

Recommendations to Support Mothers and Children Impacted by Albinism in South Africa



Photo Credit: Busisiwe Mahlaba and her children with albinism

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<https://motheringandalbinism.com/2023/09/12/upcoming-public-forum>

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Albinism is a rare, non-contagious, genetic condition caused by the partial or complete lack of pigment in the hair, skin, and eyes.¹ Both parents must be carriers of the gene for a child to have the condition.² It can affect anyone, regardless of gender or ethnicity. In South Africa, approximately one in 3,900 of the population has albinism, a prevalence that is similar to the rest of Africa but higher than in most other parts of the world.³ Persons with albinism have faced stigma and discrimination for centuries, and more recently, experienced human rights violations including prejudice, discrimination, social exclusion, and acts of violence.⁴ At the same time, awareness of albinism is growing worldwide and more supports are available for persons with albinism.

This report is based on a study conducted by a South African and Canadian research-advocacy-policy network on mothering and albinism. Other phases of this study were completed in Tanzania and Ghana. See Appendix for study details.

In South Africa, mothers affected by albinism (mothers with albinism and mothers with children with albinism) and key informants (e.g., health care providers, civil society advocates, and government officials) described the support and best practices that enable mothers and their families to thrive. Also, they mentioned concerns of mothers and children with albinism that put their health, safety, and security at risk.

This report provides recommendations to support persons with albinism and their families, focusing on social responses and advocacy, as well as government policies and resources to improve the livelihood of mothers and their children affected by albinism. We focus on five aspects:

- I. Birth Experiences
- II. Access to Health and Social Services
- III. Stigma and Discrimination
- IV. Gender Policy
- V. Intersectoral Collaboration

I. BIRTH EXPERIENCES

Giving birth to a child with albinism in South Africa, as in many parts of sub-Saharan Africa, is a life-defining moment for mothers and their families.⁵ When they are well supported and provided with education, they and their child can flourish. Without such a start and ongoing support, they are set on a trajectory of health-related stigma, gender inequalities, reduced access to healthcare, and human rights violations. There is a stark contrast between mothers' experiences when comparing the birth experiences of mothers who received support and those who did not receive support.

One of the mothers explained that her



Photo Credit: Patricia Willcoq's White Ebony Collection

experience was positive because healthcare providers knew that her child was born with albinism and provided immediate positive affirmation of the child. She was referred to genetic counselling (genetic counselling is when individuals are provided with services to understand and adapt to the medical, familial, and emotional implications of the genetic contribution to disease, which in this case, albinism), and was also given referrals to a skin and eye doctor before being discharged from the hospital.

*"Health care providers just told me that I must love and care for her. They just said **I'm blessed**. They were not surprised as me. I was the one who was shocked, not them... I received a lot of attention from everyone. They were talking to me. They wanted to see my baby with albinism. They carried her... I was so happy to see that. **It felt like I'm special**... After giving birth to my baby, they immediately told me that I must go to the clinic where they will **teach** me on how to care for a kid with albinism. So, I immediately went there. So, they **referred** me to a genetic clinic, they said at there they know a lot more about children with albinism. So, after giving birth to my child, they did a referral letter for me. So, when I went to genetics clinic, I took the letter with me and I gave it to them."*

In contrast, another mother shared that she did not know anyone in her family with albinism and it was a shock to her when she gave birth to a child with albinism. The healthcare providers did not share with her any educational information about albinism.

*"With the doctors and the nurses, they are not used to albinism. So they were trying to come to me **as if there was something wrong with the child**. I did not feel bad about giving birth to a baby with albinism until they the way they were acting towards me, the way they were treating me. I just felt like maybe there's something wrong with that baby with albinism.... No education was given. Being honest, I just did my own research after leaving the birthing clinic. **There was not enough information**. It came to a point when they were arguing: 'This mother's child has albinism, this child is an albino.v' At that moment, **I was quite miserable.**"*

Mothers of children with albinism all shared that their initial reaction was shock when they gave birth to a baby with albinism. Those who had a positive experience stated it was because of the assistance of healthcare providers who:

I. had positive and respectful responses upon seeing their baby,

II. gave them health information about albinism, and

III. provided them with other resources such as where to get free sunscreen and referrals to eye and skin doctors (i.e., dermatologists and ophthalmologists) and genetic counselling.⁶

Those mothers who were not provided with health information about albinism prior to leaving the hospital or birthing clinics were confused about why their child had pale skin, eyes, and hair. Some shared the negative responses from health care providers, including the false accusation of sleeping with a white man. When it was time for the mother and baby to come home, they were ill-equipped to take care of a baby with albinism. As a result, the mothers searched the internet (e.g., Google) for health information or alternatively gained support from peer support groups, non-governmental organizations (NGOs), and civil society organizations (CSOs). Mothers from rural areas experienced even more challenges because of the lack of dermatologists, ophthalmologists, and genetic counsellors, and poor access to health information.

RECOMMENDATIONS ABOUT THE BIRTH OF A CHILD WITH ALBINISM	
Audience	Best Practices
Birth Attendants (midwives, nurses, doctors)	<ul style="list-style-type: none"> Positively affirm the arrival of the baby with albinism -- the immediate response from the birth attendant sets the tone for the mother's adjustment. Create a respectful relationship with mothers so that they will feel empowered, nurtured, and safe. Mothers need to be included in the decision-making process during birth and delivery. Provide birth attendants with genetic education about albinism and health information about albinism so that they do not rely on common stereotypes and biases. Provide mothers with genetic information about albinism so that they understand the condition and the needs of their baby prior to leaving the health centre or hospital. Make referrals to resources such as eye and skin doctors, genetic counselling, and social worker. Referrals should be integrated into a clinical system, not dependent upon whether a healthcare provider remembers to do so. Facilitate access to mental health counselling because the birth of a baby with albinism may be difficult for the mothers and their families. Engage the partner or father of the baby and other family members to educate them about albinism. Ensure that mothers and their families have the necessary information and support they need before being discharged from the clinic or hospital. Book follow-up appointments to enable continuity of care.
Government	<ul style="list-style-type: none"> Incorporate information on albinism into all curricula for the training of health care professionals and teachers. Ensure that quality sunscreen is available and accessible for persons with albinism across all provinces, paying particular attention to rural areas. Promote Respectful Maternity Care as guided by the World Health Organization in all sectors (i.e., higher education, clinical practice, government policy)
NGOs/CSOs	<ul style="list-style-type: none"> Connect with local clinics and hospitals to provide them with information about albinism and ways to contact albinism NGOs and CSOs. Create strong relationships with persons with albinism and their families. Create and enable support groups for mothers and families affected by albinism.
Families and Communities	<ul style="list-style-type: none"> Be involved in the birth of the baby with albinism. Embrace the baby and their family. Participate in the education about albinism. Share information on albinism to sensitize the community about the condition.
Mothers and fathers of a child with albinism	<ul style="list-style-type: none"> Take courage in welcoming your baby with albinism into your family. Seek information about albinism from your doctor, local albinism advocacy groups such as the Albinism Society of South Africa (ASSA) and reputable online sources.

RESOURCES FOR FAMILIES AFFECTED BY ALBINISM AND COMMUNITIES

What is albinism as defined by the South African government:

<http://www.kznhealth.gov.za/albinism.htm>

A pamphlet for new mothers who give birth to a baby with albinism (Mothering & Albinism, 2023):

<https://motheringandalbinism.com/2023/09/12/upcoming-public-forum/>

Genetic counselling clinics are available at all tertiary state hospitals and at Donald Gordon Hospital, Johannesburg.

Organizations that provide support:

- Albinism Society of South Africa: +27 11 838 6529
- Vanilla Mamas, Northern Cape, please connect with Mpho Tjope: +27 83 200 2133
- Reamogelemg Community Organisation, Northern Cape, please connect with Tshego Keitsemore: + 27 78 818 7334

RESOURCES FOR SERVICE PROVIDERS AND GOVERNMENT

The Health Department of the Republic of South Africa (2016) created the Guidelines for maternity care in South Africa: A manual for clinics, community health centres and district hospitals. Follow the link here: <https://knowledgehub.health.gov.za/elibrary/guidelines-maternity-care-south-africa-2016>

A submission from the Global Respectful Maternity Care Council can be found here: <https://www.ohchr.org/sites/default/files/Documents/Issues/Women/WRGS/FollowUp2018/GlobalRespectfulMaternityCareCouncil.pdf>

World Health Organization released the following:

- A statement on the prevention and elimination of disrespect and abuse during facility-based childbirth (2015). https://apps.who.int/iris/bitstream/handle/10665/134588/WHO_RHR_14.23_eng.pdf
- Recommendations on intrapartum care for a positive childbirth experience: Transforming care of women and babies for improved health and well-being (2018). <https://apps.who.int/iris/bitstream/handle/10665/272447/WHO-RHR-18.12-eng.pdf>
- Recommendations: Intrapartum care for a positive childbirth experience (2018): <https://apps.who.int/iris/bitstream/handle/10665/260178/9789241550215-eng.pdf;jsessionid=7E800B590A164DC7FC879E73B480D6FC?sequence=1>

II. ACCESS TO HEALTH AND SOCIAL SERVICES

Access to and utilization of health and social services, including healthcare, education, employment, and safety/security, influences the everyday lives of mothers and children impacted by albinism and supports the achievement of their human rights.

ACCESS TO HEALTHCARE

One mother, from an urban setting, of a child with albinism reported that they did not have access to health and social services, including sunscreen and social services:

*“We need sunscreens, we **need full support** for our children with albinism. For us mothers don’t even have a job. We also need money to buy them long sleeves and glasses.”*

If they obtained sunscreen lotions from public clinics or hospitals, some mothers reported that they were watery and insufficient to protect the skin from the sun. Some mothers were homemakers and were unable to afford to buy sunscreen lotion, eyeglasses, and protective clothing. Moreover, some mothers with albinism and mothers with children with albinism said that they experienced stigma and discrimination from health care providers

when they did access health services.

Another mother with albinism stated that there is a need for cancer screening for all persons with albinism.

*“And then when it comes to healthcare providers, we would like to ask them that they **take the condition for albinism very serious...** they must screen you every time when you go there and check for cancer cells and all those things”*

Other mothers who have children with albinism are typically the primary individuals searching, scheduling, and attending doctors’ appointments with their children. They also stated difficulty in locating and scheduling appointments with eye and skin doctors because of long waiting times or the need to travel long distances to access these healthcare providers.

When mothers were provided with referral letters by their local clinics, their access to eye or skin doctors was much easier. These referrals allowed mothers to be more aware of what government services were available for their children, where and the processes to obtain these services. Some mothers were also able to access services through NGOs or CSOs.

RECOMMENDATIONS TO PROMOTE HEALTHCARE	
Audience	Best Practices
Health/Service Providers	<ul style="list-style-type: none">• Acquire accurate knowledge about albinism as a disability and its characteristics.• Provide education for the prevention of skin cancer. Children and adults with albinism need to apply sunscreen everyday, especially when going outside.⁷• Facilitate yearly skin screening with a family doctor or dermatologist as part of routine checkups to screen for skin cancer.• Ensure access to available and quality cancer treatment if persons with albinism develop skin cancer.• Provide regular checkups with an eye doctor and access to prescription eyeglasses because persons with albinism often have varying degrees of visual impairment. It is recommended that children are seen by an eye doctor before they start school.• Promote access to mental health counsellors or social workers. Mothers, children, and families impacted by albinism may have mental health concerns due to the stigma and discrimination they experienced.• Provide access to genetic counselling for all parents, siblings, and other family members so that they understand the causes of the condition and the health needs of a person with albinism.• Develop guidelines and apply them to the care and management for persons with albinism and their families.



Photo Credit: Patricia Willcoq's White Ebony Collection

ACCESS TO SERVICES AT SCHOOL

A concern by mothers was access to supportive and adaptive services when children with albinism were at school.

*“They **can’t see properly at school** and teachers don’t have idea how to deal with people living with albinism.”*

Because many persons with albinism have a visual impairment, it is difficult for them to see what is written on the blackboard. Mothers shared that the schools had no assistive devices available,

or adaptations provided for their children and that teachers did not always have an understanding about the genetic causes of albinism. The lack of assistive devices and adaptations for children often negatively impacted their academic performance, leading to higher school dropout rates amongst this group.⁸ The teachers’ lack of understanding about the genetic causes has often meant teachers do not often counter negative beliefs around albinism and impact the information provided to other learners, leading to the stigmatisation, discrimination, bullying, and isolation of students with albinism.

RECOMMENDATIONS TO PROMOTE INCLUSION AT SCHOOL	
Audience	Best Practices
Teachers at School	<ul style="list-style-type: none">• Acquire accurate knowledge about albinism as a disability and its associated problems.• Promote inclusion and support for the learning of persons with albinism. Students with albinism need to sit in front and at the centre of the class. They should be provided with a copy of the writings on the board and allowed to stand up and get closer to the blackboard, when necessary.• Make larger font sizes for paper materials available for persons with albinism, when needed.• Allocate accommodations, for example, additional time to complete tests and exams as students with albinism may take longer to finish because of their low vision.• Ensure that students with albinism wear sunscreen and protective clothing, stay in the shade when outside, and avoid sun exposure between 10:00 am and 3:00 pm. Students with albinism need to avoid the sun as much as possible.• Ensure that security measures are implemented at school to keep children with albinism safe.

ACCESS TO SAFETY AND SECURITY

Mothers impacted by albinism stated that even though there were no attacks against persons with albinism in their local community (there have been attacks against persons with albinism in South

Africa, although not as many as in some other countries)⁹, they continued to be afraid for the safety of their children because the news and social media report about the violence against them and the negative beliefs about albinism in the community. As example, one mother of a

child with albinism explained why she was scared that people would hurt her child.

*“Now I don’t feel safe. **It’s not safe** now because our children now are being kidnapped. Since I watched that show, I started seeing that our children with albinism could be unsafe because of muti. That muti thing started from other countries in Africa. I told my mother and we watched the show together. Oh, it was so painful to watch, even right now, when I speak to you, I still feel that pain. Because there were people, that their legs were cut off, they were*

*broken into their house to do stuff, maybe cut their foot off and take it... So, since that day and then as she was getting older, I didn’t think that it was going to come to this side of our country. And then **I started hearing about it**. There are people who take our children and do those stuff. So, every time when she goes, she knows that I don’t feel safe. When she goes out, I only pray to God that He must keep her safe.”*

However, hope was there as efforts were starting to be made to ensure security for persons with albinism, including having security services present to guard schools.

RECOMMENDATIONS TO PROMOTE ACCESS TO SAFETY AND SECURITY	
Audience	Best Practices
Teachers at School	<ul style="list-style-type: none">• Enforce laws and policies that protect and promote the rights of persons with albinism and their families.• Develop strategies to monitor, investigate, and document acts of discrimination and violence against persons with albinism and families.• Train police officials to address the harmful cultural and spiritual practices which are the causes of violence against persons with albinism.



Photo Credit: Busisiwe Mahlaba’s child with albinism

FURTHER RECOMMENDATIONS TO PROMOTE ACCESS TO HEALTH AND SOCIAL SERVICES

Audience	Best Practices
Government	<ul style="list-style-type: none">Facilitate the availability of sunscreen for children and adults with albinism in all rural clinics and hospitals. Sunscreen needs to be repurchased regularly because it is worn by persons with albinism everyday and applied multiple times a day.Include skin cancer as a priority in the national cancer strategy.Promote access to affordable prescription eyeglasses for persons with albinism.Provide targeted and appropriate training for nurses, midwives, and other relevant healthcare providers on albinism.Ensure that guidelines and policies are implemented so that children with albinism at school can access assistive devices and that education and training are available for the teachers.Engage and act in demystifying the myths associated with albinism and heighten policing measures to keep persons with albinism safe.Enhance access to quality education and skills development that prepares persons with albinism and mothers for work.Enact inclusive laws and policies that promote the rights of persons with albinism. The South Africa Human Rights Commission should institute an investigation and research into the incidence of human rights violence against persons with albinism, including infanticide and human trafficking, in South Africa.Implement the African Union Plan of Action on Albinism (2021-2031)
NGOs/CSOs	<ul style="list-style-type: none">Partner with healthcare providers, policing, teachers, and the government to ensure support is provided for children with albinism for community access, such as healthcare, education, and employment.Provide scholarship opportunities for persons with albinism, if available.
Families and Communities	<ul style="list-style-type: none">Families should be educated about how to care for persons with albinism and to reach out to health services or NGOs or CSOs.Promote education for girls and young women with albinism, so they are able to become self-sufficient.Become advocates for persons with albinism.
Mothers and fathers of a child with albinism	<ul style="list-style-type: none">Be persistent in seeking access to eye and skin care for your child with albinism, accommodations at school, and protection against discrimination.

RESOURCES FOR FAMILIES AFFECTED BY ALBINISM AND COMMUNITIES

Health services are available in all tertiary state hospitals, including the following:

- Chris Hani Baragwanath Hospital Soweto
- Dermatology and ophthalmology departments, Johannesburg
- St Johns Eye Hospital, Soweto, Johannesburg

There are pamphlets available with your service providers:

- Albinism, a manageable condition
- Information on albinism, for teachers
- Genetic counselling; Living with low vision

RESOURCES FOR SERVICE PROVIDERS AND GOVERNMENT

The South African government specifically addressed the rights for equal access to health, education, and safety and security under the Ekurhuleni Declaration on the Rights of Persons with Albinism (2013). You can find the full declaration here: <https://www.gov.za/ekurhuleni-declaration-rights-persons-albinism#:~:text=Persons%20with%20albinism%20are%20South,3>.

The African Union has an action plan specifically on albinism, titled Implementation Matrix Of The Plan Of Action To End Attacks And Other Human Rights Violations Targeting Persons With Albinism In Africa (2021–2031). You can find it here: <https://www.ohchr.org/sites/default/files/2021-11/AU-Plan-of-Action-EN.pdf>.



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III. STIGMA AND DISCRIMINATION

Mothers impacted by albinism reported that they experienced name-calling, and many were excluded from the community. Their children were called names such as inkawu (Nguni term for monkey), or isishawa (Zulu word for a person who is cursed). Name-calling can perpetuate the dehumanizing of persons with albinism, such that stigma and discrimination are not seen as problematic. Persons with albinism were seen as visually different from the community because of the colour of their skin. The colourism that resulted contravenes International Convention on the Elimination of All Forms of Racial Discrimination (CERD) which is designed to protect people from discrimination that stems from racism and colourism.

A mother with a child with albinism recommended:

*“We need support from our community because **our children are not safe**. They can’t play freely and people must stop calling them by names and we will also need workshops where we talk about albinism so that our kids could understand why are they having the skin and also for people who always talk bad things about albinism.”*

Because of the awareness raising locally, nationally, and internationally, some mothers started to feel a sense of ease where the community were gaining more understanding of the causes of albinism.

“My main worries are I would say it’s the abductions that are happening, yeah. But somehow, I still feel like when he grows up, there won’t be more abductions going on because people are being aware of albinism and the albinism like is really growing each and every day. People are being told about albinism and they now have knowledge about it. Yes, it’s not like the old times where they didn’t know about albinism and all that... It’s an NGO and also at the clinics, they do teach us about albinism.”

Social change has begun and mothers shared hope that one day, they will no longer be concerned about the attacks. These sensitization initiatives to albinism were mainly facilitated by non-governmental and civil society organizations and healthcare providers.

RECOMMENDATIONS TO ADDRESS STIGMA AND DISCRIMINATION	
Audience	Best Practices
Health/Service Providers	<ul style="list-style-type: none">• Show an immediate positive response and normalize the situation when encountering families who have a child with albinism.• Explain the genetic cause of albinism to others
Teachers at School	<ul style="list-style-type: none">• Teach all children about the genetic cause of albinism.• Encourage social integration of the child with albinism by encouraging other children to include and support the child (e.g., calling them by name, playing in the shade).
Government	<ul style="list-style-type: none">• Build capacities and provide resources for educators such as health care providers and organizations to promote a genetic understanding of albinism.• Plan and implement targeted campaigns promoting the rights of persons with albinism and their families.
Faith Leaders and traditional healers	<ul style="list-style-type: none">• Advocate through teaching and engagement among your congregation and local community for persons with albinism. Faith leaders and traditional healers have great influence in their community to provide education and support, especially to correct false beliefs about albinism.• Promote acceptance and belonging of persons with albinism.
NGOs/CSOs	<ul style="list-style-type: none">• Be empowered to raise awareness on albinism with families, healthcare professionals, government, and communities. Undertake public education on albinism, especially in areas where attacks have been reported and awareness campaigns have not yet been reached.• Enable peer support for families impacted by albinism. Support peer groups as human rights defenders.• Demystify albinism through media, theatre, music, and art.
Families and communities	<ul style="list-style-type: none">• Facilitate acceptance of persons with albinism as members of society.• Participate and/or facilitate support groups for persons with albinism and families.• Disseminate accurate information about albinism and debunk the beliefs when you hear others in your community talk about these harmful beliefs and practices.
Mothers and fathers of a child with albinism	<ul style="list-style-type: none">• Engage your community to ensure your child’s safety and security.• Learn about the rights of your child including their right to access healthcare services they need because of their condition, their right to be provided with support at school, and know the avenues to report where these rights are violated.

RESOURCES FOR FAMILIES AFFECTED BY ALBINISM AND COMMUNITIES

Women, Youth and Persons with Disabilities, Republic of South Africa

- Persons with Disabilities: SMS 'help' to 31531

To spread awareness on albinism, share resources including this: <http://www.kznhealth.gov.za/albinism.htm>

There is a booklet available which can be used to teach persons with albinism, families, and children and adults in the community about what albinism is and how to support those with the condition: <https://www.firah.org/upload/l-appel-a-projets/projets-laureats/2018/albinisme/bootklet-en.pdf>

RESOURCES FOR SERVICE PROVIDERS AND GOVERNMENT

Minister Nkosazana Dlamini Zuma (2023) of Women, Youth and Persons with Disabilities, committed to heighten campaigns against the attacks of persons with albinism: <https://www.gov.za/speeches/minister-nkosazana-dlamini-zuma-women-youth-and-persons-disabilities-dept-budget-vote>

The Department of Social Development (2021) implemented a community-based prevention and early intervention programme for orphans and vulnerable children, the RISIHA programme. Please view the following:

- <https://www.dsd.gov.za/index.php/21-latest-news/394-minister-zulu-to-officially-launch-risiha-a-community-based-prevention-and-early-intervention-programme-for-orphans-and-vulnerable-children?highlight=WyJhbGJpbmlzbSJd>
- <https://www.pactworld.org/Risiha%20fact%20sheet>

The United Nations Independent Expert on the enjoyment of human rights by persons with albinism made a country visit and the report, which includes recommendations, can be found here (2020): <https://www.ohchr.org/en/documents/country-reports/ahrc4342add1-visit-south-africa-report-independent-expert-enjoyment-human>

IV. POLICY DEVELOPMENT AND IMPLEMENTATION FOR GENDER EQUALITY

South Africa has strong human rights frameworks to protect mothers and their children with albinism. The South African Constitution's Bill of Rights¹⁰ prohibits discrimination on the grounds of race, colour, sexual orientation, disability, and culture. There are constitutional provisions protecting the right to education, health, social protection, and freedom from violence. The Ekurhuleni Declaration on the Rights of Persons with Albinism, of 2013, was a key achievement.¹¹ The Women Empowerment and Gender Equality Bill (WEGE), passed in 2013, aims to promote equality between men and women in South Africa, as does the corresponding Policy Framework.¹² Human rights are indivisible and intersectional, requiring the concurrent reliance on multiple policy frameworks. Regulatory frameworks include the White Paper on the Rights of Persons with Disabilities¹³ and the National Strategic Framework on Reasonable Accommodation for Persons with Disabilities.¹⁴

And yet the implementation of these human rights policy frameworks proves to be difficult, such that many of the mothers impacted by albinism did not benefit from these. Mothers expressed the need for

financial assistance to pay for the necessary services for their children. Some mothers lacked knowledge about their eligibility for certain grants, such as the South African Social Security Agency (SASSA) Disability Grant.¹⁵ If they did know and apply, they were often denied funding because the condition might not be considered a disability by the agent. As a result, they were not receiving any financial support from the government. A mother described such a situation:

*"The government does **provide grants** but it's not every child who receives the grant. Like mine now, she is not receiving it, but I believe at some point it's necessary she will receive."*



Photo Credit: Busisiwe Mahlaba and her children with albinism

Because many mothers are homemakers, and some lost their jobs due to the COVID-19 pandemic, they and their children faced hardship and poverty. A person with albinism who works with an

*“I think there is quite an intersection between being a mother with albinism and mother of a child with albinism with **issues of poverty and other social ills**. You notice that stigma and discrimination is quite real in South Africa, especially in remote areas or the rural areas. So, whereas for example, a mother has a child with albinism, they are likely to face exclusion from society. No one wants to involve them in community activities whether it’s a food gathering or other things. People just start isolating them because of the fact that they have a child with albinism. So, at the end of the day all these community activities that are meant to enhance ones’ livelihood, they are your community with food gatherings or whatever food programs or development programs that are in that community, these people **tend to be excluded**. They end up even failing to make ends meet because of that stigma that they have within the community. So, the women are likely to be much more poorer and with very little chances of improving their economic outcomes because of the stigma and discrimination. And also, most of the women that we have interacted within our advocacy project, they have not had access to education.”*

albinism NGO described the challenges some mothers experienced.

The challenge of sufficient economic income is placed in the context of the intersecting social factors that influence opportunity and safety. A policy maker explained the multiple challenges:

*“I always find it very difficult to just speak about women as if they are a homogenous group. In South Africa, race really matters. As a black woman you are not safe at all. Whether you work, you’re not safe from a whole range of things. As a white woman you usually have more privilege, and you often can buy your safety to some extent. If you have albinism, you have this **race, gender, colourism and disability** compounded intersectionality that really gives you very little agency to negotiate, to just launch yourself from a positive. **So, safety is a massive issue**. And it’s not just safety as I say from being having albinism, it’s safety just from being a woman, and then from being a black woman so I must probably live in areas where there’s a lot of violence generally. So, that’s really, I think for me, the overriding*

RECOMMENDATIONS FOR POLICIES	
Audience	Best Practices
Health/Service Providers	<ul style="list-style-type: none">• Involve partners or fathers as much as possible, to support gender equality. Person- and family-centred care is a key dimension of quality care.• Inform mothers that their child may be eligible for the Disability Grant.• Ascertain that the person has a disability that hinders them from gaining employment.• Promote access to respectful maternity care for pregnant individuals and their families and communities.• Strengthen healthcare leadership and accountability to provide quality, comprehensive, and integrated maternity care across the healthcare continuum.
Government	<ul style="list-style-type: none">• Appoint spokespersons and advocates with albinism, such as Commissioner Nomasonto Mazibuko, to influential public roles to promote the rights of persons with albinism.• Implement the National Action Plan to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa• Incorporate a gender dimension and an intersectional lens to support mothers of children with albinism and women and girls with albinism.• Address intersecting issues relating to discrimination based on colour and disability.• Apply the World Health Organization’s Health in All Policies (HiAP) Framework.¹⁶• Facilitate the self-regulation of traditional healers and religious bodies (e.g., churches)• Continue to invest in Universal Health Coverage, as advocated for by the WHO, the World Bank, and the OECD, to meet Sustainable Development Goal 3.8• Provide free access to health services for persons with disabilities (including those with albinism) so that access is de-linked from the Disability Grant.
NGOs/CSOs	<ul style="list-style-type: none">• Provide information to mothers about government resources such as the Disability Grant.• Empower and equip mothers to access justice (as human rights claimants). Encourage mothers and families to act as human rights defenders.• Ensure gender is mainstreamed across all programmatic areas the NGO/CSO is working in.• Create programs that target women affected with albinism including mothers of children with albinism.
Families and communities	<ul style="list-style-type: none">• Commit to protecting the safety and security of mothers and their children impacted by albinism.• Create welcoming spaces in the community and invite full engagement by persons with albinism.• Include mothers impacted by albinism in community poverty reduction, livelihood strengthening, and development activities.
Mothers and fathers of a child with albinism	<ul style="list-style-type: none">• Be active with peer support through mothers’ and fathers’ groups which can be human rights activists (defenders) for the promotion of the human rights of persons with albinism.• Connect with NGOs/CSOs working in human rights and albinism to support parent groups in the promotion of human rights advocacy strategies

RESOURCES FOR FAMILIES AFFECTED BY ALBINISM

Women, Youth and Persons with Disabilities, Women Abuse Helpline: 0800 150 150

Disability grants are available.

- Please view the requirements and how to apply here: <https://www.gov.za/services/social-benefits/disability-grant>
- You may contact the South African Social Security Agency (SASSA) via telephone 0800 60 10 11 or email GrantEnquiries@sassa.gov.za

RESOURCES FOR SERVICE PROVIDERS AND GOVERNMENT

Women, Youth and Persons with Disabilities, Strategic Plan 2020-2025:
<https://n-preview.co.za/images/ResourceCentre/Strategic/Strategic%20Plan%202020-2025.pdf>

Women Empowerment and Gender Equality Bill (2015):
<https://www.gov.za/documents/women-empowerment-and-gender-equality-bill>

Constitution of the Republic of South Africa, 1996 - Chapter 2: Bill of Rights:
<https://www.gov.za/documents/constitution/chapter-2-bill-rights>

Sustainable Development Goals: <https://sdgs.un.org/goals>

V. INTERSECTORAL COLLABORATION

Promoting positive change is not an easy task but mothers and stakeholders shared that collaboration is crucial to continuous learning, co-creating ideas, and taking action. One policy-maker described the importance of collaboration.

*“What’s very important is where we have a **multidisciplinary group**, it’s with a non-government organization, together with the department of health, together with the department of social development, department of higher education and training, our international relations, our national police office. All are crucial.”*

Mothers and stakeholders stated that many sectors should come together to support and protect mothers and children affected by albinism, such as NGOs/CSOs, spiritual leaders, traditional healers, healthcare providers, educators, researchers, and policy-makers. One policy-maker described the achievement where a National Albinism Conference involving more than 300 persons with albinism, activists, and government. They gathered in 2013 in Ekurhuleni, Gauteng. It culminated in the Ekurhuleni

Declaration on the Rights of Persons with Albinism which addressed concerns of discrimination and violence against persons with albinism and emphasized their equal access to healthcare, education, job skills, and economic development. An intersectoral Roundtable was hosted in Geneva in 2018 to establish a research-advocacy-policy network with the research agenda of mothering and albinism.¹⁷ Intersectoral collaboration is foundational to this network.

RECOMMENDATIONS FOR INTERSECTORAL COLLABORATION	
Audience	Best Practices
Health/Service Providers	<ul style="list-style-type: none">• Get involved in educating the community about the genetics of albinism. Healthcare providers are trusted by the community because of their health knowledge.• Collaborate and engage with the government and advocates to promote awareness of albinism in schools and the community.• Identify ways to work on multidisciplinary teams and build partnerships with other sectors, such as NGOs/CSOs, educators, and local community leaders in your workplace.
Government	<ul style="list-style-type: none">• Educate government officials through building capacity, knowledge, and skills to engage in disability issues, including direct collaboration with persons with albinism and civil society advocates.• Implement the Sustainable Development Goals¹⁷ as a unifying vision for intersectoral collaboration.• Provide funding and resources for programs where civil society, healthcare providers, government, and educators can share, network, and collaborate.
NGOs/CSOs	<ul style="list-style-type: none">• Collaborate with teachers, healthcare providers, and the government to disseminate information about albinism in the community.• Hold social events and support group meetings and invite different sectors.
Families and communities	<ul style="list-style-type: none">• Be involved in the discussion and information sharing. Engage with the government and NGOs and CSOs when they have activities near your area.
Mothers and fathers of a child with albinism	<ul style="list-style-type: none">• Find and build connections with the different groups in your community (such as NGOs, faith communities, parents of children with other disabilities).

RESOURCES FOR FAMILIES AFFECTED BY ALBINISM

Connect with albinism organizations in your community:

- Albinism Society of South Africa: +27 11 838 6529
- National Albinism Task Force: info@natf-sa.org.za

RESOURCES FOR SERVICE PROVIDERS AND GOVERNMENT

The South African government (2016) specifically addresses the rights of equal access to health, education, and safety and security for persons with albinism. You can find the full declaration here: <https://www.gov.za/ekurhuleni-declaration-rights-persons-albinism#:~:text=Persons%20with%20albinism%20are%20South,3>

The South African government (2015) has the White Paper on the Rights of Persons with Disabilities, implementation matrix: <https://dwypd.gov.za/index.php/resource-centre/rights-of-person-with-disability>

Another resource is the National Strategic Framework on Reasonable Accommodation for Persons with Disabilities (2020): <https://www.gov.za/documents/national-strategic-framework-reasonable-accommodation-persons-disabilities-september-2020>

The African Union has an action plan specifically on albinism, titled Implementation Matrix of the Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031). You can find it here: <https://www.ohchr.org/sites/default/files/2021-11/AU-Plan-of-Action-EN.pdf>



Photo Credit: Tshogo Keitsemore and her child with albinism

APPENDIX

MOTHERING AND ALBINISM RESEARCH PROJECT

The Mothering & Albinism study is a global health research project with an international intersectoral network of researchers and advocates working together to promote and protect the human rights of persons with albinism and their families. This ethnographic study is funded by the Social Sciences and Humanities Research Council Canada to explore the day-to-day experiences of mothers with albinism and mothers with children with albinism through a gender, disability, and human rights lens in South Africa, Tanzania, and Ghana. Fieldwork is complete in South Africa and have interviewed 36 participants. We interviewed 19 mothers with a child(ren) with albinism and three mothers with albinism. We also interviewed six healthcare providers (genetic counsellors, a nurse, and a social worker), three civil society activists, two policy-makers, two traditional healers, and a faith leader.

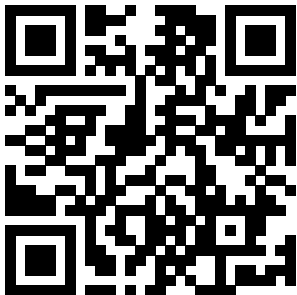
Mothers experience human rights violations due to social constructs about gender and albinism that resulted in various forms of discrimination, stigma, exclusion, and

attacks. They may be blamed for having children with albinism or having albinism themselves, abandoned by their partner or their families, and ostracized by the community. Many mothers report constant worry for their safety as well as for their children because of reports of attacks.

Mothers are central to the narratives of a family impacted by albinism. The findings from our study have shown their resilience, as they raise, advocate, and provide for their children. Their resilience is fostered by the peer support of mothers in similar circumstances; access to health information, genetic counselling, and disability services; and the support of civil society organizations such as Albinism Society of South Africa (ASSA), National Albinism Society, and Albinism Advocacy for Access. As they are resilient, so too are their children, families, and communities.



Photo Credit: Patricia Willcoq's White Ebony Collection



To learn more about the project, please visit:
www.motheringandalbinism.com

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We honour and give tribute to two team members who passed away during the study period: Dr. Maxwell Thabede (University of KwaZulu-Natal, South Africa), and Busisiwe Mahlaba (Community Researcher, South Africa).

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