors. One day I saw my daughter being followed by other children from her school who were name-calling and pushing her. It traumatized me deeply to see my daughter being treated this way. I ended up moving her from that (a government/public) school to a private school as I wanted her to have a better experience, where she would not experience abuse from other children.**

— Father of a child with albinism from a rural community

Women and girls with albinism, who face intersectional discrimination on the basis of sex, disability, and gender, often face the risk of sexual violence due to harmful myths, which fetishize their sexual prowess, and the false belief that sex with a female with albinism can cure HIV.[57]

> **I was walking at the taxi rank in Harare when touts began commenting loudly to each other about how "sweet" women with albinism are in bed. They were shouting to each other that if you get a woman with albinism, you will be very lucky. I felt ashamed and angry at the same time because of how they continued to loudly remark to each other in front of strangers. As an activist, this kind of behavior worries me because it places me and other women and girls at risk of sexual violence. Additionally, it makes it hard for us to form meaningful intimate relationships. We can never tell if a man without albinism is genuinely in love or just approaching you because of these fake myths.**

— A female albinism rights activist from an urban community

Scholars and experts have noted that the constant deluge of discriminatory attitudes, practices, and myths about persons with albinism often results in psychological problems, such as reclusive behavior, withdrawal from society, and inferiority complexes, among others.[58] One mother shared that her six-year-old son with albinism had already experienced discrimination from other children who ran away screaming when he tried to engage in play with them. She shared that he can tell when he is shunned by his peers and then will decide to withdraw from all the other children; the rejection, discrimination, and social withdrawal of her sociable son deeply hurt her.

Within the workshops, some participants talked about standing up to bullies and discrimination as persons with albinism — a triumph of resilience in the face of systemic hate. One mother proudly shared that her daughter who attended a government primary school made sure to report and take every one of her bullies to the school headmaster/principal's office.

Stigma, Discrimination, and the Right to Health

From birth to childhood, adolescence, and adulthood, discrimination impedes the enjoyment of a wide range of human rights by persons with albinism. Climate change compounds these harms and further impacts the quality of life and the enjoyment of human rights for persons with albinism, particularly the right to health.

To respect, protect, and fulfill the right to health, states have a duty to ensure that all health care services are available, acceptable, accessible, and of high quality.[59] For persons with disabilities, including persons with albinism, states must guarantee that the quality of treatment by health care professionals is on equal footing with others without disabilities, ensure training and promulgation of ethical standards for public and private health care, and prevent discriminatory treatment or denial of care.[60]

Furthermore, the African Disability Protocol obligates states parties to create health services that are responsive to the needs of persons with disabilities[61] and ensure the provision of appropriate facilities and services.[62]

DISCRIMINATED FROM BIRTH

Mothers in the workshop who gave birth to children with albinism reported discrimination in maternal health care settings, identifying the following issues they faced:

1. **Lack of medical and health information from nurses about the condition of albinism**
2. **The provision of incorrect medical and health information from health care workers**
3. **Discriminatory practices and attitudes from health care workers**

Lack of Information

Mothers reported that public health care providers did not provide adequate information about albinism and, in some cases, were perceived to be afraid to talk about albinism as they did not want to offend mothers or feared the mother would abandon her child. Research has found that often health care providers not only have insufficient knowledge about albinism but may also hold misconceptions about the genetic condition, which results in discriminatory practices,[63] and can undermine patient experiences in health care centers.

> **I gave birth to my child in 2021. I wasn't told that my child had albinism and I had never seen a baby with albinism. When I asked the nurse about my baby's appearance, the nurse ignored my question and didn't respond. Later, a different nurse came to explain the baby had albinism but she said she didn't know what we should use on his skin. She advised us to use She advised us to use a white fragrance-free moisturizer often used for newborns, which caused my son to experience sunburn. Later, my friend who had a child with albinism taught me how to use sunscreen lotion.**

— Mother of a child with albinism from a rural community

In the workshops, participants reported that when they gave birth to children with albinism, the nurses, and doctors, particularly in public hospitals, failed to advise new mothers that their infant had albinism, explain the genetic condition, or share the importance of applying sunscreen lotion and keeping the child's skin protected from direct sunlight through protective clothing. In some cases, parents were told their baby had albinism but did not receive further medical guidance on infant care. One mother reported that in addition to being denied access to information, the nurses were discriminatory, making her feel uncomfortable in the health care center where she gave birth.

> **When I gave birth to my son with albinism, I asked the nurses why his skin color was so pale. The nurses said that nothing was wrong with my baby, but I was surprised when they kept calling each other to come and stare at my baby as if he was a spectacle of some sort. No one told me he had albinism, nor explained to me how I should care for and protect his skin. At first, I used petroleum jelly on his skin. It was only later when I was introduced to the Zimbabwe Albinism Association that I learned about using sun sunscreen lotion.**

— Mother of a child with albinism from rural Zimbabwe

Literature confirms that the lack of guidance and information on albinism from health care workers is a major challenge.[64] This undermines the quality of care for infants with albinism, harming their health. Sun protection measures are lifelong and must start early in life, ideally at birth to be maximally beneficial.[65] Over time, if care is not taken, continual sunburn predisposes children with albinism to skin cancer later in their lives. Researchers have determined that "regular use of sunscreen in temperate regions with an effective sun protection factor (SPF) of 7.5 within the first 18 years of life has been shown to reduce the lifetime incidence of non-melanoma skin cancers by 78%."[66]

In some cases, health care providers may also be afraid to discuss albinism due to the high prevalence of stigma in society. This failure to discuss the genetic condition within medical settings and provide adequate counseling to parents reinforces attitudes of stigma, which can lead to the abandonment of mothers by their partners, and have long-term effects on the mental health of both the mother and child. Women often bear the brunt of criticism and blame for giving birth to children with albinism, fueled by harmful myths of infidelity or being cursed — further predisposing women to intimate partner violence or ostracization by their partners.

> **When I gave birth to my daughter at a rural hospital, I didn't know that my child had albinism. No nurse explained to me the condition of my baby. When my husband's relatives came to visit me, they rejected my daughter with albinism. They blamed me for her condition and wanted to know what caused the albinism. On the way home with my daughter, after I was discharged, my mother-in-law was carrying the infant. As we approached a river, we needed to cross to get home, she suggested we throw the child in the water. When I refused, she handed the baby angrily to me, and we continued on our journey. The stigma and discrimination continued to the point that I felt like killing myself and my daughter. Eventually, I decided against it and left my husband's home and returned to my paternal home where I now live with my daughter.**
>
> *— Mother of a child with albinism from an urban community*

The ostracization and mental abuse from family and, in many cases, total abandonment force women to raise the children alone as single parents, which may have adverse economic impacts and affect the quality of life, access to education, and health of the child. Where there is no counseling or community support, women are often divorced by their husbands after giving birth to children with albinism. The financial challenges of raising a child as a single mother, especially a child with albinism who needs specialized care and regular skin check-ups, can push women deeper into poverty.

One father of a child with albinism from rural Zimbabwe reported that nurses did not tell him that his newborn had albinism. He reported a widely held myth that, when a woman gives birth to a child with albinism, it is a sign that she has engaged in prostitution and must confess her wrongdoing. It was only after the man's own mother accepted and celebrated his daughter with albinism that the man relented and also began to prioritize and accept his child with albinism. In this case, the love of the relatives of the child with albinism helped to stop the discrimination, and the man ended up not abandoning his child or verbally abusing his wife.

This story demonstrates the importance of communities and organizations partnering with the government to address myths that fuel discrimination against children with albinism and provide support and a safety net to women who give birth to children with albinism. Another father in the workshop shared his experience with discrimination, providing insight into male perspectives, which should be further explored through future research. He stated, ***"It is hard for men who have children with albinism. Other men will look down on you for having a child with albinism, and you might begin to blame yourself for the albinism. Men believe that if you have a child with albinism, it is the woman's fault and that she cheated. Some men can even ask you, 'So, now what are you going to do about this child?'"***

Health care providers, particularly in maternity wards, were seen by workshop participants as key partners in helping to dispel myths and address stigma and discrimination against persons with albinism and equipping new mothers and fathers to support their infants. For example, in

South Africa, genetic counselors or genetic nurses are available in some health centers to counsel any woman who gave birth to a child with any genetic condition or disability including albinism.[67] A recent study affirmed the importance of genetic counselors' role in providing information about the condition of a child with albinism and how to care for the child, as well as equipping new mothers and families with the language to explain their baby's condition to the community.[68] In the workshop, one participant shared how counseling outside of health care centers helped her accept her baby with albinism. Health care workers who provide accurate information on the care of infants with albinism can also act as an important factor in building climate resilience for persons with albinism and their caregivers.[69]

> **When I gave birth to my daughter, I was very troubled. The attending doctor did not explain albinism or how to care for the child. I received counseling from an NGO, and this really helped me. I was encouraged not to hide my baby, and this helped me. I was also able to get access to sunscreen lotions.**

— Mother of a child with albinism from a rural community

Zimbabwe's Ministry of Health should, in partnership with disability rights advocates, create ethical standards and guidelines and institute regular training to improve health care for persons with disabilities in both public and private sectors.[70]

Incorrect Information or Lack of Knowledge about Child Care

In some cases, nurses provided incorrect information to mothers and families that asked about the condition of their infant.

> **When my grandchild was born, I asked the nurses why the baby was so different. They couldn't explain that the baby had albinism. They said to me, "We also don't know what is wrong with the baby." Since we didn't know anything about her skin needs, when we went out to work on the farm, we took the baby with us. When she experienced sunburn, that is when we realized she shouldn't be out in the sun. So, my daughter and I had to learn how to look after the baby's skin on our own.**

— Grandmother of a child with albinism from a rural area

> **After I gave birth to my child with albinism, I asked the nurse what to use on his skin. The nurse told me he was exactly the same as any child with melanin, so I could use the same lotions and products on his skin. So, I did, but he experienced sunburn. Later, I met another mother of a child with albinism who then advised me to use sunscreen lotion.**

— Mother of a child with albinism from the outskirts of Harare

One mother of a child with albinism shared that, upon giving birth, she was surprised that her child had pale skin. She was advised by the nurses that her child's pale skin color was only temporary and that it would darken over time. As a result, the mother would leave her baby out in the sun assuming that the skin color would change. She only learned after the fact from other families that her child had albinism and that exposure to the sun was quite harmful.

Where there is an information gap from health care experts, mothers resorted to alternative options for infant skin care until they learned about sunscreen lotion, often from community-based organizations or other persons with family members with albinism, including other mothers of children with albinism. Without adequate information, infants and children with albinism suffer sunburn, wounds, and other challenges affecting the health of their skin, including chronic skin damage by 12 months of age,[71] which can create health challenges for them in the future. Access to health-related information and preventative services to support families and communities to safeguard the right to health of children is an essential element of the right to health and to lower the incidence of skin cancer in light of climate change.[72]

Health care providers are critical partners in addressing discrimination and dispelling myths about persons with albinism, as they are often the first point of contact for mothers and fathers of children with albinism. They are also key agents of climate-responsive health care systems through the provision of scientifically sound information on how to protect infants and persons with albinism against climate-related health impacts.

DISCRIMINATION WITHIN THE HEALTH SYSTEM

As persons with albinism grow from infancy and into adulthood, the toll of deeply entrenched harmful attitudes and beliefs leads to health discrimination. In this report, we define health discrimination as occurring when the lack of tailored and inclusive services in the public health sector, coupled with harmful societal attitudes and beliefs, negatively influence health-seeking behavior and the quality of health services at points of care for marginalized populations. Health discrimination also ultimately drives these populations away from accessing services promptly, impacting health outcomes.

Discrimination in the health system has a three-fold impact on persons with albinism: (i) it impedes access to quality and adequate physical and mental health care, (ii) it exacerbates the stigma and inequality that persons with albinism face due to their disability, and (iii) it negatively influences health-seeking behavior, often causing individuals to delay visiting health clinics and medical facilities for preventive screenings or care. This form of health discrimination presents in two ways:

1. **Systemic discrimination by omission in health systems not designed to cater to certain minority groups**
2. **Lack of knowledge, training, and/or desire by health care workers to understand and treat individuals from certain minority groups**

Systemic Discrimination by Omission

Health discrimination, characterized by the lack of inclusive or tailored health services, was evidenced through the general sentiment in workshops, where participants from both urban and rural settings expressed the paralyzing fear of receiving a skin cancer diagnosis regardless of whether they had access to adequate sunscreen lotion or not. Participants reported that they had no confidence in the possibility of receiving effective treatment in Zimbabwe and, in this way, a skin cancer diagnosis was equivalent to a death sentence. There are only two functional public health centers in Zimbabwe that offer diagnostic and treatment facilities for cancer. Additionally, the centers lack formal accommodation for patients seeking services and have "limited availability of resources, including chemotherapy medicines, opioid analgesics, and cancer control skilled manpower."[73]

The large-scale exodus of health workers and poor working conditions have affected the health care workforce in Zimbabwe, impacting health outcomes in the country.[74] Notably, Zimbabwe's public health sector provides 65% of health care services in the country.[75] In 2018, it was reported that less than 10 of the 787 medical specialists in Zimbabwe practice medicine in public hospitals.[76]

In addition, participants in the workshop shared that health care costs can create significant barriers to access to treatment. Cancer survivors from the workshops shared that patients often need three to six (or more) cycles of chemotherapy depending on the depth and width of the wound for effective treatment. In addition to chemotherapy, patients also need blood transfusion and chemotherapy drugs. A cancer patient in Zimbabwe can expect to pay between $40 to $60 for a single regime of drugs.[77] Participants confirmed these costs anecdotally as well, sharing that biopsies can cost $400, a cycle of chemotherapy costs $300, and blood transfusions cost $200.

There is a lack of diverse treatment options to care for persons with albinism affected by skin cancer. Non-invasive treatment options, such as nanorobotic surgery and cryotherapy, are not available to patients accessing public health services. Until June 2024,[78] there was no functional radiotherapy machine, a non-surgical treatment that can destroy cancer cells on the skin, in any public hospital in Zimbabwe. Currently, there is only one functional radiotherapy machine located at Parirenyatwa Public Hospital in Harare.[79]

With high costs of medical care and high levels of poverty among most persons with albinism, many end up abandoning conventional care for traditional or complementary medicine to treat the cancer. There is potential that the interaction of conventional medication and herbal medicines could lead to adverse reactions, such as increased toxicity or a decreased effectiveness of oncological treatment.[80]

Preventative care, such as regular skin checks, is inaccessible to most persons with albinism. Participants from the workshops reported only having the ability to receive skin check-ups through NGOs such as the Zimbabwe Albino Association (ZIMAS) and the Noble Hands Trust of Zimbabwe (NHTZ). ZIMAS and NHTZ offer free screening services, but the frequency and availability are dependent on access to funding and may not be provided regularly. Organizations supporting persons with albinism in accessing dermatological services have reported that Zimbabwe only has three dermatologists in the whole country — two based in Harare and one in Bulawayo urban areas — but only one of these three has the clinical knowledge and expertise to treat skin conditions affecting persons with albinism.[81]

The government should ensure radiotherapy machines and technicians are available at public hospitals, provide regular free skin cancer screenings, engage in public campaigns on skin cancer education, and ensure access to subsidized/free sunscreen lotion and cancer care.

Discriminatory Attitudes, Approaches, and Practices Among Health and Care Workers

Participants also raised the issue of lack of quality care when they presented at health care facilities with dermatological conditions, such as sunburn or wounds from sun damage. While the Zimbabwe nurse and health care worker training curriculum reportedly contains assessment questions on the health of persons with albinism, this has not translated into quality care at points of service. Participants reported being told by nurses and doctors that they could not treat "their kind" — even when it was related to care for non-dermatological issues. Health discrimination is present for persons with albinism of all ages — making health services inaccessible to them in many public health institutions.

> **When my granddaughter with albinism developed open sores on her head, we took her to the local clinic. When we arrived at the clinic, a nurse said to us, "We don't know how to treat people like this. Go to another hospital."**

— Grandmother and female caregiver of a child with albinism

There was also a general perception that health care workers were reluctant to treat skin conditions in persons with albinism on the basis that they present with challenging health conditions that are "difficult" to manage. There may be a need for the government to work closely with health care workers with albinism to ensure the robust nature of the curriculum and add regular supplemental training and awareness on albinism within health care institutions. The UN has reported that a lack of knowledgeable medical professionals presents a barrier to access to health care services for persons with albinism.[82]

Workshop participants reported that, when persons with albinism enter a hospital with advanced skin cancer, hospital staff are often reluctant to admit them. If they were admitted, participants reported that many were simply ignored and left to manage without any pain medication or ever being assessed by a doctor. Additionally, when persons with albinism visit hospitals for outpatient treatment of growths or wounds, they are often prescribed painkillers and are generally not referred for cancer screening.[83] Many persons with albinism also reported being prescribed betadine, an antiseptic solution, to treat their wounds, which was often ineffective and led to the wound expanding and deepening.

The collective of organizations, and workshop participants reported that they have encountered persons with albinism who were prescribed sunscreen lotion to treat pre-cancerous wounds or given antibiotics, rather than being advised to visit the hospital for cryotherapy to treat wounds.

In other circumstances, persons with albinism who have cancer or precancerous wounds shared that they were asked to return for treatment at a later date or experienced a long delay in receiving biopsy results, which worsened their health condition. In one case, a woman married to a man with albinism reported that her husband suffered from skin cancer for 11 years without ever receiving adequate or quality care at a health facility. Her husband eventually died.

Sunburns and open wounds can also increase the risk of isolation from society and experiencing discriminatory acts as individuals are shunned by members of the public or abandoned by their family members. Such additional stigma compounds upon the exclusion and forms of discrimination persons with albinism already face based on their skin color, further taking a negative toll on their mental health. Additionally, due to internalized stigma and negative attitudes from members of the public, one participant shared the shame that she felt when taking public transportation to visit a medical professional due to the physical appearance of her sunburns, wounds, and cancerous tumors. She shared that she started to avoid medical appointments altogether, despite the severity of her wounds, until a family member agreed to accompany her on the journey.

As a result of substandard care in public health care settings, persons with albinism often feel burdened by the demands of disease management on top of the general challenges they face in daily life.[84] These burdens compound for patients, leading to treatment fatigue, which in turn drives them away from the regular healthcare visits needed to prevent and treat skin conditions. Ultimately, they bear the burden of continually educating health care providers about the nature of their wounds and advocating the urgent need to receive treatment for their skin condition.

Climate Change, Health, the Right to Work

There is also a harmful cyclical relationship between albinism, climate change, informal work, livelihoods, and health. Many of the workshop participants with albinism reported engaging in some form of informal employment, more commonly either as a vendor or as a farmer, which predisposes them to climate-related health challenges.[85]

> **My husband, Farai (pseudonym), worked as a vendor and spent a lot of time outdoors. As a result, he developed blisters, which worsened over time until he developed cancer. In seeking treatment, Farai was repeatedly turned away from health services and told to return for treatment over the course of one year. Due to a failure to access timely services, his wounds became deeper and wider. Eventually, because the cancer had advanced, he was advised to go for four cycles of chemotherapy. When Farai presented at a health care facility for chemotherapy, the machines were not working, so he had to travel to another hospital for treatment. Unfortunately, due to COVID-19, Farai had erratic access to chemotherapy services, and he eventually died after having only undergone one chemotherapy cycle out of the prescribed four cycles. When Farai died, due to stigma and discrimination no one from my family bothered to check up on me and my children, two of whom are children with albinism.**

— The widow of a man with albinism from urban Zimbabwe

Farai's story illustrates a harmful dynamic: to maintain a quality of life, persons with albinism must work, but, if they work outdoors in unfavorable conditions, they risk their health. In the end, the choice is between being able to protect one's health and the ability to work and provide.

The UN reports that persons with albinism face many difficulties in accessing formal employment, including discrimination and unaccommodating work environments.[86] Additionally, due to the failure to make accommodations in many public education institutions, persons with albinism end up dropping out of school and are unable to obtain the necessary qualifications to secure jobs in the formal sector. According to the UN, these barriers cause many persons with albinism worldwide to be "unemployed or precariously employed, with many forced to work low-paid, short-term jobs in the informal sector."[87] Climate change can also result in the loss of employment completely or diminished hours of productivity due to the harsh environmental factors.

> **2024 was very hot, and I couldn't farm as well as I have managed to do in past years. I usually start farming at 6 a.m. but, by 8 a.m., it's already so hot that I have to return to my home. This means I have shorter hours available to engage in my farming activities — only two hours. By 5 p.m., when it is cooler and I want to return to the field, the sun is setting and the day is already over.**
>
> *— Female farmer from rural Zimbabwe*

GENDER, ALBINISM, AND CLIMATE CHANGE

Climate change impacts the livelihoods and employment of persons with albinism in urban and rural areas, with a differential impact on women — who are more likely to be in vulnerable employment compared to men.[88]

In urban areas, vendors with albinism are affected by high temperatures due to climate change, which may interfere with or limit the hours they can work and earn money. Many mothers who work as vendors in Zimbabwe tend to ply their trade with their infants or young children strapped to their backs. Mothers of infants or children with albinism tend to spend shorter hours in their vending activities or cease their livelihoods completely because of the risk of sunburn to their infants or children, impacting their overall income. As a result, climate change has a disproportionate gendered impact on mothers of children with albinism — where female-headed single-parent households result in women taking on the added burden as caregivers and breadwinners. This heavy load is made cumbersome by the lack of familial and systemic support towards childcare due to prevailing and entrenched societal attitudes of discrimination towards persons with albinism of all ages.

Women constitute 70% of the labor in rural communities, making up the majority of subsistence farmers.[89] Because of gender roles in Zimbabwean society that women contribute to household food security, the ability to engage in agricultural activities is critically important and central to womanhood.

As a result, women face additional pressures due to the competing interests of safeguarding their health, fulfilling their gendered roles of labor and caregiving, and securing household nutrition. Workshop participants shared that women with albinism are often burdened with the stereotypes of being labeled as lazy because of the limited time they can spend outdoors for health reasons. Rising temperatures and longer days result in fewer opportunities for them to safely work on tasks that are often carried out by women. Many women in the workshops reported that family members would criticize their work ethic and productivity, especially in rural settings, where families often rely on a woman's farming labor for subsistence. This impact of climate change affects intimate relationships and can result in divorce or rejection of the woman and her children from the family.

> **My in-laws used to call me a "vampire" because I used to do all the necessary chores — plowing the fields and collecting water — before the sun came out. My husband never defended me against their verbal attacks. In the end, he eventually moved to another country, abandoning my child and me. I tried to continue living with his relatives, but I eventually left as living with them was hard. They did not love me or my child.**
>
> *— Woman with albinism from urban Zimbabwe*

Due to the adaptation measures of working very early in the morning or late in the evening to avoid sun exposure, women with albinism are potentially at risk of endangering their security from violent attacks.

For both urban and rural women with albinism, living with the fear of a skin cancer diagnosis negatively impacts their mental health. One female farmer from rural Zimbabwe who had wounds around her eyes expressed fear of being screened for skin cancer, noting that such a diagnosis would make her think of death and likely cause extreme emotional stress and high blood pressure.

For women with albinism, who are often left to parent their children alone, the fear of skin cancer means that women live in perpetual fear of leaving their children orphaned.

CLIMATE CHANGE AND ACCESS TO SUNSCREEN LOTION

In Zimbabwe, participants and activists reported that they did not have regular and reliable access to sunscreen lotion. A female farmer in the workshop explained that to access sunscreen lotion, she needed to find a vehicle that would transport her to the distribution point — a 1 hour and 15-minute drive. If she did not manage to collect the sunscreen lotion, she would not be able to work.

Workshop participants from rural communities reported being hardest hit by climate change[90] and, thus, have a higher demand for sunscreen lotion due to a multiplicity of daily outdoor activities, such as fetching water, herding cattle, and farming. Generally, rural communities reported having erratic access to sunscreen lotion, relying on donations from NGOs who were able to travel to the remote outlying areas. Participants shared they used the following untested and potentially harmful substitutes for sunscreen lotion.

- Paraffin and Kerosene
- Wild Fruit
- Camphor-Based Lotions
- A Mixture of Lemon Juice and Cooking Oil

However, many of these products lack requisite sun protection factors, increase risks of sunburn, and can be otherwise harmful to one's health when applied to the skin.

Paraffin and Kerosene: Paraffin is readily available in rural areas as it is used to fuel paraffin stoves or to light paraffin lamps. People have reported that using paraffin on the skin on hot days has a cooling effect. Kerosene is a flammable pale yellow or colorless oily liquid with a characteristic odor and belongs to a heterogeneous group of substances called hydrocarbons. It is used domestically for cooking and lighting wick lamps or kerosene lamps.[91] In human beings, chronic exposure to kerosene on the skin revealed a high incidence of oil acne and dermatitis of varying degrees.[92] While no testing has been conducted on human beings, laboratory testing on rats has found that kerosene spillage on the skin compromised dermal barrier function and the ability of the skin to retain water, negatively affecting the skin's ability to prevent entry by potentially harmful foreign substances.[93]

Wild Fruit: A poultice was made by mashing the wild fruit and spreading it on the skin.

Camphor-Based Lotions: Lotions made of camphor oil are popular and widely available in the country. These commercial products can be harmful when applied to broken skin and typically have low or no sun protection factor. Many workshop participants reported experiencing sunburn after use.

A Mixture of Lemon Juice and Cooking Oil: Utilized over the skin like a lotion.

CONCLUSION

Persons with albinism face extreme forms of discrimination and stigma, which leads them to live as outcasts in most societies. The climate crisis threatens the human rights of persons with albinism, particularly their right to health and work. Climate change brings into sharp focus the structural flaws and limitations of how many national health systems are ableist — making them either inaccessible or unable to provide quality care to persons with albinism. Zimbabwe has the opportunity to reform and tailor its health care and protection systems in response to the climate crisis and in line with its international treaty obligations.

Including the voices and participation of persons with albinism is critical in designing climate-resilient systems and structures that effectively address mental and physical health impacts. National leaders and policymakers must adopt an intersectoral and intersectional lens to health in the age of climate change — the economic, the environmental, the social, and the biological cannot be treated in isolation.

Recommendations

TO THE GOVERNMENT OF ZIMBABWE:

To fulfill its obligations as a state party of the African Disability Protocol, the Maputo Protocol and other international treaties, the Constitution, and Zimbabwe's National Disability Protocol, the government of Zimbabwe through its various ministries needs to:

1. Conduct public national advocacy and education campaigns in partnership with the organizations supporting persons with albinism to address stigma and discrimination, and promote inclusion and acceptance to end stigma and discrimination. (*Article 4 (d) and (e) of the African Disability Protocol*)
2. Ensure that it has accurate data on the number of persons with albinism in the country by training enumerators on the importance of the recently added question on the national census on persons with albinism in Zimbabwe. The collection of accurate data will enable the government to:
    - Provide access to sunscreen lotion, wide-brimmed sun hats, preventative health checks, and skin cancer screening services to lower the risk of incidence in the community. This is in line with its most recent national cancer strategy, which has noted that public health actions by governments towards prevention are the most effective approach to cancer management.
    - Provide adequate numbers of visual aids (e.g., magnifying glasses or monocular eyewear) and assistive learning devices (large font textbooks) to children with albinism in schools across the country
    - Support the right to work and live a dignified life of persons with albinism in both rural and urban areas
3. Update existing climate change policies to take into the physical and mental health needs of persons with albinism, recognizing that climate change is a real and immediate threat to the lives of the community
4. Improve access to clinically tested sunscreen lotion for all persons with albinism in need, including in rural areas
5. Conduct regular training programs for health care workers to minimize discriminatory encounters that negatively affect health-seeking behavior and health service experiences for persons with albinism
6. Support efforts at the global level to reinstate sunscreen lotion on the WHO Essential Medicines List
7. Implement policies aligned with the SADC Declaration on the Protection of Persons with Albinism
8. Create social protections for women with children with disabilities and persons with disabilities, including those with albinism who are employed in the informal sector (*Article 13(f) of the Maputo Protocol*)

9. Provide social protections to female-headed households of women with albinism and other disabilities and of those that provide care to children with albinism or other disabilities (*Article 13 (h) of the Maputo Protocol*)
10. Provide grants to organizations supporting persons with albinism access to health and work opportunities

TO CIVIL SOCIETY ORGANIZATIONS WORKING TO SUPPORT PERSONS WITH ALBINISM IN ZIMBABWE:

1. Form coalitions to support lobby efforts for the rights and welfare of persons with albinism in Zimbabwe in both rural and urban settings — to ensure fulfillment of that “no person is left behind” in the enjoyment of human rights
2. Collaborate with the Ministry of Health to support efforts to improve child health for babies with albinism by advocating for the introduction of genetic counselors or genetic nurses to provide medical information and educational support for women and their families when a baby with albinism is born
3. Organizations should work with communities with albinism to develop climate mitigation and adaptation strategies that can help support mental and physical wellness. These strategies should include education on climate change, how persons with albinism can protect themselves, and exploring alternative methods to maintain their livelihoods, while also protecting their health
4. Work in partnership with organizations, such as Friendship Bench, to provide tailored, accessible support groups and programs to mitigate the mental health impacts of climate change on persons with albinism

TO RESEARCH AND ACADEMIC INSTITUTIONS:

1. Research the health implications regarding the use of alternative products (kerosene, wild fruits, etc.) as a form of sunscreen
2. Research and map the current attitudes and perceptions driving stigma and discrimination in Zimbabwe among health care workers
3. Partner with government and civil society to drive local innovation that enables access to low-cost assistive devices in the country for persons with albinism
4. Study male attitudes and gender norms around the birth of children with albinism in Zimbabwe. Address gender-based discrimination and explore opportunities for building the resilience of fathers to minimize abandonment of children

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