

## Hacettepe University Graduate School Of Social Sciences

Department of Social Work

# ATTITUDES OF SOCIAL SERVICES PROFESSIONALS TOWARDS PEOPLE WITH ALBINISM IN DAR ES SALAAM, TANZANIA

Halima Ali SHEKUWE

Master's Thesis

Ankara, 2020

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## **DEDICATION**

I sincerely dedicate this work to my beloved parents Al-Hajj Ali Malik Shekuwe and Hajjat Maryam Hassan for always being my pillar of strength. It is they who have taught me patience and given me support throughout my work. Thank you, Baba and Mama, for always believing and investing in me. I will always strive to fulfill my dreams of making you proud.

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#### **ABSTRACT**

SHEKUWE, Halima Ali. Attitudes of Social Services Professionals towards People with Albinism in Dar es Salaam, Tanzania, Master's Thesis, Ankara, 2020.

Social services professionals are agents of change in any society. For many years, people with albinism in Tanzania have faced many injustices and malicious acts like murder, kidnapping, rape, cutting and selling their body parts. In Tanzania due to their condition, they have been placed under the category of "people with disability". It has befallen social services professionals to be their saviors and protectors into helping them voice their problems and other issues.

This study aims at examining the attitudes of social services professionals, roles and precautionary measures taken towards protecting people with albinism in the Dar es Salaam region. In this study, 30 participants were contacted but only 24 responded and these were 6 social services professionals from the government, 6 from the non-governmental organizations, 10 people with albinism who acted as volunteers, 1 journalist and 1 social service professional from an embassy. This study was carried out between May to September 2019. A qualitative research design was adopted through a semi-structured interview guide. The analysis of these participants' opinions was carried out with Nvivo 12 software.

The results of the analysis reveal that social services professionals have more positive attitudes like acceptance, respect, defense, support and love than negative attitudes which included unhelpfulness, pessimism, and unfairness towards people with albinism. Promoting education, advocacy and awareness-raising were some of the roles and precautionary measures used towards protecting people with albinism. From the findings, recommendations to the government, non-governmental organizations, social workers and people with albinism were to bring changes to the education, and health sector. It was realized that self-awareness concept on people with albinism themselves and the challenges facings social services professionals should be examined as an area for further research; these will positively stress and broaden the compassion about people with albinism and how to support them.

**Key Words:** Attitudes, social services professionals, people with albinism, diversity, Dar es Salaam, Tanzania

#### ÖZET

SHEKUWE, Halima Ali. Tanzanya, Dar es Salaam'daki Sosyal Hizmetler Profesyonellerinin Albinizmli Insanlara yönelik Tutumları, Yüksek Lisans Tezi, Ankara, 2020.

Sosyal hizmet profesyonelleri her hangi bir toplumda değişimin temsilcilleridir. Uzun yıllar boyunca, Tanzanya'da albinizmli insanlara cinayet, adam kaçırma, tecavüz, kesim ve vücut parçalarını satma gibi birçok adaletsizlik ve kötü niyetli eylemlerle karşı karşıya kalmışlardır. Tanzanya'da durumları nedeniyle "engelli insanlar" kategorisine girmişlerdir. Sosyal hizmetler profesyonellerinin kurtarıcıları ve koruyucuları, sorunlarını dile getirmelerine yardımcı olmak için oluşturulmuştur.

Bu çalışma Dar es Salaam bölgesinde albinizm ile insanları korumaya yönelik sosyal hizmet profesyonellerinin tutumlarını, rollerini ve ihtiyati tedbirleri incelemeyi amaçlamaktadır. Bu çalışmada 30 katılımcı ile temasa geçilmiştir, ancak sadece 24 kişi yanıt vermiştir ve bunlar hükümetten 6, sivil toplum örgütlerinden 6, gönüllü olarak hareket eden 10 albinizmli insan, 1 gazeteci ve bir elçilikten 1 sosyal hizmet profesyonelidir. Bu çalışma Mayıs - Eylül 2019 tarihleri arasında gerçekleştirilmiştir. Yarı yapılandırılmış bir görüşme rehberi aracılığıyla nitel bir araştırma tasarımı benimsenmiştir. Bu katılımcıların görüşlerinin analizi Nvivo 12 yazılımı ile gerçekleştirildi.

Analizin sonuçları sosyal hizmet profesyonelleri daha olumlu tutumlara sahip, kabul, saygı, savunma, sevgi gibi destek tutumlarla albinizmli insanlara yardımcı olunması gerektiğini, bu sayede onların karamsarlık gibi olumsuz psikolojik durumlarının ve haksızlığa uğramarının önüne geçilebileceğini savunmuşlardır. Eğitimi, savunuculuğu ve farkındalığı arttırmayı teşvik etmek, albinizmli insanları korumak için kullanılan rollerden ve ihtiyati tedbirlerden bazılarıdır. Bulgulardan hükümete, sivil toplum kuruluşlarına, sosyal hizmet uzmanlarına ve albinizmli insanlara öneriler eğitim ve sağlık sektörüne değişiklikler getirecekti. Gelecekteki araştırmacılar için, albinizmli insanlar hakkında öz farkındalık kavramının ve sosyal hizmet profesyonellerinin karşılaştıkları zorlukların incelenmesi gerektiği, çünkü bunlar albinizmli insanlar ve bunların nasıl destekleneceği hakkında daha fazla bilgi edinmeye olumlu yardımcı olacağı görülmüştür.

**Anahtar Sözcükler:** Tutumlar, sosyal hizmetler profesyoneli, albinizmli insanlar, çeşitlilik, Dar es Salaam, Tanzania

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## LIST OF ABBREVIATIONS

BAF Brigitte Alfred Foundation

NGO Non-Governmental Organization

NOAH National Organization for Albinism and Hypopigmentation

PWA Person/persons/people with albinism

SSP Social Services Professionals

TAS Tanzania Albinism Society

UDHR Universal Declaration of Human Rights

UN United Nations

UNICEF United Nations Children's Fund

UTSS Under The Same Sun

WHO World Health Organization

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#### INTRODUCTION

Over the past few years, rape, murder, kidnappings, mutilations of body parts and violence have been part and parcel of the lives of people with albinism in some African countries. Many people with albinism in Africa are stigmatized and discriminated due to their white skin and other conditions that are looked to be different in most black skinned populated societies. In Tanzania, a rapid change for people with albinism begun when a BBC journalist exposed these malicious acts to the world. To bring peace and protection towards people with albinism in Tanzania, alarms were raised in various fields of work, social work being among these fields of work.

The field of social work dates back to the dawn of mankind and like many, this field has attracted the attention of researchers, practitioners, policy makers, leaders, activists and professionals as well as other random people alike. Social work is indispensable with our thinking, plans and actions in different walks of life. One of the key proponents of social work down the history lane is the attitudes of social services professionals.

A person's attitude towards another person can bring different changes towards them. It can either help that person or break that person. It was important to understand how the attitudes of social services professionals can bring changes towards people with albinism in Tanzania. Dar es Salaam region was selected as a working environment because most of the non-governmental organizations working with people with albinism in Tanzania have established their headquarters there as well as the Ministry of Health which deals with people with albinism before it was moved to the capital city Dodoma also had their headquarters there.

The key aims of this study is to demonstrate the attitudes of social services professionals towards people with albinism, whereas they have been credited for their compassionate ways like accepting them for who they are, respecting them, loving and defending them but the compassionless side like being unfair to them, pessimistic towards them, lack of passion to help them as well as being lazy to help them are also revealed. The study also exposes how these attitudes have shone out a light in the roles the social services professionals play towards people with albinism. Promoting education and advocacy, providing psychological and material support, and promoting

empowerment are some few roles that are used by these social services professionals to help not just people with albinism but the environment around them. Elaborating the precautionary measures taken by these social services professionals from the government and the non-governmental organizations in protecting and promoting the human rights of people with albinism are also discussed as these measures help in the betterment of not only Tanzania as a country but the people with albinism as well.

For data collection in this study, 30 participants were selected but only 24 participated in this study. These were social services professionals from the government and non-governmental organizations, people with albinism who acted as volunteers, a journalist and a social services professional from an embassy. One thing that was very essential in this study is the discovery that most of these social services professionals from the non-governmental organizations were people with albinism themselves. To show that they are capable of following their dreams about being who they want to be and also act as role models to other people with albinism, they decided to become social services professionals. The methodological framework is qualitative and based on semi-structured interviews.

This study consists of four chapters. The first chapter is an attempt to understand Tanzania and albinism as well as how it is a disability in Tanzania. This chapter also discusses the prevailing myths about people with albinism, attacks done on people with albinism, challenges they face and the legal framework. Then, it also discusses the theories on attitudes, the rationale and the limitation of the study. The second chapter of the study gives a concise explanation of the research methodology on how and where the study was conducted. Data collection tools, process and analysis are also discussed in this chapter. The third chapter of the study refers to the analysis of the semi-structured interviews that provides ground to answer the research questions which were initiated in the study. The fourth and final chapter of the study is consisted on the conclusion and the recommendations to the government of Tanzania, non-governmental organizations and other stakeholders, social services professionals as well as to the people with albinism themselves.

#### CHAPTER ONE

#### 1.1. UNDERSTANDING ALBINISM

According to Brocco (2015), albinism is a term that is used to refer to medical conditions that develop from a progressiveness of a genetic mutation that causes the absence of pigment in the body known as melanin. This medical condition is not only seen in humans but the rest of the animal kingdom as well. Some animals share the same characteristics with humans in the lack of color which normally leaves an animal to be different than the others and appear whiter than their normal color. According to Brilliant (2015), albinism has been defined as an inherited disorder of melanin biosynthesis that leads to a variable phenotype classified according to the mutation in one among many genes.

In an article written by Under the Same Sun organization, "What is Albinism?" Albinism is defined as a genetically inherited condition that is rare and non-contagious that can occur to any person in all the countries of the world regardless of their ethnicity. It happens to people that have both their father and mother carrying the albinism gene themselves even though they might not have been affected but they still can pass it over to their children who might also pass it over to their children's children. This condition brings about the lack of pigmentation in the skin, eyes, and hair as well as making someone becomes vulnerable to the exposure of the sun and any kind of bright light.

People manifest many different hues, from black to brown to white and shades in between but the genetics behind this spectrum of skin colors have continued to be an enigma. According to the National Organization for Albinism and Hypopigmentation - NOAH (2014), the chief determinant of skin color is the pigment melanin, which protects against ultraviolet rays and exists in cellular organelles called melanosomes. The word "albinism" refers to a group of inherited conditions when people have little or none of the pigment melanin in their eyes, hair, or skin. They have inherited altered genes that do not make the usual amounts of this pigment melanin.

As to the realization that albinism is just a lack of pigment in melanin, there are also reasons for what causes these situations.

The following are types of albinism;

- Albinism that affects the skin, hair, and eyes: This type of albinism is also known as *oculocutaneous* (*ock-you-low-kew-TAIN-ee-us*) *albinism* (*OCA*). Not only in Tanzania but in most Sub Saharan African countries is this most visible form of albinism. It is said to be the most visible because the subjects are particularly vulnerable and noticeable in countries that have nearly dark-skinned people.
- Albinism that only affects the eyes: This type is known as Ocular albinism (OA), and is somewhat uncommon. In many cases, males are said to be the verified ones. Normally, the children with OA may have skin and hair color that are ordinary but slightly lighter than those of other family members.
- Albinism with HPS: Researchers have also acknowledged a type of albinism that comes with extra characteristics. This is the Hermansky-Pudlak Syndrome (HPS). With just having albinism, people with HPS have a tendency to bleeding and bruising. Some that are also associated with HPS suffer lung and bowel disease. But in Tanzania, it is said to be so rare and no records of it can be proven.

According to Robins (1991) in her book, "Biological Perspectives on Human Pigmentation", she described albinism as a genetic disorder of the melanin pigmentary system that occurs throughout the animal kingdom from insects, fish, and birds to human beings. In other meaning, albinism does not just exist in humans but in all animals as well. So, with all this, it explains why people with albinism exist through different places around the world. It was further explained that albinism is characterized by the absence of or a decrease in melanin which takes two forms in the human varieties; oculocutaneous albinism and ocular albinism.

Robins (1991) further explains that oculocutaneous albinism is the lack of pigmentation in the skin, hair, and eyes while ocular albinism is when melanin does not spread towards the eyes but the skin pigmentation remains normal. All people with albinism have visual problems – there is hypopigmentation of the iris, choroid, and retina as well

as maldevelopment of the fovea, a part of the retina which mediated central vision. The typical eye signs are photophobia (an abnormal, often very painful, sensitivity to the sunlight leading to its evasion), nystagmus (involuntary, rhythmical wavering of the eyeballs, usually in a horizontal plane), squint and a decreased visual insight (in severe cases resulting to partial blindness).

Historically, the term 'albino' was derived from the Latin word "albus" meaning white. This word was created during the seventeenth century by a Portuguese explorer called Balthazar Tellez who had sighted a group of 'white' Negroids on the west coast of Africa. In 1502, it was claimed during his fourth voyage to America Columbus encountered such people near Trinidad. During this period of time, the identification of albinos was hardly a feat of recognition: compared with normally pigmented Negroids, these albinos were highly conspicuous and it was noted that their marked photophobia confined them to their huts until twilight (Robins, 1991).

Garrod (1908; Cited in White, 2011) in his book "Inborn Errors of Metabolism", albinism is categorized as a disorder either through synthesis or in the maintenance of the melanin pigment where the cells might have been disordered.

"Albinism is congenial and persists through life is self-evident, the condition is as obvious as any structural malformation and its rarity in man is also evident. It stands to reason that in error of metabolism which persists from birth into an adult, and even into advanced life, must need to be relatively innocuous."

In his Second Edition of "Inborn Errors of Metabolism", Garrod (1923; Cited in White, 2011) suggested that the absence of the pigment from the skin and hair of albinos was attributable to the lack of a specific enzyme in the cells that were the normal seats of pigmentation.

According to Brilliant (2015) in his work, "Albinism in Africa: A Medical and Social Emergency" the American geneticist Dr. Murray Brilliant explained that it has been overall estimated that oculocutaneous albinism is 1 in 36,000 people worldwide but very common among individuals of African descent. Thus meaning that albinism varies among different ethnic groups and geographical regions. Oculoculatenous albinism frequencies are seen among various tribes in Africa: 1 in 1100 among the Ibo in

Nigeria, 1 in 7900 among the Bamileke of Cameroon, 1 in 3900 in South Africa and 1 in 1400 in Tanzania. This rules out Tanzania to be the country that has the world's highest rates of albinism in the world. Through a form of genetic mutation among the oculocutanoeus albinism, Africans seem to have derived this from their common ancestor who lived 2000-5000 years ago.

Through an interview conducted in 2017 by one member from Under the Same Sun (UTSS) Don Sawatzky and a journalist, a question about why the percentage of albinism is so much higher was given in two general answers. The *first* was because of the "founder's effect" which refers to the region where the genetic mutation first began. According to Don, through Dr. Murray Brilliant's suggestion that Tanzania or East Africa being the place of where albinism first began due to the preliminary genetic testing in Tanzania that suggested that approximately 1 in 2000 to 3000 people have albinism hence a stark contrast to 1 in 17,000 to 20,000 in Europe and North America. The *second* reason as to why Tanzania has the highest rate of albinism is based on the discrimination of the people with albinism. Because of the segregation or the social isolation and exclusion by their societies, PWA tend to stick to themselves thus congregate and marry each other hence creating more population with albinism. Sawatzky further explained that when two PWA give birth to a child, it is most likely to be born with albinism. There is a 1 in 4 chance for a child to be born with albinism when two non-PWA who both carry the gene reproduce.

Studies on albinism disclose that most people with albinism in Africa die in early adulthood or in middle ages (Okoro, 2006; Aquaron, 1990). Due to some African cultures which embrace supernatural based explanations rather than scientific explanations, the presence of people with albinism is regarded and treated differently from in other parts of the world and as a result people with albinism in African countries are at higher risks (Lund and Gaigher, 2002).

#### 1.2. TANZANIA AND ALBINISM

This part of the study introduces Tanzania as well as how albinism is being looked at as a disability in this country.

Tanzania is one of the 54 countries on the continent of Africa. It derived its name from Tanganyika and Zanzibar after achieving its independence from the British on 9<sup>th</sup> December 1961. They unified to create The United Republic of Tanzania on 26<sup>th</sup> April 1964. Tanzania also includes the three spice islands of Zanzibar, Pemba, and Mafia. Tanzania consists of more than 120 ethnic groups and with a population of almost 54 million people. The mother language in Tanzania is Swahili, whereas English is the official language of the country although Arabic is widely spoken in Zanzibar.

According to report done by Central Intelligence Agency (2017), on their world factbook page, different religions are practiced in Tanzania but the most practiced ones are Christianity and Islam. In the mainland; 61.4% are Christians, 35.2% are Muslims, 1.8% are folk religion, 0.2% are others and 1.4% are unaffiliated. In the Island of Zanzibar, the population is 99% Muslims.

The country is well known for her precious gemstones called Tanzanite that in the whole world can only be found in Tanzania. Cloves, wheat, cashew nuts, sisal, tea, coffee, wheat, and pyrethrum are few examples of agricultural merchandise that are manufactured in Tanzania. Not only that but she is also rich in different natural resources like hydropower, tin, phosphates, iron ore, coal, diamonds, gold, natural gas, and nickel.

Geographically, Tanzania is the largest country in East Africa and Africa's highest point – Kilimanjaro at 5,895 meters. Kilimanjaro is a volcanic mountain that is snowcapped despite the fact it is near the Equator. It is also bordered by three of the largest lakes on the continent; In the West, there is Lake Tanganyika which is the second deepest lake in the world, in the north, there is Lake Victoria which is also the second-largest freshwater lake in the world and finally, in the southwest, there is Lake Nyasa which is also known as Lake Malawi.

Tanzania is also known as the place where the world's first human skull was found, Olduvai Gorge in Arusha. It is also popular because of its wildlife safaris to the different national parks like Serengeti, Ngorongoro Crater, and Tarangire. Some other game reserves can also be seen in Figure 1.

Bukoba Vic © Nations Online Project Musoma KENYA BURUNDL Kibondo o Kasuli Kigoma Singida Tobora QUjiji" Tanga Korogy Handeni 9 Dodoma Sadan Morogoro Salaan RUAHA NAT. PARK Mafia I CONGO Iringa Sumbawanga Mohoro Mbeya Induma Tukuyu ZAMBIA Njombe UNITED REPUBLIC OF TANZANIA Mtwara National capital Nachingwea Provincial capital Masasi Town, village Newala Tunduru Airport International boundary Main road Secondary road 100 200 300 km Railroad 100 38° 200 mi

**Figure 1:** Political Map of Tanzania

Source: One World - Nations Online, 2019

Despite her richness geographically as seen in Figure 1, the tourism industry and the abundant resources of the likes of gold, diamonds, and tanzanite, Tanzania is still categorized as a poor country. Even though, according to World Bank's 2019 overview on Tanzania, it is illustrated that Tanzania has sustained a relatively high economic growth over the last decade averaging 6-7% a year. It further states that the Tanzania National Bureau of Statistics reported that the real gross domestic product (GDP) growth was 7.0% in 2018, slightly higher than that in 2017 which was 6.8%. Despite the fact that the most recent poverty measured based on the Household Budget Survey of 2017/2018 are still be processed, efforts between 2007 and 2016 that have reduced the country's poverty rate from 34.4% to 26.8% can still be acknowledged hence the

absolute number of poor people has been held at 13 million due to the high population growth (World Bank, 2019).

Due to the fast rise of population, the Tanzanian government's efforts to expand access to social services like education, health and water have been compromised. This has led to inevitable hardships, insecurities, lack of resources as well as insufficient social services.

Tanzania is still a state that fulfills and adheres the human rights obligations satisfactorily to its people compared to other African countries. However, due to some challenges here and there the performance to adhere to these rights has sometimes been so poor. The number one challenge being poverty has played a crucial role in corruption which has led to the impending realization of human rights to its people. Such situations tend to hinder providing not only the necessary but adequate education, health care services as well as employment opportunities to all groups in the society particularly to the vulnerable group where PWA are concerned.

#### 1.2.1. Albinism as a Disability in Tanzania

According to the World Health Organization – WHO (2011), nearly one billion people everywhere in this world live with some forms of disabilities. Disability is perceived as a socially shaped problem, and any hurdles formed by society need to be abolished to facilitate those people with disabilities to relish their human rights (United Nations, 2008). Disability also results from the interaction of health conditions, personal (motivation and self-esteem) and environmental factors (natural and built environments, support, relationships, services, and attitudes). The operative provision of services and social life, knowledge, and attitudes are important environmental factors (WHO, 2011).

Disability is a state whereby any being is unable to accomplish something due to the magnitude of being physically or mentally unstable, lack of hearing, visual impairment, lack of reasoning, lack of being emotional, as well as the lack of speech or being unable to verbalize words (WHO, 2011).

According to the research report done in Tanzania, it was stated that the formal meaning of disability has been changing over the previous decades as a reflection of

the policies and the legal texts. The definition has changed due to the global developments as well as the evolution from medically-based focus on the observed deficiencies of the individuals to acknowledging that a disability can also be socially constructed due to a phenomenon which at the end results in the formation of that disability; physically, mentally, intellectually or sensory impairments which can be caused by various barriers in that individual's environment or surroundings (Myamba et al., 2015).

In Tanzania's National Policy on Disability of 2004, disability is defined as;

"The loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical, mental or social factors. Therefore in Tanzania people with albinism fall under the category of "disabled people"."

In 2010 an act called the Persons with Disability Act was launched in Tanzania as a formalization of the 2004 Disability Act's definition of 'disability' in the National Policy but it contained a new separate meaning of 'a person with disability' which is basically in-line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) approach. This act was enacted to give legal effect to both the Tanzania National Policy on Disability as well as the UNCRPD where the rights of people with disabilities may be compromised in the getting equal access to education, health, as well as employment (Myamba et al., 2015).

According to Myamba et al. (2015), the Tanzanian Persons with Disability Act of 2010 states that a person with disability is a person with a physical, intellectual, sensory or mental impairment and whose functional capacity is limited by encountering attitudinal, environmental and institutional barriers.

In Tanzania, disabled people are victims of discrimination, stigmatization, and segregation. Sometimes, they even face more tough factors that cause them to have a greater risk of health problems especially those that are through the misconceptions and cultural beliefs in a community to where they live. The government of Tanzania came up with different strategies to recognize the disabled not only as people with special needs but as people with equal rights like other people in the country.

In 2004, the Ministry of Labour put "The National Disability Policy" that would give different guidance regarding disabled people at all levels in the society. It also pointed out about sensitizing towards change in opinion, attitudes and political involvement towards recognizing and implementing rights for the disabled. But even with such efforts, the community still has very little knowledge of the disabled people and this continues to boost the misconceptions and beliefs of their existence.

Through an example in a research report by Myamba et al., (2015), it was stated that in 2010 the Ministry of Health and Social Welfare launched a National Mainstreaming Strategy anticipated to mainstream disability into all government policies, programs, and budgeting but unfortunately most of the government staff are either heedless or unaware of this document hence no concrete and existing examples can be stated of its implementation among any of the ministries that identify this strategy.

This goes to show that, no matter how the Tanzanian government tries to adopt positive strategies to help vulnerable groups like persons with disabilities, the implementation of these strategies is zero hence demonstrates how the human rights to these groups are not reasonably applied to them.

Over the previous years in Africa, information about the killings of people with albinism in the continent particularly in a country like Tanzania has been a noiseless cry. For the people with albinism, their organs especially the genitals, limbs, breasts, fingers, and tongues are the most valued because they are very high in demand by the people who are involved in fishing and mining activities. This is associated with the belief that the organs of PWA can bring them luck towards earning their daily bread. So in Tanzania, some killings are just likely to happen because in rural areas people are very superstitious.

The African PWA are stigmatized because of their white skin as many of them live in black-skinned societies. The stigmatization becomes intensive as most of the people with albinism have disabilities like low vision or blindness and some even have tendencies towards contracting skin cancers. Many people brand people with albinism with their cultural beliefs and myths that are attributed to magical powers and people with albinism being sub-humans.

Like with other African countries, in Tanzania, there are many superstitions surrounding albinism and the majority in the community fail to realize that, albinism is a genetic disorder (Kiprono et al., 2012). Albinism is seen as a disability for being worthless and useless. The beliefs and myths that talk about the causes of this disability and how the community responds to the people are a bit similar to different regions in Tanzania. Many of the negative attitudes are due to the lack of knowledge and mostly because of fear.

The manslaughters of PWA (albinos) came to the attention of the world through the efforts of a Tanzanian BBC journalist in 2008 (Alum, Gomez, and Ruiz 2009; Ntetema 2008). Most of the reports and stories about murders of people with albinism in Tanzania are from the subsequent effort writing by newspaper journalists in the media reports, and by bloggers who make use of their blogs in reporting these malicious acts. Numerous news articles have called on academics and social workers to apply themselves to the issue on killings of people with albinism (Navuri 2009; Mosha 2009).

According to a report from Red Cross, because most body parts of people with albinism are sold on black markets for thousands of dollars, their attacks done to them tend to also go unreported. Vaguely, a limb is able to be sold for thousands of US dollars whereas a complete set of body organs or any other body parts are able to be sold up to \$75,000.

In the CIA World Fact Book it is stated that in a country where the average annual income (using GDP per capita) is roughly \$2,000 US dollars per year, the only people that can afford such prices are likely the rich elite who are also better placed to bribe people into silence.

In 2017, through an interview done by the director of Under The Same Sun Don Sawatzky and a journalist while talking about the prices of a body of a person with albinism in Tanzania, it was said that the prices vary considering if it is just a single body part which will sell for between \$1,000 to \$3,000 US dollars or if it is a whole-body meaning a complete set of the body parts the prices become higher from \$75,000 to \$150,000 US dollars.

To the present day, through a report made by UTSS (2017), Tanzania has had reports of violence against people living with albinism, including murdering, cutting their body parts and all appears to be because of traditional witchcraft and killers who make money through selling the body parts of a person with albinism that they believe will provide them with wealth and great fortune. Not only has the Tanzanian government has morally condemned these killings, but also worldwide through United Nations Children's Fund (UNICEF), United Nations (UN) as well as both European and American parliaments as well.

According to Under The Same Sun (2012), the prevalence of albinism is estimated as high as 1 in 1,400 and 1 in 19 persons carry this gene. This means that in Tanzania, there are over 33,000 people with albinism. In the 2012 census, the Tanzania National Bureau of Statistics (2020) confirmed that the population of people with albinism in the mainland was 0.04% whereas in the islands was 0.03% making Dar es Salaam region to hold the largest number with 1,637 people with albinism. But the then Prime Minister Pinda said that these statistics underpresented people with albinism in Tanzania.

#### 1.3. PREVAILING MYTHS ABOUT PWA

Tanzania has one of the highest frequency rates of albinism in the world. As the killing of people with albinism gained the attention of the world, it has also been noted that most efforts are done more by the non-governmental organizations than the government. Under the Same Sun (UTSS), Standing Voice (provides low vision clinics and skin screening/cancer clinics in Tanzania), Global Medical Relief Fund (provides functional prosthetic limbs for children with albinism in Tanzania and who have survived malicious attacks that caused them to lose their limbs), are the organizations that are more involved with PWA. There is also the Tanzania Albinism Society which is a national non-profit organization founded by the PWA in 1978 to protect and empower them.

According to UTSS (2012), in the different research done in Tanzania, there are several dangerous myths about albinism. These include the belief that the pasts of PWA can bring wealth and good luck when ground into witchcraft potion; that they do not die

but disappear; and that PWA are not human beings but ghosts. Some of the prevailing myths can be seen on Figure 2 below:

Figure 2: Prevailing myths against persons with albinism in Tanzania

# PREVAILING MYTHS AND TRUTHS ADVOCATED BY UTSS AND OTHER HUMAN RIGHTS DEFENDERS OF PERSONS WITH ALBINISM

MYTH: Albinism is a curse from the gods or from dead ancestors. As a result, contact with a PWA will bring bad luck, sickness or even death

**TRUTH:** Albinism is no more or less than a genetic condition of the human body. As such, there is nothing magical or supernatural about it. You cannot "catch" albinism – it is not a disease and it is not contagious

#### MYTH: People with albinism never die. They are not human - they are ghosts

TRUTH: The on-going killings in Tanzania demonstrate that PWA do die. They are NOT ghosts. Their pale skin and hair results from having very little of the substance responsible for colour known as melanin

#### MYTH: It is the mother's fault if a child has albinism

TRUTH: Both the mother and father must carry the gene in order for their child to have albinism

#### MYTH: Having sex with a woman with albinism will cure AIDS

TRUTH: No one can or has ever been cured of AIDS by having sex with a woman with albinism. Belief in this myth will only further spread the virus to others including PWA

#### MYTH: PWA have normal vision

TRUTH: All PWA are visually impaired to various degrees AND have a very high sensitivity to light (due to the lack of melanin). When outdoors, PWA need to wear sunglasses to protect their eyes from the sun. Many PWA are legally blind and all require special glasses or magnifiers to aid in reading and daily functioning

MYTH: A charm or potion made from the body parts of PWA has magical powers – bringing its owners wealth, success and good luck

TRUTH: No one can or has ever become rich, successful or lucky from having or using body parts of PWA

#### MYTH: PWA come from and live only in Tanzania

TRUTH: Albinism occurs in every race and nationality of planet earth

Source: UTSS 2012

Through those prevailing myths on figure 2 above, one of the cruelest myths about PWA is that having sex with a woman with albinism will cure a person of AIDS. This has led women with albinism to become targets of rape and thus increase the rate of the disease in some communities. In December 18<sup>th,</sup> 2014, the United Nations General Assembly discussed to make an International Albinism Awareness Day that will educate people to learn more about people with albinism from different attacks as well as discrimination. On June 13<sup>th,</sup> 2015 it was marked the official day of International Albinism Awareness Day worldwide, the United Nations Human Rights Council adopted this resolution in 2013.

#### 1.4. REPORTED ATTACKS ON PWA IN TANZANIA

According to UTSS (2019) on their recent findings of the reported attacks on PWA, there has been a total of 211 killings and 384 attacks which include survivors of mutilations, violence, rape, attempted abductions, missing, grave violations, asylum, and other refuge cases. This brings a total of 595 atrocious acts done to PWA in a total of 30 countries. UTSS is one of the only organizations that collects, documents and reports the attacks and killings of PWA in many African countries since not many countries document or report such attacks. They gather their own data from their own field research and from the partners on the ground. Most of the cases they record are thoroughly verified though it is not always something that is possible.

The common countries that are known to be involved in the cross-border trade of PWA and their body parts are mentioned to be Tanzania, Burundi, Kenya, DRC, Mozambique, Malawi, South Africa, and Swaziland.

Through the World Press Freedom Index, Tanzania has ranked 118 of 180 in 2019, dropping from 93 in 2018. UTSS explains that in Tanzania, most of the information they collect on the killings and attacks are gathered through fieldwork and research as well as reports from victim's families and police reports.

The following are some of the graphic data that UTSS has come up with on the reported attacks on PWA. All the presented graphs in this section were retrieved from the UTSS website.

Attacks by year in Tanzania 45 40 35 30 ■ Grave Robbery 25 Missing 20 Asylum 15 Survivor 10 ■ Murder 5 2005 2007 2009 2015 2011

**Graph 1:** Attacks by year in Tanzania

Source: UTSS 2019

According to UTSS, over the years there have been 76 killings, 85 survivors; all were deeply traumatized and some severely mutilated, 1 missing, 24 grave violations, and 3 asylums have been reported and documented in Tanzania. In the above graph, since UTSS began to personally document these data it shows that the murdering of PWA was very high between 2008 to 2010. There have also been very many PWA survivors from 2007 to 2019 but the highest rate of survivors was in 2013. Grave robbery was also at its highest peak in 2008. Asylum seekers were granted refugee status in Canada and those that went to the United States of America (USA) were just granted asylum without the refugee status.

Tanzania Albino Society (TAS) also reported that at least 35 albino people were murdered in 2008 alone; the main reason for their killing in order to supply witch doctors with limbs, organs, and hair for their potions. The number of murders and mutilations of albino bodies that have occurred is difficult to estimate.

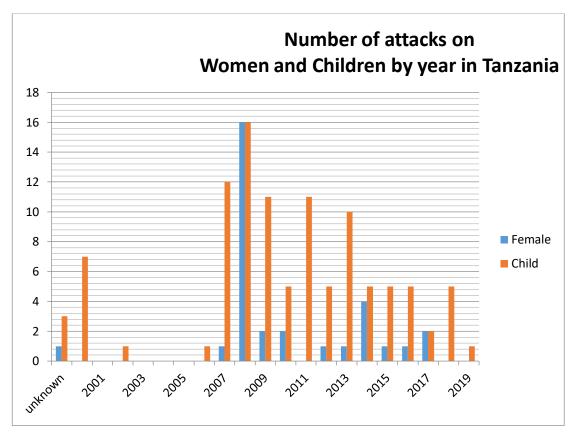
Number of attacks by gender in Tanzania Male ■ Female Unknown 

**Graph 2:** Number of attacks by gender

Source: UTSS 2019

According to Amnesty International (2016), women and children with albinism are the highest victims to be abducted or killed because they are seen as easier targets. Graph 2 can testify to this being true because it can be seen that the highest attacks were in 2008 and those attacked were all female and they were 26 in number. For the male, the highest attacks were also in the same year with 14 in number. This means that in Tanzania, 2008 was a very difficult year for PWA. In 2010, as seen in graph 2 there is an unkown group that might bring to the meaning that it was hard to know of what gender the attacked PWA was.

The graph also shows that the male gender ranked higher than the female in the years 2009, 2011, 2015, 2017, 2018 and also in 2019. 13 males were attacked in 2009 while the females were 9. In 2011, 7 males were attacked and 3 females. 5 males were attacked and 3 females in 2015. 5 males while 3 females were attacked in 2017. For 2018, 6 people were attacked whereas 5 were males and 1 was female. In 2019, 3 males were documented to be attacked only. The female gender ranked more than male gender in the years 2007, 2010, 2012, 2014 and 2016.



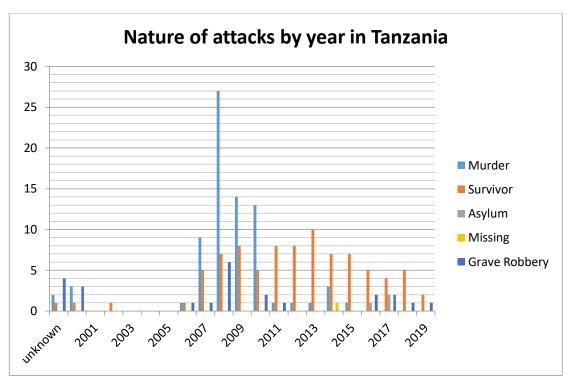
**Graph 3:** Number of attacks on women and children in Tanzania

Source: UTSS 2019

Women and children are especially attacked because they are vulnerable. Many toddlers and children are either kidnapped because they are easier to abduct and carry or they are snatched from their single mothers or while walking to or from school.

According to UTSS, for some children because of their parent's superstitions, they completely abandon, reject or kill them when they are just newborn babies. And sometimes, a baby born with albinism is considered a curse or a bad omen to the family where this leads to them getting killed or used by witch doctors for charms and potions that would apparently bring power, wealth and good luck to the family.

Graph 3 above illustrates that the rate of attacks on children is higher than that of the women in Tanzania since the 90's to 2019. The only time these attacks have ranked the highest was in 2008 where both the women and children were equally attacked in numbers.



**Graph 4:** Nature of attacks in Tanzania

Source: UTSS 2019

During an interview with a journalist, Don Sawatzky a director at UTSS said that attacks happen to PWA because in many African countries they believe the body parts of a PWA holds magical powers where people think of getting power or good luck if harnessed by a witchdoctor. Another reason they are attacked is a purpose for ritual killings and this sometimes done by close members of the family or neighbors.

Graph 4 above proves that murder or killings of PWA have been the highest form of attack especially in 2008. UTSS documented the deaths of 28 PWA who were murdered during that year. From 2007 till 2010 the rate of attacks on PWA getting murdered was very higher than other forms of attacks.

In conclusion to all these graphs, the year 2008 illustrates the highest in the attacks done to PWA by year, number of attacks by gender, number of attacks on women and children by year as well as the nature of attack by year. It is fair to appreciate the effort UTSS has put in documenting these attacks on PWA in Tanzania as they make it easier for other researchers or even the government to understand how and where to take a step forward in helping to protect PWA in these brutal and malicious acts.

## 1.5. CHALLENGES FACING PWA IN TANZANIA

In this study, when interviewing some of the volunteers who were the PWA, they explained that the sun was one of their biggest challenge in Tanzania. Most PWA in Tanzania come from low or middle class income families. This has forced many to become self-employed people by either doing farming or selling goods and merchandise on the streets meaning street vendors in order to improve their standard of living as well as their families. Low vision, economic challenges, availability of employment opportunities and cancer were also mentioned as the day to day challenges that face PWA. In general, the following are some few challenges that people with albinism face in Tanzania;

## The awfulness of a quickly growing market or industry of selling body parts of a PWA

As the most demandable and valued parts of the organs being the fingers, limbs, breasts, tongue, and genitals, the cruel killings have continued as the wrong beliefs are widely spread by the witch doctors just to get money. Many of these witch doctors tend to manipulate the fishermen and the miners in bringing the body parts of a PWA in order to make them rich. Some of these people, especially the fishermen who are found around the lake zones, believe that when they weave their fishnets with the hair of a PWA which sometimes is red in color, the fish will be attracted by the golden glow and they will catch a lot of fish.

For the miners, they have the belief that they will end up mining the most valuable gems like the tanzanite, gold or rubies but in larger sums. Others are believed to even bury the bones of the people with albinism in their digging grounds so that more sums of gemstones will later give them back in those larger sums.

#### Lack of vision utilities

Many of the PWA do not own vision utilities like sunglasses, magnifiers or other specialized computer gear for their vision. This becomes a huge burden when they want to read sometimes, walk out in the sun, and play around with friends or even doing different outdoor activities.

Some of the people with albinism have no clear vision but can be correctable by the use of sunglasses. The vision difficulties are a consequence of abnormal growth of the nerve that is connected to the eye and the brain as well as the low or complete lack of melanin. Few PWA have sufficient vision to even drive a car. Due to most of them not getting proper jobs because of their vision problems, some end up unemployed and cannot be able to get these utilities and some are just so into being constantly poor.

## • Incurable skin problems

Due to lack of the special protective sunscreen lotion, wide hats and proper sunprotective clothing to cover their skin from the contact of the sun, sometimes this leads to incurable skin cancer. The lack of melanin in persons with albinism's body is the one that creates a higher risk for them to get skin cancer. Some avoid the sun because it damages their skin so they have to take safety measures. The average life expectancy for a person without albinism in Tanzania is 64.9 years but for people with albinism it is only 30 years with just 2% of them might live to see their 40s. But in some western countries, people with albinism are projected to live and have the same life expectancy as any other person in those countries.

#### • Extensive discrimination is driven by powerful myths

Many PWA are at risk of being isolated because their condition is ever so often misunderstood. Families that have members with darker skin and appearance tend to socially stigmatize the persons with albinism in their own communities. Difficulty in contacting and sharing experiences with fellow PWA in a community as it is very rare to find a community with many of them.

Because of the lack of public awareness, many communities in Tanzania are still blind about the situation of PWA. The powerful myths and superstitions that surround the people with albinism are mostly that they are evil or a curse from the Creator. Some communities tend to even think that no matter what bad situation they face; the ones to blame are the people with albinism as they believe them to be the main cause of their bad luck.

People also believe that people with albinism just vanish and they can never die. Others especially the black men who have black wives and end up giving birth to a child with albinism often blame the women to have slept with a white man and they turn out to abandoning their families.

The belief that PWA have an infectious disease is too famous in Africa, to an extent that many people are scared of hiring them. They normally assume that when their customers see the people with albinism as their employees their customers will not return due to fear or that they will also have the condition of becoming a person with albinism.

## Medical problems

Most PWA have a normal lifespan and have the same medical complications that other people have. But those with Hermansky-Pudlak Syndrome may have a short lifespan because it mostly affects their lung hence causing lung diseases. Hot, sunny and tropical climatic countries like Tanzania to people with albinism suffer medically as some do not use skin protection thus end up developing lifethreatening skin cancers. In countries that are hot, sunny and tropical, people with albinism are forced to use appropriate skin protection like sunscreen lotions or wear proper clothing for them to enjoy outdoor activities like normal people.

## Educational challenges

Most of those that go to school face the struggle to read from the board when they are in class because of their vision impairment. Many are forced to sit closer to the board. Handouts or notes from teachers have to clear and with very large print.

In an interview I conducted in the research, a social services professional from Tanzania Albinism Society (TAS) mention that reading glasses to some of the PWA is hard to get whereas some also do not understand the reason as to why they have low vision hence a struggle to them. This has led many of the students to drop out of school. Many teachers in Tanzania lack knowledge in the whole issue concerning PWA, so many of the times they tend to ignore what is happening to the students with albinism. The probability of a student with albinism to lose hope

in getting education is very high. Especially those who are in primary level and those that are supposed to head out to high school.

## Lack of knowledge about albinism by PWA themselves

The interview went further to explain this point whereas the social services professional pointed out that many PWA do not have enough knowledge about themselves and their own conditions. They gave an example and mentioned how you would find a PWA walking in a very hot sun without wearing the necessary protective gears as it is normally suggested that a PWA should wstay in the sun for a very few hours; from 7 in the morning till 9am. From 10:30am, the sun rays are not very good for the skin of a PWA. Then in the evenings, from 04:30pm to 06:00pm it is the perfect time to walk outside when it is sunny. It is not prohibited for PWA to go outside during the day, but they are suggested to wear the necessary gears to protect their skin from the sun.

#### 1.6. THE LEGAL FRAMEWORK

In protecting and promoting the human rights of PWA, it is important for a country to be lead by the laws, rules, and regulations that have been designed to achieve the policies created. It is also important for a country to nationally, regional or through its local government to adapt to its legal framework in perspective of the relevance of the human rights of its citizens. In this part of the research, the researcher explained the promotion of human rights internationally using the Universal Declaration of Human Rights and nationally through the institutional framework.

# 1.6.1. Global International Standards of Human Rights and its Relationship with PWA

There is a vast of law worldwide that covers the rights of PWA both internationally and nationally. The Universal Declaration of Human Rights (UDHR) is a historic founding body for international human rights since 1948. It is a document which states the basic rights and fundamental freedoms to which all human beings are entitled. This declaration was created because of the concerns over the outrages of the preceding world wars especially the Second World War. The UDHR was the origin of the

formation of legally binding international human rights agreements which as a result create obligations for state parties to respect, protect and fulfill the rights of its citizens.

UDHR stresses the equality of rights among all people. According to the UDHR, the following are some very important articles that have been enacted by this declaration (United Nations, 2015);

- Article 1: "All human beings are born free and equal in dignity and rights...."
- Article 3: "Everyone has the right to life, liberty, and security of person."
- Article 5: "No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment."
- Article 6: "Everyone has the right to recognition everywhere as a person before the law."
- Article 7: "All are equal before the law and are entitled without any discrimination to equal protection of the law...."

Through the few articles above, it demonstrates that every person is entitled to have their social, cultural, economic, civil as well as political human rights. But with all these laws established, it is becoming hard on some groups of people to claim their rights, people with albinism can be set as an example. Laws, policies, and practices are bound to help strengthen these human rights in order to bring equality and non-discrimination. So through the killings of PWA in Tanzania, this has now been regarded as a serious violation of human rights as it has taken away their right to life, which they are entitled to have been protected, recognized and respected as human beings.

#### 1.6.2. Institutional Framework

In order to understand the set of formal organisational structures that successful put forward the implementation in protecting and promoting the human rights of PWA in Tanzania, the institutional framework is assigned as the primary responsibility in depicting the authority to the agencies that shape the socioeconomic activity and behavior.

According to the Persons with Disabilities Act of 2010, different responsibilities per ministries were stated. This was done under the established council known as the National Advisory Council for Persons with Disabilities (NAC). The function of NAC is to advise the Ministry of Health and Social Welfare and to all persons with disabilities on every matter regarding the Act as well as any relevant policies and programs that are formed. In Tanzania, the Ministry of Health and Social Welfare is the ministry appointed to be responsible for people with disabilities through the Department of Social Welfare. This department's main aim is to ensure that there is a provision of nominal welfare services for the vulnerable groups in society.

Since its establishment, the Department of Social Welfare has been moved four times. In 2006 it was moved from the Ministry of Labour and Youth to the Ministry of Health where it is now even though located under the Ministry of Health headquarters, it is still perceived as marginalized within the structure of the ministry. This, however, has brought up different challenges in the provision of adequate services to persons with disabilities which leads to not fulfilling the human rights to this group in an unjust and unfair way.

Through an interview report, the challenge of staffing levels being low in the Department of Social Welfare was also mentioned, where it was pointed out that within the Department of Social Welfare, they were receiving a very limited budget although the management of the department is competent but not very efficient while performing their roles. Not only is the leadership of this Department not appropriately aware of these challenges it also has no capacity or the knowledge of how to tackle these challenges. With this happening, different stakeholders from the government, NGOs and civil society have expressed their views of the necessity of this Department to be relocated to the Prime Minister's office or the President's Office so that it would be on the watchful eyes of the highest levels of the government (Myamba et.al., 2015).

Apart from the Ministry of Health and Social Welfare, there are some other key line ministries that the Persons with Disabilities Act has mentioned to cultivate into the 'sectoral plans'. The Act has outlined these measures to be taken relating to the persons with disabilities per each ministry involved. These can be seen in Figure 3 below;

**Figure 3:** The Tanzanian Key – Line Ministries involved with Persons with Disabilities

Ministry	Responsibility
MoLE	Implementing National Employment Policy (2008) and Employment and Labour Relations Act (2004), responsibilities include the enforcement of minimum quotas for employment of persons with disabilities
MoEVT	In charge of providing educational services for persons with disabilities at the primary, secondary and tertiary levels. The Ministry is tasked with providing education in special schools, integrated units and in inclusive educational settings. Also oversees vocational education through the Vocational Education and Training Authority (VETA) which includes the training needs of persons with disabilities.
MoW	Responsible for overseeing the construction industry and ensuring that buildings and transportation infrastructure are accessible to persons with disabilities.
RALG	In charge of Local Government Authorities, which have been given a crucial role with respect to service delivery for persons with disablities at regional, district and ward level.
President's Office, Public Service Management	In charge of ensuring that persons with disabilities occupy the allocated vacancies in the public service and that there are adequate public facilities for persons with disabilities
MCDGC	Responsible for issues related to women and children with disabilities.

Source: Myamba et.al., 2015

## **Key:**

MoLE = Ministry of Labour and Employment

MoEVT = Ministry of Education and Vocational Training

MoW = Ministry of Works (It was formerly known as Ministry of Infrastructural Development)

RALG = Regional Administration and Local Government (Swahili for TAMISEMI), in the Prime Minister's Office

MCDGC = Ministry of Community Development, Gender, and Children

## 1.7. SOCIAL WORK IN TANZANIA

Historically, in many traditional African societies, there were no social workers during the period of pre-colonial. Instead, most of these societies had very long-standing traditions that supported their social systems. During the pre-colonial era when a problem arose in these societies, they had their own ways of solving these problems. They would either solve a problem between themselves or through well-respected elders of the society. In this era, with the many ethnic groups in Tanzania communities ties and deep-rooted kinship existed hence acted as shields in protecting those people that needed social protection and security. Not only did extended families play a role in meeting the social, spiritual and economic needs of other family members but also the community members who acted as the benefactors in providing social services and assistance.

According to the Tanzania Social Work Centre (2019), the history of social work in Tanzania can be traced back from the pre-colonial periods where communities lived in assisting each other in times of need. A child was regarded as a child of the community and the community was obligated to raise this child as their own. The elders and disabled people in the society were seen to be the highest and well-respected people in the hierarchy.

In Tanzania, the basic foundation for social work was laid in the period of preindependence which was around 1947 where it was due to the coming of the colonialists who were in search of raw materials, areas for investments, markets, and cheap labor that schools, hospitals, and other basic infrastructural areas were established. Through the establishment of these, different laws such as the Children and the Young Persons Ordinance of 1937, Probation of Offenders Ordinance of 1947 and Foster Care and Adoption Ordinance of 1955 were generated. These laws were introduced as a way to socially control the society whereby it helped the colonialists to transform the law violators to become law abiders.

But the root for the expansion of modern social work in Tanzania was during the 'Ujamaa' (Swahili word mean extended family, brotherhood or socialism) era. During this period, services to vulnerable groups such as social protection were handled by the government whereby it was freely provided. Other social services like education and health were compulsory regardless of someone's income or status hence the founding of the Department of Social Welfare in Tanzania after independence in 1961 which led to the establishment of services to the old people, children as well as people with disabilities. In a journal written by Zena M. Mabeyo "The Development of Social Work Education and Practice in Tanzania," she explains that the Department of Social

Welfare is a government organ that has the responsibility of overseeing and supervising the social welfare services to the people.

Despite the fact that the social work profession in Tanzania existed for more than half a century ago, this profession is not well recognized and accommodated by either the people or in the development plans and programs of the government. Many societies are still abundantly relying on the traditional methods in solving problems, that is the solving of problems within one's family, extended families or community members. It is not easy for people to open up their problems to a third party of the likes of a social work professional whereas this limits the major purpose of these professionals hence remaining under-represented in the societies.

On their website in 2019, the Tanzania Social Work Centre elucidated that currently through the Institute of Social Work in Tanzania which was formerly known as the National Social Welfare Training Institute established in 1973 gave rise to a professional group of social workers, particularly in the government sector. The Institute was formed for its purpose in preparing qualified human resources who could be able to strengthen the social service delivery structure in Tanzania.

Finally, social services being a field that dates back to the dawn of mankind and like many, this field has attracted the attention of researchers, practitioners, policymakers, leaders, activists, and professionals as well as other random people alike. Social work is indispensable with our thinking, plans, and actions from different walks of life. One of such key proponents of social work down the history lane is the attitudes of Tanzanian social workers towards the people with albinism. The social workers have been credited for the compassionate they have towards the people with albinism. This can be elaborated with how social workers in the government and in NGOs who are working towards the betterment of other people.

But due to confrontation of the barriers such as lack of resources, lack of innovation, nature of social work training and curricula, absence of regulations as well as low budget in the social work departments in different regions in Tanzania, the department is losing its strength, therefore, sucking the social services professionals dry. This can be attested by the words of many social services professionals who were met by the

researcher. If a government can not take care of its professionals in the right way, how are these professionals expected to provide their services to the societies they work for? As a social work is just a profession and a discipline, a social services professional is a person who publically or voluntarily gives their efforts to enhance the social wellbeing and protection of the people in need.

## 1.8. THEORIES ON ATTITUDE

Baron and Byrne (1991: 138) defined attitudes as "internal representations of various aspects of the social or physical world- representation containing affective reactions to the attitude object and a wide range of cognitions about it (thoughts, beliefs, judgments)." Attitudes reflect past experience, shape ongoing behavior and serve essential functions for those who hold them. Hogg and Vaughan (2005: 150) defined an attitude as a relatively enduring organization of beliefs, feelings, and behavioral tendencies towards socially significant objects, groups, events or symbols.

An attitude can be defined as a learned predisposition to acknowledge in a consistently favorable or unfavorable manner with an account to an accustomed object. Attitude is typically viewed as a masked or underlying variable that is assumed to influence behavior. It strongly influences social thought, the way in which humans anticipate and process social information. It furthermore functions as schemas-cognitive frameworks that hold and organize information about specific concepts, situations or events. Attitudes absorb what humans contemplate about, feel about, and how they would like to behave towards an attitude object. This means that attitudes towards other people are acquired through experience and they are learned from that experience (Baron & Byrne, 1997).

The theories selected for this study are the social learning theory and acquisition on attitudes as well as the cognitive theory. Theories are important in a study because they help to understand the broad base of the human behavior and in this case it is understanding the attitudes of social services professionals.

## 1.8.1. Social Learning Theory and Acquisition of Attitudes

Social learning theory postulates that attitudes are acquired from other people through the progression of social learning. This means that people's views are acquired in situations where they cooperate with others or merely observe their behaviors. The following are types of learning people obtain in their environment:

## • Classical conditioning: Learning based on association

This is the basic form of learning a new behavior through the process of association. This means that two stimuli are joined together to produce a first-hand learning response from another person. It must be realized that people are not born with attitudes but learn and develop them over time. According to Baron and Byrne (1997), attitudes may be learned indirectly by means of observing others and seeing their reactions. Examples here a child observes the behavior of her parents when they meet a person with albinism, and the parents show an attitude of displeasure every time, the child may also be subjected to do the same thing as the parents if ever they also encounter people with albinism. Children are normally so unbiased to anybody despite people's characteristics. But if at all they see their parent's negative reactions towards something, they immediately back down. The child negatively reacting because of their parents towards something is how classical conditioning happens.

## • Instrumental/Operant conditioning

Instrumental or operant conditioning is the basic form of learning in where attitudes are followed by positive outcomes are reinforced and are more likely to be repeated than the attitudes that are followed by negative outcomes. This can be seen when someone can be praised or rewarded by other people for stating different views. When getting a reward from a certain view, a person leans to see which views are seen as the "right" attitudes and which ones receive more rewards when voicing them out. Behaviors followed by positive outcomes are strengthened and tend to be repeated. In contrast, behaviors that are followed by negative outcomes are weakened, or at least suppressed (Baron & Byrne, 1997). For example, when a community is discriminating against people with albinism because of cultural reasons, a child who grows up to see this in their community will see it as the right attitude as well.

#### • Observing conditioning: Learning by example

This process of learning is when an attitude is learned just by observing another person. This process is also called modeling. A person can acquire new types of attitudes and behaviors by observing other people's actions. For example, when children observe or

see their parents fighting, they will also end up growing to be like their parents because it became an attitude that their parents modeled them to when they were young.

## • Social comparison and attitude formation

Social learning is not the only way of which attitudes are formed. Attitudes can also be acquired through social comparison. According to Festinger (1954; Cited in Selepe, 2007), this is the tendency to compare ourselves with others in order to determine whether our view of social reality is correct or not. People determine that the attitudes and ideas of someone have to agree with another to make them accurate. Because if all the people hold the same views, ideas, or attitudes, it means that they must be right. This leads to the manipulation of people's attitudes as many will change to be closer to those who seem to be right. For example, children might hear a person they like and respect expressing negative opinions towards people with albinism. This will influence the children's views, making them want to be the same as the person they like. To them, it will not matter that it might be a bad thing to express a negative opinion towards a person with albinism because they have already copied this negative attitude from someone.

## • Prejudice and discrimination

In his book of "The Nature of Prejudice" Allport (1954) said that prejudice is an antipathy based on faulty and inflexible generalization. It may be felt or expressed and it may also be directed towards a group as a whole or towards an individual because he is a member of that group.

Discrimination on the other hand, refers to a negative action towards a social group or its members on account of group membership (Jones, 2002; Cited in Verderber et al., 2009). In other words, a person who is prejudiced toward some social group tends to evaluate its members in a specific manner, merely because they belong to that particular group (Jones, 2002; Cited in Verderber et al., 2009). Sometimes it is not just the negative evaluations towards that group but also a person will start to have negative feelings when they are even in the presence or just thinking about the group they distaste. Baron and Byrne (1997) explained that prejudice may also involve beliefs and expectations about members of these groups, specifically, stereotypes suggesting that all members of these groups demonstrate certain characteristics and behave in a certain

way. This involves generalizations about the typical or "modal" characteristics of members of various groups.

## **1.8.2** Cognitive Theory

This theory stresses attitudes to bring changes hence the behaviors of someone can determine their attitudes. Cognition includes a person's own perception, expectations, and ideas on their attitudes, behaviors and beliefs. The cognitive theory hypothesizes that people develop thinking habits based on their environment, experiences and judgment on how to behave. Albert Ellis, the first cognitive therapist believed that people can adopt the principles of reasoning consciously. Many social services professionals combine different intervention approaches with the cognitive theory whereas it helps in improving the cognitive capacities like enhancing perceptual skills, decision-making, and assessment skills.

In this study because of what they underwent in their childhood, some of the participants who were PWA gave vivid examples of how it affected their attitudes growing up as well as how it has helped them in their profession. This can be attested in the following excerpt:

"Before I got to work for this place (NGO), got to mingle with other PWA everyday and got to find this is normal you know, other people's attitudes affected my attitude. You know, that feeling ashamed of yourself, feeling inferior, the way they see you inferior you also feel inferior because you have grown up been treated that way and you get used to it. But when I came here, and started working with people like me (PWA) and I got to grow. It's growing, you get used to it. You change. And right now, whatever they think doesn't affect me because right now my target is to change what they think." (Participant 14)

This theory was used in this study to show how the attitudes of social services professionals can bring changes towards the misconceptions of PWA in Tanzania. Not only changes to their societies but also to the PWA who have a negative image about themselves. Exposing the attitudes can help to bring changes to their behaviors as well as their perceptions and expectations.

## 1.8.3 Social Aspects of Albinism: Attitudes

The presence and the belief of different myths about PWA in Tanzania, has been among one of the reasons behind the killings of PWA. Due to such fragmented understandings of albinism, it has been difficult to annihilate the outcomes from different people especially from their own family, peers, teachers as well as those around their environment. Because of this, different attitudes emerge within the society hence they tend to nurture as they grow and manifest intensely into the environment thus making it impossible to eradicate.

## 1.8.3.1 Perceived Attitudes of the Community Members

According to Nzagi (2009), the knowledge about albinism as a condition or a disease is very poor not only within the Tanzanian society but among the PWA themselves. Most of the PWA in Tanzania believe that they were born with the condition either because it was a curse put on their family, a pregnant woman was cruel towards her child during her pregnancy or that the devil appeared during the delivery to replace a 'black' child with a 'white' one.

Nzagi (2009) further explains that superstition has been a common thing in Tanzania, especially about albinism. This means that for a very long period of time, PWA have constantly suffered socially and psychologically due to the stigma that has surrounded them with their condition. In the past, because of their color of skin in a black populated society, PWA in Tanzania were referred to as 'zeru zeru' meaning albino in Swahili. Other terms used were 'mzungu' meaning a white person and 'nguruwe' meaning pig in Swahili.

According to Selepe (2007), it was stated that traditionally, PWA were killed at birth because they were considered as a curse from the gods whereas in some rural villages, PWA were rejected as many thought them to be products of witchcraft. This was one of the reasons where families would choose to kill a baby for the fear of being labeled as witches. Some even said that PWA have supernatural powers and they are contagious because they have a short life span.

## 1.8.3.2. Perceived Attitudes of Family

According to Braathen & Ingstad (2006), it was explained that most parents especially mothers have a positive reaction when asked about having children with albinism. Many of them expressed happiness when asked. But while the mothers expressed love and happiness, the fathers often reject the children born with albinism. Even though the research was carried out in Malawi, this situation also happens in other African countries as well Tanzania included. If a woman gives birth to a child with albinism, fathers often tend to abandon his family to go and marry another woman. Some even reach the extent of wanting to kill their own children either by negotiating a price for their children's body parts for witchcraft or other things.

Some fathers also have the belief that they cannot father such children as some are still illiterate to understand that albinism is a genetically caused disease hence blame the woman for the cause or even slander them with cases of committing adultery which also creates mistrusts between a wife and a husband. In many cases, these misunderstandings led to broken marriages, divorce, and rejection. Some mothers face the wrath of the husband's family as many might as well refuse to acknowledge the child with albinism in their family. Children with albinism are often segregated, discriminated and would not even be treated as a member of the family as some are perceived to have brought shame to the whole family. Though in some cases where the load is heavy for the mothers, some mothers who get tired to the point of them also abandoning the child or even abusing or punishing them.

With faith-based and educated families, them believing that children are God's gift people with albinism tend to get more positive attitudes towards them. They tend to accept them and treat them as special gifts from God, whereas they find these 'golden children' attractive and become very proud of having them in their lives (NOAH, 2014). The positive attitudes that they receive from their own families tend to bring lesser worries from other people's reactions and attitudes towards them. As long as their families around them accept them for who they are and not judge them for their skin color.

#### 1.8.3.3. Perceived Attitudes of School and Friends

In her research Selepe (2007) stated that children with albinism that go to school experience name calling among their peers. This is something that has been practiced for a long period of time. She continues to explain that ancient people used to believe that name-calling was something you do in order to bring control over that thing.

Lund (2002) stated that children with albinism faced some social problems at school. The social problems they were exposed to were; name calling, others were ridiculed, bullied, beaten by their fellow pupils, and treated as a misfit or outcast. Some of their peers even avoided them by refusing to sit, eat or play with them. With too many negative attitudes from school or even their peers, many children with albinism end up illiterate as many tend to drop out of school because of being subjected to name calling, stigmatization, oppression, and discrimination.

Braathen & Ingstad (2006), indicated that some children with albinism who have many friends tend to feel normal when interacting with their friends. But when they move out of their safe circle, they however often experience discrimination. From the stories that most mothers participated in explaining about their children with albinism going to school, some said that their children are afraid of going to school because they were beaten, pinched (to see if they have the same blood as others) and even segregated by their peers. In order to stop some of these evil acts done on them at school, some of these children had to report to their teachers hence action was taken for it to stop. Some teachers also went to the extent of talking to their students on fearing God and accepting different types of people because that was how they were created. With this fear of God, some children understood and stopped segregating and ridiculing their fellow peers with albinism.

In conclusion, it has been noted that the attitudes of people around PWA affect them deeply. Be it at home with their families and relatives, be it at school with their peers, friends and teachers, or their community members, PWA are bound to be positively and negatively affected because of what they experience with these attitudes.

## 1.9. RESEARCH PROBLEM

In an article by Burke, Kaijage & John-Langba (2014) it was explained that the African PWA are stigmatized because of their white skin as many of them live in black-skinned societies. The stigmatization becomes intensive as most of the PWA have disabilities like low vision or blindness and some even have tendencies towards contracting skin cancer.

When the killings of PWA became a national problem in Tanzania, human rights practitioners such as social services professionals, used their roles in being vocal witnesses for social change and prevention of harm in their communities. Hugaas (2010) argues that social work should 'prioritize the prevention of more evil' and act as 'moral agents' to provide moral guidance, education and some social control. One crucial way of doing this is by being outspoken witnesses for social change rather than silent bystanders, upon which evil seems to depend.

In Tanzania, there is very little knowledge of PWA. Therefore, this has brought out a great involvement of social services professionals to work as the educators for the societies. But due to the limited data on research regarding the attitudes of social services professionals towards PWA, the researcher found it appropriate to explore more about this as well as the roles the social services play towards PWA and the precautionary measures taken towards protecting PWA.

#### 1.10. PURPOSE OF THE RESEARCH

This research aims to examine the attitudes of social services professionals towards PWA in Dar es Salaam, Tanzania. In this context, the sub-objectives of the research are as follows:

#### In Tanzania:

- How much do social services professionals understand PWA in Tanzania?
- What is the current situation of PWA in Tanzania?
- How have the social services professionals' attitudes affected PWA?
- How has the community's attitudes affected the attitudes of social services professionals towards PWA?

- What are the roles played by the social services professionals in Tanzania towards helping PWA?
- What roles played by institutions and government towards helping PWA in Tanzania?
- What are the roles that PWA can play to change their own society's attitudes towards them?
- How does the Tanzanian government support the social services professionals who work with PWA?
- How does your institution tackle down barriers/challenges facing PWA in Tanzania?
- What ways can be used in eradicating the misconceptions about PWA?
- What are the precautionary measures taken by social services professionals towards protecting PWA in Dar es Salaam, Tanzania?

The questions above are set forth in detail as the research topic was entitled to examine the attitudes of social services professionals in Dar es Salaam, Tanzania.

## 1.11. IMPORTANCE OF THE RESEARCH

The study will be of a very great importance to the body of knowledge in the field of social sciences, specifically social work, sociology and psychology as it examines the attitudes of social services professionals towards PWA, their roles and precautionary measures taken towards PWA. There was also a need to understand the PWA and use the appropriate mechanisms to help make their lives in their own societies easier. This study will also be of great guide and assistance to the social services professionals and the government of Tanzania especially when there is a need to develop new policies concerning PWA. Above all, this study will be of a great help in enlightening Tanzanians about PWA and albinism.

## 1.12. LIMITATIONS OF THE RESEARCH

The researcher encountered some of the following limitations:

a) It was difficult to hold a focused group discussion for the PWA as most of them had different schedules and priorities in their daily lives. So, the researcher did the one-on-one interviewing process.

- b) It was tough to find participants with albinism to interview on a daily basis. The researcher had to patiently wait for them at the Ocean Road Cancer Institution every Thursday as it is a special day for them to go for their skin treatment. Some days they did not come at all, and some days they appeared in a small number.
- c) The questionnaires sent through emails to some of the social services professionals were not replied back.
- d) Dar es Salaam is a huge city with five districts, the researcher was limited to do the research on just two districts that the NGOs were based on.

## 1.13. DEFINITIONS

In order to understand this research in a very large context, there is a need to know the concepts regarding this topic. In this sense, Tanzania as a country highlights some of the concepts regarding this topic and they are as follows;

**Disability:** In Tanzania's National Disability Policy (2004,1) disability is described as "a loss or limitation of opportunities to take part in the normal life of the community on an equivalent level with others due to physical, mental or social causes." Therefore in Tanzania people with albinism fall under the category of "disabled people". Disabled people are victims of discrimination, stigmatization, and segregation.

**Albinism:** The word "albinism" refers to "a group of inherited conditions when people have little or none of the pigment melanin in their eyes, hair, or skin. They have inherited altered genes that do not make the usual amounts of this pigment melanin (NOAH, 2014)."

**People with Albinism (PWA):** This is the term used and preferred to the term "albino" because this puts the person before the condition rather than equate them to it. This term also helps to show them that they are also humans and they should not be discriminated in their own society.

**Tanzania Albinism Society (TAS):** This is a national non-governmental organization founded by the PWA in 1978 and officially registered in 1980. Its main branch office is located in Dar es Salaam and 168 of their offices have been opened in every region in Tanzania. The main purposes of this organization were to bring together PWA and

to protect and defend the rights in the areas of health, education, awareness-raising and involving them in different sectors in the community. Though the general reason as to why the organization was started was because of the biggest challenge PWA face, and that is skin cancer.

Under The Same Sun (UTSS): This is a charitable/non-governmental organization founded by Peter Ash, a Canadian person with albinism and Vicky Ntetema a former journalist and Tanzania's BBC bureau chief in 2008. It was through one of Vicky's report in July 2008 that caused the breakout of the crisis of people with albinism to the world. They joined forces to battle the negative forces done against PWA as some were seriously mutilated, murdered or even part of their body parts were trafficked in Tanzania.

Brigitte Alfred Foundation (BAF): This is a non-profit organization founded in 2014 by Brigitte Alfred, a former Miss World Tanzania 2012 and an ambassador of Tanzania Albinism Society (TAS). Its main branch office is situated in Masaki, Dar es Salaam. The main mission of this organization is to empower, secure and improve the welfare of PWA from family to community levels. In order to empower people with albinism, it is the only organization in Tanzania that organizes and holds beauty competitions/pageants like Mr. and Miss Albinism where people with albinism are the core participants.

**Social Services Professional:** In Tanzania, this is a person who should have the ability to attend problems facing individuals, families and small groups hence enhancing social functioning as well as have the practical knowledge and skills to provide social welfare services and being able to perform social work practice including managerial and supervisory roles, leadership and program evaluation at micro, mezzo and macro levels. A social services professional is someone who assists others when dealing with personal and social problems hence providing their services.

# 1.14. TANZANIA – TURKEY RELATIONSHIP IN SUPPORTING PWA

Through the presence of the Embassy of Turkey in Tanzania under the leadership of His Excellency Ali Davutoğlu and his humanitarian wife Madame Yeşim Meço Davutoğlu, great support has been made in contribution in raising awareness to dispel the existing myths to not just the Tanzanian public but the whole world about PWA. They support PWA in many events and provide essentials like school bags to children with albinism, sunscreen lotion, sunglasses and other protective gear like hats as proven in Plate 1. With such contribution towards the PWA in Tanzania, it shows a great and awe-inspiring relationship between these two countries hence the strengthening of their associations together in their countries.





Source: Madame Yeşim Meço Davutoğlu's Twitter page (@YESIMMECODAVUTO)

The Embassy of Turkey in Tanzania also helps in hosting events for PWA. On January 2018 through an event organized by the Brigitte Alfred Foundation, a fashion show called "My Skin, My Pride" was held at the Turkey Ambassador's residence in Dar es Salaam and was hosted by the Ambassador's wife, Madame Yeşim Meço Davutoğlu as seen in Plate 2 and 3 below. In 2018, through reports covered by the Daily News in Tanzania and Makoye, they spoke to the host who explained the aim of the event as a

process of raising awareness to the public that PWA deserves everything right like other human beings.

**Plate 2:** His Excellency Ali Davutoğlu, his humanitarian wife Madame Yeşim Meço Davutoğlu, their son Balkan and one participant of the "My Skin, My Pride" beauty pageant.



Source: Sunday News Reporter from the National Newspaper DAILY NEWS, 2018

**Plate 3:** The organizer Brigitte Alfred with the host Madame Yeşim Meço Davutoğlu and some guests at "My Skin, My Pride" beauty pageant.



Source: Sunday News Reporter from the National Newspaper DAILY NEWS, 2018

The Embassy of Turkey in Tanzania has always stood upfront in supporting not only the PWA but also other persons with disabilities. One of a prime example is through their orphanage that was opened in Dar es Salaam, called *Aşure Vakfi* (in English meaning The Ashura Foundation) as seen in Plate 4 below. They are currently supporting almost 70 orphans both boys and girls to which 2 are girls with disabilities. The Embassy has also played a part in bringing Turkish organizations like Remedy Aid And Development Association (*Çare Yardımlaşma ve Kalkınma Derneği*) and Association of the Friends of Africa (*TADD - Tüm Afrika'nın Dostları Derneği*) to show support and provide aids to Tanzania as seen in Plate 5.

Plate 4: The Ashura Foundation



Source: Researcher, 2019

**Plate 5:** Remedy Aid And Development Association (*Çare Yardımlaşma ve Kalkınma Derneği*)



Source: Researcher, 2019

## CHAPTER TWO: RESEARCH METHODOLOGY

This chapter focuses on the research methodology, which is composed of the tools and techniques that were based on the entire research. It includes the following sections: research design, study area, data collection methods, sample and sample size, data collection and methods for data analysis.

## 2.1. RESEARCH DESIGN

In this research, a qualitative method was used to mainly deal with examining the attitudes of social services professionals towards the PWA in Dar es Salaam city. According to Denzin and Lincoln (1994, p.2), qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This goes to mean that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, occurrences in terms of the meanings people bring to them.

Through the qualitative method, the variety of methods that will be used will develop deep understandings of how people perceive their social realities and the consequence of how they as well act within the social world. According to Denzin and Lincoln (1994, p.14), the researcher has several techniques for collecting empirical materials, ranging from the interview to direct observation, to the analysis of artifacts, documents, and cultural or traditional records, to the use of visual tools or personal experience.

## 2.2. WORKING ENVIRONMENT: DAR ES SALAAM CITY

The city of Dar es Salaam was the former capital city of Tanzania until 1996. It is located on a large harbor on the Eastern Indian Ocean coast of Africa. It is now the most populous city in Tanzania and a regionally important economic center. According to the Strengthening Urban Engagement of Universities in Africa and Asia's website in 2019, it was stated that Dar es Salaam is the fastest growing city in the world and it is the leading city in East Africa by population. It is a city that consists of 5 districts or municipalities: Kinondoni which is based in the North, Ilala is located in the Center, Ubungo and Temeke are both located in the South and lastly Kigamboni which is based in the East across the Kurasini Creek.

Dar es Salaam is Tanzania's most prominent city in arts, fashion, media, music, film, and television and a leading financial center. The city is the leading arrivals and departure point for most tourists who visit Tanzania, including the national parks for safaris and the islands of Zanzibar, Unguja and Pemba. Dar es Salaam is also the largest and the most heavily populated Swahili-speaking city in the world. According to the official 2012 population census the city had a population of 4,364,541 (Central Intelligence Agency, 2017).

This city has been selected to be an exemplary city in this research because it is the city that many non-governmental and governmental organizations involving people with albinism are either established or founded. Another reason is that the ministry concerned with people with albinism also had its headquarters here before it was moved to the capital city, Dodoma in 2018 by the then-president. It is said that Dar es Salaam is currently one of the cities in the world that is on the rise. This means that it is growing at a rapid pace.

The research was conducted in Dar es Salaam City specifically in two municipals. These municipals were Kinondoni and Ilala. In these two municipals, information was collected through in-depth interviews with social services professionals who are working in the government and the non-governmental organizations from UTSS, TAS, and BAF.

In 2019 through the municipal profile on their website, Kinondoni is a municipality with a projected population of 1,245,861 where in 2018 male were estimated to be 605,258 and female were 640,603 with a growth rate of 5% per annum. According the social welfare officer interviewed in this research, there are almost 180 PWA in the Kinondoni Municipal. The household per person has been estimated on the average of 4 people with the total of 311,465 households in the municipal. The municipal has four divisions which constitute 34 wards and 169 sub-wards. Kinondoni Municipal's vision is to have a municipal that is vastly enthused, unique, and with advanced socioeconomic infrastructure. The mission for Kinondoni Municipality is to provide worthy services to their people in their municipal by operative and proficient usage of resources; respect to the rule of law, good governance, capacity building, and henceforth improving the living standard of their people.

The Ilala Municipal through their webpage in 2019 stated that according to the 2012 census the municipality has a population of 1,220,611, males being 595,928 whereas 624,683 were females with the sex ratio of 95 and estimated growth of a population of 5.6 per annum. The social welfare officer interviewed in this study mentioned the possibility of Ilala Municipal having almost 200 PWA. It is made up of 3 divisions where it is divided into 36 wards and further subdivided into 159 sub wards. Among the strategies for Ilala Municipal are; to improve good governance and administration services, to improve social welfare, gender, and community empowerment, managing of the environment and it natural resources enhanced, access, quality, and equitable social service delivery are improved as well as quantity and quality of commercial facilities and infrastructure are as well upgraded.

All these social services professionals that were interviewed are those that closely work with the PWA. In order to acquire more information from the affected group, interviews with volunteers who were PWA were also prepared. Because of the difference in availability of time for each participant for the focus group discussions, the researcher was forced to opt to conducted in-depth interviews with the people with albinism.

The general population of this research was composed of social services professionals who work in the government and those that work in the non-governmental organizations that are involved with the PWA. With the large population in Tanzania, it is known that social services professionals are very few but with the help of non-governmental organizations, it has helped to curb down few critical situations like looking after the PWA.

The researcher also held a meeting with the wife of the ambassador of Turkey in Tanzania, who not only is she a housewife and a philanthropist but among the social services professional in Tanzania that contribute to different social events in supporting different groups of people in Tanzania, PWA being among this group.

The limitations of the research in terms of time and possibilities led the researcher to only work with just one city, Dar es Salaam. Dar es Salaam is one of the biggest cities in Tanzania and is also considered one of the cities that holds different headquarters

for different NGOs as well as where some government offices are still located. The study population consisted of 24 participants; eleven were male and thirteen were female. The age bracket of those interviewed was between the ages of twenty four being the youngest and sixty one who was the oldest with the rest belonging to different ages within the bracket. Most of the social services professionals were holders of a Bachelor degree or a Master's degree while the volunteers' level of education were primary school. All in all, these interviews were held between the months of May and September 2019.

In the data collection process, all data that were collected have been granted permission to use for the research.

## 2.3. DATA COLLECTION TOOLS

Semi-structured inteview forms were developed by the researcher to collect information in accordance with the purposes of the research. The semi-structured interview form in Appendix 1 was applied to social services professionals, and it was used to interview those who are working in the government as well as the non-governmental organizations as seen in Plate 6. 21 questions were prepared for this. In order to understand the targeted group, a semi-structured interview form in Appendix 2 was also used to volunteers who were the PWA themselves as seen in Plate 7. The semi-structured interview form for the volunteers consisted of 10 questions.

The interviews with the social services professionals working at UTSS were conducted in their offices in Mikocheni, a ward from the Kinondoni Municipal. The interview between a social service professionals from BAF was also held in their offices in Masaki, also a ward from the Kinondoni Municipal. For the social services professionals working at TAS, the interviews were held at Ocean Road Cancer Institute where their offices are located and they are under the Ilala Municipality. Emails were sent to two social services professionals who were not physically present for face to face interviews. For the case of the volunteers, the interviews were conducted at the Ocean Road Cancer Institute at the TAS offices. An email was also sent with the interview form to the journalist as she was not available to meet with the researcher physically.



Plate 6: Interview with a social service professional at UTSS offices

Source: Researcher, 2019





Source: Researcher 2019

For the social services professionals that work in the government, the research had to travel to their offices in each selected municipal. All the interviews with the social services professionals from the Ilala and Kinondoni Municipals were held at their Social Welfare Offices at their specified municipals.

In addition to that, the interview questions were designed in three languages, English, Swahili and Turkish in order to give the participants a chance to be open and feel free to use the language that was easier and understandable to them. To fulfill the aim of this research, the researcher decided to create and use open-ended questions as it was a way to get answers through the participant's own knowledge, feelings, and views on the concerned topic. The interviews were held between 30 to 60 minutes on average. Voluntary participation forms as seen in Appendix 3 were also filled by each and every participants.

#### 2.4. DATA COLLECTION PROCESS

The research used both primary and secondary data sources. In the primary data for the purpose of accessing the knowledge, feelings, and views of the participants through the qualitative method of research, the data was collected through in-depth interviews, observation, and documentation. Interviews were conducted with a fairly open framework hence which allowed focused, conversational and two-way communication between the interviewer and the participant. Observation is a technique of collecting data which involves getting information non-verbally and through behavioral elements. In this study, I was also able to obtain valuable information through observing the participants' behaviors, interactions and their working environment. Throughout these interviews, with permission from the participants, an audio recording was used.

The secondary data was obtained from reviews and evaluations on already published literature in books, journals, and newspapers.

## 2.5. DATA PROCESSING AND ANALYSIS

NVivo computer software was used in the processing and analyzing of the collected data. The researcher chose to use this software because it is one of the best software that is easy to store, manage, evaluate and analyze data. The responses to the openended questions, audios, quotations, photographs and documentation that were

collected were analyzed using this software. In the analysis process, I printed the interviews in order to review them thoroughly. This helped me to create thematic codes through the Nvivo 12 software program. The themes that were founded within this research include; (1) Attitudes of social services professionals towards PWA, (2) Roles played by social services professionals towards helping PWA and (3) Social services precautionary measures towards PWA. The findings of the study are linked with the theories as they have been put together into the research context in order to examine the attitudes of social services professionals towards PWA in Dar es Salaam, Tanzania. The following table (Table 1) outlines the themes and subthemes of the research.

**Table 1:** Summary of Themes and Subthemes

Themes	Subthemes
3.1 Findings of the attitudes of	3.1.1 SSPs' understanding of PWA in Tanzania.
social services professionals towards PWA	3.1.2 Current situation of PWA in Tanzania.
	3.1.3 SSPs' attitudes towards PWA
	3.1.3.1 Positive attitudes.
	3.1.3.2 Negative attitudes.
	3.1.4 SSPs' attitudes effect on PWA
	3.1.5 Community's attitudes effect on the attitudes of the SSPs towards PWA.
	3.1.6 SSPs' thoughts on how PWA should be treated.
	3.1.7 Future of the PWA in Tanzania
3.2 Findings on the roles	3.2.1 Individual roles played by SSPs towards PWA
played by social services professionals towards PWA	3.2.2 Roles played by institutions towards helping PWA.
	3.2.3 Roles played by the government towards helping PWA.

3.3 Findings on the social	<ul> <li>3.2.4 Roles PWA can play to change their own society's attitudes towards them.</li> <li>3.2.5 Government support towards the SSPs who work with PWA.</li> <li>3.2.6 Improving the social status of PWA in Tanzania.</li> <li>3.3.1 SSP's thoughts on people that should be involved to</li> </ul>
services professionals' precautionary measures towards PWA.	participate in understanding PWA.  3.3.2 How institutions tackle down barriers/challenges facing PWA in Tanzania.  3.3.4 Ways that can be used to eradicate misconceptions about PWA.  3.3.5 Measures needed to be taken to end stigmatization, discrimination, persecution and ensure effective protection of the PWA in Tanzania.

Source: Researcher compilation, 2020

## 2.6. ETHICAL CONSIDERATION

Ethics can be regarded as a body of moral principles that determine a human's behavior. The research considered ethical issues by carefully preserving the collected data and ensuring the privacy of the participants. The participants were first and foremost briefed fully about the purpose of the research. The rationale behind this research was carefully explained to them. Consent was sought before conducting any interviews as most of the participants voluntarily accepted. Confidentiality was preserved by using numbers to conceal identities to some participants.

The face to face interviews were carried by using a voice recorder with the consent from the participants. The interviews that were carried via email were consented to be used by the research as well. Any photos used in this research were either taken or given by the researcher with the permission from the participants.

According to Kerlinger (1993), seeking permission to conduct a study is one of the important ethical issues to consider during research. With this, the researcher followed the logical and ethical considerations by seeking permission to conduct research in both Kinondoni and Ilala Municipal as well as UTSS and TAS. Clearance letters from Hacettepe University were presented to the Municipal Director of Kinondoni and Ilala Municipal Councils who kindly issued permission to collect data in their area.

## CHAPTER THREE: RESULTS AND DISCUSSION

In this section of the research, findings and evaluation of various findings were examined into three main themes. These themes were selected because they are act and move together as a unit to develop the main objective of the research. The first theme is the findings of the attitudes of social service professionals towards PWA. The second theme introduces the findings on the roles played by social service professionals towards PWA. The third theme is findings on social work and social services professional's precautionary measures towards PWA.

## 3.1. FINDINGS OF THE ATTITUDES OF SOCIAL SERVICES PROFESSIONALS TOWARDS PWA

In this theme, the main purpose was to investigate the attitudes of social service professionals towards PWA. In terms of finding the answers, the subthemes included; findings about the understanding of PWA by social service professionals, current situation of PWA in Tanzania, attitudes towards PWA, how these attitudes have affected PWA, community's attitudes effects on the attitudes of social services professionals, thoughts on how PWA should be treated and the future of PWA in Tanzania will be discussed.

## 3.1.1. Social Services Professionals' understanding of PWA in Tanzania

In order to understand their community, social services professionals should be able to understand who they are working with, who they are working for and why they are working. In understanding about PWA in Tanzania, some of the participants from the government and non-governmental organization stated them to be; a group of people from the disability category in Tanzania;

"My understanding of PWA is that they are among the known groups of people that have a disability in Tanzania. PWA is a group of people that are affected health-wise as they have to overcome different challenges in having albinism. I understand PWA as people that have a disability here in Tanzania." (Participant 10)

Participant 5 illustrated more about the type of the disabilities that PWA in Tanzania have as below;

"It is one type of disability in Tanzania. This disability comes from a lack of melanin or natural color that affects the eyes, hair, and skin. This disability differs from other types of disability by looking at their needs which are essential as the likes of sunscreen (sunscreen lotion), solar sunglasses, wide caps, clothes that will be covering all body parts and umbrella. They are also not required to perform their activities in the sun. The major impact they have is that their skin is attacked by cancer if they do not take care of themselves."

Some participant's understanding of PWA in Tanzania is because of the many challenges PWA face either from the past or the current situations. This has conveyed a message to not only social services professionals but other professionals too like journalists. On their understanding about PWA, one of the participants had the following to say;

"Persons with albinism in Tanzania are marginalized, discriminated against and stigmatized. Some of them have been mutilated and murdered for their body parts due to harmful myths and beliefs spread in the community by witchdoctors who tell their clients that persons with albinism possess magical and supernatural powers that can make their clients rich, successful and win elections. Graves have been desecrated and body parts stolen for witchcraft purposes. In some areas, persons with albinism have been murdered/are still being murdered at birth to what those who practice such an inhumane customs believe, "avert the curse in the clan/family and community". (Participant 3)

Another participant went further to explain their understanding of PWA in Tanzania as follows;

"I understand that they are people who are discriminated, they don't have equal opportunities and they are not treated as equal. There is so much stigma around albinism and so many myths and ignorant facts about them. And they are people who have to really watch their backs and they are not safe in

Tanzania as they have to do so much more to be seen and to be treated equally than they are other people." (Participant 1)

With some social services professionals being PWA themselves, they stressed about their understanding of PWA scientifically. One of the participants explained how albinism is a genetic condition that is caused by both parents who carry the albinism gene.

"Albinism is a hereditary thing, it's not just from one parent, and both father and mother have the albinism genes which when they meet together is when you get a child with albinism. If the albinism gene from the father meets the same gene from a mother, a child with albinism is born. But if the father has the albinism gene and the mother doesn't or vice versa, a child will be born without albinism. We come from a society, and if the society understands all these they should be able to change." (Participant 13)

Using science to explain their understanding about PWA, one Participant went further to explain that the albinism inheritable gene being carried in a family, not only will the gene stop from their children but it might also go from one generation to generation.

"Now, science tells us, it's a gene responsible for albinism that is albinism is genetic, it's inheritable. That means, when you have someone with albinism in your family it is possible for family members to have a child with albinism in the future and so forth. So it is transmitted through genes, parents with genes with albinism can give the genes to their children and their children also can give it to their children from generation to generation." (Participant 11)

Being a person with albinism themselves, one participant had to include themselves in their understanding about how PWA are a minority group in Tanzania and how they can be distinguished from other groups because of the challenges PWA face especially for those that reside more in the rural areas than those that live in the urban areas.

"We are a minority group but we have special needs that are more special than that general minority group. We are a significant number in relation to the general population but currently, there is no accurate data with regards to the census in population and settlement data but for most who are residing in rural areas they are not in such friendly environment especially in relation to the challenges that come with the conditions. When I talk about challenges I'm talking about skin challenges, being eye-impaired and attitudinal beliefs towards albinism. Though in town, there are the same challenges but not to that extent in comparison to the rural areas." (Participant 11)

In an interview written on an article by Brocco (2015), a 19-year-old girl born with albinism affirmed having no knowledge of what albinism is but knowingly for sure that she was created by God as being the creator to other creatures on earth. This was also accepted by a young mother who has a daughter with albinism. She does not know why her daughter's skin is white but she only knows that she was born that way because of God's will. To some of the people, albinism is perceived as a condition initiated by God's will and plans therefore humans have to accept it.

Nzagi (2009) explained that the lack of correct knowledge and awareness about albinism in Tanzania has been the main source of the spread of the myths in the societies. It is said that not only is a huge number of people in rural areas Tanzania lack awareness about albinism but also the trained medical professionals.

#### 3.1.2. Current Situation of PWA in Tanzania

During the past years, PWA have suffered either through killings, abduction, stigmatization, discrimination and even mutilations. With such evil acts either due to superstitious beliefs or myth, PWA lived in fear. Due to the measures that the government took, such as putting harsh laws, bringing to justice the perpetrators as well as interventions from the UN, there has brought some peace to PWA. Through the use of social service professionals, NGOs have used advocacy and education to bring awareness to the public about PWA. This has brought not only just families to accept a person with albinism in their empires but also communities to finally understand the situation that PWA live in. Interacting with not just the public but with the PWA as well, social services professionals are able to understand what situation PWA are in. Participant 10 had the following to say;

"The current situation of PWA; first socially the Tanzania community and the government has now begun to know and understand more about albinism and

PWA being categorized as a disability group here in the country. The communities' attitudes towards PWA have now been that people understand that it is a group that needs special care especially when they face violence, stigmatization, discrimination as well as killings. Families have also now accepted and acknowledged that once you have gotten a child with albinism it means that the child will need more special care like how we know about others who have a disability."

One participant who has worked with PWA since 2010, had the following to add;

"There has been a lull in the killings, mutilations, and abductions of persons with albinism since 2016 (The most recent murder was in February 2015). However, there was a rise in grave robberies for the past three years (the most recent grave robbery was in April 2019). Further, there have been foiled abductions of 8 children with albinism in 2018 alone and four attempted abductions in 2019. Advocacy and public awareness-raising about albinism by NGOs that offer services to persons with albinism, foreign governments' and parliaments', the UN and AU interventions and resolutions, and also the Tanzanian government's interventions (by law enforcement agencies, arresting arraigning the culprits in court, convictions and penalties), including albinism in the agenda of peace and security committees, played a big role in reducing the number of atrocities against PWA in the country." (Participant 3)

As a government official working with the PWA, a participant also expressed the happiness they see in the communities, as many have begun to not just understand PWA but are able to support them in any matter in their communities.

"There has been a very large proportion of people that have begun to understand more about PWA. Currently, people through understanding them have brought there more support towards them in the community where it reaches a point where you don't have to know or ask who is a person with albinism and who is not though physically you can see the difference. A person with albinism now can work normally like any other person and there will be no isolation, segregation or discrimination towards them. The killings that

happened before are also no longer heard like how they used to be. I can say that people have really become knowledgeable about PWA." (Participant 8)

Some of the interviewed social services professionals responded that the current situation of PWA in Tanzania is more peaceful than before. Bringing out the meaning that even though they are still very few cases brought up here and there about PWA, the cruel ones like killings and mutilating the PWA's body parts have lessened or cannot be heard like before. This is because of the public awareness that has spread in Tanzania about PWA. In general, people are no longer in the dark about PWA. Many of the communities have begun to understand the bad myths and beliefs that were put there in the past about PWA to be untrue.

"Through the awareness done to the community concerning PWA, people gained a lot of knowledge about PWA so since 2015 till we are here today in 2019 the community has finally understood that PWA are just normal people like the rest and they have also taken them as their fellow community members. Also through awareness rising, people have stopped having superstitious beliefs as well as witchcraft. There are also by-laws that have been put forward to those who kill PWA. We can say that the incidents of violence towards PWA have decreased to almost 90%." (Participant 6)

Being a PWA themselves, one Participant who has worked with PWA for almost 7 years, shared their views about the current situation of PWA in Tanzania by looking at how the awareness and public understanding on PWA has improved from years around.

"There are improvements if you compare with last years around 2008 to 2014 and now 2019. The situation is improving so, I can say that we are now moving from one stage to another. And therefore, we can say the status of awareness and public understanding towards this group is improving day today." (Participant 12)

Participant 13 deeply explained the current situation of PWA in Tanzania as a 50/50 situation. This means that, even though the government has used measures like harsh punishments for some perpetrators, some attacks are still happening because they take place in rural areas than urban areas. The most common recent attacks, two ambushes,

and abduction were also mentioned to emphasize how even though the killings have stopped different types of silent attacks are still ongoing.

"It's 50/50. If you base it on their security, and if you look at the killings which are done by the attackers, it has largely decreased. I won't say that the killings have stopped but they have decreased in quite a number. Because we don't hear events of ambush, events of attacks to date with the exception of two events that happened in January in Ngorongoro and Kwimba, Mwanza. In Mwanza, unknown people wanted to ambush a family who has a 6 years old child with albinism. This was around January 4th this year where no one was caught for such an attack. The same event to place in Ngorongoro, where a 19 years old boy was about to be abducted. There was also a recent event on grave digging of a person with albinism in Mbeya. With all these few examples, you can't say that the killings have stopped, you just have to say that they have immensely decreased."

They went further to enlighten the researcher that, even though these killings in the sense of PWA attacks, there is also another type of killer that is finishing the PWA community. This killer is skin cancer. A larger number of PWA in Tanzania have no enough knowledge about their own condition as well as being economically poor. So with this, many of them have no understanding of the danger of staying out in the sun for a long period of time and have no means of buying protective gear or sunscreen lotion. As said before, many die even before the age of 40. And one of the reasons that lead to early death is because of the lack of education they have about what albinism is.

"But if you are looking at the killings in the sense of attacks, you can say they are decreasing. But there is also the killings in the sense of skin cancer. This one kills so many people with albinism more than you can imagine. So with this, I can still say that the killings are unending. If we talk about the killings in the sense of survival, a lot of PWA have a very bad situation in life, and economically. Why? Because in a large perspective the community of PWA have poor education because of physical challenges that they have."

Tanzania is a country with many different religions but having a big number of either Christians or Muslims, religion was also pointed out to be an impact on the decreasing of PWA killings. It was further illustrated that it is easier for a PWA to conduct their business in a religious environment because people have enough faith to understand how different people are created than in places that people have no faith at all.

"Religion might be one of the influences that might be the reasons as to why these coastal regions have such progress. It might be true. Because if you look at the lake zone regions, many of the killings have happened there more than any other place. I have been told though I have yet to research, that more than 60% of people from the lake zone regions are neither Muslims nor Christians. In a large part, these coastal regions if a person is not a Muslim they are a Christian. So here you can also say that religion also plays a part." (Participant 13)

It was also drawn to attention about the difference of PWA who live in rural areas and those that live in urban areas. It came to be derived that PWA in villages have it tough than people in urban areas. This is because the voice of bringing awareness is mostly preached in towns and cities and very less in the village. So this creates a situation where people in the village still do not accept PWA for who they are and lack the understanding of albinism at large. This is also the reason why attack cases, as well as segregation, discrimination and isolation cases, are reported from the villages more than the towns. Two participants had the following to say;

"If you differentiate urban and rural areas, it's true that in urban areas there is an advancement a little a bit. Even if you divide Tanzania region-wise, you can say that the coastal regions and the northern regions meaning regions like Tanga, there is progress. There is an inclusion of its own kind. Don't ask me why but that's the reality that here at our region in Dar es Salaam, Tanga, Zanzibar you can establish a shop where you can sell things and people will buy. But in other regions, in a larger perspective, it is very hard. However, in the town areas PWA have opened up their shops and they are doing their businesses." (Participant 13)

"Right now that fear PWA in Tanzania have has lessened though it hasn't stopped because the killings haven't stopped. The killings are still going on and we still get news about them from different places. And even though the killings have lessened, the threats towards them from different people are still ongoing. But little by now, the situation of being uneasy has subsided. Here in Dar es Salaam, I have not heard of cases about killings on PWA, also in the Ilala Municipal. Such situations normally occur in interior places and villages." (Participant 7)

The Tanzania government is also using its power to make sure it brings awareness about PWA to the public. This has been done through the political arena where the president has appointed people with different disabilities which PWA are among them into his cabinet to hold different positions such as members of the parliament, ministries, diplomats, and ambassadors. This has painted a positive image to the public to understand that PWA have the ability to do great achievements like any other person.

"For instance in the arena of albinism, we have a Tanzanian Ambassador to the Federal Republic of Germany, who is representing Tanzania there. And I am told he is not only representing in Germany but also some other countries as well though he is based in Germany. This is a person with albinism, Dr. Abdallah Possi. This is a very positive portrait of persons with albinism that they can do anything normal, they can be trusted. Because this person has been trusted at the national level and he is there. So for the young generation, for parents having children with albinism, it's an encouragement that if such a person is presenting our country abroad, then persons with albinism can do A, B, C and D. We also have a solicitor general of the United Republic of Tanzania, this is Dr. Ally Possi, a sibling to the ambassador." (Participant 11)

Even though currently the malicious acts done to PWA in Tanzania have decreased, this has been opposite in countries such as Malawi. This can be attested by a report done by Amnesty International (2016), where the realization that the kidnappings, abductions, killings, and grave robberies by individuals and criminals gangs done towards PWA are abusing the human rights against PWA. 7,000 to 10,000 PWA in Malawi live in fear of losing their lives to criminal gangs who sometimes include even

close family members. The ones affected more in these atrocity acts are mostly women and children who above all are vulnerable to abductions and killings by these criminal gangs.

In a 2017 report done by UTSS in Kenya on "Kenyans with Albinism and Racial Discrimination," Jayne Waithera a Kenyan co-founder of an NGO called Positive Exposure and an activist explained that no matter her being a citizen of Kenya she still feels that it is not safe for a Kenyan living with albinism because of the malicious acts done to people with albinism. She said the following;

"You don't feel safe at all, you feel like a foreigner, I mean I'm a Kenyan citizen, but I don't feel entitled to a Kenyan, I feel like my life is at stake, as in I don't know how many more days I got to live. We die out of skin cancer but now I would rather die out of skin cancer rather than die in the hands of a witch doctor, you know? When you go to these urban areas, like Nairobi, Kisumu, Mombasa, it's so scary. See, these people have access to information and they know exactly what is happening in Tanzania (where demand for body parts is concentrated). See, they sell us for a lot of money, around \$25,000 to \$75,000 (USD), that's a lot of money. You walk on the street and somebody just points at you: "that's money!" I mean, "That's walking banknotes!"

# 3.1.3. Social Services Professionals' attitudes towards PWA

Attitude is a very small thing that makes a huge difference. So, the results from this theme are presented in a form of two types of attitudes that emerged from the analysis of the interviews from both the social services professionals and the volunteers who were persons with albinism. There are 4 basic kinds of attitudes; positive, negative, neutral and sikken attitudes. In this study, the researcher selected to use only the positive and negative attitudes.

#### 3.1.3.1. Positive attitudes

When the social services professionals and volunteers were asked to comment about their attitudes towards people with albinism, various positive themes emerged as presented in Figure 4 below:

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Figure 4: Social Services Professionals' positive attitudes towards PWA

Source: Researcher 2020

# • Acceptance

Showing acceptance to the PWA in the community was given many of the social services professionals. Most of them professed their acknowledgment of PWA, how they have come to understand them, accept them for who they are as normal people who also have rights, as well as accepting their needs, ideas and sharing them with others. One of the social services professional who is a PWA themselves also expressed their acceptance of being normal human beings. This is proven by some of the following responses:

"..... they are just like me and you. Actually, it has gotten to a point where I don't even like to see their albinism. They have just become like my friends like the ones I work with." (Participant 1)

"I look to them like they are normal people, they have all the rights like any other person. They have the right to work, right to live, right to vote, right to own properties." (Participant 6)

"My attitudes are that PWA are so much like all other people. They have their own opinions, good ideas and many other good things that we can share with them. Because when we are serving them, it doesn't mean we are the ones to decide everything for them, we listen to them first on what they need and what they think as we share ideas in what we have so that we can see how we can help them in dealing with the challenges they face." (Participant 8)

"We are fine. We are humans. They are fine. They have challenges that require attention. But in general, for me, I see them as humans." (Participant 14)

One participant being a person with albinism themselves expressed their attitude on accepting who they were and what attitudes other PWA should have in order to expect positive results from the communities they live in. This is confired as follows:

"It's me. They are my brothers, they are my sisters. I like them, I like myself. The only thing is that, if you want other people to love you or to like you, the first thing you have to do is to love yourself. If you protect yourself, people can protect you. If you love yourself, other people can love you. So, I love them. That is why I am committing my time and my humanity as well to going through the country undergoing advocacy works. I want them to be participatory and contributing members of society. That's what I am doing. I love them and I love myself." (Participant 13)

In a research done by Selepe (2007), it stated that not only peers but family members and relatives have an attitude of accepting those persons who have albinism and those with albinism feel the acceptance, as well as no doubts, are raised among them because they are never treated differently among themselves. She also explains that also many teachers have shown the students with albinism an attitude of acceptance, treating them very well and love them unconditionally. Selepe further expresses the negative

attitudes of some teachers not accepting some students with albinism hence being very harsh, rude and insensitive to them.

#### • Love and value

The majority of the participants expressed their love and value as their attitudes towards PWA especially after meeting them or working together with them. For some participants, with the love and value that they have over PWA, some even have anticipations for helping them with their problems. This is proven by the responses below:

"I love them and I want to find solutions to their problems." (Participant 2)

"They are human beings first and foremost. I respect, love and value persons with albinism." (Participant 3)

"PWA should be appreciated and valued like any other person. For example, a PWA can marry a person without albinism vice versa." (Participant 6)

"If you love yourself, other people can love you as well. So, I love them. That is why I am committing my time and my humanity as well to going through the country undergoing advocacy works. I want them to be participatory and contributing members of society. That's what I am doing. I love them and I love myself." (Participant 13)

One volunteer went further to explain how the attitudes of social services professionals have helped them to get different opportunities in their communities and how they would make sure they participate together with other people. This is attested by the following response:

"....when there is an issue that doesn't even concern the disabled, they would still want to put disabled people so that they would participate with the others. When opportunities arise they normally don't think twice about disabled people. "If I give this one a chance to participate here, I know s/he will be able to do it." So they normally engage us with different opportunities regularly.

For example; on the lighting of the Uhuru Torch –Torch of Freedom (Siku ya Mwenge) there was a group of PWA that participated because it was suggested by the social workers. So for that, I am thankful for such acts." (Volunteer 5)

# • Faith and belief

Some participants' positive attitudes towards PWA are having faith in their ability as normal people, that despite their skin challenges they still can do anything. One Participant's attitude towards PWA is the belief that they can change the differences that are in communities where people will one day not differentiate between a PWA and a person without albinism. This is attested by the responses below:

"My attitudes towards PWA is that first I know that they are people with disability but their disability is not that severe for them to not be able to work, to personally take care of oneself as well as acquire the basic needs. So, for me, my attitude towards PWA is that yes, they have a skin disability but they are still people that are able to work and they do work." (Participant 7)

"I have positive attitudes toward them. And among the group of people with disabilities, I'm working with, I don't consider them as disabled people. I just consider them as disabled people because of their skin challenge. At least they are competent and they are not much disabled comparing to other disabled people. For them at least they can walk, they can see regardless of the low vision but at least they can read and walk by themselves and they can do their chores." (Participant 9)

"My attitude is having the belief that one day PWA will live their lives freely and well like any other citizen that is in this country. And I also believe that they will come a day that the PWA will be happy with the devotion and efforts that we (TAS) started and those that started before us in helping PWA become recognized like other people that no difference can be seen between a PWA and a person without albinism. The community to see that a PWA is just like a normal person that can do everything like any other person and they can do

anything they want as well as participate in doing anything in the society without looking at the perspective that this is a PWA and that they can't do certain activities. I want to see that, and I believe that one day PWA in this country will live peacefully and have a better life than where we came from. I believe." (Participant 10)

"My attitude towards PWA, I can say that albinism is normal. I am not able to say it's good because I don't know the other side for persons without albinism but albinism is normal. And that PWA can do and serve the community, they can return something to their community. That's what I believe." (Participant 11)

Through observation, I personally saw how the social services professionals at TAS and UTSS receive PWA and how they behave towards them. Most of them had a friendly attitude towards PWA as it seems that they were comfortable with the social services professionals who were also PWA like them. Discussing their problems to the social services professionals was easily done because the social services professionals have shown them the attitude of accepting them for who they. Some of the PWA that reached the offices were those that had different problems. And because they feel very valued by the social services professionals, they feel free to express what their problems are.

# • Defense

To fight for someone else's rights is one form of defending them. This is an attitude that some participants have towards PWA. Many participants showed their acknowledgment about the rights that PWA should have and deserve like any other normal person. Another participant had used the defense mechanism for the PWA in that if empowered they can also do something to and for their communities as well as work like any other people. This is attested by the following responses:

"They are people who deserve all the basic rights just like any other human being." (Participant 4)

"I look to them like they are normal people, they have all the rights like any other person. They have the right to work, right to live, right to vote, right to own properties. PWA should be appreciated and valued like any other person. For example, a PWA can marry a person without albinism vice versa." (Participant 6)

"If these people are empowered, the environments are accessible, the environments are conducive they can work like any other persons. If at all they have the devices like the sun-screen lotion, their bodies are well covered, they are provided with sunglasses. Also if it is in schools the words and prints on blackboards are enlarged, and additional time during exams per the educational policy. With all these, PWA can be like any other person without albinism. The issue is not the disability, the issue is the accessibility of the environment, infrastructure to be accessible. If it's a computer or a laptop is it programmed to have large printing fonts? If it allows so, then he/she can be like any other person. That's my belief or attitude I can say." (Participant 12)

When a PWA is being insulted or put down in their community and they ask for help, many social services professionals come to their defense because they already understand the life challenges that PWA face. And to attest the truth about social services professionals defenses to PWA, one of the volunteers who is a PWA had the following to say:

"Most of the time defense from them comes when outside circle segregates and discriminates us they will stand with you and defend you no matter what."

(Volunteer 5)

#### Respect

Through observation from the researcher, many of the participants showed an attitude of respect towards PWA. While conducting the interviews, many of them showed their sensitivity towards the whole research topic as it was being about PWA. It is evident that not many kinds of research are conducted on this group. This is also attested to some of the following excerpts:

"I respect, love and value persons with albinism." (Participant 3)

According to Selepe (2007), teachers in South African schools especially special schools treat the students with albinism with respect because they appear to have been trained about people with albinism. They treat them like any other normal people.

In Malawi, this situation is the opposite. Through the report done by Amnesty International in 2016, it was proven that many PWA are disrespected by enduring verbal abuse, name-calling as well as insults due to their condition. This shows how PWA are treated as sub-human. Some women are even blamed for the condition of their children's albinism as they are told that they drank too much water while pregnant and that is what caused their children to lack melanin. Women with albinism or those that give birth to children with albinism tend to not only suffer the abuse and rejection by their husbands or fathers of their children, they also face the wrath of the family members and relatives who accuse them of either being curse or unfaithful.

# • Understanding

Every human being has their own needs, ideas, opinions, thoughts, and the likes. PWA also have the same as well as other more special needs. One of the participants responded about how it is important for the PWA to share their own opinions and ideas with the social services professionals. This is because, in order for the social services professionals to understand what they or how they want it, they should be able to speak up for themselves. This Participant had the attitude of understanding that no matter how you work as a social service professional, you should listen to those that you serve as this is attested as follows:

"They have their own opinions, good ideas and many other good things that we can share with them. Because when we are serving them, it doesn't mean we are the ones to decide everything for them, we listen to them first on what they need and what they think as we share ideas in what we have so that we can see how we can help them in dealing with the challenges they face." (Participant 8)

# • Helping hand and support

With the help PWA gets from the government and different stakeholders, some social services professionals still help them when they need help from them. In Tanzania, by introducing the free loan interest has been one way of the government helping people with disabilities. The participants help PWA through providing them with education about the government, emphasize them to participate and join different groups that will help them support themselves as well as giving them advice in any matter. This is attested by one of the social services professionals as follows:

"We also provide education for them and emphasize them to join different groups and associations. There are very many different associations for disabled people. If a person with albinism is needed or wants to join into these associations so that they can connect with other disabled people because in these groups is where they get different chances in order to support themselves." (Participant 8)

"The social workers give out education about what the government is doing and what disabled people are supposed to do. The social workers are like our speakers or microphones that help our problems to be heard. They also arrange different seminars for us in the communities." (Volunteer 5)

"Interacting with them (social services professionals) is very pleasant. They show so much support towards us (PWA)." (Volunteer 7)

"With some of the social service professionals that I have met have all shown different attitudes towards me. Some positive and some negative. On the positive side is that some have very good advice for me. For instance, some would advise me on different issues I have like getting a job." (Volunteer 8)

Social services professionals also uplift PWA by being a helping hand to their communities to show that PWA can also be involved in their communities in doing something. One of the volunteers mentioned that social services have been their speaker in supporting them even in their businesses as well as selecting them to

participate in huge events that would help and support them. This is proved by some of the following responses:

"The other thing that these social service professionals do for us is that when we need customers to buy our products they are the first ones to support us in buying them. They also become speakers in advertising our businesses to other people. They really do support us in this." (Volunteer 5)

"During big events like "IAAD – International Albinism Awareness Day" and "World Disability Day," the social welfare workers would normally select 3 – 4 PWA that they would sponsor through the budget of the municipal to go and participate during these important days. So each person can be guaranteed to get about 450,000 up to 500,000 for these trips. This includes a go and returns ticket as well as the allowances to use during this whole trip which might also be accommodation and everything else." (Volunteer 7)

Social services professionals have positively potrayed the positive attitudes towards PWA like accepting them for who they are, loving and valuing them, believing in them as well as respecting them. As explained before that most of these social services professionals are PWA themselves, so understanding is seen to be a very normal and positive attitude whereas some participants even used themselves as examples to explain more about what PWA face through the attitudes they portray.

# 3.1.3.2. Negative attitudes

When the social services professionals and volunteers were asked to comment about their attitudes towards people with albinism, none of the social services professionals had negative attitudes towards people with albinism. Many of the negative attitudes of social services professionals towards PWA were expressed by the PWA volunteers themselves. Various negative themes emerged as can be seen on Figure 5 below:

Figure 5: Social Services Professionals' negative attitudes towards PWA



Source: Researcher 2020

# Forgetfulness

It is hard to expect the people who are supposed to help and support you let you down in one way or another. Chatting with the volunteers, forgetfulness by the social services professionals toward them was one of the negative attitudes that was mentioned. One volunteer who expressed how some social services professionals show different attitudes towards them explained how they have a tendency of being forgetful with promises they give them. This is attested as follows:

# Fearfulness

Fearfulness means an act of being scared. A social service professional should not have fear as a trait. A social service professional should be ready to overcome anything that is a problem to the society they work with. Many of the volunteers mentioned fear being one of the negative attitudes that the social services professionals have especially those that are working in the government sector. Through the interviews, the volunteers expressed their disappointments about social workers not standing up for them when it becomes and involvement between them (PWA) and the higher government officers. This has caused many PWA to lose hope in asking for help from any social worker. The following excerpts attest on this:

".....for if you have a problem that concerns the director of social welfare that a social worker will stand to defend you? This is can never happen. You have to stand as who you are (a disabled person) and defend yourself. Because many times I see that when we want something and go to the social worker when they take our applications at the higher level and then get stuck, they come back and tell us to go and do it ourselves. They have no strength above their bosses so no matter what, they have to defend their side." (Volunteer 5)

"...when it comes to anything from the government which is the one that holds their jobs, there is no defense there for you." (Volunteer 10)

# • Lack of passion to help

When you lack the ability to have the characteristic of a social services professional this is called incompetence. Through the interviews that were taken with the PWA, incompetence of the social services professionals was mentioned as an attitude towards them. A volunteer explained this by pointing out that the social services professionals are not playing their roles as some still have negative attitudes towards. Social services professionals are doing their jobs just because they studied and not because they want to help others. They lack passion for helping PWA immediately whereas some of the problems taken by PWA to them are normally pushed aside or postponed to a later date. This is attested in the following excerpt:

"What I have seen so far about social welfare workers is that they work because they are forced to work. They don't work because it's their passion to be social workers. This is because, for instance, you (PWA) leave them with a case to help you, and they tell you to come the next day or any other day. When you go to get your answers, you realize that how you left that case is the same way you will find it. They do not work on helping you until you go there physically, even if it was a matter to talk to their director you will be forced to go and do it yourself. There is almost like 25% of them feeling the need to help you." (Volunteer 6)

#### Laziness

Some volunteers pointed out the attitude of social services professionals being lazy. This was elaborated more by those PWA who took their cases or problems to be helped by the social workers and they find that nothing was done at all. This becomes a burden to the PWA as they end up getting tired and their cases unsolved. They added that many times that they took their cases for help, they would take a longer period of time to be solved which is different from other groups of people without albinism. The following excerpts attest to this attitude:

"Most of the time, our (PWA) cases take a very long time for social workers to solve than any other people. The waiting period for them to solve our issues take a long period of time." (Volunteer 7)

"When you (PWA) have a problem and you go and see a social welfare officer, they take time to help you. They make you go around a circle which at the end of the day, you get tired and just leave. In a high percentage, if you follow up on what is done at the social welfare offices, there is nothing they are doing. It just seems that the social welfare offices are just there but they are not there 100% to help people. You go there and they do nothing to help you. For instance, you go there and they tell you to bring such documents, you might go back and they still tell you to bring other stuff. This becomes tiresome at the end of the day you just give up......" (Volunteer 4)

#### • Unhelpfulness

The concern about social workers not being helpful towards people with albinism appears to be mentioned as well. One volunteer further explained that this is mostly done by the governmental social services professionals who are even supposed to be representing the government in helping people but it is vice versa. Them not getting help from social services professionals has led to it becoming another challenge in their lives. This is attested as follows:

"The social workers not helping us has become a big challenge. Because as they represent the government, and when you take your problems to the government to believe that they will help you but you go there and all they tell you to do is write a letter where at the end of the day, the response you thought to get is very different." (Volunteer 1)

# Unfairness

This is an act of not treating people in an equal way. This attitude was pinpointed by one volunteer through their own experience with the governmental social services professionals. They elaborated about the unfairness they experience through getting different opportunities from the government or any other places. Many times, other people without albinism are given a go-ahead to something but when it is a person with albinism they are told otherwise. This is attested in the following excerpt:

"For example; before I got the job working as a gardener, I had written a letter under the TAS organization where I saw a potential place of finding a place to sell some boiled eggs near a hospital. It was a place that was on the corridor and there was no sun, which was a great opportunity for me. So I thought that if I can boil eggs and come and sell them here, I would get some profit out of it because the sun will not affect me so much. I went to the social welfare offices with a letter written by TAS. The results came that that area is not a safe place to allow anyone to do any business there. But, these recent days I passed through that same hospital and I saw two women selling samosa and the other

selling cooked bananas. And both women are women without albinism. So I asked myself if these social workers told me that this place is unauthorized to do any business here, why are these women selling here then? But I just had to let this topic go but I said I will do a follow-up but I don't have time. Sometimes, acts like this done by social workers, discourage people a lot. It seems that they give these positions with people they know." (Volunteer 9)

Unfairness towards PWA can also be pinpointed in the employment sector in Tanzania. Through the research that was done by Marcon (2013), it is found out that due to some beliefs about PWA they are always at a higher risk and disadvantage of getting employed because it is either the employers not wishing to contact them or the working environment is not suitable for them to work in. Sometimes, the lack of understanding of albinism plays a vital role in affecting PWA while seeking employment.

#### Pessimistic

The situation where a social service professional emphasizes more of a bad situation made an observation of pessimism. Through one interview, a Participant expressed about PWA being people that are always complaining about the government than considering what is happening to them as well as people that want attention when it comes to following procedures for instance about taking free interest loans. This is reflected by the following excerpts:

"You know if you give them a chance to speak, they only complain about the government. They cannot even tell you, "oh, my father did this and that, my neighbor did this and that." For them if you give them time to speak, you give them an opportunity it's just to complain about the government. "The government doesn't do this and this, the government doesn't give me this... Etc." They don't even analyze what is happening to them socially." (Participant 9)

"You know these people, as I told you before they need attention, they need to draw attention to everybody even to the person who is not responsible for them they want attention. If terms and conditions are there, and you don't want to follow them just because you are a PWA, is that how it is supposed to be

working? So for them, they just want attention even in places where attention is not supposed to be there, the terms and conditions are still supposed to be followed. The problem is with attention. They just want attention." (Participant 9)

These negative attitudes were mostly proven by the volunteers who were the PWA themselves, as many spoke from experiences of how social services professionals' attitudes have affected them. Many of the interviewed volunteers expressed social services professionals as people that should be a bridge in helping them but due to having lack of passion into helping them, forgetfulness, laziness, unhelpfulness, fearfulness and being pessimistic it has made many PWA to lose hope about social services professionals in standing with them and supporting them even on a daily basis.

# 3.1.4. Social Services Professionals' attitudes effect on PWA

On this subtheme, many of the social services professionals from both the governmental and NGOs responded with their own experiences on how their attitudes towards PWA has affected this group. Behaving positively towards someone will give out positive answers hence vice versa. As positive as many of the attitudes towards PWA mentioned above, social services professionals also expressed how these attitudes have affected the PWA.

#### Confidence

Many PWA after facing different challenges they become scared of facing their communities. For those who have undergone humiliating, discriminating, name-calling, or even isolation, it becomes a hard challenge to build back the comfortability of being a normal person in one's community. Through the presence of people to believe in them, to love and care for them like social services professionals, it brings back the normalcy of comfort in their lives. This is confirmed by the following:

"I think because I treat them like not so fragile, they are comfortable and they feel like they are not like people who just need so much attention. I think that has also helped the people that I have interacted with. It's because of how I am

close with them and I just treat them like a normal person, they take themselves to be normal people." (Participant 1)

#### • Pride

Through the social services professionals showing them the attitudes of accepting them for who they are, respecting, loving, understanding and giving value to them like other people, this has affected the PWA to realize that they are not alone as well as become proud of who they are as the following excerpt show:

"They have realized that not all people in society discriminate against them and that there are people who would go to any length to fight for their human rights. This has encouraged some of them and their families to be proud of who they are facing the community and educate them about albinism." (Participant 3)

#### • Build trust

Many PWA meet with social services professionals either in their offices or different celebrations like the "International Albinism Awareness Day." Through the help, they are given by the social services professionals many of them build trust towards them. Social workers through this gain a lot of respect from PWA as they tend to help them in facing their challenges. When working with people with albinism, many social workers create an environment where they feel safe to share and tell social workers anything. This is attested in the following:

"The many times I meet with them as a coordinator, be it at the celebrations or the municipal offices where they come and take these necessities and because I am among those that distribute these things to them, they become very trusting towards you as they also accept your positive attitudes towards them." (Participant 7)

# • Strength and courage

As a social service professional, you should know how to handle people in different situations. In Tanzania, social services professionals through their understanding of the PWA, have come to be people that also encourage them to overcome different challenges. One participant explained that the more they become close to PWA the more they believe that they are accepted in the community. They further added that through cooperating with PWA, it has been like giving them a voice to express their own ideas and opinions as to the following excerpt from a social service professional explains:

"Because I have been close to them in very many things that they do, through work, through getting advice and everything that we do together, they accept them positively. Cooperating with them has given them the strength to open up about wanting to do things together through the ideas that they have and what they want to do." (Participant 8)

#### • Education

A good example is UTSS. UTSS provides education for the students with albinism by sponsoring them with everything from kindergarten to university. Sometimes, they also train them for employment as well. This has affected many PWA, as many of them become educated while others get many employment opportunities. UTSS has given them an opportunity to see that they can also become someone in life and not just be vulnerable people. These effects can be attested as following:

"Yes, they have been affected. For instance, for those whom we serve, many are in school and there are those that are graduating from school. We are assisting them in looking for employment. At one time they have this mindset, "Oh, my God where am I going to start? Will I be able to penetrate the labor market? Will I really be employed?" And we tell them, "You can do." (Participant 11)

"We have a group of children to adults with albinism that are in school. We pay for everything; school fees, the supplies, and other necessities needed for school. They are more than 200 in all levels, from kindergarten to university. And then, education in the sense that we go to communities and educate them of what albinism is, what challenges it comes with it, how to solve those challenges and it has been working because if you look at the trend of attacks from the time that we started operating, UTSS started operating in 2008 until this time 2019 the reports have gone down." (Participant 14)

Individually, one participant proved on how their attitude has affected one of the people with albinism through the advice that they had given them. This is proven as follows:

"I can give you an actual example, a testimony from one young lady who completed a certificate course and was struggling. She did her certificate in Early Childhood Education. I personally advised her that while looking for a way forward, look for any school and try to volunteer as this is how you can build your personal confidence. But when you get that opportunity of volunteering, show the school community that you can regularly delivery. In 3 months of volunteering, she got a job contract. She is now an employee at that school. So I can say that my attitude is changing these people." (Participant 11)

# 3.1.5. Community's attitudes effects on the attitudes of Social Services Professionals towards PWA

When commenting about how much the community's attitudes have affected their attitudes towards PWA, many of the social services professionals reported having not being affected by the community's attitudes as many have seen them as normal people while others are bringing a positive image to the community about PWA. Thus for some other social services professionals, it has further made them become more firm to use their power in helping PWA face different challenges and to keep working with them as it is a duty of social services professional to easier the struggles of the people as well as protecting their well-being. This can be demonstrated in the following excerpts:

"No, not at all. Because I see them as normal people and some to which are now my friends." (Participant 1)

"Not at all. I cannot control their attitudes but I can find ways of getting a positive image to them about persons with albinism, raise awareness about the inherited condition and help them to change their perception about persons with albinism and regard them as normal human beings." (Participant 3)

"It has made me use more power to change their views about PWA and to put the Disability Act of 2010 into more actions." (Participant 4)

"Personally, the community's attitudes towards PWA has not affected me. I will continue to work with them, firstly because my profession doesn't need me chose which person to serve and which one not to serve. PWA will still get services from me, through advice, counseling, and encouragement for them to do better. For example; there are some who have come to me to ask for advice about getting loans from the municipal. We keep on pushing them and encouraging them as people from the disabled group to come together in getting these loans so that they open up their own businesses because these loans have no interest." (Participant 8)

"No, it has not affected me at all." (Participant 9)

Some participants who are social services professionals with albinism gave answers according to their own experience of how in the beginning, the community's attitudes towards them affected them so much that they used to feel negative about themselves. But the more they learned to accept themselves for who they are, the community's attitudes towards them no longer affect them negatively but strengthens them into becoming much stronger. This is shown in the following responses:

"I think I consider myself as a person who has a lot of knowledge about albinism now. And the negative community mindset is not affecting me negatively but builds me to become much stronger. Actually, what they say and their attitudes make me stronger because they say, "A, I want to prove that this

is not A it's B" so that is the kind of effect I can say I now have." (Participant 11)

"Before I got to work for this place, I got to mingle with other people with albinism every day and got to find this is normal you know other people's attitudes affected my attitude. You know, that feeling ashamed of yourself, feeling like inferior....you know the way they see you inferior you also feel inferior because you've grown up been treated that way and you get used to it. But when I came here, and started working with people like me and got to you know grew.... It's growing, you get used to it. You change. And right now whatever they think doesn't affect me. Because right now my target is to change what they think." (Participant 14)

# 3.1.6. Social Services Professionals' thoughts on how PWA should be treated

Living in an environment where you are seen as a different person always brings different thoughts from different people. Many PWA in Tanzania have either experienced discrimination, segregation, isolation, abuse, name-calling and so forth. To able to understand more of the attitudes of socials services professionals towards PWA, the researcher had to question their thoughts about how PWA should be treated. The majority of the participants reported that PWA should be treated as normal as other human beings, everyone should understand that as normal as they are they just have a different skin tone hence should be given first priority as they have more challenges than other disabled groups. This is proved by the following excerpts:

"They should just be treated normally. You know, albinism is a skin condition and when they have the right supplies when they have proper clothing (protective clothing) and sunscreen, they can be anyone and do anything. So we should just treat them like normal people and where you can help them." (Participant 1)

"I want everyone to change their attitudes so that they understand that PWA are no different from others." (Participant 2)

"As normal human beings and cater to their special needs." (Participant 3)

"They should be treated like any normal human being with all the human rights and should live happily in their own societies." (Participant 4)

"They need to be treated like anyone else, a human being as a normal human being. The only difference that they have is that they have pale (white) skin." (Participant 6)

"....they should be given the first priority. There are things that they should get more than any other group of people with disabilities because of the challenges they face." (Participant 7)

"First, they should be respected like any other person and they should be treated like any other person. This is how we often encourage people, they should not segregate, discriminate, or isolate them. PWA having the condition of albinism doesn't mean they aren't able to do anything better than a normal person." (Participant 8)

"PWA should be treated as normal as other people or human beings." (Participant 11)

"Like humans." (Participant 14)

One participant explained how they don't categorize PWA as people with disabilities because being disabled is not the problem but not getting the necessary supplies is what makes them vulnerable. Putting them in a category of disability is not out of their skin condition but because of poverty. This is shown as follows:

"To me, because I believe their disability is not a problem, it is a problem because of poverty, I can tell you that. Because if you find some of the developed countries they don't treat people with albinism as disabled people. So for us, especially I myself, I don't see them as disabled people because they are

mentally okay, they are physically okay except for their skin and their nature of genes which if they are treated or accommodated with their basic needs, you cannot call them disabled." (Participant 9)

Some of the participants expressed how PWA should be treated by pointing out that as normal as they should be treated, PWA as persons who have their rights as well. So, people should understand that PWA have human and basic rights as the following excerpts attest:

"Like other people who deserve all the basic rights as they do other people without albinism." (Participant 5)

"First and foremost they should look at them as any other human being. Because like Tanzania as a country, it has accepted to follow the rights of PWA, like the right to live, right to freedom, right to get an education, right to get health services and other social services are the main absolute rights for the PWA. Here in Tanzania, we are supposed to be taken as any human beings as well as a group of people with a disability just like any other group with disability." (Participant 10)

"They should be treated as normal as other citizens are treated. They deserve their rights, they deserve respect, and they deserve to participate in any aspect in the community and they should be included in everything in the community." (Participant 13)

Another participant expressed more about treating the PWA with equality. This is because as all human beings being created by God, everyone should be treated equally meaning given equal opportunities as well as inclusive policies to be administered in every sector in the communities. This is explained in the following response:

"They should be treated with equality. We are all equal, we are all created by God. And these differences, whether color or whichever is just variations and therefore people should be treated equally. Secondly, is that PWA should be given equal opportunities like any other person. Whether it's on employment, where they should be employed using the same qualifications and criteria. If

it's education, in schools, they should not have special schools for persons with albinism. We should have inclusive policies; our employment policies, health policies, education policies should address an inclusive system rather than exercising on a specialty. What I can say is that, IF in the community we have the inclusiveness or the inclusive policy, then they can feel themselves as part and parcel of the community. But if we have to keep on exercising special systems, they themselves feel stigmatized, isolated, being abandoned. Policies made should be inclusive policies." (Participant 12)

Wadula (2018), on their article "Treat people with albinism with utmost respect," narrates the significance of PWA in enjoying the same rights as normal South Africans under their constitution as well as receiving equal protection against hate speech, killings, discrimination, and other malicious acts. Wadula who is also a human rights activist for PWA and former chairman of the albinism society of South Africa further adds that not only do their communities need to put efforts to increase the awareness of the human rights for the PWA but to also understanding of albinism.

The Albino Foundation (2019), in Nigeria stated that because all people are born free and are equal to human rights and self-worth, then PWA deserve inclusion, freedom, and participation in enjoying everything like other people because they are human beings as well. They also think that the governments, organizations, civil society groups, media, and other individuals should help PWA in their communities in achieving their dreams and aspirations in consideration of their skin health challenges, low vision and the general stigma they normally experience.

# 3.1.7. Future of PWA in Tanzania

It is apparent that the Tanzanian government is trying to find ways to bring more acknowledgment about PWA. Through using social services professionals from the government or the NGOs who have helped in the protection, education, and raising awareness about PWA in the communities. This has brought social services professionals to understand to what direction is the PWA community heading. When asking about how they see the future of PWA in Tanzania, through their experience and their own observations as they have been working close to PWA, many of the participants had positive answers to where they expressed about the presence of the

changes towards PWA will eventually bring peace, hope, and happiness in their lives. They also expressed that due to some communities understanding more about PWA, stigmatization, discrimination and the likes are fought against, hence PWA living peacefully. This is confirmed in the following responses:

"The future is bright and full of hope and progress. I envisage a future where the public will have a more understanding of albinism from a tender age and a more positive public mindset about persons with albinism and all myths that fuel discrimination, stigma, and atrocities against persons with albinism. I see a future of an inclusive society at all levels and communities that continue to promote human rights for PWA and more engagement, participation, and involvement of more persons with albinism at all decision-making levels. I see a future of more visibility of persons with albinism who are taking their rightful places in the community who are role models for other persons with disabilities. I see a future of no discrimination and stigma against PWA." (Participant 3)

"As society continues to embrace and give them their rights such as health, education, right to life, and employment PWA will have a peaceful and happy life." (Participant 4)

"Their future will be very bright and good. Because they now have the freedom to do many things for their own; freedom to own their own properties, to get married. In future years, there wouldn't be any distinction between a person with albinism and a person without albinism." (Participant 6)

"I see it very bright. With more advocacy, now we see albinism in different levels, plus the international level, the United Nations has passed a resolution that has brought June 13<sup>th</sup> to be the International Albinism Awareness Day. This is to bring awareness all over the world about albinism.....Having the "International Albinism Awareness Day" has brought and captured attention to people in the community, to the government leaders and so forth." (Participant 11)

While responding to the question about the future of PWA in Tanzania, other participants expressed their thoughts about the capability and success of some PWA who have now become role models to the PWA themselves, as a way to motivate the other PWA in the country. Through citing these examples, they have shown their beliefs that PWA can do anything like any other person and be who they want to be if they are willing to work for it. In addition to this, they also expressed their thoughts about how the community should learn about PWA, encourage them, embrace them and accept them. This is evidenced in the following excerpts:

"I think with time the albinism stigma and discrimination will just be like something in history. I am hoping as time, people will understand more and more what albinism is because we also have more and more PWA who are rising and are doing great. You know we have the ex-Minister Abdallah Possy, now he is the Ambassador of Tanzania to Germany. We have musicians, we have artists who are people with albinism. So I think as time goes and people are kind of educated about albinism, I think albinism will be embraced in society. And that's only if the society learns about albinism because that's when they can accept them." (Participant 1)

"First of all, for their own future, if they (PWA) engage themselves so much with other people in different activities, if they also do many good things like parents taking their children with albinism to school should encourage them so much in studying, I believe they will come to hold big positions instead of the few that we currently have in power in the government." (Participant 8)

Few participants explained that through enough help from the government, international cooperation and NGOs, PWA will be noticed by their communities and they will live in a guarded environment where even their own communities will understand about their conditions as the following excerpts explain:

"A peaceful and happy life based on all the principles and rights. Also taking into account the implementation of the United Nations Convention on the Rights of Persons with Disabilities, which our country signed and ratified 2009 also the existence of People with Disabilities. Act 9 of 2010 as well as the National

Development Policy and People with Disabilities in 2004. All these guidelines lead the government to implement the benefit of people with disabilities in the country including PWA." (Participant 5)

"It is my hope that through the lives of PWA will help the Tanzanian community at large to understand more about us. Also, there will be a very precautious environment that would help in the wants and needs of the PWA here in the country. It's not now, or tomorrow but in the future as this process can take time as they are goals of a living strategy let's say 5 years to come. I believe that PWA will have the best in their lives after these changes are done." (Participant 10)

"If the current advocacy that we are doing continues, then I believe that one day this is going to be just history. Because it all goes into education. Everything that is wrong with society is because of belief, because of attitude and the only way you can change that is by educating someone getting them to understand that biology behind everything. So if they understand it and the belief system changes, then at least we are going to live in peace." (Participant 14)

One participant through the organization they work with believes that with a lot of effort PWA themselves they can build their own bright future if they become educated about themselves as to some do not understand their own condition. Not just the PWA, and also the public around them should be well educated enough to bring a future with positive changes because ignorance is among the knives that hurt PWA. This is shown in the following excerpt:

"A lot of work is needed to be done but I believe lives will change. Because in the year 2006 till around the middle of 2013 when UTSS was registered and started to work in educating the public, the situation was very bad. But as days go by there are changes. The biggest concern was people being illiterate. Many people didn't know what albinism is and others used to think it was a curse or someone has put a spell on them. All these presumptions have been on people's heads for a very long time. But after the work that UTSS is doing now, even if you go to the villages and ask almost 10 people about albinism at least 2-3

know something about albinism. So if they understand, there wouldn't be parents that will abandon their children 100%. Maybe in that 100%, you might just find 3 – 4. There wouldn't be, for example, problems with skin cancer because the doctors are there. The problem is that they have not committed resources meaning they themselves, have not committed to solving the problem. If education will be provided and people will take effort, these problems will finish. Stigmatization and discrimination will not disappear completely but it won't reach that stage of killing or murdering each other or even reaches a stage where you are qualified for them to not give you a job. That won't happen. Even though with the sudden silence that we have now, there is still a lot of work to be done in Tanzania." (Participant 13)

One participant had a very different but sensible response towards the future of PWA in Tanzania. They pointed out that because of how the PWA perceive themselves as weak, disabled and people who need special attention and care they lead themselves to their own failure as this mentality slows them down in upgrading themselves. The weak spirit they have about themselves, how they do not trust in themselves as well as their mentality of waiting for the government to help them with everything is crumbling their future down. They go on and explain that without PWA changing themselves, will create a problem with their future as the following is explained:

"Mmh, probably it might be a problem. Because they are still identifying themselves as people in need, people who want special attention and special care. That is the problem. They don't want to treat themselves as they are physically fit where they can do their works and they can sustain their lives as themselves and that is the big problem with people with disabilities. They don't trust themselves and even if they trust themselves they still take that advantage of disability to sit down. For instance, there is a company that requested for the people with disabilities to employ them, to give them some amount of money for the first week at least till the second week. For the first and second week, it was some kind of orientation and other things. I am telling you, these people went there and saw that the money was very less as it was just 5,000/= or 10,000/=. They just ran away and left the job. The spirit of begging, the spirit of

identifying themselves as people with special need and special attention is killing these people. Not because they are not competent no, not because they are mentally okay, it's their mindsets "we are disabled people. We deserve this and this from the government, or from anybody maybe a stakeholder needs to see us we are disabled we need special attention." This is in their mindsets. Even if you give them capital, you tell them to come and collect free interest loans from the municipal funds, I am telling you they won't come. Even if they try to come, expect lies, expect defaults, expect everything." (Participant 9)

# **Conclusion**

In concluding to the findings of this theme where the main purpose was to investigate the attitudes of social service professionals towards PWA, on how these attitudes have affected PWA, community's attitudes effects on the attitudes of social services professionals, through their understanding of PWA, the current situation of PWA in Tanzania, thoughts on how PWA should be treated and the future of PWA in Tanzania.

It has come to the researcher's conclusion that not many of the social services professionals in Tanzania are professionally trained to handle PWA or even understand the condition. Many of them come to grasp the whole knowledge about albinism after they have interacted or worked with them. The same goes to PWA themselves. Many of them do not understand their condition while others think that God has reasons to create them the way they are hence not looking for any information about their albinism condition. Social services professionals have shown the eagerness to help protect and promote the rights of PWA because they are wholeheartedly committed in their roles as change-makers in their communities.

Looking at the current situations of PWA in Tanzania, many of the social services professionals expressed their sorrows about how the past few years have been cruel and unjust to the PWA as they have suffered either through killings, abduction, stigmatization, discrimination and even mutilations. This has also triggered the social services professionals to be more passionate and extreme using education and advocacy to bring awareness to the public about PWA. The Tanzanian government has also played its role in placing harsh laws and punishments on the perpetrators that do

malicious acts to PWA. Social services professionals further explained that with the help of the government, a larger number of the malicious acts done to PWA has decreased as different forces were used; religion is one of the key allies in encouraging the communities to love their neighbors as they love themselves hence promoting love, peace, and unity in Tanzania.

This can reflect on how well social services professionals have also displayed their attitudes towards PWA where the positive attitudes have overshadowed the negative ones. Many of them have shown respect, acceptance, understanding, love, and value towards the PWA because they have come to understand that as social services professionals, it is their duty to act or show examples to the societies they live in. Displaying positive attitudes towards PWA reflects this to community members whereas they tend to copy or listen to what the social services professionals are doing hence the widespread of community members accepting and living peacefully with PWA were at the end of the day they begin to see them as their fellow human beings.

Lund et al. (2010) explained that positive and negative attitudes towards PWA can considerably influence their life experiences. Social services professionals displaying negative attitudes such as fearfulness, laziness, unfairness, forgetfulness and the lack of passion to help PWA has brought the PWA to be scared and give up hope in asking for help from these professionals. It has even brought mistrust towards the government as some of the PWA interviewed expressed their lack of believing in the government because the social services professionals were reluctant to help them in their daily problems.

PWA gaining confidence, pride, courage, and strength were few effects that the social services professionals explained that were caused by their attitudes towards them. In the research, the social services professionals explained that with the positive attitudes they portray towards PWA, the PWA have been more open to speaking up for themselves and it has brought them to see that they have people to lean on to when they have problems. This was initiated with the social services professionals confessing that the community member's attitudes towards PWA have not made them look at the PWA lesser than other human beings but to be closer to them as it is their duty to protect them and their rights as humans.

Social services professionals conveyed the importance of the PWA to be treated equally and as normal as any other human being. Because no matter what skin tone PWA have they are still human beings and they are bound to have their human rights respected. Treating PWA with respect and equality also helps in boosting the self-confidence and belief in themselves hence bringing them to intermingle and be open towards other members of the communities they live in.

For the future of PWA, social services professionals expressed that Tanzania is already turning on a new leaf in protecting and supporting the human rights of PWA. With this, communities have become more open and understanding about PWA whereas acts like name-calling, stigmatization, discrimination and the likes are fought against, hence PWA living peacefully. PWA are recommended to put themselves out there and shine to be role models in their own communities. This will help to bring out other PWA who are afraid of accepting and showing who they are to themselves and their own societies. Through someone's attitudes, albinism can have a remarkable influence on a PWA whereas these influences can differ from persons to persons and at a very different stage in life. So, this can explain how important the attitudes of social services professionals can bring an impact to this vulnerable group.

# 3.2. FINDINGS ON THE ROLES PLAYED BY SOCIAL SERVICES PROFESSIONALS TOWARDS PWA

Within this theme, the foremost purpose was to investigate the roles played by social services professionals towards PWA. Understanding how a person's attitude can reflect on how they work, the researcher had to investigate the roles played by the social services professionals towards PWA. In positions to finding the answers, the subthemes included: individual roles played social services professionals towards PWA, understanding the roles of the Tanzanian government, and the NGOs towards supporting PWA, Tanzanian government support towards social services professionals who are involved in helping PWA, roles of PWA in changing their society's attitudes towards them and lastly what to be done to improve the social life of PWA in Tanzania will altogether be discussed. In this research, the individual roles were roles played by social services professionals at a more personal level where not only in office but out of office where through the roles they play can reflect on their attitudes towards PWA. Due to the fact that Tanzanian government does not interfere with the NGOs activities, I decided to have two subthemes that showed the roles played by both the government and NGOs to understand the roles played by social services professionals have mirrored with their attitudes towards PWA.

# 3.2.1. Individual Roles played by Social Services Professionals towards PWA

Most of the social services professionals that were interviewed have worked either in the government sector or in an NGO for more than one year and some even 20 years with PWA. So, through their own time, apart from their roles in their offices, the researcher wanted to understand the roles they play personally/individually towards helping PWA at any given time. It is sometimes important to remove your office attire and be a normal person for someone else to feel free to communicate with you. Sometimes, you even get more ideas, opinions, and thoughts being you than being a social services professional. Through this, PWA feel that they are not alone hence them having the strength to succeed and feel their importance in their own communities. Most of social services professionals acknowledged the different roles they play in helping PWA in their communities through cooperation, working together with them,

being a reliable arm towards their needs, interacting and creating a network with them as the following responses demonstrate:

"For example; one person I'm very close too, she took part in our Mr. and Miss Albinism East Africa Beauty pageant (Khadija). I have been collaborating with her on her projects and we have been talking you know, I have some relationship with them. She has now started her own organization called "The Nation" and I'm seeing how I can support her." (Participant 1)

"A reliable arm." (Participant 2)

"Out of my profession, the role that I have towards them first is to interact with them and create a network that will help them and me because they might know something better than me." (Participant 8)

"For example; I have set myself to every year to provide or give back to others. May it be in education, healthy wise also those who want to travel from one far away from the city to another just to get health services. I am bound to share it with others as it means that I have returned what God gave me. I try and involve my fellow PWA for them to understand that they can do it too." (Participant 10)

"I normally interact with them so much. Even before coming to work here, I used to go to an organization called Tanzania Albinism Society (TAS). I worked with them for many years, I have talked to them so much, I have shown them examples, and I have persuaded them so much as well. Because others do not believe that you can study. So when they see you studying, they see that it is a possibility." (Participant 13)

On the other side, some of these social services professionals, continue with their professional roles but they still implement them in their communities with more emphasize. Some of the social services professionals that work in the government elaborated their roles to PWA by ensuring that laws and basic rights are followed,

advocated, and implemented in their communities from the grassroots levels. This is captured in the following quotes:

"I ensure that laws, guidelines, and procedures for serving people with albinism are implemented in regional administration and local government authorities." (Participant 4)

"To ensure that their basic rights are being implemented. To continue to educate the community to avoid brutal acts against people with albinism, to stop stigmatization and exclusion towards people with albinism, and social inclusion in every activity done in the community. To ensure that their needs are available, as well as educating people with albinism themselves about skin cancer." (Participant 5)

#### Another participant from an NGO explained:

"I advocate for their rights. This group of PWA are of 2 groups; the educated ones that have jobs and those that are uneducated and have no jobs. I make sure those that uneducated have a chance to get good jobs through the advocacy that I do. I do media tours to advocate their rights as PWA." (Participant 12)

Two participants also reported about how they feel a responsibility in defending and helping PWA at all times. This is because they understand the challenges that they face and for a PWA, help might be needed at any time. This is attested in the following responses:

"I have a responsibility to defend them whenever I see any unfairness or violent attacks done toward them. I am ready to defend them at any time." (Participant 6)

".....whenever I meet with a person who is disabled and they need help, I normally try in all my power to help that person because I know what challenges or limitations that they face." (Participant 7)

Another participant uses encouragement as their major role. Through an example of a challenge of low vision, they have targeted the young group in encouraging them to go

to school as education is important to them. They also share success stories to uplift the younger generations of PWA to understand that no matter what challenges they face they can still overcome it and become successful in their communities. This is proved in the following:

"My major role is an encouragement, exposing the reality to persons with albinism, sharing successful stories but also sharing how to overcome the challenges that they are challenges we can't avoid like low vision. This is a major challenge especially for the young generation who are going to school. Growing up with low vision has its problems especially in a country where you don't have many people understanding what low vision really is and how it can block someone. They have to know it is there and they have to know the mechanism of how to overcome it." (Participant 11)

In most of the Tanzanian societies, many people do not believe in psychological treatment after a person undergoes a traumatic experience. Many of them are even scared for a third party like social services professionals to know about their business hence solve everything like a family problem. With the lack of proper psychological support that the majority of PWA face, many of them are traumatized by the different encounters they face daily. One of the participants expressed their role of providing psychological support as well as investigating the atrocities against the PWA as follows:

"Investigating atrocities against persons with albinism, root causes of the attacks and also providing psychosocial support for persons with albinism, their families and communities surrounding them." (Participant 3)

On participant who is also a PWA expressed their role as a person that has invested in sharing with his fellow PWA. They elaborated more about how it is important for them to give back as for what they have been blessed with is like returning a favor to God. This is also because they want the other PWA to not feel abandoned or neglected by their fellow PWA who are successful in life. So, in many of their activities, they try to involve as many PWA as possible in order for them to understand that they can succeed as well. This is reflected in the following statement:

"Like personally, whatever I have, whatever God has given me, I am bound to share it with others as it means that I have returned what God gave me. This also creates a good feeling not just to me but to the PWA that I help. They feel that they are not alone and they can see the services we provide to them as helpful ones." (Participant 10)

### 3.2.2. Roles played by Institutions towards helping PWA

The NGOs and stakeholders that were involved in this research are UTSS, TAS, Brigitte Alfred Foundation as well as the Embassy of Turkey in Tanzania. All these have worked with PWA for more than 10 years while others since after independence. In order for their works to reflect their attitudes, social services professionals should play their roles effortlessly when helping PWA. Through their dedication to the roles they play, many of them tend to give out positive attitudes and feelings. The following are the roles played by social services professionals from NGOs and other stakeholders towards helping PWA:

#### 3.2.2.1 Promoting education and advocacy

Many of the participants emphasized how education is important for not just the PWA themselves but the whole community as well. This is done through debates, meetings, concerts, print and electronic media and seminars. Participants acknowledged that promoting education and advocacy is one of the best ways to promoting the rights and wellbeing of PWA, eradicate the bad beliefs about PWA, and also spread awareness about albinism in Tanzania. This is attested in the following quotes:

"Promoting the rights and wellbeing of PWA via education and advocacy."

(Participant 3)

"The biggest job that we (TAS) have is to continue with making the community understand more about PWA through different ways like debates, meetings, and concerts. The organization is greatly involved in skin health, education and bringing awareness to the society. It is in the hope of TAS that through all this, even the discrimination and stigmatization that takes place in the society will be eradicated as people will become more aware of what albinism is as well as who are PWA Apart from that, we have educational programs where we go to

different places especially in the districts and the regions to educate them all about albinism." (Participant 10)

"Advocacy is changing people's mindsets and it's done through different methodologies like the presence of face-to-face meetings, public seminars also we use print media, electronic media on reaching the communities. There are also the outreach programs to reach the villages for the villagers, in schools for students and so forth." (Participant 11)

"Advocacy here means, educating the public about albinism because some people don't believe that you can study, enter a class, learn and understand." (Participant 13)

One participant from the UTSS organization had the following to explain how through their promotion in education has impacted the changes in the societies they have met:

"And then, education in the sense that we go to communities and educate them of what albinism is, what challenges it comes with it, how to solve those challenges and it has been working because if you look at the trend of attacks from the time that we started operating, UTSS started operating in 2008 until this time 2019 the reports have gone down. And when you go to those areas that in which the reports were intense they've gone down. So we know that the efforts that we've been putting in educating the society are paying off. It's not like they no longer happen, attacks happen but not at that pace." (Participant 14)

The education and advocacy provided by these social services professionals are able to uplift the hunger to overcome challenges to the PWA as well as show the public about how it is acceptable to be a PWA. Through education, UTSS sponsors students with albinism with the aim of making role models out of themselves. If you have a lot of role models with albinism in a community, it would be educating the community that even PWA can do well as any other person without albinism. Also, with education, comes employment. Promoting education molds and prepares PWA for their future in getting any employment they want. This was evident in the following excerpts:

"And in education, actually they are about 400 and something beneficiaries of the education fund in different levels of education. This was designed in order to create role models with albinism. But again, in order to enable the community to understand or come to know that when a child with albinism is in school, what kind of support can be provided and have room to compare." (Participant 11)

"Advocacy, public awareness and education sponsorship where they give them the opportunity to go to school and learn so that to be an example or role model that they can do what other people can do and make something out of themselves." (Participant 12)

"The biggest role we do here at UTSS is advocacy. Though I can say education is the first role. I mean education by advocacy, as well as education by sponsoring students with albinism to study in qualified schools and universities.......So we have made a small sample of students where we put them to school, we provide them with everything to remove the challenges they face in class. It has been seen that they can study and they can also perform very well like other students getting grade 1. To be totally honest they are doing very well." (Participant 13)

Promotion of education and advocacy is not just to the PWA and the public, but also the government itself and other professionals that work together with the PWA. Through making them understand the needs of PWA, they are able to work with them accordingly. Educating the government and other professionals about PWA, benefits their standard ways of living and it makes it easier for them to have people that understand more about their conditions and needs. It is pleasant to have people that understand them when they go to hospitals, health clinics, schools, and areas of employment in order to not face rejection, discrimination, and stigmatization. Many of these social services professionals in these organizations interviewed were mostly PWA. So they were speaking through experiences for what needs are to be catered in order to properly help their fellow PWA through education. These were proved in the following excerpts:

"We facilitate training on safety and security for PWA for the social welfare officers at the Council level...... Capacity building to councils through social welfare officers on various service delivery guidelines towards PWA which include the law and contracts." (Participant 5)

"TAS has encouraged the government to create a law like that of the Disability Act (9) in 2010 which should explain the needs of PWA more openly especially in schools. For instance, when going to school they are allowed to wear long trousers, long-sleeved shirts and wide-brimmed hats from the protection of the sun. The government has already issued an act in schools for teachers to make sure that students with albinism are wearing the necessary protective gear for their skin when they are either in school or universities. Even during examinations, students with albinism are given their own special colored examination papers that do not cause their eyes to hurt no matter how long they look at them during the whole exam period." (Participant 10)

"UTSS not only educates the government social workers but also doctors, nurses, midwives, teachers, students in schools everywhere in every place." (Participant 11)

"The government should learn about the challenges that the PWA face in class. This is also a job that UTSS does with assistance from the Ministry of Education. We have created a guidance where the first editorial/article is already out. And right now the second one is almost coming out. If the government understands this very well, I am without a doubt that they will make students with albinism come to school and enter classes in the inclusive education where they will study and pass very well." (Participant 13)

In 2016, a United Nations Independent Expert PWA formed a consultative forum which produced an outcome report on "Action on Albinism in Africa," whereby educating the public on the medical condition of albinism was mentioned to be one of the preventive measures. The main actors to make this action happen were listed to be the government, NGOs, academics, intergovernmental organizations, and the

international community. Education of PWA together with their families and community, educating and using traditional leaders and local practitioners to spread information on albinism, the use of media especially television advertisements for educating the public and the showcasing of successful PWA as role models for the public were few measures that were mentioned to help in conveying the message of education about PWA.

According to Burke et al. (2014) in order to support their advocacy purposes, some NGOs in Tanzania have been documenting cases of attacks and the killings in Tanzania and other African countries. A good example mentioned was UTSS. This NGO produced a film called "White and Black: Crimes of Color" for the purpose of educating the public about albinism.

In the Amnesty International 2016 report done in Malawi, it confirms that through organizations such as the Association for Persons with Albinism Malawi (APAM) and the Federation of Disability Organizations in Malawi (FEDOMA), English and vernacular booklets about albinism are provided and distributed to people across the country for the main purpose of educating and raising awareness about this condition.

An Annual Activity report done by UTSS (2018), declared their use of social media to promote education and online advocacy. They have two accounts on Facebook going by Under The Same Sun and *HAKI YETU* (Swahili word meaning OUR RIGHT). An Instagram account @utsstz is also available in educating the public about matters related to albinism as well as different projects they do. Leaflets, DVDs about albinism, UTSS bags, and long-sleeved white shirts are distributed to the public to ensure enough publicity about albinism.

### 3.2.2.2. Promoting empowerment

One participant from the BAF pointed out empowerment as the biggest role they play in helping PWA. They promote empowerment through a unique holding beauty pageants for PWA. Many PWA hide behind their masks of make-up, wigs, sunglasses and the likes. For them to feel comfortable in their own skins, for them to accept that they are also beautiful, for them to accept their conditions and challenges, BAF organizes beauty pageants to empower them. This is proved in the following quote:

"One of them is empowerment. That's why we have pageants like the Mr. & Miss Albinism. You know those are unique ways that have an impact and we are trying to make more and more of our programs and projects along those lines whereby it's something different that people are not doing and it's something that has an impact. So I would say, our largest probably contribution has been towards empowerment and also advocacy and showing people that albinism is something to be accepted. That I can say for sure is something we have contributed." (Participant 1)

In 2018, on her blog called "Albinism in Africa," Baker wrote about how PWA are empowered in Zimbabwe. A project was launched by the Buhera District Association for Persons with Albinism in the district to create opportunities for PWA to practice activities like dressmaking. The project's main purpose is to empower the PWA to strive for equal treatment and opportunities in their own society. A Miss Albinism beauty pageant was also hosted for the purpose to empower women living with albinism in Zimbabwe hence reducing misconceptions and stigma about albinism in the country.

# 3.2.2.3. Influencing the government, other organizations and stakeholders to help PWA

Another major role that these organizations face is influencing others into helping PWA. Social services professionals in these organizations fight tooth and nail to try and make things possible for PWA. When you make life easier for the PWA, it helps to improve their standards of living. Through the influence that they do, some changes occur at a slower pace or immediately. These changes have occurred in the health and education sector. This following excerpt is for the health sector:

"This sunscreen cream, one bottle of oil is almost from Tshs 30,000/= to Tshs 50,000/= which is \$13 - \$22. TAS is influencing the government to be making orders as an important medicine and importing for the PWA to use. If PWA do not get this special type of oil, it means that in Tanzania, only those capable of affording this sunscreen are the ones who are able to buy it. The PWA that can't buy are either going to lose their lives at a very young stage or even sudden

deaths. TAS consulted with the government who took a step with MSD – Medical Stores Department with the help of bringing the medical tubes that help in skin health for the PWA against sunlight." (Participant 10)

For the education sector, UTSS collaborated together with the United Nations Children's Fund (UNICEF) to bring a guide for teachers that will assist them to help students with low vision and albinism in schools. This is proven by the following response:

"....UTSS had an idea that maybe we should come up with a document to help teachers who have not gone to the special needs schools, to know how they can take care of children with albinism. And this idea was taken to UNICEF, and UNICEF said it was an incredible idea that we can assist not only persons with albinism but also those children with low vision, they don't have albinism but they have low vision. And so the collaboration came up with a guide for teachers. So the government took the document and made it a public document." (Participant 11)

## 3.2.2.4. Material support

The most important necessities for a PWA are sunscreen lotion, a wide-brimmed hat, sunglasses and protective gear like long-sleeved clothes. Many of the organizations often give these necessities to PWA for free. During the interviews, it was noted that the sunscreen lotions are normally very expensive for the PWA who are in a lower class to buy every after 3-4 months. So it was decided upon the government and other organizations to be freely providing them. This is attested in the following:

"We provide auxiliary materials such as broad hats (wide-brimmed), sunscreen lotion, sunglasses for children with albinism, groups, and individuals in different centers." (Participant 5)

The Embassy of Turkey in Tanzania are among the stakeholders that play a role in providing the material support and other kinds of support to the PWA. This is attested in the following quote:

"At the moment, we are covering their wounds by providing them with the necessary necessities like skin cream, hat, work, health treatment as well as trying to help them in the field of education. We are conducting special projects to ensure their self-confidence." (Participant 2)

In 2009, on an interview with Voice of America (VOA) the general secretary of the Albino Association of Malawi spoke about how a project of providing free sunscreen ointment created by the Netherlands-based charity called the African Albinos Foundation was making a difference in most of the rural areas in Southern Malawi. It difficult or unbearable for most PWA who live in rural areas to afford to buy a bottle of sunscreen lotion.

Raising Malawi, an organization founded by the American pop star Madonna was also mentioned to be one among the NGOs that help the underprivileged group especially the PWA in Malawi. They provide PWA with items like long-sleeved shirts, sunhats, and sunglasses to protect themselves against the sun making it an easier and possible way for children with albinism to go to school (Voice of America, 2009).

### 3.2.2.5. Psychological support

In Tanzania, many PWA face trauma in their lives. Be it from their communities or just from stories about other PWA. It is not a common thing to find people seeking treatment from a psychologist, therapist, psychiatrist or even a counselor. So because of this habit, many of PWA suffer from the traumatic expresses they encounter. One of the major roles played by UTSS is to bring a psychologist to help the PWA who are dealing with trauma. This can be demonstrated in the following passage:

"Almost all PWA are suffering and living with trauma. They are traumatized because of what is practiced in the community; being discriminated against, been called names and so forth. These lead them to have different kinds of trauma. And now for three years since 2017, there has been a doctor a psychologist who is Dr. George Rhoades from Hawaii who has volunteered to come and actually teach people about how to conduct and deal with trauma, how to do trauma counseling especially for traumatized persons with albinism. The psychologist is brought to Tanzania from Hawaii by UTSS to hold different

training courses. And now, in these training courses, among the people who are trained are social workers, not all from the country but are spotted from different regions in different places where we have been working especially the lake zones." (Participant 11)

#### 3.2.2.6. Promoting skin health

It is evident that many of the PWA die before the age of 40 and skin cancer is mentioned as one of the main cause. Because of this, the government of Tanzania has administered PWA to get free skin checkups. TAS as an organization has based its offices at the Ocean Road Cancer Institute whereby every Thursday is a skin clinic day for PWA. PWA who go there are offered treatment for their skin as well as educated about how to overcome different challenges to prevent them from getting cancer. This is encapsulated in the following:

"The organization is greatly involved in skin health, education and bringing awareness to the society....... For example; here at TAS every Thursday of the week we have a skin clinic where many PWA come to check their skin in order to prevent them from early skin cancer." (Participant 10)

The roles played by the social services professionals towards PWA reflect on their attitudes whereas it has played a part in bringing out positive outcomes like in the education sector where an act was passed to benefit students with albinism in schools and universities. Not only that, but due to the determinations and attitudes of social services professionals towards helping and supporting PWA, they have involved other national and international bodies like UNICEF into promoting education as well as the health sector.

## 3.2.3. Roles played by the Government towards helping PWA

Ever since the massive killings of PWA occurred as well as other immoral acts done towards them, the Tanzanian government has taken very many steps to prevent any repetition of such cruel acts against them. These can be attested by some of the following roles they have played through their use of social services professionals.

#### 3.2.3.1. Promoting peace and security

It is always important for a country to have peace. After the PWA attacks, the Tanzanian government put its foot down and decided to use different methods to promote peace and provide enough security for the PWA. The effort that was immediately put forward was putting harsh laws and punishments for perpetrators that were caught doing atrocity acts like witchdoctors towards PWA. This can be explained in the following:

"The government has really put some effort into helping PWA especially during the times when the violence attacks happened. The government put the harsh laws in punishments for those who were involved in those attacks. This was especially to the witchdoctors who were the main perpetrators that lead people into harvesting the PWA's body parts." (Participant 6)

"The government is actually the father of everyone in this country. And number one is security-wise, as you can see now the situation we don't hear much of what happened in the years of 2013, 2014 and 2016. So this implies that the government is doing its part in ensuring that security measures are observed. But again, to those who were attacked in some situations, their attackers were caught and those people were taken to court. There are some cases that have been judged and the attackers have also received their punishments. So this is also how the government is supporting people with albinism." (Participant 11)

An editorial done by Moretti (2019) on the Inside Over website, "The Albinos Born with Targets on Their Heads" further explained that due to the increase of PWA attacks in 2015, the government of Tanzania started to require traditional healers to have a legal government license. Owning a license from the government would maintain them to continue working with herbal medicines yet those witch doctors that use human body parts were completely banned. This shows the role played by the Tanzania government in protecting the PWA against witch doctors.

In a European Parliament resolution of 2016 on the "Situations of PWA in Africa, notably in Malawi," affirms that in 2015 the government of Malawi introduced the Malawian National Response Plan where its major aims were education, raise

awareness and reporting, intensification of internal security, improve human rights observation, supervision in justice and victim support in addition to empowering or endowing PWA.

One participant, a government official explained more of a technical measure that the Tanzanian government has taken to promote security to PWA. A hotline specifically for PWA has been created for them to call at any time they feel that they are in a dangerous situation. This is shown in the following quote:

"The Tanzanian government has now put down different measures to protect PWA. For example, there is a telephone number where PWA can call or use anytime they see or feel any suspicious act against them. This is mostly done by the police force where they have put their own network because of just protecting PWA. So whenever a PWA feels unsafe in any environment, they call through this number and they are able to get fast help or assistance." (Participant 7)

One participant from UTSS added on how the changes done by the government to bring peace and security for PWA:

"Of course the government is trying to have friendly policies, friendly laws, and security. As you can see now the number of attacks has decreased from one day to the next. Also, the government has ensured that those perpetrators are punished effectively and accordingly. So, the government is doing its best. I can say that the support the government is giving PWA is enough or not but with this regime, the Magufuli regime is trying very much. That's why I can say, even just appointing PWA as part of his cabinet members, members of parliament, judiciary, diplomatic missions, decision making organs is one of the ways forward to show its involvement with PWA to its best." (Participant 12)

## 3.2.3.2. Collaborating with NGOs

Many NGOs in Tanzania have very little to do with the government. Each NGO has its own duties and the government does not interfere as long as they do not break the law. Due to this, it is prominent that the government has its own roles so as the NGOs. But that does not deter the fact that they still cooperate with each other in order to bring

development in a country. Governmental social workers have a role to work with NGOs who work with special groups like PWA as this is evidenced as follows:

"We don't really work with the government but we interact with the government social workers because you can't actually do something without them. If you are doing a project you usually need a social worker from the government to oversee what you are doing." (Participant 1)

On the other hand, in order to help PWA, the social services professionals from the government work together with different NGOs. This was proven by a social worker who works at a municipal in Dar es Salaam:

"We work together with different sponsors or NGOs that want to distribute essential products like sunscreen lotions and the wild brimmed hats to the PWA in Ilala. They normally would bring them at the office and we fairly distribute to the PWA here at our municipal. One of these NGOs that we work with is TAS. Normally when things are brought directly to us, oftentimes we send them to TAS so that they can distribute them. Sometimes, we go and supervise the action in order to see that it has reached the intended person." (Participant 6)

Social services professionals also link PWA with different stakeholders to support them in different activities as mentioned in the following excerpt:

".....and we link them with different stakeholders who sometimes support them in attending different celebrations that they have to celebrate like the "International Albinism Awareness Day." (Participant 8)

## 3.2.3.3. Economical support

Most of the governmental social services professionals attested to the presence of free interest loans that are specifically for disabled group in which PWA are also within this group. These loans have been introduced to help people with disabilities to support themselves and they are distributed in each municipal where social workers supervise them. This is proven by the following excerpts:

"Apart from giving the PWA free sunscreen lotions and wide-brimmed hats, for now, we also offer them loans that have got no interest. We give out these loans for those that don't work so that they can manage to work for themselves and make a living out of the income they make. As social welfare workers, we normally supervise them on how to handle these loans they take." (Participant 7)

"....as the Kinondoni Municipal...We also have a specific portion of loans because of people with disabilities in case they want to start supporting themselves through small businesses that they can create. The government supports them economically as I said before giving them loans without any interest. The government also supports some of them health-wise in treatments as well as in buying the sunscreen lotions for free. The government also supports them during their conferences, seminars and other celebrations regarding them." (Participant 8)

One participant from the Kinondoni Municipal explained more of how these loans are distributed within the people with disabilities as follows:

"The other activity is to link them with economic activities. How do we link them? At least we give them free interest loans from the municipal funds. They are qualified for 2%. You know the municipal has budgeted a 10% free interest loan; 4% is for youth, 4% is for women and 2% is for people with disability. What does this mean? The people with disabilities including the PWA they are still enjoying and benefitting from all the percentages the 4, 4, 2. That means if she falls within the category of a woman, she is qualified for the 4% as a female within the municipal, as the same time she is qualified within the 4% if she falls under the category of youth and the 2% she is still a full beneficiary. As of now, we have 55 groups of people with disabilities who have secured loans and are benefitting for free loan interest. Till now we have given out more than 100 million points something of the loans." (Participant 9)

## 3.2.3.4. Promoting education

On the 27th November in 2015, the government of Tanzania delivered a new policy over education. The education policy was that education in secondary schools was to be provided freely for all students. This included the removal of any arrangements of

school fees and contributions. This was to add to the before policy that suggested primary education to be free. The Tanzanian government also provides student's loans and scholarships for those who would go to university. Sometimes people with disabilities and other people from other vulnerable groups are favored. This can be attested by the social services professionals that have to help the students that need referential letters as they provide evidence of their status so that the government to give them the first priority as this is explained as follows:

"In case of students with albinism who want to get scholarship from the government, when they come to ask for official letters that will ascertain that they are really in need of that scholarship, we as social welfare often help them out in writing these reference letters that help them in getting the scholarship easily as they are given a priority in such cases." (Participant 8)

Another social welfare worker added the following on education:

"As a government, first of all, education. At least we have some schools which are considering PWA though not in Kinondoni as Kinondoni but at least the government, we have some schools which are caring for these young kids or the primary students just like other normal students. And as our current education policy, it means free education for all." (Participant 9)

Governmental social services professionals also bring awareness about PWA to their communities by educating them more through arranging seminars and meetings where they would explain about albinism and how they are supposed to unite together and live as a community. This can be attested by a social worker from Kinondoni municipal in the following excerpt:

"We have this kind of activity about educating community members about them to see PWA as part and parcel of their community and to trust them. We have 20 wards, and in all these wards we have social welfare officers who are working with them. So for the case of creating awareness for the community, we at least try to educate the community. But generally, it's with all disabled groups not just with PWA, we educate and encourage the community members to treat them in a manner that they would feel comfortable living with them.

Through education, we normally arrange seminars and meetings although we truthfully we aren't very good at that through these forums we share with the communities about PWA." (Participant 9)

One participant from UTSS evidently explained how the Tanzanian government has embraced the changes to help PWA in making them comfortable in the education sectors. Where due to their physical challenges like low vision and near blindness, students with albinism are allowed to wear protective uniforms with wide-brimmed hats and long-sleeved shirts. They went further to explain that it's not just PWA but people with disabilities in general. Also, the government has assigned the best government special schools for students with albinism and other disabilities giving the reason to being easier for them to be allocated and attended to when for instance donors want to donate for them. This is demonstrated in the following excerpt:

"So, they also monitor the education sector and they have done a lot towards albinism and disability in general. One, it's now allowed that children with albinism in schools are to wear protective uniforms, long-sleeved, and wide-brimmed hats. And they can wear their hats even in classes because it depends hats serve as protection against the sun but also they serve as in adjusting the lights when it's too bright then your hat can assist in at least reducing the light. Second, children with disabilities including albinism, when they complete primary school and they have done well in their exams, now the government has assigned special schools where these children with albinism can be taken there. These best government schools have been assigned to accommodate these children with disabilities. Even when funders come and want to donate and do something in a specific group, then it's easy to direct them, "go at this school, you will find this population. This is not just for those people with albinism living in Dar es Salaam but even those who are in the interior places are now taken to these schools." (Participant 11)

Selepe (2007) mentioned awareness campaigns playing a vital role in causing an increase in the desire of community members in South Africa to learn more about albinism. With their findings from their research work, it confirms that many of the community members were curious about the whole subject of albinism. A National

School Essay competition for grade 11 to 12 students was intended to help in raising awareness and squashing the malevolent myths and superstitions about albinism. Albinism Society of South Africa (ASSA), Development Bank of Southern Africa, Department of Health and The Sowetan newspaper were among the campaigners. Awareness campaigns even though they promote awareness about albinism they also raise the level of curiosity in the society about albinism.

### 3.2.3.5. Giving PWA leadership positions

In the Ilala municipal, there are different committees that help the community's members. The social welfare workers there try to promote equality by giving chances to everybody to be a leader in these committees. PWA are also given a position in some of these committees in order to promote equality and the communities to understand that they can also be people you trust and they are people who can also lead others. This is explained in the following response:

"We also give them positions in different committees. For example; we have a Child Protection and Safety Committee where there are to positions for disabled persons. In this position, we have there a person with albinism holding this position. We also have an HIV/AIDS Committee where two disabled people are giving a spot to hold, so there is also a PWA that is holding this position together with another disabled person. Within these positions, they get to go to different seminars and participate whereas later on they go and educate the others in what they know about maybe child protection and safety, about HIV/AIDS." (Participant 7)

## 3.2.3.6. Promoting health services

The Tanzanian government promoted free health services and the availability of free sunscreen lotions to PWA. This is to help them sustain the different challenges they face. This is mentioned by a social worker from the municipal as quoted:

"Even at the Ocean Road Cancer Institute, they get free skin treatment. Not only free treatment, but the government is also planning to make sure that at least the equipment is available at any time they need. Lotions are also distributed to the municipals, even I have some here." (Participant 9)

To further testify this, a participant from UTSS added that the Tanzanian government is playing its part in the health sector by providing the sunscreen lotions in the country. Not only that, but dermatologists specialized in the PWA skins are also available in different hospitals. This is explained in the following excerpt:

"Also in the health sector, the government has insisted and it has given directives to the RMOs – Regional Medical Officers and the DMOs – District Medical Officers. You know in public hospitals those medications and so forth are controlled as they are ordered according to the needs of the population. The government has instructed these authorities when they order the medications, they should ensure that they include bottles of sunscreen lotions to be distributed to persons with albinism for free. I can say the government is co-operative. So I can say the government is playing its part I can say so. And even in the health arena again, we have the dermatologists, these doctors who are specialized in skin, they are now supplied in different hospitals. And even those area identification of cancer treatments are now expanding." (Participant 11)

## 3.2.3.7. Material support

Occasionally, the Tanzanian government provides free sunscreen lotions and other gears to the PWA. These are distributed to the municipals where the PWA can go and collect at any given moment. This is proved in the following response:

"One role of the municipal is to provide PWA with gears. The way it is supposed to be quarterly or monthly or upon need. For example, if a person comes and wants a wheelchair and the wheelchair is there, I cannot tell that person to come another time." (Participant 9)

According to the United Nations in Malawi (2017), through the UN Women with the partnership of the government of Malawi, the civil society organizations and the PWA, an Albinism Awareness Week was piloted. The week-long event which was supported by about 4000 members of the community exhibited services like eye testing and skin

screening for PWA. Eyeglasses and sunglasses were provided to those with vision problems while sunscreen lotions were also delivered.

## 3.2.4. Roles PWA can play to change their own Society's Attitudes towards them

Social services professionals were asked to give their thoughts about how PWA can help in changing their own society's attitudes towards them because having worked with PWA it's important to understand their own ideas, thoughts, and opinions. Through this, it's easier for social services professionals to understand how to work with them and how to handle them and also to understand what attitudes are negative or positive towards PWA. PWA portraying different attitudes in their societies would help their society members to as well reflect on these attitudes towards them. The following were the thoughts from the social services professionals from both the government and NGOs.

#### • Building their self-confidence and self-esteem

It is always important for a person to positive about themselves and how they have the ability to do anything at any time. Some participants mentioned about the PWA to first build their own self-confidence and self-esteem that would help to build them overcome different situations or challenges in their lives as it would portray that they are as normal as other people in their communities as these were said:

"First of all, building their self-confidence. Because I think it really starts with that. You know, them being discriminated against and just not being treated equally, first of all, it affects your self-esteem and your confidence." (Participant 1)

"Build their self-esteem, live their lives to the full, realize their dreams."

(Participant 3)

"Be confident and show that they are no different from other human beings."

(Participant 4)

Two participants added that PWA should show their communities that they are able to do anything like any other person and they should be able to speak for themselves as they are the only ones who understand their situation. They should be the front liners in advocating about themselves. These were mentioned in the following excerpts:

"First of all, they are supposed to tell the community that "Yes, we are here. Yes, we can do what you see that we cannot do. Yes, we are people and we can voice. Not because we are disabled, not because we are PWA. We can voice like you. We can identify our needs as you. We are humans, and we have the right to life, right to education, right to everything as a human being just because of being human and not a disabled person." Being a disabled person comes in when it comes to a particular need that supports my wellbeing." (Participant 9)

"They have one law; "No one will stand and speak for their problems. They are the ones to speak about their own problems." They should not wait for someone to come and speak out about their issues. They are the ones to come out and speak for themselves. They should not feel inferior and should feel that they are perfect, strong and shouldn't wait for their issues to be addressed by others. And if they don't stand for themselves, they will keep on being behind. They should be on the front line advocating for themselves and their genders because no one will speak and say of what they are facing apart from themselves." (Participant 12)

#### • Believing and accepting themselves

Many of the participants mentioned that PWA should believe and accept themselves for who they are and what they condition they were born with. If they are able to accept themselves for who they are, the attitudes of the people surrounding them will not be able to make them feel inferior. This is shown in the following responses:

"I think that when they become accepting of their condition and they love themselves for who they are, then no one can really tell them anything, they won't be bothered. So, definitely, it starts from within and then also for them not to be scared to go for opportunities just because they are persons with albinism, they just have to be pushing and working hard and going after things like anybody else and not just staying in the back because that's what you are used to." (Participant 1)

"Accept themselves for who they are and believe in themselves and be positive about themselves and their conditions." (Participant 3)

One participant evidently pointed out about how believing in themselves and how they interact with other community members can help bring a positive attitude towards them:

"For what I have seen so far on their part, they now don't exclude themselves from others like before. They now have a huge interaction with other people in their communities where they tend to mix themselves up in different groups. They tend to involve themselves in different social activities that are on-going on in their communities. Through all these changes that they are showing in their communities, they are helping them bring a positive attitude towards them." (Participant 6)

Believing in oneself means a person should not self-stigmatize themselves. One participant pointed this out as a situation where many PWA see themselves as the problem in their communities. Having this mentality will also reflect the people around them and will bring negative attitudes from their communities. This is shown as follows:

"They themselves can change the society's attitudes towards them by first to not self-stigmatize themselves. Because there is this situation whereby when a person sees themselves with a problem, they start to self-stigmatize themselves. They should show that they can, that they also have potential, if its education they can also get an education, if its work they can also work. This is when they can remove or alienate the ideas or misconceptions from the society about them." (Participant 7)

"But through believing in themselves and achieving their dreams. That's the only way society can be changed." (Participant 11)

Showing their skills and creativity in addition to sharing their ideas and thoughts to their communities will erase the misconceptions about them. One Participant had the following to add on how believing and accepting themselves will also help bring more manpower to the country:

"They can change people's attitudes if they display or show their creativity and skills that they have, the good things that they can do, as well as sharing the good ideas and thoughts that they have with their societies. Because when people see that a PWA can do anything, the misconceptions that they have about PWA will slowly deteriorate. Also, they will come to understand that sometimes, what a PWA might know about something, another person might be in the dark about it. So to share their thoughts, ideas, skills and other things with the people in their society will even help to bring more manpower in our own country." (Participant 8)

One participant answered that PWA should change into believing themselves as if they do not change the society will not change as well:

"They (PWA) themselves need to change. I would repeat this very many times. "You cannot change a person unless they alone want to change." Even in religious books, in the Islamic book, it states that "God doesn't change a thing in a society until the society itself decides to change." If we ourselves decide to change, others will change as well whether they want it or not." (Participant 13)

Testifying through their own experience, one Participant explained that PWA should accept who they are because it is a mirror towards what the society is going to see about them. Not accepting the person you are would also reflect to the society you live in. This was attested in the following quote:

"Number one is, just accepting who they are. Because it is only a few of us have accepted the way we are. You are sitting with me right now and I don't have any make-up on, I don't have a big wig and all that. It's cute, it's nice but many people like me use that as a mask. They can't walk out like the way I am walking right now (without make-up) for many, because they feel ugly. They feel

ashamed of who they are. Now if I feel ugly and if I feel ashamed and I handle myself that way, you are going to take me the same way I feel about myself. But for some, I am not saying everyone. Because you came here and you saw not everyone. But many that I have met, it's a mask. They mask what they feel. So, number one, if they have that self-confident, self-love that they are human, they are normal and everything and they can do anything just like anyone." (Participant 14)

In an interview by BBC News (2012) during the African Fashion Week in Johannesburg, Diandra Forrest, a model with albinism from the US was quoted saying, that what matters to her so much is the fact that she participated in the African Fashion Week because she wants to change the way people see or imagine girls with albinism in the African continent. She also felt that her presence as a PWA on that beauty pageant will hold much greater importance towards other PWA who have a challenging idea of what being their own people worth their own beauty. As a PWA she believes herself to be a person who can bring changes to how people view PWA.

During her 2017 interview with Western Cape Government, Delicia De Vos a PWA and an Administrator of Disability Support at the Disability Unit at the Cape Peninsula University of Technology (CPUT) in South Africa expressed that having albinism doesn't affect her life but the people's attitudes towards her. She says that even though albinism doesn't affect her life because it doesn't limit her from doing things, however, it does affect her life in a way because of people's attitude towards her condition of having albinism. She further suggested that PWA should learn to accept themselves and their condition which will help them move on from people's criticism and positively start to not just change their lives but the lives of other PWA as she drew an example of her own life experiences.

In how PWA can bring by the changing attitudes and making communities openminded about albinism as well as being better together, she was quoted explaining the following;

"As a society in general, we get so used to the idea that when someone doesn't fit neatly into the boxes we have of what a person should look like, then we judge them. Change has to start with you as a person living with albinism. We need to spread the word and help educate people with albinism."

She finished the interview by pouring advice to the younger generation living with albinism that they should accept themselves for who they are as well as going for their dreams and goals thus not allowing other people to break their wings and spirits or even taking their life experiences form them. She finally said that there was a need to not only work hard to bring change in attitudes of not just PWA but also towards people who are different from PWA as well. She is optimistic that as a PWA learning about the condition will not only help other people to understand them better but also to raise awareness which will lead to a greater acceptance in their own communities.

#### • Educating their societies about them

Many participants pointed to education being a weapon that PWA can use to change their society's attitudes towards them. Through education, they are able to first educate themselves about their condition and challenges and also their communities about who they are wherever they are. These are attested in the following excerpts:

"Understand albinism thoroughly and educate others about their inherited condition." (Participant 3)

"Provide community the education on how an individual becomes a person with albinism." (Participant 4)

"Continuing to educate the community and especially through the annual celebration of the year where a great opportunity to educate the public, as the celebrations are held around every year from one region to another. Also to educate the community through the media (TV) where people with albinism show their talents and activities they do. Through conferences, debates on which various topics are discussed." (Participant 5)

"Through the use of the educational programs and various motivations that are provided to them. With these, they can also try and educate their communities about albinism." (Participant 10)

One participant from UTSS who is a PWA also mentioned that PWA should be able to share their experiences with other people for them to be understood well. The Participant explained more by sharing her experiences

"Number two is sharing. Being able to share what they experience with other people so that they get to be understood. I can't expect you to understand what is inside of me when I haven't shared. So if I share with you what I feel, I share with you my challenges, and then I know you will understand and you are human just like I am. So we'll be able to assist one another, we'll be able to coexist. And then teaching and learning more about our condition. But when I came here and I was taught the biology behind and I understood why this is happening. "Okay, I am like okay, fine it happens." So after I understood that and now if I meet someone who doesn't, I teach them. If you teach someone they understand you. That's how we change people." (Participant 14)

To add more to this point, in Mali an Afro-pop singer and songwriter called Salif Keita who is a person with albinism is quoted saying, "It is very, very important for me to help albino people, because they need help, and it is my duty to help them because I am an albino too." Being a PWA, together with his spouse Coumba, they have set a nonprofit organization called the Salif Keita Global Foundation which has been helping PWA in accessing education and health care. Most of his earnings from his music are directly donated to his foundation. Many successful PWA are often eager to help other PWA in climbing the success ladder. So this elaborates on the importance of PWA to have their own role models in all the professions (Laylin, 2018).

# 3.2.5. Government Support towards the Social Services Professionals who work with PWA

A government is a body that governs a certain community or unit. Through different people with different professionals, the government has the responsibility to take care of its citizens. In Tanzania, through the government, social services professionals are the people that deal with the vulnerable groups or the people with disabilities in which PWA are grouped. When the government treats its professionals well, they will obviously bring good fruits from their labor. This goes to mean that if social services professionals that are working with PWA are not well accommodated, their services

towards this group will be not as expected and vice versa. Attitudes from the social services professionals can inform a person of how they are treated or how they feel. Interviews were carried out to participants who work for the government and NGOs. Many of the responses were negative as they indicated that the government lacks sufficient resources like educational resources about PWA. The government does not provide enough for the social services professionals to be able to help PWA in their municipals. Most of the time, different stakeholders and NGOs are the ones that support the social services professionals to reach their goals in supporting PWA. This is attested in the following excerpts:

"Another thing is that, educating the public needs a good and enough budget because we want to raise awareness to the community. For instance, the people in the community to stop bad beliefs against PWA. We don't get enough government support in such situations where we are supposed to educate the community. In awareness-raising, we need to publish posters, make fliers, in the mass media like television and radio where the whole community should be able to understand. To be honest in this, the government lacks in this department. We have talked about this with our director but the implementation process is never followed. I guess this might be because this sector (social work) isn't given a priority in the things they do. Other sectors seem to matter more in the government. Many stakeholders or NGOs give us huge support but the government as the government is very behind in showing us the needed support." (Participant 6)

"There is a very big challenge in this area. Those at the national levels tend to have the knowledge and understand many things about PWA, but those at the local levels (city councils) have very little to no education about PWA. Even when planning those department officials, you find that the department that manages PWA or people with disabilities is not prioritized at a high level." (Participant 10)

Two participants from UTSS had the following to say about the government's support towards social services professional who works with PWA:

"Social services officers, actually you can say are in trouble. Not only for helping people with albinism but even in implementing their activities. However, I have witnessed in some places, I can't say that the government is not assisting them. No, they are implementing their duties even in assisting persons with albinism. Yes, they are doing it although they have to squeeze themselves. They don't have enough knowledge about albinism and that is a problem. Albinism is unknown actually not only to social workers but in many fields." (Participant 11)

"The social workers face a lot of problems because they don't have enough references. And these references should come out from the government where the government itself is trying to learn about albinism right now. So there are still challenges here and there." (Participant 13)

The government having budgetary challenges was mostly mentioned. It was discovered that in many of the government offices where these social services professional work lack vital necessities like cars, laborers, and social welfare officers. Challenges that the social services professionals were revealed as well. These can be proven in the following statements:

"This is one of our biggest challenges. For example; an incident can happen where a person with albinism has been attacked and a social worker is immediately needed to go at the place of incident, and you find that during that time the social worker doesn't have enough money for transport (which is normally supposed to be on the government's budget in case of such situations). This forces a social worker to use their own money to pay for such situations." (Participant 6)

"Sometimes when the budget is not enough, we find that we have to remove what we have in our pockets so that we can be able to move forward in providing our services to the community. It doesn't matter whether the budget is there or not. But as a social welfare officer, it is our duty to serve the people first. For instance, you get a case where you need to save a victim within 24

hours, whether there is a budget or not, you are supposed to take action in order to save this person. The budget always is not enough and the budget that is given out is the one and only that you should work with. Here in the office itself, we do not even have a car that will help us with transportation. In the social welfare unit itself, we have to share transportation with the whole department of health because we are within their department. If in need of a vehicle for transport we have to ask if they available vehicles for us to use from the health department first. If they are not using them, it's when we are given them to use." (Participant 8)

"Sometimes we don't fulfill our objectives just because of financial constraints. Yes, we arrange activities with PWA, but fulfilling them is another issue. Because at times we depend on the municipal funds which are not enough." (Participant 9)

"The government is now trying to appoint them (social services professionals) even from the ward level but the way they deliver their services towards the PWA is very little. They don't have enough budget and sometimes it takes a lot of convincing to work with them. Some of them sit in the office with nothing to do. For example, here at TAS, we are raising awareness about albinism, and as government social workers, they should also find different ways to raise awareness to the communities. We have the International Albinism Awareness Day, they should also create something like this in their work plans. You will come to find out that even at the national level it is still a challenge. To them, everything they do needs a budget. And many of them confess it to us that the budget is the main problem for them. This means that if there is no budget, then PWA are not prioritized enough in Tanzania." (Participant 10)

Responses about the budgetary challenges from the government were mentioned by social services professionals from UTSS as follows:

"So the problem to the social service officers have is actually the budget. They have a lot to implement to visit the population and so forth." (Participant 11)

"Many that we have met have complained about the budgetary challenges. Some say that they may want to visit a certain area for a case follow up or investigate and they need a car. There would be a car but there would be no fuel hence them to give up on doing a thorough follow up of the case."

(Participant 12)

Few participants explained the positive support the government assists social services professionals that help PWA. This is showed with the following excerpts:

"Providing training to deal with social well-being of PWA, presence of a social welfare officer in each of the councils, regional hospitals, and health centers, and giving social welfare officers' guidelines for working." (Participant 4)

"Yes, the government helps us enough. Especially when there are different seminars that we are supposed to participate that are within or outside our municipal. They pay our transportation as well as per diem if any that exists and it's paid in full." (Participant 7)

"The government supports us through the municipal. But until we identify that we have some certain activities dealing with PWA this year and it will cost this much." (Participant 9)

## 3.2.6. Improving the Social Status of PWA in Tanzania

Most of the PWA in Tanzania face challenges in their daily lives. Within these challenges, some can be stopped or even eliminated in order to help them improve their social status. Working with PWA, social services professionals are the adjoining individuals who can have ideas on what can be done. In gathering the responses to this, many of the participants mentioned education as the mother foundation. Be it educating the public by raising awareness, talking to a community or educating the PWA themselves, education was the main motive in helping PWA improve their social lives here in Tanzania because it is the key to eradicate the misconceptions people have about PWA. This is attested in the following statements:

"Raise public awareness about albinism and debunk the myths about the genetic condition." (Participant 3)

"Education should continue to be provided to the community to keep them out of misconceptions." (Participant 4)

"First of all the society should take them more positively especially to remove the bad misconceptions about PWA like having albinism is a curse or bad luck. If all this is done, people will start seeing them as normal people." (Participant 7)

".....its public education. The way the public, the community perceives a person with albinism damages in one way or another the relationships between. And so when the community understands albinism because you find some people don't even want to be close with persons with albinism in the mindset that they will get children with albinism or so forth. And this has an impact on PWA." (Participant 11)

"I think the basic one is education. People should be educated and be aware of what albinism is, how it happens. Because all the sources of these challenges of discrimination, stigma, killings of PWA comes from awareness. So if people are educated, if people are aware, all these we are speaking will be no longer there. So, awareness is the paramount element or strategy of removing all these we are speaking about." (Participant 12)

"Just education. Public education concerning albinism. If education spreads, there will be changes." (Participant 13)

"Education. Getting the community to understand the biology about PWA." (Participant 14)

Without education, neither the PWA nor the social services professionals would understand how to help or support PWA. Having the idea and skills about what

albinism is and the conditions about this genetic disorder helps for a person to understand how to improve the social status of PWA. Through education, a PWA can understand what they are supposed to do, like in protecting themselves against the sun rays, how to use the sunscreen lotions as well as what different opportunities you can get to improve their standard of living.

Some of the participants suggested that parents with children with albinism should encourage and motivate them to go to school to get an education which will help them with their future. This is confirmed by the following excerpts:

"First is to encourage parents with school children who have albinism, to encourage their children to study. Even for those of age of going to school, to put the effort into encouraging them and motivating them more to study. Because I believe when you liberally educate someone, you have saved them from everything else. Also for those that have no jobs especially those that couldn't continue with their studies after primary school, they should involve themselves more in appropriate businesses even join in vocational schools so that they uplift themselves. Though education about albinism should also be sustainable and constant in our societies in Tanzania." (Participant 8)

".....encouraging them to go to school is very important. Because as other PWA, school is important. The majority of persons with albinism in this country have not gone to school. They have not. And this is because of the challenge of low vision..... So the first thing is for them to go to school but not only to go to school, there are many who have gone to school and they have never achieved it. So they have to go to school and achieve. This is one step towards changing their social lives." (Participant 11)

One participant emphasized on the communities to end name-calling and discrimination towards PWA and accept them as normal people. This is indicated in the following quote:

"People should just stop discriminating against them and include them socially as well as stop treating like you are being scared of them and calling them

names. Not referring to them as people like "zeru zeru" name. Just treat them like who you treat anybody else." (Participant 1)

Two participants suggested that PWA should be helped capacity building. Giving them a push will help them not to be left behind and work harder to support themselves. This is attested in the following responses:

".....giving them jobs and to make sure they get an education without being left behind." (Participant 5)

"I think they should be helped in capacity building. If they are well helped in the capacity building department, I believe it would help them support themselves in many things that they do as normal people." (Participant 6)

# **Conclusion**

In conclusion to the findings in this theme where the main aim was to investigate the roles played by social services professionals towards PWA. It was seen that even out of their pockets social services professionals individually play their roles very well in supporting people in their communities to understand and protect the PWA.

Through the responses from the social services professionals in NGOs and those working in the government, it has been noted that be similar but different. In Tanzania, NGOs perform a lot of activities to support the communities so their activities are bound to be fruitful and ongoing hence constructing a large number of roles for the social services professionals who work in that organization. This is also because they face their own challenges by themselves. The social services professionals working in the government might have the capability and strength to help special groups like the PWA but due to government constraints like lack of budget, many activities to promote and protect PWA are either dropped or go at a small pace.

For the social services professionals who work in the government, their roles towards PWA sometimes are determined by the government budget. This is said because as many of them have ideas, opinions and innovate activities to support PWA but cannot perform them for the reason that the budget at the office is limited to other activities.

The government of Tanzania has proven to be worthy of promoting and protecting the human rights of PWA. As much as the fight in the decreasing of the malicious acts done to the PWA, the government is still playing its part in promoting albinism education, supporting PWA materially and economically as well as bring peace through the promotion of harsher laws and punishments towards the witchdoctors and perpetrators who rob the PWA a chance of life.

In addition to this, the government of Tanzania has not turned a deaf ear to the NGOs, other stakeholders and also the PWA themselves. The government has listened and is still listening to these parties hence the changes in the social services like education where PWA are well accommodated to their needs in classes and in the provision of free sunscreen lotions in the health sector. Some NGOs like UTSS have collaborated together with the government of Tanzania to bring changes in different policies that would benefit the PWA.

Through the admissions of social services professionals that work closely with the PWA as well as those that have albinism themselves express their knowledge about how PWA can help to change the attitudes of their own societies. A social services professional should play their role well in learning and understanding the people they serve hence bring changes in society. PWA should be able to believe in themselves and portray the image of strength in their community so as not to be taken as a weaker group.

The social services professionals who work in the government are stranded into playing their roles effortlessly towards PWA. And this is because the government of Tanzania has not put enough effort and has yet to prioritize into PWA. Budgetary challenges in the government offices are like sounding bells where this cause the stagnant in productive activities towards helping vulnerable groups like PWA.

To sum up this conclusion, many of the social services professionals mentioned education to be the main mechanism to help to improve the social life of PWA in Tanzania. Education about albinism to the public, the family members, the PWA

themselves is important in the Tanzania societies for it is the main problem solver towards ending acts like discrimination and name-calling.

# 3.3. FINDINGS ON SOCIAL SERVICES PROFESSIONAL'S PRECAUTIONARY MEASURES TOWARDS PROTECTING PWA

Inside this theme, the main aim was to understand the Tanzanian social services professionals' precautionary measures that are taken towards protecting PWA. Social services professionals are supposed to understand who they are working for in every aspect. In order to understand about the precautionary measures that are taken towards PWA the subthemes included were: social services professional's thoughts on which people should be involved to participate in understanding PWA, how institutions tackle down barriers or challenges facing PWA, ways that can be used to eradicate the misconceptions about PWA, measures needed to be taken to end stigmatization, discrimination, persecution and ensuring effective protection of PWA and the changes that Tanzania can take for the benefit of PWA.

# 3.3.1. Social Services Professional's thoughts on people that should be involved to participate in understanding PWA

In many communities with different people, everyone has their own opinions regarding different situations. For instance in Tanzania on the situation of PWA, some people in the communities might think that PWA should deal with their own problems by themselves. To understand what social services professionals' views and thoughts on this, the researcher questioned them on who they think should participate in understanding PWA. Almost all of them answered, that everybody in the society, meaning the whole community as well as the family where understanding PWA should first start there. This is attested in the following excerpts:

"Shouldn't everyone participate? Yeah, everyone." (Participant 1)

"Everybody in the society including PWA and their families; education and medical institutions. Educate the media about albinism and the use of the right terminologies for persons with albinism." (Participant 3)

"The society itself, family, government, various institutions, and various external and internal stakeholders." (Participant 4)

"The community in general." (Participant 5)

"Understanding PWA should first start at the family level. I think if people were educated from the family level, the whole community will be educated." (Participant 6)

"I think the whole community should participate in understanding PWA." (Participant 7)

"Everyone. Us, PWA ourselves and those that are surrounding us; parents, guardians. But first, it should start with the family members, then teachers provided that everyone has a contribution to this according to their position. A doctor, a parent, a PWA themselves." (Participant 13)

"Everyone." (Participant 14)

According to Lund and Gaigher (2002), it was pointed out that children, teachers, parents, health officials and the community as a whole should participate as a team whenever a social problem arises. Recommending that should there be social problems, they should be tackled by everyone in an interactionist kind of approach.

Some participants added that it is the duty of the social workers and government to educate and motivate the community as well as because PWA are people born within their communities. This is attested in the following statements:

"The whole community as a whole. First, the social worker should motivate and educate about PWA because it is one of the duties of a social worker. This is for the whole community to understand more. If I, as a social worker can't explain to the community well enough about my duties and responsibilities towards PWA and the services that I give to them, the community might not understand the whole context." (Participant 8)

"The whole community. Because PWA are born within the communities and it's not their choice of where they are to be born." (Participant 11)

With a substantial example, one participant logically explained why the Tanzanian government should be the major participant in understanding PWA as well as them being their first priority. This is demonstrated in the following statement:

"The community should be the one to understand PWA. Also, the government. Because if the government doesn't have an understanding of PWA, we will be finished. All these we are talking about social services to upgrade because the ones that should upgrade them is the government. So the first people that should understand PWA are their communities and the government. Especially the government. They are the ones that are supposed to go and give out the services to the people no matter where they are. For example; the Ambassador of Kuwait seems to understand the PWA and they have put it upon themselves to be contributing to this group each and every year. Things like wheelchairs. The Tanzanian government should just put it as their priority that we PWA are supposed to be their first stakeholders hence they should have a wide range of understanding that our survival might also depend on the actions that they take towards us. Because every time, the PWA is forgotten. Who is responsible to remember PWA group? The government. If the government remembers us, even another stakeholder will not forget about us since the more noises the government makes about us, people in the communities will see how important PWA are." (Participant 10)

One participant mentioned religious leaders as the main participants to understand PWA because of their importance in preaching about love and promoting peace in a community. This is proved in the following passage:

"The public, religious leaders who are the ones to preach about loving one another (love) and equality, police officers, judiciary officers, and any other stakeholders." (Participant 12)

# 3.3.2. How Institutions tackle down barriers/challenges facing PWA in Tanzania

An institution is a social structure in which people cooperate and which influences the behavior of people in the way they live. It further explains that an institution has to have a purpose and most of them are permanent. This goes to mean that they do not collapse or end when one person leaves because they are based on rules that enforce human behavior. In every society around the world, an institution can work differently pertaining to the different cultures they have. A government, education, religion,

marriage, trade, kinship, an NGO are some of the important institutions that can be found in a society.

In Tanzania, it's either the government or the NGOs that get very involved in supporting and fighting for the rights of PWA. During these progressions, these institutions overcome different challenges that face PWA and they tend to have solutions that help PWA overcome these challenges. Many of the responses came from participants who work in NGOs and other stakeholders. The following were their responses as to how they tackle down these barriers facing the PWA:

## • By education, advocacy, and public awareness-raising

Many of the participants from UTSS explained how they use education, advocacy, and public awareness-raising to face these barriers. It was explained that through these three methods, rights and the wellbeing of PWA are promoted, people are able to understand deeply who PWA are and even PWA themselves learn more about albinism and its challenges. Not only them but also teachers who have students with albinism and health committee members in communities because they are the professionals to understand more about the challenges of skin cancer and low vision sight of the PWA. This is attested in the following excerpts:

"By promoting the rights and wellbeing of PWA via education and advocacy about the inherited condition and promoting positive images about PWA." (Participant 3)

"Challenges or barriers facing PWA are tackled through awareness-raising. There are direct beneficiaries that receive help from us and they are connected with UTSS. For instance, we have these social groups of women who have children with albinism and women with albinism trying to bring them together and provide them with an education on economic empowerment projects. And finally, we provide them with startup kits so that they can do something on their own. These groups started with mothers or parents or guardians of children in our education program. Although in some cases there are those who are not connected with UTSS but are also encouraged to participate in these programs." (Participant 11)

"Through advocacy, public awareness, and education sponsorship." (Participant 12)

"We here at UTSS use education and advocacy to tackle down these challenges. We collaborate with the Ministry of Education, we teach teachers about the challenges PWA face in the class where some teachers know about them and some of the students also benefit from this. We have also created a guidance that would help to guide and treat a student with albinism in class. We are also struggling with the health committee members where we want to tackle the challenges of skin cancer and low vision sight. We tell them what is needed to be done." (Participant 13)

"With education and education." (Participant 14)

# • By working together with the government

NGOs in Tanzania stand on their own, meaning that the government does not interfere with the services they provide to the communities unless the needs to be. So, many NGOs sometimes have to work together with the government for their objectives to be implemented. UTSS uses this endeavor to advise the government on how to help them tackle the challenges that are facing PWA. This is proved in the following passage:

"We are also advising the government on how to give equal rights to students with albinism. As I have said before, there are laws that you make, but how are you standing by that law? You as the government needs to implement it first. So when we get the chance, we tell them that they can solve a challenge through this, this and this. We recently went to parliament and talked to policymakers. We go to district councils and talk to the heads of districts because this is our responsibility and duty. So this is the major thing that we do. We show the challenges and we provide the ways that can solve this challenge. And many things that we advise the Ministry of Education is that this issue of disability and albinism should best be included in the education curriculum. Meaning for a person that would finish nursery school they would know A, B, C about albinism. If they finish standard 7 to form 4 they will have known more about albinism which would have helped enough." (Participant 13)

This can also be confirmed by some NGOs in other African countries where they also co-operate with their governments in breaking down the challenges that PWA face. Nduru (2006) on his work about "NGOs take on challenges of albinism," cited a good example from Zimbabwe, where according to John Makumbe, the then president of the Zimbabwe Albino Association (ZIMAS) in 2006 and also a Political Science professor at the University of Zimbabwe explains how some ministries in Zimbabwe approached their organization to find PWA that can be employed as clerks and office messengers. Makumbe also added that by their organization's successful efforts they have been able to move teachers with albinism from hot areas to warmer areas where they are safer from the sun.

## • By finding stakeholders for support

For some NGOs, it is difficult to support themselves and properly help the PWA. With this, they go knocking to other doors for assistance to reach their goals of supporting PWA in their communities. This shows how important it is to some social services professionals to go as far as using different methods in tackling the barriers or challenges facing PWA. One of the participants attested to this as follows:

"To find stakeholders (to work with development partners) who can help where the institution has failed to reach or implement." (Participant 5)

According to Nduru (2006), Joseph Ndinomupya, the then president of Namibia Albinism Association Trust an NGO in Namibia said that they not only look for assistance from companies but they also go to church and tribal leaders as well as councilors to plea to them that they help the PWA with sunhats, sunscreen lotions, and sunglasses. In South Africa, church leaders, social workers, and teachers are encouraged to raise their volumes in speaking about the condition of albinism. This was said by the then director of Johannesburg-based organization, Tony Ngwenya.

In 2013, Mswela a researcher from the University of South Africa (UNISA) collaborated with the Albinism Society of South Africa and organized a prosperous seminar to raise awareness about albinism. PWA, health and genetics professionals in addition to academics within the legal field were provided an opportunity to discuss the challenges facing PWA in South Africa. The positive outcome of this seminar was

that there was a publication of peer-reviewed articles on how to tackle or wrestle the issues facing PWA in South Africa.

# • By providing them with different necessities

Through the Embassy of Turkey in Tanzania, one participant mentioned how they provide material support for the PWA. This is proved in the following passage:

"At the moment, we are covering their wounds by providing them with the necessary necessities like skin cream, hat, work, health treatment as well as trying to help them in the field of education." (Participant 2)

In addition to the researcher's observation, during the commemoration of International Albinism Awareness Day June 13<sup>th,</sup> 2019 which in Tanzania was held in a town called Morogoro Standing Voice an organization based in Mwanza was providing different necessities and services for free on this day to the PWA. Speaking to a social worker from the organization, Mr. Cheyo explains that not only does their organization freely gives out sunglasses and eyeglasses to the PWA at the same time they conduct optometry services for free under their Vision Programme and they mostly enable students with albinism so that they can achieve their educational and professional perspective. This can be proven as seen on Plate 8 below:

**Plate 8:** Standing Voice conducting free optometry services to PWA at the International Albinism Awareness Day in Morogoro



Source: Researcher 2019

# 3.3.3. Ways that can be used to eradicate misconceptions about PWA

One of the biggest triggers that led to the atrocities done to PWA is the bad misconceptions that some of the Tanzanian communities have about them. In order to eliminate these misconceptions, social services professionals were questioned about their thoughts on the best way to help abolish these misconceptions in today's society. The following were the responses:

# • Through education and advocacy

Education and advocacy are mentioned by many of the participants who believe that if the whole society is to learn and understand about PWA, the bad misconceptions will be easily put to an end. For this to happen, suggestions on how the education and advocacy should be spread were through media, meaning through radio, television and also the use of fliers, and posters. Social services professionals also play the role in society to help end these misconceptions as some even participated in different activities to make this happen. This is attested in the following excerpts:

"The traditional ways like grass-roots advocacy, going to like rural areas and addressing and having these conversations. Also, digital ways using stream media. You know the problem is not just in the villages, even people in town. It's not a social-economic problem, not just people in a certain social class understand albinism, and everybody doesn't get it. Also using digital techniques which is also what we have been doing and having PWA that are doing great." (Participant 1)

"More that is needed is to provide education. This will help in annihilating all these misconceptions about PWA. Providing education to people will make people understand the importance of PWA and the bad misconceptions about them are just heartless." (Participant 8)

"Only through education." (Participant 9)

"To continue to educate the society about albinism. Enough education will even make people abandon the bad and false superstitions, beliefs, attitudes, and misconceptions on PWA. Education can also be in different forms like creating concerts, singing songs, dances as well as advertising through social media." (Participant 10)

"To have an education as well as awareness about PWA. If people are misinformed, then all these challenges will keep on being there. But if people are perfectly informed, everything will be well." (Participant 12)

"Education." ((Participant 14)

With an example of the Sukuma people (a tribe in Tanzania), one participant from UTSS further suggested that the education shouldn't just be based on the society but to the PWA and the people that have children with albinism as well. People should stop believing that the different beliefs about PWA are true and through seeking education they would eradicate all these misconceptions. And if the PWA themselves and families with PWA are educated enough about their conditions, the bad misconceptions can be easily wiped. This is proved in the following statement:

"Education. For some of the Sukuma people who reach the extent of calling their children "mbili-melo which means white goat", if the child is a white goat what is of the father and mother in this? So if they are educated that having a child with albinism is a state of inheriting genetically, they would solve this problem. People should stop believing that PWA's body parts can make them win in elections, or the hair of a PWA can help them catch a lot of fish while fishing. These are all senseless beliefs. If you want to win in elections, do the best campaign. You should look for more modernized fishing equipment for fishing because it's not true that you will get a lot of fish through using the hairs of a PWA." (Participant 13)

The participant continued to explain that not only should educating the public be a job for NGOs and other stakeholders but the government should also take an obligation to make people understand more about PWA as the following suggests:

"So all these misconceptions are going to be solved and eradicated through education through one question after another. Therefore, educating the public especially at the national level, shouldn't just be UTSS doing this by themselves, because it will take very many years. But if the government could take the obligation like how they have taken obligations through other disasters, people would understand and those with bad misconceptions will change." (Participant 13)

A participant from Ilala Municipal through the duties they perform for their society contributed to some of the ways they use education to spread the word about PWA. But through these means they also met challenges from their society as this is attested in the following passage:

"We also make fliers about albinism which we distribute to the community and which by the way not all get them because sometimes you give a person and they have no interest in reading it. Those that read are very few hence they become the only ones that get to understand more about albinism." (Participant 7)

This is added by another participant that if education is massively spread through media, it is easier and faster for a larger population to learn and understand all about PWA as suggested in the following:

"Providing education through media, community-level professionals, public meetings, schools (curriculum), etc." (Participant 4)

"Most of it all is just education. If education about PWA is spread through the media, the community will be able to understand very fast. Also, we should use flyers though not all will be able to get them or even read them. But through the radio, television, and news, people will be able to get an education about PWA." (Participant 7)

Two participants from UTSS and BAF suggested that through PWA themselves becoming role models is enough education to the public that will reflect on how they can also be involved with activities in their communities. This is verified in the following:

"...showcasing their success and then being role models to everyone else." (Participant 1)

"Actually, in eradicating the misconceptions, number one is "public education and awareness-raising". Number two, PWA can also be role models where they have to involve themselves in these community activities. This will help the community to understand more and see that PWA can also do different activities." (Participant 11)

One participant from the Ilala Municipal suggested that the Tanzanian government change the education curriculum in consequence that students learn about PWA very earlier. This is attested in the following:

"Apart from awareness-raising, I think the education curriculum in Tanzania needs to change whereby students in schools should understand that PWA are just people like any other normal human being. This can also be done in social media as well." (Participant 6)

# • Through awareness-raising

In order to support the changes in eradicating these bad misconceptions in the society, some of the participants recommended public awareness through campaigns, media, public meetings, concerts, debates, church and mosque sermons, and promoting social inclusion. This is attested in the following excerpts:

"Also digital ways using stream media. You know the problem is not just in the villages, even people in town. It's not a social-economic problem, not just people in a certain social class understand albinism, and everybody doesn't get it. Also using digital techniques which is also what we have been doing and having PWA that are doing great." (Participant 1)

"National-wide public awareness campaign about albinism and promote social inclusion." (Participant 3)

"Concerts, public meetings, debates, media, celebrations on people with albinism, church and mosque sermons, and at various people's gatherings." (Participant 5)

One participant from the Ilala Municipal gave an example of how they raise awareness in public during celebrations where they provide a piece of significant information about PWA. This is showen in the following:

"Spreading word about albinism normally occurs when there is a celebration where we post posters with significant information about albinism so that people would join and celebrate these days with the PWA. A number of people go, and through that small number of people, they get educated in understanding what albinism is. That's it. And they are not very many people that go just PWA themselves." (Participant 7)

# 3.3.4. Measures needed to be taken to end stigmatization, discrimination, persecution and ensure effective protection of the PWA in Tanzania

With the small population of PWA in a large population that Tanzania has, it should be able to take measures to ensure the effective protection of the PWA by ending all the atrocities done to them. In Tanzania, social services professionals are the people that work closely with this group, therefore, they are the people who can understand what measures can be taken to ensure the atrocities done to the PWA are eradicated and ensure a safer environment for them. In order to understand what measures to be taken to end these atrocities and ensure effective protection of PWA in Tanzania, the researcher grouped the participants' answers into three categories: government, community and education, and awareness-raising.

#### Government

Most participants suggested that the government should be more involved with ensuring the effective protection of the PWA because as the main body in the country, the government has the duty to protect all of its people no matter what. The participants that the government should strengthen the laws, policies, and punishments regarding PWA. The strict and harsh laws should be able to scare any person that would want to cause harm to any PWA, as the following statements are proven:

"Strict legal measures should be taken against perpetrators of albinism, protection committee should be strengthened so that when there are signs of stigma, discrimination, persecution, and actions should be taken promptly." (Participant 4)

"The government should modify the laws that govern disabled people. Harsh laws should be put in order to punish those that are found doing malicious acts to PWA like harvesting their organs. Nowadays in Tanzania, those who are caught killing PWA are judge according to any criminal offense but there are specific cases that for a person who has killed a PWA should be punished in a different way." (Participant 7)

".....to have good policies, good laws, and strong institutions in protecting the rights of PWA." (Participant 12)

About the punishments, one participant had the following to add:

"Taking actions along with giving severe punishment to all those who do these acts." (Participant 5)

The government should also be able to show enough support to the PWA in different social sectors as with this, PWA will be able to freely cooperate and interact with other people as well as improve their standards of living. This is proved in the following:

"......to give the PWA enough support in different sectors; health-wise, educational wise (encouragement) and cooperating with them in different sectors." (Participant 8)

### • Education and awareness-raising

Few of the participants acknowledged that through education and awareness-raising about PWA, people will be able to eradicate the bad misconceptions as well as the cruel myths, beliefs, and traditions about PWA. This is to be done mostly by the government as well as the PWA themselves. The government should be to make sure that education about PWA is national widespread. Also, PWA displaying themselves to the communities that they can do anything and that they are normal human beings will lead to their communities to end the stigmatization, discrimination, and persecutions done towards them. This is explained in the following excerpts:

"I just think that education is enough for the people to understand that these evil ways should stop hence to remove all these bad misconceptions about PWA. First, Tanzania should make sure that the education given about PWA is understood and reached by everyone. Second, the government should make sure to eradicate the cruel myths, beliefs, customs and traditions about PWA." (Participant 8)

"Just to continue to give education and creating awareness. Also, the PWA themselves to continue telling the community and implying that "we are this

and this." At least for themselves, they are supposed to identify themselves that we are complete human beings and we can do this and this." (Participant 9)

"My priority is awareness-raising." (Participant 12)

One of the participants from UTSS mentioned education and persecutions of attackers being a two-way thing and that through educating the society and the PWA themselves, the government should also strengthen its laws and policies for it has so many loopholes. This is shown by the following statement:

"Two measures. Number one education as usual plus persecutions of attackers. It's a two-way thing; education and persecution of attackers. Education meaning educating the society at the same time educating the person with albinism. There are so many gaps between the laws and policies that are there in the Tanzanian government has so many gaps. Because of the time when they were being made, albinism was not a topic. Albinism started becoming a topic when the killings began. And it's not like they began at that time they began, they have been here in time in memorial. It's just that it wasn't a topic people were treating it secretly. But when the journalist made that BBC report in 2008 that was when it started to be a topic. If it wasn't for her, this whole thing (regarding UTSS) wouldn't be here. So when it began to be a topic that is when people started taking actions." (Participant 14)

#### • Community

A community is sometimes given the definition of a group of people who are living together sharing a common interest. Tanzania as a country is bestowed with very many different communities. And in each of these communities, people have different attitudes, ideas, opinions, and even interests. A community is also a place where everybody should protect each other. Some of the participants enlightened that through communities and families, PWA should be protected because as a community it is everyone's duty to ensure the safety of another person. This is indicated in the following excerpts:

"Also, communities protecting each other and being accountable for each other. Because if you are in a community and a person with albinism disappears, if you are all there to protect him, you are all their fighting for their rights as well." (Participant 1)

"Protection from their communities." (Participant 2)

"But also to communities and family level. Because in the end, the government is a single person, but what is done in families, at the family level. What is done in the families, if families are strong in protecting their relatives who have albinism, then it is easier to penetrate in other levels." (Participant 11)

# 3.3.5. Changes that Tanzania can take for the benefit of PWA

In this subtheme, the social services professionals suggested different changes that the Tanzanian government could take and be beneficial to the PWA. Improvement in education and health sectors, change of policies, cooperation between different organizations and institutions, inclusion and economic empowerment were some of the participants mentioned. Each of these are discussed as follows:

# • Improvement in education and health sectors

Many of the participants suggested that Tanzania can bring changes in the education and health sectors for the benefit of PWA through the education system to be friendly to students with albinism through all levels and educating the communities as well. It is through education that PWA themselves and people around them tend to understand and support them more. This is demonstrated in the following excerpts:

"And then, getting into the schools but that would also include children with disabilities because children in schools their biggest challenge is their eyesight and them not getting special attention or the teachers not being aware children with albinism should sit in front. So the education system to be friendlier towards PWA and disabilities." (Participant 1)

"I just think educating the community in order to bring awareness about PWA is enough." (Participant 6)

"Tanzania should first improve the social services like the education and health sectors." (Participant 10)

One participant from UTSS suggested that education about PWA should be more focused from the lower level of primary schools as it is easier for children to learn about PWA from an earlier stage but also to educate the older people who already have culturally cultivate in the misconceptions about PWA to change their bad thoughts and be open to bringing change in Tanzania. This is attested in the following statement:

"But right now, with these educational runs on teaching about albinism, I really think that they should focus more on the student's unit in primary, secondary and if even possible in nursery schools as well. Why this? Because these are the units that have not yet been polluted in their heads. So it is very easier to teach them and after they understand they will grow up that way and it would be a liberation. Also to deal with these higher leveled people, it is possible even though they are already polluted, already they have given their culture and tribe as their priority even though they have their profession, it will still take time to change. But if they want to change they can change because already they have the presumption of changes. They have education and exposure already. If education spreads, there will be changes." (Participant 13)

One participant from the Kinondoni Municipal added that government should put more of their efforts in the health sector as well as be able to support in providing education to the PWA because most of them don't have enough knowledge about themselves. This is attested in the following:

"I think their responsibility is that they should put more effort into the health sector and provide more education about PWA. This is because many of the PWA don't even understand their own situations hence they are supposed to know how to protect themselves so that they can be able to live comfortably and safely. Providing education is more to the parents and it is where the government should support them more in this. The government should allocate more budget on them because they are more at risk in suffering if a parent has no knowledge of how to protect their child." (Participant 8)

# • Change of policies

This was mainly aimed at what the government can do in terms of changing the policies that would be helpful in benefitting the PWA. Participants mentioned that through the changes of policies, people would understand that this group is a priority to the government and it would also help to teach people about PWA more. This is attested in the following responses:

"I think the biggest thing they can do is policy changes and very strict laws against discrimination and harming PWA, I think that's the first change they can do." (Participant 1)

"There should be an existence of legal changes, policy changes as well as structural changes. For example in the policy for disabled people, if you look at it they have not mentioned PWA. If you ask, they just tell you that you are included in that policy that is in the Persons with Disability Act, Act No 10 of 2009. So, policy changes are needed, educational, and legal and in every aspect need changes." (Participant 13)

With an example from a change that took place in a neighboring country, one participant had the following to add about the change of policies regarding PWA in Tanzania:

"During the time of changing or correcting the constitution or in any legal processes, the Tanzanian government should ensure that they should put the PWA situation in a clear plate so that it can be easier for the people to understand about this group. The constitution of the country should also be aware of us like in countries like Kenya. The Kenyan Constitution is very much aware of the PWA situation that's why even in their parliament there is a cabinet for PWA. So no matter whoever is in the government, if they resign, step down or finish their term, the constitution still guards the PWA in the country. Even for the PWA, it is easier for them to directly take their problems to their leader because they are free to do so as their problems will directly reach the intended body." (Participant 10)

# • Cooperation between different organizations and institutions

One participant proposed that the organizations working with PWA should cooperate and share information on the activities they do and work together as attested in the following:

"Organizations working for persons with albinism should cooperate and share information on their activities, work together."

Another participant from UTSS who is a PWA, further added that Tanzania should use religious institutions because they are very influential in changing people through their faith and belief of something. This is proven in the following excerpt:

"By engaging religious institutions because they are very influential. And trying to change what people believe. And you know preaching love, love your neighbor and all that. If we are insisted to love one another and treat each other as human beings, plus education and everything else, it will work." (Participant 14)

The participant went on to suggested that people should abandon their bad beliefs about PWA and also gave an example of how faith can play a role in bringing changes to different places:

"Stop believing bad things about us (laughs). I guess it's difficult to change the belief system. That's why when you go to the lake zones, many people don't have any religions. You find a Juma (Islamic name) there and ask, "Are you Muslim?" "I'm not Muslim" "How come you are Juma?" "I'm just called Juma". So in areas that are religious, you don't find this. That is why you don't hear of many attacks in Zanzibar. It's an Islamic state." (Participant 14)

#### • Inclusion and economic empowering PWA

One Participant suggested including PWA in any matter in the communities regardless of their abilities or disabilities as it is also a right that they should be respected and appreciated as any valuable member in their own communities. This is attested in the following:

"First of all, its inclusion. This is the major tool. If PWA are included in the mainstream of the society, then actually this will benefit persons with albinism. Families will never separate because a father has agreed that this is my child and I will take care of him. But in all the levels of the society, if inclusion is done then the stigma and everything will be ended and persons with albinism will benefit in one way or another." (Participant 10)

Another Participant further added that empowering PWA would be helpful to better their lives as they would be able to conduct their own dealings independently therefore also improve their standard of living.

"Empowering the PWA in the economic strategies like giving them loans for their businesses, training them in some entrepreneurship skills in order to conduct their own businesses where they can be independent (economic empowerment)." (Participant 12)

# Conclusion

This section summaries the findings and contributions on the precautionary measures that social services professionals take towards protecting PWA. In Tanzania, through the nightmares they have had to witness, undergone or even heard about concerning them, PWA are entitled to be understood by each and every person in their communities. And this what many of the social services professionals have agreed about. Being a small group in a very large population should be something the Tanzania government to look out for them and understand them well so as to prioritize their needs.

And for if the Tanzanian government focuses to truly understand the PWA, many of the communities will understand them well. The government should properly utilize the availability of social services professionals through uplifting the country to bringing changes in the societies for they are the possible professionals that can help in the fight against the atrocities done to the PWA in Tanzania.

Families and communities in Tanzania should also be the agents of teaching their children from the grassroots about albinism. When a younger generation has no knowledge about the misconceptions about PWA, they will grow up to understand that they are as normal as other human beings just with a few special needs.

In finding the precautionary measures towards protecting PWA, challenges are never unnoticed in this hard work. The biggest challenge many institutions face or deal with is the ignorance of many people and even PWA themselves have about albinism. So because of this, many NGOs overcome this challenge by using education, advocacy, and awareness-raising the most. Every institution uses either the same strategy or a different one to overcome challenges.

But through the observation of the researcher, it has been discovered that many social services professionals who work from NGOs are more to face and understand these challenges because they closely can relate with working to this vulnerable group as they physically see these challenges. Social services professionals from NGOs physically go to the targeted population and go against these challenges but most of the social services professionals from the government sectors are office-oriented and can only work as far as what they are entitled to do in the office.

The use of education, advocacy, and awareness-raising was again marked to be the major solution finders towards helping in eradicating the misconceptions about PWA. Through these, information about PWA and albinism is certainly to reach many of the uneducated communities in Tanzania in the hopes of abolishing the malicious acts. Providing material support and cooperating with the government and other stakeholders has also played a part in ensuring that PWA are provided with certain necessities so they can be able to live as freely and peaceful like other people in their societies.

Social services professionals mentioned the government, community and education and awareness-raising again are considered the measures that should be taken in ending the stigmatization, discrimination, persecution and ensuring effective protection of PWA. If the Tanzania government stands upright with the laws they have placed in protecting PWA, then it would be easier for the communities to follow suit. The Tanzania government is the mother of everything, so what it says as law and stands by it, the people will as well copy from it. If for instance, it stands by the punishment laws

that it has put forward to punish the perpetrators that mercilessly kill PWA, do you think someone would be ready to face a death penalty just because of killing a PWA?

To sum up findings in this theme, most of the social services professionals pointed the Tanzanian government to be the party that can bring tremendous changes that can be of benefit to the PWA. Improving the education curriculum to the changing of ancient policies in order for the PWA to feel comfortable within their daily lives. Yes, no one is closing an eye on the improvement they have done in helping students with albinism adjust to the environments in schools and universities, but the government of Tanzania needs to make sure this is accurately applied to all the schools and universities be it in rural areas or urban areas. Even though the government of Tanzania has tried to include PWA in the government sectors as leaders, they should as well include them when they are conducting and making decisions that apply to them.

# CHAPTER FOUR: CONCLUSION AND RECOMMENDATIONS

# 4.1. CONCLUSION

This study aims to examine the attitudes of social services professionals towards PWA, the roles played by social services professionals and the precautionary measures taken by social services professionals in protecting PWA in Dar es Salaam, Tanzania. Primarily, data collection was done through interviews with social services professionals working in the government and NGOs, PWA who acted as volunteers, and a journalist.

In examining the attitudes of social services professionals towards PWA, this study has tried to show that positive attitudes like respect, acceptance, understanding, love, value and defense were more than the negative attitudes like the lack of passion to help PWA, laziness, unhelpfulness as well as being pessimistic when dealing with PWA. The positive attitudes that social services professionals had towards PWA affected the PWA in a positive way as well, whereas it has resulted to some of the PWA to gain confidence, pride, courage and strength. This shows how a person's attitude can reflect on another to bring better changes in a society.

Investigating the roles played by social services professionals towards PWA, the study found out that social services professionals not only do they work in office but also personally they still provide their services towards PWA. Also, it was discovered that social services professionals who work in the NGOs perform alot of different activities like promote education and advocacy, provide material and psychological support, promote empowerment and skin health towards supporting PWA whereas those from the government due to governmental constraints like lack of budget end up doing little to less work from the offices. The government of Tanzania is also playing it's role by promoting peace and security to PWA by construction of harsh punishments to those culprits that do malicious acts towards PWA and it has done a major change in the education sector by providing students with albinism with the basic requirments like specialized examination papers as well as allowing students to wear full protective gears in schools and universities.

We can see that the precautionary measures taken by the social services professionals towards protecting PWA were through the government, education, awareness-raising and the community. They were found to be the measures that help in ending the stigmatization, discrimination, persecution and ensuring effective protection of PWA. The government of Tanzania should stand firm in making sure the laws they have put up are followed in order to protect the PWA. If the government take the precautionary measures seriously, even the communities will follow suit as the government's words are law.

This study is relevant to not only just social services professionals but also the PWA themselves and their communities. This is because it has depicted how attitudes can bring changes in a society, from the social services professionals, to the government, the community as well as the PWA. It is through attitudes that a person can learn from another person whereas if they learn good and positive things, they will also provide positive outcomes. The same goes to if a person learns bad and negative things, they will offer negative outcomes.

In conclusion, the attitudes of social services professional towards people with albinism are without a doubt very vital in any society. Do you think that a society can sustain to have social services professionals who have more negative attitudes than positive attitudes towards them? Clearly, there is a need for more positive attitudes towards vulnerable groups like PWA where they would be able to prosper and stand on their own in protecting their rights.

#### 4.2. RECOMMENDATIONS

In order to successfully protect, promote and support PWA in Tanzania as it has been stipulated in various situations, the following recommendations to the government, NGOs and other stakeholders, social workers and PWA are offered as followed:

#### 4.2.1. Recommendations to the Government

• The government should modify the laws and policies governing PWA. Harsh laws should be put in order to punish those that are caught undertaking any malicious acts towards a PWA. This would also discourage those that want to involve themselves in committing such violent acts towards PWA.

- The government should work with NGOs and other stakeholders and use various media like cinema, radio, television, posters, and fliers in different activities to promote public awareness about albinism during campaigns, debates, meetings, and seminars, especially in rural and remote areas.
- The government should promote awareness-raising programs in the mining and fishing industries in the areas where miners and fishermen still have bad misconceptions about PWA. The government should educate them on how to use scientific methods to boost their trade rather than using witchcraft.
- The government should include PWA in every mainstream of the society regarding them. This includes any legislative processes which are either from the parliament sessions or any other legal actions from the constitution. The national and international agreements concerning PWA should be implemented as well.
- The government should improve the health sector for the PWA, by providing health insurance to improve their access to health services, provide free skin cancer screening and treatment, and provide free sunscreen lotion and low vision devices for students with albinism. Also, due to the deficiency of cancer treatment hospitals in many regions in Tanzania, the government should look into adding more cancer institutions to many different parts of the country.
- The government should improve the education sector for and about PWA. The education curriculum should include albinism and other disabilities from the kindergarten level to higher learning institutions and educate medical practitioners about albinism. The government should learn and be educated more about PWA; their situation, their albinism, their challenges, and their needs. Understanding PWA would help the government to determine how to prioritize them in general things.
- The government should promote inclusivity for PWA in the employment sector. The government should stand behind implementing its law for people with disabilities while employing people. The law states that two percent of the labor force in work places or companies with more than 50 personnel should be persons with disabilities where PWA are among these group of people with disabilities in Tanzania. If the government cannot back up on its own laws and

regulations, then it will be hard for other institutions to follow. The government being the biggest employee of the country, should put the means to follow and implement its laws and regulations so that the other institutions to follow after them.

- The government should ensure the social welfare offices have enough budget for the social services professionals to work in an unlimited capacity in bring changes to the societies they are assigned.
- The government should ensure that the free hotline for PWA to work across thw whole country at any given time.

# 4.2.2. Recommendations to NGOs and other Stakeholders dealing with PWA

- NGOs and other stakeholders should cooperate with the government about PWA in the education sector. Not only to the PWA but also to the communities they live in. It is easier and faster for NGOs and other stakeholders to provide and spread the education needed about albinism to the communities in Tanzania.
- NGOs and other stakeholders should be not be biased in providing services towards PWA. The services they provide should both be in rural areas as well as in urban areas. For example; providing free sunscreen lotions and other protective gear should also be in interior places like villages and in different regions in Tanzania and not just urban areas or cities.
- NGOs and other stakeholders dealing with PWA should share ideas, thoughts, and opinions on how to improve the health services towards PWA in Tanzania with the government. For example; the importance of every hospital to acquire a cryogun (for the liquid nitrogen gas), a machine that doctors use to test for the early symptoms of skin cancer.
- NGOs and other stakeholders dealing with PWA should continue their initiatives of providing financial and technical support in conducting researches, investigations as well as public inquiries in order to increase awareness, education, and advocacy in the country as well as seeking more answers to the problems facing PWA.

# **4.2.3.** Recommendations to Social Services Professionals

- Social services professionals should acquire accurate knowledge and education about albinism.
- Social services professionals should apply for their roles in bringing change to
  the society vastly especially when dealing with PWA. They should be able to
  help and support them in any matter that arises in their communities.
- Social services professionals that work in the government should be creative in promoting and creating educational incentives to the public about albinism through fliers, posters, meetings, seminars, debates and the likes.
- Social services professionals should promote, protect, and fight for the rights of PWA at all times.
- Social services professionals should encourage peace and love in the communities where PWA live in order to discourage and eliminate any discrimination, segregation, isolation, name-calling and other malicious attacks towards PWA by other community members.

#### 4.2.4. Recommendations to PWA

- PWA should fight for their own rights by standing up and raising their voices
  to fight against any injustice done towards them. They are the only ones that
  can bring changes in their communities by fighting for their own rights.
- PWA should accept themselves for who they are and not feel inferior because
  of their skin conditions. By accepting themselves, they will able to love and
  accept themselves hence the communities they live in to accept and love them
  for who they are.
- PWA should acquire more accurate knowledge on the whole topic about albinism and not just part of it.
- PWA should be the leaders in promoting health awareness to the public and themselves as well.
- PWA should promote self consciousness as well as self awareness where they
  would act as real role models to other PWA and the society.

#### 4.3. FUTURE RESEARCH

Having outlined the attitudes of social services professionals towards people with albinism the researcher found out that many PWA have no or less knowledge about their albinism condition. So a future research will prove important in conducting a long-term study on the 'self-awareness' concept on the people with albinism themselves in order to bring an advantage to them in understanding more about their condition and overcoming their daily challenges.

Concentrating or focusing in improving the capacities in knowledge, attitudes and values of PWA is also suitable for another future research. This will help the PWA to comprehend with any situation that they will face in their lives without the assistance of anyone like a social service professional.

In addition, examining the impact of various ongoing activities that are been carried out by NGOs associated with PWA might also prove an important area for future research. This will possibly be a calling to other NGOs and stakeholders in lending a stronger hand towards PWA as well as making it a wake-up call for the government to face its responsibility and obligations in promoting and protecting the human rights of PWA.

Lastly, a study on challenges and problems facing social services professionals in Tanzania should also be taken into account as a future research. Social services professionals being the forces of bringing changes in their society also face roadblocks that force them to deter in their line of work. These roadblocks should be found so as to bring more positive changes in a country like Tanzania.

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#### APPENDICES

# APPENDIX 1: ENGLISH VERSION OF THE SEMI-STRUCTURED INTERVIEW FORM FOR THE GOVERNMENTAL AND NON-GOVERNMENTAL SOCIAL SERVICES PROFESSIONALS

QN 1: Investigating the attitudes of social services professionals towards people with albinism

- 1.1 Please introduce yourself briefly;
  - Name
  - Age
  - Gender
  - Level of education
  - Occupation
- 1.2 How much do you understand about people with albinism in Tanzania?
- 1.3 What do you think is the current situation of people with albinism in Tanzania?
- 1.4 As a social services professional, how long have you worked people with albinism?
- 1.5 What are your attitudes towards people with albinism?
- 1.6 How have these attitudes affected people with albinism?
- 1.7 How much do the community's attitudes affect your attitude towards people with albinism?
- 1.8 How do you think people with albinism should be treated?
- 1.9 How do you see the future of people with albinism in Tanzania?

### QN 2: Investigating the roles played by the social services professionals towards people with albinism

- 2.1 Individually, what role do you play towards people with albinism?
- 2.2 How long has been your institution providing help to people with albinism?

- 2.3 As the government/NGO, what roles does your institution play towards helping people with albinism in Tanzania?
- 2.4 What role does the Tanzanian government play in supporting people with albinism?
- 2.5 What role do you think people with albinism can play in changing their own society's attitudes towards them?
- 2.6 How does the Tanzanian government support the social services professionals who are involved in helping people with albinism?
- 2.7 What can be done to improve the social life of people with albinism in Tanzania?

### QN 3: Social Services Professionals' precautionary measures towards protecting PWA

- 3.1 Which people do you think should be involved to participate in understanding people with albinism?
- 3.2 How does your institution tackle down the barriers/challenges facing people with albinism?
- 3.3 What ways do you think can be used in eradicating the misconceptions about people with albinism in the society?
- 3.4 What measures do you feel are still needed to end the stigmatization, discrimination, persecution and ensure effective protection of people with albinism in Tanzania?
- 3.5 What are the changes you think that Tanzania can take for the benefit of people with albinism?

## APPENDIX 1: SWAHILI VERSION OF THE SEMI-STRUCTURED INTERVIEW FORM FOR THE GOVERNMENTAL AND NON-GOVERNMENTAL SOCIAL SERVICES PROFESSIONALS

### SW 1: Kuchunguza mitazamo ya wataalam wa huduma za jamii kwa watu wenye ualbino

- 1.1 Tafadhali jitambulisha kwa ufupi;
  - Jina
  - Umri
  - Jinsia
  - Kiwango cha elimu
  - Kazi
- 1.2 Je, unaelewa kiasi gani kuhusu watu wenye ualbino nchini Tanzania?
- 1.3 Je, unaweza kuelezea hali ya sasa ya watu wenye ualbino nchini Tanzania?
- 1.4 Kama mtaalam wa huduma za kijamii, umefanya kazi na watu wenye ualbino kwa muda gani?
- 1.5 Una mitazamo gani kwa watu wenye ualbino?
- 1.6 Mitazamo hii imewaathirije watu wenye ualbino?
- 1.7 Je, ni jinsi gani mitazamo ya jamii imeathiri mtazamo wako kwa watu wenye ualbino?
- 1.8 Je, unadhani watu wenye ualbino wanapaswa kuchukuliwaje?
- 1.9 Je, unayaonaje maisha ya baadaye ya watu wenye ualbino nchini Tanzania?

### SW 2: Kuchunguza majukumu ya wataalam wa huduma za jamii kwa watu wenye ualbino

- 2.1 Binafsi kama wewe mwenyewe, una jukumu gani juu ya watu wenye ualbino?
- 2.2 Je, taasisi yako ina muda gani inatoa misaada kwa watu wenye ualbino?
- 2.3 Kama serikali / shirika lisilo la kiserikali, taasisi yenu inafanya kazi gani (au ina majukumu gani) juu ya kuwasaidia watu wenye ualbino nchini Tanzania?
- 2.4 Je, serikali ya Tanzania ina jukumu gani katika kusaidia watu wenye ualbino?
- 2.5 Unadhani watu wenye ualbino wanawezaje kubadilisha fikra au mitazamo ya jamii zao juu yao?

- 2.6 Je, serikali ya Tanzania inawasaidiaje wataalam wa huduma za jamii ambao wanashiriki katika kusaidia watu wenye ualbino?
- 2.7 Ni nini kinachoweza kufanywa ili kuboresha maisha ya kijamii ya watu wenye ualbino nchini Tanzania?

### SW 3: Hatua za tahadhari zinazoweza kuchukuliwa na wataalam wa huduma za kijamii katika kulinda watu wenye ualbino.

- 3.1 Je, unafikiria ni watu gani wanapaswa kushiriki katika kuelewa watu wenye ualbino?
- 3.2 Je, taasisi yako inakabiliwaje na vikwazo / changamoto zinazokabili watu wenye ualbino?
- 3.3 Je, unafikiri njia gani zinaweza kutumiwa katika kutokomeza mawazo mabaya kuhusu watu wenye ualbino katika jamii?
- 3.4 Je, unadhani ni hatua gani zitakazoweza kutumika ili kukomesha unyanyapaaji, ubaguzi, mateso na kuhakikisha ulinzi bora wa watu wenye ulemavu nchini Tanzania?
- 3.5 Je, ni mabadiliko gani unafikiri kwamba Tanzania inaweza kuchukua kwa manufaa ya watu wenye ualbino?

#### **APPENDIX** 1: TURKISH VERSION **OF** THE SEMI-**STRUCTURED INTERVIEW FORM** FOR THE NON-GOVERNMENTAL SOCIAL GOVERNMENTAL AND **SERVICES PROFESSIONALS**

### SORU 1: Sosyal hizmet uzmanlarının albinizm insanlarına karşı tutumlarını incelemek

- 1.1 Lütfen kendinizi kısaca tanıtın;
- İsim
- Yaş
- Cinsiyet
- Eğitim seviyesi
- Meslek
- 1.2 Tanzanya'daki albinizmi olan insanlar hakkında ne kadar anlıyorsunuz?
- 1.3 Tanzanya'daki albinizmi olan insanların şu anki durumu hakkında ne düşünüyorsunuz?
- 1.4 Bir sosyal hizmet uzmanı olarak ne kadar süredir albinizm ile çalıştınız?
- 1.5 Albinizm ile insanlara karşı tutumunuz nedir?
- 1.6 Bu tutumlar albinizmi olan insanları nasıl etkiledi?
- 1.7 Topluluğun tutumu, albinizmi olan insanlara karşı tutumunuzu ne kadar etkiliyor?
- 1.8 Albinizm olan insanlara nasıl davranılması gerektiğini düşünüyorsunuz?
- 1.9 Tanzanya'daki albinizmi olan insanların geleceğini nasıl görüyorsunuz?

### SORU 2: Sosyal hizmet uzmanlarının albinizmi olan insanlara karşı oynadıkları rollerin araştırılması

- 2.1 Bireysel olarak, albinizmi olan insanlara karşı nasıl bir rol oynuyorsunuz?
- 2.2 Kurumunuz ne kadar süredir albinizmi olan insanlara yardım ediyor?
- 2.3 Hükümet / STK olarak kurumunuz Tanzanya'daki albinizmi olan insanlara yardım etmede hangi rolleri oynuyor?
- 2.4 Tanzanya hükümetinin albinizmi olan insanları desteklemedeki rolü nedir?

- 2.5 Albinizmi olan insanların kendi toplumlarının kendilerine yönelik tutumlarını değiştirmede oynayabileceği rol nedir?
- 2.6 Tanzanya hükümeti, albinizm konusunda insanlara yardım etmek isteyen sosyal hizmet uzmanlarını nasıl destekliyor?
- 2.7 Tanzanya'daki albinizmi olan insanların sosyal yaşamını iyileştirmek için neler yapılabilir?

### SORU 3: Sosyal Hizmetler Uzmanlarının PWA'yı korumaya yönelik ihtiyati tedbirleri

- 3.1 Albinizmi olan insanları anlamada hangi insanların yer alması gerektiğini düşünüyorsunuz?
- 3.2 Kurumunuz albinizmi olan insanların karşı karşıya kaldığı engelleri / zorlukları nasıl aşmaktadır?
- 3.3 Toplumda albinizmi olan insanlar hakkındaki yanlış algıların giderilmesinde hangi yolların kullanılabileceğini düşünüyorsunuz?
- 3.4 Tanzanya'daki damgalama, ayrımcılığı, zulmü ve albinizmi olan kişilerin etkili bir şekilde korunmasını sağlamak için hala hangi önlemlere ihtiyaç duyulduğunu düşünüyorsunuz?
- 3.5 Tanzanya'nın albinizmi olan insanların yararına yapabileceğini düşündüğünüz değişiklikler nelerdir?

## APPENDIX 2: ENGLISH VERSION OF THE SEMI-STRUCTURED INTERVIEW FORM FOR THE VOLUNTEERS (PWA)

- 1. Please introduce yourself briefly;
  - Name
  - Age
  - Gender
  - Level of education
  - Occupation
- 2. How was your childhood like? Do you think your albinism had an impact on your childhood?
- 3. What do you think albinism is? Do you know why your skin is lighter than most people in your society?
- 4. Who helps or supports you on a daily basis? Is it the government, the NGO, family or friends?
- 5. Do you know who is a social services professional or social worker?
- 6. What challenges do you face as a person with albinism?
- 7. What roles do social services professionals play in helping or supporting you to overcome these challenges?
- 8. What are the attitudes of the social services professionals towards you?
- 9. How have the attitudes of the social service professionals affected your life?
- 10. What do you think is the role of the government in helping people with albinism in Tanzania?

## APPENDIX 2: SWAHILI VERSION OF THE SEMI-STRUCTURED INTERVIEW FORM FOR THE VOLUNTEERS (PWA)

- 1. Tafadhali jitambulisha kwa ufupi;
  - Jina
  - Umri
  - Jinsia
  - Kiwango cha elimu
  - Kazi
- 2. Je, utoto wako ulikuwaje? Unafikiri kuwa mtu mwenye ualbino uliathiri utoto wako?
- 3. Unafikiri kuwa na ualbino kunamaanisha nini? Unafikiri ni kwanini ngozi yako ni nyeupe kuliko watu wengine katika jamii yako?
- 4. Ni nani anayekusaidia au anayekuunga mkono kila siku? Je, ni serikali, shirika lisilo la kiserikali, familia au marafiki?
- 5. Unajua nani ni mtaalamu wa huduma za kijamii au mfanyakazi wa kijamii?
- 6. Ni changamoto gani unazokabiliana nazo kama mtu mwenye ualbino?
- 7. Wataalamu wa huduma za kijamii wanafanya kazi gani kukusaidia au kukuunga mkono ili uweze kukabiliana na changamoto hizi?
- 8. Wataalamu wa kijamii wana mitazamo gani kwako?
- 9. Je, mitazamo ya wataalamu wa huduma za kijamii umeathiri vipi maisha yako?
- 10. Unafikiria nini ni jukumu la serikali katika kuwasaidia watu wenye ualbino nchini Tanzania?

### APPENDIX 2: TURKISH VERSION OF THE SEMI-STRUCTURED INTERVIEW FORM FOR THE VOLUNTEERS (PWA)

- 1. Lütfen kendinizi kısaca tanıtın;
- İsim
- Yaş
- Cinsiyet
- Eğitim seviyesi
- Meslek
- 2. Çocukluğunuz nasıldı? Albinizminizin çocukluğunuz üzerinde bir etkisi olduğunu düşünüyor musunuz?
- 3. Albinizmin ne olduğunu düşünüyorsunuz? Cildinizin neden toplumunuzdaki birçok insandan daha açık olduğunu biliyor musunuz?
- 4. Günlük olarak size kim yardım eder veya destekler? Hükümet mi, STK mı, aile mi, arkadaş mı?
- 5. Sosyal hizmet uzmanının ya da sosyal hizmet uzmanının kim olduğunu biliyor musunuz?
- 6. Albinizm ile bir insan olarak hangi zorluklarla karşılaşıyorsunuz?
- 7. Sosyal hizmetler uzmanlarının bu zorlukların üstesinden gelmenize yardım etmede veya desteklemede hangi rolleri oynarlar?
- 8. Sosyal hizmet uzmanlarının size karşı tutumları nelerdir?
- 9. Sosyal hizmet uzmanlarının tutumları hayatınızı nasıl etkiledi?
- 10. Hükümetin Tanzanya'daki albinizmi olan insanlara yardım etmedeki rolünün sizce nedir?

#### APPENDIX 3: VOLUNTARY PARTICIPATION FORM

#### (Researcher's Statement)

We are conducting a new research on attitudes of social services professionals. The name of the research is "Attitudes of Social Service Professionals towards People with Albinism in Dar es Salaam, Tanzania." The necessary permission was received from Hacettepe University Ethics Commission for this research.

We plan to reach the social services professionals in Dar es Salaam, Tanzania. But let us immediately say that you are free to participate in this research. Participation in the study is voluntary. We would like to inform you about the research before your decision. If you wish to participate in the research after you have read and understood this information, sign the form.

The reason why we want to do this research is the need to learn about the attitudes, roles as well as precautionary measures that of social services professionals take towards protecting PWA.

More clearly and in detail; we want you to share your inner thoughts and feelings towards how the social services professionals deal with people with albinism, those that work in the government also those that work in different non-governmental organizations as well. In order to fulfil this research, we will also want to participate with the main affected participants in this research and those are the people with albinism. The main aim of the study is to determine the attitudes of social service professionals towards people with albinism.

The application of the study will take place with you in the face-to-face interview, which will take an average hour and record your voice. Your personal experiences, feelings and thoughts about the people with albinism are very valuable for us to understand you in detail. It is very difficult to write down or keep in mind all of your conversations, and the conversation must be recorded with the recorder as every word you pass is very important.

Under the responsibility of Dr. Tarık Tuncay of Hacettepe University Department of Social Services, this study will be carried out by a graduate student Halima Ali Shekuwe of Hacettepe University. You will not be charged any fees for your participation in this study and you will not be charged any additional fees.

The information you receive from the research application will not be used except for scientific research purposes. The confidentiality of the information you provide us will be strictly protected. You may refuse to participate in this study. Participation in this survey is entirely voluntary, and you have the right to consent at any stage of the study. This will not bring you any responsibility.

#### (Participant's Declaration)

Professor Dr. Tarık Tuncay under the responsibility of social researcher Halima Ali Shekuwe by specifying that a research will be done by the above information was transferred to me. After this information, I was invited to this research as a participant.

If I participate in this research, I believe that the confidentiality of the information I have to keep between me and the researcher will be treated with great care and respect during this research. I was given sufficient confidence that my personal information would be protected with care during the use of the research results for educational and scientific purposes.

I can withdraw from the research without showing any reason during the execution of the project. (But I am aware that it will be appropriate to notify the researchers that I will withdraw from the trial in order not to leave the researchers in a difficult situation). I don't take any financial responsibility for the research expenses. There will be no payment for me.

When I have a problem with the research topic or the process, or when I have something I want to ask, at any hour I know that I can call Prof. Dr.Tarık TUNCAY 0 (541) 515 65 96 and social worker Halima Ali SHEKUWE from +90 542 816 3513 or I can reach them from Hacettepe University Social Services Department.

I don't have to take part in this research and I am not forced to participate in it as well. I don't have a compelling attitude to participate in the research. If I refuse to participate, I know that this will not harm me in any way.

I have understood all the explanations made to me in detail. I decided to take part in this research project as a araştırma participant "at the end of my own thinking period. I accept the invitation on this subject in great satisfaction and volunteering.

#### Date:

#### **Participant**

Name and surname:

Address:

Tel:

Email:

Signature

#### Researcher

Halima Ali SHEKUWE halima\_ali07@yahoo.com +90 542 816 3513

#### Responsible Researcher

Professor Dr. Tarık TUNCAY
Hacettepe University Faculty of Economics and Administrative Sciences
Department of Social Work
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0 (541) 515 65 96

#### **APPENDIX 6: TURNITIN REPORT**

ORIGINALITY REPORT		
<b>7</b>	% % 2% 6% ARITY INDEX INTERNET SOURCES PUBLICATIONS STUDENT	「PAPERS
PRIMAR	RY SOURCES	
1	Submitted to Mount Kenya University Student Paper	<1%
2	Submitted to Australian Catholic University Student Paper	<1%
3	Submitted to Erasmus University Rotterdam Student Paper	<1%
4	Submitted to Eiffel Corporation Student Paper	<1%
5	Ashley H. Robins. "9 Disorders of hypopigmentation", Cambridge University Press (CUP), 1991	<1%
6	Submitted to Institute of Accountancy Arusha Student Paper	<1%
7	Submitted to Vrije Universiteit Brussel Student Paper	<1%
8	Charles R. Scriver. "Garrod's Croonian Lectures (1908) and the charter 'Inborn Errors of Metabolism': Albinism, alkaptonuria, cystinuria,	<1%