**Preliminary findings of Country Visit to Kenya by the United Nations Independent Expert on the enjoyment of human rights by persons with albinism**

**7 to 17 September 2018**

Nairobi, 17 September 2018

At the invitation of the Government of Kenya, I conducted an official visit in the country from the 7th to 17th of September 2018.  First, I wish to sincerely thank the Government of Kenya for its openness and good cooperation in ensuring that the visit was most fruitful. I am also grateful to the United Nations, in particular the Office of the High Commissioner for Human Rights in Kenya for facilitating all aspects of my visit.

During my visit, I travelled to the cities of Nairobi, Thika, Embu, Eldoret, Kisumu and Migori. The following comments represent my preliminary findings following consultations with a wide variety of stakeholders including members of the Executive, Judiciary, Legislature, Health service providers, the Kenyan National Human Rights Commission, Gender and Equality Commission, civil society, persons with albinism themselves including victims of attacks and their families, the United Nations Country Team and Development Partners.

**Overall**

I wish to deeply congratulate the government of Kenya for the specific and concrete measures it has undertaken to improve the situation of persons with albinism and their enjoyment of human rights. All measures taken to-date particularly the entrenchment of an annual substantial budget dedicated specifically to persons with albinism indicate that the government had – even before the global adoption of Agenda 2030 – “set out to leave no one behind, starting with the furthest behind first”. This approach has been indispensable to the ongoing process of bringing persons with albinism from the margins into the centre, to stand as empowered constituents of the disability movement and to begin to access their rights in all areas such as health, education and above all, to life and security of person. That said, there are gaps that need to be closed, efforts that need to be consolidated, and more steps to be taken, for Kenya to fully take its place as a deserving champion on this issue in particular, as well as a leader in the area of effective strategies for leaving no one behind.

**Attacks and Security of Person**

As this mandate was created in context of alarming witchcraft-related physical attacks against persons with albinism in the region, it is fitting that I begin with observations concerning the right to life and security of persons with albinism. In total there are 14 reported cases of such attacks in Kenya from civil society. These include murder, mutilation, kidnapping, attempted kidnapping, and trafficking of persons and body parts. These are reported cases alone. It is important to note that no single organization in Kenya is dedicated to or focuses on monitoring and reporting attacks in a systematic way. A preliminary field research conducted this year revealed that e persons with albinism in many parts of Kenya, particularly in the border areas such as Migori and Taita Taveta counties still live in fear of attack particularly during the elections of Kenya and those of neighboring countries. Given the minority status, quantitatively-speaking, of persons with albinism, an attack on one is a significant threat to all. Accordingly, many persons with albinism in Kenya take protection measures on their own initiative including maintaining around-the-clock watch over their children. Some take their children everywhere with them while others have quit or altered their job and career paths to dedicate more time to protecting their child.

Given the regional patterns of these attacks, which – from the hundreds of cases reported to date - indicate that family members and close friends are often involved, including in some cases reported in Kenya, it is important that a situational analysis be conducted to amass evidence of a wider scope to ascertain the real state of affairs concerning security issues faced by persons with albinism.

**Access to Justice**

Persons with albinism in general need improved access to legal protection and remedies. I welcome reports of care shown by police in certain instances and the creation of a hotline by the National Council on Persons with Disabilities. However, these measures need to be widely publicized in addition to the work of other existing mechanisms supporting and protecting the rights of peoples with albinism such as the Kenyan National Human Rights Commission and their branch offices and partners. Moreover, victims of attacks and violations as well as their families are in need of support in rebuilding their lives and restoring their dignity including the provision of legal, medical and socio-economic assistance. Perpetrators of violations against persons with albinism also need to be systematically brought to justice. Indicators of access to justice properly implemented should include not only victim support but also proper remedies including holding those responsible accountable for their acts. Efforts should also be made to raise awareness about existing mechanisms for remediation and their respective locations.

**Right to Education**

I visited several students with albinism from different districts, in order to assess the situation for persons with albinism enrolled in private and public schools in Kenya.

I noticed that children with albinism are usually enrolled in special schools, such as schools for the blind, even in cases where they are not legally blind. At these schools, some of them are taught braille and are therefore not enhancing the use of their total or residual vision. That said, many persons with albinism still prefer to attend these schools for various reasons from security to acceptance as well as understanding from teachers and students alike. These are elements which are – for the most part – not present in the mainstream schools even though Kenya has adopted an inclusive education policy.

Furthermore, I learned that there is no tuition fee for primary schools in Kenya. While there are no tuition fees per se at these schools, there is a boarding fee at special schools, amounting to 26.000 Kenyan Shillings (260 US Dollars) per year. According to several of my interlocutors, an overwhelming majority of persons with albinism are poor or extremely poor and therefore unable to attend these schools. Although there is a Cash Transfer Program for financially supporting persons with severe disability who are financially challenged, the program is generally not applied to persons with albinism even though the criteria for qualifying is open and includes persons with disabilities who report living in danger. Without the requisite support, many with albinism are forced to go to mainstream schools where there is no reasonable accommodation and sometimes (severe) bullying occurs.

In both public special schools and even in a well-funded private integrated school, I noticed that students with albinism did not have all the necessary assistive devices, particularly monocular, which are indispensable for achieving quality education for persons with albinism in primary and secondary schools.

Unfortunately, without reasonable accommodation and sometimes lack of understanding from the teachers, students tend to drop out from both public and private schools. The effect being low education levels, which usually results in the absence of the necessary social or economic tools to live productive lives. This in turn leads the majority of persons with albinism into outdoor jobs that expose them to the sun and subsequently a higher risk of skin cancer. Data from neighboring countries show that skin cancer is the number one killer of persons with albinism with reports indicating that only 2 percent live beyond age 40.

With simple and concrete measures, such as a provision of monocular which I understand are already available in the country, low vision materials, extra time on tests and exams, specialized teachers and the proper support, including financial support to the students with albinism, they can break out of the vicious cycle.

**Discrimination**

Discrimination and stigma against persons with albinism is still prevalent in Kenya although it varies from city to city. When persons with albinism walk in the streets, it is common to hear people call out to them: “millions” or “*pesa*” meaning money. The normalization of these names creates a context of insecurity for persons with albinism including by confirming the misbelief that their body parts can generate wealth. It also indicates that there is a dearth in understanding around the condition of albinism itself.

Many of my interlocutors also reported bullying in job-recruitment processes owing to the colouring and appearance of persons with albinism, even before the potential employer is aware that the person with albinism also has vision impairment.

That said, several persons with albinism indicated that in their subjective assessment, discrimination and stigmatization against persons with albinism in the country has begun to decline - but only slowly. The decline was largely attributed to the presence of high-level officials with albinism including the Senator and the Judge of the high-court. Such affirmative action should be increased given their effectiveness in changing mindsets. However, to further speed up the change in mindset at the rural and border areas, the strategy of sensitization has to include mass sensitization efforts at the grassroots for a – based on best practices - minimum period of two years. Such sensitization should be wide in scope, continuous and not ad hoc; they should also target particular sectors such as education and health and should use both Kiswahili and local languages and involve persons with albinism themselves.

**Right to Health**

I was pleased to learn that the Government, through its Albinism Programme, housed at the National Council for Persons with Disabilities (NCPWD), has launched a special program to provide free sunscreen, after-sun products and sun protective lip balm (“prevention kits”) to all persons with albinism in Kenya. For this and other related programs, I was informed that the Government has allocated 100 million Kenyan Shillings (1 million US dollars) each fiscal year. This programme is of immense importance for preventing skin cancer.

The prevention kits are distributed in 190 hospitals in Kenya, and offered to persons with albinism free of charge. Unfortunately, I also heard of cases where persons with albinism had been denied the prevention kits because they did not have health insurance which some cannot afford. Moreover, there are inconsistencies in distribution such that some hospitals or health workers distribute the prevention kits without proof of health insurance while others do not. I welcome the NCPWD’s commitment to audit and refine this process to ensure accessibility and availability of this essential health product to all persons with albinism in all regions of the country.

Although sunscreen is an essential health product, it is not listed as an essential drug, which could make it available in areas outside of the districts and result in a lower tax on imports. In addition to listing it as an essential drug, I also strongly encourage Kenya to start producing sunscreen locally. The modalities of doing so in the region exist and this venture promises to further refine this portion of the albinism program and serve as another avenue for employment.

For some people, especially those living outside of Nairobi, access to free sun care can become a financial challenge, as they will sometimes have to travel far to receive it. In addition, I was informed that the hospitals often run out of the prevention kits which adds to the logistical difficulties and the financial burden for those who travel in vain. In the districts where there is an active civil society, such as in Embu district, a group of people take it upon themselves to inform those who live in remote areas when the hospitals run out

There are around 30 clinics for persons with albinism in Kenya. I have met some truly dedicated health care providers, who informed me that they offer counselling, proper skin care and if necessary refer them to other hospitals that are better equipped. However, both the health care providers and the clients recognised a need for more special training for health providers in order to provide better service for persons with albinism. It was also evident that wide-spread advertisement is needed to make persons with albinism all over the country aware of this health service. It was made very clear to me that many people, mainly those living outside of Nairobi, had never heard of the sunscreen program, or the clinics.

I welcome the Government’s approach to introduce Universal Health Care. It is my understanding that persons with disabilities including persons with albinism are part of the process of developing this framework. I look forward to learning more about this and to what extent it affirms and builds up the existing Albinism Programme

**Data Collection**

I welcome the inclusion of the indicium on albinism in the Washington Group Set of Questions to be used in the 2019 Household and Population Census. Such information is crucial to improving and fine-tuning the Albinism Programme. That said, the highest standards of data protection should be applied in context of ongoing security concerns in certain parts of the country. Data from the census should also lead to a situational survey of the particularities of this group of people so that existing measures can reach those who have been left behind.

**Recommendations**

Summary recommendations are listed as follows with a comprehensive list to be provided in the official report of my visit to Kenya which will be presented at the UN human rights council in March 2019.

It is generally recommended that Kenya

* Undertake a situational survey to identify gaps in security and protection measures for persons with albinism particularly in rural and border towns
* Carry out intensive continuous awareness-raising about albinism across the country but particularly at the local and rural community levels with emphasis at border towns; and these should involve persons with albinism in all stages of the process.
* Refine the Albinism Programme, in particular improving the availability and accessibility of sunscreen; and also improving the affordability, quality and availability of low vision devices particularly monocular for students and prescription glasses. The Programme also needs to enhance stakeholder engagement including through a coordinated audit of the Programme and a simultaneous development of a national action plan.
* Adopt a national action plan on the issue as recommended by the African Commission on Human and Peoples’ Rights consisting of specific and concrete measures achieved to date as well as those to be carried out and achieved.