The Discourse of Disability Gowa, Malawi

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What would a person who is completely 'abled' look like? One can quickly give a description of someone who is disabled; a person who is blind, deaf, has a physical deformity such as a missing limb, or has mental disabilities. But what certain lack of ability leads to labeling someone as disabled? Being 'abled' does not mean that you have endless ability, it merely suggests that you are physically, emotionally, mentally, and socially normal. However, normality is not static; it grows and shrinks to fit different cultures, time periods, and ideas of personhood. In addition, the attitude of society and of the individual can alter the stigmatism surrounding the disability. For example, the society may broaden their definition of normal to include the disability or the individual may find an alternative way to include himself in the activity that the disability formally inhibited. FEDOMA, the Federation of Disabilities Organizations in Malawi, embodies this idea in the motto "Disability is not inability"(www.fedoma.org). The motto emphasizes the idea that one's identity should be defined by the actions and characteristics of the individual outside of their disability. This statement reflects a growing awareness and increasing strength among the disabled organizations in Malawi. The mission of FEDOMA is "To enhance the welfare of all persons with disabilities and enable them to assume their rightful role in society" (www.fedoma.org). In the past few decades, Malawians have become more educated, aware, and exposed to different disabilities; in addition to this change, the disabled of Malawi have developed an inner strength within themselves and collective strength in the society through organization. Although there is still a constant struggle for the disabled in Malawi, the combination of these two developments is slowly creating positive change surrounding the attitude, definition, and stigmatism of disability.

In 2011, I traveled with a group of students to Malawi in order to learn about Malawi's history and culture and to conduct research. Before traveling to Malawi, I specifically wanted to learn about Malawian Sign Language and the collectivity and culture of the deaf in Malawi and later compare these findings to Deaf American culture. However, upon arriving at Gowa Mission, a village a 200 people but not one deaf person, I was confronted with the little information available surrounding my desired topic. This paper begins by focusing on the history of the deaf in Malawi. Over the past few decades, organizations and schools have been established in order to improve the rights and lifestyles of the deaf and to form a collective in hopes of strengthening deaf identity. The second half of this paper follows my experiences in Gowa while trying to learn about the deaf and the transformation and broadening of my initial research topic to encompass not only the deaf, but other people that are classified as "disabled". Through interviews, personal contacts, and sources, I attempt to uncover definition, stigmatism, rights, and awareness of disability in Malawi.

From the 1970 to mid 80s, funding for disabilities in Malawi depended on international charity, but in the late 80s, the government-funded organization MACOHA (Malawi Council for the Handicapped) launched the Community Based Rehabilitation Programme. The goal of the program was similar to that of FEDOMA, to identify and address the needs of the disabled and integrate them into the community. Likewise, in 1998 the Ministry Responsible for People with Disabilities (now called Ministry of Social Development and People with Disabilities) was formed. The policy of this ministry is "to integrate fully persons with disabilities in all aspects of life, thereby equalise their opportunities in order to enhance their dignity and well being, so that they have the essentials of life" (www.macoha.com). Finally, in 1999 FEDOMA was established. FEDOMA operates in Blantyre, the financial capital, but is represented throughout the country. So far FEDOMA has developed projects on raising awareness, rights of disabled, training staff and members, and lobbying for policy writing. FEDOMA is a partner to MACOHA and is also responsible for the creation of MANAD, the Malawian National Association of the Deaf.

Similar to FEDOMA's motto, Deaf advocates in developed countries, such as the United States, promote deafness as a culture rather than a disability. In the 1960s, William Stokoe finished the first American Sign Language dictionary and proved that American Sign Language was a natural and complex language. After this accomplishment, the "d" in deaf became capitalized. The significance of this change embodies a shift of identity; deafness was no longer viewed as a hindrance or something to be cured, but as a culture to take pride in and root one's identity in. Has this same shift of agency occurred in Malawi?

The organization, Deaf Action, funded by MANAD, estimated that there were 200,000 deaf people in Malawi; however this is merely an estimate because many deaf are undiagnosed. Ninetyeight percent of this population is illiterate, two percent have jobs and three percent of deaf children are in school. Among the majority of the hearing and deaf, deafness is viewed as a disability instead of an opportunity for cultural development. Unlike American Deaf culture, the culture of the Malawian deaf people struggles to develop. Because Malawian Sign Language is not yet recognized as official means of communication for the deaf, deaf Malawians cannot unite and interact in order to create a collective Deaf identity. In addition, the chairperson for the MANAD, Julia Mwase, states that there are "not nearly enough [interpreters] to meet the needs of the country's hearing-impaired people...interpreters are essential for churches...hospitals, markets, schools, police offices, courts and banks"(Voice of America). So although some deaf Malawians use Malawian Sign Language,

they are still isolated from the hearing world and also disconnected from fellow deaf who do not know MSL. Due to a lack of knowledge, lack of education, and lack of health services and technology, deafness is commonly misunderstood and mistreated. Also, due to the importance and prevalence of the Christian faith (around 80%) and traditional beliefs, deafness may be viewed as a punishment and therefore something to be ashamed of or hidden. In addition to faith, family and collectivity is very important in the Malawian culture. Not all Deaf people are shunned from their families and communities, but if they are there is little hope for them to survive on their own as outcastes.

Unlike, Deaf Americans, Malawian Sign Language is a new development and therefore deaf Malawians have not yet completely developed a stable language to identify with. However, as Malawian Sign Language continues to develop so does the culture and overall identity of the Malawian deaf. In the past 60 years, many organizations, many with Christian affiliations, have traveled to Malawi to promote deaf education, health, technology, and awareness. There are now 4 main Deaf schools in Malawi. Three schools are funded by the Monfort Missioners (AKA Brothers of Christian Instruction) they include the Mua School for the Deaf, the Mountain View School for the Deaf, and the Mary View School for the Deaf. In 1960, 30 missionaries came to begin the construction of these three schools. The Mua School for the Deaf is in the central region of Malawi, while the other two schools are in the southern region. The fourth school is called the Embangweni School for the Deaf and is in the northern region and is funded by the Church of Central African Presbyterians (CCAP). All four of the schools are boarding schools because many children have to travel far from their homes or their families abandoned them because of their deafness.

Sign language has only been used in the education of the Deaf in Malawi for under 10 years. The three schools funded by the Monfort Missioners are slowly beginning to accept the use of sign language, but are still very hesitant to accept its legitimacy. The means of education of the Deaf in these three schools is called the oral method. The oral method is still widely used internationally in the education of the Deaf, but looked down upon many Deaf culture advocates. The goal of the oral method is to completely assimilate deaf people into the hearing world. Although the oral method may have good intentions, this method assumes that every child can learn how to speak and understand speech, but this is not the case. Only a very small percentage of Deaf people around the world can lip read and/or speak in a way in which hearing people can understand them. For those who only suffer from mild or moderate deafness, learning to speak and lip-read is plausible and

would definitely be useful in a world that is mostly hearing. But for those who are between moderately and profoundly deaf, trying to learn through the oral method can be more frustrating and more traumatizing than helpful. Two other important problems with the oral method are the banning of sign language use and the discouragement of Deaf communities and culture. Oralists believe that in order for the deaf to be completely integrated into the hearing society they need to use the dominant language of the region. Deaf communities, which lead to the development and growth Deaf culture, act against the oralist's ideal situation in which deaf people would be completely assimilated with hearing people. In America, many deaf oralists feel as if they are stuck in between two worlds or identities. These oralists are never completely accepted by the hearing world because simply, they cannot hear. But at the same time, they are not accepted by the Deaf because they do not know the language of this world, American Sign Language. Although culture can lead to isolation, Deaf culture for many Deaf individuals provides a feeling of belonging, confidence and a sense of identity. Signed languages are an essential part of any Deaf culture, if sign language is taken away, the communication is lost and the people become oppressed and isolated. Oralists do not realize or do not accept that sign language as a deaf person's natural language and it is not right to try to force a deaf person to speak and lip-read. Instead, the ideal would be for the hearing majority to learn the sign language because we have the ability to do so.

As more information was brought to Malawi about deafness. Educators and professionals began to realize that sign language was extremely important to the deaf. In 1994, the Embangweni School for the Deaf was founded and led by Edward Mtonga until 2005. Mtonga's goal was to create an atmosphere in which the deaf would become self-supporting members of society; he now works with a 4 year-program that prepares teachers to serve children with special needs. The school is funded by CCAP and Marion Medical Mission and like the three Monfort Schools. Embangweni School for the Deaf stresses the importance of Christian faith. A regular school day usually begins and ends with worship or prayer. During services, children are allowed to volunteer to lead a prayer by sign. The Embangweni School is different from the Monfort schools because it promotes "total communication". Total communication is a combination of learning skills similar to those of the oral method, but also, this method promotes the use and importance of sign language. Sign language is extremely important to a deaf child because it can improve their quality of education, even to the point where they're at an equal level or higher than hearing pupils. One student's poetry illustrates the school philosophy of promoting sign language, "Deaf is not Death. Our cry to you has been heard. Disability is not Inability. Come and see for yourselves. Today our dream is a reality. Glory be to God" (embangweni.com/deaf). This poem is a wonderful example of how, with the help of MSL, the view of deafness is changing from disability to valued culture. When deaf children are placed in an environment where their deafness is not looked down upon, but rather accepted as a positive aspect of their identity and culture, the child cultivates feelings of belonging, motivation, and pride.

Speech training and Malawian Sign Language training begin at the preschool level and continue as long as the child attends the school. One issue is that the children begin learning speech techniques and MSL too late in life and have missed the critical period for optimal language development. In the deaf schools, children also take other classes such as English, ASL, Chichewa, math, religion, reading, writing, and older students are offered vocational training at the Robert Laws Secondary School (ROLASS). The secondary school's goal is to provide the children with an opportunity to contribute to society and earn a living. The terms for the three primary schools run from January to mid-November; it was noted that when the term ends the children can be heard saying, "we don't want to go home, because there is no one to chat with" (embangweni.com/deaf). For many children, the school is a much better environment than their home. Similar to American deaf children, school provides an arena for the children to communicate, express themselves, and make friends while feeling a sense of belonging that they may not feeling at home among their hearing families. In addition, all the children have a place to sleep and are given three meals and two snacks daily compared to 1 or 2 meals they may have at home. The Embangweni School for the Deaf is constantly growing and improving. But there are still many children that are not able to get into the school due to lack of staff and resources.

Although deaf education in Malawi is slowly improving, there is still a lot that can be done to create the best environment for deaf children. Katherine Steentjes, a Professor of Behavioral Studies at the University of Twente in the Netherlands, conducted interviews at the 3 Monfort Schools and discovered commonalities among the schools that needed improving. Steentjes stressed that there are 3 factors that affect the educational productivity of a child: individual factors (the hearing ability of child, motivation, self-esteem), quality and quantity of instructors (number of teachers, learning material, furniture, curriculum), and psychosocial environments in the home and classroom. In order to determine the general situation of the Deaf in the Monfort schools, Steentjes interviewed various teachers, professionals, and missionaries with different points of view about the education of the deaf. After conducting these interviews Steentjes concluded that the information she gathered led to

a number of improvement possibilities. First, even without adequate data, it can be concluded that deafness is a huge health issue in Malawi. There are no official numbers concerning deafness due to lack of government involvement and overall national attention. In order for the there to be a clear insight about the situation of the deaf, further research needs to be done. Second, it is important to raise social awareness and knowledge surrounding deafness. If the stigmatism surrounding deafness is confronted and lifted, the situation of the deaf child can be improved. Thirdly, only a few, if any, teachers have a background in deaf education. Even though the Monfort Schools promotes the oral method, teachers still need to know some local signs to be able to initially communicate with the students. Many teachers don't know any local signs, this can lead to frustration, misunderstanding, and mistrust on both sides. The Monfort School should take advantage of the development of Malawian Sign Language because it is the most effective and beneficial way for the deaf students to learn. Organizations like Deaf Action have already graduated 14 sign language interpreter trainers and 12 Malawi Sign Language teachers, but this is obviously not enough for the 200,000 deaf, estimated by Deaf Action. Lastly, on a bittersweet note, more and more deaf children are being diagnosed and admitted into deaf schools, but on the other hand, there are many hard of hearing children that are going under the radar. Hearing impaired children do not get the same special placement as profoundly deaf children and are integrated into hearing schools. At the normal schools, there are teachers for children with disabilities, but if the teacher cannot sign or if the student cannot lipread or speak, the specialized teachers are useless. Also, there is an unbalanced student to teacher ratio. Frequently, a hard of hearing child enters a normal school, falls far behind the other child, feels isolated, and drops out of school.

Although Malawian Deaf culture is not as developed as American Deaf culture, there is progress being made. When the first Monfort School was established in 1968 the school was strictly oral and consisted of 37 students and 4 teachers. Now there are 3 other schools, one of which promotes sign language, plus a secondary school, and a huge increase in teachers and students. If more attention is brought to these issues through international organizations and through the government, the situation of the deaf in Malawi will continue to improve and the culture of the deaf will continue to develop.

Due to the research I completed before I left for Malawi, I felt confident in my knowledge about the topic. Because I had spent time learning about deafness in Malawi, I made the mistake of assuming that all Malawians would know about this topic as well. However, once I reached Gowa

Mission, a village in Ntcheu of about 200 people, and began to question people I realized that the situation in Malawi is similar to the US; few people are knowledgeable about deafness. Most of the information I received upon asking about deafness included the following: there are schools for the deaf and deaf people use sign language. Beyond these two facts, the people that I spoke with knew little else about deafness. This is not a problem exclusive to Malawi, every country has a lack of awareness surrounding deafness and until 2 years ago I knew little about it, as well. Even in the United States, where we have the only Deaf University (Gallaudet), there are still many misconceptions and a lack of knowledge about deafness. For example, many people believe that sign language is international and that all deaf people communicate using the same language; however, just like spoken languages, sign languages are different in every country. After realizing that there was little information to collect on deafness in Gowa, I began to search for another topic; a meeting with the *sing 'anga* and the chief sparked my interest.

A few days after settling into Gowa, we traveled to Kaludzu, a nearby village, to visit the *sing 'anga* and the chief. Two translators, native to Malawi, aided our discussion. In Malawi, a *sing 'anga* is a traditional healer. *Sing 'anga* are more abundant in the villages, but have become less popular overtime as health clinics, hospitals, and biomedicine has taken their place. However, significant amounts of people, mainly in rural areas, still receive treatment from *sing 'anga*, mainly when they suspect witchcraft. When asked to describe witchcraft, the *sing 'anga* said, witchcraft is usually suspected when an unexplainable, mysterious, or unlucky event occurs and is usually blamed on an uncle or someone who is better off than the rest. For example, if there are five people in a car during an accident and only one dies, it may be concluded that this person was bewitched. Why should this man have died when the others lived? Or perhaps a mother has seven children, but only one of them is blind; this may be because the mother was bewitched during this pregnancy. During our discussion, the chief was put on the spot; we asked the chief if he goes to the hospital or the *sing 'anga* if he dreams of a disease or injury and this dream comes true. The chief added that if he doesn't dream about a disease or injury, he would go to the hospital.

Unlike the chief who was seated in a chair, above everyone else, the *sing'anga* sat on a bamboo mat. As the *sing'anga* spoke, eager children, who were possibly more intrigued by the weird *azungu* (white people), surrounded him. His mat was covered in dusty jars full of mysterious herbs, a 'diagnostic tool', and many other curious objects. I decided to ask him about deafness,

hoping he might know more than the others I had interviewed. First I asked him if he was able to cure deafness, keeping in mind that he introduced himself by saying he could cure all diseases except HIV/AIDS. Without taking a moment to absorb the question, the *sing 'anga* replied with a confident yes. Of course, he said, all you need to do is pour hot oil and crushed leaves down the ear. To follow my first question, I asked if he was able to cure deafness from birth. Upon hearing this, the *sing 'anga* realized that he had misinterpreted my first question. He had interpreted 'deaf' as clogged ears instead of an inability to hear. He then replied by saying he can cure someone who has become deaf later in life by using the same medicine used for the clogged ears, but there needed to be multiple treatments. However, if someone was deaf from birth, he could not cure this. "Do you know how deafness at birth is caused?" I asked.

"It's just natural." (Translator quoting sing 'anga) He answered nonchalantly.

This answer was surprising. This man had been saying that pneumonia, HIV/AIDS, epilepsy, and house fires are caused by witchcraft, but he is completely comfortable and confident in saying that deafness is natural; why is this so? Are blindness, mental retardation, and other physical disabilities always viewed as "natural" if they occur at birth? Or are there other causes? Although I didn't get a chance to talk with the *sing'anga* further, I had the chance to ask the chief one last question. Knowing that a chief usually chooses his first son to take his place, but can choose another son or even a daughter if the first son does not meet the criteria, I asked the following question: If you have a son who is disabled, but has the personality and character of a chief, would you still consider choosing him? The chief replied by saying, no matter the disability, if the person had the character of a chief, he would give them the position. He also said that he knew of chiefs that were blind or had leg deformities.

So how do biomedicine and culture interact with the disabled? In biomedicine, a disability is something to be diagnosed as a disease or condition and should be cured, "almost-cured," or attended to by a professional. For example, deafness is defined by hearing loss. Depending on the level of hearing loss, cochlear implants and hearing aids serve as cures or treatments. The stigmatism of the disabled depends on their ability to be cured. However, according to cultural standards, a disability is exclusive in terms of social participation. In this situation, it is up to the individual and the society to make accommodations so that the disabled can be included. The definition of disability is created by society based off of ideology, religion, culture and whether or not the disabled person can successfully participate in the society. After interviewing the chief, I continued to interview a diverse group of Gowa residents. I decided upon interviewing the following people^{*1}: Reverend S, Nurse F, Abambo F, and 3 students (CM, MJ, and JJ). One of our translators, GM, also suggested that we could go to the *masamba* (the market) and interview people with disabilities. I hadn't come across anyone in the village that appeared to be disabled and I had also asked around the village and no one seemed to know of any currently in Gowa. The day before we were going to travel to *masamba*, GM went alone to see if he could set up interviews. When I met with him the next day, he said he found the following people:

- 1. Older male, deformed legs, carpenter
- 2. Male, deformed legs, drunk
- 3. Female, deformed legs, owner of grocery store
- 4. Female, deformed legs, sitting

After GM told me about the people he found, I asked if any of them were willing to talk to me, but unfortunately GM said no. GM guessed that individually they may feel okay about speaking to me, but it seemed that their families were ashamed or perhaps skeptical. Although I was not able to interview any of these people, GM's encounter still gave me some important information and things to ponder. Why were there so many people with leg deformities and what was the cause? Did the drunken male and sitting female have jobs? Why were there families ashamed or hesitant about answering questions?

After GM's encounter at *masamba*, I realized that I would probably only capture the viewpoint of those who would not consider themselves disabled, those who were 'normal'. From here, I created a small survey to help guide my interviews. I decided to open each interview with: "When you hear the word disability, what do you imagine?" Among four secondary school students, Nurse F, Abambo F, and Reverend S, all initially replied by describing physical disabilities such as problem with the legs. No one mentioned mental disabilities until prompted about it. Reverend S gave the most interesting definition.

The Reverend was the most welcoming and excited informant, but at the same time, he seemed the most self-conscious. His house is relatively big compared to the other houses in the village. Reverend S was eagerly willing to be recorded and asked to hear part of the recording when the interview was finished. When I asked the Reverend to define disability he said, "To my own

¹ pseudonyms

understanding, disabled people are born with deformities such as deafness, they are not able to speak, they are not able to walk, or they are paralyzed." After a short pause he added, "A disabled person is unable to do things which other people can do." The second part of the Reverend's answer stood out to me, because he was the only one who included this in the definition. (Also, when I first met the Reverend a few days earlier he said that the disabled were "just like everyone and well attended too". How can they be like everyone else, but unable to do what others do?) Every other informant only described physical or sensory disability, but the Reverend actually mentioned a comparison of disabled to the 'abled' or normal. At the time, I didn't think to ask, who are the 'other' and what exactly can they 'do'? But his answer did lead me to ask what the disabled persons role is in the family and community. Reverend S replied by saying that the roles vary. He believed that many disabled people feel frustrated do to lack of communication, lack of acceptance, or poor treatment; but he felt that many families and communities are accepting of the disabled. He also emphasized that if families and communities know the cause of the disability, the disabled person is more likely to be accepted and understood. Next, I wanted to ask the Reverend how a few different aspects interplayed with disability. I ask the Reverend about government, religion (the Reverend along with around 80% of Malawians are Catholic), and the sing 'anga, the results are shown in the table below.

	Positives	Negatives	
Government	 Ministry of Disabled-encourages disabled Introduced schools for disabled 	 Doesn't provide accommodations for disabled in villages Schools mostly funded by NGOs 	
Religion (Catholic)	 Leads to acceptance of themselves and acceptance from others Church is a source of hope-provide gifts, money and food Prayer and faith can heal Participating in church helps you forget about your disability 		
Sing'anga	• Can sometimes heal disabilities	 Mother can be blamed for giving birth to bewitched child Usually uneducated people go to the sing 'anga Some people believe having sex with disabled virgin can cure HIV/AIDS 	

Positive and Negative Experiences of Disabled 1

The Reverend was very adamant of religion's positive role in helping the disabled; he had a negative view towards the *sing'anga*, and seemed neutral about the government.

The next morning I met with Abambo F at his house. Abambo F was very welcoming and seemed very relaxed. Abambo F seemed very intelligent and kind. Abambo defined disabilities as only physical, but when prompted about mental disabilities he included these as well. He also added that people with physical disabilities are more easily accepted because their disabilities are visible; only those who are educated are more likely to recognize and understand mental retardation. Like the Reverend, I also asked Abambo F about positive and negative treatments and accommodations the disabled experienced from different aspects of society. Because Abambo F is a teacher, he was able to include information about education as well. The information received is shown in the table below:

	Positives	Negatives	
Government	• Pay for old people, provide blankets or houses		
Education	 Some students get scholarships for university Disabled schools University paths are wheelchair accessible 	• Students can get teased if they go to school-knew a boy with stammer who dropped out	
Religion (Catholic)	• Can use bible verses to encourage disabled		
Sing'anga		• People believe having sex with disabled virgin can cure HIV/AIDS	
Marriage	• Can marry other disabled (ex. blind marry blind)	 Sometimes people marry educated disabled for their money Hard to find someone to marry "They love, but they are not loved" 	

Positive and Negative Experiences of Disabled 2

While talking with Abambo F he told a story about a friend he had as a child who was disabled. This friend was a girl whom had metal poles as legs and she was number one is every class from Form 1-Form 4 (this is equivalent to high school). He spoke very fondly and highly of this girl and it sounded like she was very intelligent. Unfortunately, this girl's parents were not able to pay for education after secondary school. The girl ended up marrying another man who was disabled, but he doesn't know what happened to her after that. Abambo F emphasized that many students do not

continue with their education after secondary school because of cost, transport, or interest. Abambo F seemed to be replaying memories of her in his head and he kept repeating softly, more to himself, about how intelligent she was. In contrast to the Reverend, Abambo F had a personal relationship with someone with a disability. Abambo also knew of 10-12 people with disabilities, compared to the Reverend's 2 or 3.

Chapter IV of the constitution states that all persons are entitled to education and primary education should be compulsory and free; this includes the disabled. Since the free primary education policy in Malawi was introduced in 1994, the enrollment has almost doubled. Now more children had the opportunity to be educated; however, the jump in enrollment led to shortage of classrooms, qualified teachers, and materials. Although it is difficult for many children in rural areas in Malawi to access education, especially after primary school, it can be even more difficult for children who are disabled. There are many reasons why disabled children do not attend school; the cost is too high, schools for disabled are too far away and the family doesn't have or can't afford transport, the child is not accepted into a special school, lack of specially trained teachers, the family is ashamed and hides their child, the child is ashamed and afraid of being teased, and just lack of overall accommodations for the special needs of the child. In 2001, the Ministry of Education, Culture, and Sports tried to address the need to strengthen special education and in 2005, the Special Needs Education Unit was upgraded into a Department. Goals of this department consisted of promoting accessibility into school buildings and toilets, raise awareness about the abilities of the disabled to change negative attitudes, to establish a training institute for special education teachers, and to increase supply of specialized teachers, materials, and assistive devices. Currently, there are around 500 specialized teachers and over 50,000 students enrolled in primary schools (Salmonsson, Disability is not Inability).

At Gowa Primary and Secondary School there are no specialized teachers. Some teachers told me they didn't know of any disabled children that were enrolled in the school, while others spoke of some who were partially deaf, had poor eye sight, had epilepsy, or one girl "just went mad". One teacher said that there were two deaf students from the village, but they were currently attending the Mua School for the Deaf. Through our translator FN, I decided to ask the students to raise their hand if they knew anyone who was disabled. After a few moments of laughter and then an uncomfortable silence, 3 male students raised their hands; CM, MJ, and JJ. This was the information I received from them:

3 Informants Relationships with Disabled:

	СМ	МЈ	11
What is their disability? How did it happen?	Deformed arm from car accident	Missing leg from birth	Lost both legs from polio at 7 yrs
Do you know them personally?	no	His mother	His brother, 16 yrs old
Are they from Gowa?	No, from his original village	No, from his original village	Yes
How are they treated?		Treated normally	His family encourages him
Other?			His brother and family feel frustrated. His brother is sad all the time. They would like something to help him walk, but it's too expensive. He is not able to help in the house, just lays in bed all day. Will you do something to help him?

This encounter made me wonder if any of the students talk to each other about these personal issues in their lives or if they just keep it to themselves. I also wonder if these three boys would have answered my questions differently if they weren't in front of all of their friends.

My last interview was with Nurse F who worked at the Health Clinic in Gowa. Nurse F is one of only three nurses who work at a clinic that serves 40-50 people/day during the cold season and 200-400/day during the hot season. Surprisingly, Nurse F knew the least about disabilities out of all of the informants. Many of the questions I asked her, she turned to the translator GM, looking confused, whispered a short phrase, which was followed by a translation of, "she says she doesn't know." We all sat in a small brick building, which was meant for out patients. I started by asking Nurse F to define disability. She replied that most disabled people are born with polio or have high blood pressure. She did not know much about deafness, blindness or any treatment for disabilities; she only knew that there was a shot for polio that should be given to children in their first year. After considering the resources of the health clinic, I realized that her answers were not so surprising. The Gowa Health Clinic, is not able to treat people with disabilities because the doctors don't have the training nor the resources. To get care for many medical issues such as emergencies or surgeries, Gowa citizens must travel to the district hospital in Ntcheu, which is sometimes impossible due to cost or transport. The Gowa Health Clinic mainly offers shots and education about diseases, such as pneumonia, for children under 5 years. Also, the Health Clinic does not have any electricity. Nurse F also admitted that she doesn't personally know anyone who is disabled and therefore doesn't know

how disabled are treated by their families and the community. Although, Nurse F knew little about disabilities she seemed to have a positive attitude towards them. She guessed that families and communities are accepting of the disabled and are treated well, she also was confident that many disabled are married.

When I asked my informants to define disability, the majority first responded by saying a deformity of the legs. Two of the students I interviewed knew someone with a deformity of the legs, and all of the people GM encountered at masamba who were disabled had leg deformities. On the other hand, no one ever mentioned mental disabilities unless prompted. From my results, all of my informants described disabilities as something that was medical, a physical problem with the body. However, no one really talked about trying to find a cure or that the disabled are people that need to be fixed. Perhaps this is because people don't have the money or access to hospitals where they can get treated, or maybe this is due to prevalence of Catholicism in Malawi and the preaching of acceptance of all people. I also think that mental or learning disabilities are not as commonly mentioned because education is not always of the highest priority. In a way, slight mental disabilities are able to stay under the radar. However, if you are missing a leg and because of this you cannot farm or retrieve water for your family, this disability would be more detrimental. Although I heard a lot of talk about acceptance and encouragement of the disabled, I was not able to see this at first hand. Every informant that I spoke with mentioned that most communities and families and supportive and encouraging; and from the chief I learned that the disabled can be leaders as well. However, I am still a bit skeptical because I never saw this in action. From my informants I learned that different parts of society all serve different roles in terms of improving welfare of the disabled. The government has certain ministries that deal with welfare of the disabled and also provides some money for special schooling. Religion and church provide hope, prayer, faith, and emotional/community support. There are different kinds of treatments provided by the sing 'anga and hospitals however both of these present their own problems. I think that the government can always do more in terms of supporting education, providing jobs, and raising awareness, but I also think that acceptance and awareness begins within the desire of the disabled and of their community. From the informants I spoke to, and my research prior to and after my field, it seems that the disabled are becoming more accepted and accommodated for and most of this work is being done by those not involved with the government. If the disabled continue to join together and raise awareness, they may be able to eventually prove that inability is not disability and there are always roles available for any kind of 'abled' in society.

In the Nyasa Times, a Malawian online newspaper, there is article about a boy named Maliwa. Maliwa had polio when he was younger which caused him to lose his arms and have deformed legs. For a while, Maliwa felt shunned by his village but when he started to repair radios, the community began to notice. Maliwa is quoted saying, "Before I started repairing radios people always thought of me as a beggar. But now all this has changed. They refer to me as the radio repair man and not the disabled man." This story illuminates the conflicting identities of a disabled person. Before the boy could contribute to society he was pitied and seen as an outcast, but once he proved he could be helpful, his identity changed from disabled boy to radio repair man. The motto of FEDOMA, "disability is not inability" and Reverend S's definition of disabled as "A person [who] is unable to do things which other people can do" highlight this clash of disabled identity and disabled identification. Organizations like FEDOMA, MANAD, and MACOHA fight to encourage a positive disabled *identity* by promoting inclusion and acceptance of the disabled in an "abled". However, when a society *identifies* a disabled person as "unable", the beggar with deformed legs, or the deaf man, this negative identification placed by society and the positive identity trying to form within the disabled clash. In order to overcome this conflict, biomedicine and cultural beliefs must be confronted. Instead of thinking of deafness as something to be cured, it should be viewed as it's own distinct culture. For example, in the U.S., the acceptance of American Sign Language as the official language of the Deaf, the appearance of Deaf organizations, and the creation of literature such as poetry and stories, all served to construct what is now known as Deaf American culture. At the same time, like Maliwa's story, it is crucial that people with disabilities work with their families, societies, and governments in order to become a productive members of society.

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