

A Conversation with Ikponwosa Ero: Insights from a Former UN Independent Expert on Albinism who Fought Goliath—And Won.

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Ikponwosa Ero is a lawyer by training and the first United Nations Independent Expert on the enjoyment of human rights by persons with albinism. Ms. Ero's work is extensive, ranging from crafting groundbreaking, landmark advocacy initiatives, including the African Union Plan of Action on Albinism in Africa (2021-2031) and the Pan African Parliament Guidelines on Accusations of Witchcraft and Ritual Attacks: Eliminating Harmful Practices and other Human Rights Violations. This interview is greatly supported by the Center of Global Studies, featuring Ms. Ero's public lecture on albinism human rights. This interview has been edited for clarity.

Jackson School Journal: Firstly, thank you for making time for this interview. You often speak of having albinism yourself and how that experience and the discrimination you've faced have played a role in your desire to work in the field of human rights for people with albinism. How much do you believe positionality contributes to people's ability to work on specific human rights issues?

Ikponwosa Ero: I believe having what people call lived experience and what you've described as "positionality" really contribute to the richness of what you can do working in human rights. However, that has to be tempered with a more objective reality. Positionality, or lived experience, is not objective reality, and that's very important. It's necessary that the person who has that positionality be aware that they are part of a larger paradigm of human rights and that they need, for instance, to bring in allies, people who don't have that positionality, to their side. Because, if we're talking about inclusion, and inclusion is one of the ultimate goals of human rights, then you need people who don't have the positionality to be understanding of your position. So, while positionality is key, it is not the only necessary element.

Jackson School Journal: Regarding collaboration and solidarity, you mentioned in your talk that you had some issues trying to find where albinism fit within the human rights community. When you approached the disability community, there was a sentiment that your issue was detracting from the unity of the community or pulling focus from larger issues concerning the community as a whole. This perception that the issue of albinism was producing a kind of "spoiler effect" led to problems with your albinism contingent getting support and alienated you from the disability community. Do you believe this kind of "spoiler effect" is real when it comes to human rights issues?

Ikponwosa Ero: I believe that the people who complained about albinism detracting from the solidarity [of the larger movement] had their reasons, and it is very important that we listen to each other. The issue is whether the reasons are justified. Are they good? Can I see reason with you? Some reasons I heard were: "You guys are taking away from what we've worked so hard to do." And I think what they did was formidable. Uniting one billion people with disabilities around one cause is not an easy thing to do, and they ultimately got a convention out of that. I think that's huge. The Convention on the Rights of People with Disabilities was adopted in 2006. Then we showed up about seven years later, saying, "Should we pay attention to people with albinism?" I think [the larger human rights community] was enjoying the benefits of solidarity when we showed up, so it was very jarring [for them to be asked to focus on albinism]. Other people had tried to do things outside the movement, but they were not as visible, so maybe they did not appear as threatening as we did. However, we gained a lot of visibility right away because albinism is quite intriguing from different angles, and I think this made us appear threatening to the larger disability community. It made us look like we were going to detract from the solidarity of their movement. So, I think they had a reason to feel like they did.

The one thing I regret is that we [as advocates for the human rights of people with Albinism] could have done more to engage the disability community. Although we did try, it didn't work. We knew that we had an emergency on our hands [people with albinism were being murdered and dismembered], so we kind of went "rogue" because we believed in the convention. That was the funny thing: we used the convention to justify our actions. The convention has specific measures to bring people from behind, you can call it affirmative action. [This affirmative action] applies

to people with disabilities as a whole, so, by extension, it applies to specific groups within the movement. So, what we're asking for is support. Even if you stop supporting us after 10 or 20 years, that's fine. We're going to take advantage of that time and do a lot with it. So that's how we started selling specific measures to remove the perception of the threat we imposed on the disability community.

Jackson School Journal: On this question of solidarity, it seems that there is a framing that solidarity means rallying around an issue that we can all agree on and sidelining these kinds of "spoiler issues" that generally concern minorities within these already marginalized groups. Do you believe that that is true solidarity? Or is there something else we can agree is more attuned to true solidarity that can allow us to show solidarity for these minority issues without framing them as detractors or "spoiler issues"?

Ikponwosa Ero: Solidarity does have to have a certain level of fluidity in practice so that we can change the circumstances and not become rigid. What solidarity meant at one point when we were trying to get the convention is different from what solidarity meant after the convention. The convention is like a collection of standards on how we want to treat people with disabilities, and once that has been achieved, then solidarity needs to be reconsidered. For example, we need to think about whether we need everyone to be towed into the same line. Yes. Before the convention, we did have to show the outside world [a united front] that we needed the convention. We had to stand together, have a strong, united voice, and see exactly what we wanted. Because if detraction happened at that point, it wouldn't be good for establishing a set of standards.

Once that standard was adopted, it became a question of what solidarity meant in terms of implementing the convention. Does it really mean everyone is towing the same party line? Does it really mean gatekeeping and making sure only certain people are allowed so that only the elite in the movement can speak? And once a convention is adopted and it is time to focus on implementation, do you need the same elite? Probably not. So, I think most movements would have to reconsider what solidarity means at that point and maybe allow for more voices and welcome a wider variety of elites beyond what you need while working on the convention. We need elites in terms of implementation because we need knowledge in language translation and in terms of promoting the issue. So, we basically need to declassify the movement while being united or maintaining solidarity around the convention. The convention itself is the consequence of solidarity, not so much of people. So, solidarity should shift, and the people themselves become more diverse in terms of who among them should become

speakers for the movement. Even I am working through this process because I'm witnessing how solidarity progresses within the movement. [Currently] the kind of solidarity we have is not serving us well because it's the same as the solidarity pre-convention; it is what we're still carrying over, and we are realizing we have to shift.

Jackson School Journal: Related to this concept of broadening the scope of solidarity, declassifying movements, and diversifying the leadership and voices in the disability movement and the human rights struggle generally, you've been quoted several times stating that the principal role of human rights movements should be "leaving no one behind" and "starting with the furthest behind first." Along with dispelling these myths about minority issues creating a "spoiler effect" within movements, how else can we highlight the importance of solidarity with these kinds of minority groups, and emphasize this principle of starting with the furthest behind first and elucidate the way that prioritizing those furthest behind does indeed benefit the entire human rights movement?

Ikponwosa Ero: One of the ways to do that is action planning. For example, have a very practical implementation strategy in writing so everyone can see what you're doing and where you're going. That's engaging because [otherwise] nobody knows what you're thinking. One of the things we did was to come up with an action plan for Africa [because] that's where the urgent issues were. In the plan, we had short-term, mid-term, and long-term [strategies]. So, people could see that in the short term, we were going to do a lot of specific measures for people with albinism, and in the long term we were setting the bones of integrating albinism back into the larger disability contingent. I think that helped people settle down because they could see our vision. This two-track approach was the standard approach, specifically to integrate into a broader movement. So, when people saw the published plan in around 2018, there was a lot less resistance because people could see that we were not denying being a part of the disability community. We just wanted to inject short-term measures to settle the attacks, or at least eliminate them if we could, and then, in the long term, integrate people with albinism into the disability movement. So, I think when that was up and public, everyone saw what we were thinking, and it was more engaging. Sometimes, you also need to engage your so-called detractors in that process. We invited a lot of people who surveyed people with disabilities to our action-planning processes so that they could see that we were actually not their enemies. We just needed short-term to mid-term measures, and, in the long term, we would come back into the movement full-time.

Jackson School Journal: Thank you for sharing this

adaptive, strategic, and cohesive way of addressing these concerns. Some of this sentiment about detraction and this idea of “spoiler issues” comes from the fear that there are limited resources and attention or focus for these human rights issues and global justice. It can be easy to feel pulled in a million directions and struggle to figure out where to start. How do we, as a global community of individuals, prioritize where to focus our energy and resources when fighting for human rights?

Ikponwosa Ero: This is a pressing question. It is very central for funders [of human rights movements] right now because they get approached by many pressing issues. It’s an easy question to answer on the private level because people naturally gravitate to what drives them and gives them energy, which is good. This work is tough, so you need to go where you will have the energy to sustain yourself, and the answer to that is going to issues that are more personal to you. For example, supporting people who have this certain condition because your family member had it is totally fine. We need people to go where they have passion, where it’s easy for them to have empathy, where it’s easy for them to regenerate themselves. So, that’s on the private level.

In terms of the funders, it’s very challenging. I will be on the panel for an event to discuss this issue in one month. It’s a funders-only event, and it was by invitation only. They are asking us, as activists, “What would you do if you were us?” “We’ve been approached by all these amazingly necessary issues, and we only have limited funds. What would you suggest we do?” So, one of the approaches that my colleagues and I on the panel are going to propose is intersectional funding. For example, If you’re supporting women, then make sure that in the game of women, you are supporting women with disabilities. I have thought out the implications of those resources, and it seems that you will need somebody who drives the partnerships, drives the processes, and ensures that people are included and evaluated. This also means that it’s extra money, but it will cost less in the long run instead of supporting women and disabilities as silos. So, everyone kind of agrees with that, but how to do it is something we have to figure out in the next few years.

Jackson School Journal: Related to this issue of intersectionality, there has always been much discussion about whether human rights and documents like the Universal Declaration of Human Rights (UDHR) are fundamentally Western conceptions and whether we can achieve true liberation or human rights using mechanisms of Western ideology. Do you believe that these are fundamentally Western conceptions? And if they are, can these Western systems be used to achieve liberation?

Ikponwosa Ero: The answer is yes and no. Yes, they are Western, but no, they’re also not Western; they are human. Human experiences are different, but they are also similar. So, it’s both, and that’s why we’re kind of paradoxical creatures. After fighting so many wars and seeing the horrors of humanity, coming up with a document to prevent that is quite commendable. Because firings have happened everywhere, everyone can benefit from the Western approach to resolving and preventing conflict. But non-Western people also have an opportunity to take what’s good about human rights and adapt them to their situation. The question about that is ensuring the right people are in the room.

For instance, when the African Charter on Human and People’s Rights was drafted, of course it mirrored a lot of the fundamental rights of the UDHR. However, they took time to change things a little. Their own document is called the Charter on Human and People’s Rights. By doing so, they recognize that the African sentiment is not only about an individual’s rights but also about the people’s rights as a collective. Because there are a lot of indigenous groups, there is also a lot of emphasis on community-centered cultures, and cultural rights are not individual; they are inherently collective rights and are therefore included in the Charter on Human and People’s Rights. So, right away, they picked up on that and changed their charter to reflect this. Now, could they have done more? Yes, but I think even just having that was a huge example of how you can take what’s good from elsewhere and adapt it to your situation. Because of this, our own charter has some particular rights of peoples. African individuality is quite different from Western notions, and they tried to fix that in their own charter. So yes, the UDHR came from a Western culture, but we also know there’s something human about it that we can take, use, and assimilate into our own realities.

Jackson School Journal: Regarding rights, some believe that our civil rights protect and ensconce our human rights, and they, therefore, should precede our human rights, and other people believe that our human rights by virtue of being human rights are intrinsic and they should precede our civil rights. So, there’s this division that’s created and sometimes a hierarchy between civil and human rights. How do you perceive this division? Is it beneficial? Is it necessary? What is your opinion on the way that some countries seem to prioritize only some sets of rights and not others?

Ikponwosa Ero: So, two types of dichotomies happen: there’s one between civil and political rights on the one hand and economic, social, and cultural rights on the other. So, there’s that dichotomy. They take human rights and split them into those related mostly to the state protecting the citizens, for instance, the state giving people

basic human rights to shelter. Civil and political rights also include the right to life, the right to security, economic and social rights, the right to housing, the right to work, and all that the state feels will take time [to provide to its citizens]. Then there's also another dichotomy between people who feel development should come before human rights. So, for example, let's allow Walmart into the country to get people jobs before you start badgering us for human rights. Because when there are people employed, there will be fewer people without their rights basically. And it does make some sense because if a Walmart is there, this right to work has been fulfilled, and the right to health and health insurance is also fulfilled. So, there's these two debates.

I believe the dichotomy between civil and political rights and economic and social rights is artificial because they're so interlinked. If you want to provide people with life and security, you better give them the right to health and work. The other dichotomy of development versus human rights is also a non-starter because it's a chicken-and-egg situation. You can put one over the other, except when the context demands that countries push either human rights or development. For example, if there's a war or imminent war, it makes more sense to focus on human rights rather than development at that point. If there's no war, and the country just doesn't have any funding – for example, I spoke to a friend from Malawi who works in the government, and he told me, “The government is broke. We don't have money”. So, for now, it makes sense for the government of Malawi to welcome Walmart before it does have money to focus on human rights. Things are not so black and white, and these debates are kind of artificial because, at the end of the day, it's mostly contextual.

Jackson School Journal: It seems like for people with albinism, the right to life without guaranteed health care is a bit useless when many people with albinism die before the age of 40 because they don't have access to health care, sunscreen, cancer screenings, and the like. And on the issue of development versus human rights, you deal with the argument that states make that this is an issue of development, and we should just work on the country's development. But the attacks are urgent; people are getting mutilated and murdered now; what good is the development of the country to a group of people suffering this immense violence right now? So, when you further flesh out this weird division of rights that happens, both false dichotomies pose horrible outcomes.

Ikponwosa Ero: Exactly. Some issues are more immediate. States try to separate what they see as immediate human rights from progressive realization of human rights so that when we move into account, they can say, “No, no, that's immediate, so we're going to do something about it, but

that one is progressive realization, so, we need like 50 years or more.” The states' goal usually is to try to push as much as possible under the principle of progressive realization as opposed to considering them as immediate. For example, they see war as an immediate issue or something like Ebola as a crisis or an immediate issue. For them, everything else is seen as an issue of progressive realization unless it's an issue with the right to life, which our issue fell under. But because the right to life [in our case] was not everyone being attacked at the same time, it was kind of one-at-a-time, individual attacks; so, for some of them, this also fit under progressive realization. It was not all the states that said that, but there was at least one country that was really bent on demarcating between these two things and was saying, “People with albinism, they're like, okay” or, “well, the attacks have slowed down, so now, let's focus on progressive realization.”

Jackson School Journal: So, would you say that these dichotomies are largely artificial and damaging to the advancement of human rights in the interest of economic progress and other such projects?

Ikponwosa Ero: They can be damaging depending on the situation. Suppose an NGO (Non-Governmental Organization) comes into the UN reporting on what is happening with albinism, and the country responds by saying that it is an issue of development. In that case, the UN can look back at the record. It's open to the world, so you can immediately see if something is not adding up. But it's not reasonable to say that this is a development issue. States have to wait for their capital city to sign off on statements, so they usually don't come out using that dichotomy. They usually only use it when there is a gray area. For example, in the beginning, when we were pushing for a response to the attacks on people with albinism, we didn't hear anything from the state because they knew it would be bad to use that language of development. But as soon as there was a decline in the attacks, then you heard them say, “The effects are going down. Here's proof. Can we now move this issue to more of a development issue/progressive realization?” That way, we would stop putting the fire on their behind, so to speak.

Jackson School Journal: The UN has little actionable power outside of naming and shaming and other “soft power.” What is the true benefit of the kinds of actions that the UN can take using this kind of soft power? Do you believe the UN should adopt some sort of human rights enforcement agency? Would it be beneficial, or is it dangerous to have some kind of international

enforcement agency that can override or supersede the sovereignty of nation-states?

Ikponwosa Ero: The UN was founded principally on sovereignty, aside from human rights. So, the UN's units are countries, and the people who drive the UN are countries. Anything that would override sovereignty will probably be rejected, as we have learned from the European Union. There will be lots of backlash because countries don't like being controlled when the agency barely knows what is happening on the ground.

There is also this principle in the philosophy of subsidiarity that people closer to the issues are in the best position to solve them. For example, you can't have someone from Nevada or New York controlling what is happening in Seattle. That makes no sense. And it's almost an insult to the human rights community of people in that place because they have a right to self-determination and to decide the outcome for themselves, which I think is why there's no enforcement mechanism. Let's not deny that power is unequal at the UN. Some people contribute more to the system than others and feel they are more entitled to control things. So, as a country, why would I donate millions to a system that then comes and enforces my rights? A lot of countries will not stand for that. The best thing they're doing right now is naming and shaming, or at least bringing to light what's happening in countries.

Every convention at the UN has a committee that governs documentation. For example, the Committee on the Rights of People with Disabilities would call in a country every few years to report on how they have implemented the constitution from year to year. The committee also receives reports from CSOs (Civil Society Organizations) saying, "Don't listen to the country's report; this is what is really happening." Then, the committee takes all the reports and issues its own third report, making recommendations. It's all politics. Everyone can say, "This country is not doing these things because I believe the CSO over the government." Countries care how they look, even though some try not to show it. They do. The fact that they try to address the issues in their own report shows that they care. So, I think naming and shaming has more power than we think because people care about their country's reputation at the end of the day.

Jackson School Journal: On a separate note, you mentioned that some scholarship has been produced linking the capitalist wave in Africa to the rise of incidents of Harmful Practices Associated with Witchcraft and Rituals (HPAWR). Do you believe there's an intersection between capitalism and the commodification of the bodies of people

with albinism as it concerns the harvesting, selling, and trade of human remains and body parts for the uptick in Harmful Practices Associated with Witchcraft and Rituals?

Ikponwosa Ero: I think in some countries like Tanzania, where the study by Cimpric¹ was done, it makes sense that it was a contributing factor. I have to clarify that I am not anti-capitalist. I have seen capitalism take people out of poverty. It's like every system; it has its good and bad sides; it just has to be done properly and checked. I've seen a lot of good come from it in terms of helping people in a dignified way because sometimes, the charity or even the service model can be very undignified. Whereas if people get loans, they can start their own businesses which is very uplifting. So, capitalism is not a terrible thing. However, it's nicer when people grow into the system so that they know how to operate the system. When a government suddenly says, "We are now taking away all the safeguards, and now we're going to be capitalist." It's very jarring to people who've never been in that system. Especially if they're coming from a more communist/socialist system where care for one another is emphasized. Because sharing goods and services is central, a push for harsh individualization would make absolutely no sense to socialists. So, yes, I think in some countries like Tanzania, where the study by Cimpric was done, it makes sense that [capitalism] was a factor. Because people didn't understand how you're wealthy so quickly. So, what made sense was to blame it on witchcraft because that was the tool they had to understand it. Also, the so-called "witch doctors" are capitalists because they capitalize on this thinking and say, "Hey, I can make you rich too, so give me money." So, capitalism [can go very wrong when the] system is not checked. But I don't think capitalism by itself is a causal factor, but unchecked, it was a contributing factor. The government probably also did not anticipate capitalism meshing with harmful practices in that manner. I don't think anyone foresaw that, especially in that country.

Jackson School Journal: Do you believe this was a very specific case in Tanzania in which we saw this kind of odd effect of capitalism on harmful practices?

Ikponwosa Ero: It takes other forms in other countries. For instance, when I was working on harmful practices related to witchcraft as a whole, I worked with some NGOs based in Nigeria who were fighting against child witchcraft accusations. These were often propelled by so-called pastors and Christian pastors. They're called "pastoral premiers" because, these pastors are using their congregants to make money. So, that's another type of capitalization outside of Tanzania. The Pastors would say, "Your child is a witch," even though the child just has autism. Then, they will

move along and say, “I can exorcise them. Give me a small amount of money, and I’ll do it,” and this was capitalization as well. So, it’s similar to the question you asked about human rights being a Western ideal. Capitalism is a Western idea that we inherently have adopted, but we need to adapt it, check it, and say, “How can we check capitalism against these harmful beliefs and practices?”

Jackson School Journal: Related to this subject of how Human Rights issues for people with Albinism vary by country, you’ve been able to achieve a nearly impossible task of getting many different countries to coalesce around one human rights issue and work together towards the elimination of violence against people with albinism. How do you get so many people to cooperate on something? How do you garner so much support for an issue, tactically speaking?

Ikponwosa Ero: This is my favorite question because I’m trying to push and replicate it in other people’s lives right now. It’s a current interest for me because I realized that school doesn’t prepare you for dealing with complexity. We have become specialists in instruments, but life is an orchestra. So how do you then make sure that these instruments coordinate? The ones you’ve played and ones you don’t play, and then produce beautiful music out of it. That takes conducting, in a way, managing complexity without being crushed. It’s a delicate balance and takes a constantly high level of self-awareness. A high level of awareness of the potential of others, a very high emotional capacity, empathy, and high EQ (Emotional Quotient) to be able to gauge other people’s potentiality by testing other people’s potential through psychometric testing to see what their natural talents are and how they use that. Even if you don’t have access to psychometric testing, you can still observe them long enough and listen to them deeply enough to see what their likes, dislikes, and strengths are. Then, you can know when to bring them into the orchestra and what instrument to give them to play. That way, they feel engaged and like they’re used in a good way, and you don’t have to carry the burden alone, and you can protect your mental health in the process. This is something that I feel is necessary in every field. At the heart of the reason why people are collapsing more readily under mental health issues is that the complexities are getting more complex, and the tools are not readily available. So, in my current transition to coaching young managers and executives, this is part of what we’re trying to get at (myself and my business partners) to help people anticipate and manage complexity.

I did that throughout my time at the UN, really by necessity. My issue of albinism was not attractive enough to get big funding. It was the necessity that drove me into that state

of mind. From not having any funding for the mandate to plans that are ready to go and end up with a lot of funding. How did I do that? I did everything I just mentioned. When I met anyone who showed even the slightest interest, I sat with them; I listened to them to see what their likes and dislikes were and what their natural talents seemed to be; I attuned myself to that. I would even ask them what they thought their strengths were and how they could help. And I just kept that in mind. When the opportunity came up, I would call, even if it was five years later. Some people were surprised and asked, “Why do you remember that?” and I told them, “I need to draw on your strengths right now.” It is a lot of work, but what’s beautiful about it is that it’s learning to rely on others so that you don’t carry everything and learning to see in others the talent and potential they have. It’s about finding how each person can support you and getting them engaged so that they also enjoy the process.

Jackson School Journal: Thank you very much for making time for this interview. It’s been great talking to you and hearing about your experience working at the UN advocating for human rights.

Endnotes

1 Aleksandra Cimpric, Children Accused of Witchcraft: An anthropological study of contemporary practices in Africa, UN Children's Fund (UNICEF), April 2011, <https://www.refworld.org/reference/them-report/unicef/2011/en/104141>