



**SITUATION ASSESSMENT OF THE CENTRES OF DISPLACED PERSONS WITH
ALBINISM IN THE LAKE ZONE AND TANGA REGIONS
FINDINGS FROM UNDER THE SAME SUN SURVEY 2011**



**SITUATION ASSESSMENT OF THE CENTRES OF DISPLACED PERSONS WITH
ALBINISM IN THE LAKE ZONE AND TANGA REGIONS
FINDINGS FROM UNDER THE SAME SUN SURVEY 2011**



UNICEF Funding and technical support

PMO-RALGA, MoEVT, MoHS, of Tanga and the Lake Zone regions

Under The Same Sun - UTSS

October 2012

© Under The Same Sun - UTSS

Cover photo: Rick Guidotti, Positive Exposure





Permission to reproduce any part of this publication is required.

Please contact

Executive Director
Under The Same Sun
P.O. Box 32837
Dar es Salaam
United Republic of Tanzania
Tel: +255222780224
Email: info@utsstanzania.org

Permission will be free granted to educational or non profit organizations

Others may be requested to make a small donation

Dar-es-Salaam, October 2012

ISBN: 979-9987-9611-4-6





PREFACE

According to Kirk (1972), albinism is a hereditary and congenital condition characterized by relative absence of pigment from the skin, hair choroids coat and iris. Whitting (1977), adds that albinism occurs in every race whether white, black or yellow and it is in every part of the world.

According to UNESCO (1982), the origin of albinism is thought to be supernatural in the Central African area. These are myths and cultural beliefs in that region engrained in the society where persons with albinism are seen as reborn spirits who have to be treated with great respect. They are sometimes feared in the sense that their mishandling may cause misfortunes. For instance, among the Congo sub-groups, persons with albinism were regarded as reincarnation of some spirit and hence had a special status in the group. On the other hand the Solongo of Congo subgroups viewed persons with albinism as having separate existence from their parents.

People with albinism at regional level for instance in some East and Central African countries have been killed and mutilated for their body part. They continue to suffer from discrimination, stigma and social exclusion. Recently, in Tanzania, Burundi, Rwanda, Kenya and Uganda, killings of people with albinism have been witnessed occurring due to myths, witchcraft and cultural beliefs. The murders have instilled fear among individuals with albinism and their families. Indeed, many Tanzanians have been disappointed by the killings conducted by uncouth and ruthless people (Possi, 2008). The killings have forced individuals with albinism and in some cases the whole family from their homes ending in government-designated centres for displaced persons with albinism.

Apart from the plight of persons with albinism, there are other men and women, as well as children without the genetic condition who have found themselves in the same predicament as a result of the atrocities, discrimination and stigma in their home villages. These include parents, especially mothers or grandparents who have children or grandchildren with albinism. In fact, they have been denied their rights of living in their own homes, where they are born and bred





Under The Same Sun (UTSS) conducted a current research aimed at assessing the situation of the centres where individuals with albinism and other disabilities are currently living after they were rescued from rural Tanzania, they became targets of the murderers in search of organs of persons with albinism.

The study area included Tanga, Mwanza, Shinyanga, Tabora, Kagera and Kigoma regions. The violence, killings and / or maiming of individuals with albinism are associated with witchcraft, myths and some false cultural beliefs. These inhumane acts against persons with albinism leave them with emotional and psychological trauma; recurring memories of past painful events have long term impact on the individuals.

It was evident that children who experienced killings and serious physical abuses could be in danger of harming themselves or others, and that such behaviours may persist for a long time if no steps are taken to address the situation. It was noted that some of such children refused to go to school for fear of being attacked on the way to and from the institution and /or dropped in their performance. They also lost interest or pleasure in activities that were once pleasurable for them. This report provides information of the results of the situation assessment which was conducted by UTSS in 2011, highlighting what was going on in the established centres where people with albinism were dropped to live after being rescued from rural hostile environment.

The obligation for all states to work towards elimination of all forms of violence, harming and or killing others, in this case, people with albinism, protecting individuals and human rights including the right to survive or live, is well recognized by the Convention on the Rights of the Child which was ratified by Tanzania in 1990. Efforts to prevent violence are part of the government's national commitment to uphold the right of each individual to his or her human dignity and physical integrity. This commitment is reflected in the Tanzania law of the Child Act No.21 of 2009 and the People with disabilities Act (2010). The results of this study will help the





Government of Tanzania through her line Ministries, the multi-sector Task Force and leadership of the established rescue centres to establish effective mechanisms:

- To use professionalism of her people in the Social welfare department in rendering services to persons with albinism;
- To regularly monitor and evaluate the functioning of the established rescue centers as well as improving the infrastructures;
- To establish a system which will allow children to reunite with their parents and relatives on a regular basis;
- The development agencies and CSOs, shall be well vested with clear information they can work on in order to improve the conditions in the designated centers of the displaced persons with albinism;
- Activists shall play their role better to lobbying and advocating for improved conditions of PWA and their centers.

CSOs and other development agencies may offer technical support and human and material resources for sustainable and improved standards of living of PWA. All in all, it should be noted that responses to the highlighted challenges facing people with albinism are required to come from all sectors including health, education, justice, social welfare and at all levels from individuals, families, communities, CSOs, regions, national and international in general. UNICEF and other stakeholders would be willing and ready to support the initiatives to render care, protection and support for the wellbeing of persons with albinism.

UTSS is proud to have hosted this study. However, it recognizes the most important challenge which lies ahead; how to translate the findings of the study into effective responses that will end the atrocities, butchery, mutilations, violence, stigma and discrimination against persons with





albinism. Otherwise, UTSS for its part remains strongly committed to this noble cause of promoting the wellbeing and rights of PWA in Tanzania. With this in mind, UTSS will develop a five years Plan of Action at national level to deal with the problem as a response to the above challenges (2014 – 2019).

Delivering against the plan to make measurable changes that will create a secured and conducive Tanzanian environment for persons with albinism to live peacefully and comfortably. This of course will require strong partnership and commitment from individual citizens, communities, development agencies, CSOs and the nation at large aiming at making Tanzania a model African country where PWA and other pigmented citizens can live in harmony without fear of being persecuted.

Vicky Ntetema
Tanzania Executive Director,
Under The Same Sun – UTSS





Table of Contents

PREFACE.....	4
SITUATION ASSESSMENT OF THE CENTRES OF DISPLACED PERSONS WITH ALBINISM IN THE LAKE ZONE AND TANGA REGIONS.....	11
FINDINGS FROM UNDER THE SAME SUN SURVEY 2011.....	11
LIST OF ABBREVIATIONS AND ACRONYMS	16
ACKNOWLEDGEMENT	17
EXECUTIVE SUMMARY	18
1.1.3 Objectives of Situation Assessment.....	32
1.1.4 The specific research objectives	32
1.1.6 Research design	33
1.1.7 Sampling Techniques.....	33
1.1.8 Sample size	34
1.2 Data collection methods.....	42
1.2.1 Observation.....	43
1.2.2 Secondary Data review	43
1.2.3 Focus Group Discussions.....	43
1.2.4 Data analysis methods.....	44
LITERATURE REVIEW	49
3.0 Introduction.....	49





3.1 Description	50
3.2 Demographics	50
3.3 Causes and symptoms	51
3.5 Diagnosis	53
3.7 Prevention	55
3.8 Parental concerns	56
3.9 Public Sector Response.....	61
3.10 Future Direction/Recommendations	62
5.3 First conviction	77
5.4 International reaction	78
DISCUSSION AND RECOMMENDATIONS	86
8.1 Conclusions	97

Table of Figures

Figure 1 The number of people who participated in the Study.....	34
Figure 2 Frequency of Violation of Human rights at the centres	36
Figure 3 Treatment of CWA at Mitindo centre	37
Figure 4 Treatment of CWA at Mugeza centre	39
Figure 5 Value centre infrastructure	Error! Bookmark not defined. 40
Figure 6 Value a need for leisure and entertainment provision	42





Figure 7 Number of CWA who participated in the study.....	Error! Bookmark not defined.
Figure 8 Number of children with other disabilities - CWOD	48
Figure 9 Treatment of CWA a case at Mitindo centre.....	49
4.0 Case Studies	63
4.1 Case Study One.....	64
4.2 Case Study Two	66
4.3 Case Study 3	68
Figure 10 Percentage of CWA at each centre.....	80





SITUATION ASSESSMENT OF THE CENTRES OF DISPLACED PERSONS WITH ALBINISM IN THE LAKE ZONE AND TANGA REGIONS

FINDINGS FROM UNDER THE SAME SUN SURVEY 2011

The UTSS study was guided by the efforts as part of the government's national commitment to uphold the right of each individual to his or her human dignity and physical integrity. The commitment reflected in the Tanzania law of the Child Act No.21 of 2009 and the People with disabilities Act (2010) which were even re-emphasized for implementation by the Prime Minister Hon.Kayanza, Peter Pinda in January 2009 when he was responding to the pleas of persons with albinism after a series of atrocities including mutilations and macabre killings of PWA in the area. Moreover, a pilot survey which was conducted by UTSS reinforced the initiatives to looking into possibilities of doing an official survey to assess all centres of the displaced PWA in Tanga and the Lake Zone . UTSS visited the government established centres in Buhangija (Shinyanga region) and Kabanga in Kigoma region as for pilot survey, where they found the centres were in bad condition that is not conducive for people with albinism to securely live.

Recommended Citation: Possi (1984) Facts and Myths about Albinism, Some aspects of education of the albino children in Tanzania, From Special to Inclusive Education for Children in Special Needs in Tanzania, People with Albinism in Tanzania: Endangered Species? Tracy et al (2006), Nightmares, demons and slaves: Exploring the painful metaphors of workplace bullying, Zubenko, et al (2002), Children and Disasters. The findings and commendation of this report are those of the authors (UTSS) and do not necessarily represent the official position of UNICEF or the Government of Tanzania.





CONTRIBUTORS

UNICEF Tanzania, PMO-RALGA, MoEVT, MoHS, of Tanga, Mwanza, Shinyanga, Tabora, Kigoma and Kagera regions.

Study Coordinators/contact persons – UNICEF Tanzania: Asa Olsson

Study Design, Protocol Development and Implementation – Under The Same Sun - UTSS

Lead Researcher

Professor Mwajabu Possi

Field team leaders

Gamariel Mboya, Professor Mwajabu Possi and Vicky Ntetema

Interviewers

Benedict Mashaka Barnabas, Deo Mbakile, Gamariel Mboya, Graceana Kavishe, Happiness Ngaweje, Mwamrisho Kasule, Nemes Temba, Prof. Mwajabu Possi, Sono Kusekwa, Sydney Mwamulima and Vicky Ntetema

Data analysis, technician and report writing

Paschal J.Maziku





KEY TERMS AND DEFINITIONS

In this report, the terms below are defined as

Albinism

According to Miller-Keane (2003), albinism is a hereditary disorder, usually transmitted as an autosomal recessive trait, in which there is partial or total absence of pigment in the skin, hair, and eyes (*oculocutaneous albinism*) or in the eyes alone (*ocular albinism*), caused by defective or absent function of the enzyme tyrosinase. It is imperative that individuals affected with albinism be taught how to protect themselves from the harmful effects of the sun.

Atrocities - extremely wicked, brutal, or cruel

Disability - A **disability** is an impairment that may be physical, cognitive, mental, sensory, emotional, developmental, or some combination of these. A disability may be present from birth, or occur during a person's lifetime

Anxiety - **Anxiety** is an unpleasant state of inner turmoil, often accompanied by somatic cognitive and behavioural elements. It is the subjectively unpleasant feelings of dread over something unlikely to happen, such as the feeling of imminent death. Anxiety is feeling unrealistic fear, worry, uneasiness, and dread, usually generalized and unfocused.

A state of mild to severe apprehension often without specific cause, resulting in body changes such as quickened heartbeat, panic and sweat.

Amino acid —An organic compound composed of both an amino group and an acidic carboxyl group. Amino acids are the basic building blocks of proteins. There are 20 types of amino acids (eight are "essential amino acids" which the body cannot make and must therefore be obtained from food).

Astigmatism —An eye condition in which the cornea doesn't focus light properly on the retina, resulting in a blurred image.





Carrier —A person who possesses a gene for an abnormal trait without showing signs of the disorder. The person may pass the abnormal gene on to offspring. Also refers to a person who has a particular disease agent present within his/her body, and can pass this agent on to others, but who displays no symptoms of infection.

DNA —Deoxyribonucleic acid; the genetic material in cells that holds the inherited instructions for growth, development, and cellular functioning.

DOPA —The common name for a natural chemical (3,4-dihydroxyphenylalanine) made by the body during the process of making melanin.

Enzyme —A protein that catalyzes a biochemical reaction without changing its own structure or function.

Gene —A building block of inheritance, which contains the instructions for the production of a particular protein, and is made up of a molecular sequence found on a section of DNA. Each gene is found on a precise location on a chromosome.

Hairbulb —The root of a strand of hair from which growth and coloration of the hair develops.

Hermansky-Pudlak syndrome —A rare type of albinism, most common in the Puerto Rican community, which can cause pigment changes, lung disease, intestinal disorders, and blood disorders.

Melanin —A pigment that creates hair, skin, and eye color. Melanin also protects the body by absorbing ultraviolet light.

Nystagmus —An involuntary, rhythmic movement of the eyes.

Strabismus —A disorder in which the eyes do not point in the same direction; also called squint.

Tyrosinase —An enzyme in a pigment cell which helps change tyrosine to dopa during the process of making melanin.

Discrimination- Discrimination refers to the treatment or consideration of, or making a distinction in favour of or against, a person or thing based on the group, class, or category to which that person or thing belongs rather than on individual merit.





Displacement -The act of displacing; the act of removing from the usual or proper place, or from a state, condition or office. It is being shifted from one's home area or place to another against one's wish.

Hyperactivity is a physical state in which a person is abnormally active. The colloquial term hyper is used to describe someone who is in a hyperactive state.

Perpetuating- to cause to continue indefinitely; make perpetual. To prolong the existence of; cause to be remembered.

Reincarnation- Reincarnation is the religious or philosophical concept that the soul or spirit, after biological death, begins a new life in a new body that may be human, animal or spiritual depending on the moral quality of the previous life's actions

Segregation- Segregation is a system that keeps different groups separate from each other, either through physical dividers or using social pressures and laws

Superstitions- Superstition is a pejorative term for belief in supernatural causality: that one event leads to the cause of another without any physical process linking the two events, such as astrology, religion, omens, witchcraft, etc., that contradicts natural science.

Victimize- a person who suffers from a destructive or injurious action or agency. A person who is deceived or cheated, as by his or her own emotions or ignorance, by the dishonesty of others, or by some impersonal agency: for instance a victim of misplaced confidence; the victim of a swindler; a victim of an optical illusion. A person or animal sacrificed or regarded as sacrificed: war victims.



LIST OF ABBREVIATIONS AND ACRONYMS

BBC	British Broadcasting Co-operation
FGD	Focus Group Discussions
MoEVT	Ministry of Education and Vocational Training
MoHSW	Ministry of Health and Social Welfare
MSD	Medical Stores Department
NGO	Non-Governmental Organisation Organization.
PMORALG	Prime Minister's Office Regional Authority & Local Government
PWA	Persons with albinism
TAS	Tanzania Albino Society
TRCS	Tanzania Red Cross Society
UNESCO	United Nations, Educational, Scientific and Cultural
UNICEF	United Nations Children's Fund
UTSS	Under The Same Sun





ACKNOWLEDGEMENT

This report would not have been a reality without the institutional support and cooperation between Under the Same Sun (UTSS) and UNICEF. We consequently wish to thank very much not only the financial assistance from UNICEF, but also the invaluable advice received from Åsa Olsson and other UNICEF representatives. It is through their linkage that UTSS managed to smoothly forge ahead with the research. Åsa is also instrumental in training research assistants. Her input is very constructive during preparation of instruments and data collection.

Our thanks should also go to PMO-RALGA, MoEVT, MoHS, Misungwi District, Karagwe District, Bukoba Rural District, Kasulu District, Tabora Urban District, Shinyanga Municipal Council, Tanga City Council and Urban District, Management and staff of the surveyed schools, all individuals who participated in the research from the sampled regions and institutions. We thank them a lot for their contributions, especially for their candid information and advice.

Our heartfelt thanks should also go to all children in the centres who provided valuable information amidst fear that their names would be exposed. They provided us vital information when they are required to verify some issues emanating from the research findings. To them we say, *“We abide by research ethics and promise to keep your names unanimous as requested”*.





EXECUTIVE SUMMARY

This 2011 UTSS study was conducted to assess the conditions of the government designated centres for the displaced PWA where they live with children with other disabilities following a wave of macabre killings of persons with albinism. The study also looked into conditions of the individuals in the centres in terms of quality of the services rendered to them. Issues on focus included the care which was rendered to PWA in the centres, basic needs and human rights, their safety, security and whether they would like to maintain family ties. The study explored the nature of services and how such services were provided by the general staff, care givers, doctors, social welfare officers as well as the district and regional educational officers.

The study was guided by the International Convention on the Rights of a Child (CRC), the current Child Act No 21 of 2009, the recent government call through the Prime Minister of the republic Government of Tanzania who urged Tanzanians to join hands in care and protection of persons with disabilities and in a special way persons with albinism whose lives are threatened by the continued brutal killings and mutilations. Moreover, UTSS as an implementer of such decisions, fulfilling its obligation to achieving its goals and objectives, decided to conduct this research for better, scientific, well informed and effective programming aimed at improved holistic care, support and protection of persons with albinism in Tanzania.

Within the six regions where the study was conducted, the research team visited 9 centres namely; Buhangija (Shinyanga region), Bukumbi and Mitindo (Mwanza region), Kitengule and Mugeza centres (Kagera region), Furaha and Missionaries of Charity (Tabora region), Kabanga (Kigoma region) and Pongwe in Tanga region.

The regions were strategically sampled depending on reported cases and how alarming were the survival threats against PWA in those regions, development, the nature of the students and care





provided to them, as well as the existence of children and adults who are affected by atrocities and killings in their home villages. Purposive sampling is used to obtain participants of different age strata and took into consideration aspects of gender, sex, and type of disability.

The focus of the study was PWA. However, the study had to look into the situation of other children and individuals with other disabilities who initially were the residents before children with albinism (CWA) and adults were sent there by either government officials or parents and relatives for their safety and security. Individuals found living with PWA include the hard of hearing and dumb, those who are physically challenged those with vision impairment and those with low vision. There were few cases also of some individuals who had mental disorder.

The results of the study have indicated that the situation of children, especially those residing in centres/schools, is generally on the average while in some centres, the condition is very appalling. Some children complained of being sexually harassed, others complained of not being given quality care and that were being discriminated against, and that others complained of loneliness and wished to go back to their home places. With children's protection and rights, it is discovered that efforts are being made to protect the children in some centres and schools, while in others, there are no adequate protection measures in place. Some of the centres/schools had no fences and security officers were either irresponsible or too old to manage the task, or were sexually harassing the children. It was also discovered that many of the schools/centres, had dilapidated infrastructure and with very few members of staff.

In terms of ownership, it was learned that some of the centres are under the government (Ministry of Education and Vocational Training (MoEVT) as well as Ministry of Health and Social Welfare (MoHSW), District or Municipal Councils), while others are owned by Faith-Based Organizations (FBO). All the surveyed institutions have boarding facilities. It was also learnt that some schools and centres have very meagre resources in terms of human and financial resources, infrastructures and physical environment, teaching and learning materials/





equipments, as well as poor food diet for the children. The institutions had poor health and hygiene conditions, safety, security and child protection facilities. For instance, there were risk concerns due to lack of fences around some of the centres.

In analysing the recreational facilities, it was discovered that some centres lacked places for recreation such as games, sports, concerts, plays, poetry, and singing (choir). There was also lack of psychosocial support for children at the centres. Some of them had matrons and teachers who were very supportive while others did not have such support. Some children were interacting with members of the community through visitors' days as well as open days. Further, some children were visited by family members and relatives while those who were dumped by their families in the centres did not maintain family ties. The main challenges were that, except for a few children and adults at the centres who had horror and tragic experiences, the majority of CWA were unhappy at the centres.

There is need of finding out which children have to live in the centres as opposed to those who do not have to do so. It is also important to establish the type and extent of support needed, and find out which children could be sent back to their families after raising public awareness on albinism and on the importance of accepting, loving and caring for children with disability. Further, it is important to educate people on the causes of albinism, and that body parts of the individuals do not and would never, make one wealthy and successful. Awareness raising seminars and training should be conducted for teachers, caregivers, students and members of the community on the importance of taking care of children in difficult conditions as well as those with albinism and other disabilities. It is also recommended that there be training of parents or awareness rising so that they accept their children regardless of their physical and mental conditions. It is suggested that the government should step-in in assisting parents to take care of children living in difficult conditions.





The government, faith-based organizations, members of the community and well wishers should provide food and maintenance funds, personnel as well as necessary infrastructures to the centres. For instance, the centres should be made user friendly and accessible for individuals in special needs by having in place the necessary infrastructures.





SITUATION ASSESSMENT OF THE CENTRES OF DISPLACED PERSONS WITH ALBINISM IN THE LAKE ZONE AND TANGA REGIONS

FINDINGS FROM UNDER THE SAME SUN SURVEY 2011

KEY FINDINGS

UTSS conducted the current research with the intention of assessing the situation of the centres in Tanga and other five regions of the Lake Zone, where individuals with albinism and other disabilities were living by the time of the study.

Witchcraft killings and atrocities against PWA were threatening and disturbing.

Many children residing in the centres did not have siblings and family members living with them. There were 415 Children with albinism who participated in the study.

Protection of Children with Albinism: Three hundred and sixty two Children with albinism which is 87.2 percent of the total number of CWA, who participated on a focussed group discussion, said that the living environment at that time was poor. Some centres were reported to have had poor infrastructure including lack of security fence, weak doors while some did not have locks. Four centres were reported to be freely accessible by community members. The security guards at five centres were reported to be drunkard, serving their duties unarmed and sometimes slept in the office throughout the night.

Moreover, there were water and electricity problems. Children at four centres complained of being forced to walk for a long distance without escort across bushes or forests to fetch water and firewood. All of them were afraid of either getting attacked or being bitten by snakes. The





toilets at six centres were reported to be built very far from the dormitories. Children were afraid of going to the toilets at night. Some younger children either eased on themselves or used a corner of the dormitory as makeshift toilets.

Corporal punishment: A total of 415 children with albinism participated in the survey. 348 children, that is 89 percent of children with albinism complained against corporal punishment which is given to them.

In almost all nine centres (Buhangia, Bukumbi, Furaha, Kabanga, Kitengule Missionaries of Charity, Mitindo Mugeza and Pongwe) complained about corporal punishment administered to children with disabilities. About four children of them witnessed to had been severely and randomly beaten for no apparent reasons. At Mitindo a child said, *“Teachers punish us in the sun. They give us corporal punishment even when we have not done anything wrong. They call us names and say they will take us to our villages to be slaughtered.”*

356 CWA said that there is violence against CWA because corporal punishment was normal in almost all centres. At Mitindo, 62 percent of the total number of CWA, that is, ninety nine children, shared their experience of corporal punishment including being flogged under the sun.

Stigma and Discrimination: There is a high level of stigma and discrimination against CWA reported almost in all nine centres. 407 CWA out of 415 children with albinism who participated in the survey, that is 98 percent, said that there was high stigma and discrimination at the specified centres. This group of persons reported to have been stigmatised, discriminated against and/or abused in one way or another by fellow students, teachers, matrons and patrons, cooks and watchmen. In short, stigma and discrimination, some cases of sexual abuses were reported





and fear of killings and atrocities against individuals particularly those with albinism prevailed in these centres.

For instance one child at Bukumbi witnessed that PWA were unhappy staying at the centre because of rampant discrimination and stigma. *“They discriminate against us because we have albinism. The matron does not take care of the younger ones,”* she concluded.

Buhangija has a total population of 775 (405 females and 370 males). 15.6 percent of the total population that is 121 children have albinism. 65 CWA at this centre participated in this study and amongst them, a total of 51 children, that is 78 percent of those who participated in focused group discussion said that they were discriminated not only by some teachers and caregivers but also their fellow students who did not have disabilities; corporal punishment and abusive language against them were also said to be the order of the day. They complained that sometimes they were canned while standing in the sun for a long time which resulted to them getting sunburn.

Security and observation of child rights: The situation is different at these centres. One would have expected high observation of child’s rights and human rights but it is not so in practice. The researchers discovered serious violation of children’s rights witnessed by children themselves. For instance at Mugeza, 74 CWA participated in the study. 75.7 percent of children that is 56 CWA who participated in the focused group discussion said that they had been continuously terrified by continuous utterances by their teachers and caregivers that they would be returned to their home villages to be murdered. This mental torture was used to force them to do whatever some of the members of staff wanted them to do. For instance, children were ordered to do the following: to fetch water from the river and go into the forest to collect firewood without escort and or protection precaution; to go to the fields to cut grass for cows; to milk cows; to till the land and other tasks un-related to normal school activities. Such orders were not only put the





lives of children in danger, but also they psychologically tormented the minors who had no one to turn to.

At Mugeza a child with albinism in a Focus Group Discussion said, *“We have water problems. We are sent to fetch water very far. Security is not good. Security guards are always drunk. We do not have a kitchen. Dormitories are insufficient and there is no ventilation. Classrooms do not have lights and therefore we cannot read at night. Text books are not enough. Teachers are not helpful. One calls us bad names. She is the worst teacher in the school. Our matron is very bad,”* she narrated.

Centres’ Infrastructure and Teaching material: Out of 15 Staff (head teachers, academic masters and centre in charges) who were interviewed from all 9 centres, 13 staff that is 86.7 percent admitted that the centres had poor infrastructure. For instance, they said that there were insufficient learning and teaching material, shortage of desks, classrooms, the rooms were small in size but also insufficient dormitories with poor ventilation and few mattresses to the extent that to some centres two to three children had to share a bed or mattress; toilets were in appalling conditions; there was no fence; there was lack of security lights; water problem was the order of the day. Two centres that seemed to have relatively good infrastructure were Missionaries of Charity in Tabora and Bukumbi Centre whose infrastructure was observed to be satisfactory.

At Furaha centre a child in a Focus Group Discussion said that there were poor accommodation facilities, people shared beds, mattresses were in a bad condition and there were insufficient washrooms. Children with visual impairment felt isolated and uncared, one said, *“The matron does not love us and care for us.”*





At Mitindo a child pondered, *"We are on our own most of the time. Classroom windows have wide security grills that could allow a person to pass through. Anyone can come through these windows and into the dormitories and attack us without the knowledge of the security guard. Further, door locks are weak or absent on all doors"*.

Entertainment and Leisure Provision: It was noted that chances for sports, play, games and other leisure services were minimal in the centres. Figure 6 shows that 367 CWA of those who participated in this study said that it was their desire to have regular timetable for sports and other leisure services in their centres. Only 14 CWA out of 415CWA who participated in the study said that there was no need to struggle for leisure and entertainment services while 34CWA did not see if sports and leisure services would make any difference to the standard of life they were living. A child in Buhangija put it clearer when he said, *"There is no specific day for games at our school. We do not have a sports and games teacher. Neither do we have audible balls for those with visual impairment. We don't have playing grounds"*.

Psychosocial Care and Support: CWA and children with other disabilities in the surveyed schools/centres lacked quality care and support. It was observed that the centres lacked trained people with specialised skills to help children who are traumatised, bereaved and those who suffer lonesomeness. There found children who were physically and psychologically abused before coming to the centres, yet they were still abused in the centres.

Scarcity of resources: It was found that the surveyed institutions were operating in meagre resources which could be detrimental to the academic, psychosocial and health development of the children/residents in the schools/centres. A matron at Mugeza considered children with albinism as a burden to the centre. She said, *"The coming of children with albinism has not only*





worsened the financial constraints but has also increased the burden of responsibilities on the few members of staff who have to ensure that the children are safe,” she concluded.

Teaching and Learning Materials: Almost all centres/schools were found to have a shortage of teaching/learning materials and other related facilities. For instance, at Kabanga the Head-teacher supported by the academic master said, *“There is a great shortage of teaching and learning materials. For instance, if we could get a photocopy machine we would make copies to assist those with albinism to have their own notes because of low vision – the condition which prevents them from reading from the blackboard.”*

Participants from Mugeza and Furaha Primary schools said that the availability and use of learning and teaching materials was a big problem. *“Teaching facilities for students with blindness and low vision are very expensive, and we have no money to purchase them. We also do not have a technician to repair the available equipments once they get damaged or when we encounter some technical problems,”* they concluded.

DISCUSSION SUMMARY

The findings of this study indicate that violence, abuse, stigma and discrimination against children with albinism and other disabilities are rampant at Buhangija (Shinyanga Region), Bukumbi and Mitindo (Mwanza Region), Kitengule and Mugeza centres (Kagera Region), Furaha and Missionaries of Charity (Tabora Region), Kabanga (Kigoma Region) and Pongwe in Tanga Region.





People could expect children living in such designated centres are highly protected and cared for. However, this is not the reality. Though there is still limited information about the magnitude of the problems facing children in the government designated centres, this study could be regarded as a baseline study for a thorough research aiming at improving the quality of life of the displaced children with albinism and their colleagues with other disabilities in the centres. The report highlights how children's rights are violated in these centres. It also suggests through the recommendations below what to do solve the problems.

Identifying the magnitude of stigma and discrimination, violence and abuse facing children with albinism and other disabilities in the specified centres is a critical step towards improving the standards of living of CWA and easily planning effective strategies to care, protect and support all children living in adversity as a result of the macabre killings. This will be part of implementing the Law of the Child Act No21 of 2009 and Convention on the Right of the Child – CRC. UTSS, UNICEF and other development partners are critical in implementing a strong programmatic response that will protect children with albinism in Tanzania from the scale of infringement of children's rights including abandonment, stigma, discrimination, abuse and violence.

UTSS proposes the following immediate medium and long term responses to the survey results which are further expounded upon in the discussions and recommendations below. Immediately the findings should be widely shared with UNICEF and government officials, development agencies and other key stakeholders. The recommendations in this report should be strategically implemented including community awareness creation and other highlighted issues particularly around social norms surrounding the above mentioned problems facing PWA. In the medium term, UTSS and UNICEF in collaboration with other development partners should develop a three or five years' strategic plan to prevent and respond to stigma and discrimination, violence and abuse, killings and atrocities against PWA. Develop organizational rules and regulations to





implement the 2009 Law of the Child Act, identifying and implementing evidence based prevention, protection and response programmes to address all forms of abuse and violations of children's rights. Finally in the long term the work should build evidence base on how PWA suggested protection systems can address existing challenges facing CWA. A strategy should be developed for national scale-up, support UNICEF to develop a social welfare workforce to increase the numbers and capacity of caregivers, matrons and teachers in the centres to respond to the mentioned problems facing children with disabilities and create a surveillance system for monitoring and evaluation to track long term trends in problems facing PWA.





SECTION ONE

INTRODUCTION, BACKGROUND AND METHODS

1.1.0 Introduction

Persons with albinism (PWA) in some of East and Central African countries have been killed , and continue to face discrimination and stigma. Recently atrocities against PWA fuelled witchdoctors who use organs of people with the genetic condition for superstitious and witchcraft practices beliefs have been witnessed in Tanzania, Burundi, Kenya, as well as Uganda. The killings have raised eyebrows, and instilled fear among individuals with albinism and their families.

Persons with albinism are human beings hence should enjoy life to the full just like those without the hereditary condition. Indeed, many Tanzanians have been dismayed by the butchery committed by uncouth and ruthless people (Possi, 2008). The murders s have forced individuals with albinism to flee from their home villages becoming internal refugees in government designated centres / camps such as those surveyed centres by UTSS in Tanga and the Lake Zone regions.

People with albinism are human beings like any other persons, and worth living like everyone else on the planet. Indeed, many Tanzanians have been disappointed by the killings conducted by uncouth and ruthless people (Possi, 2008). The killings have led to the fleeing of individuals with albinism and their relatives from their home places, rendering them to be displaced and living poor life, living in centres like the surveyed centres by UTSS in Tanga and other regions of the great lakes.

1.1.1 Background





According to Richard A.K.(2004), Albinism is a rare, non-contagious, genetically inherited condition occurring in both genders regardless of ethnicity, in all countries of the world. Both the father and mother must carry the gene for it to be passed on even if they do not have albinism themselves. The condition results in a lack of pigmentation in the hair, skin and eyes, causing vulnerability to sun exposure and bright light.

The term “*person with albinism*” (PWA) is preferred to the term “albino” as it puts the person before the condition (UTSS official definition of albinism).

According to Lapidos J.(2009), three men armed with machetes killed an 8-year-old albino boy in Burundi towards the end of February 2009 and were believed to have smuggled his limbs to Tanzania, where witch doctors use albino body parts for potions. At least 35 persons with albinism were killed in Tanzania in 2008, prompting police officials to set up an emergency hot line and a program to distribute free cell phones to all albinism. How many persons with albinism are there in Tanzania?

Albinism, a genetic disorder characterized by lack of melanin pigment in the skin, hair, and eyes, is listed as a rare disease by the National Institutes of Health - meaning it affects fewer than 200,000 Americans. Around the world, between one in 17,000 and one in 20,000 people are persons with albinism. The prevalence in parts of Africa, however, is far higher than the global average. PWA make up about one in 4,000 people in South Africa and perhaps one in 5,000 in Nigeria. According to a 2006 review published in the journal *BMC Public Health*, the prevalence in Tanzania is one in 1,400, but this estimate is based on incomplete data. Since Tanzania's total population is currently 44,929,002 according to 2012 census result (<http://www.nbs.go.tz>) and ranking 30 in the world map of population, that would suggest an albino community of about 32,092. However, Tanzania Albinism Society believes the total figure could be more than





150,000 which supports the estimate by *ABC News' Traci Hunte* (2010) that Tanzania has one of the largest PWA population in the world with an estimate population of 170,000.

1.1.2 Rationale of the Research

The rationale of the research is to establish the extent of security and comfort among children and individuals from displaced homes and families, including those with disability that is: finding out the welfare of the children, determining whether in these centres PWA are secured, offered quality care, protection and support and whether objectives of establishing the centres are met. The assessment focuses on suggesting best ways to improve the standard of living of PWA in these centres.

1.1.3 Objectives of Situation Assessment

The overall objective of the assessment was to determine whether there are risks associated with the general functioning of the centres where People with Albinism are currently accommodated. The centres were established as shelters to rescue PWA who are shifted from various places in Tanzania where witchcraft killings and atrocities against PWA are threatening and disturbing. The centres may have set of risks, such as lack or poor infrastructures, having incompetent and or unskilled workers to care and protect PWA, continued threats, violence, stigma and discrimination, general violation of human rights, scarcity of resources (human and material) and general poor working environment. Each of the risks should have a set of solutions that are highlighted in the recommendations of this report, so that they are prevented upfront to further endanger and or continue to threaten PWA.

1.1.4 The specific research objectives

In order to meet the overall objective mentioned above, the researcher set the following specific objectives for its step by step successful accomplishment.





1.1.4.1 To determine satisfaction of the living environment of the specified centres.

1.1.4.2 To determine whether there is health social relation between PWA and other community members including matrons, patrons, teachers and other workers.

1.1.4.3 To identify and assess the developmental opportunities that PWA in the specified centres can exploit to sustainably meet their needs.

1.1.5 Research Methodology

For the sake of looking systematic ways of solving problems facing PWA – CWA in the specified centres, the research process involve a research design, sampling techniques to ensure involvement of the PWA to respond this research, that is to participate in data collection, data analysis and give constructive recommendations thereafter

1.1.6 Research design

The researcher applied survey design in selecting sources of information to answer the research question. Both qualitative and quantitative designs were applied whereby qualitative design was employed to explore the challenges facing PWA in these centres while quantitative design was applied to collect statistical data.

1.1.7 Sampling Techniques

The researcher ensured a balanced distribution of representation of people from different cedar
Due to the nature of the information sought from participants as well as the nature of the study; both purposeful and random sampling techniques were used to make a sample size of 507 people.

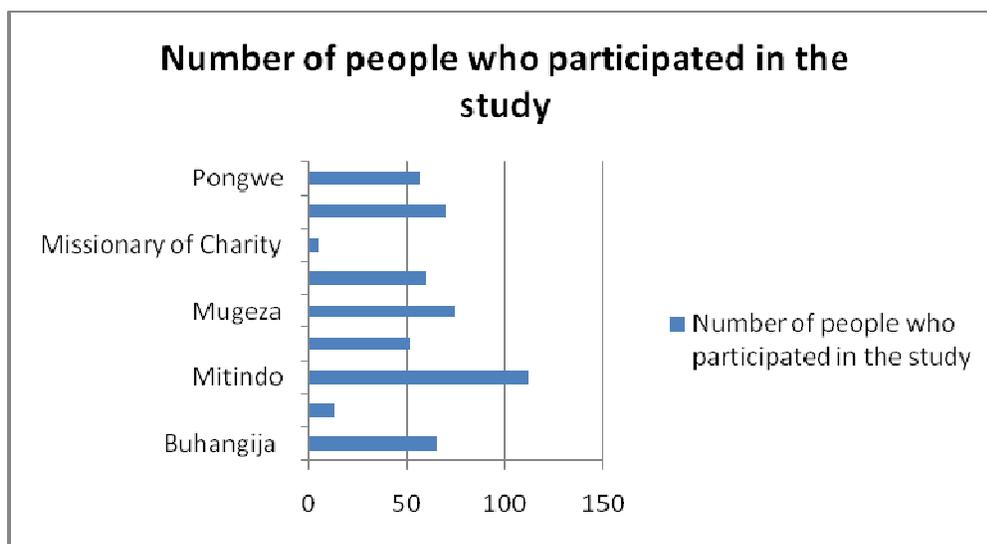




1.1.8 Sample size

The sample size included People/Children with albinism, head of centres, head teachers, security officers, CDOs, academic teachers, District medical officers, Ward executive officers, Security guards, Discipline masters, Cook, Nurse and Care givers. The number of those who participated is distributed as per Figure 1 below.

Figure 1: **The number of people who participated in the Study**



Source: UTSS Survey findings 2011



1.1.9 Sample Distribution

Table 1 below summarises the distribution of the sample as per group representation

Table 1: Number of people who participated in the study at each centre.

Participants	Name of Region and School/Institution and Number of Participants									Total
	Shinyanga	Mwanza	Mwanza	Bukoba	Bukoba	Tabora	Tabora	Kigoma	Tanga	
	Buhangija	Bukumbi	Mitindo	Kitengule	Mugeza	Furaha	Missionary of Charity	Kabanga	Pongwe	
Head of the centre		1					1			2
Head Teacher	1		1	1	1	1		1	1	7
Security Officer	1	1	1		1	1	1		1	7
Community Development Officer	1		1	1	1	1		1	1	7
Academic Teacher	1		1	1	1	1		1		6
District Medical Officer	1	1	1	1		1		1	1	7
Matron	1	1	1	1	1	1	1		1	8
Patron	1			1	1	1		1	1	6
Social Welfare Officer	1	1	1	1	1	1	1	1	1	9
District Education Officer	1		1	1	1	1		1	1	7
Ward Education Officer			1							1
Security Guard	1	1	2	1	1	1	1	1	2	11
District Medical Officer	1	1	1	1		1		1	1	7
Discipline Master			1		1				1	3
Cook				1					1	2
Nurse					1					1
Care Giver									1	1
Subtotal 1	11	7	13	11	11	11	5	9	14	
Focus Group Participants(students)										
10 to 13 Boys	7		20	10	10	10		10	11	78
10 to 13 Girls	10		48	10	24	10		10	10	122
14 to 17 Boys	10		21	10	19	9		11	12	92
14 to 17 Girls	10		10	10	10	10		10	10	70





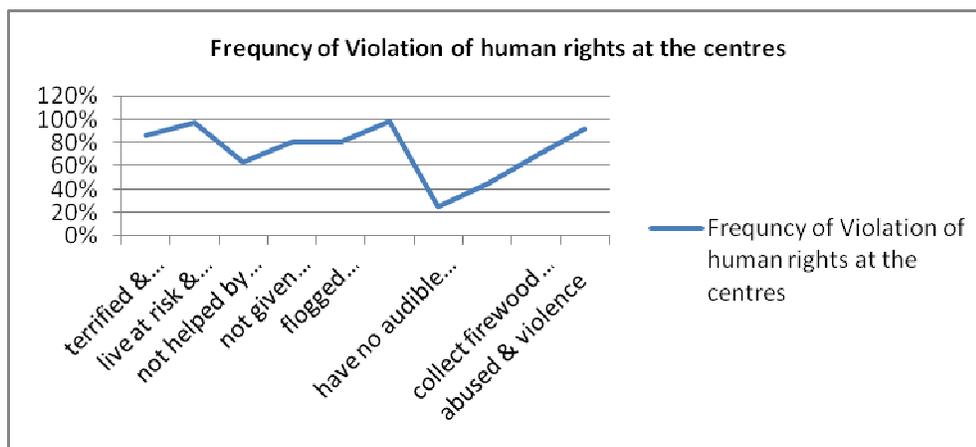
18 and above Girls	17	6						10		33
18 and above Boys						10		10		20
Subtotal	54	6	99	40	63	49	0	61	43	
Total	65	13	112	51	74	60	5	70	57	507

Source: UTSS Survey findings 2011

Figure 2 below summarises the situation facing 415 CWA in the specified centres, that is the frequency of violation of Human rights

1.1.10 Protection of Children with Albinism - 362 CWA which is 87.2 percent of the total number of CWA who participated on a focussed group discussion, said that the living environment is poor, they feel insecure because some security guards are always drunkard, dormitories and or the centres are not fenced, some CWA go always into the bush and forests to fetch water and firewood unescorted by armed guards, doors and windows of dormitories are weak and some have no locks.

Figure 2 Frequency of Violation of Human rights at the centres



Source: UTSS Survey findings 2011

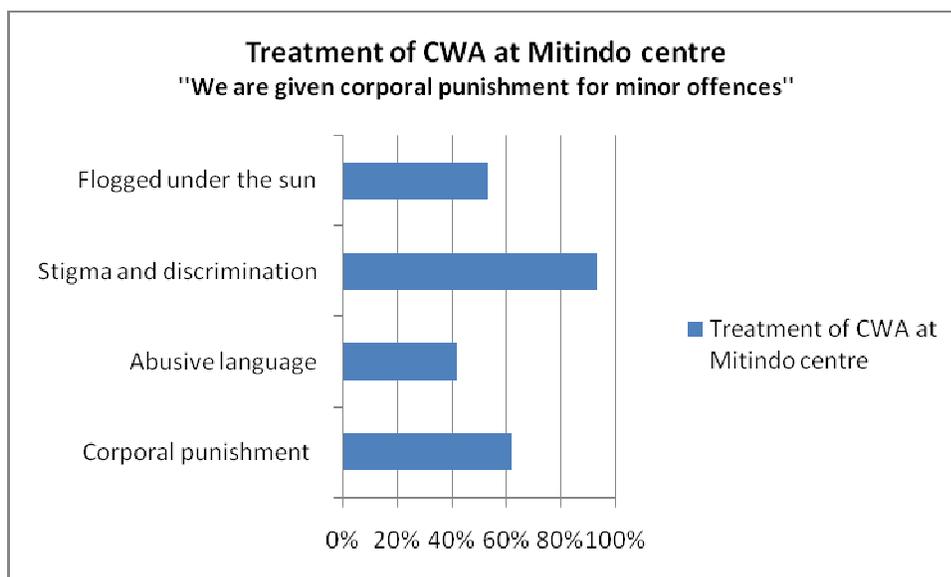
1.1.11 Corporal punishment – 356CWA said that there was violence against CWA accompanied by corporal punishment which was children’s normal in almost all centres.





Sometimes children were flogged under the sun and suffer sun burn thereafter. Refer treatment of CWA - a case of Mitindo centre in Figure 3 below.

Figure 3 **Treatment of CWA at Mitindo centre**



Source: UTSS Survey findings 2011

At Mitindo centre 62% of the total number of CWA, that is 100 children, shared their experience of corporal punishment including being flogged under the sun. This is one example of human rights violation against children with disabilities at his centre.

1.1.12 Learning Materials – 388 CWA that is 93.5 percent of CWA who participated in this study said that the learning environment was not conducive, not friendly because they lacked user friendly learning material. For instance they said there were no Classroom accommodations such as video magnifiers, large-print textbooks, audio tapes to supplement reading, large-print copies of board notes, and use of computers to catch up with technological challenges of globalization.

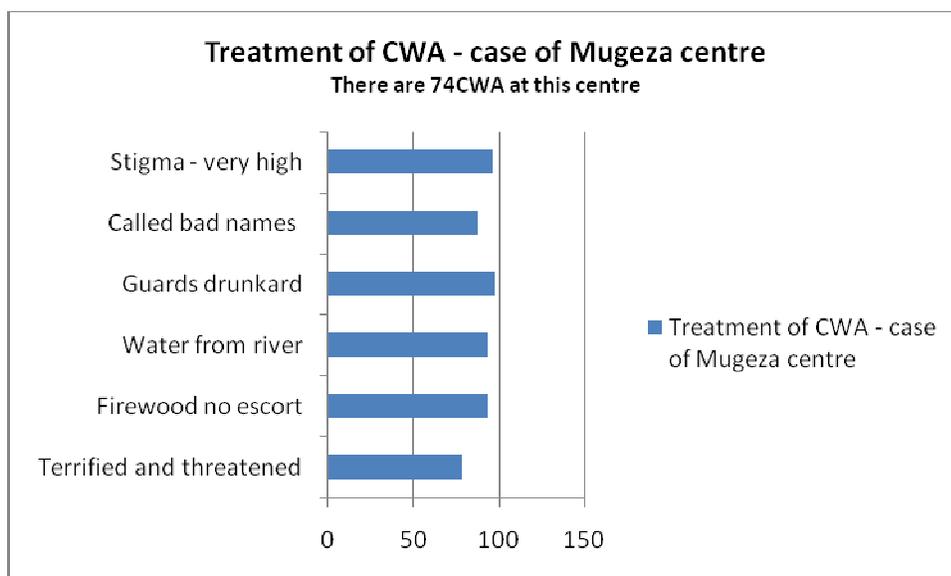


1.1.13 Security and observation of child rights - The situation was different at these centres, one could expect high observation of child's rights and human rights but it was not so in practice. The researcher discovered serious violation of child rights witnessed by children themselves. For instance at Mugeza, almost 80 percent of children, that is 56CWA out of 74CWA who participated in the focused group discussion said that they had been continuously terrified by the leaders that they would be returned to their original places where they were forced to run away. This was like a pain in their necks which was used to force them to do whatever they wanted them to do. For instance children were ordered to fetch water from the river and go into the forest to collect firewood without escort and or protection precaution. Moreover, they used to go out to cut grass for cows, to milk cows, to till the land and other tasks of the sort without sure protection. Such an environment was putting them at risk and insecurity. They were actually psychologically disturbed from their own witness because it was like being taken back to the same original threatening places where they ran away.

In reference to figure 4 below, at Mugeza centre, a child with albinism in a focused group discussion said, *"We have water problems. We are sent to fetch water very far. Security is not good. Security guards are always drunk. We do not have a kitchen. Dormitories are insufficient and there is no ventilation. Classrooms do not have lights and therefore we cannot read at night. Text books are not enough. Teachers are not helpful. One calls us bad names. She is the worst teacher in the school. Our matron is very bad,"* she concluded.



Figure 4 Treatment of CWA at Mugeza centre



Source: UTSS Survey findings 2011

1.1.14 Centre infrastructure and teaching material- Out of 15 Staff (Head teachers, academic masters and centre in charges) who were interviewed from all 9 centres, 13 staff, that is 86.7 percent admitted that the centres had poor infrastructure. For instance, they added that there were insufficient learning and teaching material, shortage of desks, classrooms and even the size of the classrooms was small. There were insufficient dormitories with poor ventilation and few mattresses to the extent that to some centres children were reported to had been obliged to sleep 2 – 3 on one bed or mattress. There were poor toilets, no fence, and lack of security light and intermittent water problem. Two centres were observed to have had good infrastructures that were Missionary of Charity Tabora and Furaha while at Bukumbi the infrastructure was observed to be satisfactory, please refer to figure 5 below!

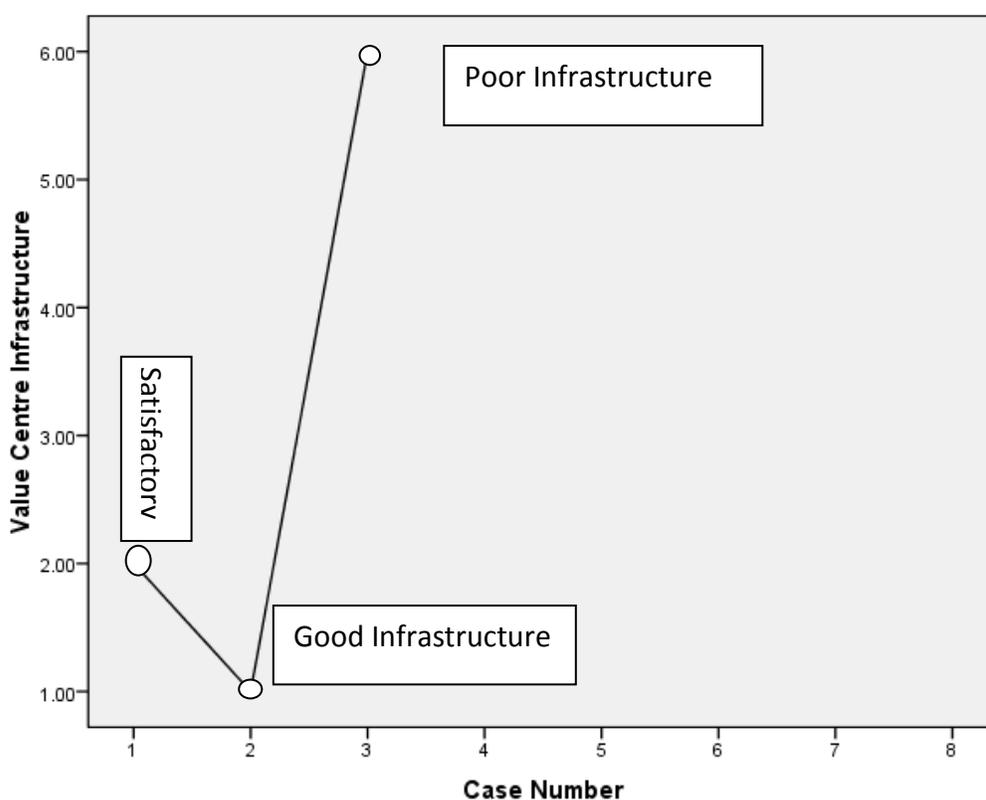
1.1.15 Entertainment and leisure provision - It was noted that there was no room for sports, play, games and any leisure services provision at these centres. 367 CWA, that is 88.4 percent of





those who participated in this study claimed for their right to play, entertainment and leisure. Only 14 CWA out of 415CWA who participated in the study said that there was no need for leisure and entertainment while 34CWA said that it made no difference having or not having such an opportunity when compared to the standard of life they were living.

Figure 5 Value centre infrastructure



Source: UTSS Survey findings 2011

A child with albinism at Buhangija, put it more clear as she said "There is no specific day for games at our school. We do not have a sports and games teacher. Neither do we have audible balls for those with visual impairment nor playing grounds."she concluded

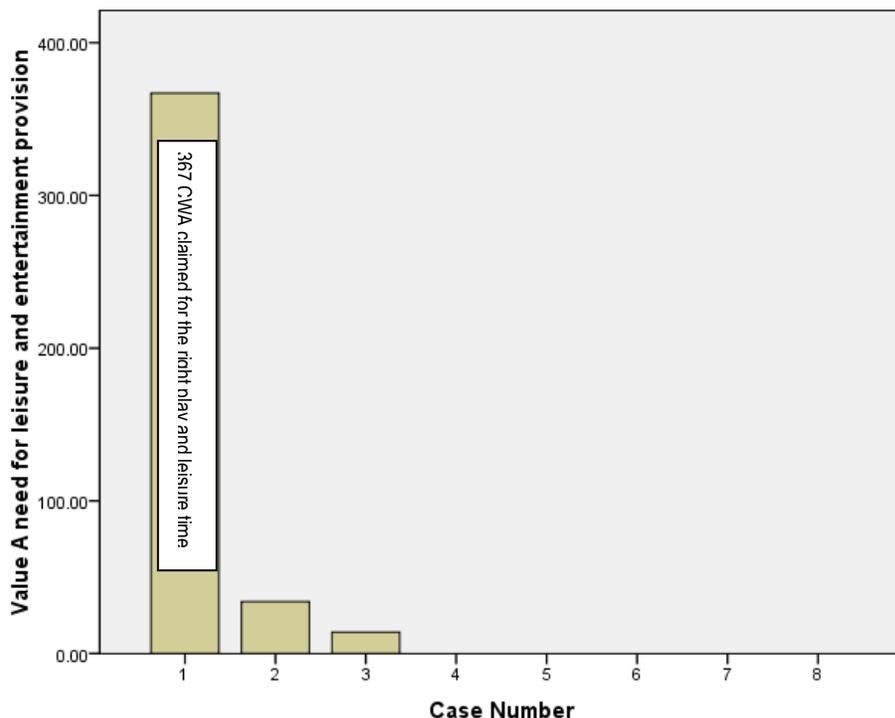


In figure 6 below, it is evident that the majority claimed of their right to play, leisure and entertainment.

1.1.16 Scarcity of resources – It was found that the surveyed institutions were operating in meagre resources which could be detrimental to the academic, psychosocial and health of the children in those centres. 12 staff members (Head teachers, academic masters and centre in charges), that is 80 percent of the top leaders who participated in this study cried for the serious scarcity of resources. Poverty seemed to be worsening the living condition of CWA. You can imagine, that a matron at Mugeza considered children with albinism as a burden to the centre, she said “the coming of children with albinism has not only worsened the financial constraints on the institution but has also increased the burden of responsibilities on the few personnel who have to ensure that the children are secured.” She concluded. This is an alarm that in such a situation, workers attitude and the way of treating the children would be characterised by obvious violation of child rights.



Figure 6 Value a need for leisure and entertainment provision



Source: UTSS Survey findings 2011

1.1.17 Stigma and Discrimination -407 CWA said that there was high stigma and discrimination (stigmatized by teachers, fellow students, matrons and or patrons and other staff)

1.2 Data collection methods

Data was collected from two sources; primary and secondary. Primary data was obtained directly from the centres through observations, focus group discussion and interviews, while secondary data was collected through literature review. In terms of quantity constituted quantitative methods applicable to phenomena that can be expressed in terms of quantity, where as qualitative methods included interviews, documentation and focus group discussion.



The rationale behind using the two methods was to enable the researcher come out with valid and reliable information about the real situation of the assessed centres. Interviews covered different categories of respondents among them being key informants; those who provided the needed information on particular subjects for instance teachers, matrons, patrons, watchmen, social workers or community development workers

1.2.1 Observation

The researcher applied observation method also by paying a visit to the 9 centres where currently PWA live. Observation is actually one of the best investigative methods that the researcher used in order to directly observe the situation. The type of information which was collected by observation included the physical appearance of centres' buildings, education material including desks, laboratories, library, learning and teaching material, play ground, classrooms, dormitories, toilets, fence, source of energy, armed security firm and various types of activities conducted at the centres. The practice was conducted along with taking photos and notes for verification.

1.2.2 Secondary Data review

A documentary study which is also called secondary data review was conducted which included review of various documents such as archival data, journals and newsletters and papers, published and unpublished material, internet surfing and review of various reports.

1.2.3 Focus Group Discussions

PWA at various centres were comfortable to joining focus group discussions to other modes of data collection like filling up a questionnaire and interviews.

Focus group discussion sounded to be more powerful because group representatives had ample time to share their feelings and suggestions on how they could meet their needs.





1.2.4 Data analysis methods

The data collected from the centres was analyzed by use of Ms Excel and statistical Package for social science (SPSS) computer software analysis tool version 16.0 but also summarized and presented in tables and figures for easy and meaningful interpretation.

SECTION TWO

DEMOGRAPHIC AND SOCIOECONOMIC CHARACTERISTICS OF THE SAMPLE

2.0 Demographic

Despite the fact that the researcher included a few adults in the survey, data was mostly collected from the children, that is under 18years but not below 8years because most of them were primary school children.

Table 2 below is the distribution summary of the number of children who participated in the study:

Table 2: Number of people who participated in the study at each centre.

Participants	Name of Region and School/Institution and Number of Participants									Total
	Shinyanga	Mwanza	Mwanza	Bukoba	Bukoba	Tabora	Tabora	Kigoma	Tanga	
	Buhangija	Bukumbi	Mitindo	Kitengule	Mugeza	Furaha	Missionary of Charity	Kabanga	Pongwe	
Head of the centre		1					1			2
Head Teacher	1		1	1	1	1		1	1	7
Security Officer	1	1	1		1	1	1		1	7
Community Development Officer	1		1	1	1	1		1	1	7
Academic Teacher	1		1	1	1	1		1		6
District Medical Officer	1	1	1	1		1		1	1	7





**UNDER THE
SAME SUN**

Matron	1	1	1	1	1	1	1		1	8
Patron	1			1	1	1		1	1	6
Social Welfare Officer	1	1	1	1	1	1	1	1	1	9
District Education Officer	1		1	1	1	1		1	1	7
Ward Education Officer			1							1
Security Guard	1	1	2	1	1	1	1	1	2	11
District Medical Officer	1	1	1	1		1		1	1	7
Discipline Master			1		1				1	3
Cook				1					1	2
Nurse					1					1
Care Giver									1	1
Subtotal 1	11	7	13	11	11	11	5	9	14	
Focus Group Participants(students)										
10 to 13 Boys	7		20	10	10	10		10	11	78
10 to 13 Girls	10		48	10	24	10		10	10	122
14 to 17 Boys	10		21	10	19	9		11	12	92
14 to 17 Girls	10		10	10	10	10		10	10	70
18 and above Girls	17	6						10		33
18 and above Boys						10		10		20
Subtotal	54	6	99	40	63	49	0	61	43	
Total	65	13	112	51	74	60	5	70	57	507

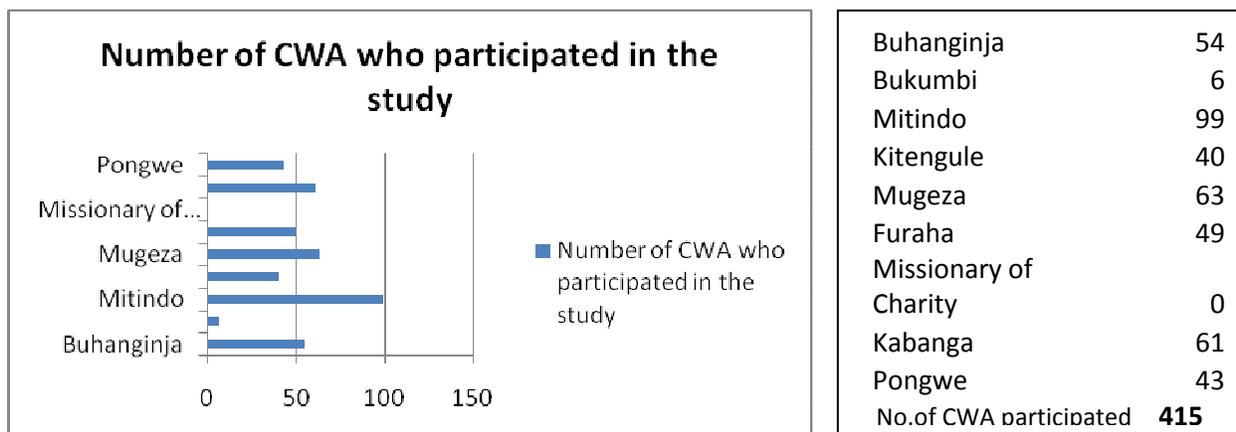
Source: UTSS Survey findings 2011

Among 871 students with disabilities who were reached in the centres, 415 children which is 47.6 percent of them were individuals with albinism. The number of individuals with albinism in the mentioned centres above, are 9.4 percent of all 4,407 students found at those centres by the time of the study. Figure 7 below shows the percentage of persons with albinism in the specified centres.





Figure 7 Number of CWA who participated in the study



Source: UTSS Survey findings 2011

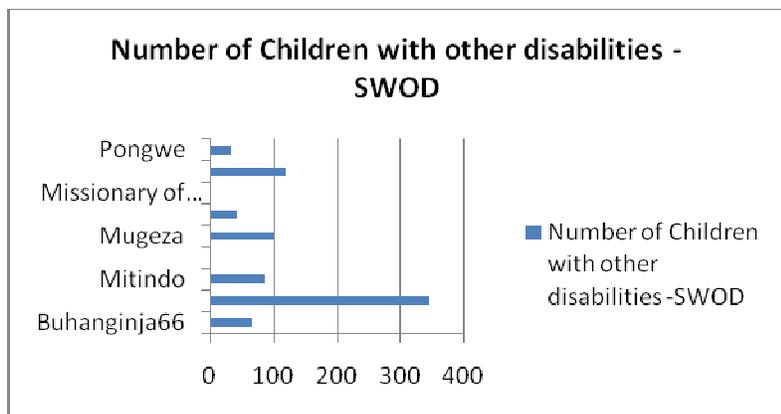
2.1 Percentage of children with other types of disabilities

In figure 7, it is evident that in terms of quantity, Mitindo centre has the greatest number of PWA that is 99CWA followed by Kabanga. But in terms of frequency, Furaha centre has got a high percentage of persons with albinism because the majority at this centre are people with disabilities but they are also fewer in number as compared to the population at Mitindo, that is 1147 people.

At the Missionaries of Charity, the researcher was denied the information to the extend that even the little information that was provided seemed to be unreliable to be presented in this section. Figure 8 on the other hand summarises the number of people with other disabilities in the specified centres.

Figure 8 Number of children with other disabilities - CWOD





Source: **UTSS Survey findings 2011**

2.2 Children with albinism, CWOD and other people who participated in the study.

Table 3 below summarises the composition of children who are accommodated at the given centres. One can observe that at Furaha centre 76 percent of the population are people with disabilities followed by Mugeza 18.4 percent, Kabanga 16.7 percent, Buhangija 8.5 percent, Mitindo 7.5 percent, Pongwe 4 percent while at Kitengule 0.4 percent of the population are people with disabilities including those with albinism.

The percentages of people with other types of disabilities are indicated in Figure 8 above and table 3 below. At Furaha centre, the majority of its members are referred to as people with disabilities except the workers. Other people with other disabilities include hard of hearing, mentally and physically challenged people. From the statistics, different from the other centres that were surveyed, at Furaha almost all children at this centre were with disabilities including PWA. Amongst the centres, Mitindo has the greatest population of children with disabilities, the community has a total number of 1147 children, and 8.7 percent (100 PWA) of this population are people with albinism. It was observed that the smaller number of people with disabilities, the





more intensity of violence, stigma and discrimination, abuse and or violation of human rights in general is felt.

Table 3 Statistics of Children with albinism, CWOD and total population in the centres

Centre	CWA	% of SWA at the centre	SWOD	% SWOD	No. of day scholars	% of day scholars	Total No. of student	Teachers	TSR
Buhangija	121	15.6%	66	8.5%	588	75.9%	775	21	1 : 37
Kabanga	73	10.1%	121	16.7%	530	73.2%	724	38	1 : 19
Mugeza	74	13.5%	101	18.4%	416	75.8%	549	15	1 : 37
Pongwe	32	3.7%	34	4%	798	92.3%	864	32	1 : 27
Furaha	49	53%	43	47%	0	0 %	92	21	1 : 4
Mitindo	99	8.6%	86	7.5%	961	83.8%	1,147	35	1 : 33
Kitengule	52	20.3%	1	0.4%	100	39%	256	7	1 : 37
Bukumbi	10	2.8%	346	97%	0	0%	356	15	1:24

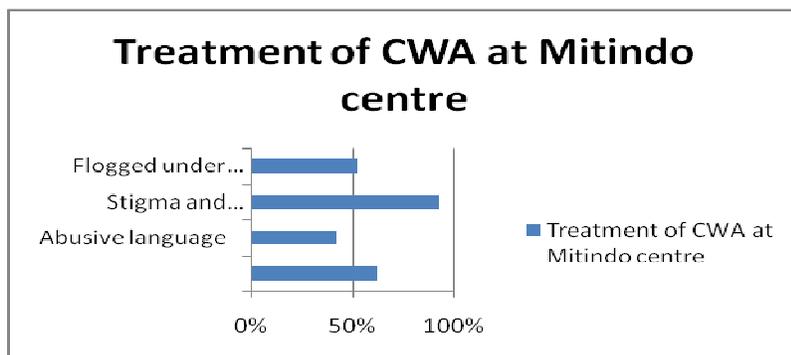
Source: UTSS Survey findings 2011

At Mitindo centre, because of the greater number of people without any disability, ignorance and the ratio of people with albinism to the population is and there were more complaints of discrimination, corporal punishment and abuse by some teachers and the assistant cook.

Figure 9 below is a summary of the unsatisfactory life condition of CWA at Mitindo as it was expressed by children in a focused group discussion during the survey.



Figure 9 Treatment of CWA a case at Mitindo centre



Source: UTSS Survey findings 2011

At Mitindo there were 99 CWA, 62 out of them, that is 62% of that population at this centre complained to have been severely punished by teachers and other staff even for minor offences. One child said that the teacher insulted them while another child in a focused group discussion witnessed by saying, ‘ We are given corporal punishment even for minor offences.’

SECTION THREE

LITERATURE REVIEW

3.0 Introduction

There are children living in camps in various regions in Tanzania because of intertribal wars and conflicts. There are other children and adults in camps as a result of wars in the neighbouring countries. We have also children and adults with disabilities such as those with albinism because they are being hunted so that they can be killed and parts of their bodies used for superstitious motives. UNICEF has been striving to alleviate problems facing such individuals that is children and their families living in their own countries as well as in host countries. Both the children and parents living in places with such killings face psychological and social problems. Similarly,





camps hosting displaced people face problems of over-crowdedness in schools, higher crime rates, pressure upon local services and food shortages. This section contains literature review on superstition on albinism and displacement, scientific outlook, scientific causes, and killings of persons with albinism.

According to Judith, S.(2006) Albinism is an inherited condition that is present at birth. It is characterized by a lack of melanin, the pigment that normally gives color to the skin, hair, and eyes. Many types of albinism exist, all of which involve lack of pigment in varying degrees. The condition, which is found in all races, may be accompanied by eye problems and may ultimately lead to skin cancer.

3.1 Description

The most common type of albinism is oculocutaneous albinism, which affects the eyes, hair, and skin. In its most severe form, hair and skin remain completely white throughout life. People with a less severe form are born with white hair and skin that turn slightly darker as they age. Everyone with oculocutaneous albinism experiences abnormal flickering eye movements (**nystagmus**) and sensitivity to bright light. There may be other eye problems as well, including poor vision and crossed or "lazy" eyes (strabismus).

The second most common type of the condition is known as ocular albinism, in which only the eyes lack colour; skin and hair are normal. Some types of ocular albinism cause more problems, especially eye problems, than others. Albinism is also referred to as Hypo-Pigmentation.

3.2 Demographics

Albinism is a rare disorder found in fewer than five people per 100,000 in the USA and Europe. Although albinism can affect all races, other parts of the world have a much higher rate; for





example, albinism is found in about 20 out of every 100,000 people in southern Nigeria. The parents of most children with albinism have normal hair and eye colour for their ethnic background and do not have a family history of albinism.

3.3 Causes and symptoms

Albinism is an inherited problem caused by an alteration in one or more of the genes that are responsible for directing the eyes and skin to produce or distribute melanin, which is a photoprotective pigment that absorbs ultraviolet (UV) light coming from the sun so that the skin is not damaged. Sun exposure normally produces a tan, which is an increase in melanin pigment in the skin. Many people with albinism do not have melanin pigment in their skin, do not tan with exposure to the sun, and as a result develop sunburn. Over time, people with albinism may develop skin cancers if they do not adequately protect their skin from sun exposure.

Melanin is also important in the eyes and brain, but it is not known what role melanin plays in those areas. Parts of the retina do not develop correctly if melanin pigment is not present during development. Also nerve connections between the retina and brain are altered if melanin is not present in the retina during development.

Albinism is a autosomal recessive disease, which means that a person must have two copies of the defective gene to exhibit symptoms of the disease. The child therefore inherits one defective gene responsible for making melanin from each parents. Because the task of making melanin is complex, there are many different types of albinism, involving a number of different genes. It is also possible to inherit one normal gene and one albinism gene.

In this case, the one normal gene provides enough information to make some pigment, and the child has normal skin and eye color. The child has one gene for albinism. About one in 70 people are albinism carriers, with one defective gene but no symptoms; they have a 50 percent chance of





passing the albinism gene to their child. However, if both parents are carriers with one defective gene each, they have a one in four chance of passing on both copies of the defective gene to the child, who will have albinism. There is also a type of ocular albinism that is carried on the X chromosome and occurs almost exclusively in males because they have only one X chromosome and, therefore, no other gene for the trait to override the defective one.

People with albinism may experience a variety of eye problems, including one or more of the following:

- They may be very far-sighted or near-sighted and may have other defects in the curvature of the lens of the eye (astigmatism) that cause images to appear unfocused.
- They may have a constant, involuntary movement of the eyeball called nystagmus.
- They may have problems in coordinating the eyes in fixing and tracking objects (strabismus), which may lead to an appearance of having "crossed eyes" at times.
- They may have reduced depth perception due to altered nerve connections from the retina to the brain.
- Their eyes may be very sensitive to light (photophobia) because their irises allow stray light to enter their eyes. It is a common misconception that people with albinism should not go outside on sunny days, but wearing sunglasses can make it possible to go outside quite comfortably.

One of the myths about albinism is that it causes people to have pink or red eyes. In fact, people with albinism can have irises varying from light gray or blue to brown. (The iris is the colored portion of the eye that controls the size of the pupil, the opening that lets light into the eye.) If people with albinism seem to have reddish eyes, it is because light is being reflected from the back of the eye (retina) in much the same way as happens when people are photographed with an





electronic flash. In addition, albinism does not cause blindness. In addition to characteristically light skin and eye problems,

people with a rare form of albinism called Hermansky-Pudlak syndrome (HPS) also have a greater tendency to have bleeding disorders, inflammation of the large bowel (colitis), lung (pulmonary) disease, and kidney (renal) problems.

3.4 When to call the doctor

The doctor should be called when a person with albinism exhibits symptoms such as photophobia that cause discomfort. Also the doctor should be consulted if there are any skin changes that might be an early sign of skin cancer.

The parent of a child with albinism should also call the doctor if the child bruises easily or has unusual bleeding, such as repeated nosebleeds or bloody diarrhea . The child may have the rare Hermansky-Pudlak syndrome, which requires additional medical care.

3.5 Diagnosis

It is not always easy to diagnose the exact type of albinism a person has. The specific type is sometimes determined by developing a thorough family history and by examining the patient and several close relatives. In the early 2000s, a blood test has been developed that can identify carriers of the gene for some types of albinism; a similar test during **amniocentesis** can diagnose some types of albinism in an unborn child. A chorionic villus sampling test during the fifth week of pregnancy may also reveal some types of albinism.

There are also two tests available that can identify two types of the condition. The hairbulb pigmentation test is used to identify carriers by incubating a piece of the person's hair in a





solution of tyrosine, a substance in food which the body uses to make melanin. If the hair turns dark, it means the hair is making melanin (a positive test); light hair means there is no melanin. This test is the source of the names of two types of albinism: "typos" and "ty-neg."

The tyrosinase test is more precise than the hair-bulb pigmentation test. It measures the rate at which hair converts the amino acid tyrosine into another chemical (3,4-dihydroxyphenylalanine, or DOPA), which is then made into pigment.

The hair converts tyrosine with the help of an enzyme called tyrosine. In some types of albinism, a genetic defect in tyrosine means that the amino acid tyrosine cannot be converted by tyrosine into melanin.

3.6 Treatment

There is no treatment that can replace the lack of melanin that causes the symptoms of albinism. In addition, doctors can only treat, but not cure, the eye problems that often accompany the lack of skin color. Glasses or corrective lenses and low vision aids, for example, magnifiers, monoculars (handheld telescopes used with only one eye), or bioptics (glasses with small telescopic lenses mounted in the standard lenses) can improve vision but usually cannot correct vision to 20/20. The lenses can be tinted to ease pain from too much sunlight. For reading, children with albinism may or may not need materials with large print text, depending on the severity of their vision problems. There is no cure for involuntary eye movements (nystagmus), and treatments for focusing problems (surgery or contact lenses) are not effective in all cases.

Crossed eyes (strabismus) can be treated during infancy by using eye patches, surgery, or medicine injections. Treatment may improve the appearance of the eye, but it can do nothing to cure the underlying condition.





Patients with albinism should avoid excessive exposure to the sun, especially between 10 a.m. and 2 p.m., and should wear long sleeves and pants if possible. If exposure cannot be avoided, they should use a UVA / UVB sunblock with an SPF rating at least over 45.

Most children with albinism function satisfactorily in a mainstream classroom as long as the school provides classroom assistance for their vision needs. The child's eye doctor, the classroom teacher, and the school's vision resource teacher should work as a team with the parents to determine what classroom modifications and vision aids will best help the child. The local school district or the state agency for people with vision impairment should be contacted during the child's infancy or during preschool years to determine what assistive services might be available for the child. Early intervention allows parents and teachers to develop an educational plan for the child.

3.6.1 Prognosis

In the United States, people with this condition can expect to have a normal lifespan. However, one of the greatest health hazards for people with albinism is excessive exposure to sun without protection, which may lead to skin cancer.

Wearing opaque clothes and sunscreen lotion with at least an SPF rating of 30, people with albinism can safely work and play outdoors when the sun is mild.

3.7 Prevention

Genetic counselling should be considered for individuals with a family history of albinism.





3.8 Parental concerns

Children with albinism may experience complex social problems because of their unusual appearance, especially when a member of a normally dark-skinned ethnic group has albinism. The eyes of children with albinism may move rapidly and not focus together, and the children may have to squint, tilt their heads, and hold reading materials close in order to see. These behaviors may result in the child being treated badly by peers. Modifications made for the children in the classroom and in physical education classes to compensate for low vision may make them feel even more isolated. Parents often feel that teasing and name-calling, insensitivity, and ignorance are the greatest challenges that they face with regards to their child's albinism. The support and love of these families of children with albinism are essential to helping the children understand and accept themselves. Support groups for the children and for their families, as well as counselling, may be useful for developing means of coping with the social effects of albinism.

Albinism is a rare disorder found in fewer than five people per 100,000 in the United States and Europe. Other parts of the world have a much higher rate; for example, albinism is found in about 20 out of every 100,000 people in southern Nigeria.

There are 10 types of the most common form of the condition, known as "oculocutaneous albinism," which affects the eyes, hair, and skin. In its most severe form, hair and skin remain pure white throughout life.

People with a less severe form are born with white hair and skin, which turn slightly darker as they age. Everyone with oculocutaneous albinism experiences abnormal flickering eye





movements (nystagmus) and sensitivity to bright light. There may be other eye problems as well, including poor vision and crossed or "lazy" eyes (strabismus).

The second most common type of the condition is known as "ocular" albinism, in which only the eyes lack color; skin and hair are normal. There are five forms of ocular albinism; some types cause more problems-especially eye problems-than others.

According to Tromsness M.E (2004), Albinism is an inherited condition that is present at birth. It is characterized by a lack of melanin, the pigment that normally gives color to the skin, hair, and eyes. Many types of albinism exist, all of which involve lack of pigment in varying degrees. The condition, which is found in all races, may be accompanied by eye problems and may ultimately lead to skin cancer.

According to Richard A.K.(2004), Albinism is a rare, non-contagious, genetically inherited condition occurring in both genders regardless of ethnicity, in all countries of the world. Both the father and mother must carry the gene for it to be passed on even if they do not have albinism themselves. The condition results in a lack of pigmentation in the hair, skin and eyes, causing vulnerability to sun exposure and bright light. The term "*person with albinism*" (PWA) is preferred to the term "albino" as it puts the person before the condition (UTSS official definition of albinism).

According to Lapidos J.(2009), three men armed with machetes killed an 8-year-old albino boy in Burundi towards the end of February 2009 and were believed to had smuggled his limbs to Tanzania, where witch doctors use albino body parts for potions. At least 35 PWA were killed in Tanzania in 2008, prompting police officials to set up an emergency hot line and a program to distribute free cell phones to all PWA. How many persons with albinism are there in Tanzania?





Albinism, a genetic disorder characterized by lack of melanin pigment in the skin, hair, and eyes, is listed as a rare disease by the National Institutes of Health—meaning it affects fewer than 200,000 Americans. In Africa, incidences ranging from 1 in 2,700 to 1 in 10,000 people have been reported in various studies with the highest incidence of 1 in 1,000 people in Zimbabwe. In Tanzania the frequency of albinism has been estimated to be approximately 1 in 2,500.

(<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3483204/>). However, Tanzania Albino Society believes the total figure could be more than 150,000 which supports the estimate by *ABC News' Traci Hunte* (2010) that Tanzania has one of the largest populations of albinos in the world with an estimate population of 170,000.

Albinism may be more prevalent in some geographic areas because of inbreeding. A study published in 1982 notes that albinism is less common among the South African Zulu and Xhosa tribes (1 in 4,500) than the Swazi and Sotho-Tswana tribes (1 in 2,000), which have no taboo against cousins marrying. In Zimbabwe, about four-fifths of persons with albinism belong to the majority ethnic group, the Shona. Since the Shona discourage consanguineous relationships, this prevalence may be the result of the founder effect, wherein a small number of people from a larger population form a new community, resulting in the loss of genetic variation. But the extraordinary rate of albinism in Tanzania is not yet fully understood.

In any case, albinism is especially dangerous in sunny climates, like Tanzania's, because lack of melanin predisposes persons with albinism to severe skin damage from UV exposure. PWA frequently suffer from sunburns, blisters, and solar keratosis as well as visual problems like myopia.

According to Irin (2011), thousands of people with albinism in Tanzania and Kenya have left their home villages out of fear of persecution and moved to live in urban areas where they believe they are safer, according to activists defending the rights of persons with albinism. *"Many persons with albinism are migrating more and more to big cities and fleeing from their villages,"* Ernest Kimaya, chairperson of the Tanzania Albino Society, said. *"But the Tanzanian government has made a big effort to make sure that the killings of persons with albinism are*





stopped by strengthening the protection of persons with albinism in the villages.” Kimaya, who was speaking on 10 February at a public lecture in Nairobi to raise awareness about albinism, said his society had so far registered 7,124 PWA in Tanzania, of whom 3,580 are female.

The actual numbers are, however, believed to be higher. PWA have a genetically inherited condition caused by the body's inability to produce melanin pigment. This pigment helps the skin protect itself from the sun's damaging ultraviolet rays.

Their killings are driven by the false belief that their body parts have a special potency when included in concoctions used in witchcraft. Most reported killings have occurred in Tanzania, where a “set” including limbs, ears, tongue, nose and genitals sells for thousands of dollars.

The meeting heard that persecution of PWA was also common in Kenya. In August, a man was arrested for attempting to sell a Kenyan albino for US\$250,000. *“A lot of young people with albinism in Nairobi are uncomfortable about being in certain areas, particularly when it gets dark,”* Mumbi Ngugi from the Nairobi-based Albinism Foundation of East Africa, said. *“We have also been told about threats to people living in rural areas. “Yesterday, I was informed about a young man with albinism who has had to have security provided as he has been threatened that he would be killed and his organs sold,”* Ngugi added. *“Parents with young children are living in fear as many of the Tanzanian attacks have been against children, and many are afraid that it may spread in Kenya too.”* In August, a court in Tanzania sentenced a Kenyan who was trying to sell an albino, to 17 years in jail and a fine of \$50,000.

Between 2007 and 2009, at least 10,000 people with albinism in Tanzania, Kenya and Burundi abandoned their villages and went into hiding, according to the International Federation for the Red Cross and Red Crescent Societies. The Nairobi meeting discussed the rights of PWA to security, health care and education - two other reasons for their increased movement into urban areas. *“The Kenyan minister for planning promised last year to carry out a census; there is a*





promise to provide sun screen, and persons with albinism have been included in some programmes targeting persons with disabilities such as the fund for persons with disabilities, but little has been done in the way of providing protection for persons with disabilities,” Ngugi said. She urged the meeting to recommend to policy-makers strategies to meet the health and education needs of PWA, reduce social stigma and educate parents of children living with albinism. Figures published on 4 February by Under the Same Sun (USS), a Canadian NGO campaigning for the rights and protection of persons with albinism, show that 59 PWA have been killed in Tanzania since 2007, while nine were mutilated in brutal machete attacks.

In Kenya, at least seven killings were reported, the most recent on 24 December. Other deaths were reported in Burundi, the Democratic Republic of Congo, Guinea, Swaziland and South Africa. However, many attacks and killings of PWA in Africa, according to USS, are not documented or reported.

Tanzania has one of the largest populations of persons with albinism in the world - an estimated 170,000.

Since ABC News' interview with Prime Minister Pinda last year, seven more people with albinism have been killed, including a 7-year-old girl who was kidnapped from her grandmother at gunpoint. Her headless body was found the next day, also missing a hand -a hallmark of an occult murder.

The threat to persons with albinism is spreading throughout the continent. In neighbouring Burundi, at least 14 PWA have been killed since last year, and a 2-year-old boy, in Ghana, was terrorized in a botched kidnapping plot. Just last week, a Kenyan man was caught by police in an undercover sting trying to sell an albino man for the equivalent of \$260,000. He pleaded guilty to human trafficking. Also last week in Swaziland, an 11-year-old girl with albinism in was found





beheaded and missing one of her arms. A similar attack took place only months earlier in the tiny country.

You can watch the following three video posted on U-tube as javascript:void (0) by Rick Guidotti at <http://abcnews.go.com/2020/tanzanians-albinism/story?id=8725048> that evidence how insecure people with albinism are in Tanzania; Tanzanians with Albinism Hunted, Tanzanian Premier Discusses Albino Attacks And Family Traumatized By Sister's Murder

While the government and international community work to bring the murders to justice, Staford lives with daily reminders of the pain of her attack. Even the simplest tasks are now impossible for Staford, and she can no longer take care of her son.

"Sometimes I cry, because it's the same thing over and over again. ...Waking up, sitting on the chair and when I'm tired of sitting, I go and sleep," Staford said. "I miss feeling the love of my child, because I can't even carry or hug him anymore."

3.9 Public Sector Response

Paul, J. (2012), says that over 200 people were present at “Albinism Awareness Day” on September 16, 2010, including both persons with albinism and their dark-skinned relatives and friends, which was a drastic improvement from the initial few who first listened to Dr. Sethi’s message in 2007. Members of the Ministry of Disability and Rehabilitation, the Director of Kamuzu Central Hospital, Dr. Noor Alide, and Dr. Sethi spoke on behalf of the PWA population. A clear message of solidarity was conveyed at this event, as many of the speakers were PWA themselves. Boniface Massah, a ministry official who also has albinism, was one of the main speakers at the event. He is one of six children, and two of his siblings also have albinism.

As part of the event’s skin cancer prevention campaign, he explained to those in attendance the proper method for applying sun block, a supply of which was graciously donated from the





Netherlands. He also demonstrated the importance of using wide brimmed hats and wearing sunglasses. The entire event was videotaped and many journalists were present, thereby allowing the widespread dissemination of the vital and important messages delivered during “Albinism Awareness Day.” The hope was to reach and educate more than those in the audience, and to help change the cultural attitude towards albinism. In this way, hopefully the stigma associated with albinism will dissipate, and persons with albinism will be able to reclaim their rightful place as productive members of society.

3.10 Future Direction/Recommendations

Education-awareness campaigns are only as beneficial as the audience that receives them. In order to truly deter and prevent human rights violations against persons with albinism, societal views regarding albinism and the culture of witchcraft needs to change. The government has an immense role to play in both of these issues. As mentioned previously, Africans are not ignorant to the fact that individuals with albinism are being slaughtered for their body parts; therefore, the police should be able to identify potential and past perpetrators by simple questioning in neighbourhood with high prevalence rates. Swift conviction of these criminals will send a clear message that these horrific acts are unethical, and no longer justified by myth or wealth.

This process is already starting in Tanzania: in 2008, three murderers were sentenced to death by hanging for the killing of a 14-year-old albino boy named Matatizo Dunia. This case was the first of its kind, and has the potential to significantly alter the way Africans think about albinism. In that same year, 170 witch doctors were arrested under the leadership of President Jakaya Kikwete. President Kikwete also appointed Tanzania’s first Member of Parliament with albinism, Al-Shymaa Kway-Geer in 2008. Prompt and appropriately severe governmental response is necessary, as it will inspire otherwise uneducated or recalcitrant community members to promote and uphold the rights of their fellow citizens with albinism.





However, the law is limited in how much influence it has on its populace. Molly Melching, founder of Tostan and a human rights activist, is noted to have said, “Law is a quick-fix solution, and then people think you don’t have to do anything else...The real thing that will make a difference is education.” Education campaigns, such as “Albinism Awareness Day” in Malawi or the “Albinism in Southern Africa” project should be conducted throughout Africa and internationally in order to promote the rights of those with albinism. Subsequently, a holistic approach to terminating these atrocities against individuals with albinism will be achieved, and

SECTION FOUR

EMPIRICAL REVIEW

4.0 Case Studies

It is the zeal of the Tanzanian government, local and international development agencies, Civil Society Organizations (NGOs, FBOs CBOs) including Under the same Sun and Unicef to ensure People with albinism enjoy life to the fullest of the human dignity. For the continued struggle to care, support and protect PWA in Tanzania, one can learn from the following case studies for improved service delivery to these people in the specified centres.





4.1 Case Study One

Siloe School in South Africa



A group of students playing at the Siloe School in South Africa.

Life with Albinism

Most children with albinism can attend mainstream schools. Parents should contact the school system before kindergarten to plan for their child. Classroom accommodations include video magnifiers, large-print textbooks, audio tapes to supplement reading, large-print copies of board notes, and use of computers for writing projects [source: International Albinism Centre]. Despite these gestures, people with albinism still face teasing, stares, well-meaning but ignorant questions, feelings of otherness and isolation, and myths about the condition [source: NOAH]. Parents should equip children early to cope, recommends June Waugh, a child and family counsellor affiliated with the National Organization for Albinism and Hypo-Pigmentation (NOAH). Strategies include discussing albinism and a child's feelings, developing a positive attitude toward albinism, practicing responses to bullies, and meeting others with albinism.





Once you have made friends with people with albinism, you may wonder if it's okay to call your new pals "albino" or a similar informal name. Many people with albinism don't think so, seeing themselves as a people first, not a condition, and preferring "person with albinism." Yet opinions differ. "If I were to be completely politically correct, I would have to say I was born with a condition called femaleism, African Americanism, and albinism. But that's silly: isn't it?" writes Virginia Small, former member of NOAH's board of directors, on her website.

Despite vision impairment in those with albinism, playing sports rarely becomes an issue. "The 'can't do' list is small... squash, tennis, [and] badminton," writes Martin Lang, a member of the Albinism Fellowship, about sports for his ten-year-old daughter with albinism [source: [Lang](#)]. Sports with small balls can be difficult for people with albinism, but these can be adapted using sound [source: [Winnick](#)].

Depending on vision, preference and local laws, people with albinism can drive under certain road conditions, with the use of bioptics [source: [Grover](#)]. Poor vision can limit careers for people with albinism, but most limits can be overcome with technology, adaptation, and determination. People with albinism become doctors, athletes and artists [source: [NOAH](#)].

In other places, however, people with albinism have more serious problems. In some parts of Africa, lack of classroom accommodations and stigma can prevent people with albinism from holding profitable jobs [source: [Machipisa](#)]. Even worse for Africans with albinism, dangerous myths are circulating in Kenya, Tanzania, Zimbabwe and other countries that perpetuate the raping, killing, and dismemberment of people with albinism. These include that body parts of people with albinism carry good luck and that intercourse with a woman who has albinism can cure HIV [sources: [Gettleman](#) and [Machipisa](#)]. Governments and local support groups are working on education and protection campaigns.





4.2 Case Study Two

Uganda Albinos Association

4.2.1 Organization Profile

The Association was started in 2007 by three Makerere University students who had experienced discrimination based on skin colour, which contravenes the Constitution of Uganda. The Association was formed by Albino persons to create a future for them and for generations to come. Albinism affects all races, ages and genders. It is an inherited, recessive condition caused by lack of melanin. Albino persons are extremely sensitive to sunlight and highly susceptible to skin cancer.

Our vision is to build a community that promotes equality, justice, respect, rights and freedom for all Albino persons.

Our mission is to advocate for awareness, and acceptance and to establish an Albino Persons' Law in Uganda.

So far the Association has five branches in Eastern, Western, Southern, Central and Northern regions of Uganda. This is because of massive awareness campaigns backed by international pressure. For example, a Tanzanian journalist, Vicky Ntetema, won an international award for a BBC report on the murder of Albino persons, and CNN has reported on the murder of persons with albinism in Burundi.

4.2.2 Successes

4.2.2.1 Increasing our membership from three Makerere students to a nationwide organization of 3,700 Albino persons.

4.2.2.2 Forming regional branches in Central, Western, Northern, Eastern and Southern regions of Uganda.





- 4.2.2.3 Successfully petitioning government to confirm and recognize Albinism as a disability.
- 4.2.2.4 Reaching a Memorandum of Understanding with the government to allow us to import products such as sunscreens duty-free.
- 4.2.2.5 Sensitising the public and strengthening the Albino fraternity through websites, radio and newspapers.
- 4.2.2.6 Running income generating activities such as piggeries, cow and poultry raising.
- 4.2.2.7 Partnering with various organisations like Disability Rights Fund, Action on Disability and Development, Amnesty International, and Uganda's Ministry of Gender.

4.2.3 Challenges

- 4.2.3.1 Regional branches are still in a poor state due to limited resources.
- 4.2.3.2 Albino persons continue to suffer extreme prejudice arising from cultural and social beliefs. Fathers often deny and neglect their Albino babies; cases of murder and ritual sacrifice of persons with albinism still occur. Yet the majority of PWA themselves in sub-saharan Africa remain largely ignorant about their rights.
- 4.2.3.3 HIV/AIDS prevalence is high among persons with albinism.
- 4.2.3.4 Skin cancer is the number one killer of Albino persons, most of whom lack access to sunscreens and other protection. The Association hopes to address some of these problems by further advocacy work, by starting a Savings and Credit Cooperative for





Albino persons to save and borrow money at low interest, and by increasing the availability of sun protection equipment and the specialized eyeglasses that many persons with albinism need.

4.3 Case Study 3

The plight of PWA in Tanzania

4.3.1 Stop Slaughter of PWA in Tanzania

The atrocities, stigma and discrimination against persons with albinism in Tanzania and parts of East Africa have garnered worldwide attention. After the first story on BBC World Service hit the airwaves on 21st and 22nd July 2008 Peter Ash, a Canadian businessman with albinism decided to act. “These are my brothers and sisters getting slaughtered, what can I do to help?” When he went to Tanzania for the first time on a fact-finding-mission, he realized that many persons with albinism in the country were not educated and that stigma and discrimination were fuelled by harmful believes and myths surrounding the genetic condition. He started an international Canadian-based organization named Under The Same Sun with the aim of focussing the education for persons with albinism and eradication of prejudice and discrimination that has plagued PWA via advocacy and public awareness.

To learn more about this issue, and the work that is being done, please visit Under The Same Sun (UTSS) at www.underthesamesun.org

4.3.2 About UTSS

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.





4.3.3 UTSS Vision

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.

4.3.4 UTSS Story

UTSS began as a collision of the heart, mind and vision of Peter Ash and Vicky Ntetema. At the time, Vicky was a journalist and Tanzania's BBC bureau chief, and Peter a Canadian businessman whose professional life was in transition. It was *Vicky's report in July of 2008 that broke the crisis* of persons with albinism (PWA) in Tanzania to the world. *It also broke Peter's heart.* Shortly after her report, Peter called Vicky and 2 people with big visions were united in a battle against discrimination so sinister that it had turned into grisly mutilations, murders and the trafficking in the human body parts of persons with albinism in Tanzania. Later in 2008 founder and CEO Peter Ash, registered UTSS as a Canadian, federally registered, non-profit organization. In 2009 UTSS - Tanzania branch was also registered as an international non-government organization (NGO) and the doors of our office in Dar es Salaam were opened to the public. Vicky Ntetema has resigned her post with BBC and joined UTSS as Executive Director. Today UTSS - Tanzania has 20 staff and interns, over half of whom are PWA serving their own people in their own country.

4.3.5 UTSS Projects

Education Scholarship Fund (ESF) Programme: To date, UTSS greatest success comes through *our ESF program* which has seen more than 300 PWA, mostly abandoned and displaced children, relocated into some of Tanzania's finest private boarding schools. They will be future





models in their society of what persons with albinism can be when given equal opportunity. This could not have happened without 2 *amazing teams* which have been gathered to form our offices in Tanzania and Canada.

Advocacy and Public Awareness Programme: *The production and distribution of Our documentary* will forever capture and honour the story of PWA in Tanzania while dispelling the discriminatory myths and informing people about the genetic condition of albinism. It casts the LIGHT of dignity on all persons with albinism and is an amazing advocacy and education tool. There has also been *a significant drop in both the attacks and killing of PWA in Tanzania since 2007*. While this gives us great delight, the profound discrimination that gave rise to the killings is still deeply rooted in African culture. Radio and TV programmes in collaboration with community radio stations and national electronic media in Tanzania. We also publish newsletters, brochures and leaflets on albinism. Photo exhibitions on the plight of PWA and interactive seminars and discussions on the Truth about albinism for part of our awareness campaign.

First Responder Mission

UTSS team is dispatched to the crime scene as soon as the information reaches the organization with the aim of consoling and comforting the survivors and victims' families, investigating the atrocities, data documentation and liaising with families, the police, local authorities and government officials including social welfare officers and community development officers on how best to support the families and survivors.

Low Vision Clinics

Frequent Low Vision Clinics run by Dr. Rebecca L. Kammer, an Associate





Professor of optometry and low vision at the Southern California College of Optometry in Anaheim, California. These have served our ESF grantees and staff with albinism. Low vision devices are also provided at no cost.

Legal Representation

UTSS team is ready to testify / give evidence before courts in support of persons with albinism fleeing atrocities in their countries.

4.3.6 UTSS Successes

Over 300 ESF grantees ranging from nursery to PhD levels.

Our Documentary on albinism titled *White and Black: Crimes of Colour* has been widely viewed in Africa through community outdoor and indoor screenings. Publication and distribution of various material on albinism. Publication of the Guide for teachers, caregivers and parents (in collaboration with UNICEF and the Ministry of Education and Vocational Training)

Legal history was made in the Spanish Canary Islands on December 29, 2009 when a man with albinism from Mali, was granted asylum.

Legal history was made in Italy in April of 2009 when a man with albinism from Cameroon was granted asylum.

Legal history was made in the state of Florida, USA on February 16, 2011 when a man with albinism from Nigerian was granted asylum.





Legal history was made in Spain on May 12, 2011 when person with albinism from Guinea was granted asylum.

Legal history was made in Israel on October 1, 2011 when an Ivory Coast family with an infant daughter with albinism was granted refugee status. The minister of interior signed the final asylum documents on November 6, 2011.

For the second time in USA history, on November 29, 2012, a woman with albinism from Zimbabwe was granted asylum in Atlanta, Georgia.

4.3.7 UTSS Dream

Our dream is that a day will come when persons with albinism in Tanzania will take their rightful place in every aspect of society and that the days of discrimination will be a faint memory. While there are traces of hope now, we will likely not see this day in our lifetime except in our dreams.

SECTION FIVE

POLICY REVIEW

5.0 National Policy on Disability

According to Prof. Juma A. Kapuya (MP) Minister for labour, youth development and sports (2004), Tanzania has been actively involved in both international and local initiatives that address disability issues. At the international level, Tanzania is a signatory to various disability





specific United Nations instruments which include the declaration on the Rights of People with Disabilities (1975), Convention on the Rights of the Child (1989) and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993).

At the continental level Tanzania is a signatory to the Plan of Action for the African decade of Persons with Disabilities and a member of African Rehabilitation Institute (ARI). Currently Tanzania is working with the international community to realize the finalization of a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities.

Locally, Tanzania has taken measures to address the problem of disability from various angles including the national health initiatives to eradicate childhood diseases that cause disablement such as polio, enactment of disability legislations, inclusion of a question on disability in the 2002 National Population and Housing Census and the ratification of the United Nations standard Rules on the Equalization of Opportunities for Persons with Disabilities. In reference to the National Policy on Disability (July 2004), 1.2.14 Human Rights and Legal Protection:

The current laws were enacted without consideration of the differential needs of persons with disabilities. The administration of such legislations as relating to construction where stairs are preferred to ramps or information where persons with disabilities have no access to Braille prints or sign language interpretation. The two disability specific legislations have serious shortcomings. These legislations are: -

- (i) Disabled Persons (employment) Act No. 2 of 1982: This Legislation requires employers to employ 2% (persons with disabilities) of every 50 employees in an establishment.





Political and Social economic changes have made these legal provisions difficult to enforce.

- (ii) Disabled Persons (Care and Maintenance) Act No. 3 of 1982: This Act provides to local authorities to own and provide institutional care to disabled persons. The government however, is yet to provide mechanisms that would allow local authorities to assume this role.

Article 5.1 of the 2004 National policy on Disability, Under Policy statement 3.4 Policy Issue about Early Intervention:

Early intervention forestalls onset of disability later in life. Early identification followed by treatment has the potential of eliminating onset of disability and or reduce the impact of disability in adult life. Early intervention is therefore an all time solution to the problem of disability. Despite its importance only a negligible percentage of disabled children are reached. In chapter 4 of the policy on stakeholders responsibilities, persons with disabilities have the right and equal opportunity for development and receive the same services from the society as the nondisabled. Their participation in the life of the community must target on reduction or elimination of dependency. In order to focus on development and improved service to people with disabilities in the implementation of this policy, the following shall be the responsibilities of principal stakeholders.

5.2 Article 4.1 of the policy on role of the Central Government

- 5.2.1 Supervise service provision to people with disabilities.
- 5.2.2 Review relevant legislation so as to bring about development to people with disabilities.
- 5.2.3 Ensure participation integration and equal opportunity for people with disabilities in





their daily life.

5.2.4 Encourage local authorities and NGOs to provide services to people with disabilities. **While on article 4.2 Local Authorities are expected to**

5.2.5 Assessment of people with disabilities and their needs.

5.2.6 Provide protection to people with disabilities.

5.2.7 Provide basic needs.

5.2.8 Include people with disabilities in the planning and implementation of income generating programmes.

5.2.9 Identify NGOs that provide services to people with disabilities and coordinate their activities.

Aside from the discrimination, they face the constant threat of being attacked, mutilated and killed for their blood and body parts for use in witchcraft. Amadou Diallo, a person with albinism, left Africa after he was nearly killed by armed men in Guinea.

He offered this plea to African leaders and citizens. *"We are different only because we don't have pigmentation,"* said Diallo. *"Beyond that we are human beings just like them, so we need them to accept us, to integrate us among them, to give us a job when there is a job available, to not discriminate."*

Diallo now works for Under The Same Sun a Canadian-based organization that advocates for the rights of persons with albinism in Tanzania. Founder and CEO Peter Ash said the problem exists in more than a dozen African countries. *"Some of the organs are shipped out of the country,"* he said. *"There is also a cross-border Internet trade of various African countries in these parts. This is not just a Tanzanian phenomenon."*





A large surge in such crimes took place in 2008, when 24 people with albinism in Tanzania were killed for body parts. In the murky and secretive world of witchcraft, so much remains speculative. But one thing is clear: a good deal of money is paid out for the body parts, according to Ash. *"The people who are buying these organs are spending thousands of dollars,"* he said. *"The arm or leg of a person with albinism sells for about \$2,000 to \$4,000. A complete set of organs of a person with albinism sells for over \$100,000. Now you have to ask yourself, in such in a black market, who in a poor country like Tanzania has that kind of money? Very, very few people,"* concluded Ash.

The Tanzanian government has in fact publicly condemned the attacks in recent years. It has also opened shelters for albino people, and called for the prosecution of witch doctors linked to killings. Those actions are believed to have helped lower the number of attacks - until now. The Human rights agencies and activists are calling for the government to help combat the by aggressively prosecuting witchcraft-related violence. ***"Justice has not come and horrifying crimes against children with albinism continue unabated in Tanzania. Only firm and decisive action on the part of Tanzanian government and society will stem this tide of innocent blood being spilled!"*** declared Peter Ash, a person with albinism himself and Founder/CEO of Under The Same Sun (UTSS). *"To date there has been 78 documented attacks resulting in 62 murders and 16 survivors. Only 5 of these cases have resulted in convictions in Tanzanian courts,"* concluded Ash.

[http://www.underthesamesun.com/sites/default/files/October%202011%20Press%20Release%20-%20Updated 0.pdf](http://www.underthesamesun.com/sites/default/files/October%202011%20Press%20Release%20-%20Updated%200.pdf)

In December 2007 the Tanzania Albino Society accused the government of inactivity in the face of four albino killings over the previous three months. While older albino women with red eyes





had been at risk for being murdered sporadically in the past as witches, this killing spree may have been the beginning of the ongoing persecution of persons with albinism with the intent to harvest the victims' body parts. With escalating killings, President Kikwete publicly and repeatedly condemned witch doctors, their helpers and middlemen, and the clients, which include members of the police force, for these murders. Victims include children snatched or abducted from their parents. The killers and their accomplices use hair, arms, legs, skin, eyes, genitals, and blood in rituals or for witch potions. Fishermen incorporate albino hair into their nets in their hope to catch more fish from Lake Victoria or to find gold in the belly of the fish that they catch. A number of steps were taken by the government to protect the albino population. The president ordered a crackdown on witchdoctors in the spring of 2008. In addition, a woman with albinism, Al-Shymaa Kway-Geer, was appointed as the Member of Parliament with the genetic condition in the history of Tanzania. Police have also been advised to generate a list of PWA and provide special protection for them. Graves of PWA were to be sealed with concrete to deter grave robbery.

However, by October 2008, killings had not abated, and while some suspects had been apprehended, no convictions had taken place. It was estimated that over 50 murders had taken place since March 2007, many of them in the mining and fishing communities surrounding Lake Victoria, especially in Mwanza, Shinyanga, Mara and Kagera. In January 2009, Prime Minister Peter Pinda declared war on the albino hunters, and in an effort to stop the trade in albino body parts he had revoked the licenses of all the country's witchdoctors to use the body parts in their black magic fetishes.

5.3 First conviction

The first ever conviction for the killing of an albino in Tanzania occurred on 23 September 2009 at the High Court in Kahama. The conviction came about following the murder and mutilation





of a 14-year-old boy, Matatizo Dunia, who was attacked by three men in Bukombe District in Shinyanga Region in December 2008. The assailant chopped off Dunia's legs just outside the family house and left him bleeding to death. One of the murderers was later found with Dunia's legs in his possession. The rest of Dunia's body parts were found in a bush.

The men confessed a desire to sell Dunia's parts to a witch doctor, yet despite this, their legal team had not anticipated the death sentence of hanging which the three men would receive. Canada's Under The Same Sun albino activist organization praised the breakthrough but its founder Peter Ash remarked, *"This is one conviction. There are 52 other families still awaiting justice"*. The Tanzania Albino Society's chairman Ernest Kimaya called for the hanging to be made public to further demonstrate to others that the issue of killing PWA was to be taken seriously.

5.4 International reaction

After events involving murders of albino humans by three Tanzanian men had been publicized by the BBC and others, the European Parliament strongly condemned the killing of persons with albinism in Tanzania on 4 September 2008. The U.S. House of Representatives passed H. Resolution 1088, introduced by Rep Gerry Connolly (D, VA), by a vote of 418-1 on February 22, 2010. The resolution condemns the attacks and killings; categorizes them as human rights violations, and urges the governments of Tanzania and Burundi to vigorously prosecute such cases and to conduct educational campaigns to combat the superstitious beliefs that underlie the violent attacks.



SECTION SIX

6.0 KEY FINDINGS

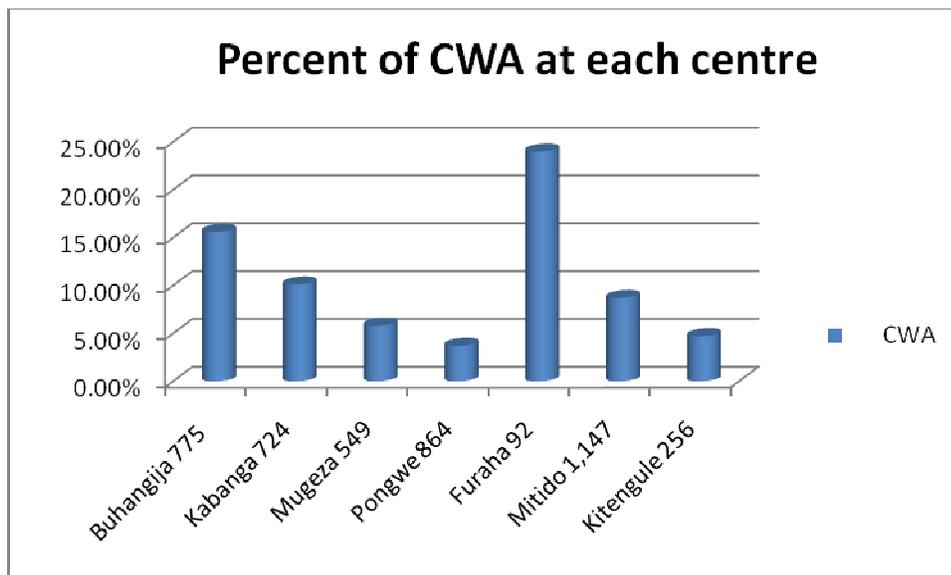
UTSS conducted the current research with the intention of assessing the situation of the centres in 5 Lake Zone and Tanga regions where individuals with albinism and other disability were living by the time of the study.

Witchcraft killings and atrocities against PWA were threatening and disturbing to the extent that a number of PWA were forced to leave their original places to Diaspora where they are displaced. The findings of this study give a general picture of the really situation of the centres where PWA from various places in Tanzania were shifted to. There are recommendations given in this study for improved condition to ensure quality care, support and protection of PWA in those centres. Figure 10 gives a summary of the percentage CWA at each centre.





Figure 10 Percentage of CWA at each centre



Source: UTSS Survey findings 2011

6.2 Protection of Children with Albinism

UTSS surveyed 9 of all centres passed and recognised by the Government where children with albinism were shifted for care, security and protection. Unfortunately to some of these centres, children reported to had been living with insecurity because 6 centres (67 percent) were reported to have had poor infrastructure including lack of fence, weak doors while some having no locks, 4 centres were reported to be freely accessible by community members in the sense that their way to and from the villages crosses via the centres.

The security guards at 5 centres were reported to be drunkard, some sleep at night and some are even not armed to assure protection to the children. Moreover there were problems of water, electricity and energy to the extent that children at 4 centres complained to had been matching a distance without escort across bushes or forests to fetch water and firewood which makes them fear the more and even failing to differentiate the threatening situation of their original places



and at these centres. The toilets at 6 centres were reported to be built at a distant in such a way that at night children fear to go out alone to extent that the little ones out of fear to go out at night sometimes they urinate themselves.

6.3 Corporal punishment

A total of 392 children with albinism were interviewed during the survey. 348 children, that is 89 percent of children with albinism complained against corporal punishment which is given to them. In almost all 9 centres (Buhangia, Bukumbi, Furaha, Kabanga, Kitengule Missionaries of Charity, Mitindo Mugeza and Pongwe) complains against corporal punishment were given. About 4 children of them witnessed to had been severely and randomly bitten for no apparent reasons. At Mitindo a child said, *“Teachers punish us in the sun. They give us corporal punishment even when we have not done anything wrong. They call us names and say they will take us to our villages to be killed.”*

6.4 Stigma and Discrimination

There is high level of stigma and discrimination against children with albinism reported almost in all 9 centres. 356 children with albinism, which is 91 percent of children with albinism in the 9 centres, reported to have been stigmatised, discriminated and or abused in one way or another by fellow students, teachers, matrons and patrons but even cooks and watchmen were reported to have had been mistreating them.

In short, stigma and discrimination, some cases of sexual harassment were reported and of course great fear of killings and atrocities against individuals particularly those with albinism prevails in these centres.

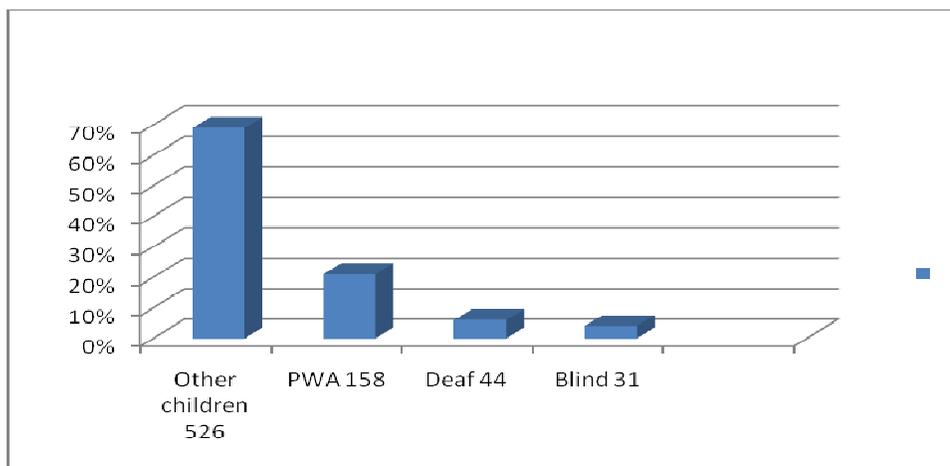




For instance one child at Bukumbi witnessed that PWA were unhappy staying at the centre because of rampant discrimination and stigma “They discriminate against us because we have albinism. The matron does not take care of the younger ones.” She concluded.

Buhangija has a total population of 759 (371 females and 190 males). 526 children are day scholars while 232 are residential. 20 percent of the total population that is 156 children (83females and 73 males) have albinism while there also 2 adults with albinism to make the total population of PWA to be 158.

Figure 11 Population of Children with disabilities at Buhangija centre



Source: UTSS Survey findings 2011

There were 44 hard of hearing and 31 with vision impairment too. 233 children (that is 30 percent) of the total population, were children with disabilities. Despite the bigger number of children with albinism at Buhangija, stigma and discrimination was said to be high. A total of 92 children with albinism (that is 59percent of them) who participated in focused group discussion said that they are discriminated not only with some teachers but even fellow students who have



no disabilities; punished and abusive language against them prevails. They even complained to had been given severe corporal punishment by being stroke all over the body and sometimes during sunshine which cause them to get sunburn.

6.5 Teacher Students ratio

At all 9 centres, the teacher students ratio is good in the sense that children could have nice moments to interact with teachers for better school performance academic-wise. But the problem observed was that these staff lack psychosocial care and support skills and technical knowhow to caring and supporting children with disabilities and living in adversity situation.

6.6 Security and observation of child rights

The situation is different at these centres, one could expect high observation of child's rights and human rights but it is not so in practice. The researchers discovered serious violation of children's rights witnessed by children themselves. For instance at Mugeza, 80 percent of children who participated in the focused group discussion said that they had been continuously terrified by the leaders that they would be returned to their original places where they were forced to run away. This was like a pain in their necks which was used to force them to do whatever they wanted them to do.

For instance, children were ordered to fetch water from the river and go into the forest to collect firewood without escort and or protection precaution, to go out to cut grass for cows, to milk cows, to till the land and other tasks of the sort. Such an environment was putting them in a risk and insecurity, psychologically disturbing to the children because it were like being taken back to the same original threatening places where they ran away. At Mugeza a child with albinism in a Focus Group Discussion said, *"We have water problems. We are sent to fetch water very far. Security is not good. Security guards are drunk always. We do not have a kitchen.*





Dormitories are insufficient and there is no ventilation. Classrooms do not have lights and therefore we cannot read at night. Text books are not enough. Teachers are not helpful. One calls us bad names. She is the worst teacher in the school. Our matron is very bad”.

6.7 Poor Infrastructure

There is dilapidated infrastructure and physical environment. Some children feel unprotected in some of the schools/centres due to insecurity i.e. schools/centres are not well protected, lack fences, poor safety, security and child protection facilities. There are no recreational facilities in most of the centres for children clubs activities and or facilities for concerts, plays, poetry and singing (choir). Scarcity of resources lead to poor health conditions, shortage of water, sanitation and poor hygiene facilities, shortage of food, shortage of teaching and learning materials and other basic needs. A case from Kabanga centre can be taken to demonstrate this as quoted from a Focus Group Discussion when a resident complained about shortage of beds, sleeping facilities, dirty and unfriendly environment and lack of privacy while the Academic Mistress commented on indecent acts inadvertently that due to that situation *“children are exposed sexual acts and that some of the students get preferential treatment.”*

At Furaha centre a child in a Focus Group Discussion said that the institution has poor accommodation facilities, people share beds, mattresses are in a bad condition and there are insufficient washrooms. Children with visual impairment feel isolated and unvalued. *“The matron does not love us and care for us,”* she concluded.

At Mitindo a child pondered, *“We are on our own most of the time. Classroom windows have wide security grills that could allow a person to pass through. Anyone can come through these*





windows and into the dormitories and attack us without the knowledge of the security guard. Further, door locks are weak or absent on all doors".

6.8 Entertainment and leisure provision

It was noted that there is no room for sports, play, games and any leisure services provision as a priority in these centres. A child in Buhangija, puts it more clear as he complained, *"There is no specific day for games at our school. We do not have a sports and games teacher. Neither do we have audible balls for those with visual impairment. We don't have playing grounds."*

6.9 Psychosocial care and support

PWA and those with other disabilities in the surveyed schools/centres lack quality care and support. It was observed that the centres lacked trained people with specialised skills to help children who are traumatised, those who suffer loss of their beloved ones, those who suffer loneliness, bereaving, those who were abused and are still abused in the centres, some were physically wounded and psychologically disturbed.

6.10 Scarcity of resources

It was found that the surveyed institutions are operating in meagre resources which can be detrimental to the academic, psychosocial and health of the children/residents in the schools/centres. You can imagine that a matron at Mugeza considers children with albinism as a burden to the centre, she said, *"The coming of children with albinism has not only worsened the financial constraints on the institution but has also increased the burden of responsibilities on the few personnel who have to ensure that the children are secured."*





6.11 Teaching and Learning Materials

Almost all centres/schools were found with a shortage of teaching/learning materials and other related facilities. For instance at Kabanga The Head-Teacher supported by the academic master said "There is a great shortage of teaching and learning materials. For instance, if we could get a photocopy machine we could make copies to assist those with albinism to have their own notes because of low vision which prevents them from reading from the blackboard." Participants from Mugeza and Furaha Primary school said that the availability and use of learning and teaching materials was a big problem. *"The teaching facilities for students with blindness and low vision are very expensive, and we have no money to purchase them We also do not have a technician to repair the available equipments if they at all get damaged or in case of technical problems,"* they concluded.

SECTION SEVEN

DISCUSSION AND RECOMMENDATIONS

7.0 Discussion

The findings of this study indicate that violence, abuse, stigma and discrimination against children with albinism and other disabilities are serious problems at Buhangija (Shinyanga region), Bukumbi and Mitindo (Mwanza region), Kitengule and Mugeza centres (Kagera region), Furaha and Missionaries of Charity (Tabora region), Kabanga (Kigoma region) and Pongwe centre in Tanga region where PWA and other disabilities currently live.

People could expect children living in such specialized centres highly protected and cared for, but in practice life is not so. Though there is still a limited information about the magnitude of





the problems facing children living in the centres, there is still a chance to build on this information to conducting a thorough research aiming at improving the standard of life of PWA and other disabilities who are shifted from their original place to live at identified centres as recommended by the government. The report highlights how child rights are violated in these centres but also suggests through the recommendations below what to do solve the problems.

7.1.1 Key Findings

In reference to the key findings, there must be a thorough research which will come up with strategies to improve the living standards of PWA in the centres including right based programs to care and support them.

Lack of specialised skills in the areas of love, care, protection and support of PWA and other children living in adversity situation has lead to the serious violation of child right in the centres, the recommendations given below as regards to the capacity building should be taken seriously too. Poverty on the other hand is contributing much to the mistreatment of children, for instance some staff members were reported to have been stealing food and other materials donated by resource providers to support the children. Arrangements should be made to support the careers hence the need for economic strengthening program for them will help to meet family needs. The situation is threatening to the children, an extra eye to the issue is crucial.

The toilets at 6 centres were reported to be built at a distant in such a way that at night children fear to go out alone to the extent that the little ones sometimes wet their mattresses or use a dormitory corner as a makeshift washroom.

Effective strategies for lobbying and advocating for change of behaviour and attitude towards PWA is crucial. Community capacity competence enhancement programs including awareness





creation and information, education and communication material dissemination, community economic strengthening, team spirit, specialised training to all workers in the centres are crucial in the struggle to improving the standard of living of the people with albinism in Tanzania and other countries in the region.

7.1.2 Strengths and Limitations

The strengths and limitations of this study should be considered when reviewing and or interpreting the results. The study and the results which are reported herein based on literature policy and empirical review to see if there can be done some changes in terms of peoples' behaviours, attitudes and beliefs towards PWA that human rights are strictly recommended to be observed.

7.1.3 Protection and humanitarian services.

According to UNICEF, (2013) An estimated 20 million children are currently displaced by armed conflict or human rights violations. Two thirds are internally displaced within their own national borders. These children are forced to flee their homes, often travelling great distances to escape enemy fire, and become the most frequent victims of violence, disease, malnutrition and death. In the chaos of flight, children may become separated from their parents and families. They are exposed to far greater danger and exploitation, including forced recruitment, abduction, trafficking or sexual exploitation. Displaced children urgently need assistance and protection. *“My dream is to return home for one or two days before I die. It would give me everything. I'd go back to my house, my garden, my school,”* said an adolescent, Azerbaijan

When families and communities abandon their homes, taking what few possessions they can carry, they may plan to return at the earliest opportunity. But 'temporary' displacement can





extend well over a decade. In such cases, children may spend their entire childhood in camps. Other long-term effects of displacement are an increased risk of poverty resulting from the loss of land, inheritance or other legal rights; incarceration or discrimination; and an inability to resume schooling. This is the situation of PWA who are living in the centers mentioned above. It is the duty of Tanzanians as individuals, government, civil society organizations and development agencies like UTSS and UNICEF to intervene this situation for proper care and protection of PWA. Knowing the situation, it will be easy for UTSS to take up the responsibility as an initiator to build from this information better foundation for improved standard of living of PWA in the set centers in Tanzania.

7.2 Recommendations

Basing on the findings, it is recommended that;

7.2.1 People living with Albinism in the identified Government centres in the Lake Zone and Tanga regions.

7.2.1.1 UTSS can consider a model that will encourage formation of support groups that will create conducive learning environment and protection of children living with albinisms and those with other disabilities.

7.2.1.2 UTSS can design programme on targeted existing centers where PWA currently live to scale up efforts to child protection and eliminate all forms of discrimination against PWA and those with other disabilities.

7.2.2 Community Awareness Raising and Sensitisation in regards to children Rights





7.2.2.1 UTSS can consider establishing a sensitization programme in all targeted regions focusing on enabling and enhancing community competence in observing children's rights and following up to ensure no community members violates child rights out of knowledge of the community members to report to the police and or facilitating filing a case in a court.

7.2.2.2 UTSS can work with other child development partners to lobby and advocate for change in attitude, beliefs and policies that perpetuate stigma and discrimination against PWA and or other disabilities.

7.2.2.3 It was evident that large parts of population in the specified centers are not aware on child rights and their responsibilities to children with disabilities and or those living in adversity situations.

7.2.2.4 UTSS should organize awareness seminars on child rights and elimination of all forms of stigma and discrimination against children with albinism and other disabilities. This should never exclude empowering village leaders, development partners like NGOs, FBOs and CBOs, centers staff/workers, families and communities, and children themselves for them to claim for their rights when there is a violation of their rights.

7.2.2.5 UTSS can design and or enhance the existing national sensitization programmes targeting community/local culture and beliefs that are resistance to change for example using body parts of PWA for rituals, cleansing and or good luck or sake of success in business and mining

7.2.3 Capacity Building and Empowerment in realization of children rights

7.2.3.1 UTSS can setup programmes aimed at skilling the workforce or strengthening the





capacity of all workers in the identified centres where PWA and those with other disabilities are accommodated for realization of children rights according to CRC and our current law of Child Act 2009.

7.2.3.2 The concept of children's council is fundamental in promoting children participation and raising voices for various issues of children rights.

7.2.3.3 UTSS needs to enhance community competence through awareness creation and use of media, dissemination of Information education and communication material, internet, facebook, twitter, youtube and other communication technologies all for information sharing and institutional capacity building to enable and facilitate effective functioning of children clubs and or children councils.

7.2.3.4 Psychosocial care and support services are crucial in these centre hence recruiting trained and or skilling the workforce should be taken seriously

7.2.4 Entertainment and leisure provision

there should be space for children clubs, debates, competitions, sports, play and games in these centres as for leisure provision and entertainments which is their right also.

7.2.4.1 UTSS in collaboration with UNICEF and other development partners can provide training and support to the workers at the centers but also build capacity of community members outside the centers for them, including FBOs, CBOs, Local volunteers, Police, Prison wardens, school teachers, nurses and staff of child care facilities about child social protection by targeting districts.



7.2.5 Income Generating Activities and realization of children rights

It is becoming a normal thing that once a child with albinism has been accepted at a certain centre, the parents and or guardians tend to wash their hands for the development agencies to take their responsibility, to care and support the children on their behalf. This is wrong! It is still communities responsibility to care and support their children while UTSS and other development partners only facilitate communities and families to smoothly taking up their responsibility. For that reason it is recommended that UTSS facilitate community economic strengthening and in a special way to families of PWA and other disabilities through finances, material and technical support for them to implement child rights programs and raise small business/enterprises for income generating so that they have enough resources to cover the unmet children needs or deficit left by UTSS and other support agencies.

7.2.6 Nutrition and Food Security

UTSS in collaboration with the government and other development partners can join efforts to effectively mobilize more resources to ensure nutrition and food security and proper management of the same in the specified centers where PWA currently live. This should include but not limited to food and health services at school, enough water and toilets, and enabling the communities to have enough resources to meet the survival needs of their children.

7.2.7 Water and sanitation

It was observed that in almost all centers there were energy, water and sanitation problems to extent that some PWA were obliged to walk a distant in forests to fetching water and firewood which puts them at risk and feel insecure.





UTSS in collaboration with the government and other development agencies should set aside financial, material and human resources for effective implementation of child development programme targeting on such centers water and energy supply, school feeding and environment reservation.

7.2.8 Other areas of recommendation

7.2.8.1 Child protection in the schools/centres, (especially safety and security) should be a number one priority within the community, local and central government agenda and plans.

7.2.8.2 A thorough assessment should be conducted to all existing centres in Tanzania to facilitate policy and decision making for conducive living environment creation at the identified centres for PWA and other disabilities.

7.2.8.3 Parents with children living in difficult conditions should be assisted by the government in taking care of their children, especially in education.

7.2.8.4 The government, faith-based organisations, NGOs, members of the community and well wishers should be mobilized to provide food and maintenance funds, personnel as well as necessary infrastructures in the centres.

7.2.8.5 Trained and armed security officers should be deployed to the centres
Infrastructure the schools/centres should be improved.

7.2.8.6 Improvement of financial resources, infrastructures and physical environment, teaching and learning materials i.e. equipments etc.



7.2.8.7 Adequate food and well-balanced diet should be provided to the school on a regular basis.

7.2.8.8 Health, water, sanitation and hygiene facilities should be improved and made accessible to all individuals.

7.2.8.9 Qualified medical personnel, including dermatologists / skin cancer experts, eye specialist and paediatricians should be assigned to the school/centres and make regular medical and health visits to prevent and treat diseases.

7.2.8.10 All teachers, matron/patrons, caregivers, members of school/centre administration staff should be imparted with special needs skills, at least in childcare, guidance and counselling.

7.2.8.11 The roles of SWOs and CDOs should be clearly delineated for social responsibility and accountability.

7.2.8.12 Qualified technicians should be deployed to repair and maintain the institutions' equipment and also train members of staff on how to take proper care of the same.

7.2.8.13 The assessment should be scaled up to other schools/centres intended to accommodate children with albinism and other disabilities aiming at improving them for friendly services provision to the clients.



7.2.8.14 Another research should be conducted aiming at improving the centres to offer right based programs for improved standard of living of PWA and other disabilities.

7.2.8.15 A survey should be conducted through proper assessment to establish who exactly has to live in the schools/centres so that only the needy and those in difficult conditions are hosted in the centres.

SECTION EIGHT

Summary and Conclusions

8.0 Summary

This study was conducted to assess and determine the situation of displaced children in the various centres hosting individuals from displaced homes as well as those with albinism in North Western Tanzania. The research sought to find out how children and disadvantaged groups from displaced families were living in the centres, including those with albinism. Another objective of the research was to find out the care they received, their safety and whether or not the children communicated with their families, or if they were maintaining family ties etc. Further, the study was geared towards finding out if there were aspects of child abuse. Furthermore, the study was conducted to assess the suitability of the environment for the people living in the various centres. The study was also conducted to explore the nature of services provided by care givers, doctors, social welfare officers as well as the district and regional educational officers. In summary, the study was conducted to get a vivid picture of the situation in the centres where displaced children lived, as well as finding out their perceptions concerning the reunification with their families.





The study tasks included the following: Understanding the situation of children, with a special focus on those residing in the centres/schools as well as, evaluating the situation of their protection and rights, getting the profiles of the schools/centres, their background/history, number of staff, number of residents, ownership (Ministry, district, mission etc), students (in day school or, boarding), school (primary, secondary); assessing the resources of the school/centre: budgets, infrastructures, staff, staff capacity, physical environment etc, assessing the teaching and learning materials i. e equipments etc., investigating the situation of food for the children, health as well as hygiene situation of the centres/schools, examining the safety, security, protection, risks and concerns in the areas, analysing the recreational facilities and psychosocial support for children at the centres, examining the interaction and attitudes among the children in the school and members of the community, as well as finding out the main challenges facing the children and adults in the centres and proposing the kind of support required by staff and solutions thereof.

In order to realize the objectives, a survey was conducted used qualitative and quantitative data collection techniques for the purpose of getting in-depth understanding and analysis of the problem. Considering the nature of the problem, it was prudent to use more qualitative research approach.

The survey was carried out in the north-eastern, north-western and western parts of Tanzania i.e. Tanga, Tabora, Mwanza, Kigoma, Shinyanga, and Kagera regions. The regions were strategically sampled according to the historical development, nature of the students and care provided to them, as well as adults in the centres following the atrocities and killings of people with albinism in the regions and districts. Purposive sampling was used to obtain proper participants of the study.



8.1 Conclusions

The study was designed to determine whether there were risks associated with the general functioning of the 9 centres (Buhangia, Bukumbi, Furaha, Kabanga, Kitengule, Missionaries of Charity, Mitindo Mugeza and Pongwe) where People with Albinism are currently accommodated. The centres were established as shelters to rescue PWA who are shifted from various places in Tanzania where witchcraft killings and atrocities against PWA are threatening and disturbing. The set of risks under assessment included poor infrastructures, ignorance and or incompetency of workers to care and protect PWA, continued threats, violence, stigma and discrimination, general violation of human rights, scarcity of resources (human and material) and general poor working environment. The study suggested solutions to the unsatisfying living condition for the children.

Literature, empirical and policy review, helped to cement the bases of the recommendations given in this report for improving the centres functioning. Most of the writers and researchers emphasized the importance right based programming and professionalizing the services offered to the children. The assessment revealed that lack of specialized skills on psychosocial care and support amongst workers in the centres, worsened the living condition of Children with albinism. It was observed that centres have poor infrastructure, there was scarcity of resources, continued child abuse and violence, stigma and discrimination, and all in all insecurity life amongst children with albinism prevailed. For instance at Pongwe a child witnessed saying, *"Security is the main problem. God is great because He is protecting us. The security guards here apart from being old, they do not have weapons, they are always drunk. They walk around with simple traditional weapons such as machete, small axes and clubs,"* he concluded.





Citations / Bibliography:

1. ABC News' Traci Hunte (2010), Africans -albinism hunted -Tanzania, at Boston: Houghton Mifflin.
2. Campbell, Donald T., Stanley, Julian C. *Experimental and Quasi-Experimental Designs for*
3. Carolyn Boyce, and Palena Neale (2006), *Conducting in depth interviews: A Guide for*
4. Chowo, (1978). *Adult Education. A Manual*
5. Coatworth, J. D. (2002). *Social Ecological model of Development.* In <http://www.google>.
6. *Concise Encyclopedia of Education* (2002).
7. Henderson, Naomi R. (2009). *Managing Moderator Stress: Take a Deep Breath. You Can Do*
8. <http://abcnews.go.com/2020/tanzanians-albinism/story?id=8725048>
9. Irin (2011), EAST AFRICA: Albinos still targeted for body parts, at <http://www.irinnews.org/Report/91898/EAST-AFRICA-Albinos-still-targeted-for-body-parts> or follow@irinnews
10. Judah,S. (2011), Uganda Albinos Association: http://www.ugandagirectory.org/index.php?option=com_mtree&task=viewlink&linkid=117&Itemid=2
11. Judith,S. (2006), Albinism Gale Encyclopedia of Children's Health: Infancy through Adolescence at <http://www.encyclopedia.com/topic/Albinism.aspx>
12. King, Richard A., et al.(2004) "Facts about Albinism." *International Albinism Center, University of Minnesota*, at <http://www.cbc.umn.edu/iac/facts.htm>
13. Kirk, S. A., Gallagher, G. J., & Anastasiow, N. J. (2000). *Educating Exceptional Children* (9th ed.).





14. Lapidos J.(2009), How Many Albinos Are in Tanzania?:
http://www.slate.com/articles/news_and_politics/explainer/2009/01/how_many_albinos_are_in_tanzania.html
15. Miller-Keane Encyclopedia and Dictionary of Medicine, Nursing, and Allied Health, Seventh Edition. © 2003 by Saunders, an imprint of Elsevier, Inc. All rights reserved.
<http://medical-dictionary.thefreedictionary.com/albinism>
16. Nachmais, Chava Frankfort; Nachmais, David. 2008. *Research methods in the Social*
17. Nasr, Susan L.(2008). "How Albinism Works" at
<<http://health.howstuffworks.com/skin-care/problems/medical/albinism.htm>>
18. Paul, J.(2012), Strategies to Address Vulnerable Populations, at
<http://hir.harvard.edu/strategies-to-address-vulnerable-populations?page=0,2>
19. Possi, M. K. (2006). From Special to Inclusive Education for Children in Special Needs in Tanzania: Old Wine in New Bottle? *Journal of Open University of Tanzania. Journal of Issues and Practice in Education*. Pp. 47— 63.
20. Possi, M.. K. (2008). People with Albinism in Tanzania: Endangered Species? A Manuscript
21. Sprinthall, R. C., Schmutte, G. T., and Siros, L. (1991). *Understanding Education research*. Prentice Hall, Englewood Cliff, New Jersey: USA
22. Tracy, S. J., Lutgen-Sandvik, P., & Alberts, J. K. (2006). Nightmares, demons and slaves
23. Tromsness, M.E. (2004) *Albinism in the Family: Albinismo en la Familia*, at
<http://www.healthofchildren.com/A/Albinism.html#ixzz2ObQJRtkO>
24. UNICEF, (2013) Unicef in emergencies, displaced children at
http://www.unicef.org/emerg/index_displacedchildren.html
25. Under The Same Sun (UTSS): <http://www.underthesamesun.com/>
26. Under The Same Sun (UTSS): **QUICK GUIDE for TEACHERS & Educators of Persons with Albinism:** <http://www.underthesamesun.com/documents/QUICK-GUIDE-for-TEACHERS-and-EDUCATORS.pdf>





27. Under The Same Sun (UTSS): <http://www.underthesamesun.com/aboututss>
28. Wikimedia Foundation, Inc. (2013), Persecution of people with albinism, at http://en.wikipedia.org/wiki/Persecution_of_people_with_albinism

