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Promotion and protection of human rights: human rights questions, including alternative approaches for improving the effective enjoyment of human rights and fundamental freedoms

Enjoyment of human rights by persons with albinism

Note by the Secretary-General

The Secretary-General has the honour to transmit to the General Assembly the report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond, in accordance with Human Rights Council resolutions [28/6](#) and [55/18](#).

* [A/79/150](#).



Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond

Children with albinism and the right to a family life

Summary

In the present report, the Independent Expert on the enjoyment of human rights by persons with albinism provides perspectives, the findings of a joint research project, and recommendations on improving the daily challenges and life experiences of children with albinism in the context of the right to a family life. The report underlines the range of violations experienced by children with albinism and highlights the practical risks to children with albinism when separated from their families owing to discrimination, lack of access to education or health services, ritual attacks and poverty, among other factors. It also presents sets of good practices to prevent and respond to separation.

The Independent Expert also outlines in the present report activities undertaken in the implementation of her mandate over the period from June 2023 to June 2024, including, inter alia, collaborative research initiatives, consultation workshops and training programmes.

I. Introduction

1. The present document is the report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond. It is submitted pursuant to Human Rights Council resolutions 28/6 and 55/18.

2. In preparing the report, the Expert collaborated with Lancaster University through a joint research project commissioned in 2023. The research included a desk review of relevant literature and interviews with 31 experts from academia, civil society organizations and persons with albinism. In April 2024, the Expert sent a questionnaire to Member States and held a virtual consultation with over 100 non-State actors. The following States provided information for the report: Colombia, Dominican Republic, Italy and Uzbekistan. The following organizations also provided information: Africa Albinism Network, Better Care Network, Disability Rights International, Global Albinism Alliance and Lumos. The views of persons with albinism with lived experience of family separation as children also informed this report.

3. The report focuses on the risks of children with albinism being separated from their families owing to discrimination, lack of access to education or health services, ritual attacks and the “burden” of care and poverty. It considers the harm that this causes children with albinism, as well as good practices to prevent and respond to separation.

4. Albinism is a rare, non-contagious, genetically inherited condition that affects people worldwide, regardless of ethnicity or gender. It most commonly results in a lack of melanin pigment in the hair, skin and eyes (oculocutaneous albinism), causing vulnerability to sun exposure. The prevalence rate is contested and believed to be underestimated. Africa as a continent has the highest prevalence which ranges from 1 in 1,755 to 1 in 7,900. However, some estimates around the world have a prevalence of up to 1 in 22. In Europe, the prevalence is said to range from 1 in 10,000 to 1 in 15,000 but those rates are also believed to be underestimated.¹ Owing to their visual impairment and high susceptibility to skin cancer, persons with albinism are also considered persons with disabilities.

5. Persons with albinism experience a range of human rights violations which disproportionately impact children. These include discrimination and ostracization, a lack of accessibility to inclusive education and health services and, in the worst cases, in some African countries, ritual attacks and killings due to a mistaken belief that their body parts hold magical powers.

6. Due to these human rights challenges, children with albinism are at risk of being separated from their families. States, families, or both, may consider a family environment unsuitable and/or unsafe for them because of the prevalence of discrimination, violence and a lack of access to education and health care. However, separating children with albinism from their families and placing them in institutional care can further infringe on their rights, particularly their right to a family life.

II. Activities of the Independent Expert in 2024

7. During the period from July 2023 to June 2024, the Expert undertook various activities, some of which are highlighted below.

¹ Jennifer G.R. Kromberg, Kaitlyn A. Flynn and Robyn A. Kerr, “Determining a worldwide prevalence of oculocutaneous albinism: a systematic review”, *Investigative Ophthalmology and Visual Science*, vol. 64, No. 10 (July 2023).

8. The Independent Expert conducted country visits to Panama and Lesotho, where she met various stakeholders. She participated in conferences, both in person and virtually, on topics that included human trafficking, climate change, access to medicines and other health products, State budgeting, mothering and albinism, and inclusion as they relate to albinism.

9. The Expert continued to engage with albinism groups around the world, including by participating in activities organised by those groups and carrying out capacity-building programmes for persons with albinism around the world. In addition, the Expert conducted workshops and engagements with diplomatic entities and members of the justice sector, including the judiciary, lawyers and police in the Southern Africa region.

10. In support of the growing work around children with albinism, the Expert held a consultation workshop on children with albinism and the right to a family life. She continued to collaborate with the African Committee of Experts on the Rights and Welfare of the Child, including by participating in the 2024 Day of general discussion on the solutions to the challenges faced by children with albinism in Africa on 17 April, in Maseru, Lesotho.

III. Normative and policy frameworks

A. Children with albinism

11. Children with albinism are protected by international human rights treaties and standards. The Human Rights Council has called for the prevention of attacks against persons with albinism;² and has recommended that States adopt measures to protect their right to life and security, and their right not to be subjected to torture and ill-treatment, and to ensure their access to adequate health care, education and justice.³ It has additionally called for perpetrators to be brought to justice and for a more holistic approach to addressing ritual attacks.⁴ The Expert has submitted 20 thematic reports with recommendations to the General Assembly and the Human Rights Council, addressing, inter alia, the right to health, the rights of women and children impacted by albinism, access to justice, protection, harmful practices and hate crimes and the right to education.⁵

12. Although there are several regional instruments that protect children's rights in general, only the African region appears to have standards specifically referring to children with albinism. Those instruments include the Pan-African Parliament guidelines on eliminating harmful practices and other human rights violations;⁶ and the African Union Plan of Action on Ending Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa,⁷ which aims to eradicate discrimination and violence. Furthermore, in the outcome statement of the 2024 Day of general discussion on the solutions to the challenges faced by children with albinism, the African Committee of Experts on the Rights and Welfare of the Child called for States members of the African Union to safeguard the rights and welfare of

² Human Rights Council resolution 23/13. See also www.ohchr.org/en/resources/databases.

³ See A/HRC/24/57. See also www.ohchr.org/en/resources/databases.

⁴ Human Rights Council resolution 47/8. See also www.ohchr.org/en/special-procedures/ie-albinism/witchcraft-and-human-rights.

⁵ See www.ohchr.org/en/special-procedures/ie-albinism/reports.

⁶ Pan-African Parliament, *Accusations of Witchcraft and Ritual Attacks: Towards Eliminating Harmful Practices and Other Human Rights Violations* (2021).

⁷ African Union, "Implementation matrix of the Plan of Action to end attacks and other human rights violations targeting persons with albinism in Africa (2021–2031)", 2019.

children with albinism, including their rights to affordable health care services, inclusive education, psychosocial support and to “advocate for their rights in their families and communities”.⁸ The European Union has also adopted a policy on albinism, although it focuses on the situation of persons with albinism in Africa, notably in Malawi.⁹

B. Right to a family life

13. All children have a right to family life. This is articulated in multiple international and regional instruments.¹⁰ The Universal Declaration of Human Rights recognizes “[t]he family is the natural and fundamental group unit of society and is entitled to protection by society and the State.”¹¹ The Convention on the Rights of the Child¹² reflects the Universal Declaration of Human Rights in recognizing the family as the “fundamental group of society and the natural environment for the growth and well-being of ... children”, and that children should “grow up in a family environment”. The Convention on the Rights of Persons with Disabilities¹³ further recognizes that “children with disabilities have equal rights with respect to family life” and that “where the immediate family is unable to care for a child with disabilities, [States must] undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting”. In addition, general comment No. 5 of the Committee on the Rights of Persons with Disabilities, provides that children have a “right to grow up in a family”.¹⁴ According to the Guidelines for the Alternative Care of Children,¹⁵ all efforts should be made for children to remain or be returned to their families, and only when that is not possible should children be placed in alternative care. It is reiterated in the guidelines on deinstitutionalization, including in emergencies,¹⁶ of the Committee on the Rights of Persons with Disabilities that “children with disabilities, like all children, have the right to family life and a need to live and to grow up with a family in the community”. According to general comment No. 5 and the guidelines on deinstitutionalization, institutionalization is not a measure for the protection of children with disabilities and violates the prohibition of deprivation of liberty based on impairment, established in article 14 of the Convention on the Rights of Persons with Disabilities.

14. At the regional level, the African Charter on the Rights and Welfare of the Child¹⁷ emphasizes the importance of family life, and where a child is separated and cannot be reunified with their family, the critical importance of family-based alternative care. The right to family life is also recognized in the Association of Southeast Asian Human Rights Declaration,¹⁸ and in the American Convention on Human Rights.¹⁹ The Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights)²⁰ protects the right

⁸ African Committee of Experts on the Rights and Welfare of the Child, “Day of general discussion on the solutions to the challenges faced by children with albinism: outcome statement”, 2024.

⁹ See <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52016IP0314&from=ET>.

¹⁰ See A/HRC/31/37.

¹¹ Universal Declaration of Human Rights, art. 16(3).

¹² General Assembly resolution 44/25.

¹³ General Assembly resolution 61/106.

¹⁴ See Committee on the Rights of Persons with Disabilities, general comment No. 5 (2017).

¹⁵ General Assembly resolution 64/142.

¹⁶ See CRPD/C/5.

¹⁷ See <https://au.int/en/treaties/african-charter-rights-and-welfare-child>.

¹⁸ Association of Southeast Asian Nations Human Rights Declaration, art. 19.

¹⁹ American Convention on Human Rights, art. 17.

²⁰ Convention for the Protection of Human Rights and Fundamental Freedoms, art. 8.

to respect for family life. These instruments make clear that preventing family separation and – if separated – then enabling a child to maintain contact with their family and return to a family environment, is the priority for States. They also make clear that poverty should never be the only justification for the removal of a child from parental care.

15. The 2019 report of the Third Committee on the promotion and protection of the rights of children²¹ builds on the Guidelines for the Alternative Care of Children in urging States to support families and prevent separation through mechanisms including: child protection and social work services that protect children from violence; support for children with disabilities and stigmatized and marginalized families; inclusive and responsive family-oriented policies and programmes, including for inclusive education, health and well-being; equal access to economic resources; social security; livelihoods; and protection of the human rights of all family members.

IV. Separation of children with albinism from their families

A. Drivers for family separation

16. Vulnerable children are generally at risk of separation from their families due to poverty and lack of access to services such as education, health care, social protection and family support.²² They are often separated from their families and placed in alternative care – including institutional care – to have better access to those services. The same is true for children with albinism, and their albinism often exacerbates the existing drivers and creates new drivers towards family separation. The result is intersectional disadvantage for children with albinism. There are four specific reasons why those children are separated from their families.²³

17. Children with albinism and their families may experience discrimination, stigmatization and ostracization within their community, mostly on the grounds of disability and colour.²⁴ That may include bullying within their own families, in schools and communities. Some may seek to justify placing the child in alternative care to remove the child – and the wider family – from those discriminatory experiences.

18. Due to their visual impairment and risk of skin damage, children with albinism require reasonable accommodations and innovative approaches to make education accessible. They also require accessible and affordable health care services and products, such as dermatological and ophthalmological services, including sunscreen.²⁵ In some contexts, those services and products may be more readily available to children with albinism in specialist boarding schools or other institutional care settings, especially for those in rural or remote areas.

19. Children with albinism are at risk of being ritually attacked, mutilated or murdered for their body parts in some African countries owing to a mistaken belief that their body parts hold magical powers for use in ritual practices.²⁶ In areas where there is a high prevalence of attacks, a child may be removed from their family and placed in the perceived “safety” and “protection” of alternative care; often a secure form of

²¹ [A/74/395](#).

²² Hope and Homes for Children, “Families. Not institutions”, 29 September 2022.

²³ Martin Punaks, “Children with Albinism and Care: Annex to UNGA report”, 2023.

²⁴ See [A/74/190](#).

²⁵ See [A/HRC/37/57](#).

²⁶ Julie Taylor, Caroline Bradbury-Jones and Patricia Lund, “Witchcraft-related abuse and murder of children in sub-Saharan Africa: a conceptual review”, *Child Abuse Review*, vol. 28, No. 1 (January/February 2019).

residential care, such as a shelter or specialist boarding school. The removal may be driven by the fear and psychological distress caused by a real or potential attack.

20. For some families, the combination of the above three drivers creates a fourth driver. The stigma, risks and financial burden on the wider family result in parents or carers relinquishing the “burden” of care for their child to an external body – usually a type of residential care – which may be better resourced to manage the challenges.

21. Family separation for children with albinism is often caused by a convergence of two or more of the above drivers. Furthermore, poverty is associated with, and further exacerbates those drivers for several reasons.²⁷ First, in multiple cases, fathers abandon the mother of a child with albinism owing to the mistaken belief that the child is not theirs and/or the associated stigma of having a child with albinism. Second, families of children with albinism are more likely than others to experience financial hardship due to prioritizing the care and protection of their child over earning a livelihood, thus, paradoxically, putting them at a higher risk of separation. Third, since poorer families can less easily afford inclusive education, health care and security, they may be driven to access it through an alternative care placement. Fourth, in poorer families, in some African countries for instance, other family members may take advantage of the opportunity to profit from trafficking body parts of a child with albinism due to their familial proximity to the child (there are many examples of ritual attacks being organized by a child’s own relatives).²⁸ Fifth, broader societal poverty has been linked to ritual attacks; for example, a sudden increase in ritual attacks in the south of Madagascar was associated with poverty, food insecurity and drought,²⁹ and attacks in Tanzania have been linked with securing success in gold and diamond mining.³⁰

B. Scope and scale of family separation

22. The separation of children with albinism from their families manifests itself in different ways in different countries. In view of the high incidence of ritual attacks in Tanzania in the late 2000s, the Government established 32 “temporary holding shelters” to protect and educate children with albinism.³¹ The shelters were described by the African Committee of Experts on the Rights and Welfare of the Child as being more like a “detention facility than a safe house” and as violating many of the children’s rights including health, family life, education, adequate food, nutrition, accommodation, water and sanitation.³² In Malawi, owing to a rise in threats and attacks, linked with poverty and harmful practices related to witchcraft, many mothers moved their children with albinism to live with relatives in safer areas or in boarding schools.³³ More recently, in Madagascar, owing to a rise in attacks, children with albinism have been placed by their families or the police in boarding schools for the visually impaired, inclusive boarding schools and police stations (gendarmierie) for

²⁷ Ikponwoso Ero and others, *People with Albinism Worldwide: A Human Rights Perspective* (Office of the United Nations High Commissioner for Human Rights (OHCHR), 2021); and Martin Punaks, “Children with Albinism and Care”.

²⁸ Agence France-Presse, “Mozambique authorities arrest father allegedly planning to sell children with albinism”, News 24, 25 July 2022.

²⁹ See [A/HRC/52/36/Add.1](#).

³⁰ Deborah Fahy Bryceson, Jesper Bosse Jønsson and Richard Sherrington, “Miners’ magic: artisanal mining, the albino fetish and murder in Tanzania”, *The Journal of Modern African Studies*, vol. 48, No. 3 (September 2010).

³¹ African Committee of Experts on the Rights and Welfare of the Child, “Report on investigative mission on the situation of children with albinism in temporary holding shelters: Tanzania”, March 2016.

³² *Ibid.*

³³ See [A/HRC/34/59/Add.1](#).

their protection.³⁴ In South Africa, where ritual attacks are rarely reported, children with albinism still experience discrimination, lack of reasonable accommodations in community schools and limited access to, or unaffordability of health services, resulting in some families sending them to specialist boarding schools.³⁵

23. There is some evidence that similar drivers – except for ritual attacks – are also causing family separation in countries outside Africa. In Panama, parents of children with albinism have told the Expert that they have sent their children to live with extended family members in Panama City to have access to better education and health services.³⁶ In Brazil and Fiji, the Expert has reported cases of abandonment of children with albinism, alongside discrimination, poverty and lack of access to health care for persons with albinism.³⁷

24. In China, there are reports of high levels of children with disabilities, including children with albinism,³⁸ in institutional care due to discrimination and a lack of social welfare provisions.³⁹ Children with disabilities in China may constitute over half of all outgoing intercountry adoptions.⁴⁰ Interviewees have reported many examples of Chinese (as well as Korean and Russian) children with albinism being adopted in North America and Europe.⁴¹ The Government of Uzbekistan has recorded 143 children with albinism studying in “17 specialized schools and boarding schools for blind and visually impaired children”.⁴² Other European and Central Asian countries have less disaggregated data on children with albinism, but with 456,000 children living in residential care in the region (the highest rate in the world), and children with disabilities being overrepresented among them,⁴³ it is likely that they may include children with albinism.

25. The circumstances of all children globally who have been separated from their families vary substantially, making it hard to quantify. However, the global estimate is 5.37 million separated children living in institutional care.⁴⁴ In view of the absence of disaggregated data, there are no accurate estimates of how many of them are children with albinism. The research identified reports of high numbers of children with albinism being institutionalized in China, the Democratic Republic of the Congo, Madagascar, Malawi, Mozambique, South Africa, Tanzania, Uzbekistan and Zambia.⁴⁵

C. Child institutionalization

26. “Institutionalization” means all types of residential care for children with an “institutional culture”. An institutional culture means a care environment where children are separated from their families, isolated from the broader community and/or compelled to live together; where children and their families do not have sufficient

³⁴ See [A/HRC/52/36/Add.1](#).

³⁵ Martin Punaks, “Children with Albinism and Care”.

³⁶ Expert visit to Panama.

³⁷ See [A/HRC/46/32/Add.1](#); and [A/HRC/40/62/Add.1](#).

³⁸ Interviews.

³⁹ Erin Raffety, “Chinese special needs adoption, demand, and the global politics of disability”, *Disability Studies Quarterly*, vol. 39, No. 2 (Spring 2019); and interviews.

⁴⁰ *Ibid.*

⁴¹ Martin Punaks, “Children with Albinism and Care”.

⁴² Response from Uzbekistan.

⁴³ United Nations Children’s Fund (UNICEF), Regional Office for Europe and Central Asia, *TransMonEE Analytical Series: Pathways to Better Protection – Taking Stock of the Situation of Children in Alternative Care in Europe and Central Asia* (Geneva, 2024).

⁴⁴ Chris Desmond and others, “Prevalence and number of children living in institutional care: global, regional, and country estimates”, *Lancet: Child and Adolescent Health*, vol. 4, No. 5 (May 2020).

⁴⁵ Martin Punaks, “Children with Albinism and Care”.

control over their lives and the decisions which affect them; and where the requirements of the organization take precedence over the individualized needs of the children.⁴⁶

27. The Guidelines for Alternative Care only consider large-scale residential care to be institutional and therefore requiring progressive deinstitutionalization, thus leaving an acceptable place for temporary small group residential care in certain situations. The Committee on the Rights of Persons with Disabilities, on the other hand, considers any large or small residential facility, including “family-like” facilities, an unacceptable form of institutional care.⁴⁷ In its deinstitutionalization guidelines, the Committee rejects all segregated spaces – including “small group homes”, “special boarding schools”, “family-like homes”, and “albinism hostels” – and considers any placement that is not family-based to be institutional. The Committee defines the elements of an institution⁴⁸ as “obligatory sharing of assistants with others and no or limited influence as to who provides the assistance; isolation and segregation from independent life in the community; lack of control over day-to-day decisions; lack of choice for the individuals concerned over with whom they live; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of individuals under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and a disproportionate number of persons with disabilities in the same environment”. It considers institutionalization as constituting “detention and deprivation of liberty based on impairment” and “a form of violence against persons with disabilities”.

28. Accordingly, when family separation results in a child being placed in institutional care, it denies the child their right to a family life and is proven to be harmful.⁴⁹ The institutionalization of children harms their physical, psychological and cognitive development, 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. Furthermore, children risk abuse by staff or peers and may be denied access to kinship networks. Long-term outcomes for institutionalized children with disabilities are particularly concerning with higher likelihoods of experiencing violence and early death.⁵⁰ When young people “age out” and leave institutional care, the impact of that care on their development continues to present challenges. Individuals who grow up in institutional care have worse levels of employment and educational attainment compared to those who have grown up in foster care, and care leavers have worse outcomes across a range of parameters than those who have not been in care.⁵¹

⁴⁶ Vladimir Špidla, “Report of the Ad Hoc Expert Group on the transition from institutional to community-based care”, February 2009.

⁴⁷ Committee on the Rights of Persons with Disabilities, general comment No. 5 (2017).

⁴⁸ See [CRPD/C/5](#).

⁴⁹ Anne E. Berens and Charles A. Nelson, “The science of early adversity: is there a role for large institutions in the care of vulnerable children?”, *The Lancet*, vol. 386, No. 9991 (July 2015); and Marinus H. van IJzendoorn and others, “Institutionalization and deinstitutionalization of children 1: a systematic and integrative review of evidence regarding effects on development”, *The Lancet: Psychiatry*, vol. 7, No. 8 (August 2020).

⁵⁰ Kevin Browne and others, *Mapping the Number and Characteristics of Children under Three in Institutions across Europe at Risk of Harm* (Birmingham, University of Birmingham, 2004); and Lisa Jones and others, “Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies”, *The Lancet*, vol. 380, No. 9845 (September 2012).

⁵¹ Nadine Cameron and others, “Good practice in supporting young people leaving care”, 16 February 2019; and Evgenia Stepanova and Simon Hackett, “Understanding care leavers in Russia: young people’s experiences of institutionalization”, *Australian Social Work*, vol. 67, No. 1 (2014).

29. Persons with albinism with lived experience of child institutionalization – often at specialist boarding schools – have described their initial sense of relief at being withdrawn from the stigma, discrimination and threats of violence they faced in wider society.⁵² They reference the increased security, specialist learning and health provisions, and friendships made with other children with albinism. However, they go on to describe the challenges of integrating with wider society after leaving the segregation of an institution. They report differences in the long-term outcomes between those who attended inclusive and community-based schools, and those who were institutionalized in specialist boarding schools or shelters, with the former group reportedly being “happier” and “more successful” in life. They report similar differences between those who were able to regularly visit and maintain contact with their families, and those who could not.

V. Good practices

30. The research identified several good practices that support the right to a family for children with albinism.

A. Prevention of family separation

31. Preventing the separation of children with albinism from their families is always the priority before alternative care. There are several good practices that demonstrate where this is working.

32. The provision of community-based inclusive education that provides reasonable accommodations for the needs of children with albinism prevents them being placed in specialist boarding schools. Reasonable accommodations include access to assistive devices such as glasses and protection from the sun’s harmful rays. A Ugandan albinism organization, for example, reports that most children with albinism in Uganda attend inclusive community schools. Such schools not only reduce the need for shelters or specialist boarding schools, but also increase the visibility of persons with albinism in the community. That in turn helps reduce stigmatization and ostracization, and consequently prevents family separation.⁵³

33. Accessible community-based health facilities, goods and services are essential to prevent separation. Children with albinism need access to affordable sunscreen and medical services to prevent and treat skin damage and skin cancer.⁵⁴ The national network of community-based health volunteers in Kenya is an example of an initiative which provides community-based access to health services for vulnerable families who may not otherwise afford transport to health facilities.⁵⁵ Health professionals also need sensitizing as to the medical basis for albinism, so that they can appropriately support and advise parents. In Uganda, the civil society organization Source of the Nile Union of Persons with Albinism trains doctors, midwives and birth attendants as first responders that can reassure and support parents immediately after the birth of a child with albinism, when the risk of abandonment by one or both parents is high.⁵⁶ Brazil has a Federal Bill that is focused on improving health care services for persons with albinism in the country and the municipality of Maceió adopted Law No. 6605, which provides for the distribution of sunscreen free of charge.⁵⁷ Respondents to the

⁵² Martin Punaks, “Children with Albinism and Care”.

⁵³ Ibid.

⁵⁴ Ero, *People with Albinism Worldwide*.

⁵⁵ Kenya, Ministry of Health, “Kenya Community Health Policy 2020–2030”, 2023.

⁵⁶ Martin Punaks, “Children with Albinism and Care”.

⁵⁷ See [A/HRC/46/32/Add.1](#).

consultation have also highlighted the importance of mental health services in supporting children with albinism and their families in the many challenges that they face.

34. As poverty significantly exacerbates the drivers of family separation, social protection schemes that target vulnerable families through cash transfers and livelihood programmes are a key factor in preventing family separation. The Government of Kenya provides cash transfer programmes that directly target the families of orphans and vulnerable children and persons with disabilities.⁵⁸ Day-care services also have proven benefit in supporting vulnerable families – in particular, single mothers – to have respite from care duties to earn a livelihood.⁵⁹

35. Panama’s Law 210 on albinism is another example of a good measure, which if effectively implemented can help reduce the incidence of separation of children with albinism from their family. It provides for access to specialized health services, reasonable accommodations in school and workplaces, educational bursaries, and special protection for employees with albinism and those who are parents of children with albinism. It further calls for awareness-raising and data collection in relation to albinism.

36. Discrimination and ritual attacks against persons with albinism often go unreported, underreported or unpunished.⁶⁰ Therefore, addressing barriers to justice and the perceived impunity of perpetrators works to deter others from committing discriminatory acts or crimes, and makes families feel safer in caring for their children with albinism at home. The Expert has highlighted several ways to strengthen criminal justice systems,⁶¹ including justice machinery being made more proactive than reactive, improved legal aid, legal reform to cover legal gaps and ensure stricter penalties for perpetrators, training to increase legal awareness for law enforcement and judicial practitioners, action to address barriers such as the perception of persons with albinism as unreliable or incapable witnesses, and greater accountability of formal justice actors.

37. The provision of security is an essential factor in reducing both the fear and the real possibility of children with albinism being ritually attacked. Examples of such measures include the strengthening of community policing structures by the Government of Malawi and the allocation of adequate police forces in districts most affected by attacks, as well as reportedly providing housing subsidies and personal alarms for persons with albinism to mitigate attacks.⁶² The police in Madagascar⁶³ and Burundi⁶⁴ have supported community-led initiatives to develop their own neighbourhood surveillance and security mechanisms. In addition, the International Organization for Migration and the United Nations Children’s Fund (UNICEF) have developed actions to tackle cross-border attacks between Mozambique, Tanzania and Malawi.⁶⁵

38. The role of awareness-raising regarding the scientific basis for albinism and a human rights perspective on the condition is essential for changing attitudes and behaviours and reducing discrimination and attacks. The previous mandate holder

⁵⁸ UNICEF, “Social protection in Kenya: investing in human capital, boosting economic growth, and unlocking the country’s full potential”, September 2023.

⁵⁹ Victoria Hidalgo and others, “The effectiveness of a child day-care programme in child welfare services”, *Children and Youth Services Review*, vol. 89 (June 2018).

⁶⁰ Ero, *People with Albinism Worldwide*.

⁶¹ See [A/HRC/40/62](#).

⁶² Ikponwosa Ero, *Best Practices in the Protection of Human Rights of Persons with Albinism* (2020).

⁶³ Martin Punaks, “Children with Albinism and Care”.

⁶⁴ Ero, *Best Practices in the Protection of Human Rights*.

⁶⁵ *Ibid.*

cited examples of how awareness-raising had resulted in local community members intervening during attacks or donating stronger doors and locks to neighbours with a child with albinism.⁶⁶ Good practice tools to support those aims include the UNICEF Social Behaviour Change Guidelines⁶⁷ and the EKISA Ministries guide, which supports Ugandan parents and caregivers of a child with disability.⁶⁸ Several respondents to the call for inputs also highlighted the important role of schools and teachers in raising awareness.

39. Related to awareness-raising is the role of advocacy in getting the needs and rights of persons with albinism formally recognized in regional and national legislation and policy frameworks. The International Bar Association's Human Rights Institute (IBAHRI) report on regional and international standards for the protection of the rights of persons with albinism in Africa⁶⁹ provides information on State obligations and recommendations on steps to be taken to meet those obligations. The recent outcome statement of the 2024 Day of general discussion on children with albinism held by the African Committee of Experts on the Rights and Welfare of the Child is a good example of how advocacy by albinism organizations has resulted in States members of the African Union being called to safeguard the rights and welfare of children with albinism.⁷⁰ Respondents to the call for inputs have highlighted the need for albinism to be more explicitly recognized as a disability within the framework of the Convention on the Rights of Persons with Disabilities, based on visual impairment and susceptibility to skin damage. This is demonstrated in the decision taken by the Committee on the Rights of Persons with Disabilities in *Z v. Tanzania*.⁷¹ The African Disability Rights Protocol, in its preamble, also specifically recognizes albinism as falling within the framework of the protocol.⁷²

40. Awareness-raising is also a key component of grassroots approaches to community mobilization that use existing community networks and structures to identify local priorities, resources, needs and solutions to effect social change.⁷³ Those approaches have been used successfully in tackling harmful practices such as female genital mutilation and cutting and child marriage in Kenya,⁷⁴ programmes that prioritize family-based care in Kenya and Rwanda⁷⁵ and community-based awareness-raising and surveillance systems to tackle ritual attacks in Madagascar.⁷⁶ Source of the Nile Union of Persons with Albinism has also used this approach in Uganda to, inter alia, make persons with albinism highly visible in the community to dispel any sense of otherness.⁷⁷

⁶⁶ Ikponwosa Ero, "Children with albinism: from invisible to visible", in *Celebrating Childhood: A Journey to End Violence against Children* (United Nations publication, 2016).

⁶⁷ UNICEF, *Social and Behaviour Change at UNICEF* (2024).

⁶⁸ Ekisa Ministries, "Finding Value: Helping a Parent Find Value in their Child with Disabilities", 2020.

⁶⁹ International Bar Association, "*Waiting to Disappear*": *International and Regional Standards for the Protection of the Human Rights of Persons with Albinism* (London, 2017).

⁷⁰ African Committee of Experts on the Rights and Welfare of the Child, "Day of general discussion on the solutions to the challenges faced by children with albinism: outcome statement", 2024.

⁷¹ See [CRPD/C/22/D/24/2014](https://www.cprpd.org/2024/02/24/2024-02-24/).

⁷² See https://au.int/sites/default/files/treaties/36440-treaty-protocol_to_the_achpr_on_the_rights_of_persons_with_disabilities_in_africa_e.pdf.

⁷³ Mercy Corps, "Community mobilization sector approach", 3 December 2009.

⁷⁴ Martin Punaks, "Children with Albinism and Care".

⁷⁵ Diego Ottolini and others, *Towards Evidence-Based Reform of Policy and Practice in Child Protection in Kenya* (Nairobi, CEFA, 2011); and Republic of Rwanda and others, "Evaluation of the Tubarerere Mu Muryango (Let's Raise Children in Families) Programme in Rwanda, phase 1: summary", 2019.

⁷⁶ Martin Punaks, "Children with Albinism and Care".

⁷⁷ *Ibid.*

41. A social work case management approach addresses the needs of children and families with vulnerabilities.⁷⁸ It identifies the risks facing a family that could result in separation and works collaboratively with the family to address those needs. Case management recognizes that each child and family are unique and require their own tailored solutions. The civil society organization Standing Voice Malawi uses that approach to support vulnerable families of children with albinism.⁷⁹ The caseworker works with the family to identify needs and facilitate solutions, including livelihood training, help with access to cash transfers, improved physical security of houses, psycho-social support, and awareness-raising.

42. To facilitate the sharing of good practice, including the above preventative measures, it is important to support peer-to-peer learning between States as well as between albinism rights, disability rights and child rights organizations. Through peer-to-peer learning, States can share their experiences of best practice in preventing discrimination, ritual attacks and family separation.

43. The African Union Plan of Action on Ending Attacks and Other Human Rights Violations Targeting Persons with Albinism⁸⁰ provides a regional mechanism to eradicate discrimination and violence against persons with albinism in the continent. Its objective is to monitor the impact of efforts to protect and integrate persons with albinism by multiple stakeholders across Africa, and it includes some of the preventative strategies detailed above. It has four main pillars: prevention, protection, accountability, and equality and non-discrimination, and has served as a point of reference to assist African States to develop their own national action plans.

B. Alternative care

44. Alternative care is defined as: “A formal or informal arrangement whereby a child is looked after at least overnight outside the parental home, either by decision of a judicial or administrative authority or duly accredited body, or at the initiative of the child, his or her parent(s) or primary caregivers, or spontaneously by a care provider in the absence of parents”.⁸¹ The Guidelines for the Alternative Care of Children recognize alternative care as including: (a) “family-based care” which includes kinship care, foster care and “other forms of family-based or family-like care placements”; and (b) “residential care” which is “care provided in any non-family-based group setting, such as places of safety for emergency care, transit centres in emergency situations, and all other short- and long-term residential care facilities, including group homes”.⁸² The Guidelines recognize that family-based alternative care can be temporary or long-term, while residential care can only ever be a temporary arrangement. The Committee on the Rights of Persons with Disabilities does not recognize residential care as an acceptable form of alternative care, as it is not family-based.⁸³

45. Alternative care may take the form of: (a) “formal care” ordered by an administrative body or judicial authority and including all residential care whether

⁷⁸ Child Protection Working Group, *Inter-Agency Guidelines for Case Management and Child Protection* (2014).

⁷⁹ Martin Punaks, “Children with Albinism and Care”.

⁸⁰ See <https://africaalbinismnetwork.org/wp-content/uploads/2022/09/1640085668084rgprabbsh8-1.pdf>.

⁸¹ Better Care Network, Glossary of Key Terms, available at <https://bettercarenetwork.org/glossary-of-key-terms>.

⁸² See General Assembly 64/142.

⁸³ Committee on the Rights of Persons with Disabilities, general comment No. 5 (2017); and CRPD/C/5.

because of administrative or judicial measures; or (b) “informal care” consisting of all private arrangements in a family environment.⁸⁴

46. Where it is not possible, even with appropriate support, for a family of a child with albinism to provide adequate care and protection for their child, this responsibility must be taken on by the State in arranging for the child to be placed in alternative care,⁸⁵ and as far as the Committee on the Rights of Persons with Disabilities is concerned, that should be in a family setting. Such a decision should always be preceded by rigorous gatekeeping procedures; it should be based on an assessment, be in the best interests of the child and be appropriate for the child’s needs. Furthermore, the placement should be temporary and be reviewed regularly, with a view to rectifying the causes of the removal. It is the State’s responsibility to both arrange and supervise alternative care to ensure the safety, well-being and development of the child.

47. 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”.⁸⁶ It can include varying degrees of parental contact, short or long-term care arrangements, children moving between households, and arrangements that may be forced upon children due to circumstances.⁸⁷ Kinship care is the most common form of alternative family care in some places, including in sub-Saharan Africa, where it is culturally accepted, and children report preferring it to other forms of alternative care. It generally results in good outcomes, and children describe feeling loved by family members.⁸⁸ It is, however, not without its challenges. Extended family members may not understand the specific health, education and security needs of a child with albinism. Moving location from one branch of a family to another also doesn’t automatically remove the wider societal threat of discrimination or being attacked. There are, however, many examples of children with albinism living safely in informal kinship care to improve their circumstances. It has been used as a strategy to improve children’s proximity to quality inclusive education in South Africa⁸⁹ and to reduce the risk of being attacked by living with extended family members in safer areas of Madagascar and Malawi.⁹⁰ Kinship care is also used successfully in Brazil as a strategy to protect other children from the risk of drug and gang-related violence.⁹¹ If offered alongside caseworker monitoring and support – where needed – kinship care provides a low-cost, flexible and viable form of family-based alternative care for children with albinism.

48. 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”.⁹² Formal foster care can take many forms including: emergency foster care, short or medium-term foster care, long-term foster care, specialized foster care (including for children with disabilities), respite or short-breaks foster care, fostering to adopt or pre-adoption foster care, and parent and baby fostering (where a mother and child go together into foster care to support parenting skills).⁹³ There are some examples of

⁸⁴ Ibid.

⁸⁵ General Assembly resolution 64/142; and A/74/395.

⁸⁶ Family for Every Child, *How to Support Kinship Care: Lessons Learnt from around the World* (2024).

⁸⁷ Emily Delap and Gillian Mann, *The Paradox of Kinship Care: The Most Valued but Least Resourced Care Option – A Global Study* (Family for Every Child, 2019).

⁸⁸ Ibid.

⁸⁹ Martin Punaks, “Children with Albinism and Care”.

⁹⁰ See A/HRC/52/36/Add.1; and Martin Punaks, “Children with Albinism and Care”.

⁹¹ See www.acerbrasil.org.br/.

⁹² See General Assembly resolution 64/142.

⁹³ UNICEF, Eastern and Southern African Regional Office, “Supporting foster care in Eastern and Southern Africa”, 2022.

successful formal foster care programmes, including with children with disabilities. EKISA Ministries in Uganda has trained and supported specialist foster carers to successfully care for children with disabilities.⁹⁴ However, such initiatives are often run by civil society organizations, reaching only a small number of children, and are not fully integrated into national care and protection systems. African States have generally struggled to establish State-run and regulated foster care at scale, but in places where it has been able to establish itself, formal foster care could offer an effective and flexible form of family-based care for children with albinism in high-risk situations. For example, emergency or short-term foster care could be offered during periods of transition or risk for a child with albinism. Short-term and long-term foster care placements could also be offered in locations where high-quality inclusive education is available and the risk of ritual attacks are low. Informal foster care is culturally better understood and more readily practiced in African contexts, but as with kinship care, there are risks that need to be carefully managed.

49. The research identified several examples of children with albinism living under the care of “well-wishers” in the community who offered better security and support than parents were willing or able to.⁹⁵ One interviewee reported albinism organizations in Sierra Leone arranging for children with albinism to be “adopted” into another family where the main carer or their children also have albinism. The rationale for this being that the new carer’s experience in this area is considered to make them more effective at caring for children with albinism.⁹⁶ The biological parents may or may not continue to play a role in the child’s life. Those sorts of placements are usually authorized by local community leaders and are sometimes arranged and monitored by social workers from non-governmental organizations. They can be considered informal or semi-formal care practices that do not neatly fit into the categories of either foster care or adoption. Such practices are common in Africa, and they provide children with albinism with family-based care that may otherwise not be available, especially where a formal care system is under-developed. They do however pose safeguarding risks to children if they are not accompanied with appropriate gatekeeping and social worker monitoring.

C. Domestic adoption

50. Adoption can be defined as: “The legal transfer of parental rights and responsibilities for a child which is permanent. Domestic (national) adoption involves adopters who live in the same country as the child.”⁹⁷ Under the Convention on the Rights of the Child, States parties that recognize or permit adoption shall ensure that the best interests of the child shall be paramount. There is, however, no international instrument guiding States’ best practice with regard to domestic adoption.

51. Adoption is considered an appropriate permanent family-based option when all possibilities for the child to be reunified or to maintain a relationship with their biological family have been exhausted. Adoption is not a form of alternative care because, in transferring legal guardianship to adoptive parents, it becomes permanent parental care. Interviewees have reported that in some contexts, particularly in Africa, the permanency of adoption is not fully understood by biological families, who may relinquish the care of their child in the belief that adoption is temporary. It may be incorrectly understood as a way of gaining access to quality education or better security for a child, on the assumption that the child will later be reunified with the

⁹⁴ Ekisa, “Finding value”.

⁹⁵ Martin Punaks, “Children with Albinism and Care”.

⁹⁶ Interviews with informants.

⁹⁷ Better Care Network, Glossary of Key Terms, available at <https://bettercarenetwork.org/glossary-of-key-terms>.

biological family. Domestic adoption should always be prioritized over intercountry adoption, as it allows a child to remain in their country and culture of origin.⁹⁸ In lower-income countries, domestic adoption systems are often not well-established, or if they are, the numbers of adoptions are small, and even smaller still for children with disabilities.⁹⁹ However, where a domestic adoption system is operating effectively and a permanent care solution is needed for a child without parental care, then it offers an effective solution. Nevertheless, the assessment of the adoptive family should ensure that the family has the means to provide the child with access to inclusive education and health care and can protect them from discrimination and violence.

D. Safe houses

52. The use of safe houses is a model that could be used to protect the families of children with albinism during periods of particularly high risk of violent attacks. The Albinism Foundation of Zambia currently uses that approach for the victims of ritual attacks.¹⁰⁰ It rents a secure and inconspicuous house in an area away from where the attack took place and moves the child, along with its mother, and potentially other relatives too, to the house where they can recover and receive psycho-social support. A housekeeper may also stay in the house to support the family's material needs as well as to facilitate occasional excursions outside in the local community or arrange for facilitated visits by other relatives. The family usually remains in the "safe house" for a few months until they feel confident returning to their own community. That approach preserves family unity and has the potential to be adapted for protection from attacks as well as response. The approach may, however, disrupt the child's education, and potentially the family's livelihood.

E. Care reform

53. Care reform can be understood as: "The process of transforming the system of care from one orientation to another, in pursuit of an approach to care and protection that better meets the needs of children and their families and is in accordance with their rights. A common goal of system reforms in many countries is the reorientation of the system from institutions to family-based care."¹⁰¹

54. The Guidelines for the Alternative Care of Children call for the "progressive elimination" of institutions. The Third Committee report urges States to "improve care reform efforts", which should include increased multisectoral collaboration and coordination between authorities including "progressively replacing institutionalization with quality alternative care". In addition, the Committee on the Rights of Persons with Disabilities calls for States to "adopt a high-quality and structured plan for deinstitutionalization (care reform), which must be comprehensive and contain a detailed action plan with timelines". In developing care reform strategies, States should closely consult with persons with albinism, including children and their representative organizations, as required under the Convention on the Rights of Persons with Disabilities, article 4(34).

55. Care reform serves to prioritize and build the services that support the prevention of family separation and, where prevention is not possible, ensure that there are safe and temporary family-based alternative care options available. Care reform serves to manage the transition to the new care system, including the

⁹⁸ See General Assembly resolution 44/25.

⁹⁹ *Child Adoption: Trends and Policies* (United Nations publication, 2009).

¹⁰⁰ Interviews.

¹⁰¹ See <https://bettercarenetwork.org/practitioner-library/care-reform>.

reintegration of children from institutions back to their families or other family-based care placements, as well as support for older care leavers. Over recent decades the global momentum towards care reform has grown.¹⁰² States such as Armenia, Bulgaria, Latvia, Lithuania, Moldova, Romania, Slovakia,¹⁰³ Guatemala, Mexico, Nicaragua,¹⁰⁴ Cambodia,¹⁰⁵ Indonesia,¹⁰⁶ Ghana, Kenya, Liberia, Rwanda and Uganda¹⁰⁷ have issued government laws, policies, directives and strategies prioritizing care reform, and have made progress in implementing them.

56. Care reform includes: an overarching strategy guided by evidence to bring about systems change; a strong legislative and policy framework that supports reform; effective coordination mechanisms to facilitate the roles of a wide range of stakeholders; the strengthening of the social service workforce; gatekeeping mechanisms to ensure appropriate placements of children in the care system; awareness-raising regarding care reform and the importance of family-based care; the engagement of communities in the process of reform; the meaningful participation of children in care and their families; redirecting the resources from institutional care to a family-based care system; establishing accountability and monitoring mechanisms to measure progress; and the use of care reform to leverage wider change in the child protection system, especially for children with disabilities.¹⁰⁸

57. Care reform strategies should always be evidence-based and inclusive of the specific needs of children with albinism. States therefore need to collect disaggregated data on the situation of children with albinism in their countries. Kenya, Tanzania, Namibia and Malawi already include questions on albinism in their national censuses,¹⁰⁹ Uzbekistan collects disaggregated data on children with albinism,¹¹⁰ and United Nations organizations have carried out specific studies on persons with albinism in Madagascar, Mozambique and Uganda.¹¹¹ Those efforts should be expanded to more countries to better understand the needs of children with albinism and their families.

VI. Other care practices

58. The research identified several other care practices that present ethical challenges in terms of their implementation or ability to ensure the right to a family life of children with albinism. Those care practices deserve a more nuanced discussion.

¹⁰² Philip S. Goldman and others, “Institutionalization and deinstitutionalisation of children 2: policy and practice recommendations for global, national, and local actors”, *The Lancet: Child and Adolescent Health*, vol. 4, No. 8 (August 2020).

¹⁰³ UNICEF, Regional Office for Europe and Central Asia, *TransMonEE Analytical Series*.

¹⁰⁴ Hope and Homes for Children, *Beyond Institutional Care: A Roadmap for Child Protection and Care System Reform for Governments in Latin America and the Caribbean* (2020).

¹⁰⁵ Pamela Michel Lizarazu, “The deinstitutionalization of children in Cambodia: intended and unintended consequences”, Masters dissertation, Graduate Institute of Geneva, 2018.

¹⁰⁶ Ni Luh Putu Maitra Agastya and others, “Transformation of child welfare institutions in Bandung, West Java: a case of deinstitutionalization in Indonesia”, *Children and Youth Services Review*, vol. 159 (2024).

¹⁰⁷ Better Care Network and UNICEF, “An analysis of child-care reform in three African countries: summary of key findings”, March 2015; Republic of Kenya and others, *National Care Reform Strategy for Children in Kenya 2022–2032* (2022); and Republic of Rwanda and others, “Evaluation of the Tubarerere Mu Muryango”.

¹⁰⁸ UNICEF, Eastern and Southern African Regional Office, “Caring systems: maximizing synergies between care reform and child protection system strengthening in Eastern and Southern Africa”, August 2021.

¹⁰⁹ Ero, *Best Practices in the Protection of Human Rights*.

¹¹⁰ Response from Uzbekistan.

¹¹¹ Ibid.

A. Intercountry adoption

59. Intercountry adoption involves adoptee parents who live in a country different to that of the child. Interviewees have reported cases of children with albinism being adopted from countries such as Sierra Leone, Lesotho, Malawi and China to families in Europe or North America.¹¹² There are also websites that promote intercountry adoption of children with albinism.¹¹³ The Convention on Protection of Children and Cooperation in respect of Intercountry Adoption outlines the standards and regulations that should be followed in the process of intercountry adoption, including the preference for domestic adoption.¹¹⁴ According to article 21 of the Convention on the Rights of the Child, intercountry adoption should only be considered after all other local family-care options have been exhausted, and domestic adoption should always be prioritized over intercountry adoption.¹¹⁵ Concerns have been raised in several countries around intercountry adoption being prioritized over domestic adoption.¹¹⁶ Worse still, allegations of children being “stolen” or “trafficked” from their biological families for the purpose of exploitation through intercountry adoption have resulted in several States issuing moratoriums against intercountry adoption.¹¹⁷ The campaigning organization Intercountry Adoptee Voices – run by intercountry adoptees – raises concerns around “identity loss, trafficking, rehoming, deportation/citizenship and abuse” and advocates for a “world in the future where intercountry adoption is rarely necessary”.¹¹⁸ States are therefore obliged to ensure that any intercountry adoptions involving children with albinism happen in accordance with the Convention on Protection of Children and Cooperation in respect of Intercountry Adoption and all other child rights policy frameworks.

B. Emergency shelters

60. As shown earlier, one of the pervading challenges for children with albinism in family settings – including parental care, kinship care and foster care – is that the risk of being attacked in some countries is always present. This is particularly the case during periods when the demand for body parts of persons with albinism is higher than usual, such as election times.¹¹⁹ During these periods there may be a need for temporary secure shelters to protect children with albinism. The challenge, however, is ensuring that such shelters are not institutional, and that family connections are preserved and maintained, as even short-term separation from the family is harmful. If there are no safe family-based options available to protect children with albinism during high-risk periods, there is room to explore the possibility of temporary placement in small-scale residential emergency shelters that offer individualized care and protection for children with or without disabilities. However, safeguards must be put in place prior to the move. States must ensure that the decision to place a child in such an arrangement is done on a case-

¹¹² Martin Punaks, “Children with Albinism and Care”.

¹¹³ See for example, C. Gail Summers and Bridget Kathleen Berigan, “Consider adopting a child with albinism”, Rainbow Kids, 15 April 2015.

¹¹⁴ See www.hcch.net/en/instruments/conventions/full-text/?cid=69.

¹¹⁵ General Assembly resolution 44/25.

¹¹⁶ Kenya, Ministry of Labour and Social Protection, press statement from the Cabinet Secretary on State reforms on child welfare, adoption and protection, 16 May 2019; Joseph Aguetant, *Adopting the rights of the child: A study on intercountry adoption and its influence on child protection in Nepal* (Lausanne, Switzerland, Terre des hommes Foundation and UNICEF, 2008); and Kyung-eun Lee, “South Korea’s legacy of orphan adoption and the violation of adoptees’ rights to know their origins”, *Childhood*, vol. 29, No. 2 (2022).

¹¹⁷ Joseph Aguetant, *Adopting the rights of the child*.

¹¹⁸ See <https://intercountryadopteevoices.com/about/vision-mission/>.

¹¹⁹ See A/71/255.

by-case basis with consideration of the best interests of the child and full consent of the child's parents or guardians. An exit strategy should be put in place, based on what would be needed to prepare for the full reintegration of the child into their family and community. Learning from the lessons of Tanzania, such an exit strategy should ensure adequate registration of the child and their family, with measures in place to ensure continued communication between the child and their family and outreach to the community to facilitate their support and acceptance, including through regular visits by the family and of the child to the community. All efforts should be made to return children to family-based care at the earliest safe opportunity. Such places must have appropriate funding and be regulated by the State as an alternative care to ensure that the rights of children with albinism are fully upheld for the duration of their stay. That includes the right to education, health, and dignity. Furthermore, States should make it a priority to address both the causes of the threats to children's lives, the increased availability of secure family-based placements in such circumstances (such as emergency foster care) and the implementation of community-based security mechanisms to prevent the need for children with albinism to require emergency shelters during periods of violence.

61. In some countries, inclusive boarding schools are being used as a form of emergency shelter for children with albinism at risk of violence. "Inclusive education" emphasizes "equity in access and participation ... respond[ing] positively to the individual learning needs and competencies of all children ... [and placing] the responsibility of adaptation on the education system rather than the individual child";¹²⁰ it allows "all children in the same classrooms, in the same schools".¹²¹ That is in contrast to "specialist education", which provides segregated education to groups of students based on that group's specific needs, for example, schools for the visually impaired.

62. Whether or not boarding schools should be considered a form of alternative care or institutional care is debated. UNICEF in Europe and Central Asia¹²² notes that boarding schools serve both an educational and care function and therefore recommends that they are regulated as a form of alternative care. It also argues that many boarding schools – particularly specialist boarding schools for children with disabilities – are segregated spaces that expose children to the dangers of institutionalization. Others argue that whether or not boarding schools are considered alternative care is influenced by: (a) the "degrees of contact with homes and communities"; and (b) whether children live there because "they lack parental care, or because they have parents willing and able to care for them but lack access to basic services close to home," which, if that is the case, would indicate that the facilities are serving the purpose of alternative care.¹²³ The Committee on the Rights of Persons with Disabilities specifically identifies "special boarding schools" as a form of institutionalization.¹²⁴

63. Albinism organizations that use a case management approach to support the families of children with albinism in countries such as Malawi (Standing Voice) and Tanzania (the Under the Same Sun (UTSS) Education Programme of the Village of Hope) have found that, in some situations, social work assessments show there is no safe family-based placement for a child with albinism due to the very high risk of being

¹²⁰ Save the Children, *Inclusive Education: What, Why, and How – A Handbook for Programme Implementers* (London, 2016).

¹²¹ See www.unicef.org/education/inclusive-education.

¹²² UNICEF, Regional Office for Europe and Central Asia, *The Role of Boarding Schools for Vulnerable Children in the Europe and Central Asia Region* (2024).

¹²³ Emily Delap and others, "Scaling down: reducing, reshaping and improving residential care around the world", *Positive Care Choices: Working Paper, No. 1* (Every Child, 2011).

¹²⁴ See [CRPD/C/5](#).

attacked.¹²⁵ In those situations – and also directly through the initiative of parents – children with albinism are often placed in secure inclusive boarding schools. In those settings they can have access to inclusive education, health care and, importantly, protection from attacks. Caseworkers support the children and families to maintain regular contact through visits by the parents to the school, and visits home by the children (albeit often with pre-arranged temporary police protection). In Tanzania, the Under The Same Sun Education Programme labels that approach “deinstitutionalization” as many of the children have been removed from harmful institutional “temporary holding shelters” where they were segregated and had no family contact.

64. While specialist boarding schools clearly fall into the category of institutional care, the evidence for inclusive boarding schools with facilitated family visits being classed officially as a form of institutional and alternative care is dependent on circumstances. Inclusive boarding schools that facilitate family visits may avoid some of the institutional characteristics of Tanzania’s “temporary holding shelters”. However, when we consider that the parents of children with albinism are effectively coerced into sending their children there for their care and protection, as well as the large-scale residential nature of such schools, then their alternative care function and institutional characteristics do become apparent. In countries such as Malawi and Tanzania, parents and practitioners are being forced to make a very difficult decision between risking children’s lives in the community or protecting their children’s lives in those “least bad option” settings. The view of the Expert is that inclusive boarding schools with facilitated family visits may mitigate some (though not all) of the institutional characteristics of Tanzania’s “temporary holding shelters” but should never be seen as good practice. They are merely an interim emergency shelter measure until States fulfil their legal obligation to reform their care systems to provide safe family-based care for all children with albinism. As inclusive boarding schools are settings which are de facto alternative care, States should regulate them as such to ensure that children with albinism are safeguarded and are receiving the best quality care possible in such a setting.

65. The Expert is concerned that parents and practitioners are currently being placed in a difficult situation where they may face no choice but to use emergency shelter facilities, such as inclusive boarding schools, to protect a child’s life. While those measures may be compliant with standards of the Committee on the Rights of the Child – if they meet very specific requirements as outlined above – they are not compliant with the standards of the Committee on the Rights of Persons with Disabilities, and therefore States need to remedy that as a priority. As part of implementing care reform strategies, States must not invest in new forms of institutional care but must use the resources to develop family-based alternatives.

VII. Conclusions and recommendations

A. Conclusions

66. Children with albinism and their families, particularly in African contexts, face a compounded set of challenges. In many cases families have to deny their children’s right to a family life so that they can enjoy other rights such as their right to life, protection from discrimination, protection from violence, quality education and health care. Children and families should not have to make those compromises. States have a responsibility to ensure that children with albinism can enjoy all their rights.

¹²⁵ Martin Punaks, “Children with Albinism and Care”.

67. The root causes that drive the separation of children with albinism from their families can only be resolved through long-term systemic change at a societal level. That systemic change must be led by States. States should implement measures to change the social norms and behaviours that cause discrimination and ritual attacks against children with albinism through a combination of legislative and policy reform, awareness-raising and sensitization. States should reform education, health care, social protection, justice, security and other services that prevent separation by ensuring that they are operating effectively and are fully accessible to children with albinism. To that effect, States should incorporate into their domestic legislation the African Union Plan of Action on ending attacks against persons with albinism.

68. States should further reform child protection and care systems to ensure that families receive the support they need to prevent separation and, where separation is unavoidable, that there are safe family-based alternative care options available to temporarily care for children with albinism until they can be returned to their families. To achieve that, States need political commitment from their leaders, a sufficient allocation of resources to implement reform strategies, and disaggregated data on children with albinism and their families to develop evidence-based plans for reform.

69. Systemic change to resolve the root causes of family separation in cases of violence against children with albinism will take time. In the meantime, in situations where the right to a family life is being compromised, States may need to identify and implement pragmatic interim measures that ensure children with albinism are able to access all their rights, including their right to a family life, as best as realistically possible. Any pragmatic measures that compromise on allowing for children with albinism to access all their rights, including the right to family life, need to be proportionate, legitimate, temporary and for the shortest time possible, and to be permitted only on the basis that there are realistic evidence-based and fully resourced plans in place to eliminate the need for such measures at the earliest opportunity. In developing such measures, States should listen to and respond to the views of children with albinism, their families and their advocates in the form of organizations of persons with albinism.

B. Recommendations

70. Regarding services which prevent family separation, the Independent Expert recommends that States:

(a) Ensure that the right to a family life for all children, including children with albinism, is recognized in national legislation and policy;

(b) Ensure that all efforts to prevent the separation of children with albinism from their families are a priority over alternative care, and when separation is unavoidable, all efforts are made to rectify the causes of the separation and to reunify the child with their family at the earliest safe opportunity;

(c) Ensure that children with albinism have access to community-based inclusive education;

(d) Ensure that children with albinism can access affordable health services and products, including dermatological and ophthalmological services, skin cancer screening and treatment, as well as sunscreen;

(e) Ensure that the families of children with albinism who are economically disadvantaged can access social protection schemes, including cash transfers and employment, livelihood and health schemes;

(f) Ensure that the parents or caregivers of children with albinism can access day-care services to provide them with respite and an opportunity to earn a livelihood;

(g) Strengthen criminal justice systems to ensure swift prosecution of perpetrators of crimes against persons with albinism;

(h) Strengthen security services to prevent children with albinism being ritually attacked and murdered;

(i) Increase awareness and understanding of the scientific basis for albinism, and albinism from a human rights perspective, to change attitudes and behaviour towards persons with albinism;

(j) Strengthen the social service workforce and social work case management practices to better understand and support the needs of all children with albinism and their families;

(k) Support the work of organizations of persons with albinism that support children with albinism and their families, including the support of peer-to-peer learning.

71. With regard to alternative care, the Independent Expert recommends that States:

(a) Ensure that legal and policy provisions support kinship care, and that those practices are sufficiently supported, monitored and safeguarded by the social service workforce, where necessary;

(b) Ensure that there is a strong legal and policy framework to support foster care and ensure formal foster care programmes are developed to offer a range of foster care services to meet the needs of children with albinism and their families.

72. With regard to adoption, the Independent Expert recommends that States:

(a) Ensure that adoption is only used where measures to keep children with parents or extended family members or in foster care are unsuccessful;

(b) Ensure that there is a strong legal and policy framework to support domestic adoption;

(c) Ensure that domestic adoption is always prioritized over intercountry adoption;

(d) Ensure that legal and policy frameworks for intercountry adoption services and agencies are fully compliant with the Convention on Protection of Children and Cooperation in respect of Intercountry Adoption.

73. With regard to safe houses, the Independent Expert recommends that States ensure that they preserve family unity while protecting a child's life and that they are only used as a temporary measure. All efforts should be made to mitigate disruption to a child's education or their families' right to earn a livelihood.

74. With regard to care reform, the Independent Expert recommends that States:

(a) Design and implement care reform strategies to reform the care system for children, ensuring that children with albinism can always enjoy their right to a family life;

(b) Ensure that disaggregated data about children with albinism is collected, recorded and utilized to ensure care reform strategies are evidence-based;

(c) Ensure that care reform is informed by the involvement and views of people with albinism, including children and those with experience of alternative care;

(d) Ensure that care reform is fully resourced.

75. In the interim period, while States are actively advancing strategies to fulfil their legal obligations to implement the above reforms, in exceptional circumstances where a child with albinism's right to life and protection from violence cannot be guaranteed alongside their right to a family life, and on a case-by-case basis, taking into account the best interests of the child and ensuring full consent of the child's parents or guardians, then States may temporarily protect children with albinism in emergency shelters in: (a) small-scale residential emergency shelters that offer individualized care and protection for children with or without disabilities; or (b) inclusive boarding schools with facilitated family visits. Such placements must preserve family connections, be regulated as a form of alternative care and be fully funded to ensure that the rights of children with albinism are fully respected, protected and upheld for the duration of their stay. All efforts should be made to return the child to family-based care at the earliest safe opportunity. Furthermore, States should make it a priority to address both the causes of the threats to children's lives, to increase the availability of secure family-based placements in such circumstances (such as emergency foster care) and the implementation of community-based security mechanisms to prevent the need for emergency shelters for children with albinism during periods of violence. In implementing that strategy, States should consider that no new institutions should be created or funded, as well as their obligations to ensure movement towards rapid compliance with the requirements in that regard of the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities.

76. In implementing all the above recommendations, the Independent Expert recommends that all States collect disaggregated data and conduct further research about the situation and needs of children with albinism within their countries, so that it can be used to inform more targeted and better-quality legislation, policies and services which ensure the rights of children with albinism.