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INTERVIEW

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The United Nations Independent Expert on the Rights of Persons with Albinism with Ms Ikponwosa Ero

Ikponwosa Ero (Nigeria) was designated in June 2015 by the UN Human Rights Council as the first UN Independent Expert on the enjoyment of human rights by persons with albinism. Inspired by her experiences as a person with albinism, Ms. Ero has spent the last seven years fulfilling her mandate.

As international advocacy and legal officer of Under the Same Sun, an NGO with a focus on albinism, she has participated in multiple activities and panels at the UN in Geneva and New York. She has extensive experience in research, policy development and advocacy in the field of albinism. She is the author of numerous papers and articles on the issue, including ones examining the categorisation of persons with albinism in the international human rights system.

Can you briefly tell us about your mandate as the Independent Expert on the enjoyment of human rights by persons with albinism?

My mandate was created nearly three years ago by the Human Rights Council of the United Nations. It was created in response to increasing reports of attacks and other grave human rights violations against persons with albinism. The attacks are linked to witchcraft beliefs and practices, which propagate the absurd and erroneous notion that the body parts of persons with albinism can generate wealth and good luck when used in rituals, potions and amulets. Nearly all reports of attacks have come from sub-Saharan Africa. Globally, there are challenges over and above the attacks, including reports of infanticide, abandonment and discrimination in the areas of socio-economic rights, such as being denied jobs or places at school.

As with all other thematic mandates, I have general duties, such as reporting to the UN Human Rights Council and to the General Assembly, and visiting countries for fact-finding and first-hand assessment of the situation. My main focus in this mandate is to end the attacks against persons with albinism and to tackle their root causes. Consequently, I spend a lot of effort on the region of sub-Saharan Africa, where violations against person with albinism are severe. In so doing, I meticulously search for good practices and also seek out partners to replicate these good practices at the local level and national levels.

I also prioritise research. Since this issue [albinism] has been neglected for centuries and its members have suffered and continue to endure great violations, it is highly important to gather the facts to feed them into ongoing intervention. This means I engage in frequent dialogue with persons with albinism, academic researchers and other stakeholders. I am now working on building an international research collaborative on the issue. The collaborative will look into all relevant legal frameworks, but will also include the difficult questions surrounding harmful practices emerging from belief systems that pervade sub-Saharan Africa.

What is albinism?

The condition of albinism is non-contagious, genetically inherited and affects people regardless of race, ethnicity or gender. It results from a significant deficit in the production of melanin and is characterised by the partial or complete absence of pigment in any or all of the skin, hair and eyes.

Persons with albinism therefore often appear pale in comparison to members of their family and their communities.

Today, it is estimated that in Europe and North America the frequency is 1 in 17,000 to 1 in 20,000 births. In sub-Saharan Africa, the reported frequency ranges from 1 in 5,000 to 1 in 15,000, with prevalence rates of 1 in 1,000 for selected populations. A higher frequency has been reported in certain parts of the Pacific (1 in 700) and among some indigenous peoples in North and South America (1 in 70 to 1 in 125). While the condition is global, the impact of the condition on human rights, and its perception by others, including its effect on social inclusion, varies from region to region.

There are different types of albinism. The most well-known type is oculocutaneous albinism, which affects the skin, hair and eyes. Within this type are subtypes that may reflect varying degrees of melanin deficiency in an individual. Lack of melanin in the eyes results in high sensitivity to bright light and significant visual impairment, with the level of severity varying from one person to another. This visual impairment often cannot be completely corrected. In addition, one of the most serious health implications of albinism is vulnerability to skin cancer, which remains a life-threatening condition for most persons with albinism in certain regions. All violations of civil and political rights relating to albinism reported to date have been linked to its oculocutaneous form, which is also the most visible type of albinism.

Since your appointment as the Independent Expert on the enjoyment of human rights by persons with albinism, what would you consider to be the major challenges facing persons with albinism worldwide, particularly in Africa?

The overarching challenge faced by persons with albinism is long-term neglect of the issue, resulting in the absence of their voice in the public sphere. Also, a significant number of persons with albinism globally are not aware of the laws that protect them and continue to linger in various forms of suffering and neglect. Efforts need to be made to build their capacity (particularly that of civil society leaders and advocates) on the norms and standards of human rights and also on the human rights approach.

The second overarching challenge is a lack of understanding of the condition and consequently a failure to apply a robust legal framework to their experiences.

In the past, there was often a lack of clarity in the application of the disability framework to persons with albinism. Nowadays, with the advent of the Convention on the Rights of Persons with Disabilities (CRPD), which broadened the understanding of disability, persons with albinism are officially a constituency of the larger groups of persons with disabilities. However, in sub-Saharan Africa, this knowledge is not always known widely by state officials, where it's needed the most. Various reports, along with my own experience (even in states that have ratified the CRPD many years ago), confirm that very few national and community-level personnel of the state charged with the implementation of disability rights are aware of the CRPD's implications, including their duties.

In addition to the CRPD, the Convention on Elimination of Racial Discrimination (CERD) also applies to persons with albinism. The Committee governing the CERD has explained that 'racial discrimination' is not only linked to race but to other grounds, such as colour and heritage, and racial discrimination can be found even when these grounds are independent of each other.

National laws on trafficking in body parts – not just in persons – are also highly beneficial to the issue, yet many countries lack this aspect in their trafficking and criminal laws. International and national trafficking laws ought to be applied to address the cross-border aspect of this issue, as cases of body parts and persons moving across borders have been reported. Further, national laws or policies on witchcraft practice also need to be evoked. However, most of these are archaic and need revision in a way that may be helpful to persons with albinism and others who are often victimised by the phenomena.

I have used the plural of 'phenomenon' on purpose, to recognise the plurality of definitions, forms and aspects of 'witchcraft' beliefs and practices. I am also working with experts on the issue to come up with some early-stage understanding of what it means, not only to guide my work but to support the work of countries reviewing their so-called witchcraft laws.

The intersection of these laws provides a thorough understanding of the issues faced by persons with albinism and potential solutions, yet public knowledge of these, and how to implement them effectively, remains lacking.

How have these challenges, particularly the issue of discrimination, affected the enjoyment of socio-economic rights by persons with albinism?

In sub-Saharan Africa, the impact of these overarching challenges is a vicious cycle. Once a child with albinism is born, there is a risk of infanticide and abandonment. Mothers of children with albinism also risk being expelled from their communities on the grounds of alleged infidelity, since the baby has white skin, or on the grounds that the baby is a curse on the family or on the community.

A common consequence is that the child grows up in dire poverty and vulnerability to attacks and other serious human rights violations.

If the children survive this stage, they are unlikely to attain an education due to their visual impairment and the lack of reasonable accommodation for the impairment in the classroom. Moreover, discrimination, bullying and name-calling from students and teachers alike force children not to return to school. The absence of education means persons with albinism often cannot access gainful employment – in particular, employment indoors. Oftentimes, they become farmers, peddlers and petty traders, working outdoors where they expose themselves to the risk of developing skin cancer. Skin cancer is the number-one cause of death in persons with albinism in the region. In some countries, only two per cent reportedly live beyond age 40, with a majority succumbing to this preventable disease.

Furthermore, the absence of work in a secure environment produces endemic fear and impacts the livelihood of persons with albinism, as insecurity often shortens the number of work hours they are able or willing to undertake away from home. Similar impact on the right to work of family members and carers of persons with albinism has also been reported.

Essentially, a significant number of persons with albinism, particularly on the sub-continent, live a Hobbesian life: poor, nasty, brutish and short, with a theme of fear of attack threading through it. It is true that a majority of the attacks, and fears of attack, occur in rural areas, but this should not be a diminishing factor since the lives of people everywhere count – human rights are universal. Moreover, even the people with albinism whom I spoke to in the urban centres in countries with records of attack, do not feel completely safe from attackers seeking their body parts, as there have been a few cases reported from cities.

There are also reported cases of discrimination in the cities. It has been reported that landlords often fear renting their accommodation to persons with albinism, on the basis that 'they would run away overnight to escape attack, leaving their bills unpaid'.

Also, tenancy has been denied to persons with albinism who feared being implicated in attacks, while other landlords feared an invasion of bad luck in their enterprise by having persons with albinism as tenants. In addition, the colouring of persons with albinism in particular is commonly used as a basis to deny employment, on the ground that it would drive clients away or create a perception of contagion, particularly in the food or hospitality industry. This latter issue has been reported in regions outside of Africa.

Do you think African governments are doing enough to address the challenges facing persons with Albinism?

I believe African governments are making good but slow – and in some cases, very slow – progress. However, I am optimistic, because most governments in the region are willing to cooperate with my mandate.

Many citizens have also shown a large amount of resolve to end the attacks. The political and collective will is generally present, as seen in various high-level condemnations of attacks. However, converting these into concrete, effective and sustained results remains the challenge. That said, recorded attacks are reducing in the aggregate, even though they continue to emerge generally. There are also some investments being made by government, civil society activists and myself in terms of filling gaps in law, raising public awareness, and improving self-advocacy among persons with albinism themselves. I use this medium to call on African governments to implement particular measures, as elaborated below.

Are their good practices in addressing discriminatory practices against persons with albinism which you wish to share with us?

Effective good practices involve the adoption of special measures such as national action plans to carry out protection and non-discrimination measures for persons with albinism, while spreading understanding of the condition to demystify it through the use of the applicable science and legal frameworks. Kenya, Malawi, Nigeria and Mozambique all have both de jure and de facto plans and policies addressing issues of persons with albinism. However, implementation remains lacking in many countries. This implementation gap can and has been addressed with the appointment of a champion on albinism into high public office. This singular act is a concrete way of injecting into public affairs the voice of persons with albinism, which has been historically excluded from that sphere of influence. Where government has carried out this affirmative action in a proper way, including through broad consultation with people with albinism themselves and with the goal of sourcing effective advocates on the issue, the result has been significant.

For example, in Kenya, the appointment of a Member of Parliament with albinism was key in ensuring the participation of persons with albinism and channelling their concerns to the decision-makers. His action in championing this cause led to the establishment of an albinism support programme and a desk officer within the National Council for Persons with Disabilities – a state entity established by the Disabilities Act (2003). As a further result of his advocacy, this specific programme has an annual budget of 100 million Kenyan shillings. This is a significant budget, with a large part of the reasonable accommodation measures for persons with albinism being met through the provision of free visual aids, and in terms of health, free sunscreen products..

The visibility of an active Member of Parliament also promoted public education on the condition, highlighted the capacity of those with the condition, and promoted – and continues to promote – social inclusion.

Similarly, in Tanzania, the appointment of a person with albinism as Deputy Minister was widely applauded by all stakeholder and was key to the visibility of the specific needs of persons with albinism. The Member of Parliament also played a championing and coordination role in terms of the initiatives taken by various ministries and civil society.

In Malawi, the participation in public life of persons with albinism is benefiting from the dedication of civil society and government to the international human rights principle of 'nothing about us without us'. This has been increasing the trend of involving organisation of persons with albinism in the development of projects and policies designed to address their security and correlative human right needs.

In May this year, during the 60th Ordinary Session of the African Commission in Niamey, Niger, you shared your thoughts on the Continental Strategy on albinism. Can you tell us more about this and what you hope to achieve with it?

The Regional Action Plan on Albinism in Africa (Regional Action Plan) aims to – through concrete measures – prevent and end attacks against persons with albinism by the year 2021. The timeline seems short when compared to other ambitious Plans. However, in this case, I think it is important to keep it short to remind us of how unacceptable these violations are and the fact that they needed to have ended yesterday.

The Plan is the result of broad consultation with persons with albinism, civil society organisations, African Union mechanisms and United Nations agencies. Moreover, the Plan has been endorsed by the African Commission on Human and People's Rights since the session you refer to in May 2017. The Plan consists of 15 concrete measures of prevention, protection, accountability and equality and non-discrimination.

The implementation strategy lies in the use of the Plan as a broad vision for spurring the adoption of detailed national action plans, each of which adapts the Regional Action Plan to national contexts. The implementation strategy includes the support of international and regional organisations through advocacy work, technical cooperation and direct delivery of programmes and activities, both at the regional level (African Union, cross-border initiatives and sub-regional bodies) and at the national level.

What would you consider to be your major achievements so far since your appointment as Independent Expert?

The regional action plan is certainly a major achievement. It took three consultative forums to achieve the end result. The effort, costs and partner-coordination it took was momentous, but all of this was accomplished in a period of about two years.

Another achievement is the ground-breaking workshop on witchcraft and human rights in Geneva which I will be organising later this year.

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It will be the first time that the issue of witchcraft-related beliefs and practices and the human rights violations it spurs in many cases, will be addressed in depth and systematically at the international level. The phenomena of witchcraft are complex and yet affect thousands of vulnerable people yearly, including, and going beyond, persons with albinism. Consequently, I will work with various experts on the issue to start to create a working understanding, including definitions and measures that might assist governments in tackling impunity around these violations and that mandate-holders such as myself and other experts make on the issue.

A third achievement is the country visits that, to date, have been made to three countries. These include assessment trips to Malawi, Mozambique and Tanzania. The visits have been very fruitful in engaging government on the issue and in discovering more cases of attacks, gathering facts and [identifying] patterns in correlating issues such as the trafficking of body parts of persons with albinism.

What would you like to be remembered for after your tenure as the Independent Expert on the enjoyment of human rights by persons with albinism?

I hope I leave with no attacks happening [anymore], or with the last one that was last heard of having happened long before I left. I also hope that concrete and sustainable steps are put in place to prevent and treat skin cancer in all affected countries, as the condition kills far more persons with albinism than the attacks being reported. I also look forward to ample awareness-raising and self-education for persons with albinism themselves, so that the condition will be less of a novelty and more of a condition of life.

Furthermore, I hope that persons with albinism would be far more empowered to engage with both their governments and the international community in advancing their socio-economic rights and participation in public affairs. I also hope significant inroads would have been made to address and stamp out the root causes of attacks, particularly witchcraft-related beliefs and practices which have spurred the attacks.

Would you want to share any thoughts with African governments on the way forward?

Political will and support are only one side of the coin; implementation is the key for real change in the lives of people. In this regard, there is much more to be done. I would like to reassure African governments that the situation of persons with albinism is one which can be successfully improved over a relatively short period of time.

With estimates of 1 in 1,500 to 1 in 15,000 persons with the condition in the sub-region, quality service to this group is manageable and deliverable at relatively low cost. Their comparatively small number should persuade, not dissuade, an investment of resources. African governments will do well to see the issue for what it is: a litmus test of their commitment to all human rights for those in vulnerable situations. *Some excerpts of this article have been taken from her report to the UN General Assembly (2017, to be*

published), and from her article in Women's Rights in Africa, 'Persons with albinism, in particular women'. For more, read: >http://www.ohchr.org/Documents/Issues/Women/WRGS/WomensRightsinAfrica_singlepages.pdf.

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Events

Workshop unpacks issues around women's involuntary sterilisation in South Africa

In commemoration of Women's Month, the Socio-Economic Rights Project (SERP) convened a one-day Stakeholders Engagement Workshop on 7 August 2017 on involuntary sterilisation of women in South Africa as gender-based violence.

Although South Africa has developed policies that address the practice of involuntary sterilisation, what is missing is a framework that recognises and links it to vulnerability and gender-based violence as well as to the proper enforcement of policies.

The workshop brought together a cross-section of stakeholders to address the issue of involuntary sterilisation of women holistically as a human rights violation. Participants included representatives of relevant government departments, the medical profession, public health practitioners, Chapter 9 institutions, local community leaders, and members of academia and civil society organisations active in women's rights.

Adopting an interdisciplinary approach, the workshop aimed to broaden understanding of, and highlight issues around, involuntary sterilisation, create awareness, and galvanise the process of advocacy and policy change.

One of the key points made at the workshop was that there is a crucial need for human rights training for health practitioners and community members