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تعزيز وحماية جميع حقوق الإنسان، المدنية والسياسية والاقتصادية والاجتماعية والثقافية، بما في ذلك الحق في التنمية

زيارة إلى كينيا**

تقرير الخبرة المستقلة المعنية بمسألة التمتع بحقوق الإنسان في حالة الأشخاص
المصابين بالمهق

موجز

يتعلق هذا التقرير بزيارة الخبرة المستقلة المعنية بمسألة التمتع بحقوق الإنسان في حالة الأشخاص المصابين بالمهق إلى كينيا من ٧ إلى ١٧ أيلول/سبتمبر ٢٠١٨. ويشيد التقرير بمختلف الممارسات النموذجية التي تنفذها حكومة كينيا بخصوص الأشخاص المصابين بالمهق. ويركز التقرير أيضاً على التحديات والانتهاكات المرتبطة بحقوق الإنسان التي يواجهها هؤلاء الأشخاص، بما فيها الاعتداءات والتمييز والحواجز التي تحول دون تمتعهم بالحق في الصحة والتعليم والمشاركة في المجتمع. وتحدد الخبرة المستقلة التحديات التي لا تزال قائمة، بما فيها الحاجة إلى جملة من الأمور، منها جمع بيانات دقيقة عن الأشخاص المصابين بالمهق كي يتسنى فهم أوضاعهم فهماً أفضل، وتنفيذ تدابير مناسبة وفعالة على سبيل الأولوية ضمن الإطار التوجيهي للالتزام الأساسي بأهداف التنمية المستدامة: "عدم ترك أي أحد خلف الركب"، وتقدم توصيات في هذا الصدد.

* أُنقِ على نشر هذا التقرير بعد تاريخ النشر الاعتيادي لظروف خارجة عن إرادة الجهة المقدمة له.

** يعمم موجز التقرير بجميع اللغات الرسمية. أما التقرير نفسه، الوارد في مرفق هذا الموجز، فيُعَمَّم باللغة التي قُدِّم بها فقط.



الرجاء إعادة الاستعمال

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Annex

Report of the Independent Expert on the enjoyment of human rights by persons with albinism on her visit to Kenya

Contents

	<i>Page</i>
I. Introduction	3
II. Background	3
A. General overview	3
B. Persons with albinism	4
III. Legislative and institutional framework	5
A. Legal framework	5
B. Institutional framework	7
IV. Exemplary developments	9
V. Main challenges	10
A. Attacks	10
B. Stigmatization and discrimination	12
C. Health	12
D. Education	14
E. Access to justice	15
F. Employment	16
G. Availability of data	16
VI. Conclusions and recommendations	17
A. Recommendations to the Government of Kenya	17
B. International community and cooperation	21

I. Introduction

1. In accordance with Human Rights Council resolutions 28/6 and 37/5, and at the invitation of the Government of Kenya, the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, conducted an official visit to the country from 7 to 17 September 2018. The objective of the visit was to assess the human rights situation of persons with albinism, to identify existing best practices and challenges, and to provide relevant recommendations to the Government and other stakeholders.
2. During the visit, the Independent Expert held meetings in Eldoret, Embu, Kisumu, Migori, Nairobi and Thika. She met with representatives from the Ministry of Foreign Affairs and International Trade, the Ministry of Labour and Social Protection, the Ministry of Health, the Attorney-General and Prosecutor's Office, the Kenya National Bureau of Statistics, the National Council for Persons with Disabilities, the Kenya National Commission on Human Rights, the National Gender and Equality Commission and the Commission on Administrative Justice. She was pleased to have had the opportunity to meet with the Chief Justice and other members of the judiciary, as well as members of the Senate, the National Assembly and county assemblies.
3. The Independent Expert benefited greatly from meetings held with civil society organizations, including those working directly with persons with albinism. She was particularly grateful to have personally met with various persons with albinism, including victims of attacks and their families. The Independent Expert also met the United Nations country team and development partners. She extends her sincere appreciation to all interlocutors for the opportunity to dialogue and exchange information on her mandate's focus.
4. The Independent Expert would like to express her appreciation to the Government of Kenya for the invitation, and for its openness and excellent cooperation in ensuring that the visit was a fruitful one. She particularly thanks the government focal points who assisted in organizing her official meetings. Furthermore, she expresses her gratitude to the Office of the High Commissioner for Human Rights in Kenya for its valuable support in the preparation and conduct of the visit.

II. Background

A. General overview

5. Kenya is located in East Africa and directly borders Ethiopia, Somalia, South Sudan, Uganda and the United Republic of Tanzania. The Government is led by an elected President and the executive is made up of 18 Cabinet ministers, the Attorney-General and the Director of Public Prosecutions. The legislature is a bicameral parliament comprising around 337 Members and 67 Senators. The judiciary is made up of the Supreme Court, the High Court and various subordinate courts. The country is divided into 47 administrative counties of around 47 million people, with Nairobi as its capital and largest city. An estimated 26.4 per cent of the population live in urban areas. Estimates show that around 83 per cent of Kenyans are Christians, 11.2 per cent are Muslims and 1.7 per cent identify as traditionalists.
6. Kenya became independent from the United Kingdom of Great Britain and Northern Ireland in 1963. Over the years, its constitutional, political, social, cultural and economic environments have experienced dramatic changes. Most notable is the political crisis in 2007, which arose from disputed presidential elections, and led to unprecedented political violence that lasted until March 2008. The presidential elections of 2017 were also marred by violence resulting in several deaths.
7. Kenya has made significant political, structural and economic reforms that have driven economic growth, social development and political gains over the past decade. Its

key development challenges still include poverty, inequality, climate change and the vulnerability of the economy to internal and external impacts.

8. Kenya was ranked 142 out of 189 countries in 2018 in the United Nations Development Programme's Human Development Index. The country faces many challenges, including social and economic inequalities. Access to basic, quality services, such as health care, education, clean water and sanitation remains difficult for many people. Kenya is mainly an agricultural country, which produces tea, coffee, maize, horticultural products and sugar cane. Other economic activities revolve around tourism, transportation and communication, as well as, to a limited extent, mining.

9. Currently, the Government is trying to foster economic development through a long-term plan known as Vision 2030, which, inter alia, prioritizes manufacturing, universal health care, affordable housing and food security. The Government has also focused on decentralizing services and resources to subnational levels to address disparities among regions. With its growing youthful population, a dynamic private sector, its highly skilled workforce, its improved infrastructure, advances in information and communications technology, and its pivotal role in East Africa, Kenya has great potential to be among Africa's rapidly developing countries.

B. Persons with albinism

10. Albinism is a relatively rare, non-contagious, genetically inherited condition that affects people worldwide regardless of ethnicity or gender. It results from a significant deficit in the production of melanin and is characterized by the partial or complete absence of pigment in any or all of the skin, hair or eyes. Persons with albinism often appear pale in comparison to members of their family and their community. In order for a person to be affected by albinism, both parents must carry the gene and, in that case, there is a 25 per cent chance that a child will be born with albinism at each pregnancy. The frequency of albinism varies by region. In Europe and North America, the frequency reported is 1 in 17,000 to 1 in 20,000. The frequency in certain parts of the Pacific region is reported to be 1 in 700. Among some indigenous groups in South America, the reported frequency is 1 in 70 to 1 in 125. In sub-Saharan Africa, the reported frequency ranges from 1 in 5,000 to 1 in 15,000 with prevalence rates of 1 in 1,000 for selected populations in southern Africa.

11. There are different types of albinism. The most common and visible type is oculocutaneous albinism, which affects the skin, hair and eyes. Within this type, subtypes reflect varying degrees of melanin deficiency in an individual. Almost all human rights issues relating to albinism reported to date have been linked to the oculocutaneous form of albinism. A key physiological consequence of albinism includes vision impairment, in nearly all cases. The severity of impairment varies from person to person. The other key physiological consequence is vulnerability to skin cancer, which is fatal when left untreated. Skin cancer accounts for a significant number of deaths of persons with albinism, particularly in sunny climates such as in the African region. Persons with albinism are commonly recognized as persons with disabilities. They have also been recognized as persons facing racial discrimination on the ground of colour.¹

12. In the past decade, 28 countries in sub-Saharan Africa, including Kenya, have reported cases of attacks against persons with albinism. These attacks, increasingly viewed as hate crimes,² target persons with albinism for the use of their body parts in rituals associated with harmful practices related to certain manifestations of witchcraft beliefs. Women and girls with albinism are also targeted for ritual rape, due to the belief that this would cure HIV/AIDS.

13. Persons with albinism often face discrimination in access to health care and quality education, and encounter economic barriers as well as threats to their safety and security.

¹ CERD/C/ZAF/CO/4-8, paras. 20–21.

² See, for example, A/HRC/37/57/Add.2, para. 28.

They often experience mental and psychosocial distress related to the stigmatization of their condition.³

14. In Kenya, there are currently no verifiable data on the number of persons with albinism, although the Government, through the National Council for Persons with Disabilities, has registered around 3,500 persons and estimates that the true number could be 5,000 or higher. Although concrete data on albinism in Kenya is lacking, there are opportunities for increased awareness, advocacy and changes to policy, and efforts to significantly improve the human rights situation of persons with albinism in the country.

III. Legislative and institutional framework

A. Legal framework

15. Under international human rights law, persons with albinism have legal protection covering all their fundamental human rights, including the right to life, physical integrity, liberty and security, the right to the highest attainable standard of physical and mental health and the right to an adequate standard of living. The Constitution of Kenya recognizes international law by stipulating that any ratified treaty or convention forms part of the country's law.

16. Kenya has ratified seven of the nine international human rights treaties, namely the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of Persons with Disabilities, the Convention on the Rights of the Child, the International Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination against Women and the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. Kenya has yet to ratify the Optional Protocol to the Convention on the Rights of Persons with Disabilities.

Regional framework and cooperation

17. Kenya has ratified the African Charter on Human and Peoples' Rights, the African Charter on the Rights and Welfare of the Child, the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, the African Union Convention Governing Specific Aspects of Refugee Problems in Africa and the African Union Convention on Preventing and Combating Corruption. Kenya has yet to ratify the African Commission on Human and Peoples' Rights draft protocol on the rights of persons with disabilities.

18. In 2017, the African Commission on Human and Peoples' Rights adopted a resolution on the Regional Action Plan on Albinism in Africa (2017–2021). The Plan lays out specific measures to address attacks and discrimination against persons with albinism and members of their families. As part of a number of regional initiatives, two meetings were held in Kenya, in November 2016 and February 2018, to develop targets under the Plan.⁴

19. The East African Legislative Assembly, of which Kenya is a member, is reportedly in the process of adopting a law to protect persons with albinism, in the wake of increased attacks and killings in the region. This is an important initiative to combat impunity, and for promoting regional cooperation on the cross-border elements of these crimes. Such a law should consider incorporating specific measures identified in the Regional Action Plan as well as those identified in the cross-border cooperation plan between Malawi, Mozambique and the United Republic of Tanzania.

³ A/HRC/37/57, chap. III.

⁴ See www.ohchr.org/EN/Issues/Albinism/Pages/AlbinismInAfrica.aspx.

National legal framework

(i) *Constitution*

20. The Constitution of Kenya 2010 provides a strong framework for the protection of human rights in the country. Chapter 4 encompasses an expansive Bill of Rights, which includes protection of the right to life, as well as of economic, social and cultural rights. These include the right to the highest attainable standard of health, the right to accessible and adequate housing, and the right to emergency medical treatment and to social security for those who are unable to support themselves and their dependants. Article 27 further provides that “the State shall not discriminate directly or indirectly against any person on any ground, including race, sex, pregnancy, marital status, health status, ethnic or social origin, colour, age, disability, religion, conscience, belief, culture, dress, language or birth”.

21. Article 54 protects the rights of persons with disabilities and states that such persons are entitled to be treated with dignity and respect, and in a manner that is not demeaning. Access to educational institutions and facilities for persons with disabilities, reasonable access to all places, public transport and information, and access to materials and devices to overcome constraints arising from a person’s impairment, are also safeguarded. Further, affirmative action is provided in that at least 5 per cent of members of elected and appointed bodies should be persons with disabilities. This has seen Parliament nominating persons with disability, including persons with albinism, to both the National Assembly and the Senate in order to fulfil this constitutional requirement.

22. Article 56 of the Constitution, on minorities and marginalized groups, requires that affirmative action programmes be designed to ensure that minorities or marginalized groups participate and are represented in governance and other spheres of life.

(ii) *Persons with Disabilities Act, of 2003*

23. The Persons with Disabilities Act, of 2003, came into effect in June 2004, before Kenya ratified the Convention on the Rights of Persons with Disabilities. The Act provides for the rights and rehabilitation of persons with disabilities, for equal opportunities and for the establishment of the National Council for Persons with Disabilities. The Act does not expressly mention persons with albinism. It did, however, create a fund known as the National Development Fund for Persons with Disabilities, which has been used to support the provision of sunscreen and other protective material for persons with albinism.

(iii) *Persons with Disabilities Amendment Bill (2018)*

24. The Persons with Disabilities Amendment Bill was drafted to ensure that the provisions of the Persons with Disabilities Act were harmonized with international instruments, in particular with the Convention on the Rights of Persons with Disabilities, and with the Constitution. The bill is progressive, in that it expressly mentions persons with albinism. It has been approved by Cabinet and is to be tabled. It is crucial that the bill recognize harmful practices against persons with albinism, in line with the Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Persons with Disabilities.

(iv) *Penal Code*

25. The provisions of the Penal Code⁵ address the crimes of murder, attempted murder, threats to kill, assault and grievous harm. They also cover conspiracy to murder and abduction with intent to murder or cause grievous harm. These are relevant provisions in relation to attacks on and killings of persons with albinism. However, the Independent Expert was not informed of any recent convictions under the Penal Code in relation to persons with albinism.

⁵ Penal Code (revised in 2012), chap. 63.

(v) *Witchcraft Act (Act No. 23 of 1925)*

26. The Witchcraft Act criminalizes acts of witchcraft, although it does not define the concept of “witchcraft”. Section 3 provides that any person professing a knowledge of so-called witchcraft or the use of charms, who advises any person applying to him how to bewitch or injure persons, animals or other property, or who supplies any article purporting to be a means of witchcraft, shall be guilty of an offence and liable to imprisonment not exceeding 10 years. Harmful practices related to the manifestation of witchcraft beliefs, which are linked to the brutal attacks and killings of persons with albinism, can be covered by this law. The Act is currently under review.

(vi) *Law on trafficking in persons*

27. The Counter-Trafficking in Persons Act⁶ criminalizes human trafficking and imposes a penalty of imprisonment of not less than 30 years or a fine of not less than K Sh 30 million or both and upon subsequent conviction, imprisonment for life.⁷ The Act provides that “exploitation” includes, but is not limited to, the “forcible or fraudulent use of any human being for removal of organs or body parts”. Hence, recruiting, harbouring, transporting or transferring another person for the purpose of the forcibly or fraudulently removing their organs or body parts may amount to trafficking. The Act also criminalizes the aiding and abetting, controlling and financing of human trafficking. However, it is not clear if the Act only covers the trafficking of persons for the purpose of removing their body parts, or whether it extends to situations whereby body parts are taken from a person who is not trafficked and are trafficked apart from the person.

(vii) *Other legislation*

28. Additional important legislation that has an impact on the rights of persons with albinism includes the Employment Act, 2007, which explicitly prohibits an employer from discriminating directly or indirectly against an employee or prospective employee, or harassing an employee or prospective employee on the ground of disability.

29. The Basic Education Act, 2013 specifically requires the Government to ensure that children belonging to marginalized, vulnerable or disadvantaged groups are not discriminated against and prevented from pursuing and completing their basic education. Furthermore, the Children’s Act provides safeguards for the rights and welfare of all children in Kenya and explicitly prohibits discrimination against a child on the ground of disability.

B. Institutional framework

National Council for Persons with Disabilities

30. The National Council for Persons with Disabilities was established by the Persons with Disabilities Act (Act No. 14 of 2003). Due to the disabilities often linked to albinism, the issues faced by persons with albinism fall under the purview of the Council. The Council has representation in all 47 counties in Kenya and provides protective clothing, glasses and sunscreen lotion for persons with albinism in these localities.

31. The National Council for Persons with Disabilities is a multi-actor initiative inclusive of government and non-government entities. It is mandated to, inter alia, coordinate and liaise with the relevant government departments or agencies on disability matters and coordinate during national censuses to ensure that it receives an accurate count of the population of persons with disabilities. It also liaises with the Government for the provision of suitable and affordable housing for persons with disabilities and for other services.

⁶ Act No. 8 of 2010 (Rev. 2012).

⁷ See part II, sect. 3 (5).

32. In 2011, the National Council for Persons with Disabilities employed one person with albinism. The Council registers persons with albinism, and has a fund earmarked for them that is dispensed through its Albinism Programme.⁸ The fund helps provide assistive devices and services that improve the lives of persons with albinism.

33. The National Council for Persons with Disabilities also has a Disability Mainstreaming Department, which promotes, within government institutions, universal principles including reasonable accommodation and social inclusion for persons with disabilities. It also has a Legal Department that provides specific legal services to persons with disabilities, government and other stakeholders, to ensure compliance with the requirements of the Council as well as standards in the Convention on the Rights of Persons with Disabilities.

National Cohesion and Integration Commission⁹

34. The National Cohesion and Integration Act provided for the establishment of the National Cohesion and Integration Commission. The Act outlaws discrimination on the grounds of ethnicity, race, colour, religion, nationality or origin, in both the private and public spheres of national life. Reportedly, human rights activists have petitioned the National Cohesion and Integration Commission to investigate a former councillor for allegedly making hate speech remarks against persons living with albinism in Kwale County.

National Special Needs Education Policy

35. The National Special Needs Education Policy 2009 was developed to address critical issues related to education for learners with special needs, while creating a conducive environment and providing equal access to quality and relevant education and training. In accordance with the policy, special needs education has continued to expand, and currently includes children with albinism. The policy aims to provide free education for all children with disabilities in an inclusive setting and to create an enabling environment so that their diverse learning needs do not hinder them from receiving the appropriate education. The policy addresses critical issues, which determine access to and delivery of quality and relevant education to learners with special needs.

“Article 59” institutions

(i) Kenya National Commission on Human Rights

36. The Kenya National Commission on Human Rights was established in accordance with article 59 of the Constitution of 2010. It is the State’s lead agency in the promotion and protection of human rights. In 2015, the Commission was designated as the national monitoring agency in accordance with article 33 (2) of the Convention on the Rights of Persons with Disabilities. This role obliges the Commission to monitor the extent to which persons with disabilities are able to enjoy their rights under the Convention on the Rights of Persons with Disabilities, the Constitution, and the Persons with Disabilities Act (Act No. 14 of 2003). In fulfilling this role, the Commission has embarked on countrywide monitoring visits targeting learning institutions, hospitals, law courts, local authorities, caregivers, disabled persons’ organizations and other offices offering public services.

37. The Kenya National Commission on Human Rights, pursuant to the Prevention of Torture Act (Act No. 12 of 2017), has the power to investigate alleged violations, upon receipt of a complaint or on its own initiative, and is mandated to, inter alia, promote the right to freedom from torture and cruel, inhuman or degrading treatment or punishment and to work with enforcement agencies to ensure compliance with existing national and international laws that prohibit such violations.

⁸ See A/HRC/WG.6/21/KEN/1.

⁹ CERD/C/KEN/5-7. See also www.cohesion.or.ke (accessed 23 July 2018).

(ii) *National Gender Equality Commission*

38. The National Gender Equality Commission is a constitutional commission that was established in 2011 with the objectives of promoting gender equality and promoting freedom from discrimination. The overarching goal of the Commission is to contribute to the reduction of gender inequalities and of discrimination against all – women, men, persons with disabilities, youth, children, older persons, minorities and marginalized communities.

(iii) *Commission on Administrative Justice*

39. The Commission on Administrative Justice is also known as the Office of the Ombudsman and is a constitutional commission mandated to investigate any conduct in State affairs or any act or omission in public administration in any sphere of government – including complaints of abuse of power, unfair treatment, manifest injustice, or unlawful, oppressive, unfair or unresponsive official conduct.

IV. Exemplary developments

40. The Government has initiated several specific and concrete measures to improve the situation of persons with albinism. Since 2013, it has specifically provided for the entrenchment of a substantial annual budget of K Sh 100 million (nearly \$1 million), dedicated to persons with albinism.

41. These funds have enabled the provision of sunscreen lotions, adaptive devices such as glasses and monoculars, and awareness-raising to sensitize the public on albinism and to fight against harmful practices. The funds have also enabled advocacy to be conducted across the country through grass-roots organizations. Moreover, more than 1,000 persons with albinism have been provided with prescription glasses and other optical devices. The funds have also financed the provision of what could be termed skin cancer prevention kits, which include sunscreen, after-sun care products, lip balms containing sunscreen and, occasionally, protective clothing. These kits are available in 190 hospitals across the country, including in rural areas. The funds are overseen by a person with albinism who is employed within the National Council for Persons with Disabilities.

42. To address the problem of a lack of accurate data on persons with albinism, the Independent Expert commends the Government for its inclusion, for the first time, in the 2019 population and housing census, an indicium specifically on albinism. The indicium will be integrated into the Washington Group Short Set of Questions for capturing data on persons with disabilities. This is an important opportunity to not only capture vision impairment data on albinism but also data on the condition as a whole – including on skin cancer prevention, discrimination based on colour, and harmful practices.

43. Regarding representation, the Independent Expert was pleased to note the presence of persons with albinism among State interlocutors whom she met. These included Senator Isaac Mwaura; Grace Mumbi Ngungi, a judge of the High Court; and Timothy Aseka, a member of the County Assembly of Kakamega – all of whom have been or are advocates for the human rights of persons with albinism.

44. There are also currently around six organizations working exclusively on the issue of albinism in Kenya. Common objectives among these organizations include programmes to raise public awareness on albinism, and to provide ad hoc first response services in case of reported attacks or other violations, and being forums of ongoing support where persons with albinism and their family members can safely share their experiences and collectively find solutions.

V. Main challenges

A. Attacks

45. Upon arrival in Kenya, the Independent Expert had information and reports confirming seven cases of attacks on persons with albinism in the country, including killings, mutilation, kidnapping, attempted kidnapping, rape, and trafficking of persons and body parts. In the course of the visit, the Independent Expert received reports of 11 more cases.

46. These included a renewed trafficking attempt in 2017 on a victim who had been successfully trafficked in 2010, cases of ritual rape, cases of infanticide which interveners tried in vain to prevent, and cases of persistent death threats and attempted trafficking. Most of these cases had occurred in the past three to five years, with the most recent occurring less than a month before the visit of the Independent Expert.

47. Most reported attacks appear to have the purpose of using, or selling for use, body parts for witchcraft purposes. As a result of reports of attacks and the overall insecurity faced by persons with albinism, the Independent Expert observes that many persons with albinism and their families in Kenya take protection measures on their own initiative. In some cases, parents have not been able to find caregivers as the child has been deemed cursed and this has frightened caregivers or potential caregivers, due to possibly being implicated in any potential attack on the child. Therefore, some parents have resorted to taking their children everywhere with them. Others have quit or altered their job and career paths to dedicate more time to protecting and being with their child. This situation is not uncommon in countries with records of attack, and indicates that any assessment of the impact of these attacks – from socioeconomic to psychological – should take into consideration not only the person with albinism but also their primary caregivers and family members.

48. The level of fear of attacks reportedly increases, the closer a person lives to the border with neighbouring countries, particularly in areas such as Migori and Taita Taveta counties, which are close to the United Republic of Tanzania. Reportedly, during elections, many persons with albinism fear leaving their houses in these areas. This situation has been fuelled by common beliefs that elections can be won through witchcraft practices, and that some of these practices can be rendered more potent with the use of body parts of persons with albinism. The Independent Expert was informed about a case where a member of the County Assembly in Narok had sought a witchdoctor's services to win the election.

49. Outside of elections, and beyond the border areas, in places such as Embu County and in Nairobi, there is also a constant ubiquitous fear of attack and kidnapping for persons with albinism and their family members. The Independent Expert noted that the fear was not only perpetuated by actual cases, of physical attack and danger, but also by the hypervisibility of persons with albinism and the unwanted and threatening attention they constantly receive. When walking down the street, persons with albinism, irrespective of their age and gender, are called "money", "pesa" or "millions" to indicate that their body parts are sellable for significant amounts of money. At times, on frequented routes, the same persons call out and pursue the person with albinism, thereby escalating the situation to intimidation, harassment and threats.

50. The Independent Expert reminds the Government that failing to take appropriate measures or failing to exercise due diligence to prevent, punish, investigate and bring perpetrators to justice for the harm caused by private persons or entities is a breach of the provisions enshrined in international human rights law, including the International Covenant on Civil and Political Rights.

51. The Independent Expert was also informed that most cases of physical threats and attacks had not been reported to the police. Although action had been taken in some cases – mostly those that had been well publicized – others had had no follow-up action in regard to their cases. Unfortunately, information on relatively recent cases was not known to officials, even though a majority of these cases were known by civil society organizations

working with persons with albinism. Several officials referred to the well-publicized murder and trafficking of body parts of Enock Jamenya in 2015 as being the last known case in Kenya.¹⁰ The Independent Expert urges authorities to properly acknowledge the existence of attacks and invites them to conduct their own assessment and situational analysis with persons with albinism to obtain facts about cases, without threats of reprisals for those involved. In the same vein, the Government ought to increase efforts to bring to a definitive end the various forms of crime targeted at persons with albinism and to ensure prompt investigation and prosecution of cases of attacks against them.

52. The Independent Expert welcomes reports of care shown by police in certain instances and the creation of a hotline by the National Council for Persons with Disabilities. However, these measures need to be widely publicized, in addition to the work of other existing mechanisms supporting and protecting the rights of peoples with albinism such as the Kenya National Human Rights Commission and its branch offices and partners. The National Council for Persons with Disabilities also needs to consider investing some of the funds for persons with albinism in the recommended situation analysis, particularly portions earmarked for awareness-raising and grass-roots interventions, for which previous usage has reportedly not been properly accounted for.

53. Moreover, such support could be extended to a capable civil society organization serving persons with albinism to report and monitor cases and proceedings concerning attacks and various violations against persons with albinism. Without such studies, trends of progression or regression will remain debatable and unverified, and persons with albinism will continue to live in fear.

54. In terms of legislation, the Independent Expert observes that the Witchcraft Act does not define “witchcraft”, and she received no reports that the Act had been used in the prosecution of crimes against persons with albinism. She suggests that the review of the Act should include the reiteration of the criminality of harmful practices in this context. Such review should also include the principle that freedoms of religion or beliefs can never justify these harmful practices.¹¹ Restrictions to such liberties are justified where they are aimed at protecting, inter alia, public safety, health or the fundamental rights and freedoms of others.¹² Moreover, harmful practices concerning manifestations of witchcraft beliefs ought to be generally considered an aggravating factor, given the extent of the harm they precipitate.

55. The Independent Expert notes that the Counter-Trafficking in Persons Act specifically includes “forcible or fraudulent use of any human being for removal of organs or body parts” as exploitation and human trafficking. She commends Kenya for having included the prohibition of trafficking of body parts under the existing law, which could cover the purposes of attacks and harmful practices instigated by witchcraft belief and practices. However, the law should also be applied to cases that are particularly related to persons with albinism and should be interpreted broadly to include the extraction and harvesting of body parts for trafficking purposes regardless of whether the victim has been moved from one place to another.

56. The Independent Expert commends the Government for creating more awareness through the media and through public rallies against ritual killings. Political goodwill from the Government is evident, and a number of targeted workshops, and support programmes with various partners in different sectors that cater to the educational, health-care and employment needs of persons with albinism, have been implemented. The Independent Expert encourages the authorities to continue to implement long-lasting awareness-raising campaigns broadly as well as campaigns targeted at communities and family members, which demystify albinism and highlight the criminality of harmful practices. Persons with albinism should also receive vigilance training beyond the protection measures that they

¹⁰ See the allegation letter sent by the Independent Expert to the Government of Kenya on 24 September 2015 (KEN 4/2015), accessible at <https://spcommreports.ohchr.org/TMResultsBase/DownloadPublicCommunicationFile?gId=20009>.

¹¹ *X v. United Republic of Tanzania* (CRPD/C/18/D/22/2014).

¹² See Human Rights Committee, general comment No. 22 (1993) on freedom of thought, conscience and religion.

self-impose. Best practices for all these initiatives exist and require adaptation and implementation in Kenya as a matter of urgency.

B. Stigmatization and discrimination

57. In Kenya, discrimination and stigma against persons with albinism is still prevalent although it varies from city to city. Ridicule, stigma and social exclusion are common, including name-calling referring to the purported financial value of persons with albinism as described above. Often friends, relatives, community members or people in positions of power perpetuate the stigma and discrimination.

58. Many interlocutors reported that they had experienced discrimination and bullying in job recruitment processes, owing to the colouring and appearance of persons with albinism, even before the potential employer was aware that the person with albinism also had vision impairment. The lack of trust in peers, teachers, government authorities, and even friends and relatives, leads to psychosocial issues and excludes many persons with albinism from social, economic and cultural activities.

59. Several persons with albinism indicated that in their subjective assessment, discrimination and stigmatization of them in the country had begun to decline. The decline was largely attributed to the presence of high-level officials with albinism in both the judiciary and the executive branch of government. Such affirmative action should be increased, given its effectiveness in changing mindsets and countering prejudices.

60. However, to further speed up the change in mindsets in regard to persons with albinism in rural and border areas, there is a dire need for massive awareness-raising efforts. Such sensitization should be wide in scope, continuous and not ad hoc; it should also be targeted at particular sectors, such as education and health, and should use both Kiswahili and local languages, always involving persons with albinism themselves.

C. Health

61. Health issues are among the most significant challenges that persons with albinism face. The Independent Expert commends the Government for the Albinism Programme through which the National Council for Persons with Disabilities provides free sunscreen, after-sun products and sun protective lip balm (“prevention kits”) to persons with albinism in Kenya.

62. However, the Independent Expert notes the need to ensure that the programme is effective in benefiting persons with albinism throughout the country, particularly in rural and hard-to-reach localities. For some people, especially those living outside of Nairobi, access to free sun care can become a financial challenge, as they sometimes have to travel long distances, spending up to K Sh 3,000 (approximately \$30) in transportation costs, to receive it. For many beneficiaries and their families who live in extreme poverty, this is an insurmountable barrier. For this reason, children as young as 2 years old have been severely sunburned and had precancerous lesions all over their bodies. The Independent Expert reiterates the urgent need for free and accessible sunscreen, especially in remote areas.

63. The Independent Expert heard of a number of cases where persons with albinism had been denied the prevention kits because they were not preregistered with the National Council for Persons with Disabilities. While registration is administratively sound, it could become a barrier to accessing an essential health product, especially for those who cannot afford to travel to distributing hospitals. There also appear to be inconsistencies in distribution, as some hospitals or health workers distribute the prevention kits without proof of registration with the Council, while others do not. The Independent Expert also heard accounts of hospitals where kits were not restocked immediately or at all. This creates logistical and financial barriers to access for those travelling from afar.

64. Reportedly, sometimes portions of the kit were missing. For example, an overwhelming majority of persons with albinism whom the Independent Expert met, who had accessed the kits at some point in the recent past, did not receive the after-sun care

product. After-sun care products are widely believed to be either not purchased at all by the Albinism Programme, or are in high demand generally, including by persons without albinism, so they are often stolen before reaching the intended beneficiaries.

65. After many encounters with both persons with and persons without albinism in Kenya, the Independent Expert noted the need for more awareness-raising on skin cancer and how to better detect and recognize the symptoms before the situation worsened. Widespread advertising is also needed to make persons with albinism all over the country aware of the existence of the prevention kits. In this regard, the Independent Expert welcomes the planned audit of sunscreen delivery services by the National Council for Persons with Disabilities, and urges the full participation of and consultation with persons with albinism, particularly those outside of urban centres.

66. In addition, several beneficiaries reported that the instructions on the use of the prevention kits, and other relevant health advice, were not provided, leading to poor product compliance. The Independent Expert welcomed the commitment of the National Council for Persons with Disabilities to audit and refine this process and improve the delivery of prevention kits through the Albinism Programme, to ensure accessibility, acceptability, quality and availability of this essential health product to all persons with albinism irrespective of preregistration and geographical location.

67. The Independent Expert strongly encourages Kenya to start producing sunscreen locally. The modalities of doing so in the region exist and this venture promises to further refine this portion of the Albinism Programme and serve as another avenue for employment for persons with disabilities, particularly those with albinism. To this end, a proper and objective viability assessment ought to be conducted for a thorough and reliable cost-benefit analysis. Local production should not be thwarted merely in the interest of a general preference for procurement, which often serves as a channel for corruption and waste.

68. The Independent Expert also observed that there are now about 30 skin clinics for persons with albinism in Kenya, with some truly dedicated health-care providers. Some informed her that they offered treatment for precancerous and cancerous lesions, provided counselling on proper skin care when necessary, and made referrals to other hospitals that were better equipped to deal with advanced cases of skin cancer.

69. However, both the health-care providers and clients recognized a need for more specialized training for health-care providers, particularly dermatologists. Medical practitioners should be incentivized or made aware of the possibility of receiving available training support in this field.

70. The Independent Expert observes that lack of financial means is a big part of the reason why some persons with albinism cannot receive the life-saving cancer treatment they need. In order to receive the treatment, one needs to have health insurance, which could cost up to K Sh 1,200 per month (\$12). Lack of affordability could compromise the health of a person needing immediate care.

71. Thus, the Albinism Programme could financially support cancer treatment for persons with albinism who are economically disadvantaged. This information should be widely disseminated, alongside information on the skin cancer clinics, which appear to be unknown outside of Nairobi, as well as information on the benefits of obtaining health insurance, for those who can afford it.

72. Nonetheless, the Independent Expert welcomes the fact that the Albinism Programme has set aside funds to provide comprehensive eye care for all persons with albinism, through a service provider that is yet to be identified. The selected health-care provider will work closely with the National Council for Persons with Disabilities. The check-ups and the costs of eyewear and adaptive devices will be fully funded by the Council. Due to the high correlation between the provision of these adaptive devices, including glasses, and success in school and employment, the Independent Expert urges the Council to implement this aspect of the Programme without delay.

73. Finally, the Independent Expert welcomes the Government's approach of introducing universal health care. She notes that persons with disabilities, including persons with albinism, are part of the process of developing this framework. She looks forward to learning more about this and to what extent it affirms and builds up the existing Albinism Programme.

D. Education

74. Although the Special Needs Education Policy emphasizes integration and an inclusive approach to students with special needs, it is yet to be fully implemented. There are inadequate resources for assessing and identifying learners with special needs, which include those with albinism. Moreover, there is a lack of funding to operationalize the Education Assessment Resource Centres envisaged by the Government, as well as a lack of data on learners with special needs and disabilities, in and out of school. These factors can lead to inadequate learning facilities and inadequately skilled teaching staff. Further, there is a need to harmonize this policy with the constitutional requirements and the Government's Vision 2030 plan to enable Kenyan children, including those with albinism, to access quality and essential education.

75. The Independent Expert visited several students with albinism from different districts, who were enrolled in private and public schools in Kenya. She noted that children with albinism were usually placed in special schools, such as schools for the blind. Consequently, some are taught using Braille, and are therefore not using their total or residual vision. However, many persons with albinism still prefer to attend these schools, for various reasons. They often feel a greater sense of acceptance from students, and understanding from teachers who accommodate their low vision. In instances where the student with albinism with a vision impairment was not taught with Braille, teachers at the special schools allow students with albinism to sit in the front row so that they can see the blackboard, and distribute handouts and texts in large print. The students concerned are also given extra time to finish writing exams.

76. These are elements which are, for the most part, not present in the mainstream schools, even though Kenya has adopted an inclusive education policy. There is also a security aspect that is crucial. The special schools that the Independent Expert visited also function as boarding schools. Enrolling the students in a residential school, where they live and study, reduces their risk of being kidnapped or attacked outside of the school. However, increased security measures are still needed in the areas surrounding some of these special schools.

77. Furthermore, the Independent Expert learned that although there is no tuition fee for primary schools in Kenya, there is a boarding fee at these special schools which amounts to K Sh 26,000 (\$260) a year. According to several interlocutors, including persons with albinism and their parents, the overwhelming majority of persons with albinism are poor or extremely poor and are therefore unable to afford these schools.

78. Both in special schools and in mainstream public schools – and even in a well-funded private integrated school – the Independent Expert noticed that students with albinism did not have all the necessary assistive devices, particularly monoculars, which are commonly indispensable for achieving quality education for persons with albinism in primary and secondary schools. A few special schools had glasses and monoculars, but they were of such poor quality that the students could not benefit from them. Prescription glasses have been provided via the National Council for Persons with Disabilities' Albinism Programme to some persons with albinism, mostly in Nairobi. However, these were, in most cases, not appropriate, as they were not custom-made for the individuals' particular impairment.

79. In certain towns visited by the Independent Expert, such as Migori, there were no special schools that could properly accommodate persons with albinism. Rather, persons with albinism attended mainstream schools but these were not equipped for inclusive education. The teachers trained to attend to special needs are sparse and assistive devices are not provided.

80. Without reasonable accommodation, and sometimes with a lack of understanding from the teachers, students with albinism tend to drop out from both public and private mainstream schools. This results in persons with albinism having low levels of education. Consequently, they do not have the necessary social or economic skills to live productive lives, which results in a majority of persons with albinism doing outdoor jobs that expose them to the sun and, subsequently, to a higher risk of skin cancer. Data from neighbouring countries show that skin cancer is the number one killer of persons with albinism, with reports indicating that only 2 per cent live beyond the age of 40.

81. With simple and concrete measures, such as the provision of quality monoculars and of low-vision materials, extra time for tests and exams, specialized teachers and the proper support, including financial support for students with albinism who wish to access specialized schools, they too can get an education and break out of this vicious cycle. The Independent Expert stressed that it should not be left to only a limited number of special schools to accommodate the needs of persons with albinism. Every school should have teachers who are trained in inclusive education and can assist students with diverse needs. Ideally, students with and without albinism should attend the same school, as this has strong potential to reduce stigma and discrimination.

E. Access to justice

82. In general, persons with albinism need improved access to justice. In particular, they need access to redress for discrimination across the spectrum – from economic, social and cultural rights at one end to extreme discrimination manifested in various forms of attacks at the other. The most common barriers to access to justice observed by the Independent Expert included lack of information on existing mechanisms for redress, poverty, and the high prevalence of single mothers whose partners absconded after the child with albinism was born and who have little to no support or knowledge on where to receive redress. Moreover, historical disenfranchisement, and weak, underfunded civil society, run by volunteers, compound the barriers to access to justice.

83. The Independent Expert heard of cases in which victims of attacks did not receive justice after reporting ritual attacks, because the perpetrator had absconded to a neighbouring country. She observes the urgent need for increased and enhanced cross-border cooperation, in order to ensure that attacks are properly investigated, perpetrators are brought to justice and effective remedies are provided to victims.

84. There was also a lack of information on the legal status of cases that had been reported to law enforcement personnel. The monitoring by civil society actors of court proceedings concerning these crimes is also rare, and organizations representing persons with albinism often lack the financial means and expertise to conduct legal monitoring activities. For instance, from the widely published case of the trafficking and attempted murder of Robinson Mukhwana in 2010, very little is known by the victim, and by persons with albinism and the public at large, about the legal proceedings and outcome, which reportedly took place in the United Republic of Tanzania. In this regard, the National Council for Persons with Disabilities could divert some of the funding of the Albinism Programme to support civil society in monitoring and promoting access to justice, including judicial remedies.

85. Existing measures and mechanisms could make a difference in this regard. Measures such as the hotline at the National Council for Persons with Disabilities for reporting incidents against persons with albinism ought to be widely publicized. This should also be for the work of other existing mechanisms supporting and protecting the rights of peoples with albinism, such as the Kenya National Human Rights Commission, which has successfully mediated cases for single mothers of children with albinism in various contexts of violations. The branch officers of this important mechanism also need to be brought to the attention of those living outside of the capital of Nairobi.

86. The Independent Expert was informed that a Legal Aid Bill and the National Legal Aid Policy were in a pilot phase with the Government. This would significantly assist persons with albinism, who are often unable to navigate the legal system, not only due to

financial barriers but also due to educational limitations or lack of legal literacy. The presence of the Legal Department within the National Council for Persons with Disabilities may also serve as an important channel for persons with albinism to receive legal advice and important pertinent information. The Council has the requisite mandate and experience to use information from the forthcoming census not only to improve its Albinism Programme generally, but also to ensure effective access to justice.

87. The Independent Expert stresses the fundamental need to ensure access to justice for persons with albinism and to combat impunity. The lack of prosecutions of perpetrators is concerning and yet not uncommon in these types of cases. Impunity nullifies deterrence and creates conditions enabling perpetrators. It also increases insecurity and fear among persons with albinism, including fear of entering proper relationships, which they need in order to build an adequate social ring of protection and support.

F. Employment

88. While the Constitution of Kenya enshrines affirmative action by providing that at least 5 per cent of elected and appointed bodies should be persons with disabilities, this has not been realized. According to article 56 of the Constitution, minorities and marginalized groups should also be provided with special opportunities in the educational and economic fields, be provided with special opportunities for access to employment, and have reasonable access to water, health services and infrastructure. In some cases, persons with albinism have been overlooked in favour of persons with other types of disabilities, as many employers, including government, do not regard them as properly belonging to the category of persons with disabilities.

89. The National Council for Persons with Disabilities offers grants to both individuals and groups of persons with disabilities for self-employment purposes. While some components of this programme are several years old, most persons with albinism of employment age were unaware of them. The few who were aware flagged problems accessing the programme on the grounds that they had been rejected because the Albinism Programme existed.

90. Once employed, persons with albinism often suffer multiple levels of discrimination, as employers assume that their capacity to deliver within the workplace is below par. Sometimes they may also be subject to working conditions that are hostile to their health, such as working directly under the hot sun or bright light, which puts them at risk of skin cancer and the possibility of their visual impairment being aggravated. They are also the subject of regular ridicule from colleagues, and sexual harassment from superiors seeking sexual encounters with a person with albinism for good luck and other alleged benefits linked to witchcraft beliefs and practices. Victims of this type of sexual harassment were both male and female. It is evident that in all efforts for disability mainstreaming by the National Council for Persons with Disabilities and other civil society organizations, the issues faced by persons with albinism ought to be visibly integrated and employers sensitized on preventive measures as well as redress.

G. Availability of data

91. In Kenya, there is a lack of evidence-based data on the nature and extent of disabilities as a whole, including albinism. This lack of data poses challenges in terms of planning for this group within the population. The Independent Expert welcomes the advocacy work of the Office of the High Commissioner for Human Rights in Kenya and the cooperation and receptiveness of the Kenya National Bureau of Statistics, which led to the inclusion of the indicium for the 2019 census. Such information is crucial to improving and fine-tuning the Albinism Programme.

92. Data from the census should also lead to a national survey of the particularities of persons with albinism, including in rural and hard-to-reach areas, so that existing measures can reach those who have been left behind. That said, the highest standards of data protection should be applied, in the context of ongoing security concerns in certain parts of the country.

VI. Conclusions and recommendations

93. Kenya has made many positive strides in improving the human rights situation of persons with albinism. With this foundation and the due exercise of its obligations under various human rights instruments, Vision 2030 and the Sustainable Development Goals, it can continue to set the standard for the region on this issue. The investment made to date in the Albinism Programme shows that Kenya has the political will, and more importantly, that it has taken concrete steps to “leave no one behind, starting with the furthest behind first”. The Independent Expert commends the approach by Kenya to the situation faced by persons with albinism, namely the provision of funding for persons with albinism, while increasing their visibility as constituents among persons with disabilities.

94. However, there remain challenges and gaps that need immediate attention, particularly in the light of attacks, ongoing insecurity, stigma, and subsisting discrimination in the areas of health, education, employment, and access to justice. In this regard, the following recommendations are made. These recommendations require long-term and unwavering commitment from the Government so that the current gains are not lost and persons with albinism can fully enjoy the human rights, dignity and security that they rightly deserve.

A. Recommendations to the Government of Kenya

The Independent Expert recommends that Kenya,

Data collection

95. Ensure that all data collected relating to the situation of persons with albinism in the 2019 Population and Housing Census are disaggregated at least by sex and age, in both rural and urban areas;

96. Ensure that all data collected during the 2019 census takes into account all forms of albinism;

97. Provide adequate safeguards for all data collected on persons with albinism in order to prevent misuse for attacks, discrimination or other illicit acts;

National Action Plan

98. Adopt and implement, in line with resolution 373 of the African Commission on Human and Peoples’ Rights, the Regional Action Plan on Albinism in Africa (2017–2021), and ensure the effective protection and promotion of the rights of persons with albinism and members of their families;

99. Ensure that a coordinated, multisectoral and comprehensive approach is taken to the enjoyment of the human rights of persons with albinism by developing a national action plan mirroring the Regional Action Plan on Albinism in Africa (2017–2021);

Legislative framework

100. Ratify the Optional Protocol to the Convention on the Rights of Persons with Disabilities;

101. Review the Witchcraft Act and define “witchcraft” – or better still – harmful practices related to certain manifestations of witchcraft, in order to furnish greater clarity and foster effective use of the Act;

102. Review the Counter-Trafficking in Persons Act or provide interpretive guidance in order to ensure that existing provisions on possession of body parts sufficiently address trafficking of body parts of persons with albinism where the body from which the part was taken has not been trafficked;

103. Consider listing as aggravating factors in sentencing guidelines, motives linked to harmful practices related to certain manifestations of belief in witchcraft, when sentencing perpetrators;

104. Facilitate international law enforcement cooperation with neighbouring countries, for example through memorandums of understanding, shared databases and the implementation and formulation of extradition treaties, where these do not exist;

105. Ensure that the Persons with Disability Amendment Bill (2018) retains its express mention of persons with albinism and equally ensure that it recognizes harmful practices against persons with albinism, in line with the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities;

Reporting of cases

106. Undertake a situational survey to verify and identify gaps in security and protection measures for persons with albinism particularly in rural and border areas. Information obtained from the 2019 census concerning persons with albinism will facilitate this process;

107. Promote and support cooperation between the authorities and civil society with a view to addressing attacks, including through joint missions to collect, compare and assess information on cases;

Investigation, prosecution and access to justice

108. Ensure that all cases of offences against persons with albinism are promptly and thoroughly documented and investigated and that reported cases of harassment and threats are taken seriously;

109. Ensure the judicious use of legislation to fully address all types of attacks against persons with albinism, including those involving possession of body parts;

110. Inform victims and/or their families of the outcome of cases that are being or have been investigated and prosecuted;

111. Effectively utilize law enforcement personnel on the ground, particularly in border towns, to facilitate investigations and obtain information on trafficking cases, including the particularities of cases involving persons with albinism;

Victim support

112. The Independent Expert recommends that the Government of Kenya ensure the provision of shelters and redress services to both past and recent victims and their families, including legal aid and medical, psychosocial and socioeconomic assistance;

Awareness-raising

113. Redouble efforts to raise awareness of albinism to combat rampant myths about the condition through far-reaching campaigns sustained continuously for at least two years. The campaigns should be in all national languages, involve persons with albinism, and target communities in rural and border areas in particular. They should also involve key stakeholders, including traditional authorities and faith-based organizations, as well as persons with albinism;

Health

114. Ensure that skin cancer prevention kits are complete and that they are consistently accessible and available including in rural areas;

115. Consider the local production of sunscreen. To this end, a proper and objective viability assessment should be conducted for a thorough and reliable cost-benefit analysis;

116. Continue to facilitate access to skin cancer treatment, including chemotherapy and radiotherapy, by reducing indirect costs, or, where necessary, by providing financial support to ensure prompt access to treatment;

117. Train health-care workers, community leaders, persons with albinism, families of persons with albinism, particularly mothers of children with albinism, and women generally as potential mothers of children with albinism, on the scientific explanation for and all physiological and social implications of albinism. Such training should be integrated into ongoing programmes targeting women, and persons with disabilities, or through other specific programming;

118. Incentivize health-care workers to obtain, through continuous medical education, training in dermatology in order to ensure accessibility, availability and quality care in skin cancer prevention treatment;

Education

119. Ensure full implementation of the inclusive education policy, not least by allocating the necessary resources;

120. Ensure the provision of reasonable accommodation to students with disabilities including those with albinism, by providing low-vision aids, adaptive devices and large-print materials in all schools;

121. Train all teachers on the special needs of children with albinism, by systematically incorporating this into the teacher-training curriculum and noting that Braille is not necessarily a required learning tool for all learners with albinism;

122. Ensure that schools that have children with albinism are equipped with the necessary basic protections, such as fences, and that teachers and staff are aware of the situation of students with albinism and are trained to respond adequately;

123. Facilitate access to vocational training opportunities, so that persons with albinism, regardless of their performance in academic subjects, can prepare for careers that would allow them to work indoors and lift themselves out of poverty, and therefore into both financial and physical safety;

Poverty

124. Continue to adopt measures to address poverty in the light of Vision 2030 and the 2030 Agenda for Sustainable Development to ensure that Kenyans with albinism are not left behind, that they have full access to employment and social welfare programmes and that they are included in all poverty-reduction programmes;

125. Invest more in grants for self-employment for persons with disabilities in order to reduce competition and benefit more persons who are eligible;

126. Continue to implement affirmative action provisions in the Constitution which stipulate that at least 5 per cent of elected and appointed bodies should be persons with disabilities and which also require that affirmative action programmes be designed to ensure that minorities or marginalized groups participate and are represented in governance and other spheres of life;

127. Consider extending social security support and grants to single parents of children with albinism whose work life is negatively impacted by necessary protection measures taken in the interests of their child;

128. Sensitize employers about their crucial role in ending stigma and discrimination, not only by providing employment but also by putting in place and implementing a zero harassment policy at work and by incorporating albinism in all diversity and disability training;

Participation

129. Continue to place and facilitate the placement of persons with albinism in senior office at the central and county levels, as this affirmative action has proved

effective in reducing myths and stigma even though there remains a long way to go in this regard.

National Council for Persons with Disabilities

130. Audit the Albinism Programme as planned and include persons with albinism in that process;

131. Train persons with albinism on how to use the kits distributed using more effective means such as direct communication with beneficiaries;

132. Consider the local production of sunscreen, with proper and objective assessment as to the cost and benefits;

133. Incorporate civil society actors serving persons with albinism in training opportunities for persons with disabilities;

134. Immediately purchase and efficiently distribute adaptive devices such as monocular and prescriptive eyewear to facilitate reasonable accommodation and education, as a proper education amounts to a strong protection measure for persons with albinism;

135. Advocate within government for and consider supporting a situational analysis after the census to assess the safety and security of persons with albinism countrywide;

136. Consider supporting civil society beyond awareness-raising activities to monitor and follow up on cases of attacks and threats which tend to go unreported through official channels;

137. Formally evaluate and produce reports assessing funding designated for awareness-raising to measure its impact and efficiency;

138. Widely publicize all aspects of the Albinism Programme, such as the hotline, hospitals and other locations where skin cancer prevention kits are distributed, and the location of support services providing precancer and cancer treatment for people living in extreme poverty. Use tools such as WhatsApp and other commonly used channels to ensure effective communication with beneficiaries;

139. Widely publicize other relevant components of the National Council for Persons with Disabilities, such as the self-employment grant programme;

140. Include persons with albinism in other programmes at the National Council for Persons with Disabilities, such as the programme on the self-employment grant. They ought not be excluded merely on the basis that an Albinism Programme already exists;

141. Consider providing a grant for the boarding fees of children with albinism living in remote and border areas who wish to attend specialized schools for safety;

142. Train persons with albinism in proper and effective self-help security and vigilance techniques based on best practices. The manual on the subject produced by CBM (Christian Blind Mission) is an important resource;

143. Enhance access to justice for persons with albinism regarding all forms of violations by consolidating all relevant mechanisms and disseminating these widely;

144. Continue to develop strategies and ways to facilitate the reporting of cases, and ensure prompt follow-up to reports of attacks;

“Article 59” institutions

145. Monitor census processes and results concerning persons with albinism. As this is an inaugural initiative, constructive assessment and follow-up are necessary;

146. Continue to record, mediate and monitor cases of attacks and other violations against persons with albinism and their family members;

147. Widely publicize your organization and the specific services you can provide to persons with albinism, particularly concerning not only civil and political rights but also economic and social rights. It is important to begin this process with all relevant staff serving the Albinism Programme at the National Council for Persons with Disabilities so that referrals can be facilitated;

148. Continue to make individual and concerted efforts to include organizations serving persons with albinism in relevant human rights training programmes and public forums offered by your institution including in the areas of access to justice, disability, health, education and employment;

149. Reach out to, and maintain relationships with, organizations serving persons with albinism to receive and incorporate their input for all human rights reports on Kenya.

B. International community and cooperation

The Independent Expert,

150. Calls upon international partners to support civil society and national efforts on the issue by supporting specific programmes, or integrating the issue into their pre-existing or forthcoming development programmes, on the Sustainable Development Goals, for persons with disabilities, on health, and on marginalized persons, inter alia women and children;

151. Calls upon the United Nations to consider providing technical assistance and support to the Government and also civil society who are in dire need of human rights capacity-building in the area of access to justice, among others;

152. Calls upon the Government of Kenya to establish mutual legal assistance and exchange of information with surrounding countries, to facilitate greater exchange of evidence and information, in order to secure convictions for perpetrators of attacks against persons with albinism.
