

Demystifying Albinism:
An analysis of legal, social, and cultural practices in the Lake
Victoria Region

Giorgio Caviglia

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Supervisor: Lone Lindholt
Southern Denmark University

Abstract

Albinism, in the Lake Victoria region, presents an interesting case of combined medical and sociological concerns in a particularly degraded environment with profound human rights implications. This research aims to review and synthesize the situation through the collection of data and by addressing the phenomena considering the conceptual framework from both a medical and sociological point of view. It will continue by considering which legal framework is the most feasible in the protection of people with albinism's rights. I will center around four countries, Burundi, Kenya, Tanzania and Uganda, focusing on the relationship between disabilities and witchcraft related to albinism. An examination of successful practices within the countries and an analysis of developing albino societies in the region will bring me to analyze the conceptual paradigms on disability and refer to them for the classification of attitudes towards albinism.

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Acronyms

ASF	Albinos Sans Frontiers
ASK	Albino Society of Kenya
CAT	Convention Against Torture
CCPR	Covenant on Civil and Political Rights
CERD	Convention on the Elimination of all form of Racial Discrimination
CEDAW	Convention to Eliminate all forms of Discrimination Against Women
CRPD	Convention on the Rights of Persons with Disabilities
CWA	Children with Albinism
KACSU	Kenya Albino Child Support Program
ICCPR	International Covenant on Civil and Political Rights
ICESR	International Covenant on Economic, Social and Cultural Rights
NOAH	National Organization for Albinism and Hypo Pigmentation
OP	Optional Protocol
PWA	Person with Albinism
TAS	Tanzanian Albino Society
UAA	Uganda Albinos Association
UDHR	Universal Declaration of Human Rights
UNV	United Nations Volunteer
UTTS	Under The Same Sun (Tanzanian NGO)

This research uses the term ‘Persons With Albinism (PWAs)’ rather than the term ‘Albino(s)’ which has been labeled as demeaning and offensive by various quarters of the community of PWAs for failing to appreciate their humanity first before the condition.

Gasper Elikana

Hunted like elephants for ivory tusks gorillas poached for heads and hands
who benefits from feeding this ignorance? Entrenched in superstitions and myths
a hereditary condition becomes a magical creature, beheaded. Ten year old boy or not,
sun blistered. Nearly blind... One leg hacked off awake. Heart pumping fear. Such
violence. Such agony. Alive.

Do you hear me? Hacked alive. Bleeding out... With no way but to stand out
An albino in Tanzania dismembered... Worth \$75,000. And ignorance about you
has always been well fed...

Introduction

In recent times international attention has been drawn to East Africa regarding the persecution and murder of people affected by albinism (PWA) for witchcraft purposes. Reports of brutal killings and body part trafficking have been released since 2006 highlighting the marginalized situations of PWA. The main recognized threats are social stigma (leading to prejudice and discrimination), gender based violence, harvesting of body organs for witchcraft, lack of medical attention, discrimination regarding employment and in the education system. Albinism, in the Lake Victoria area, presents an interesting case of combined medical and sociological concerns in a particularly degraded environment with profound human rights implications.

This research aims to take stock of the situation reviewing, collecting data and addressing the phenomena from a human rights perspective. In the first part of the research I will analyze the conceptual framework from a medical and sociological point of view focusing, then, on which legal framework best protect PWA. Most of the challenges will come from the domestic body of rules and the involvement of non-derogable human rights. In fact, the definition of PWA itself is problematic: they are neither a race nor a minority characterized by different languages or traditions; e.g. albinism is a medical condition which cannot be addressed under minority rights or anti-racist frameworks.

The best protection might be including them in the group of people with disabilities (PWD). Burundi, Kenya, Tanzania and Uganda recently signed the Convention on the Rights of Persons with Disabilities (CRPD) and of those three recently ratified it. Nonetheless a discordance exists between international and domestic theories, which prevents the recognition of albinism as a disability in some cases.

Besides the groups classification, another grave challenge in the marginalization of PWA exists. Witchcraft practices are responsible of one of the most alarming violations of fundamental human rights in Africa. Witchdoctors and the persecutions of PWA are strictly linked, yet difficult to quantify or qualify. Tanzania and Burundi are the countries most affected in the whole continent: I will therefore analyze the accuracy of

such data and why these countries have such a sad supremacy. The governments and the civil societies of the area have reacted differently to the peak of murdered PWA in 2008, developing different strategies, focusing on different aspects and achieving different results.

This will allow, in the second part of my research, the consideration of the country context, through a thorough analysis of four different nations: Tanzania, Uganda, Kenya and Burundi. Each paragraph will focus on the violations of PWA rights in the country, analyze the domestic legal framework and compare the government and the NGOs policies and projects. My essential questions are as follows: how does the state protect this marginalized minority? In which frame can we better protect PWA rights? An examination of the most successful practices within the countries and an analysis of the developing PWA' movement in the area will allow me to answer the above-mentioned questions.

The third part of the research focuses on the new paradigm of the concept of disability that has shifted from an old exclusive medical model to a social model. This “*revolution*”, raised in the 60's in Europe and North America, would greatly benefit the debate regarding human rights and PWA in Africa. Nonetheless this new encompassing concept has only been partially acknowledged and included in the domestic framework of the states of the area. The push for the inclusion of the new paradigm is led by the PWA associations of the countries which demand for a smoother integration and recognition. Nonetheless different political approaches and priorities lead to very differentiated outcomes.

The conclusion will address the most relevant aspects of the research: great results have been achieved in relatively few years despite the escalation of violence towards PWA in some countries. Nonetheless several aspects raise concerns: the lack of official census and statistics, the lack of coordination between the countries of the area and the difficulties on mainstreaming the PWA emergency are just few of the conclusions that I will draw.

Methodology

Evaluations will be carried out by contacting the local policy makers, NGOs and academics. At the primary stage of the research I will focus on publications and reports, providing both an emic and ethic view of PWA situation and environment. I will then focus on the international and domestic framework on defense of PWA based on legal documents. Concerning the data, all the information have been checked with locals NGOs working on the field: there are not hard information but the degree of certainty is various depending from the country analyzed. It is also worth noting that the majority of the documents come from American university: European scholars did not have a great focus on this topic.

Tanzanian government and local NGOs pushed society to achieved marked progress in the protection and empowerment of people affected by albinism: relevant material and analysis can be found from online documentation, contacting government officials and through numerous lobbies advocating for the rights of PWA in the country. The Tanzanian parliament enacted the “Persons with Disabilities Act” in 2010.¹

Burundi, Uganda and Kenya present a different profile. The first country saw a spill-over effect of the “albino killing phenomena” which has been partially addressed under a practical point of view (police escorting, enhancement of PWA communities) but disappointed under the legal point of view: as today laws in protection of disables and more in particular PWA are lacking. Uganda and Kenya ratified the CPRD² and they have a legal domestic framework on disabilities (Kenya Disability Act of 2003 and Uganda Disability Act of 2006). Nonetheless PWA is not properly addressed since not included or not legally fitting within “certain parameters”. The little information available has being in this case further investigated through correspondence and interviews with local academics, members of the government and NGOs.

¹ Enacted by Parliament in April 2010 and assented by the President of the United Republic of Tanzania on 20th May 2010.

² Both the countries signed the 30-3-2007 and ratified the year after.

1- The conceptual framework.

PWA might be object of discrimination in today's society without distinction between developed and developing countries. A prejudicial treatment of an individual based on the perceived membership involves exclusion and restriction of one group of person from opportunities that are available to another group.³ Prejudices and marginalization are still the day-by-day challenge, which a PWA face because they are “*different*” from the rest of the population. In this chapter I will describe the medical point of view, the stereotypes which PWA stand in everyday life, the sociological point of view and finally the international legal framework. This will lead me to identify two different tracks of my analysis: a disability track and a witchcraft track.

PWA mainly suffers from skin diseases and visions problems. Though these are not a matter of concern in the most developed countries, they arise, as more of an issue, in cases poor health care is the norm and where a hot climate is prevalent. In the case of African PWA, for example, the sub-Saharan countries' sun is the main cause of skin cancer.⁴ The lack of a basic knowledge regarding sun protection leads to a very low life expectancy, third-five years old, which could be lengthened by clothing like hats and sun creams.⁵ The situation is similar concerning the low vision problems characteristics of PWA: what can be corrected by glasses in a developed country, can become a serious disability in a developing one.

Under the sociological point of view, stereotypes and disbelief are still today the real cause of the marginalization and discrimination of PWA, all over the world. Marginalization is especially high among children and women, the most vulnerable part of society. The civil pressure is more pronounced in poor societies in Africa and America where ancestral beliefs play a major role in the construction of stereotypes. In particular marginalization is higher concerning the concession of shelter, availability of education, inclusion, discrimination within public administration and marginalization from the community. The social stigma is far reaching, and it differs markedly and is therefore difficult to analyze and address. Often myths and misconceptions are deep

³ W. W. Norton, 2009, p. 334.

⁴ McLeod, 2010, p. 6.

⁵ Wynter, 2010, p. 8.

rooted in the community leading to very fragmented situations difficult to understand and confront. The list can be long ranging from stereotypes as “an albino will eat you up!” said to the children in Uganda⁶ to the sadly famous killing phenomena experienced in Tanzania and Burundi. In other community a child with albinism (CWA) is considered a demon or a curse, inflicted upon the family for something “bad” done in the past, or a ghost who can be eliminated; since he is not even considered a human being in case of murder, he just vanish.⁷

The policies on inclusion and protection of PWA are temporally and substantially differentiated among continents. In Europe and north America albinism is nowadays saw as a normal congenital condition which does not affect the normal life of the persons.⁸ During the last century the majority of the countries have enhanced the quality of the protection working hard on inclusion and non-discrimination. Developing countries for the most part have been delayed due to cultural differences and lack of budget and they present a variegated situation that it will be addressed properly in the next chapter. Globalization and international awareness are putting pressure on respecting certain standards and better protecting PWA. Among other things, the fulfillment and protection of human rights is in direct ratio to the level of freedom and democracy present in the country. Peter Ash⁹ believes that the big steps forward made in Tanzania in the last 5 years are directly linked to the Freedom of Press rank of the country which is 34th worldwide and 5th in Africa.¹⁰ Good practices, awareness and proper funding narrow the current gap present between North and South.

⁶ Allen, 2010, p.7.

⁷ RCN, 2011, p. 28.

⁸ NOAH, 2010, p.1.

⁹ Phone interview with Peter Ash, CEO of Under The Same Sun, 27/04/2012.

¹⁰ Reporters Without Border 2011/2012.

1.1 A medical point of view

Albinism is an inherited genetic condition that reduces the amount of melanin in the skin, in the hairs and/or the eyes. There are different types of albinism with different rates of incidence depending from geography and type of disorder. Approximately only one out of 17.000 peoples is affected by albinism; the occurrence can also be as high as one in 3.000 in Africa.¹¹ Most persons with albinism (PWA) are born to parents with normally pigmented hair and skin, since the albinism gene is recessive. Albinism occurs in every human ethnic group and all the animal species and it is considered one of the most common genetic disorders in the world.¹²

People with albinism always have vision problems. Their eyes can, in some cases, tend towards the color red, but also the abnormal development of the retina and the nerve connections between the brain and the eye can cause vision problem. Often low vision and astigmatism are not correctable with eyeglasses and tend to worsen with the age. This is one of the reasons why PWA may be considered “legally blind” even if they are able to read, bike or even drive a car. The low vision is caused by lack of melamine during the early ages of formation of the retina and the iris.¹³

The iris is transparent and it does not stop the light from outside which normally enters only through the pupil. This causes photophobia. In the retina the absence of melamine stop the development of the *fovea centralis*, responsible for sharp central vision, which is necessary for any activity where visual detail is of primary importance¹⁴ (reading, watching, driving...). Neural connection's imperfection determines difficulties on recognizing multidimensional objects. Often PWA has also nystagmus, an involuntary horizontal eye movement acquired in infancy, or strabismus, both of which contributes to some negative myths in sub-Saharan Africa. The gravity and the entity of the disability differ from the quantity of pigment present during the development of the eye.

¹¹ Alum & al, 2009, p.2.

¹² Abide 8, p. 1.

¹³ Ibidem 8, p. 5.

¹⁴ IFRC, 2009, p. 7.

In addition to visual impairment, some types of albinism¹⁵ can experience problems regarding blood coagulation and hearing.

PWA are more sensitive to glare, since their eyes are weaker. Sunglasses or tinted contact lenses help with sensitivity outdoors. Various optical aids are available on the market nowadays such as glasses, lenses, hand-held magnifiers or special small telescopes.

Genetics of albinism

Albinism can affect persons differently: when involves eyes, hair and skin it is referred to as Oculocutaneous albinism (OCA). When instead it involves the same body parts but similarly or slightly lighter than that of other family members is called Ocular albinism (OA), which is much less common. The Oculocutaneous albinism, following the most recent analysis of DNA, can be divided in four parts: OCA1, OCA2, OCA3 and OCA4. OCA1 (tyrosine-related albinism) is a genetic defect in an enzyme (tyrosine), which is responsible of the change of the amino acid¹⁶ tyrosine into pigment. This, in turn, is subdivided in two subtypes: in OCA1A, where the enzyme is completely inactive and no melanin is produced, leading to white hair and very light skin; in OCA1B, instead the enzyme is partly active causing blond, light skin and some more pigmentation in the skin.

OCA2 (P gene albinism) results from a defect in the P protein that concurs with the tyrosine enzyme to create pigmentation. Individuals with OCA2 are close to OCA1B condition having hair color ranging from very light blond to brown and light skin. OCA3 is less common and depends from a genetic defect in TYRP1, a protein related to tyrosine. The pigmentation tends to be normal. Finally OCA4 results from a genetic defect in the SLC45A2 protein involved in the function of the tyrosine enzyme as well. The pathology is really similar to OCA2.¹⁷ Recent research finds out that several others less common pathologies can affect PWA: for example the dysfunction Hermansky-

¹⁵ Less incident in PWA.

¹⁶ An amino acid is a “building block” of protein.

¹⁷ Ibidem 8, p.2.

Pudlak Syndrome (HPS). HPS sometimes can be associated with chronic hemorrhages and bruising or lung and bowel disease.¹⁸

As said before, the most common type of albinism (Oculocutaneous albinism, involving skin, hair and eyes) is autosomal recessive. Autosomes are the chromosomes that contain genes for our general body characteristics. One type of albinism (ocular albinism, which basically involves only the eyes) is X-linked recessive.¹⁹

In every cell of our body (except the reproductive cells, i.e. sperm and egg cells), there are 23 pairs of chromosomes: 22 pairs, equal in both sexes, are called independent, 2 pairs, different in the two sexes (2 X chromosomes in female, one X chromosome and one Y chromosome in males) are called sex chromosomes. The chromosomes are "structures" that carry information necessary for the construction and operation of our body, i.e. the genes, from many hundreds to thousands of genes per chromosome. Each pair of independent genes brings one gene of maternal origin and one of paternal origin (provided respectively by the egg cell and the sperm that come together at the time of conception). As for the sex chromosomes, the female will have two copies of chromosome X, and the male will have only one gene X and one Y chromosome.

Since Oculocutaneous albinism is autosomal recessive, PWA must have both the parents manifesting the condition (recessive). If one of two parents is normal, the disorder does not occur: the person, male or female, is a healthy carrier. The healthy carrier is able to produce a sufficient amount of pigment. When both parents carry the defective gene (and neither parent has albinism) there is a one in four chance that the baby will be born with albinism. This type of inheritance is called "autosomal recessive" inheritance. The ocular albinism is recessive X-linked: the faulty gene that causes it is localized on chromosome X (X linked) and there must be two copies of the faulty gene (recessive) in the female while just one in the male. Male having only one chromosome X suffer more often of the disorder. Ocular albinism mainly affects males who inherit the X from the mother and then, possibly, a copy of the defective gene. The mother is usually a healthy

¹⁸ Oh & others, 1998, p. 597.

¹⁹ Ibidem 8, p.3.

carrier that carries a defective copy of the gene on one X and one normal copy of the gene on the other X. Therefore almost all of the people with OA1 are males.²⁰

It is impossible for the couples that never had a child with albinism to determine if they are healthy carrier. Even if a DNA analysis is possible, the defective gene responsible of the albinism can be in different pieces of the DNA making impossible to determine if the child will have albinism. If instead the parents had a child with albinism previously, through an amniocentesis test or a chorionic villous sampling (CVS) is possible to examine the present of an albinism gene.²¹

As written above, basically no different health problems prevent a PWA from having a normal life if vision correction and skin protection occur: precautions and modern medicine technology allow PWA to have a life that does not differ greatly from the rest of the population. The reduction or absence of melamine in the skin, hair or eyes does not affect other parts of the body.

²⁰ Ibidem 8, p.5.

²¹ The American College of Medical Genetics and the National Society of Genetic Counselors in its internet site remember how PWA “usually adapt quite well to their disabilities and lead very fulfilling lives.”

1.2 A sociological point of view

Many albino animals lose their natural ability to camouflage and have weak vision, which is a challenge in nature just as humans are challenged in society. Women and men are differently affected by albinism: in the north part of the world there is a lower percentage of PWA that rise progressively getting closer to the equator. As seen above, several populations in Central America and Center Africa exhibit heightened susceptibility to albinism, usually small and isolated community or islands. An example can be the Native American Kuna of Panama and Zuni nations of New Mexico;²² also in Japan and India albinism is relatively common. In other cases the concentration of PWA can also be caused by external factors: Ukerewe Island in lake Victoria in Africa is a perfect example since the concentration of PWA is the result of the deportation of the previous centuries, creating a sort of sanctuary for PWA in a region where they are strongly persecuted.²³

Several PWA are well integrated and they do not face any marginalization at all enjoying a life that does not differ from the life of others human beings. It is not unusual found famous singers, models or politicians all over the world: e.g. the singers Salif Keita from Mali or Johny Winter from United States or the model Connie Chiu from China. In different cultures PWA can enjoy a special status: Cuna Indians believe that a PWA will have a better place in heaven and every person must make friends with eight PWA during his life. *“They are considered to be special charges of God, particularly free of sin, and the only Cuna Indians able to scare off the demon who devours the sun and moon during eclipses”*.²⁴

Unfortunately PWA face negative stereotypes in our everyday life even today. The societal prejudice and discrimination can be easily found among children or on implicit behaviors and derogatory labels, more often where PWA are a consistent composition of

²² Woolf Charles, 1962, p391. “PWA are so noticeable in a population of dark-skinned individuals that the number with this disorder is relatively easy to obtain for small or moderately sized populations.”

²³ Howden Daniel, 2008, p. 2.

²⁴ Ibidem 22, p. 377 citing Scout 1947.

the society.

Another interesting phenomena is named by some anthropologists “*evil albino*” plot or “*albino bias*”.²⁵ In several movies a PWA play the role of the antagonist of the main character of the movie, clearly using the color of the skin as a recognizable pattern for the audience. The character is usually stereotyped exacerbating some visual characteristics (pale skin, white hair and red eyes), leaving out the low-vision. The National Organization for Albinism and Hypo pigmentation (NOAH) released a document in 2005 underlining how in a total of sixty-eight films from 1960 to 2006 there was an “*evil albino*” character.²⁶

While sociologically and medically speaking PWA have almost no problems in the most developed countries, the situation differs slightly in countries that lack education, have strong sun exposures and weak democracies. Often those countries lack of reliable data, making really difficult, if not impossible, to analyze and understand the entity of the problem.²⁷

²⁵ Skyema, 2008, p.1 Hollywood's unwritten rules for characters with albinism

²⁶ Reese Vail, 2005, p.1.

²⁷ Ibidem 6, 2010, p.19.

The international legal framework

The Universal Declaration of Human Rights (UDHR) recognizes all persons should enjoy their rights without being subjected to discrimination. The role of the state and the international community is to ensure such rights. Article 2 of the UDHR provides:

*“Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.”*²⁸

The words “*other status*”, despite a more specific definition can be desirable on a local framework, conveniently provides a comprehensive category which include PWA as well. The UDHR protect “*life, liberty and security of person*”²⁹ against “*cruel, inhumane or degrading treatment*”³⁰. PWA can fit properly also in article 23 and 25 stating “*just and favorable conditions of work*”³¹ 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.*”³²

The enforcement of these universal human rights principles goes beyond the UN system since an International Criminal Court is responsible only for victims of genocide, crimes against humanity and war crimes and not individual human rights violations. Nonetheless countries included the principles of UDHR in their national constitutions, and in their national laws and regulations. Often the UDHR is a powerful instrument to use for public accusations of rights violations bringing the violator to refrain from his misconduct.

²⁸ UN General Assembly, Universal Declaration of Human Rights. Art. 2: resolution adopted by the General Assembly, 10 December 1948, res. 217A(III)

²⁹ UN General Assembly, Universal Declaration of Human Rights. Art. 3: resolution adopted by the General Assembly, 10 December 1948, res. 217A(III)

³⁰ UN General Assembly, Universal Declaration of Human Rights. Art. 5: resolution adopted by the General Assembly, 10 December 1948, res. 217A(III).

³¹ UN General Assembly, Universal Declaration of Human Rights. Art. 23: resolution adopted by the General Assembly, 10 December 1948, res. 217A(III).

³² UN General Assembly, Universal Declaration of Human Rights. Art. 25: resolution adopted by the General Assembly, 10 December 1948, res. 217A(III).

Others powerful instruments in the United Nations system, are that treaties and Charter bodies which can receive individual petitions. Five of the human rights treaties bodies (CCPR, CERD, CAT, CEDAW and CRPD) may, under particular circumstances, consider individual complaints or communications from individuals. The Human Rights Committee and CEDAW may consider individual communications relating to States parties to the OP ICCPR and OP CEDAW; CAT and CERT may consider individual communications relating to the parties who have made the necessary declaration respectively under article 22 of the CAT and 14 of the CERD; the CRPD may consider individual communications relating to States parties to the OP CRPD.

More in the specific, the Optional Protocol to the CRPD is a separate treaty which can be pivotal to enhance protection of PWA establishing a complaints procedure and an inquiry procedure. The OP CRPD is aiming to supplement the CRPD strengthening and promoting its implementation and monitoring. In case of allegations where a State party has violated its obligations under the CRPD and if the complainant has exhausted all available domestic remedies he can appeal to the CRPD body. Instead the inquiry procedure permits to the Committee to start its own inquiries where there is any reliable information suggesting that a State party has violated the convention.

Also the Declaration on Social Progress and Development (DSPD) is committed on condemn the inequality and exploitation of individuals³³ giving special attention to marginalized part of the society. Another special example is the African (Banjul) Charter on Human and People's Rights (ACHPR), because it is the regional document concerning human rights. Following the UDHR article 2, it underlines how all the provisions are recognized and guaranteed without any distinction such as race, ethnic group, color, sex, language, religion, political or "*any other opinion, national and social origin, fortune birth or other status*" while article 4 states "*Human beings are inviolable*". The path followed by the ACHPR is similar to the others regional human

³³ UN General Assembly, Universal Declaration of Human Rights. Art. 25: resolution adopted by the General Assembly, 10 December 1948, res. 217A(III)

rights instruments, without any specific reference to albinism. Albinism can be easily connected to the “*other status*”. Considerable attention has to be paid to the wording of the provisions since listing specific vulnerable groups may leave out or marginalize others groups.³⁴

Also the Banjul Charter, as the OP CRPD, under article 55, mandates the Commission to receive communications other than those of states. It provides:

*“Before each session, the Secretary of the Commission shall make a list of the communications other than those of states parties to the present Charter and transmit them to the members of the Commission, who shall indicate which communications should be considered by the commission. A Communication shall be considered by the commission if a simple majority of its members so decide.”*³⁵

The African Commission first tries to reach a friendly settlement after checking the admissibility.³⁶ It might decide into the merits of the case once the friendly settlement attempt fails. Unluckily the mandate of the African Commission is very weak: besides recommendations to the Assembly of the Heads of States and Government, it does not have any credible enforcement mechanism. Often the Assembly of the Head of States and Government does not pronounce itself after the recommendations³⁷ and the African Commission it has not any follow-up procedure to monitor states’ compliance with its decisions.³⁸

Through the African Court of Human Rights, article 3 gives the mandate to receive individual communications and decide on possible violations of rights. Article 3 (1) provides:

³⁴ Ibidem 6, p. 13.

³⁵ Article 55, Banjul Charter.

³⁶ Article 56 of the Banjul Charter.

³⁷ Nigeria, for example, several times ignored the recommendations and condemns: see e.g. recommendation 87/93.

³⁸ Kidanemariam, 2006, p. 49.

*“The jurisdiction of the African Court shall extend to all cases and disputes submitted to it concerning the interpretation and application of the Banjul Charter, this protocol and any other relevant human rights instruments”*³⁹

Unluckily also in this case there is a very low binding status of the recommendations.⁴⁰

Classifications

The difficulties in finding a clear classification of the groups are clear if we take in consideration PWA. They are not an ethnic group, they do not have another language, and they are not related to any different social or national origin. There is neither any convention clearly addressing albinism, also because the difficulties on find a cluster in which albinism can properly fit in. A list of vulnerable persons is generally including women, children, elderly, migrant workers, and refugees. None of them is clearly related to albinism even if Race, Minority and Disabled are the closer one.

Several studies have hypothesized a better protection of PWA under the anti-racist framework.⁴¹ Racial discrimination is:

*“Any distinction, exclusion, restriction or preference based on race, color, 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 fundamental freedoms in the political, economic, social, cultural or any other field of public life”*⁴²

This definition would work if we do not consider that albinism is not only observable on the skin but it also provokes low vision and occurs within races.

³⁹ Article 3.1 of the African Court of Human Rights.

⁴⁰ Ibidem 37, p. 53.

⁴¹ Ibidem 6, p. 11.

⁴² 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

If we consider PWA as minority, it is definitely a minority in the country but it does not fit the *International Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities* of 1992. Francesco Capotorti, Special Rapporteur of the United Nations Sub-Commission on Prevention of Discrimination and Protection of Minorities, in *Study on the Rights of Persons*, defined minority 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.”*⁴³

The emphasis on institutions such as language and culture does not consider at all the fact that a PWA shares the language and culture of the majority and often it is relegated and cast away from his/her environment which he/she belong.⁴⁴ Furthermore if we analyze Article 27 of the ICCPR minorities are only “*ethnic, religious and linguistic*”,⁴⁵ as we can also infer from the title of the convention: “Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities.”⁴⁶

Besides Minority Rights Group International (MRGI), in March 2011, gave the Minority Voices Young Journalist Award to Roman Stanek, a freelance journalist, on a nice article on Tanzanian PWA, MRGI did not find any legal room to include PWA as a truly and protected minority. Moreover albinism, being also a medical condition further complicates the inclusion.

The most compatible group passes through the international definition of “disabled.”

⁴³ E/CN.4/Sub.2/384/Rev.1, para. 568.

⁴⁴ Religion, Culture are language are almost always the same. Art. 27 ICCPR “In those States in which ethnic, religious or linguistic minorities exist, persons belonging to such minorities shall not be denied the right, in community with the other members of their group, to enjoy their own culture, to profess and practice their own religion, or to use their own language.”

⁴⁵ UN General Assembly. Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities. Art 27.

⁴⁶ A/RES/47/135

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.”*⁴⁷

Under this framework albinism can be the object of a campaign focus on raising awareness about the importance of article 5 (equality and non-discrimination), article 10 (right to life), article 14 (liberty and security of person), and article 15 (freedom from torture) as a way of protecting the rights of PWA from severe rights violations (ritual sacrifice, killing, etc.).

Two states out of four ratified the CRPD and the OP CRPD, Burundi signed both of them but it did not ratify them. Kenya signed and ratified only the convention. The OP CRPD includes both the inquiry procedure, as well as a complaints procedure to make sure the CRPD is actually enforced. The CRPD state clearly some inviolable rights of PWD, therefore applicable to PWA as well.

⁴⁷ Preamble CRPD, section E.

1.3 Addressing Albinism as a Disability

On the 13th December 2006 the General Assembly of the United Nations adopted the Convention on the Rights of Persons with Disabilities which opened for signature on the 30th of March 2007. The CRPD is finally enhancing the rights of one of the largest and most marginalized minority in the world.⁴⁸ The first convention of the new millennium has been characterized by the highest level of participation of representatives of the civil society following the motto of “*nothing about us without us*”. Moreover it followed a drafting and ratification process that was incredibly fast considering that 153 countries already signed the convention (110 ratifications) and 93 signed the Optional Protocol (63 ratifications). The Convention and its Optional Protocol entered into force on 3 May 2008, after receiving its 20th ratification (the Optional Protocol, instead, only 10 ratifications).

Parties to the Convention committed themselves to promote, protect, and ensure the whole body of human rights by persons with impairments and ensure non-discrimination and equality under the law. The CRPD is made up of a Preamble and 50 articles; its Optional Protocol (hereafter OP) include 18 Article aimed to receive the complaints of individual and enforce the Convention.⁴⁹ While the OP follows the model of the Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women, the CRPD is “*the densest exposition of human rights by the UN to date*”.⁵⁰ As a consequence this is also the first Convention containing descriptive titles for each article to summarize the provision.

The CRPD has a long preamble of 25 paragraphs without binding legal obligations but containing many elements useful for a correct interpretation of the text. Even if the drafting of the Convention has been one of the fastest ever registered in the history of

⁴⁸ UN estimates there are 650 millions of persons with disability worldwide. See note 6 as well.

⁴⁹ OP Article 1: “A State Party to the present Protocol (“State Party”) recognizes the competence of the Committee on the Rights of Persons with Disabilities (“the Committee”) to receive and consider communications from or on behalf of individuals or groups of individuals subject to its jurisdiction who claim to be victims of a violation by that State Party of the provisions of the Convention”

⁵⁰ Kayess Rosemary and Phillip French, 22.

the United Nations some issues have been unresolved like the definition of “disability.” Most of the states and the vast majority of the NGOs lobbied for a convention inclusive to all persons with disabilities. Western states refused this interpretation concerned that this would have open the “*Pandora box*” of the domestic implementation of the CRPD for a very diversified group of persons with impairment (persons with HIV/AIDS, asthma or mood disorders among others). The minimalistic attitude of the European states in particular seems to remember the same opposition the European Union had relating the creation of a new Convention of some years before, new burden to fulfill in the domestic arena.⁵¹ At the same time some important NGOs, like International Disability Caucus (IDC), opposed a written definition of disables since it did not want to crystalize an evolving concept, varied between societies, running the risk of time-locking the concept. At the end Article 1 of the CRPD states:

*“The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”*⁵²

Important is to note the adjective “*long*” underlining how, at the end, “*the boundaries of the categories of persons to benefits from the CRPD will be determined domestically, potentially depriving some impairment groups of human rights protection.*”⁵³ At the same time also the adjective “*long-term*” has to be seen as a consequence of the oppositions to inclusiveness of the people with impairments.

Nonetheless the CRPD brought to some level a revolution that can be summarized on the eight guiding principles of Article 3. The guiding principles are enlightening the

⁵¹ Mexico and the Latin American states have been the promoter of the new convention, for a long time opposed by Western countries. See note 4, 17.

⁵² CRPD, art 1.

⁵³ Schnoebelen, 2009, p. 24.

core concepts of the Convention which is not formally creating any new rights. The eight principles can be summarize with key-concepts as dignity and self-determination (art 3.a), non-discrimination (3.b), inclusion and participation in the society (3.c), respect for difference (3.d), equality of opportunity (3.e), accessibility (3.f), equality between men and women (3.g), respect for the evolving capacities of children with disabilities and their identities (3.f).⁵⁴ Non-discrimination, the new right of accessibility and the right to reasonable accommodation are innovative concepts recognized formally in a UN treaty for the first time. The concept of self-determination, the right to personal integrity, and legal capacity with informed consent and political participation are the others new inclusive rights addressed.

These characteristics are the core of the CRPD, but there is space also for some concepts reformulating and amplifying the enforcement of some revolutionary provisions. In particular some “new” group rights like the right to research and development,⁵⁵ awareness raising,⁵⁶ social protection and poverty reduction,⁵⁷ international cooperation.⁵⁸ Not only third generation rights are included but also some fourth generation rights like accessible environment⁵⁹ and even fifth generation like right to leisure, tourism and recreation.⁶⁰

The Convention is therefore a big step to ensure the rights of disables but it still has dark spots that would be in need of clarifications: the contemporary conceptual confusion between impairment and disability,⁶¹ confusing the characteristics of the impairment and the right of the state to intervene or approaching the drafting of some articles (like art. 23 CRPD) in a misleading way.⁶² From an implementation perspective, civil and political rights are subject to immediate realizations and through the OP

⁵⁴Preamble CRPD.

⁵⁵ CRPD, art. 4.1 (f-g).

⁵⁶ CRPD, art.8.

⁵⁷ CRPD, art.28.2 (b).

⁵⁸ CRPD, art 32. It recalls art. 45, CRC. It enforces the new concepts of third generations rights.

⁵⁹ CRPD art.3(f) and art.9.

⁶⁰ CRPD art.30.

⁶¹ Ibid note 53, p. 21.

⁶² Ibid note 53, p. 22.

individuals and groups of individuals can claim against the violation of their rights where they have exhausted the domestic remedies.⁶³ At the same time the big “*margin of application*” allowing discretion at the domestic level is showing the weakness and the strong point of the CRPD.

The Africa Union includes provision in defense of people with disabilities in its main treaty, the African Charter on Human and People’s Rights, protecting them from non-discrimination and enhancing equality. The enforcement of the international provision and subsequently of the CRPD is at the domestic level, and only some countries have ratified it. Today out of 36 countries in Sub-Saharan Africa, 16 countries have signed and ratified the CRPD,⁶⁴ 11 have just signed or request the accession⁶⁵ and 19 are still non-party to it.⁶⁶

⁶³ CRPD OP art.1.

⁶⁴ United Nations Treaty Collection: Belize, Burkina, Cape Verde, Ethiopia, Gabon, Guinea, Kenya, Malawi, Mali, Niger, Nigeria, Senegal, South Africa, Uganda, Tanzania and Zambia.

⁶⁵ United Nations Treaty Collection: Benin, Burundi, Cameroon, Comoro, Congo, Cote d’Ivoire, Central Africa, Guyana, Lesotho, Rwanda.

⁶⁶ United Nations Treaty Collection: Angola, Botswana, Chad, Republic of Congo, Equatorial Guinea, Eritrea, Gambia, Ghana, Guinea-Bissau, Lesotho, Liberia, Mauritania, Mozambique, Namibia, Sierra Leone, Somalia, South Sudan, Togo, Zimbabwe.

1.4 Addressing Witchcraft Phenomena

Parallel to international and domestic legal framework aimed to better include and protect PWA, another aspect is predominant if we want to fully address albinism in Africa. A paragraph has to be dedicated to the witchcraft phenomena since it plays an important role on traditional healing and magic potion which are often harmful, in different ways, to PWA. The term witchcraft denotes a set of magical practices and rituals, often of symbolic nature. The term over the centuries has taken several positive or negative implications depending on the point of view of the authors who have treated the subject. It can be found in a large number of societies through the history and the continents with very different characteristics. Monotheistic religions witchcraft was labeled in a derogatory way, with the belief that the witch was trying to dominate and use it for own occult powers. In paganism, or neo-paganism, witchcraft was re-evaluated and used to indicate those ancient practices (mainly rural), which survived the advent of monotheism.⁶⁷

Witchcraft and the persecution of accused witches continue nowadays around the globe. *“Unexpected hardship or bad luck, sudden and incurable diseases, all can be accounted to the actions of evil people, to magical forces...the diagnosis of witchcraft opens up the possibility of combating the causes of hardship.”*⁶⁸ This gives us the real entity of the phenomena: witchcraft is real for those who believe in it and it has real consequences for those living in an environment where it is practiced. The simple belief is not a problem unless *“the actions taken in consequence of [the] belief,”* violate human rights standards.⁶⁹ While the violations in Africa (and historically in the world) were usually concerning the persecutions of accused witches, regarding PWA, the situation is different.⁷⁰

The killing of PWA in the whole sub-Saharan continent is based on occult practices

⁶⁷ See Stregheria or the Feri Tradition.

⁶⁸ Behringer, 2004, p. 23.

⁶⁹ Haar, 2007, p. 9.

⁷⁰ Ibidem 53, p. 2.

which are today still taboo.⁷¹ Only through the collaboration of activists and NGO and the collection of various fragmented sources online it has been possible to a further understand of the PWA attacks.

Today, I counted more than 100 murders since 2008 that can be related to witchcraft. PWA body parts are used in making of charms by traditional witch doctors. One of the most important “*ingredient*” are hair, genitals, limbs, breasts, fingers, or the tongue. The beliefs are similar within the area: the blood has magical properties which brings prosperity and luck. The fingers are perfect amulets and are worn on necklaces around people’s necks. The skin is prized to catch more fish or to find gold in mines. With the bones you can create love potions. It is said that sex with a girl with albinism can save you from AIDS (resulting in raping and the infection of the PWA with HIV).⁷² Victims have been left to die after having their limbs hacked off. Several PWA have been saved but remain paraplegic. Several died hours after the attack left in some ditch in the countryside.⁷³

The market for body parts lead men to attempt an attack based on the fact that a PWA can be worth US\$250,000.⁷⁴ Often the offenders are friends or even relatives.⁷⁵ Each component has a different price for a different magic potion: for example blood is one of the more valuable ones, but also “*a leg or an arm can fetch between US\$1,000 and US\$3,000 — big money in a country where the annual average income is just \$800*”.⁷⁶ PWA are in danger even after death. Their graves are hidden and made of concrete since the body parts are a powerful call to grave robbers.⁷⁷

Several studies have been carried out to understand why this is a recent phenomena:

⁷¹ Often informal conversation with Tanzanian or Burundi colleagues came to an end when I explained what I was researching. Even if locals have a degree and a good job in Europe speak about *albinos* and traditional healer is making them uncomfortable, and suddenly taciturn.

⁷² Ibidem 53, p. 24.

⁷³ Ibidem 45, p. 2.

⁷⁴ Ibidem 9.

⁷⁵ Cases of fathers selling his CWA are not uncommon.

⁷⁶ Ibidem 11, p. 11.

⁷⁷ Nicwame, 2012, p. 17.

despite the suspicion of infanticide, there are no reports of PWA killing in the traditions and history of this area. Following Pascal,⁷⁸ Swahili language often calls a white man “*Mtasha*.” This is the causative form, of “*kutaka*” (to want or to desire), applied to a person. *Mtasha* is linked to “*the one who causes me to want*.” White persons are associated to wealth and high quality of life and therefore subject of envy. Summarizing the studies of Pascal, bones are the hidden and most vital part of a human body having the capacity to attract the wealth so “*characterizing*” white westerners.⁷⁹

A more effective thesis linked the killing of over three thousand suspected witches between 1970 and 1988, of which 80% were women. The area concerned is a Sukuma region of Shinyanga and Mwanza in Tanzania, exactly where the peak of PWA killing has been registered between 2008 and 2010. In a first analysis seems the society needed a different scapegoat and in connection with the old traditions operated a transposition targeting the PWA. The use of body parts in preparation of magic potions have been reported since 1951 in Usukuma, a region with poor western monotheistic traditions.⁸⁰ Similar activities have been proved in Singida in the 1940s and in Utete about the same time.⁸¹ The whole area concerned have the same language, Bantu, and live in a very disperse area.

Through an educated deduction the situation can be analyzed as followed. The region experienced a long colonial period during which the colonial forces dragged out resources and focused mainly on cotton plantations. Independence did not produce great improvements in their standards of living and corruption and poor maintenance made water supply and infrastructures a chimera rather than a reliable service. Urbanization destroyed the old structures of villages of the region, abolishing the figures of the chiefs and their symbolic roles.⁸²

⁷⁸ Pascal, 2009, p.10.

⁷⁹ Isaac Mwaura, vice-president of KAS, consider this is one of the main reasons of the attacks. Often prices in the market are higher for PWA compared to others clients.

⁸⁰ Tanner, 2010, p. 229.

⁸¹ Ibidem 80, p. 229.

⁸² Tanner, 1970, p. 35.

Furthermore, from a purely anthropological point of view, it is important to consider that the societies have few occasions in which an event is clearly understood through a system of cause and effect. A farmer bitten by a snake will likely blame the fate rather than the fact that he paid poor attention. The connection between two identifiable and isolated events to cause a third is often difficult to draw. For example whatever can be analyzed under a scientific point of view, as it could be the virus of HIV, will be more easily connected to the malevolence of an ancestor or a neighbor. The doctor have to *fight* for his affirmation against traditional healer, whereas a traditional healer can call to a supernatural *will* relying on his personal and institutionalized charisma.

“Many studies have shown that people’s general ideas, which they get from their cultural backgrounds and socialization, lead them to make illusory correlations”. If we analyze the situation as outsiders we might find that no connections possible, even if locals find out unequivocal links which leave no doubts on the correlations between two facts. Due to the various factors at hand it becomes difficult to prove what causes various thoughts, beliefs, and actions within society. The killing of witches, before, and PWA, more recently, seem similar: *“the fact that this is scientifically impossible is socially irrelevant in these distressing circumstances”*.⁸³ The rituals are so deeply rooted that even in Mwanza hospital an officer is escorting doctors in charge of blood collection to prevent violence and assaults. The same escorting happens for some body parts extracted in medical operations.⁸⁴

Following the idea that something believed true become real in its consequences, we can better understand the PWA emergency in East Africa. Through an emic point of view the gruesome killing of PWA does not differ from disbeliefs in others populations, including the western countries. Today there are more studies published on astrology than psychology, and monotheistic religion has been an explanations for the inexplicable for centuries, as it could be to HIV which still today is not visible and full

⁸³ Ibidem 80, 231.

⁸⁴ Ibidem 80, 232.

comprehensible.⁸⁵

This is why the killings are not pursued by “*isolated malevolent individuals*” but they are actions of groups of men and women which have been using these rituals for a long time and they see in their use economic opportunities “*permitted*” or not “*deeply opposed*” by the majority of the society.⁸⁶

These gruesome practices have been brought to the attention of the media thanks to undercover reports and private NGO's founded mainly by rich western PWA: the Malian Salif Ketia Foundation or the Tanzanian Under The Same Sun (UTSS) of Peter Ash is pivotal to understanding why and how some international media like BBC, Al Jazeera or CNN started to report the brutal killings. Mainly thanks to journalists such as Vicky Ntetema⁸⁷ or Richard Mgamba⁸⁸, the veil has been disheveled and the first data started to circulate. Despite the fact that the information is often unreliable,⁸⁹ some trends can be analyzed more deeply in the next chapter.

⁸⁵ Concerning the killing the “western cultures” are responsible of Holocausts and massive deportations and killing, as to say: point of view.

⁸⁶ Ibidem 80, p. 235.

⁸⁷ Ntetema, 2008, p. 1.

⁸⁸ Mgamba was awarded the Lorenzo Natali Journalism Prize for Africa for his coverage of the Great Lakes albino emergency.

⁸⁹ After the first approach I was confused since some articles were speaking about 400.000 PWA in Tanzania and others reporting 10.000. No official census or government report, make the readers really confused.

2- The country context – empirical, examples.

Lake Victoria borders three countries: Uganda, Tanzania and Kenya. A fourth country can be added if we consider the Great Lakes region: Burundi. The four countries are part of the EAC – the East African Community and they represent an area of 1.791.610 km² with an estimated population of 112.382.167 inhabitants.⁹⁰

The lack of reliable data, due to a weak bureaucratic apparatus, makes the estimation of PWA living in the area aleatory. They could reach the 12.000 people if we take in consideration of an incidence of 1 PWA every 10.000 people or 113.000 if we consider the estimation done in 2010 by the Kenya Albino Child Support Program, that is 1 PWA every 1.000 people.⁹¹ Compared to the more extensive group of PWD, in which they belong, they account for almost the 5% of the total population, which means, for example, 1.7 million PWD in Kenya alone. Because of the small dimension of the PWA, compared to PWD, albinism has been for several years relegated to a secondary role, often not even recognized as a disability.⁹² Two of the four countries saw a violent and macabre escalation on persecution of PWA. Kenya and Uganda, instead, have been only partially affected but they still experience problems on integration and non-discrimination of its population affected by albinism. Albinism in the horn of Africa is an issue of human rights. PWA in the area have been discriminated and often persecuted. Besides the famous killing phenomena, they still face denial of equal access to health care, employment, education, political participation, as well as being subjected to violations of dignity. Often they are regarded as legally incompetent because of their disabilities.

The most alarming and evident human rights violation is that the first police report is not until the end of 2006. Tanzania, a state with a strong and independent media service, started releasing and investigating the killing and assaults only then. Difficulties in collecting data are the main challenge in conducting research. Attacks with machete characterize the zone around the Lake Victoria, making it really difficult not only to find the perpetrators but even the victims. Still today, in a political framework that is paying

⁹⁰ CIA World Fact Book.

⁹¹ Kenya Albino Child Support Program (KACSU) estimations.

⁹² Nyong'o, 2012, p. 2.

much attention to the persecution of PWA, the data often lack of pivotal information like gender or age.⁹³ Often NGOs are the only institutions to collect statistics and many crimes are not denounced. In the Mwanza and Shinyanga regions of Tanzania, the police reports are fragmented for different reasons. Often the attaches are not denounced because the family is involved.⁹⁴ This situation often forces PWA or relatives of CWA to escape from the villages. The community oppression is so severe that often mother and CWA are cast away from the village and become an easy prey for PWA hunters.⁹⁵ Thousands of PWA are unable to move for fear of attack.⁹⁶ Investigations of local journalist and NGOs found out that even policemen can be involved in the trafficking, having, therefore, no interest in investigating the crime.⁹⁷

The killing phenomenon as a graph shows a curve that had the peak in 2008 increasing and decreasing following pivotal events. The demand of magical potions and PWA body parts increased during elections, long dry periods and economic recession to decline noticeably after. In some countries major societal changes can be seen by the numbers of attacks. This is the case of Tanzania with the shift from a series of nation-wide centralized economic plans (Ujamaa) to the open market. Before that only the chief of the tribes had enough power to ask witchdoctors for human sacrifices. Old rituals have been blended with more recent phenomena: a clarifying example can be the small-scale miners. They used to find gold in superficial mines. Today they must drill 400meters deep to find some gold or Tanzanite stones.⁹⁸

The small scale miners face an impossible challenge: globalization. After the economic shift of the country, large-scale mining factories literally invaded the area excluding and revolutionizing the precarious social balance of the population. The lack of education of locals does the rest: rather than investing in technology and skills, many turn to

⁹³ UTSS has the most complete data on PWA killing in East Africa. Nonetheless often the age and the gender of the victims is unknown.

⁹⁴ Email of Don Sawatzky, Director of Operations – Canada, Under The Same Sun (UTSS), 29-04-2012.

⁹⁵ Ibidem 94.

⁹⁶ Ibidem 5, p. 5.

⁹⁷ Ibidem 6, p.8.

⁹⁸ Mgamba, 2009, p. 3.

witchdoctors.⁹⁹ The situation of the fishermen on the Lake Victoria is quite similar. Over-fishing and environmental degradation has leaded the fishermen to address witchdoctors in the hopes of fuller nets.¹⁰⁰ Despite current crisis hitting harder than in other places, no magic potion seems to resolve the poor quality of life of the population on the lake: the declining Nile-Perch catch is sent daily to Europe and Asia leaving only the bones for the population.¹⁰¹

Reading the last report “*Witchcraft allegations, refugee protection and human rights: a review of the evidence*” released on 2009 by the UNHCR¹⁰² we can basically reverse the analysis for the horn of Africa: witches being persecuted become the tool to persecute PWA and make them the new scapegoat. “*Witchcraft accusations have been explained as a consequence of rapid cultural or social change. Witch hunts are “at once reflective of and an agent of sociocultural change.”*”¹⁰³ Events like “*ecological changes (i.e., climatic, floral, and faunal changes), natural cataclysms (epidemics, famine, catastrophic storms, floods, and earthquakes), wars, and internal conflicts (caused by economic, political and intellectual revivals and declines)*” contribute to sociocultural distortion that leads to cultural disorganization. At this stage, ‘*witchcraft,*’ ‘*communist plots,*’ and the like are viable (and sometimes the only) explanations of misfortune (especially in situations where traditional coping mechanisms have been lost or rendered ineffective).¹⁰⁴

After the first official shift of the Tanzanian government towards protection of the PWA community the phenomena saw the involvement of neighboring countries. Burundi and Kenya were particularly affected, where, despite the strong stereotypes on PWA, no PWA body hunters were reported before 2008. In Burundi, a small country related to Tanzania, the police was able to gather and even census the PWA thanks the

⁹⁹ Ibidem 98, p. 4.

¹⁰⁰ Ibidem 98, p. 3. To better understand the environment it can be useful watch the documentary *The Darwin's nightmare* directed by Hubert Sauper.

¹⁰¹ Ibidem 100.

¹⁰² Ibidem 53.

¹⁰³ Ibidem 53, p. 4.

¹⁰⁴ Ibidem 53, p. 4.

commitment of the European Union and a Belgian NGO.¹⁰⁵ PWA now live in secure urban location with police patrolling twenty-four hours a day. Tanzania also reinforced the protection of PWA, appointing the first PWA deputy to the Parliament, escorting CWA to school, developing campaign and raising awareness. In September 2009 the first PWA hunters were prosecuted and, for the first time for these kinds of crimes, were sentenced to hanging for murdering a young boy.¹⁰⁶ In Kenya the body part trafficking that seemed to peak in 2009 has been brought under control by law enforcement. Uganda, another state lying on Victoria Lake, seems not affected by the persecution. Unluckily as the Tanzania office director of the UTSS reported in early June: “*albinism-related killings of PWA continue without being reported.*”¹⁰⁷

¹⁰⁵ “RCN Justice & Démocratie is an international NGO based in Belgium. They work to contribute to guarantee respect of fundamental rights recognized by international conventions, especially the right of fair justice. In Burundi, the work of RCN Justice & Démocratie is done through radio documentaries, theatres and capacity building sessions focused on justice, human rights protection and democratic practices. They operate in the central provinces of Gitega, Ruyigi, Muramvya and Mwaro.”

¹⁰⁶ Marealla, 2009, p. 2.

¹⁰⁷ Vichy Ntetema official statement after the last PWA killing on 13-06-2012 founded after three months. No one in the community denounced the missing.

2.1 The Persecution: Overview on Data¹⁰⁸

Africa presents a unique situation since the main obstacles PWA face to full enjoy a normal life involves both medical complications and a strong social reproach. The persecution and misbelief have deep roots in ancient Africa. The World Health Organization (WHO) found that the prevalent form of albinism is Oculocutaneous albinism (OCA) with an autosomal recessive inheritance.¹⁰⁹ This implies a hypo pigmentation of the skin, hair and eyes due to a reduced or lack of coetaneous melanin pigment production. Consequently PWA in Africa have sandy hair, white chalky skin and light brown or blue eyes: all characteristics that make them more susceptible to the effects of ultraviolet radiation. The visual difference between PWA and “*black*” citizens made them an easy target.

Anthropologists consider the social stigma a phenomenon that has affected PWA for centuries. The African continent, excluding the north along the Mediterranean Sea, experienced several kinds of persecution. Few records are available for a simple reason: often PWA were killed at birth or kept hidden from the community to better protect them. Unfortunately not all the data we have today are accurate. The WHO Studies Findings¹¹⁰ stated a higher density of PWA in urban areas: this is due to various factors. First at all the higher population density in cities compared to rural areas is an obvious data; in addition the study was school-based and therefore we must consider the attendance of the children.¹¹¹ A PWA’s family in a city has more opportunities to enroll in a school and officially register within society compared to those that live in rural areas. The quality of the education also affects the analysis: a school lacking commodities for visually disabled or without a policy towards PWA (for example no UV protection of the children, without Braille language or magnifiers...) is less attractive.¹¹² The economic status of the family plays a role as well since often only a

¹⁰⁸Ibidem 33.

¹⁰⁹Hong & others, 2006, p. 6.

¹¹⁰Ibidem 28, p. 8.

¹¹¹Ibidem 28, p. 8.

¹¹²Kacsu project of action 2012 is addressing mainly this problem.

limited number of children can join a school. In those countries without any school fee the expenditure can be, anyway, relevant if the family is poor and there are obligations for uniforms, books or the school is far from the village.¹¹³ Usually the family, considering the shorter life expectancy of a CWA, chooses another son for what is considered an onerous investment.¹¹⁴ In this way the CWA is often not denounced and therefore not counted.¹¹⁵

PWA are not only considered good luck charms, but are regarded by the some as immortal, able to see eternity, possessing supernatural powers, because even with all the facial features typical of sub-Saharan populations, these people are blonde with white skin.¹¹⁶ Years of drought affecting the land of these countries, is due not so much to lack of rain (being an area within the tropics), but often it is related to the lack of knowledge and techniques of extensive crops. In response of difficult times PWA suddenly becomes demi-gods and are buried in their own fields to make it fertile;¹¹⁷

The problems in Africa are not only within the community but also within the family. Parents that gave birth to a child with albinism (CWA), an anathema to the whole family and the tribe, think that God has cursed them: very often the decision is to cast the child from community. It is not uncommon that the bloodiest attacks on PWA happen in the countryside, or at the border of the village where mother and child have been relegated.¹¹⁸ Isolated from the community and their families, life is not easy, with additional medical complications given the risks of skin cancer since the strong sunlight literally burns their sensitive skin.

To better contextualize the phenomena, one must consider the African continent where several emergencies overlap each other making really difficult to mainstream one emergency over the others. This is why starting only in the late 1990's we can register a

¹¹³ Kacsu report 2012.

¹¹⁴ Ibidem 109, p. 10.

¹¹⁵ Data courtesy of director of operations of UTSS and findings through the articles published on internet.

¹¹⁶ See annex for a list of myths.

¹¹⁷ See chapter 3.

¹¹⁸ Ibidem 115.

rise in awareness. Documentary and movies have been released internationally and locally,¹¹⁹ the radio played a big role in reaching the most disperse communities,¹²⁰ and, in some cases, even the religion has been used to teach universal values such as brotherhood, equality and respect of the life and dignity of PWA.¹²¹

Several albino societies have been created for the empowerment and protection of PWA. For example the Zimbabwe Albino Association (ZAA) serve 14.000 registered PWA, creating citadels where PWA are treated by the trauma suffered ranging from the simple expulsion of the village, to amputation to the many rapes of women. Others countries are also moving quickly to enhance PWA rights in various regards ranging from education to inclusion. Tanzania in 2010 appointed a PWA member of the national parliament, Barwany Salum Khalfan,¹²² in the effort to stop the killing and improve the conditions of the local PWA population.

Improvements and efforts are not only at institutional level; several NGOs and as well as civil society such as the South African one, are active in raising awareness by trying to educate and convince civil society to understand what albinism really is.¹²³ Unluckily it is not enough. Some countries are involved in long term civil wars or they are just recovering from recent political unrest; in Somalia, Sudan and South Sudan despite being geographically close to areas like Kenya and Uganda there are no reports available on PWA: face similar challenges of PWA of the lake Victoria area. The lack of data, statistics and funding, as usual in Africa, prevents a clear picture of the situation.

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Giving a fast overview only few countries have official data available on the killing phenomena. Sensitivity and engagement of the civil society have been pivotal in

¹¹⁹ The spell of Albinos, Crimes of Colours, Murder & Myth amongs others.

¹²⁰ Above all in Burundi as stated in RCN, 2011, p. 36.

¹²¹ Catholic missions in Tanzania developed plans of inclusions of PWA in some regions of the country. See, e.g., Missionaries of Africa (formerly known as the White Fathers). See also note 57.

¹²² Ipost, 2010, p. 1.

¹²³ Ibidem 69, p. 18.

¹²⁴ Odula, 2009, p. 1.

achieving reports and denounce. A part the focus on the countries of the Lake Victoria region several others countries have reports on killing. *Namibia* stands out with 30 official reports while *Swaziland* account for only 3 reports, the most recent of which is an attempted killing which took place in April 2011. In *Guinea* and *Nigeria* both experienced 2 killing, the first country in September 2010, Nigeria in March 2011. *South Africa*, 2 reports, the *Democratic Republic of Congo (DRC)* and *Zambia*, 1 report each one.

Countries like Namibia experienced 30 killings, neighbors countries only one. The collaboration of the civil society should be pivotal to achieve more denounces and better address the problem. Once more we have to remember that the common belief reduces PWA to ghosts, magical beings or curses, etc. making them a really vulnerable group. Don Sawatzky, Director of Operations of Under The Same Sun (UTSS)- Canada “*We know that PWA have been kidnapped, mutilated and killed by fellow citizens (sometimes family members “friends” or neighbors) for the purpose of witchcraft related rituals.*” Murders or “*medicine*” killings have a deep, longstanding history, and are a familiar concept to most Africans. On rare occasion the discrimination is reversed and the PWA are “*deified*” into “*gods*”. Either way, they rarely get to enjoy their status as normal human beings. Many countries have stories about the mysterious disappearance of PWA. *There is a growing, documented truth to these rumors*”¹²⁵ which have been confirmed by the interviews I carried out during the research.¹²⁶

Map number 1 in the annexes includes countries where no data on PWA are reported.¹²⁷ I considered the available data and inserted a list of suspected countries. Among the criteria considered are the form of government, the last publication of “*reporter without borders*”,¹²⁸ the index on poverty and corruption released by the United Nations, and a HIV-AIDS analysis released by WHO. The freedom and independence of the press is

¹²⁵ Interview with Don Sawatzky, Director of Operations of Under The Same Sun (UTSS)- Canada on 04-2012.

¹²⁶ See the Interviews ‘section in the annexes.

¹²⁷ See Map number 1 in the Annex.

¹²⁸ Report senza frontiere 2011-2012

necessary to receive the acknowledgment of the internal situation in the country. The poverty line, and therefore the social tension in the country and the distribution of the HIV epidemic let me guess the probability of hidden cases that would require deeper analysis. In addition I carried out online research on local newspapers, often without any results.

Applying merely those simple criteria, out of 49 sub-Saharan states, 4 of them had numerous cases of PWA assaults,¹²⁹ 7 countries had few cases,¹³⁰ while the other 23 countries have no data but violence towards PWA is likely.

Countries like Sierra Leone, Somalia, Sudan and South Sudan are experiencing extended periods of political unrest. In these conditions it is really difficult to have information regarding such a specific issue. Besides that, several indexes are similar to countries having a high numbers of attacks on PWA. Several countries are characterized as at risk based on the criteria listed above: Mozambique, for example despite the impressive economic recovery, is among the world's 20 poorest countries, ranking 175 out of 179 countries on the 2008 Human Development Index. About half of the adult population lives in poverty. The freedom of the press is sufficient (66th) but there are about 1.6 million people living with HIV and AIDS. About 350.000 children have lost their parents to AIDS-related illnesses.¹³¹ More over the country has some controversial cases: in 2010 parents of a PWA were arrested while trying to sell their child.¹³² Each country categorized as suspected, even if it does not have official reports or documents, was included in the map. I included every country where low index, alleged violence and human sacrifices tradition were the norm.

The same hypothesis can be made for countries such as the Democratic Republic of Congo and Zambia: the few public cases are all unofficial data, both of them reported

¹²⁹ Tanzania 103, Namibia 30, Burundi 18 and Kenya 10.

¹³⁰ Swaziland 5, Nigeria 2, South Africa 2, Guinea 2, Ghana 2, the Democratic Republic of Congo 1 and Zaire 1.

¹³¹ Mozambique at a glance – UNICEF report 2012.

¹³² Agencia de Informacao de Mocambique - Mozambique: Guebuza Receives Albino Association

by NGOs. In conclusion, the phenomenon is probably more variegated and complex than the reported isolated cases. Often cases of harassment, violence, and even murders are not denounced.

As seen in the Great Lakes area, it is evident that borders are not a real barrier: the differences between the countries on the Lake Victoria bordering Tanzania are not dissimilar from Tanzania itself. This is even clearer where there are old traditions of witchcraft and a less widespread distribution of traditional monotheistic religions. In areas where Christians or Muslims are the majority the incidence of the attacks are much lower. Where animism is still present and the old structure of the society did not change greatly in the last 40 years more attacks have been reported, such as in the Lake Victoria region.

It is then worth noting how countries with high number of cases, like Tanzania, Kenya and Namibia are characterized by stable multi-party parliamentary democracy, relatively low percentage of population below the poverty line and long periods of peace (>20 years). Tanzania and Namibia have a great independence and freedom of press compared to the others countries, even on level with some European nations (e.g. UK, France, Italy) leading to transparency and, therefore, a commitment to addressing the various problems of the country. The lack of freedom of press in Kampala and Bujumbura show opposite results. Uganda lists 139 and Burundi 130 out of 179 countries. The small amount of information available is being threatened by new repression in the countries: Uganda lost 43 positions in a year. The freedom of press and public information is the main challenge of the persecution of PWA.

Countries that have higher quality of life have more reported cases most likely based on the fact that it takes a level of importance since there are less competing factors such as civil unrest. The role of free press and successful government is of primary importance. The role of NGO and INGO concur too: Burundi is an example. Today, despite the low index, Bujumbura carried out the first censuses on PWA in Africa and developed several initiatives in defense of people with albinism thanks the efforts of the international

community. Unfortunately the mainstreaming of other African emergencies and the lack of funding do not allow the international community to create a clear picture of the situation despite the fact that the emergency is widespread over the sub-Saharan continent.

Tanzania, Burundi, Kenya and Uganda have different situations and different legal enforcement. I analyzed the PWA situation in the country, the data available, the legal framework of human rights and the government and NGOs actions.

2.2 Tanzania

The country

The name "Tanzania" is a portmanteau created by the merger of "Tanganyika" (name of the trust that corresponds to the British mainland Tanzania) and "Zanzibar". It was adopted when the two entities merged in 1964. In 2009 the estimated population was about 38,329,000 inhabitants, with an annual growth rate of around 2 percent.¹³³ The distribution of the population is very heterogeneous, with densities ranging from 1 person per square kilometer in arid regions, to 51 per square kilometer highland humid, up to 134 per square kilometer island of Zanzibar. Nearly 80 percent of the population is living in the rural part of the country.¹³⁴

The population consists of more than 120 different ethnic groups, of which the Sukuma, the Nyamwezi, the Hehe-Bena, the Gogo, the Haya, the Makonde, the Chagga and the Nyakyusa compose at least 1 million people each one.

PWA in Tanzania

Tanzania is paying a high price to the fight against prejudice and misbelieves against PWA: at today 78 persons with albinism have been killed in the country.¹³⁵ Moreover there are 102 reports of assaults to PWA denounced, which means ranging from violent assaults where arms or legs can be chopped off to physically less important attacks, like cutting the hair, which may psychologically be an emergency as well. This brings to focus more on the killing of PWA rather than policies of inclusion. Deeply rooted in the traditional culture PWA has been marginalized for centuries besides the poor historical data available. Infanticide and the perception of PWA as "zeru-zeru", mzungu or ghosts are not enough to explain how strongly marginalized the group is in the country.

Sentiments are opposed: from one side Tanzania suffers the worst stigma about PWA, but also it has been the first country clearly addressing the problem not only under a charity or paternalistic point of view. Human sacrifices and fetization of body parts have a deep story in tribal life in the country: for a long time the disbelief brought the

¹³³ Ibidem 90.

¹³⁴ Ibidem 90.

¹³⁵ See Map number 2 in the annexes.

family itself to sell their own child for money or cast away from the family and the community the CWA with the mother. The disbelief is differentiated and might involve not only the PWA which is consider a ghost, a lucky charm for his/her body parts or a cure for HIV but also to the mother, which could be accused to have slept with a white man, made something evil or against nature. Eventually towards the whole community as well which can be afraid of a curse for some particular reason. The spell of PWA for a long time, despite been macabre and gruesome, has been completely unknown and without any remarkable reaction in the local communities. It is indicative of the situation in the country consider that the few data available on albinism have not been collected more than 5 years ago.¹³⁶

The entity of the phenomena is difficult to understand considering that until 2006 not even the police was prosecuting the assaults to PWA. Rosemary Mathayo (a 16 years girl), Pracseda Mathayo (14) and Focus Mathayo (4 years boy) were 3 PWA children from the same family who were poisoned and died on the same day in Kagera Region in 2000. This report is based on Mr. Mathayo (the fathers') testimony to UTSS on April 28, 2011. The deaths were reported to police at the time of their occurrence but it appears that the Tanzanian police department did not begin to document the attacks and killing of PWA until 2006,¹³⁷ precisely only after newspaper investigations.¹³⁸ The government and the police, often accused of being involved or being covering some killing had to stand front the international public opinion and address the phenomena.¹³⁹

Two journalists in particular carried out two different investigations disclosing the horrendous trade of PWA body parts and several gruesome rituals. Going undercover and passing through numerous life threats, Vicky Ntetema of BBC news¹⁴⁰ and Richard Mgamba of Aljazera¹⁴¹ find out, in two different reportages, the thick net of which-

¹³⁶Thanks a private NGO, the UTSS.

¹³⁷Ibidem 125.

¹³⁸Ibidem 87, p. 1.

¹³⁹Ibidem 11, p. 24.

¹⁴⁰Ibidem 87.

¹⁴¹Ibidem 88.

doctors, clients and hunters. Through the free press of Tanzania,¹⁴² police and NGOs investigations came out that clients profile is variegated, ranging from miners and fishermen near the Lake Victoria to chief, businessman and politicians in search of a reelection when getting closer to the capital. Starting from the first official police report of 2006 the government had been forced to get involved and address the problem. Today the reports can be defined the most reliable, even if still incomplete, of the whole continent.¹⁴³

Therefore some trend can be analyzed: the persecution of PWA is stronger in the rural area and the percentage of the attacks raise getting closer to the great lakes area. Despite no data collection on age and gender I can reasonably state that women and children are more targeted than men. Following the studies of Edward Miguel¹⁴⁴ focused on popular belief of witchcraft in Tanzania I can draw a parallelism: the relation poverty-witch killing and the climate seems working also for the persecution of PWA. The author used rainfall variation to estimate the impact of income shocks on murder in rural Tanzania. The findings show that there is a link between extremely rainfall and the witch killing at least during the early years of the century. *“More important, an income shock is a causing factor for violent crime, and religious violence to be specific. He arrives to the conclusion that weathers pawns witch killing in Tanzania.”*¹⁴⁵ The situation is really similar if we take in consideration miners and fishermen of the Lake Victoria: the common base is the poor education and the crisis which the *“clients”* are undergoing. The mine are exploited by new international companies leaving the locals with few instruments and exhausted mines on the superficial level: the need of deeper mining, the scarce education and the few instruments available for the locals make the poor miners victims of people without conscience which send them to invest the few money left on magic (and harmful) potions rather than serious projects of excavations.¹⁴⁶ The environmental degradation of the lake brings the Tanzanian fishermen to a similar

¹⁴² Ibidem 9.

¹⁴³ Ibidem 9.

¹⁴⁴ Edward, 2004.

¹⁴⁵ Boniface Makulilo, 2010.

¹⁴⁶ Ibidem 88.

behavior. The area of the lake has strong history of occult powers and magic practices which often openly supported by the locals. Several communities, like in the region of Sukuma, have never adopted Christianity or Islam which makes them to define and confine any calamity or misfortune as a curse.¹⁴⁷

Data

As said before, in Tanzania there are 102 reports: 97 of them are police documented, 4 are fruit of the investigation of the UTSS.¹⁴⁸ 79 are murders and 22 survivors in the last 5 years; most are severely mutilated.

Usually the attacks have several things in common: young age of the PWA, during the night, gruesome and violent, domestic assaults. One of the last attack in Tanzania was on October 21, 2011 Kulwa, 15 years old; she was attacked at home in Mbizi Village, Mega Ward, Msalala Division in Kahama District, Shinyanga Region. UTSS spoke with Kulwa's mother, Mrs. Habi Lusana (48 yrs), who said three masked men had attacked at her daughter around 1:00 AM. Kulwa had been sleeping with another sibling in a shed near the main house. The three assailants managed to open the door without force and, knowing exactly where Kulwa was sleeping, used a machete to sever her arm above the elbow. In response to her screaming, the father came out of the main house but was immediately attacked by one of the masked men. The mother also tried to rescue Kulwa but it was too late. She saw the men disappearing with her daughter's arm wrapped in one of the men's coats. At the time of this research Kulwa was still in Kahama District Hospital with her father, Mr. Kola Lusana (75 yrs).

In addition to the reported attacks, there have also been 13 grave robberies. In 2011 there were also 2 failed grave robbery attempts (10 robberies are police documented; 3 robberies are UTSS documented). Tanzania was the first country reporting the murders in official police documents in 2006. The last attack happened in June 2012, in Arusha

¹⁴⁷ See the paragraph on witchcraft.

¹⁴⁸ UTSS – Under the Same Sun, Canadian NGO focus on the protection of PWA in Tanzania.

region, quite a far area considering where it usually happens.¹⁴⁹

The legal framework of human rights

Tanzanian Constitution recognizes: “[a]ll human beings are born free” and are entitled to have their dignity respected.¹⁵⁰ Following the Constitution’s Bill of Rights, the government has an affirmative duty to protect every person’s life, including, obviously persons with disabilities.¹⁵¹ In case the government fails to protect its citizens, individuals may take legal action to see their right protected.¹⁵²

Tanzanian common laws define PWD who has “*physical or mental conditions arising from [sic] imperfect development of any organ.*”¹⁵³ This has been the key to include albinism in the disability cluster, even if, curiously, it is intended as a disability only concerning the skin, leaving out the low vision which affects almost 100% of PWA.¹⁵⁴

Tanzanian law enforces differently the provisions of the Bill of Rights, enshrined in Articles XII – XXIX of the Constitution, from others law. Nonetheless a pivotal role in protection of PWA has the Disabled Persons Care and Maintenance Act (“DPCMA”) of 1982 and the Disabled Persons Employment Act (“DPEA”) of 1982 focused on the protection and enhancement of the rights of PWD. As often occurs, some provisions are not fully respected, so even if the DPCMA requires authorities to maintain records of disabled persons, a census of PWA is still a project on the paper. Other parts of the DPCMA are working somewhat since the obligation of establish a national fund to provide assistance to PWD have never been properly founded. The same happens with the DPEA, focus on the promotion of employment for PWD: business with more than fifty employees should be obliged to hire a certain number of PWA.

¹⁴⁹ Ibidem , p. 1.

¹⁵⁰ Tanzania Constitution, art. 12 (1998).

¹⁵¹ Ibidem 101.

¹⁵² Tanzania Constitution, art. 26 (1998)

¹⁵³ Tanzania Disabled Persons Care and Maintenance Act, No. 3 (1982)

¹⁵⁴ Interview with Don Sawatzky, Director of Operations – Canada, Under The Same Sun (UTSS) on 02-05-2012.

Government action

A better focus of Tanzania's government came after the killing reports in the countries. Facing a situation that it was almost getting out of its hands, several initiatives have been taken. Right after the phenomena denounced on the newspaper Tanzanian police carried out approximately 170 arrests, most of them released after for lack of clear evidences.¹⁵⁵ Starting at the end of 2009 the first death penalties have been committed: the first ever for a blood-drinking killer of a five years old PWA girl¹⁵⁶, followed by other murderer, human traffickers including even parents.¹⁵⁷ At today more than 15 people have been sentenced by the Tanzania High Court of North Western Zone, only apparently stopping the gruesome acts.¹⁵⁸ Unluckily the law enforcement caused a spillover effect on neighbor countries, first of all Burundi.

Other provision of the government have been during the mandate of the President Kikwete's the appointment of an albino to serve as a Member of Parliament ("MP") in 2008.¹⁵⁹ In 2010 Salum Khalfani Bar'wani became the first member of the parliament to be officially elected from the Lindi Urban electoral district. They both raised awareness on the PWA around the country particularly addressing the most retrograde disbelief. Many Tanzanians used to doubt PWA' intelligence and ability on the job place.¹⁶⁰ Even highly educated PWA in the capital suffered of discrimination resulting in long periods of unemployment.

The government has been very active developing program with very different outcomes. Selected boarding schools are escorting CWA, as a way of protecting them from being haunted on their way to school. The establishment of community policing and an "ad hoc" task force in every region and district brought some results: 7.000 CWA have been identified in 96 councils and public health programs have been started.¹⁶¹ Currently,

¹⁵⁵ Ibidem 11, p. 16.

¹⁵⁶ Ng'wanakilala, 2010.

¹⁵⁷ Ng'wanakilala, 2009.

¹⁵⁸ The last murdered was registered in Arusha Region in the beginning of July.

¹⁵⁹ Ibidem 11, p. 17.

¹⁶⁰ Ibidem 11, p. 17.

¹⁶¹ Kitembo, 2012.

there are some programs in place to address the medical concerns of this population. For example, the Regional Dermatological Training Center (RDTC) in Moshi , Tanzania runs a mobile skin care clinic where a doctor and a nurse regularly visit villages to check the skin of people with albinism and provide education on protection from UV exposure.¹⁶²

Other project had been proved less congenial: the distributions of mobile phone to PWA¹⁶³ seem a mere electoral spot: often PWA are living in zone not covered by the phone signal or the are lacking of electricity. Also the call for a special countrywide referendum to make secret votes to whom they suspect to be part of the PWA body trafficking¹⁶⁴ seemed more a middle age witch-craft hunters carrying vendetta opportunities rather than a real and effective intervention of the state. Alexander Alum, Michael Gomez and Edilsa Ruiz carrying out a study on the field warned also of the legal conflicts which can arise with the Tanzanian Witchcraft Ordinance of 1928, which remains valid law in Tanzania.¹⁶⁵

The suspension of the entire traditional healer licenses¹⁶⁶ have been proven a weak provision as well: the lack of enforcement caused only the alienation of the sympathy of this big group of practitioners, the closest one to witch-doctors, often covering an important social role in the Tanzanian community.

NGO Action

A pivotal role in the country and in the whole area is played by local NGOs and the albino society. TAS – Tanzania's Albino Society is giving relief to who is attacked and raise awareness in case of episodes of marginalization or discrimination. UTSS play more an international role since it became in these last year a point of reference for the whole area, denouncing, collecting founds and bringing the case to the UNCHR in

¹⁶²American Academy of Dermatology, founded project.

¹⁶³Ibidem 5, p. 27.

¹⁶⁴Ibidem 11, p. 18.

¹⁶⁵Ibidem 11, p. 21.

¹⁶⁶Ibidem 11, p. 21.

Geneva. Curious and successful the history of the Albino United Soccer Team, a team composed only by PWA to sensitize public awareness on equality and respect.

Despite some unsuccessful efforts most of the Tanzania experience can be taken as an example. Spurred by the emergency and with still a lot of work to do, the situation has changed markedly since 2008 improving inclusion and enforcement of the law.

2.3 Burundi

The country

Burundi is a small African country of 27,830 km² with a population of 8,988,091 inhabitants.¹⁶⁷ Bordered by Rwanda to the north, the Democratic Republic of the Congo to the west, and Tanzania to the south and east, it is a landlocked country and figure as one of the five poorest countries in the world. Its capital is Bujumbura. Since 1966, Burundi is a presidential republic and the current head of state and government is the president Pierre Nkurunziza. The second-largest population density in Sub-Saharan Africa characterizes Burundi. The population is made up of three major ethnic groups – Hutu, Tutsi and Twa, concentrated mainly in the countryside.

PWA in Burundi

As we seen, most in African countries, albinism is considered a supernatural phenomenon and the PWA is perceived as a separate being.¹⁶⁸ It undergoes any sort of rejection and abuse because of its supposed beneficial powers or evil. Burundi is no exception, despite the development of society and tolerance is one of the values of Burundian culture. PWA therefore continues to be scorned, discriminated against and other inhuman acts as kidnapped or even murdered.

At birth, CWA is considered an unlucky person in the family. In this regard, the cases of infanticide and abandonment have been reported by PWA in the national census.¹⁶⁹ The disbelief reach the top with the murders of children with albinism because of a false belief that their members have special powers when they mix with concoctions used in witchcraft rituals.

If the child survives, he is a burden to parents who are ridiculed by the rest of the community. The community can even consider the child a threat and often the family is forced to hide him/her. Often at school children with albinism are subjected to verbal

¹⁶⁷ Ibidem 90.

¹⁶⁸ See the witchcraft paragraph.

¹⁶⁹ Ibidem 7, p. 20.

abuse becoming the odd character of the class (nicknames, piques and even marginalization by the teachers, e.g., avoiding to take special action for their low vision) In adulthood, young albino who wishes to start a family struggle to find a partner because the community continues to regard them as odd. Finally, people with albinism will have difficulty finding work because people believe they have a very poor health which is incompatible with the exercise of any activity. I will therefore present a list of “croyances et prejudices” about the perception of PWA in Burundi:¹⁷⁰

- PWA is the fruit of adultery (as punishment from God);
- Albinism is the result of a conception during a woman's period;
- The born of a child with albinism is a punishment against a woman who have made fun of a PWA or another white person;
- A PWA come from a divine power;
- Body parts (legs and arms) of a PWA can bring a lot of money;
- A PWA is a "muzungu" (white);
- A PWA is a divine curse.
- PWA are victims of the behaviors of the entourage, forms of verbal and physical abuse include the exclusion of children with albinism from playing with other schoolmates; people avoid sharing meals with them, arguing their skin etc...

Data

There have been 18 killings plus one Burundian child murdered on Tanzanian soil.

The most recent killing took place on May 6, 2012

Between 12:30 and 1:00 AM, a 14-year-old girl with albinism by the name of Chantal Ngendakumana was murdered in Bujumbura Rural, Kabezi Ward in Burundi. Two kilometers from the home where Chantal was abducted she was beheaded, her legs and arms were chopped off and what remained of the girls' body was thrown into a ditch. I will report the last email I received from UTSS on the 8th of May 2012, two days after the last attack:

¹⁷⁰ Thanks to Francesco Galtieri, UNV human rights department, whom provided me with these valuable documents.

“I have just received some very devastating news from Burundi.

A 14-year-old girl Chantal Ngendakumana was murdered last night between 0030 and 0100. Her legs and arms were chopped off. The murder was committed in Bujumbura Rural, Kabezi Ward.

A group of armed men with guns, machetes and spears broke into the girl's parents' house, Albert Ndarahuveye (about 45yrs) and Leokardy Shiliimana. Albert was at his night watchmen job in town. The men gagged Leokardy and her other four children and tied their hands and legs so that they do not escape and raise alarm. When they searched the house and could not find Chantal, the only child with albinism in the house hold, the murderers untied Leokardy's legs and forced her to lead them to the house where her daughter was spending the night with her cousins, 500 meters from their homestead. They then forced her to pretend as if there was a sick person in her house and that she needed their assistance. When she refused they threatened to kill her children one by one. When the relative opened the door, the armed men attacked him and warned that if any of his family members made noise they would be murdered. They gagged everyone abducted the girl and ran away with her.

Chantal's body was found two kilometers away from her home mutilated. Her legs were chopped off from the ankle and her arms were severed from just below the shoulder.

Kassim Kazungu, the Secretary General of Burundi Albinism Association, narrated the incident to me as he was taking Chantal's mutilated body in his car to Bujumbura Hospital morgue. My prayers and thoughts are with Chantal's parents, siblings and relatives! May the Lord Almighty comfort them at this difficult time!

I called the BBC and gave them the breaking news and asked them to go to the morgue in Bujumbura to verify the story for them. Meanwhile, there is some bad news also here in Tanzania - not that bad as in Burundi though. I am investigating some information about an alleged Social Welfare Officer who threatened a father of twins with albinism here in Dar es Salaam saying that the twins will be murdered if he does not surrender them to the Social Welfare Department. The man narrated the incident to Wivina - his current colleague at Family Health International. Wivina asked the man to leave his current accommodation and take the family to her house in town. I have asked her to

arrange a meeting so that I get more details of the story and set up a trap. The meeting will take place on 11th May 2012.

What is it that we are not doing to stop the killings! I am very upset and angry!

God please help us!

Vicky

Burundi The Return of the murder of albinos

African Diplomacy - Monday, May 7, 2012¹⁷¹

The seven of June 2012 Burundi police arrested three persons accused of involvement in the killing at Kabezi, some 20 km south of the Burundian capital Bujumbura. The shift in Burundian public opinion is evident considering that “*furious residents at Ruziba wanted to kill them*”.¹⁷²

The legal framework of human rights

The legal protection of PWA in Burundi is insufficient. The country signed the CRPD and the OP CRPD but at today it does not started the process of ratification. Therefore the CRPD is officially not binding.¹⁷³ Moreover, until now, there is no law in Burundi protecting PWA, all the prosecutions refer to the criminal law.¹⁷⁴ The constitution of Burundi beside including 307 articles does not provide a special protection to PWA (or PWD) It states in article 13 the equality and the dignity of every Burundian, the right to live in peace (article 14) and the refusal of every kind of discrimination (article 17).

Article 21, 22 and 25 are these which give more protection to PWA. “*Human dignity is respected and protected. Any attack on human dignity is punishable under the penal code*”¹⁷⁵ together with “*All citizens are equal before the law, which ensures equal protection. No one shall be discriminated against because of their origin, race,*

¹⁷¹ Ibidem 115.

¹⁷² Xinhua, 2012, p. 1.

¹⁷³ In this case, anyway, it seems relevant remember that Antonio Cassese consider the wiliness of the country since it signed. In case of gross violations not only the others convention would be violated (like first generations rights) but also, in a way, the CRPD.

¹⁷⁴ Email exchange on 14-06-2012 with Anne-Aël Puhu - Responsable des programmes Rwanda et Burundi RCN Justice & Démocratie.

¹⁷⁵ Article 21 of the Burundian Constitution of 28-02-2005.

*ethnicity, sex, color, language, social position, of his religious beliefs, philosophical or political because of a physical or mental disability or because of being HIV / AIDS or other terminal illness.*¹⁷⁶ In the last provision, the protection could be granted thanks the different color of the skin which would lead to a sort of marginalization. *Every woman, every man has the right to freedom of person, including the physical and mental integrity and freedom of movement. No one shall be subjected to torture or to cruel, inhuman or degrading.*¹⁷⁷ In this case not only the *inhuman or degrading* treatment but also the *freedom of movement* is strictly related to PWA: often PWA living in the most remote zones of the countries do not go around for fear of attacks.

Unluckily not only the law is ineffective since it does not clearly address the PWA (and PWD) problems but the enforcement too is problematic: since the independence of the country, litigation has never been able to address properly the cyclical violence crimes generated. Few crimes have been found, even fewer responsible for massacres and other violations of human rights have been prosecuted, victims are not compensated and the evocation of the conflict remains taboo.

Government action

After the *Arusha Peace and Reconciliation Agreement for Burundi*, involving the neighbor country Rwanda, many reforms tried to address the impunity and to prosecute the killing in the country, often-real war crimes and crimes against humanity.¹⁷⁸ Codes of criminal procedure and penal code were reformed but are not yet in force. Also the restructuring of the defense and security of Burundi National Police¹⁷⁹ is delayed in part also for the difficulties to reintegrate ex-combatants of the rebel movements with

¹⁷⁶Article 22 of the Burundian Constitution of 28-02-2005.

¹⁷⁷Article 25 of the Burundian Constitution of 28-02-2005.

¹⁷⁸Law No. 1/004 of 8 May 2003 on Punishment of the Crime of Genocide, crimes against humanity and war crimes; Law No. 1/014 of 22 September 2003 on the tasks, composition, organization and operation of the national Observatory for the prevention and eradication of genocide, war crimes, crimes against humanity and exclusion; Act No. 01/011 of 30 August 2003 ratifying the International Criminal Court, the Law No. 1/018 of 31 December 2004 establishing the mandate, composition, organization and functioning of the National Commission for Truth and Reconciliation..

¹⁷⁹Law No. 1/019 of 31 December 2004 on the establishment, organization, missions, composition and functioning of the National Defence Force.

various police forces.¹⁸⁰ In this precarious framework is easily understandable how enforcement of violations concerning PWA is just another drop in the sea.

Like the police, the judiciary system lack of equipment and training to properly fulfill its tasks and has not the confidence of the population. Dysfunctions include the non-respect for the independence of the judiciary, bias, corruption, inadequate legal texts, lengthy proceedings, the failure of judicial decisions, impunity and inefficiency in the Prevention and Punishment of the Crime.

One of the most sensitive issues is the establishment of a transitional justice mechanism that involves the creation of a special tribunal for crimes against humanity.¹⁸¹

Negotiations are continuing between the government and the United Nations, which in principle excludes the possibility of immunity or amnesty for genocide, crimes against humanity and war crimes. In 2009 a national consultations on transitional justice in Burundi led by a tripartite government, UN and civil society. Their goal will be to involve the people of Burundi in the process of national reconciliation. This would be a first step that might have positive influences on the protection of PWA, also in Burundi where PWA problems are not mainstreamed.

The weak government acted with extemporaneous provisions which have been effective considering the small dimension of the country. On this regards CWA have been directed only to some schools in the region of Ruyigim, prepared to assist them, they enjoy police escorting and PWA have been addressed on the public media to raise awareness. Some PWA communities have been established to better defend them, even if this should be only a provisional provision relaying on the official press release of the

¹⁸⁰ The Public Security Police (PSP), the judicial police, police and air borders and foreigners (PAFE), police from the general direction of the prison, members of the ex-police, armed forces and combatants of Burundian parties and armed political movements signatories to the Arusha agreement and the cease-fire.

¹⁸¹ Memorandum of the Burundian delegation responsible for negotiating with the United Nations the establishment of a Commission for Truth and Reconciliation Commission and a Special Tribunal in Burundi, in March 2006.

government.¹⁸² The project of inclusion and non-discrimination has been supported by the European Union.¹⁸³

The sentence of imprisonment of eleven people accused of assassinations and attempted assassinations of ten PWA opened on the 19th May 2009 before the High Court of Ruyigi, near the Tanzanian border, marked a real change in Burundi. The convicted were committed from one year's imprisonment, to life imprisonment.¹⁸⁴ With this trial, the prosecutor handling the case hoped to dismantle a network that is responsible for a dozen murders of PWA in Burundi. The network, sponsored from Tanzania, was engaging in trade of human organs. This trial, the first in an area suffering the killing spillover effect from Tanzania, has been somehow frustrated by the evasion of some of the murderers. To underline once more the spell of PWA in this zone of Africa is important to report how, two of the escapees, Hasabumutima Salum and a college student, Tanzanian of Burundian origin who were sentenced to 15 years in prison for plotting were in league with the 26th battalion of military Kinyinya (Ruyigi). The involvement of the army on the murder of two CWA and the consequent selling their body parts in Tanzania, as today, had never been prosecuted.¹⁸⁵

NGO Action

Despite the efforts of the locals and international organizations which saw several investments on tribunals,¹⁸⁶ the mainstream news about PWA came only recently and on fragmented topics. In 2011 with the first “Profil Sociodemographique des personnes albinos au Burundi” the UN and some NGOs started addressing directly the problem. The NGO RNC Justice&Democratie developed the first inclusive program focused only

¹⁸² Bongos, 2012, p. 1.

¹⁸³ European Union - EEAS (European External Action Service)

¹⁸⁴ Baldé, 2012, p. 2.

¹⁸⁵ Ibidem 99, p. 1.

¹⁸⁶ Design and dissemination of extension materials and dissemination of the right of legislation (6488 copies outreach tools, 100 copies of the electronic version of CPF and year of the basic texts). Producing radio reports "Justice, Law and Society" (49 weekly programs) and three radio documentaries on the history of justice in Burundi have been mounted. 78 Theatrical performances on the theme of conflict and justice for 60.000 spectators, followed by 38 groups composed of 950 participants. Story tellers around the country for an estimated audience of 2.160 children, recording five stories.

on PWA. The census report shows the presence of 863 PWA and highlights cases of discrimination against them (355 cases) and their extreme vulnerability. While 42.9% of PWA are under 10 years old and must be accompanied in their schooling, 92% reported having health problems associated with albinism (ocular or cutaneous). The census was part of a project funded by the European Union aiming to make awareness about the situation of PWA in campaigns, radio spots, income generating activities and the construction of the headquarters of Albinos Sans Frontieres (ASF).

2.4 Kenya

The country

Kenya has a population of 41 million persons with more than 42 different tribes.¹⁸⁷

Several cultures are mixed in the country following the Bantu, the Nilotic and Cushitic populations which include from the famous Masai tribes to the more numerous Kikuyu, Luhya and Kalenjin tribes. English is used as a lingua franca while the majority of the people speak different dialects of Swahili. Culturally diverse and cosmopolitan, Kenya has to face different challenges compared to the other countries in the lake Victoria region, first at all the pressure of the migrants coming from Somalia and South Sudan and the complex social structure within the country.

PWA in Kenya

The PWA situation is slightly different from Burundi or Tanzania. The spillover effect on killing the PWA has been contained and efficaciously stopped during the peak of the emergency in 2008-2009.¹⁸⁸ Some murdered can be accounted but the police forces and the government reinforced the punishment and the controls on the borders to avoid human body trafficking basically stopping the phenomena.¹⁸⁹ Following the reforms which every African state is undergoing in the last ten years, Kenya is focusing on inclusion policies and non-discrimination, trying to enhance the welfare of PWA. Following the good practices of Tanzania both the government and locals NGOs started to focus on the most marginalized groups, above all after the spread of killings. Nonetheless the marginalization of PWA in Kenya is still really high. Often women are abandoned and CWA have several difficulties on find a proper school and get accepted. Life in Kenya does not differ too much from the neighbor Tanzania: casted away in the early periods of their life, PWA face several difficulties to find jobs, have relationships and even carry out the normal duties during a day like shopping and share public spaces.¹⁹⁰

¹⁸⁷Ibidem 90.

¹⁸⁸BBC Africa News, 18-08-2010.

¹⁸⁹Ibidem 124.

¹⁹⁰Interview with Isaac Mwaura. See annex.

According to a National Survey on disability from 2008, about 4,6 % men and women have a disability even if a more reliable estimation which take in consideration the population living in the slum, speak of about 10% of the population (or 3.280.000 inhabitants) living with a disability. WHO estimates that the rate is 1 PWA every 17.000, which would mean in a population of 33 million Kenyans, 2.000 PWA.¹⁹¹ ASK instead is advocating for 20.000 PWA in the country.¹⁹² It raises some doubts the uncertainty about the number of PWA since the government is providing funding without knowing the consistency of the group.

Data

There have been at least 7 killings and 2 near death episodes for a total of 9 reports. On August 16, 2011 The Standard, a Nairobi newspaper, reported a near death case where the father of a daughter with albinism was being charged with human trafficking. The arrest revealed that he was in the process of selling his daughter to a Tanzanian buyer for an undisclosed amount of money. This case was still before the courts on the date of the newspaper report.

The most recent killing took place on December 24, 2010.

A 3-week-old baby boy with albinism was killed by his mother because the father was threatening divorce saying that the baby was a ghost and not his offspring. Several allegations of NGO and activist are denouncing how the absence of PWA in some part of the country is extremely suspected.¹⁹³

The legal framework of human rights

The Person with Disabilities Act¹⁹⁴ would include albinism as a disability, but regrettably is not officially recognized. As shown in article 2 of the Act:

“Disability means a physical, sensory, mental or other impairment, including any

¹⁹¹Ibidem 113, p. 7.

¹⁹²Ibidem 114.

¹⁹³Interview with Isaac Mwaura on the 16-06-2012.

¹⁹⁴Act No.14 of 2003 of the Republic of Kenya.

visual, hearing, learning or physical incapability, which impacts adversely on social, economic or environmental participation;”

Kenya adopted a new constitution in August 2010 which remarks the importance of non-discrimination and inclusion of disables in the state. The new constitution in article 27 prohibits discrimination on the grounds of health status and disability¹⁹⁵ and commits the state to citizens’ social and economic rights in article 43.¹⁹⁶ Article 36 provides “*Every person is equal before the law and has the right to equal protection and equal benefit of the law. Equality includes the full and equal enjoyment of all rights and freedoms.*”¹⁹⁷

Several human rights and legal aspects are following the indication of the Convention on the Rights of Persons with Disabilities (CRPD) which is part of the laws of Kenya as embodied under Section 2 of the Constitution. The CRPD has been signed on the 30-3-2007 and ratified the year after (19-5-2008). The application of international norms on the domestic legal framework has been characterized by long debates.¹⁹⁸ In particular the domestication of the CRPD had to pass through extensive parliamentary passages since *The Persons with Disabilities Act* was already into force. The Act was promoted in 2003 and it is based mainly on the most recent paradigm of disabilities,¹⁹⁹ ensuring equality and dignity to people with impairments. In this regard employers of PWD are entitling to tax reduction according the degree of their disability. Nonetheless gaps and barriers for a truly implementation of the CRPD are still present and we can regrettably recognize that asymmetries are still present between the international agreement and the domestic legal framework.

In fact if CRPD shaped the Disable Act of 2003 some incoherence are still present in the

¹⁹⁵*The State shall not discriminate directly or indirectly against any person on any ground, including race, sex, pregnancy, marital status, health status, ethnic or social origin, colour, age, disability, religion, conscience, belief, culture, dress, language or birth.* Art. 27 part 4.

¹⁹⁶Art. 43 Kenya Constitution

¹⁹⁷Art. 36, Kenya Consitution.

¹⁹⁸Kindinki Kithure, p. 319.

¹⁹⁹See chapter on paradigms and disabilities.

domestic law. This lead to an incomplete harmonization characterized by different outcomes: from one side, for example, Kenya had into force a ludicrous provision regarding disabled persons in the “Vagrancy Act” where a vagrant beggar was considered disabled. The same Act was defining minors under the age of eighteen as disabled persons. This is a clear example of the negative attitudes towards people with impairment. The “Vagrancy Act” has been repealed and replaced.²⁰⁰ On the other side some people with disabilities are still marginalized and they are not recognized as “disabled” under the law. This is the case of people affected by albinism.²⁰¹ The non-inclusion in the official group of disabled persons deprives them from a long series of rights as health, education and political inclusion within the country. Despite the laudable adoption of the Persons with Disabilities Act of 2003 an alignment need to be done. For example the Mental Health Act and the Kenya Society for Blind Act should be amended to include rehabilitation, preventions and equality. All these rights are included in the Disable Act and in the CRPD, but they have never been combined.²⁰²

At the end if the Disable Act seems to be inclusive and move with the times, the real problem come to the implementation of these rights since they are not included in several other Act as Local Government Act, Custom and Excise Act’s, Public Health Act...that are the relevant frame of the social, civic and political life in Kenya. Regrettably the Optional Protocol of the Convention has not been signed. The CRPD and the civil society made the Kenya government pass a list of parliament provisions stating disabilities as a main concern.

This provides a series of subsidiary legislations which are associated with PWA since they are part of the PWD group. These include but are not limited to:

- Access to employment, services and facilities (regulated in 2009);
- Cost, care, support and maintenance (regulated in 2009);

²⁰⁰Rights at Risk: Issues of Concern for Kenyan Children, A Report Prepared for the Committee on the Rights of the Child by Human Rights Watch, 2010. Often children are target since they are a marginalized part of the society.

²⁰¹Despite the efforts of ASK, at today, albinism is not considered a disability in Kenya.

²⁰²Ibidem 198, 326.

- Income Tax Deductions and Exemptions (Order, 2010);
- Registration (regulated in 2010 but still not enforced);
- National Development Fund for Persons with Disabilities (Conduct of Business and Affairs of the Board of Trustees -Regulations, 2009).²⁰³

The persons with disabilities act would be a pivotal part in the fulfillment of PWA rights, if enforced: section 11 provides, inter alia *"The Government shall take steps to the maximum of its available resources with a view to achieving the full realization of the rights of persons with disabilities set out in this Part"*;²⁰⁴ this spurred the government to allocate funds for sun-creams, solar protection clothes like hats and free medical care in the hospitals.

Section 12, concerning the employment, reads as follows: *"No person shall deny a person with a disability access to opportunities for suitable employment"*²⁰⁵ and Sub-section 2 continues further *"A qualified employee with a disability shall be subject to the same terms and conditions of employment and the same compensation, privileges, benefits, fringe benefits, incentives or allowances as qualified able-bodied employees."*²⁰⁶

Sub-section 3 *"An employee with a disability shall be entitled to exemption from tax on income accruing from his employment."*²⁰⁷ The Albino Society of Kenya is carrying out a campaign to make all these provisions fully applicable to PWA since the differences between the different disabilities are still big. For example discrimination by employers on the working place is prohibited but it would be naïf to state that there is no discrimination in the country.²⁰⁸

Nonetheless the provision is pretty clear in section 15: *"Subject to subsection (2), no employer shall discriminate against a person with a disability in relation to -*

²⁰³ Kenya's initial report submitted under article 35(1) of the UNCPRD, 2011, p. 16..

²⁰⁴ Ibidem 194, section 11.

²⁰⁵ Ibidem 194, section 12.

²⁰⁶ Ibidem 194, section 12.

²⁰⁷ Ibidem 194, section 12.

²⁰⁸ Emails exchange with Mwaura M Isaac, president of ASK, 12-05-2012.

- (a) *The advertisement of employment;*
- (b) *The recruitment for employment;*
- (c) *The creation, classification or abolition of posts;*
- (d) *The determination or allocation of wages, salaries, pensions, accommodation, leave or other such benefits;*
- (e) *The choice of persons for posts, training, advancement, apprenticeships, transfer, promotion or retrenchment;*
- (f) *The provision of facilities related to or connected with employment; or*
- (g) *Any other matter related to employment.*”²⁰⁹

The real problem, as said before, is the enforcement of such a provision.

Education is covered in the Act under Section 18. It reads "*No person or learning institution shall deny admission to a person with a disability to any course of study by reason only of such disability, if the person has the ability to acquire substantial learning in that course.*" Subsection 2 provides "*Learning institutions shall take into account the special needs of persons with disabilities with respect to the entry requirements, pass marks, curriculum, examinations, auxiliary services, use of school facilities, class schedules, physical education requirements and other similar considerations.*"²¹⁰

Subsection 3 "*Special schools and institutions, especially for the deaf, the blind and the mentally retarded, shall be established to cater for formal education, skills development and self-reliance.*"²¹¹ The Act also provides for the establishment of Special Schools and Non-formal Education under Section 19 which reads "*The Council shall work in consultation with the relevant agencies of Government to make provisions in all districts for an integrated system of special and non-formal education for persons with all forms of disabilities and the establishment where possible of Braille and recorded libraries for persons with visual disabilities.*"²¹²

²⁰⁹Ibidem 194, section 15.

²¹⁰Ibidem 194, section 18.

²¹¹Ibidem 194, section 18.

²¹²Ibidem 194, section 19.

Government action

The government of Kenya is undergoing a big effort to comply with the inclusion and integration of PWA in the country. Big steps forward happen recently on 15 May 2012. Mwaura M Isaac, national coordinator of the Albinism Society of Kenya and special advisor of the Prime Minister, declared:

*“The society [ASK] made a request to parliament [...] to have money allocated in the budget for persons with albinism increased to Kshs 400 million. The committee promised to ensure this happens in order to ensure that among other things, we are counted the whole country, there is a national albinism center established, more awareness creation is created in rural areas especially across the country and more people receive sunscreen lotions for free on a monthly basis....”*²¹³

This historical public founding will be used also to develop microfinance project to empower poor PWA in rural areas and for projects of awareness creation and civic education.²¹⁴

Public education is another sector pivotal to improve the quality of life of PWA. Children often suffer from discrimination and lack of education because of their condition. Often a simple campaign of awareness makes it possible to educate professors on the weakness of CWA: places close to the blackboard, so they can read and follow the lessons, is a simple and economic solution to avoid marginalization. Unluckily lenses and magnifiers are today provided through the numerous NGOs²¹⁵ in contrast with the marginal role of the government.

²¹³ From Mwaura M Isaac’s social network. On the 15 of June 2012 the Kshs 400 million have been conceded to ASK – email of Wanyonyi M Pepela, researcher at Terry Child Support and Youth Resource Centre in Nairobi.

²¹⁴ Ibidem 114.

²¹⁵ Several examples are available. StartFund has supported the Kenya based organization Kacsu in two similar projects in assisting albino children to access educational facilities and provide basic necessities for them to cope with their condition.

One of the main concerns is still today the education system which cannot fully integrate CWA. At the present, 80% - 90% of them attend schools for visually impaired at primary school level in Thika, Kitui and Meru.²¹⁶ The lack of medical attention and the poor funding made most of them unable to read and they need to use Braille in school. The difficult situation the CWA are facing at home where often are relegated outside the community and with only one parent, affect their health and education as well. Often private community schools accept CWA with the help of private NGOs. In addition the non-integration in normal school concurs on the future marginalization of the PWA.

As seen before, several parts of the new constitution refer explicitly to the People with Disabilities Act of 2003. Unfortunately the progress and the implementation are slow. Several provisions of the disability act after almost 10 years are still in limbo. The National Council for People with Disabilities was established in 2004 organized as a semi-autonomous Government Agency under the auspices of the Ministry of Gender, Children and Social Development. It is made up of 21 members in order to represent various disability organizations and government ministries. The Council through a National Development Fund for Persons with Disabilities provides some organizational support. The Albino Society of Kenya is advocating to become a part of it. The Council is leading on implementing the action plan of the African Decade of PWDs 1999-2009, recently extended until 2019.²¹⁷

NGO Action

PWA situation got some tangible improvement only in October 2007 when the Albinism Society of Kenya (ASK) was created at Thika School for the blind. The association, which is recognized as a *disabled person organization* [DPO] from the Kenya government, started a strong advocacy in cooperation of international actors under the slogan “*Don’t just stare-ASK.*”²¹⁸ They are mainly focus on the monitoring of the first

²¹⁶ Ibidem 113.

²¹⁷ Nilsson, 2011, p. 1.

²¹⁸ Rick Guidotti of Positive Exposure, a photograph project concerning people with albinism all over the world, had a pivotal role in the creation of the society.

generation right of PWA, the provision of sunscreen with a high Sun Protection Factor SPF (30-50) and the provision of eye care services. Another pivotal point of intervention has been the access to education for learners with albinism through policy advocacy, school placement, sponsorship and counseling.²¹⁹ In 2011 the albinism national day was established to strength the awareness of the PWA community funded by the Kenyan government.²²⁰

Also some local NGO like KACSU has on the budget of the year 2012/2015 projects to conduct country specific surveys to find out the prevalence of albinism, age, income, and gender.²²¹ Moreover trough the founding of a community-integrated school, Kacsu developed a program including CWA in Eldoret which provides prescription glasses. Kacsu recently stated that out of 54 CWA *“a good number of them have near-perfect eyesight and should not have been in special schools. [...] Our findings therefore show that most of the students were condemned to blindness by default.”*²²²

The AFEA-Albinism Foundation of East Africa is lobbying, instead, the provision of free sunscreen for every PWA, leaving a serious census for a later stage. AFEA estimates it would cost € 200.000 a year, way less than the medical expenditure to cure the cancers which affect a big percentage of the PWA population. Again it is difficult to understand how to make reliable estimations without knowing the composition of the population.²²³

²¹⁹Ibidem 215.

²²⁰The first ever national albinism day was hold on 04-05-2011.

²²¹Kacsu Internet site, intervention areas: <http://www.kacsu.org/>

²²²AFEAC, About Albinism pamphlet 2012.

²²³Report 2012, Albinism Foundation of East Africa.

2.5 Uganda

The country

Uganda is a democratic republic with a non-party political system; currently the head of state Yoweri Museveni and the chief minister is Apolo Nsibambi. It is divided into 4 kingdoms: Buganda, Busoga, Bunyoro and Toro. The estimated population in April 16th 2012 amounted to 28,579,952 people.²²⁴ The country has experienced, since the early sixties, a rapid population growth as in many other developing countries. The history of Uganda is tormented, characterized of long civil wars, which seem to involve neighbors' countries tribes as well.

PWA in Uganda

Uganda did not officially experience PWA killing or persecution even if the discrimination in the country is present and harsh to fight. Culturally there is not a big difference from the others country of the area, the fascination from pagan rituals and traditional healer is still strong and widespread in the country. Illustrative can be the case of Alice Auma Lakwena, which funded an insurgent movement and fought in the country for more than twenty years through the common belief of being the personification of a spirit of an Italian officer drowned in the Nile during the IWW. This movement will turn to the unfortunate and well known Lord's Resistance Army (LRA) of Joseph Rao Kony.²²⁵

Data

No official data are reporting assaults or persecution of PWA in the country. Beside that the suspect denounced by several NGO working on the field, should push the government and the international actors to further investigate the condition of PWA in Uganda.

²²⁴Ibidem 90.

²²⁵Behrend, 1997, p. IX-XVI..

The legal framework of human rights

Despite the development of a legal text to enhance equality and non-discrimination, the conditions of PWA in the country are far from being acceptable. Chapter 4 of the Ugandan Constitution of 1996 provides the basic framework for the domestication of international Human Rights in Uganda. The UDHR and the Banjul Charter are the main references which the lawmakers followed to protect and enhance human rights in the country. Article 45 of the Uganda constitution states “*The rights, duties, declarations and guarantees relating to the fundamental and Human other human rights and freedoms [...] shall not be regarded as excluding others not specifically mentioned.*”²²⁶ making it clear that the rights listed are not exhaustive. Article 51 establishes a Human Rights Commission²²⁷ and the subsequent articles define the powers and the limitations of such commission.²²⁸ Despite the fact that these documents declare that all persons are equal and condemn all forms of discrimination, like article 21 (Equality and freedom from discrimination), article 24 (Respect for human dignity and protection from inhuman treatment) and article 35 (Rights of persons with disabilities) these rights are commonly violated when it comes to PWA in Uganda.

A lack of recognition is intrinsic to The Persons with Disabilities Act since the provisions should be specific and inclusive but provide that 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.”²²⁹

Furthermore article 32 states: “*groups marginalized on the basis of gender, age,*

²²⁶Art 45 of the Uganda Constitution.

²²⁷Art 51 of the Uganda Constitution.

²²⁸Art. 52, 53, 54, 55, 56, 57 and 58 of the Uganda Constitution.

²²⁹Uganda Persons with Disabilities Act, article 2 “Interpretation”.

disability, or any other reason created by history, tradition or custom”²³⁰ creating an “other” group which is detrimental of protection. “*Sometimes to list is to limit...To this effect, policies have been developed in this very rigid categorization, ignoring other marginalized groups*”²³¹. This happens in every provision in Uganda making really confuse the enhancement of the protection of PWA in the country. For example the exclusion of albinism from disability definition prevents the collection of official data on PWA under the census conducted by the Uganda Bureau of Statistics. The status of PWA in the country is therefore in a limbo, included in the CRPD, ratified by the country, but excluded by the national legislation.

Government action

The persons with disabilities act was promulgated in 2006 and marked a precious step in defending PWD. Starting from that date, for example, five representative of PWD were allowed to sit in the parliament: none of them has ever been a PWA. The current legislature will finish in 2016 and despite the call for a reform launched by different PWD and PWA associations in the country, seems difficult a reform that will double the number of PWD in the parliament.²³² The government is currently failing to improve the conditions of PWA in the country paying little attention to inclusion policies embracing them. This is probably due to the political crisis of Uganda of the last 2 years which leaded to repression and clashes in the north part of the country.

The scarce attention of the government and the international community is clear reading the 12th session on the universal periodic review. The Working Group of the Human Rights Council during the review of Uganda, out of 171 recommendations, cited PWA only related to CWA: “*Guarantee equal opportunities for minors with disabilities with a particular attention to albino children*”.²³³ The director of the Vulnerable Persons Unit UHRC on 16 April 2010 declared that the lack of PWA killing in the country determined the scarce intervention and attention from the international community. Probably a main

²³⁰ Uganda Persons with Disabilities Act, article 32.

²³¹ Nyirinkindi, 2007, p. 30.

²³² Email exchange with Don Sawatzky, Director of Operation of UTSS – Canada on 07-05-2012

²³³ Proposed by Spain it has been accepted. UPR report of 07-09-2011.

role has to be attributed also to the lack of knowledge on the basic human rights of the “*local stakeholders*”.²³⁴

NGO Action

After the emergency in the area spread by the media, also the Uganda civil society organized them: a Uganda Albino Society was established reaching the associations of 3.700 PWA in just a few years. Volunteer regional branches were established in Central, Western, Northern, Eastern and Southern regions of Uganda advocating for the recognition of Albinism as a disability, which occurred “partially”.²³⁵ Several agreements have been focused on medical cooperation and social inclusion as the Memorandum of Understanding with the government to allow more import of products duty-free, such as sunscreens. Through radio, TV and newspaper massive campaigns have been developed to raise awareness. The National Union of Disabled Persons of Uganda (NUDIPU) considers the stigma associated with albinism makes PWA even more discriminated and threatened than PWD.

To fight the scarce education of the population on PWA condition markedly local organizations are born all over the country: the Nazigo Albino Persons Association (NAALPA) was founded in 2004, the Uganda Albino’s Association (UAA) and the African Albino Foundation of Uganda (AAFU) two years after. Better synergies are desirable since the three of them are lacking of project coordination, founding and clear objectives.²³⁶

²³⁴ Ibidem 7, p. 17.

²³⁵ UAA 2012 pamphlet.

²³⁶ Email exchange with Dan K'Oliech, Economics of Education (Kenyatta) Centre for Development Research and Policy Analysis on 14-02-2012.

3- Paradigms and Albinism

As we seen in the first chapter, the best international legal framework to enhance the protection of people with albinism is include them in the disability cluster following the Convention on the Rights of the Persons with Disabilities.

The CRPD is the crystallization of a long debate concerning people with impairments which began in the 70's in the US and England. Before the 70's disability has been an invisible element in the international legal framework. In the formulation of the Universal Declaration of Human Rights (UDHR) adopted by the United Nations General Assembly on the 10 December 1948 PWD have not been explicitly recognized as a group worth it of specific protection. Also later in 1966 their rights have been neglected since no clear reference is done in the International Covenant on Economic, Social and Cultural Rights (ICESCR), and the International Covenant on Civil and Political Rights (ICCPR).

It is during these years that activists and NGO's started campaigning to see recognized specific rights to persons with disabilities, and in these same years scholars started to address the problem. Michael Oliver locates the origins of the concept of disability as a socially constructed category developed in the beginning of the Industrial Revolution. The differentiation between normal and "disabled" was created during this period when men were categorized in regards to their ability to work: a person was defined normal when he was able to participate actively in economic life. Handicapped persons were seen as unproductive and often as a burden for the society.²³⁷ Furthermore impaired people suffered of a real marginalization "*with little social value or individual human worth and were exiled from the productive center into institutions and an existence outside society where their only claim to social resources was in the charity of others.*"²³⁸ This new social-based interpretation of disability has been the result of different inputs coming from the society in the early 1970's. The radical experience of oppression and apartheid Vic Finkelstein experienced in South Africa began to be

²³⁷ Oliver Michael, p. 27.

²³⁸ Ibídem 237, p. 5.

associated to the systematic segregation of disabled people.²³⁹ Debates hold first in UK, like at the *Union of the Physically Impaired against Segregation* where Vic and the wife were active participant, spread in Europe and the US in few years. At the end of the decade the social model of disability was born and it would have influenced all the next laws and debates regarding disables.²⁴⁰

Seto and Buhal expanded on this idea in 2006 documenting four different phases: the affliction paradigm, the medical/charity paradigm, the civil rights paradigm and the emergence of a variation paradigm.²⁴¹ Even if focused on the American society these four paradigms can easily be comprehensives of Europe and Australia. The affliction paradigm is characteristic of the pre-industrial era where disability was seen as “*punishment or a test imposed by God [...and...] disability was brought by sin.*”²⁴² Along the whole XIX century and the first decades of the XX this has been the main paradigm. Every paradigm has a different historical period, homogeneous or with secondary variations in every industrialized countries.

The medical/charity paradigm developed between the industrial era and the 1970's when people with impairment were seen as “*object of pity, philanthropy and paternalistic rehabilitation.*”²⁴³ Nowadays this model is still present in numerous approaches emphasizing the several medical solutions which can be applied to better integrate persons with disabilities. This approach based on a “compassionate” or just society which invests as part of its welfare resources in health care and services is aiming to 'cure' disabilities medically, or at least to reduce the impact of the disabilities in the perspective to give PWD a more “normal” life. Clearly this model is violating the dignity of disabled people often through degradation, promoting a pitiable image of people with impairments. Even if often this paradigm seems to be anachronistic, there

²³⁹ Finkelstein, South African Connection, p. 6.

²⁴⁰ “*In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society.*”. Finkelstein, *Physically Impaired Against Segregation*, p. 4.

²⁴¹ Ibidem 1, 1053.

²⁴² Ibidem 1, 1058.

²⁴³ Ibidem 1, 1058.

are numerous provisions still based on it: for example over seven million people with disabilities in the United States of America currently are receiving Supplemental Security Income.²⁴⁴ As proved Theodore Seto in his article *“in other words, over half the beneficiaries of America’s so-called “safety net” had some kind of disability.”*²⁴⁵

The most recent paradigms shifts are, in my opinion, what the Convention on the Rights of Persons with Disabilities is trying to crystallize right now. First of all the Civil Rights paradigm. The call for the application of the full body of civil rights link disability to a social constructed concept, like race. Thanks to the civil rights movements in the 60’s and the 70’s the medical approach has been successfully challenged. Under this paradigm the focus is not on the impairment but on the barriers, for example, the stairs that have been built without considering a ramp. They have been built as a “societal decision” excluding and marginalizing a part of the society. Social exclusion is the true problem that transforms impairment in disability. Inclusiveness is the best option to create an egalitarian society. Furthermore the focus on social barriers and the recognition of autonomy and self-determination are pivotal concepts presented in the convention. The movement has been pivotal to a change in all the mayor industrialized countries ranging from the “American with Disabilities Act” of 1990, requiring equal opportunity for individuals with disabilities and affording similar protections against discrimination to PWD as the Civil Rights Act of 1964, or the Disability Discrimination Act.²⁴⁶ The Equality Act 2010 in United Kingdom is another good example where not only discrimination is prohibited but also indirect discrimination is forbidden.²⁴⁷ In Australia, the federal Disability Discrimination Act 1992 followed the example of the American with Disability Act.²⁴⁸ The EU states have followed this trend as for example Italy embraced, even though the Constitutional Court, the social model.²⁴⁹ All these provisions have in common non-discrimination and non-marginalization of people with disabilities. Different and quite surprising is the recent decision of European Court of

²⁴⁴ 7.183.900 recipients in February 2012 based on the SSI statistics online.

²⁴⁵ Ibidem 1, p. 1062.

²⁴⁶ Pam Thomas, p. 2.

²⁴⁷ Ibidem 246, p. 3.

²⁴⁸ Ibidem 246, p. 3.

²⁴⁹ National law, 10 May 1999, n. 167.

Human Rights in 2006 in *Chacón Navas v Eurest Colectividades SA* where the Court is looking toward a medical approach.²⁵⁰ Several human rights expert have openly criticized the decision.

An evolution from formal equality is the raising of “substantive difference equality”²⁵¹ where discrimination can be individuated by unconscious acts of the institutions and structures of the society.²⁵² This is the new emerging paradigm that underlines how “equality is not enough.”²⁵³ A deaf person treated exactly the same of a hearing individual in a classroom would be excluded from participation. The new movements are trying to focus on the social paradigm underlining how the above-mentioned needs have to be considered. People with disabilities still face numerous difficulties often also because of aptitudes shown to them. The route traced by the convention for example in article 9 is to activate those provisions not on the basis of “*direct knowledge of personal characteristics but on the assumption that all characteristics will be encountered.*”²⁵⁴ In this case the Convention is really innovative enhancing the most progressive scholars like Jonh Rawls’ view: “*if it were possible that you might be paralyzed from the waist down, how would you like society to be structured?*”²⁵⁵

One of the most enlightening examples is the taxation system: several countries in Europe²⁵⁶ are trying to, in a way, combine the medical and sociologic paradigm: the additional burden sustained by disabled people to have an “inclusive” life, like the expenses for wheelchairs or special nurses are tax-deductible.²⁵⁷ Once again the Convention is really progressive since reasonable accommodations are provided and promoted.

²⁵⁰(2006) C-13/05, [2006] IRLR 706, [2007] All ER (EC) 59

²⁵¹ Maria Liisberg, *New Dawn and Dilemmas under UN Disability Convention*, oral presentation on 14-03-12

²⁵² Fredman, 211.

²⁵³ Marcia H.Rioux, Lee Ann Bassier and Melinda Jones, 310.

²⁵⁴ Rosemary Kayess and Phillip French, 11.

²⁵⁵ *Ibidem* 1, 1072.

²⁵⁶ Due to the characteristics of the paper I focus only on Denmark and Italy. I believe the trends follow the borders of the European Union though.

²⁵⁷ This is also the view of Harlan Hahn, *Can Disability Be Beautiful?*, 1988.

3.1 The paradigms in the Victoria Area

Taking in consideration the model proposed for the CRPD in Africa, we can use the same framework to analyze the persecution and marginalization of PWA in the region. The four historical paradigms of disability (affliction, medical, sociological and the emergence of a new paradigm) can be related to the four dominant approaches in the area. The main difference with the analysis described by Seto is the contemporary presence of the paradigms: often in the same country there is asymmetry between the society, the lawmakers' orientations and implementation of specific provisions. The results are the coexistence and the overlapping of different attitudes towards PWA. Several laws have an outdated approach to PWA situation or they are a mere agreement on international standards without real domestications. Doing so we have some provisions very proactive and some poor implementation: for example the ratification of the CRPD and its OP CRPD. Others provisions are instead technically wrong beside the fact that they bring some kind of modernization, see in this sense the votes of denounce and accusation of witchcraft in Tanzania. Some other attitudes are, instead wrong or, simply, fruit of ancient popular belief: the persecution of PWA can be fully located in this framework.

Following the scheme of Seto, the affliction paradigm which see the disability as a "*punishment of God*" or "*brought by sin*", is easily linkable to the killing phenomena, the witchcraft disbelief and the infanticide of PWA. Two countries in the area are particularly affected: Tanzania and Burundi. The poor data available and the involvement of policemen or politicians do not prevent to classify this as an approach follow by a vast majority within some tribes mostly in Mwanza and Shinyanga regions. Traditionally prone to witch-hunting²⁵⁸ and with a strong believe in supernatural medicine this approach is still a challenge to others approaches. Most of the efforts of the law makers has been focus on fighting the prejudices and discrimination of PWA, often with a mediocre and only superficial result, considering the cases of police

²⁵⁸ Between 1970 and 1988, over 3,000 (80% women) were brutally killed, of which 2/3 in Sukumaland (Mesaki, 1994)

officers and politicians involved.²⁵⁹

The medical paradigm is mainstreamed in the four countries. Low-vision, skin cancer and in general health education is one of the priorities in which governments and NGOs are investing money. Numerous are the stereotypes which PWA are still suffering today under the medical paradigm which often involve paternalistic attitudes or philanthropic projects above all by the local administrations. The local communities are often convinced of the total blindness of PWA, the weak constitution which make them unable to work in the field or about their supposed stupidity. To enhance a medical approach inclusive of non-discrimination and marginalization several associations and albino societies have been created (ASK, Albinos sin Frontiers, TAS, UAA) and the government recognized the right of representation in the Parliament (like in Tanzania) or in disabilities councils in the efforts to make awareness.²⁶⁰ The creations of ghetto in schools or jobs place are part of the medical paradigm: the exclusion of the PWA from the rest of the society is today still a reality.

This brings us to the third paradigms analyzed by Seto. The frames of these new approaches are ephemeral and confused. In fact the inclusion of the PWA is relatively a new thing since for a long time they have been neglected or addressed barely as a health problem. The shift from the affliction paradigm is still an ongoing process which brings PWA to face challenges which, sometimes, appears bizarre to western scholars. The main focuses are on social inclusion, mainstreaming primary-secondary education, vocational training, indoor job and education on sun protection. The inclusion and the effort in fitting the legal definition as the reintegration after hiding or the displacement as well are challenges which PWA and groups advocating for PWA are facing today. Undeniably a pivotal passage has been the attention of the international community on the persecution of PWA, which has driven founding and best practices in the area. The approach is today accepted and embraced officially by everyone; still a subculture of prejudice is preventing full implementations of provisions nicely written on papers.

²⁵⁹ Ibidem 6, p 6.

²⁶⁰ Recently Kenya is undergoing a reform aiming the empowerment of PWA in the country.

The *new paradigm* is almost absent in some countries like Burundi or where the persecution has been more harsh (north of Tanzania) at least considering the implementation of it. International NGOs are working also under this aspect: UTSS is releasing advertisement and making awareness focusing on the full inclusion of PWA in the Tanzanian society. This means special provisions in the school like magnifier and glasses but also a welfare state more orientated to PWA through free health assistance for some pathologies, like skin-cancer. Kenya set up a sort of priority line in the health system so they can be medically checked by specialist within two weeks. Beside it is a provision working for the capital area only,²⁶¹ the focus of the minister of health is clear: since PWA are suffering special and sensitive medical conditions a higher grade of welfare assistance is needed.

²⁶¹ Isaac Mwaura interview. See annex.

CONCLUSION

The attention of the media on PWA conditions in East Africa began in 2007-2008 contemporaneously to the peak of the PWA killings in Tanzania. Along with the national authorities several IGOs also moved through acts of condemnation and projects on the field.

The *European Parliament resolution of 4 September 2008 on the killing of albinos in Tanzania* has been the first followed by the US House of Representative²⁶² on the 10 of May 2010 and a motion to the Canadian House of Commons²⁶³ presented on 26 October 2011. The escalation of murders was brought to the attention of the United Nations. Peter Ash, leader of UTSS spoke to the UN Human Rights Council in Geneva raising further attention on the cases and gaining the condemnation of the Secretary General Ban Ki-moon.²⁶⁴ Also UNICEF released a statement condemning the persecution as “*barbaric and inhumane practices*” in which perpetrators are stopped and “*brought to justice, [...] ensure albinos like other citizens enjoy their fundamental rights to life, freedom and protection.*”²⁶⁵

NGOs and civil society play a major role as well: awareness campaigns, educational projects and indispensable supplies such as sun creams and magnifiers are distributed evenly in the four countries. Governments are conscious of the PWA needs and as seen in chapter 2, in asymmetric and differentiated policies are addressing them.

There is room for further improvements.

²⁶² US House Resolution 1088.

²⁶³ Proposed by the conservative MP Mark Warawa.

²⁶⁴ Dahee, 2009.

²⁶⁵ “*Following the spate of gruesome murders of albinos in Tanzania, UNICEF has called for more concerted action to stop the ongoing atrocities and speed up prosecution of the perpetrators.*” United Nations Children’s Fund, 2008.

PWA in the area - the country context

More research and information about albinism is required to fully address the situation in the Lake Victoria area. Statistics and censuses are pivotal to properly understanding and addressing the challenges of PWA in the area. Only Burundi has a clear view of the composition of its own population. A census has been planned in Tanzania but the low budget does not consider the amount needed to conduct the surveys. Kenya and Uganda's Albino Societies have already requested an official census of PWA and to be included in the official number of PWD with the right of a parliament deputy. Only knowing the composition of the society, proper policies can be put into place.

The legal framework of human rights

Under a legal point of view, the UN CRPD's first decision concerning an individual complaint was delivered during the first months of 2012 setting precedence for enforcement of non-discrimination in East Africa and the rest of the world. The Committee found a violation of Sweden on Articles 26, 28, 19 and 5 on the right to rehabilitation, health, independent living and discrimination.²⁶⁶ This is no doubt a step forward for the enforcement of the CRPD in which all but one of the states analyzed are included. States have the obligation to respect, protect and fulfill the rights of all the persons under their jurisdiction. No different treatment can be accorded to special groups or individuals since they are universal rights.

International actors can play a pivotal role in mainstreaming protection and the full enjoyment of rights for PWA: the Africa Union and the East Africa Community above all. The first promulgated was the African Commission on Human and Peoples' Rights, in existence since 1986, established under the African Charter on Human and Peoples' Rights. This is the premier African human rights body, with responsibility for monitoring and promoting compliance with the African Charter which the four countries are part of. The African Court on Human and Peoples' Rights was established in 2006 followed by an African Court on Human and Peoples' Rights which have two chambers:

²⁶⁶ CRPD/C/7/D/3/2011

one for general legal matters and one for rulings on the human rights treaties.²⁶⁷

The EAC is establishing a judicial body like the ECHR to better enforce the rights of PWA. A better integration within the four countries not only at an economic but also political level would enhance the possibility of protecting PWA. Police cooperation is already into force leading out arrests and conjunct investigations. Sharing the best practices, establishing common research programmes and developing common programmes can address a lack of funding.

The domestic level seems like a more proactive forum for the justiciability of PWA rights. The lack of enforcement of existing laws is the weakness of most countries analyzed with remarkable differences. After an initial period of *inertia* Tanzania prosecuted the murders and the persecution of PWA. The affliction paradigm is today opposed following rule of law and the human rights conventions of the XX century. Also Burundi and Kenya are strongly persecuting PWA crimes. Besides different legal frameworks and varying levels of enforcement there is no doubt that the countries' elite are refusing gruesome antiquated practices harmful to PWA.

Where there is still a lack of enforcement it is related to social paradigms: signing or even ratifying international instruments and updating local disabilities acts are useless if they are not enforced. The ratification of the OP CRPD in Kenya is also important and the ratification of both, convention and optional protocol, in Burundi as, at today, the CRPD have been only signed.

A specific enhancement of a disability legal framework in Burundi would be advisable, since criminal law is the only instrument in which PWA are addressed, reducing the

²⁶⁷ On July 1, 2008, at the African Union Summit in Sharm El Sheikh, the members of AU signed a protocol on the merger of the AfCHPR with the still non-existent African Court of Justice following a decision by member states at a June 2004 African Union Summit. As today Algeria, Benin, Burkina Faso, Chad, Côte d'Ivoire, Congo, Democratic Republic of Congo, Gabon, the Gambia, Ghana, Guinea, Libya, Mali, Nigeria, Niger, Senegal, Sierra Leone, São Tomé and Príncipe, Tanzania, Togo and Zambia have signed the protocol. Only two of them ratified it, Libia and Mali out of 15 needed for its entry into force. The new court will be known as the African Court of Justice and Human Rights.

legal intervention of the state only to cases of aggression. Moreover Uganda and Kenya should include albinism in their disability acts amending the current provisions which prevent official recognition. This would grant better inclusion through *ad hoc* interventions of the PWA: reserved seats in the parliament or in the disabilities councils for PWA would directly address the need for self-representation.

Government action

Considering that the richest country in the area, Tanzania, has 36% of the population living below the line of poverty, it is understandable that advocating for a better education can be viewed as naïve considering the other issues at hand. Nonetheless the key to putting an end to PWA discrimination is a major investment in education, even before the law and its enforcement; an inclusive school where PWA learn with the rest of the scholars and avoid marginalization is a tangible solution. I think the area is undergoing a slow cultural shift which can be sped up through schools and public plans. Inclusion right now is an internalized concept which has shown some results, already: PWA sit in the Tanzanian parliament today, in the Kenyan High Court²⁶⁸ and some key positions in government or private businesses.²⁶⁹

Unfortunately this concerns only some elite PWA. Often PWA suffers of solitudes and they believe albinism exist only in their area: remarkable results have been achieved through awareness campaign focusing how this condition is not unique and not landlocked just in their local area. The need now is to mainstream the majority of societies: this is possible only reaching the real society outside the capital in the rural areas, providing medical facilities and free periodic medical checks, enhancing education and fighting the prejudices. Some practices are already into force in mainstream areas, making them positive standard for the future.

Concerning education the CWA have to be seated close to the blackboard, to ensure they can follow the lessons. Considering the low vision condition the characters of the

²⁶⁸ Kenya's good move: Albino as High Court Judge among 28 new appointees, African Press International, August 22, 2011.

²⁶⁹ Isaac Mcwaura is special advisor of the prime minister in Kenya.

alphabet should be clear and of a proper size. They should be granted extra time to complete exams based on their low vision. An exemption of the school fee, school grants for uniforms, and books should be available for poor families in rural areas (as in Kenya). Handheld magnifiers and monacles for students should be available in every school, respecting in this way the fourth paradigm on disabilities.

Special rights to health must be granted: free or subsidized sunscreens, low vision aids and sunglasses should be available for poor PWA. The elimination of custom tariff on these items as financial aids to start local production should be a priority of the EAC.²⁷⁰ Rather than simply prevention, states should also enhance free treatment for skin cancer and free anti-retroviral therapy for PWA infected by HIV. A similar solution should be taken in effort to support who has been attacked and lives with prosthesis because an arm or leg has been amputated. Some NGOs have developed counseling and post-trauma healing centers to psychologically support the victims.

Today the cream used by PWA is common sun-protection bought in the grocery store. Studies should develop a proper cream adapt for PWA skin since, at today, the sun protection factors are the highest possible but remain inadequate.

Concerning those countries affected by trafficking, beside studies in Comparative Refugee Law advocates for granting a refugee status to PWA fleeing the country,²⁷¹ today there are conditions for internal relocation in the short term to put an end to the persecution in the long term. To do so society has to be acculturated regarding albinism, the police must be properly trained and the government machinery must work properly.

The paradigms

In an initial analysis, that would require further studies, it seems there are two main critical situations: a lack of political commitment to facing the marginalization of people with impairment (PWA in this case but the situation can be generalized to other marginalized groups as people with HIV or AIDS, pigmy, sickle-cell anemia, leprosy or

²⁷⁰It is instead the project of an NGO from Netherland in Tanzania: the Hand of Africa Foundation.

²⁷¹Larson, 2011.

even sexual minorities) and a lack on the theoretical approach concerning the law making process.

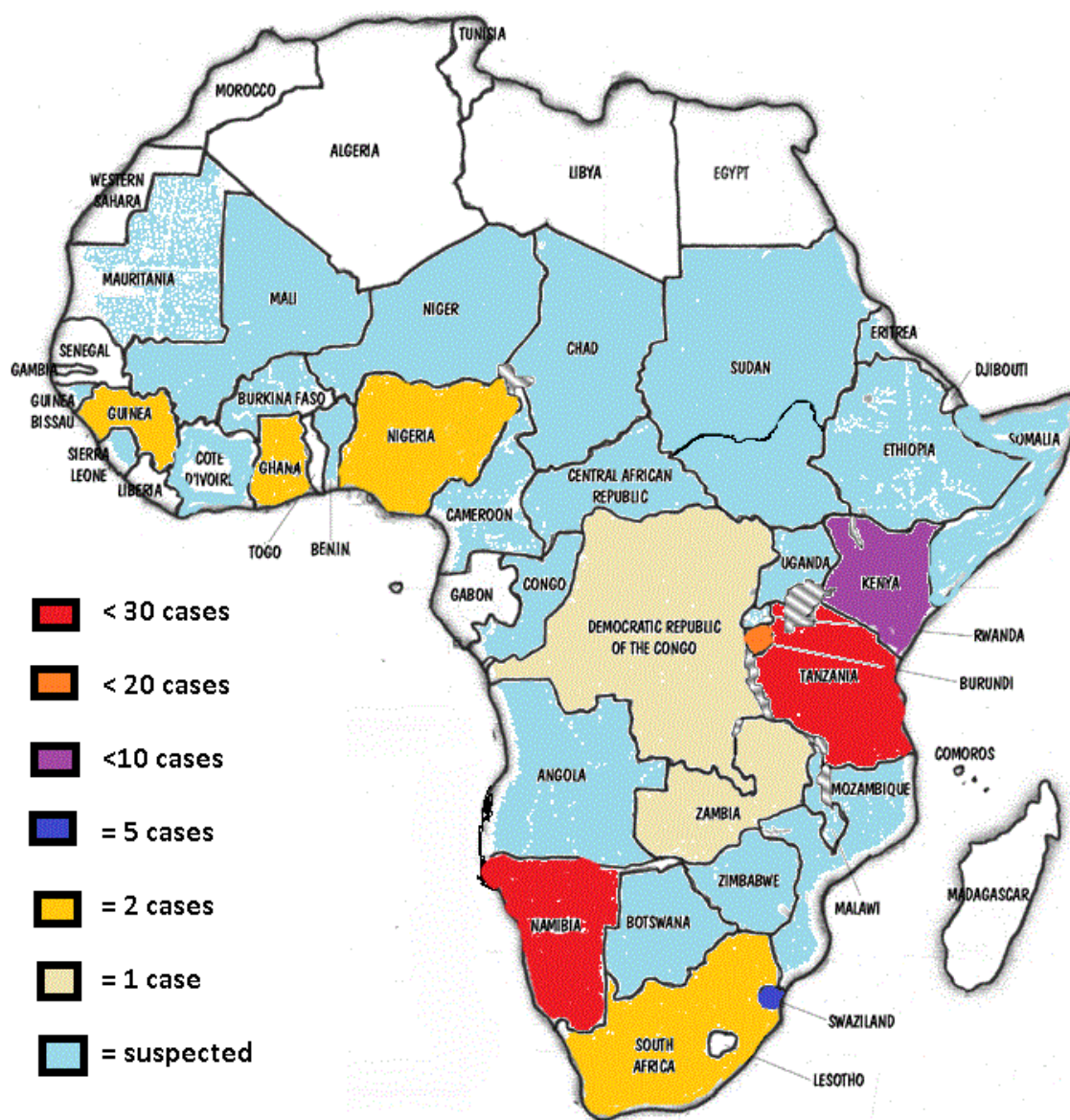
Often the states take commitments with the international community ratifying international convention like the CRPD, which are at the end not respected or neglected. Nonetheless a Disability Act enhancing non-discrimination and dignity for all is enough only if applied and not banished to a mere declaration of principles. The shift to the new paradigms is primarily cultural: the civil society must be educated towards the most recent paradigms. Only through awareness within the society the law can play a decisive role avoiding that some groups of people with impairments are not included, for example, in the legal definition of “*disabled*”.

Hence the major clash seems to be between the affliction paradigm and the more recent ones. In fact the role of the law in this case is secondary compared to deep traditions. Still today speaking about albinism and PWA is taboo in most of the rural families in Tanzania. Even in a different context (Europe) and in a proper environment (an office) speaking about albinism is extremely difficult because the interviewee becomes uncomfortable. The affliction paradigm is therefore prevalent in the society where most of the attacks are carried out.

The situation is different in official *fora* and institutions. The international civil pressure and the new conventions ratified by the governments include the most recent paradigms in the domestic legal framework. Beside that when it came to the implementation the law is influenced by low budgets and provisions far from the perceptions of the locals. Workers at international organizations and NGOs must be aware of the strong belief concerning witchcraft and of the barriers to a full implementation of the law. Ignorance and ambiguity generated gross violations of human rights in the whole Lake Victoria area. Education, awareness, accountability and rule of law are the answer to combat discrimination and persecution of PWA in the Lake Victoria area.

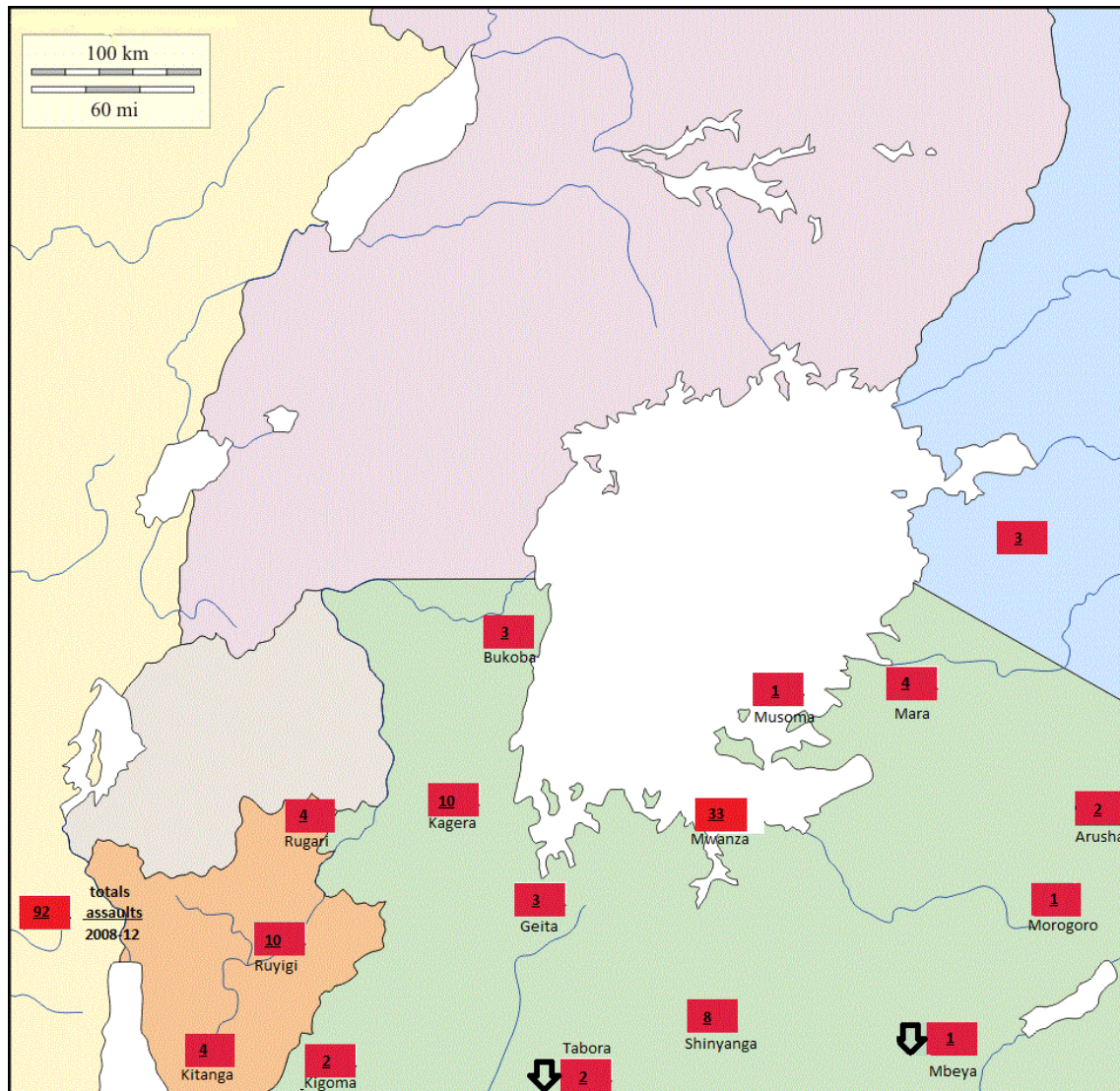
Annexes

Map 1: Attacks on PWA 2006-2012²⁷²



²⁷² UTTS and others data.

Map 2: Locations of PWA attacks in Burundi, Tanzania and Kenya²⁷³



²⁷³ UTTS and others data.

Data collected for others African Countries²⁷⁴

Swaziland, 3 reports:

The most recent attempted killing took place in April 2011.

32- year-old Dalton Muntfungaye Vila Kati had been stationed as a security guard at the Arrow Feeds office in Mustapha. Vila Kati claims that while he was going about his duties on the night which includes patrolling the premises, just before midnight he saw a group of armed men but did not read much into it. He said the men stood in darkness and ordered him to come closer for chitchat. This was when he got worried. Vila Kati's worries were motivated by the recollection of two previous attempts on his life last year, specifically because of his albinism. This was at the height of Albino killings in the country. Suspecting that they were on a mission to do something bad to him, he decided to run to his office for cover. "They (alleged attempted murders) called me by name, which was strange on its own, for over three times. Upon seeing that I was not responding and that there was no way they could gain entry, one of them shouted saying I was lucky to have a security room otherwise they would have cut my head to sell it. I heard one of them claiming they had lost an E1.5 million deal," said Vila Kati. Vila Kati said as the men cursed the failed attempt to behead him he heard one of them say they already had a buyer waiting for his head.

Two 11-year-old children were killed in August of 2010, with the most recent killing-taking place Thursday, August 19, 2010.

Guinea, 2 reports:

There were 2 killings reported in September 2010.

Nigeria, 2 reports:

The most recent killing took place in March of 2011 when a mother beheaded her 1-year-old son. Tragedy struck in Angyo village in Buruku LGA of Benue State recently when a mother of three children allegedly beheaded her last child for being an albino. The woman, Mrs. Doosuur Hembraor, a 35 year old house wife has therefore been

²⁷⁴ UTTS data.

charged before a Chief Magistrate Court in Makurdi for murder.

On October 10, 1999, a 1 and half year old boy was killed. While being breast fed, Chukwudinma Amamife was stolen from the arms of his mother by 2 men. Early the next morning reports came in that the headless body of an infant boy had been found. On February 16, 2005, all 4 accused, who were known to the mother of the boy, were charged in The High Court of Justice, Ogwashi-Uku, Delta State, Nigeria.

South Africa, 2 reports:

Since May 1, 2011 PWA youth (14), Sibusiso Nhatave has been missing. He is a Grade 8 boy from the north coast of KwaZulu-Natal - witchcraft feared. On November 11, 2010, a priest with albinism was killed. Mr. Sithole belonged to the Assemblies of God Church. He was killed and then burnt on his way to church in Kwaggafontein Village.

Democratic Republic of Congo (DRC), 1 report:

In November of 2008, a man was arrested in DRC. The man was caught carrying the head of a girl with albinism. He later confessed to police that he intended to sell the head “by weight”.

Zambia, 1 report:

In December of 2011 a 5-year-old girl with albinism was killed in Lusaka, Zambia. She was found with hair missing on the side of her head according to John Chiti, Director of the Albino Association of Zambia (Zambian Watchdog).

Namibia, 30 reports.

Several cases might be unknown.

Interview

Despite a long list of possible interviews I find in early February through contacts and former colleagues, only few of them have been prove useful for the research. Several have been really time-consuming without any relevant information added and for some of them valuable data have been given from the researcher to the interviewed. The lack of support and cohesion between NGO's and albino societies made difficult to find real expert on albinism with the result that often the information given was lacking of grounded fact. No single local PWA have been interviewed but I got in contact with one PWA refugee in Italy, from Cameroon that have been important to better understand the context in Africa. I also followed some workshops at the Danish Institute of Human Rights, which improved my knowledge on disabilities rights. Here there are two of the drafts I prepared for the interviews that have been used as models, even if I feel free to follow the stream of the conversation rather than a fix questionnaire. I prepared one for the organizations and another draft for single expert, academics or researcher on disability rights. The interviews will not follow the questions, but I will rather transcript the conversation.

Drafts

Dear CLARE WABULE,

I am currently writing a research thesis on persons with albinism (PWA) in the Lake Victoria Area taking in consideration four countries: Burundi, Kenya, Tanzania and Uganda. I am working for the Danish Institute of Human Rights in Copenhagen in partnership with EIUC - European Inter-University Center on Human Rights and Democratization - in Venice. As you may know, there is a very small body of work researching PWA in Africa, not to mention East Africa. This is why I am asking for your help concerning all the updates you might have including reports, statistics, projects or available budgets concerning PWA.

I attached two documents: a synopsis of my research and a short interview. You can decide to answer only some questions of the interview. Any help will benefit the research and the fight for a better inclusion and empowerment of PWA. In addition, you may ask to have your data withdrawn from the study after the research has been conducted.

A copy of the research will be available in July 2012. Thank you for your collaboration,

Best Regards,

You have been asked to participate in this short interviewer's research on the status of persons with albinism in Tanzania, Kenya, Uganda and Burundi. I attached a synopsis with the main objectives of the research. You have been chosen as an authority on the issue by the researcher. Quotes will be cited using your name unless you ask to remain anonymous. If you would prefer anonymity, please choose a pseudonym. You can answer in English, French, Italian or Spanish.

If you want to know more about this research, please contact me at:

gica@humanrights.dk

A copy of the research will be available in July 2012.

Sincerely,

You can decide to answer only some questions of the interview. In addition, you may ask to have your data withdrawn from the study after the research has been conducted.

I used two different versions depending if the interviewed was representing him or the organization/society/government.

1. How does your organization define disabled? Do you think the subdivision on the four paradigms of disabilities can be a good framework for an analysis on people with albinism as well?
2. Are PWA recognized disables under your national law? In which way the country protect, respect and fulfill the rights of PWA?
3. In some countries PWA are considered disabled because of low-vision (egg Canada), others for skin problem (Tanzania). What about your country? In which frame do you think PWA would be better protected?
4. Taking in consideration the four paradigms, which one has to be considered the real emergency in the country where you live?

- a) Killing/witchcraft/infanticide (affliction)
- b) Low-vision/skin cancer/health education (medical)
- c) Marginalization/mainstreaming primary-secondary education/vocational training-indoor job (sociological)
- d) Inclusion/fitting the legal definition/reintegration after hiding or displacement (new paradigm)

a) From my understanding the peak of the phenomena occurred in 2007-2008 when several killing have been reported. How is the situation now?

When the last attack occurred?

Are children and women with albinism particularly in danger compared to men with albinism?

Does the government properly address the problem? Do you have statistics?

What your association does in case of an attack?

Do you associate the rising killing phenomena to a loss of power of the traditional chiefs in local tribes?

Has the shift from a rural economy focused on shared resources with annual

government planning to hardcore capitalism contributed to the peak of 2007?

b) Under a medical point of view how your organization is moving? Information, sunglasses, creams distribution? What is the main need or emergency right now? If you have projects ongoing on the field, where your budget is focus on?

c) Addressing discrimination in employment and in the education system, do you have any project for the Lake Victoria area concerning school, mainstreaming primary-secondary education?

Do you currently have partnerships with other NGO's or IGO's? How is the collaboration with other sister organizations (other albinos societies, governments, local NGOs?

How much a degraded environment can be called responsible under a sociological point of view?

d) Do you think that PWA enhanced a better level of inclusion compared to 10 years ago?

Media are a powerful way to reach awareness, but Africa is dealing with several “human rights crisis”, how do you cope with more powerful campaign? Do you think other initiatives (e.g. Kony 2012) are detrimental to your cause?

3. Do you currently have PWA working or volunteering in your organization? Did you have any in the past?

4. If a PWA came seeking assistance, where would you refer them? Which kind of assistance can you provide?

5. Clearly the persecution of PWA is not a recent phenomenon. Why the civil society and the media started to address it only in 2007?

6. How your organization is coping with the poor data available, both under an academic point of view and statistically speaking?

7. How much is the year budget of the association? How is it used? (Percentage

administration, people's care, infrastructure...)?

Thank you very much for your collaboration, feel free to add any comments or note. As you may know, there is a very small body of work researching persons with albinism (PWA) in Africa, not to mention East Africa. Thank you, as your answers will help to change this.

Tanzania

I had the occasion to interview both Don Sawatzky, Director of Operations of the Under The Same Sun (UTSS) and Peter Ash CEO of the association. The UTSS states on his website:

“Under The Same Sun (UTSS) Fund 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. The UTSS Fund will support causes globally that meet these objectives and are approved by the Board of Directors. Currently, all UTSS efforts are focused on the crisis of persons with albinism in Tanzania.”

UTSS is the most active and committed association related the protection of PWA. Vicky Ntetema was a journalist and Tanzania's BBC bureau chief, and Peter Ash a Canadian businessman affected himself by albinism. Thanks to Peter Ash founding UTSS opened in 2008 in Canada as a local NGO and in 2009 as an International NGO with an office in Dar es Salam, Tanzania. The exchange of information and data have been an ongoing stream for the last 5 months and despite the few information available in general on the area concerned, UTSS resulted to be by far the most reactive, committed and collaborative.

Interview with Don Sawatzky (DS).

Director of Operations - Canada

Under The Same Sun (UTSS)

400-15225, 104 Avenue

Surrey, B.C. V3R 6Y8

W. 604-587-6509

F. 604-634-0244

don@theashteam.com<mailto:don@theashteam.com>

DS considers the inclusion in the disability cluster as part of the solution to enhance the protection and the rights of PWA. Not everybody agree, deep differences there are between north and south countries of the world. Tanzania considers PWA disables taking in consideration only their skin, not taking in consideration the low vision. Despite in several countries the skin is a secondary issue compared to low vision, no legal framework provide a legally blind status for PWA in Tanzania. Tanzania face the most numerous and gruesome attacks on PWA. The numbers are not reliable and UTSS consider the numbers of killing (80) and attacks (24) way below the real quantity. In the country the machete attack is a common offense that often is not denounced.

Following an introduction on witchcraft and persecution of PWA, DS sustained how capitalism had a pivotal role on the raising killing phenomena. The big structural and economic changes that Tanzania underwent some decades before made available a big quantity of money: what was reserved to tribe chief is nowadays affordable to a wider group of population. In the past human sacrifices were uncommon between “normal” people and only the chief were asking to witch-doctors special potions or requests. The combination of social adjustment where the tribes were losing power on their people and capitalism create a tsunami in the society.

The poor data collected by the authorities and UTSS do not make possible to understand if the violence is gender based. The association focused more on the quality of the attacks analyzing it depending it on the events. This is why the data can be divided on grave robbery, murderer, and normal robbery. It is not possible to determine the average age of the victims, the gender and the quality of the attacks. Lack of data there are due of the difficulties on retrace the information.²⁷⁵ This is a critic that makes some data

²⁷⁵ and small stuff in my opinion.

irrelevant. It would be important to know how many persons have been buzzed for their hair or how many underwent to nails cutting, since it is a form of violence as well. The 55, 9% of the assaulted are children.

DS considers the efforts of Tanzania still not sufficient, blaming the English code of law where an accused is innocent until is proved guilty. Instead in Burundi the accused is guilty until when is proved innocent.

The cooperation with other associations is poor. Some contacts have been established with Tanzania's Albino Societies (TAS), and some common workshops and visits have been carried out with the South African Society, Nigeria Albino Society and Guinea Albino Society. Several contacts with other local or other national NGOs have been disappointed since corruption and rivalries have marked the process.

Concerning the founding, UTSS is basically relying almost completely on Peter Ash family, the CEO and founder of UTSS. Out of 1, 3 million of budget in 2012, almost 1 million come from him contribution. Unluckily no public budgets are available. No public funding is granted from IGO or other states, the rest of the funds come from private donations, mostly in Canada and US.

UTSS office in Vancouver, B.C., Canada, has a total of 7 staff. Three are PWA. 1 Full time, 3 Part times, 2 Volunteers. One full time will be hired soon. UTSS office in Dar es Salaam, Tanzanian has a total of 14 staff. Ten are PWA. 11 Full time, 1 Part time, 2 Interns. As of May 2012, UTSS has 2 offices and 21 staff, including Peter Ash. Thirteen are Persons with Albinism (PWA).

The Education Scholarship Fund (ESF) program has more than 57 education institutions in which we are sponsoring ESF grantees. Among these schools, a few are primary schools with a good number of students. The rest of the schools are secondary schools universities and colleges. UTSS ESF program to date has 318 registered grantees. Actual numbers who are in schools are 273, within this number 12 have graduated and 8

are expected graduates this year. Every year UTSS advertise new vacancies to maintain 300 grantees each academic year. These numbers will change by the time this research will be published.

Phone interview of the 17 of May 2012.

Burundi

During the first census of the number and composition of the PWA in Burundi the NGO RCN Justice & D  mocratie started a project in defense of the people affected by albinism. I consider this quotes can work the best to make an idea of the situation in Burundi:

"Mutoyi wanjye yaratotejwe, umwigisha wiwe yaguma amubwira ngo" ehe ico cana this ikivagundu kitabona, abandi bana nabo ehe ca ngo nyamyoma, ikinyeshamba, ibindi bitutsi ntosubiramwo do." Uwumuremyi Desiree, 17, Student. My little sister was traumatized by her teacher. He told her it was not normal because his vision was flawed, and worse his friends told him that his place should be somewhere in a forest.

"Nta rubanza did rumwe ndajamwo, ntibantumira Kuko baranyinuba" Bigirimana Winnie, 18, farmer. I never participated in a social ceremony because they do not invite me, people discriminate against me.

"Ntibantumira, Ngenda nk'umuvumvyi ndondera ivyonywa not ivyondya" Tagato Antoine, 50, farmer. (Speaking about a weddings) They do not invite me, I would like to go without invitation just to eat and drink.

"Abanyamwema bari mu bandi badasa baca Baguma bibaza igituma badasa not abandi kandi bakagira Kubera isoni Baguma bamuraba" Kaneza, Evelyne, 10, student. When albinos are found with others who do not look like them, they often wonder why this difference in color and they (PWA) are often ashamed to see that other people regard them with disdain.

"Nkiri umusore naragiye i gusabayo Akazi Bujumbura, nipfuza umukozi kuba wo mu NZU Mugabo barakanyimye bavuga ngo sinoshobora kurinda ubushuhe BWO mu gikoni " Nshimirimana Ernestine, 30 years, farmer. When I was young, I traveled to Bujumbura in search of work, I wanted to be a chef, but I was denied the job claiming

that I could not withstand the heat the kitchen.

"Ubuzi bwabo buragoye Kuko Bamana ingorane z'urukoba abantu barabinuba kandi cane" Niyonzima Jacqueline, 42, mother of a PWA. Having a job for PWA raise conflicts in the society not only for the poor health, but because the people disdain him.

"Umunyamwema ntimwosangira ubutsima Kuko uruhu rwiwe ruca rummyokera matured ubwo butsima" Niyongabo Jonas, farmer 45. Nobody wants to share a flat with an albino, especially because of the peeling problem.

"Nari nakowe hanyuma abavyeyi b'umuhungu baranka ngo sinzobagerera rugo. Umuhungu we muyarankunda muga nemeye gusubiza inkwano Kuko ntashobora kuja mu rugo ntakundwa. Kuva igo gihe uwo Muhungu yaciye yigira i i Bujumbura ntarasubiza ikirenge Muhira ubu twandikiranira udukete " Habonimana Emeline, 18, waitress in a restaurant. I have an albino child but the parents of my husband did not agree with our marriage. I could not venture to go in a household where I would feel never safe. Today, the boy is in Bujumbura, he never set foot in his home. For the time, we send letters to keep each other closer.

"Baradukumira kibano mu, bamwe bavuga turi ibihume ngo, ntamwidegemvyo tugira Kuko ntidushobora gutemberera ahantu kure Kuko dutinya kwicwa. " Niyoyitungiye Eric, 19, Student. We are discriminated against in our environment, some say that we are monsters. We cannot move freely because we are afraid of being killed.

"Mu buriro, hariho abadashaka ko ko dusangira ibifungurwa canke dutizanya udukoresho tumwe tumwe" Nshimirimana Felix, 21, Student. In the refectory, my friends do not want to share the meal or other effects.

These remarks were reported by albino people who spoke of the discrimination they suffer. This is even more alarming when those who commit such acts are close: neighbors, schoolmates, teachers etc..

Another testimony shows that people with responsibilities in the state institutions can also have a pattern of discrimination against persons with albinism. I will report the denounce of an officer of the National Defense Force of Burundi: "One day I went into a micro-finance institution called CECAD7, someone had commissioned to withdraw money from his account. Waiting to be served, we were in a queue and a military launched these words: "Look at that booty, money that walking around in the street (sic)." The PWA answered: "There are heads that are the shame of their bodies and need to be strengthened to be consistent with the ethics required by their profession". And he added: "Would you believe that you are responsible for protecting the entire population including persons with albinism?!" After my reply, he did not answered and even those who were in the queue remained silent. I felt that my message in a firm tone has surprised many who thought, perhaps, that I was going to accept this denigration without reacting".

Kenya

Mwaura Isaac is the Special Interest Group Advisor in the Office of the Prime Minister. He is also the National coordinator of the Albinism Society of Kenya (ASK). He had several years of experiences as human rights advisor in Papua New Guinea and he has been senior researcher at the Kenyatta University.

As the official speaker of ASK, on the 12-06-2012 he succeed on raise the public founding from 100 K shillings to 400. The 20.000 PWA registered in the albino society will therefore benefit of regular provisions of sun creams, the institution of an official center for albinism in charge of research and data collection, a new headquarter for ASK and the institutions of a micro-financing system for PWA in economic problems. The new foundlings will also help to ensure policy structures through social development and justice.

Beside the People with Disabilities Act of 2003 is a good instrument to enhance PWA rights, it does not include albinism as a disability. By the end of June 2012 Mwaura Isaac will start a series of meeting with the minister of justice to change and let include PWA in the cluster through numerous amendment already presented front to the Parliament.

Differently from how is intended in Tanzania, PWA are considered have an impairment only concerning visions problems and not skin problems. In the meantime the society is wondering how to exclude the categorization on impairment without losing the accessibility to additional rights. In fact the categorization is misleading the rest of society, from one side, and it does not give enough public founding on the other side since they need to *share the cake* with others disabilities, which often has the priority. In sum albinism is considered a second league disability concerning the mainstreaming and the founding but it is still experiencing a strong societal reproach, worse than the others minorities and disabilities group in the country.

Under a more practice point of view, PWA can enjoy free medical check in the main hospital of Nairobi enhancing the new social paradigms. ASK is providing sun creams and counselors to all them associates.

Isaac Mwaura underlined also how the sun creams is directly bought from the supermarket: in this way no dermatological test have been ever carried out. The highest protection, skin type 1, is still too lower considering the sensitivity of their skin. A new focus on the needs of PWA have to be created since not only technical stuff, like the cream, are precarious but the more you travel outside the capital the most PWA you find are carrying out really basic and manual jobs and they suffer of low self-image. On the 4 May 2011, on the first albinism day celebration of the country the association had the opportunity to quickly enquire the conditions of their associated: most of the women present to the celebrations have sons and daughters but not partner. CWA are often casted away and they suffer of solitude.

According to Isaac the prejudice is based on the white skin which makes them, in a way, similar to white people. Often in public market he does not buy items directly but let his girlfriend do it: he would be charged up to half more of its prize just because is an *albino*. The situation changes markedly outside the capital: around the Lake Turkana area no PWA can be found. If Tanzania saw an escalation on witchcraft well documented on the media, Kenya did not report so many killing and assaults. The absence of PWA in some area is extremely suspicious. Often ASK received allegations that cannot be proved and, therefore, are not further investigated.

The Albino Society of Kenya is currently working thanks 7 paid clerk focusing on advocacy, support membership, sun creams distributions and aware creation and civic education. A proposed sector on microfinance might be open soon thanks the new allocation of founding of the ministry of social development. No volunteer are present in the society.

Phone Interview of the 16-06-2012

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