

FINAL PROJECT REPORT

December 2017 – Dec 2019

PROMOTING THE HUMAN RIGHTS OF PERSONS LIVING WITH ALBINISM IN SIERRA LEONE



Promoting a Society that offers equal opportunities to and protecting the RIGHTS of Persons with Albinism.



LEGAL EMPOWERMENT SHARED FRAMEWORK PROGRAMME
Funded by: *Open Society Initiative for West Africa (OSIWA)*

EXECUTIVE SUMMARY



In many parts of Africa, 'Persons with Albinism' (PWAs) face discrimination and violence not just from society at large but sometimes even from their own families. According to the Office of the United Nations High Commissioner for Human Rights, as many as 1 in 5,000 people in sub-Saharan Africa are albinos.

In Sierra Leone, the **2015 Population and Housing Census report** states that 501 persons out of a total population of 7,092,113 are PWAs; this is about 0.5% out of 1.3% disabled population. Based on public knowledge and target-group testimonies, PWAs are facing discrimination, stigmatization and neglect from society and family members with impunity. The consequences has led largely to their exclusion from society and decision making processes. They mostly seem not to live purposeful lives due to lack of educational opportunities which requires special needs. Their right to enjoy the highest standard of health care is limited. They also sometimes suffer from harmful traditional practices including ritual attacks, infanticide and abandonment of children by parents.

Since June 2013, due to the recurrence of attacks against PWAs, international and regional bodies have given more attention to their plight and declared JUNE 13 as *International Albinism Awareness Day*. Consequently, in 2013 and 2014 respectively, the *United Nations Human Rights Council* and the *African Commission on Human and Peoples' Rights* have adopted resolutions (**HRC resolutions 23/13, 24/33 and 26/10, ACHPR resolution 263**) calling for the prevention of attacks and discrimination against PWAs. Also, in response to calls from civil society organizations (CSOs) advocating for the consideration of PWAs as specific group with particular needs that require special attention, on the 26th of March 2015, the United Nations Human Rights Council adopted resolution 28/L.10 creating the mandate of independent expert on the enjoyment of the human rights of PWAs.

Despite the progress being made at international and regional levels, PWAs in Sierra Leone has continued to face huge challenges in the realization of their rights. There is little activism on the part of CSOs as well as people living with the condition to advocate for the promotion and protection of their rights. They have no voice compared to other marginalized groups such as persons with disabilities and Women. Over the years, they have been largely excluded from progressive efforts undertaken by government, CSOs and donors to protect these vulnerable and marginalized groups in Sierra Leone. Issues affecting them have generally gone unnoticed resulting in deep engraved stigma, exclusion, discrimination and violence against them.

In joining International and Regional efforts to trigger national discourse and amplify tangible awareness, the 'Lady Ellen Women's Aid Foundation' – Sierra Leone (LEWAF-SL) under its 'Response and Advocacy theme' with grant from 'Open Society Initiative for West Africa' (OSIWA) started work with a project titled '**Promoting the Human Rights of Persons with Albinism in Sierra Leone**'. The project was designed to achieve 3 main objectives as follows: (1) *Highlight the plight of PWAs in the country amongst government, civil society and the public*; (2) *Give a voice and/or amplify the voices of persons with albinism*; and (3) *Facilitate the establishment of an Organisation to be led by persons with albinism in a bid to build their*

capacity to lead advocacy effort for the protection of their rights and general wellbeing. The OVERALL GOAL is - **to promote a Society that offers equal opportunities to and protection of the rights of persons with albinism.**

At the end of project implementation, LEWAF-SL is confident to say that, there is a visible improvement on the acceptability and recognitions of PWAs in communities and institutions in Sierra Leone. The tangible achievements detailing this optimism include the following: **firstly**, the first ever RESEARCH was COMMISSIONED and the REPORT titled '**Harassed, misunderstood and forgotten: challenges persons with albinism face in Sierra Leone**' officially LAUNCHED by the Deputy Mayor of Freetown. Following the launching of the report, the project activists engaged in Strategic dissemination of the findings and recommendations of the report through defined public education in the forms of School visitation meetings; Radio and Television discussion programmes and the production and dissemination of classified social media clips. This perhaps saw the '**National Commission for Persons with Disability**' (NCPD) classing PWAs as disabled persons thus officially qualifying them to benefit from free *basic social services and welfare schemes such as education, health etc.* **Secondly**, regional support networks of PWAs have been formed in all four regions of Sierra Leone including the Eastern, Southern, Northern and Western regions of Sierra Leone. **Thirdly**, in galvanising efforts towards PWAs themselves taking the lead in championing their own course, the project successfully established the '**Sierra Leone Albinism Foundation**' (SLAFo). SLAFo is now officially registered with the Ministry of Social Welfare and Gender and Children's Affairs with a certificate of recognition as an independent non governmental organisation. **Lastly** but not the least, to STRENGTHENING the institutional CAPACITY of SLAFo moving forward, LEWAF secured a 2 years grant from OSIWA valued at US\$ 69,458 starting January 2020. *To summarise, it is but appropriate to safely state that the "Promoting the Human Rights of Persons with Albinism in Sierra Leone" project has made significant achievements as the PWAs in Sierra Leone has been constructive unveiled, the platform for PWAs themselves to amplify their voices at national level has been constructed and an Organisation (SLAFo) led by PWAs themselves is now fully established and functional.*

However, in the mist of the numerous challenges, LEWAF-SL has learnt that PWAs appears to be peaceful, friendly and wishes to continue being together as one family. This simply means that any advocacy and development initiative that have the potential to promote and protect the rights and welfare of PWAs is highly likely to be successful if lead and managed by PWAs themselves. Thus, the **WILLINGNESS and ENTHUSIASM** observed in PWAs to lead and manage their own affairs has proved to be the most significant take-away from this project.

It is true that nothing could have been achieved for this project without the moral and financial support from our faithful partner - OSIWA; therefore, on behalf of the **Board of Directors and Management** of LEWAF-SL, I extend our profound gratitude to everyone including individuals and institutions for your **valuable supports** and **productive collaboration** in the implementation of this project.

Signed: Mohamed Bobor Jalloh - **EXECUTIVE DIRECTOR.**

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ABBREVIATIONS

CAPRI ----- Centre for Alternative Policy Research and Innovation

LEWAF-SL ----- Lady Ellen Women’s Aid Foundation – Sierra Leone

MDAs ----- Ministries, Department and Agencies

NCPD ----- National Commission for Persons with Disability

NHRC ----- National Human Rights Commissions

OSIWA ----- Open Society Initiative for West Africa

PWAs ----- Persons with Albinism

SLAFo ----- Sierra Leone Albinism Foundation

SLBC ----- Sierra Leone Broadcasting Corporation

SECTION 1

ATTAINMENT OF THE OVERALL OBJECTIVES OF THE PROJECT – AN ANALYSIS

Objective 1: Highlight the plight of persons with albinism in the country among government, civil society and the public.

To achieving this objective, the project undertook the following activities:

1.1. A RESEARCH COMMISSIONED – TO HIGHLIGHT THE PLIGHT OF PERSONS WITH ALBINISM IN SIERRA LEONE.

The project implementation started with the recruitment of a research consultancy firm - the 'Centre for Alternative Policy Research and Innovation' (CAPRI). CAPRI is a policy think tank research firm registered and operating in Sierra Leone. In May 2018, CAPRI officially commenced the research process and on the 3rd of September 2018, submitted a draft report for review and validation.

The REVIEW and VALIDATION of the draft research report: Reviewing and validating the research findings was a key activity of the project. The initial methodology for the reviewing and validation process as designed by the project would have been through a day workshop. However, taking into consideration the fact that the draft report document in itself contained 78 pages and is the first ever structured research to be undertaken on the plight of PWA; the project activists and LEWAF technical team with guidance from OSIWA technical unit, talked through a crucial concern around the '**thoroughness**' of the review and validation process at a DAY workshop. Moving forward, LEWAF sorted the INDEPENDENT REVIEWERS methodology and subsequently recruited a total of 5 'independent reviewers' - 3 nationals and 2 internationals. All 'independent reviewers' were found to have wealth of experiences in the review of ground breaking researches have either held or are currently holding high level positions in research firms, development agencies, and national commissions. Their area of expertise ranges from sustainable development, human rights, social policy, to albinism associations both at national and international levels.

In the first and second week of August 2018, the independents reviewers were engaged and subsequently completed their review tasks providing feedbacks in the form of comments, suggestions and opinions. These feedbacks were further jointly discussed by the technical team of LEWAF, CAPRI and OSIWA to enhanced common understanding of the details and proffered re-structuring leading to the validation of the draft report in line with international standard and best practice.

The FINAL research report was submitted to LEWAF on the 25th September 2018 and was OFFICIALLY LAUNCHED on the **24th October, 2018.**

1.2. RESEARCH REPORT LAUNCHED

It was a moment of Joy for all PWA in Sierra Leone especially those present at the launching ceremony as they observe the First ever research report titled '*Harassed, misunderstood and forgotten: challenges persons with albinism face in Sierra Leone*' officially LAUNCHED by the Deputy Mayor of Freetown, his worship Osman Koroma - **Pictured Right.**



The launching ceremony took place at the British Council Auditorium, Tower Hill in Freetown on the 24th October 2018 and was honour by over 65 persons from all sectors across the country. These included Paramount Chiefs, Women's and Youth leaders from Bo, Kenema, Makeni and Freetown. In addition, top-government officials from the relevant line ministries, commissions, diplomatic missions, trade unions, local councils, civil society's organisations etc and most significantly, a large number of **PWA** from across the country attended the launching event. A team from OSIWA Senegal office who are working around albinism also witnessed the ceremony to support with advocacy tasks and sharing of experiences.



The event provided participants the opportunity to hear real life stories and experiences from **PWAs** themselves. To trigger a sense of national cognisant, the event hosted a 45 minutes 'PANEL DISCUSSION' session where the panellists included the Paramount Chief of Bo district, Deputy Director of the Human Right Commission of Sierra Leone; and the Executive Secretary of the '*National Commission for Persons with Disability*' (NCPD). It was planned that the panellists would have included the Ministers of Social Welfare Gender and children Affairs; and Health and Sanitation, but both ministries were unavoidably absent. In responding to multiple questions during the panel discussion session, the Executive Secretary of the NCPD Mr Saa Lamina Korteque said, quote "*the challenges PWAs continue to experience as revealed by the*



Mr. Saa Lamina Korteque – Executive Secretary
'National Commission for Persons with Disability'

report is a cause for national concerns, my commission will work to promote the inclusion of PWAs as disabled thus opening up opportunities for them to benefit from FREE basic social services and welfare schemes such as education, health etc”... quote ends. The Paramount Chief of Bo district, Hon Lappia Boima pledged his continued commitment to uphold and protect the rights of PWAs in his chieftdom. Expressing similar sentiment, the deputy director of programme from the ‘National Human Rights Commissions’ (NHRC), Mr Richard M’Bayo said “the NHRC has the mandate to promote and protect the human rights of all persons in Sierra Leone and that PWAs are no exceptions; he reiterated that his commission will continue to work with LEWAF-SL, Ministries, Department and Agencies (MDAs) across the country to tackle the challenges revealed by the research report such as the right to free or subsidies health care opportunities and education etc.” end...

The launching ceremony was covered and broadcasted on both the print and electronic media including African Independent radio, Awoko Newspaper, African Young Voices television, the Sierra Leone broadcasting television and radio, standard times news paper, Star television and radio; and radio democracy - 98.1 etc.

1.3. SCHOOLS VISITATION

The school visitation meetings organised to disseminate the findings and recommendations of the research report proved to be an eye-opener not only for the activists themselves but also for public audiences that included both PWAs and non PWAs that were engaged by the activists. The activity opened up frank discussions and eventually established clear understanding about the longstanding misconceptions, myths and real life of PWAs.

In total, 13 primary and secondary schools were targeted in both the Freetown Western area Urban and Rural districts; and were successfully engaged by the three activists. Key messages were built around the findings and recommendations of the research report.



Visit to Albert Academy Secondary School

The discussions with the students/pupils were centred on causes of albinism, the misconceptions around albinism, why PWAs are considered to be Persons with Disability and how PWAs are to be treated in schools as persons with special needs. The school visitation was accomplished over a period of 9 working days between 19 February 2019 and 7 March 2019.

Objective 2: Give a voice and/or amplify the voices of Persons with Albinism.

To achieving this objective, the project undertook the following activities:

1.4. RADIO AND TELEVISION DISCUSSION PROGRAMMES HELD AND TWO EDUCATIONAL VIDEO CLIPS DEVELOPED.

The numerous radio and television discussion programmes and the circulations of social media clips arguably raised further awareness on the plight and challenges of PWAs to another level. The project activists has continued to **engage in public education** through these medium using evidence based data as a defining tool. A total of two classified Video clips were produced and dissemination on social media including whatsapp, face book etc. These have continued to go viral across Sierra Leone.

In a live Radio program hosted at the **Kamboi Agricultural Radio Station in Kenema**, majority of the listeners expressed satisfaction for knowing that PWAs are now championing their own cause; and appealed for such educative programs to continue. *Batturu* – is a PWAs and a nurse by profession was a panellist on one of the radio discussion session. In her contributions, *Batturu* was very clear in her opinion and said that *her lack of melanin that made her to become a PWAs did not and will not limit her to pursue her career. Batturu* ended up by encouraging other PWA's and their relatives not to relent in their quest to pursue their career dreams just because they are PWAs.

Similar interactive radio discussion program was hosted at the 'Sierra Leone Broadcasting Coorproation' (**SLBC**) in **Bo** - the Southern Region of the Sierra Leone on 29th August 2019. This session also attracted more public contributions. For instance, Mr Abu Bakarr Sidique, a local businessman, called during the program and said *"I am not a PWAs, but I have the passion for the movement as they are unique people"*.

Also, at the **SLBC Radio Station in Makeni** - the Northern Region of Sierra Leone, the radio discussion program was very interactive. It attracted positive public perception on albinism in general. In his contribution, Pastor Kelfala Keegan Kamara said – quote *"PWAs are just like any other person. I had slept with them, eaten with them, work with them and even befriend them. They are very clever people"* – end of quote.

1.5. FOUR REGIONAL SUPPORT NETWORKS OF PERSONS WITH ALBINISM ESTABLISHED.

The setting up of networks comprising of PWAs in all the four regions of Sierra Leone has proved to be vital from two key perspectives: (i) to enhancing national recognition of PWAs and (ii) to creating the ideal platform for the establishment of a national organisation to be lead and managed by PWAs themselves. To date, regional Support Networks in the Northern, Southern, Eastern and Western regions of Sierra Leone has been successfully established which having an executive team set-up through electioneering process. These regional executives are now the focal points for PWAs

living in each region and are charged with the responsibility for advocacy and other activities aimed at promoting the rights and well-being of PWAs at regional levels.



Western Area Executive - Freetown



Northern Region Executive - Makeni



Southern Region Executive - Bo

1.6. MEDICAL PRACTITIONERS SENSITIZE 250 PERSONS WITH ALBINISM AND THEIR FAMILIES ACROSS THE COUNTRY TO DISCUSS ISSUES RELATED TO THEIR HEALTH CONDITIONS.

At the *Togetherness Secondary School* in Kenema, the Consultant Medical Specialist of the Kenema Government Hospital, **Dr. Munda Charles** on 28th August 2019



addressed about 50 PWAs including their family members and stakeholders on health issues. His topic was on “the cause, myths, health issues and actions that must be taken by PWAs for them to live a healthy life free from cancer and other

diseases. Madam Aminata Kamara - a middle age woman, who is a mother of three

PWAs, in her remark said: *I gave birth to eight children, four of which are black and the other four are PWAs. One of them died sometime ago, but I want to say that I love the PWAs children more than the others because I want to set the example for people around me to follow.*



In another related engagement, **Dr. Dauda Mohamed** in Bo town, Southern province on the 30th August 2019, facilitated medical session for PWAs and their relatives at the *Sir Milton social home* at Tikonkoh road. In his Medical sensitisation, the medical practitioner, **Dr. Dauda Mohamed** mentioned that ‘Albinism is not transferable, but PWAs are considered disabled because they lack the melanin which serves as a protector to their skin. He advised PWAs to always put on sun glasses, long sleeves clothes and use sun cream if affordable - when going out’. The activity was coupled with the establishment of the PWA Southern Regional Network.



In the Northern region headquarter town of Makeni, Ms **Elizabeth Queen Conteh** a **Community Health Officer** of the Makeni government hospital on the 1st of September 2019 gave different reasons for being born a PWAs. She shared statistics on the birth rate of PWA in the world. She pointed out that *PWAs should try to avoid the sun, especially when they are not protected*. She encouraged PWA to go for regular eye check- up. One participant – a father of two PWAs (Male and Female), has this to say: *“I am blessed and highly favoured by God for given birth to whites (PWAs) even when my colour is black”*. The sister of her late brother (Mahied Hassan Jalloh) who was a PWAs said that *“I am happy that you now have an organization that is pushing your case, so that you will not die of cancer like my brother”*.

***Objective 3:** Facilitate the establishment of an Organisation to be led by persons with albinism in a bid to build their capacity to lead advocacy effort for the protection of their rights and general wellbeing.*

To achieving this objective, the project undertook the following activities:

1.7. SLAFO OFFICIALLY REGISTERED AS A NATIONAL NON GOVERNMENTAL ORGANIZATION

Following the successful launch of the first ever Research Report on Albinism in Sierra Leone, PWA that participated at the launching unanimously agreed to set up an organisation that was eventually named the 'Sierra Leone Albinism Foundation' (SLAFO). SLAFO is now registered as a Nongovernmental organisation with the 'Ministry of Social Welfare and Gender and Children's Affairs' (MSWGCA), to operate within Sierra Leone.



1.8. SLAFO AWARDED A FOLLOW-UP GRANT BY OSIWA FOR INSTITUTIONAL STRENGTHENING AND CAPACITY BUILDING.

In April 2019, LEWAF-SL supported SLAFO in developing a new project proposal and submitted to OSIWA. The new project is an Institutional Development and Capacity Building project designed to influence the internal control systems, processes and strategies that will enable SLAFO to operate an independent NGO. The overall objective of the new project is to operationalize SLAFO as an efficient and functional advocacy and welfare-base organisation for PWAs in Sierra Leone. The project will be entirely lead, managed and implemented by PWAs themselves.

SLAFO's proposal was successful and was awarded 2 years grant valued at US\$ 69,458 which has already started since January 2020.

To summarise, it is but appropriate to safely state that the project '**Promoting the Human Rights of Persons with Albinism in Sierra Leone**' has made significant achievements as the plight of persons with albinism in Sierra Leone has been constructively unveiled, the platform for PWA themselves to amplify their voices at national level has been constructed and an Organisation (SLAFO) led by PWAs themselves is now fully established and functional. Above all, SLAFO's Institutional Development and Capacity Building is now set to be strengthened by the advent of the new project.

SECTION 2

WHAT WORKED WELL AND OUR INITIAL ASSUMPTIONS ABOUT THE IMPLEMENTATION OF THE PROJECT

2.1. WHAT HAS WORKED WELL.....

Generally, all activities undertaken throughout the entire duration of project implementation went well as planned. But ideally, the following activities proved to have worked exceptionally well:

- a. **The Research:** The findings and recommendations in the final research report provided the **data** and **informed information** to engage in 'evidence based' advocacy efforts.
- b. **The engagement of INDEPENDENT EXPERTS to review the draft research report:** Their standalone comments, opinions and suggestions proved to be very objective and went a long way in fine-tuning the content, facts and the overall presentation of the draft report; thus producing a **credible** and **validated** final report.
- c. **The CONVERSION of the report document into info-graphic formats/versions.**

The final 78 page research report document was reduced into short info-graphic



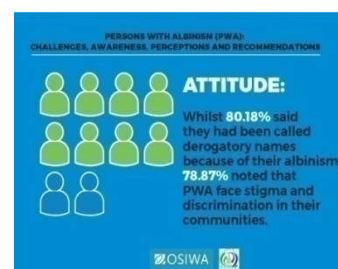
formats and versions including - **info-graphic leaflets; STILL and MOTION picture frames** and illustrations for mental visualisation; **video clip** for dissemination on social



media like WhatsApp, You-tube etc. Also, the FULL research report was redesigned

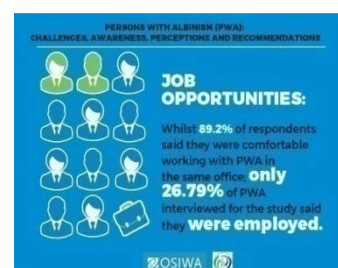


and presented into a visually appealing and easier to read version. This initiative was adopted considering the fact that this research is the **FIRST EVER** formal and accredited



research undertaken to highlight the plight of persons with albinism in Sierra Leone.

So our aim was to ensure that every individual across Sierra Leone, including the **literate** and **non-literate** can quickly read and easily comprehend the findings and recommendations.



Amazingly, after the displayed and distributions of these info-graphic versions/formats at the launching event, participants were quickly and easily able to conceptualise and comprehend the findings and recommendations and were able to relate them to their real life experiences.

- d. **The Platform panel discussion session:** This set-off and heightened a sense of STATUTORY need amongst MDAs to promote and protect the rights and welfare of PWAs in Sierra Leone.
- e. **The Sharing of real life stories:** This session created an inspirational atmosphere thus triggering continued hope and motivation for the PWAs who participated in the launching event.
- f. **The AFTER-LAUNCH debriefing meeting:** All participating PWAs at the launch clearly saw the need to regroup and renew their commitments to take the lead in managing their affairs. This saw the appointment of acting '**focal Persons**' for the four regions across Sierra Leone.
- g. **The production and dissemination of Social Media Video clips** on facebook, WhatsApp etc. It is impressive to have seen that the video clips that were posted on SLAFo facebook page attracted over 10,000 people who **likes** – in less than 3 weeks.
- h. **The formation of the Regional Support Networks** has made SLAFo's work very easy in terms of outreach and control over of any future intervention at national level.

2.2. LEWAF INITIAL ASSUMPTION ABOUT THE PROJECT

Generally, LEWAF initially assumption about the project's expected results has remained unchanged. The following are evident that substantiate our positive assumption:

- a. **The Report launching:** set-off and heightened a sense of STATUTORY need amongst government MDAs such as NCPD, NHRC, SLBC etc to promote and protect the rights and welfare of PWAs in Sierra Leone. This perhaps saw the NCPD classing PWAs as disabled persons thus officially qualifying them to free *basic social services and welfare schemes such as education, health etc.*
- b. Setting up PWAs regional support networks in all the four regions of Sierra Leone has created a sense of national visibility and recognitions of PWAs. This has also augmented the possibility of PWAs outreach efforts and control over of any future intervention at national level.
- c. The establishment of SLAFo considerably enhanced the motivation of PWAs themselves to lead in championing their own course.
- d. The **production and dissemination of Social Media Video clips:** It is impressive to have seen the video clips posted on facebook attracting the attention of over 10,000 people who likes – in less than 3 weeks.

SECTION 3

THE BROADER TAKEAWAY, CHALLENGES AND LESSONS LEARNED

3.1. THE BROADER TAKEAWAY

- ***The WILLINGNESS and ENTHUSIASM observed in PWAs to lead and manage their efforts*** has proved to be the most significant take-away thus far in the implementation of this

The launching event which brought together about 40 PWAs from across Sierra Leone was a unique scene and enticing discovery. It was observed that PWAs appears to be peaceful, friendly and wishes to continue being together as one family. This simply means that any advocacy and development initiative that have the potential to promote and protect the rights and welfare of PWAs is highly likely to be successful if lead and managed by PWAs themselves.

3.2. CHALLENGES.....

- Difficulty in mobilising and seeking the genuine attention of PWAs:*** The activists discovered that, in the past, PWAs have faced FALSE encounter with unscrupulous individuals/organisations promising to support them. So during the research exercise, PWAs were at some point resistant to accommodate the project activists.
- Difficulty in seeking empirical information from 'frontline' public officials.*** For instance, some health care facilities, MDAs etc appeared to be reluctant to entertain in-depth discussions during the research interview process without approval from their senior authorities.
- Inadequate official Identification to authenticate enumerators authority:*** The activists confessed having faced challenges of been accepted to collect vital data from not only the general public but also from their colleague PWAs; without an authentic identification such as identification cards, authority letter etc.
- Tight project budget:*** The budget for project implementation did not provide for many essential activities such as *media coverage for the report launching ceremony*, *visibility t' shirts for activists* and invited PWAs, inadequate funds to support the accommodation cost of external participants etc.
- Late submission of the final research report:*** The final research report was submitted **three-months** beyond deadline date. This exhausted the enthusiasms of project activists and management of LEWAF-SL. For example, PLANNED activities such as evidence based ***community meetings, school visitations, radio and television discussion programmes*** etc. that were planned to be undertaken within the first phase of project implementation were done in the second phase of the project - thus considerably shifting the implementation time-line as per work plan.

- f. ***Delay in starting the second phase of project implementation:*** Following the Launch of the Final Research Report, there was a four-month period of inactivity (from October 2018 to January 2019) due to the delay in submitting the first phase donor Financial Report. This undue delay came as a result of some financial accounting bottleneck that should have been otherwise settled by the research consultancy firm CAPRI.

3.3. LESSONS LEARNED.....

- a. ***Future engagement of PWAs must be structured and consistence:*** Now that a feasible campaign/advocacy efforts to promote the rights of PWAs has been unveil, any intervention with PWAs must be structured and consistence - as this will greatly help to allay the fares of PWAs and enhance their receptiveness to any future engagement and participation.
- b. ***Pay attention to key details in future project budget preparations:*** We will endeavour as-much-as it will have to take to be meticulous in paying attention to key details in future project budget forecast.
- c. ***Identification and authorisations is VITAL:*** In the future, identification and all authorisations from the relevant and legitimate authorities MUST be secured before community engagement.
- d. ***Transparency and active involvement of project beneficiaries will enhance sustain participation and ownership:*** Opening up to beneficiaries and involving them in planning and implementation from the word GO is important to promote ownership and sustain participation. LEWAF-SL believes that engaging the four activists who are PWAs in every aspect of project planning and implementation brought about an atmosphere of confidence and motivation. For instance, developing the work-plan together, reviewing project budget as a team and contentious agreeing on cost for activity implementation has gone a long way to winning the confidence, interest and commitment of the project activists.
- e. ***Information on albinism in short supply in schools:*** Despite the emerging goodwill not to discriminate and stigmatize PWAs pupils in schools, there is still a huge gap on information around issues of albinism among pupils and some teachers in the schools visited. Most of the stigmatization is based on deep-rooted myths and false perceptions held by people in these communities. There is therefore the need to cover more schools in the Western Area and the rest of the country, if we are to address the negative attitudes towards PWAs in educational institutions, nation-wide.
- f. ***Non-PWAs school population (teachers & pupils) do not discriminate against PWA:*** In most of the selected schools visited, it was noticed by the project activists that teachers and pupils behave normally to PWAs pupils as they do to other Students in

their Schools. For Instance, the Albert Academy and Yamakai Primary schools, PWAs students are among the brightest and are like budding stars in their own rights taking part in many school activities. They interacted freely in a very friendly manner with their non-PWAs counterparts.

- g. Ministry of education has no coherent strategy to support PWAs students:** A visit by the project activists to the Ministry of Education, confirmed the finding of the Research Report which states that *'the Ministry of Education in Sierra Leone lack coherent strategy to address the special educational needs of PWAs Students*. As far as the Ministry of Education is concern, PWAs are not persons with disabilities. Devices to assist PWAs in schools such as reading glasses are absent in all the schools visited by the project activists.
- h. Teachers struggling with the skills to manage special needs of students with albinism:** The visiting team realized that teachers lack the necessary skills to handle PWAs. Even simple techniques relating to where PWAs must be positioned to maximize learning in class is not known to most teachers. Many teachers are unaware that PWAs are in the same category of Persons with Disabilities requiring special attention and assistive learning devices like reading glasses.
- i. Many PWAs are unaware of the health issues facing them:** The activists observed that majority of the participants were unaware of the health issues affecting PWAs. The level of interest and the questions posed by participants to the medical practitioners showed how much the participants appreciated the knowledge gained around their health issues.

Generally, in the mist of all the challenges, all the activities undertaken by this project have had the desired impact as expected.

SECTION 4

THE BENEFICIARIES PERCEPTIONS ABOUT THE PROJECT

To trigger ownership opportunity and capacity building drive, CAPRI engaged the four activists as enumerators to administer research questionnaires and collect data across the four regions in Sierra Leone. These included **Bo** in the south; **Kenema** in the east; **Makeni** in the north and **Freetown** in the western regions.

These four activists including other enumerators spend two weeks interviewing and collecting data from targeted research informants. During these periods, the activists had the opportunity to meet a good number of other PWAs that are considered by this project as the **DIRECT** beneficiaries. However, this final report has also endeavour to capture the perceptions of people who are **not** PWAs as the **INDIRECT** beneficiaries.

4.1. DIRECT Beneficiaries' Perception



Osman Bobson Sesay – Project activist spent two weeks in **Makeni**, the Northern Region of Sierra Leone.

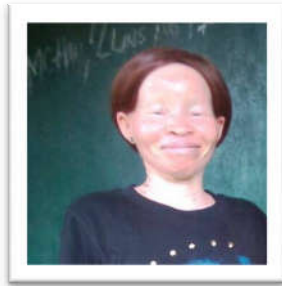
Whilst in Makeni, Osman met with **Mahied Hassan** – *arrowed*. **Mahied** was an information technology student at the University of Makeni, but dropped out for reason he did not disclose to Osman (the activist). Giving his opinion on the initiative, Mahied said quote *"I am happy to meet with you living with the same condition as me. Such a move is what I have been yearning for - this shows that though people look at us as less important, we must show the world that we are important"* end of quote.



Haja Dankay Conteh – *pictured below left* is also a school drop-out and currently engages in petty trading. During an interview with Osman she was quoted as saying *"I am only encouraging you because you have the same skin colour with me. If it is not for that, I will not give you ears because several organs has come around ant took my photo in the name of helping me because of my condition, but never returned"*, end of quote.



In another related engagement, Osman met with **Bai Turay**, a senior secondary school pupil and also a technician in training. Bai was full of praise for Osman, having taken the effort to come all the way from Freetown to meet with him in his remote corner in Makeni, *"I have been thinking of joining an organization that deals with people like me and you, but there was none, May God bless the sponsors of this research"*, Bai Turay concluded.



Jeneba Sesay – Project activist spent two weeks in **Kenema, the Eastern Region** of Sierra Leone.

Jeneba travelled all the way to ‘Boma-4 community’ in Kenema region where she met **Jamilatu Salami** – *arrowed*. Jamilatu a university graduate reveals that after graduating from University, she had applied several times for jobs fully confident that she has the requirement to secure jobs, but has never been contacted. In her words *“I don’t know if because I am an albino that is why they are not employing me”.....*



Fatmata Sheriff – *arrowed* is a petty trader *“I feel normal like any human being even though I faced a lot of discrimination because of my skin and my hearing difficulties, but I give thanks to God because I can do things on my own”.....*



Alimatu Ansumana – *arrowed* is a student living in ‘Boma-3 section’ in Kenema. During conversation with Jeneba (the activist) she reveals that, *“people don’t normally eat my food or even interact with me that often, they say I am evil and my skin is not worth to be touched or even have an affair with me because I am an albino”.....*



Mohamed Osman Kamara – Project activist spent two weeks in **Freetown Western Urban and Rural region** of Sierra Leone.

Giving an account of his experience after engaging with various research informants - this is Mohamed Osman Kamara’s own perception – *‘As an enumerator and a person with the albinism condition, it was an opportunity to interact with so many people both WITH and WITHOUT the albinism traits. Haven learnt a lot from everyone I interviewed, I have now realized that most of our challenges cut across all PWAs. They are most often discriminated; neglected and stigmatized - hence that has resulted to most of them being dropped-out of school and socially isolated. At the end of my survey I found*

traditional cases and that if given the Rights that we deserved, we will change the world to a better place and the negative mind-set of some people, that is, the myth, superstitious beliefs, misconception etc about albinism will end soon.'

In substantiating his perception, Mohamed made reference to 3 instances of PWAs interviewed as follows:

Elizabeth Kargbo is an Albino and a serving Police Officer in the Sierra Leone Police force. In a meeting with Mohamed, Elizabeth said *"I had faced so many discrimination in life.... even my father neglected me from birth because I was born with Albinism. I have one male child that I love so much, but his dad left me long time ago. Now I am single by choice because most men will just come around females living with Albinism to get a feel of making love with us and leave without valid reason but for the physical appearance. I faced a lot of discrimination from my squad mates in the police training camp, but I have continuously overcome them and today I am proud to be a Police Officer. I am so happy to see and hear that my kinds (PWAs) are the ones leading the way to advocate for our Rights and will love to be a member of this association.*

Ruth Hawa Kondeh is also an Albino and works at Eco Bank in the customer service department. During conversation with Mohamed (the activist), **Ruth** was clear on the fact that PWAs should start to handle their own affairs. She stated that... *'I am favoured by God because i have been always successful in my job applications'*. Ruth acknowledged that she sometimes faced discrimination and stigmatization from colleagues at work and even her neighbours in the community, but she proudly mentioned that majority of her neighbours hold her to high esteem because she is not idle and jobless.... Ruth concluded by saying that-*"I want to see an association of PWAs that will influence government to enact laws that will protect our Rights and give free access to good education and health care as that will improve our confidences and livelihood... and i pray we work as one to change the negative thought about us by the public"* end of quote.

In another related engagement, **Mohamed Lamin Jalloh** a cattle seller narrated his ordeal to Mohamed (the activist). Lamin had this to say, *"I am married with three children and was a member of 'Albino Savers' - an Organization headed by Mr. Tee (not real name). I had to quit because I realized Mr. Tee was only using us to funds himself. I had always wished for an Organization lead by someone with Albinism. I am so happy to understand that some Organizations are trying to help us champion our course in advocating for our Rights. We must unite and speak for ourselves; nobody without the traits should lead us, because they are not feeling our pains as we do. So am ready to involve in any way to speak up for our human Right"*.



Mohamed Kelfala Sesay – Project activist spent two weeks in **Freetown Western Urban and Rural Region** of Sierra Leone.

Kelfala met **Sallay Buani** who has two children - the girl is black and the boy is an albino.



According to Sallay, she dropped out of school (Junior Secondary School level 3) because of lack of support. She said friends of her husband sometimes provoke her but her husband has always being there for her. *"I sometimes feel normal but sometimes disappointed as PWAs"*. **Sallay** is a volunteer assistance teacher in a community nursery school.

Kelfala (activist) found out that **Ibrahim Sesay** – *arrowed* is a freelance Disco Joker (DJ)



and a musician who believes in singing about equality. Ibrahim said quote *"I have faced a lot of discrimination but i accept my condition and life goes on"* end of quote. Kelfala also learnt that Ibrahim has concluded his West Africa Senior Secondary Certificate Examination (WASSCE) level and now preparing for university.

In engaging **Mohamed Turay** – *arrowed*, Kelfala learnt that Mohamed has never gone to



school because he lost his parents when he was an infant. He however secured a job as pub assistant but was unable to sustain the job because the owner was not paying him as arranged and at the same time always discriminating against him. According to Kelfala, Mohamed is now a petty trader.

In another related engagement, **Richard Tambe Gauja** – *arrowed*, told Kelfala (activist)



that he is hoping to see a structure/association that will champion the welfare of PWAs in Sierra Leone. However, according to Richard, *"life is very comfortable – as I am a businessman and have a child"*.

4.2. INDIRECT Beneficiaries' Perception

Madam Juliana Sheku – is not an albino but she was hired by CARPRI as one of the enumerator covering Kenema district in the eastern region of Sierra Leone. In summarizing her perception after spending 2 weeks in Kenema, she has this to say *'PWAs are just human beings with little or no form of melanin. But uncouth tradition and superstitious beliefs have led individual with the condition in Kenema district to see themselves as inferior causing them to drop out of school and restrain themselves in their community. This belief has made it difficult for non-albinos to accept that there are people who are actually born with genetic disorder and Albinism could be one of those genetic disorders'*.

In sharing her observation, Juliana continue to say that, *"During the course of my survey, I observed that the lives of Albinos continue to be at risk both within the community at large and the Albino family due to the misconception and societal attitude about people with albinism; they continue to undergo great deal of marginalization and segregation in all spheres of life"*.

Juliana was reasonably convinced to say that - *Majority of the albinos I interviewed said that they were physically abuse followed by hurtful words both within the family and outside the community on the bases of their gender - this has created widespread insecurity in their society. And every day the economic, social and political rights of albinos in Kenema District are deliberately compromised in debilitating ways due to the ignorance of the society about albinism. This has contributed to the exclusion and denial of their rights such as the right to educate and rights to health. These marginalization and exclusion has made them to feel left out, poor, relegated and suffer other insurmountable barriers to enjoy their basic human rights. While collecting my data from the respondents, I asked that whether society will abuse albinos if they have the opportunity? 80% of my respondent agreed that society will surely stand the chance to do so once they are given the opportunity as albinos are always provoked whenever they are in public places. A respondent by the name of **Mary Baidu Ben** told me that... quote "whenever I see an albino I laugh because I see them funny - how can you live with us and when it's time to die you just disappear, it really funny to me. And when the sun is hot, they don't see objects as we all do they just see shadow and when it is night; they will see more clearly than us - is it not funny? In fact I normally call them names like the night-devil or white people whenever I see them".... end.*

*Another respondent a nurse at the government hospital by the name of **Yatta Buckarie** stated that "I will rather die single than settle for an albino partner as my husband. I don't want to be close to them at-all as their smell irritates me. People always laugh at them and for that reason, i will also never settle for them." This was what Yatta said to me when I asked her if she would choose an albino for a life time partner.*

SECTION 5

MISSSED OPPORTUNITIES; FOLLOW UP PLANS AFTER THIS PROJECT; AN ASSESSMENT OF LEWAF COLLABORATION WITH OSIWA AND RECOMMENDATION.

5.1. MISSED OPPORTUNITIES

The project was designed to achieve 3 main objectives as follows: (1) Highlight the plight of persons with albinism in the country among government, civil society and the public; (2) Give a voice and/or amplify the voices of persons with albinism; and (3) Facilitate the establishment of an Organisation to be led by persons with albinism in a bid to build their capacity to lead advocacy effort for the protection of their rights and general wellbeing.

Practically, both the internal and external actions undertaken to support project implementation and thus creating the road map towards achieving the above three main objectives has been reasonably exhausted within the context of project design. As much as possible this has been captured under section 1 of this final report.

However, the LEWAF-SL technical team have realised that, there is need for SLAFo to build upon the gains this project have made. The enabling environment has been established by this project for SLAFo to strategically position itself as a LEAD national advocacy organisation with a comparative advantage to championing the course of PWAs in Sierra Leone. For this to be possible, SLAFo technical team must intensify defined efforts to mobilised and lead network of partnerships both at national and international levels. In addition, the need for constructive collaboration with relevant ministries, departments and agencies in Sierra Leone will be a golden opportunity for SLAFo to sustain its visibility and productive existence.

5.2. FOLLOW-UP PLANS AFTER THIS PROJECT

Fortunately, the new follow-up project for SLAFo has presented a clear plan on LEWAF's future engagement with SLAFo after this project. The new Project is an Institutional Development and Capacity Building project designed to influence the internal control systems, processes and strategies that will enable SLAFo to operate as an independent non governmental organisation.

Therefore, over the next 24 months of implimentation of this new project, LEWAF-SL has offered to be working with SLAFo to construct its institutional capacity and strengthen the capacity of its personel in program management, administration and accountability. In other wards, the LEWAF-SL support will focus on areas around positioning SLAFo into a formidable, well capacitated, transparent and accountable humanitarian organisation that will be better placed to attract technical and financial supports from donor/funding agencies both at national and international levels; entirely lead and managed by PWAs themselves.

5.3. LEWAF COLLABORATION WITH OSIWA: The Assessment

LEWAF-SL has over the years realized that collaborating with OSIWA in the implementation of their funded projects has always proved to be very worthwhile. Once again, in the implementation of this project, OSIWA has extended relevant capacity building opportunities as much as possible. The project activists who are PWAs have been at the forefront of the immediate beneficiaries. LEWAF-SL has continually classed this opportunity as the **first-step** towards enhancing the **‘mental agency’** of PWAs to be able to lead and manage their affairs.

It is appealing to state that LEWAF has been able to utilise all the appropriate opportunities offered by OSIWA. Below are some vital instances:

- a. **International workshops:** From the 15th – 17th November, 2018 the four activists participated in a three days program in Mali to discuss on the **‘action on albinism in Africa’** work plan and raise awareness about the condition PWAs are facing. The programme organised by the Salif Keita Foundation created a unique opportunity for the project activists to interact, learn and to take stock of their collective knowledge and build upon it.



SLAFo Activists posed with the UN Expert on Albinism - Ikponwosa Ero

- b. **International courses:** From 17th- 21st June, 2019, Mr Osman Bobson Sesay – the Coordinator for SLAFo attended the 11TH annual Disability summer school organised by the National University of Ireland, Galway. The course was a 5 days continuous Learning process on the theme **‘Persons with disabilities and their rights to family life’**. In outlining his plan on how he intend to use the knowledge gained to promote work around PWAs, Bobson said quote **“This knowledge is really timely as it will help me and other activists on how to tackle parents and families that are abandoning PWAs that are related with them; this tool will be used greatly in the community visits and in our media outreaches”** end of quote.



- c. **Programming work related trainings:** These included:
- Project Finance Essentials and Planning for Financial Sustainability’** training facilitated by **Humentum** from the 3rd to 8th of June 2019 in Freetown.

- ii. **Advocacy and Monitoring & Evaluation training** – 25th to 27th Sept 2019 in Freetown.

d. Hands-on Technical support:

Throughout the implementation of this project, LEWAF-SL has continually worked and subsequently benefited from OSIWA technical team. The Hands-on Technical support has been in the form of expert reviews, strategic suggestions and complimentary logistical supports. For instance, OSIWA actively supported LEWAF-SL in the recruitment process of the consultancy firm to undertake the research. Also, OSIWA provided expert oversight and suggestions on the info-graphic formats conversion of the 78 pages research report. In addition, OSIWA was very much instrumental in the planning process of launching the final research report etc.

Overall, it is candid to state that LEWAF's collaboration with OSIWA over the period of project implementation has been **REMARKABLE** and **PRODUCTIVE**.

5.4. RECOMMENDATION

Thus far, the LEWAF candid recommendations to OSIWA if it was to fund similar project in the future - regardless the organisation, will be as follows:

- a. **Timely Disbursement of Funds:** However, OSIWA should endeavour to **improve** on the timely disbursement of fund to implementing partners. By so doing, it will NOT ONLY contribute to partners planned activity implementation within **time-lines** but will also reduce **undue pressure** on partners in their bid to achieving the overall objective of OSIWA with regards to **timely** and **quality** project deliverables.
- b. **OSIWA to continue supporting capacity building opportunities:** The participation of the project activists on designed training sessions and international workshops has broadened the mentality of the activists by comprehending the true context of work that lies ahead. Their exposure and mingling with other PWAs across the region has instil a sense of '**not alone**' mind-set and has enhanced their determination to champion a noble course with no turning back.
- e. **OSIWA to continue providing Hands-on Technical support to implementing partners.** – By this way, both parties' expectations will be managed as much as possible without undue misconceptions.

SECTION 6

ADDITIONAL INFORMATION BEYOND THE PROGRAMMATIC OUTCOME

Moving forward, LEWAF will maintain its strategic position as a parent organisation that will continue to identify and propel the visibility of Minority rights at all levels in Sierra Leone. The memorable moment of this project was when the relevant institutions in Sierra Leone conceived the need for PWAs to be considered as Sierra Leonean that must be recognised, valued and respected in an enabling environment where opportunities will be available for them to live and thrive. See related photos in ending the report.



The **Minister** of *'Social Welfare Gender and Children Affairs'* welcome SLAFo Activists



The **Deputy Mayor** of *'Freetown City Council'* receiving an invitation from SLAFo Activists



The **Executive Secretary** of '**National Disability Commission**' engages SLAFo Activists



The **Executive Secretary** of '**Human Rights Commission**' with SLAFo Activists