Joint Shadow Report to the CESCR: Human Rights situation of Persons with Albinism in Zambia

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Executive Summary

Persons with albinism in Zambia remain among the most marginalized and at-risk groups in the country. Despite constitutional and legislative provisions recognizing their rights and disability status, persons with albinism continue to experience widespread violations that limits their full enjoyment of economic, social, and cultural rights guaranteed under the International Covenant on Economic, Social and Cultural Rights (ICESCR). This Joint Shadow Report responds to Zambia's implementation of the ICESCR, particularly in relation to persons with albinism, who constitute approximately 64,026 individuals (0.325% of the population) per the 2022 national census. The report provides empirical and legal analysis of the State party's failure to respect, protect, and fulfil key rights under Articles 2(2), 3, 6, 9, 12, and 13 of the Covenant.

This report assesses Zambia's implementation of ICESCR Articles 2(2), 3, 6, 9, 12 and 13, drawing on desk research, legal and policy review, semi-structured interviews with albinism organizations, and focus group discussions with leaders of organizations of persons with albinism and disability rights advocates. While national laws recognize disability and prohibit discrimination, enforcement remains weak and Zambia lacks an adequately resourced, albinism-specific national strategy.

Both structural and attitudinal barriers, especially the lack of reasonable accommodation, stigma and discrimination, continue to block equal access to education and employment. Persons with albinism face high unemployment and are pushed into precarious livelihoods, often involving prolonged sun exposure without protection. Social protection schemes do not address core disability-related needs such as sunscreen, protective clothing, and low-vision aids, while disability registration processes remain difficult and exclusionary.

Health services are insufficiently equipped to prevent and treat skin cancer and to provide low-vision and mental health support. In education, learners with albinism face bullying, safety fears, lack of assistive materials, and limited teacher capacity to support low-vision learning, contributing to low completion and transition rates especially for girls, who face compounded risks of gender-based violence and discrimination.

Key recommendations to CESCR

The report calls on the Committee to press Zambia to:

- Require updated, disaggregated data on persons with albinism and formal recognition of persons with albinism as a minority group requiring special protection measures.
- Urge the government of Zambia to adopt a National Action Plan on Albinism with a dedicated budget and clear targets and accountability.
- Press for prevention, investigation and prosecution of albinism-related violence, including harmful practices and hate crimes targeting persons with albinism, and stronger community protection measures.
- Institutionalize free, continuous provision of broad spectrum SPF (50+ SPF) sunscreen and low-vision/assistive devices through public healthcare systems.
- Mandate reasonable accommodation standards in workplaces and schools, backed by enforcement and incentives.
- Expand disability-inclusive social protection and simplify registration through community-based approaches.
- Integrate women and girls with albinism into GBV prevention/response frameworks and ensure justice-sector training.
- Support the participation of persons with albinism organization, in the consultations, design and implementation of social protection programmes towards attaining the social inclusion of persons with albinism

Introduction

Persons with albinism in Zambia remain one of the most marginalized and vulnerable citizens, facing pervasive human rights violations despite the State’s obligations under the International Covenant on Economic, Social and Cultural Rights (ICESCR). Albinism is a rare genetic condition resulting in lack of melanin, causing visual impairment and extreme sensitivity to sunlight. According to the 2022 national census, 64,026 persons with albinism live in Zambia (about 0.325% of the population), with a slight majority in rural areas[1]. By virtue of their condition, they experience a distinctive form of disability and *“multiple and intersecting forms of discrimination and violations of their rights, such as physical attacks, sexual violence, and lack of access to education, health and employment”*[2]. Deep-seated myths portray albinism as a curse or, conversely, imbue body parts of persons with albinism with magical wealth-bringing powers, fueling stigmatization and horrific ritual murders. The United Nations Special Rapporteur on disabilities reported testimonies that *“at least ten persons with albinism are murdered in ritual killings every year in Zambia for their body parts,”*[3] causing some families to hide their children out of fear. This extreme reality underpins the failure of Zambia to respect, protect, promote and fulfill the ICESCR rights of persons with albinism on an equal basis with others.

This report focuses on Articles 2(2), 3, 6, 9, 12, and 13 ICESCR, highlighting the State party’s gaps in ensuring non-discrimination, gender

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[1] *Zambia 2022 Census of Population & Housing – National Analytical Report*, Chapter 9 (Activity Limitation and Albinism) – official statistics on population with albinism

[2] *Albinism & Rights in Zambia: An Exploration of Experiences, Sociocultural Conditions and Access to Justice* (2024), Ministry of Community Development and Social Services/UNZA/UNICEF – findings and recommendations on discrimination, education, health, etc.

[3] Country Brief: Situational Analysis of Disability in Zambia (Nov 2023), UNPRPD/UNICEF – analysis of legal framework, social protection, and vulnerable groups including persons with albinism

equality, and the rights to work, social security, health, and education for persons with albinism.

Methodology

The report employed a desk research approach to investigate violations of rights of persons with albinism. We obtained information from both primary and secondary sources of data. The report also adopted in-depth interview where we design semi-structured questionnaires, contacted Albinism organisations in Zambia and obtained key insights from them through the interview. The report also made use of focus group discussions with leaders and members of organisations of persons with albinism and allied disability and human rights organisations in Zambia.

The report also draws extensively on the national report "*Albinism and Rights in Zambia*," commissioned by the Ministry of Community Development and Social Services with support from UNICEF and published in 2024, which used a mixed-methods approach (survey, in-depth interviews, focus groups and desk review) across four provinces (Lusaka, Western, Northern and Eastern). That report documents the lived experiences of persons with albinism regarding equality, violence, access to justice, health, education and employment, and provides the most comprehensive empirical picture currently available. We had a focus group discussion with leaders of organizations of persons with albinism and disability rights advocates in Zambia, whose anonymized testimonies are cited throughout the report to illustrate lived experiences and systemic gaps in the implementation of ICESCR rights

Secondly, it uses findings from the *Situational Analysis of the Rights of Persons with Disabilities in Zambia* (UNICEF/UNPRPD, 2023), which analyses legal, policy and institutional frameworks, disability-inclusive service delivery, equality and non-discrimination, social protection and accountability mechanisms affecting persons with disabilities in general, including persons with albinism.

Thirdly, this report has been informed by a review of relevant constitutional and legislative provisions (including the Constitution as amended in 2016, the Persons with Disabilities Act 2012, the Penal Code, the Human Rights Commission Act, the Children's Code Act 2022 and sectoral legislation on health, education and social protection), as well as policy documents such as the draft National Policy on Persons with Disabilities and national social protection strategies.

Finally, the submission is informed by academic work and expert analysis on access to justice and the rule of law in Zambia, including scholarship on the role of the judiciary in ensuring access to criminal justice, which is particularly relevant for the safety and justice needs of persons with albinism.[4]

Principles

Article 2(2): Non-Discrimination

ICERD obliges States to guarantee that the rights enunciated in the Covenant "will be exercised without discrimination of any kind," [5] including on grounds of *disability or other status*. In Zambia, persons with albinism continue to face systemic discrimination and social exclusion in nearly all aspects of life, undermining enjoyment of their Covenant rights. This

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[4] Anderson Ngulube, "The Role of the Judiciary in Safeguarding and Ensuring Access to Criminal Justice: The Case of Zambia", in *Goal 16 of the Sustainable Development Goals*.

[5] Article 2(2) of the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)

discrimination is both attitudinal (stemming from stigma, myths, and fear) and structural (inadequate legal protections and accommodations).

Social stigma and violence. The 2024 Albinism and Rights in Zambia report found a persistent lack of public awareness about albinism, giving rise to harmful myths and superstitions.[6] Many Zambians falsely believe albinism is a punishment or curse (for example, attributed to a mother's supposed infidelity) or that people with albinism are "ghosts." On the other hand, witchcraft-related beliefs treat persons with albinism as sources of wealth, their *body parts are erroneously believed to bring prosperity*. These myths "have aroused hate, fear or ambivalence" toward those with the condition. Consequently, people with albinism are often *ostracized from community life and live in fear*. In extreme cases, they are targeted for violent attacks: as noted, ritual killings and trafficking of body parts have been documented, and survivors of such attacks rarely see justice. Even in daily life, persons with albinism face frequent verbal abuse, name-calling, and intimidation. The United Nations Independent Expert on albinism has classified these practices as *hate crimes*, noting that pervasive myths "*strip persons with albinism of their humanity, paving the way for exclusion and attacks*". Such dehumanization entrenches social exclusion as a "natural" outcome.

Importantly, discrimination starts at home and in communities. The 2024 Albinism and Rights in Zambia report documented that some families conceal children with albinism or keep them indoors to "protect" them from abduction or harm. This protective isolation, however well-intentioned, results in denial of basic rights – children kept at home may not attend school or participate in society. Community members also often exclude

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[6] Republic of Zambia, Albinism and Rights in Zambia: An Exploration of Experiences, Sociocultural Conditions and Access to Justice (Ministry of Community Development and Social Services 2024).

or avoid persons with albinism due to superstitions that merely touching them or even sharing food will bring misfortune. Such social ostracism has profound psychological effects and denies persons with albinism equality of opportunity in every sphere.

Zambia's domestic law does formally prohibit discrimination on grounds of disability, which by statutory interpretation encompasses albinism. The Persons with Disabilities Act, 2012 (PDA) does not explicitly recognizes albinism as a disability but it can be inferred. The recent parliamentary motion asked government to include specific mention of albinism within the definition of persons with disabilities. Despite this framework, there remains a policy gap: there is no dedicated strategy or action plan addressing the unique needs of persons with albinism. The 2024 Albinism and Rights in Zambia report emphasizes that *"currently, the laws and policies in Zambia do not expressly provide for the rights of persons with albinism,"* apart from the general disability provisions. In practice, enforcement of anti-discrimination laws is weak. There have been no known prosecutions for hate crimes or discriminatory offenses specifically targeting persons with albinism, despite the well-documented violence they suffer. Perpetrators of attacks are rarely brought to justice, fostering impunity and fear among victims.

Discrimination also manifests in structural barriers that the State has failed to remove. For example, schools and workplaces often lack reasonable accommodations for persons with albinism's visual impairment and photosensitivity. Furthermore, the 2024 report observes that something as simple as poor lighting or small font on a classroom blackboard can render the entire environment "a barrier to the right to education" for a student with albinism. Likewise, outdoor workplaces without provision of protective clothing effectively exclude persons with albinism, as unprotected exposure to the “scathing sun” puts them at immediate risk of skin damage and skin cancer. These shortcomings in accessibility and accommodation are a form of indirect discrimination, as they disproportionately harm persons with albinism and have not been adequately addressed by the State. While Article 13 of the CRPD (which Zambia has ratified) mandates States to provide necessary accommodations to ensure persons with albinism enjoy equal access to services (including education, health, and justice), Zambia has yet to operationalize this in its schools, courts, and public institutions.

A focus group participant emphasized that existing measures have failed to translate into real protection for persons with albinism, stating that there is a need for “*tangible interventions beyond meetings, beyond papers, things that can be seen and measured, where people with albinism can really say: I am a direct beneficiary of the protection of my life*.”[7]

Article 3: Equal Rights of Men and Women with Albinism

In the context of albinism, women and girls with albinism face intersecting forms of discrimination on account of both their gender and disability. The evidence reveals that females with albinism are particularly vulnerable to gender-based violence, social exclusion, and inequities in health and education, indicating the State’s failure to secure substantive equality as required by Article 3 (and as reinforced by CEDAW).

Additionally, the 2024 Albinism and Rights in Zambia report found that “women were more vulnerable to attacks” motivated by witchcraft and prejudice, compared to their male counterparts. These attacks include extreme acts of gender-based violence: *“Women with albinism faced gender-based violence and hate crimes in the form of rape”*[8] in Zambia.

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[7] Participant during the Focus Group Discussion

[8] *Albinism & Rights in Zambia (2024)*

In focus groups discussion, women with albinism reported living in constant fear of sexual assault. Some had received direct threats of rape, which caused intense anxiety about their personal safety and constrained their freedom of movement. Community myths in parts of Southern Africa (also present in Zambia) falsely claim that having sex with a woman with albinism can cure HIV/AIDS or bring fortune, which *motivates brutal sexual assaults* under the guise of ritual. Rape of women with albinism is thus not only an act of misogyny but also one driven by harmful superstition – a doubly egregious violation of their rights to security, health, and dignity. The State has not reported any specific measures to address this vulnerability (for instance, no specialized protocols or awareness campaigns focusing on the sexual exploitation of women with albinism). The Maputo Protocol (to the African Charter) and CEDAW[9] obligate Zambia to protect women with disabilities from violence and harmful practices, yet women with albinism remain in peril due to inadequate implementation of those protections.

In addition, women with albinism frequently experience domestic and intimate partner violence. The 2024 Albinism and Rights in Zambia report noted cases of women with albinism being targeted by men who feign romantic interest to gain trust, only to later harm or even kill them for their body parts. This horrifying tactic exemplifies how gender dynamics (women's generally lower social power) are exploited in the context of albinism-related violence. It also underscores a lack of effective policing and community awareness to prevent such crimes. Many women with albinism face abandonment or abuse in family settings as well for example, some husbands reject wives who give birth to children with albinism, blaming the mother and leaving her to care for the child alone.

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[9] CEDAW Committee, General Recommendation No. 18 (1991) – on women with disabilities, relevant to the compounded discrimination against women with albinism

Such outcomes, noted in the UNICEF situational analysis, contribute to high rates of single motherhood among caregivers of children with albinism, deepening their economic insecurity.

In education, girls with albinism are often pulled out of school earlier than boys, reflecting gender-biased safety concerns and caretaking expectations. Families fearful for a daughter's safety may keep her home, especially after reports of attempted abductions or bullying. Indeed, disability advocates in Zambia report pervasive bullying of girls with albinism in schools. Such harassment ranging from name-calling and social isolation to physical attacks can push girls to drop out. This contributes to a gender gap in educational attainment within the albinism community.

Healthcare access also reflects gender disparities. Women with albinism have reported discriminatory treatment in maternal health settings some were met with derogatory attitudes by healthcare workers or lacked support during pregnancy, owing to misconceptions that giving birth as aa woman with albinism is "problematic." Women and girls with albinism also need specific sexual and reproductive health education (for example, on protecting their skin during pregnancy, or dealing with low vision in child-rearing), which is not provided in mainstream programs. The UNICEF (2023) Situational Analysis report highlighted that *women and girls with disabilities (including albinism) are often left out* of targeted health interventions and social protection linkages, undermining their well-being.

Article 6: Right to Work

Article 6 of ICESCR guarantees the right to work, including the right of everyone to gain a living by work freely chosen or accepted, and obligates States to take steps to achieve full employment and remove employment discrimination. For persons with albinism in Zambia, this right is far from realized. Unemployment and underemployment are pervasive, driven by both societal discrimination and lack of supportive measures. As a result, persons with albinism are often among the poorest segments of society, surviving in precarious informal jobs or subsistence activities.

From the outset, many persons with albinism are denied equal opportunity to develop employable skills. As detailed later under Article 13, most individuals with albinism attain only low levels of formal education, which limits their job prospects. The 2024 Albinism and Rights in Zambia report stated that only 9.6% of surveyed persons with albinism had any education beyond secondary school, and 7.7% never attended school at all. By comparison, the 2022 national census indicates that 24.9% of the general population has never attended school and that approximately 4.9% have completed post-secondary education. While national averages mask inequality, they demonstrate that persons with albinism remain systematically excluded from higher education pathways, even when compared with other marginalised groups. Notably, census data further show that persons with disabilities (12% of the total population) experience reduced educational access, yet their outcomes still surpass those of persons with albinism, underscoring the distinct and compounding barriers faced by this group.

These disparities point to the failure of inclusive education policies to adequately accommodate the specific needs of learners with albinism, particularly with respect to visual aids, teacher training, stigma reduction, and targeted financial support

This educational gap directly translates into lower qualifications in the workforce. Moreover, pervasive stigma means that employers are often reluctant to hire a person with albinism. There are anecdotal reports of job-seekers with albinism being turned away from interviews once visible, or being passed over for promotions due to customer bias (for instance, in public-facing jobs where employers fear that clients will react negatively to a staff member with albinism). Such attitudinal discrimination by employers contravenes Zambia's own laws, the Employment Code Act, 2019 and the Citizens Economic Empowerment Act, 2021 both prohibit discrimination on grounds of disability (explicitly including albinism) in hiring and employment conditions. However, enforcement and awareness of these provisions are weak. The UNICEF (2023) Situational Analysis report[10] noted that even though these legal safeguards exist, many employers (especially in the private sector) remain unaware or unconvinced of the need to include persons with disabilities in their workforce.

A significant practical barrier is the lack of reasonable accommodations in workplaces. Persons with albinism often have low vision, requiring adaptations such as large-print materials, magnifiers, or bright but diffused lighting at their workstation. They also need protection from prolonged sun exposure for example, if a job involves outdoor activity, employers should provide protective clothing, wide brimmed hats, or schedule flexibility to avoid midday sun. In Zambia, such accommodations are rare. The 2024 albinism and rights in Zambia report highlighted that without adaptive measures, "the whole [workplace] environment can become a barrier" for an employee with albinism. Yet, most employers have not made these adjustments, effectively excluding persons with albinism from many jobs. Even simple measures like allowing sunglasses or visors on duty, or providing digital enlargers, are not commonplace. The government has no specific program incentivizing workplace accommodations beyond a

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[10] UNICEF (2023) Situational Analysis of the Rights of Persons with Disabilities in Zambia. Compiled by Heidi Loening-Voysey, Michaela Pelser and Theresa Wilson for UNICEF.

general tax rebate for employers of persons with disabilities (PDA, Section 37). It remains unclear how many employers have utilized this incentive, if at all, and whether any persons with albinism have benefited from it.

As a result of these barriers, most persons with albinism are unemployed or confined to informal, low-income work. Precise statistics are not readily available because labor force data is not disaggregated by albinism. However, qualitative evidence from the field is telling. In one rural district (Sefula) studied, researchers found that adults with albinism especially women had *"limited educational attainment, lacked formal employment opportunities and thus had limited financial resources."*[11] Many are self-employed in informal rural work such as farming or petty trading, largely by necessity. Tragically, this often means persons with albinism end up farming under the hot sun without adequate protection. One interviewee lamented: *"Sunscreen is beyond the reach of many persons with albinism… Most of us are farmers [exposed to the sun]."* This scenario illustrates a vicious cycle: discrimination and poor support drive persons with albinism into unsafe, marginal livelihoods, which in turn imperil their health (leading to illness that further hampers their ability to work).

Even in urban areas, those with albinism frequently engage in the informal economy e.g. running small stalls, tailoring, etc due to exclusion from formal employment. The UNICEF (2023) Situational Analysis report cited a 2022 study which indicated that persons with albinism and other disabilities were "usually among the poorest in society," lacking stable jobs and income. Poverty rates are extremely high in this group; many cannot afford necessities (discussed under Article 9). Without targeted

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[11] Albinism & Rights in Zambia: An Exploration of Experiences, Sociocultural Conditions and Access to Justice (2024), Ministry of Community Development and Social Services/UNZA/UNICEF – findings and recommendations on discrimination, education, health, etc.

interventions, persons with albinism struggle to compete equally in Zambia’s job market.

The Government of Zambia acknowledges on paper that people with albinism have the right to work and that disability-inclusive employment is necessary. For instance, the *Seventh National Development Plan* and other policy documents mention inclusion of persons with disabilities in empowerment programs. However, implementation is insufficient. There are no known government training or vocational programs tailored for persons with albinism, who might need special support (such as assistive devices for training in trades). General youth and women empowerment funds have not reported any disbursement aimed at beneficiaries with albinism. Moreover, while the Persons with Disabilities Act 2012 establishes the Zambia Agency for Persons with Disabilities (ZAPD) with a mandate to support economic empowerment (e.g. soft loans, skills training for persons with disabilities), the reach of these programs is very limited. As of August 2023, only about *63,340 persons with disabilities* of all types were officially registered with ZAPD (out of an estimated 1.5 million persons with disabilities nationwide). Registration is effectively a gateway for access to any state benefits. The complex and centralized registration process requiring medical assessments and travel to provincial offices means many persons with albinism (especially in rural areas) remain unregistered and thus invisible in employment support schemes.

Regarding employment, focus group participants underscored that reasonable accommodation must be treated as non-negotiable, particularly within government systems. One participant stated: “*Government should ensure that if a person with albinism is hired under a* *project, reasonable accommodation must be provided. These should be non-negotiables*."[12]

Article 9: Right to Social Security and Social Protection

ICESCR Article 9 recognizes the right of everyone to social security, including social insurance. For persons with albinism, who often face heightened poverty and health risks, social protection measures are crucial to compensate for discrimination and disablement. In Zambia, however, social security systems do not adequately cover or support persons with albinism, revealing significant gaps in implementation of Article 9.

A focus group participant noted that protection mechanisms should be designed so that *"real people with albinism are actually feeling protected and can say they are direct beneficiaries*," rather than remaining policy commitments without practical effect

Zambia's primary social security programs for vulnerable populations are the Social Cash Transfer (SCT) scheme (unconditional cash transfers to the poorest households) and some categorical schemes for persons with disabilities (such as a disability grant or increased SCT for households with a disabled member). While persons with albinism *in theory* qualify as persons with disabilities (and many are among the extremely poor), coverage remains minimal. The UNICEF (2023) Situational Analysis report[13] found that existing social protection programmes "were not inclusive and sufficient enough" for persons with disabilities and called for an increase in both the reach and adequacy of such programs. There is no evidence that persons with albinism are specifically identified or

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[12] Participant during the Focus Group Discussion

[13] UNICEF (2023) Situational Analysis of the Rights of Persons with Disabilities in Zambia. Compiled by Heidi Loening-Voysey, Michaela Pelser and Theresa Wilson for UNICEF.

prioritized in the rollout of social grants. For instance, sunscreen and protective clothing vital supports to mitigate the disability caused by albinism are not provided for free by any social program, forcing individuals to bear these costs (if they can). This omission directly impacts their right to an adequate standard of living (Article 11, closely linked to Article 9). The Human Rights Commission of Zambia has received complaints about the lack of government-provided sunscreen for persons with albinism. One case even reached the courts, as indicated by the Commission's note that it had no mandate over a matter "pending before courts of law" regarding sunscreen provision. The typical 250 ml bottle of high-SPF sunscreen costs between K300-450 (approximately USD $30–$50), lasts only about two weeks, and is "out of reach for most families" with albinism. Despite this, the social support system has not addressed the issue, effectively denying persons with albinism a key health entitlement that could be delivered as part of social security (e.g. free distribution in clinics or through disability welfare schemes).

Participants stressed that protection must be experienced in practice, not only promised in law. As one participant explained, protection should be reflected in "*police patrols, police protection, home protection interventions that can be seen and where people with albinism actually feel protected.*"[14]

Zambia does not currently provide a dedicated disability cash benefit nationwide (aside from slightly higher SCT amounts for households with a person with severe disability, in limited cases). As noted, very few persons with disabilities are formally registered (only 63,340 out of an estimated 1.5 million), due to cumbersome processes and lack of awareness. Persons with albinism face particular challenges here:

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[14] Focus Group Discussion quote from one of the participants

because albinism’s impairments (low vision, skin condition) are not immediately understood by all medical officers, there have been cases of assessment officers downplaying the “severity” of the disability, thus affecting eligibility for any potential support. The assessment system still follows a medical model, focusing narrowly on degrees of impairment and overlooking the social barriers (like stigma and risk of attack) that significantly disadvantage persons with albinism. The result is that many persons with albinism are either not certified as disabled or are not aware of the benefits of registration. As one local official observed, *“it is a requirement for any person with a disability to be registered…but that is the information that lacks for many people… they don’t see the benefit”*. This points to a failure of the State to properly disseminate information and simplify processes, as required by ICESCR General Comment 19 (which stresses accessibility of social security systems).

For the few persons with albinism who may be accessing social protection (for example, some may benefit from general poverty-targeted schemes), the level of support is insufficient to meet their distinct needs. Costs related to albinism such as regular skin cancer check-ups, purchase of sunscreen, sunglasses, low-vision aids, transportation to specialist clinics are not accounted for in the standard cash transfer amounts. Without additional support, families with members with albinism face catastrophic health expenditures, or they forgo needed care and items, undermining their health and well-being (a violation of the right to health and an adequate standard of living, linked to Article 9 obligations). The lack of “reasonable accommodation” in social protection is notable; for instance, delivering transfers in formats accessible to those with visual impairment, or ensuring persons with albinism can collect benefits safely (not having to stand long hours in the sun at pay-points), are often overlooked practical issues.

Article 9 also covers social insurance (like pensions, health insurance, etc.). Most persons with albinism do not work in the formal sector and thus are outside contributory pension schemes. There is no indication of any affirmative action to include them in informal sector pension initiatives. Health insurance in Zambia is in early stages (National Health Insurance Scheme), but again, coverage and benefits for vulnerable groups are not clearly defined. The Persons with Disabilities Act, Section 27, prohibits denying persons with disabilities health insurance or care on the basis of disability a legal protection that would include albinism. Compliance with this provision is not well-monitored. There have been anecdotal reports of insurance companies initially refusing to insure a person with albinism (considering them “high risk” for skin cancer), though such practices are unlawful under the Act. The extent of enforcement by regulatory bodies is unknown.

Article 12: Right to the Highest Attainable Standard of Physical and Mental Health

Article 12 of the ICESCR guarantees everyone the right to the highest attainable standard of health. For persons with albinism, this right has specific and critical implications: they require ongoing dermatological care (including cancer prevention), visual rehabilitation services, and protection from harmful environmental factors. Moreover, they should be able to access general health services without discrimination. The evidence shows that Zambia is failing to ensure adequate healthcare for persons with albinism, leading to preventable illness, disability, and even premature death in this group.

Due to melanin deficiency, persons with albinism are extraordinarily susceptible to sun damage and skin cancers. In tropical climates like Zambia's, skin cancer is a leading cause of early death for people with albinism. Studies in Africa indicate that few people with albinism survive beyond age 40 without proper skin protection and care. This stark statistic underscores the life-and-death importance of preventive healthcare measures such as sunscreen provision, sun-protective clothing (hats, long sleeves), and regular dermatological check-ups. Yet, Zambia has no sustained program to provide these essentials. The 2024 Albinism and Rights in Zambia report starkly noted that *"sunscreen, protective clothing and hats are often expensive or unavailable"* across much of Africa, including Zambia. Indeed, interviewees in Zambia consistently reported that government clinics rarely stock sunscreen. One person with albinism shared: *"I hardly find sunscreen at the hospital. Each time I go there, they tell me to go and buy… they don't even [have it]."* This indicates a systemic failure: sunscreen, which is as vital as medication for this population, is not treated as an essential medicine in the public health system. Although some NGOs have donated sunscreen in ad-hoc projects, these efforts are piecemeal. The result is that many persons with albinism suffer repeated sun burns and precancerous lesions from an early age. By their 20s or 30s, numerous individuals develop actinic keratoses or malignant lesions. Without timely medical intervention (biopsies, surgeries, chemotherapy), these cancers are often fatal. The State's neglect in this area amounts to a de facto violation of the right to life and health for persons with albinism. One participant stressed that protection "should start with government by providing interventions in health, education and justice," rather than fragmented or one-off initiatives.

Another health concern is mental health. Living under constant threat and social rejection, many persons with albinism suffer anxiety, depression, or trauma. Young people with albinism often experience low self-esteem or social withdrawal due to bullying and isolation. Article 12’s definition of health includes mental health. Yet there are no targeted mental health support programs for this group in Zambia. Counselling services or peer support networks (such as through the Albinism Foundation of Zambia) are scarce and not state funded. The psychological toll of violence (for those attacked or whose relatives were killed) is also not adequately addressed by the health or social services systems.

Our Findings also noted that Zambia has taken some steps on paper. The Ministry of Health’s “Health in All Policies Strategy” recognizes societal inequities causing marginalization of persons with disabilities and ostensibly promotes disability mainstreaming in health services. The Persons with Disabilities Act 2012 forbids denial of health care or food/fluids based on disability. These are important commitments. Additionally, the Government has collaborated with UNICEF and NGOs on occasional clinics or distribution campaigns (e.g., a past program where a limited number of sunscreen lotions were distributed in a few districts, or skin cancer screening camps by volunteer dermatologists). However, these efforts are not institutionalized or nationwide. The 2022 National Budget did increase social sector spending (30.5% of budget, with 11.4% to health), but none of the budget documents earmark funds specifically for albinism-related health needs. The CESCR should question the State on how its health budget and policies address (or intend to address) the *specific requirements of persons with albinism*, given the dire consequences of inaction (i.e. preventable cancers and blindness).

Article 13: Right to Education

Under ICESCR Article 13, education is recognized as both a right in itself and an indispensable means of realizing other rights. Zambia is obliged to ensure universal access to quality primary and secondary education without discrimination, and to provide reasonable accommodation for students with disabilities. In the case of persons with albinism, however, the right to education is frequently undermined at every stage – from early childhood to higher education – due to a combination of environmental barriers, inadequate support, and discriminatory attitudes. This results in significantly lower educational attainment for persons with albinism compared to the general population, which in turn perpetuates their marginalization in other areas of life.

Empirical data from the first-ever study on albinism in Zambia (2024) shows alarmingly poor educational outcomes. Among 208 respondents with albinism surveyed across six districts, 7.7% had never attended school at all, and over half had not gone beyond primary level. Only a minority managed to complete secondary education, and a mere 9.6% pursued any form of higher education. This contrasts starkly with national averages and reflects systemic exclusion. The table below summarizes these findings:

Table 1: Highest Education Level Among Surveyed Zambians with Albinism[15]

Education Level	**Percent of respondents (n=208)**
No formal education	7.7%

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[15] *2024 Albinism & Rights in Zambia study. Note: "Primary" and "Secondary" percentages indicate those whose highest completed level was primary or secondary, respectively*

Primary education	29.8%
Secondary education	52.9%
Above secondary (tertiary)	9.6%

This distribution shows that persons with albinism drop out in large numbers by the primary-to-secondary transition. Virtually nine out of ten never reach college or vocational training. The consequences are far-reaching, as low education traps many in unemployment or low-skilled labour. It is therefore critical to examine why these educational disparities arise.

Children with albinism face unique challenges in school. Foremost is visual impairment. Standard classrooms are often ill-suited to low-vision learners: blackboards with small writing, lack of magnification devices or large-print materials, and seating arrangements that don’t account for a student’s need to sit very close to the board. If not addressed, these issues severely hinder learning. As the 2024 report pointed out, if the lighting or font size in class is such that a student with albinism cannot read the board, *“then the whole classroom is a barrier to [their] education.”* Unfortunately, many Zambian schools especially in rural areas – have not implemented inclusive education practices that would accommodate such needs. Teachers are generally not trained in simple adaptations like providing high-contrast printed notes or allowing a child to move closer to the chalkboard. The Ministry of Education does have Special Education Units and resource rooms in some zones, but these typically focus on hearing or visually impaired students using Braille; there is little focus on low-vision aid for albinism, which is a distinct need (because students with albinism usually have some vision and can use print with enhancements).

Another major issue is safety and bullying. Many children with albinism (and their parents) fear for their security on the journey to school or even at school, due to the risk of abduction or peer violence. The Independent Expert on albinism and civil society have documented cases in East and Southern Africa of children with albinism being attacked or even killed on their way to school. In Zambia, such extreme cases are rare but the fear is present. The study found that *learners with albinism reported experiencing attacks, which made them afraid of moving alone*. In response, some families choose to send children with albinism to boarding facilities (often at great expense) or to keep them home. Bullying by classmates is also pervasive – derogatory nicknames ("ghost", "milk", etc.), social exclusion, or even physical abuse. Girls with albinism are particularly targeted (as noted in Article 3 section). School authorities often lack guidance on how to handle such harassment or enforce anti-bullying rules. In some cases, teachers themselves may hold prejudices, consciously or unconsciously sidelining a student with albinism (for instance, not calling on them in class, or assuming they cannot see well enough to participate). This creates a hostile learning environment, violating the spirit of Article 13 which emphasizes education's role in promoting human dignity and enabling all persons to participate effectively in society.

There are indications that enrollment rates of children with albinism lag behind national averages. The Children's Code Act (2022) and the PDA (2012) outlaw refusal of admission to schools based on disability. Thus, formally, no school can deny entry to a child for having albinism. However, subtle barriers affect enrollment: parents of children with albinism sometimes do not enroll them due to low expectations or fear of them being bullied.

At the tertiary level, representation of persons with albinism is extremely low. Those few who make it to college often encounter continuing challenges – lecture halls without visual aids, no accommodations for reading materials, and sometimes social isolation. The University of Zambia and other institutions have disability offices, but their capacity is limited. Notably, in the late 2010s, a blind student successfully litigated against UNZA for better accommodations; a student with albinism might face similar issues with large class sizes and unadjusted materials. There is no record of any specific programs to encourage persons with albinism to enter higher education (for instance, no reserved scholarships, unlike some programs for other disability categories or marginalized groups).

Conclusion and Recommendations

Considering the foregoing analysis, including desk research and focus group discussions with organizations of persons with albinism and disability rights advocates in Zambia, this joint report recommends that the Committee on Economic, Social and Cultural Rights include the following issues in its List of Issues to Zambia and reflect them in its Concluding Observations:

- **Data, recognition, and policy targeting (Arts. 2(2) & 3)**

Request updated, disaggregated data on persons with albinism, including socio-economic indicators relating to education, employment, health outcomes, social protection, and exposure to violence, building on the 2022 Census which recorded 64,026 persons with albinism. The Committee should ask how this data is being utilized to design targeted policies and whether the State party will formally recognize persons with albinism as a vulnerable group requiring special measures, in line with

African regional action plans. The Committee should further urge Zambia to adopt a **National Action Plan on Albinism**, with clear timelines, budgetary allocations, monitoring and accountability mechanisms.

- **Combating stigma, violence, and harmful practices (Arts. 2(2), 3 & 10)**

Urge the State to conduct sustained nationwide awareness campaigns to dispel myths and superstitions surrounding albinism, including beliefs linking persons with albinism to wealth, curses, or disease. These campaigns should actively involve traditional leaders, faith leaders, educators, and local authorities. The Committee should press the State to ensure prompt investigation, prosecution, and punishment of all acts of violence, harassment, hate speech, and ritual-related threats against persons with albinism, and to consider adopting **albinism-specific protective legislation** to address the unique nature of these crimes.

- **Women and girls with albinism (Arts. 3 & 10)**

Encourage the State to integrate the specific situation of women and girls with albinism into gender-based violence prevention and response frameworks, including the Anti-Gender-Based Violence Act and related policies. The Committee should recommend systematic collection of data on GBV cases involving women and girls with albinism, targeted awareness campaigns addressing myths that fuel sexual violence, and mandatory training for police, prosecutors, judges, and social welfare officers on handling such cases in a survivor-centred and disability-inclusive manner, in consultation with organizations of persons with albinism.

- **Right to work and reasonable accommodation (Art. 6)**

Request detailed information on employment rates of persons with disabilities, disaggregated to include persons with albinism, and on the implementation of affirmative action measures in both public and private sectors. The Committee should recommend that Zambia operationalize and enforce employment reservation quotas through clear regulations, explicitly including persons with albinism.

It should further urge the State to develop binding national guidelines on reasonable accommodation, requiring employers to provide workplace adjustments such as large-print materials, screen magnifiers, protective clothing, flexible duties, and appropriate postings. The Committee should also encourage the introduction of a disability-related employment allowance or targeted support to offset albinism-related costs (including sunscreen and visual aids), and the provision of tax incentives or subsidies to employers who implement reasonable accommodation.

- **Social security and social protection (Art. 9)**

Urge the State to expand the Social Cash Transfer scheme and other disability benefits to effectively reach persons with albinism, including through simplified and community-based registration processes. The Committee should recommend reform of disability assessment procedures to move away from a purely medical model toward a social and human-rights-based approach that captures the real vulnerabilities faced by persons with albinism. The State should also be encouraged to ensure that essential albinism-related needs such as sunscreen, protective clothing, and low-vision aids are treated as core social protection items rather than discretionary or cosmetic goods.

- **Right to health, including skin cancer prevention and mental health (Art. 12)**

Ask the State to describe existing programmes for the prevention, early detection, and treatment of skin cancer among persons with albinism. The Committee should strongly recommend that Zambia institutionalize the free and continuous provision of high-SPF (50+ SPF) sunscreen in all public health facilities, including its inclusion on the national essential medicines list, and establish regular dermatological screening and referral services in areas with known populations of persons with albinism. The Committee should also urge training of healthcare providers on albinism to eliminate discriminatory attitudes and ensure appropriate care, and the inclusion of persons with albinism in mental health and psychosocial support services.

- **Inclusive education and protection of learners with albinism (Art. 13)**

Urge the State to strengthen inclusive education measures by mandating teacher training on low-vision and inclusive methodologies, providing assistive devices and reasonable accommodations in classrooms (including large-print materials, magnifiers, appropriate seating, and adapted assessments), and enforcing robust anti-bullying policies. The Committee should further recommend targeted retention measures, scholarships, and transition support for learners with albinism, particularly in rural areas, to address high dropout rates and low access to secondary and tertiary education.

- **Institutional coordination, implementation, and accountability**

Encourage the State to ensure adequate resourcing and coordination among institutions responsible for disability, gender, health, education, and social protection, and to strengthen monitoring mechanisms to ensure that existing legal and policy commitments translate into tangible improvements for persons with albinism.

Finally, the principle of “Leave No One Behind” in the 2030 Agenda for Sustainable Development resonates strongly in this context. Persons with albinism, though a small minority, cannot be forgotten. Zambia’s progress on ICESCR rights will be incomplete until these individuals enjoy the rights to live, study, work, and thrive free from discrimination and fear. By heeding the above recommendations, Zambia would move closer to honoring both its international commitments and the fundamental humanity of persons with albinism. The co-submitting organisations hope the CESCR will use this information to drive concrete improvements and remain available for any further information the Committee may require.

List of references

1. *Albinism & Rights in Zambia: An Exploration of Experiences, Sociocultural Conditions and Access to Justice* (2024), Ministry of Community Development and Social Services/UNZA/UNICEF – findings and recommendations on discrimination, education, health, etc.
2. *Country Brief: Situational Analysis of Disability in Zambia* (Nov 2023), UNPRPD/UNICEF – analysis of legal framework, social protection, and vulnerable groups including persons with albinism
3. *Zambia 2022 Census of Population & Housing – National Analytical Report*, Chapter 9 (Activity Limitation and Albinism) – official statistics on population with albinism
4. *Persons with Disabilities Act, 2012* (Zambia) – domestic law prohibiting discrimination and ensuring access to education, health, employment for persons with disabilities (including albinism)
5. African Commission on Human and Peoples' Rights, *Resolution 263 (2013)* and Regional Action Plan on Albinism (2017-2021) – regional standards calling for protective measures for persons with albinism (e.g. sunscreen provision)
6. United Nations Human Rights Council, *Report of the Special Rapporteur on the rights of persons with disabilities, on her visit to Zambia* (A/HRC/37/56/Add.2, 2017) – noting challenges faced by persons with albinism in Zambia (e.g. ritual killings).
7. CESCR, *General Comment No.5* (Persons with Disabilities) and *General Comment No.20* (Non-discrimination) – interpretative guidance affirming that disability-based discrimination (including

albinism) is prohibited under ICESCR Article 2(2) and that States must provide necessary support for disadvantaged groups.

8. CEDAW Committee, *General Recommendation No. 18* (1991) – on women with disabilities.