The situation of Women with Albinism in the Republic of Niger

This report is respectfully submitted by NGO Under the Same Sun in regard to the concluding observations prior to reporting for the Convention on the Elimination of all forms of Discrimination against Women on the republic of Niger.

Under The Same Sun (UTSS) is a civil society organization committed to ending the often-deadly discrimination against people with albinism. UTSS promotes, via advocacy and education, the wellbeing of persons with albinism who are misunderstood, marginalized, and even attacked and killed because of their genetic condition. While UTSS acts globally, much of our focus has been on the crisis faced by people with albinism in Tanzania.

Introduction

- Located in the heart of the Sahara, Niger is among the widest countries in West Africa with a surface area of 1,267,000 Km2; fully landlocked with a population of 19,9 million inhabitants (World Bank 2015). Niger is one of the poorest countries on Earth with a literacy rate of 16% (UNDP 2014).[1]

- People with albinism in Niger are part of the category of people with disabilities, but data about them remain unknown to date.

- The association nationale des albinos du Niger has, nevertheless made a report on people with albinism in the country's capital city of Niamey in 2014, and partly on the situation of those living in the regions of Maradi and Zinder in 2015.

- The number of people with albinism has been estimated to seventy. With a population of less than 2 million, the city of Niamey represents 1/9 of Niger's total population, and by extrapolation based on estimated frequency of occurrence, the number of people with albinism in the country can be estimated to be around nine hundred.[2]

- In Niger, people with albinism are often referred to as zabia[3], a term from the Hausa local tribe. It's a derogatory and degrading term used to scoff at their skin colour.

[1] Rapport sur l'albinisme au Niger: situation des femmes et des enfants atteints de l'albinisme sent to UTSS on April 11, 2017 by Association nationale des albinos du Niger (ANAN).
[2] Rapport sur l'albinisme au Niger: situation des femmes et des enfants atteints de l'albinisme sent to UTSS on April 11, 2017 by Association nationale des albinos du Niger (ANAN).
[3] From ongoing exchange of information between ANAN and UTSS.

What is Albinism?

- Albinism is a rare, non-contagious, genetically inherited condition characterized by a lack of pigmentation in the hair, skin and eyes. It occurs regardless of ethnicity or gender. Both parents must carry the gene for it to be passed on, even if neither have albinism themselves. In Africa it is estimated that 1 in every 5,000 to 15,000 people have albinism with some populations having estimates as high as 1 in 1,000.[4]

- Almost everyone with albinism is visually impaired. While most can read large print and don't require Braille, they often cannot see a blackboard in a regular classroom.

- With no melanin or pigment for protection, skin burns immediately in the sun. Most African children with albinism have severely sun-damaged skin, acquiring dramatic, visible skin damage at an early age.[5] Fatal skin cancer will claim the vast majority before they reach 30 to 40 years of age. There is little awareness of the need for sun protection and sunscreen is not commonly available or affordable in most African countries.

- In countries where the population has dark-coloured skin, hair and eyes, children with albinism stand out, making them targets of taunts, discrimination and dangerous myths. Moreover, structural barriers prevent full participation in society on an equal basis with others.

The situation of women with albinism

- The situation of women with albinism in Niger is characterized by the following[6]:

[4] Preliminary Report of the United Nations High Commissioner for Human Rights, "Persons with Albinism," September 12, 2013 at para 14, http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session24/Documents/A_HRC_24_57_ENG.doc, and Esther S. Hong, Hajo Zabeed, Michael H. Repacholi, "Albinism in Africa as public health issue", BMC Public Health, vol. 6, No. 212 (August 2006). www.biomedcentral.com/1471-2458/6/212

[5] Yakubu, Alkassim, Mabogunje and Oluwatope. "Skin Cancer in African Albinos" Acta Oncologica, Vol. 32, No. 6, pp. 621-622. 1993.

[6] Rapport sur l'albinisme au Niger: situation des femmes et des enfants atteints de l'albinisme sent to UTSS on April 11, 2017 by Association nationale des albinos du Niger (ANAN).

- Considered as people with disabilities, women with albinism live in very precarious conditions with very limited access to basic social services i.e. health, education and employment.
- Very harsh weather conditions: the average annual temperatures in Niger are very high, reaching their highest peak in March, April, May with 45°C.
- Stigmatization: like males with albinism, marriage is even more challenging for women with albinism in the Nigerien society. This can be very damaging socially especially in a society where marriage determines social privileges.

The situation of children with albinism

- Their situation is characterized by the following aspects[7]:

  - 90% of the families of children with albinism live in poverty.
  - At school level, children with albinism face stigmatization by schoolmates and sometimes teachers.
  - The major problem faced by students with albinism in primary and secondary schools is vision impairment combined to the ignorance of teachers of how to address their specific needs in the classrooms and at school.
  - Constantly hostile weather conditions, detrimental to the physical health of people with albinism as explained above.

Applicable Human Rights Instruments

- Until recently, albinism was unacknowledged by human rights statutes. But in 2013 and 2014 The United Nations Human Rights Council adopted resolutions 23/13, 24/33 and 26/10 and the African Commission on Human and Peoples' Rights adopted resolution 263 calling for the prevention of attacks and discrimination against persons with albinism. On 18 December 2014, the General Assembly adopted resolution 69/170, proclaiming every June 13th as International Albinism Awareness Day.

- Lately, in May 2017, the African Commission on Human and Peoples' Rights, on its 60th Ordinary Session in Niger, issued a communiqué that included a groundbreaking endorsement of a continental action plan to address albinism.

[7] Rapport sur l'albinisme au Niger: situation des femmes et des enfants atteints de l'albinisme sent to UTSS on April 11, 2017 by Association nationale des albinos du Niger (ANAN).

This action plan maps out concrete, achievable, and time-bound measures to prevent violence against people with albinism, protect and uphold human rights, hold governments to account, and combat systemic and societal discrimination related to albinism. The official resolution is expected soon.

- As well, the Constitution of the Republic of Niger contains articles which clearly apply to the situation of women in general and to women with albinism in particular. For example:

  - article 22 states "The State endeavours to eliminate all forms of discrimination against women, young girls and people with disabilities. Public policies assure their full empowerment and participation in local development."
  - article 26 further states that the State endeavours to create access of equal opportunities to people with disabilities for the purposes of their promotion and social rehabilitation.
  - another article (article 33) mentions "No one can be subject to discrimination at their workplace."
  - article 100 states:" the law determines the fundamental principles […] of the protection of the elderly and the integration of people with disabilities.

Violence against people with albinism in Niger

- In Niger there have been one recorded missing and presumed dead over the last five years.[8] This is part of a wider pattern of murders and attacks across sub-Saharan Africa. Since 2006 there have been 522 reports of violence against people with albinism across 28 countries, including 191 killings, 331 abductions, mutilations, rapes and grave violations.[9]

- On the 17th day of the 2012 Islamic month of Ramadan in Niger (likely August 6, 2012), a young man born with albinism in 1986 by the name of Seyni Hama went missing in the ward of Dar es Salam in the capital city of Niamey, Niger. He has not been seen since. On September 13 & 20, 2014, Ms. Kadidjatou Moumouni, leader and founder of the association of persons with albinism in Niger interviewed the victims' family and neighbours to confirm Seyni's disappearance. Both parties told her that the abduction did in fact take place. At the time Seyni went missing, his family reported the case to the Police who did their

[8] Report provided to UTSS by Ms. Kadidjatou Moumouni, the chairperson of the Association nationale des albinos du Niger (ANAN)
[9] Reported Attacks of Persons with Albinism (PWA) – 1 Page Summary Date of report: May 8, 2017 http://underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%201%20page_0.pdf

investigation, but sadly were not able to find him. Two of Seyni's brothers also have albinism.[10]

- In addition to this, some cases of discrimination against women with albinism in Niger have been brought to our attention recently by the albinism group Association nationale des albinos du Niger.

  - The first case is that of a woman with albinism who graduated in secretarial studies. She was promised a job of secretary in a law office. The day she showed up for the job, she was turned away by the potential employer who promised to call her back. She was never called back, and the reasons remain unclear to date.
  - The second case is that of another young woman with albinism who was denied access to a sewing apprenticeship workroom in a rather offending manner due to her vision impairment.
  - The third case is about a young school girl with albinism who was expelled by the headmaster of a school in Tillabéry, not for her bad academic performances but for her vision challenges. The headmaster explained that she could not study well since she could not see well. Her family has now relocated to Niamey. She has now grown up and can only undergo a vocational training, thus missing her normal education.

Recommendations

Collect data

- The Government of Niger should investigate, collect and publish data about discrimination, attacks, murders, abductions, assaults and other incidents involving Nigeriens with albinism including women with albinism. As well, information should be kept on investigations, arrests, charges, prosecutions, trials and convictions for perpetrators of violence against women with albinism. Information on attacks is sparse yet there is no guarantee that attacks are not happening. Better data is needed. Often, albinism NGOs in Africa have limited capacity to investigate reports as they are often volunteer-based, grossly under-resourced and members have minimal training in human rights approaches

- Albinism NGOs should be funded to collect data to increase response rates and build confidence among the population with albinism. Data should be stored

[10] On September 20, 2014, UTSS interviewed Ms. Kadidjatou Moumouni, leader and founder of the PWA group in Niger; ANAN Niger

securely, so as not to provide information for those interested in profiting from the trade in body parts of persons with albinism.

Raise awareness

- The Government of Niger should work with albinism civil society groups to build on the success of awareness-raising campaigns conducted in recent years, such as the seminar organized by the Association Nationale des Albinos du Niger during the World Disability Day on December 3rd 2015 in Niamey. The seminar aimed at educating regional primary and secondary school leaders and many other actors from heath, social protection and disability sectors on the education of students with albinism. At the end of the seminar, all participants became aware of the actual challenges pertaining to albinism, particularly the difficulties faced at school by students with albinism. In addition, commitments were made from all sides to take concrete steps at all levels to raise awareness and educate teachers and educators on albinism.

- Such seminars and workshops are to be encouraged and supported by the government.

- Albinism awareness TV and radio spots, seminars, “in-person” encounters and public health campaigns should be produced to raise awareness about the condition and its stigma and to humanize and normalize albinism. Family members, legal guardians, caregivers, youth, schools, labour organizations, communities, community leaders, the media and other civil society organizations should be targeted with de-mythologizing messages about human dignity and respect, focusing on simple medical explanations, offering easy ways to live with and care for the condition.

- Therefore, Under The Same Sun applauds and encourages the Radio albinism awareness-raising show aired on the National Radio ORTN with the close cooperation of the Association nationale des albinios du Niger. every June 13 since 2016.

Protect Health– particularly prevent early deaths to skin cancer

- Sunscreen should be on the national list of essential medicines in the same manner as anti-retroviral are for people with HIV.

- The Government of Niger should make sunscreen and sun protective garments more readily available to Nigeriens with albinism – including women with albinism and mothers of children with albinism. The vast majority of Africans with albinism will die from skin cancer. Sun protection awareness and materials are urgently needed.

- Sunscreen is prohibitively expensive and hard to access for most that need it. Sunscreen should be imported or manufactured and subsidized by the Government of Niger. Distribution should occur in partnership with albinism civil society groups like the Association nationale des albinos du Niger (ANAN).

- UTSS co-operates a local sunscreen production unit and a garment manufacturing shop at the Regional Dermatology Training Centre, Kilimanjaro Christian Medical Training Centre, in Tanzania. Persons with albinism are employed at this facility. UTSS is available to provide advice to Niger about creating such local indoor employment opportunities that produce sun protection clothing.

- UTSS congratulates the young and dynamic albinism group Association nationale des albinos du Niger on the success of International Albinism Awareness Day 2016 and 2017.

- The Government of Niger could also consider as a model the health services of Standing Voice, a Tanzania and UK-based NGO with a specialization in mobile clinics targeting persons with albinism in both rural and urban settings. Standing Voice could provide requisite training to health care providers such as ophthalmologists and dermatologists in Niger.

Partner with NGOs

- Civil society groups and NGOs are partners in the successful implementation of any of the above recommendations. Thus, their activity should be enabled.

- NGOs like Under the Same Sun can be key partners for the Government of Niger as well as local actors like the Association nationale des albinos du Niger (ANAN).

Invest in training and education

- The Government of Niger should invest in training and education for women and girls with albinism. Education is the key to future indoor employment and the associated possibility of avoiding a short life expectancy due to skin cancer.

- The government of Niger should also fund workshops and seminars on income-generating activities for women with albinism and mothers of children with albinism. These will enable them to start their own businesses, which at term will help them become financially independent. Cooperating with local albinism groups like ANAN will make this effective and fruitful.

- The Government of Niger should consider as a model the UTSS Education Program, which funds education for 300 Tanzanian children with albinism, from kindergarten to graduate studies. This number represents only a small fraction of people with albinism in need of such opportunities. UTSS covers personal expenses, school supplies, uniforms, medical services (regular dermatology and optometry examinations) as well as sun protective clothing, sunscreen lotion and low vision devices.

Change Policy

- The government of Niger should consider the suggestion of the UN Independent Expert on albinism and create a task force on albinism consisting of members of various relevant Ministries: disability, education, justice, health among others. This task force can help the government carry out its short to medium term goals and assist in implementing other recommendations herein. The task force should have a budget and should consist of consult with civil society including people with albinism.[11]

[11] Report of the UN IE during 31st ordinary session of the UN Human Rights Council, 4 March 2016