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Disabled: Watching Stories of the Malagasy Deaf

Nadeen Hamza
SIT Study Abroad

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DISLABELED: Watching Stories of the Malagasy Deaf



SIT Study Abroad: Madagascar, Urbanisation and Rural Development

Spring 2014

Nadeen Hamza

Advisor: Roland Pritchett

Abstract

Dislabeled: Mislabeled and Disabled - two words that Malagasy Deaf individuals have used in this project to describe themselves and the struggles of their community. This project explores dynamics between the mainstream Malagasy society and the marginalised Deaf community as well as the dynamics within the Deaf community of Antsirabe. I argue that mainstream stereotypes of the Deaf are manifested in the ways these individuals see themselves as well as the opportunities that society offers them. I also argue that individuals who have high proficiency in Malagasy Sign Language have wider access to public services as well as a higher degree of participation in daily life, both with other Deaf individuals as well as hearing communities.

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To the Deaf community in Antsirabe: I owe an immense amount of gratitude to you. Thank you for letting me into your lives and sharing your incredibly inspiring stories with me. I don't know what I did to deserve this amount of hospitality and trust from you. I will never forget you.

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List of Acronyms

AKAMA	Deaf School in Antananarivo
AUD	African Union for the Deaf
CBM	Christoffel Blindenmission
FLM	Malagasy Lutheran Church
FMM	Deaf Association of Madagascar
FOFAMA	Deaf School in Antsirabe
FBO	Faith Based Organisation
IMF	International Monetary Fund
MSL	Malagasy Sign Language
NGO	Non Governmental Organisation
SEMAFI	Deaf School in Fianarantsoa
SEFAMA	Deaf School in Diego
SEMAMA	Deaf School in Mahajanga
SEMAMO	Deaf School in Morondava
SEMATO	Deaf School in Toamasina(Tamatave)
WFD	World Federation for the Deaf
WHO	World Health Organisation

Chapter I: Introduction

“We are Malagasy and our language is Malagasy, they are Deaf and their language is Sign Language” -Teacher at the Deaf School in Antsirabe

Excerpt from Field Journal: Antsirabe, 10th of April

On my very first day of fieldwork in the city of Antsirabe in Madagascar I was faced with the harsh distinctions made between hearing and Deaf people. I arrived at the Deaf School in Antsirabe (FOFAMA) to attend an annual workshop held by the school for hearing parents of Deaf children. The workshop mainly focuses on teaching parents basic Sign language but also provides a safe space to discuss tendencies towards depression and domestic violence that Deaf individuals face as a result of being isolated due to not sharing a common language with their closest family members.

Deaf people in Madagascar are situated within multiple imbalanced power structures. Malagasy Deaf people live in an environment and community that is ambivalent and often openly hostile to people with disabilities. There are many reasons why Madagascar makes an interesting study site for an ethnography of Deaf people. Whereas Western dialogues on disability and deafness are relatively uniform, Deaf people in Madagascar have very different perceptions of themselves and of their positions in society; in contrast to Western Deaf communities where intellectuals as well as members of Deaf communities draw distinctions between disability and deafness, Malagasy Deaf individuals live a different, harsher reality. Deaf people in Western countries generally

do not consider themselves as part of the disabled community, Deaf people in Madagascar draw distinction between themselves and other disabled people only by their language use. The Deaf population in Madagascar operates with close to no support from the Malagasy government. They have very little access to education, if any, and are often isolated from the mainstream community.

I set out to do this project in Antsirabe, a city in the highlands of Madagascar that is known across the island for ,among other things, the establishment of the first school for the Deaf 65 years ago. Many graduates of the Deaf School in Antsirabe, many of whom were participants and contributors to this project, stay in the city after they graduate and choose to live in communities of Deaf individuals. Even though most of my interview participants are graduates of the Deaf School, their education makes them part of an elite Deaf group in Madagascar. F.M.M, the Deaf Association in Madagascar, estimates that less than 1% of the 170,000 Deaf individuals in Madagascar receive any form of formal educational training throughout their lives. In some cases my research population included limited language as well as limited conversational abilities. I often realized during interviews that some of these individuals have never been asked questions about their experiences as Deaf individuals at all. However, even those who have never been asked questions or expressed their lived experiences verbally, had stories to tell and experiences to share.

This research project set out to answer the following questions:

Q1: How do social contexts of living in Madagascar affect Deaf people's constructions of themselves in terms of how/whether they see themselves as a community and how they see their deafness?

Q2: What role does sign language and access to education play in the participation of a Deaf individual in daily life?

The research questions explore the a relationship between Malagasy mainstream society and Deaf people as well as dynamics within the Deaf community. I will argue that Deaf people who have had training in sign language are the Malagasy Deaf community's main and most important asset in terms of advocacy for equal rights and that their high proficiency in sign language gives them better access to support networks, public services as well as participation in daily life.

This project mainly contributes to the field of Deaf studies and international development. I believe that the study fills an important gap in literature and on site research on disabled communities in developing countries. Previous projects have focused on the needs of disabled populations in Madagascar but this is the first research project focusing solely on the Deaf population. I hope that the data and observations included in this project will provide facts beyond common sense that will help advocates lobby for better services and support deaf people. This project will be provided upon request to all organisations and individuals working to improve the lives of the Malagasy Deaf.

Chapter II: Literature Review

Disability in the Field of Anthropology

The field of anthropology has taken an interest in disabilities and persons of disabilities since the 1940s. However, most of the early literature that has been written on disabled communities has analysed these communities from medical models of disabilities. In the later decades of the twentieth century research in the field of disability has taken a more humanitarian and less medical approach to the living conditions of these individuals.

Researching disabled communities, especially in developing countries where they are less favoured by the general abled masses, is extremely important and helps further the access of these marginalised communities to public services and equal rights. In 1999 Gleeson wrote: "Disability is a vitally important human experience. A failure to embrace disability as a core concern can only impoverish the discipline, both theoretically and empirically".

One of the first and most cited ethnographies of disabled communities done in the field of anthropology was done by a blind researcher named Gwaltney in 1970. The researcher lived in a Mexican village with the highest incidence of blindness. Following that ethnography more and more researchers took interest in disabled communities outside of the Western world. In 2001 Colligan, who is a paralysed anthropologist, went to Israel to do fieldwork. Her approach to her research was more of a reflexive approach, where she focused on her own disability and how it affected her research and interview participants responses and attitudes towards her research. Countless

literature on disabled communities exist today, however there has been a clear shift of focus from the “dysfunction of disability” to incorporate more contemporary understandings of these conditions that do not solely rely on medical models of disability.

Sociological studies have also contributed a great amount to the field. Two researchers in particular have added a great amount towards understanding the situation of disabled individuals within communities: Parsons (1975) and Goffman (1963). Parsons writes:

Once a person is sick, they are relieved of all other social roles (such as mother, husband, leader). Second the sick person must be passive, they must accept help and care from others, and seek qualified professional help. Finally, and most problematic, the sick must get better.

Parsons’ ideas about changed positionally that disabled individuals have to live with has been extremely helpful for this research. It helped put into perspective when hearing interview participants told me that “Deaf people can not make good parents”, and made me realise that this doubtful attitude towards disabled individuals is not strictly cultural in Madagascar but rather a worldwide trend that can be observed across more than one culture. Whereas Parsons focuses on societal roles and relationships to other people that the disabled person is familiar with, Goffman focuses on stigma and stereotypes that are held by the wider population. He writes that there are three kinds of stigma: abominations of the body(disabilities and physical deformities), blemishes of character(mental illness, homosexuality, and alcoholism), and tribal stigma(race, religion, or ethnicity). Even though not all these stigmas have equal impact on the individual’s life it still affects the perception of the person as a whole. He also talks in

detail about the importance of “passing”, where those who are victims of stigma are always trying to ‘pass as normal’. This is particularly important for this study, Deaf people’s ‘disability’ is relatively hidden compared to other disabilities and as long as they don’t sign in public, they can ‘pass as normal’. In addition to that, Goffman also argues that “people with stigma only find comfort in associating with other stigmatised people, when there is a relief from having to pass as normal.” This can be seen in the popularity of Deaf clubs, which will be discussed in a later chapter.

Western Distinctions between Deafness and Disability

Prior to this study, my only training in the field of Deaf studies has been in the United States, a Western Deaf cultural community. Naively, I was convinced that certain self-perceptions of deaf individuals and how they see themselves within the larger society was international rather than local notions that were based on equal shifts happening in Western society caused by hearing individuals advancing their perceptions of the Deaf community to be one that is equal to theirs.

In Western countries, and dominantly in the United States, there is a clearly marked distinction between deaf people and people with disabilities. Since the 1800s Deaf communities in these countries have fought to keep this distinction alive (Buchanan, 1999 & Robinson, 2010). Whereas communities in Western countries have fought and struggled for the linguistic recognition of their respective sign language (Ladd, 2003), Deaf communities in developing countries are still at early stages of documenting their languages in dictionaries. However, the difference in harshness of the realities of Deaf

communities in Western countries and developing countries is grounded in the fact that in Western countries Deaf people are protected by a functioning legal and justice system that has a capacity to protect them from injustices and guarantee a real educational experience. Although legal structures to protect persons of disabilities does exist in Madagascar, high rates of poverty, lack of accessibility to services and corruption prevent these laws from being practiced fully.

During my first interview with a Deaf individual, namely the vice president of F.M.M, the Deaf Association of Madagascar, I posed the following question: "Are you deaf or disabled?". Coming from a Western trained perspective that strictly enforces this difference, I expected to hear a different answer than the one I received. The woman stared blankly at me, and answered my question with: "Both." Throughout my research I have encountered the absence of this distinction and slowly came to realise that 'positive' self-perceptions of Deaf individuals in Western countries, no matter how advertised they are or how hard Deaf individuals from Western countries try to spread them, are simply grounded on very different lived experiences and cannot exist in the Malagasy context at the moment.

Chapter III: Methodology

“R. never had any formal training in sign language, neither did she attend any schooling throughout her whole life. She doesn’t know her last name or her birth date. In comparison to other responses received by Deaf individuals who have received formal education, her answers were very short and very basic in vocabulary. When I asked whether she had a spouse she responded that she “dated a hearing person but we separated because hearing people are bad. Hearing people just speak, speak, speak and I don’t like that.”

Excerpt from Field Journal: Antsirabe, 16th of April 2014

This three-week long project relied on many established methods of sociological and anthropological fieldwork. The main method used is participant observation, while interviews and surveys come in second for the most utilised methods. In this section, I will explain and describe the methods used to make this research possible as well as I and the implications of the methods used. In addition to that, I will also describe in detail the reasons for failure of some of my planned methods that proved to be inefficient and sometimes impossible to follow through once I started conducting the research and was faced with harsher realities than I expected.

This research project has been quite challenging not only in a methodological sense but also from a theoretical standpoint, because once I started meeting Deaf individuals and realised our different ideas of disability and deafness, many of my research questions and my tactics of approaching certain topics had to be completely changed.

Most of the research was conducted in participants’ homes. After gaining access to a home visit, many participants allowed me to accompany them to their places of work as well as meetings for their individual Deaf organisations.

Access to Participants

Before conducting this research, I had some exposure to deaf communities in the US. Conducting research with stigmatised and marginalised groups requires initial access to that group in a certain way that reflects trustworthiness and genuineness. In other words, had it not been for my Malagasy interpreter who had, to some extent, some personal relationship with most of my participants that seemed very positive, the results and even more importantly the individual responses I received from various participants, would have been radically different. My first contact with a Malagasy individual involved in the deaf community occurred in Mahajunga, a large city on the West coast of Madagascar. I visited the Deaf school there in February and made initial contact with the head of the school, who had received formal training in sign language and has been responsible of the school in Mahajunga since 2011. The educated community of deaf people in Madagascar is very close knit, for one particular reason; that is, there are only seven schools on the island that exclusively serve to educate the hard of hearing and the deaf. Therefore, my initial contact with Mr. Mamy and his connection to FOFAMA, the biggest Deaf school in Madagascar that is located in Antsirabe, assured me contact to other schools as well. I visited the school in Antsirabe for the first time in March and made some initial contact with a young female teacher named Mamy. My second visit to FOFAMA was towards the end of March and I managed, with the help of two SIT program staff, to finalise my plans to get assistance from the school in terms of finding contacts. The school would be closed during the period of my research but the teachers

live in the school and are familiar with most of the deaf population that resides around the school.

I arrived at the school at the beginning of my project to attend a sign language and deaf psychology training session led by the school for hearing parents. The head of the school announced my presence and asked me to get on stage for everyone to see me and be familiar with my presence and my goal. That was the moment I truly realised that my nationality allowed me extensive access to events that would not be open to local communities in the same way. Nonetheless, I cannot deny how grateful I am for the almost unlimited access I was offered throughout my time here.

More specifically, I gained access to Deaf individuals through the directory and contacts of FOFAMA. Many of the school's Deaf graduates live in Ivory, the same Fokontany in Antsirabe that FOFAMA belongs to, and together with Mamy we ventured out into Ivory and Antanambao (another neighbouring Fokontany) to search for deaf individuals that she had some relationship with.

Gaining access to deaf individuals in Antsirabe, an urban city, was relatively easy, all we had to do was ask around for the name of the participant we were searching for. However, gaining access to deaf individuals in more rural or semi-urban areas was much more difficult. One day we ventured out to Betafo and decided to stop halfway through at Alakamisy, a small town between Antsirabe and Betafo. Mamy knew of a hearing parent with four deaf children who lived there and since we did not have an address, we decided to follow rumours and ask random individuals around the town if they know of any deaf individuals who reside here. Our inquiry led us to the home of a hearing woman whose daughter is currently attending FOFAMA. Even though it was not

planned to meet with her, we walked about 2km to find her house and she warmly welcomed our questions. This anecdote is just an example of what it would be like to focus one's research on a stigmatised community in a more remote area, not only are homes wider apart, but there is a factor of isolation that makes it harder to locate individuals of disabilities because of the degree of stigmatisation that is attached to them and the widespread desire to hide them.

Sample

My research sample was by far the most unexpected sample part of my project. In total, I conducted 25 interviews with Deaf individuals in the Vakinankaratra region, most of which were in Antsirabe. Out of the 25 subjects 20 are female. The subjects' age ranged between 20 and 48 years old. Due to restrictions related to working schedules and my own schedule that limited me to working in the mornings, since my interpreter was mostly available in the mornings, many of the deaf men I wanted to interview were absent during my field work hours. Even though my study only included women, it is important to make distinctions between these different women in terms of their education level, their involvement in the local deaf community as well as their signing level. Almost all participants of this study were (98%) were fluent signers due to their former and sometimes current affiliation with FOFAMA, where they had access to and learned sign language for years. Only 2% of my participants were non-fluent signers, both of them had not attended FOFAMA and they were taught sign language as part of their membership in a Deaf club. They both originated from rural areas around Antsirabe

and had their first informal as well as formal exposure to sign language as adults when they moved to Antsirabe and had more extensive contact with a bigger, signing Deaf community there. Because of time constraints I couldn't include more non-native signers from rural areas; the one day I ventured out into a more rural area it took me about 5 hours to locate two interview subjects.

It is fair and realistic to say that given the time constraints as well as the purpose of this research, it was sometimes easier to settle for signing subjects in more urban areas, time for building a common signing rapport with a non-native signer simply did not exist.

Asking hearing people in the same Fokontany for information about deaf people's locations was also a very useful tool. Often times we couldn't locate a certain house and many generous residents of the area guided us to find them.

In addition to that, I also gathered data regarding religious affiliation of my participants. Out of the 25 Deaf participants 23 were Lutheran and 2 were Catholic. Since FOFAMA is a school funded by the Lutheran church and that offers religious spaces for the Deaf every month in form of a signed service, being a Lutheran deaf individual who is seeking spiritual guidance makes sense. One of the catholic participants was from Alakamisy and the church closest to her home was Catholic, her family interprets services for her every sunday.

Even though most of my research participants are female and there is a resulting gendered bias in terms of responses I will get about deaf issues in general, it also gave me access to issues and information about clubs I had not thought of before the start of the project. The women I interviewed were all members of Deaf clubs for women. The

separation of the women into two clubs is a result of a monetary conflict that resulted in the split, another methodological challenge I will address later.

Gathering Data

Before formally starting my project in Antsirabe, I had a set of interview questions laid out that would guide me through the points I was trying to explore. However, after an interview I conducted in Antananarivo one day before my departure to Antsirabe I quickly realised I needed to take a different approach. My interview was with the Vice President of FMM(the biggest organisation and head club of the Deaf in Madagascar). The woman I interviewed works as a teacher in FOFAMA and struck me as a very strong and independent character that was very ready to sacrifice herself for the greater good of the deaf in Madagascar. When I asked her how she would describe the “Deaf community” in Madagascar, she simply did not understand my question and told me that this she doesn’t think that such a concept in that form exists here in Madagascar. Coming from a Western educated standpoint on disability and deafness, as well as being educated and a proponent of the idea of an “Imagined community” of deaf(see Literature review on imagined communities) I was struck when I realised that Deaf people here have very different lived experiences than Deaf individuals in western countries. Whereas there is a commonly agreed on sense of pride in being Deaf abroad, here it is often a source of shame for the deaf individual’s family. This radical difference has unimaginable consequences on how deaf individuals see themselves, but more importantly how Deaf people relate to one another as a “community” (or the

lack thereof). This difference in mentality forced me to not only change my interview questions as well as my approach to the topic but also made me realise that any western ideas of glorifying disability are non-existent here, and therefore if I were to stick with my interviewing approach I would search for something that did not exist.

Participant Observation

This method of my research was the most time consuming method used. After conducting interviews, especially at the market where many Deaf women had their own stands lined up close to each other, they would allow me to stay there for a while and observe their interactions with buyers as well as other hearing sellers. Participant observation not only allowed me to form my own opinions of the subjects but also allowed me to see them in a more specific context that included their interactions with hearing people. It allowed me to witness first hand some of the discrimination that they experienced by other hearing sellers who would laugh as they saw them signing or curiously and shamelessly stared at them while they were having their own conversations in sign. In addition to that particular situation, right before I conducted my first interview with my first participant, I had to wait because coincidentally a police officer walked into the subjects' yard at the same time as me and was trying to communicate with the Deaf individual. I watched a frustrated police officer walking away once my subject signaled to him that he was Deaf. Experiences such as that one are invaluable both personally and for my research, and without participant observation and taking note of these interactions, I would not be able to put the responses I received from my participants into a broader context.

Individual Interviews

I conducted individual interviews with all of my subjects that were divided into two parts. The first part was a formal survey about their age, place of birth, occupation, marital status as well as yes/no questions. The second part consisted of getting their own personal life story as well as their own ideas of other deaf people they have encountered in their lives. The responses and success of each individual interview depended entirely on the relationship they had firstly to FOFAMA, to Mamy and then their own idea of what my research outcomes are going to look like. Out of the 25 individual interviews, 19 were formal and 6 were informal. The formal interviews were set up at least a day earlier and the informal interviews were all set up based on recommendations and connections made by the 19 individuals interviewed before. They would lead us to other Deaf individuals and neighbours that were willing to be interviewed and usually we interviewed them right after the first interview with the primary contact was completed. That way the primary contact would lead us to the second subjects' home and there would be a higher sense of familiarity, trust and comfort in each of the interviews that were conducted through secondary contacts.

All of my interviews with deaf individuals except one were conducted inside their homes. Due to their sense of comfort in their own home as well as always making sure I make eye contact and do not look away from them as they were signing, I got a sense that many interview subjects felt at ease sharing their experiences with me, even the most personal ones. These experiences, of course, were shared under the agreement of mutual trust between me and them, as well as my interpreter.

Since my interviews were mostly conducted in Malagasy Sign Language, constant attention was required and therefore most note taking took place on my computer, since that was faster and required less looking away from them as they were sharing their stories.

Group Interviews

In total, I conducted 3 group interviews that were unstructured and relied on what the subjects wanted to talk about as a group and more importantly what they felt comfortable sharing with me as a group in front of other Deaf subjects. The group interviews resulted out of several of my subjects living in the same vicinity, and following individual interviews we would gather and conduct a group interview. In one instance, it was necessary to have a group interview to translate and have a common rapport, because the intended subject of my individual interview had not received formal sign language training and therefore the Deaf living with her had to mediate her signs and interpret them to my interpreter. Two of my interviews were with female singers while one of them was a mixed group of two female singers and a male singer. There was no obvious difference between the two gendered groups in terms of responses, the mixed group lived together and they all felt comfortable sharing their stories in front of each other.

However, the only interview conducted in a group setting with mixed hearing and deaf individuals was unintentional to be that way and I observed clear uncomfot on behalf of the Deaf interview subject. That particular interview was with a non-native signer who has a Deaf son who attends FOFAMA. She is Deaf and the rest of her family is hearing.

We conducted the interview at the atelier she works at, the employees there are mostly family members who can sign and as we were conducting the interview many of them came to watch what was happening and what was being said (that leads to one of the challenges relating to forming crowds of hearing people that I will address later in this section). It seemed to me that the informant was clearly uncomfortable and often looked to her hearing family members for reassurance that what she was saying was "acceptable".

Surveys

As mentioned in the previous section on individual interviews, many of these interviews included a quick survey section before the start of the actual in depth interview. However, the most extensive survey application in this research was at the workshop at FOFAMA for hearing parents. The workshop was 3 days long, I arrived on the second day and on the same day I had to come up with survey questions for the hearing parents. In total, 39 pairs of parents completed my survey that had to be translated into Malagasy and in many cases also read to them by my interpreter as well as other employees of the school because of literacy issues. The surveys focused on their own perceptions of their hearing children as well as society's general perception of them and included a section of yes/no questions about their proficiency in sign language as well as their predictions of other people's proficiency (i.e. gendarmerie, their neighbours, their friends, etc). The surveys were a very helpful way to quickly gather information from that focus group, since many of them live hours away from Antsirabe and I would have no access to them once the workshop was over.

Challenges

Crowds

Specifically in Tsena Alsabotsy, the biggest market of Antsirabe, where three of my interview subjects worked, many hearing sellers as well as buyers would often stop what they were doing just to form small crowds around us while conducting the interview. Partially, because sign language was being used, but also because based on my appearance they were surprised that a foreigner was taking interests in their issues. A couple of people even asked me why I was doing this interview and whether I was a missionary looking to help the deaf. Yet, crowds of unfamiliar hearing people was not my biggest issue. The problem with crowds were familiar ones. Crowds that included family members, neighbours, or friends because these crowds demanded information, sometimes translation and even went as far as answering some questions for the deaf subjects.

Language and Interpreting

Even though I made a conscious effort to learn some Malagasy Sign Language long before I started the project and that helped me understand and communicate briefly with many of my subjects, this project would have not been possible in any way without my interpreter. Her proficiency in both English and Malagasy Sign Language made it possible for us to enter intellectual realms of deafness and deaf experiences that would have not been possible with a stronger language barrier. I believe that the main language used in this project being sign language makes it quite unique. It offers

participants with a window to vent in their own native language and talk about issues in sign language that they were never asked about before, as well as make them discover more about themselves. However, as beautiful and useful as sign language is, it is very stigmatized. As a result, many interviews were more ideal to conduct in the subjects' home to avoid mocking or crowd forming. In addition to that, there were many interview subjects who despite of their level of education, still had a somewhat harder time understanding my interpreters signing system, and it took longer to explain certain questions than expected.

Confidentiality and Informed Consent

Issues of truly informed consent were extremely challenging in this project because of the projects' target population. Even though many of them had received formal education at least until secondary school, many of them struggled with formal language(i.e. spoken Malagasy) and are part of a marginalized community that fears hearing people, a group that I belong to. During first introductions to my interview subjects, Mamy would explain to them that I'm an Egyptian student studying in the US , what my research focuses on, who would potentially have access to my research and that my main objective after I finish studying was to open a Deaf school in Egypt. That last part was very crucial to many participants, they did not want to be seen as a focus group or as a 'disabled' population that I was pitying and researching but rather as a group I genuinely take seriously as equal to the hearing community.

Confidentiality

The idea of confidentiality was a very prominent and important one among participants in this subject due to one particular reason. There is a great split in the Deaf community here in Antsirabe that resulted in a split in deaf clubs as well as social splits between the families of those involved in the conflict. Many participants asked me to “keep it a secret” when they were talking about monetary and personal conflicts between the two Deaf clubs and many even refused to address the issue revolving around Deaf clubs. Many of them were concerned about local confidentiality, they only cared that their neighbours and other members of the group do not hear the particulars of our conversation but at the same time they were interested in having their stories heard by non-local communities. Because of that conflict, I decided that I would change all names of those who have participated in my study, to protect their identity as well as assure that my project will not cause more unnecessary conflict between the two groups based on what is being cited from our conversations.

Another issue of confidentiality I came across relates to the documents that one of the women’s groups was proposing to the government. I received these documents from the head of one of the womens' organisations and she told me that the information in the documents was “sensitive” but at the same time asked me to make copies for the purpose of my project and read them. After putting a lot of thought into the ethical considerations of having copies of these confidential documents, I decided against having physical copies and instead just asked my interpreter to give me a gist of what the papers say and what type of aid they are asking for from the government.

Informed Consent

Communicating and explaining the idea of informed consent to a population that has never interacted with a person trying to research their particular situation is extremely challenging. I continually assured my subjects of my role as a student, that I'm not a volunteer or a researcher and that I am here to hear their stories. I also always made sure to ask them whether they were comfortable with certain sensitive questions before I asked them and once they agreed to answer it I would proceed. Consent was not only given verbally but also physically, one time in the small town of Alakamisy I was having a conversation(not an interview by any means) with a deaf girl who attends FOFAMA. The conversation started after the end of my interview with her hearing mother. The girl was 15 years old and after getting consent from her mother to have a conversation with her, she started getting very shy and started crying and walked out of the room. I waited there for about 30 minutes for her to come back so I can heal the situation, even though I did not ask any questions that would trigger that reaction("How was your day?", "What did you do today?"), the pressure that she was under from her hearing family members to answer my questions, as a foreign student that they thought deserved more respect from the young girl, made her breakdown.

This particular situation has been my only one where I felt a sense of uncomfot from the person I was talking to but otherwise my experiences have been very positive. People have opened up and shared their heart-wrenching stories, often because they explicitly told me that have never been asked about them.

Field Sites

The following field sites are described in order of time spent in each field site, starting Antsirabe where I did most of my field work(only including interview hours), then in Antananarivo and following that Alakamisy and Betafo. My project was mainly set in urban areas due to practical reasons of connections in terms of access to participants and includes one day of fieldwork in rural areas.

Antsirabe(~55 hours):

The city of Antsirabe is the third largest city in Madagascar with a population of about 180,000.

It is characterised by its wide, clean streets and rickshaws or the so called “pousse pousse” as its main form of transportation.

However, it is also characterized by its large and ongoing presence of missionaries, specifically Norwegian missionaries. The first Norwegian missionaries arrived in 1868 and have had a dominant role in providing education for the disabled. The seven major schools for the Deaf in Madagascar are all run by associations connected with the Norwegian Lutheran Church, with the oldest school for the Deaf being first established in Antsirabe around 65 years ago. Antsirabe is a hub for Deaf education, the school is widely known across the country for its intensive education system for the Deaf and is currently the school with the largest group of students currently enrolled as well as the main training center for those who are interested in teaching the Deaf. The school has a dominant presence in the city, everyone I have spoken to is aware of its existence and

praises its mission. Therefore, the Deaf in Antsirabe have the advantage of hearing people knowing about their condition and of their existence, which is not the case in many rural areas. As a result of the missionary presence and the dominant influence that is ongoing, FOFAMA offers signed church services once a month, many deaf individuals from rural areas come and attend the service if they can afford the travelling fee.

Antananarivo(6 hours):

As the largest city of the island, Antananarivo is an important political, social and economic center of Madagascar. According to an estimate in 2005 the city's population is about 1.6 million.

The capital is home to the only school with post-secondary education(AKAMA) as well as various organizations and unions for the Deaf. I spent my project preparation period in Antananarivo, where two of my most important meetings for this project took place. On the two days preceding the project I visited AKAMA, the deaf school in the capital as well as FMM, the union for the Deaf in Madagascar. In addition to these two major organizations, it is also home to CBM(Cristoffel Blinden Mission), a christian organization that strives to improve the lives of 'disabled' individuals in developing countries. CBM is a major partner of all the Deaf Schools affiliated with FLM.

Betafo and Alakamisy(5 hours):

The town of Alakamisy can be reached by Taxi-Brousse from Antsirabe. It is about 15 minutes away and is home to many agricultural practices. It is more remote than Betafo

and much smaller, we had to walk long distances from one house to another just to inquire about the presence of possible Deaf informants in the area.

Betafo is about 40 minutes from Antsirabe by Taxi Brousse and is home to many Deaf individuals who frequent Antsirabe for meetings of Deaf clubs, who attended FOFAMA and who attend the monthly signed church service at the school. Similar to Alakamisy, it is also home to many agricultural practices.

Chapter IV: Sign Language in the Malagasy Context

“Apart from Eli, who attends FOFAMA, there is one other Deaf girl in the village they know of. When I asked her whether she thought the lives of Deaf people in Madagascar were hard, she said it depended on their level of education: “If the Deaf went to school their life is easy but if they did not it’s very difficult. Here in society there is a Deaf person who has never went to school and she can’t communicate with the rest of the people around her, she feels like a crazy person. Before Eli went to school I thought she was crazy too and I did not know what she did but after she went to school she knows many things and is responsible at home. “

Excerpt from Field Journal: Antsirabe, 23rd of April 2014

People with disabilities are among the most vulnerable populations in the developing world (Groce, 2003). The deaf population, specifically is set apart by one unique feature: their form of communication. In Madagascar, Malagasy Sign Language(MSL) is the dominant sign language, but by far not the one most used by Deaf people in Madagascar and not recognised by the Malagasy government. FMM(Association of the Deaf in Madagascar) estimates that there are around 170,000 Deaf individuals living on the island, however this number is likely to be lower than reality because of underreporting and other stigmas around disability. Access to Malagasy Sign Language is only possible through one of two options: attending a deaf school or joining a Deaf club that provides Malagasy Sign Language classes.

All of the 25 interviews I had with Deaf individuals would have not been possible in any shape or form without the access to education that these individuals had when they were younger. The sign language rapport they have not only allows them to communicate with each other, but also has serious cognitive advantages towards their

development in comparison to non-signers and have little ways to communicate their feelings and desires.

Development and Spread of Malagasy Sign Language

A sign language generally develops when Deaf people are in the same vicinity, attempts of visual communication develop over time into complex syntax and an equally complex of vocabulary that is unique to each sign language. Each country has its own official sign language, whether recognised by the state or not, and regional dialects of sign exist as well. Here in Madagascar, I was told by multiple interview subjects that regional dialects can differ so radically that some of them are not mutually intelligible (i.e. Antsirabe Sign and Diego Sign). Because of these differences in language, FMM has committed to the sign language dictionary project. The project aims to document existing signs and adjust to changing signs in the future, it is available in book format and sold at AKAMA in Antananarivo. It was surprising to see the limitations that come with distributing this book: the largest Deaf school in Madagascar which is in Antsirabe had no copies to sell and the only access I personally had to it was to buy it at AKAMA in Antananarivo. The *Malagasy-Malagasy Sign Language* is sold for 30,000 Ar and the *Malagasy -English- French- Sign Language* version is sold for 80,000 Ar. Considering the economic situation of many Deaf who cannot even afford the fare to attend a Deaf school in their region, the prices and availability of this book seem to defeat the purpose of the project.

In a 2011 report of the World Federation for the Deaf the head of the organisation stated that the three crucial factors for advocating and advancing the rights of the Deaf in any country are a formally recognized sign language, a strong interpreting professional cadre and strong national-level deaf associations. To date, none of these three factors exist in a solid form in Madagascar. The state has yet to recognize Malagasy Sign Language as one of its languages, there are currently 33 certified interpreters in all of Madagascar for 170,000 Deaf individuals and national-level associations such as FMM are lacking the funds to support their lobbying projects.

Role of Sign Language in Everyday Life

As mentioned above, the value of sign language in a Deaf person's social, familial and economic life cannot be underestimated. With 99% of Deaf people having no access to formal education, many find other ways and spaces to learn the language, often at older ages, and to communicate with other Deaf members of society. The place of origin of a deaf person, whether the place is rural or urban, the family's financial situation as well as the existence of other deaf family members are all factors that determine the age at which a Deaf person will have their first exposure to sign language.

Since my study subjects were overwhelmingly contacts of the Deaf school in Antsirabe, many of them had learned sign language in a formal setting. However, two of the study subjects had their first exposure to sign language when they were older at Deaf clubs. The two interview subjects were not born Deaf, in fact they turned Deaf in

their teenage years and moved to Antsirabe short after. Both subjects described a sense of frustration when they turned Deaf since communication with their family had suddenly become much harder and their families made little to no attempts to learn sign language:

“When I turned Deaf my family told me that they were ashamed of me using sign language. They tried to force me to speak because for the first 12 years of my life I could. My father’s family doesn’t like me because I am Deaf and it is difficult to have communication with me.” -E.M. (Personal Interview, Antsirabe, April 22nd 2014)

“I communicated with my family through reading their lips. At home, they did not let me use sign language because they thought that it would make me dumb. I asked them to learn sign language for me, but they never did, so I stopped asking.” - R.E. (Personal Interview, Antsirabe, April 18th 2014)

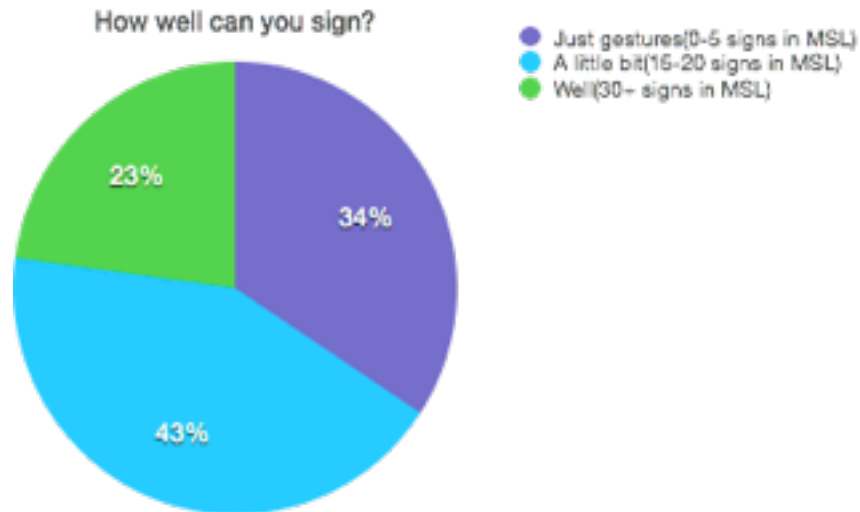
The role of sign language in everyday life, especially in families depends on many factors. The first factor is whether there are multiple deaf individuals in the family. This can sometimes lead to a positive incentive on the family’s side to learn sign and be able to communicate with the Deaf. In a survey completed on the 10th of April 2014 at FOFAMA by hearing parents of Deaf children enrolled at the school, the following results illustrate the role of sign language at their homes:



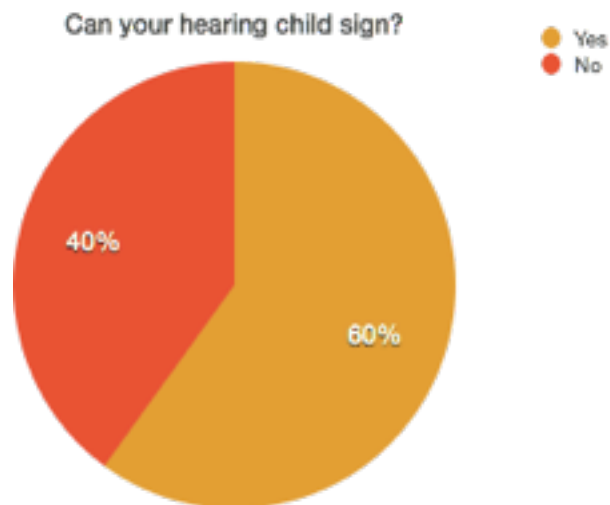
Out of 35 respondents, 34 of the parents said that they can sign. That was an expected result, since many of them had been returning parents to that workshop and are also part of a small group of parents who are involved in their Deaf child's education. There are around 250 children attending FOFAMA, yet only 39 pairs of parents attended the workshop. Many of the parents simply couldn't make it because of transportation fees, professional or personal obligations, but it is important to point out that this sample of parents who can sign are certainly not the usual in the Malagasy context. In fact, results are likely to be reversed in parents who live in rural areas and who have not attended any of the yearly workshops held by the school, the vast majority of these parents would have no proficiency in sign language.

However, what is more interesting in the light of the response to the previous question is to see how the response to the question above relates to their response about their proficiency in sign language. Even though 97% of respondents said that they can sign, only 23% of them actually know more than 30 signs (which is in itself a low number) in Malagasy Sign Language. That suggests that even though 77% of them

know at least five signs, that is not nearly enough for any meaningful communication with their Deaf child.



When asked about the proficiency of the hearing siblings in sign language 21 parents said that the hearing siblings of their Deaf child could sign, whereas 14 said they couldn't.



As a result, isolation, depression and lack of communication amongst Deaf individuals and family members is a clear result of this survey. The numbers in this survey are even positively high because they only account for the number of parents that made a conscious effort to support their child's deafness and attend a workshop of this nature, but it doesn't account for those who feel ashamed by their child's deafness and do not want to even go as far as learning some sign language to have basic communication with their child.

Access to Services

"I'm proud to be Deaf, but I need an interpreter with everything that needs to get done" -President of the Deaf women's association of Antsirabe(Personal Interview, Antsirabe, April 14th 2014)

Many of my interview subjects did not address sign language as a form of communication but rather as a barrier to access to services and information. Because there is a poor accessibility infrastructure in Madagascar, those who can only sign have much trouble accessing services such as police, government officials and healthcare.

My first encounter with the language barrier between Deaf individuals and government officials was on my first day of interviews in Antsirabe. I walked into the informants house with my two interpreters. Suddenly, two officers walked into the house. They had some questions but as soon as they realised that the residents of the house were Deaf, their face turned and they were clearly disappointed, kept speaking to them

in Malagasy assuming they would understand and then after two “Veloma’s”(Malagasy for “Goodbye”) that were unresponded to, they quickly left the scene. Not once did they try to find a hearing person to interpret or to find different ways to communicate, they just dismissed them. In my survey for the hearing parents I asked them whether they thought officers of the police or of the gendarmerie sign, and the majority answered “No”. This was a clear example of the big gap between government enforcement and the role that governments play in people’s lives and the role they play in the lives of Deaf people. I was appalled by how lightly they took the issue and how they seemed so careless about inclusion or even trying to let them know why they were there, regardless of what questions they intended to ask.

However this situation in the Malagasy context is a very real lived experience that is far from an anomaly, in fact it is a daily part of a Deaf individual's life when trying to communicate with hearing officials. All of my interview subjects when asked whether they think or know whether gendarmerie officers can sign responded with “No”.

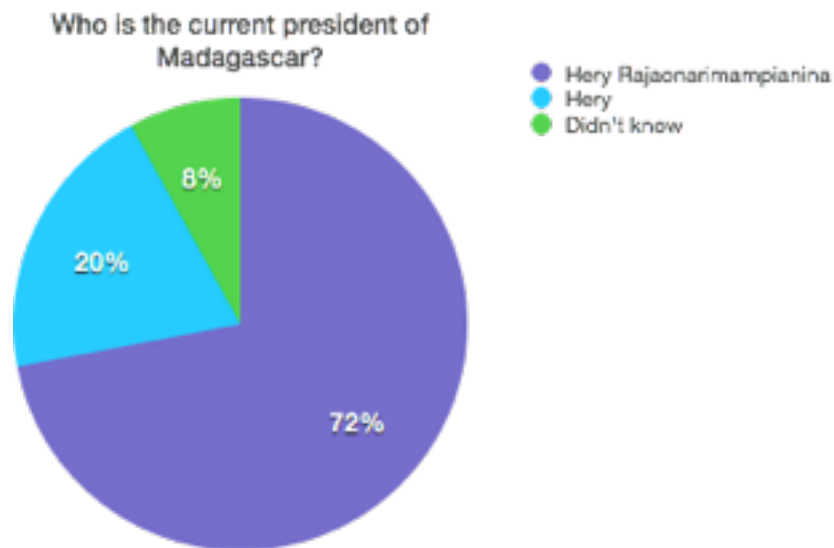
However, the Vice President of FMM, a deaf woman who works as a teacher at AKAMA said the following:

“If there are problems in public domains Deaf people are often rejected and also isolated because workers have no knowledge of sign language. There are also people who pretend to be Deaf when they do a crime and are let off based on that by the Gendarme.” -Vice President of FMM(Personal Interview, Antananarivo April 8th 2014)

Apart from communicating with government officials, communicating with healthcare providers and doctors has been another major issue mentioned by many of my

subjects. All of them said that they never witnessed an interpreter being available on site at a hospital, they always had to bring a family member along to interpret for them.

In addition to healthcare and government services, access to information about political and social life is also extremely limited to Deaf individuals. Madagascar's main news outlets are the radio, TV and newspaper. Apart from relying on their hearing family members to deliver the news, deaf individuals only have access to a signed "TV Journal" three times a week. Even though this might seem like an adequate number on first sight, it is important to think about the economic realities that Deaf individuals face and that many of them cannot afford access to a TV. Many of the Deaf individuals I have met have admitted to not having the required level of education to read and understand the newspapers; none of them received schooling beyond the secondary level of education. Yet, most of the Deaf individuals I have met over the course of this project voted in the past elections. One subject reported that only one candidate in the past electoral round had a campaign with an interpreter, and that the interpreter's signing dialect was incomprehensible to her, yet she decided to vote for him because he tried to communicate with the Deaf. When I asked the interview subjects to name the current president I received the following results:



Out of the 25 interview subjects, 18 knew the presidents full name, whereas 6 knew his first name and one did not know his name at all. The only interview subject who did not know the name was also my only non-signing interview subject who had not received any formal education until she arrived in Antsirabe and learned sign language at the Deaf club she is a member of.

Stigma associated with Sign Language

Having a hearing disability, being hard of hearing or profoundly deaf are all 'disabilities' that in comparison to other disabilities such as blindness or physical handicaps can be hidden. Deaf individuals can move freely within crowds and pass as 'normal' until they start using sign language. As a result of that, in countries and communities where disabilities are highly stigmatized as seen as shameful, any public and outward indication of these disabilities is often hidden by members of the disabled

communities. Therefore, using sign language in public can often cause uncomfot and shame by those using it and is often avoided until necessary.

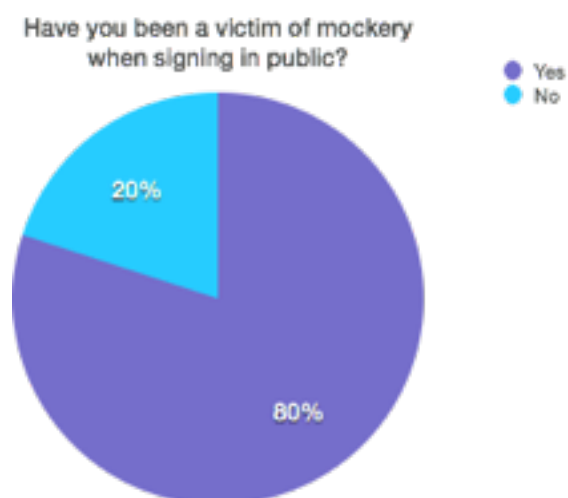
Many of the individuals I interviewed, both hearing and deaf, echoed notions of fear when signing in public. These individuals have often been victims of mockery and in some cases physical abuse.

These notions are even more apparent in individuals who became Deaf at a later stage in life. Since many of them remembered a time when they were hearing and had a so called "hearing mentality" being Deaf is not just a reality they grew up with but are rather forced into that reality.

"I don't sign in public. I only speak" -R. (Personal interview, April 16th 2014)

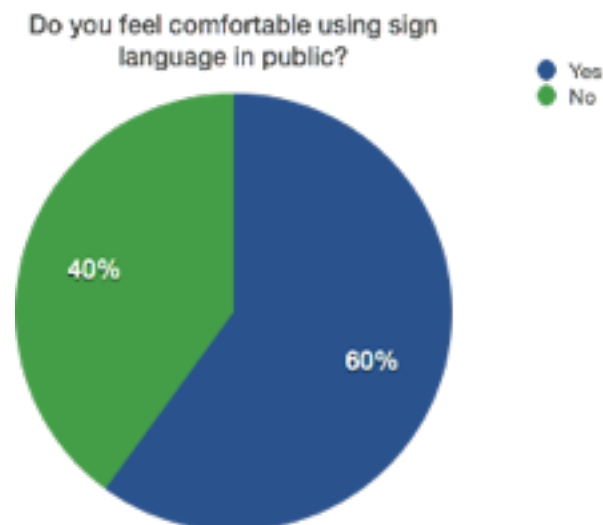
The quote above was uttered by many of the interview subjects, signing in public for them is a public attestation to their disability.

In a survey of the hearing parents ,conducted on April 10th 2014, asking them whether they had been victims of mockery while signing with a Deaf person in public, the following responses were given:



A follow up question was asked about their reactions to the mockery, and most of the respondents said that they do not react. Passivity in reacting to discrimination against practices of disabled people has been a trend that I have come across many times in my study.

In a survey for Deaf individuals, I asked them whether they felt comfortable signing in public and received the following responses:



However, there are many subjects who also feel proud of their sign language and teach it to hearing people. One of my two interviews in more rural areas was in Betafo, with a mother of a Deaf girl who attends FOFAMA. The mother works at the police station in Betafo and is incredibly proud of her daughter's deafness. She told us stories about how her daughter teaches sign language to hearing children and adults in their village and how her daughter's deafness has helped her realise struggle of disabled people in Madagascar. This discovery was equally shocking to me, because prior to my

visit to rural areas I was convinced that life must be harder for Deaf individuals in rural areas because of their isolation and limited access to meetings that Deaf clubs hold. However, after my visit to Betafo and hearing this story, it made me realize that rural areas have much more tight knit communities that have a stronger support system than those living in urban areas. Therefore, differences in experiences as a native signer depend more on the community one lives in rather than its degree of urbanization and the associated availability of special education.

Individuals without Malagasy Sign Language (MSL)

“We had our own home sign language, our hearing family knows and understands it too. I never learned to read and write or sign like my son who is now at FOFAMA, but he is teaching me now.”

-C.A. (Personal Interview, Antsirabe, April 17th 2014)

In this section, it is important to shed light on those with no access to education but still manage to develop their own language and maintain communication. Home signing systems develop when a household has (more than) one deaf individual and they have not been introduced to the formal education of the local sign language. Thus, the deaf individuals develop their own signs with the rest of their family members and these signs becomes part of their own distinct and unique signing system. It is important to address home signing systems in the Malagasy context, since it is very likely that most Deaf individuals with no access to formal education at Deaf schools have developed home signing systems with their families and their communities.

In countries with a high degree of standardisation in their sign language, home signing systems are not very popular. Generations of a deaf family attend schools with rigorous and standardised sign languages and there is little to no need for home signing systems. On the 17th of April I visited a well known Atelier in Antsirabe where a Deaf woman in her late 30s was awaiting my arrival. The interview subject is the mother of a seven year old deaf boy at FOFAMA. C.A. grew up among six Deaf siblings, her parents were both Deaf, but none of them had received any formal training in MSL. Thus, growing up her family had their own home signing system that is completely separate from MSL. The atelier she works at belongs to her family and all the employees are also family members. C.A., luckily and unlike most Deaf individuals, works in a signing environment, where the employees of the atelier can sign in her home signing language. Her son is currently teaching her Malagasy Sign Language as well as reading and writing.

C.A. is an example of a positive shift that is currently taking place in Malagasy society in terms of accessibility and Deaf education. She is part of a generation that still had limited access to various educational services and still to this day has trouble with Malagasy Sign Language, but through her son, who is part of a new generation of Deaf individuals who are being actively taken in by schools like FOFAMA, she has a chance to get an education through him.

Chapter V: Deaf Education

“My second interview subject was called Rasoavololona. Rasoavololona never had any formal training in sign language, neither did she attend any schooling throughout her whole life. She doesn’t know her last name or her birth date. She has been a very special interview subject for me for a variety of reasons including: even though Raphaelina taught her sign language at the Deaf club, her vocabulary is still lacking a lot and she often did not understand many of the questions asked and she is also the only Deaf subject that I have asked about the name of the current president of Madagascar and she did not know it. In comparison to other responses received by Deaf individuals who have received formal education, her answers were very short and very basic in vocabulary. “

Excerpt from Field Journal: Antsirabe, 16th of April 2014

Deaf Schools

As discussed in previous chapters, education and access to education are two subjects that were highlighted by almost all of my participants. There are currently nine schools for the Deaf in Madagascar: three in Tana, one each in Antsirabe, Mahajunga, Diego, Tamatave, Morondava and Tulear. It is worth noting that eight out of the nine schools only offer formal education until primary school and then shift towards vocational training approaches once students receive the CP1 degree. The school in Tana, like seven out of the nine schools, was established by the Fiangonana Loterana Malagasy(F.L.M) and the Norwegian Missionary Society(N.M.S). In 1992, the first movement for extracurricular activities(i.e. vocational training) for the Deaf had success, and starting that year, each week students would gather in conferences and their teachers had the responsibility of teaching them skills to enhance independency and self-reliance.

In 1994 education took a revolutionary turn for the Deaf in the capital. It was decided that the school would now start offering the option to continue schooling beyond primary

level, and middle school classes were instituted. Students who wanted to be considered for entry were expected and are still expected to score at least 60% on the examen officiel du CEPE. In 1997, the school was given a substantial donation by the Cristoffel Blinden Mission of Germany to build an additional building to make space for students who were now transitioning into middle school. The decision to open a middle school also drew many students of Deaf schools from other provinces, if their parents could afford it, and many teachers at AKAMA offered lodging for these students. It was not until a year later that the first activities of vocational training were offered at the school. In 2001, the school continued its efforts towards the improvement of the quality of education and there was now a fully functional, independent department within the school with the sole responsibility of heading vocational training policies, practices as well as potentially helping the graduates of the vocational training department with finding jobs. Five years later, in 2006, thanks to donations by the Embassy of Japan, the vocational training department was able to expand its territory and now had a full building dedicated to vocational practices and training, the school now provided additional training in informatique, art culinaire and couture.

It was not until 2009 that the first Deaf person in the history of Madagascar was able to graduate from high school. The school had finally received an authorisation from the Malagasy government to go ahead and establish a Lycée and in September of the next year the first (female) student made history as the first Deaf person with a Baccalaureate. AKAMA remains the only school with any formal education beyond primary school in Madagascar. The school celebrated its 25th anniversary in 2010, this year the Deaf School in Antsirabe celebrates its 65th anniversary, but there doesn't

seem to be a plan for furthering formal education beyond primary school there. All the Deaf schools in Madagascar are either supported by CBM or the Lutheran Church, or both.

The fact that to this day there is no schooling beyond primary school in more than 90% of the Deaf schools only reflects a mentality of hearing members of society who run these schools and run society. In each of the Deaf schools, committees consisting of solely hearing board members decide whether a Deaf child has a high enough "intellectual capacity" to continue formal education. These same committees also decide which vocational training the students will get into based on their own observations of the Deaf individual and sometimes taking into account which vocational branch the student requested. The current state of education and the degree of control hearing workers at the schools have over these deaf individuals is yet another example of audism.

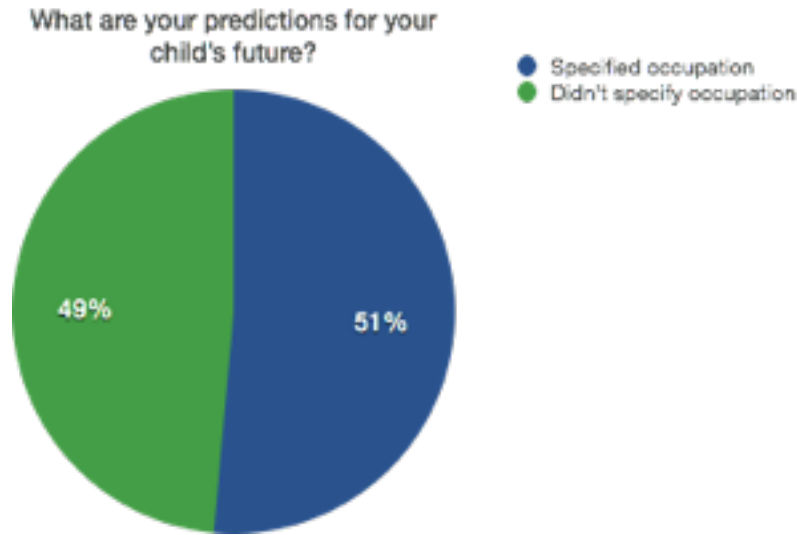
Efforts towards inclusion

Inclusion at the University level

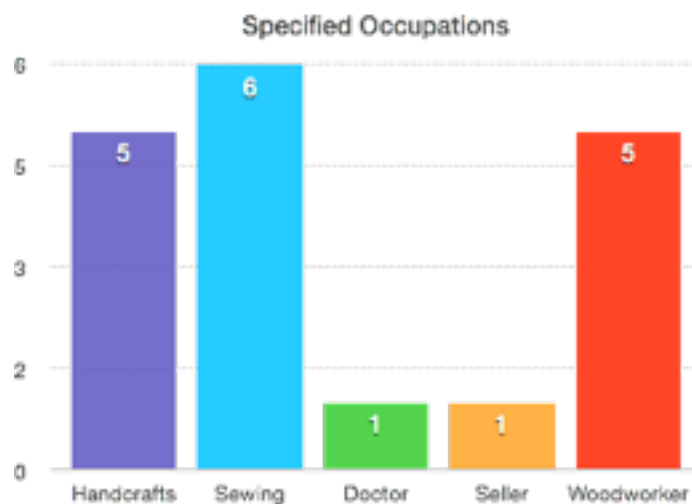
To this day, there have been no Malagasy Deaf who have attended university in Madagascar. The only individual who has attended university, and not finished, was a girl who graduated from AKAMA in 2009. She went on to Norway to complete her studies there, because of similarities between MSL and Norwegian Sign Language, as well as the close ties between the Malagasy Lutheran Church, the Norwegian Lutheran Church and the Deaf schools. However, only after 2 weeks of being there, her deaf

husband who she had met at AKAMA, refused to let her stay in Norway and demanded she come back. She came back without a degree.

Currently, there are efforts by FMM to lobby for university-level inclusion of Deaf graduates of AKAMA in local universities. The Malagasy government requested that there are at least three Deaf individuals that apply and get accepted to the University of Antananarivo, and then the government would provide an interpreter at no cost. However, it is not as easy as it sounds. There are three main problems with the proposition that the government has made. The first problem is the low number of Deaf that AKAMA lets finish a BAC degree. The second problem is the median age, which is 24, by which Deaf individuals graduate at from AKAMA; by that age both parents and students do not see a point in continuing education when they could start financially supporting themselves. The third problem is the willingness of the parents of Deaf individuals to fund their deaf child's university education, because many of them believe that they will end up doing handcrafts anyways. Deaf people are thought of as destined for handcrafts and are seen as having a 'talent' in handcrafting and therefore formal education from the perspective of their hearing family members that fund their continuing education makes little sense. In a survey for hearing parents at the workshop in FOFAMA, I asked the parents what they predict for their child's future and received the following results:



More than half of the participants, when asked what they predict for their child's future named a specific occupation, while the other half gave responses along the lines of leaving it up to God's will and letting their children do what they what. Of the ones that specified occupation, the following responses were given, with "Sewing" as the top named occupation for parents of female students and "woodworker" being the top named occupation for parents of male students:



Inclusion in Primary, Secondary and High School Education(UNICEF)

“To date more than one child in four does not have access to education”

Primary School Exclusion and ways to improve inclusion- UNICEF Report on Malagasy practices of educational inclusion (February 2012)

I was informed about the growing prominence inclusion in Madagascar during my first interview here in Antananarivo with the Secretary of AKAMA. I must admit that I was very skeptical at first and rejected the idea, simply because of numerous literature I had read on the subject that indicated higher rates of depression among Deaf children who attend hearing schools and feel isolated. However, based on the interviews I completed during the past three weeks and the clear lack of access to specialized education, inclusive education in hearing schools is a good first step towards educating marginalized groups. According to the UNICEF report (2012), their definition of inclusion is as follows: “A process of recognising the diverse educational needs of children in local schools. An inclusive education system can only exist if mainstream schools adopt a more inclusive approach, that is to say, they succeed in educating all children in their communities.”

The first general policy for inclusive education in Madagascar was set out in a decree dated 4 September 2009 by the Ministry of education: “the basic principle adopted is that inclusive education for all children with special needs, whether these are health related(physical, sensory developmental) socio-economical, geographical, cultural or related to learning difficulties.”

While I was in Antsirabe during the fieldwork period, there were several inclusion workshops for teachers taking place. They emphasised the idea of “sensibilisation”, of making abled communities and students aware of the needs of their potential disabled peers. However, the main problem is not only an institutional one, but also a cultural one. Attitudes towards

disabilities shape the degree of “sensibilisation” that needs to take place in various schools, regions or countries.

However, reluctance from “abled schools” is not the only barrier for accessing education as a disabled child. Often times, the barrier starts before the school and exists at the child’s home. The report states that “a considerable number of parents refuse to enrol their children because of motor, sensory, developmental, or intellectual impairments. Justifications reveal that they are ashamed of their child’s disability and there is a perceived loss of time and money for the education of a disabled child. To date, disabled children who go to school are, for most part, those who are hard of hearing or who have a motor disability with their arms or legs.”

Percentage of School Enrollment of children with hearing impairments:

(According to UNICEF Report)

	Enrolled	Dropped out	Never attended school
<u>Partially deaf</u>	41,4%	25,7%	16%
<u>Deaf</u>	4%	0,9%	13,9%

After seeing these numbers it is clear that once profoundly deaf children get initial access to education, the retention rates are very high. That is because profoundly deaf children attend deaf schools whereas partially deaf children attend hearing schools that were prepared by sensibilisation processes, however dropout rates in these schools is much higher due to lack of sufficient preparation and accommodation for the child.

In conclusion, inclusion efforts in the Malagasy context are positive if they are done in the right way, in a way that will truly make the Deaf child feel included in the classroom with his hearing peers, but if the numbers of partially deaf tell us anything about these efforts it is that they have not been sufficient.

Chapter VI: Deaf Organisations and Clubs

Deaf Organisations

“The first contact that people in developing countries had with what we today call rehabilitation came through missionaries and representatives of the colonial powers.[...] For missionaries preaching the gospel of love and mercy, the seemingly most disadvantaged members of a society would often become the focus of attention. [...] Some missionaries would focus their activities only on people with a disability[...] Yet for the most part, the mission’s activities for people with disabilities have been apart of their general setup of church, hospital, and educational purposes. These early services for people(mostly children) with disabilities were usually located in the capital or larger centers and catered to children of the newcomers and sometimes to children of the local educated elite. [...] The colonial powers brought with them the principle that assistance to people with disabilities should be financed through fundraising and private donations and organized by specially committed groups or private persons.”

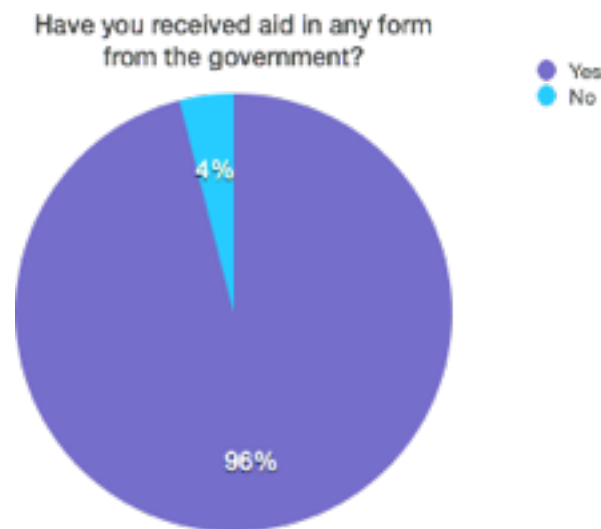
Disability in the Developing World, Benedicte Ingstad(2011)

Malagasy members of the Deaf community often rely on external resources and donors to access services that are usually provided by the government such as healthcare and education. In cases where the government provides small portions of aid, these funds are distributed by NGOs and organizations that are involved in the aid of the Deaf. An example was seen last year, when the government donated 2,400,000 Ar to the Deaf in celebration of the Year of Persons with Disabilities (Anonymous interview subject, personal communication, April 14th 2014). Because of limitations in information about the exact locations of Deaf individuals, the donation was given directly

to F.M.M(Federasionan'ny Marenina Eto Madagasikara), and they were the ones responsible for distributing these funds equally among those in need.

It is not surprising that Deaf individuals who are part of a marginalised community within Malagasy society, rely on external sources for aid. Even schools for the Deaf rely on Faith Based Organisations(FBOs) and Non Governmental Organisations(NGOs) for the funding of their most basic operations such as paying teachers and providing lodging for their students.

In a survey asking Deaf interview participants whether they had received aid in any form from the government, 24 out of 25 participants responded with “No”:



As seen in these results and in the minimal amount of financial assistance given last year, on a special occasion, FBOs and NGOs play a big role in helping Deaf people live an educated and financially stable life in Madagascar, especially those who have access to these services.

Organisations for the Deaf can generally be separated into two major categories: Organisations that are run by Deaf individuals and organisations that are run by hearing individuals. It is necessary to make this clear distinction, not only because it has been made by many of the Deaf participants of this study, but also because these different categories of organisations cater to different needs of the Deaf community. Whereas organisations for the Deaf lead by hearing people often cater to the community's educational and employment needs, organisations led by the Deaf also cater towards the emotional, psychological and social needs of Deaf members of society. Because organisations led by Deaf individuals have more insight on the everyday struggles with depression that are caused by isolation, Deaf led organisations focus more on providing these communities with Deaf Spaces such as Deaf clubs and Deaf sports groups.

Currently, there are mainly three organisations operating in Madagascar that aim to improve the lives of the Deaf:

The World Federation for the Deaf(WFD): was created in 1951 and is now a mother organisation to Deaf organisations from 127 countries. The creation of the World Federation for the Deaf has been one of the most revolutionary developments in the history of Deaf culture. To date, the WFD is the only organisation for the Deaf that is not region specific. In addition to that, it also has strong ties with the United Nations, the International Labor Organisation and the WHO. In Madagascar, F.M.M receives support for their sign language dictionary project, lobbying purposes of the organisation and interpreter training programs.

Federasionan'ny Marenina Eto Madagasikara(F.M.M): was established as FMSM(Association for the Deaf and Friends) in 1971. It has changed its status from a hearing-deaf organisation to a deaf organisation and renamed to the Federation for the Deaf in Madagascar in 2004. F.M.M's headquarters are in the neighbourhood of 67ha in Antananarivo, just five minutes away from AKAMA. F.M.M hires hearing staff as well, they serve as secretaries, interpreters and guards. Members of the F.M.M administration are truly the elite of the Deaf community: They have attended international conferences organized by the WFD and met leaders of the Malagasy government. The organisation is by far the most established and well known organisation that works with Malagasy Deaf. Even on an international level, F.M.M is listed as the only well established organisation for the Deaf in Madagascar on the WFD's website. The organisations most well attended and well funded projects are workshops on democracy and governance, HIV/AIDS prevention(according to the organisation's brochure, 0,1% of the Malagasy Deaf are informed about HIV/AIDS and family planning) as well occupational education in the form of vocational training workshops. FMM states that it "is an independent association but welcomes all cooperations with governmental or non governmental organisations. F.M.M does not have any faith affiliations, political or ethnic segregation." The organisation aims to promote deaf rights. To reach the goal, projects have been set up in cooperation with the Norwegian Federation of the Deaf(NDF), Atlas Alliansen and NORAD. F.M.M has nine member associations and two interpreters.

Christian organisations: fund most of the deaf schools in Madagascar as mentioned in the Deaf education chapter. The Lutheran Church supports seven out of nine schools. All of my interview participants were members of the Lutheran Church. Support for the Lutheran church to fund these projects often comes from Scandinavian countries , specifically Norway. In addition to support from Norwegian Churches as well as Norwegian missionaries that visit the Deaf schools and the Deaf communities year-round, Christoffel Blinden Mission(CBM) is another major sponsor of the Deaf community. CBM's main goal is to "improve the quality of life of people with disabilities in the poorest communities of the world." CBM does not make distinctions between different disabilities in terms of their funding, but groups disabilities and provides financial assistance for the "disabled".

Deaf Clubs

" For S. , Deaf clubs are a way of socialising like he has never before and that strictly around deaf people, where he feels neither shame nor fear to use his native language: Malagasy Sign Language. The Deaf club is also a place for S. to meet future spouses. He told me about his former girlfriend that he met at the Deaf club and how Deaf clubs are great meeting spaces for Deaf people. "

Excerpt from Field Journal: Antsirabe, 16.04.2014

Deaf clubs are an international facet of deaf communities, there is not one deaf community that I have come in contact with in the US or in Egypt that has not mentioned the existence of a deaf club. In response to a survey question asking

participants whether they are members of a local deaf club, the following responses were given:



It is important to note that the only two Deaf individuals who responded with “No” have cited time constraints as reasons of dropping out of the clubs, however, they used to be members of Deaf clubs in the past. Deaf clubs in the Malagasy context are extremely important. The two (competing) deaf clubs I visited in Antsirabe held monthly meetings on the second Sunday of every month to discuss everything from organizing sports events to finding employment opportunities for unemployed members of the club. Some members of the clubs often lived in more rural areas(e.g. Betafo and Alakamisy) and traveled on the days of the meetings to Antsirabe, in order to gain access to a deaf community that they are isolated from and use sign language. Jessica Lee (2012) writes on Deaf clubs:

Deaf clubs are temporary spaces that are important sources of information both in the global sense and within the community. They also serve as a site for reaffirmation of community. Members seek advice from other members, material and emotional support, and a sense of normalcy and belonging, even if temporary, knowing they must return to the hearing world that is often indifferent and even, at times, openly hostile[...] Deaf clubs are important sites for community recruitment and maintenance.

Late deafened adults, recent deaf school graduates, and others seek out the clubs as a way to enter a new deaf community. These clubs are especially important for late deafened adults or deaf people moving in from rural areas who rely on them for sign language learning and initial entrance into the local deaf networks. Expert signers spread information about new signs and correct new signers.

The impact of the existence of Deaf clubs in the building or breaking of a Deaf community is immense. As seen in the quote above, they are not only places to socialize, but also places to escape harsh realities- even if just for a few hours. All the things mentioned by Jessica Lee were clear to me before the start of the project, however, once I started exploring the Deaf community in Antsirabe, specifically the female Deaf community, my perspective of the role of Deaf clubs in that specific community changed very quickly. The conflict that exists within the Deaf community in Antsirabe and the resulting split of the major Women's Deaf club into two separate Deaf clubs was a clear attestation to the importance of these spaces. I interviewed women from both clubs and tried to remain as neutral as possible. Due to confidentiality reasons as well as hesitations that my project and my own opinion expressed will further escalate conflict between the two sides, I will not discuss the details of the conflict. The conflict was based on accusations of misusing funds that belonged to the original main women's organisation: VMA. The club has existed in Antsirabe since the 1960s. In the 1980s, some of the members converted and became Jehova's Witnesses. They then decided to split from the main organisation, the members of VMA are Lutheran. The most recent split from VMA occurred due to a financial conflict with one of its former members, who then formed her own club, TVMV. The number of members in TVMV is smaller and the club has limited funding from local NGOs and FBOs because of its relatively short history and limited establishment in the area. Issues of funding are

a major cause of conflict in marginalized communities because of the limited funding and attention they receive. In addition to that, conflict and splitting that occurs in marginalized groups can cause a great deal of weakening in terms of their collective strength in requests for funding from the government; the smaller the lobbying group, the harder it will be to receive legitimized and adequate funding. Benedicte Ingstad (2001) writes in *“Disability in the Developing World”*:

“The problem with such organisations in developing countries seems to be that they easily become a city or elite activity advocating for specialized and centralized services for their particular group. Also in a situation when there is a shortage of fund and positions for persons with a disability, they easily end up in internal struggle and eventually may split instead of joining forces. This was the case in Botswana, where for many years, two organisations by the blind and physically handicapped went into what seemed like an endless power struggle, which kept them from presenting joint demands to the government.”

Donor Organisations and their role in shifts between disability and deafness

“Today was the meeting all VMA women have been telling me about ever since my first interview with one of them. The meeting was organized by three entities: Vehivavy Mandray Andraikitra, Vehivavy Manana Fahasembanana, and R.N.F(Reseau National des Femmes Handicapees de Madagascar). Attendees consisted of four groups of ‘handicapped’ women: the Deaf, the Blind, the physically handicapped and the mentally handicapped. The Deaf and the Blind women were sitting next to each other on two separate tables, but I did not see any interactions between the two groups. That was the first time it dawned to me, that even though these women identify as part of the same “handicapped” group and share many experiences, they have almost no way to communicate these shared experiences. Next to the blind women were the physically handicapped girls, and I say girls because their mothers had brought them to the meeting on wheelchairs and there were very few physically handicapped women that were older than 20 years old. On the left of that group was the group of mentally handicapped girls and they were also present with their families. At the front of the room was a large elevated table where the Mayor, a doctor and the CBM representative gave short opening talks about today’s workshop. They announced that they would the handicapped women would be divided into groups based on their handicap and share their experiences of violence and mistreatment that they had as women of disability. I thought it was interesting to see this gathering of women in the light of the responses given to me by Deaf women to the question of the difference between handicapped women and Deaf women, although they said they were all handicapped, they still made sure to make a distinction in the level of functionality. But as it seems from this

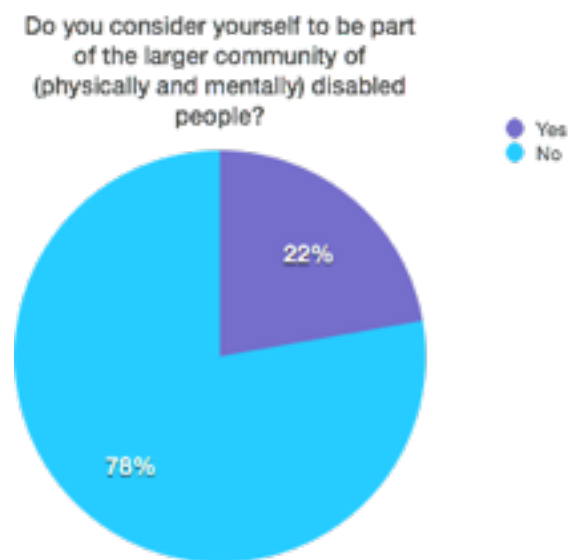
meeting, when it comes to the exhaustion of resources and opportunities where organizations do not make distinctions in aid recipients based on the type of handicap, Deaf women choose to group with the other handicapped women even though they are convinced of their functional superiority. “

Excerpt from Field Journal: Antsirabe, 25th of April 2014

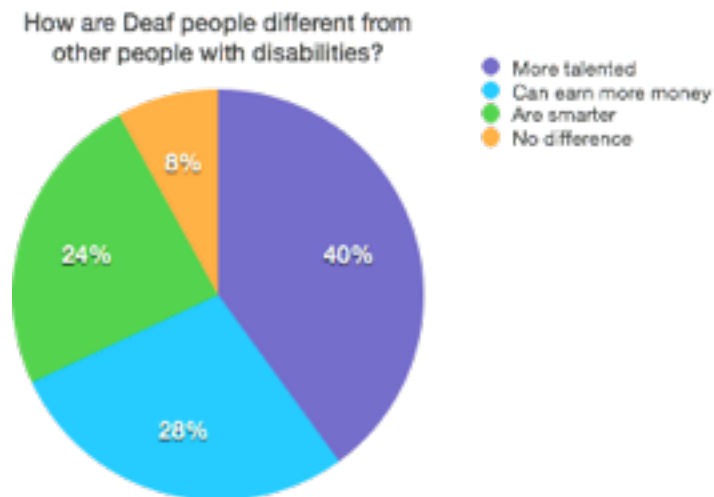
In contrast to attitudes I have observed in the past weeks, distinctions that are often made between deafness and disability are rarely made in the Malagasy context. Deaf people tend to see themselves as part of the disabled, disadvantaged and marginalized community in Madagascar more often than as a strong, independent and abled community regardless of a hearing deficiency. Deaf Malagasy individuals move strategically and carefully between calling themselves disabled and calling themselves deaf, that depending on what each term implies and what personal benefits come with each term.

The event described in the excerpt above is an appropriate illustration of this phenomenon. The event hosted blind, deaf, physically and mentally handicapped women that were all gathered to discuss domestic violence against women with disabilities. Even though women with different disabilities face different types of violence, the workshop guaranteed them a safe space to talk about their problems with others who might have experienced similar issues. In workshops and seminars like these, I have found that a distinction between Deafness and disability is unlikely to be made, because events like these are so limited in number that the deaf community cannot afford to split from the general disabled community. Because donor organisations in Madagascar have limited funding and often cannot afford to make distinctions between target groups because many different target groups are in equal need of funding, they often contribute to how these different groups see themselves by grouping them together. When NGOs and FBOs organize such events, they lead the different groups to think they are more similar than they are in reality. In a survey asking Deaf interview subjects whether they consider themselves part of the larger community of disabled Malagasy almost 80% of them answered yes(a statistic that would not be nearly as high in Western countries, where clear distinctions between deafness and disability exists). Another factor contributing to the self-image that Deaf

people have of themselves as part of the disabled community is that the organisations that group these events for 'disabled women' are led by hearing people who feel no need to make such distinctions, when they know that the society they live in does not make them either. In other words, had a strong movement for distinction between deafness and disability existed in Malagasy mainstream society, this grouping of multiple disabilities would have not happened.



However, when asked whether they thought Deaf people were different from other people with disabilities, many of them gave responses such as “we are more talented”, “we earn money and can find work”, etc. indicating a sense of functional superiority over others with disabilities and thus implying that deafness is different than other disabilities.



In the Malagasy context, it is logical that Deaf communities strategically group themselves in with those with other disabilities. For one, there is no Deaf elite that has enough funding to support a Deaf movement separate from those with other disabilities, Deaf communities can simply not afford to split from other disabled communities because it does not make financial sense to do so. Even though they clearly view themselves as differently abled from other communities with disabilities, at this point in time it is the smartest strategy for survival.

Chapter VII: Fanambadiana Marenina: Deaf Marriage Practices

“The nun was baffled by how many Deaf marriages are occurring these days, “why do they want to create more Deaf people?”. It amazed me how you can work so closely with such a genuine and amazing community and actively advocate for the extinction of that same community. “

Excerpt from Field Journal: 17th of April 2014

Throughout my study, I've encountered a mutual mistrust and sense of suspicion between hearing and deaf people especially when it came to the question of intimate relationships. Lack of communication, not sharing a common language, and horror stories about failed marriages between deaf and hearing people dominate the thoughts of both sides. Most of my interview subjects who were married were in bonds with deaf people, while the minority was married to hearing individuals. In this chapter I will explore, through several case studies, the causes of mistrust between the two groups as well as show examples of successful marriages between hearing and deaf individuals and analyze their reasons of success.

My first encounter with the subject of deaf-hearing marriages was during my first interview with the hearing secretary of AKAMA in Antananarivo. She said:

“It's not good that a deaf woman marries a hearing man, because of communication reasons. The man doesn't understand the communication and thought process [of the deaf woman]. Deaf women really want to marry hearing men and it's very rare for a Malagasy man to learn sign language to marry a deaf woman.

If a Deaf man wants to marry a hearing woman that's better; if it's the man who's deaf and the woman is hearing she will hear more patience for communication. “
(H.Ranoeliasoa, personal communication, April 7th 2014)

Communication issues have been the most cited issues when I asked women who are married to deaf men why they prefer deaf men over hearing men. It has also been one of the main reasons cited by interview subjects of why they broke off a relationship with a hearing spouse. Trust issues often arise when each counterpart refuses to translate conversations for the other spouse if they happened in spoken or signed language. Once a pattern of secrecy arises in the relationship and that is added to a language barrier that exists to different degrees based on different proficiencies of hearing partners, the relationship becomes almost impossible. Jessica Lee (2009) writes in "They Can See Us" that "Speech is the weapon hearing people wielded against deaf people their entire lives and there was no reason to expect any different in intimate relationships." The same idea was echoed by many of the interview subjects. The case studies following exclude names and locations of my participants for the protection of their own identity and safety.

A story of success: Deaf Woman and Signing (Hearing) Spouse

The concept of consensual marriages in the context of deaf and hearing partners is very important, especially in cultures where being hearing is seen as superior to being deaf in social as well as economic contexts. Often, parents and families of deaf individuals will try to marry them to hearing individuals, that often can not sign, just to secure a better future for them.

I have encountered several women who have shared their marriage experiences with me and I have been lucky to have earned their trust and have heard their powerful

stories. In this section, I will explore the story of a powerful and dominant member of the Deaf society in Antsirabe. My interview with Emma¹ started very formally, asking her for her name, her age and her place of birth. Emma was born hearing. She got sick for a long time around the age of 6 and gradually lost her hearing until she was Deaf. Her parents are not Deaf and she is one of 2 Deaf children, among 9 siblings. Unlike her, her brother who is Deaf was born deaf. I then moved on to ask more personal questions about her family life. She told me she was married, her husband is hearing and he signs. When I asked her how she had met her husband, I received the most unexpected response I could've ever imagined:

“My husband and my hearing brother attended the same school for hearing people. One day he saw me using sign language, he called me and I came over. My brother said to me that maybe this man will work abroad, I accepted to marry him and the day after that I was at FOFAMA and he asked me what time he can pick me up from school, the day after that we had a date. My hearing sister was jealous and sad. She lied to our parents and said that I had a boyfriend and my parents were angry with me because they thought that I was lying to them. They said to me that if I was stubborn and acting like that I should stay at home and leave school. A day later a responsible at FOFAMA talked to my parents about my absence, they told the employee that they wanted to keep me at home because I have a boyfriend. The responsible of FOFAMA came to my house to check on me, the responsible was very angry at me as well, I apologised again. I then continued my studies, a female teacher asked me if I had already had sex and I said that I hadn't done that. They did not believe me. I then physically showed them that I was a virgin, only then did they believe me. After that I had a fight with my sister again. A year after that my parents asked me to marry a soldier, he was hearing, my parents did not like my current husband back then. My brother fought with me as well and hit me, I was bruised and very angry. I saw a pair of scissors and stabbed him in his thigh. After that incident my brother ran away from the house. My parents asked what happened, I told them about the fight and after that my boyfriend became a soldier as well and he was in training to be a soldier for 2 years. He came back after two years and met me, he told me that he was ready to ask my parents for my hand. I told him to not do that

¹ Name changed

because I knew that they did not like him. After a month we ran away and moved in together. I became pregnant three months later. My parents told the government that I was pregnant from a hearing man, and since he is also a soldier and I am Deaf that was considered rape. We received a letter saying that my husband did not respect my rights. After that we went to the gendarme and my parents were waiting for me there as well, the gendarme told my dad to stay calm, they asked my husband(only boyfriend at the time) about the issue and he said that he is ready to get married also because I was pregnant now. We then went back to the countryside and I gave birth to my first daughter. When I gave birth I told my husband to ask someone to help us with domestic things, my parents did not want to help us. They cursed us. My sister in law was busy as well so no one was available and I was alone in taking care of my baby. My parents then moved to Fort Dauphin to retire. Almost 20 years later my husband received a call from Tana and was told that my father was very sick and that he wants to see me. My friends gave me 300 000 Ar and me and my two children went to visit my father. I arrived in Fort Dauphin and met a Deaf person, this Deaf person was my brother, I did not realise that at first because the last time I had seen him was when we were very young. I met the whole family and we all cried, they were happy that we were meeting. My parents regretted cursing me and treating me that way around the time of my pregnancy. When my mother saw me she was very happy, she became unconscious. While I was in Fort Dauphin my father was doing better, I came back to Antsirabe. He started getting sick again and died a couple of days later.”

(Anonymous interview subject, personal communication, April 15th 2014)

Emma's story is shocking to me on many levels. The most obvious one is how an educational institution like FOFAMA could actively participate in the emotional torture and oppression of a Deaf person in a way like that. When I asked her whether she thought her parents would have reacted in the same way if her hearing sister was in the same position she very assertively said no and that they only did that because she was deaf. Emma also said that her “parents did not take care of the Deaf, they took care of my hearing siblings much more. There are many layers to the story that Emma shared with me. The first layer is that her parents were trying to force her to marry a hearing man because they thought that she as a Deaf woman was incapable of making these

decisions herself in a wise manner. The second layer is that her parents believed her hearing sister more than her, simply because her hearing sister was able to lie in spoken language while Emma was telling the truth in sign language. Therefore, there is an automatic sense of mistrust towards sign language and a tendency to trust spoken language and those who are able to express themselves in it.

Although Emma is married to a hearing man now, he can sign and translates everything she needs for her. He always makes sure to use sign language in her presence, even when I met him when I was with Emma, he signed to my interpreter and had her translate for me to include his Deaf wife.

A story of failure: Deaf woman and Non-Signing Spouse

Based on my observations through spending times with mixed hearing and deaf individuals, hearing individuals tended to have a paternalizing and worrisome attitude towards the deaf members of their family. These attitudes are not necessarily rooted in a sense of superiority, but rather based on stories they have heard of where Deaf people were exploited by their hearing spouses based on their hearing disability. Emma's story of success in a marriage with a hearing man is not an anomaly but is also far from common.

The following section will explore a story of financial and emotional exploitation faced by a Deaf woman who was married to a hearing man.

The story of Salma² starts in Antananarivo. Salma grew up in a dominantly hearing family. Her hearing mother forced her to marry a hearing man at a relatively young age. Her husband did not sign, was unemployed and their only way of communication was through Justine making a conscious and constant effort to lip read his Malagasy words. Justine's mother forced her to marry him, I don't know the exact reason why but it seemed to me from the way she was talking about him that him being a hearing man that was interested in marrying a Deaf woman was an opportunity that cannot be missed. After several years of misery she finally ran away and started a new life in Antsirabe.

In contrast to Emma, Salma's marriage failed because of two reasons. Her husband who did not make any effort to learn sign language to communicate with his spouse contributed a lot to the failure of their relationship. But the real reason why their marriage failed was because of her husband's financial reliance on her. Salma said that hearing people often choose to marry deaf people because deaf people are talented, know how to find good work and earn a lot of money. This was something I heard from many deaf individuals that I spoke with, many hearing people who are unemployed or have financial troubles resort to marrying deaf individuals because they have a secure source of income. This secure sense of income is often a result of tight knit and well supported communities of deaf people who help each other with employment opportunities, whereas communities like these are hard to find amongst the hearing, according to many interview subjects.

² Name changed

Marriages between Deaf Individuals

It is a mystery to many why Deaf individuals would choose to get married in societies that discriminate against them and potentially “risk” the prospects of having hearing children by passing on opportunities for marriage with hearing individuals. These ideas are not only insensitive, uninformed and genetically inaccurate but also do not consider the beauty and bonds that exist in Deaf cultures all over the world. Married deaf individuals who I have interviewed in this project were mostly married to other deaf individuals. The most cited places for meeting a deaf spouse were local deaf clubs and deaf schools.

In a group interview I held with a deaf couple I interviewed Andry and Rimma, two Deaf adults who are married and met at the Deaf school in Antananarivo. Rimma got pregnant with their son Andre who is hearing at the age of 18. She still lives in the capital teaching sign language to deaf adults who have had no access to it when they were younger whereas Andry lives in Antsirabe and works as a computer literacy teacher at FOFAMA. Andry and Rimma’s story of success in their marriage can be attributed not only to the fact that they are both deaf, but also to the fact that they are both passionate about helping other deaf individuals and dedicate their lives to the deaf community that they live in. They are not just hard of hearing and communicate in sign, but they dedicate their lives to others who have the same struggles as them. When I asked them whether they were happy or sad when they found out that their son was hearing, they said that they were very happy because their son can now translate for them when their hearing neighbours or their family gossip about them. While being in a

Deaf marriage certainly has its advantages, it sometimes also furthers the divide between the Deaf couple and the hearing community that surrounds them. They no longer feel the need to engage with others seeking meaningful communication since they have each other. And their son, who signs, is now their bridge between their deaf culture that they are maintaining at their house and the outside hearing world that they mistrust.

Chapter VIII: Conclusion

Deaf individuals that I have encountered in this study have taught me about passive resistance, the importance of inner strength and realism. The insights and opinions they had about their own roles in their homes, community and in society have not only been illuminating for the purpose of my study, but have also been extremely heart breaking at many points. I questioned my own ability to finish this study because of how much trust these individuals have put in me by sharing their most personal stories with me, even though they had just met me.

Participants of this study found ways to create their own networks of support through their common signed language, membership in deaf clubs and establishing their own deaf spaces in a society that marginalises them. Those who could, chose to live in close proximity to other Deaf individuals and often chose to be in a community of Deaf adults rather than moving back to their hometown to be with their hearing family.

Many adults who I interviewed have attended FOFAMA and grew up with a strong network of other Deaf individuals, feelings of isolation caused by Deafness are often childhood memories of living in a hearing family. However, for two of the participants who did not have a chance to attend school, experiences around hearing people without access to a deaf network is still a real lived reality. Even though the nine schools for the Deaf on the island are not able to serve all Deaf children, deaf schools continue to do their best to educate those who have access to them.

Evaluation of Research Questions

As previously mentioned, up until the start of this project, my only training in the field of Deaf studies has been in a Western context that ignores medical models of disability and embraces Deafness as a linguistic minority that often calls itself “the people of the eye”. In contrast to perceptions and notions of Deafness in the West, the harsher realities that dominate Deaf people’s lives in Madagascar do not allow for idealistic perceptions of their physical disability. I quickly came to realise that the reality here in Madagascar required a different mindset for this study according to the lived experiences of Deaf Malagasy individuals. In this section I will briefly evaluate the two study questions that guided this project.

Q1: How do social contexts of living in Madagascar affect Deaf people’s constructions of themselves in terms of how/whether they see themselves as a community and how they see their deafness?

Not a single interview subject in this study referred or identified a “deaf community”. Even though there are several groups of Deaf individuals that I encountered who live in proximity to each other, no existence of a community based on their common disability was mentioned. Instead of referring to a deaf community, participants often grouped themselves in with other groups of individuals with disabilities. In contrast to Western social contexts where clear boundaries exist between disability and deafness, deaf individuals in this study often avoided that distinction for practical reasons: the competition for limited financial resources from donors and organisations.

Many of the participants that grew up in hearing families who expressed a desire for them to speak instead of sign, and thus developed a sense of shame when it came to using their sign language in public.

The most indicative example of the mainstream society's conceptions of the deaf can be seen in current marriage customs. Hearing parents often try to marry their Deaf son or daughter to a hearing partner. This phenomenon is rooted in the inherent perception of hearing individuals as superior and having more potential for financial and personal success. The current legislative regulations, even though protective of deaf individuals in theory, are not applied in practice. This can be seen in the example of Emma's story, whose husband got called in by the gendarme accusing him of raping her because her hearing parents did not approve of the relationship. Simply because hearing individuals made a statement it was perceived as more truthful than statements of Emma as a deaf individual. Mutual mistrust that exists among deaf and hearing communities is grounded in communication barriers and perceptions of each others languages as tools for gossip rather than tools for healthy communication.

Q2: What role does sign language and access to education play in the participation of a Deaf individual in daily life?

Goffman's ideas about 'passing as normal' are very accurate in the Malagasy context. Many participants echoed fear and shame when using sign language in public. They are often victims of mockery and sometimes even violence.

Even though sign language can be a source of insecurity and trouble for some when used in public around hearing people, one cannot underestimate its importance for the mental and emotional health of deaf individuals. Those who could sign were also members of deaf clubs and deaf networks where they met their spouses, friends and personal support networks. Deaf individuals who could sign participated in public and daily life to a higher degree by voting in the elections, having access to a wider variety of occupations where deaf employers were more likely hire them and accessed healthcare services through interpreters. Those who do not sign have little to no way to communicate their needs with others around them, both within personal interactions with family and community members as well as interactions with employees of public services.

Implications for Future Research

My sample of interview participants overwhelmingly consisted of women. The issues that arose from this sample were often related to domestic and sexual violence as well as experiences with what some of them called a "double handicap", being women and being deaf. In the future, it would be interesting to do gendered on disabled communities, to see how their gender influences how others see their disability and how their gender and their disability plays a role in determining the prospects that await them in comparison to men with the same disability.

Final thoughts

The three weeks of the project were easily the most transforming, emotionally exhausting but also enlightening weeks of my life. I cannot find the words to express my gratitude to each individual who participated in this study and guided me through their personal lives with an incredible amount of trust that I have never felt before. I consider myself truly lucky to have had the chance to meet each of these inspiring individuals who have managed to find their own support networks and resources and do their best to spread awareness and understanding of Deafness. I could not be more grateful for this opportunity and will continue to stay in solidarity with them, even if just from thousands of miles away.

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Appendix I: List of Interviews

04/07/2014, Antananarivo, 67 ha: Interview with Secretary of Deaf School, AKAMA.
04/08/2014, Antananarivo, 67 ha: Interview with Teacher at the Deaf School, AKAMA.
04/08/2014, Antananarivo, 67 ha: Interview with Teacher at the Deaf School, AKAMA.
04/10/2014, Antsirabe: Interview with Doctor leading workshop, Deaf School in Antsirabe FOFAMA
04/10/2014, Antsirabe: Interview with hearing parent, Deaf School in Antsirabe FOFAMA
04/10/2014, Antsirabe: Interview with hearing parent, Deaf School in Antsirabe FOFAMA
04/10/2014, Antsirabe: Interview with hearing parent, Deaf School in Antsirabe FOFAMA
04/10/2014, Antsirabe: Interview with hearing parent, Deaf School in Antsirabe FOFAMA
04/11/2014, Antsirabe: Interview with hearing parent, Deaf School in Antsirabe FOFAMA
04/11/2014, Antsirabe: Interview with hearing parent, Deaf School in Antsirabe FOFAMA
04/11/2014, Antsirabe: Interview with hearing parent, Deaf School in Antsirabe FOFAMA
04/14/2014, Antsirabe: Interview with Deaf adult, Fokontany of Antanambao
04/14/2014, Antsirabe: Interview with Deaf adult, Fokontany of Antanambao
04/14/2014, Antsirabe: Interview with Deaf adult, Fokontany of Antanambao
04/14/2014, Antsirabe: Interview with Deaf adult, Fokontany of Antanambao
04/15/2014, Antsirabe: Interview with Deaf adult, Fokontany of Ivory
04/15/2014, Antsirabe: Interview with Deaf adult, Fokontany of Ivory
04/15/2014, Antsirabe: Interview with Deaf adult, Fokontany of Ivory
04/16/2014, Antsirabe: Interview with Deaf adult, Fokontany of Ivory
04/16/2014, Antsirabe: Interview with Deaf adult, Fokontany of Ivory
04/16/2014, Antsirabe: Interview with Deaf adult, Fokontany of Ivory
04/17/2014, Antsirabe: Interview with Deaf adult, Fokontany of Ivory
04/17/2014, Antsirabe: Interview with Chef of the Fokontany of Ivory
04/18/2014, Antsirabe: Interview with Chef of the Fokontany of Antanambao
04/18/2014, Antsirabe: Interview with Deaf adult, Fokontany of Ivory
04/18/2014, Antsirabe: Interview with Deaf adult, Fokontany of Ivory
04/22/2014, Antsirabe: Interview with Deaf adult, Fokontany of Ivory
04/22/2014, Antsirabe: Interview with Deaf adult, Fokontany of Antanambao
04/22/2014, Antsirabe: Interview with Deaf adult, Fokontany of Antanambao
04/23/2014, Antsirabe: Interview with Deaf adult, Fokontany of Antanambao
04/23/2014, Antsirabe: Interview with Deaf adult, Fokontany of Antanambao
04/28/2014, Antsirabe: Interview with Teacher at the Deaf School in Antsirabe, FOFAMA
04/28/2014, Antsirabe: Interview with Teacher at the Deaf School in Antsirabe, FOFAMA

Appendix II: Interview Questions and Surveys

Survey for Hearing Parents of Deaf Children(Translated from Malagasy):

Nom:

Nom et age d'enfant(s) a l'ecole:

Place de residence:

1)Combien des enfants est-ce que vous avez?

2)Combien des enfants sourds est-ce que vous avez?

3)Combien d'enfants sourds il y a t-il dans la grande famille(cousins, etc)?

4)Est-ce que vous avez tentez de voir un medecin/un specialiste pour votre enfant?

___ Oui ___ Non

5)Est que vous pouvez communiquer en langue de signe?

___ Oui ___ Non

a)Si oui, ou est-ce que vous apprenez la langue de signe?

b)Quand est-ce que vous utilisez la langue de signe?

___ chaque jour

___ quand je suis avec des gens sourdes

___ avec ma famille

6)Comment est-ce que vous decrivez votre competence de la langue de signe? ___ Oui

___ Non

Si oui:

___ juste des gestes ___ 0-5 signes/mots

___ un petit peu ___ 5-20 signes/mots

___ tres bien ___ 30+ signes/mots

7)Est-ce que la famille(soeurs et freres) peut communiquer en langue de signe? ___ Oui

___ Non

Si oui:

___ juste des gestes ___ 0-5 signes/mots

___ un petit peu ___ 5-20 signes/mots

___ tres bien ___ 30+ signes/mots

8) Est-ce que votre amis peut communiquer en langue de signe? ___ Oui ___ Non

Si oui:

___ juste des gestes ___ 0-5 signes/mots

___ un petit peu ___ 5-20 signes/mots

___ tres bien ___ 30+ signes/mots

9) Est ce que votre voisins peut communiquer en langue de signe? ___ Oui ___ Non

Si oui:

___ juste des gestes ___ 0-5 signes/mots

___ un petit peu ___ 5-20 signes/mots

___ tres bien ___ 30+ signes/mots

10) Est-ce que vous pensez que la police/la gendarmerie peut communiquer en langue de signe? ___ Oui ___ Non

Si oui:

___ juste des gestes ___ 0-5 signes/mots

___ un petit peu ___ 5-20 signes/mots

___ tres bien ___ 30+ signes/mots

11) La vie pour les sourds a Madagascar est:

___ très facile ___ dure

___ facile ___ très dure

12) Comment avez-vous su l'existence de l'école pour les sourds?

13) Quelles sont les problèmes pour les parents des enfants sourds?

14) Est-ce que vous êtes confortable avec utiliser la langue du signe (in public)(par exemple: dans le Taxi-Be, au marché, etc):

Oui Non

15) Est-ce que vous pensez que l'école est chère/est-ce qu'il y a des problèmes pour envoyer les enfants à l'école?

16) Avant d'avoir votre enfant, est-ce que vous avez eu de contact avec une personne sourde?

Oui Non

Si oui: Qui était la personne?

17) En générale, quelles sont les impressions des personnes sourdes envers la société?

18) Est-ce que votre enfant a des amis entendants?

Oui Non

Si oui: Comment est-ce que votre enfant a rencontré la personne? And how would you describe their relationship?

19) Avez-vous vu quelqu'un se moquer de vous / votre enfant lorsque vous utilisez la langue des signes?

Oui Non

Si oui: Comment était votre réaction?

20) Est-ce que le gouvernement aide les sourdes?

Oui Non

21) Quelles sont vos prédictions pour l'avenir de votre enfant?

Interview Questions for Deaf adults(Translated into MSL by Interpreter):

Personal information

Name:

Place of residence:

Place of Birth:

Date of Birth:

Work:

Deafness:

- When did you become deaf?
- (If not born deaf) Do you remember the time you turned deaf?
- Why did you become deaf?
- Are your parents deaf?
- How many children do your parents have?
- How many deaf children do your parents have?
- Are there other deaf members of your family?
- How did being Deaf influence your childhood in a dominantly hearing family?
- Did you have Deaf friends growing up? What was their family life like?

Marriage and Personal Life:

- Are you married?
- How did you meet your partner?
- Why did you choose a deaf/hearing partner?
- What does your partner do for work?
- How did you communicate with your partner?

Schooling:

Have you been to school?

If Yes:

Where?

Deaf Organisation:

- Do you know any organisations that work with the deaf?
- What are the existing deaf clubs here? Are you a member of any?
- What do they do?
- Do deaf people from rural areas attend meetings?
- When are their meetings?
- What are the current problems with the deaf clubs?

Politics:

- Does the Malagasy government help you?
- Does the Malagasy government of Madagascar help the Deaf?
- Who is the president of Madagascar?
- Do you know where the government office here is?
- Do you vote? (yes/no) why?

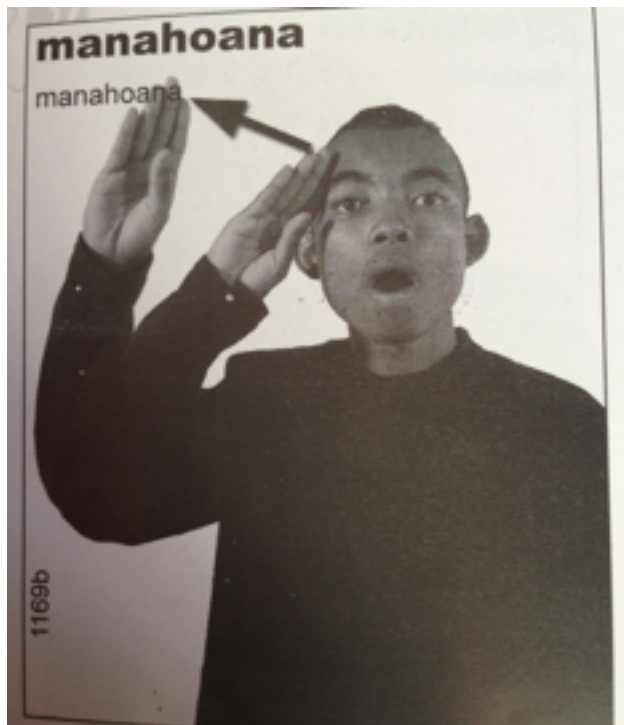
Communication:

- Do you know sign language?
- Are you comfortable using sign language in public?
- Where did you learn it?
- Do your parents know sign language?
- Do your siblings know sign language?
- Do your coworkers know sign language?
- Does your boss know sign language?

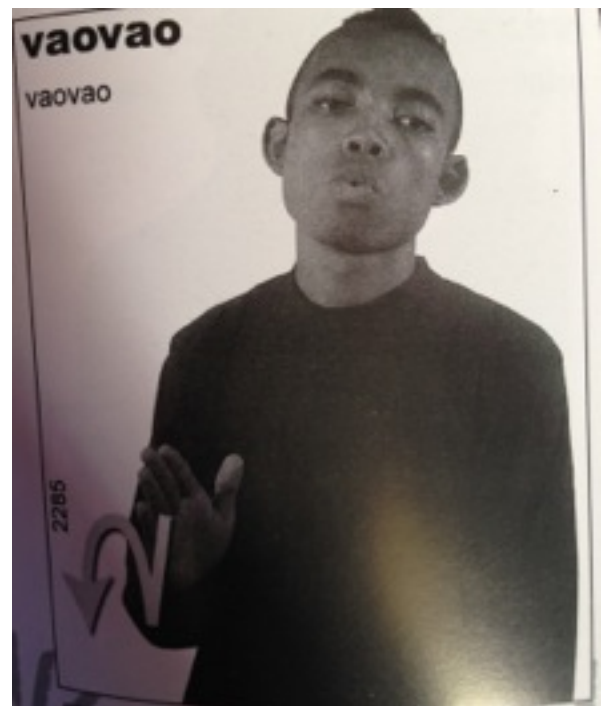
Life problems and identity?

- Are you deaf or disabled? Or both?
- Is there a difference between being deaf and being disabled?
- What kind of problems do deaf people have?
- What kind of problems do you have?
- Do you think Deaf people are discriminated against here?

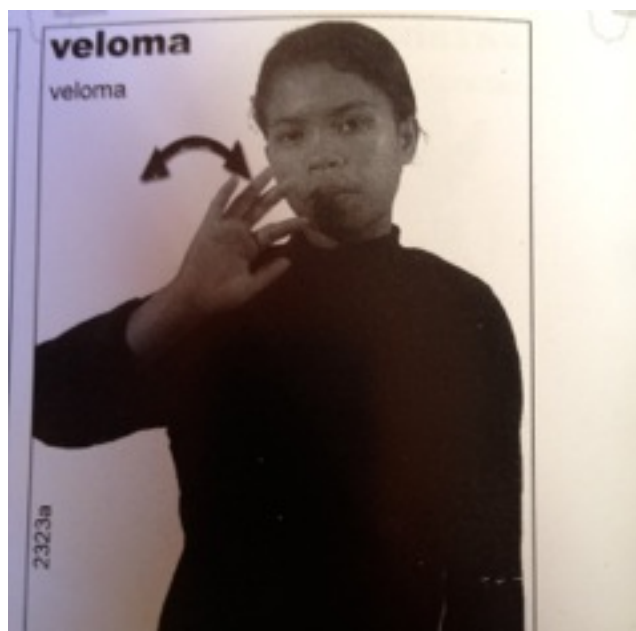
Appendix III: Examples of Malagasy Sign Language



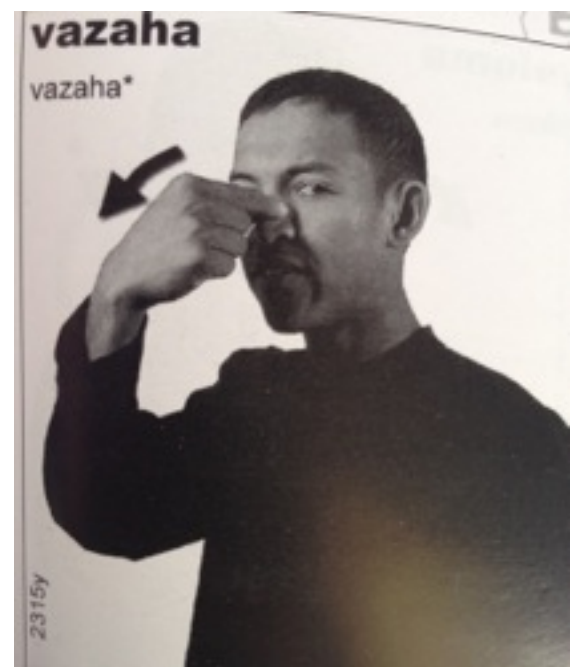
Manahoana: Hello!



Vaovao: News



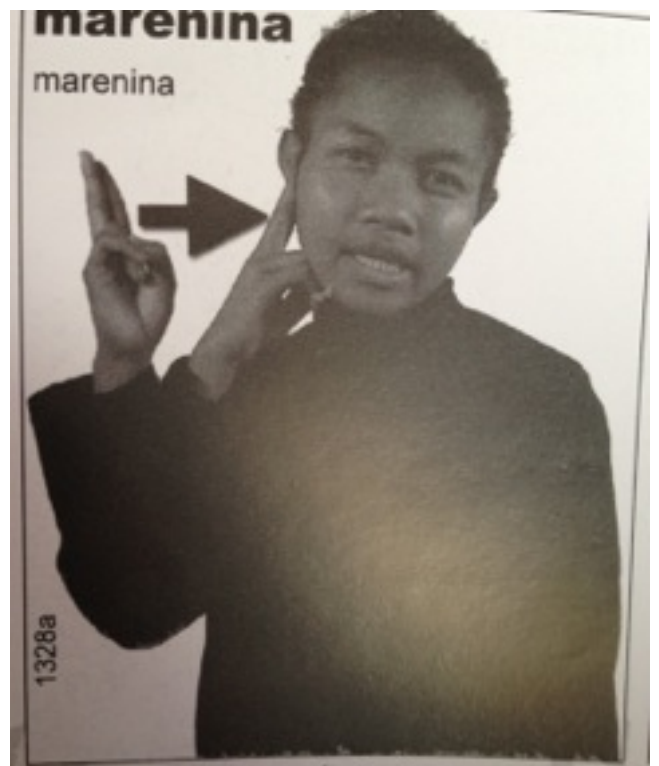
Veloma: Goodbye!



Vazaha: Foreigner



Mandre: Hearing



Marenina: Deaf