

# **Best Practices**

In the protection of human rights of persons with albinism.



Addendum to the report of the Independent Expert on the enjoyment of human rights by persons with albinism (Presented to the 75th session of the General Assembly, A/75/50343)

















# Contents Introduction

l.	Introduction	. 3
II.	Methodology	. 3
	National Action Plan	
	Implementation and Monitoring	
	Best Practices	
	Prevention	
В	. Protection	11
С	. Accountability	18
D	. Equality and non-discrimination	23
Ε	Guiding principles for implementing action plans	36

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# I. Introduction

Attacks against persons with albinism remain a concern, particularly in the African context. In addition, violations of the enjoyment of the rights to health, education and work have been insufficiently addressed in most regions of the world. The Independent Expert has called on States to produce national plans of action to address these concerns and protect the rights of persons with albinism. This compendium of best practice has, therefore, been produced as a blueprint to assist States with the development of such national action plans.

The compendium compliments the Independent Expert's report on protection measures for persons with albinism. It summarizes measures to be included in action plans and provides recommendations for interventions, as well as resources for States seeking to develop their own interventions. It further gives recognition to exemplary interventions under the Regional Action Plan for Africa (RAP)<sup>i</sup> and identifies relevant best practices worldwide.

# II. Methodology

The RAP, which has proven to be useful in the African context, was used as the basis of this compendium. Further measures, not included in the RAP, were added following desk research and consultation with associations of persons with albinism from around the globe, including Argentina, Brazil, China, France, Kenya, Malawi, Malaysia, Nepal, Nigeria, Puerto Rico, Rwanda, Spain, Turkey and Zambia. Measures, interventions, and resources have also been gleaned from an analysis of core principles of human rights and research into protection measures for other vulnerable and marginalised groups, such as persons with disabilities in general, women and children. Relevant measures and interventions for such groups have been adapted and included in this compendium

# III. National Action Plan

As pointed out in the Independent Expert's report on protection measures, a national action plan should be developed with the inclusion and participation of persons with albinism, through a multi-sectoral and interdisciplinary approach. It should provide the framework for governments to outline objectives, establish timelines, assign responsibility to particular entities, and allocate the necessary financial and other resources. In line with the SDGs, States should seek international cooperation in the implementation of action plans, including seeking technical and financial assistance in the areas of capacity building, research and resource mobilization.

The best practices below set out measures to be taken to prevent attacks and protect persons with albinism from attacks. It further sets out measures for ensuring accountability where attacks occur. Protection of the rights to health, education and work are as important as protection from physical attacks. This compendium therefore also addresses protection measures in relation to equality and non-discrimination.

# IV. Implementation and Monitoring

It is envisaged that the development and implementation of action plans, on the basis of this compendium, will be carried out in consultation with persons with albinism and other stakeholders in the respective countries. Such implementation will need to be regionally and nationally determined according to indicators and timelines set out by the key stakeholders. The targets, timeline and indicators set out in the RAP are exemplary and provide guidance for States in this regard.

# **V.** Best Practices

### A. Prevention

Sub- thematic Area	Inclusion and active participation of persons with albinism in development of a national action plan and all decision-making processes related to them
Specific measures	<ul> <li>Enter into partnerships with associations of persons with albinism through formal MOUs; seeking advice and information from such associations regarding the experiences of persons with albinism and barriers to the enjoyment of rights; as well as including them in any structure for the coordination of protection measures for persons with albinism.</li> </ul>
	<ul> <li>Involve persons with albinism in the development of laws and policies and policies related to them.</li> </ul>
	<ul> <li>Employ qualified persons with albinism as staff in relevant programmes, particularly providing peer-to-peer support and awareness-raising</li> </ul>
	<ul> <li>Support the capacities and efforts of associations of persons with albinism as agents of change in their families and communities.</li> </ul>
Best practices	<ul> <li>In Fiji, Kenya, Malawi and Nigeria, for example, associations of persons with albinism have worked with the authorities in the development of national policies on albinism and have been empowered to provide services to communities, including through implementation of awareness raising programmes.</li> </ul>
	• In Argentina, associations of persons with albinism have been involved in the development of the National Bill on Albinism. <sup>ii</sup> The Federal government of Nigeria also worked with the Albino Foundation of Nigeria in producing the national education policy and national guidelines on reasonable accommodation measures for persons with albinism. <sup>iii</sup>
	<ul> <li>Human rights training programmes for associations of persons with albinism have been carried out in Malawi and for Portuguese speaking African countries</li> </ul>
	<ul> <li>In Kenya and Malawi, the State has provided an annual budget for programmes related to albinism, which include</li> </ul>

empowerment of persons with albinism to, for example, understand measures they can take to prevent skin cancer, where they can access relevant health services and other support

- Report of the Independent Expert on albinism, Addendum -Regional Action Plan on Albinism in Africa (2017–2021)<sup>iv</sup>
- The 2030 Agenda for Sustainable Development and the human rights of persons with albinism<sup>v</sup>
- Applicable international human rights standards and related obligations addressing the issues faced by persons with albinism<sup>vi</sup>
- Thematic report: Women and children impacted by albinism<sup>vii</sup>
- UN High Commissioner for Refugees (UNHCR), Need to Know Guidance: Working with Persons with Disabilities in Forced Displacement<sup>viii</sup>
- Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action<sup>ix</sup>
- European Union Agency for Fundamental Rights, Violence against children with disabilities: legislation, policies and programmes in the EU<sup>x</sup>
- Preventing and responding to violence against children: UNICEF's approach<sup>xi</sup>
- UNICEF, Guidelines to Strengthen the Social Service Workforce for Child Protection<sup>xii</sup>
- WHO, Violence prevention: the evidence. (Series of briefings on violence prevention: the evidence)<sup>xiii</sup>
- WHO, INSPIRE: Seven Strategies for Ending Violence Against Children<sup>xiv</sup>

	<ul> <li>Preventing and responding to violence against children: UNICEF's approach**</li> </ul>
Sub- thematic Area	Research and data collection
Specific measures	<ul> <li>Carry out a situational analysis, including through research into the numbers of persons with albinism in the country, their specific challenges and needs, the availability of services and the gaps in the provision of such services, laws and policies.</li> </ul>
	<ul> <li>Ensure data collection disaggregated at a minimum by gender, age, health status and rural-urban prevalence</li> </ul>
	<ul> <li>In line with SDG 17, seek international assistance to support disaggregated data collection</li> </ul>
	<ul> <li>Continually monitor and evaluate the impact of measures adopted and adapt such measures as required, including in response to lessons learned, as well as new and emerging trends and on the basis of new technology.</li> </ul>
Best practices	<ul> <li>The OHCHR and Equal Opportunities Commission carried out an analysis in relation to discrimination against persons with albinism in Uganda, looking at the root causes for this, effects and providing recommendations on how to ameliorate it.</li> </ul>
	<ul> <li>A situational analysis was carried out by the International Organisation for Migration (IOM) in Mozambique specifically in relation to trafficking of persons with albinism.</li> </ul>
	<ul> <li>Tanzania established Disability Committees at the village, ward, district and regional levels which, among other things, collect data and report on issues affecting persons with disabilities including persons with albinism</li> </ul>
	<ul> <li>Where there is widely accessible health care with appropriate data systems, data may be obtained from health professionals</li> </ul>
	<ul> <li>Kenya, Tanzania, Namibia and Malawi have included questions on albinism in their national census.</li> </ul>
	<ul> <li>Data can also be obtained from demographic health surveys and other national surveys e.g. on disability, health and</li> </ul>

education. For example, in 2019, China started a national registry for rare diseases. Persons with albinism are included and all cases diagnosed are included in the national register.

- The Argentine Province of Misiones has a law requiring the creation and maintenance of database with cases detected in the Province.
- Panama's newly approved law also requires the Ministry of Health and Social Security Fund to provide statistical data on persons with albinism.
- In Mali, a mobile phone application on albinism (Yefeke) was created and made available to download free of charge. It contains information to raise awareness on albinism but also aims at collecting data on persons with albinism, their family members and health professionals. It also contains an emergency number to call in case of attack or to report human rights violations
- First doctoral thesis on albinism in Togo, presented at the Faculty of Health Sciences of the University of Lomé.

- Round table on human rights and albinism: seeking consensus and priorities on advocacy and research: Report of the Independent Expert on the enjoyment of human rights by persons with albinism<sup>xvi</sup>
- OHCHR and Equal Opportunities Commission (EOC), Enhancing Equality and Countering Discrimination against Persons with Albinism in Uganda<sup>xvii</sup>
- Situation Analysis on the Human Rights and Protection of Persons with Albinism in Mozambique with a Special Focus on Human Trafficking<sup>xviii</sup>
- The 2030 Agenda for Sustainable Development and the human rights of persons with albinism<sup>xix</sup>
- ASEAN and Trafficking in Persons: Using Data as a Tool to Combat Trafficking in Persons<sup>xx</sup>
- UNODC Toolkit to Combat Trafficking in Persons. Global Programme against Trafficking in Human Beings<sup>xxi</sup>

## Sub-Addressing root causes thematic Area Specific Address root causes of violations through, among other things, measures putting in place public education and awareness-raising campaigns which seek to demystify the beliefs and superstitions that dehumanise persons with albinism, and increase the understanding of albinism and the rights of persons with albinism Campaigns to specifically counter Harmful practices related to accusations of witchcraft and ritual attacks (HP- AWRA) Work with civil society to establish or adapt existing measures to prevent trafficking which are applicable to persons with albinism, addressing their specific vulnerabilities Best South Africa, in addition to commemorating International practices Albinism Awareness Day, has designated September as Albinism Awareness month The parliament of Uganda holds an annual Parliament Albinism Charity Walk to raise awareness around albinism. In Malawi, the State helped support a Mr and Miss Albinism contest through funding and the attendance of the First Lady. This helped increase the visibility of the event. The appointment of persons with albinism to senior government positions in Kenya and Tanzania, has also helped to counter negative stereotypes of persons with albinism. A similar effect has been achieved by the positive portrayal of persons with albinism in television programmes in South Africa. In Mozambique, the Ministry of Health has a traditional medicine department which works with medical practitioners and traditional healers to ensure they are aware of the need of persons with albinism, and to demystify associated harmful myths The OSCE has adopted measures which include carrying out awareness raising campaigns with NGOs in villages, schools and universities; training embassy and immigration staff; using the media; and establishing well-publicised hotlines to give

advice.

- An example of a prevention strategy targeted at a vulnerable group is the Republic of Moldovia's programme to support the economic empowerment of vulnerable women, including women victims of domestic violence. Such women are given guidance and counselling, partial coverage of expenses associated with vocational training and support to set up businesses.xxiii
- UNODC global media campaign on human trafficking featured 30- and 60-second videos on trafficking in women for the purposes of sexual exploitation; and trafficking in men, women and children for bonded and forced labour. The videos were featured in national, regional and international media, including on BBC World, CNN International and MTV Asia.
- Commemorating World Day against Trafficking in Persons on 30 July

- Preliminary survey on the root causes of attacks and discrimination against persons with albinism<sup>xxiii</sup>
- Thematic report: Women and children impacted by albinismxxiv
- INSPIRE: Seven Strategies for Ending Violence Against Children<sup>xxv</sup>
- UN High Commissioner for Refugees (UNHCR) Need to Know Guidance: Working with Persons with Disabilities in Forced Displacement.
- Witchcraft and the human rights of persons with albinismxxvi
- Report of the Independent Expert on albinism, Addendum Expert workshop on witchcraft and human rights<sup>xxvii</sup>
- Draft Pan-African Parliament regional guidelines on witchcraft
- Papua New Guinea National Action Plan against Sorcery- and Witchcraft-related Violencexxviii
- UK National action plan to tackle child abuse<sup>xxix</sup>

	<ul> <li>Tool 9.3 of the UNODC toolkit to combat trafficking provides an awareness-raising campaign checklist which can assist States in developing such a campaign.xxx</li> </ul>
	<ul> <li>Tool 9.2 provides examples of awareness-raising measures<sup>xxxi</sup></li> </ul>
	World Day against Trafficking in Persons websitexxxii
	Trafficking in Persons and Migrant Smuggling: campaigns**
Sub- thematic Area	Social protection measures
Specific measures	<ul> <li>Put in place social protection measures for persons with albinism aimed at mitigating vulnerability to attacks</li> </ul>
	<ul> <li>consider additional costs and challenges which make it hard for persons with albinism to access social protections.</li> </ul>
Best practices	<ul> <li>To mitigate attacks in Malawi, the government has provided housing subsidies<sup>xxxiv</sup> and personal alarms<sup>xxxv</sup> for persons with albinism</li> </ul>
Resources	<ul> <li>WHO, INSPIRE: Seven Strategies for Ending Violence Against Children<sup>xxxvi</sup></li> </ul>
	<ul> <li>Aleksandra Posarac, Lead Economist, World Bank, Social Safety Nets and Disability<sup>xxxvii</sup></li> </ul>

### **B.** Protection

Sub- thematic Area	Appropriate legislative and policy framework
Specific measures	<ul> <li>Adopt a law which defines trafficking in a manner which leaves no doubt that the removal of a person with albinism from one place to another, either in or outside the country, for the purposes of removing any body part, including hair and nails, constitutes human trafficking. Such a law should ensure that trafficking is treated as a serious offence with strict penalties.</li> </ul>
	<ul> <li>Criminalise all acts associated with trafficking, such as abduction, unlawful confinement, corruption, bodily injury,</li> </ul>

fraudulent promises, false consent of parents/guardian, intimidation or subversion of officials, etc

- Put in place policies and laws to identify public-sector involvement or complicity in trafficking and take steps to prevent this and hold perpetrators accountable regardless of their rank
- Avoid criminalising witchcraft itself, but ensure all ritual attacks; accusation of witchcraft which advocates for or leads to the death of, or bodily injury to persons accused of being a "witch"; as well as related acts such as trafficking; the possession of human tissue or body parts; solicitation of body parts; and provision of advice or remedy by a healer requiring the use of body parts, are proscribed by law with appropriately harsh sentences in place for such crimes.
- Repeal any outdated laws related to witchcraft
- Put in place a legal framework regulating all types of healers, including faith healers

# Best practices

- South Africa and Kenya have trafficking laws which cover trafficking within and across borders for any form of exploitation and include body parts, not just organs. South Africa's law further provides strict penalties of a fine up to R100 million and/or imprisonment up to life.
- Malawi's Criminal Code and Anatomy Act criminalize unauthorized possession of human tissue, body parts or bones. The South African Human Tissue Act also proscribes possession of human tissue.
- Malawi's Criminal Code and Anatomy Act criminalize unauthorized possession of human tissue, body parts or bones. The laws further provide for greater penalties for those involved in HPAWR. The South African Human Tissue Act also proscribes possession of human tissue, but only provides oneyear prison sentence.
- Papua New Guinea repealed its sorcery law in 2013
- Ghana's Traditional Medicine Practice Act requires traditional healers to be registered and to have their premises registered. However, this does not cover faith healers.

### Resources

 Convention against Transnational Organised Crime and its Protocol to Prevent, Suppress and Punish Trafficking in Persons, especially Women and Children.<sup>xl</sup>

UNODC, Toolkit to Combat Trafficking in Persons IBA, Human Trafficking and Public Corruption<sup>xii</sup> Report of the Independent Expert on albinism, Addendum – Expert workshop on witchcraft and human rights Draft Pan-African Parliament regional guidelines on witchcraft Papua New Guinea National Action Plan against Sorcery- and Witchcraft-related Violencexlii UK National action plan to tackle child abusexliii Report of the Independent Expert on albinism, Addendum – Expert workshop on witchcraft and human rights Draft Pan-African Parliament regional guidelines on witchcraft Papua New Guinea National Action Plan against Sorcery- and Witchcraft-related Violencexliv UK National action plan to tackle child abusexiv Report of the Independent Expert on albinism, Addendum – Expert workshop on witchcraft and human rights Sub-Strengthening the capacity of the public sector to protect persons with thematic albinism from attacks Area Specific Strengthen the capacity of the police to appropriately protect measures persons with albinism, including through investigations before attacks occur and working more closely with communities. Ensure sufficient budget for police, including in terms of remuneration. Implement capacity building projects to strengthen the capacity of police and border officials to respond to trafficking of persons with albinism Best In March 2015, Malawi developed a plan of action which practices included strengthening community policing structures and the allocation of adequate police forces in the districts most

affected by attacks. Burundi also introduced neighbourhood policing to protect persons with albinism.xlvi

- The police in Zambia and South Africa, for example, have signed MoUs with organizations representing person with albinism, which facilitate information exchange among other things.
- Some countries have mechanisms in place for training of officials. For example, South Africa has institutions and programs whose functions include providing training to government officials that deal with human trafficking. In 2003, South Africa established the Human Trafficking Desk within the Organized Crime Unit (OCU) of the South African Police Service (SAPS). One of functions of the Desk to train members of the OCU that investigate trafficking offenses.xivii
- Regional bodies of administration of justice professionals have been developed in some regions to facilitate cooperation in the area of trafficking. The European Union Agency for Criminal Justice Cooperation (Eurojust) supports and strengthens coordination and cooperation between national investigating and prosecuting authorities.xiviii

- UNICEF, Study on challenges and best practices in investigations, prosecutions and sentencing in offences against persons with albinism in Malawixlix
- UNODC Handbook on the crime prevention guidelines: Making them work<sup>1</sup>
- UNODC Handbook on planning and action for Crime Prevention in Southern Africa and the Caribbean Regions<sup>li</sup>
- ASEAN Handbook on International Legal Cooperation on Trafficking in Persons Cases
- Interpol Global Standards to Combat Corruption in Police Forces / Services<sup>lii</sup>
- Manual for training of Immigration personnel and border police in trafficking in minors' issues<sup>liii</sup>
- Training Related to Combating Human Trafficking in Selected Countries<sup>liv</sup>

	UNODC, Toolkit to Combat Trafficking in Persons <sup>lv</sup>
Sub- thematic Area	Asylum/refugee
Specific measures	<ul> <li>support the capacity of those making asylum and refugee status determinations to appropriately determine cases of persons with albinism, including through raising awareness of the multiple layers of discrimination and other human rights violations persons with albinism are often exposed to and the impact of these on the lives of persons with albinism. Associations of persons with albinism should also be approached for training and information.</li> </ul>
Best practices	<ul> <li>In a 2007 case involving a man with albinism from Indonesia seeking refugee status in the US,<sup> v </sup> the judge held that the claimant was a member of a particular social group because of his albinism. According to the judge, "[a]Ibinism is an immutable characteristic that [one] is incapable of changing. It clearly identifies [one] on sight."</li> </ul>
	• in the 2016 case involving a 7-year-old boy with albinism in the UK facing deportation to France, the court noted, "if there is a failure to provide necessary protection against persecution,, then there is a proper basis for finding that [persons with albinism] are refugees." The court further held that the societal discrimination and ill-treatment might amount to real persecution in relation to a child in circumstances where it would not amount to such in respect of an adult. The court also used a subjective analysis stating that the ill-treatment was more likely to amount to persecution in respect of the child as he had not been brought up in Nigeria and was not accustomed to the negative perception towards persons with albinism. Iviii
	<ul> <li>France granted refugee status to a Nigerian woman with albinism who had had fled to Nigeria after being blamed for the death of men in her clan, because of her albinism. The court took into account the strong beliefs, traditions and customs relating to albinism in Nigeria, as well as the dearth of protective measures for persons with albinism, in deciding that there was a real risk of persecution if she were to return to Nigeria.</li> </ul>
Resources	<ul> <li>Guidelines on International Protection: "Membership of a particular social group" within the context of Article 1A(2) of the 1951 Convention IX</li> </ul>

Guidelines on International Protection: The application of Article 1A(2) of the 1951 Convention and/or 1967 Protocol relating to the Status of Refugees to victims of trafficking and persons at risk of being trafficked lxi Guidelines on International Protection: Child Asylum Claims Ixii Guidelines on international protection No. 1: Gender-related persecution within the context of Article 1A(2) of the 1951 Convention and/or its 1967 Protocol relating to the Status of Refugees<sup>lxiii</sup> Handbook and guidelines on procedures and criteria for determining refugee status under the 1951 Convention and the 1967 Protocol relating to the Status of Refugees Ixiv Inter-Parliamentary Union and UNHCR, A guide to international refugee protection and building State asylum systems. Handbook for Parliamentarians<sup>lxv</sup> Persons with albinism as human rights defenders Subthematic Area Specific Create an enabling environment for the work of persons with measures albinism as human rights defenders (HRDs), including through highlighting their activism as a positive thing and ensuring accountability for violations against such HRDs. Diplomatic entities should actively seek to meet with HRDs working on albinism to understand their specific support needs. Best Human rights awards have been developed as a way of practices creating a positive image of HRDs. Some of these awards provide financial benefits to help HRDs in their work. While many of these are provided by the private sector, the State can support such initiatives financially or by partnering with the private sector. In some countries, National Human Rights Institutions and parliamentary human rights committees, respond to cases of intimidation and attacks against HRDs, including through inquiries and through the making recommendations to relevant institutions for appropriate steps to be taken. Brazil, Burkina Faso, Colombia, Côte d'Ivoire, Guatemala, Hondouras, Mali, Mexico, and Peru reportedly have some form

of legislation whose primary aim is to protect human rights defenders. Ixvi

- There are a number of regional networks of HRDs that provide resources and support to HRDs. |xvii | However, none appear to have a special focus on HRDs with albinism working on albinism.
- The International Services for Human Rights has produced a 'Model National Law on the Recognition and Protection of Human Rights Defenders' which States can use in developing similar laws. |xviii
- The EU Guidelines on HRDs call for diplomatic entities to monitor the status of HRDs through regular contacts with them, receiving them in missions and visiting their places of work; supporting their work publicly through the media; reacting to cases of threats; raising specific cases with third government; providing emergency visas and offers of temporary accommodation for HRDs in danger; as well as providing access to financial support.
- In Mali, there was a launch of a project on protection of human rights and the promotion of economic empowerment of persons with albinism, supported by the Ministries of Justice, Health, the Police force, as well as various religious leaders and traditional healers.

- 'Model National Law on the Recognition and Protection of Human Rights Defenders' lxix
- Front line Defenders, Protection Manual for Human Rights Defenders<sup>lxx</sup>
- Protection International, New Protection Manual for Human Rights Defenders<sup>lxxi</sup>
- Front Line Defenders, Workbook on Security: Practical Steps for Human Rights Defenders at Risk<sup>lxxii</sup>
- OSCE Office for Democratic Institutions and Human Rights (ODIHR), Guidelines on the Protection of Human Rights Defenders<sup>|xxiii</sup>
- Digital Defenders Partnership lxxiv

- Civil Rights Defenders, Security Guidelines for Human Rights Defenders, 2019/2020<sup>lxxv</sup>
- Amnesty International, Digital surveillance threats for 2020 lxxvi
- Declaration on the Right and Responsibility of Individuals, Groups and Organs of Society to Promote and Protect Universally Recognized Human Rights and Fundamental Freedoms<sup>lxxvii</sup>
- See the following reports of the Special Rapporteur on the situation of human rights defenders: Security and protection of human rights defenders, A/HRC/13/22; Protecting human rights defenders, A/HRC/22/L.13; Elements of a safe and enabling environment for human rights defenders, A/HRC/25/55; and Good practices in the protection of human rights defenders, A/HRC/31/55.
- Ensuring Protection European Union Guidelines on Human Rights Defenders<sup>lxxix</sup>
- Regional and international bodies have set up mandates<sup>lxxx</sup> and mechanisms for the protection of HRDs.<sup>lxxxi</sup>

### C. Accountability

Sub- thematic Area	Strengthening the capacity of the justice sector to respond to attacks against persons with albinism
Specific measures	<ul> <li>Strengthen the capacity of the police, prosecutors and members of the judiciary to appropriately investigate, prosecute and sentence cases of attacks against persons with albinism, including in relation to knowledge of laws applicable to albinism; methods of investigations, including forensic investigation techniques; case management, analysis, interviewing vulnerable and intimidated witnesses with sensitivity; and drafting charges.</li> </ul>
	<ul> <li>Target capacity building programmes at senior police officers, prosecutors and members of the judiciary who should work on such cases, as well as ensure wide dissemination of any capacity building handbooks and information on changes to laws.</li> </ul>

- Ensure sufficient budgeting for police, prosecutors and the judiciary, including for investigations, and developing cases and dockets
- Put in place education campaigns to address erroneous beliefs and superstitions amongst members of the justice sector and protective measures to ensure police, prosecutors and members of the judiciary are able to carry out their duties without fear of intimidation, hindrance, harassment or improper interference. Such measures should extend to their physical protection as well as that of their families, when their personal safety is threatened as a result of the discharge of their duties.
- Consider the use of ad hoc and mobile tribunals to ensure speedy resolution of cases and accessibility of courts to victims and witnesses.

# Best practices

- Malawi produced a Handbook for Investigators, Prosecutors and Magistrates on Offences Concerning Persons with Albinism which brings together all applicable charges that can be filed from different legislation applicable to crimes against persons with albinism and provides guidance on the correct use of these for investigators, Prosecutors and Magistrates.
- Malawi has engaged in training of relevant police officers in handling such cases and the police in Malawi and Mozambique have signed an MoU to facilitate investigations.
- In Malawi, a directive was passed stating that all cases involving offences against persons with albinism should be handled by Chief Resident Magistrates, Principal Resident Magistrates and Senior Resident Magistrates.
- The police in Zambia<sup>lxxxiv</sup> and South Africa, <sup>lxxxv</sup> have signed MoUs with albinism organisations for cooperation around investigations. <sup>lxxxvi</sup>
- In Cameroon, the organization, African Albinism Ambassadors, has established links with a law firm to train and raise awareness on albinism and human rights, among lawyers to specifically address cases of discrimination or human rights violations against persons with albinism

### Resources

 Right to access to justice for persons with albinism - Report of the Independent Expert on the enjoyment of human rights by persons with albinism. |xxxvii

Independent Experts report, Vision of the mandate IXXXVIII 'Waiting to disappear' International and Regional Standards for the Protection of the Human Rights of Persons with Albinism<sup>lxxxix</sup> UNICEF, Study on challenges and best practices in investigations, prosecutions and sentencing in offences against persons with albinism in Malawi.xc Guidelines on the Role of Prosecutors<sup>xci</sup> Standards of Professional Responsibility and statement of the Essential Duties and Rights of Prosecutors xcii International Bar Association (IBA), Access to justice for persons with disabilities: From international principles to practicexciii Handbook for Investigators, Prosecutors and Magistrates on Offences Concerning Persons with Albinismxciv Sub-Strengthening capacity of the public sector in relation to trafficking of persons with albinism thematic Area Specific Strengthen regional law enforcement and other cooperation in measures relation to trafficking of persons with albinism, including through shared databases, MOUs, mutual legal assistance agreements. multi-lateral and bilateral cooperation agreements extradition treaties. Specifically incorporate work on trafficking of persons with albinism into the work of regional police and other regional justice bodies. Best The inter-America region has developed a number of treaties practices on mutual assistance in criminal matters.xcv Similar treaties exist in Europe and west Africaxcvi Regional bodies of administration of justice professionals have been developed in some regions to facilitate cooperation in the area of trafficking. For example, the European Union Agency for Criminal Justice Cooperation (Eurojust), which supports and

strengthens coordination and cooperation between national investigating and prosecuting authorities.xcvii There are also regional police organisations such as the European Police Office (Europol)xcviii and the Southern Africa Regional Police Chiefs Coordination Organisation<sup>xcix</sup> which cooperate on transnational organised crime matters. Resources UNODC training manual on the implementation of the ECOWAS Plan of Action against Trafficking in Persons<sup>c</sup> Law Enforcement Manual for Fighting against Trafficking in Human Beings (UNDP)ci Awareness Training on Trafficking in Human Beings for Police, Border Guards and Customs Officialscii Training materials for judges and prosecutorsciii Training materials for judges and prosecutors (International Centre for Migration Policy Development)civ Model Treaty on Extradition<sup>cv</sup> Model Treaty on Mutual Assistance in Criminal Matters<sup>cvi</sup> Sub-Witness protection thematic Area Specific Establish and implement witness protection laws and policies measures setting out special measures to protect vulnerable witnesses before, during and after a trial, based on individual assessment and taking into account wishes of the witness, and ensuring effective coordination of all relevant services and protections. Ensure all witnesses receive access to information, at the earliest possible opportunity, on expected steps and stages of the case, as well as their rights, available support, where to make complaints if needed, and on the outcome of the police investigation. Such information must be in an accessible format, for example in large print and verbally, particularly for those with low literacy. Ensure police, lawyers, prosecutors and judges, as well as health workers, social workers and other relevant professionals who are likely to come in contact with the victim and witnesses, are trained on particular issues of witness protection specific to

	cases in relation to albinism, as well as information on available victim assistance programmes and their duty to direct victims to places where they can get such assistance
Best practices	<ul> <li>In Bolivia and Bulgaria, for example, training of law enforcement officials who come in contact with child victims and witnesses of crimes is a legal requirement.</li> </ul>
	<ul> <li>In Egypt, the General Administration for the Legal Protection of Children of the Ministry of Justice is responsible for designing training and qualification programmes for members of legal institutions, sociologists and psychologists concerned with matters related to minors.</li> </ul>
Resources	United Nations Convention Against Corruption <sup>cvii</sup>
	UN Convention against Organised Transnational Crime <sup>cviii</sup>
	<ul> <li>UNODC, Good practices for the protection of witnesses in criminal proceedings involving organized crime<sup>cix</sup></li> </ul>
	<ul> <li>Development of a Witness and Victim Support System Croatian experience: good practices and lessons learned<sup>cx</sup></li> </ul>
	<ul> <li>UNODC, Cross-cutting Issues: Victims and Witnesses. Criminal Justice Assessment Toolkit 3<sup>cxi</sup></li> </ul>
	<ul> <li>United Nations International Drug Control Program (UNDCP) Model Witness Protection Bill<sup>cxii</sup></li> </ul>
	Justice in Matters involving Child Victims and Witnesses of Crime Model Law <sup>cxiii</sup>
Sub-	Victim assistance
thematic Area	
Specific measures	<ul> <li>Specifically, in relation to victims, work with civil society to ensure provision of medical, psychological and material assistance as necessary, including counselling and information, in particular as regards their legal rights, in a language they understand, the provision of appropriate housing, and available employment, educational and training opportunities.</li> </ul>

# Best practices

- The European Convention on the Compensation of Victims of Violent Crimes, includes measures designed to alleviate psychological distress as well as to make reparation for the victim's physical injuries." cxiv
- The European Parliament and European Council has also adopted a directive establishing minimum standards on the rights, support and protection of victims of crime.<sup>cxv</sup>
- Organisations such as Safe Child Africa provide medical and emotional support and emergency accommodation shelter for children accused of witchcraft.<sup>cxvi</sup> It is essential that governments take ownership of such programmes, including through providing budget for them and overseeing their functioning to ensure wide coverage, sustainability and prevent further intentional or unintentional violations of rights of victims.

### Resources

- 'Waiting to disappear' International and Regional Standards for the Protection of the Human Rights of Persons with Albinism<sup>cxvii</sup>
- Convention against Organised Transnational Crime<sup>cxviii</sup>
- The Protocol to Prevent, Suppress and Punish Trafficking in Persons<sup>cxix</sup>
- the Declaration of Basic Principles of Justice for Victims of Crime and Abuse of Power.cxx
- UN toolkit to combat trafficking<sup>cxxi</sup>
- Caring for Trafficked Persons: Guidance for Health Providers<sup>cxxii</sup>

### D. Equality and non-discrimination

# Specific measures • Carry out research and data collection, in relation to albinism, aimed at identifying, among other things, the number of persons affected, the prevalent types of albinism, the health needs of persons with albinism, availability of relevant services and support, and obstacles to accessing the services, including capacity needs of health professionals.

# Best practices

- The OHCHR and Equal Opportunities Commission carried out research into discrimination against persons with albinism in Uganda, which looked at concerns regarding the national health programme for persons with albinism.
- Kenya, Tanzania, Namibia and Malawi have included questions on albinism in their national census.
- France's National Plan for Rare Diseases (2018 2022)<sup>cxxiii</sup> aims to improve scientific research in the area of rare diseases, including in relation to identification and detection of rare diseases. Albinism is covered under this plan.<sup>cxxiv</sup> China also started a national registry or rare diseases in 2019 which includes persons with albinism.
- Kuwait uses genetic testing, as well as other technological services and approaches in all hospitals to ensure complete diagnosis, including physical examinations, descriptions of changes in pigmentation and thorough eye examinations.<sup>cxxv</sup> In countries, such as Spain and China, children born with albinism are often referred for genetic testing. However, in China the cost of this is, reportedly, privately-borne.

- Right of persons with albinism to the highest attainable standard of health<sup>cxxvi</sup>
- Applicable international human rights standards and related obligations addressing the issues faced by persons with albinism<sup>cxxvii</sup>
- The 2030 Agenda for Sustainable Development and the human rights of persons with albinism<sup>cxxviii</sup>
- OHCHR and Equal Opportunities Commission (EOC), Enhancing Equality and Countering Discrimination against Persons with Albinism in Uganda<sup>cxxix</sup>
- UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 3<sup>cxxx</sup>
- CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health<sup>cxxxi</sup>

### Sub-Strengthening capacity in relation to health thematic Area Specific Strengthen the capacity of health care professionals to identify measures potential cases of albinism, provide support and advice, as well as refer families to places where they can receive appropriate testing, counselling, information and other relevant services. Take measures to ensure adequate resources, facilities and training of medical professionals to carry out skin cancer screening, detection and treatment, as well as provide optometric and ophthalmological examinations. **Best** In South Africa, genetic counsellors at large public hospitals practices provide counselling to families when a baby is born with albinism. They further provide useful information on how to care for, and protect the child. The Kuwait Medical Genetics Centre provides parents with instructions and advice on precautions to help children learn self-care practices.cxxii Regional Dermatology Training Centre (RDTC) based in Tanzania, for example has provided ophthalmology and dermatology training for doctors from Uganda, Malawi and Kenya. The Dermatology Training Centre at Twomey Hospital in Suva, Fiji also provides similar training for the pacific region. The Fiji Albinism Project has two staff members based at the hospital to provide support in relation to albinism. cxxxiii Countries such as Kenya have also participated in medical professional exchanges with counterparts from the US and Germany on identification and treatment of skin cancer and scientific advances. Optometrists and ophthalmologists in the country have also received capacity building to better understand

how to provide assistance to persons with albinism.cxxxiv

Standing voice has carried out capacity building of health

organisations to work with hospitals.cxxxv

professionals in Malawi. Such trainings were facilitated with the collaboration of the government who issued credentials for the

• In the Democratic Republic of Congo, the organization, Corbetta, created a network for research and multidisciplinary medical care for oculocutaneous albinism in the DRC. They envisage a durable change in the approach to persons with albinism by providing accessible, evidence-based health care, by multidisciplinary expert teams employing tailored electronic health records. This will equally provide a strong basis to promote long-term follow-up and research and thus capacity building among health workers. The network also aims to provide an anchoring point for future initiatives to promote the well-being of persons with albinism, including psychosocial and legal aspects.

### Resources

- Standing Voices, Manual of Best Practice: Skin Cancer Prevention and Management for Persons with Albinism in Africa<sup>cxxxvi</sup>
- WHO, Guide to Cancer Early Diagnosis cxxxvii
- The National Clinical Programme for Rare Diseases, Model of Care for Rare Diseases<sup>cxxxviii</sup>
- Developing methodology for the creation of clinical practice guidelines for rare diseases: A report from RARE-Best practices<sup>cxxxix</sup>

### Subthematic Area

### Addressing boundaries to accessing healthcare

# Specific measures

- Include health professionals as targets of public education aimed at helping individuals understand albinism as a health condition and the needs of person with albinism, thereby demystifying erroneous beliefs about the condition.
- Take measures to ensure adequate resources, facilities and training of medical professionals to carry out skin cancer screening, detection and treatment, as well as provide optometric and ophthalmological examinations.
- Take steps to ensure health services and professionals are available in more remote areas, including through the use of mobile clinics and relevant social protection measures, such as transport allowance.

# Best practices

- Many countries, particularly in Latin America and Europe provide free or subsidised travel for persons with disabilities and persons with albinism qualify for these.
- Organisations such as Standing Voice and Beyond Suncare, working together with government authorities, have put in place programmes carrying out early detection and treatment of skin cancer among persons with albinism through mobile clinics, particularly in Malawi and Tanzania.

### Resources

- Applicable international human rights standards and related obligations addressing the issues faced by persons with albinism<sup>cxl</sup>
- 'Waiting to disappear' International and Regional Standards for the Protection of the Human Rights of Persons with Albinism<sup>cxli</sup>
- WHO, Increasing access to health workers in remote and rural areas through improved retention: Global policy recommendations<sup>cxlii</sup>

### Subthematic Area

### Social protection measures

# Specific measures

 Put in place social protection measures targeting the health of persons with albinism that extend beyond visual impairment to include barriers to interaction, such as susceptibility to skin cancer and other complications, including provision of sun care products, protective clothing, screening, detection and treatment of cancer, as well as genetic testing to determine type of albinism. Social protection measures should also take into account extra related costs, such as travel for those unable to afford these

# Best practices

- Measures specifically for persons with albinism include, the provision of free sunscreen, lip care, after sun, protective clothing, screening, detection and treatment of cancer, optometric and ophthalmological tests, as well as access to visual aids and other forms of adaptive devices, such as glasses and magnifying glasses. Such measures are in place in countries such as Fiji, Kenya, cxliii Malawi, Mozambique, cxliv Nigeria and Tanzania, cxlv as well as some States in Brazil.cxlvi
- In France, persons with albinism can obtain sunscreen as part of the rare diseases plan, but this is reportedly difficult to access.<sup>cxlvii</sup>

- In many European countries, persons with disability may qualify for subsidies, tax exemptions and rebates, access to free services or products, as well as cash transfers depending on the extent of their impairment. In the UK, depending on their age, persons with albinism often meet the criteria for Disability Living Allowance or Personal Independence Payments. Both seek to help with the costs of having a long-term disability and can be used for costs beyond those associated with visual impairment
   In Uganda, the revenue authority provides tax exemptions on imported products to support the health of persons with albinism, such as sunscreen, thus enabling organisations to import donated sunscreen and other products duty-free. cxlix
- Organisations such as Standing Voices and Beyond Suncare, working together with government authorities, have also put into place programmes carrying out early detection and treatment of skin cancer among persons with albinism, particularly in Malawi and Tanzania. Senegal provides free basic health care to persons with albinism.<sup>cl</sup>
- In most countries in the EU, persons with albinism also receive free skin cancer screening, detection and treatment as part of the public health service.<sup>cli</sup>

### Resources

- Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Rwanda<sup>clii</sup>
- Report of the SR on Disability, Social Protection and Disability Cliii
- International Alliance of Persons with Disabilities, Ensuring that the Social Protection Floor Works for Persons with Disabilities<sup>cliv</sup>
- World Bank, Social Safety Nets and Disability<sup>clv</sup>

### Subthematic Area

Laws and national policy framework

# Specific measures

 Enact laws and policies to guarantee the rights of persons with albinism to relevant social protection measures and nondiscriminatory treatment in public and private health services and ensure effective remedies for the violation rights.

# Best practices

 Tanzania has enacted a Persons with Disability Act which provides for healthcare fee waivers for persons with disabilities, including for persons with albinism. Guidelines on support

services for children with albinism have been developed under the Act. clvi Panamaclvii and the Argentine Province of Misionesclviii have specific laws on albinism, including in the area of health and education. • Argentina<sup>clix</sup> and Brazil<sup>clx</sup> have proposed laws on albinism which, among other things, provide for regular skin examination, skin cancer treatment, sun care products and assistive devices for persons with albinism, as well as calling for scientific research and training for health professionals on the care of persons with albinism. Uganda, Nigeria and Puerto Rico have proposed laws specifically on albinism. Resources Applicable international human rights standards and related obligations addressing the issues faced by persons with albinism<sup>clxi</sup> Right of persons with albinism to the highest attainable standard of healthclxii The 2030 Agenda for Sustainable Development and the human rights of persons with albinism clxiii UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 3clxiv • CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Healthclxv 'Waiting to disappear' International and Regional Standards for the Protection of the Human Rights of Persons with Albinism<sup>clxvi</sup> Sub-International cooperation thematic Area Specific Seek technical and financial assistance to strengthen health measures services, particularly in relation to detection of albinism and treatment of associated conditions, as well as understanding scientific and technological advances in prevention and treatment of such conditions, assistive and adaptive devices and other advances relevant for persons with albinism.

### Best WHO has also produced guidelines to facilitate health planning practices and improve timely diagnosis and access to cancer treatment. clxvii • Organisations like Beyond Suncare have partnered with countries like Malawi and Tanzania in producing tailor-made sunscreen. clxviii • Official launch in Togo of a project for prevention and treatment of dermatological conditions specific to people with albinism during the 2nd Pan-African tele-dermatology forum organized by SOTODERM and the Pierre Fabre Foundation in June 2019. WHO, Guide to Cancer Early Diagnosisclxix Resources Education Sub-Research and data collection thematic Area Specific Carry out research and data collection to understand challenges measures to accessing education for persons with albinism and ensure appropriate measures are developed to address the situation. **Best** The OHCHR and Equal Opportunities Commission carried out practices research into discrimination against persons with albinism in Uganda, which included barriers to education Resources Applicable international human rights standards and related obligations addressing the issues faced by persons with albinismclxx The 2030 Agenda for Sustainable Development and the human rights of persons with albinism<sup>clxxi</sup> OHCHR and Equal Opportunities Commission (EOC), Enhancing Equality and Countering Discrimination against Persons with Albinism in Ugandaclxxiii 'Waiting to disappear' International and Regional Standards for the Protection of the Human Rights of Persons with Albinism clxxiii World Bank's Strategies to increase girl education<sup>clxxiv</sup> UNICEF, Barriers to Girls' Education, Strategies and Interventionsclxxv UNICEF, strategy on inclusive education clxxvi DfID, Girls' education: towards a better future for allclxxvii

### Sub-Strengthening capacity in relation to education thematic Area Specific measures Build the capacity of educators to understand the needs of students with albinism, enable them to make reasonable accommodations, respond to cases of bullying and direct students to where they can obtain services to assist them. Provide schools with relevant resources to assist students with albinism, including textbooks in large print, or printers to provide large-print material, as well as assistive and adaptive devices. Best In Kenya, part of the budget provided by the State in relation to practices albinism includes awareness raising campaigns by organisations of persons with albinism, included targeted at places of learning. In Tanzania, Under the Same Sun carries out "Understanding Albinism" seminars targeting educators of all levels including training on reasonable accommodation for persons with albinism. • NOAH, Schoolkitclxxviii Resources Quick Guide for Teachers and Educators of persons with albinism by Under the Same Sunclexix • Albinism: An Information Booklet for Teachers in Tanzania.clxxx • Federal Republic of Nigeria, Core Messages on Albinism Educationclxxxi Sub-Countering attitudinal barriers thematic Area Specific Put in place awareness-raising programs targeting schools, measures parents and the community to counter attitudinal barriers to education. Best Organisations of persons with albinism carry out sensitisation at practices schools or provide information to parents and teachers of children For example, the National Organization for with albinism. Albinism and Hypopigmentation (NOAH), has developed a Schoolkit which provides information and resources to guide parents in supporting teachers of a student with albinism in their classroom.clxxxii Such activities by NGOs require State funding to ensure sustainability as well as adequate coordination to prevent duplication and ensure wide coverage throughout its territory. In this regard. Kenya has allocated part of the State budget for the

national albinism support program to awareness raising campaigns, including in schools.

In Togo, the Association Nationale des Albinos du Togo (ANAT)
has organized awareness trainings targeted at the Education
system: regional directors for education, inspectors, school
directors, teachers and parents.

### Resources

- NOAH, Schoolkit
- Quick Guide for Teachers and Educators of persons with albinism by Under the Same Sun
- Federal Republic of Nigeria, Core Messages on Albinism Education<sup>clxxxiii</sup>

### Subthematic Area

### Appropriate legal and policy framework

# Specific measures

 Develop and implement legislation and national education policies for inclusive education of persons with albinism, setting out required reasonable accommodation measures including and beyond those related to visual impairment.

# Best practices

- In Tanzania, the government introduced the Inclusive Education Strategy (2012–2017), which included a guide for teachers of students with albinism in their teacher-training curriculum. The Ministry of Industry and Trade has also been instructed the to produce assistive devices for children with albinism. clxxxiv
- In Malawi, the government has printed low-vision-friendly, special texts for students with albinism since 2012.clxxxv
- In Fiji, the ministry responsible for education and civil society organisations have worked together through the Fiji Albinism Project to develop a special inclusive education policy for students with albinism.<sup>clxxxvi</sup>

The Federal government of Nigeria worked with the Albino Foundation of Nigeria in producing the national education policy and guidelines on reasonable accommodation measures for persons with albinism.clxxxvii

- NOAH, Schoolkit
- Quick Guide for Teachers and Educators of persons with albinism by Under the Same Sunclexxxviii

- Albinism: An Information Booklet for Teachers in Tanzania. clxxxix
- Federal Republic of Nigeria, Core Messages on Albinism Education
- OHCHR and Equal Opportunities Commission (EOC), Enhancing Equality and Countering Discrimination against Persons with Albinism in Uganda<sup>cxc</sup>
- 'Waiting to disappear' International and Regional Standards for the Protection of the Human Rights of Persons with Albinism<sup>cxci</sup>

### Subthematic Area

### Tackling physical and security barriers to school

# Specific measures

- Ensure social protection measures aimed at increasing school attendance are available to children with albinism.
- Put in place measures to protect children traveling to school from increased exposure to the sun, as well as from attacks in countries where these occur.

# Best practices

 Measures that have been adopted in relation to other vulnerable groups have included school mapping aimed at ensuring schools are within a reasonable distance to communities, and the provision of transport or transport allowance for those living a specified distance or more away from schools. Security measures such as increasing police patrols on routes to schools, street lights where children have to walk home in the dark particularly in winter, and flexible school times to prevent students walking home in the dark have also been used.

- OHCHR and Equal Opportunities Commission (EOC), Enhancing Equality and Countering Discrimination against Persons with Albinism in Uganda<sup>cxcii</sup>
- UNICEF, Barriers to Girls' Education, Strategies and Interventions<sup>cxciii</sup>
- UNICEF, strategy on inclusive education<sup>cxciv</sup>
- DfID, Girls' education: towards a better future for all<sup>cxcv</sup>

Sub-	Alles de tipo e financial la amiana
thematic	Alleviating financial barriers
Area	
Specific measures  Best practices	Put in place social protection measures aimed at increasing school attendance for children with albinism which take into account the extra costs associated with ensuring protection from the sun and attacks.  • Zimbabwe's National Plan for Orphan and Vulnerable Children (2011 – 2015) provided access to primary and secondary schools
	In Bangladesh, the government provides stipend for children with disabilities in education, as well as a school feeding programme.
	disabilities in education, as well as a school feeding programme. Similar cash transfer programmes exist for persons with disabilities in Malaysia and children with albinism qualify on the basis of low vision. cxcvii
	<ul> <li>In the Democratic Republic of Congo, UNICEF has worked with Ministry of Education to provide grants to schools to cover fees for students from lower-income households, including children with albinism, as well as school supplies and extracurricular activities, and tutoring sessions for children with learning difficulties.cxcviii</li> </ul>
	<ul> <li>In some countries, like in China and Rwanda, the State provides scholarships an assistive devices for persons with visual impairments attending tertiary education, but persons with albinism do not usually qualify for these. Similar measures should be implemented for persons with albinism.</li> </ul>
Resources	Social Protection and Access to Education <sup>cxcix</sup>
Sub- thematic Area	Policies beyond formal education
Specific measures	<ul> <li>Ensure children with albinism are able to access early childhood care and education, including through requiring nursery schools to accept them and ensuring social protection measures in relation to education extend to pre-primary school children.</li> <li>Adopt measures to assist persons with albinism to transition from</li> </ul>
	school to the workforce.
Best practices	<ul> <li>The Adolescent Girls Initiative implemented in several countries with the support of the World Bank could be a useful initiative for persons with albinism as well. The initiative seeks to combine education grants with business development skills training, technical and vocational training targeting skills in high demand,</li> </ul>

as well as life skills training to change behaviours and instil confidence.cc In relation to albinism, organisations in Kenya for example, have worked with the private sector in assisting graduates with albinism obtain internships and work opportunities.cci Some countries have sponsored vocational training programmes which include persons with albinism. For example, in China, persons with albinism are provided training in traditional Chinese massage and piano tuning. Resources The World Bank, Adolescent Girls Initiative ccii Work Sub-Research and data collection thematic Area Specific • Carry out research and data collection to fully understand the measures barriers to work for persons with albinism and put in place measures to counter these. Best practices Resources Applicable international human rights standards and related obligations addressing the issues faced by persons with albinismcciii The 2030 Agenda for Sustainable Development and the human rights of persons with albinism<sup>cciv</sup> Sub-Countering attitudinal barriers thematic Area Specific Put in place educational and awareness raising campaigns to tackle attitudinal barriers to accessing work measures Best practices Resources The Purple Workforce: A report by Leigh Day into the experiences of disabled people in the workplace<sup>ccv</sup> European Commission, Combating discrimination in the workplaceccvi

Sub- thematic Area	Appropriate legal and policy framework
Specific measures	<ul> <li>Provide appropriate legal and policy framework, including requiring workplaces to make reasonable accommodations for persons with albinism and affirmative action programmes for persons with albinism to level the playing field.</li> </ul>
Best practices	Some countries, have positive action programmes in place, including measures requiring workplaces to employ a certain percentage of persons with disability. Persons with albinism are often included in this due to low vision. In such countries, employers are expected to make reasonable accommodations for persons with disability in their employ and the State may provide tax rebates for those who do.
Resources	Council Recommendation of 24 July 1986 on the employment of disabled people in the Community (86/379/EEC) <sup>ccvii</sup>
Sub- thematic Area	Social protection measures
Specific measures	<ul> <li>Implement social protection measures to assist persons with albinism access work opportunities, such as the provision of vocational and skills training.</li> </ul>
Best practices	<ul> <li>In China, persons with albinism are provided training in traditional Chinese massage and piano tuning.</li> </ul>
Resources	None reported

### E. Guiding principles for implementing action plans

Sub- thematic Area	Multi-sectoral and inter-agency approach at national level
Specific measures	<ul> <li>Put in place a method of ensuring multi-sectoral coordination and cooperation in the development, implementation and evaluation of the national plan, such as setting up an inter- agency coordination mechanism to facilitate cooperation, including in relation to training and capacity-building of various agents</li> </ul>
Best practices	<ul> <li>UNICEF sponsored a multi-sectoral situational analysis of barriers to accessing justice for attacks against persons with</li> </ul>

albinism in Malawi. The country also carried out a joint parliamentary committees' formal enquiry into the problem of attacks on persons with albinism, done jointly by the Legal Affairs; the Defence and Security; and the Social and Community Affairs committees.

- Malawi has a National Technical Committee on Albinism Issues in Malawi. The committee is composed of stakeholders from various sectors, including government ministries, association of persons with albinism, other civil society and faith-based organisations and organisations of traditional healers. Mozambique has a similar structure in place per its Multisectoral Plan to Address the Issue of the Protection of Persons with Albinism.<sup>ccviii</sup>
- The Fiji Albinism Project, which seeks to raise awareness and address issues around albinism, is governed through multisectoral coordination among the ministries responsible for health, education and women's issues. It also includes civil society.<sup>ccix</sup> South Africa also has a similar set up with State and civil society coordination.<sup>ccx</sup>
- In relation to trafficking, a number of coordination mechanisms have been set up such as the Netherland's National Rapporteur on Trafficking in Human Beings and Sexual Violence against Children.<sup>ccxi</sup> In Finland, the Non-Discrimination Ombudsman is the National Rapporteur on Trafficking in Human Beings.<sup>ccxii</sup> Other countries in Europe have mechanisms responsible for oversight of trafficking as part of other bodies.<sup>ccxiii</sup>

#### Resources

- SDG 17 calls for global partnerships for the implementation of the SDGs. This includes in relation to resource mobilisation, technology, capacity building, data, monitoring and accountability.<sup>ccxiv</sup>
- UNODC Tool 2.5 provides guidelines for States in developing a multi-sector plan of action<sup>ccxv</sup>
- COMPENDIUM of good practices on the implementation of the Council of Europe Convention on Action against Trafficking in Human Beings<sup>ccxvi</sup>

Subthematic Area

Regional and international coordination and collaboration

## Specific measures

- Cooperate with other States, including through research, capacity building, information exchange, sharing of best practices, technical and financial assistance, for the purposes of increasing the knowledge base and capacity to carry out and improve protection measures
- Develop regional action plans on albinism

# Best practices

- Regional Action Plan on Albinism in Africa provides a framework for collaboration in the region
- In August 2019, the Parliamentary Forum of the Southern Africa Development Community adopted a motion condemning attacks, abductions, killings and discrimination against persons with albinism.<sup>ccxvii</sup>
- The governments of Malawi, Tanzania and Mozambique have also drawn up MoUs and joint plans of action in relation to albinism
- International organisations have developed regional approaches to working which include State authorities. For example, IOM and UNICEF in Mozambique, Tanzania and Malawi have partnered in developing actions to counter attacks against persons with albinism in the three countries and across the borders of the countries.<sup>ccxviii</sup>

### Resources In relation to developing a national plan of action:

- Report of the Independent Expert on albinism, Addendum -Regional Action Plan on Albinism in Africa (2017–2021)<sup>ccxix</sup>
- The 2030 Agenda for Sustainable Development and the human rights of persons with albinism<sup>ccxx</sup>
- Applicable international human rights standards and related obligations addressing the issues faced by persons with albinism<sup>ccxxi</sup>

#### In relation to trafficking

- Legislative Guide for the United Nations Convention against Transnational Organized Crime and the Protocols thereto ccxxii
- ASEAN Plan of Action Against Trafficking in Persons<sup>ccxxiii</sup>

- Regional Policy on Protection and Assistance to Victims of Trafficking in Persons in West Africa and Central Africa<sup>ccxxiv</sup>
- Guiding Principles for the Protection of Victims of Trafficking in the Greater Mekong Sub-Region<sup>ccxxv</sup>
- OSCE Action Plan to Combat Trafficking in Human Beings<sup>ccxxvi</sup>

### Subthematic Area

#### Budgeting for human rights

## Specific measures

- Prioritise marginalised groups, such as persons with albinism in national budgets, in accordance with international human rights standards; immediately implement measures not requiring much funding, such as enactment of laws; and actively mobilise resources for the implementation of other measures, including through international cooperation.
- Seek to continually move towards the full realisation of rights for persons with albinism and ensure transparency and active participation of persons with albinism in resource mobilisation, allocation and expenditure.

# Best practices

- Some countries have put in place measures to reduce costs for associations of persons with albinism. For example, in some countries, such as Argentina, Burundi, China, France, Malaysia and Spain, associations of persons with albinism qualify for a small cash transfer or tax rebate given to all charities from the State to assist with their work.<sup>ccxxvii</sup>
- Tax exemptions on sunscreen and assistive devices have also enabled associations to obtain such products free or at a reduced rate. Tax rebates for donations to associations of persons with albinism also assist these organisations.
- In Spain, an association for persons with visual disabilities, which also supports persons with albinism, has an agreement with the State to run a lottery to raise funds.
- In Nigeria, the State has worked with civil society in raising funds for disability rights, including for persons with albinism. The Ministry of Finance signs agreements between development partners and civil society as a grantor, with civil society having to report both to the development partners and the State.

- In Uganda, parliament carries out an annual charity walk which aims to raise funds for the construction of a rehabilitation centre for persons with albinism. ccxxviiii
- Kenya, Malawi, and Nigeria have specific budgets allocated to protection measures. These budgets were developed with the inclusion of persons with albinism. In some cases, a small part of the budget is allocated directly to relevant associations to carry out programmes, while the rest is allocated to public institutions for implementation of specific measures.

#### Resources

- The 2030 Agenda for Sustainable Development and the human rights of persons with albinismccxxix
- Applicable international human rights standards and related obligations addressing the issues faced by persons with albinism<sup>ccxxx</sup>
- Report of the Special Rapporteur on poverty, Philip Alston' (2015) UN Doc A/HRC/29/31<sup>ccxxxi</sup>
- 'Report of the Independent Expert on foreign debt, Juan Pablo Bohoslavsky' (2016) UN Doc A/HRC/31/60<sup>ccxxxii</sup>
- General Comment No. 20, Non-Discrimination in Economic, Social and Cultural Rights (art. 2, para. 2) U.N. Doc. E/C.12/GC/20 (2009)
- Guiding principles on human rights impact assessments of economic reforms - Report of the Independent Expert on the effects of foreign debt and other related international financial obligations of States on the full enjoyment of human rights, particularly economic, social and cultural rights<sup>ccxxxiii</sup>
- IBAHRI, "The Obligation to Mobilise Resources: Bridging Human Rights, Sustainable Development Goals, and Economic and Fiscal Policies" CCXXXIV
- OECD (2014), "How to better mobilise resources for sustainable development<sup>ccxxxv</sup>
- Human rights budget work: What, why, how?, Briefing paper 3: Human right budgeting<sup>ccxxxvi</sup>

- OHCHR and International Budget Partnership (IBP), Realizing human rights through government budgets<sup>ccxxxvii</sup>
- IMF, The Fiscal Transparency Code (2019) CCXXXVIII
- IMF, Fiscal Transparency Handbook (2018) ccxxxix

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https://www.ohchr.org/EN/Issues/Albinism/Pages/AlbinismInAfrica.aspx

11/IASC%20Guidelines%20on%20the%20Inclusion%20of%20Persons%20with%20Disabilities%20in%20Humanitari an%20Action%2C%202019.pdf (accessed 26/03/2020)

<sup>&</sup>lt;sup>1</sup> Report of the Independent Expert on albinism, The 2030 Agenda for Sustainable Development and the human rights of persons with albinism, A/73/181, <a href="https://ap.ohchr.org/documents/dpage\_e.aspx?si=A/73/181">https://ap.ohchr.org/documents/dpage\_e.aspx?si=A/73/181</a> (accessed 11/05/2020)

il Interviewee from Argentina referring to Ley Nacional De Albinismo, Camara de Diputados de la Nacion, Buenos Aires, 20 Nov 2019

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