



NATIONAL COUNCIL FOR PERSONS WITH DISABILITIES REHABILITATION AND HABILITATION PROGRAM (ALBINISM DIVISION)

TERMS OF REFERENCE FOR AWARENESS ACTIVITIES ON ALBINISM

BACKGROUND

The National Council for Persons with Disabilities (NCPWDS) is a parastatal established by an Act of Parliament-the Persons with Disabilities Act No. 14 of 2003. The Act provides for the management, powers, functions and duties of the Council and for connected purposes.

The main objective of the Council is to ensure that Persons with Disabilities are empowered socially, economically and politically to maximize their full potential, have access to regular services and opportunities and become active, contributing members to the process of Nation building.

Persons with Albinism are derogatorily referred to as 'Albinos' and are deliberately excluded from mainstream development and social life. There exist various myths about why children are born with the genetic impairment ranging from witchcraft, curses, bad omen to unfaithfulness of the mother with men of other races especially the Caucasians. This therefore means that from the onset, many children with albinism are treated as outcasts by the society. It is a common practice to hide PWAs from the public and to shun them in community life at times under the guise of protecting them from the sun.

The situation is made worse by ritual killings of persons with Albinism, due to the false misconceptions that their body parts could bring fortunes and good luck there is therefore a dire need to sensitize communities and the public on issues relating to albinism if such incidences of gross violation of human rights are to be permanently abetted. Therefore there is need to address the whole awareness issue under the following key pillars;

- Equalization of opportunities; measures provided in the policy are to ensure that persons with albinism are accorded opportunities on an equal basis with able-bodied persons through affirmative action.

- Human rights approach to the albinism agenda: The principle underscores the conscious departure from the ethos of charity to the articulation of human rights and development approach to disability concerns. Hence, the approach provides for protection from discrimination based on real or apparent grounds.
- Mainstreaming: Persons with albinism are part and parcel of the society and hence, their needs should be addressed within their communities and not in isolated service delivery settings.

OBJECTIVES OF THE AWARENESS

The identified group will be required to help the council achieve the following objectives;

- I. To enlighten persons with albinism and their parents/care-givers on health conditions arising from the condition of albinism so that they can take appropriate and timely health actions.
- II. To advocate for availability of enabling environment for access to health services by persons with albinism
- III. To equip the target clients with knowledge on health conditions associated with albinism to inform timely and right health action by the people with albinism, parents or their care-givers.
- IV. To equip persons with albinism, parents and care-givers of persons with albinism with self-care and protective measures for skins of persons with albinism
- V. To equip target clients with information on causes and types Albinism
- VI. To demystify Myths and Misconceptions about Albinism
- VII. To provide factual information on the basic biology of albinism to people in the community of persons with albinism
- VIII. To provide factual information on socio-cultural beliefs and misconceptions that underlie external stigma from people in the community of the persons with albinism in order to demystify myths and misconceptions about Albinism
- IX. To enlighten people around persons with albinism on the condition of albinism
- X. To demystify socio-cultural contexts and misconceptions underlying external and internal stigma
- XI. To equip target clients with information on causes and types Albinism
- XII. To lobby the government of Kenya to provide adequate and relevant health services for persons with albinism

SPECIFIC TASKS AND DELIVERABLES:

- Increase profile of network of association and organisations that advocate for the rights of persons with albinism
- Advocate and educate as well as assisting Persons with Albinism to access external information, education bursaries, healthcare and other community support available to assist with their genetic condition
- Improve the lives of Persons with Albinism by establishing a well-staffed office and resource centres.
- Improve the lives of persons with albinism, such as raising awareness about sun protection, educating teachers about simple steps to make materials accessible, and countering the prejudices of family and community.
- Raise the profile of albinism at the national and county levels.
- Publicly condemn persecution of people with albinism for their body parts, and preserve their rights to life and security including initiating legal action against perpetrators of attacks against persons with albinism, public condemnation of attacks against persons with albinism, and public awareness-raising campaigns
- Open up new perspectives on albinism and the exchange of knowledge on albinism
- Ensure the effective protection of persons with albinism and members of their families;
- Take effective measures to eliminate all forms of discrimination against persons with albinism, and to increase education and public awareness-raising activities;
- Promote, in collaboration with relevant regional and international organizations, bilateral, regional and international initiatives aimed at protecting persons with albinism;
- Address the relevant aspects of the safety and non-discrimination of persons with albinism
- Ensure accountability through the conduct of impartial, speedy and effective investigations into attacks against persons with albinism, the prosecution of those responsible, and by ensuring that victims and members of their families have access to appropriate remedies;
- Provide information and support regarding albinism and related conditions, to promote public and professional education about these conditions, to encourage research and funding that will lead to improved diagnosis and management of albinism, and to provide networking for those with special interests related to albinism such as minority groups
- Spread knowledge about albinism and work to improve attitudes towards those with the condition through television

appearances, newspaper articles, billboards, information packets for libraries, media campaigns and outreach to professionals, and networking with support groups for people with albinism in other countries, and promoting the development of albinism support groups

- Offer information and support to people with albinism, their families and the professionals who work with them.
- Bring together persons without albinism, researchers, NGOs and associations to facilitate the sharing of knowledge and expertise across disciplines and to open up new areas for possible collaboration.
- Prevention of attacks on Persons with Albinism
- Advocate for Specific needs of Persons with albinism including Security, displacement from insecurity; discrimination ,skin cancer, protective clothing, optician services, assistance in participating in mainstream primary and secondary education and vocational training to maximize the chance of indoor work out of the sun.
- Take all measures necessary to ensure the effective protection of persons with albinism and members of their families; including initiating legal action against perpetrators of attacks against persons with albinism, public condemnation of attacks against persons with albinism, and public awareness-raising campaigns
- The parties undertake to rescue and assist Persons with Albinism in distress situations and those predisposed to cancer and report to the Council of such rescue efforts for further action.

TECHNICAL CRITERIA

A detailed proposal is required that should demonstrate a track record and experience in conducting awareness on issues related to albinism on the following forums;

- Workshops/Seminars
- National Symposiums and Debates
- Television and/or Radio talk shows
- Print Media
- Information packs

Also selected organisation **must be able** to provide the following information

1. Current Registration certificates from relevant government agencies, including tax returns.
2. Top management of the organisation must be persons with albinism/disability

3. Registration with the NCPWD as an organisation for person with disability
4. Must have a physical office with at least necessary staff manning the office and program activities. Must provide detailed CVs of the staff
5. Must have working accounting structures within the organisation

DURATION AND CONTRACTUAL ARRANGEMENTS

- The duration of the grant shall be 6 months or as shall be determined by a memorandum of understanding that will be signed upon successful selection of the organization.

DELIVERABLES:

Selected organizations shall be required to draw a timetable for awareness activities, execute these activities and provide comprehensive monthly report of all activities undertaken in the month coupled with documentary evidence which include but not limited to pictures, reports, and other materials of the activity.