Identifying family and community-based care solutions for children with albinism

Abstract

In sub-Saharan Africa, discrimination and stigmatisation, lack of access to appropriate health services and inclusive education, the risk of ritual attacks, and the perceived burden of care, mean that some children with albinism are being placed in residential care or boarding schools by the State or families, purportedly for their care and protection. Whilst there is a wealth of information available in the respective areas of 'albinism' and 'care', there has been little attention to how the two areas intersect and how they overlap with questions of health, education, social protection, justice and disability rights. Equally, there has been limited critical attention to the experience and perspectives of children with albinism, and their lives in African contexts (Franklin et al., 2018), which means that interventions to better support, empower and protect them remain elusive. Our article responds to the particular situation of children with albinism who are vulnerable to attack or ritual abuse in sub-Saharan Africa and considers how these children should best be cared for.

Keywords: Albinism; Tanzania; Malawi; Madagascar; ritual attacks; care; protection

Introduction

Albinism is a relatively rare, non-contagious, genetically inherited condition that results in a lack of melanin in the skin, hair and eyes. Albinism occurs worldwide and affects approximately 1 in 12,000-15,000 people, but the prevalence is as high as 1 in 4000 in Africa (Kromberg et al., 2023). The lack of pigmentation in the skin of persons with albinism means that they are vulnerable to skin damage from ultraviolet rays, which can lead to skin cancer. Persons with albinism often suffer from sunburn, blisters, wrinkles and skin cancers, with sun-exposed areas, including the face, neck, shoulders and arms, particularly prone to skin damage. Those who live in areas with stronger UV radiation, such as African countries near the equator, experience greater rates and severity of skin damage and cancer (Ma et al., 2023). However, in many African contexts, a lack of awareness and education about the importance of basic skin protection measures and limited access to appropriate healthcare mean that persons with albinism are at particular risk of developing skin cancer and, as a result, many die before the age of 40 (Luande et al., 1985; Saka et al., 2020).

The absence of the pigment melanin in the eyes also leads to visual impairment from birth, although the degree of impairment varies between individuals. The eye problems associated with albinism, which include nystagmus, photophobia, poor depth perception, refractive errors, strabismus, and poor visual acuity, mean that it is difficult to obtain appropriate corrective lenses, even when these are available. In one study, 85% of children with albinism in South Africa were found to have less than 30% vision, even with the best optical correction (Raliavhegwa et al., 2001). With limited accommodations for children with visual impairments in schools, education can be inaccessible for children with albinism. Many persons with albinism also face barriers to employment, which include stigma and discrimination, lack of accommodations, inaccessible buildings and public transport.

The visibility of albinism in sub-Saharan Africa fuels superstitions and beliefs about this condition and persons with albinism often face multiple and intersecting forms of discrimination (Baker et al., 2010; Burke, 2013; Brocco, 2016; Baker et al., 2021). They may face bullying, name-calling and labelling (Baker et al., 2010; Cruz-Inigo et al., 2011; Brocco, 2015, 2016). This discrimination can extend to social avoidance and exclusion from the family or community, and when accessing education, health, or social services (Reimer-Kirkham et al., 2019), which can lead to loss of self-esteem, depression, isolation or suicide (Mutasa, 2013; Attama et al., 2015; Phatoli et al., 2015).

The beliefs attached to albinism have fuelled violent attacks, mutilations, the killings of persons with albinism and grave robberies because it is believed that their body parts, organs, hair, and nails hold supernatural powers when used to make charms by diviners or witchdoctors (Aquaron et al., 2009; Baker et al., 2010; Cruz-Inigo et al., 2011; Brocco, 2015; Imafidon, 2017). The NGO Under the Same Sun records over 700 reports of violence against persons with albinism since 2006 in their report of November 2023. However, the former UN Independent Expert on the enjoyment of human rights by persons with albinism (UN Independent Expert), Ikponwosa Ero, signalled in her report to the Human Rights Council in January 2019 that a greater number of attacks against persons with albinism take place than are formally recorded due to fear related to witchcraft beliefs, a code of silence surrounding such crimes, and the location of such attacks in often-remote settings (A/HRC/40/62). Women and children are disproportionately vulnerable to such violent attacks (Ojilere and Saleh, 2019).

Beliefs related to albinism in African communities and the harmful practices that can result from them are deeply rooted in the fabric of society and are justified by the understanding of being or reality, or by the ontology operational in such communities or societies (Imafidon, 2017; Imafidon, 2019). However, as scholars including Schule (2013) and Bryceson et al. (2010) have remarked, the attacks on persons with albinism are driven by an economic motive. Schule remarks that a commonality in accounts of the killings of persons with albinism in Tanzania is that those buying body parts work primarily in two specific industries: mining and fishing (Schule, 2013), while Bryceson et al. contend that the killings in Tanzania in particular 'are connected to gold and diamond miners' efforts to secure lucky charms for finding minerals and protection against danger while mining' (2010). A similar connection was reported by the current UN Independent Expert following her official visit to Madagascar, where attacks were connected with rituals to ensure success in new mining projects. Some were reported to believe that the eyes of children with albinism could help Zebu (cattle) raiders evade detection (A/HRC/52/36/Add.1). The attribution of value to the body parts of persons with albinism is underscored in the comment of a person participating in a focus group discussion in Malawi, who remarked 'People with albinism, they are witchcraft, they are diamond, they are wealth', an idea reiterated by another focus group informant who remarked that 'They are wealth for a businessman and bring success in an election' (Baker et al. 2021). These statements reveal that the beliefs associated with albinism are manipulated for economic gain with the consequence that persons with albinism are targeted for their body parts for use by witchdoctors. As Burke et al. observe, the oppression of persons with albinism 'cannot be understood only as arising from traditional beliefs, but also emerges for structural reasons which are related to rapid change and new forms of inequity in wealth and power' (2013).

Children with albinism are among the most vulnerable members of society. They often experience bullying, verbal and physical violence and exclusion from their peer groups, and they are also most at risk of attack. However, there has been limited critical attention to their care and protection. As Franklin et al. remark, 'The experiences and perspectives of children with albinism are underexplored and little is known about the psychosocial issues facing this group. Limited understanding of their lives in an African context and a lack of attention given to the particular needs of this group of children means that interventions to better support, empower and protect them remain elusive' (2018). The paucity of information on the lives of children with albinism in

Africa limits the development of appropriate interventions to support, empower and protect them (Taylor et al., 2019).

The UN Convention on the Rights of the Child (1989), UN Convention on the Rights of Persons with Disabilities (2006), UN Guidelines for the Alternative Care of Children (2009), UN Committee on the Rights of Persons with Disabilities' Guidelines on Deinstitutionalizing (2022) and UNGA Resolution on the Rights of the Child (2019) all advocate for the importance of children being cared for by their own families, and where this is not possible, being placed by the State in alternative care. However, a deeper analysis shows that there are different understandings of what constitutes safe and acceptable forms of alternative care. Our article draws on existing scholarship, policy reports, and interviews with stakeholders undertaken in 2023 to better understand the challenges of ensuring the full enjoyment of the right to family life for children with albinism. We explore options to prevent family separation or provide alternative care where efforts to keep families together are not immediately implementable, and we consider their implications for children with albinism and their families in African contexts. We focus on Tanzania, Malawi and Madagascar as case studies to consider alternative provision and conclude our article with a set of recommendations.

Methodology

We set out to understand the interface between the area of discrimination and rights violations against children with albinism and the area of children's right to a family life. We wanted to understand both why and how children with albinism's rights were being violated through family separation and institutionalisation, and what good practices are available and are being used to prevent and address these violations.

We undertook a literature review of international, regional and national policy documents, academic and grey literature, and media reports. We also undertook key informant interviews with thirty-one experts on these topics. Interviewees consisted of seven experts from UNICEF and other UN-associated institutions, four academics with a specialism in the topics being researched, eight child protection and child care experts from civil society and consultancy-oriented organisations, and twelve disability rights and albinism rights experts from civil society organisations. Eight of the disability rights and albinism rights experts were people with lived experience of albinism, six of whom had direct lived experience of the topics being researched and were living in the African region. A loose semi-structured interview format was used for all interviewees and was focussed on the research questions set out above. The format and questions were adapted in each case to fit the area of expertise of the interviewees. Ethical approval for this research was granted by Lancaster University in the United Kingdom.

The research was global in scope, but initial findings showed that the majority of the literature on the topic of children with albinism and rights violations was focussed on the African region, and similarly the interviewees with expertise and lived experience of this topic were also located in this region. More specifically, the data available tended to be focussed on a number of particular African countries, which explains the bias in the research towards the African region and specific countries. This does not necessarily mean that these issues are not also prevalent in other parts of the African region or the world, but data is not readily available to show this.

Drivers for children with albinism being institutionalised

In African contexts where there is a risk of children with albinism being ritually attacked, it is common for States and/or families to place children in the perceived ‘safety’ and ‘protection’ of boarding schools or residential care. One of our interview participants, a person with albinism who working as an independent consultant with the UN Independent Expert on Albinism, remarked that the institutionalisation of children with albinism is driven by the very real risk of being attacked, but also the fear and psychological distress caused by the anticipation of an attack. In most cases, the motivations of both the State and the family are at least partly driven by what they believe to be in the best interests of the child, i.e. to protect them from harm. However, for some families, the combination of societal discrimination and exclusion, as well as lack of access to inclusive education and healthcare drives a further motivation to relinquish the burden of care for a child with albinism. The decision to institutionalise a child with albinism is sometimes undertaken under the jurisdiction of the State. For example, in Tanzania, children with albinism were placed in 32 'temporary holding shelters' under the jurisdiction of the Government for their protection and education' (Human Rights Watch, 2019). However, in other cases it is the family that makes this decision and organises the placement without approval from the State.

The socio-economic status of a family plays a role in the probability of a child with albinism being institutionalised. As several of the albinism rights experts that we interviewed remarked, poorer families are less able to access healthcare and inclusive education, to arrange for secure housing or other security measures, and they are also at higher risk of other family members seeing the opportunity to profit from their proximity to a child with albinism (such as through assisting those who wish to attack the child for body parts). Furthermore, families of children with albinism are more likely than others to experience financial hardship due to the need to prioritise the care and protection of their children over earning a livelihood. Abandonment by the father of a child with albinism - leaving the mother to care for her child alone - exacerbates this situation (Ero et al., 2019). Poverty, a lack of access to education and healthcare and stigma associated with children with disabilities are common factors driving child institutionalisation globally (Hope and Homes for Children, 2022), thus contributing to the estimated 5.4 million children living in institutional care worldwide (Desmond et al., 2020). However, the attribute of being at risk of ritual attacks adds an additional intersectional disadvantage for the families of children with albinism.

Defining institutionalisation

There is broad consensus within the child rights and disability rights sectors that institutional care is harmful for children - as we will go on to explain - but there are different views on which types of care are considered ‘institutional’. All proponents largely agree that an ‘institution’ is a type of residential care with an ‘institutional culture’ (Špidla, 2009). This means a childcare environment where children are separated from their families, isolated from the broader community and/or they are compelled to live together; where children and their families do not have sufficient control over their lives and the decisions which affect them; and where the requirements of the organisation take precedence over the individualised needs of the children. How this definition is interpreted in practice is where the disagreement lies. The United Nations Committee on the Rights of the Child recognises institutional care as ‘large residential care facilities’ which leaves space for other types of small-scale temporary residential care, with individualised care for children, to be seen as having an acceptable role to play in some situations (2009, Article 23). The United Nations Committee on the Rights of Persons with Disabilities, however, takes a narrower view that all placements in a ‘non-family setting’ constitutes institutional care, and specifically includes ‘group homes’, ‘family-type homes’ and ‘albinism hostels’ in this definition (CRPD/C/5).

Boarding schools - where many children with albinism are placed for their protection - similarly face a categorisation problem. Fundamentally, the main purpose of boarding schools is to provide education in a *temporary* residential setting, and as such, they are usually regulated under education ministries rather than ministries responsible for alternative care. It is assumed that families place their children in boarding schools on a voluntary basis for educational purposes, unlike formal alternative care where children are - at least in theory - placed by the order and under the jurisdiction of the State (CRPD/C/5). But, as Delap remarks, in practice the distinction between boarding schools and institutional care is often blurred (2011). Far from being a voluntary and temporary placement, some children do not return home to their communities regularly, or at all, and some children may be placed in boarding schools because of a lack of access to parental care, or because of lack of access to basic services closer to home, which effectively removes parents' choice in the matter. This is certainly the case for many families of children with albinism who feel compelled to place their children in boarding schools for their protection and/or to access education and essential services which are unavailable in their own communities. Furthermore, due to security risks, some children with albinism placed in boarding schools remain there on an almost permanent basis. In these situations, boarding schools do appear to be playing an alternative care role and, and due to their size and culture, can be considered to be de facto institutions. This view is supported by UNICEF Europe and Central Asia which argues that many boarding schools should be viewed as alternative care providers, should be regulated as such, and should be recognised as having harmful institutional characteristics (UNICEF 2024).

As we shall see, these challenges in defining acceptable and unacceptable forms of alternative care present some difficulties in proposing safe care solutions for children with albinism. But before moving on to this, we explain why institutional care is considered harmful and therefore an unacceptable care option.

Why institutional care is harmful

A significant body of research over eighty years demonstrates the harm caused by institutional care (Berens et al., 2015; Lyneham and Facchini, 2019; Van Ijzendoorn et al., 2020). It shows how institutional care harms the physical, psychological and cognitive development of children, increases the risks of them developing attachment problems, and limits their long-term life chances. The high turnovers in the institutional workforce limit nurturing relationship building with children and create insufficient time to provide a basic standard of care. Children in institutions are at risk of abuse by staff or peers and are denied access to kinship networks which have a major role to play in many societies. Long-term outcomes for institutionalised children with disabilities are particularly concerning with higher likelihoods of experiencing violence and early death (Browne et al., 2004; Jones et al., 2012).

Once young people ‘age out’ and leave institutional care, the impact it has had on their development continues to present challenges for them (Cameron et al., 2019; Stepanova and Hackett, 2014). The research suggests that individuals who grew up in institutional care have worse levels of employment and educational attainment compared to those who have grown up in foster care, and that care leavers have worse outcomes across a range of parameters than those who have not been in care. The findings are similar across both high-income and low-income countries.

Among our interviewees who had been children with albinism that were institutionalised in specialist boarding schools, we heard stories that validated the above evidence. For example, one interviewee described how his mother felt anxious about the continual threat he and his brother (both children with albinism) faced daily in terms of being abducted or attacked on their walk to and from the local community school. The mother was persuaded by well-meaning friends to place the siblings in a charity-run boarding school for the visually impaired which offered fully-funded places. The interviewee described how he ‘loved the school’ initially. He enjoyed being with other children like himself, having teachers who understood his needs, the relief at no longer being bullied and the feeling of safety within the boundaries of a secure compound. In this environment he was educated using braille and benefited from free glasses, sunscreen and hats provided by the charity – items which his mother had been unable to afford. The problems began though when he was transferred in Grade 10 to a mainstream school, where most of the other children did not have albinism or visual impairments. In this environment he described his realisation that he lacked the social skills needed to interact with children who did not share or understand his needs. He struggled severely with his confidence and in forming relationships with other children. He explained how he and other children with albinism became depressed and felt isolated in this environment, a feeling which persisted into their adulthood. The interviewee described how many of his peers from the boarding school found it difficult in adult life to form social relationships and were unable to secure meaningful employment meaning they were often ‘living on the poverty line’, despite having an apparently ‘good’ education. The interviewee felt strongly that if he and others like him had been supported to grow up in a family and safe community environment, and had been educated in an inclusive community-based school, then they would not now the face the many obstacles they do in life: ‘If you hide them [children with albinism] away, there will never be people with albinism in positions of power and influence… boarding schools stops them being seen, and not being seen adds to the discrimination’.

Other interviewees with lived experience of albinism and institutionalisation similarly reported differences in long-term outcomes between those who attended inclusive community schools, and those who were institutionalised in specialist boarding schools or shelters, with the former group being viewed as happier and more successful in life. They also reported noticing differences between those who were able to regularly visit and maintain contact with their families and communities, and those who could not. Some of these interviewees reluctantly believed that there is a role to play for boarding schools for children with albinism in places where the risk of ritual attacks is high, so long as the schools are fully inclusive, and the children can maintain contact and visits with their families and communities. But all our interviewees considered that institutional settings are ultimately not helpful for children with albinism in the long-term, and that the focus should instead be on the full inclusion of persons with albinism in a safe society.

Proposed solutions to prevent the institutionalisation of children with albinism

Whilst institutional care will in some cases protect the right to life of children with albinism as set out in Article 3 of the *Universal Declaration of Human Rights,* it is simultaneously violating many of their other rights associated with family and community-based life outlined in the Convention on the Rights of the Child (1989), the UN Guidelines for the Alternative Care of Children (2009), the Convention on the Rights of Persons with Disabilities (2006), the UNGA Resolution on the Rights of the Child (2019) the CRPD Guidelines on Deinstitutionalising, Including in Emergencies (2022), and potentially causing long-term harm. Solutions which can practically uphold *all* the rights of children with albinism are challenging, but we propose that their achievement is possible, over time, if viewed through the lens of shorter-term pragmatic solutions and longer-term systems change.

Prevention of family separation

The Guidelines for the Alternative Care of Children (2019) and the UNGA Resolution on the Rights of the Child (2019) are clear that preventing family separation, especially through the provision of community-based services, is a priority over alternative care arrangements. Community-based services which address the causes of children with albinism being institutionalised include affordable and accessible inclusive education, accessible primary healthcare services, social protection for poverty reduction, criminal justice to ensure prosecution of those who perpetrate violence, security to protect those at risk of violence and secure and inclusive day-care services to free-up carers so that they can earn an income. Many of these services are lacking in areas where children with albinism are institutionalised. Social work case management approaches to identify the needs of families of children with albinism could further support families in accessing services (Global Child Protection Working Group, 2014).

A broader preventative strategy concerns awareness raising and behaviour change. As the former UN Independent Expert on Albinism, Ikponwosa Ero, explains:

> The importance of spreading the truth about albinism cannot be overstated. Ignorance of albinism is what fuels the attacks and discrimination faced by persons with the condition. There is an urgent need to promote scientific and human rights knowledge on the condition globally and particularly in areas where there is violence; where children are the most vulnerable of all (Ero, 2016).

Ero cites examples of how awareness raising has resulted in local community members intervening during attacks against children or donating stronger doors and locks to neighbours with a child with albinism. In their study of albinism and security in Malawi, Baker et al. (2021) remark that ‘the security of people with albinism in Malawi today relies on individuals adopting safety measures in their daily lives and families and communities being alert to the various threats and aware that they need to take effective action to protect persons with albinism’. They call for the development of a coordinated collaborative response to bring about effective and lasting change. However, it is also argued that the complexity of how deeply entrenched spiritual beliefs, cultural norms and economic interests are in many African societies means that it may be hard for people to change what they believe to be true (Imafidon, 2019). As one of our academic interview participants proposed that changing people’s spiritual beliefs should not be the goal, but rather ‘finding ways of decoupling the association of persons with albinism from these beliefs’ so that they no longer become the object of ritual attacks.

Community mobilisation is a bottom-up approach to awareness raising, behaviour change and community surveillance. It is ‘the process of engaging communities to identify community priorities, resources, needs and solutions in such a way as to promote representative participation, good governance, accountability and peaceful change’ (Mercy Corps, n.d.). It involves strong engagement with community leaders and faith leaders, as well as active participation and dialogue with community members, particularly those from vulnerable or under-represented groups. It uses existing networks, such as women's and youth groups, rather than creating new structures through which to work. It has been successfully used to tackle practices such as FGM/cutting, child labour and child marriage (Baker, Punaks and Miti-Drummond, unpublished data; Satyarthi 2023; Cambodia Children's Trust). It has also worked well as a means by which to facilitate community ownership of system change initiatives such as care reform (Ottolini, 2011; Republic of Rwanda, 2019). As the 2023 report of the UN Independent Expert on a recent visit to Madagascar demonstrates, community mobilisation has also been used successfully to promote the inclusion and security of persons with albinism (A/HRC/52/36/Add.1).

Alternative care

The UN Guidelines for the Alternative Care of Children state that 'Where the child's own family is unable, even with appropriate support, to provide adequate care for the child, or abandons or relinquishes the child, the State is responsible for protecting the rights of the child and ensuring appropriate alternative care' (2009). The decision to place a child in alternative care should always be informed by the principles of necessity, appropriateness, and the best interests of the child (Cantwell et al., 2012). These principles are supported by the concepts of the 'continuum of care' and 'gatekeeping'. The continuum of care prioritises prevention of family separation, and where this is not possible, recognises family-based alternative care options such as kinship care and foster care, followed by adoption (Faith to Action, 2015). Failing this, the continuum may recognise small-scale temporary residential care, with individualised care for children, as having a role to play (UNICEF ECARO, 2020), although as discussed earlier, not all proponents agree with this view. Gatekeeping is the process of preventing the inappropriate placement of a child in formal care (Cantwell et al., 2012).. It recognises that an alternative care placement should be preceded by an assessment of the child's physical, emotional, intellectual, and social needs, matched to whether the placement can meet these needs. Several alternative care options deserve discussion in relation to the needs of children with albinism in African contexts.

Kinship care is defined as 'family-based care within the child's extended family or with close friends of the family known to the child, whether formal or informal in nature' (Family for Every Child 2024; Global Child Protection Working Group 2014). It includes varying degrees of parental contact, short or long-term care arrangements, and includes children moving between households (Delap and Mann, 2019). Kinship care is the most common form of alternative family care in Sub-Saharan Africa (Idem) and is well-accepted culturally in the region, in so far as the responsibility of extended family members to care of children is a social norm (in a way it is not in most Western societies). Kinship care has many benefits including children generally preferring it to foster care or residential care, children mostly being loved and well cared for, and the provision of continuity and stability. As one of our interviewees, a person with albinism who is an external consultant with the UN Independent Expert on Albinism, remarked, there is some evidence of children with albinism living in informal kinship care as a strategy to improve their access to quality education or to reduce the risk of being attacked by living with family members in safer areas, and this was supported by stakeholders we interviewed from UNICEF Madagascar and from the NGO Standing Voice Malawi. Kinship care is an under-recognised area of alternative care, which deserves further policy attention.

Foster care is defined as 'situations where children are placed by a competent authority in the domestic environment of a family other than the children's own family that has been selected, qualified, approved and supervised for providing care' (United Nations 2009). Foster care can be provided formally with approval from the State, or through informal arrangements, as is more common in African contexts (UNICEF ECARO 2022). Foster care can be short-term or long-term and specialist foster carers can be trained to care for children with disabilities (EKISA Ministries

2020). While foster care is beneficial for some groups of children, it requires a significant investment by governments to establish legal, policy and oversight mechanisms (UNICEF ECARO, 2014). Furthermore, the availability of a 'qualified, well-funded and supported social service workforce that works in close coordination with other professionals should be seen as one of the most critical requirements for an effective foster care service, given that social workers play a leading role in determining the best interest of a child ' (Ibid). Therefore, without these pre-requisites in place in many African countries, they have struggled to provide it at scale (UNICEF ECARO, 2022). Where foster care has been able to establish itself, it could offer an effective and flexible form of family-based care for children with albinism in high-risk situations. For example, short-term foster care could allow children to temporarily be removed from their community during periods of high risk,[1] or to provide family-based care placements in locations where there is greater security and more accessible inclusive education and health services.

Small-scale temporary residential emergency care is where 'each child is treated individually [and] receives love and care and the opportunity to grow up in a family-like environment' (Ulikhanyan, 2019). It is seen as having a valid role to play in the continuum of care as a place of safety for emergency care or as a transit centres in emergency situations (UNICEF ECARO, 2020), and therefore it could play this role during periods of high risk for children with albinism when emergency foster-care is not an option. But as the Guidelines for the Alternative Care of Children state, this should only be 'for a predetermined and very limited duration, with planned family reintegration or other appropriate long-term care solution as its outcome' (United Nations, 2009). However, as discussed earlier, the role of residential care remains contentious, and unless it is fully inclusive it may be seen as discriminatory and institutional by some actors. Furthermore, we

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[1] In some countries events such as elections and festivals have been associated with higher incidences of ritual attacks. The desire for election success and money appears to correspond with the demand for body parts of persons with albinism to be used as 'lucky charms'.

need to remain realistic that that there will still be some risk that these homes could also be attacked.

Our interview participants gave examples of traditional family-based care practices in sub-Saharan African contexts in which community members take on the care of a child with albinism. These placements are often authorised by local community leaders rather than under formal State jurisdiction. Learning from a pan-African event in 2015 led by Save the Children and which looked at care reform in Africa, recognised the need for contextually appropriate alternative care services which build on traditional positive care practices (Save the Children, 2015). There are reports of children with albinism in Sierra Leone being informally ‘adopted’ by other families with more experience of caring for children with albinism, through a process facilitated by albinism organisations (Baker, Punaks and Miti-Drummond, unpublished data). The adoptive parents are considered to be better able to meet the best interests of the child than the biological family, although the latter sometimes maintains contact with the child. These sorts of informal and semi-formal family-based alternative care placements are common in African contexts and provide children with care solutions which would otherwise not be available in contexts where formal care systems are under-developed (Republic of Kenya, 2022). However, children in such placements are vulnerable to safeguarding risks without some form of government oversight including gatekeeping procedures and monitoring of placements (Ibid).

Domestic adoption and inter-country adoption are permanent care solutions which remove the possibility of a child with albinism being reunited with their biological families if the root causes for their separation are later addressed.[2] The UN Convention on the Rights of the Child states that intercountry adoption should only be considered after all other local family care options have been exhausted, and national adoption should always be prioritised over intercountry adoption where

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[2] Adoption is technically not a form of alternative care because full parental rights are given to the adoptive parents, this making it a form of parental care.

both options are available (United Nations 1989). Concerns have been raised in several countries around intercountry adoption being prioritised over domestic adoption, and worse still, allegations of children being ‘stolen’ or trafficked from their biological families for the purpose of exploitation through inter-country adoption, resulting in governments issuing moratoriums against inter-country adoption (Aguettant, 2008; Lee, 2022; Ministry of Labour and Social Protection, 2019). Furthermore, the strength of domestic adoption systems in some lower-income countries has been questioned (Department for Economic and Social Affairs, 2009). Even where well-established systems exist, very few children are domestically adopted, and even fewer of those with disabilities.

Kinship care, foster care, domestic adoption and traditional family-based care practice – despite their implementation challenges – could provide family-based alternative care solutions for children with albinism, in some situations. But they are by no means an assured safe option, as even trusted members of families and communities have been implicated in ritual attacks against persons with albinism. For example, in July 2022, a father was arrested in Mozambique for allegedly attempting to sell his three children with albinism (AFP, 2022). In another example from Malawi in April 2022, a priest was sentenced to 30 years imprisonment for his role in the abduction and killing of 22-year-old MacDonald Masambuka, a man with albinism (Guardian, 2022). Furthermore, family members have been implicated in similar cases.

The most widely-used alternative care settings for children with albinism in African contexts – and arguably the most contentious – are boarding schools. As discussed earlier, boarding schools can become forms of alternative care and can be institutional in culture. In practice, the circumstances of different boarding schools vary considerably. At one end of the spectrum, boarding schools may provide specialist segregated education and children may remain there almost permanently – and are therefore undeniably harmful institutional settings – whilst at the other end of the spectrum, boarding schools may be fully inclusive and community-based and accommodate regular family visits. As our interviews with representatives from the NGOs, Standing Voice Malawi and Village of Hope Under the Same Sun Education Programme in Tanzania confirmed, this latter group of inclusive boarding schools are used as alternative care placements by some albinism organisations as part of their case management work with children at risk of ritual attack.

In Tanzania, the Village of Hope Under the Same Sun Education Programme removes children with albinism from highly institutionalised shelters and places them in inclusive boarding schools where they arrange regular visits to their families. Village of Hope views this approach as the only pragmatic and realistic option for the protection of children. In the absence of reliable State security to protect these children to live with their families permanently, Village of Hope is arguably acting in accordance with the principles of necessity, appropriateness, and the best interests of the child. Such circumstances highlight the need for interim pragmatic solutions for practitioners in contexts where States are not realistically able or willing to provide effective security to persons with albinism. Situation like these, where practitioners have no choice but to adopt the 'least worst care option' for a child, highlight the need for States to urgently adopt comprehensive care reform strategies (Hope and Homes for Children, 2022) to replace these potentially institutional care settings with a range of safe family-based care options. Part of an effective care reform strategy, in this context, would need to include an albinism awareness campaign to prevent discrimination and attacks towards children with albinism, thus addressing the root causes for children with albinism needing alternative care in the first place.

Care in the case of attack

The body parts of children are believed to be more potent due to their innocence (A/HRC/31/63; Under the Same Sun 2012), therefore children with albinism are disproportionately impacted by attacks, resulting in many being separated from their families, including through being placed in shelters or boarding schools ostensibly for their protection. In Tanzania, for example, between 2000 and 2013, over 72 persons with albinism were reportedly killed and 30 others mutilated, predominantly in the Lake Zone region of the country. In response, 32 ‘temporary holding shelters’ were established by the government where many children with albinism, and some adults with albinism, were placed for their protection. The shelters were also intended to ensure their continued access to education. However, in 2015 the African Committee of Experts on the Rights and Welfare of the Child (ACERWC), after an investigative mission to Tanzania, referred to the shelter visited as more like a ‘preventative detention facility than a safe house’. The ACERWC found that many of the children in the shelters were suffering from sun burns, pre-cancerous lesions, fungus, malaria, and other complicated health problems accompanied by high fever (ACERWC, Tanzania report, 15). Many of the children had no birth registration documents and there were poor records of their family to enable them to be traced later. Furthermore, many of them had no contact with their parents or visits from them whilst at the school. In fact, it was reported that some parents deliberately provided wrong information about themselves with the view of hiding their identity. Organisations also informed the ACERWC that, in some cases, children had been separated from their parents by government authorities without the consent of the parents and without consultation or determination of the best interests of the child.

Concerns were also raised regarding the lack of learning materials at the shelters, which meant that many of the children were not receiving an education. In addition, many of these shelters were extremely overcrowded, with 405 children reportedly living in accommodation intended for 50 in one shelter. Access to adequate food, accommodation, water, and sanitation was also highlighted as a problem in most of the shelters. In short, while the shelters were meant to be a temporary measure to protect the right to life of children with albinism, they became long term and effectively violated several of their other rights, including the right to health, family life, education, access to food, water, and sanitation (ACERWC, Tanzania report, 15; IBAHRI 2017; RC/C/TZA/3-5).

In 2018, Tanzania embarked on a process of deinstitutionalisation of children with albinism in these shelters (Human Rights Watch, 2019). However, interviewees raised concern regarding the lack of transparency and publicly available information in relation to the deinstitutionalisation process. Interviewees also reported that some children who were removed from institutions were unable to trace their families because of inadequate record keeping. In other cases, children were reportedly returned to villages without communities being prepared to receive them. For example, an interviewee reported a case of a child being moved from a shelter to their home village with no preparation for the child or the family. The child was not welcomed home and was put in a situation of considerable danger.

The separation of children with albinism from their families due to attacks has been particularly evident in Madagascar. In 2021, the current UN Independent Expert, Muluka-Anne Miti-Drummond, started receiving reports of attacks against persons with albinism in Madagascar. Prior to this, no attacks specifically targeting those with albinism had been reported. The attacks have continued and have been associated with poverty, food insecurity and climate-change-related disasters (A/HRC/52/36/Add.1). The main victims of attacks have been children, who have been targeted for their eyes, which are believed by some to grant success in mining, and by others to allow Zebu raiders to evade detection during their raids (A/HRC/52/36/Add.1).

Fearing their inability to protect their children, as well as the potential for attacks against themselves, parents in places with high incidences of attacks have moved their children out of the family home. In some cases, children have been sent to stay with extended family or friends in parts of the country without reported cases of attacks. Such arrangements have effectively amounted to informal kinship or informal foster care arrangements. Other parents have taken their children with albinism to boarding schools with the hope that they will be better protected. There have also been cases where children have been left at police or gendarmerie stations/posts either for the whole day or just at night for their protection (Rabemananjara, 2023; A/HRC/52/36/Add.1). Civil society organisations also advocated for the creation of safe houses for children with albinism with concerns being raised that they may not be safe in informal kinship or foster care during the time of heightened risk, as well as reluctance of extended family members or friends in taking in a child with albinism due to stigma, or the threat of attacks. An interviewee who helps run inclusive education boarding schools also raised concern that the presence of children with albinism at the school was putting the lives of other children and staff at the school at risk, as those looking for children with albinism might attack the school.

In May 2022, a Technical Committee was established with representation by the Government's key ministries, UNICEF, *L'Association Albinos Madagascar* (Association for People with Albinism in Madagascar) and the media with the view to developing a national action plan for ending the attacks and protecting persons with albinism. As part of the process of developing the national action plan, the Technical Committee carried out a situational analysis of persons with albinism in Madagascar (Rabemananjara, 2023), which was then used to better understand the concerns that had to be included in the national action plan. The proposed action plan calls for awareness raising and sensitisation to debunk the myths around albinism, as well as for the involvement of community leaders and families of children with albinism in the development of local solutions. It further includes Government commitment to inclusive education. UNICEF aims to tackle the issue in the longer-term through continued sensitisation and by integrating issues concerning albinism into its broader work to strengthen the child protection system in Madagascar.

The Guidelines for the Alternative Care of Children make it clear that preventing family separation and enabling a child to remain or return to a family environment is a priority over any alternative care arrangements. Article 32 specifically requires states to adopt policies to address the root causes of child abandonment, relinquishment and separation of the child from his/her family. In relation to albinism, a number of international documents and recommendations contained therein are useful in this regard. On 12 July 2021, the UN adopted Resolution 47/8 on the Elimination of Harmful Practices Related to Accusations of Witchcraft and Ritual Attacks (HPWAR). A year later, the Pan African Parliament adopted their Guidelines on the Elimination of Harmful Practices Related to Accusations of Witchcraft and Ritual Attacks. And in March 2023, the UN carried out a study on HPWAR (A/HRC/52/47). These documents provide recommendations for states on measures to be taken to tackle one of the drivers for the separation of children with albinism from their families, i.e. the ritual attacks. They advocate for education and public awareness raising campaigns to demystify conditions and situations wrongly believed to be related to witchcraft, such as albinism, recommend working with traditional and community leaders to prevent HPWAR, as well as education campaigns targeted at health workers, those in the justice sector, educators, and the media. The documents also call for research and data collection to better understand the drivers of ritual attacks.

In addition, in 2017, the African Commission on Human and Peoples' Rights adopted the Regional Action Plan on Ending Attacks and Human Rights Violations against Persons with Albinism in Africa (2017-2021). This was superseded by the Plan of Action on Ending Attacks and Discrimination against People with Albinism (Plan of Action, 2021–2031). The plan of action provides a multisectoral and holistic approach to tackling the myriad of challenges faced by persons with albinism. It includes preventive, protective and accountability measures in relation to attacks, as well as measures to ensure equality and non-discrimination for persons with albinism. It further calls for the active participation, self-representation, and inclusion of persons with albinism in relevant programs developed for them and calls for capacity strengthening to support them in this. Among the protection measures are legal measures and social protections to increase human security. Angola, Uganda, Malawi, Tanzania and Mozambique have all adopted national action plans on albinism based on the AU Plan of Action, and Madagascar's proposed national action plan is based on this as well. Other countries, such as the DRC are in the process of developing such plans.

Important measures implemented to ensure protection of persons with albinism in terms of these action plans have included public awareness campaigns by authorities together with albinism groups, such as the celebration of International Albinism Awareness Day; legal reforms, including to ensure attacks against persons with albinism fall within the definition of trafficking and have appropriate sentences; capacity building of members of the justice sector to ensure better protection; social protection measures for those with albinism and their families; as well as community-based interventions such as community policing and the disability committees at village level in Tanzania for example (A/HRC/37/57/Add.1; A/HRC/34/59/Add.1; A/HRC/34/59/Add.2; A/HRC/43/42/Add.1; A/HRC/52/36/Add.1).

Conclusion and recommendations

Whilst comprehensive international instruments and policy frameworks exist to prevent family separation, and to guide the care of children who have been separated from their families, the unique set of challenges facing children with albinism – in particular the risk of them being violently attacked or killed in the community – present an additional layer of complexity for States and practitioners in implementing these frameworks.

There is no doubt that the priority for States and practitioners should always be the prevention of separation of children with albinism from their families. There are a wide range of mechanisms needed to create an environment where the families of children with albinism can safely and responsibly care for children at home in their own communities. These include community-based services such as inclusive education, accessible primary healthcare, social protection, criminal justice, security, day-care services, social work case-management and other services. Awareness raising of the scientific basis for albinism is also needed to debunk the harmful myths that drive ritual attacks so as to change people’s social norms, values, beliefs and behaviour towards children with albinism. Awareness raising can be approached through top-down methods such as the media and societal influencers, but it can also be pursued through bottom-up community mobilisation approaches which draw on existing community-based networks.

Whilst prevention of family separation is the long-term goal, full realisation of this goal will require long-term systemic change in how societies perceive persons with albinism and provide all the services needed to ensure they can safely remain together. As with all vulnerable communities some temporary alternative care options will always be needed, and for children with albinism, these will continue to be needed until ritual attacks are stopped. The decision to place a child with albinism in alternative care should always be informed by a social work assessment of their physical, emotional, intellectual and social needs – including their need for physical safety – and any alternative care placement should be informed by the principles of necessity, appropriateness and the best interest of the child. In ensuring these gatekeeping mechanisms are properly implemented, children with albinism should, where possible, be placed in temporary family-based alternative care, such as kinship care, foster care or other traditional forms of care. Adoption is also a possibility, but its permanency removes the opportunity for a child to return to their biological family if the drivers which caused the initial separation are resolved, so it should be used with caution. Where alternative care is needed, these family-based approaches should be the priority. However, we must remain cognisant that in these family-based placements the risk of ritual attacks is still present, and they should be carefully considered as part of any care plan.

The ongoing risk of children with albinism being ritually attacked or abused is so prevalent in some contexts that we must face the uncomfortable reality that a social work assessment may determine that there is no safe family-based placement for a child. This has been the conclusion of some albinism organisations, such as Standing Voice Malawi and Village of Hope's Under the Same Sun Education Programme in Tanzania. These organisations have resorted to placing some children with albinism in security-vetted inclusive boarding schools where arrangements are put in place to for the children to have regular visit with their families and communities. Whilst such placements are a step forward from the highly-institutionalised 'temporary holding shelters' that characterised the Government of Tanzania's earlier response to ritual attacks, they are by no means a 'good practice' or a long-term solution. Whilst this model may be the most realistic 'least worst option' for some highly vulnerable children with albinism, we must recognise that it still has institutional characteristics which are harmful for children, and therefore it remains problematic. If such placements are ever used as a temporary pragmatic option, which practitioners have no meaningful choice other than to use in the absence of any safe family-based alternatives, it is imperative that States ensure there is a comprehensive care reform strategy in place to develop safe family-based alternative care at the earliest opportunity. It is also important that States regulate such placements as a form of alternative care to ensure the safety and welfare of the children placed there. It is of serious concern that practitioners are currently being presented with such an ethical dilemma. States must be held accountable for ensuring that the use of secure inclusive boarding schools never become a long-term strategy for the protection of children with albinism; they are an interim option only that should be phased out. To this effect, States must ensure that the decision to place a child in a such an arrangement is done on a case-by-case basis which takes into account the best interests of the child and ensuring full consent of the child's parents/guardians. An exit strategy should be put in place, which is based on what would be needed to prepare for the full reintegration of the child into their community and family. Learning from the lessons of Tanzania, this exit strategy should include ensuring adequate registration of the child and their family, putting in place measures to ensure continued communication between the child and their family, and outreach to the community to facilitate support and acceptance of the community upon return of the child.

Solutions which uphold children with albinism’s right to life, right to a family life and all the other rights they are entitled to, remain challenging in the current situation of wide-spread ritual attacks and killings. But through a focus on long-term systemic change to prevent family separation in the first place, this can ultimately be achieved. In the meantime, we need to remain pragmatic and flexible in identifying safe temporary care solutions, which are ideally family-based, whilst not losing sight of the longer-term goal. We also need to listen to and value the knowledge and lived experience of persons with albinism and their organisations which are grappling with these very real life and death situations and decisions daily. Finally, further research is needed to better understand these challenges, as well as further collaboration between the albinism sector, wider disability rights sector and children’s care and protection sector, to understand this unique situation of children with albinism and continue to identify solutions.

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