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POLICY PAPER

**Improving The Effectiveness of
The National Albinism Sunscreen
Support Programme (NASSP)**

INTRODUCTION

According to the World Health Organization (WHO), albinism occurs across all ethnicities and in every part of the world. The probability of being born with albinism is 1 in 17,000 (Gronskov & Brondum-Nielsen, 2007). The rate of albinism is highest among people living in sub-Saharan Africa where it affects an estimated 1 in 5,000 people (Greaves, 2014). The 2019 Kenya Population and Housing Census indicates that there are 9,727 (0.02%) persons with albinism (PWAs) in Kenya. However, it is likely that this number is higher because this figure does not account for those who were born after the Census. Kakamega County has the highest number of PWAs at 568 while Lamu County has the lowest population at 17.

A study done in 2017 observes that Kenyans with albinism who live along the equator are at constant risk of developing skin cancer due to constant exposure to the sun. PWAs in sub-Saharan Africa face multiple challenges, including visual impairment and vulnerability to skin infection, which restricts their daily lives. A significant number of PWAs cannot afford skincare products and services such as the sunscreen lotion and therefore remain very vulnerable. As a result, a majority of PWAs die from skin cancer between 30 and 40 years of age if there is no intervention (UN, 2020).

The rights of persons with disabilities are anchored in several international and domestic instruments. The Universal Declaration of Human Rights (UDHR, 1948) guarantees the extension of social security to all citizens and the Convention on the Rights of Persons with Disabilities (CRPD), reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms, including social protection. The CRPD articulates equal opportunities for persons with disabilities (PWDs) to participate in society, to ensure access to education, health and employment among other basic rights. The Constitution of Kenya Article 27 (4) provides for non-discrimination on the basis of colour and disability.

The Persons with Disability Act of 2003 of Kenya defines disability as “a physical, sensory, mental or other impairment, including any visual, hearing, learning or physical incapability, which impacts adversely on social, economic or environmental participation.” Both the definition by the Constitution of Kenya and this Act do not explicitly mention albinism. Part III of the Act (rights and the privileges of persons with disabilities) section 20 requires the government to implement the national health programme under the Ministry of Health for the purpose of

- (a) Prevention of disability
- (b) Early identification of disability;
- (c) Early rehabilitation
- (d) Enabling persons with disabilities to receive free rehabilitation and medical services in public and privately owned health institutions
- (e) Availing essential health services to persons with disabilities at an affordable cost
- (f) availing field medical personnel to local health institutions for the benefit of persons with disabilities
- (g) prompt attendance by medical personnel to persons with disabilities.

National Albinism Sunscreen Support Programme (NASSP)

In the effort to address this challenge, the National Albinism Sunscreen Support Programme (NASSP or the Programme) was launched by the Government of Kenya in 2011, through the National Council for Persons with Disabilities (NCPWD). Ten years into the Programme's history, the overall intentions of the Programme are sound, but challenges related to implementation prohibit the Programme from being as effective and impactful as it could be. The Programme is being implemented by the partners in the table 1 below.

Table 1: Role(s) of NASSP implementing partners

Category of organization	Identity	Role(s) in NASSP
Government agencies	National Council for Persons with Disabilities (NCPWD)	<ul style="list-style-type: none"> • Fund Manager • Procurement of products • Disbursement of funding for implementing partner organizations • Monitoring of Programme
	Kenya Medical Supplies Authority (KEMSA)	<ul style="list-style-type: none"> • Receives the consignment from the NCPWD • Distribution to hospitals and health centres

Category of organization	Identity	Role(s) in NASSP
Implementing Partners	Albinism Society of Kenya (ASK)	Raises awareness in three regions including Central, Nairobi and Coast
	Albinism Empowerment Network (AEN)	Raises awareness in Western and Nyanza regions
	Pastoral Heritage Concern (PHC)	Raises awareness in arid and semi-arid regions

Key facts about NASSSP

- The Programme has reached a rolling total of 3,169 PWAs since it began in 2011.
- The sunscreen support products are distributed through a total of 209 hospitals and health centres across the country.
- To benefit from the Programme, one must have a disability identification card from NCPWD.
- The products and services provided by NASSP are:
 - Provision of sunscreen lotions.
 - Provision of after sun lotions.
 - Provision of protective clothing (Caps and Long sleeved T-Shirts.
 - Cancer intervention.
 - Provision of comprehensive Eye Care.
 - Provision of lip care.
 - Awareness activities which includes Dissemination Workshops, interactive sessions and media activities.

Assessment of the NASSP

To understand the challenges that limit the effectiveness of NASSP, an assessment was commissioned by the Albinism Society of Kenya (ASK) with support from the National Democratic Institute (NDI). The assessment was guided by three objectives including

(A)

To identify the levels of access to the Programme, measured in terms of access to information on the Programme; access to distribution centres and availability of the products and services and user satisfaction.

(B)

To identify challenges faced in the Implementation of the Programme.

(C)

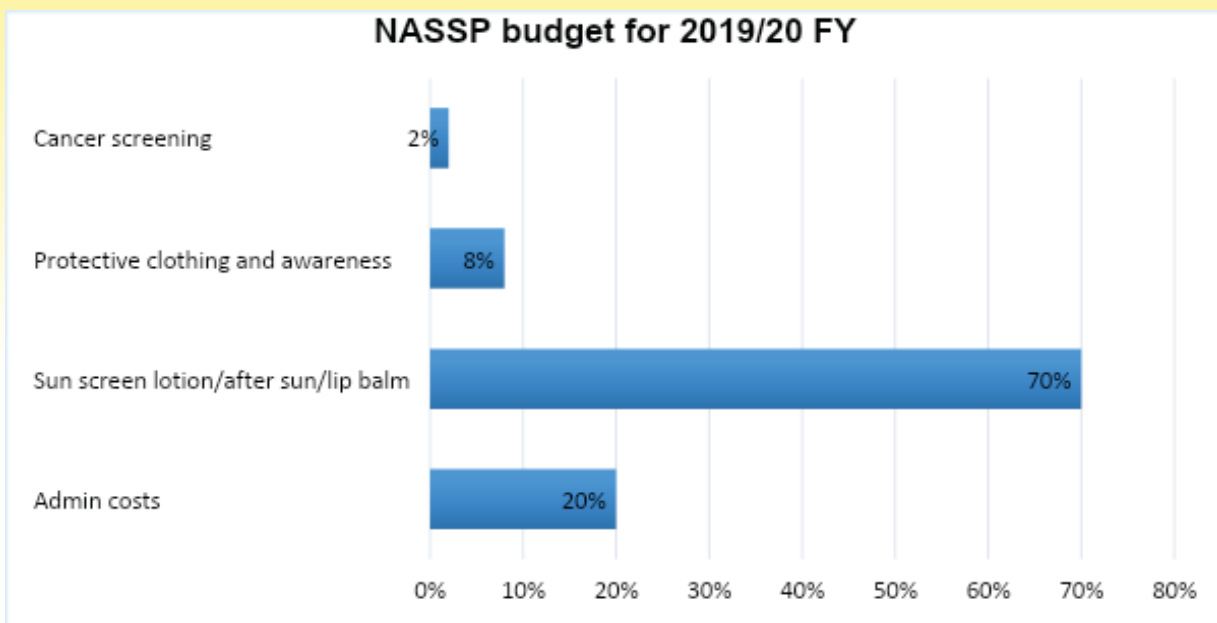
To make recommendations for improving the Programme. As an end product, this policy paper aims to advise the Government of Kenya on policy actions that need to be taken to improve the Programme.

FINDINGS FROM THE ASSESSMENT

Several key challenges have impacted on the efficiency of the Programme including the policy gaps and low budget to sustain the programme.

A. Policy gaps. Albinism is not explicitly mentioned as a form of disability in the Constitution of Kenya and the Persons with Disabilities Act except the Sector Policy for Learners with Disabilities. The Constitution of Kenya and the Persons with Disabilities Act are critical legislations that inform other policy documents. Lack of inclusion of albinism may easily be misconstrued as lack of a commitment to address it as a disability by both the national and the county governments. This would easily lead to persons with albinism to continually be ostracised from service delivery which goes against the principle of equality and non-discrimination.

B. Financial limitations. The NASSP has been running on a budget of KES. 100 million since its inception despite the factors of inflation and increased cost of products.



Low budget allocation has several implications on the Programme:

- **The rations provided by the Programme are below the monthly needs of PWAS.**

The Programme distributes one bottle of sunscreen lotion every month, one bottle of after sun lotion to be used for two months, a piece of lip balm per month. However, PWAs use an average of two 200 ml bottles of sunscreen lotion and one bottle of 200 ml after sun lotion and two pieces of lip balm. This therefore exceeding the amount of products available to them under the Programme. Lip balm and after sun lotion are not always available in the distribution centres and are procured based on the availability of funds.

- **There is limited access to skin cancer treatment.**

The cancer screening component has not been implemented as initially designed. It was intended to address the issue of affordability of skin cancer treatment which is costly. However, this component has low uptake. The NCPWD supported about 30 PWAs to undergo treatment in the financial year 2019/2020. Some of the major reasons for low uptake include low levels of awareness by PWAs and lack of experts to run this component. As a result, many patients who exhibit pre-cancerous signs, who lack funding, cannot afford to complete the treatment process. NCPWD distributed 30 cryotherapy machines to 30 county hospitals but they have not been effectively utilized by the county hospitals due to lack of experts and low levels of awareness by PWAs on skin cancer treatment services available to them.

- **Inefficient management of the Programme.**

The Programme is currently being run by only one full-time staff is running the Programme with the support from regional coordinators who run other programmes.

- **Delayed procurement and distribution impacts the overall effectiveness of the Programme**

For example, products that were procured in 2019 were distributed in February 2020 and no other distribution was done since.

RECOMMENDATIONS

Policy Recommendations for the Government of Kenya

Allocate more financial resources to the NASSP. The budget should be Increased to KES. 753,811,320 to provide adequate products and services to the entire population of PWAs in Kenya. (See table 2 below).

Develop a national albinism action plan that feeds into the Regional Action Plan on Albinism in Africa (2017–2021).

The Ministry of Labour and Social Protection should develop an action plan to serve as a policy framework on proactively addressing the needs of PWAs in Kenya. The action plan will document both short term and long term actions. Some of the thematic issues that can be incorporated into the plan include, but not limited to, prevention, protection, accountability and equality and non-discrimination.

National and county governments should develop and/or review policies that includes the need of persons with albinism.

For example, the amendment to the Persons with Disabilities Act should include albinism in the definition of disability. The development of policies, plans and programmes should acknowledge the needs of persons under different sectors and provide for them as appropriate.

Revive the eye care component. Eye care component has not been actively implemented under this Programme. The eye care should include but not limited to regular assessment and prescription spectacles and telescopes.

Create programme sustainability and ensure affordability.

The distribution is done using public existing facilities. However, they require facilitation to support the Programme to run. Part of the 20% administration costs from the Programme should facilitate the distribution centres to avoid the issue of them charging the users 'registration' fees.

The government needs to introduce tax incentives to skincare products. This means that more affordability of the products by those who cannot access the services offered by the Programme or in case the Programme does not run. It will also ensure that other products such as spectacles that are not actively included in the Programme will aid PWAs in their daily life. Promote local production of skincare products such as the sunscreen lotion, after sun and lip balm. This will meet the local needs of PWAs and lower down the cost to ensure affordability and lead to some community level sensitization on the needs of PWAs

Item	App. Cost (KES)	Beneficiaries	Freq.	Total	Notes for calculations
Sunscreen lotion	1,800	9,727	12	210,103,200	One 200ml bottle per month
After sun lotion	2,000	9,727	6	116,724,000	Six 200ml bottles annually
Lip balm	250	9,727	24	58,362,000	Two pieces per month
T-shirt	1,100	9,727	2	21,399,400	Two pieces per year
Wide brim hut	500	9,727	2	9,727,000	Two pieces per year
Skin cancer major surgeries	200,000	486	1	97,270,000	The no. of beneficiaries for the skin cancer treatment assumes about 5% of PWAs will require treatment per year. Skin cancer treatment is on a <u>needs</u> basis.
Skin cancer minor surgeries	30,000	486	1	14,590,500	The no. of beneficiaries (9,727) for the products assumes that every PWA will need the products. Out of this probably some will not use the services and thus will cover the gap of those who were not enumerated in the Census and the <u>newborns</u>)
Eye care	10,000	2,000	1	20,000,000	Takes care of regular assessment and prescription spectacles and telescopes. Every FY 2,000 PWAs will be targeted.
Awareness creation	10,000,000	8	1	80,000,000	Currently 3 implementing partners are getting KES. 5M for awareness creation. Each region should be allocated a budget of 10M per year to increase the level of awareness.
Programme subtotal costs				628,176,100	
Administrative costs				125,635,220	Admin. Costs take 20% of the programme budget
Total				753,811,320	

Table 2: Budget estimated calculations by ASK (informed by NCWPD figures)

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