Albinism: When Skin Becomes A Death Sentence

Using Advocacy In NGO Communication

Bachelor Thesis in Media and Communications Specializing in Peace and Development Studies. 
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Abstract

Title: Albinism: Hunted For Your White Skin. Using Advocacy In NGO Communication

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Aim of Study: The thesis is about a small NGO that is working with the rights of persons with albinism in Tanzania. It deals with the NGOs advocacy work on a local and national level, and addresses the challenges that come with their work.

Methods: Sharma’s Advocacy Model, semi-structured interviews, participatory observations

Theories: Advocacy, Media Advocacy, Policy Advocacy, ICT4D, Intercultural Communication

Material: Interviews collected in February and March 2014 in Tanzania, participative observations, case study of Tanzania Albinism Society

Main Conclusions: I have concluded that advocacy is a powerful tool for NGOs to use as a part of their strategic communication. NGOs in the Global South and especially Africa are given less attention, thus having less opportunities of reaching out with their message. I have also concluded that for an NGO to succeed in its advocacy work it needs to carefully identify its target audiences and adapt the messages thereafter. To build a relationship with the audiences is also an important part of the process, as a strong relationship increases the chances of involvement in the organization. ICTs can be very useful for NGOs that strive to reach out to the global community.

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List of Abbreviations and Acronyms

ICT – Information and Communication Technology
ICT4D – Information and Communication Technology for Development
MFS – Minor Field Study
NGO – Non-Governmental Organization
NPO – Non-Profit Organization
OCA – Oculocutaneous Albinism
PWA – Person/s With Albinism
SIDA – Swedish International Development Cooperation Agency
TNAD – Tanzania National Albinism Day
TAS – Tanzania Albinism Society
UN – United Nations

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1. Introduction

Since advocacy is a large part of the work that NGOs do striving to change the world into a better place, it was something that I wanted to focus on. I also wanted to focus on minorities that are not given much attention in the media, thus the case of persons with albinism (PWA) in Tanzania is most suitable. I find this subject highly important, partly because advocacy is an important communication tool for NGOs but still the topic of NGO advocacy in general stands relatively untouched in the academic world in comparison to how widely used it is. I also find it important as I wish to highlight the fact that PWA in East Africa, and most of all in Tanzania, are living in fear for their lives every day. Except for the fact that they are persecuted for their body parts they are also prone to develop skin cancer, which dramatically decreases their life span.

The thesis researches human rights NGO Tanzania Albinism Society (TAS) that advocates the human rights of PWA. It looks at TAS’ policy and media advocacy as well as their use of information and communication technology for development (ICT4D) and also partly intercultural communication in order to map out a part of the organization's strategic communication on a local and national level. There is a clear focus on advocacy throughout the thesis, and challenges that TAS face in their advocacy work. There is as well a more general approach where it looks at why advocacy is a useful tool for NGOs in their strategic communication work. The field research was conducted as a case study, as the empirical material gathered in field is based on one NGO that stands as a representative for small NGOs in this study.
2. Background

This part of the thesis contains background information about the subject itself, a description of what an NGO is, as well as previous research in this field. The historical background is presented in order to give a full understanding of the current situation for persons with albinism in Tanzania. The part about NGOs is included for the reader to understand the role of TAS as an NGO.

2.1 Historical Background

Oculocutaneous albinism (OCA) is a genetically inherited condition most often referred to as albinism. The condition is inherited from both parents (Hong et al, 2006:1). The occurrence as well as murders of persons with albinism is higher in Tanzania than in other countries. There is an estimation of 1/1,000 to 1/5,000 Tanzanians born with albinism, in comparison to Europe where 1/20,000 are born with albinism.

Discrimination against persons with albinism is deeply rooted in Tanzania’s history due to superstitious beliefs in poor rural areas, but the violence against them sparked in the early 2000. Since then the situation has escalated with nearly 80 documented murders (UNHRC Report 2013:5, 6, 10., BBC 2015) and another 67 violent but not fatal attacks (Under The Same Sun 1, 2014).

Due to the lack of comprehensive studies made on the subject, there is still no explanation to why the prevalence of persons with albinism is generally higher in East and South Africa in comparison to the rest of the world (Hong et al, 2006:2,3,5).

The superstitious beliefs have resulted in myths about persons with albinism, such as body parts bringing luck (Dave-Odigie, 2010:69) or having intercourse with a woman with albinism can cure HIV/AIDS. The body parts of a grown man with albinism are estimated to be worth in total US$250.000, offering the perpetrator financial security. The discrimination and stigmatization is further widespread throughout education, health care, and work environment amongst others (UNHRC Report, 2013:5, 9, 10).

The life expectancy of a person with albinism in Tanzania is estimated to be 30, whereas life expectancy in general in Tanzania is 60. This is due to the serious problem of skin

TAS is the largest NGO operating in the country in advocating for human rights specifically for the persecution of PWA. They work with different strategies including co-operations with other NGOs, as well as managing the establishment and annual celebration of Tanzania National Albinism Day (TNAD), which is their most successful awareness raising strategy. They also work with PWA right and opportunity to education and empowerment. TAS’ work and campaigning in cooperation with other NGOs, whom are presented further below, have resulted in improved media coverage and international interest in the issue.

2.2 Previous Research

Strategic communications is the very core of organizational communication with a certain purpose. It is a wide and thoroughly researched area within communication theory, and deals with how organizations shape and transmit a message in order to convince the audience to support the organization in its work (Patterson and Radtke, 2009:7-9). Strategic communications is fundamental in organizational communication toward an external audience, although it is too broad to use as a theoretical standpoint in this thesis. One dimension of strategic communications is advocacy, which can be used by all sorts of organizations and for all sorts of purposes.

Wherever change needs to occur, advocacy has a role to play. (Sharma, 2013:1)

Advocacy is strongly connected with NGOs and their communication work, and an often-used strategy in NGO work. Advocacy can be used in different ways and with the purpose of different outcomes. There is advocacy for organizational benefits and advocacy for social benefits, of which NGOs work with the latter (Garrow and Hasenfeld, 2014:80, 81). Advocacy can thereafter be applied in a variety of ways, it can be shaped for the use in different channels, to be aimed toward different audiences, and to be
purposed to achieve different changes. Policy advocacy is adapted by NGOs that aim to achieve policy changes that will serve the wellbeing of society and/or groups of people. A basis of policy advocacy is lobbying the government simultaneously as seeking the public's support in order to demand e.g. political changes (Mosely, 2013:231). Media advocacy derives from the idea that the media can produce messages that serve society in a positive way. NGOs using media advocacy in their communication use the media to provoke and shape public debate. Focus is not primarily laid on providing the audience information, but rather influencing the public agenda through including a social theme into the media content (Waisbord, n.d.:24). Advocacy can be adapted by NGOs in several more ways, however policy and media advocacy are the two kinds that will be focused on in this thesis. Thus, advocacy is one dimension of an organization’s strategic communication, and as explained above often the most crucial one as well for achieving change.

The previous research in this field is both wide and narrow. Strategic communications is well elaborated within academic research as well as different kinds of advocacy. However, when narrowing further into NGO advocacy the research changes from being plentiful into being less as well as more case specific. As I discovered there is lack of research on specifically NGO advocacy rather than organizational advocacy, I have approached the subject with sources from both case specific and the general organizational advocacy research, combined with the data acquired in field. I consider the data used in this thesis appropriate, even though not all of it is written with a focus on NGO advocacy specifically, but on advocacy in a more general manner. What is important to differentiate when choosing sources is looking at studies that work with advocacy in general or advocacy for social benefits, and excluding research on advocacy for organizational benefit as it is not applicable on NGOs in this case.

Information and communications for development (ICT4D) is a more well-researched area. Deriving from ICT it simply focus on how information and communications technologies can be applied and adapted in a development context (Unwin, 2009:33, 56).
Also intercultural communication is an area that offers a wide variety of research and plenty of information to attain. It deals with how communication is affected by culture, and what might happen when parties from different cultures communicate with each other. I have used intercultural communication very restrictedly in the thesis, however it does play a role in explaining certain communicative behavior, as will be seen further on in the text. Both ICT4D and intercultural communication are however given relatively little space in this thesis in comparison to advocacy, which is the main theoretical focus.

Furthermore, research on OCA is limited and unable to explain why the occurrence of persons with albinism is higher in East Africa than the rest of the world (Hong et al, 2006:2,3,5). It remains a mystery why Tanzania particularly has much higher numbers of PWA in the country compared to Europe.
3. Research Problem

TAS is focusing much of its work on raising awareness about albinism on a local, national, and international level. Being a small NGO in a developing country (World Bank) might imply obstacles in working with communications and advocacy, and to be able to reach all audiences the organization needs to be adaptable. Thus I have chosen to research how TAS is managing its advocacy work on two of the levels identified: local and national. I chose to exclude the international level as the data collected during the field study was almost exclusively for the local and national level, and the data for the international level was not extensive enough to use.

3.1 Research Questions

This thesis will deal with the following questions:

- By using Sharma’s Advocacy Model, how is Tanzania Albinism Society working with advocacy on a local and national level?

In order to answer the first question thoroughly by analysis and connection to the field of other NGOs working with advocacy, I will work with two follow-up questions:

- What are the challenges for Tanzania Albinism Society in their advocacy work?
- Why and how is advocacy a useful tool for NGOs in their strategic communication?

The questions will be answered by using the information I have acquired through interviews and participatory observations during a 10-week long minor field study in Tanzania March to May 2014, as well as books, newspaper and academic articles. The case study of Tanzania Albinism Society makes most of the thesis, with the exception of the last research question, which approaches the area more generally. I chose this field of study as well as research questions after in field experiencing great differences in how TAS worked with advocacy in different settings, and wanted to know why they work as they do, and what challenges that might impose. There is also a focus on advocacy, and
why it is an important dimension of NGOs strategic communication.

### 3.2 What is an NGO?

Heins (2008) describe NGOs as symbolic holders of power in their work of trying to create new categories of actors (15). The people who constitute NGOs are voluntarily members whom are active by personal choice. Heins further characterizes NGOs as not taking part of power struggles between or within states and as organizing activities driven by public well-being, thereby being representatives for the mass on a global scale and not only members of the organization. NGOs are also non-territorial political actors working internationally, either by working through different national branches of an international organization, or creating affiliates to the NGO in different countries (Heins, 2008:17-19). In other words, an NGO seeks no position of power, but is rather trying to affect those in power in order to achieve what the public want.

Furthermore, I am using the term “small NGO” in this thesis to define TAS’ organizational status and to give an understanding of their presumptions. As the use of the term small NGO is common and widely used in the academic world, I have chosen to continue with it in spite of the non-existing distinction between small and large NGOs. After reading numerous articles about small NGOs and contacting international organizations working with NGOs asking for some directions in how to distinct between small and large NGOs, and still standing without a definition, I have concluded that is because one has not been formulated yet.

From the organization PLANET’NGO I was informed that indeed there was no definition of small NGOs to be found, although within their organization they looked at financial assets. An NGO with less than 300,000€ would be considered a small NGO in their opinion. This further justifies my use of the term to define TAS as a small NGO, as their budget is below 300,000€. Onwards, by using the term small NGOs in this thesis, I like to highlight the need for a proper and universal distinction between small and large NGOs.
4. Theoretical Framework and Methods

[...] strategic communications is the combination of plans, goals, practices, and tools with which a nonprofit organization sends consistent messages about its mission, values, and accomplishments. (Patterson and Radtke, 2009:7)

Strategic communications is built up and adapted to the organization that applies it in its work. The purpose of strategic communications is to persuade and convince the audiences to help the organization in achieving its goals and missions. As Patterson and Radtke describes it, strategic communications can be built up by public education, fundraising, and advocacy, and will use different angles of communication aimed at a certain audience in order to achieve the greatest impact. These angles are articulations of mission, vision, and desired outcomes; presentation of the organization toward the audience/s; and definition of the issues and policies. The strategic communications plan assist the organization with implementing a strategy that will help it reach its strategic goals, and it should always be focused on moving towards the organizational goals and gaining more support. The challenge in this is articulating the organizational values in such a way that the audience can relate to it, and start supporting the organization in its work. When an organization start to implement strategic communications it creates a framework. This framework can assist staff and those involved in the organization in asking themselves whom they are trying to reach, why they want to reach them, and how they will know when they have succeeded. The framework can also help understanding why certain audiences are more important than others, and encourage collaboration between communications staff when they are working toward a shared goal (Patterson and Radtke, 2009:7-9).

After finishing the data collection it seemed clear to have a theoretical focus on advocacy. ICT4D and intercultural communications will also be focused on for smaller parts of the thesis as a tool to interpret data collected in field and for analysis of the content. Advocacy is seen as a single theory in this thesis, and also as the main theory. It is described below from a general point of view, but also from a media and policy
perspective as advocacy will be applied in media and policy contexts.

4.1 Advocacy
Sharma (2013) provides a visual model of the basic elements of advocacy (Table 1). These elements can be used in different combinations and be adapted in a way that is most useful to reach a certain advocacy goal (5-6).

![Diagram of the basic elements of advocacy]

Table 1 – Basic Elements of Advocacy

Sharma further explains the different elements of advocacy. Objectives are the goals of the advocacy effort. The objectives must be achievable, address the actual problem, and enable different groups to come together. Data is the information and research needed in order to identify solutions, and is an important dimension of advocacy work as good data is persuasive by mere existence. Data is also a useful tool in identifying whether the goals are achievable or not. Audiences are those who can influence and realize the
objectives, implying both policy makers and those who can affect the policy makers, such as advisors. Thus, being able to identify which audience to turn to is crucial in successful advocacy. *Messages* is the information provided for and adapted to the audiences. It is equally important to take in regards what audience to turn to as well as how to shape the message for that certain audience in order to gain as much response as possible. *Presentation* is the skill of using opportunities to present the objectives persuasively. This means being prepared to professionally being able to present at any time under any given circumstance. Decision makers and donors are not always able to book a 45-minutes long meeting to hear the objectives. *Evaluation* is knowing how to receive feedback and become more effective, thus learning from strengths and weaknesses in order to improve the future advocacy work. *Fundraising* is gaining financial or other resources to support the work, and it includes the organization’s ability to find those who are willing to invest. *Coalitions* is the ability to build coalitions with people who can support the work. These people can be policy makers, private persons, other organizations, anyone who can share the organization’s objectives and work toward the achievement of them (Sharma, 2013:6,7).

The purpose of this model is to identify which of the elements that are focused on in TAS’ work on the local and national level. By looking at how the different elements are applied in TAS’ advocacy work, I will answer my first research question “By using Sharma’s Advocacy Model, how is Tanzania Albinism Society working with advocacy on a local and national level?” and build a foundation with which I will analyze the empirical material. The model is especially useful in this thesis as it can be used to analyze advocacy work by different actors and on different levels. The model is useful in this thesis also because it is easily understood, visually and in text, thus allowing the reader to follow the text.

Obar et al (2012) explains advocacy as groups such as NGOs lobbying and advocating for e.g. policy change when the public, or groups of people, are affected in a negative way. These policy changes can be on the local, national, and international level. Hence, advocacy groups seek to influence the political decision-making process, but want no
position of power themselves. That is, no power other than that of 'the voice of the people' whom they represent (p 4).

4.1.1 Policy Advocacy

Advocacy with the specific aim of changing policies is often referred to as policy advocacy. There are many different factors affecting how effective the advocacy work will be. Some of them are hard for the organizations to influence, such as how the advocacy work by the organization is perceived by the policy makers themselves. Others depend on the organization's ability to respond to audiences, e.g. by using social media and adapting a more modern way of advocating, and as low funds is a recurring problem in the majority of NGOs, resource allocation is also a cornerstone in advocacy work (Mosely, 2013). The incentives of NGOs advocating for policy changes is a subject that needs to be considered as a factor that might affect the advocacy work. As Mosely mentions, many NGOs depend on government funding; hence they also have a financial interest in keeping the relationship with the government on good terms. Thereby, the NGO has to keep this in mind when advocating for things to be changed within the government, and this might hinder the NGO from working at its full potential and capacity (Mosely, 2013).

It is citizens represented by nonprofits that initiate policy advocacy, a bottom-up approach that represents the vulnerable individuals in society. Also deliberately influencing decision makers, as well as transforming the policy making process into being more transparent and accessible to the public. Policy advocacy does imply some issues, one of them being time. Changing policies is not something achieved overnight but are long-term projects, something not all organizations can afford nor very attractive to supporters whom want instant change and results (Gen & Wright, 2013:164, 165).

4.1.2 Media Advocacy

Media advocacy is using the mass media strategically to advocate for policy changes,
often with its focus on public health issues. By using the media and the many channels available through it, organizations disseminate information in order to inform the public about health issues. The approach is never on the individual level, but on the societal (Waisbord n.d.:24, Dorfman & Wallack 2001:394). According to Dorfman (2003), media advocacy focuses on the so called ‘power gap’, meaning that health issues in society arises from powerlessness in terms of changing and affecting the surrounding environment. This implies that the media advocacy approach to health issues, as mentioned above, are not about changing individuals’ behavior, but rather changing society as a whole. This implies that public health is viewed as a social, not individual, responsibility. Media advocacy also usually do not intend to reach those affected by the problem, but instead those who are in position to change. Dorfman further argues that one role of media advocacy is to reduce the existing power gap, and thereby striving toward the ability to make change happen (Dorfman, 2003).

Media advocacy theory goes by the notion that public opinion and debate are affected and shaped by the media. Thereby going by the media to advocate is not the only way of advocating, but being able to influence the news agendas is equally important in order to provide the public with debate for the common good (Waisbord, n.d.:24). Dorfman and Wallack (2001) argue that the media is useful in advocacy in order to reach a larger audience and amplify their voices and opinions on health issues. It is not the strategy per se to achieve policy change, but rather supposed to work as a catalyst for change by using the media to inform the public about a given issue and what needs to be done about it (Dorfman & Wallack, 2001:393-395).

4.2 ICT4D

ICT4D means using information and communications technology (ICT) in a development context and purpose. In his book ICT4D, Unwin (2009) explains information as “something that exists […] for use in a diversity of ways” (ibid, 53). Communication is defined as “[…] the means by which people create their identity. It underlies our sense of community, our sense of belonging and our sense of difference” (ibid, 61). Information is produced and communicated, and becomes knowledge when it has been processed by
the receiver (ibid, 21). Information needs communication to be of any value; especially in a development context in which communication between stakeholders and policy makers needs to exist in order to meet the stakeholders needs (ibid, 61).

Using information and communication technology for development (ICT4D) implies that the user has a moral agenda in its communication goals, thereby not focusing on the technologies per se, but rather the function of the technologies in a development context (Unwin, 2009:33, 56). A typical mistake in the past has been primary focus on the technologies instead of the development process itself, which results in unsustainable projects that does not focus on the needs of the poor people firsthand. Onwards it is crucial to keep in mind that the technologies also can be fully understood and benefit the user, another dimension of focusing on the person rather than the technology (ibid, 2009:39, 76).

Two main approaches to use information in development work have been defined by Unwin as the delivery of a certain message, and the focus on discussion and networking. It is seen how the first approach is one-way communication whereas the second is two-way with consideration given to those involved in the development process. This division stems from the changes that the communications field has gone through since the 1960s, transforming from a linear and non-participatory style into a participatory and bottom-up approach (ibid, 2009:62, 63).

4.3 Intercultural Communication

Samovar (2009) defines intercultural communication as “[…] interaction between people whose cultural perceptions and symbol systems are distinct enough to alter the communication event” (12). Communication serves people in different ways, e.g. it can define the relationship between two people, and it can change the way you communicate with different people depending on how they communicate with you. Communication is thus also very depending on the context, of which culture is the strongest influence. What is considered a respectful gesture in one culture might be seen as highly offensive in another, e.g. touching the other person (ibid, 2009:15, 18). Hall states that “culture is
communication and communication is culture” (Hall, 1977:14) which clearly points out the strong connection between the two, and the difficulty in separation the two from each other. This is because your own culture is learned through communication, at the same time as your communication reflects your culture. Culture serves as a blueprint for your life as you can predict your surroundings as long as it is within your own cultural framework, and thus also protects you from unknown cultures as long as you stay within your own (Samovar, 2009:22-24).

In different cultures it is possible to see age groups that affect the way people of different ages communicate with each other. For an example, in the United States youth is highly valued whereas African tradition values age and seniority much higher than youth (ibid, 2009:71-73). When age is viewed as superior to youth in a culture, naturally it will affect the communication between these two groups of society, and the way youth communicate toward the elderly might differ radically to how the elderly communicates toward youth. For an example, it is common for youth to lower his or her eyes and avoid eye contact when communicating with someone who is older in order to show respect (ibid, 2009:187, 263). Thus it is crucial to keep the cultural values in mind when analyzing communication in different settings, for what might mean something in one culture might be the opposite of another, as also discussed later on.

4.4 Summary of Theoretical Framework

In sum, the analysis of the strategic communications will be approached from an advocacy perspective, from a general perspective but also with a focus on policy and media advocacy. Advocacy is one dimension of strategic communications, and a very important one for NGOs looking to reach out to their primary audiences and gaining support for their work. Thus advocacy is the main theoretical angle in this thesis. ICT4D is used to highlight the information and communication technologies can be applied in this specific case study and the NGOs advocacy work in certain situations. It is a relevant theory to be applied where technology is directly involved as a means for communication in this case study, and where the use or non-use of ICTs is connected to advocacy. Intercultural communication is the final and least used theory, although useful
for analyzing observations of interactions and styles of communication between people. The theoretical framework has been put together after the field studies, and based on information gathered during the field studies.
5. Methodology
The research in field was conducted for 10 weeks between March and May 2014 in Tanzania, although preparations for the thesis started in September 2013 in order to apply for the Sida financed minor field study (MFS) scholarship. Researching in field has been very prioritized during the whole process of planning the thesis, as experiencing in real life rather than solely through books and articles seems like the best way to put knowledge into practice. The research has been conducted as a case study as all the empirical material, both interviews and participatory observations, collected in field has come from one organization.

In the early writing process I was focusing on three levels of advocacy work; local, national, and international. After considering the data collected in field I decided to remove the international level, as there was an insufficient amount of data on that particular level to properly answer the research questions.

5.1 Tanzania Albinism Society
TAS is a national umbrella non-governmental and nonprofit organization established in 1978, and registered in 1980. The NGO’s main purpose and function is advocating for the rights of persons with albinism, and raising public awareness about what albinism is. They do so by advocating on different levels, local, national, and international. One of the major advocacy tools of TAS is Tanzania National Albinism Day (TNAD) established in 2006 and celebrated annually since, on the 4th May (Attachment 1, TAS Profile). TNAD is an opportunity to gather persons with albinism, the community, the media, other organizations, and policy makers to bring up issues surrounding persons with albinism in Tanzania, to create a forum for discussion, and to educate the community about albinism. TAS is currently advocating for the United Nations (UN) to turn 4th May into World Albinism Day in order to raise awareness not only in Tanzania, but all over the world where persons with albinism are experiencing stigma due to their genetic condition (Odunga, 2014).

During TNAD, TAS arranges for different activities: dance performances by persons with
albinism, free skin cancer screenings, lectures and discussions on different aspects of albinism, and a two-day long international conference in Dar es Salaam (Ziada Nsembo, 2014).

5.2 Cooperative NGOs and nonprofits
Asante Mariamu and Standing Voice are two of the main organizations that arranged TNAD in 2014 in cooperation with TAS. Asante Mariamu is an American nonprofit organization that was started after a Tanzanian woman with albinism was attacked and injured for protecting her son from assailters. The purpose of the organization is to spread information about the situation for PWA in Tanzania and East Africa, and to promote a safer and accepting environment for PWA (Asante Mariamu website). Standing Voice is a UK charity promoting social inclusion and wellbeing of PWA in Tanzania. The organization was started as a joint project by the makers and key protagonists of documentary In the shadow of the sun (Standing Voice website).

5.3 Research Design
While in Tanzania, I conducted a case study with non-governmental organization Tanzania Albinism Society. In order to gain an insight of the organization, I spent time with staff from TAS, made participatory observations with the organization in its work, through email correspondence, and by interviewing TAS staff. Through this I have concluded that TAS is advocating mainly on three levels: local, national, and international, of which in this thesis I will focus on local and national.

The methods used in this thesis have allowed me to analyze from a qualitative perspective. The first research question “By using Sharma’s Advocacy Model, how is Tanzania Albinism Society working with advocacy on a local and national level?” is answered mainly through the data collected from observations and interviews. The second question “What are the challenges for TAS in their advocacy work?” is based on the data collection from the field studies, but completed with information from books and academic articles. The third question “Why and how is advocacy a useful tool for
NGOs in their strategic communication?” is partly based on TAS’ advocacy work, and partly in information obtained from articles.

5.4 Structure of the Interviews
The first two interviews with Executive Committee Member Mr. Mohamed Chanzi and Secretary General Ms. Ziada Nsembo on 14th March 2014 were semi structured and prepared for in beforehand. They developed into being more of unstructured interviews as I allowed the interviewees to steer the interviews, and I thereby adapted my questions to them. Both interviews lasted approximately 45 minutes and were held in Singida.

My third and final interview was with Head of Communications Office Mr. Josephat Torner on 30th April 2014, and went by the same method and prepared questions. Overall I let him talk freely, only steering him with questions when needing clarifications or more information about something specific. The questions were open and allowed for the interviewee to give his own point of view. The interview lasted approximately 40 minutes, and was held in TAS main office in Dar es Salaam. This proved to be somewhat negative as the interview was interrupted at several times, there were much background noises, and the transcript of the interview was at times difficult due to the noises.

The themes of the interviews differed somewhat, as I in the beginning of my field studies planned to focus my thesis more on TAS’ relationship to the media, whereas I at the end was focusing more on their advocacy work in connection to TNAD. My main reason for shifting focus of my thesis was the difficulty of getting in contact with journalists whom could and would answer my questions. Many journalists choose to be anonymous when writing about albinism, which also made it difficult to reach journalists specializing specifically in that area. After the first two interviews I found I had plenty of material to write about TAS’ advocacy work per se instead of their relationship to the media, and thus chose to do so.

The Program Officer of TAS, Mr. Severin Edward, has provided complementary
information mainly via mail correspondence. I have been in contact with him since the
beginning of October 2013, and since then he has provided me with information about
TAS and their work. While in Tanzania we corresponded also via text messages, phone
calls, and meetings in person. He has provided me additional information via mail after
my return to Sweden.

The date and place of the participatory observations are presented in short below.

Monday 10th March, Dar es Salaam
First meeting with TAS staff at main office on Ocean Road Cancer Institute in Dar es Salaam. Lasted a couple of hours during which we discussed the purpose of the thesis, TAS’ work, an upcoming field trip to Singida, the upcoming conference and Tanzania National Albinism Day celebrations in May.

Thursday 13th March, Singida
Visited Kizega Primary School outside of Singida with five PWAs whom are working with TAS. The visit lasted about two hours during which TAS had a meeting with the principal and staff of the school, and met the children to hand out the donations. Due to the language barrier, I was not able to understand most of the conversations or speeches as they were speaking Kiswahili. When the visit was done, all staff from TAS were interviewed live for a radio show by a journalist whom accompanied TAS to the school. Kizega Primary School is a privately owned school.

Friday 14th March, Singida
Visited government owned Ikungi Primary School outside of Singida with same TAS staff as previous day. The visit lasted about two hours as well, of which about 30 minutes were spent with the children. The rest of the time was spent in the principal’s office. As during the visit at Kizega Primary School, most talking was in Kiswahili.

Thursday 3rd May, Dar es Salaam
The international conference was arranged by TAS in cooperation with organizations
Asante Mariamu and Standing Voice, and the Turkish Embassy, and held at the Serena Hotel in Dar es Salaam. Full-day conference, timetable is attached as Attachment 2. Approximately 100 people attended the conference, which was expected prior to the conference.

Friday 4th May, Tanzania National Albinism Day, Dar es Salaam
Although I was unable to attend the celebrations and event on this day in person, I am still able to highlight the 4th May in this thesis thanks to interviews with TAS staff.

Other
Informal conversations and unstructured interviews have been made with staff at TAS and other people of relevance for this thesis. Even though what was said during these have not directly been used in this thesis, it has had a great impact in terms of leading me in the right direction, and being better prepared for actual interviews by already having some information. The most valuable part of this information is enabling me to get to know TAS and their field of work, as well as others related to their work.

5.5 Critical Aspects of Fieldwork in Tanzania
Since I had no previous experience of field studies like this prior to going to Tanzania, there are some things that I have learned and would do differently in the future. I would start off earlier with trying to reach interviewees (in my case journalists for the original purpose of the thesis), I would also contact the cooperative organizations earlier for interviews with their representatives, and I would want a clearer schedule for activities with the organization/s. Interviewing more people that have no direct connection would have enabled me to have more objective data, however I do not consider the data I do have less valid because of this. The purpose of including observations was to provide opportunities to not only hear the interviewees talk about their organization, but to also see how they work. However, there are some methods to ensure that the study will be as valid and reliable as possible.

Darawsheh (2014) explains reflexivity as an important part of research and its
credibility. Reflexivity is defined as “[...] the continuous process of self-reflection that researchers engage in to generate awareness about their actions, feelings and perceptions” (561). He further explains that reflexivity improves the transparency of the study in which it is used, and can be applied to the research e.g. during the data collection (ibid). While in Tanzania I took notes from the participatory observations as well as field journal notes and reflective and analyzing notes about the observations. These notes were focused on the observations and organization per se rather than self-reflective.

Regarding the validity of the information gathered through interviews and observations it is possible that the interviewees said or did certain things based on the social structures and an expectations of receiving something in return that might help them in their work. Mikkelsen (2005) describes this as a transaction between human beings, in which resources are given and received. These resources can be symbolic, social approval, and/or material (158). Expectations on an exchange, e.g. information for a donation, might decrease the validity of the content, as the information provided could be adapted to the expectations. One example of this is from when I visited Kizega Primary School on 13 March 2014. The principal was very eager for my visit and told me much about the school’s work, and finished with asking for a donation. I decided not to include the principal’s information in my thesis due to this, as it clearly was provided in a way to encourage me to make a donation.

The participatory observations did provide me an insight of how TAS is working and communication. The symbolic interaction between people is dependent on the social situation, which might have changed when I was present to how it is elsewise (ibid). In order to avoid disturbance of the “usual setting” I tried to keep a small distance at times and observe from e.g. a corner or a chair a few meters away. This however does not assure that the social situation and thus the interactions were affected by my presence. I am also aware of the cultural influence when doing participatory observations, and how being in a culture that is different from my own indeed can give me impressions that are more coherent with my own culture rather than the one that I am observing.
In the end I do consider the data used in this thesis as valid information. The validity could have been further secured through also interviewing people that are indirectly involved with TAS, such as staff from collaborative organizations Asante Mariamu and Standing Voice. It would not be as valuable as information from TAS staff however, as it is specifically TAS’ communication that is approached in this study. I could also have focused more on my own ability to be as objective as possible during the research process by using the reflexivity approach, i.e. taking notes also on my personal feelings in order to reveal any subjective parts in the research. Also being able to get to know the culture a bit more before doing participatory observations might secure that the observations are fairly understood and analyzed.
6. Results

TAS is working with policy advocacy and media advocacy on two levels: local and national. Embedded in part of their advocacy work is ICT4D, i.e. the application of information and communications technologies in their development work. The levels have been identified through interviews with staff at TAS and during participatory observations. By working actively on the two levels it is important for small NGOs to be able to use different tools in order to reach out to different target groups. Small NGOs like TAS in particular need to reach out to the rural communities by working at a local level, simultaneously as working on a national level to achieve policy changes, gain funds from donors, and reach out to the national and sometimes also international community. As staff at TAS stressed their need to work on the two levels, I consider them equally crucial in TAS’ advocacy work and as a means to achieve their goals, as defined below:

[...] to emancipate people with albinism from all forms of discrimination and negative attitudes and advocate for their rights while empowering them to realize their potentials. (Attachment 1, TAS Profile, 2)

The results have been put together by analysis of TAS’ work on the two levels with a focus on their advocacy. This part will be used to answer the first research question “By using Sharma’s Advocacy Model, how is Tanzania Albinism Society working with advocacy on a local and national level?”.

6.1 Local Level

Everything is an advocacy plan. It is important to advocate the parent and the teacher since the children with albinism don’t always know their own risks. We talk to the parents since not many parents know how they can help their children with albinism. (Mohamed Chanzi, 14/3-14)

Being a small NGO with low funds, TAS and its staff focuses much of its advocacy work in the community on a local level. TAS stresses the importance of taking every opportunity
of advocating for the wellbeing of persons with albinism, such as small talk on the streets, in the super market, and visiting homes. As all three of the interviewees are persons with albinism, they often encounter opportunities to explain what albinism really is, and what it is like living with it in Tanzania.

Families hide children with albinism at homes hence denying them their rights to education. TAS works hard in both rural and urban to identifying such families and ensures that children with albinism are sent to [school]. It has been our work to also link people with albinism with their peers in their areas through our branches so as to reduce stigma and promote positive exposure. (Attachment 1, TAS Profile, 3)

Informing the community means reaching out to everyone in society in order to work against discrimination, stigma, violence, and dehumanization. Schools have been especially important to TAS in their work on the local level. Due to the lack of melanin production, persons with albinism are visually impaired and need special schooling in order to become educated (Dave-Odigie 2010:69, Hong et al 2006:1). Thereby, teachers need to know how to provide children with albinism a way to have equal opportunities to learn as the other children in the classroom. This requires the children to sit in the front of the classroom, to have books with larger print, etc. (Ziada Nsembo, 2014).

In their advocacy work on the local level TAS is focusing mainly on audiences and messages, as shown in Table 2 and the following text.
6.1.1 School Visits – Audiences and Messages

In their work, TAS visit schools in different regions in Tanzania to inform children and teachers about albinism and what it is like living with it. This material is based on participatory observations from visits at two primary schools outside of Singida and interviews with TAS staff. These visits were arranged for mainly three reasons. First, TAS donated sunscreen, sunhats, information slips, pens, and other items to the schools. The hats were printed with TAS’ logo. Second, they talked to the children and staff at the schools about albinism and about their organization. Third, they met reporters at both schools to document the donation, and to highlight the upcoming Tanzania National Albinism Day. On the first school visit they were interviewed live in Tanzanian radio, and at the second school they were interviewed for a newspaper article.

Working face-to-face is an important dimension of TAS’ advocacy work and a
cornerstone of their educational work in local communities. Face-to-face communication enables direct feedback from the listener, and the message can be understood easier combined with the non-verbal communication. By doing visits as those at the primary schools, TAS have the ability to personally meet people, give them a chance to ask questions, and show them in person that they too are people, and not “ghosts” (UN News Centre 1 2013, McManus and Tennyson 2008:46).

We educate the parents in how to protect their children from the sun by using good clothes, and to love and care for their children, and to take their children to school when they grow up. In school, the children are facing many challenges in the classroom. They are sitting far away from the blackboard, and there are so many children in one classroom with few books, and it is hard for a person with albinism to share a book with ten other people. (Ziada Nsembo, 2014)

In the case of visiting schools, TAS is actively seeking out mainly the aware public; those who are aware of the issues related to albinism in Tanzania and might become active later on. They do so by visiting children and young adolescents with albinism or people that are related to persons with albinism. This is a strategic move in terms of transforming the aware public into becoming engaged in the issue, and later to work actively for TAS. It is strategic for small NGOs with low financial means to target specific audiences as it increases the chance of the recipients of TAS’ message to actively become involved (Patterson and Radtke, 2009:65).

TAS targets children with albinism, teachers, and principals of the schools as primary audiences. These audiences are particularly important for TAS’ work as they represent the future of persons with albinism in Tanzania. The message in this way of advocating is specifically shaped after the two primary audiences. The way TAS spoke to the children was a very formal and informative way, whereas the meeting with the principal and teachers were friendly and informal, thus more focused on relationship building. A third audience during these visits was the journalists and the media, for which the
message brought forth was specially shaped for this audience.

Participatory observations allowed me to observe the communication process between TAS and the three audiences at the schools. The meetings with staff and principals of the schools were given most time, with a focus on introductions and informal conversation before the actual meetings began. When TAS spoke to the children, however, it was formal and one-way communication from TAS’ side.

We are at a meeting with the principal of the Ikungi Primary School. Like the previous meetings it is very relaxed. There is much focus on presentations, and every meeting is started with a somewhat ceremony of introductions. Also, I am introduced by Ms Ziada Nsembo at every meeting. By the end of every meeting we write our contact information in a guestbook, an important part of being able to keep in contact in the future. Most of the time spent at the school is in the principal’s office due to heavy raining outside. We are waiting for it to stop so that we can take pictures of the children. (Louise Jönsson Andersson, 3, 14 March 2014)

With the journalist from the first primary school, TAS staff spent much time for informal talk and relationship building before doing the live radio interview.

A journalist is present at the meeting with TAS in Singida, which seems to make staff from TAS very pleased. The communication between the journalist and TAS staff is not hierarchical in any way, but open and respectful. The journalist interviews everyone whom are present in the room (except for myself) and they are talking about today’s visit at Kizega Primary School and about the items that TAS donated to the school. (Louise Jönsson Andersson, 1, 13 March 2014)

TAS’ differing relationships to the audiences may be rooted in cultural values. The one-way communication with the children may have been simply the formal relationship
between a grown person and a child. In many African cultures age is valued higher than youth, which would affect the way a young and an old person communicates with each other, as seen when TAS visited the schools (Samovar, 2009:71-73). When comparing TAS’ distant way of communicating with the children to the informal and friendly way they communicated with the journalist, it is reasonable to assume that this is rooted in how the journalist had something that TAS did not have, but needed: access to larger audiences. By acting in this way with the journalist, TAS increased their chances of getting as much as possible out of the relationship with him, accordingly with cultural values. Cook and Emerson (1978) explain this behavior as the exchange of e.g. information resources between different parts, in accordance with exchange theory. Exchange theory is based on the premise that all human interaction is an exchange, be it social, economic, or other resource exchange. The exchange between two or more people can be positive or negative, this depending on several factors such as social power as well as how much the parties gain from the exchange (Cook and Emerson 1978, Mikkelsen 2005:158).

6.1.2 Changing Attitudes and Values – Audiences and Messages
Another focus of TAS’ work on the local level is changing the negative attitudes in the communities toward persons with albinism. Their work for changing attitudes is integrated in all levels of their advocacy work, but it is most prominent on the local level as it is part of TAS’ personal connection with the community. By visiting schools, going to villages, speaking at churches and mosques, etc., TAS is able to inform the community of the challenges that PWA experience, and even more important; that they can achieve the same things in life as anyone else, if given the opportunity. One example is when Mr. Josephat Torner climbed Mt Kilimanjaro in order to show the public that a person with albinism can also achieve extraordinary things.

I told the media that before I climbed Mt Kilimanjaro people saw me as a person with albinism, but after the climb, they saw a person. (Josephat Torner, 2014)
By this, Mr. Torner and TAS emphasizes perhaps mostly the importance of changing values in society before enabling any substantial changes in the long run. The negative attitudes toward PWA are rooted in superstitious beliefs, and the situation is further escalated by the high demand of body parts on the black market. This demand is especially high among Tanzanian fishing and mining industries, in which body parts of PWA are said to secure income (Dave-Odigie, 2010:71, 72).

TAS focuses on changing the society's negative attitudes and values toward PWA in different ways, this in order to reach out to as many as possible. Another way of working is showing the community craftwork of PWA.

When people see what persons with albinism can make with their own hands, it will mean that people that think that persons with albinism are not like others, will understand that persons with albinism are the same as others, through their work. This reduces negative attitudes. (Ziada Nsembo, 2014)

TAS both addresses and engages the community, providing people the chance to participate and focus on building a relationship to those outside of TAS (Grassroots Advocacy Handbook, 9). In accordance with the basic elements of advocacy model (Sharma, 2013), also here TAS focuses its advocacy work on the audiences and on the message, although differently compared to the primary school visits. Instead of focusing on health and security issues as when aimed at students and teachers, the messages are focused on transforming negative attitudes into accepting persons with albinism in society, and aimed toward a much broader audience; the community as a whole.

When transmitting a message to different audiences it is necessary to know how to express the message in a way that correspond with the target audience as well as its values, experiences, and perspectives (Patterson and Radtke, 2009:89). In order to express it accordingly, the organization should consider how the message can best be adapted and transmitted to the targeted audience, as “a strong message will help the
nonprofit organization achieve its objectives” (ibid, 88). When creating a message the organization can use the message triangle as guidance for what things to consider. The triangle method consists of three steps that are the core of creating a message, and can be adapted to any audience. First, the issue needs to reflect the common values of the audience, and it can then create a connection between the organization and the audience. Second, the message should express to the audience why they should care for the given matter and hand them a direct and relevant reason. Third, asking the audience to commit to the cause of the organization in order to help solve the issue (ibid, 102, 103). Should the message be successful, the audience will feel personally involved in the issue, and that will encourage them to take action.

In the cases of Mr. Torner climbing Mt Kilimanjaro and PWA displaying their artisan work as described by Ms. Nsembo above, the message triangle shows the following: the issue is that PWA are regarded not as people but as “ghosts”, the audience (in these cases the general public in Tanzania) should address the equal rights of all people in Tanzania, and that the first step toward this is for people to realize that PWA are people just like anyone else.

6.2 National Level
On the national level, Tanzania Albinism Society is working mainly with addressing the government for policy changes and raising awareness about albinism in the media, but perhaps most importantly they have Tanzania National Albinism Day in which many advocacy tools are included and shown in varied ways. Compared to their work on the local level, TAS is more focused on using technological tools such as the Internet in their awareness raising as well as reaching out to a broader audience including decision-makers.

The political work on the local level has proven to be a large part of TAS’ work on the national level, as political changes are considered a foundation for a future improved livelihood for persons with albinism through by law being given better prospects for e.g. education and security.
As shown in Table 3 and the following texts, on the national level TAS is focusing its advocacy work mainly on coalitions, data, audiences, presentation, and fundraising. As seen already when regarding the model below, the step up from the local to the national level is large and includes more elements of advocacy, mainly because of Tanzania National Albinism Day.

![Diagram of advocacy elements]

*Table 3 – National Advocacy Elements*

### 6.2.1 Lobbying The Government - Coalitions

In the beginning there was nothing. A person with albinism could not go to a government office and talk to the politicians. (Ziada Nsembo, 2014)

Advocating for policy changes in the government is a cornerstone of TAS’ work. Persons with albinism are more prone to develop skin cancer than others due to the lack of
melanin production (Dave-Odigie, 2010:69). This has been a problem in public schools, as by law children previously had to wear shorts and short sleeved shirts in the first years of school. They were also not allowed to wear hats. This increased the risk for children and adolescents with albinism to develop skin cancer. In her interview, Ms. Ziada Nsembo explained how TAS addressed the problem with the government, and had them approve special uniforms for children with albinism in order to protect them from the sun.

[...] in schools children wear short sleeves and they are not allowed to wear hats. So we went to the government and spoke to some people, who are the owners of the schools, about the problem for the children with albinism. They allowed children with albinism to wear hats, long sleeved shirts, and trousers. (Ziada Nsembo, 2014).

By this way of working, TAS is approaching the issue from a bottom-up perspective, focusing on the core of the issue, in terms of preventing skin cancer and addressing the issue of short life expectancy among persons with albinism. Simultaneously as they are dealing with adult persons with albinism suffering from skin cancer, they are also doing preventative work with children and adolescents to provide them better living conditions in the future.

One of TAS’ objectives in lobbying the government is the implementation of the UN Convention of Human Rights of People With Disabilities, which was promoted during Tanzania National Albinism Day in Dar es Salaam 2014 (Odunga, 2014). The convention addresses the same issues as TAS is working actively with, and calls for e.g. equality, awareness raising in order to strengthen persons with disabilities in society, and to provide equal access to justice. Article 16, “Freedom from exploitation, violence and abuse” and article 24, “Education” are amongst the currently most important parts of the convention that need to be focused on by the government, as physical and psychological safety as well as access to education are both cornerstones of changing the situation for many PWAs in Tanzania today (United Nations, 2006).
During Tanzania National Albinism Day, themed “Right to health, right to life”, TAS had the Minister for Health and Social Welfare, Dr. Seif Rashid, speak about the government’s initiatives for providing persons with albinism in Tanzania better living conditions. Dr. Rashid spoke on the behalf of the government as being there for all citizens of Tanzania in terms of creating a safe environment and counter the negative beliefs about albinism. TAS’ policy advocacy has brought up the need for educating the community about albinism and adapting legislation to increase security for persons with albinism, which the government has been working with actively since the killings of persons with albinism started, and when it peaked in 2009 and 2010 (Kimaro 2014, Ziada Nsembo 2014).

6.2.2 The Media/ICT4D - Data
The media is the information and communication technology most used by TAS in their advocacy work on the national level. When asked about TAS’ relationship to the media, the interviewees described it as a good relationship in which both parts actively seek each other out.

Sometimes the media call us and sometimes we contact them to arrange a meeting. (Mohamed Chanzi, 14/3-14)

Although reaching out to the media, such as newspapers and tv stations, can be problematic for small NGOs, TAS appears to have been successful in gaining the general media's attention. As described by Mr. Chanzi, TAS has been actively seeking out the media and journalists for TAS to keep appearing in news coverage regularly. They understand the possibilities of using the media to reach out to communities and educate the public on what albinism is. Unwin (2009) describes the modern world as “24-hour seven-day”, implying that every hour of the day counts. Modern technology and ICTs makes it possible for NGOs to gain and spread information and communication to large audiences (Unwin, 2009:19), making ICTs and the media a cornerstone of working in larger contexts and reaching more people. Thus, but putting focus and effort into
creating and maintaining a relationship with the media, TAS has made itself more visible through news coverage. TAS’ communications officer Mr. Torner has been the most prominent media figure of the organization, working both nationally and internationally with the media.

The media, national and international, have done so much. They are the ones working on the ground; they highlighted what has been going on. For sure, the media have done a great job. (Josephat Torner, 2014)

Mr. Torner is actively working with different kinds of media to raise awareness about albinism. He has done numerous interviews in TV, radio, and newspapers, and he had the lead role in the UK documentary In the shadow of the sun released in 2012. His experience in working with media for several years has left him aware of both the positive and negative aspects of the media's role in raising awareness.

[...] there are some of the media who are approaching the subject the wrong way. They are writing that persons with albinism are worth a lot of money. The people who are poor will be tempted by this. I’m not saying the media is hanging the society, I’m saying that some of the journalists are not following the ethics. (Josephat Torner, 2014)

Mr. Torner refers to the media’s tendency to focus on the negative aspects only of being a person with albinism. He and TAS believes that the media needs to focus more on the positive aspects of albinism, the things that PWA can accomplish, and what makes them equal to any other person rather than what separates them from the rest of society. He stresses the media’s tendency to focus only on the negative aspect of albinism in Tanzania as offending because it hinders persons with albinism from living like other people (Josephat Torner, 2014).

The killings of persons with albinism in Tanzania have become highlighted in national and international media, which TAS make use of as often as possible. Appearing in the
media gives TAS a chance to advocate for their cause, raise awareness, and educate the public. TAS is using the media to present information about the current situation, as when a new murder or attack has occurred.

This morning I was in a TV and a radio show, and two days ago I was in another show, increasing awareness about albinism and telling people to protect persons with albinism. (Josehat Torner, 2014)

TAS’ frequent appearances in the media have resulted in the media seeking out the organization when writing a story on the subject of persons with albinism. Also, having Mr. Torner in the organization has further enabled TAS’ visibility in media, as Mr. Torner is a somewhat international representative advocate for persons with albinism after working with several organizations and appearing in internationally screened documentary In the shadow of the sun.

On Tanzania National Albinism Day 4th May 2014, the documentary was officially released in Tanzania. The documentary, starring TAS’ communications officer Mr. Josehat Torner, deals with the persecution and murders of persons with albinism in Tanzania, and is a useful advocacy tool for TAS and other NGOs working for the same cause to reach out internationally.

[...] when I was working, the media were sometimes negative things, which is creating a meaning in the community. I have seen many movies before I made In the shadow of the sun, and all of them were only talking for one side of the problem and showing the negative sides only. If you see today someone that had been chopped and cut, for us that is offending because we would like to live like other people. (Josehat Torner, 2014)

Screening In the shadow of the sun is an opportunity for TAS to show a different aspect of the persecution and use new ways of raising awareness on what albinism is. Documentaries and other recorded media have proven to be good tools in advocacy.
This in accordance with Tim Unwin (2009), who claims that film can deliver information to the audience in such a way that it engages all senses and emotions; it enables sharing of information that elsewise can be very hard to present; it enhances the learning experience; and it stimulates discussion among the audience (87).

For an NGO to focus its advocacy also on the media including information and communication technologies such as TV, radio and the Internet, it is important to keep in mind that the information immediately will not be available for some due to a digital divide. A digital divide implies the different opportunities for use of information and communication infrastructures, thus diminishing the access to information for some. Although the digital divide is closing up as ICTs are spreading and becoming increasingly more accessible, it is prominently present in some countries. A digital divide is most often caused by different socioeconomic conditions as well as geographic location, which might hinder access to ICTs either by e.g. simply not affording them or by household not being covered by the network (Unwin, 2009:177, 178). Thus, when ICTs are applied as an advocacy tool, those who cannot access the ICTs due to the digital divide are immediately excluded from the information flow, something that needs to be taken into consideration.

6.2.3 Tanzania National Albinism Day – Data, Audiences, Presentation, Fundraising, Coalitions

Since 2006 TAS arranges Tanzania National Albinism Day on the 4th May, which is considered one of the most effective tools in TAS’ advocacy work. It provides an opportunity to gather persons with albinism, NGOs, and the government to discuss issues surrounding PWA, and how to proceed with priorities in their work to improve the current conditions. Another excellent outcome of TNAD is increasing public awareness about albinism, made possible by the media attention and activities arranged by TAS (Attachment 1, TAS Profile, 5).

TNAD 2014 was held in Dar es Salaam, with displays and conferences on the 2nd and 3rd, and the celebrations on the 4th May. The three days were themed and together they
made a completion of TAS’ advocacy goals. The 2\textsuperscript{nd} May focused on changing negative attitudes toward PWA through displaying craftwork and dance performances, in order to show the public that PWA are able to do these things as good as anyone else, a way of showing that they too are people. The 3\textsuperscript{rd} May was a full day conference with lectures and discussions on subjects such as the scientific explanation of albinism, information about skin cancer, and the role of education. The timetable for the international conference on 3\textsuperscript{rd} May is attached in this thesis as Attachment 2, International Conference Time Table. The 4\textsuperscript{th} May consisted of a march through Dar es Salaam and a presidential speech.

During the arrangement of Tanzania National Albinism Day, TAS addresses albinism as an issue that is affecting people on a national and international level, although the situation has proven to be dire in East Africa and especially Tanzania. Thus, TAS has been advocating for making TNAD to be marked as an international day to increase public awareness not only on a local and national level, but also international (Attachment 1, TAS Profile, 5). The impact of TNAD is currently most prominent on the national level, although TAS is hoping for International Albinism Day to bring more attention to the situation of PWA internationally. International Albinism Day was announced by organization Under The Same Sun as an official international day to be marked on the 13\textsuperscript{th} June. The date was chosen in recognition to the first United Nations Resolution on albinism adopted on 13\textsuperscript{th} June 2013 (Sandton Chronicle, 2014).

Tanzania National Albinism Day has proven to be an excellent event to attract national media’s attention. By arranging the three-day long event with national and international actors such as the Turkish Embassy, American nonprofit Asante Mariamu, and UK charity Standing Voice, TAS managed to gain attention from these mentioned countries in particular.

6.3 Summary of Results
By working with Sharma’s model of advocacy it has been possible to divide TAS’ advocacy work into different elements that together create advocacy. This enables an idea of how they work with advocacy on different levels, and which elements that are
being focused on in different contexts. As the results part in this thesis has shown, on a local level TAS focus their advocacy mainly on audiences and messages. Their approach toward their audiences on this level is focused on face-to-face contact and how they best can communicate with people, be it on the street or during a school visit. It can be considered as a more personal approach to the target audiences on a local level, as TAS appreciate different ways of showing people that persons with albinism are just like everyone else, and they do this by interaction with the community by e.g. school visits, talking to parents of children with albinism, and visiting religious associations.

On a national level it is possible to see a much wider variation of elements of advocacy applied by TAS. Data, audiences, presentation, fundraising, and coalitions are focused on in different ways, and all of them are applied in the TAS initiated Tanzania National Albinism Day, held annually on 4th May. They focus on the coalitions element when lobbying the government as they aim for a political agenda that addresses persons with albinism and the threats that they face. Furthermore it is data, i.e. the content, which is being focused on in their work with the media and ICT4D. As the results part show, TAS work with advocacy on both a local and a national level, however they use advocacy in different ways, as it is being adapted to and shaped to fit the context in which it is being used.

Finally, Sharma's model of advocacy has proven to be useful in analyzing TAS' application of advocacy in their work. However, two elements remain untouched in the analytical process and have been given no connection to TAS' advocacy work: objectives and evaluations. Whereas the other six elements appear in one or more contexts in the previous parts of results, objectives and evaluations have not been possible to place specifically in any of the advocacy settings that have been used in this thesis. By that it is possible to draw the conclusion that TAS is lacking a clear strategic objective with the advocacy, as a clear and outspoken plan has not been visible during the time of the case study with the organization. Even though ideas of what they want to achieve as an organization in their work, it has been insufficient to connect it as direct goals of the strategic communications in the different settings per se. Evaluation has also been
absent in the sense that TAS’ standpoint to feedback and how to receive the audience’s input was not brought up or discussed. By putting more effort into evaluation, TAS as an organization could gain insights in their weaknesses and strengths, which in turn could enable them to develop and grow closer to both their audiences and goals, and most of all improve their advocacy work on the levels that it is applied in.
7. Analysis

In the previous chapters I have presented how TAS is working with advocacy on two different levels, local and national, toward different audiences. This part will deal with the second and third question of this thesis, “What are the challenges for Tanzania Albinism Society in their advocacy work?” and “Why and how is advocacy a useful tool for NGOs in their strategic communication?”.

7.1 Relationship Building with the Audiences

Through observations I have noticed how TAS is acting toward their audiences and noticed a large difference in their approach to school staff and journalists compared to children with albinism.

[...] the relationship between the persons from TAS and the children with albinism (whom have been given much attention prior to the meetings) was in fact seemingly non-existent. The persons from TAS spoke only to those of “importance” and never spoke with the children. (Louise Jönsson Andersson, 4, 2014)

Kanter and Fine (2010) describes individuals whom engage in social change outside of organizations as free agents (15). TAS should consider children and adolescents with albinism in Tanzania as future free agents, as I in field have observed that many of the persons with albinism whom are involved with either TAS or other organizations started off as free agents, “[...] working outside the organization to organize, mobilize [...] and communicate with constituents” (ibid, 2010:15). Thus the challenge for TAS in their advocacy work toward children and adolescents with albinism on a local level is not solely to change their communication style, but changing their entire attitude toward the audience. TAS should consider this particular audience as future free agents as well as future active members of TAS or similar organizations working toward better conditions and opportunities for PWA in Tanzania. It is crucial for an NGO to be able to recognize target audiences and why they are important for the organization, since the NGO is entirely depending on people's engagement to be able to achieve anything.
As described by Hahn and Holzscheiter (2013), there might arise problems in the relationship between the NGO and their beneficiaries. This occurs when there are different views in the matter of representation of the NGO toward the intended beneficiaries. When the viewpoints of the beneficiaries differ from those of the NGO there might arise conflict. In order to avoid such a problem it would be recommendable for TAS to make sure that all the groups they represent as an organization also are given a chance to raise their voice and concerns, and to be fully included in the organization. If children and adolescents with albinism in Tanzania are continued to be excluded in comparison to the older age groups of PWA that are represented by TAS, there is a risk for the young persons with albinism to feel excluded and misrepresented by TAS (Hahn and Holzscheiter, 2013:498, 502).

Relationship building is paramount for NGOs as it is hard to engage individuals without creating a relationship with them firsthand. Focus on building coalitions is seen on the national but not as much on the local level. By increased focus on coalitions also on the local level, TAS would be able to build up and strengthen the relationship to children with albinism in Tanzania, whom one day will be grown up and hopefully taking part in advocating for their rights. In the case of TAS’ relationship building with the audiences, it is possible to see open and closed communication. Open communication is fruitful, concrete, and focused on possibilities, and it is good for the relationship between the parties. Closed communication on the other hand is unclear and controlling, and is not useful when trying to build relationships (Nilsson and Waldemarson, 2007:146, 147). This suggests that TAS is prioritizing some audiences more than others, and that children and adolescents with albinism are not as important to build a relationship with as it is with e.g. journalists. In order to improve the relationship with children and adolescents with albinism, the future free agents, TAS could focus on changing their direct style of communicating with them, and adapting a more open and two-way style in order to engage rather than hold back the audience.

As NGOs are independent from governments, they are instead depending on the public
and of donors. The problem with this dependency is the geographical and psychological distance toward the NGOs work that the public may experience, as it might be difficult for a person to relate to a situation that is geographically far away, or if the person is unable to relate to it (Heins, 2008:20-22). The gap between sympathizing with the NGOs work and actual participation is large, but it can be made smaller by building a relationship with the public. This can be done by personally engaging the public by reaching out face-to-face, truly engaging the public in the work, and using storytelling to make the relationship building more personal. Storytelling is effective in decreasing the psychological gap and can be used both in the media and face-to-face (Kanter and Fine, 2010:139-142). Using storytelling in the media, and especially in social media, gives the organization an opportunity “[...] to use a megaphone they would not have had access to before” (Kanter and Fine, 2010:143).

Thus on a local level TAS needs to improve their relationship building with children and adolescents with albinism in order to encourage these potential future free agents to become engaged in TAS’ work. With this I would like to emphasize that TAS need to put equal effort into building a relationship with children and adolescents with albinism, as they did with journalists and staff at the schools that we visited. On a national level and seen from a larger aspect, TAS needs to focus on relationship building also with audiences on a distance by using the Internet and social media.

7.2 Lack of ICT4D in Tanzania National Albinism Day Advocacy

TAS has been successful in their advocacy for TNAD with regards to reaching out to the national albinism community and also the international, especially the Turkish, American, and UK communities. However, a challenge for TAS is reaching out beyond those who have a personal interest in the matter. Referring to TAS’ vision statement “Tanzania Albinos Society envisions an inclusive society respecting, promoting and defending human dignity for all” (Attachment 1, TAS Profile, 2), in order to achieve this the message needs to be transferred also outside the albinism communities. Using ICTs for this would enable TAS to reach more audiences outside the albinism communities, and using the Internet and social media specifically would be a good way for TAS to
engage the public. These channels provide NGOs such as TAS to share information, communicate directly with individuals from all over the world, to raise awareness of albinism, and to promote events such as TNAD (Kanter and Fine, 2010:62).

TAS does have a Facebook page in which they mainly post articles about albinism and the latest news on the persecution of PWA. This is a good forum for creating discussion on the subject. However, their ordinary webpage is no longer working and they are not using any other social media forums, although forums such as Twitter would be considered very useful for organizations like TAS. Twitter is an excellent tool as both a conversation starter and a network builder, and it does not require much time or effort to keep it updated. Since social media has proven not to be just a trend on the Internet, but here to stay with a large influence on the younger generation, it should be prioritized for TAS to use this inexpensive, effective and global way of reaching the public (ibid, 5). As Thrall et al states, “[...] the Internet is ‘supersizing’ the NGO community’s capacity to conduct information politics of various kinds” (2014:136).

Onwards, there are other opportunities to be found through the Internet and social media that could benefit TAS as a small NGO with limited resources. Crowdsourcing is when people mobilize and participate in projects. The most relevant and useful way of crowdsourcing for TAS is crowd-funding, meaning that social media is used to connect with the crowd in a specific channel, and ask for funding for a specific project or event. To achieve funding this way, TAS would have to carefully connect with the crowd, integrate them in their work, and be able to show the results in order to provide a sense of fulfillment (Kanter and Fine, 2010:108).

Yet again, while proposing ICTs as a suitable means for Tanzania Albinism Society to reach out to both the national and international community, the digital divide must be considered. To highlight the intention of including ICTs in the context of Tanzania National Albinism Day as purposed to engage people beyond the albinism communities; it is specifically seen as a strategic way of connecting with people across the globe that, via ICTs such as the Internet, can engage in TAS’ cause. This engagement might be e.g.
donations and sharing information online about albinism in Tanzania and East Africa, TAS, and their work.

7.3 Why and how is advocacy a useful tool for NGOs in their strategic communication?

The fieldwork in Tanzania has allowed this thesis also to research the importance and role of advocacy for NGOs. Some conclusions are based on information compiled during the field studies, whereas other is collected from articles.

Advocacy is a crucial part of NGOs strategic communication, and how advocacy is performed might serve to affect the outcomes of the NGOs work greatly. Advocacy offers endless ways for an NGO to transfer a message to the intended audience. It could be small talk in the supermarket, an action with symbolic value, or in written text posted on Facebook. An NGO can advocate in principally any way, as long as it is well adapted to the intended audience. Sharma’s (2013) model of advocacy shows the multifaceted functions of advocacy, as it clearly points out the various cornerstones of the communication style that can all be combined as the NGO please, and as suits the target group best. When creating a strategic communications plan, one of the first steps for the NGO is to determine the intended audience (Patterson and Radtke, 2009:2), and once that has been established the NGO can continue and start thinking about how to transfer the message in a suitable way with regards to the intended audience.

The advocacy goal of an NGO can enable the organization to collaborate with other NGOs sharing the same advocacy goals. Such collaborations can be fruitful for all participating parts by e.g. strength in numbers and capacity, and the sharing of information, knowledge, and resources. TAS, as an example, started a coalition (Holloway, 1998:80) with organizations Asante Mariamu and Standing Voice for TNAD 2014, meaning they temporarily collaborated specifically for this event. A coalition can enable an NGO not only to be strengthened with more resources, people, and knowledge, but also with being able to reach out to more platforms in a greater way than earlier. This indicates how advocacy can work not only toward a single organization’s goal, and does not have
to provoke competition for the audience, but can instead create collaborations and enforce organizations working toward the same goals.

There are other aspects of NGO advocacy to be considered. As I have experienced in field, resources might play a large role in the NGOs ability to fulfill and complete their advocacy work. Financial resources are necessary for e.g. traveling to rural and distant areas. Knowledge resources are necessary also; as it can determine how many channels the NGO has to choose from in its advocacy work. For an example, with no financial resources the NGO might not afford a computer and access to Internet. Even if it does, if there is no one within the NGO that knows how to set up a webpage or how to transmit messages in e.g. social media the NGO immediately miss out on probably the most potential channel through which they can real the global community, or any community that is not physically accessible for the NGO. Thrall et al (2014) describes resources such as financial, technical capability, relationships with decision-makers, and credibility as necessary for an NGO to be able to gain the media’s attention and thus perform a more successful advocacy work in reaching out to more people through the media. Because of uneven resource distribution however, the presuppositions for NGOs are different (139).

Working with advocacy in different parts of the world plays a role in how effective it will be. As showed previously in the text, media advocacy can indeed be a very useful and successful way of advocating for a cause. However, the coverage of African countries and stories in the media and on the Internet is very low compared to the rest of the world. In fact, as Wu (2007) found in his study, no African country made it to the top-twenty list of countries most covered in U.S. news media, both online and traditional. Because of this, African NGOs such as TAS might put much effort into an advocacy campaign by using the Internet or the media, but regardless of how well it will be done, the outreach will not be as large and successful as it would had been about a country in the developing world (546).
8. Conclusion and Suggestions for Further Research

The experiences gained in field have shaped and created this thesis into what it is today. Without the field experiences, my appreciation of the subject would indeed be different from what it is now. I have been able to see the diversity of advocacy, and come to understand that advocacy more or less can be performed in any given situation. It is my hope that this thesis will provide some idea partly about TAS’ advocacy work and of the role of advocacy in NGOs communication work.

8.1 The Individual Organization

In order to understand the advocacy work that is happening, one needs to take a closer look at the organization that is behind it. There is no doubt that organizations from different parts of the world face different opportunities, partly because of resource allocation but also because of attention allocation.

In order to create a strategic communications plan with advocacy, there is a need to consider the variety of advocacy as presented by Sharma (2013) in the model of advocacy. By this, the advocacy needs to be adapted to the NGO and its audiences, rather than the opposite. In adapting the model to the NGOs specific needs, the NGO firsthand need to consider what message they want to transmit, and toward which audience they want to transmit it. Once that has been established the NGO can move on and focus on the channel that will be used, which is mainly determined by the message and the target audience.

8.2 Research Findings

Tanzania Albinism Society face a number of challenges in their advocacy work, as has been brought up previously in the text. These are:

- Relationship building with the audience
- Age gap
- Lack of focus on future free agents
- Low focus on coalition building on a local level
• Less one-way face-to-face communication, focus on two-way communication instead
• Risk of misrepresentation of young persons with albinism
• Lack of online advocacy
• Lack of ICT
• Geographical and psychological distance as a consequence of not using ICT and online advocacy
• Problems in reaching out beyond the albinism community

There are also some keywords in why and how advocacy is a useful tool for NGOs in their strategic communication:
• Crucial part of strategic communication
• Adaptable to different organizations, purposes, and intended audiences
• Can enable collaborations with other organizations that are working toward the same goal

8.3 Suggestions For Further Research
My primary suggestion for further research is the elaboration of a universal distinction between small and large NGOs, thus providing a definition of the term small NGOs for future research like this thesis. Seeming as NGOs exist and operate on a global level, and can be found in different sizes and with different budgets, I believe it is important to be able to distinguish between small and large NGOs not only in terms of size (e.g. number of staff) but also with regards to financial and other resources, factors that indeed make a difference for the NGO and its opportunities.

My second suggestion is more research to be done on the subject of advocacy in small NGOs that is not case- or country-specific, but rather applicable to small NGOs in different areas of work and different parts of the world.
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Attachment 1 – TAS Profile

Tanzania Albino Society

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Tanzania Albino Society
Tanzania Albino Society (TAS) is a not for profit and Non-Governmental organization, dedicated in empowering, protecting and supporting people with albinism. It operates in all regions of Tanzania mainland and has offices and leaderships in 21 regions. It was established by people with albinism themselves in 1978 and got its registration in 1980. Since its establishment, TAS has been working in rural and urban areas in its strive to improve social wellbeing of children, men and women with albinism as well as their families. TAS is made up of individuals and organizations of people with albinism.

Mission Statement
Tanzania Albino Society strives to emancipate people with albinism from all forms of discrimination and negative attitudes and advocate for their rights while empowering them to realize their potentials.

Vision Statement
Tanzania Albinos Society envisions an inclusive society respecting, promoting and defending human dignity for all.

Our Work
Tanzania Albino Society (TAS) supports people with albinism and their families while increasing public awareness on albinism and advocating for their rights. Our works are mainly in the following areas:

1. Advocacy and awareness raising
   We advocate for the rights of children, men and women with albinism while fostering a culture of human rights and raising public awareness about albinism. TAS is the founder...
of the National Day of Albinism marked every year in May 4, been celebrated since 2006 which is supported by the government of Tanzania and has been gaining attention from all over the world. The work ahead is to advocate and lobby for the establishment of the World Day of Albinism.

2. Education
TAS supports children with albinism in schools with learning aids such as magnifiers, lenses and sun protection gears. We also educate teachers on how to care for them and increase their understandings and that of other children about albinism and special needs of children with albinism. We also seek supports of school fees, books, stationeries and uniforms from individuals and organizations to sponsor those in need to achieve equality of access and opportunity that will ensure freedom of choice in their lives.

Families hide children with albinism at homes hence denying them their rights to education. TAS works hard in both rural and urban to identifying such families and ensures that children with albinism are sent to. It has been our work to also link people with albinism with their peers in their areas through our branches so as to reduce stigma and promote positive exposure.

TAS works hard in promoting inclusive education as a way of continuous awareness raising about albinism and other disabilities, for inclusive society!

3. Empowerment and partnerships
We support individuals and groups of people with albinism and their families in their good doings for better life. TAS encourages and facilitates the establishment of
entrepreneur groups and links them to business opportunities in a way to curbing unemployment rate. We also organize or provide them with support and or information on different trainings and opportunities that increase their skills and ability to improve their well-beings. Our partners have been playing a big role in rural and urban to empower women and men with albinism!

4. Health

We support children, men and women with albinism undergo treatment especially for skin cancer. Being one of the reasons behind our existence, TAS has educating about skin cancer, organizing and supporting screenings and treatments for. We distribute sunscreen lotions, hats and sunglasses donated by different partners and friends.

TAS has a wide coverage and outreach to grassroots levels in the districts. It uses different strategies to unite people with albinism and their families, main one being establishing and supporting different groups, which operate in cooperation with district, regional or head offices. Groups are of and comprised artists and entrepreneurs. These groups have been evident in fighting stigma and promoting positive exposures for people with albinism.
We work closely with different partners; include activists, NGOs and development actors in the field of albinism and human rights.

Tanzania Albino Society Chairperson, Mr. Ernest Kimaya (left) Chairperson, Edith Matata, Reginald Mengi and Hon. Barwan Khalifan (MP) joined by people with albinism in accepting the Martin Luther King awarded to Tanzania Albino Society in 2009.

Successful Story!
TAS advocates for the rights of people with albinism through different strategies. One of the best tools we use annually, in form of National Event is the “National Albinism Day” an initiative we have established in 2006 aiming to scale up our efforts of increasing public understanding about albinism, and use the mark to evaluate our work and plan together with the Government and other partners on how to move with priorities. The day is marked in every May 4 with special focus. Policy makers and implementers join the day to discuss and provide their views which in the other hand easy our work in making follow ups or advise the government, as we also work closely with it, in the capacity of watch dogs!

National Albinism Day marked on May 4 each year is an opportunity for people with albinism, their families, government, and all partners to unite in evaluating the progresses and plan on how to strategically deal with challenges associated with albinism, include increasing public awareness. It was established in 2006 by Tanzania Albino Society (TAS) and fully supported by the Government of Tanzania and has been celebrated since then with varying degrees of success; include mainstreaming albinism in political, social and cultural arenas.

“Albinism Day shall be recognized by WHO and be marked globally. This is what we want to see happening because albinism is everywhere, although the condition affects social affairs of people in sub-Saharan Africa than in other parts of the world.” Says Ziada Nsembo, Secretary General for TAS

Chairman of the Tanzania Albino Society Ernest Kimaya who received the award on behalf of the community pose with the award he received today, Thursday, January 15, 2009.
Hon. Anna Makinda (MP), speaker of the Parliament of the United Republic of Tanzania getting information from TAS leaders on the application of sunscreen lotions during the mark of the 7th National Albinism Day in Lindi region in May 2010

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Attachment 2 – Time table for international conference on albinism on 3rd May 2014

<table>
<thead>
<tr>
<th>TIME</th>
<th>ACTIVITY</th>
<th>RESPONSIBLE PERSON</th>
</tr>
</thead>
<tbody>
<tr>
<td>07:30hr – 08:30hr</td>
<td>Registration</td>
<td>All</td>
</tr>
<tr>
<td>08:30hr – 08:40hr</td>
<td>Welcoming remarks</td>
<td>Josephat Torner, TAS</td>
</tr>
<tr>
<td>08:40hr – 09:00hr</td>
<td>Opening Remark</td>
<td>HE Aliy Davutoglu Ambassador of Turkey in Tanzania</td>
</tr>
<tr>
<td>09:00hr – 9:30hr</td>
<td>1. Presentation: The Science of Albinism and Life Expectancy Inequality</td>
<td>Prof. Masenga, KCMC</td>
</tr>
<tr>
<td>9:30 – 9:50</td>
<td>Discussion</td>
<td>All</td>
</tr>
<tr>
<td>9:50 – 10:10</td>
<td>Tea Break</td>
<td>All</td>
</tr>
<tr>
<td>10:10 – 10:40</td>
<td>2. Presentation: African Culture and Albinism</td>
<td>Prof. Possi, University of Dar es Salaam</td>
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<tr>
<td>10:40 – 11:00</td>
<td>Discussion</td>
<td></td>
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<tr>
<td>11:00 – 11:30</td>
<td>3. Violations of Human Rights Against People with Albinism</td>
<td>Adv. F. Massawe, Legal and Human Rights Centre</td>
</tr>
<tr>
<td>11:30 – 11:50</td>
<td>Discussion</td>
<td></td>
</tr>
<tr>
<td>11:50 – 12:20</td>
<td>4. Skin Cancer Prevention: Awareness, Accessibility and Availability</td>
<td>Dr Alfred Naburi and Mafalda Soto, RDTIC and KSPU</td>
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<tr>
<td>12:20 – 12:40</td>
<td>Discussion</td>
<td></td>
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<tr>
<td>12:40 – 13:40</td>
<td>Lunch</td>
<td>All</td>
</tr>
<tr>
<td>13:40 – 14:10</td>
<td>5. National Health System: Experience of Tanzania</td>
<td>Ocean Road Cancer Institute</td>
</tr>
<tr>
<td>14:10 – 14:30</td>
<td>Discussion</td>
<td>All</td>
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<tr>
<td>14:30 – 15:00</td>
<td>6. Presentation: Albinism and Mental Health</td>
<td>Dr. Mbata, SEKOMU</td>
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<tr>
<td>15:00 – 15:20</td>
<td>Discussion</td>
<td></td>
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<tr>
<td>15:20 – 15:40</td>
<td>Tea Break</td>
<td>All</td>
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<tr>
<td>15:40 – 16:10</td>
<td>7. Presentation: Albinism and Inclusive Education</td>
<td>Prof. Omari, Open University of Tanzania</td>
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<tr>
<td>16:10 – 16:30</td>
<td>Discussion</td>
<td></td>
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<tr>
<td>16:30 – 17:00</td>
<td>8. Networking and the Role of International Voice</td>
<td>Harry Freeland, Standing Voice Founder, UK</td>
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<tr>
<td>17:00 – 17:20</td>
<td>Discussion</td>
<td></td>
</tr>
<tr>
<td>17:20 – 17:50</td>
<td>Summary and Conclusion</td>
<td></td>
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</tbody>
</table>