



MINISTRY OF GENDER, LABOUR AND SOCIAL DEVELOPMENT

THE NATIONAL ACTION PLAN FOR PERSONS WITH ALBINISM 2020 – 2025



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NATIONAL ACTION PLAN FOR PERSONS WITH ALBINISM 2020-2025

EXECUTIVE SUMMARY

1.0. Introduction

1.1. Background

Persons with albinism are a vulnerable group that faces multiple and intersecting forms of discrimination just because of who they are. Their rights to life, physical integrity, liberty, security, equality and non-discrimination, health, education, and an adequate standard of living are often severely threatened. Witchcraft-related beliefs practices myths and superstitions have influenced serious violations of human rights of persons with albinism in many parts of the world. They have been subjected to discrimination, banishment, cutting of body parts and amputation of limbs, torture, and murder due to these unfounded beliefs. Violations of the human rights of persons with albinism take place in Africa including in Uganda.

Uganda has taken some steps toward addressing discrimination against Persons with Albinism (PWA). Of note is the recognition of albinism as a form of disability by the Persons with Disabilities Act, 2019, a study that analyzed the situation of persons with albinism in Uganda. The role played by albinism civil society organizations (CSO) has been instrumental in increasing awareness about albinism and promoting debate about equality and inclusion of persons with albinism. The Parliament of Uganda, the Uganda Human Rights Commission, and the Equal Opportunities Commission have supported initiatives for the inclusion and elimination of discrimination against persons with albinism. The Office of the High Commissioner for Human Rights (OHCHR) and the Open Society Initiative in East Africa (OSIEA) have partnered these efforts at the national level, engaging with both national institutions and CSOs to raise awareness, build capacity and seek to counter stigma and discrimination faced by PWA.

1.2. Situation of persons with albinism in Uganda.

The study Report *“Enhancing Equality and Countering Discrimination against Persons with Albinism”* show that persons with Albinism in Uganda remain among those left the furthest behind in society. The report noted that a complete absence of systematic interventions and strategic planning has resulted in continued stigma and discrimination against persons with albinism, which in turn affect their capacity to fully enjoy their rights to equality and non-discrimination, health, education, work, social protection and to security, among others.

Albinism is legally recognized in Uganda as a form of disability by the Persons with Disability Act, 2019. This has the effect of opening up support and protection for persons with albinism under disability schemes promoted by the government. Despite this legal recognition,

practical actions are required both at the national and community levels to address the specific needs of this marginalized group. In particular, the lack of official statistics and lack of knowledge about albinism and myths regarding this genetic condition, including among providers of basic social services such as teachers, medical personnel, and other government officials, have very detrimental effects on the enjoyment of human rights by persons with albinism.

2.0. Overview of the regional and international instruments

2.1. International Legal Instruments

Many international and regional binding human instruments are relevant for the promotion, protection, and fulfillment of the rights of persons with albinism. Uganda has ratified several of these instruments that commit her to promoting equality and combating discrimination. The instruments include the following: the International Covenant on Civil and Political Rights (ICCPR), 1966; the International Covenant on Economic Social and Cultural Rights (ICESCR), 1966; the Convention on the Elimination of Discrimination Against Women (CEDAW), 1979; the Convention on the Rights of the Child (CRC), 1989; the Convention on the Rights of People with Disabilities (CRPD), 2007; the International Covenant on the Elimination of Racial Discrimination (ICERD), 1965, among others. Based on the Universal Declaration of Human Rights, these instruments impose legal obligations on States to respect, promote and protect the right to equality and non-discrimination, including by taking steps toward the elimination of discrimination.

The ICCPR provisions guarantee persons with disabilities equal rights and protection of the law. Like the ICCPR, the ICESCR guarantees the equal enjoyment of all the economic, social, and cultural rights by all persons without discrimination of any kind including disability. The CRDP marks a 'paradigm shift' in attitudes and approaches to persons with disabilities: Persons with disabilities are not to be viewed as "objects" of charity, medical treatment, and social protection; rather as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.

2.2. Regional Legal and Policy Framework.

At the regional level, Uganda is a party to, among others, the Constitutive Act of the African Union, 2000, the African Charter on Human and Peoples Rights (ACHPR), 1981, the Protocol to the African Charter on Human and Peoples Rights on the Rights of Women in Africa, 2003 and the African Charter on the Rights and Welfare of the Child, 1990. These instruments guarantee all citizens the enjoyment of rights and freedoms recognized under them, including the right to health, and education, and under them Uganda is obliged to take the necessary measures to ensure the enjoyment of these rights.

The East African Community (EAC) has developed a policy on Persons with Disabilities. The policy objective is to promote equalization of opportunities for persons with disabilities and generally to guide member states on the best approach to promote and protect their rights. Member states agreed to use the policy to inform their policies, programs, and sectoral plans. The policy requires, among others, elevating the disability sector into a high profile ministry

for visibility; promoting special and vocational education at all levels; economic empowerment; promoting accessibility to facilities; social protection; ensuring inclusion and participation, and representation of persons with disabilities; provision of care and support; research and documentation on issues of disability; affirmative action programs; and awareness creation on disability issues.

2.3. Overview of some relevant National Legal and Policy Framework.

The Uganda Legal framework supports the promotion and protection of the rights of marginalized groups. Chapter 4 of the Constitution outlines the basic framework for the protection of everyone in Uganda including persons with albinism. It is important to note that under the Constitution *“All persons are equal before and under the law in all spheres of political, economic, social and cultural life and in every other respect and shall enjoy equal protection of the law”*. And the Constitution is explicit that a person shall not be discriminated against on the basis of color or disability. Under the Constitution, the State has the duty to take affirmative action in favor of groups marginalized on account of gender, age, and disability.

The Constitution mandates the Courts and the UHRC to entertain complaints of human rights violations and provide remedies for victims of violations. The UHRC also has a duty to monitor if state organs and agencies are complying with the human rights standards for persons with disability. It also has a duty to create awareness of the rights of persons with disability and can recommend to Parliament effective measures to promote human rights, which include the human rights of persons with disabilities. The Constitution also establishes the Equal Opportunities Commission for the purpose of eliminating discrimination and inequalities against any individual or group of persons.

2.4. The National Institutional framework

The following national institutions have a legal responsibility to promote and protect the rights of persons with albinism: Parliament under Article 35 of the Constitution, has a duty to pass appropriate laws that promote disability rights; The Ministry of Gender, Labour and Social Development has the overall responsibility for disability matters. Under the Ministry of Gender are semi-autonomous institutions namely the National Council on Persons with Disabilities (NCPD); the Equal Opportunities Commission and the decentralized Local Government Community Development Departments. In addition to these institutions, Ministries, departments, and agencies of government implement programs that should address the rights of persons with albinism. It is therefore important that albinism issues, being crosscutting, should be integrated into all central and local government programmes.

3.0. The National Action Plan

3.1. Nature of the National Action Plan

The NAPPWA was developed with the active participation of organizations of persons with albinism and other relevant stakeholders who had opportunities to make input in the selection of the priorities and content of the plan through a Task Force. The plan has agreed on principles for promoting and protecting the rights of persons with albinism in Uganda and covers the objectives and specific intervention measures. Its implementation will be supervised by a National Coordinating Committee composed of relevant ministries,

departments, and agencies of local and central government and representatives of persons with albinism.

The plan provides for its monitoring and evaluation which will be carried out through interim assessments and evaluation at the conclusion of the plan. The NAPPWA is to be a dynamic instrument to allow for possible modification by the introduction of suitable priorities in the field of measures and indicators.

3.2. Principles and fundamentals of the National Action Plan.

The Plan has fundamentals that are based on key principles that will guide the implementation of the plan. These are:

1. **Inclusion:** The goal of the NAP conforms to the United Nations Convention on the Rights of Persons with Disabilities of promoting an inclusive society in which persons with disabilities and other disadvantaged persons can participate in all activities of the society. The plan aims at implementing measures to ensure that the lives of persons with albinism will differ as little as possible from those of other persons in society.
2. **Participation:** Persons with albinism will be involved from the initial stages of all plans which are relevant to them and subsequently consulted on an ongoing basis during the implementation of the plans.
3. **Independence:** the plan has measures to enable persons with albinism to grow, develop and live an independent life in dignity and to effectively participate in society.
4. **Equal opportunities and Equal treatment:** The plan aims at eliminating discrimination against persons with albinism, particularly in the field of education, health and employment, and society.
5. **Recognition and Respect of Diversity:** The Plan will promote the general recognition of the reality that persons with albinism form part of diversity in Uganda society to be recognized and treated as human beings and appreciated within society.
6. **Albinism mainstreaming:** The plan requires that all plans of the government and its agencies must apply the principles and objectives of this plan and mainstream the issues concerning persons with albinism in all their plans and activities.
7. **Self-advocacy:** The plan calls for the promotion of the self-confidence of persons with albinism by their participation in implementing programs that concern them and in self-advocacy programs and activities that ensure they are seen and get heard in society.

4.0. Priority areas of the National Action Plan

The plan has 10 Priority Areas for implementation namely:

1. **Awareness Raising:** aimed at demystifying myths, superstitions, and stereotypes about albinism and the negative consequences of such strongly held beliefs about persons with albinism in society and in public and private institutions that provide services. This will be carried out through appropriate strategies that include sustained multimedia campaigns; sensitization of persons with albinism and their parents/families; training of journalists; awareness-raising in schools; building the

capacities of the NCPD; UHRC, EOC, MDAs, and CSOs on issues of disability; producing and disseminating relevant information, communication, and education materials; producing and distributing Guidelines on handling learners with albinism in schools; and publicizing this plan.

2. Access to health care: aims at providing persons with albinism with the same range, quality, and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs and those health services needed by persons with albinism specifically because of their condition and or disabilities, including early identification and intervention as appropriate, and eliminate discrimination against persons with albinism in the provision of health services. This will be implemented through measures that include: a minimum healthcare package that includes free sunscreen lotions, wide-brimmed hats, and protective and corrective eyeglasses; free cancer and eye services to persons with albinism; equipping medical and nursing staff and all health workers and traditional healers with knowledge on albinism and the medical needs of persons with albinism; and making available counseling services to persons with albinism and their parents.
3. Access to all levels of education: This priority aims at promoting and protecting the rights to education of persons with albinism guaranteed under Article 30 of the Constitution, Section 10 of the Children Act, 1996, Section 6 of the Persons with Disability Act, 2020, Section 28 (3) of the Universities and Other Tertiary Institutions Act, 2001 as Amended, and the CRPD. The objective is to provide persons with albinism access to inclusive and quality education at all levels on an equal basis with others, and the support required, such as reasonable accommodation, within the general education system. The priority will be implemented through measures that include affirmative action for enrolling, retaining, and supporting persons with albinism in the general education system, training teachers on albinism and concerns of persons with albinism, introducing and enforcing guidelines on responding to the needs of learners with albinism, and introducing security arrangements in schools to ensure the safety of learners with albinism.
4. Access to work and employment: This priority aims at promoting employment opportunities and career advancement for persons with albinism in the public and private sectors, opportunities for self-employment, entrepreneurship, and the formation of cooperatives by persons with albinism, and protecting their rights to favourable conditions of work. The Plan will achieve all these through measures that include providing the needed skills for the job market, reviewing or introducing laws to provide quota systems to ensure persons with albinism get employed, and financial support for them to engage in business or self-employment. In addition, persons with albinism and MDAs will be trained on the rights of persons with albinism.
5. Children with albinism: the objectives of this priority are to regularly collect official data on children with albinism for planning purposes, provide individual support to children with albinism from an early age, provide assistance to parents of children with albinism,

and ensure that the basic rights and freedoms of children with albinism are protected in all spheres of life. The strategies under this priority are implementing programs for registration of children with albinism and providing social support to them, mainstreaming their issues in early childhood development programs, and raising awareness about children with albinism within communities.

6. **Women with albinism:** This priority aims at responding to the peculiar challenges facing women with albinism because they are women. Women with albinism are disadvantaged in the areas of education, healthcare, and employment and are always in danger of sexual violence because of unfounded beliefs about the curative effect of sex with them. They are discriminated against in marriage and in sexual reproductive rights. The objectives here therefore to ensure that the basic rights of women with albinism are protected in all spheres of life, including self-determined sexuality, and to provide support to single mothers of children with albinism. The Plan will address these challenges through affirmative action to protect women with albinism, providing them awareness about their human rights, mainstreaming their issues into all plans about women, and providing material, legal, social and psychosocial support to single parents of children with albinism.
7. **Refugees with albinism:** In spite of the provisions of the Refugee Act, 2006, people with albinism who are refugees or asylum seekers are still susceptible to the risk of discrimination and suffer disadvantages in everyday life especially when they are confined in refugee settlements. Accordingly, they require specific measures for their protection. The objectives of this priority are to ensure refugees with albinism: enjoy equal rights as nationals with albinism except for those rights not accorded to refugees under international law, receive specific interventions to protect and fulfill their basic rights and needs, and refugee learners with albinism access quality education at all levels, and they receive needed skills for livelihood. These will be achieved by mainstreaming their rights and issues into refugee programs, sensitizing refugees and refugee agencies about albinism and the rights of persons with albinism, integrating the issues of refugees with albinism into national preprograms for persons with albinism, and introducing programs for skilling and building their self-esteem.
8. **Policies and laws:** The objectives of this priority are to introduce policies and laws that protect the rights of persons with albinism, implement specific affirmative action notably special grants and poverty alleviation and social protection programs for persons with albinism, and the inclusion of specific concerns and population of persons with albinism in official government data and in national and local government programs and budgets. The priority will be realized by the following measures: reviewing, amending, or repealing policies that discriminate against persons with albinism, where necessary enacting a new law to domesticate the provisions of relevant regional and international instruments, amending the Witchcraft Act, collecting accurate data on persons with albinism, and integrating the needs of persons with albinism in the national poverty alleviation, social protection, and welfare programs.

9. **Accountability:** The objectives here are to document and regularly report on the situation of persons with albinism, combat impunity for violations of their rights and support victims, and monitor the implementation of the NAPPWA. The measures for this will be implementing programs to monitor the situation of persons with albinism and the implementation of laws, policies, and programs for their protection, holding accountable violators of their rights and providing legal support to victims.
10. **Safety and security of persons with albinism:** Ensuring the safety and security of persons with albinism entails implementing preventive and protective measures to effectively respond when persons with albinism are attacked or under threat. Perpetrators must be brought to justice and victims should receive appropriate remedies. The objectives of this priority are to prevent violence and attacks against persons with albinism motivated by unfounded beliefs about their body parts and to ensure that victims of attack access appropriate remedies. The measures to be employed are engaging the public about the safety and security of persons with albinism, establishing a database about them and their places of abode, establishing protective measures within communities, and ensuring quick prosecution of violators.

5. Coordination of the implementation of the NAPPWA

5.1. Implementation arrangements

The NAPPWA implementation is to be supervised by a National Coordinating Committee (NCC) composed of relevant ministries, departments, and agencies of central government and local governments and representatives of persons with albinism. The government through the Ministry of Gender, Labour, and Social Development will be responsible for overseeing its implementation. There will be important roles for all stakeholders (public and private sectors, development partners, and CSO) because the issues about persons with albinism are crosscutting in all development sectors. Existing national structures established by the Persons with Disability Act, 2020 namely NCPD and the Local Government Councils for Persons with Disability will equally have key roles.

5.2. Functions of the NCC.

The NCC will initiate development programs and recommend them to government and development partners for funding, assist in the mobilization of funds, oversee and monitor implementation of activities, and undertake interim assessments and evaluations. It will also coordinate different CSOs serving persons with albinism, coordinate advocacy programs, and publicize the NAPPWA, link persons with albinism with national, regional, and international stakeholders. The NCC will be the Secretariat on issues of persons with albinism.

6. Budget and Financing of the NAPPWA

6.1. Financing the NAPPWA

All Priority areas of the plan have budget estimates. The total estimated expenditure for a 5-year period is Uganda Shilling **17,871,998,400** amounting to US Dollars **4,964,444** calculated at the mean rate of 1 US Dollar to 3,600 Uganda Shillings. This translates to under 1 million US

Dollars per annum, an amount comparable to what our neighbors Tanzania and Kenya spend to promote and protect the rights of people with albinism.

The success of the plan will depend largely on the availability of funds. The Government will, in accordance with its obligation, shoulder the responsibility of financing the plan. However, the task of fully undertaking this responsibility will be affected by national budgetary constraints. It is expected, therefore, as anticipated by member States under the CRPD, that the international community will generously assist in funding the plan through development partners and agencies. The Government on its part will endeavor, in the national budget, to allocate funds for some of the activities through the votes of relevant MDAs.

6.2. Budget Summary

Table: Budget Summary

No.	Priority Area	Total UGSH	Total US Dollars
1	Awareness Raising	2,617,000.000	726,944
2	Access to adequate health care	3,600,000,000	2,500,000
3.	Access to all levels of education	1,800,225,000	587,000
4	Access to work and employment	1,915,000,000	532,000
5	Protecting and promoting the rights of children with albinism	702,000,000	195,000
6	Protecting and promoting the rights of women with albinism	274,000,000	76,250
7	Protecting and promoting the rights of refugees with albinism	237,600, 000	66,000
8	Policies and Laws	162,000,000	45,000
9	Accountability	666,000,000	185,000
10	Safety and security of persons with albinism	184,500,000	51,250
	Total	17,871,998,400	4,964,444