PERSONS WITH ALBINISM (PWA): CHALLENGES, AWARENESS, PERCEPTIONS AND RECOMMENDATIONS
I. Key conclusions for policy action for PWA in Sierra Leone

- The need for urgent attention for policy makers and leaders to address issues of marginalization, discrimination, and stigmatization.
- Urgent need for government and civil society in Sierra Leone to take the necessary steps to avert challenges similar to those faced by PWA in East and Southern Africa.
- Lack of an effective and functional network has left PWA vulnerable to exploitation.

II. Challenges

- The absence of an effective and functional network of PWA has not helped their cause;
- State and non-state actors have systematically failed to protect and promote their rights;
- The Ministry of Education, Science and Technology has no coherent strategy of providing the necessary support and accommodation for PWA in educational institutions.
Whilst 80.18% said they had been called derogatory names because of their albinism; 78.87% noted that PWA face stigma and discrimination in their communities.
What did they say about their situation?

62.83% had visited a Health Centre within the last two (2) months of the study.

48.67% were living in communities indifferent to their challenges.

53.77% had been ignored or shunned during conversations because of their albinism.

80.18% had been called derogatory names because of their albinism.

41.59% had never received any special support or attention from their communities.

57.29% school-going-age PWA had not received necessary support and accommodation to enable them access education on equal terms with other students.

34.95% school-going-age PWA had been excluded from physical activities in their schools.

22.73% had interacted with justice institutions within the last 12 months of the study; 40% of those were complainants; and 43.75% were treated with dignity and respect.

26.79% were employed.

60.23% had never applied for a job.
**JOB OPPORTUNITIES:**

Whilst 89.2% of respondents said they were comfortable working with PWA in the same office; only 26.79% of PWA interviewed for the study said they were employed.
III. Albinism Awareness

Myths, Facts and Fiction on albinism:

Communities and the Public: What did the respondents know and believe?

- **69.69%** describe PWA on basis of their appearance
- **62%** did not know the cause of albinism
- **29.98%** think albinism is caused by “having sexual intercourse during a woman’s menstrual period”
- **54.62%** said albinism cannot be inherited;
- **57.66%** said albinism is not a disability;
- **86.12%** think albinism has no cure;
- **76.28%** know albinism is not infectious;
- **62.27%** had seen “quite a few” PWA in their communities;
- **71%** believe that PWA have the same abilities as persons without albinism;
- **85.17%** know that PWA live a full life, grow old and die from natural causes;
- **82.98%** know that the assertion “PWA are less intelligent as persons without albinism” is false;
- **78.87%** know that PWA face stigma and discrimination in their communities;
- **90.07%** of respondents are interested in learning about albinism.
BELIEFS:

Whilst 71% of respondents said PWA have the same abilities as persons without albinism; 82.98% noted that the assertion “PWA are less intelligent than persons without albinism” is false.
IV. Access to Services;
What did the respondents say?

84.44% - PWA have equal access to justice services
78.35% - PWA have a fair and equal access to educational services
87.92% - PWA have special educational needs;
78.84% - PWA have a fair and equal access to health services;
86.1% agree that PWA should have the same rights as persons without albinism to contest for public office;
91.37% agree that PWA should be bona fide members of their communities;
50.41% are open to choosing PWA as life partners;
91.22% - government should enact legislation to protect the rights of PWA;
89.2% - are comfortable working with PWA in the same office;
88% would employ PWA if they were employers.

V. Perceptions of service providers;
What did the Health Workers say?

60% have treated PWA in their Health Centres
84.95% treated PWA normally as they did persons without albinism;
49.47% were supportive of PWA, and 25.26% were very supportive of them;
47.73% said patients without albinism were indifferent to PWA;
48.28% said PWA were not included in regular care seeking procedures at their facilities;
EDUCATIONAL OPPORTUNITIES:
Whilst 87.92% of respondents said PWA have special educational needs; 57.29% of PWA of school-going age said their schools did not provide the necessary support and accommodation to enable them access education on equal terms as other students without Albinism.

HEALTH CARE:
Whilst 62.83% of PWA said they had visited a health centre in the last two (2) months of the period of study; 48.28% of health workers noted that PWA were not included in regular care seeking procedures at their facilities.
### What did the teachers say?

- **66.36%** had PWA in their schools;
- **75.76%** treated PWA students the same way they would treat students without albinism;
- **42.57%** were confident that teaching staff were capable of addressing the challenges of PWA;
- **36.46%** said students without albinism were indifferent to PWA students;
- **32.63%** said PWA students were included in activities organized by their schools;
- **32.29%** said PWA students were never given support when writing tests or examinations;
- **67.01%** said their schools did not provide assistive device for PWA students;
- **38.95%** said PWA students had never represented their schools in inter-school competitions or activities;

### What did the workers in the Justice sector say?

- **43.31%** had dealt with cases involving PWA;
- **47.06%** said common disputes constituted the most cases involving PWA;
- **89.22%** treated PWA as they did with all other persons accessing their services;
- **59.77%** said other parties to disputes treated PWA with indifference.
PROTECTION:

A cumulative 91.22% said government should enact legislation to protect the rights of PWA.
VI. Recommendations

What should the Government, LEWAF, OSIKA and other stakeholders do to protect PWA?

1. Identifying PWA Champion to raise challenges of PWA and influence policy makers

2. Support the establishment of a functional and unified network led by PWA, decentralized at regional and district levels.

3. Institution of Special sessions for hearing, narration and documentation of human rights violation of PWA.

4. Designing public education campaigns and programmes to raise awareness, change mindsets and perceptions of communities and the public.

5. Enactment of a specific law protecting the rights and lives of PWA.

6. Engagement of National Commission for Persons with Disability to mainstream PWA issues in their programmes beyond the “International Albinism Awareness Day”

7. Engagement of key Sectoral Ministries advocate for provision of free or subsidized social services such as Healthcare and Education for PWA.

8. Undertaking further research relating to everyday life challenges of PWA for society and policy makers to understand how to address their challenges.
HEALTH CARE:

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48B Sanda Street-Lower Mayenkineh, Bottle-field, Calaba Town-Freetown, Sierra Leone.
Freetown, Western Region, Sierra Leone
Tel: +232 (0) 76 971 418, (0) 30 196 011
Email: lewafsl.org@gmail.com