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Positive Visibility: Demystifying Albinism in Sierra Leone

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Plain English Summary

Introduction

This article explores the lives and experiences of people with albinism in Sierra Leone—one of the poorest countries in the world. The study was carried out by an international research team working with the Sierra Leone Association for People with Albinism (SLAPWA). It highlights how social stigma, poor access to healthcare and education, and cultural misconceptions about albinism affect people's lives. Using interviews, photography, and community engagement, the project aimed to challenge stereotypes, improve understanding, and promote inclusion by celebrating the achievements and potential of people with albinism.

Research Approach

The study used qualitative methods, including semi-structured interviews with 15 adults with albinism in Freetown, Bo, and Makeni. It followed inclusive and participatory research principles, co-designed with SLAPWA, and aligned with the disability rights movement's, "Nothing About Us, Without Us." The research is guided by Ernest Boyer's engaged scholarship and Paulo Freire's ideas of critical consciousness. It applies the cultural model of disability (Devlieger et al., 2003) to examine how social and cultural beliefs about albinism contribute to exclusion. Photography and advocacy materials were developed alongside the research to raise awareness and promote positive visibility.

Main Findings

The study found that people with albinism in Sierra Leone experience widespread stigma, discrimination, and misunderstanding. Common myths portray albinism as contagious, a curse, or linked to supernatural powers. These beliefs lead to isolation, bullying, and name-calling, both in schools and communities. Many participants reported being excluded from social and decision-making spaces, denied opportunities, or mocked for their appearance.

Healthcare access is extremely limited, particularly for conditions such as skin cancer and visual impairment, which are common among people with albinism. Despite Sierra Leone’s disability legislation and CRPD commitments, people with albinism often cannot afford medical treatment or basic protective resources like sunscreen, hats, or sunglasses. Participants described having to rely on SLAPWA for these essentials and for advice on protecting their health.

Educational barriers were also significant. Poor classroom conditions, lack of teacher training, and peer discrimination make schooling difficult for children with albinism. Many students drop out, while others succeed only through self-advocacy or supportive teachers. The study shows how simple changes—such as allowing children to sit near the board, providing vision aids, and raising teacher awareness—can make education more inclusive.

Stigma was identified as the most harmful challenge. Participants shared painful experiences of verbal abuse and exclusion, such as others refusing to touch them or share food. These experiences reinforce the argument that albinism is socially disabling, as beliefs and practices—rather than biology—create disadvantage. However, the study also documents powerful stories of resilience and success. Participants included a teacher, a nurse, a police officer, and a musician, all of whom challenge negative stereotypes by their visible achievements.

Local and international advocacy has played an essential role in promoting understanding and rights. SLAPWA’s work in distributing sunscreen, educating communities, and supporting members was praised by participants. The project demonstrated how advocacy can be most effective when it combines practical action with public engagement and positive imagery. The researchers’ “positive visibility” campaign, featuring portraits and personal quotes, was used in national awareness events and on social media to celebrate International Albinism Awareness Day.

Overall, the study argues that creating positive, public representations of people with albinism—rather than focusing only on their challenges—helps to transform perceptions, build pride, and foster inclusion. It calls for broader societal change through collaboration among albinism associations, government bodies, and NGOs.

Main Implications

For people with albinism and disability advocates, the study provides a model of inclusive, empowering research and advocacy. It highlights the need for national and community-level action to improve healthcare access, inclusive education, and protection from discrimination. Policymakers are urged to enforce disability rights legislation and allocate resources for medical and educational support. For Disabled Persons' Organisations, the research demonstrates the value of partnership, co-design, and storytelling in building awareness and pride. The concept of "positive visibility" offers a practical advocacy approach that shifts public attitudes from pity or fear to respect and recognition. Theoretically, the paper advances the cultural model of disability by showing how beliefs and attitudes disable people with albinism, while methodologically, it illustrates the potential of engaged, community-based research to effect real change.

Find out more

The project *Demystifying Albinism in Sierra Leone* was led by Professor Charlotte Baker (Lancaster University) with partners from SLAPWA, the Dorothy Springer Trust, Medical Assistance Sierra Leone, and the University of Nigeria, Nsukka. Funded through Lancaster University, it builds on over 20 years of research on albinism and disability in sub-Saharan Africa by Professor Baker. Further information, advocacy materials, and photographic exhibitions can be found The Disability Inclusion Africa website https://www.dia-network.org/ and SLAPWA's Facebook page https://www.facebook.com/slapwa17/ . The team acknowledges the participants who shared their stories and the ongoing work of SLAPWA in supporting and empowering people with albinism across Sierra Leone.