THE LAUNCH OF THE RESEARCH REPORT

On

“Spatial Mapping and Profiling of Persons with Albinism in Eastern Uganda”

Participants at the Launch

On 21st May 2019 at Hotel Africana - Kampala

MAY 2019
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1.0 INTRODUCTION AND OVERVIEW

1.1 Introduction
This report presents the outcomes of the launch of the Research Report: “Spatial Mapping and Profiling of Persons with Albinism in Eastern Uganda” at Hotel Africana, Kampala, Uganda on 21st May 2019. The Research was conducted by AU and a team of consultants with funding from Oxfam Uganda-the Voice Project. The launch was attended by people from the Ministries of (Gender Labour and Social Development, Education, Health), Equal Opportunities Commission, Parliament, OXFAM, District representative from the districts where research was carried out, CSOs (National and International) and other stakeholders. Refer to the detailed list of attendance attached.

1.2 Overview of Albinism Umbrella- (AU)
Albinism Umbrella (AU) is a voluntary, non-profit, nonpartisan and Non-Governmental organization that consists of human rights sympathizers, people with albinism and all other albinism well-wishers. AU was set up with the ultimate aim of having a joint voice for all persons with albinism in Uganda.

It was established to engage communities of persons with albinism and harmonize discrimination and stigma in their different communities. It further aims to empower persons with albinism to fully engage in social-economic activities that directly improves their living conditions.

2.0 OPENING REMARKS

2.1 Opening Remarks by the Executive Director
Self-introductions for participants were done, a prayer and anthems for Uganda and East Africa. The workshop was opened by Ms Olive Namutebi- the Executive Director of AU. She welcomed the participants and thanked them for honouring the invitation for the launch. She expressed her sincere gratitude for the overwhelming support and keeping time. She recognized the presence of members including representatives from: the Ministries of (Gender Labour and Social Development, Education, Health), Equal Opportunities Commission, Parliament, OXFAM, District representative from the East, CSOs (National and International) and other stakeholders, Disability Activists, Consultants, well-wishers and media houses. She extended the Parliamentarians’ regrets for not attending the Launch because it collided with a UN training on Human Rights.

2.1.1 Background and update of AU
Olive faced the same stigma as other persons with albinism in the country while growing up. She experienced rejection, mostly neglected by her father, an engineer. However, her mother never gave up on her as she worked tirelessly to educate her, she realised the need to help fellow persons with albinism thus the birth of AU.

2.1.2 Achievements of AU
- Undertaken sensitization to grassroots organisations supporting persons with albinism for example Care for Uganda in Luwero and many others all over the country.
- AU has given out free sunscreens for the last 7 years
- Successfully organised fundraising charity walks for example the January 2019 charity walk with the Parliament of Uganda which the Speaker of Parliament pledged to support for the next five years.
• Advocating for persons with albinism’s representation in different government ministries and bodies.
• Participating in Civil Society Organisations’ events for representation of persons with albinism.
• Sensitization of people both with and without albinism to ease the stigma facing the albinism in the country.

2.1.3 Strategic direction of AU

• Put persons with albinism at the heart of policy making
• Build capacity for persons with albinism to engage in IGAs in the confines of their homes.
• Build a community of professional persons with albinism employees at workplaces
• Voice to amplify persons with albinism
• Build the capacity of AU to undertake this great work they are doing
• Build a network of persons with albinism here and abroad

2.1.4 The research report

The Research was funded with a grant from the Voice Project of Oxfam to collect information of persons with albinism and build a data base. It was undertaken with careful consideration of scientific methods of research, ethical issues and clearance from lead agencies and primary stakeholders. The methodology used employed both qualitative and quantitative methods, in-depth interviews with persons with albinism and the assessment framework was based on the ecological model both for interpretation and analysis of results.

2.1.5 Future Prospects

To undertake similar research in other parts of the country (west, north and central) so as to have an evidence-based representation of the whole country and have a clear nationwide picture of persons with albinism.

2.2 Remarks by Ms. Inez Hackenberg, Voice Project Oxfam-Uganda

Ms. Inez Hackenberg, the Linking and Learning Coordinator of the Voice Project, OXFAM based in Netherlands. She has lived in Africa for 20 years and reported that albinism plight is a cause close to her heart as she has 3 family members with albinism. While living in Mozambique, they lacked enough supplies of sunscreens and other protective gears due to war conditions and lost the husband’s elder sister.

On a professional note, she expounded that the Voice Project is a voice for people who face any forms of discrimination i.e. exclusion from health services, marginalisation, people with mental impairments and one of the groups supported are persons with albinism. The program supports groups of persons with albinism Movement in Kenya, Mali, Tanzania, and Uganda among other countries. In January 2019, there was a union of the movement with representatives from all the member countries.

She pledged to support AU in its future aspirations.
3.0 PRESENTATION OF THE FINDINGS

3.1 Presentation of the research findings

A snapshot of the report was presented by Dr. Arthur Bagonza on behalf of Dr. Betty Udongo, the team leader who was in Italy to undertake pioneer experiments into the possibility of producing sunscreen locally in Uganda.

3.1.1 Introduction

Dr. Arthur reported that Albinism is a congenital condition resulting in a lack of pigment in the skin, hair and eyes of humans has not been fully addressed. He reported that, currently the initiatives for persons with albinism are done by speculation due to absence of concrete statistics, thus the need for research and mapping of persons with albinism. This report will help avail evidence-based data about people with albinism, their challenges, opportunities and situation generally in terms of health, education, security, own and society perceptions and social status.

In Uganda, persons with albinism are considered among persons with disability with numerous challenges and no clear policy to address their plights. Persons with albinism live in fear, unfulfilled lives, threat upon their lives due to uncertainty in numbers, and hence poor service provision to the persons with albinism. It was reported that approximately 50 persons with albinism died in 2017, furthermore reported that, the Eastern region is reported to have the highest number of persons with albinism hence the selection for the study area. These all could not be confirmed in the absence of statistics and actual numbers and locations.

3.1.2 Research outputs

The research was a cross sectional study carried out in Eastern Uganda focusing on Persons with Albinism. Spatial mapping was done using Tablets with GPS (Global Positioning System) capabilities to locate the physical location of the persons with albinism. Household and organisational characteristics were captured using a digital structured questionnaire, using ODK (Open Data Kit)-Collect application. Perceptions of Persons with Albinism were gathered using in-depth interviews and analysed based on the ecological model. This research profiled and created a database for all persons with albinism in 10 selected districts in Eastern Uganda including (Budaka, Bududa, Butaleja, Buyende, Manafwa, Mayuge, Kamuli, Kumi, Sironko and Soroti). GPS further, the report provides an assessment of perceptions of persons with albinism towards their surrounding communities.

Sironko (20.2%), Bududa (17.9%) and Manafwa (17.5%) had the highest number of Persons with Albinism. Most respondents (56%) in households with Persons with Albinism had primary level education. More than two thirds (67.7%) of the respondents did not know the cause of Albinism. Access to and cost of sunscreen remain major challenges to households of Persons with Albinism. About (86.3%) of Persons with Albinism do not have access to sunscreen. In addition, (75.7%) of Persons with Albinism had eyesight problem. Moreover, (76.8%) of Persons with Albinism had never gone for an eye check-up. The main reason for dropping out of school was lack of school fees. Poverty levels were highest among households that had more Persons with Albinism. The richest households of Persons with Albinism (based on the Gramin Poverty Index) were found in Bududa (24%), Buyende (18.7%) and Manafwa (18.4%). On the contrary, the poorest households are in Sironko (27.8%), Bududa (22.2%) and Manafwa (16.7%). Organisations and secondary schools meant to help Persons with Albinism are not within the recommended 5km radius on average.

3.1.3 Research recommendations

There is need to provide protective clothing, glasses and caps for Persons with Albinism to protect them from harmful sun rays. There is also need to provide free or affordable skin creams and lotions. They should be put within easy access if they cannot be distributed free on a more regular basis. For sustainability purposes, Sunscreens should be developed locally so that they can be affordable and
accessible to Persons with Albinism. In order to increase household incomes, there is need to provide Persons with Albinism with income generating skills which can be done indoors. Finally, there is need for community sensitisation and better policy inclusion for Persons with Albinism.

Furthermore:

- Seek support for further GPS profiling of persons with albinism in other areas of the country.
- Create awareness of persons with albinism challenges.
- Seek involvement in policy making; Legislators to draft laws and by-laws at district level for protection of persons with albinism.
- Government to give more protection to persons with albinism through;
  - Waiving taxes on sunscreens
  - Reduce the excessive bureaucracies on importation or the creams
  - Possibly consider sunscreen as an essential drug and available freely or at subsidized prices in hospitals.
- Education ministry to collect data of persons with albinism in schools.
- MGLSD to specifically target persons with albinism in policy formulation and programs so as to ensure conducive workplaces for persons with albinism employees.
- Disseminate information on persons with albinism to a wider audience.

3.2 Reactions and Discussions of the research findings

Ms. Harriet- UNICEF: AU should find out what service providers like the government, schools and health centres have to say about how persons with albinism are treated in their areas especially in schools and hospitals so that gaps can be established to act as starting points for it. Further, she recommended that advocacy should be inclusive of both people with and without albinism so as to ensure a fundamental change for stigmatization of persons with albinism.

Mr Gidong Peter -Officer from Chief Administrative Officer's (CAO) office, Sironko District: Commended the research team for the good research report. He suggested that persons with albinism should be involved in a number of government projects to address the problem of poverty among them. He pledged to support the initiatives in his district for the benefit of the persons with albinism.

Mr George Muteckanga- Official, Ministry of Education and Sports: He has been tasked by Hon Kadaga, the Speaker of the parliament and the Ministry officials in Mbale to establish the profile of children with albinism not attending school including: their age, sex and distance to primary and secondary school. This information would then enable them craft the support for them.

Mr Onen Negris -Commissioner Ministry of Education and Sports

also, from the Ministry of Education started by mentioning how albinism isn’t well known to many and commended AU for taking up this initiative and going ahead of government to educate and provide? But the organisation should add effort in sensitization to fight negativity in the community and involve people in activities. He pledged to take up Albinism as a priority and endeavour to provide optical devices for PERSONS WITH ALBINISM.

Mr Khamba Bernard Joseph-Manafwa District Inspector of Schools: Manafwa is doing well in integrating persons with albinism in all aspects of district activities. The district ensures that every school going age of persons with albinism is in school with the needed basic school instruction materials. The live example here is Philip Makasi who was supported. They will continue with the support especially now with the data.

Ms. Elizabeth Nekesa - Coordinator Albinism activities in Elgon Region: commended AU for the timely initiative of the research. Further, she mentioned that children in Bududa are given attention at schools and all attend school. However, they still face challenges in service delivery especially health workers fear to attend to them for various reasons i.e. delicate bodies, cursed, to mention but a few. She pledged to continue sensitizing the community in supporting the persons with albinism
Mr. Moses - an Artist and affiliate to Uganda Cancer Institute: pledged to compose and sing a song towards awareness on albinism especially skin cancer.

Dr. Sekimpi Deogratius - Uganda National Association of Occupation and Public Health (UNACOH): He elaborated on issues affecting persons with albinism as; difficulties working under the sun as result of UV rays affecting eyes and skin. Therefore, there is a need for glasses to protect the eyes which he added that the government can ably do because the numbers of persons with albinism are few.

Ms. Joyce Katende – Commissioner Legal Equal Opportunities Commission (EOC): She explained what the EOC does in addressing the issues of marginalisation and discrimination. They asses the national budgets and review national policies to ensure equity. They have just undertaken similar research throughout the country for mapping out persons with albinism that will soon be launched.

Hon. Nalule Safia Juuko - Member of Parliament for Persons with disabilities (National): is a member of the parliament for the last 3 consecutive tenures and served on several committees including EOC Human Rights, etc. She explained her four fundamental innovations during her tenure including: innovating the requirement of the human rights checklist, human rights enforcement law, gender and equity compliance certificate for all workplaces, a separate budget for special needs education, to have a separate Bill for persons with albinism. She added that this research will be very useful and informative on the bill.

She urged government to consider revising the age for accessing the elderly Persons with disabilities grant from 65 to 45 years because of their special needs. Therefore, she requested from MGLSD that a disability grant be provided, Motorcycles be provided for councillors.

She mentioned that there was a research pioneered by EOC on Persons with disabilities to be launched soon and recommended that Albinism Umbrella should participate as both reports will greatly inform the Bill on PERSONS WITH ALBINISMS.

Afande Mulekerwa Anatoli, Deputy Commissioner, Department of Community Policing, and Uganda Police: He thanked M/s Ms Olive Namutebi’s mother for enduring and raising her to the extent of becoming the voice for voiceless persons with albinism. He further added that persons with albinism and Police share a similar predicament since both of them can’t move unrecognised and are stigmatized at all times. He confessed that most police officials are ignorant of the persons with albinism predicament. He requested that persons with albinism actively corporate in their communities for effective community policing. He pledged to partner with AU in all 133 districts of Uganda to ensure safety of persons with albinism. Further, he suggested a forum be organised to sensitize police officers on Albinism issues. However, requested that a section in the report that pointed out that police services are not free be rephrased because the services are free but individuals ask for bribe and facilitation.
4.0 PANEL DISCUSSION ON KEY RESULTS FROM THE REPORT

The panel of four people was constituted to briefly share their experiences either as persons with albinism or as they interact with them at operational and policy level. The purpose was to understand their challenges, coping mechanisms, efforts in place to improve their plight, inclusion and access to social services in their respective communities.

The 4 people were:

- **Proscovia Kibuuka Mukiibi – the moderator of the panel**, a development consultant with extensive experience of supporting Persons with disabilities, the current vice chairperson of the AU board.
- **Phillip Makasi – a panellist**, a person with albinism, Grade 3 Teacher in Manafwa district for over 10 years, married with 4 children.
- **Rose Achayo – panellist**, Chairperson of National Union of Women with Disability in Uganda (NUWODU) and Disability Activist.
- **Mr. Bernard Mujuni Commissioner, MGLSD – panellist**, is an experienced Lawyer and arbitrator. He is the Commissioner Equity and Rights at the Ministry of Gender labor and Social Development. Over the last 15 years, he has acquired significant experience inclusive growth and equitable justice Administration. He has worked with the government, private sector and civil society for the vulnerable and marginalized sections of society.

Below are all the participants:

- **Phillip Makasi**: Shared his experience while growing up which was hard, difficult and challenging. And it was rare to see a person with albinism as he was the only person in 8 sub counties with albinism. So he was often seen as miraculous and the usual derogatory cliché comments such as a curse, called a pig, spat on him, to mention but a few. But he was aggressive at school to counter the attacks. He further added that at school he had a problem of sight, and he wasn’t able to see on
the blackboard. His mother was very supportive which helped him persevere by talking to the school management to have him move to zero distance from the blackboard. As he grew, he became more self-aware and came to terms with who he was, he established his aspirations and got courage which gave him a solid purpose in life.

He further narrated that: “Persons without Albinism only love you if they want something from you”. Therefore, his mother used to give him sweets and goodies to attract people to him, which he still does to date. However, when people get used to him, they treat him as an equal because of his good character.

This also applied to his former wife, who divorced him when he had an accident and his financial status deteriorated and could not provide for the family. Similarly, even when he was injured from the accident, the health workers in the hospital refused to attend to him for reasons that his skin was delicate and he was not going to die but disappear. However his pupils and children love him unconditionally. His children have no albinism. This was an emotional sharing and provided lessons for sharing from the horse’s mouth. His recommendation was to create awareness to persons with albinism, to know what they are- reality and demand for their rights, what they need and that it is a struggle to get what they need. And for the people without Albinism to know that persons with albinism are equally human beings who need to be supported rather than being discriminated against discrimination.

Rose Achayo highlighted that persons with albinism are part of the disability movement in Uganda since 2013, the general assembly of NUDIPU. And in 2016, the disability fraternity wrote a report to the National Council of Disability (NCD) about all the needs of Persons with disabilities including persons with albinism. The NCD amended the disability act and incorporated issues of persons with albinism. Further, the Disability fraternity wrote to UNCRPD about all the needs of Persons with disabilities including the persons with albinism. In Geneva, persons with albinism were part of the recommendations for the alternative report. Rose recommended that disaggregated data should be taken up by UBOS and the sunscreen lotions and glasses be considered as essential drugs.

Bernard Mujuni pointed out what the MGLSD is doing in support of persons with albinism on a technical level of which he mentioned that he has been part of the committee that has come up with policies to address their issue. He said the penal code is clear on human trafficking of organs and human beings. He noted that, everybody has gone through a segregation and they are so many policies tackling a number of issues, however a robust policy framework for Persons with disabilities, labour, equality, Youth, Women and Children. He concluded by wondering whether Uganda will design a policy specifically for albinism issues or implement the specific policies addressing each respective need? He advised that the findings should be presented to appropriate ministries, sector working groups, CSOs for action other than talking to a few invited people. He pledged to work with AU management to ensure that the findings are shared in the MGLSD.

5.0 OFFICIAL LAUNCH OF THE REPORT

Mr. Bernard Mujuni, represented the Minister of Gender, Labour and Social Development to launch the report. He extended apologies from the Minister because she was monitoring field activities. He went on to commend the ED of AU for her impressive networking, lobbying and abilities.
He advised that AU should consider benefiting from a range of development programs that the government has rolled out to steer Ugandans to self-sustenance such as: Youth Livelihood Program, USE, UPE, Students Loan Boards, etc. AU should seek affirmative action as the next step to get active inclusion and action for persons with albinisms. He further stressed that: “……the law isn’t a solution to everything, the true change and the biggest solutions lie within us as we intervene in our homes and communities towards persons with albinism….”

His recommendation was that all government bodies such as MoH, MoE, MGLSD should be presented/provided with the report for an inclusive decision-making process. He finally congratulated AU on the ground breaking research and invited the team to launch the research report.

6.0 RECOMMENDATIONS BY THEMES AND CONCLUSION
6.1 Recommendations
6.1.1 Health
- Lobby for provision of protective gear for example glasses and sunscreen for persons with albinism by donors or Government.
- Intensify counselling and guidance for persons with albinism to ease the stigma.
- Government should make sunscreen an essential drug easily available in hospitals all over the country.
- Create awareness of Skin Cancer among persons with albinism especially in rural areas.
- Educate people about albinism; cause, myths and challenges.
- Commissioner Onen Negris pledged to take up Albinism as a priority and endeavour to lobby for optical devices for persons with albinism.
- Moses from Friends for cancer, a peer group affiliated to the Uganda Cancer Institute pledged to compose and sing a song towards albinism awareness.

6.1.2 Education
- Advocate for conditions suitable for persons with albinism to go to school for example glasses to ease vision, protective school uniforms as the shorts and short sleeved shirts expose them to harsh sunshine conditions as well as other learning aids.
- Awareness and sensitization to educate masses about Albinism so as to stop the stigma
- Lobby for academic sponsorship opportunities for persons with albinism willing to go to school at all levels.
- Manafwa District- Inspector of Schools pledged to take the report to his bosses to prioritize persons with albinism’s issues.

6.1.3 Security
- Seek for Police’s active involvement in protecting persons with albinism.
- Since persons with albinism are more susceptible to kidnap for sacrifice and rituals, there is need to develop a tracking profile of every individual using a GPS profile tracker for security as well as easy service delivery.
- Afande Mulekerwa Anatoli pledged to partner with AU in all 133 districts of Uganda to protect persons with albinism.
- Create awareness about security awareness among persons with albinism and the general community especially so as to ensure safety.

6.1.4 Employment and skills development
- Skills training in small scale IGAs so that persons with albinism can be employed in the confines of their homes for protection from sunrays.
- Capacity building to enhance professional running of AU.
• Lobbying for employment of professional persons with albinism in key government ministries and bodies as well as CSOs and other employers.
• Gidong Peter pledged to handle persons with albinism issues with more priority. He pledged to find out or inquire more about projects that persons with albinism can engage in as part of the development programs of the GoU to tackle poverty.

6.2 Conclusion
Participants exhibited a very high level of participation, commitment and interest throughout the launch and gave a number of recommendations which was valuation input for AU. However, the time was limited for everybody’s participation and we got limited participation of the youth and persons with albinism.

The closing remarks were given by Christine Namatovu, Representative of the Country Director, Oxfam Uganda. She pointed out that the Voice Project helps marginalised communities find their own voice and accept themselves and this report is a key milestone for them in impacting and amplifying on marginalised communities. And assured that Oxfam intends to continue working with AU even in their next strategy. She pledged that Oxfam will keep working with AU in all their future projects.

The workshop was closed with lunch.