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The Human Rights Case of Persons with Albinism in Uganda

Kelly Allen
Beloit College

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List of Acronyms

AAFU - African Albino Foundation Uganda
ACHPR – African [Banjul] Charter on Human and People’s Rights
ADD – Action on Disability and Development
AFEA – Albinism Foundation of East Africa
CRPD – Convention on Rights of Persons with Disabilities
DRRP - Declaration on Race and Racial Prejudice
DSPD – Declaration on Social Progress and Development
FHRI – Foundation for Human Rights Initiative
HURINET – Human Rights Network
HURIPPEC – Human Rights and Peace Centre (Makerere University)
ICCPR – International Convention on Cultural and Political Rights
LAPD – Legal Action for Persons with Disabilities
MP – Member of Parliament
MRGI – Minority Rights Group International
NAALPA - Nazigo Albino Persons Association
NCD - National Council for Disabilities
NGO – Non Governmental Organization
NOAH - National Organization for Albinism and Hypopigmentation
NUDIPU – National Union of Disabled Persons of Uganda
OCA2 - oculocutaneous albinism II
PWDs – Persons with Disabilities
PWD Act - Uganda’s 2006 Persons with Disabilities Act
UAA – Uganda Albino’s Association
UBOS – Uganda Bureau of Statistics
UDHR – Universal Declaration of Human Rights

Justification

Recently in Eastern Africa, attention has been drawn to the plight of persons with albinism due to cases of their being hunted for witchcraft. There have been no official reports of such killings in Uganda, largely due to their officially ignored status, but social and political factors in the country justify a concern of potential carryover from the surrounding region. Although the recent killings of persons with albinism for witchcraft purposes in the Lake Victoria region are serious and must be stopped, most albino persons in the region have more pressing concerns. For this reason, Uganda provides a case study that presents the common issues that persons with albinism have faced for years without being over-crowded by the recent and often-sensationalized incidents of albino hunters. Without the immediate threat of being hunted, those with albinism in Uganda face a host of medical, political and societal difficulties.

If there is a “limitation that affects enjoyment of rights that cannot be handled by the individual, the state has a duty to come in...International Human Rights impose the obligation on governments to provide for its people.”¹ Albinism in Uganda presents an interesting case of combined medical and societal concerns of a marginalized group. Analysis of the current international, regional and domestic laws and initiatives reveals inefficiencies in addressing the case of persons with albinism. If such inefficiency is identified and addressed, the resulting legislation could benefit other vulnerable persons similarly marginalized.

Recent attacks in neighboring Burundi and Tanzania targeting persons with albinism have brought the issue of their rights and protection under scrutiny in Kampala, Uganda. The timing of this research is ideal because of the newly developing Albinism Movement within the country. A pivotal part of that movement is the current petition on behalf of the Uganda Albino’s Association (UAA) requesting special representation in Parliament.

The topic of this paper provides an important consideration to the developing paradigm shift in discussions on disability. Already, many institutions are adopting a new, sociological approach that is more encompassing than the medical definition of “disabilities” of the 1960s. Albinism is one group that could benefit from such a change in definition, particularly in East Africa. However, Uganda is one country that has yet to incorporate the latest definition within its domestic legislation. The timing of this paper adds further argument to the current push for legislative amendments to make the Ugandan definition for “disability” and “disabled” more inclusive.

¹ Agirembabazi, Willy, Interview, Director of Vulnerable Persons Unit UHRC, 16 April 2010.

Finally, the paper raises the question of whether this group deserves further specification and attention beyond the category of disabled and gives arguments for and against suggested proposals. Overall, the paper gives a third-party voice to a marginalized group that is in its elementary stages of mobilization. This form of global citizenship is critical, for in order to have a voice on the domestic, regional and international stage, the challenges of albinism in Eastern Africa must be documented and their particular case defined.

Methodologies

The capital city of Kampala, Uganda was chosen as the base location of the researcher. Kampala houses many sectors of the government. It also provides ample access to non-governmental organizations (NGOs), including several dealing specifically with albinism, such as the African Albino Foundation Uganda (AAFU) and the Nazigo Albino Persons Association (NAALPA), as well as access to specialists in human rights and disabilities.

Formal interviews gained through the snowballing method comprised the majority of field research. After interviewing one contact, the researcher asked for organizations and contact persons that might have relevant knowledge on the subject. This method served to introduce the researcher to persons or organizations, providing a professional way to contact these persons. As the findings will reveal, the lack of support and cohesion between albinism organizations and other human rights and disabilities organizations made it difficult for the researcher to find persons directly connected to the issue of albinism. The researcher compensated by approaching human rights and disability organizations in order to determine what protections and services are currently offered and why persons with albinism are typically not being covered by these organizations.

Despite the fact that persons interviewed were professionals of their organization, some of the information given was personal opinion rather than institutional position or grounded fact. It was up to the researcher to interpret and fact-check responses given. The paper attempts to place each quote within context and to indicate when quotes are statements of opinion if it is not obvious.

Few albino persons outside of those who were authorities on their organization were interviewed. Those that were interviewed were contacted through the organizations. The focus of the objectives was information regarding albinism as a condition within the context of a disability and human rights. There was not a need for multiple, first-hand, personal accounts of the experience of

living with albinism and the researcher did not feel comfortable interviewing persons with albinism outside of organizations due to their vulnerable status.

The researcher contacted a mix of international, regional and domestic organizations that were both governmental and NGOs. Besides formal interviews, several questionnaires were sent through emails, though only two received useful responses. A phone survey of disability and vulnerable persons organizations was similarly unsuccessful in appropriating useful information. The purpose of the phone survey was to gather data that could give an unofficial percentage of disability and vulnerable persons organizations in Uganda that work or had worked with persons with albinism.² The problems encountered rendered the survey improper for the time and expenses of this researcher. Those problems were issues of: incorrect numbers, trouble understanding the interviewee due to poor connection or accent, no one available, and expense of airtime. Ideally, such a survey would have expanded the researcher's knowledge of how albinism is either addressed or not addressed nationally.

Two events directly related to albinism were attended during the practicum period: the release of a movie on albinism and a meeting of the UAA. While the events are not represented through citations within the paper, observation of the culture surrounding albinism as well as the operations within the albinism movement in Uganda was important for allowing the researcher to better understand the context of the study. Informal interviews with Ugandans were also used by the researcher for purposes of getting a general understanding of attitudes surrounding albinism. Only one quote was used anonymously from these interviews, but many of the attitudes expressed are mentioned within the paper.

Primary documents consulted consisted mostly of international, regional and domestic conventions and statutes on human rights, disability, minorities, and race. Reports from the Uganda Bureau of Statistics were also consulted. Secondary Resources complemented the primary with reviews and reports by NGOs and governmental human rights groups and articles on human rights and disability theory. Medical journals and reports on albinism were used to support information given by persons with albinism as well as the dermatologists interviewed. Prior to field research, the domestic and regional issue of albinism was researched through current events and reports released in the media.

The issue of time put a limitation on the number of organizations and authorities consulted and the amount of human rights and disability theory that

² See Appendix 1: Phone Questionnaire

could be gone into. The lack of specific and particularly quantitative data on persons with albinism is evident in this report, which serves to support the researcher's point that such information has been ignored and is necessary in proving the difficulties of this particular population. Where no quantitative, supporting data can be given, the researcher has supported the statement with reference to the authority who gave the information. If the statement was given by multiple authority figures and was uncontested, then it was not cited.

Objectives:

1. Identify the particular challenges of persons with albinism in general and as Ugandans in the context of East Africa.
2. Determine how rights of persons with albinism are met or not met under current international, regional and domestic legislative bodies and documents.
3. Examine and assess possible reasons why this group has remained undefined in Uganda.

Note on Terminology:

There is debate within the albinism community about the use of the term "albino." Typically, the term, "persons with albinism," is preferred, as it places the humanity of the person before the condition. Within this paper, this term is alternated with "albino person," or some derivative of, mostly for brevity and variety. Occasionally, the term "albino" is used when directly quoting an interviewee. It is not the intent of the researcher to, in any way, demean persons with albinism, or to place their humanity below their condition.

Findings and Analysis

Background

Though no accurate census exists, one available statistic extrapolated from a cancer research Ocean Road hospital in Dar es Salaam suggests that the regional population of persons with albinism is 1:5,000 to upwards of 1:1,000. However, the Managing Trustee at the Albinism Foundation of East Africa (AFEA) is doubtful that the prevalence rate is this high.³ This number can tentatively be compared with the estimated average of 1:20,000 in Europe.⁴ The African Albino Foundation Uganda (AAFU) estimated the population in Uganda to be around

³ Albinism Foundation of East Africa, Managing Trustee, Email Interview, 19 April 2010.

⁴ NOHA "What is Albinism?" The National Organization for Albinism and Hypopigmentation. East Hampstead, NH. <<http://www.albinism.org>>. Accessed 15 March 2010.

3,000 to 5,000.⁵ While the numbers are inaccurate, it can be concluded that persons with albinism represent a significant percentage of the population within the countries of East Africa.

The most accessible information regarding albinism in East Africa is surrounding the plight of albino persons being targeted for their body parts in Tanzania and Burundi. These events have been documented in the international scene thanks mostly to the work of a single journalist, Vicky Ntetema.⁶ The reason for the attacks that began in 2007, has been linked back to marketing schemes by witchdoctors. A complete set of body parts of a person with albinism can be sold for the equivalent of \$75,000 U.S. dollars on the black market around the Lake Victoria region.⁷ As of now, there have been no documented attacks on albino persons in Uganda for purposes of witchcraft. Fear of spillover from neighboring countries has been one of the leading reasons behind the UAA petition for representation in parliament and general mobilization among those affected. While these attacks are brutal and heinous, they are relatively recent and isolated to selective persons looking for economic gain. The main problems facing persons with albinism in Uganda are due to low access to medical care and societal norms that exempt them from participation. These issues are unable to be addressed with current legal definitions of disability in Uganda.

I. Particular Challenges of Persons with Albinism

Medical

Albinism is one of several genetic disorders that prevent the body either partially or fully from producing melanin pigment, affecting the skin, eyes and hair. Though information is scarce, several articles suggest that the most common form of albinism in Sub-Saharan Africans is oculocutaneous albinism II (OCA2).⁸ OCA2 is characterized by little to no pigment in the skin, hair and eyes and is associated with vision problems. This is supported by AAFU patient records, which have no documentation of persons with purely ocular albinism. However, Dr. Nayebare of AAFU explained that since ocular albinism only affects the eyes and not the skin, someone with the condition may never know that they have it, and thus never seek help.⁹ Producing a child with albinism requires the gene to be

⁵ Nayebare, Dr. Josseous, Interview, Dermatologist and Chairman African Albino Foundation Uganda, 27 April 2010.

⁶ Engstrand-Neacsu, Andrei and Alex Wynter. "Through albino eyes." International Federation of Red Cross and Red Crescent Societies. Geneva, Switzerland. 2009.

⁷ Engstrand-Neacsu, p.11

⁸ "OCA2." *Genetics Home Reference*. U.S. National Library of Medicine. Reviewed July 2009. Accessed 25 April 2010. < <http://ghr.nlm.nih.gov> >.

⁹ Dr. Nayebare, Chairman AAFU, Interview, 27 April 2010.

given by both parents, thus an albino person who reproduces with a non-albino is likely to have children without albinism.

Because the skin lacks the ability to create melanin, the risk of skin cancer is a very serious threat in a country of high altitude, situated on the equator. This exposure to harmful UV rays year-round is usually compounded by the fact that many parents of albino persons and persons with the condition themselves do not know proper precautionary measures, such as wearing covering clothing and broad hats. Sunscreen is difficult to find within Kampala and usually sells at about the equivalent of \$4.20 U.S. dollars (8,400 Uganda Shillings) per 170mL.¹⁰ Outside of the city, the life-saving lotion is not sold. Taking into account that as of 2007, 86.7% of Uganda's population was rural and that 31% live below the poverty line of one U.S. dollar per day,¹¹ one can deduce the extremely limited access most persons with albinism have to sunscreen.

With poor access to information and lack of precautionary measures, persons with albinism in East Africa are expected to have a significantly stunted life-span due to skin cancer. Dr. Kenyera at the Mulago Skin Clinic explained that by the time most persons with albinism come to the skin clinic, they are already in the late stages of skin cancer. They are typically referred to surgeons to remove the cancer, but it is often too late, as the cancer has moved onto other parts of the body. "Many [persons with albinism] won't even reach the third decade of their lifetime because they expose themselves to the sun without protection."¹²

The eyes of persons with albinism are also extremely sensitive to the sun. The lack of color in the iris means that light is not deflected when it enters the eye, causing overexposure and vision problems.¹³ Poor eyesight associated with albinism can manifest in the following symptoms: crossed eyes, light sensitivity, rapid eye movements (nystagmus) and functional blindness.¹⁴ Glasses can be prescribed to improve vision and eye muscle surgery can correct nystagmus. However, affordability and access to such technology is problematic in Uganda.

Skin and eye complications were the only medical conditions associated with albinism that could be verified by both medical, secondary sources and the

¹⁰ Researcher based this on prices of four brands of sunscreen at local supermarket. 29 April 2010.

¹¹ Mugimba, Christine. "ICT Accessibility For Persons With Disabilities in Africa Region: Uganda's Country Report." Uganda Communications Commission. International Telecommunications Union. 30 June 2008. p.2.

¹² Dr. Kenyera, Mulago Skin Clinic, Interview, 21 April 2010.

¹³ Ssebyanzi, Judah, Interview, Chairman Uganda Albinos' Association, 31 March 2010.

¹⁴ Jasmin, Luc. "Albinism." MedlinePlus. A.D.A.M. Inc. 14 October 2009. <<http://www.nlm.nih.gov/medlineplus/>>. Accessed 8 April 2010.

interviews with dermatologists, Dr. Kenyera and Dr. Nayebare of the AAFU. The following are problems reported by separate albinism organizations, but which could not be substantiated. Claims were made that females with albinism have difficulty in childbirth, albinism weakens the immune system, which causes affected persons to die from HIV sooner than most.¹⁵ A second association listed early loss of adult teeth, stomach problems, and an unpleasant aroma under issues commonly faced by its members.¹⁶ The fact that such claims are made by organizations of and representing persons with albinism without having any supporting evidence reveals one of the weaknesses of the movement: lack of medical and authoritative data on the conditions of albinism within the region, specifically Uganda.

In addition to the problems of equatorial sun and lack of access to protective measures such as sunglasses and sunscreen, albino persons face socio-environmental problems in Eastern Africa that can be linked to common superstitions and widespread ignorance of the condition. The overwhelmingly “black” population of the region makes this condition especially obvious and difficult to conceal. Many of the problems stated are identical or very similar to those of albino persons within East Africa, however, the nature of the research performed will limit the findings of the paper on the issues found within Uganda, particularly with regards to certain laws.

Myths and Misconceptions

The overarching theme of myths and misconceptions associated with albinism is that a child with albinism is a demon or a curse. Similar to beliefs surrounding persons with disabilities, it is not uncommon for an albino child to be considered a curse from God, placed on the family for something bad the family had done.¹⁷ Another suggested source of the child could be that the ghost of a colonialist impregnated the mother. In a similar vein, sometimes a father will assume that the mother has cheated on him with a white man. As a result, children with albinism already face the threat of being killed or abandoned by their own parents. Outside of the family, a common myth surrounding albino persons is that they don't die, they disappear. Children are taught to run from albino persons; “An albino will eat you up!”¹⁸ For the most part, these perceptions are more strictly held in rural areas.

¹⁵ Ssebyanzi, Judah, Interview, Chairman Uganda Albinos' Association, 31 March 2010.

¹⁶ Muyinda, Robert, Interview, Vice President Nazigo Albino Persons Association Organization, 5 April 2010.

¹⁷ Nokorach, Hon. William Wilson, Interview, Disabilities Member of Parliament, Northern Region, 23 March 2010.

¹⁸ Ugandan Interviewee explaining warnings given to her as a child, Informal Interview. 19 April 2010.

Tanzania and other neighboring countries share similar beliefs surrounding Albinism as Uganda, which have allowed witchdoctors in these countries to exploit these superstitions in order to pursue their own economic gains. Society defines what it means to be human, and when a group is defined as anything less than human, acts of discrimination become acceptable. The most devastating construct in Tanzania and Burundi is the myth that certain body parts of an albino person can bring wealth. So far, Uganda has yet to have any documented cases of albino persons being killed for the purposes of witchcraft. However, it is highly feasible that the trend will carry over into Uganda, where “they are [considered] a bit sub-human.”¹⁹ First, belief in witchcraft is prevalent throughout Uganda. Second, there is already an issue of child sacrifice for witchcraft purposes.²⁰ Third, there are not currently laws in place protecting albino persons in Uganda. The laxity of Ugandan laws may make albino hunters more likely to cross the border, as Tanzania has already taken measures to address the issue. In addition to the appointment of an Albino Member of Parliament (MP) by President Jakaya Kikwete, between 2008 and December of 2009, 1,000 persons associated with hunting albino persons had been arrested in Tanzania.²¹

Discrimination Throughout the Ages

“Albinos suffer the brunt of community segregation because people continue to regard them as social misfits.” – Disabilities MP, Hon. Nokorach²²

From the time of birth, most children with albinism, particularly those impoverished and in rural areas, are immediately exposed to discrimination from within their own families. When discrimination comes from parents or caretakers, a child is constantly exposed to inhumane treatment from an early age, which has lasting effects. It is not unheard of for mothers to throw their own child away, killing or abandoning him/her because of the fear and stigma associated with albinism. Fathers are likely to abandon an albino child, sometimes along with the mother, if not outright kill the child, either from belief in the mother’s unfaithfulness, superstition, or from the stigma associated with having an albino person in one’s family. The disgrace of having an albino child can extend beyond the father and mother, causing the extended family to shun parents that have chosen to keep their child.²³

¹⁹ Magelah, Peter Gwayaka, Interview, Project Officer for Law Reform HURINET, 8 April 2010.

²⁰ Muwanga, Sheila, Interview, Deputy Director of Programmes FHRI, 14 April 2010.

²¹ Bennett, Jody Ray. “East Africa’s Albino Underworld.” *ISN Security Watch*. 4 December 2009. <www.earthtimes.org>. Accessed 27 March 2010.

²² “Albinos demand special seat in Parliament.” *Daily Monitor*. No. 057. 26 February 2010. p. 3.

²³ Muyinda, Robert, Interview, Vice President Nazigo Albino Persons Association, 5 April 2010.

Growing up in such a household, can cause low self-esteem. Similar to practices in Uganda associated with disabled family members, some will force their albino child to stay in the family's backyard, and force him or her to hide whenever anyone outside the family comes to visit.²⁴ If a family goes to this extent to hide their child, it is unlikely that they will spend the school fees needed to send this child to school. The instance of persons with albinism kept from attending school has not been officially documented, but many people attested to the fact that it is uncommon for persons with albinism to be given the chance to go to school. Even if the parents are not afraid to reveal a child with albinism, an impoverished family may not be able to send every child to school. The parents may not want to "waste" money on a child with albinism, having never heard of a successful albino.²⁵ This perpetuates the system of exclusion and leads to a high level of illiteracy among the albino person population. It is undocumented how large that population is in comparison to the estimated 31% of the population who is illiterate.²⁶

Individuals with albinism who are given the opportunity to go to school face additional forms of discrimination and are prevented from equal access to education, either directly or indirectly, from both peers and teachers. The lack of sensitization about the condition of albinism and the prevalence of myths and misconceptions creates an environment of fear and discrimination. Teachers are typically inexperienced with the condition. Not only does this make a teacher incapable of correcting other children's misconceptions, it prevents the teacher from catering to the special needs of albinism, such as sitting them sit close to the front to see or excusing them from activities done in direct sunlight. In one case, the UAA interacted with a village teacher who simply thought the albino pupil was a white person.²⁷

If a person with albinism is able to complete schooling, the attempt to find employment presents additional challenges of discrimination. With equal schooling, a person with albinism could easily compete in the first stage of an interview process, which is typically written submission. However, in the next stage of an application process, in many cases, "an albino cannot survive a face-to-face interview."²⁸ Blatant discrimination on the basis of the condition was commonly mentioned. Dr. Josseous recounted his own story of being denied a

²⁴ Nokorach, Hon. William Wilson, Interview, Disabilities Member of Parliament, Northern Region, 23 March 2010.

²⁵ Ssebyanzi, Judah, Interview, Chairman Uganda Albinos' Association, 31 March 2010.

²⁶ Male-Mukasa, J.B. Executive Director. "Uganda National Household Survey 2005/06." Uganda Bureau of Statistics. December 2006. p.15.

²⁷ Ssebyanzi, Judah, Interview, Chairman Uganda Albinos' Association, 31 March 2010.

²⁸ Ssebyanzi, Judah, Interview, Chairman Uganda Albinos' Association, 31 March 2010.

position in a hospital, because, “he would scare away the patients.”²⁹ There are additional barriers to economic activity, as certain professions should be avoided by persons with albinism on account of their medical condition. Such professions are those that require any prolonged exposure to the sun, dealing with bright lights, such as welding, or anything requiring good vision. Due to discrimination and limitations of professions, many albino persons who work create their own forms of employment.

Though most of the superstitions surrounding albinism typically foster fear and avoidance among the general population, the marginalization of this population leaves females especially vulnerable to exploitation and abuse.³⁰ It is not uncommon to hear professional albino females complain about sexual harassment and exploitation by their superiors in the workplace. An employer may use the fact that they hired the women in spite of her albinism as leverage. In many cases, women might submit, reasoning that they are lucky to have a job, and that this will just be one last trial they have to face.³¹ When asked why a man would be prompted into sexual relations with a person with albinism when this group is typically avoided, it was explained by the Chairperson of the UAA that the condition also has a certain novelty, “Men want to see if albino women are sweeter than others.”³² Though a man may engage in intercourse, when it comes to marriage, albino women are typically regarded as a “last resort” for men who cannot attract any other women. If an albino woman is married, she may be a later wife in a polygamous marriage.³³ The Uganda Albino’s Association has also dealt with at least one case of a man leaving his wife who had albinism because he could no longer stand the social stigma. The issue of marriage is not isolated to women. There is another case within the UAA in which a man was rejected by his fiance’s family because of his condition.

II. How Rights Are Met or Not Met

Fundamental Rights

The National Union of Disabled Persons of Uganda (NUDIPU) recognizes that the stigma associated with albinism and the superstitious beliefs in the magical powers of their body parts make this group even more marginalized and

²⁹ Nayebare, Dr. Josseous, Interview, Dermatologist and Chairman African Albino Foundation Uganda, 27 April 2010.

³⁰ Muwanga, Sheila, Interview, Deputy Director of Programmes FHRI, 14 April 2010.

³¹ Ssebyanzi, Judah, Interview, Chairman Uganda Albinos’ Association, 31 March 2010.

³² Ssebyanzi, Judah, Interview, Chairman Uganda Albinos’ Association, 31 March 2010.

³³ Ssebyanzi, Judah, Interview, Chairman Uganda Albinos’ Association, 31 March 2010.

threatened than the traditionally disabled.³⁴ Where are the rights of persons with albinism protected under current laws and legislation? The findings of this researcher reveal a lack of inclusion in human rights laws beyond those most basic and applicable to all groups of persons, regardless of special needs and concerns.

Under international, regional and domestic documents dealing with the most basic and fundamental assurance of human rights for all persons there is no problem of inclusion for persons with albinism. Internationally, the Universal Declaration of Human Rights (UDHR) recognizes that all persons should enjoy their rights without being subjected to discrimination and that it is the role of the state and international community to ensure such rights. Article 2 of the UDHR provides the basis for human rights reiterated in later international, regional and domestic charters: “Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.” The “other status,” conveniently provides an all-encompassing category that persons with albinism fit under. The UDHR goes on to protect, “life, liberty and security of person,”³⁵ and against “cruel, inhumane or degrading treatment,”³⁶ as well as any discrimination in violation of the UDHR.³⁷ More specifically, the UDHR gives the right to “just and favorable conditions of work”³⁸ and, “the right to a standard of living adequate for the health and well-being of himself and of his family, including...medical care and necessary social services.”³⁹

Another international document that protects the basic rights of all is the Declaration on Social Progress and Development (DSPD). Similarly encompassing in its condemnation of, “inequality [and] exploitation of peoples and individuals,”⁴⁰ it also recognizes a need for special attention to be given to

³⁴ National Union of Disabled Persons of Uganda, Policy and Research Officer, Interview, 8 April 2010.

³⁵ UN General Assembly, *Universal Declaration of Human Rights*. Art. 3: resolution adopted by the General Assembly, 10 December 1948, res. 217A(III).

³⁶ UN General Assembly, *Universal Declaration of Human Rights*. Art. 5: resolution adopted by the General Assembly, 10 December 1948, res. 217A(III).

³⁷ UN General Assembly, *Universal Declaration of Human Rights*. Art. 7: resolution adopted by the General Assembly, 10 December 1948, res. 217A(III).

³⁸ UN General Assembly, *Universal Declaration of Human Rights*. Art. 23: resolution adopted by the General Assembly, 10 December 1948, res. 217A(III).

³⁹ UN General Assembly, *Universal Declaration of Human Rights*. Art. 25: resolution adopted by the General Assembly, 10 December 1948, res. 217A(III).

⁴⁰ UN General Assembly, *Declaration on Social Progress and Development*. Art. 2: resolution 2542 adopted by the General Assembly 11 December 1969.

those parts of society that are disadvantaged or marginalized.⁴¹ There are many other documents that serve to promote and protect overarching human rights, but they vary only slightly from the ones mentioned above.

The African (Banjul) Charter on Human and People's Rights (ACHPR) serves as the regional document concerning basic human rights. It mostly reiterates the UDHR, but under the article on health rights, the ACHPR is more explicit: "1. Every individual shall have the right to enjoy the best attainable state of physical and mental health; 2. States parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick."⁴² Besides health, persons are also granted the right to education.⁴³

Chapter 4 of the Ugandan Constitution of 1996 provides the basic framework for domestic human rights in Uganda. These rights largely borrow from international and regional treaties such as the UDHR. Chapter 4, article 45 establishes that the rights mentioned are not exhaustive, allowing for inclusiveness and flexibility. This article is similar to the "other status" of the UDHR in its universality and vagueness. The responsibility for promoting and protecting the rights of all its citizens is given to the Ugandan government in Article 51.

Though basic human rights are codified within these official documents, additional laws are needed to provide support. Despite the fact that these documents declare that all persons are equal and condemn all forms of discrimination, certain groups have deemed this insufficient in addressing the issues of particularly vulnerable persons. Project Officer for Law Reform at the Human Rights Network (HURINET) in Uganda explained that, "Under the Constitutional framework, [persons with albinism] fit. Beyond that, they don't."⁴⁴ Beyond the Constitution are supposed to be laws and institutions that defend and ensure such rights for all persons.

Clearly, the broad human rights outlined in the UHRC are commonly violated in relation to persons with albinism in Uganda. They face threats against their life and security of person and they are subject to inhumane and degrading

⁴¹ UN General Assembly, *Declaration on Social Progress and Development*. Art. 5: resolution 2542 adopted by the General Assembly 11 December 1969.

⁴² OAU, *African (Banjul) Charter on Human and People's Rights*. Art. 16 OAU Doc. CAB/LEG/67/3 rev. 5;1520 UNTS 217; 21 ILM 58. 1982.

⁴³ OAU, *African (Banjul) Charter on Human and People's Rights*. Art. 17. OAU Doc. CAB/LEG/67/3 rev. 5;1520 UNTS 217; 21 ILM 58. 1982.

⁴⁴ Magelah, Peter Gwayaka, Interview, Project Officer for Law Reform HURINET, 8 April 2010.

treatment. Through direct means of prevention or indirect, through the inadequacy of school resources, many albino children are denied access to education. As adults, those that are able to procure employment often face unjust and unfavorable conditions at work. Persons with albinism in East Africa rarely enjoy adequate health and well-being compared to their counterparts in other parts of the world. For example, persons with albinism in non-tropical countries who have access to skin protection tend to live to whatever their country's average life-span, whereas the lifespan for 98% of persons with albinism in Tanzania is 40 years, due to skin cancer,⁴⁵ as compared to the national average of 55.6 years.⁴⁶

The Defined Vulnerable

Other groups who have faced particular vulnerability and continued suffering from violations against human rights have pushed for specific mentioning in human rights, and even their own conventions, finding the broad generalities of human rights documents insufficient in recognizing their particular needs. "Vulnerable" is defined by NUDIPU to be determined "by virtue of their impairment and negative societal attitudes." The Uganda Bureau of Statistics (UBOS) relates it to a "lack of security, susceptibility to risk and/or exploitation."⁴⁷

Those groups that have their own conventions and special considerations in many human rights documents are women, children, the elderly, migrant workers, and refugees. The list is growing as more categories of vulnerable persons are deemed especially vulnerable. None of these are relatable to the condition of albinism in East Africa. The following categories of Race, Minority and Disabled are more relatable to albinism.

Though a definition for "race" is not given, the International Convention on the Elimination of all Forms of Racial Discrimination recognizes "racial discrimination" as:

"Any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and

⁴⁵ "Witchcraft murderers leave East African albinos living in fear." *DPA*. 2009. <<http://www.earthtimes.org>>. Accessed 17 March 2010.

⁴⁶ World Bank, "World Development Indicators: Tanzania 2008," updated 21 April 2010. <<http://data.worldbank.org/>>. Accessed 29 April 2010.

⁴⁷ Uganda Bureau of Statistics. "Uganda Demographic and Health Survey 2006." Calverton, Maryland: Macro International Inc. August 2007. p. 118.

fundamental freedoms in the political, economic, social, cultural or any other field of public life”⁴⁸

This definition would encompass the socially disabling aspect of albinism: their appearance. Yet albinism is a condition that occurs within races.

In broadest terms, the defining of a “minority” is a question of both numbers and power. In this case, it is easy to define persons with albinism as both a numerical and powerless minority within their race and within Uganda and the region. However, the International Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities of 1992, is very specific. Using the definition made famous by Francesco Capotorti in Study on the Rights of Persons, a minority is defined as:

“A group numerically inferior to the rest of the population of a state, in a non-dominant position, whose members - being nationals of the state - possess ethnic, religious or linguistic characteristics differing from those of the rest of the population and show, if only implicitly, a sense of solidarity, directed towards preserving their culture, traditions, religions or language.”⁴⁹

The emphasis on institutions such as language and culture leave out the case of persons with albinism, who share the language and culture of the majority and yet are often prohibited from full, societal participation.

The most compatible group within which persons with albinism can best fit is the current, international definition of “disabled.” The preamble of the Convention on the Rights of Persons with Disabilities (CRPD) states:

“Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.”⁵⁰

The CRPD also recognizes that the understanding of disability is something that is continuously changing. This inclusion of the sociological aspects of disabilities gives room for albinism to be included beyond merely the visual and dermatological handicap.

⁴⁸ UN General Assembly. *International Convention on the Elimination of all Forms of Racial Discrimination*. Art. 1 : resolution 2106 adopted by the General Assembly 21 December 1965.

⁴⁹ Jayawickrama, Nahal. *The Judicial Application of Human Rights Laws: National, Regional and International Jurisprudence*. Cambridge: Cambridge University Press. 2002. p. 844

⁵⁰ UN General Assembly, *Convention on the Rights of Persons with Disabilities*. Preamble. : resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106.

Domestically, however, the definition is much less inclusive. According to The Persons with Disabilities Act of Uganda, disability is, “a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environmental barriers resulting in limited participation.” In the same vein, “[a] person with disability means a person having physical, intellectual, sensory or mental impairment which substantially limits one or more of the major life activities of that person.”⁵¹ Not only is this definition vague in its use of the term “substantial,” it does not take into account limitation that occurs from outside of the individual.

Fitting the Definition

How can persons with albinism benefit under the current specifications in human rights documents? If recognized as fitting under the targeted group, persons with albinism could use these documents to support their plight in securing basic rights. Persons with albinism need assistance in education, health and economic development. Such participatory issues could be accommodated under the DSPD, as persons with albinism are clearly marginalized and disadvantaged. Statutes on race recognize the detrimental effects of negative social attitudes, but this can only be applied to persons with albinism through taking advantage of the broad definition of “racial discrimination” before mentioned. The Declaration on Race and Racial Prejudice (DRRP) recognizes racism as including:

“prejudice attitudes, discriminatory behaviour...resulting in racial inequality as well as the fallacious notion that discriminatory relations between groups are morally and scientifically justifiable; it is reflected in...discriminatory practices as well as in anti-social beliefs and acts; it hinders the development of its victims.”⁵²

This would recognize the external impairments unrelating to the medical condition of albinism. Using other Articles in the DRRP, groups could urge the Ugandan government to actively fight stigma and prejudice attitudes of its population against albinism.

The Minority article in Uganda’s Constitution⁵³ does not specify particular types of minority, and thus can grant albino persons the right to participate in decision-making and consideration in the development of national plans and

⁵¹ Act 20. *Persons with Disabilities Act*, 2006. Acts Supplement. *The Uganda Gazette No. 47 Volume XCVIX*. Printed by UPPC, Entebbe 4 August 2006.

⁵² UN Educational, Scientific and Cultural Organization, *Declaration on Race and Racial Prejudice* : Article 2. adopted by the Educational, Scientific and Cultural Organization, 27 November 1978.

⁵³ The Constitution of the Republic of Uganda. Chapter 4. Article 36, 1995.

initiatives. Recognition as a minority would grant protection against discrimination and insurance of political participation and inclusion. However, it gives no support for medical needs.

By far the most relevant and comprehensive documents dealing with issues similar to those faced by persons with albinism are those documents that target the disabled. The CRPD would recognize albinism as a disability due to “attitudinal barriers,” thus granting recognition of impairments outside of the medical diagnosis. In addition to more explicit rights against discrimination than those outlined by the UDHR, persons with albinism could benefit from Article 8 of the CRPD, which charges the state with responsibility for “awareness-raising.” States are also expected to take steps to, “prevent concealment, abandonment, neglect and segregation of children with disabilities,” one of which is to provide information and support to the children and their families.⁵⁴ Under education, albino persons would be afforded measures in order to accommodate for their eyesight problems.⁵⁵ Under Article 31, States would be responsible for collecting data and statistics on albinism in order to allow them to tailor policies and initiatives to accommodate this “disability.”

Uganda’s Constitution is especially accommodating for Persons with Disabilities (PWDs). Chapter 4, Article 35, Clause 1, gives PWDs right to dignity and places responsibility on both the state and society to ensure that PWDs, “realize their full mental and physical potential.” This would protect persons with albinism from discrimination in education as well as charge the state with providing information and possibly “technologies” such as sunglasses and sunscreen. Clause 2 charges Parliament with the task of enacting laws specific to protecting PWDs. Additionally, the Ugandan Persons with Disabilities Act 2006 provides protection against discrimination as well as rights to support and services in all areas of society, from educational, economic and governmental.

Despite these current protective measures and possibilities for inclusion, the challenge that poses the greatest barrier to persons with albinism gaining recognition and support is the issue of definition. Addressing the complications of classifying albinism within the context of Uganda and East Africa reveals the ambiguity that is present within currently accepted and differing definitions of groups under international, regional and domestic human rights.

⁵⁴ UN General Assembly, *Convention on the Rights of Persons with Disabilities*. Article 23 : resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106.

⁵⁵ UN General Assembly, *Convention on the Rights of Persons with Disabilities*. Article 24, Clause 2, Sub-clause, e : resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106.

“By listing, you leave out”

Article 32 of the constitution provides a catch-all phrase in order to support, “groups marginalized on the basis of gender, age, disability, or any other reason created by history, tradition or custom.”⁵⁶ Since disability does not encompass albinism in Uganda, albino persons would yet again fit under the generic “other” category. While the condition was not, the prejudices that led to the marginalization of persons with albinism were created or at least perpetuated by history. Laura Nyirinkindi, of Makerere University’s Human Rights and Peace Centre (HURIPEC), points out the inefficiency in naming categories in such documents. Specifically referring to Article 32 of Uganda’s Constitution, she writes, “Sometimes to list is to limit...To this effect, policies have been developed in this very rigid categorization, ignoring other marginalized groups.”⁵⁷ An example of this is the limited and exclusive mandate of Minority Rights Group International (MRGI), discussed below.

According to the head of the UHRC’s Vulnerable Persons Unit, Willy Agirembabazi, when a group falls under the “any other” category mentioned in laws concerning human rights, “they lose out because no one will pay attention to [them].”⁵⁸ Categories such as children, women, disabled, migrants were deemed vulnerable enough to require specific mentioning outside of “other.” Such special mentioning has brought attention and recognition to these groups and provides frameworks for addressing their needs. Agirembabazi suggests that, “a review of legal and policy framework is needed to reflect albinos as vulnerable persons in the category of minority and persons with disabilities who deserve special protection that responds to their needs.”⁵⁹

Another instance of limiting the scope of protection in the Ugandan Constitution is Article 21, Chapter 4. Though it includes more categories that cannot be discriminated against than the UDHR, it does not include an, “other” category. Instead, Ugandans may not be discriminated based on, “sex, race, colour, ethnic origin, tribe, birth, creed or religion, or social or economic standing, political opinion or disability.”⁶⁰ While this would prevent discrimination based on a person with albinism’s eyesight or possibly their shorter than average life-span, none of these categories fully encompass persons with albinism. Persons

⁵⁶ *Constitution of the Republic of Uganda*. Chapter 4. Article 32.1, 1995.

⁵⁷ Nyirinkindi, Laura. “Economic and Social Rights, Service Delivery and Local Government in Uganda. HURIPEC. Kampala, Uganda. July 2007. p.30.

⁵⁸ Agirembabazi, Willy, Interview, Director of Vulnerable Persons Unit UHRC, 16 April 2010.

⁵⁹ Agirembabazi, Willy, Interview, Director of Vulnerable Persons Unit UHRC, 16 April 2010.

⁶⁰ *Constitution of the Republic of Uganda*. Chapter 4. Article 21.2, 1995.

with albinism are “extremely vulnerable because they do not fit under current legal policies and framework.”⁶¹

Currently, there is no agreement amongst human rights or disabilities organizations, or even within albino organizations themselves regarding what category albinism should fit under, or if they deserve their own category.⁶² Much of this confusion stems from the fact that the terms of “race,” “minority,” and “disabled” are defined differently depending on the organization. Another element that complicates the decision of definition is the differing benefits that each category grants.

Though race provides some protection against discrimination and rights to affirmative action, acts dealing with PWDs are far more detailed and extensive on the rights afforded. Minority rights give similar protection as those given to race and could provide a more accurate category for albinism, as the condition occurs within races. “Albinos are discriminated based on skin color, but it is not racism.”⁶³ However, the definition of ‘minority’ is currently limited by international documents. Article 27 of the ICCPR, specifically outlines minorities to be “ethnic, religious and linguistic minorities.” This clause dictates the work of such organizations as the MRGI. As a result, MRGI has been unable to facilitate in the helping of albino persons in East Africa.⁶⁴ Despite the similar forms of discrimination suffered by albino persons as by recognized minorities, such as the Batwa in Uganda, MRGI has no room in their mandate to incorporate albino persons. Moreover, albinism is a medical condition that requires particular attention not granted under minority rights.

The issue of labeling albinism as a disability in Uganda revolves around the 2006 Persons with Disabilities Act (PWD Act).⁶⁵ Overall, there is a problem of clarity: what does “significant” mean? In the case of albinism, it is not clear that any of its associated medical problems would constitute a “significant” disability. While lack of skin pigmentation is a medical concern and a threat to life, particularly in tropical climates and without proper access to sunscreen, it doubtful whether this should count as a “significant.” There are other ethnicities, particularly those native to the far northern hemisphere, who produce very little melanin, but are not considered disabled. This is probably because the inability to produce melanin does not pose as serious of a health threat when not exposed to

⁶¹ Magelah, Peter Gwayaka, Interview, Project Officer for Law Reform HURINET, 8 April 2010.

⁶² See Appendix I: Chart of Relevant Authorities and Their Perspective on Albinism

⁶³ Agirembabazi, Willy, Interview, Director of Vulnerable Persons Unit UHRC, 16 April 2010.

⁶⁴ Mulindwa, Paul, Interview, Project Officer Minority Rights Group International, 14 April 2010.

⁶⁵ See page 16

equatorial sun all year. Still, it is hard to prove “disability” to be geographically isolated. For example, if a fair-skinned person from Irish decent were to live in Uganda, they would not suddenly become disabled by virtue of their skin’s inability to efficiently deal with the increased exposure to UV rays. They would however, face similar if not nearly identical skin issues as a person with albinism: burning and blistering from the sun and eventually a high chance of skin cancer. Even though eyesight may constitute a true “disability” under the current definition, like the skin problems, it has very little to do with the obstacles most persons with albinism face in interacting with their environment.

Similar to issues of the Minority definition, such an exclusive definition as the one used for Uganda’s PWD Act has implications on what organizations and policies can be directed towards whom. When given the hypothetical case of a person with albinism attempting to prove a case of discrimination in court, a lawyer from the Legal Action for Persons with Disabilities (LAPD) explained that, while the anti-discrimination clause in Uganda’s Constitution could be used to support the case, the current PWD Act would most likely be worthless in supporting someone with albinism.

The exclusion of albinism from disability definition prevents persons with the condition from inclusion within censuses done on the disabled in Uganda. As a result, there is no official record of persons with albinism under any census conducted by the Uganda Bureau of Statistics. “The problem is they are a minority group that no one cares about.”⁶⁶ Even though in its report, the Uganda Bureau of Statistics recognizes that “PWDs are vulnerable and suffer from social exclusion, stigma, and discrimination,”⁶⁷ the questions posed to households do not account for such societal factors, but only for the individual’s disability. Both the 2002 Uganda Population and Housing Census and the Demography Health Survey 2006 structured questions on disability according the PWD act of 2006. For example, “Does (NAME) have any difficulty in moving, seeing, hearing, speaking or learning which has lasted or expected to last six months or more?”⁶⁸ Using this structure, a person with albinism would only be recorded under visually impaired. The absence of census for any group shows a lack of government interest as well as a lack of programs, as such information is vital for the establishing and carrying out of official actions. If the societal and environmental limitations are not taken into account in policy making, they are sure to be forgotten in policy implementation.

⁶⁶ Bureau of Statistics Employee, Interview, Uganda Bureau of Statistics, 12 April 2010.

⁶⁷ Uganda Bureau of Statistics. “Uganda Demographic and Health Survey 2006.” Calverton, Maryland: Macro International Inc. August 2007. Report 2006. p.21.

⁶⁸ Uganda Bureau of Statistics. “2002 Uganda Population and Housing Census.” P13.

Current and Future Inclusion

“Towards the end of the 1960s organizations of persons with disabilities in some countries started to formulate a new concept of disability. That new concept indicated the close connection between the limitation experienced by individuals with disabilities, the design and structure of their environments and the attitude of the general population. At the same time the problems of disability in developing countries were more and more highlighted.”⁶⁹

The current limbo status in which albinism rests is part of a developing paradigm shift in how disability is looked at and defined. While persons with albinism fit under the newly created definition of disabled within the International Convention on the Rights of Persons with Disabilities (CRPD) of 2007, Uganda has yet to adapt its domestic policies in order to conform to the international definition.

The splitting of “disabled” into “impairment”, “disability”, and “handicap” was recommended by the WHO in 1983. Under the “International Statistical Classification of Impairments, Disabilities and Handicaps,” “impairment” is defined as:

“A loss or abnormality of psychological, physiological, or anatomical structure or function. Impairments are disturbances at the level of the organ and include defects, loss of limb, organ or other body structure and defects or loss of mental function.”

“Disability” is defined as: “any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being”.⁷⁰ It refers to functional limitations within any population, whereas “handicap” is:

“A disadvantage for a given individual resulting from an impairment or a disability that limits or prevents the fulfillment of a role that is normal for that individual. Handicap is a classification of role reduction resulting from circumstances which place an impaired or disabled person at a disadvantage compared to other persons.”⁷¹

⁶⁹ UN General Assembly. *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. Introduction : resolution adopted by the General Assembly, 20 December 1993.

⁷⁰ WHO “Standardization in measurement of impairment, disability and handicap, as consequence of disease.” Voorburg, Netherlands. 1983

⁷¹ WHO “Standardization in measurement of impairment, disability and handicap, as consequence of disease.” Voorburg, Netherlands. 1983

A handicap is created when a disabled person's environment limits or prevents equal participation within his or her community.

This three-pronged approach is the response to criticisms of the medical model, which proved insufficient in gathering information describing the consequences of clinical health problems.⁷² The medical model approaches disability from measurable characteristics relating to the individual, not taking into account that “functionality is related to technology.”⁷³ For example, a person born without legs, but who had a wheelchair and handicap accessible facilities, was technically not “disabled” under the medical definition. The new definition of disabled uses general concepts to make a broad and encompassing category. While it would classify the person without legs as disabled, the definition allows for the distinction that a person able to operate within his or her environment does not suffer from impairment or handicap.

The new definition has been put into place in such documents as the CRPD, which Uganda ratified 25 September 2008. An earlier document, the Standard Rules on the Equalization of Rules for Persons with Disabilities of 1993 also recognizes that “causes and consequences of disability vary throughout the world.” It expresses an attitude towards disability that encompasses the sociological aspect: “Ignorance, neglect, superstition and fear are social factors that throughout the history of disability have isolated persons with disabilities and delayed their development.”⁷⁴

There is currently a push to amend the definition in Uganda's PWDs Act from the medical model to the sociological model. Lecturer Kabumba from the Makerere Human Rights and Peace Centre explained that such an amendment will probably come through a partnership between the Ministry of Gender, Labour and Social Development, the Ministry of Justice, as well as the Ministry of Foreign Affairs. He saw no reason that there would be any problems in the amendment going through other than the issue of when. He said that the appropriate ministries, “need to be awakened by interested organizations of needed changes.”⁷⁵ If and when such an amendment passes, persons with albinism will be

⁷² WHO “Standardization in measurement of impairment, disability and handicap, as consequence of disease.” Voorburg, Netherlands. 1983

⁷³ Ssenooba, Medi, Interview, Lawyer Legal Action for Persons with Disabilities, 15 April 2010.

⁷⁴ UN General Assembly. *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. Introduction : resolution adopted by the General Assembly, 20 December 1993.

⁷⁵ Kabumba, Busingye, Interview, Lecturer on International Law and Human and Constitutional Rights HURIPEC, 13 April 2010.

better able to fit under the category of “disabled,” giving them access to increased recognition and inclusion in the government as well as disabilities organizations.

Possible Need for Explicitness

The question currently under discussion in Parliament, is whether albino persons face such extremely unique circumstances that they warrant their own affirmative action representative. On the 22 February 2010, the UAA submitted a petition that listed grievances against the current government and organizations working with disabilities, stating that, “in spite of being persons with disability, albinos are not accepted as such by main stream organizations working on issues of disability in Uganda.”⁷⁶ It also stated that, “despite the presence of such relevant laws and parliamentary representatives for disabled persons, albinos are still discriminated against and not included in decision-making processes that affect their wellbeing.”⁷⁷ Research and Information Officer of Action on Disability and Development (ADD), Baraza Deusdedit separately expressed this sentiment, recognizing that, “The current disability movement does not include albinos.”⁷⁸

There are differing perspectives on the issue. Many persons interviewed felt that albino persons fit well enough under the category of disabled that they do not warrant any additional recognition. A common response when human rights and disabilities organizations were asked about the current petition for an albino representative was the question of what sort of precedent that might set for similar groups. If albinism is to fit under the category of disabled, it must be understood that all disabled have their own unique needs, which NUDIPU believes can be better advocated under a consolidated category of “disabled.”

Hon. Anifer B. Kawooya, Chairperson Equal Opportunity Committee Parliament of Uganda, did not believe a specific MP was necessary, but mentioned that there may be a need to increase the number of PWDs affirmative action seats from five to ten because of the large number and variety of PWDs. Even without the PWD representatives, Hon. Kawooya believed that albino concerns were capable of being voiced by any Member of Parliament, which has not attempted by the UAA prior to presenting their petition. “In the end, an MP must be elected based upon merit, not disability.”⁷⁹

⁷⁶ Uganda Albino’s Association. “The Humble petition of the Uganda Albino’s Association.” Presented 22 February 2010. p.1

⁷⁷ Uganda Albino’s Association. “The Humble petition of the Uganda Albino’s Association.” Presented 22 February 2010. p.1

⁷⁸ Deusdedit, Baraza, Interview, Research & Information Officer ADD, 19 April 2010.

⁷⁹ Kawooya, Anifer B., Interview, Chairperson Equal Opportunity Committee Parliament of Uganda, 20 April 2010.

Not all persons would agree with Hon. Kawooya's optimistic belief in the encompassing power of current non-discrimination and disabilities acts. The Albinism Foundation of East Africa believes that specific mentioning is necessary, as the only officially recognized challenge of albinism in the region is visual impairment.⁸⁰ Kabumba from HURIPPEC mentioned that broad laws might not be sufficient enough to address the concerns of persons with albinism and that it is sometimes best to leave no room for doubt. Additionally, law-making itself provides a form of advocacy in creating heightened awareness of a situation, which albinism could benefit from. Deputy Director of Foundation for Human Rights Initiative (FHRI), Sheila Muwanga advocated a need for specificity regarding albinism in Uganda.⁸¹ "It is no longer safe to say that the current definition is sufficient for albinos."⁸² This stance was mostly justified by the attacks on albino persons in neighboring countries, but also in recognition of the extremely vulnerable situation faced by persons with albinism in Uganda.

The current, domestically recognized definition of "disabled" renders the debate mute. As it currently stands, the definition would technically exclude persons with albinism from qualifying for a PWD Affirmative Action seat.⁸³ Unable to compete within this category, persons with albinism suffer from a greater disadvantage in trying to run for any other representative seat. Unless the definition of 'disabled' changes, the argument that persons with albinism are already represented by the affirmative action representatives is unsubstantiated. Persons with albinism clearly fall under a marginalized group within society under Clause 1 of Chapter 4, Article 32, of Uganda's Constitution.⁸⁴ The second clause states that, "Parliament shall make relevant laws, including laws for the establishment of an equal opportunities commission, for the purpose of giving full effect to clause (1) of this article." The loophole created by the limited definition of "disabled," would seem to necessitate specific attention to persons with albinism.

Barring the problems of definition, the question becomes whether the unique concern of albinism are enough to warrant their own representative and how effective that representative would be within the context of Ugandan politics. Muyinda from the Nazigo Albino Association mentioned his position against an

⁸⁰ Albinism Foundation of East Africa, Managing Trustee, Email Interview, 19 April 2010.

⁸¹ This contrasted with the Director of FHRI's comments, which will be discussed later (p.

⁸² Muwanga, Sheila, Interview, Deputy Director of Programmes FHRI, 14 April 2010.

⁸³ This assumes that the PWD affirmative action seat adheres to the Uganda PWDs Act 2006.

⁸⁴ "Notwithstanding anything in this Constitution, the State shall take affirmative action in favour of groups marginalized on the basis of gender, age, disability or any other reason created by history, tradition or custom, for the purpose of redressing imbalances which exist against them." (Constitution of The Republic of Uganda. Chapter 4. Article 32. Clause 1, 1995).

affirmative action seat reserved for albino persons in Parliament. His position is that an MP would cause albino persons to become a political category forced to follow party lines rather than advocate their particular issues.⁸⁵

III. Reasons Persons with Albinism have Remained Undefined

The issues that persons with albinism face in mobilization and recognition extend beyond problems of legal definitions, although clearly that is one of the constraining factors. The UAA has defined albinism as a disability both in its official petition and through its attempts to appeal to such organizations as Action on Disability and Development (ADD) and NUDIPU. However, African Albino Foundation Uganda (AAFU) does not consider albinism a disability.⁸⁶

The particular characteristics of the condition make albinism a difficult movement to organize and unite. Unlike ethnic, linguistic and religious minorities, albino persons are typically born to non-albinos, and in communities dominated or entirely composed of non-albino persons. This isolates affected persons from an early age. The isolation is particularly felt in Uganda's majority, rural population. It is the belief of UAA that albino persons are typically hidden in villages and suburbs and are therefore outside of Kampala.⁸⁷ This would place most persons with albinism far away from the reach of the national organizations dealing with albinism: the UAA and the AAFU. However, there is no quantitative and/or official data regarding numbers and location of albino persons in Uganda, which is yet another hindrance to mobilization, recognition, and creating and executing initiatives. As explained under the first section, the lack of general information to the public has perpetuated superstitions surrounding the condition, which causes prejudice and discrimination. The typical practices relating to the superstitions create a culture of fear around persons with albinism, causing problems of low self-esteem and preventing access to resources from health, education, economic and justice.

The main preventing factor that has kept persons with albinism from mobilizing until recently, suggested by the UHRC Head of Vulnerable Persons Unit, Mr Agirembabazi, is that most persons with albinism are unaware of their rights.⁸⁸ But even now, when groups such as the Nazigo Albino Persons

⁸⁵ Muyinda, Robert, Interview, Vice President Nazigo Albino Persons Association, 5 April 2010.

⁸⁶ Kinyerara, Dr. Santos Okot, Interview, Co-founder African Albino Foundation Uganda and Dermatologist at Mulago Skin Clinic, 21 April 2010.

⁸⁷ Ssebyanzi, Judah, Interview, Chairman Uganda Albinos' Association, 31 March 2010.

⁸⁸ Agirembabazi, Willy, Interview, Director of Vulnerable Persons Unit UHRC, 16 April 2010.

Association have realized their rights, there are difficulties in mobilizing persons with albinism due to their lack of confidence as a result of stigmatization.⁸⁹

Other groups that suffer from similar problems of discrimination and resource access, and thus issues of self-mobilization, are ethnic minority groups such as the Batwa and Mbuti in Uganda. However, these groups are officially recognized and have organizations that advocate on their behalf.⁹⁰ The main international, organization working for them is Minority Rights Group International. Albinism has traditionally never had such third party support. When asked why this might be, Managing Trustee of the Albinism Foundation of East Africa explained:

“There are still very few groups addressing issues of albinism, and most of those doing so are comprised of people with the condition. The reason could be that most people do not quite understand albinism, do not know the challenges that people with albinism have to confront, have no contact or information about albinism, and do not quite see their rights as important enough or involving a large enough group to merit attention- but these are my suppositions.”⁹¹

These suppositions are largely supported by this research.

Two troubling issue that the researcher came across during the study were a lack of concern for persons with albinism in Uganda from leading human rights and disabilities organizations and incongruences in information given from varying officers of the same organization. HURINET is an organization meant both to build capacity of existing organizations with regards to addressing human rights and to create interest in human rights abuses that are not currently being addressed. So far, it has never officially worked with issues of albinism, nor does it have any current or future plans to do so at the moment.⁹²

Another “watchdog” organization in charge of researching, monitoring and advocating human rights is the Foundation for Human Rights Initiative. When interviewed, the Director of the FHRI admitted that persons with albinism were vulnerable, but claimed that albinism was “not an issue” until the murders in Tanzania, and that those in Uganda were under no threat, nor were they a group at risk. However, he did explain that the group was at risk on the “domestic” level, within the family, which required a collective effort of public and private

⁸⁹ Wangode, David, Interview, President Nazigo Albino Persons Association, 5 April 2010.

⁹⁰ Magelah, Peter Gwayaka, Interview, Project Officer for Law Reform HURINET, 8 April 2010.

⁹¹ Albinism Foundation of East Africa, Managing Trustee, Email Interview, 19 April 2010.

⁹² Magelah, Peter Gwayaka, Interview, Project Officer for Law Reform HURINET, 8 April 2010.

advocacy.⁹³ These statements contrast with the Deputy Director of FHRI, who expressed a need for explicit recognition of albino persons in policies and protective measures.

It is within the mandate for both of these human rights organizations to not only build the capacity of current organizations, but to actively search out and address issues of human rights abuse. Despite these two organizations being “watchdogs” for vulnerable persons, they had no current projects or official relationship with persons with albinism or any concerned organization.

The recent trend of killings in neighboring East African countries has raised an alarm that has reached beyond domestic and regional bodies to the international community. Even now that there is some international concern, especially within organizations for albinism, the UAA, AAFU, as well as the Nazigo Albino Persons Association have all expressed difficulties in attracting much beyond verbal support and minimal donations of sunscreens and sunglasses. With concern over the killings in the region, much of the support and attention from international organizations is focused on those countries with documented killings of albino persons for witchcraft purposes. The fact that Uganda has not had any reports of such killings, might explain why there is a lack of concern from policy makers and human rights groups regarding this particular population.⁹⁴

Within recent years, there has been a positive trend of albinism organizations being created in Uganda. Three organizations that the researcher was able to contact were the Nazigo Albino Persons Association (NAALPA), headquartered in Nazigo and Kampala, the Uganda Albino’s Association (UAA) and the African Albino Foundation of Uganda (AAFU), both headquartered in Kampala. The NAALPA was officially established in 2006,⁹⁵ followed by the UAA in January of 2008⁹⁶ and the AAFU in September of 2008,⁹⁷ though all organizations were in existence at least one year before their official date. These three organizations differ slightly in their approach to and focus on albinism in Uganda. The NAALPA is a community-based organization that focuses on allocation of supplies such as sunscreens, member empowerment, and community

⁹³ Ssewanyana, Director FHRI, Interview, 7 April 2010

⁹⁴ Agirembabazi, Willy, Interview, Director of Vulnerable Persons Unit UHRC, 16 April 2010.

⁹⁵ Muyinda, Robert, Interview, Vice President Nazigo Albino Persons Association, 5 April 2010.

⁹⁶ Uganda Albino’s Association. “Uganda Albinos’ Association Marginal Annual Report 2008/2009.” Latrans Publishers.

⁹⁷ Nayebare, Dr. Josseous, Interview, Dermatologist and Chairman African Albino Foundation Uganda, 27 April 2010.

advocacy.⁹⁸ The UAA is also concerned with member empowerment and advocacy, but from a more national and official capacity.⁹⁹ The AAFU is concerned with the purely medical and awareness-raising through education approach.¹⁰⁰

Conclusion

The ambiguity and general lack of knowledge surrounding the condition of albinism, specifically in Uganda, causes violations of human rights from both the public and private sphere, which prevent access to resources and perpetuate a state of neglect and abuse among persons with albinism. There is serious need for immediate action to be taken, particularly in regards to education and general advocacy regarding albinism in East Africa. There must be an accepted definition and understanding of the condition, which requires accurate and official information that is both quantitative and qualitative.

In order for discrimination against persons with albinism to be properly addressed, the condition must be defined in terms that are recognized by the government and NGOs, whether that be under the category of disabled or in a newly created, separate category. Immediately in Uganda, the most widely accepted and supported option that the researcher found was for albinism to fit under the category of disability as defined by current, international standards. This would require an amendment to Uganda's Persons with Disabilities Act of 2006.

With classification under disability, persons with albinism would have legitimate claims to representation by the five affirmative action seats for PWDs in Parliament. What protections and measurements should be taken is impossible to discern without the proper information. Disability status would also allow for albinism to be considered in the next census done, under the category of disabled. "The statistics are lacking; how many Albinos are there? Where are they?" ADD Research and Information Officer, Baraza Deusdedit, recommended this information as a starting point for increasing the visibility of albinism amongst disabilities categories.¹⁰¹ In 2011, the next census will be carried out by the Uganda Bureau of Statistics. In order to be officially included in the census, albinism organizations and sympathetic groups would have to present their case to

⁹⁸ Wangode, David, Interview, President Nazigo Albino Persons Association, 5 April 2010.

⁹⁹ Kitiibwa, Tony, Publicity Officer, Interview, Uganda Albinos' Association, 12 April 2010.

¹⁰⁰ Kinyerara, Dr. Santos Okot, Interview, Co-founder African Albino Foundation Uganda and Dermatologist at Mulago Skin Clinic, 21 April 2010.

¹⁰¹ Deusdedit, Baraza, Interview, Research & Information Officer ADD, 19 April 2010.

the Bureau of Statistics, possibly through the Disabilities MPs or relevant ministries.¹⁰²

Once a proper census is done by the UBOS of the numbers and location of persons with albinism is available, associated organizations can better advocate for their needs and interests. For example, within the Ministry of Education, funding could be allocated to go towards reading materials with larger type as well as sensitization initiatives for teachers.¹⁰³ Sensitization would allow for teachers to not only address the particular needs of a student with albinism, but also to combat peer discrimination within the classroom. A budget line-item for Ministry of Health could be requested for life-saving supplies such as sunscreen, sunglasses and broad hats.

Uniting under the disabled category would give current albinism organizations access to a wide range of support under current legislation and initiatives. However, there is valid concern that such a categorization would cause albinism to be, “thrown into the camouflage of disability,” and that though a PWD representative might sympathize with issues of vision or skin problems, “some disabilities don’t affect as much on the life aspect as albinism.”¹⁰⁴ These concerns are particularly relevant with the imminent threat in the region of being hunted for purposes of witchcraft. Despite this, the Albinism Foundation of East Africa advocates placing albinism, “within the disability movement if only to obtain education, health and social services,” stressing that, “We can engage in the debate about whether or not we are disabled when people are no longer dying from cancer or dropping out of school for lack of appropriate visual aids!”¹⁰⁵

Under the category of disabled, albinism organizations would have access to already existing initiatives for the disabled, such as economic empowerment and advocacy programs. They would also gain access to the resources available to larger, more established organizations. For example, association with NUDIPU, (which the UAA is in the process of establishing) grants recognition, the ability to be included in existing service provisions, provides a base to advocate within communities, and enhances exposure to the donor community.¹⁰⁶ Furthermore, it offers a more legitimate, established and recognized voice.

¹⁰² Bateesa, Kenneth Samson, Interview, Survey Assistant Uganda Bureau of Statistics, 12 April 2010.

¹⁰³ Santos Okot Kinyerara, Dermatologist at Mulago Skin Clinic

¹⁰⁴ Nayebare, Dr. Josseous, Interview, Dermatologist and Chairman African Albino Foundation Uganda, 27 April 2010.

¹⁰⁵ Albinism Foundation of East Africa, Managing Trustee, Email Interview, 19 April 2010.

¹⁰⁶ National Union of Disabled Persons of Uganda, Policy and Research Officer, Interview, 8 April 2010.

Fundamentally, there is a need for increased knowledge about the condition within academia regarding both medical and human rights, which must translate into dissemination of information to the local population in order to combat myths and misconceptions and prevent the spread of practices such as those in Tanzania and Burundi. Even with increased representation and explicit policies, it is not certain that these will translate into tangible empowerment of persons with albinism. Merely because there is a law against discrimination, “if a family is not forced to send their albino child to school, there is no assurance that they will.”¹⁰⁷ Keeping the context of Uganda in mind, the issue of resources, both monetary and man-power, is not to be overlooked. “The problem is not with law, policy or definition, it is with implementation. [One] can point out the gaps, but there needs to be actual, available resources, both human and financial.”¹⁰⁸ This problem is compounded by issues of corruption that are found throughout the government. “Even if the resources are there, they may never reach because of corruption issues”¹⁰⁹

Recommendations for Further Research

Besides the quantitative data mentioned above, there is a need for increased general information on albinism in Uganda. Qualitative information regarding the particular experiences and perspectives of Persons with albinism from a range of backgrounds would be immensely beneficial. Such information would create better understanding of the situation in Uganda and serve as a guide to both initiatives directed at albino persons and their families as well as advocacy to the general public.

At the point of this paper’s submission, the UAA petition has been revised and is under review in the Gender Labour and Social Development Committee in Parliament. Follow-up of the official decision would allow for an updated analysis of the situation of albino persons in Uganda’s government. This research could also be done in conjunction with determining the current status of the PWD Act and the push towards amending it in order to better comply with international standards.

While studying the issue of this “undefined minority,” the researcher learned of similar issues surrounding such groups as Little Persons, HIV and AIDS positive persons, those with sickle-cell anemia, sexual minorities, and persons with leprosy. Each of these groups represents a minority (in numbers and

¹⁰⁷ Magelah, Peter Gwayaka, Interview, Project Officer for Law Reform HURINET, 8 April 2010.

¹⁰⁸ Agirembabazi, Willy, Interview, Director of Vulnerable Persons Unit UHRC, 16 April 2010.

¹⁰⁹ Agirembabazi, Willy, Interview, Director of Vulnerable Persons Unit UHRC, 16 April 2010.

access to resources) which suffer from severe stigma in Uganda and discrimination above their biological and or personal condition. Additional research into each of these groups could provide much needed information and advocacy.

Epilogue: Global Citizenship

While persons with albinism face a great deal of obstacles in Uganda, it is encouraging to see that they are not facing these challenges alone. Several organizations, such as Albinism Aid in the Netherlands, and Under the Same Sun in Canada, have joined albinism groups in Uganda and East Africa to promote their cause and to provide much needed supplies such as sunscreen. For the most part, what I saw while living in Uganda was that Ugandan albino organizations have the leadership and the drive to push for their rights, what is needed from the outside community both in Uganda and internationally is understanding and attention. As citizens of the world, we must understand that persons with albinism are not helpless victims of their culture; rather, they are capable people who have been denied basic rights due to misunderstanding and fear. We should use this case study to recognize how we limit the abilities of people within our own communities, rendering them socially disabled.

If interested in helping the organizations mentioned, please visit:

www.aafuganda.com

www.albinismfoundationea.com

www.underthesamesun.com

www.albinismaid.com

Appendix 1: Phone Questionnaire

1. Does your organization work with the disabled?
2. How does your organization define disabled?
3. Does your organization work with vulnerable persons?
4. How does your organization define “vulnerable persons”?
5. Are you aware of the condition of albinism?
(It is a genetic condition in which the person is incapable of producing melanin, making their skin colorless. It also typically results in very poor vision.)
6. Has your organization served any albinos/persons with albinism?
 - 7a. If yes - what services did your organization provide?
 - 7b. If no - has your organization ever been approached by an albino?
 8. If yes - Why was your organization unable to assist them?
9. Has your organization ever actively sought out albinos?
- 10a. Would you consider them disabled?

- 10b. Why/Why not?
 11a. Would you consider them vulnerable?
 11b. Why/Why not?
 12. Why do Persons with albinism not fit under your organization’s statute?
 13. If an albino came seeking assistance, where would you refer them to?

Appendix 2: Chart of Relevant Authorities and their Perspective on Albinism¹¹⁰

Name/Org.	Are PWAs Disabled?	Are PWAs a Minority?	Are PWAs Marginalized/Vulnerable?	Has your organization worked with PWAs?	Should PWAs have an MP?
Hon. Nokorach/ PWDs Representative MP	Unknown	Unknown	Definitely	Presented UAA petition to Parliament	No (Fit under PWD)
Hon Kawooya/ MP Chairperson of Equal Opportunity Committee	Yes	-	Yes	Yes	No – Slippery Slope Argument (other Disabilites categories will want their own)
Robert Muyinda/ Vice Chair NAALPA	Yes, “but- worse”	-	Yes	Yes	No, “would politicize the condition”
David Wangode/ Chairman NAALPA	Yes	They could be considered a “special race”	Yes, “especially in Africa”	Yes	No – Slippery Slope Argument (Fit under PWD)

Appendix 2 (continued)

Name/Org.	Are PWAs Disabled?	Are PWAs a Minority?	Are PWAs Marginalized/Vulnerable?	Has your organization worked with PWAs?	Should PWAs have an MP?
Dr. Kinyerara/ Mulago Skin Clinic & AAFU	No	-	Yes	Yes	Yes

¹¹⁰ *Note: “Persons with Albinism” have been shortened here to PWAs

Name/Org.	Are PWAs Disabled?	Are PWAs a Minority?	Are PWAs Marginalized/Vulnerable?	Has your organization worked with PWAs?	Should PWAs have an MP?
Judah Ssebyanzi/ Chair UAA	Yes	Yes	Yes	Yes	Yes (pushing the petition)
Managing Trustee/ AFEA	Can't agree	-	Yes	Yes	-
Chief Executive/ NCD	Yes because of visual and other impairments	-	-	No	-
Ssewanyana/ Director FHRI	No	-	Yes, "but they are not threatened"	No	No "outrageous "
Sheila Muwanga/ Deputy Director FHRI	Unknown, "That's the fundamental question"	-	Yes	No	-
Peter Magelah/ HURINET	No	Yes	Yes, extremely	No	-
NUDIPU	No, Not currently, "But are because environment encapacitate s"	(They are not a race)	Yes	Currently trying to have UAA registered	No (Should Fit under PWD)
Kabumba/ HURIPEC	Internationa lly but not domesticall y	Yes	Yes	No	Amendment to disability definition is more feasible
Paul Mulindwa/ MRGI	-	No	Yes	Not Officially	-

Name/Org.	Are PWAs Disabled?	Are PWAs a Minority?	Are PWAs Marginalized/Vulnerable?	Has your organization worked with PWAs?	Should PWAs have an MP?
Medi Ssenooba, LAPD	Not officially (but could fit under newer definitions)	-	Yes	No	-
Willy Agirembabazi/ UHRC	Officially No, Personally Yes	No	Yes	No	“Could be a waste of time”
Baraza Deusdedit/ ADD	Yes, (newly)	-	Yes	Yes	No Slippery Slope (Fit under PWD)

Appendix 3: Example Consent Form

The Undefined Minority:

Revealing the Omission of Persons with Albinism from Human Rights Laws

You have been asked to participate in this interviewer’s research on the status of human rights as it relates to persons with albinism in Uganda. The purpose of the study is to determine what challenges this particular group faces as a marginalized community in a developing country.

You have been selected as an authority on the issue by the researcher. The researcher may ask for future interview sessions with you throughout the month of April, which you are at liberty to accept or reject on your own terms. In signing this form, you are giving consent to this researcher to use any information from the interview in her paper, *The Undefined Minority: Revealing the Omission of Persons with Albinism from Human Rights Laws*. Quotes given will be cited using your name unless you ask to remain anonymous. If you would prefer anonymity, a suitable pseudonym should be suggested below.

If you take part in this project, you will be helping contribute to the academic literature on the subject of albinism in Uganda, which is nearly non-existent. Your participation in this interview is entirely optional. You have every right to refuse to sign this consent form and refuse to answer any and all questions

of the researcher. If you decide to take part, you may stop at any time during the interview. In addition, you may ask to have your data withdrawn from the study after the research has been conducted.

If you want to know more about this research project, please contact me at: allenk@beloit.edu. A copy of the final paper will be available by mid May, at the School for International Training Resource Center: Plot 18, Kanjokya Street, Kamwokya. Tel: (0312) 273882.

You will be asked to sign two consent forms, one is for your personal records.

Sincerely,

Kelly Allen, School for International Training

I, _____, agree to take part in this project. I

(Please Print Name)

understand what I am being asked to participate in and that I can stop at any time. I would prefer the following name/pseudonym used in citing any and all quotes by me

(Print preferred name to be used in paper)

Signature

Date

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