The lived experiences of Persons with Albinism in the Northern Cape, South Africa

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ABSTRACT

Research has shown that persons with albinism have been victims of extreme forms of discrimination and social injustice on multiple and intersecting grounds, notably ethnicity, colour, disability, and gender. To better understand the 'lived' experiences of persons with albinism, the authors conducted interviews with participants spread across three districts in the Northern Cape Province, South Africa employing a qualitative, interpretative phenomenological approach. As this research was undertaken amid the restrictions imposed by the COVID-19 pandemic, telephonic interviews were conducted with 22 individuals with albinism or impacted by albinism. Thematic analysis was applied to the qualitative data. The study found that PWA experienced societal, cultural, and institutional barriers including stigma, discrimination, and victimisation, challenges relating to access to information, education, employment, healthcare, and psycho-social support. The authors recommended the urgent need for policy and legislative reform, proper implementation of The National Action Plan to Combat Racism, Racial Discrimination, Xenophobia, and Related Intolerance, and further extensive research on key issues that affect PWA in South Africa.

KEY TERMS: *discrimination, intersectionality, 'lived' experiences, Northern Cape, persons with albinism*

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INTRODUCTION

Albinism is a genetically inherited condition caused by a deficit in or the absence of the pigment melanin. Lack of pigmentation may be confined to the eye (ocular albinism) or may include the eye, hair, and skin (oculocutaneous albinism). It variously affects all ethnic groups and populations worldwide. The highest incidence of albinism is in sub-Saharan Africa where the prevalence is 1 person in 5 000 people (Ero et al., 2021). In South Africa, its prevalence is highest amongst Black African people – 1 in 4 000 people (Phatoli, Bila & Ross, 2015). Persons with albinism (PWA) face social injustice in the form of societal, cultural, and institutional barriers. Access to social justice is further encumbered when two more of these barriers are concurrently present. In recent years, the intersectionality paradigm has not only influenced human rights discourses, but is being applied to understand the multiple forms of discrimination that are experienced simultaneously, as is the case with PWA (Durojaye & Nabaneh, 2019:45). This study adopts a social justice and human rights lens to explore the contestations around disability; the multiple and complex intersections of race, colour, gender, and disability; the challenges related to access to justice; and the prevailing international, regional and national human rights frameworks that aim to protect the rights of PWA. The study was inspired by our participation (July 2019) in a focus group discussion with PWA in Orlando, a township outside Johannesburg, in response to an invitation by Khulisa Social Solutions. It became apparent that PWA felt marginalised, discriminated against, and deeply distressed by not being given a sympathetic audience. The paper begins by briefly reviewing the literature on albinism, and then goes on to report on the research methodology and findings of the study.

ALBINISM IN THE AFRICAN CONTEXT

Qualitative studies that explore the experiences of PWA are limited. The current literature on albinism is dominated by four main types: firstly, the literature overwhelmingly tilts towards albinism in the African context, highlighting the several sociocultural risks that PWA in some parts of Africa must endure (Mswela & Nothling-Slabbert, 2013; Mswela, 2017; Franklin et al., 2018; Imafidon, 2018; Kromberg et al., 2020), secondly the debate on the definition of disability and on whether albinism should be classified as a disability or not (Goering, 2015; Francis & Silvers, 2016); thirdly, the issues of stigma, discrimination, and victimisation and the challenges related to access to justice are examined; and finally, the literature analyses the international, regional, and national human rights frameworks that protect the rights of PWA.

The disability dilemma

The disability dilemma is birthed in how ableist attitudes and understandings of disability affect PWA, who may not be regarded as disabled in the traditional sense, but whose impaired vision and sensitivity to direct sunlight remain a serious structural barrier. Disability itself is a contested concept; even though there is an increasing awareness and acceptance that PWA should be considered disabled (Mswela, 2017; Franklin et al., 2018), the question of who qualifies as a disabled person still remains unclear. While the medical definition of 'disability' does not recognise albinism as a disability, the social model pays greater attention to the social and cultural barriers which exclude and marginalise PWA, i.e., the social model focuses on how the socio-cultural context affects PWA. At times, therefore, a sociological rather than a medical perspective must be applied to albinism because complications can arise not from how PWA are physically different, but from how others respond to these differences. Article 2 of the AU Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (2018) states: "The purpose of this Protocol is to promote, protect and ensure the full and equal enjoyment of all human and people's rights by all persons with disabilities, and to ensure respect for their inherent dignity." Article 1 of the United Nations Convention on the Rights of Persons with Disabilities – UNCRPD (UN, 2007) – adopts a human rights model and conceptualises disability as an evolving concept that arises when persons with impairments are hindered by attitudinal and environmental barriers from "full and effective participation in society on an equal basis with others." The UNCRPD's stance is supported by the United Nations Disability Inclusion Strategy (2021) which provides a foundation for "sustainable and transformative progress on disability inclusion."

Stigma, discrimination, and victimisation

History shows that colourism, which originated from either slavery or colonisation, evolved in different ways in different geographic locations. As a colonial legacy in Africa, skin-tone discrimination against dark skin and perceptions of fair skin as beautiful are common (Phoenix, 2014). However, it must be mentioned that discrimination based on colour has also been reported in predominantly white communities, where persons with albinism are discriminated against for being "too white." (United Nations General Assembly Report (A/72/169) 2017, 4). No matter what race or ethnicity PWA come from, they do not look like people within their own racial

group. Their lack of pigmentation makes them visibly different from their dark-skinned families and communities (Franklin et al.; 2018). Because PWA do not resemble people from their own racial group, the issue becomes a more complicated one. They experience discrimination and marginalisation because they are neither white nor black (Phatoli et al., 2015:106) and in societies where most of the population has dark skin, the hypervisibility of PWA makes them 'different,' and particularly vulnerable to stigmatization and discrimination. According to Phatoli et al (2015:1), "People with albinism do not fit neatly into black and white categories, they are likely to experience social discrimination and marginalisation." Their skin colour leads to negative social constructions amongst Africans and beliefs that they are evil cannibals or cursed (Ntinda, 2012 cited in Mswela & Nothing-Slabbert, 2013).

There are many myths surrounding albinism in Africa, especially sub-Saharan Africa. The belief that using the body parts of PWA for witchcraft rituals and traditional medicine will bring about good fortune and lead to success in life has led to a lucrative trade in body parts (Kajiru & Nyimbi, 2020). As a result, PWA have had to endure unprecedented levels of violence. Young girls with albinism are extremely vulnerable, because of the myth that sexual intercourse with them can cure HIV and AIDS. Inevitably, because of the constant fear of victimisation, the mental health of PWA is severely affected (Baker et al., 2010).

The stigma attached to PWA in several African countries is evident in the labels used to refer to them (Brocco, 2015). For instance, in the Congo, individuals with albinism are called *mbunzu gozo* (black eater of manioc) in the sangho language; emphasising the ambiguous status of the disability within the social sphere of the community (Ogrizek, 1983 cited in Brocco, 2015), while in Mali, they are referred to as *gomblè* (red man) because they are susceptible to severe sunburn which turns their skin red (Imperato, 2006 cited in Brocco, 2016). In Malawi, the terms *mzungu* (white man, European) and *napwere* (which refers to a pea-brownish color) are used (Braathen and Ingstad, 2006 cited in Brocco, 2015). The term 'albino' is often used in many languages, including English, to refer to people with albinism and although some people are comfortable with its use, others argue that the word can have a derogatory connotation. People consider it dehumanising to refer to a person in terms of a condition; hence, the terms *person with albinism* and *people with albinism* are largely accepted, as it puts the person first and the condition second (Ero et al., 2021). In South Africa, the terms 'albino' and 'people with albinism' are used interchangeably.

Intersectionality

Intersectionality refers to an integrated analysis of the complex and multiple forms of discrimination people face based on their identities and character traits. Despite increasing activism and awareness campaigns, people of African descent continue to experience discrimination based on race alone. As for women and girls with albinism, the discrimination is compounded by gender (Ero et al., 2021). Crenshaw's (1989:1245) analysis of 'structural intersectionality' facilitates an understanding of the lived experiences of women with albinism. Black women with albinism are particularly vulnerable as they are also exposed to historical and structural oppression. However, while women with albinism in theory enjoy general protection under existing regional and international human rights instruments, none of these takes specific cognizance of their special vulnerability (Ojilere & Saleh, 2019:7). Then, too, there is the issue of stigma that attaches to the condition which often results in a reluctance to seek help or treatment, low self-esteem, and the perpetuation of harmful stereotypes. In South Africa, stigmatisation, and 'othering' of PWA is further entangled and embedded with its "long history of apartheid, power differences and institutionalised racism, and the continued existence of these divisions" (Phatoli et al., 2015:106). Despite the protections provided for in the South African Constitution of the Republic of South Africa Act 108 of 1996, PWA continue to suffer severe discrimination, stigmatisation, victimisation, and violence, based on both race and colour (Mswela & Nothling-Slabbert, 2013:25). The AU Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (2018), expresses concern that "persons with disabilities continue to experience human rights violations, systemic discrimination, social exclusion and prejudice within political, social and economic spheres."

Access to justice

The United Nations 2030 Agenda for Sustainable Development emphasises the importance of access to justice as the *primum mobile* behind the enjoyment of human rights. Goal 16 specifically calls on countries to promote peaceful and inclusive societies for sustainable development, provide access to justice for all, and build effective, accountable, and inclusive institutions at all levels. Access to justice for all South Africa's citizens remains a major challenge and is entwined with seeking justice for the injustices of the past. This access embraces the inalienable right to enjoy a wide range of human rights that are enshrined in the South African Constitution, including access to economic, social, political, and legal rights.

International human rights bodies have raised concerns about human rights violations against PWA and recommend that states introduce mechanisms and strategies to protect PWA. The aim is to achieve a rights-based,

mainstreaming, and life-cycle approach by focusing on the themes of empowerment and equality and ultimately eliminating legal, social, and attitudinal barriers for people with disabilities.

States are encouraged to develop national plans of action on albinism by adopting a collaborative and multisectoral approach A national plan of action should provide the framework for governments to outline objectives, establish timelines, assign responsibility to particular entities, and allocate the necessary resources for them to meet their objectives (Ero et al., 2021:3). Drawing on the UNCRPD, The White Paper on the Rights of Persons with Disabilities in South Africa (2016) (White Paper) emphasises the social model for addressing disability and eliminating legal, social, and attitudinal barriers for people with disabilities.

In South Africa, the National Action Plan to Combat Racism, Racial Discrimination, Xenophobia, and Related Intolerance (NAP) (2019) emerged as a response to the limited attention and debate in South Africa on the state's obligation to protect the rights of PWA. Its aim is to give effect to international human rights obligations related to the elimination of racism, racial discrimination, xenophobia, and related intolerance. The NAP was informed by some of the core principles of community development, namely, universality, participation, and inclusion. The NAP goes on to outline several measures that are imperative: ensuring the arrest and prosecution of offenders that target PWA, providing psychosocial support for victims, and developing and/or reforming policies and legislation to improve access to justice for PWA.

METHODOLOGY

The study adopted a decolonising research methodology combined with an advocacy/participatory worldview as an overarching approach. Broadly, the former refers to approaches that are used to challenge "those research methods that undermine the local knowledge and experiences of marginalised population groups" (Keikilame & Swartz, 2019:1), while the latter holds that research has to be linked with politics and a political agenda. More specifically, a qualitative, interpretative phenomenological approach was adopted.

The study was located at three sites in the Northern Cape: Kuruman, Kimberley, and Pampierstad. Participants were recruited through purposive sampling and selected if they themselves had albinism, or if they were impacted by albinism. The snowball sampling method was used to locate and recruit PWA. The sample size was further expanded through the creation of a WhatsApp group. A non-governmental organisation (NGO) (Reamogeleng), which provides services for PWA in the Francis Baard District (covering Pampierstad and Kimberley), provided contacts for PWA. The COVID-19 pandemic meant that interviews had to be conducted telephonically. This affected the sample size as potential participants did not have smartphones. Informed consent was obtained from all participants.

In addition, debriefing and support for secondary trauma were offered by a local NGO which provided PWA with a range of services such as information and knowledge sharing and psycho-social support. Data was collected from February to April 2020 by a field worker from Khulisa Social Solutions, a non-profit organisation operating nationally in South Africa. Convinced of the imperative for a deeper understanding of the actual experiences of PWA, the researchers drafted an appropriate research instrument in the form of a semi-structured interview schedule with a mixture of open and closed-ended questions to gather data relevant to issues of concern.

The first part of the schedule determined the demographic profile of the sample population, while the open-ended questions enabled probing and allowed participants to answer in their own words. The interview schedule was in English, but participants could respond in their local language. The fieldworker was fully conversant with the local language and able to translate questions and participant responses and probe further to stimulate conversations. The data collection process was enhanced because the fieldworker himself was a PWA, and was hence able to easily establish rapport and trust with research participants. A voice recorder was used to capture participant responses. The data was analysed qualitatively through content analysis.

FINDINGS

The demographic characteristics of the sample population is represented in the table below and discussed.

Demographic characteristics	*Number of participants*
1. Person with albinism	16
2. Persons impacted by albinism (Mothers of children with albinism)	6
3. Location	
Kuruman	7
Pampierstad	5
Kimberley	9
Other: Douglas	1
2. Age	
18 - 20 years	3
21 – 30 years	9
31 – 40 years	5
41 – 50 years	4
50 – 60 years	1
4. Gender	
Male	10
Female	12
5. Marital status	
Single	17
Married	5
6. Highest educational level	
Primary	3
Secondary	14
Tertiary	2

In total, 22 individuals participated. There were seven from Kuruman, five from Pampierstad, and nine from Kimberley (One participant was from Douglas which is about 100 km outside Kimberley). Of these, 16 were PWA, while six were persons impacted by albinism (mothers of a child/children with albinism). There were 10 male and 12 female participants, and their ages ranged from 18 years to 52 years. Only two participants were married, and the other 14 were single. It was interesting to note that only two participants had actually entered tertiary level education, while 14 had attended secondary school, and three participants indicated that their highest educational level was primary school.

The overarching and converging issues identified by all participants related to their experiences of fear, stigma, and discrimination. In addition, the following thematic categories were identified: limited awareness/knowledge of albinism; barriers to education; economic challenges and access to employment; access to justice; and access to health care.

Fear, stigma, and discrimination

Most participants indicated that they had experienced some form of discrimination. It included name-calling, teasing, and bullying, which occurred more in mainstream schools and the community. One participant described how she was abused by her own mother.

> Some in the family couldn't even eat with the same spoon I ate with. Our mother didn't care for me as she left me at my uncle's place. I was abused to the point where I found another elder who was supportive and encouraged me.

Another participant described how she had been abused as a child and was now a victim of domestic violence. She did not report the abuse as she was financially dependent on her husband.

> Now my husband abuses me physically, even with money; he spends all his money alone and I survive just with the grant…If I report him he will be arrested. So, I am afraid as he is the only one working.

Some participants, however, through the support of their families (especially mothers), were able to generate fortitude and resilience.

> *...but my family was supportive, they told me I am beautiful, I am strong, and wise. And with time I did not complain anymore. I have never made a case for name-calling as with time you get used to being teased.*

> *Yes, I get teased a lot but now I have a copy of a book on albinism, and when someone says bad stuff I show them the book and explain things.*

> *Yes, in the community, it is difficult as people don't understand, I try to make my son strong and know his worth and do not really care what people say.*

The responses suggested that women and children with albinism were at a greater risk of becoming victims of violence, abuse, and intimidation. Their vulnerability was heightened by the prevailing myths which included the following: that having sex with women or children with albinism will cure HIV/AIDS, and that use of the body parts of PWA will bring good luck. The experiences of female participants and children with albinism in relation to sexual crimes, abuse, and intimidation are illustrated below:

> *Others rape women and children with albinism because of myths – heard of many cases of women with albinism who are said to be raped because there are myths it cures AIDS. Also, there is a fetish for having sex with a woman with albinism.*

> *...because there was an incident where a guy came to me out of nowhere, I don't know him, but he said "Do you know that you guys are raped and killed for your body parts and that they rape you, women, with albinism as you are in risk" and he isn't the first person to say this. I don't know what radio station I listened to where they told me that women with albinism are more at risk than men. So yes, women and children are surely at more risk.*

> *Again, we hear about children and women being killed a lot, and also in my son's case, there were a group of women who wanted my son's nails or hair, as they feel that persons with albinism hold luck, and they can win the lottery. It is a bit traumatic to have a child with albinism, the stress levels you go through as a mother.*

Limited knowledge about albinism

A significant challenge confronting PWA, as acknowledged by participants, was the general lack of knowledge about albinism in the family, community, and schools, which, in turn, led to discriminatory behaviours (Durojaye & Nabaneh 2019; Mswela, 2017). At least 17 participants indicated that they had limited knowledge about their condition, while 5 said that they had no knowledge at all. A participant's response below is revealing:

> *Poor knowledge, in both family and even community, as I would be teased by family members and community members.*

An interesting finding was that those who understood their condition got the information from television, radio, or social media late in their lives. Some participants suggested that educating people in the governmental sector was crucial to dispelling myths and allowing knowledge to filter down and empower PWA.

> *Education on the condition is key. According to me, departments must be visited and their management to be taught that persons with albinism are people. If the head of departments can be educated, it will be easier for others to be taught.*

> *Government must treat albinism issues seriously. Fund awareness and fund ways to teach and empower persons with albinism.*

Barriers to education

In this study, 15 participants indicated that they had attended mainstream, 'normal' schools, while only 4 had attended special boarding schools for PWA. Those participants that attended mainstream schools lamented the long distances they had to walk in order to get to school, which exposed them to the harsh sunlight. In addition, they had to endure discrimination and abuse in the form of bullying, name-calling, and teasing by other school children.

> *I went to a mainstream school, it was a long walk to school. I left school as I was abused a lot by other learners, teachers, and community members, I then decided to leave school.*

The researchers believe that currently, mainstream schools do not have the infrastructure and educational resources to support learners with albinism. Limited budgets make it impractical to purchase the necessary equipment to accommodate a presumably very small group. Several participants cited the lack of a conducive learning environment in mainstream schools as one of the most challenging aspects of attending these schools. No special measures were adopted to address their impaired vision by way of special large-print textbooks or seating arrangements close to the blackboard.

> *It was a mainstream school where everyone in the village went. I don't know about special schools. Life was hard and I left school because I was struggling to see the board.*

> *It was a normal school in the village. It was hard as I was teased and did not have glasses. It was hard. Every day was a challenge as teachers did not understand albinism.*

> *I attended a school where I was the only one with albinism. Everyone was darker than me. It was in another village.*

In terms of educational levels, 14 participants had proceeded to the secondary school level, 8 had actually completed secondary school, and 3 had dropped out at the primary level. Only 2 had attended or are currently enrolled at a tertiary institution.
Discrimination, bullying, teasing, and abuse were cited as the main reasons for poor educational outcomes, dropping out of school, and subsequent unemployment.

> *I left school as I was abused a lot by other learners, teachers, and community members, I then decided to leave school.*

> *I was smart but the issues at school made it difficult for me to finish. I think the school I went to didn't understand my needs. I was the only white one in school. The teasing, the lack of sunscreens, and the skin sores. I could not continue.*

Economic challenges and access to employment

Closely related to the right of access to education is access to employment. In reality, however, numerous obstacles hinder PWA from forming relationships and finding/maintaining a job. Therefore, most PWA are reported to be of lower, if not the lowest, economic status in their society. In this study, of the 22 participants, 16 were of employable age. Of these, only 2 were employed, one a post office employee who earned less than R3500.00 while the other, an NGO employee, who earned a meagre wage that could not meet his needs. The other 14 were unemployed with little or no income. Participants identified four main factors that reduced employment opportunities. These include limited education, poor vision and sensitivity to the sun with its associated risk of skin cancer, the stigma associated with their disability, and the perception that they were incapable of working.

> *I am unemployed, and it is increased by the lack of education and my condition. People judge us badly, they don't give us opportunities, because we don't have a high education*

> *People still look down on us, that is why they don't employ us. I mean if a person hires you in their shop, they may be afraid that if they hire you, the customers will not come as some see you as lesser, again at times if we don't take care of our skins. We get sores, and this may affect how people see us.*

Most participants were from rural/semi-rural areas where employment opportunities are in the agrarian sector; compelling them to work outdoors and being exposed to damaging ultra-violet rays.

I am not educated and our work is on the farms and I struggle to work. People work on the roads and my skin doesn't allow me to...people don't want to give me a chance.

The unemployment of many PWA meant that had to rely solely on social grants. Only 9 participants were able to access social grants; the rest were not regarded as disabled by officials. Inconsistent allocation of grants was obviously due to a lack of understanding of the disability status of PWA. Participants emphasised the need for disability grants for PWA to cope financially with their condition.

Our people are suffering. Skins, eyes, products are expensive, shading glasses, skin creams, and some are not working so this and many reasons make the grant a necessity.

Access to justice

On the issue of access to the criminal justice system, those that had been victims of intimidation, abuse, and/or violence shared their reluctance to report the matter or lay charges with the police. The main reasons cited were a lack of trust and/or faith in the police, not being taken seriously by the police, especially in the case of domestic violence, being intimidated by the police, and inaccessibility of police stations in rural areas. In response to the ongoing abuse and victimisation of PWA, one participant remarked that stricter measures must be enforced.

I think they must be strict on offenders and abuse, if they are not punished, the abuse will continue.

I was assaulted and reported it to the police. The police did not take the report seriously as I did not see the attacker and there were no cameras.

My husband abuses me physically all the time...I reported the abuse to the police and he was only warned. I am afraid if they arrest him I will have no money.

I did not report the physical abuse as it was not going to help. The police and everyone grew up with us in the same community...they know what we are facing but they don't even make people aware of our condition.

I went to the police, I knew nothing was going to be done as normally...so there was no further action taken.

Access to healthcare

Very few participants were accessing the public health care system. The main reasons cited were a lack of understanding of albinism by medical personnel, discrimination against PWA, and a scarcity of resources like appropriate sunscreens. Of the 22 participants, only 6 indicated that they had visited a health care facility for skin cancer testing, eye tests, glasses, and sunscreens. The reasons cited for not accessing services from the public health care system, were first, that they were not aware of the services available to them, secondly, they believed that because they lived in a rural area accessing health care was difficult, and thirdly, that there were limited resources in rural health care facilities as compared to those in urban areas.

I do not go to the hospital. The departments must make us aware of what services they are offering.

Participants also lamented the poor quality of sunscreens provided by the Department of Health.

I heard from the pharmacist at the Department of Health that the sunscreens used on persons with albinism is from Cancer SA and isn't necessarily for skins with albinism. So, at times, it reacts badly on our skins.

Many relied on NGOs to assist with their medical needs as they were "more comfortable getting assistance from the NGOs". Participants highlighted the role of NGO service providers in offering services that were not available to them through government departments. However, only 7 participants indicated that they accessed these services by belonging to support groups run by NGO service providers. Participants who did belong to or attended support groups cited the benefits of seeking services from NGOs and the important role that the NGO service provider played. They relied on NGOs for information about albinism, appropriate sunscreens, and counselling and psycho-

social support. They further recommended greater funding for NGOs that provided these essential services for PWA.

> *Reamogeleng and Albinism Advocacy for Access (AAA). They help with information in terms of bursaries and opportunities. Last year they helped me go to Pretoria for a workshop on advocacy. And Reamogeleng helps with sunscreens and helps with many local services.*

> *Thshego, from Reamogeleng, helps with early identification, counselling of the family, referral to the Department of Education to ensure the kids get to school and have SASSA.*

> *It helps with awareness at times. And at times we meet and talk. The NGOs help with making appointments at the hospital for skin cancer screening/testing, and assistance with sunscreens from the hospital.*

> *NGO groups must be formed, so people can share their experiences, so people with albinism can help each other. Again, awareness must be promoted as a lot of people do not know about albinism. Educate people about albinism – go to schools – create awareness as most problems are there as many PWA had to learn on their own.*

The participants impacted by albinism (as mothers of children with albinism) indicated that they had limited knowledge about the condition, were unable to gain employment, and relied on child support grants of R400.00 per month. They felt that a disability grant would better serve their needs as sunscreens and glasses were expensive. They mostly relied on an NGO for information, psycho-social support, sunscreens, and spectacles. They also expressed the need for more information sharing and training around the albinism condition.

> *Yes, but not a disability one. It is the R400 we get for every child. She only receives the regular child grand and not the needed disability one.*

> *They must get disability one because the skins are not the same and she uses expensive products. I think people with albinism should get a disability grant. She (child) uses things I cannot afford and it is only through the grant that we can assist the gap.*

> *I don't have too much knowledge, it is average and even my family, they are in the same learning space as me. I need more information. There is a need for a workshop explaining in detail.*

> *Support groups for mothers are needed. Proper inclusion plans and not just lip service on issues on albinism, but training of public and private sectors on albinism issues.*

From policy to practice

With the advent of democracy, South Africa adopted the developmental approach to social welfare and social work, with the twin aspirations of being both pro-poor and adopting a human rights framework (Patel & Hochfeld, 2012:691). Hence, social workers are compelled to adopt a social justice lens to realign their research and practice ethos with the social change function of social work. Social workers are at the forefront of not only understanding and responding to the "sources of injustices that contribute to marginalisation, social exclusion and the oppression of individuals, groups, and communities" (Lombard & Twikirize, 2014:318), but also the coping strategies used by PWA, their capacity for resilience, and their adaptation to the stresses they experience. It is recommended that for policies to translate into implementation strategies, all stakeholders must have a more comprehensive and realistic picture of the challenges faced by PWA and those impacted by albinism, through collaboration and partnership with academics and relevant civil society organisations. The following need specific attention: persons (especially children) with albinism; parents of children with albinism; the issues of poverty, inequality, and unemployment of PWA; strategies to combat prejudice, discrimination, and stigma in communities and in the public and private sectors; and resilience and coping strategies adopted by PWA to navigate their way through the barriers they face. The White Paper should be reviewed to include albinism as a condition with special disability status to ensure greater clarity in both the public and private sectors. This would, in turn, improve access to justice, healthcare, education, social services, and employment for PWA. While the NAP acknowledges that discrimination against PWA receives little attention from the criminal justice system and that many human rights cases of abuse and crimes against PWA are overlooked and go unreported, the implementation of the plan has stalled. Since its launch not much has been done practically to address the many challenges facing PWA. It is time that policies are translated to services on the ground for PWA. It would seem that due to the barriers they face in

accessing services from government departments, PWA are compelled to turn to NGO service providers. Therefore, it is imperative that the state funds and capacitates civil society organisations.

CONCLUSION

PWA experienced many societal, cultural, and institutional barriers which severely impacted their access to justice and human rights. Awareness-raising, information sharing, public education, capacity building, and training on the rights and needs of PWA, the authors suggested, were needed to sensitise not only the general public but also relevant service providers in the governmental and non-governmental sectors (social development, healthcare, education, safety and security, economic empowerment, law enforcement).

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