Voice for people with a disability in Tanzania



Name:	Fleur Verbraeken, Hanna Tsirikidis, Nina van Deventer, Puck Beens and Merlijn Jonas
Course:	Minor Beyond Borders
Institute:	Rotterdam University of Applied Sciences
Initiator:	Ellen van der Velde
Date:	21 December 2022

Table of contents

Table of contents 2
Introduction 3
Method 4
Literature 4
Practical 4
Literature 5
Practical research 7
Stakeholders 7
Sanaa 8
Person of Masaai origin 8
People with a disability, who are begging for money 9
Sibusiso 9
Patandi primary school for children with special needs 9
Teachers College 10
Person with albinism 10
Conclusion 11
Prototype 12
Discussion 13
Recommendations 14
Biography 15
Appendix 1 16
Creating awareness for people with a disability. 16
The plan 16

Introduction

This project is fulfilled by five healthcare students from Rotterdam, the Netherlands. The group exists of Fleur (speech language therapy student), Nina (occupational therapy student) and Hanna, Puck and Merlijn (nurse students). Through the minor: “Beyond Borders, challenging health equity”, the project focusses on improving of the lives of people with a disability in Tanzania. Therefore, research has been done on the current situation in cooperation with multiple organizations that are focusing on fulfilling a decent future for children and people with a disability. To obtain an image of the way people with a disability look at their own life, we have been interviewing people with a disability who make a living with begging for money on the streets of Arusha.

Through Design Thinking, information is researched and described in a report. Design Thinking is a five-stage method used to solve wicked problems. The user and his needs are central to this; Design Thinking is about understanding the people for whom a product or service is being developed. Within Design Thinking, five phases are used: empathize, define, ideation, prototype and test. We followed these steps to eventually create the following prototype.

Our main goal is to give people with a disability a voice. This involves informing both people with and without a disability about the needs and rights of someone with a disability. We think this is important because we have noticed that there are misunderstandings about people with a disability in Tanzania. We also found that people with a disability themselves are not informed on their human rights and opportunities they could have in society. To give them a voice we want to give people with a disability an opportunity to tell their story. We are going to invite professionals and activists that care for people with a disability to provide information on their vision and rights.

Method

As mentioned above, design thinking has multiple phases in which you will go through when going through the process of the project. To obtain an image of the current situation of people with a disability in Tanzania, both literature and practical research are required.

Literature

To start with, a mind map was created on the disabilities that are currently in Tanzania and what the prevalence of these disabilities are. Various search engines were used such as Google Scholar and databases which publish scientifical articles to obtain the highest level of reliability. The reliability of the articles was assessed by checking the relevance, age and origin of the article. To make sure the group was working efficiently, the different subjects that were needed to be researched and meetings were arranged to discuss the results.

Practical

Aside from the information gained in literature, the perspectives of people with a disability and people who are involved with them also needed to be investigated. Design thinking offers various methods of creating a broad and accurate image of the status.

Observe

The people with a disability were observed in a variety of settings. To create a broad spectrum both governmental and non-governmental organizations which work on creating a decent life for people with a disability have been visited. To organize our observations the POEMS-framework was used, which helped to discuss our different findings schematically.

Engage

To acquire various perspectives of people with a disability, both organizations and people with a disability were consulted. During the observations, it could be concluded that people with a disability are seen begging for money on the streets. To create a view of both people with a disability who have a steady income and who are depended on their begging income, interviews with both parties were conducted. This helped the group to step in their shoes and try to see their lives from their perspectives.

Information in the practical settings was gathered by conducting interviews with the help of an interpreter who speaks the national language, Swahili. Since the risk of misinterpretation due to a possible language barrier, there were also questionnaires written. The questions for both interviews and questionnaires were based on our earlier observations and interpretations of hypothetical problems. In this way the interpretations were tested on suitability on the perspectives and needs of the ones involved.

Literature

To get a holistic view of what a having a disability in Tanzania means, it is important to get to know the country and culture itself. To start, it is important to know which disabilities are currently existing in Tanzania and how they appear. Furthermore, research within literature is required to be up to date about the current situation and developments.

Tanzania is a country in East Africa. It covers an area of about 945,000 km2. Tanzania has nearly 61 million inhabitants, of which 30.8 million are women and 30.7 million are men. Africans are the largest population group in Tanzania. In mainland Tanzania, 45% of the people are Christian, 35% Muslim and 20% Amnist (VisumBuitenland.nl, 2022).
Also, there are a lot of tribes, more than 100 different tribes. 4% of the inhabitants belong to probably the best-known tribe: the Masai. Lots of these tribes have their own language.
Nowadays more people speak English, but Swahili remains the official language (Tanzania - Cultuur, z.d.).

To establish a definition of people with a disability in this project, the following definition was used during this period. According to Article 1 of the United Nations Convention on the Rights of Persons with Disabilities, a disability is defined as:

"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." (United Nations Convention on the Rights of Persons with Disabilities, 2006).

We have chosen to use this definition in this study, as Tanzania is one of the 185 countries being part of the Convention on the Rights of Persons with Disabilities (*UNTC*, 2008).

Disabilities can be divided into physical and mental disabilities. Having a disability means the lack of functioning of any part of the body. If it concerns one or more body parts a person can be hindered in certain actions and/or movements. Physical disability is a collective term for different types of disability. It includes the following disabilities: motor disabilities, sensory disabilities, speech or language impairments, consciousness disorders, other physical disabilities.

Tanzania has made a commitment to promote and guarantee the rights of people with disabilities through this treaty. The law and regulations of the Republic are also influenced by this definition (*United Nations Convention on the Rights of Persons with Disabilities*, 2006).

Based on traditional beliefs, children with disabilities are hidden and kept away from public because they are considered a source of shame. In addition, children and young people with disabilities are often forced to take marginalized positions in society. Women with disabilities are often described throughout Tanzania as "sick, helpless, childlike, dependent, in need of care, incompetent, asexual and genderless".

Overall disability prevalence rates for persons aged five years and older are 6.8% in mainland Tanzania and 3.2% in Zanzibar. This means that in all of Tanzania more than 3.3 million people live with a disability. Prevalence rates are higher in women than in men. About 10.8% of the women have a disability, and of which 8.7% of the men have a disability (UNICEF, 2021).

In Tanzania the following laws apply, that may have an impact on the practical research, and therefore it is important to keep these laws in mind. In 2010, the Parliament of the United Republic of Tanzania enacted the Persons with Disabilities Act. This law provides health care, social support, accessibility, rehabilitation, education and vocational training, communication and/or employment protection and promotion of human rights for people with disabilities (National Assembly [Clerk], 2010).

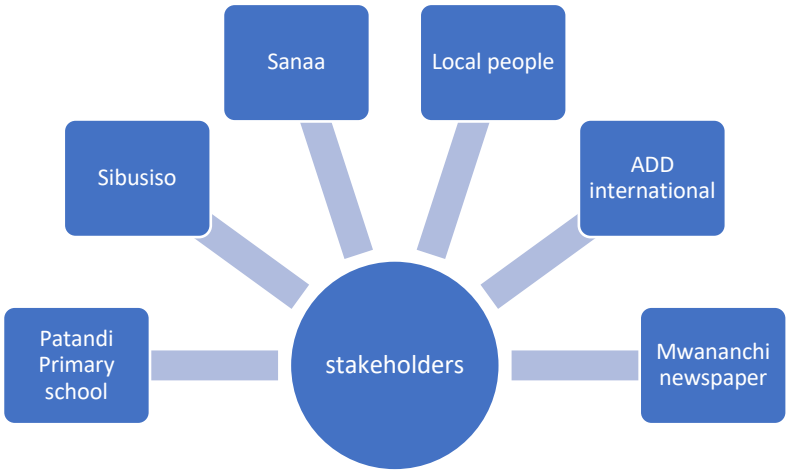
Legislation, global and local, defines "people with disabilities" in a broad sense, not specifying different types of disability. The Convention on the Rights of People with a Disability (CRPD) is an international treaty that identifies the rights of people with disabilities and mandates activities on the members of the treaty to promote, protect and ensure these rights (OHCHR, z.d.).

Table 4.1: Mainland Tanzania Disability Prevalence Rates and Population Estimates by Type of Disability

Type of disabilities	Children and young people aged 5-24 years		All population aged 5+	
	Prevalence Rate for children and young people	Estimated number of children and young people living with disability (2021)*	Prevalence Rate	Estimated number of persons living with a disability (2021)*
Difficulty seeing	1.5%	405,875	7.5%	3,570,128
Difficulty hearing	1.3%	345,123	2.8%	1.323,896
Difficulty walking	1.2%	317,978	5.9%	2,831,005
Difficulty remembering	1.7%	454,994	4.4%	2,093,137
Difficulty communicating	1.2%	306,345	1.7%	789,318
Difficulty self-care	1.2%	317,978	2.2%	1,046,568
Persons with albinism	0.6%	128,658	0.6%	301,171
Total of estimated persons with disabilities	2.3%	611,398	6.8%	3,255,154

Practical research

Stakeholders



Contact with several people in our stakeholders' network had been remained. During the project the group stayed in touch with the mentioned stakeholders to keep a healthy relationship and to conduct interviews to obtain information.

Patandi:	student-coordinator A, primary students B, teachers C,
Sibusiso:	manager D,
Sanaa:	account manager E, employees with a disability F, G, H,
Local people:	person from Masaai origin, disabled people begging on the street J, K, L and a school student with albinism M,
ADD international:	Director and activists-coordinator.
Mwananchi newspaper:	News reporter.

The first impressions were made by talking to people on the street and visiting various people and organization, both governmental and non-governmental (NGO). Through obtaining information by conducting interviews the project group learned about what lives of people with a disability in Tanzania look like. The network extended due to establishing new contacts, partly through other organizations.

Sanaa

The first few interviews took place at the organization Sanaa. This is an NGO organization, and functions as social workplace. This means people with a disability work here. They have different disabilities, for example a hearing impairment or physical impairment.
The interviews were with people who have a disability. Respondent F. has a spinal cord injury; respondent G. has difficulties with speaking and respondent H. was born without legs. After getting in touch with people with several kinds of disabilities, more insight into their lives was gained. As a result, the focus moved towards the challenges and opportunities they have encountered in their lives.

Last, there was an interview with respondent E., she works at Sanaa as an accountant and doesn't have a disability. The choice to interview her is to gain insight into the functioning of Sanaa. The personal vision of E. was discussed, and where she feels obstacles in society that relate to the target group. The interview consists of the following topics: past, present, future, school career, family, society, work, relocation, independent or dependent, tips for others, financial.

The following conclusions were made from the interviews. There is little knowledge about people with disabilities, by both society, family and people with disabilities. People themselves and their families often do not know what their options are for care, rights and opportunities such as workplaces. In addition, many parents feel ashamed and keep their children away from the outside world.

For society in general, it is true that they have a distorted image of people with disabilities.
Sanaa is a place that offers opportunities for people with disabilities that they would have not gotten without Sanaa. The people who work here are very grateful for this place.

Person of Masaai origin

To gain more insights and perspectives about a local person's view of people with a disability we decided to interview Mr. F. His origin is from the Masaai tribe. We wanted to get to know his view on people with disabilities, but also the vision of someone from the Masaai.

During the interview it became clear that parents from Masaai origin are not ashamed of their child with a disability. They will not try to hide their child with a disability. The Masaai believe in the function of nature. As they already experienced animals with a disability, they believe that when a child is born with a disability, they can't do anything about it because it is a cause of nature. People from the Masaai tribe do not know about the possibilities of work outside of their own living environment because they live very remote. The families help each other if possible.

People with a disability, who are begging for money

Due to observations on the streets in Arusha, many disabled people have been seen begging for money. Since this is a big group, we wanted to get to know them by conducting interviews with help of a translator, as well to gain more insights and perspectives about why people with a disability beg and what life is like on the streets.

After seeing the people and getting to know their stories, it became clearer what the life of someone with a disability who begs for money looks like. For one of the respondents, it is the only way to get money. She begs for money to buy food and makes enough money to live each day. Some of the respondents feel alone on the street, but when there are people with similar problems, they don't feel like they are the only one. All our respondents say that they prefer to do other work instead of begging, but with their disability they have not many options. Locals often don't know what kind of difficulties people with a disability have. Therefore, people with a disability are not always accepted. To hear their stories, it became clear that many people with a disability don't know what their options are in society. Also, it is important to know that there is no full acceptance of people with a disability in society.

Sibusiso

Sibusiso is an organization nearby Arusha. Sibusiso is committed to children with a mental disability. In doing so, they pay attention to the relationship between parents and child. By integrating the family into their local community on a weekly base, they try to reach and educate the concerning communities as well.

At Sibusiso multiple observations were done and an interview has been held with the manager of the programs. Sibusiso is a very successful organization. They work with all kinds of expertise to improve the lives of the children. Different programs are offered, in which the parents with their child or their child alone stays internally during the week. In addition to the care for the child, the care for the parents is also strongly present at this foundation.

During the interview it became clear that many strategies are used to raise awareness amongst the local people and society. The manager gives many examples, such as spreading messages through various channels, but also indicates that a lot of word-of-mouth advertising is being used to inform more people in the area. The main points Sibusiso stands for are giving the children hope and spreading success stories to make children with disabilities feel inclusive. For the project, Sibusiso is great source of inspiration.

Patandi primary school for children with special needs

To gain more information about children with a disability, there were multiple observations and interviews made at Patandi primary school for special needs. Patandi is a school for children with hearing impairments, visual impairments, or intellectual impairments.
Some children only go to school here, while other children are also on boarding school. This means they live in the dorms on the premises of the school during schooldays and go home during the weekends. Only children with a hearing impairment or visual impairments are allowed to stay at the school for boarding, because children with an intellectual impairment need more guidance.

The first observation is about the physical appearance of the school. According to the observations the most remarkable problems concern facilities, water, and hygiene. Besides, some of the lessons don't seem to be organized that well. After the observations, the questionnaire was used to gain more information from the teachers, student coordinator, the matron (housekeeping) and the cook. This

survey shows that the reason for the current hygienic condition is water shortage due to the power system that runs out often and the lack of a water system. This is a problem that has been occurring for a longer period. However, it has been determined that possible solutions to this problem cannot be solved in a sustainable way.

Due to the interviews at Sanaa and the people on the streets, there was seen that people with a disability often do not know what career options they have after school. Therefore, the following interviews were done. To research if the school pays enough attention to the future possibilities of the children, we conducted interviews with both the children and student coordinator. Both interviews show there is sufficient attention for future possibilities on Patandi school for children with special needs. Graduated ex-students will visit the school regularly to share their experiences and talk about possibilities. Besides, the school has multiple connections with organizations which take actions for the future of children with special needs.

Teachers College

To get an idea of how the teachers of Patandi Primary school are educated as teachers, a visit was made to Patandi Teachers College. This college is the only teacher college in the entire country for children with special needs. They train students to eventually teach children with a disability. This interview was held with a teacher, he has been a teacher at Patandi Teacher College for ten years. Two courses are offered: one for a certificate and one for a diploma. Teachers with a certificate may only teach at primary school and teachers with a diploma may also teach at secondary school. Both courses last two years. During the interview it became clear that lessons are given according to the curriculum drawn up by the government. Every five years the curriculum is renewed based on what teachers lack or want differently in the education of children with disabilities. It differs per child and is adapted to the needs and level of the child. In advance, examinations are done to determine the level of the child. There are seven different components, including personal research, methodology, anatomy and physiology, sensory and movement motivation.

To conclude, teachers are trained according to a certain curriculum that is drawn up by the government. This curriculum is adapted to the needs and level of the child.

Person with albinism

During the visit to Patandi Primary school, an interview took place with X and other students. She has albinism and is currently studying to become a teacher for children with disabilities at Patandi Teachers College. The main goal of this interview is to gain insight into her life with albinism, but also her life as a student teacher for children with a disability. X is in second grade and focuses on visual impairments. The reason she does this study is because she has a visual impairment herself. She can't see well in distances, only close when she has her glasses on. She also has a white skin color. X comes from the region of Kilimanjaro. The people in the village discriminate against her, and don't like to see her. In addition, they see X as a curse of God and threaten her.

The conversation with the other students showed that there is regularly negative attitude towards people with disabilities in society. They believe that having a disability is a punishment from God and therefore they treat those people differently. In the teacher college they learn that people with a disability are equal to people without a disability and that they can learn the same skills. The students also indicated that it is important to teach parents about the needs of children with disabilities. Besides, they made clear that most people with disabilities are not aware of their rights.

Conclusion

We were given the challenge to improve the lives of people with a disability in Tanzania. Both literal and practical research shows there is insufficient knowledge about disabilities and what living with a disability is like, amongst both people with and without a disability. Besides there are a lot of stigmas against and misunderstandings about people with disabilities. Given there are a lot of other problems as well, but not realistic for us to solve or make sustainable, the best way of improving the lives of people with a disability is to gain awareness for them, share their experiences and inform about causes and opportunities. Because it is general awareness that creates more opportunities.

Prototype

We have an interest in people with a disability to create awareness amongst the people of Tanzania. With help of our practical research, we concluded that people with a disability find they have no voice and do not feel involved in society. To develop involvement, we have decided, in consultation with people with disabilities, to achieve this through the media. Looking at the most affordable medium with the biggest network, we decided that the local newspaper is the most fitting. Given that the newspaper is a well-used means of communication, the fact that it is free to publish articles and the price of buying articles is suitable for all incomes, the use of the newspaper is the most suitable. By posting the articles we want to make the people of Tanzania aware of the rights and possibilities of people with disabilities. With this we want to support organizations that are committed to people with disabilities and inform the population by sharing their vision, and thereby inspire others.

The organizations we decided to include in our pilot, in consultation with them, are the ones mentioned above in our stakeholder's map. These organizations are of great inspiration for other people with, and without a disability. We wanted to give those organizations a chance to tell their stories and share their experiences of working as a person with a disability or working with people with a disability. Within these organizations there a numerous people with a story, who could have an impact on likely minded people or change the opinion of people who are thinking differently about people with a disability. By cooperating with the newspaper, these organizations will get more publicity amongst the people of Tanzania, including organizations or companies that are focusing on creating a decent life for people with a disability. In this way they can increase their network and cooperation throughout the country.

To pitch our idea to the other organizations, we wrote a plan that could be used to hand out to the ones involved. This written plan is mentioned in the appendix 1. However, this plan is not fully put into practice. The interviews have taken place, but since cooperation with the newspaper didn't run well, we weren't able to pursue the sustainability.

Discussion

Because we made the implementation of our prototype dependent on one journalist from the newspaper, the pilot became very vulnerable. Sadly, the journalist arrived late at arranged appointments, or he would not show up at all. Besides, it appeared to be difficult to make any arrangements with him and he appeared to not be reliable. This is where our plan failed.

Other points of discussion:

- Since most of the people with disabilities we interviewed barely spoke English, communication could be hard. Even with a translator, because translators act as a sort of filter with interviewing; you might not get the exact same answer from the translator as the respondent gave to the translator.
- At the beginning of our research, we focused mainly on what we observed and what we thought was important to change. This is not important, because it is about the needs of people with a disability and not what we think is necessary. Therefore, it is very important to emphasize with the focus group and figure out their needs and what they think is important.
- The way of getting in touch with people here is way different than in Europe. Reaching someone by e-mail doesn't make sense, since none replies. Making a call is better, but the best way is to visit the office or location.
- When we arranged the interview at the teacher's college, we thought we had everything set. However, when we were received by the principal, instead of the respondents, and he asked how we had arranged everything, we couldn't explain ourselves very well. This caused us to get in a bit of trouble.

Recommendations

- Whenever you are doing research about other people's needs, make sure to research all different perspectives. And besides, try to let go your perspective.
- Never plan dependent on one person, especially not in Africa. People don't share the same values as in Europe if it is about arranging reliable appointments.
- In Tanzania the culture is way different than in Europe, and values differ. To do proper research, it is important to open yourself up to integrate in another culture and to let go a bit of your own culture.
- Make sure that whenever you are about to arrange anything at a governmental organization, you discussed that in advance with the board of the organization. It is to prevent yourselves from getting in trouble.

Because our plan partly didn't make it to action, we will transfer the assignment to the next group. The assignment involves investigating the best way to create awareness for people with a disability in Tanzania and how to make this sustainable.

By working on a fundamental network of multiple organizations the plan will not be dependent on one organization. In that way there is a strong base to implement the plan. As a cause of that, the plan won't fail if one organization appears too not be reliable.
Furthermore, it is important to calculate plenty of time for creating and testing the prototype, as it might be a process of trial and error.

Biography

National Assembly [Clerk]. (2010). *persons with disabilities* [E-book]. https://www.ilo.org/wcmsp5/groups/public/---ed_protect/---protrav/---ilo_aids/documents/legaldocument/wcms_151288.pdf

OHCHR. (z.d.). *OHCHR | About albinism and human rights*. https://www.ohchr.org/en/special-procedures/ie-albinism/about-albinism-and-human-rights

Tanzania - Cultuur. (z.d.). https://rondreis.nl/rondreis-tanzania/informatie/cultuur

UNICEF. (2021, september). *Children and young people with disabilites in mainland Tanzania and Zanzibar*. unicef.org. Geraadpleegd op 21 december 2022, van https://www.unicef.org/tanzania/media/2626/file/Children%20and%20Young%20people%20with%20Disabilities,%20a%20Situation%20Analysis.pdf

United Nations Convention on the Rights of Persons with Disabilities. (2006, 6 december). un.org. Geraadpleegd op 21 december 2022, van https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf

UNTC. (2008, 3 mei). treaties.un.org. Geraadpleegd op 21 december 2022, van https://treaties.un.org/Pages/PageNotFound.aspx?src=TREATY

VisumBuitenland.nl. (2022, 15 december). *Algemene informatie over Tanzania*. https://visumbuitenland.nl/tanzania/algemeen

Appendix 1

Creating awareness for people with a disability.

We are five healthcare students from the Netherlands. Our group exists of Fleur (speech therapy student), Nina (occupational therapy student) and Hanna, Puck and Merlijn (nurse students). Together we are working on a project to improve the lives of people with a disability here in Tanzania. Therefore, we have been doing research at multiple organizations that are focusing on fulfilling a decent future for children and people with a disability. To obtain an image of the way people with a disability look at their own life, we have been interviewing people with a disability who make a living with being on the streets of Arusha.

Our main goal is to give people with a disability a voice. This involves informing both people with and without a disability about the needs and rights of someone with a disability. We think this is important because we have noticed that there are misunderstandings about people with a disability in Tanzania. We also found out that people with a disability themselves are not informed on their human rights and opportunities they could have in society. To give them a voice we want to give people with a disability an opportunity to tell their story. We are going to invite professionals and activists that care for people with a disability to provide information on their vision and rights.

The plan

We want to create more awareness throughout the community. By cooperating with the newspaper, the organization will get more publicity amongst the people of Tanzania, including organizations or companies that are focusing on creating a decent life for people with a disability. In this way they can increase their network and cooperations through the country, and with that likely increase their income which will help them to become financially independent. Expanding the income could lead to the growth of the organization.

To create awareness, we are cooperating with the newspaper Mwananchi. We have arranged for the newspaper to publish a weekly article in which people with a disability get the chance to tell their story, as well as professionals, to create awareness amongst the society. Using the newspaper as our communication tool, we are spreading the message in a low budget way. With the newspaper being published in both English and Kiswahili, we will reach a broader scale of people.

After the interviews have taken place, we will evaluate together with you what the experience was. We hope that by this experience, the organization will have found a budget-friendly way in spreading awareness and indirect also publicity.

Note:
This plan had been send to the foundation ‘Lighthouse Support’, which provided us financial support in case it would be necessary.