

Anglais / discours 2

Réunion : Conférence de presse de l'experte indépendante des NU sur les personnes atteintes d'albinisme, Fidji

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Durée : 9:50

Oratrice : Ikponsowosa Ero, experte indépendante

Difficulté : niveau 2

Introduction : Deuxième discours : Intervention d'une représentante des Nations Unies sur les personnes atteintes d'albinisme à Fidji

Éléments à fournir (vocabulaire) :

Independent Expert on the enjoyment of human rights by people with albinism	Expert indépendant sur l'exercice des droits de l'homme par les personnes atteintes d'albinisme
Sustainable development goals	Objectifs de développement durable
Leaving no one behind	Ne pas faire de laissés-pour-compte

Thank you for coming to this.

So, my mandate, which is the Independent Expert on the enjoyment of human rights by people with albinism was created at the United Nations Human Rights Council in Geneva in 2015. One of the main reasons why it was created was in response to some very extreme violations against people with albinism in 28 countries, where they have been attacked physically - they are hunted down and attacked with machetes and knives and their body parts are cut off and sold on the black market for thousands of dollars. And this is due to witchcraft-related beliefs, that these body parts can bring wealth and good luck when used in potions. So, these are very extreme violations. When the mandate was created, with this in mind, there was also the idea that it would be an opportunity to collect data from other countries as to what's happening - good or bad, because it's good not only to broadcast what's bad, but to learn from what's good.

So while I was working, especially with countries that have these problems of attacks, which unfortunately are still going on, I saw that there was some action in Fiji on awareness on albinism, and some data had come out that piqued my interest, saying that there was about 1 in 700 people with albinism, in the Pacific as a whole. This is quite high. Normally the condition is relatively rare, even though everyone seems to know about it, because it stands out quite a bit. I am a person with albinism myself, from Nigeria, and I know what it's like to have this condition where you stand out.

One of the implications of having albinism - aside from the physical appearance, which is quite striking and can be a source of stigma, and discrimination, and the coloring can be a source of these problems - there are also vision impairments, which varies from person to person, depending on what

type of albinism you have, if you got early intervention to care for your vision... so that's one. The second implication is a health implication, where there is a high vulnerability to skin cancer. This is a, it's a real problem. In countries with data, I've learned in some countries that only 2% of people with albinism live beyond the age of forty. Most die before age forty to this preventable condition, which is caused by frequent exposure to sunlight without protection, such as sunscreen, education about skincare - very basic information

Before I go into my observations, I would like to say that this is a great opportunity for Fiji to pay attention to its people with albinism, for three reasons. First, Fiji just ratified the Convention on the Rights of People with Disabilities in June this year. Fiji is also adopting a national law on disabilities, which is before Parliament. It will be adopted early next year. And Fiji is part of the Sustainable Development Goals of the UN, which is guiding the development agenda of the UN until 2030. And that's goals, those goals have many components that are applicable to this issue, including in health, in education... But it also has, seven times repeated, the principle of "leaving nobody behind". A society is judged not by what it does for the many, but what it does by those on the margins. So, I think it is very important that we understand the value of bringing in people who have been left out for centuries. While I was here, I was able to meet the executive, the legislature and the judiciary. I met with the National Human Rights Commission, and I also met international organizations, international cooperation organizations such as embassies, civil society groups including religious leaders and traditional leaders. I also met with close to 30 people with albinism who are Fijians.

Some of my findings are as follows:

First finding: data. There is no data on this issue, generally. I find that the government was very honest about this issue, they are very aware that it's a problem. Data is missing. I don't have anything. I cannot tell you how many people with albinism are in Fiji, I only have the prevalence rates. The census missed the opportunity to count people with albinism. The census had a section on disability, which is based on international guidelines, but there was nothing, no indicator there on albinism, so nobody with albinism ticked anything, because: "Do you have a hearing impairment? Do you have a vision impairment?" - they didn't tick anything because it doesn't capture their condition. It's important to have an indicator that says "albinism", so you can address not only the vision impairment, but also the skin issues. So, this is a problem. There have also been surveys that have been carried out by the government that also missed this indicator. So as a result, I am recommending supplementary data gathering.

The second finding is discrimination and stigma. A lot of people I spoke to without albinism said: "Ah, these people, they're walking amongst us, they're okay", which was interesting. When I met people with albinism, I did *not* get the same feeling. When I asked them more directly - and I guess most of them were open because I'm a person with albinism, I understand what they're going through - and there was, in most cases an emotional breakdown concerning what they've been going through. You get a sense that the suffering has been at the private level. I got comments such as: "I cannot believe I have this opportunity. I've been waiting my whole life to share this opportunity, finally somebody's listening!" Some of them just, yeah ... they've gone through a lot, including the families and the mothers... There's been child abandonment, parents who've abandoned their children. Some of them don't go out, because they're walking on the street, and you're just taunted, from the moment you

come out of the house to your destination. So, there is, there are issues there. There were exceptions, of course. Some people, due to their socio-economic situation, have managed to avoid many difficulties, but nonetheless, the majority - the overwhelming majority - had issues, in this area of discrimination and stigma. So that's attitudinal problems, on the one hand. Recommendations on attitudinal discrimination, of course, is obvious: it's awareness-raising. Awareness-raising, not only to the public at large through things like documentaries. There's also training [that] needs to be done on what disability is. There's the question of "are these people disabled, are they not disabled?". Even people with disabilities don't know the new understanding of disabilities, okay? So, we need a lot of training and awareness-raising. Even you, in the media, I think, could benefit from this training. Just to clarify, since we have the opportunity, that in the past, disability was very traditional: "Are you blind?", "Are you deaf?", "Are you using a wheelchair?" Now disability has shifted to be more flexible and all-encompassing.

The other segment of discrimination is coming from structures. So, we've talked about the attitudes. The structures are two-fold, you can generally separate them into health and education. In the health sector, the problem is largely [that] there is no specialized care for people with albinism to prevent skin cancer. Like I said, this is a fatality - people with albinism have vulnerabilities to dying from skin cancer without care. For now, all there is concerning skin screening is all done by foreigners, and there is very little government support, so I have recommended to the government to take charge of this Fiji Albinism Project, which caters to the skin problems of people with albinism. We need to train more dermatologists, there is only one dermatologist in all of Fiji, so this is a problem. We've recommended that sunscreen, which protects the skin from skin cancer, not only be for tourists, but also be an essential medicine. HIV/AIDS

has essential medicines such as the anti-retro-viral medicines, which come through an essential medicine list that the government facilitates. So, we've requested to the Ministry of Health to put sunscreen on that list, because it's essential for people with albinism. They are in agreement. So, I'm looking forward to this coming in, looking forward to them removing taxes and duties on these imports. Also looking forward to them eventually developing sunscreen in Fiji. We have countries that have done this. It's not expensive, sounds expensive but it's not.

The second and final part of discrimination is in the education sector. A lot of people with albinism are sent to the School for the Blind. And while they're there, they're taught Braille. You don't need to teach them Braille, they just need special gadgets to see distances, and most of those gadgets are not here in Fiji. So, these students are learning Braille when they don't need to. Many countries have phased out the Braille approach for people with albinism but it's still happening here.

Overall, I think we have a lot of opportunities to fix these issues, okay? They're many frameworks existing in Fiji. I don't think it's that difficult. I also look forward to operationalizing some of the recommendations that I have made concerning issues in health, and also issues in public awareness and awareness-raising, and to shift people with albinism out of the shadows of obscurity and private suffering, into the enjoyment of their human rights.

I thank you very much.