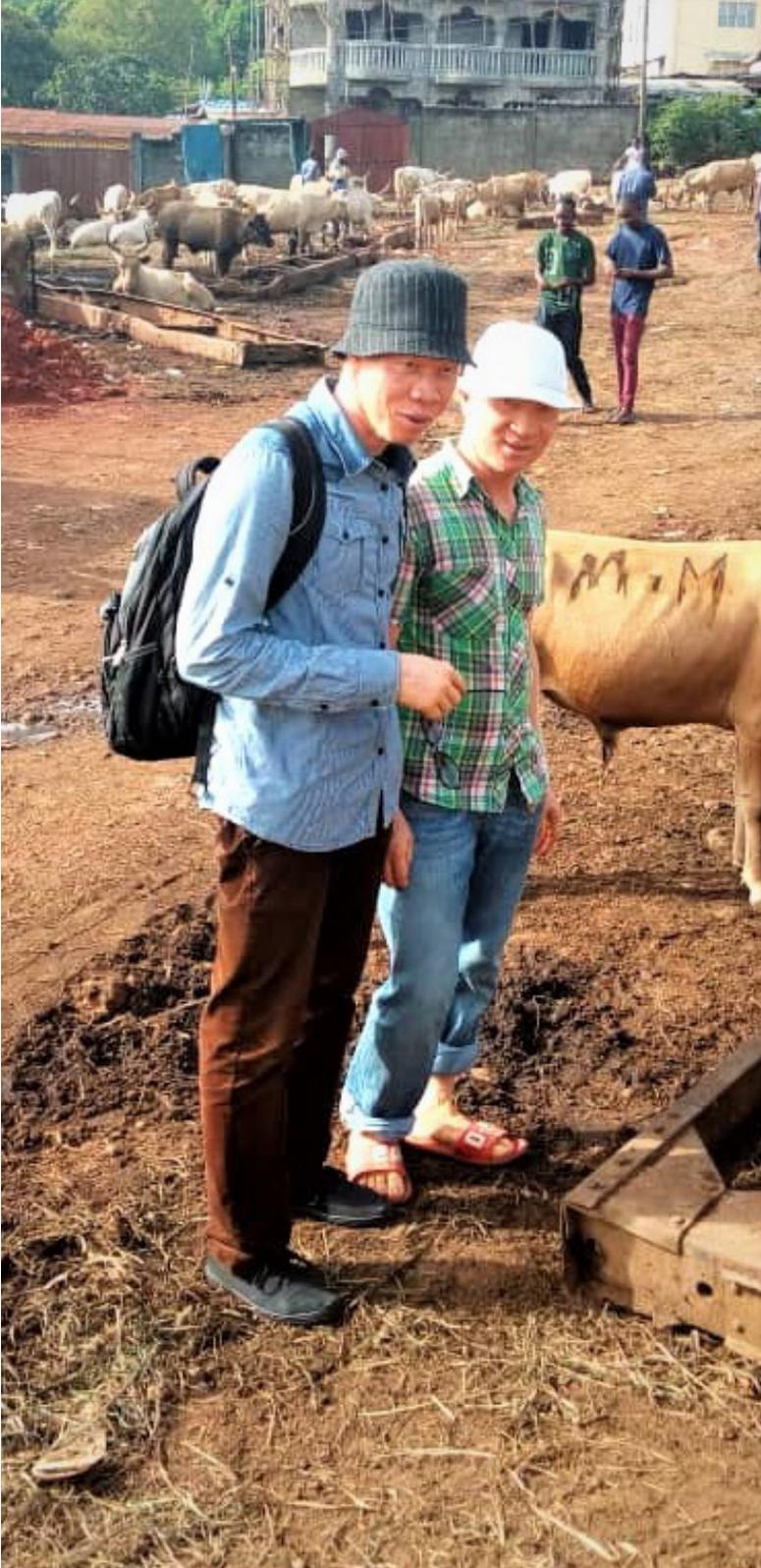


PERSONS WITH ALBINISM (PWA):

**CHALLENGES, AWARENESS,
PERCEPTIONS AND
RECOMMENDATIONS**



POLICY



CIVIL SOCIETY



NETWORK

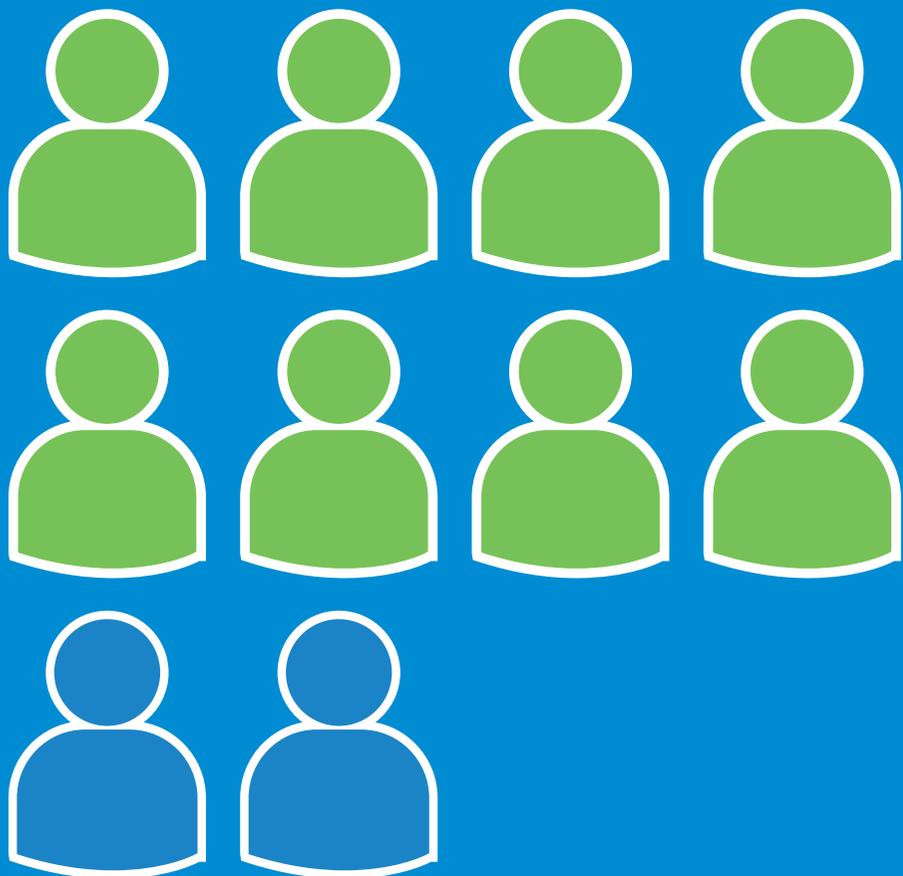


I. Key conclusions for policy action for PWA in Sierra Leone

- 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.

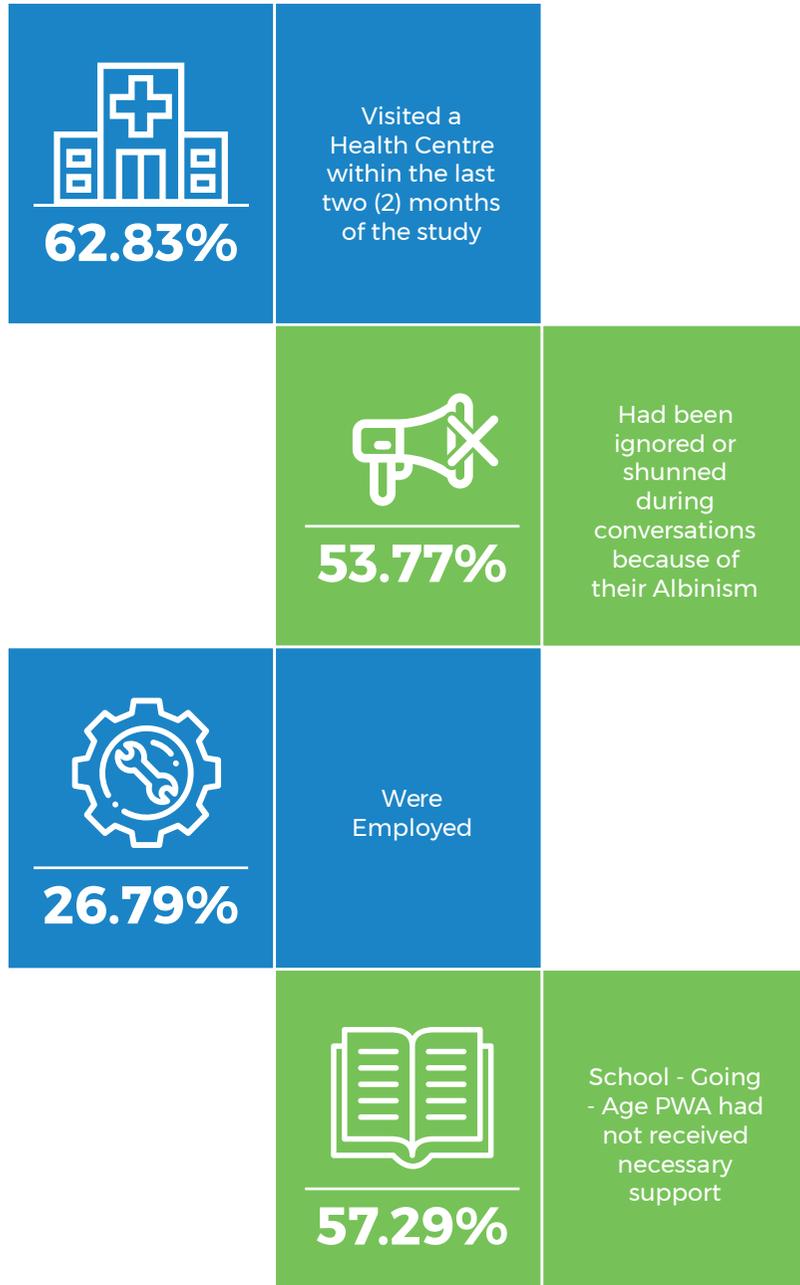
II. Challenges

- 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.



ATTITUDE:

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;

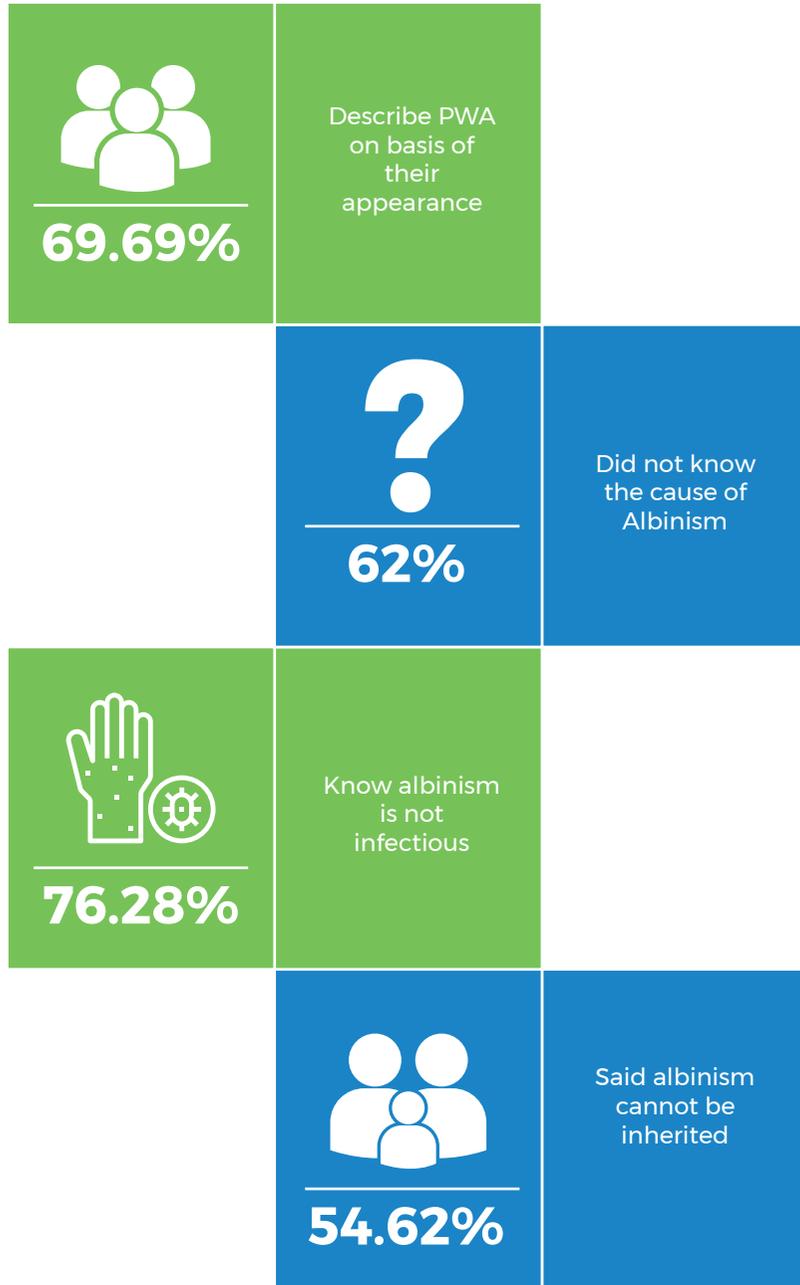


*CHALLENGES PERSONS WITH ALBINISM FACE



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.**



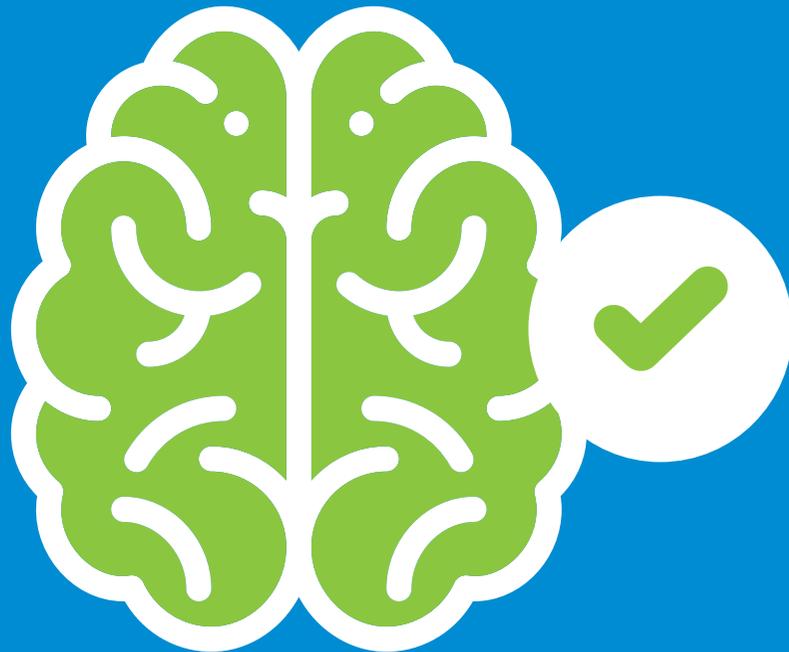
III. Albinism Awareness

Myths, Facts and Fiction on albinism;

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

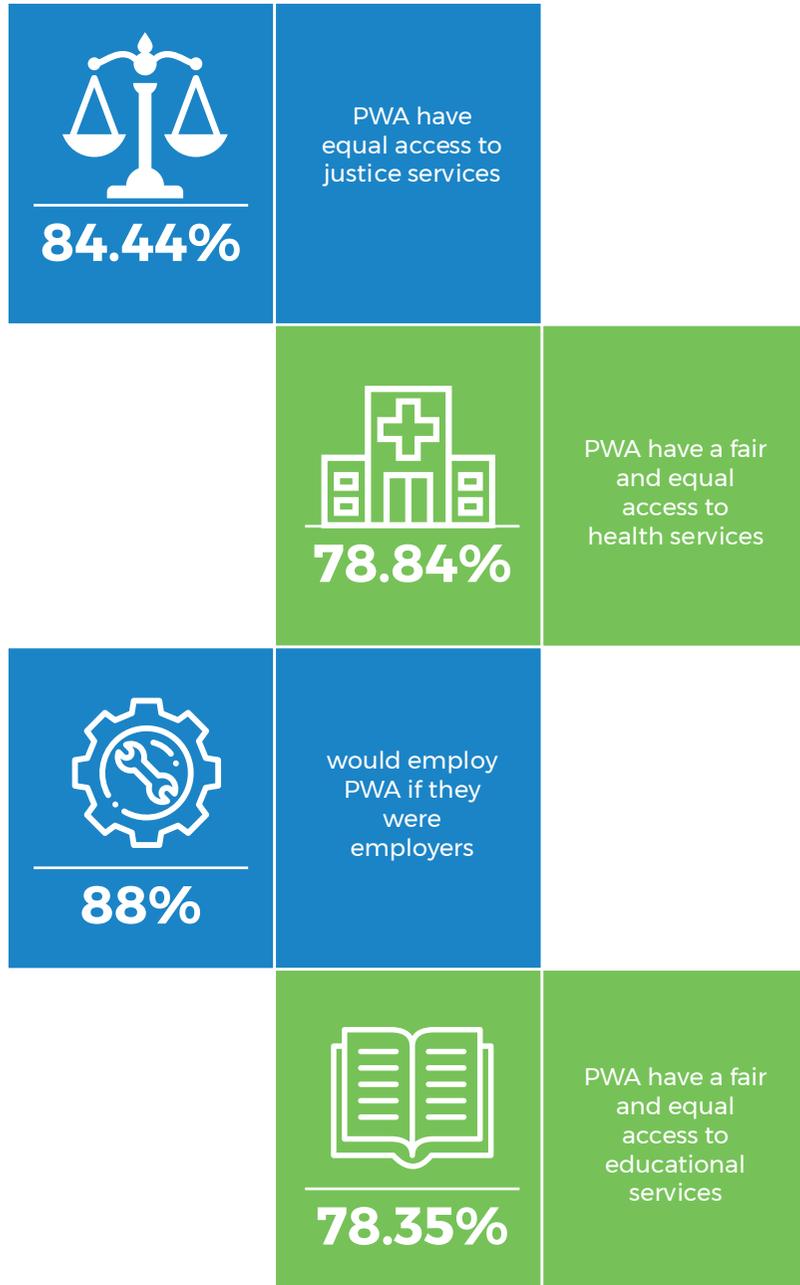
- 69.69%** describe PWA on basis of their appearance
- 62%** did not know the cause of albinism
- 29.98%** think albinism is caused by “having sexual intercourse during a woman’s menstrual period”
- 54.62%** said albinism cannot be inherited;
- 57.66%** said albinism is not a disability;
- 86.12%** think 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?

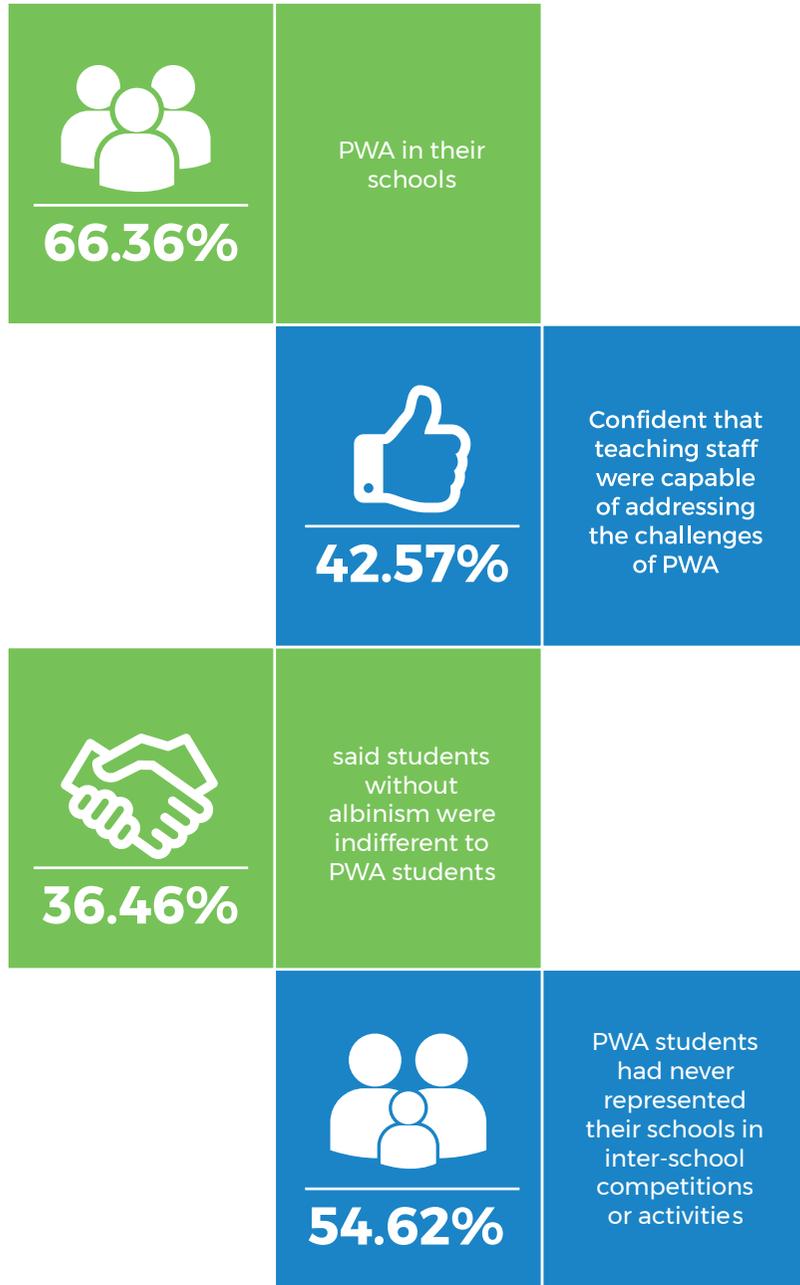
- 60%** have treated PWA in their Health Centres
- 84.95%** treated PWA normally as they did persons without albinism;
- 49.47%** were supportive of PWA, and **25.26%** were very supportive of them;
- 47.73%** said patients without albinism were indifferent to PWA;
- 48.28%** said PWA were not included in regular care seeking procedures at their facilities;





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?

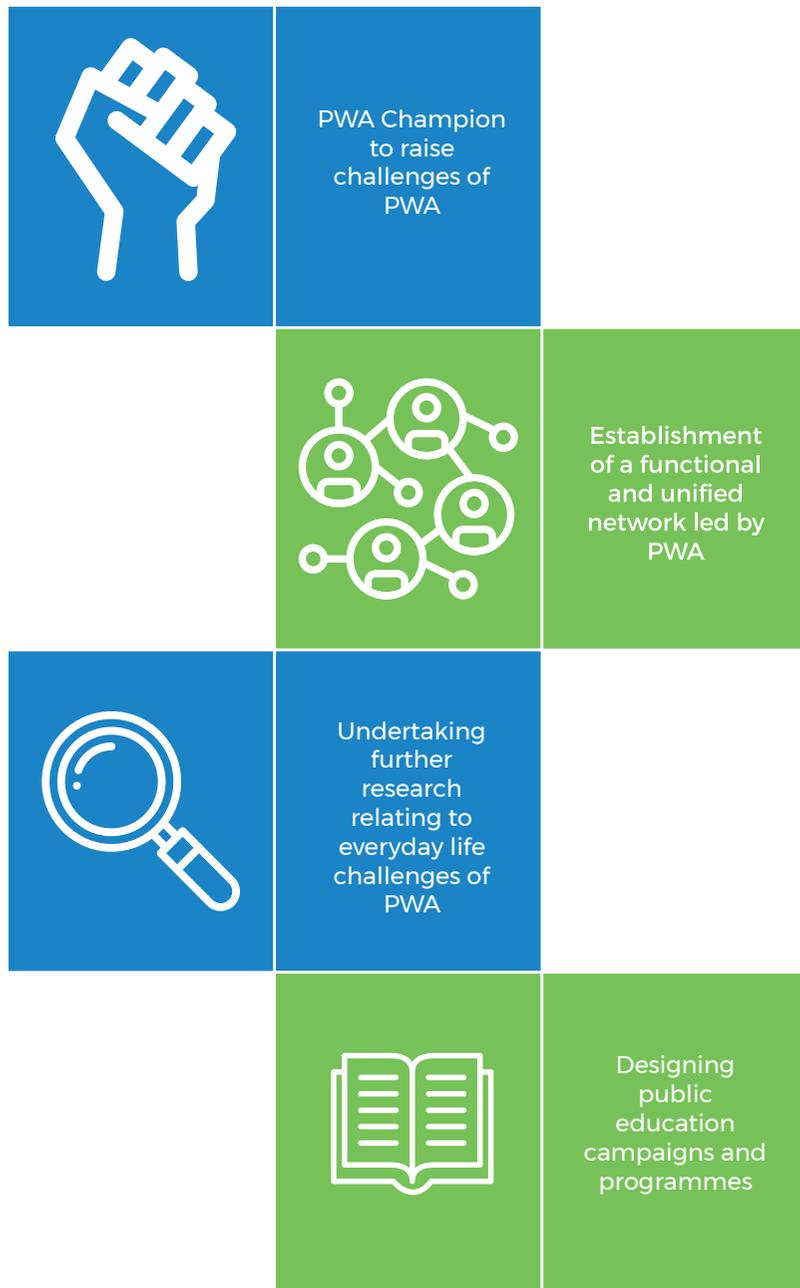
- 43.31%** had dealt with cases involving PWA;
- 47.06%** said common disputes constituted the most cases involving PWA;
- 89.22%** treated PWA as they did with all other persons accessing their services;
- 59.77%** said other parties to disputes treated PWA with indifference.





PROTECTION:

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



VI. Recommendations

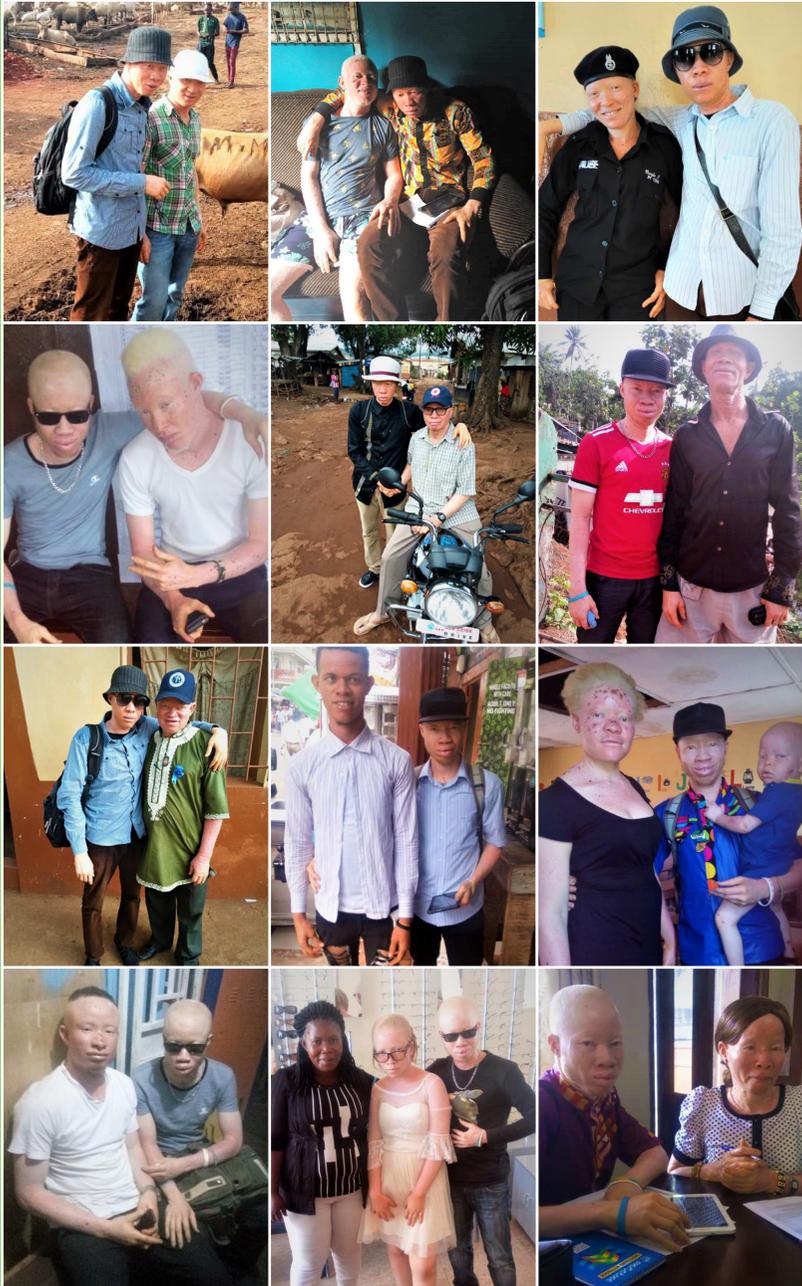
What should the Government, LEWAF, OSIKA and other stakeholders do to protect PWA?

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:

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.



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