
Perspectives on difference and stigma: researching the lives of people with albinism in Malawi

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Abstract

Albinism is a genetically inherited condition which causes a lack of pigmentation (melanin) in the hair, skin and eyes, causing vulnerability to the sun and bright light. Over the past few years there has been an alarming rise in the number of cases of violence against people with albinism including the trafficking in persons and the sale of children, infanticide and abandonment of children killing and attacks with a view to using their body parts for ritual purposes. This presentation will share some of the findings from a research project funded by the British Academy to investigate how a life-threatening, dehumanizing phenomenon is impacting the lives of people with albinism and their families and how we explored ways to better protect them in their homes and communities and ultimately raise awareness of their human rights.

We sought to use participatory research techniques the team designed tools (interviews, focus groups and observations) that would give equal opportunity and voice to children and young people with albinism, their families as well as teaching professionals and community workers who support these children in mainstream schools and resource centres. Despite limited resources, parents and older children interviewed showed great resiliency and agency in being able to deal with the barriers in different and courageous ways. There was strong evidence that the children and their families faced multiple prejudices and experienced insecurity in their communities and at school which led to feelings of anxiety and disablism, and more noticeably detachment from the communities. Many of these individuals felt isolated and vulnerable within their own communities.

In the final part of the paper I will discuss how we should critically engage with the politics of conducting research into difference and stigma in the global South and examine how we research similar disability issues in future research.

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