



Classifying Albinism: Transforming Perceptions & Ushering Protection

With The Help of International
Human Rights Law

By
Under The Same Sun

Presented to the Advisory Committee of
the United Nations Human Rights
Council

February 2014
Under The Same Sun



TABLE OF CONTENTS

PRELIMINARY CONTENT

ACKNOWLEDGEMENT

ABBREVIATIONS & ACRONYMS

DEFINITION

EXECUTIVE SUMMARY

ACTUAL CONTENT

PART 1 INTRODUCTION: ALBINISM & CONSIDERATIONS FOR CLASSIFICATION

PART 2 SUB-CLASSIFICATION OF PWA IN IHRL

PART 3 THE MAIN CLASSIFICATION OF PWA IN IHRL

APPENDICES

APPENDIX I: ALBINISM WORLDWIDE (A PHOTO ILLUSTRATION)

APPENDIX II: A SAMPLING OF NAMES USED FOR PWA WORLDWIDE

APPENDIX III: ABOUT UNDER THE SAME SUN



ACKNOWLEDGEMENT

This paper was made possible because of the hard work and commitment of the international team of Under The Same Sun (UTSS) in Canada and Tanzania. Much gratitude is owed to the dedication of the United Nations' Office of the High Commissioner for Human Rights which produced the first United Nations report of its kind on albinism in September 2013. That report has greatly contributed to this paper. Last but certainly not least, UTSS is grateful to all the persons with albinism (PWA) across the world who have submitted reports and provided information to UTSS and responded to our call for contribution on various issues.

ABBREVIATIONS & ACRONYMS

| | |
|--------|---|
| CRPD: | Convention on the Rights of Persons with Disabilities |
| HPS: | Hermansky-Pudlak syndrome |
| HRC: | United Nations Human Rights Council |
| IHRL: | International Human Rights Law |
| OHCHR: | Office of the United Nations High Commissioner for Human Rights |
| PWA: | Person(s) With Albinism |
| UN: | United Nations |
| UTSS: | Under The Same Sun |

DEFINITION

PWA: In this paper, “PWA” refers to, at minimum, the type of albinism that manifests itself in the skin. This means that the term PWA as it is used here, will refer only to persons who are visibly albinistic in appearance to their family, community, race; and likely to others outside of these groups.



EXECUTIVE SUMMARY

Background and Content:

Albinism¹ is a genetic condition characterized by minimal or total absence of melanin in the skin, hair and eyes. It leaves the person with albinism (PWA) remarkably pale especially when compared to members of their biological family and community. Aside from their appearance, PWA are vulnerable to skin cancer, and are, in most cases, legally blind.

PWA have historically been referred to as “albino.” These days, groups advocating for persons living with the condition prefer the term “person with albinism” (PWA) because unlike the word albino, which equates the person to their condition, the phrase, PWA, puts the person ahead of their condition.² PWA is also a means to end the often derogatory context in which the word albino has been used historically.

Albinism, while a relatively rare condition, occurs in all races of the world. This means that the condition is often known, but not understood. The result is that PWA have often been deeply misunderstood, mystified and consequently stigmatized. Nearly all misunderstanding, mystification and stigma are traceable to the most visible aspect, which is their appearance. Nowhere is this clearer than in the common names used for PWA worldwide such as, “goddess of the waters,” “pig,” “ape,” “unripe banana,” “monkey” and “money.”³ As aptly stated by Kelly Allen, “society defines what it means to be human, and when a group is defined as anything less than human, acts of discrimination become acceptable.”⁴

Further, PWA worldwide have been victimized by being viewed as a mystically odd group that do not belong to the mainstream.⁵ This undesirable status has resulted in very

¹ See Appendix I for some pictures of PWA worldwide, “Albinism Worldwide,” photo credit: Rick Guidotti, Positive Exposure, www.positiveexposure.org.

² For more information, see UTSS, “Albino” vs “Person With Albinism (PWA),” UTSS Resources, accessed February 15, 2014, http://www.underthesamesun.com/sites/default/files/WHY-WE-PREFER-THE-TERM-PERSON-WITH-ALBINISM_0.pdf.

³ See Appendix II for a sampling of names used for PWA worldwide. For a complete list see UTSS, “Names Used for PWA,” UTSS Resources, accessed February 19, 2014, www.underthesamesun.com/resources. Note that in this catalogue, over 70% of the names used to identify PWA worldwide are derogatory in nature. The remaining 30% are neutral at best.

⁴ Kelly Allen, “Oppression Through Omission: The Human Rights Case of Persons with Albinism in Uganda,” *Development Studies: Kampala, Uganda* (Spring 2010) at p.10.

⁵ See “Persons With Albinism: A Specific and Unique People Group,” UTSS Resources, accessed February 15, 2014, <http://www.underthesamesun.com/sites/default/files/Why%20should%20PWA%20be%20considered%20a%20specific%20group.pdf>. Also see the following documentary in which stigma in PWA was comprehensively chronicled: Garth Mullins and Lisa Hale, “The Imaginary Albino,” first aired on CBC Radio: Ideas, February 18, 2013, CBC Radio, accessed February 15, 2014, <http://www.cbc.ca/ideas/episodes/2013/02/18/the-imaginary-albino/>



unfortunate stigma-based attention from their fellow citizens and culture. Most of the stigma-based attention visited upon PWA is maintained by, often unspoken, societal rules which has resulted in endemic and structural discrimination against them.⁶

Some of the most serious human rights abuses faced by PWA to date are physical attacks. These are namely death, dismemberment, sexual assault and mutilation. To date, we have a record of 305 such attacks in 23 countries - and these are recorded cases only. Most physical attacks against PWA go unreported because they tend to occur in the secrecy of cultural infanticide. They also tend to be shrouded in the “code of silence” of witchcraft practices. Some of these practices encourage the murder of PWA based on the belief that they are ghosts and not humans; and that their body parts can be used in potions to bring wealth and good luck to the end user.

This tragedy has recently gained the attention of the international community. It has resulted in several resolutions at the United Nations and African Union levels. It has also received support via mention in declarations and statements of international and regional bodies.⁷ What remains is how to deal with this issue with the goal of answering the question: how should PWA be protected using legal mechanisms?

Purpose of Paper: Classifying PWA

This paper focuses on addressing the issue of classification or categorization as a first step in protecting PWA. In essence its premise is that classifying them into cognizable or appropriate categories for international recognition would give PWA a legal identity. That identity will in turn become a vehicle through which positive change and above all, protection can be ushered in.

⁶ See note 4 & 5. Quote: “Code of silence” is from Simon Fellows, *“Trafficking Body Parts in Mozambique and South Africa (2008),”* Human Rights League, Mozambique, <http://www.scribd.com/doc/23729111/Trafficking-Body-Parts-in-Mozambique-and-South-Africa-Mozambique-Human-Rights-League>, accessed August 3, 2010. source. Also see “Killed for Muti,” UTSS Resources, accessed February 15, 2014, http://www.press.uchicago.edu/books/turabian/turabian_citationguide.html.

⁷ Resolution 23/13, “Attacks and Discrimination Against Persons with Albinism,” 23rd Session of the United Nations Human Rights Council, June 2013 [“Resolution 23/13”]; Resolution 24/33, “Technical Cooperation for the Prevention of Attacks Against Persons With Albinism,” 24th Session of the United Nations Human Rights Council, September, 2013 [“Resolution 24/33”]; African Committee of Experts on the Rights and Welfare of the Child(ACERWC); Resolution 263, “Resolution on the Prevention of Attacks and Discrimination Against Persons With Albinism,” African Commission on Human and Peoples’ Rights, Banjul, Gambia, 05, November 2013; The Addis Ababa Declaration on Ending Discrimination and Violence Against Girls in Africa, Addis Ababa, Ethiopia, 05 November 2013. Also see joint press statement issued on 4 May 2013, “Not ghosts, but human beings ... persons with albinism,” accessed February 15, 2014, www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=13294&LangID=E. [“Joint Press Release by UN Rapporteurs”]. Specific mention has also been made in concluding observations of the Human Rights Committee, the Committee on Economic, Social and Cultural Rights, the Committee on the Rights of the Child and the Committee on the Elimination of Discrimination against Women (see UN Preliminary Report, at note 16 below, at para 61).

The Main Classification of PWA

Under The Same Sun proposes, (through the course of its work and research, and from informal consultation with PWA) that PWA have one main identity and that is:

- **A specific people group with particular needs that must be given special attention in IHRL (“specific people group”)**

This classification of albinism is not only broadly prospective in terms of preventing future human rights violations, seen and unforeseen, but one that is also retrospective in terms of creating room for correcting past errors of understanding about the condition. This is because **“specific people group”** provides room for a crucial part of their experience and that is the unique issue of global stigma stemming from the mystification of their genetic condition.⁸

To better understand this unique aspect of albinism, it is important to note that today PWA are stigmatized not only because they have pale skin and low vision issues, but also because of false beliefs and mystification of the *totality* of their albinistic appearance. These beliefs and mystification are centuries-old but continue to thrive. They are present in cultural attitudes and practices around the world. From countries in Africa to Asia to North America, albinism conjures a mystical icon in the minds of people – a “blank slate” upon which fallacies inspired by culture and religions are projected.⁹ A growing number of recent reports indicate that these beliefs and myths, which manifest as stigma and discrimination, are key to understanding the reasons behind the murder of PWA in certain areas and their marginalization in almost all regions of the world. It is this mystical reality and its impact on the lives of PWA that must be given specific attention.

Sub-Classifications of PWA

Within this key and overall classification of “specific people group” as summarized above, PWA have further sub-classifications or aspects, some of which include the following in IHRL:

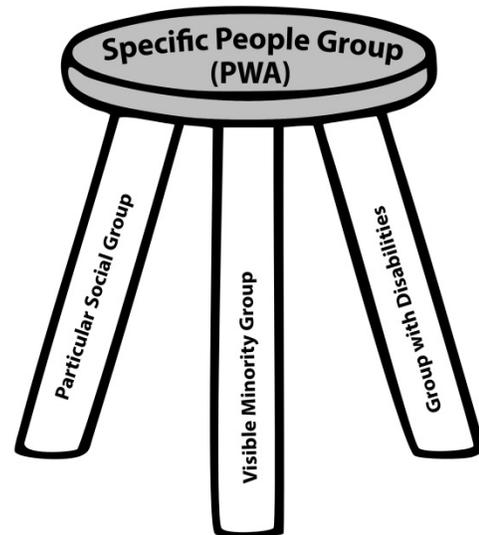
- a “particular social group” that ought to find protection under the Refugee Convention;

⁸ This was one of the two key recommendations for classification in the conclusion of Kelly Allen’s research in Uganda on the issue. The other being the classification of persons with disabilities. See Allen, at note 4.

⁹ Quote from Emily Urquhart, “The Meaning of White,” April, 2013, at p.9, The Walrus, accessed February 15, 2014, <http://thewalrus.ca/the-meaning-of-white/>.



- a “visible minority” group based on the idea of albinism as a new category of “colour. ”
Therefore, PWA ought to find protection under the Durban Declaration; and the International Convention on the Elimination of all Forms of Racial Discrimination,¹⁰ and
- a people with disabilities that ought to find protection through the Convention on the Rights of Persons with Disabilities.



Like the sub-parts of a three-legged stool, not one of these three sub-classifications is adequate enough to render the others redundant. Further, to choose only one of these sub-identities as the key classification of PWA is not only inadequate but would also be disrespectful, reflecting a deep lack of awareness of the PWA’s condition. Above all, it would be reductionistic: reducing a complex phenomena such as living with albinism into over simplified terms.¹¹ The problems with such reductionism is that it will not lead to a comprehensive plan of protection for PWA. At best, it will lead to a situations of partial, adhoc and inadequate responses - which is no different from the situation today.

¹⁰ The phrase “New category of ‘colour’” is inspired by the title of Sara Scott’s work cited at note 24 below.
¹¹ “Reductionism,” Merriam-Webster Dictionary, accessed February 15, 2014, <http://www.merriam-webster.com/dictionary/reductionism>.



ALBINISM AND CONSIDERATIONS FOR CLASSIFICATION

PART 1

WHAT IS ALBINISM?

Albinism

Albinism may be defined as a genetically inheritable condition characterized by hypomelanosis.¹² Hypomelanosis is the marked reduction or absence of melanin involving the skin, hair and eyes. Albinism is a genetically recessive trait; therefore, both mother and father must carry the gene for it to be passed on, even if they do not have albinism themselves. When both parents carry the gene, there is a 1 in 4 chance at each pregnancy that the child will have the condition. Some rare instances of albinism are limited to the eyes (ocular albinism). In this case, the person has light coloured eyes but normal coloured skin and hair. Another rare type of albinism is the type marked with Hermansky-Pudlak syndrome (HPS). HPS is a type of albinism characterized by platelet dysfunction and prolonged bleeding. All persons with HPS -- even though they display a wide range of apparent pigmentation -- have visual impairment just like the general population of PWA.¹³

Albinism occurs in every race regardless of ethnicity.¹⁴ The frequency of occurrence varies by region. The average rate of occurrence in Europe and North America is often reported to be 1 in 17, 000 to 20,000 persons. One community in Central America, the Guna, (located in the geographic region of Panama) has the highest known frequency of albinism in the world which is 1 in every 159 persons.¹⁵ In Africa, rates can be as high as 1 in 1,000.¹⁶ These numbers signify that no one knows for certain the number of PWA

¹² G. F. Cole, P. Conn, R.B. Jones, J. Wallace, V.R. Moore (1987), "Cognitive Functioning In Albino Children," *Developmental Medicine & Child Neurology*, 29 (1987): 659–665, at p. 659.

¹³ "HPS Information," from the Hermansky-Pudlak Syndrome Network Inc., accessed February 6, 2014, <https://www.hpsnetwork.org/en/hps-information>.

¹⁴ See Appendix I for some pictures of PWA worldwide in, "Albinism Worldwide," credit: Rick Guidotti, Positive Exposure, www.positiveexposure.org.

¹⁵ Kelly Allen, Fulbright Grantee "Combating Social Rejection of Albinism: Lessons from the Guna People, Panama, Central America," provided to Under The Same Sun, at p.12.

¹⁶ See Esther S. Hong, Hajo Zabeed, & Michael H. Repacholi, "Albinism in Africa as public health issue", *BMC Public Health*, vol. 6, No. 212 (August 2006), accessed February 17, 2014, www.biomedcentral.com/1471-2458/6/212. Also see, "What is Albinism," UTSS Resources, accessed February 15, 2014, <http://www.underthesamesun.com/sites/default/files/What%20is%20Albinism%20->



worldwide. Based on the aforementioned estimates, the range could be anywhere between tens of thousands to a few hundreds of thousands.

Eyes of a PWA

All forms of albinism give rise to significant vision impairment. This is the reason why medical experts agree that albinism is definitively determined by an eye exam.¹⁷ The vision impairment in PWA is caused by a combination of several overlapping eye defects including nystagmus (involuntary eye movements in horizontal patterns), photophobia (high sensitivity to glare and light), strabismus (muscle imbalance of the eyes also known as “crossed eyes”), astigmatism, foveal hypoplasia (where the retina or the interior surface of the eye that receives light, does not develop normally) and optic nerve misrouting (nerve signals from the retina to the brain do not follow the usual nerve routes).¹⁸ A helpful video demonstration showing how PWA see when compared to normally sighted people is available on YouTube.¹⁹

That said, there is wide variation in degree of visual impairment amongst PWA. A majority are unable to substantially correct their vision through any known means and are often classified as legally blind, and therefore, persons with (visual) impairment.²⁰ A much smaller number of PWA are able to restore much of their normal visual acuities from the use of powerful glasses and available technologies.

Skin of a PWA

There are various types of albinism and therefore a range of physical impact on persons who have the condition. The most common form is known as oculocutaneous albinism (OCA) and this affects the skin, hair and the eyes.²¹ There are different types and subtypes of OCA with varying degrees of melanin deficiency. The main ones are tyrosinase negative (OCA1) and tyrosinase positive (OCA2 and OCA4). In the first, OCA1, there is little or no melanin production. In the more prevalent – particularly in African countries –

%20ENGLISH.pdf. Also see: “About Albinism,” The Vision for Tomorrow, accessed February 17, 2014, <http://www.visionfortomorrow.org/about-albinism/>; “What is Albinism,” National Organization for Albinism and Hypopigmentation (NOAH), accessed February 17, 2014, http://www.albinism.org/publications/what_is_albinism.html; “Oculocutaneous Albinism,” Genetics Home Reference, accessed February 14, 2014, <http://ghr.nlm.nih.gov/condition/oculocutaneous-albinism>; Preliminary Report of the United Nations High Commissioner for Human Rights, Persons with Albinism, 12 September 2013 [“UN Preliminary Report”] at para 14.

¹⁷ Lluís Montoliu et al., “Increasing the Complexity: new genes and new types of albinism,” *Pigment Cell and Melanoma Research*, 27(1) (2014 Jan): 1-8, Epub 2013 Oct 17, DOI: 10.1111/pcmr.12167, at p. 6.

¹⁸ See note 12 and 16 above.

¹⁹ Uploaded on October 28, 2011, by Snowysnowflake21, accessed February 6, 2014, <http://www.youtube.com/watch?v=RrqdFKs2Hzw>.

²⁰ UN Preliminary Report, at note 16, para 78.

²¹ See NOAH at note 16.



OCA2 type, some melanin is produced, giving rise to white or cream coloured skin, sandy-coloured hair and light blue, grey or brown irises in those affected.²²

The absence of melanin renders PWA highly prone to sun burn which in turn can lead to skin cancer and death if left untreated. There have been no records of fatality due to skin cancer in countries where basic health education and sun protection cream is accessible to PWA. In Sub-Saharan Africa, skin cancer is the primary killer of PWA and is a major contributing factor to the average life expectancy of 30 to 40 years amongst PWA in the region. This is probably why the PWA skin has been considered by some as a disabling feature of the condition.

Appearance of PWA

PWA are often noticed by their colouring, especially in non-white races. Given the power of skin colour in human history and its determining effect in the distribution and withholding of rights and privileges, the colouring of the PWA should never be overlooked. Skin colour remains a powerful factor in human politics and in common social transactions between the PWA, their family and society. In several countries, PWA are considered to be ghosts or a type of supernatural metaphysical evil or non-human being.²³

Aside from the issue of colouring, other factors of albinism make the PWA seem peculiar and noticeable in their community. These include the involuntary eye movement of the PWA (nystagmus) which is visible to most observers. PWA also tend to have mannerisms and posturing considered socially awkward including extreme head-tilting and involuntary head-shaking in correspondence with nystagmus. Most PWA also, as a result of their photophobia, squint heavily not only in glare and sunlight but also in areas that are considered moderately lit. This squinting also contributes to noticeable facial distortion and appearance. Further, PWA tend to read by holding objects very close to their face. This is due to vision impairment but can seem very strange to observers.²⁴

In some countries, PWA are also known to have widespread and sometimes ghastly sores on their skin. To many, these sores are a permanent feature of albinism and the general belief is that PWA are born with them or will develop them at some point in their lives. The truth is that most of these sores are a result of sun damage or skin cancer that has gone untreated.

²² See UN Preliminary Report, at note 16, para 12. Also see “Albinism,” Patient Plus, accessed February 17, 2014, <http://www.patient.co.uk/doctor/albinism>.

²³ See Catalogue of Names Used for PWA at note 3.

²⁴ From UTSS experience. Also see UTSS/UNICEF, “Situation Assessment of the Centres of Displaced Persons With Albinism in the Lake Zone and Tanga Regions, Findings from Under The Same Sun Survey, 2011,” UTSS Resources, (listed as “Report on Centres Holding Displaced PWA”), accessed February 15, 2014, <http://www.underthesamesun.com/resources> at p.56. Also see: The Albino Foundation/UNICEF, “Knowledge, Attitude and Practices Study on Children With Albinism in Nigeria” 2011/2012, at pp 11-12; Sara Scott, “A New Category of ‘Color’: Analyzing Albinism Under Title VII and the Americans with Disabilities Act,” 2 J. *Gender Race & Just.* 493 (1998-1999), at p. 496 and on. See in particular from p.519.



All of the above mentioned aspects contribute to the “strange” appearance of PWA. While the severity of each factor varies from person to person, the issue of appearance remains an important consideration in understanding some of the negative perceptions of PWA around the world. Most importantly, it is essential for understanding the unique mystification and resulting stigma they face; a stigma that is not only a result of their medical needs but also due to the perception of the *totality* of their appearance.

Albinism in this paper

When the word PWA is used in this paper, it refers to, at minimum, the type of albinism that manifests itself in the skin. This means that the term PWA as used here, will refer only to persons who are visibly albinistic in appearance to their family, community, race; and to others outside of these groups.

Why is Albinism on the Agenda of the HRC?

Persons with albinism have lacked a strong voice for asserting not only their rights, but their very existence. Persons with albinism have not been heard, in part because they lack numbers, but more significantly because they are a marginalized group who have been deemed outside the norms of the dominant culture.

- Sara Scott, researcher, author²⁵ and sibling of two PWA (1999)

PWA have, in recent times, and particularly since 2009, gained the interest and attention of the international community.²⁶ This is largely due to the shocking experience they face in a number of countries including normalized singling-out, discrimination, debilitating stigma, and in some cases, attacks namely bodily dismemberment and death. To date, we have records of 305 attacks in 23 countries, most occurring after 2007. We strongly believe that there are many more attacks which have occurred over the centuries and that the majority have gone unreported. Most attacks against PWA go unreported because they tend to occur in the secrecy of cultural infanticide. They also tend to be shrouded in the “code of silence” of witchcraft practices.²⁷ Some of these practices encourage the murder of PWA based on the belief that they are ghosts and not humans; and that their body parts can be used in potions to bring wealth and good luck to the end user.

The experience of PWA goes against all fundamental human rights but had unfortunately not been discussed at the international level until a first resolution on the issue was adopted at the 23rd session of the United Nations Human Rights Council (HRC).²⁸ That resolution

²⁵ Sara Scott at note 24.

²⁶ See note 7.

²⁷ See note 6.

²⁸ See note 7.



was followed by a second resolution on albinism at the subsequent HRC session.²⁹ This second resolution put the issue in the hands of the Advisory Committee of the HRC. This committee is expected to produce a report on its assessment of the issue and likely make recommendations on ways forward at the 28th session of the HRC in March 2015.

Two UN resolutions in a span of 4 months was a remarkable feat for a relatively unknown genetic disorder. Yet, because it is a condition affecting a many persons globally, most of whom are in countries with recorded fatal attacks against them, there remains a need to take the condition from misunderstanding into clarity, classification and ultimately, protection.³⁰

UTSS' perspective on how albinism should be classified as set out in this paper is based on its experiences working and interacting with hundreds of PWA throughout the world; including a majority of staff who themselves have albinism.³¹ While UTSS' main thrust is albinism in Sub-Saharan Africa with a particular focus on Tanzania, we have scores of partnerships with local PWA groups on the ground across Sub-Saharan Africa and globally who frequently report on their plight to UTSS.³² We have also provided expert testimony before governments and judiciaries, attended numerous conferences and engaged in various governmental and non-governmental projects on albinism both within and outside of Africa. It is from these experiences that we have settled on the perspectives set out in this paper.

ALBINISM IN CONTEXT OF IHRL

The UN Preliminary Report suggested that determining the category into which PWA may fall [in context of IHRL] is an area that requires further study.³³ This is certainly true for two interrelated reasons. First, to initiate change for PWA, there must be a vehicle for change, namely a categorization or classification in context of cognizable rules and laws. That classification is also necessary because of the urgent need to create understanding of the condition and to ultimately protect those who live with it from discrimination, attack and death. This is where IHRL serves a strong purpose on the issue.

²⁹ See Resolution 24/33 at note 7.

³⁰ See UN Preliminary Report, at note 16, para 14.

³¹ Since its inception in 2008/2009, UTSS in Canada and Tanzania has had a total of nearly 60 staff, half of whom are PWA.

³² UTSS works in close contact and partnership with a wide range of organizations serving PWA including the well-established National Organization of Albinism and Hypopigmentation (NOAH) based in the US, the World Albinism Alliance, the Albinism Fellowship of Australia, and numerous local groups in Africa including groups from Botswana, Burkina Faso, Burundi, Cameroon, D.R. Congo, Gabon, Gambia, Ghana, Guinea, Ivory Coast, Liberia, Malawi, Mali, Mauritania, Niger, Nigeria, Senegal, Somalia, South Africa Swaziland, Tanzania, Togo, Uganda, Zambia and Zimbabwe.

³³ See UN Preliminary Report, at note 16, para 77. Also see Allen at note 4.



PWA and IHRL: General Sources of Protection

Basic human rights treaties such as the *United Nations Charter*, the *Universal Declaration on Human Rights*, the *International Covenant on Civil and Political Rights* (ICCPR), the *International Covenant on Economic Social and Cultural Rights* (ICESCR), the *Convention on the Rights of the Child* (CRC) and the *Convention against Torture* (CAT), all broadly cover the human rights of PWA.³⁴

For example in the ICCPR, the use of the phrases “such as” and “any other status” at articles 2 and 26 suggests that the listed grounds of prohibited discrimination are not closed.³⁵ In fact, it has been found by the Human Rights Committee which oversees the implementation of the ICCPR that the general prohibition on discrimination under Article 2 is of broad application.³⁶ Also article 2(2) of the ICESCR provides that “rights ‘enunciated ... will be exercised without discrimination of any kind’ based on certain specified grounds ‘or other statuses [and this] clearly applies to discrimination on the grounds of disability.’”³⁷ The ICESCR also calls for state protection for persons with disability.³⁸ Both the ICCPR and the ICESCR are part of a network of binding multilateral treaties which protect life and prohibit discrimination as set out in both the Charter of the United Nations and the Universal Declaration of Human Rights³⁹

Nevertheless, a more nuanced yet specific classification is needed for the particulars of the condition of albinism. Some of those particulars include the fact that PWA are a global group represented in every race; that they are often identifiable by the striking colour of their appearance; that they have a range of disabilities particularly in their skin and eyes; and that they are a relatively small number vis-à-vis their race -- a situation that exposes

³⁴ See UN Preliminary Report, at note 16, para 30.

³⁵ See original articles of the ICCPR at <https://treaties.un.org/doc/Publication/UNTS/Volume%20999/volume-999-I-14668-English.pdf>, accessed January 29, 2014; Also see key discussion on these ICCPR articles in context of albinism in this case from New Zealand: Appeal of AC (Egypt), Immigration and Protection Tribunal, Auckland, New Zealand, [2011] NZIPT 800015, before B.L. Burson [“Appeal Before NZIPT”], see from para 42 onwards, and particularly, para 50.

³⁶ See *Antti Vuolanne v Finland* Communication No 265/1987 U.N. Doc. Supp. No. 40 (A/44/40) at 311 (1989). (7 April 1989), at para 9.3, University of Minnesota Human Rights Library, accessed January 29, 2014, <http://www1.umn.edu/humanrts/undocs/session44/265-1987.htm>, cited and discussed in Appeal Before NZIPT, note 35 at para 52.

³⁷ See OHCHR, *General Comment No 5: Persons with Disabilities* (9 December 1994) E/1995/22, at para 5, UNHCHR, accessed January 29, 2014, <http://www.unhchr.ch/tbs/doc.nsf/0/4b0c449a9ab4ff72c12563ed0054f17d>; and see discussion in Appeal Before NZIPT, note 35, at para 59-60.

³⁸ See *General Comment No 20: Non-discrimination in economic, social and cultural rights* (2 July 2009) E/C.12/GC/20 at para 28 and discussion on it in Appeal Before NZIPT, note 35, at para 59.

³⁹ See article 1 paragraph 3 of the UN Charter and article 1, 2 & 3 of the UN Declaration of Human Rights ; Also relevant components of international instruments at para 30 of the UN Preliminary report at note 16 : the right to life in the ICCPR: Articles 6 paragraph 1 and article 6, paragraph 1 in the Convention on the Rights of the Child(CRC). The right to security of person at article 7 of the ICCPR and article 37(a) of the CRC. Also see the Convention Against Torture.

them to treatment akin to the experience of “Minorities.”⁴⁰ In light of these particularities it is evident that PWA face at minimum, multiple and intersecting forms of discrimination that warrant attention, beginning with proper classification in IHRL.

A Call for Particular Attention in IHRL

The classification of PWA in the context of IHRL is necessary to activate the protection mechanisms that match their unique condition. As previously stated, that unique aspect of albinism consists not only of medical aspects of the condition (skin and eyes) but also the mystification and stigmatization of the totality of their appearance which exacerbates their experience of discrimination. In other words, while PWA themselves have a relatively basic genetic condition, the historical response to their condition has caused multiple forms of discriminations warranting special attention in IHRL. Similar specific attention has been drawn to certain analogous groups such as the elderly, person living with HIV/AIDs, and more recently, the *dalits* or “untouchables” of South Asia.⁴¹ Each of these groups ordinarily have nothing warranting human rights protection beyond general human and related medical needs, yet historically entrenched stigma faced by these groups is the ingredient that has led to their particular status, and protection in IHRL. How much more is this needed for PWA who have for centuries, received next to no attention to their desperate condition? *We flesh out this need for special attention for PWA in Part 3 where we strongly propose that PWA ought to be classified primarily as a specific people group.*

SOME KEY CONSIDERATIONS FOR CLASSIFICATION

All attempts to classify PWA in context of IHRL or elsewhere must take into consideration, at minimum, the following factors:

PWA are Attacked and Shunned Because of their Appearance

While medical experts are able to conclusively identify albinism through an eye test, the average person is able to recognize albinism by appearance. This is particularly the case where the PWA is from a race that is non-white. To date, all recorded attacks against PWA are based on their appearance.⁴²

⁴⁰“Minorities” as defined in the UN Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities (“Declaration on Minorities”). See comments of UN Independent Expert on minority issues below at note 72.

⁴¹ See note 4 at p. 26 and note 5.

⁴² Our experience in the field reveals that most people in communities where there are records of attacks are not aware of the medical impairments of albinism.



Stigma and Discrimination is a Global Phenomenon Grounded in Mystification and Misconceptions about Albinism

PWA face deep stigma across the world. This stigma is often rooted in misconceptions and long-standing mystification about their condition generally and their appearance in particular. The nature and effect of stigma faced by PWA varies from region to region in the world - depending on the effectiveness of domestic human rights law. For example, in North America where protection of human rights has been generally normalized, there are no records of physical attacks against PWA. However, in aspects of life which are often outside the reach of normal legal proceedings, PWA suffer greatly. These include aggressive name calling, persistent teasing amongst peer groups, bullying and the persistent demonizing and ostracizing of PWA in pop culture particularly in literature and in film.⁴³ The effect of these portrayals on the public perception of albinism is high when one considers that these media are the primary source of information about albinism for the general public.

In Sub-Saharan Africa, there are long standing beliefs and errors about albinism, most of which mystify the condition. These include beliefs that PWA are ghosts, that they never die, that sexual intercourse with a PWA can cure HIV/AIDs, and most graphic of all, that the body parts of PWA can bring about wealth and good luck when consumed in potions and worn as amulets. There are also records of routine infanticide committed on PWA across various tribal cultures in the region.⁴⁴

Therefore it remains important that in classifying albinism, one must consider the range of stigma that PWA are exposed to, and that these are well entrenched in various cultures across the world, and must be uprooted.⁴⁵ *One must also seek out a classification of albinism that is not only broadly prospective in terms of preventing future human rights violations, seen and unforeseen, but one that is also retrospective in terms of creating room for correcting past errors of understanding about the condition.*

⁴³ See Garth Mullins & Lisa Hale, "The Imaginary Albino, at note 5. Also see Sara Scott's work at note 24. UTSS also has a compilation of popular movies made in Hollywood.

⁴⁴ UN Preliminary Report at note 16, paras 43-47. Also see "Children with Albinism in Africa: Murder, Mutilation and Violence," report submitted to the Special Representative on Violence against Children (SRSG) Mme. Marta Santos Pais by UTSS (2012), UTSS Resources, accessed February 15, 2014, http://www.underthesamesun.com/sites/default/files/UTSS%20report%20to%20UN%20-%20REPORT_0.pdf. ["Report to the UN SRSG on Violence Against Children"].

⁴⁵ While death of PWA due to their condition has been recorded solely in Sub-Saharan Africa, initial research by Under The Same Sun (UTSS) indicates that infanticide and other types of fatal attacks are also carried out in other countries of Asia but more research is needed. Global stigma in PWA was comprehensively chronicled in "The Imaginary Albino," at note 5.



Harmful Traditional Practices such as Witchcraft are a Reality in the Experience of Tens of Thousands of PWA

It is not possible to speak of the historical and contemporary experience of a significant number of PWA without discussing the issue of witchcraft. This is particularly the case in the region of Sub-Saharan Africa where belief in witchcraft is alive and pervasive. Witchcraft in this sense can be described as an amalgam of natural and supernatural beliefs, philosophies and practices aimed at manipulating nature for the benefit of the practitioner. Some of these practices involve the use of human body parts taken from live victims because it is believed that the screams of victims increases the potency of the potion in which the body parts would be used.⁴⁶

Historians speculate that the practice of, and reverence for witchcraft, has been in the region since antiquity and formed part of the social fabric of many pre-colonial African societies.⁴⁷ The practice appears to have continued in post-colonial Africa under names such as *Muti* and *Juju*, which are common terminologies in the region.⁴⁸ Today, muti and Juju practitioners continue to claim that their practice can provide a cure to disease and misfortune and that they are a channel for wealth, wellbeing and good luck to the end user.⁴⁹ A relatively recent study by the PEW Forum for religious freedom, in 2010, discovered that belief in witchcraft remains influential in a significant number of African countries even though a large number in the same countries also believed in Monotheistic religions that forbid the practice of witchcraft such as Christianity and Islam.⁵⁰

Further Consultation of PWA on a Wide Scale May be Needed

The UN Preliminary report suggested that consultation with PWA may be needed on the issue of self-identification.⁵¹ We have tried to do so, albeit in an informal way, using basic discussions with PWA we have on staff and the hundreds of adults and children with albinism that we have dealt with. However, an argument could be made that classifying PWA using IHRL may require further consultation spanning more PWA so that a more robust or representative solution will result. While useful, the absence of such further consultation should not hinder any current attempt to classify the condition with the goal of protecting PWA from further attack.⁵² This is because the attacks are on-going and are

⁴⁶ See “Killed for Muti” at note **Error! Bookmark not defined.**

⁴⁷ Simeon Mesaki, “Witchcraft and the law in Tanzania,” Department of Sociology and Anthropology, Vol 1(8), (December, 2009): 132-138, available at <http://www.academicjournals.org/ijasa>, at p. 133.

⁴⁸ See “Killed for Muti” at note **Error! Bookmark not defined.**

⁴⁹ See “History of Attacks against Persons with Albinism,” 11 July 2013, UTSS Resources, accessed February 15, 2014, <http://www.underthesamesun.com/sites/default/files/History%20of%20Attacks%20against%20PWA.pdf>.

⁵⁰ See Report to the UN SRSG on Violence Against Children at note 44, at pp 23-24. See original PEW Forum Report at Pew Forum, “Importance of Religion,” (April 15, 2010), accessed February 15, 2014, <http://www.pewforum.org/executive-summary-islam-and-christianity-in-sub-saharan-africa.aspx>.

⁵¹ UN Preliminary Report, at note 16, para 78.

⁵² In a sense, application of the *Convention Relating to the Status of Refugees* (The “Refugee Convention”) 1951 to asylum-seeking PWA has blazed the trail on this point. Examples are provided in the next part.

unlikely to stop during the length of time that such consultation might require – likely years. We suggest a working classification that not only considers the above factors, as these have emerged from informal consultation within the wide scope of our experience, but also one that is flexible enough to encompass other potential points of view. We propose that the main classification suggested, specific people group, meet these goals (see Part 3 for our complete position on this point).



PART 2

SUB-CLASSIFICATIONS OF PWA IN IHRL

There are, at minimum, three **sub-classifications** for PWA in IHRL. They promise some level of understanding and protection for PWA. Yet, as discussed in Part 3, none of them, whether standing alone or taken together, provide the type comprehensive protection contained within and promised by the main classification proposed which is that of a “Specific People Group” requiring particular attention.

Because there is much debate about how each of the three sub-classifications relate to PWA, it is necessary to assess each of them separately for their utility and the ultimate value that they each bring to our goal of protecting PWA.

1. “Particular Social Group”

This classification is a phrase from international refugee law. However, given the close relationship between international refugee law and IHRL, in that the former protects those whose international human rights have been violated, the classification warrants discussion in context of protecting PWA.⁵³

Particular Social Group and PWA

Under the 1951 Refugee Convention, there is often no question that certain groups such as women, tribes or homosexuals from several countries are a particular social group for the purposes of granting them asylum.⁵⁴ These groups are in essence, mainstreamed under the Convention so that applications for asylum on the grounds of their membership in a particular social group are anticipated. Unlike these groups however, PWA are not mainstreamed as a particular social group under this Convention. It tends to come as a surprise to many that in some national jurisdictions, PWA have been granted asylum and other similar residency permits based on their membership in a particular social group. It is not clear whether the surprise is from ignorance of albinism or ignorance surrounding how PWA are treated in certain countries. What seems clear is the necessity of drawing

⁵³ T. Alexander Aleinikoff, “Membership in a Particular Social Group,” Analysis and Proposed Conclusion, Background Paper for “Track Two of the Global Consultations, available at UNHCR, accessed January 28, 2014, <http://www.unhcr.org/3b83b1c54.pdf>, at page 3.

⁵⁴ Aleinikoff, at note 53 and UNHCR, Guidelines on International Protection: “Membership in a Particular Social Group” within the context of Article 1A(2) of the 1951 Convention and/or its 1967 Protocol relating to the Status of Refugees, accessed January 22, 2015, at <http://www.refworld.org/pdfid/3d36f23f4.pdf> at para 6. [“UNHCR Guidelines”].

international attention to this growing trend of PWA being treated as a particular social group; a trend that is likely to grow for many more years, so long as culturally-sanctioned persecution of PWA continue in various countries.

Membership of a particular social group is one of the five grounds enumerated in Article 1A(2) of the Refugee Convention through which refugee status may be determined. It is the ground with the least clarity and it is not defined by the Convention itself.⁵⁵ That said, it is being invoked with increasing frequency in national refugee status determinations.⁵⁶ The UNHCR warns that the category is not a “catch all” otherwise the integrity of the refugee-granting system would be lost. So for example, even though persecution is at the centre of membership in a particular social group, membership cannot be determined exclusively by the fact that a person in the group is being targeted for persecution.⁵⁷ Rather, “a particular social group is a group of persons who share a common characteristic other than their risk of being persecuted, or who are perceived as a group by society. The characteristic will often be one which is innate, unchangeable, or which is otherwise fundamental to human identity, conscience or the exercise of one’s human rights.”⁵⁸ There is no requirement for group members to be cohesive; no requirement that *all* members be at risk and size is not relevant.⁵⁹

PWA fit all elements of this definition. It should be no surprise that several countries have withheld removal of PWA and granted them asylum in light of their membership in a particular social group. While some of these countries have used an emphasis on albinism as an immutable characteristic (the “immutability approach,”) to find PWA in a specific group, others have focused on society’s perception of albinism, (the “social perception” approach), which examines whether the potential members of the group share a common characteristic that renders them a recognizable group apart from society.⁶⁰ In all cases we are aware of, both approaches have been touched at some level. These include the case of withholding of removal and the granting of asylum in the United States, to PWA applicants from Nigeria and Zimbabwe. The granting of asylum to an applicant from the Ivory Coast in Israel, an applicant from Benin in Spain, an applicant from Egypt in New Zealand and several successful asylum cases concerning applicants from Cameroon, Burkina Faso, Guinea, Mali and Senegal.⁶¹ The same approaches are being employed in

⁵⁵ UNHCR Guidelines, note 54 at para 1.

⁵⁶ UNHCR Guidelines, note 54 at para 1.

⁵⁷ UNHCR Guidelines, note 54 at para 2.

⁵⁸ UNHCR Guidelines, note 54 at para 11.

⁵⁹ UNHCR Guidelines, note 54 at paras 8; 15-19. While these definition has been largely used in common law jurisdiction, judicial mention and notice have been taken in civil jurisdiction as well.

⁶⁰ The immutability and social perception approaches are each discussed in the UNHCR Guidelines, note 54 at paras 6-7.

⁶¹ Four more cases were still pending as of November 2013 according to our partner group serving PWA group in France: Genespoir.



preparatory papers for upcoming asylum cases of a Tanzanian and a Senegalese in the US, and a Somali in Germany.⁶²

With this growing trend, it is now fitting that the particular social group status of PWA be recognized as a reality and encouraged as a means of protecting PWA. While membership of a particular social group is largely found in the context of the Refugee Convention, it remains useful not only for the on-going protection of PWA, but also for conceptualizing PWA since it does away with the need for consultation or similar signs of cohesive self-identification.

SUMMARY OF THIS SUB-CLASSIFICATION FOR PROTECTION

| PARTICUALR SOCIAL GROUP | |
|--|---|
| PWA are members of a particular social group because they meet all elements of the definition under the Refugee Convention as interpreted by the UNHCR and national jurisdictions. That definition encompasses both the PWA's immutable characteristics, as well as society's ability to recognize them as a group and target them for persecution. This classification has been recognized by several national jurisdictions. | |
| Advantage | Disadvantage |
| Broad recognition of PWA as a particular social group will cause states to grant asylum more readily to fleeing PWA | This is not a sustainable solution to the persecution and discrimination they face in their country of origin |
| PWA are identified as a group in need of protection with a factual and legal analysis and without the need for consultation that is likely to cost time and money | None |
| Could potentially include PWA that have only ocular albinism particularly in countries where the eye colour of the PWA markedly departs from the norm | None |

⁶² UTSS is providing testimony and other evidentiary support for these cases. It has done the same in several successful cases in the past as well.



2. A “Visible Minority” Group: Albinism as a New Category of “Colour.”

The term “visible minority,” has also been proposed as a means to sub-classify PWA. The phrase appears to have been proposed to UTSS not only because it succinctly describes the circumstances of the PWA as a minority vis-à-vis their race, but also – and more importantly - because it ushers in albinism as a new category of “colour.” Therefore, it captures the issue of the colour-based stigma and discrimination and thus promises them access to anti-racism laws and mechanisms which protect individuals from discrimination based on the colour of their skin. In IHRL some of the most relevant and pertinent documents are The *Durban Declaration and Program of Action* (The “Durban Declaration”) and *the International Convention on the Elimination of all Forms of Racial Discrimination* (“CERD”).

“Visible minority” is technically not defined in IHRL. It is largely specific to Canada, whose government, in measuring employment equity, has used it to classify persons who are not of the white race.⁶³ It is for this reason that the phrase has come under criticism from members of the international community as being inherently racist because it seems to place “whiteness” as the standard while all other non-whites are considered “visible.”⁶⁴ It is important to note that this criticism does not apply to our case. When “visible minority” is used in the context of albinism, the standard is not a particular race but the particular race in which the PWA finds himself or herself. In this sense, no race is placed above any other, since albinism exists in all races. Therefore the racism criticism cannot stand in this instance.

PWA as a Visible Minority facing colourism: an intolerance related to racism.

While vulnerable racial minorities face racism, PWA face stigma and discrimination arising from their colouring. This is known as “colourism:” an intolerance related to racism.⁶⁵ Colourism is a term often used to describe a conventionally accepted bias and discrimination based on skin tone or shade *within* a race. As a result, it is often described

⁶³ This definition can be traced back to the 1984 Report of the Abella Commission on Equality in Employment. The Commission described the phrase “visible minority” as an “ambiguous categorization”, but for practical purposes interpreted it to mean “visibly non-white”: See Frances Woolley, “Visible Minorities: Distinctly Canadian”, Worthwhile Canadian Initiative Blog, May 26, 2013, accessed February 15, 2014, http://worthwhile.typepad.com/worthwhile_canadian_initi/2013/05/visible-minorities-distinctly-canadian.html. Also see Statistics Canada: “Visible Minority Population and Population Group Reference Guide, 2006 Census,” accessed February 15, 2015, http://www12.statcan.ca/census-recensement/2006/ref/rp-guides/visible_minority-minorites_visibles-eng.cfm

⁶⁴ See CanWest News Service, “UN calls Canada racist for ‘visible minorities’ tag”, Canada.com, March 8, 2007, accessed December 20, 2013, <http://www.canada.com/topics/news/national/story.html?id=f469b36e-c587-40e7-98e5-3aa50a371318&k=23802>

⁶⁵ The specific wording is “racism and related intolerance,” see Durban Declaration and Program of Action, accessed December 17, 2013, from http://www.humanrightsvoces.org/assets/attachments/documents/durban_declaration.pdf. [“Durban Declaration”].



as intra-racial skin tone bias. The bias takes all forms: discrimination, stigma and a medium through which privileges are ascribed to, or taken from individuals depending on where they are placed on the skin colour spectrum.⁶⁶

To date, colourism has been largely harnessed in post-colonial studies and has been predominantly used to show the intra-racial preference for white skin or lighter skin tones amongst non-whites. While this background is frequently the context in which colourism is raised, the increasing awareness that lighter-skinned or “white”-skinned persons are not immune to colourism makes the notion of colourism available to PWA.⁶⁷ Further the experience of Caucasian PWA is that colourism affects them as well because they are often considered “far too white” amongst their own race.⁶⁸

In IHRL, colourism could be placed within the category of an intolerance related to racism.⁶⁹ That there are intolerances related to racism is a recognized fact alluded to several times in the Durban Declaration. While not addressing specifically the situation faced by PWA, the Durban Declaration recognizes that racism, ... and *related intolerance* occur on the grounds of race, and colour among others.⁷⁰ The Declaration goes on to note the importance of paying special attention to new manifestations of racism, racial discrimination, xenophobia and related intolerance to which youth and other vulnerable groups might be exposed.⁷¹

That fact that PWA face colourism is an issue that has rarely been spoken about. One of the most helpful statements on the issue so far came from the UN Independent Expert on minority issues who stated that the problems faced by PWA such as stigma, lifelong social exclusion and discrimination, are similar to the experience faced by vulnerable racial minorities *because of their skin colour*.⁷² Further discussion of PWA as a visible minority experiencing colourism remains necessary. It would not only validate their experience of discrimination based on skin tone but would also give them access to appropriate programs emanating from the Durban Declaration and similar structures such as the CERD and

⁶⁶ Linda M. Burton et al., “Critical Race Theories, Colourism, and the Decade’s Research on Families of Colour,” *Journal of Marriage and Family*, 72 (June 2010): 440 – 459, at p.441. Also see Deborah Gabriel, *Colourism in the African Diaspora*, Google Books, accessed December 4, 2013.

For a general view of Colourism, see Ronald Hall, “Opinion: Colorism is the New ‘Ism,’” December 13, 2012, CNN, accessed February 15, 2014, <http://inamerica.blogs.cnn.com/2012/12/13/opinion-colorism-is-the-new-ism/>

⁶⁷ See Burton et al at p.441. Also see Vic Sarin, “Hue: A Matter of Colour,” (2013) a comprehensive documentary on the issue of colourism. A brief resume of this documentary is available at <http://www.imdb.com/title/tt1516545/>.

⁶⁸ See “Hue: A Matter of Colour” at note 67. Also see Sara Scott at note 24, particularly page 505-6.

⁶⁹ Please see brief comment at note 65 above.

⁷⁰ Para 2 of the Durban Declaration. Also see UN Preliminary Report, at note 16, para 82.

⁷¹ See Durban Declaration at para 17.

⁷² See Joint Press Release by UN Rapporteurs at note 7, particularly comments of the UN Independent Expert on Minority Issues.



mechanisms emanating from it which are yet to consider the issue of colour as it relates to PWA.⁷³

SUMMARY OF THIS SUB-CLASSIFICATION FOR PROTECTION

| VISIBLE MINORITY | |
|--|---|
| “Visible minority” is apt for classifying PWA. Not only because albinism occurs in a minority of persons - quantitatively speaking – but more importantly, because of their qualitative experience around colour. Therefore this categorization brings in albinism as a new category of “colour” in IHRL | |
| Advantage | Disadvantage |
| Ushers in a new category of “colour” in current anti-racism law and mechanisms | None |
| Describes albinism totally | Appears to diminish the fact that albinism may occur in forms that may not be visible within a race, e.g. ocular albinism |
| None | Has amassed negative connotations and criticism in the minds of many due to its original use and context |

3. Persons with Disabilities

Disability in IHRL currently centres on human rights. This is known as the human rights approach to disability, as opposed to the previous medical/charity centered approach.⁷⁴

The human rights approach to disability does not define disability but recognizes it as an “evolving concept.”⁷⁵ It however defines persons with disability as “including” persons “who have long-term physical, mental, intellectual or sensory impairments which in

⁷³ See UN Preliminary Report, at note 16, para 80. Also see relevant sections in the CERD. In particular, see Articles 1.1 and 5 of the CERD, available at OHCHR, accessed February 18, 2014, <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CERD.aspx>.

⁷⁴ Arlene S. Kanter, “The Promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities,” 34, *Syracuse J. Int’l L. & Com.* (2006-2007): 287, at p. 291. See also Brian Watermeyer et al., Eds., *Disability and Social Change* (Cape Town: HSRC Press, 2006) which touches on this issue several times.

⁷⁵ See Preamble at para “e” of the *Convention on the Rights of Persons with Disabilities* CRPD, UN, accessed February 20, 2014, <http://www.un.org/disabilities/convention/conventionfull.shtml>



interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”⁷⁶ In essence it considers impairment as separate from a disability. The former being a limitation caused by a physical, sensory or mental impairment and the latter created by the interaction between impairment and barriers in the environment: both structural and attitudinal.⁷⁷ This separation of impairment from disability ultimately puts the onus on a state to cure its environment of those features that disable the person who has impairment.⁷⁸ The key document of the human rights approach to disability in IHRL is the *Convention on the Rights of Persons with Disabilities* (CRPD).

PWA have both a visual and skin impairment which are by and large, a result of albinism. Under the old (medical) approach to disability, the vision impairment has easily caused PWA to be classified as “legally blind” in some countries.⁷⁹ Historically, it has also led to PWA being institutionalized in schools for the blind and consequently considered persons with disabilities. While some countries have ended the institutionalization of persons with disabilities, the practice has continued in several countries where PWA continue to be moved into schools for the blind, where they are taught learn braille, and their vision – low as it might be – remains underutilised.

Some African countries have also tended to refer to PWA as disabled because of their skin’s absence of melanin. The absence of melanin renders PWA highly prone to sun burn which in turn can lead to skin cancer and death if left untreated. There have been no records of fatality due to skin cancer in countries where health education and sun protection cream is accessible to PWA. In Sub-Saharan Africa, skin cancer is the primary killer of PWA and is a major contributing factor to their average life expectancy of 30 to 40 years. It is no surprise then that their skin has been a basis for classifying them as persons with disability in places like Tanzania.⁸⁰ However, this is a rarer approach and most classification of PWA as disabled has come from their vision impairment.⁸¹

Under the new (human rights) approach to disability, PWA are aptly classifiable as persons with disabilities. This human rights approach leads to a finding of disability not only in cases where the PWA’s visual impairment meets social and attitudinal barriers, but also when the PWA’s entire being, namely their appearance, meets the same barriers in society. *Yet, there is the question of whether their entire appearance is an “impairment” per se. Here, take into consideration those PWA who happen to have slight pigmentation and therefore correctable visual levels and reduced susceptibility to skin cancer. Yet because they are visibly albinistic vis-à-vis their community, they remain at risk for attacks just like any PWA. There is also the question of whether a unique group such as PWA who*

⁷⁶ See Preamble at para “e” and also Article 1 of the CRPD at note 75. Also see Dan Goodley, *Disability Studies: An Interdisciplinary Introduction* (London: SAGE Publications Inc., 2011) , p.8.

⁷⁷ Kanter and Watermeyer as cited at note 74. Also see Goodley as cited at note 76.

⁷⁸ Kanter, at note 74, p. 292.

⁷⁹ See UN Preliminary Report, at note 16, para 78.

⁸⁰ The phrase in Swahili is “Ulemavu wa Ngozi.” UTSS is working hard to replace this phrase with “Watu Wenye Albinism” which is the Swahili equivalent of PWA.

⁸¹ See UN Preliminary Report, at note 16, para 78.

are still so early in their mobilization should take cover under the relatively advanced umbrella group of persons with disabilities. Here consider the fact that PWA, due to the totality of their appearance, are often considered sub-human or non-human in several communities. Yet, most persons with disability are considered human first albeit a human with impairment.

PWA themselves seem to be divided on the issue of whether they should be classified as persons with disabilities. Some feel that PWA are so behind in the disability movement that their particular needs will be subsumed and camouflaged by the on-going and relatively advanced needs of other persons with disability. Some reject the term disability due to the stigma that it carries in their societies, and the fact that it would add to their on-going stigma. Others reject it because they do not consider themselves disabled in any way shape or form. Rather, they see their visual impairment simply as an albinistic trait and wish to leave it as-is. Yet, still others do not mind having the label if the result would be getting reasonable accommodation at school and in the workplace.

This apparent divide shows at minimum that this classification of PWA as persons with disabilities, as attractive as it may seem, is not the easiest to apply for the purposes of classification. Despite this, for the sake of those who have embraced it personally or because their states have done so, it still affords a source of protection especially in light of the new (more humanizing) human rights approach to disability. Yet, if the human rights approach is to be effective on a global scale, it needs to be properly understood and entrenched at the national and regional levels particularly in Sub-Saharan Africa. There, the old approach to disability continues to take hold and the application of the new approach is at best sporadic, tentative and misunderstood.⁸²

Further, in our experience and encounter with PWA in developing countries in the Sub-Saharan Africa region, there appears to be a rejection of PWA within the community of persons with disabilities. This is not only due to the controversy of whether PWA are technically “disabled” which seems to be an object of debate in certain countries, but also because, PWA find themselves on the lowest rungs of the ladder in the community of persons with disabilities. We propose that this is attributable to the fact that PWA are relatively recent in the disability rights movement and have therefore had little or no advocacy, the result being a de-prioritization of their needs in the queue of persons demanding their rights. We further note that this rejection in the disability movement is attributable to an unspoken but conventional hierarchy in some societies in which “able-bodied” persons are on top, impaired bodies are at the centre and others considered sub-human or incomplete persons, are at the bottom. It is here, at the bottom of this hierarchy, that PWA are often placed. *As such, unlike persons with disabilities, who are often perceived first as persons and then as persons with disabilities, the starting point for PWA is often not their personhood but the perception that they are sub-human.* While this de-humanizing hierarchy seems to be most apparent in some developing countries, it no doubt

⁸² See *Africa Disability Rights Yearbook*, Vol.1 (2013): Pretoria University Law Press. See in particular . p. 99 and p.367.

lines the consciousness of some in the developed world as evident from common de-humanizing and negative portrayals of the condition.⁸³ As stated by Herman Melville in the great American classic, *Moby Dick* (1851), which is read widely in schools in North America to date:

“What is it about the Albino man that so peculiarly repels and often shocks the eye, as that sometimes he is loathe by his own kith and kin... this mere aspect of all pervading whiteness makes him more strangely hideous than the ugliest abortion. Why should this be so?”⁸⁴

SUMMARY OF THIS SUB-CLASSIFICATION FOR PROTECTION

| PERSONS WITH DISABILITIES | |
|---|--|
| PWA experience various disabilities as a result of the interaction between their visual impairment (and arguably skin impairment) and the structural and attitudinal barriers in their society. | |
| Advantage | Disadvantage |
| The human rights approach to disability seems to cover some key suffering of PWA: structural and attitudinal | There is the risk of reducing albinism to the medical approach to disability. This is because the human rights approach to disability is not universally understood and appears to be an esoteric ideal. Therefore old approaches to disability especially in developing countries continue to be applied. |
| Opportunity for inserting PWA into growing disability-related mechanisms | Inadequate for practical protection from harmful traditional practices (e.g. witchcraft) and other discriminatory practices against PWA e.g. colourism |
| None | Some PWA do not see themselves as experiencing “disability” and want to dissociate themselves from the label as much as possible. This is particularly clear in several African countries where the label of disability is stigmatized and |

⁸³ See notes 3 and 5.

⁸⁴ Ishmael, the book’s narrator, expounds on albinism in people. From Chapter 42, “The Whiteness of the Whale.”



| | |
|------|--|
| | therefore threatens to bring more stigma to the already suffering PWA. |
| None | When compared to most recognized persons with disability, PWA are far behind in their mobilization or movement for human rights. Therefore blending them with persons with disabilities threatens to camouflage their particular needs for special protection regarding some of their unique experiences e.g. harmful traditional practices and colourism. |



PART 3

THE MAIN CLASSIFICATIONS OF PWA IN IHRL

UTSS' Position

UTSS strongly supports the proposition that PWA are:

A specific people group with particular needs that must be given special attention in IHRL (“specific people group”)

This classification is important because it is both broad and yet specific. In terms of its breath, this is evident in the fact that it does not exclude all three sub-classifications discussed above but includes them and further leaves room for other sub-classifications that may be discovered or articulated in the future.

It also captures all types of PWA. It captures those with ocular albinism who have not been captured under “PWA” in this paper but might face discrimination in their respective societies. Further, it captures those who are visibly albinistic, -- that is those PWA who have been the attention of this paper, -- but who do not necessarily fall into all of the three sub-classifications proposed. This is the case with certain PWA in Sub-Saharan Africa, who happen to have slight pigmentation and therefore correctable visual levels and reduced susceptibility to skin cancer. Yet because they are visibly albinistic vis-à-vis their community, they remain at risk for attacks just like any PWA. The broadness of the specific group category will shelter this class of PWA. It also has strong potential to shelter any other particular type of PWA in any other unforeseeable circumstance.

In terms of its specificity, the classification calls for special attention pertaining to the unique issue of global mystification of albinism which has led to stigma and discrimination. It will also be a means of keeping this unique aspect alive and in waiting for other mechanisms that will arise in IHRL. For example mechanisms in the area of harmful traditional practices and others yet unforeseen.



UTSS' POSITION ON THE 3 SUB-CLASSIFICATIONS

UTSS supports all 3 sub-classifications discussed in this paper. It is important to note that each of these groupings, while important, are subordinate to the main classification of PWA as a specific people group. What each of the sub-classifications provides are vehicles for particular types of protection. None of them, whether taken separately or together, can adequately classify PWA. Each must be understood as interrelated sub-parts of the main umbrella classification of specific people group.

UTSS takes the following positions on each of the sub-classifications discussed.

First *UTSS supports the growing finding that PWA are a particular social group.* Not only for the purposes of granting asylum to refugees or withholding removal of PWA to their home country, but also for the purpose of understanding the cross that PWA have to bear. On the vertical angle of that cross is their immutable yet noticeable characteristic appearance. On the horizontal, is society's perception of that immutable characteristic; a characteristic so fundamental to their personhood and yet so grossly mutilated in societal perceptions throughout the world. UTSS wishes to see the phrase "particular social group," as an umbrella term for PWA under which they could be incorporated, not only under the aegis of the Refugee Convention but also outside of it.

Second The phrase, visible minority, is pertinent because it shows that PWA are a minority, quantitatively and qualitatively speaking, who are discriminated against because of their visible appearance and colouring.

While the phrase has come under attack for being racist that criticism does not apply to the issue of albinism as it is a condition that affects all races of the world. In fact, the phrase visible minority is best used for PWA whose visibility is at the crux of the discrimination and stigma they face and whose minority status is genetically fixed across the world both intra and inter racially.

Third, UTSS supports the finding that PWA fall under the grouping of persons with disabilities as contemplated under the human rights approach to disability in the CRPD. This is due to PWA's visual impairment, and arguably, skin impairment if it is so classified. That said, this category is insufficient to protect PWA in light of the multiple and intersecting levels of discrimination they face as caused by the totality of their albinistic appearance, a critical aspect which is not "impairment" per se. Here, take into consideration those PWA who happen to have slight pigmentation and therefore correctable visual levels and reduced susceptibility to skin cancer. Yet because they are visibly albinistic vis-à-vis their community, they remain at risk for attacks just like any PWA. There is also the question of whether a unique group that is so early in its mobilization should be camouflaged under a relatively advanced umbrella group of persons with disabilities.



CONCLUSIONS

Persons with albinism are simply people with a genetic condition causing a noticeable absence of pigment on their person. This pigment deficiency results in impairments causing high vulnerability to skin cancer and legal blindness in nearly all cases.

Yet to live with albinism is not that simple. PWA face the world's response to their overall appearance, often deemed strange, and consequently, mystified and stigmatized. PWA also live in a world historically obsessed with skin colour. In this context, PWA face colourism, bias based on skin colour akin to racism. Further, PWA live in a world of misunderstanding that has not particularly anticipated their impairments as falling under the accepted norms of disability. These issues, amongst others, have complicated an otherwise simple genetic condition.

As a result, PWA face multiple and intersecting forms of discrimination exacerbated by long-term misunderstanding about the condition. The worst form of this discrimination has resulted in physical attacks, of which there are hundreds of recorded cases. It is the horror of these attacks that have triggered recent attention on the issue culminating in 3 international resolutions at the UN and AU. However, to move resolutions into action, there is a necessary preliminary step: to classify PWA with the help of IHRL. The goal of classification is to construct legal vehicles to usher in positive change and protection for PWA.

UTSS strongly supports the classification of specific people group as the most comprehensive and flexible nomenclature for PWA. Such a classification is broad enough to allow several sub-classification which includes, at minimum, the three that have been discussed in this paper: a people constituting of a “particular social group” that ought to find protection under the Refugee Convention; a “visible minority” group that ought to find protection under the Durban Declaration and CERD; and a people with disabilities that ought to find protection through the Convention on the Rights of Persons with Disabilities. The specific people group classification is also broad in the sense that it leaves room for further sub-classifications.

The classification of specific people group is also broadly retrospective because it will make past understandings of the condition more robust by correcting past misconceptions about albinism, and bringing attention to the key issue of mystification of the condition – which is a unique and global issue facing all PWA. It is also prospective because it contains sub-classifications that can immediately usher in protective mechanisms for PWA while leaving room for future mechanisms yet unforeseen.

Due to these superior qualities of the specific people group classification, it remain the default position when dealing with PWA. Other potential sub-classifications, including the three proposed here, should always be considered subordinate to it.



APPENDIX I



Photo courtesy of Rick Guidotti of Positive Exposure: www.positiveexposure.org

APPENDIX II

A Sampling of Names Used for PWA worldwide.
See Catalogue of nearly 200 names from 35 countries at
www.underthesamesun.com/resources

| COUNTRY | LANGUAGE | NAME | MEANING | CATEGORY |
|--|-----------|------------------------------|--|---------------------|
| AFRICA | | | | |
| Botswana | | Mpopi | Doll | Object |
| Cameroon | Bamileke | Mbumbu | A banana that has ripened early | Plant |
| Central African Republic | Sango | Mami Wata | Goddess of the waters | Supernatural |
| Ghana | Dagati | Gbangu | Conceived during mother's menstrual period | Supernatural |
| Guinea | Kissi | Mogbeya | The one to be eliminated | Supernatural |
| Kenya | Kiswahili | Ngurue | Pig | Animal |
| Kenya | Sheng | Dili | Money | Object/Supernatural |
| Malawi | | Napweri | Pigeon pea that has been boiled | Plant |
| Nigeria | Yoruba | Abami Eda | Supernatural creature/creation | Supernatural |
| Nigeria | Hausa | Jambiri | White monkey | Animal |
| South Africa | Zulu | Inkawu | Ape or monkey | Animal |
| Tanzania | Nyiramba | Tyu | White monster | Animal |
| Tanzani | | Sope | Cursed whitish ghost-like creature | Supernatural |
| Togo | | Kpaja | A witchcraft charm/fetish | Supernatural |
| AUSTRALIA & OCEANIA | | | | |
| Australia | English | | Casper the ghost | Supernatural |
| Australia | English | | Abominable Snow woman | Supernatural |
| CARIBBEAN & CENTRAL AMERICA | | | | |
| Haiti | French | La diable en personne | The Devil in person | Supernatural |

| | | | | |
|----------------------|----------|-----------------------------|-------------------|---------------------------|
| Panama | Dulagaya | Ibegwa | Child of the moon | Supernatural |
| NORTH AMERICA | | | | |
| Canada | English | | Revolting | Scorned/mock ed person |
| Canada | English | | Freak | Scorned/mock ed person |
| EUROPE | | | | |
| France | French | Mouton | Sheep | Animal |
| France | French | Cachet d'aspirin | Aspirin tablet | Object |
| France | French | Coton-tige | Q-tip | Object |
| SOUTH AMERICA | | | | |
| Equador | Spanish | Mayonesa | mayonnaise | Object |



APPENDIX III

ABOUT UNDER THE SAME SUN

Under The Same Sun (UTSS) exists to promote, via advocacy and education, the wellbeing of persons often marginalized and misunderstood. Specifically, we focus on those who are disadvantaged by disability and/or poverty. *At UTSS, we are driven by the belief that all persons have intrinsic value as each is created in God's Image. Accordingly, we also believe that all persons are worthy of love, respect and, above all, dignity.* UTSS supports causes globally that meet these objectives and are approved by the Board of Directors. UTSS' efforts are focused on ending discrimination against PWA globally.

The team in our Tanzania office is composed of 2 well-staffed departments:

1. **Education Scholarship Fund (ESF).** This is the UTSS flagship, offering education grants to keen and dedicated students with albinism demonstrating a need for financial or other schooling assistance. Beneficiaries are grantees for primary, secondary and all levels of higher learning up to PhD levels. Note that due to the attacks on PWA in Tanzania, hundreds of children were herded into government boarding schools throughout the country for "safe keeping." The extreme overcrowding and poor living conditions in these schools compelled UTSS to relocate hundreds of these "displaced children" into higher quality private boarding schools. The ESF program also covers the costs of the medical services for sick grantees and ensures that they get protective gear including sunscreen lotion and low vision devices. There are currently over 300 PWA in our ESF program.
2. **Advocacy and Public Awareness (APA)** deals with public education on albinism. It disseminates information on health and offers truths about albinism to diffuse existing myths that often lead to discrimination and stigma used by witchdoctors and their clients to justify killings of PWA. APA uses media to educate and advocate both nationally and internationally. It informs and educates the public on human rights violations by investigating, collecting and publishing data about the atrocities against PWA. There is also a strong emphasis on the domestic understanding of albinism with simple, de-mythologizing messages about human dignity and respect. We also focus on simple genetic / medical explanations along with easy ways to live with and care for the condition.

INTERNATIONAL

UTSS contributed to the first report on albinism published by the OHCHR in September 2013. We have also participated extensively in the advocacy leading up to the first and second resolution on albinism adopted by the HRC. Further, our advocacy contributed to the adoption of the first resolution on albinism adopted by the African Commission on



Human and Peoples' Rights. We have also provided expert testimony at various governmental and non-governmental committees, organizations, as well as tribunals and courts of several national jurisdictions.

LOCATIONS

UTSS has 2 offices, 26 staff and 2 interns; **fourteen are Persons with Albinism (PWA)**.

- **Our office in Vancouver, B.C., Canada**, has a total of 3 full-time and 5 part-time staff; **four are PWA**.
- **Our office in Dar es Salaam, Tanzania**, has a total of 18 full-time staff plus 2 interns; all are Tanzanian citizens; **ten are PWA**.



www.underthesamesun.com

