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A Separate World: Conflicts Between Malagasy Society and the Mentally Handicapped

Jesse Travis
SIT Study Abroad

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Academic Director: Roland Pritchett
Academic Advisor: Dama Ravelomanana

Preface

Le Handicap Mental

…Ces [Personnes Handicapées] représentent environ **300.000 personnes**[1] à Madagascar … 300.000 personnes qui aspirent à la dignité et à une vie social, professionnelle, familiale, comme tout citoyen.

Malgré le poids de certains **tabous** et le **manque de moyens**, des associations luttent pour la promotion, l'éducation, la dignité des personnes, particulièrement des enfants des enfants, en situation de handicap mental.

…Pour beaucoup de gens, le handicap mental représente un **monde inconnu** qui suscite la **peur**, les **préjugés** et **l'exclusion**.

Cependant, au sein de nos associations, des mots émergent : **intégration**, **inclusion**, participation, citoyenneté.

Des mots pour un avenir meilleur, des mots porteurs d'espoir, des mots qui encouragent car ils ouvrent une porte de communication entre **le monde du Handicap** [1]et la communauté.

Mais aussi des mots qui risquent d'être vides de sens si l'on ne s'efforce pas véritablement de les vivre au quotidien.

Vivre au quotidien l'intégration : ce n'est pas vivre côte à côte dans **l'ignorance** ou **l'indifférence**. Ce n'est pas tolérer la présence de la personne différente par compassion… C'est surtout partager : donner et recevoir. Partager l'amour, partager les joies et les peines, partager les doutes, les efforts, partager la foi en l'avenir.

Certes, **un long chemin reste** à parcourir pour parvenir à enraciner cette idée dan les mentalités.

Mais que ceci ne nous empêche pas de semer les graines de conviction que nous portons en nous. Nous qui travaillons avec les personnes en situation de handicap mental, nous qui les côtoyons, nous qui savons leurs **potentialités**, leur dons mais aussi leurs **difficultés**, leurs angoisses, leurs attentes, nous nous devons de partager nos expériences, nos connaissances, nos réalisations, nos projets.

C'est à ce partage que nous vous invitons en espérant trouver un écho, pour que le regard posé sur la déficience intellectuelle **évolue** et que soit reconnue la richesse de la différence.

Les Associations

Antananarivo le 5 juin 1998
Handicap International Madagascar[2]

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[1] Emphasis by student for all bolded words.
[2] Cite Document

For the one who sings so well…

and the voice that accompanies her.

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Introduction

When *Nicole[1] was four months old, she had an extremely high fever that damaged her infantile brain to a point where she would be mentally handicapped for the rest of her life. Now; at the age of 20 she spends her days walking around her small village in the Betsileo region of Madagascar. She was never educated and while she goes to the rice fields with her mother, she does not assist in the harvesting process. Her mother says she has no friends, and that the other villagers consider her to be crazy. Some taunt her, offering her rocks to eat with the promise of candy, and sometimes she returns home with unexplained wounds. Others merely keep their distance, as when my translator physically pulled away in surprise when Nicole reached to touch her leg, exclaiming that she was afraid.

My translator is not the only one who expresses the sentiment of fear in regard to Nicole. One of eleven kids, the other children are kind to their sister, but are afraid to sleep with her as she has sporadic seizures. Therefore, the mother father and remaining nine children sleep in one bed, and Nicole sleeps alone. The family cannot afford to pay for medication for their daughter, and cannot suppress her 'crisis's' which, in addition to her physical muscle tension and convulsing eyes, include screaming, crying, and very aggressive (sometimes abusive) behaviour. When she has such traumas, which occur on average three times a month, the family removes the furniture from one room in their two room house and locks her inside. Sometimes this lasts for a couple of days, but the mother said through tears that they do not know what else to do for Nicole's and their safety.[2]

Midway through the interview, Nicole and her mother began to sing. They write songs together, and often sing when the daughter is in a capable state to do so. I later asked my translator what the words concerned. She said that they were of a Christian basis, and asked God why Nicole was so different from everyone else.

She was my motivation for this research project. Why did others think she different from everyone else? What aspects of her behavior or state influenced the society to treat her in the manner described? Was this social treatment an anomaly or common in Malagasy society?

I chose to search for the root causes of such social isolation, in the acknowledgement that only in discovering the source of such situations can one understand the resulting bahavior and offer constructive analysis. As a result of my experience with Nicole, and a personal interest in the complexities of social interactions with the mentally handicapped, I focused my project around the perceptions of this population.

The question remains as to the value of studying the role of the mentally handicapped in Malagasy culture. In studying a society, minority populations must be considered; while they may lack presence in numbers, they contribute to the depth and complexity of the society as a whole. Reflecting on one particular minority, as the mentally handicapped, provides a window into the way in which a society deals with marginalized populations while maintaining a focus that can feasibly be studied. One can often find strong cultural values and beliefs in how a population responds to atypical situations and persons, beyond the norms of daily life. In light of these principles, I set out to conduct my research.

Methodology

Research Area

I carefully structured my methodology to best be able to answer my study questions. My initial contact was with Les Orchidées Blanches (LOB), a medical-educational center in Antananarivo (Tana). In recognizing the support and access they would be able to provide to my research population, I decided to remain in Tana. This is the capital city of Madagascar. While there are not definite figures for the population, there are thought to be around 3 million citizens[3], rendering it the largest city in the country. In light of the number of inhabitants, I realized that I would need to visit a variety of *quartiers* (neighborhoods) to try to diminish bias

from only considering one area of the sizeable city. My research included participants from 16 *quartiers*, not including the neighborhoods of the employees or workers at formal structures visited. Of the 18 ethnic clans in Madagascar, the capital city has a mixture of all the ethnicities, but is majority *Merina*, a clan of the highlands. The cultural beliefs reflected through the research are, therefore, not restricted to *Merina* beliefs, but are more influenced by this clan's value system that other ethnicities.

Immersion into the Handicap

I began my work by spending a week of focused observation at Les Orchidées Blanches. The purpose of this was to better understand the particularities of persons with mental handicaps. Through observation and multiple informal conversations with the employees, I gained a deeper understanding of my research population, and of the complex array of behavioural, emotional, physical, and intellectual aspects of this state of being. Les Orchidées Blanches provided me access to spending nearly 16 hours observing around 100 mentally handicapped persons of a variety of intellectual and physical capabilities, ages, and specialized needs. As I lived in a spare room at this center, I also spent abundant time each day not only observing the students and employees, but eating, living, and developing friendships with them. While I had originally intended on maintaining objective distance in my research, I soon realized that a better approach would be to follow the advice of researchers John and Lyn Loflan that if "one is to collect rich data, the [fieldwork] tradition beckons one to 'come close.' So-called objectivity and distance vis-à-vis the field setting will usually result in a failure to collect any data that are worth analyzing."[4]

Also, this organization has been in existence for 30 years, and has put in place a variety of structures and programs for the multiple needs of the mentally handicapped. In developing a better understanding of the goals and activities of each program, I could understand the needs that these services address. I would then be able to better comprehend not only the special needs of those benefiting from these services but the difficulties associated with the population.

This was an inverse approach to understanding the complications with mentally handicapped persons. In examining how a group of aware and comprehensive employees conduct their services, the measures taken to provide effective assistance indicate potential problems and difficulties.

Formal Structures

The basic principle of my methodology was to approach the subject from a variety of different angles, searching for the common threads that united these multiple points of view. I, therefore, in the following two weeks visited an assortment of formal structures. I visited 12 forms of infrastructure, trying to address different facets of societal structures. I visited public organizations, private organizations, and religious organizations. I spoke with integrated environments, with both handicapped and non-handicapped persons, as well as separated environments as specialized workplaces and schools. In order to obtain a medical, psychological, and cultural perspective, I spoke to two doctors, two psychologists, and one professor. I interviewed organizations that promote the rights of the handicapped and structures that concern themselves with providing concrete aid for families. To obtain an opinion from the state, I spoke with a governmental official. A detailed presentation of the specific structures involved is included in Appendix A.

Informal Structures

Another level of society is that of informal social structures, as families and neighborhoods. I visited 10 families with mentally handicapped members. I aimed for a range of situations, making sure to include families with different backgrounds and dealing with different types of mentally retardation at various stages in life. I interviewed different members of families, including parents, siblings, nephews, and in-laws. Socio-economic levels of these families were varied, as observed through occupations (ranging from laundry washers to business owners) and homes (one-room houses to leather couches). The intellectually deficient family members ranged from light to profound levels, and included behavioural

difficulties as anxiety, aggression, and atypical conduct. I also spoke with those who had been dealing with the handicap for over 50 years, and those who had recently realized their children were mentally handicapped. A detailed presentation of these families is included in Appendix B.

Ethical Considerations

As this topic is considered sensitive, in light of the population with which it is concerned, I took certain precautions in order to remain ethical. The principles of informed consent and confidentiality were addressed with interviewees by asking for signatures on consent forms with an explanation of my intentions and the stated acknowledgement of the rights of the participant. These written rights included the ability to choose what personal information to be included in the write-up and the right to refuse to participate or stop involvement at any time in the interviewing process.

In dealing with the mentally handicapped, however, other constraints on ethics were taken into consideration. Informed consent requires that the participants comprehend the "purpose of the study…how the data will be collected and how the results may be used."[5] With the intellectual capacity of mentally handicapped persons, however, this comprehension is not guaranteed. Therefore, I only observed such persons (with the approval of families or the formal structures with which I was collaborating), but I did conduct interviews with the intellectually deficient. Finally, in order to protect the confidentiality of such handicapped participants, I did not use names when using information given from a family member, or any other person who could provide an indication as to the identity of the mentally handicapped individual. These family members did, however, sign consent forms.

Obstacles

I did encounter obstacles in my research. I was occasionally advised to visit structures not actually relative to my subject. One day I spent an hour travelling to an NGO to discover the location of Toby. The worker at the NGO assured me that the Toby was for mentally

handicapped persons. However, after travelling another hour to find this center, I was told that the center was actually for mentally ill persons. Fortunately, other citizens had made the same mistake and asked the Toby to care for their mentally handicapped children to which the organization had agreed, despite the differences in these two mental deficiencies. This difficulty of informants confusing mental handicaps with mental illnesses led me at times to question whether or not people were truly recounting perceptions of mentally handicapped persons or if they were using the term 'handicapé mental' but thinking about the mentally ill.

Despite these obstacles, after 50 hours of intensive interviewing and observation, 56 informed participants, and encounters with over 100 mentally handicapped persons, I collected adequate data that led me to discover the underlying threads that connect these individuals and experiences.

Research Population

Before the exploration of this social situation, it is imperative to understand the population of which I will be speaking. In the French language, Mme Lisy notes that there has been an evolution of terminology from "arrieration, idiotic, débilité, retard mental insuffisance mentale" and finally resulting in the terms "déficience intellectuelle" and "handicap mental."[6] As French was the language of communication for the research, these were the terms used for interview process. I therefore felt it these should be the terms utilized in the essay, as to not misrepresent perceptions by a bias in terminology. However, the English language still frequently utilizes the term 'mental retardation,' and in searching for a description of my research population, I have found that the definition for 'mental retardation' accurately represents those who are termed in French 'mentally handicapped.' I hope this complication in terminology does not bring about confusion in the presentation of the data.

MedicineNet.Com describes 'mental retardation' as follows:

Mental retardation: A term used when a person has certain limitations in mental functioning and in skills such as communicating, taking care of him or herself, and social skills. These limitations will cause a child to learn and develop more slowly than a typical child. Children with mental retardation may take longer to learn to speak, walk, and take care of their personal needs such as dressing or eating. They are likely to have trouble learning in school. They will learn, but it will take them longer. There may be some things they cannot learn. As many as 3 out of every 100 people have mental retardation. In fact, 1 out of every 10 children who need special education has some form of mental retardation.

There are many causes of mental retardation. The most common causes are:

Genetic conditions -- Abnormalities of chromosomes and genes. Examples of genetic conditions are Down syndrome (trisomy 21), fragile X syndrome, and phenylketonuria (PKU).

Problems during pregnancy -- When the baby does not develop normally inside the mother. For example, a woman who drinks alcohol or gets an infection like rubella during pregnancy may have a baby with mental retardation.

Perinatal problems -- Problems during labor and birth, such as not getting enough oxygen.

Health problems -- Diseases like whooping cough, the measles, or meningitis. Mental retardation can also be caused by extreme malnutrition or being exposed to poisons like lead or mercury.

The diagnosis of mental retardation is made by looking at two main things. These are (1) the ability of a person's brain to learn, think, solve problems, and make sense of the world (intellectual functioning or IQ); and (2) whether the person has the skills he or she needs to live independently (called adaptive behavior, or adaptive functioning).

Intellectual functioning, or IQ, is usually measured by an IQ test. The average IQ score is, by definition, 100. People scoring below 70 to 75 on the IQ test are considered to have mental retardation. To measure adaptive behavior, professionals look at what a child can do in comparison to other children of his or her age. Certain skills are important to adaptive behavior. These are daily living skills (such as getting dressed, going to the bathroom, and feeding one's self), communication skills (such as understanding what is said and being able to answer) and social skills (interacting with peers, family members, adults, and others).

There are many signs of mental retardation. For example, children with mental retardation may:

- sit up, crawl, or walk later than other children;
- learn to talk later, or have trouble speaking,
- find it hard to remember things,
- not understand how to pay for things,
- have trouble understanding social rules,
- have trouble seeing the consequences of their actions,
- have trouble solving problems, and/or
- have trouble thinking logically.

About 87% of people with mental retardation will only be a little slower than average in learning new information and skills. When they are children, their limitations may not be obvious. They may not even be diagnosed as having mental retardation until they get to school. As they become adults, many people with mild retardation can live independently.

The remaining 13% of people with mental retardation score below 50 on IQ tests. These people will have more difficulty in school, at home, and in the community. A person with more severe retardation will need more intensive support his or her entire life. Every child with mental retardation is able to learn, develop, and grow. [7]

Current Situation

The mentally handicapped in Tana are separated and distanced from the general population on three societal levels: formal infrastructure, informal communities, and public interactions.

Formal Infrastructure

Financial Exclusion

The vast majority of structures that exist for mentally handicapped persons are in the private sector or are supported by non-governmental organizations (NGO) or religious structures. As such, most of these services are contingent upon the monetary payments of parents. All five of the medical-educational centers in Tana ask for a monthly fee; LOB, for example, requires 64,000 Ariary although only 10-20 % of their assisted families can afford this fee. As the organization has a strong financial support base, they provide monetary aid for the rest, asking a participation of 12,000 Ariary. However, as the average Malagasy earns approximately 1400-2000 Ariary a day, this service is out of reach for many families with mentally handicapped members. As a result, an estimated 2% of handicapped persons benefit from the attention needed for their particular state.[6]

Separation from Systems: Education and Employment

Many are excluded from such structures as a result of financial discrepancies; even further, some view these structures to be a form of exclusion in and of themselves, for this type of education occurs in settings separate from the ordinary scholastic program for Malgasy children. With the collective knowledge of the participatory structures, I learned of seven schools in the regular school system that had or do receive mentally handicapped students on the primary level. However, in a city with an estimated 60,000 mentally handicapped persons,[8]

seven schools (of which four are private and require fees) scarcely scratches the educational needs of such persons.

The infrastructure for adults is even more lacking than for children. M Razafindrakero, representative of Le Collectif des Organisations des Personnes Handicapées (COPH) remarks that many families come to their office once their children have reached the age of 18 because there are so few organizations with services for adults. LOB does provide a Centre d'Aide pour le Travail (CAT) where around 20 adults can work in a workshop that produces blackboard chalk or do odd jobs around the property as upkeep of the grounds. They do receive a salary, but not SMIG.[9] Another specialized workplace exists for mentally handicapped persons, supported by the organization UNAHM, L'Union Nationale des Associations des Handicapés de Madagascar. Here 4 of the 18 workers are intellectually deficient, as the workshop is also for the physically handicapped. M Radafiniantsoa, president of the union, explains that workers get paid about one-half of the SMIG and that the workshop was nearly forced to close its doors last year from financial difficulties. He remarks that the organization has appealed to the state for funding, in the argument that closing the workshop would contribute to the rate of unemployment, but that the last time they received a subsidy was 14 years ago.

Unapplied Legal Rights

In September 2001, the Malagasy state passed a decree concerning the rights of the handicapped population. This law clearly states that handicapped person should benefit from a normal education in an ordinary school environment, and that they should have an equal access to all scholastic levels. However, the decree often uses unqualified broad phrases as "dans le mesure du possible" and "autant que le permettent"[10] rendering it the 'decree of application that is not applicated.'[11] While M Jbona, head of the Office for Handicapped Persons in the bureau of the Minister of the Population, states that public schools do not technically have the right to refuse mentally handicapped students, he says is complicated as many schools still do

not know of the existence of the law. Handicap International employee Mme Ramamonjisoa, the head of the National Project for an 'Inclusive and Adapted Education,' adds that even if the legal texts are presented to school administrators, the wording is lax enough that there are still ways to refuse students.

The law also applies to the workplace, stating that "Les Personnes Handicapées ont droit au travail et à l'emploi."[12] However, the only company I was able to find that integrated mentally handicapped persons was Savonnerie Tropicale, who currently employs four persons previously served by LOB. This is not to say that other companies in Tana do not currently employ persons with intellectual disabilities, but most participants remarked that the vast majority of adults rest at home. M Radafiniantsoa remarked that when UNAHM was on the point of closure, the parents of the workers pleaded for the organization to find a way to keep the workshop open because otherwise their children would have nothing else to do.

Resulting Situations

These exclusive educational and business conditions create such situations as the case of *Tahina, whose mother took her to register for school at the age of five, and the teacher explained that she could not continue her schooling there. Others, as the parents of 13 year old Edith* never tried to take her to school in the knowledge that public schools refuse such students and in the belief that 'it's not possible.'[13] Ando* has not worked for the past 30 years, and when describing what her son Franc* does on a daily basis, Mme Mandroseza* replies 'nothing, nothing, nothing.'

Informal Communities

Consequential Conditions from Structural Exclusion

The responsibility for caring for a mentally handicapped child is therefore left squarely on the shoulders of the parents. Many parents find that they cannot work. The mother of 7 year old *Marie does not work as she feels that her daughter develops quicker when she's stays at home.[14] Some, however, do not have the financial ability to lose this salary and are forced to

take their child to work with them, as in the case of *Mme Antinimena whose daughter remains with her always.

The more financially disadvantaged, however, are forced to continue to work beyond the household, and their only financial option is to leave their child at home since school is not a likely option. Some are lucky enough to find employment near the house, as in the case of *Mme Analakely whose employment consists of washing the dishes and laundry of her neighbors so as to be close to her mentally handicapped son. Others, however, are not so fortunate and hope for help in caring for their family member from the extended family or community, the *fihavanana*. However, when no one is available to help the family, these children or adults rest at home alone. While some are capable of such independence, others with more profound handicaps endure embarrassing or uncomfortable results from this lack of aid. *Mlle Ivandry describes the case of her mentally handicapped cousin who is also physically incapable of mobility. When her cousin's mother is not around to take care of her daughter, she is sometimes left to sit in the courtyard alone. Why in the courtyard and not inside the house? When she is left alone she cannot succeed in using the toilet, and is forced to release her bowels where she is sitting. This is easier for the mother to clean up if it occurs outside than in the furnished house.

The few structures that provide free services are unable to satisfy the high demand. Les Filles de la Charité, a community of nuns, provide a 'Charity House' called Tongarivo for 41 poly-handicapped persons to live. At Tongarivo, families request that the center house their children. Dr. Giacinta-Gobetti, a nun at this center, remarks that families make this decision for a complex array of reasons, but most often because they do not have the means to take care of their children. As a result, the center has a waiting list for those who want to place their children in the center, and sometimes the center receives two to three demands in a single day.

While the organization has no desire to expand, as they would like to remain a small family-like community, other structures have grown tremendously since their commencement.

IME Equilibre, a medical-educational center, opened its doors in 2000 with five students; six years later they have 25. Fanilon'i Madagasikara, a Catholic girl scouts program with a branch for mentally handicapped girls, started with 5 students and now have 25. This growth attests to the fact there is a need and desire for more infrastructure concerning the intellectually deficient.

Familial Interaction

While these conditions result as an exclusion from supportive social infrastructure, where families are left with no choice but to care for their mentally handicapped children in accordance with their financial abilities and communal support, there are negative circumstances that originate from within the family. One can see in the emotional and reactions families reveal to their mentally handicapped members that this is not a situation with which the family wants to deal.

Emotions

Many emotional reactions to having a member of the family as mentally handicapped were mentioned in the interview process. Some spoke of shock and disbelief. Others spoke of sadness and what Dr. Rabeantoandro terms 'desolation' at the fact that their children are not 'normal.' The overriding sentiment revealed itself to be that while they may deeply love and wish the best for their mentally handicapped child or sibling, the needs and specificities of these family members can be quite difficult at times.

Some choose to address these difficulties by not dealing with them at all. Dr. Annie, a psychologist and doctor that works with IME Equilibre pinpoints two common reactions to the progonosis of being intellectual deficient: the refusal to recognize that their children are mentally handicapped and the "cowardly" reaction of setting their children to the side, hiding them from others.

Disbelief

One indication that families do not want to deal with the consequences of having a child who is mentally handicapped is this reaction of disbelief. The parents of Michelle refused to believe that she was mentally handicapped when a doctor gave this diagnosis when she was four years old. She remained at home until she was 11, when consultations with employees of LOB finally convinced the parents that this was in fact Michelle's state of being. During this time, she became very aggressive and disruptive to the neighbors, breaking things and even one time releasing her bowels on the door step of a community member.[15]

Three year old *Naly has mental retardation and attends a class at LOB. However, when the family first visited the center, they said to each other 'These children aren't like our child. They're different." While the parents now accept her handicap, for months they searched for other explanations for her comportment. When asked how extended family members responded to this news, her mother replies that they don't believe that she has mental retardation and even asserts that many that she knows don't believe there is such a thing as a state of being mentally handicapped. These persons assert that there are two reasons a person would behave as Naly; either they are crazy or physically handicapped. Many neighbors and family members therefore, believe that she is only developing late.[16]

Concealment and Distancing

While those that live with mentally handicapped persons are forced to accept and deal with the mentally handicapped persons, many extended family members remove themselves from such situations. The extended family members of *Michelle may visit her house, but never of their voluntary will, describes her sister *Mlle Behorika. She explains that very few are compassionate and understanding. The grandparents of Nicole will not even visit the family as a result of her presence.[17]

While immediate family members can't remove themselves from those with whom they live, some try to distance themselves by separating the mentally handicapped member to the extent that it's possible. When asking about the social situation for the intellectually deficient,

nearly all of my interviewees remarked that families “se cachent” or hide them. M Lisy recalls the circumstances of a previous student at LOB whose father held a high position in the society. Many of his colleagues did not even know that he had a handicapped son, as he never spoke of him and his room was in the attic of a large house.

I visited one family on two different days, spending nearly five hours at the house, and was never introduced to the mentally handicapped member who was there the entire time. When asked if I would like to see him, I replied yes expecting a face-to-face introduction. However, when the sister-in-law returned from going to his room, she was alone and instructed me to walk to the window where the man was walking outside with his assistant.

Even families who are accepting of their children’s state and do not hide their children may ask their children to stay in their room when visitors come if they do not know how these visitors will react. *Seheno, whose sister Tahina* has Down Syndrome, explains that they ask Tahina to remain in her room sometimes if they’re afraid that the visitors might judge the family as a result of having a mentally handicapped child.

Eradication

While some address the difficulties of having a mentally handicapped person by putting them out of sight, some actively seek a means to get rid of the handicap itself. As many believe that the handicap is a sickness and not a state, they attempt to heal the illness.

Few attempt to restore the mentally handicapped person to health through hospitals. Professor Bernadin, of the Human Sciences department at the University of Antananarivo, explains that the Malagasy have three ways of healing sicknesses: traditional holy men, Christian religious healing, or modern medicine, but makes a point of noting that modern medicine is always a last choice and that traditional methods are first. These traditional healers provide talisman known as *fanafodygasy* or medicinal plants for healing the ‘sickness,’ explains Professor Bernadin. Even if families do arrive at hospitals and are told that their children are mentally handicapped and need special care, many families ‘do not accept this,

and seek the help of traditional healers' furthers Dr. Rabeantoandro, of the paediatric center at the Hôpital Befelatànana

Some families attempt to heal the sickness with exorcisms, believing the handicap to result from evil spirits. The Pentecostal church of Ando's family attempted an exorcism, but his brother explains that it seems to not have an effect on him.[18] Toby, an organization that houses mentally ill persons, but accepts mentally handicapped persons occasionally, performs 'exorcisms' daily on their inhabitants. As Dr. Suzanne of the center explains, these religious rituals are simple with scripture readings, oral explanations of the verses, and prayer; she says that the effectiveness of such exorcisms depends on the faith of the family and of the mentally deficient person.

Communal Interaction

Families have varied experiences with their surrounding communities. Some find that their neighbors are quite accepting and helpful, while other experience troubles with those nearby.

Outsider

Mlle Behorika remembers when she and her sister Michelle were young and playing in the courtyard, neighbors would approach her and tell her to take her sister home. Now she says there are some neighbors who regard Michelle as an animal, using her as a punishment or threat for their children, saying things like 'if you make a mistake, I'll make you sleep with Michelle' or 'do that one more time and I'll send you to Michelle.' In a similar experience, the mother of *Henri explains that while her son does have friends are in the immediate enclosure, those in the neighboring areas are not accepting of her child. She recounted to me that recently several neighborhood boys had wrestled with children from another *quartier* because they had fought over whether Henri was actually a human being or a dog.[19]

Lack of Contact

Of those that I interviewed, many remarked that the mentally handicapped person was not socially active. While Edith would like to be with the neighborhood children, her father says there are 'very few who will play with her.'[20] The father of Mamy* chuckled when I asked whether his 28 year old son has friends, as if this was a absurd thought, and remarks that his son has never had friends.[21] In fact, of the nine families that I interviewed with mentally handicapped members over the age of five, seven of them responded that this person had no friends.

Public Interaction

While there are acts of exclusion from the immediate community to which the family belongs, M Razafindrako of COPH notes that he is sure people from *quartiers* who have mentally handicapped members are more accepting and understanding than those who do not come in contact with the mentally handicapped on a regular basis. Descriptions of general public reactions often include the terms 'se moquer,' 'enfuir,' 'rire,' and 'regard fixement' (mock them, flee, laugh, and stare).

<u>Extraordinary Attention</u>

I observed this behaviour on two occasions during my stay at LOB. One afternoon leaving the center I observed two pre-teenager boys walking down the street; one was walking stiffly, rolling his eyes, and letting his mouth hand open in obvious imitation of a LOB student who had just left. The other boy laughed in response. I also went to the market with about 15 handicapped adults from LOB to buy materials for cookies that the group would make later that day. My field journal entry from that day reads:

> It took about fifteen minutes to walk all the way to the first store, and as there are always a many walking on the street due to the bus stops, we passed by quite a few people (in total about 100). I feel it would be fair to say that at least 90% of the people we walked by stared…Some did not hid the staring, even walking in one direction with their heads turned at us, not watching where they were going…some would do double takes walking by, then turning back around for a second glimpse…some would look and then stare determinately at the ground. Very few smiled…of all those we encountered only one man said hello directly to the students…[22]

We were treated not as members of the society taking part in a typical daily activity, but as outsiders who were bizarre and abnormal. The group was worthy of extraordinary attention, because they were viewed as just that…out of the ordinary.

Fear

Two Tana citizens with whom I spoke over the age of 20 mentioned that they were afraid of mentally handicapped persons. They both avoid people on the street they believe to be mentally handicapped, the man fearing that the person would be aggressive and the girl that the handicapped person would want to touch her. M Ratovohery, one of two employees in charge of the work program at LOB, explains that sometimes the mentally handicapped employees help garden for neighboring citizens. However, he notes that it's rare when a family asks for this service, because many people fear that they will destroy their things or cause problems.

Victimization

Ironically, these situations of violence and sexual encounters sometimes occur but with the mentally handicapped person as the victim and not the perpetrator. M Noa of LOB explains that they have sexual education for their young adults; this is not to learn about sexual interaction, but about how to recognize unacceptable sexual behaviour from strangers. Sometimes, he explains, men 'profit' from young women who, while they may have the mental capacity of a 7 year old, have the body of a young woman.

Violence, while always a rare and exceptional case, does occur. These situations are described to be defensive, from the fear that the mentally handicapped person will act destructively or influence their children. Some mentally handicapped persons, who have nothing to do, take to walking the streets in Tana. 'Families don't know what the handicapped person is up to, and worry that he's crazy and will mess up their neighborhood. They may hurt

him to give him the message ‘You’re not accepted here. There’s no space for you in this neighborhood.’’[23]

Desertion

The public, as opposed to families and neighborhoods, has the ability to abandon situations in which they must come in contact with the mentally handicapped. Mme Rasolofonidina of Fanilon’i Madagasikari notes that the greatest problem they have with the girls scouts branch for those with intellectual deficiencies is finding personnel that will stay with the program. She says that the average amount of time a volunteer will work with the branch is one to two years and then they quit saying that it’s too difficult. Some will not even agree to try helping with the group in the first place.

Analysis

Through exploring the situation for the mentally handicapped in Tana, one can see indications of distancing and separation on three levels of societal interaction. This marginalized population has very little access to basic infrastructure as the educational and occupational system. Families deal with the resulting responsibility by denying that their child is handicapped, attempting to rid the child of the ‘sickness,’ or pushing the family member out of sight from a critical public eye. The public, in turn, treats them as outsiders by ridiculing, avoiding, or victimizing this population.

I must at this point acknowledge that this is not a study on the *prevalence* of such actions. I in no way wish to indicate that behaviour as described above is categorical in the Malagasy culture, or that every mentally handicapped person experiences appalling social treatment. “One notes [in Malagasy culture] reactions of fear and or placing them at a distance, but there is hardly manifest aggression. The extreme cases of reject and abandonment by the family are rare even if the subject is sometimes hid by the family.”[24] However, my research attests to the fact that these situations *do* exist; and while there may only be a few who suffer

from extreme rejection, all live in a city that does not offer the mentally handicapped population societal worth or even the *opportunity* to live a typical life.

The deeper question then becomes 'Why do such negative situations exist?' to which I must compellingly declare: existing perceptions and conceptions. I found certain attitudes to be commonly presented by those who deal with mentally handicapped persons on a regular basis: feelings of embarrassment, frustration, shame, protection, and a sense of being weighed down by a heavy responsibility. The public, on the other hand, often associate mental retardation with those who are bizarre, incapable, crazy, worthless, and a burden.[25]

The social situation reflects that such perceptions reside within the Tana population. However, this is not a one-way relationship, as the perceptions in turn reflect the social situation. While a man may be in prison because he is perceived as being dangerous, the thought that he is dangerous is fuelled by the fact that he is in prison. The only way to change this reciprocal relationship is, therefore, in the discovery of the circle's origins.

In the careful examination and dissection of the actions, voiced opinion, and circumstances presented in the social situation for mentally handicapped in Tana, I have found these negative perceptions and situations to be a reflection of a deeper conflict. The characteristics of the handicap itself prove to be in direct clash with basic tenets of Malagasy culture and the current economic state of the nation.

Thus, five specific contradictions present themselves: [26]

1. Variety of Needs vs. Infrastructure: Lack of Organization and Access
2. Retard in Development and Daily Activities vs. Economy: Productivity in a Developing Nation
3. Abnormal Appearance and Behavior vs. Collective Identity
4. Limited Aptitude and Compliance vs. Concepts of Community
5. Inadequate Understanding of Origins vs. Religious and Traditional Beliefs

Variety of Needs vs. Infrastructure: Lack of Organization and Access

In sitting in on a class of the education service at LOB, I wrote:

> The group had observably different physical levels, with some struggling and scared to do the activities as movement was difficult, and others quickly finishing… M Anselme explained to me that the activities were hard to complete with the group…two of them can't speak and are hard to get energized, while some have attention problems. One student cannot see well, while others have no physical indications of their intellectual deficiency. I wonder if it is difficult to deal with such a variety of issues in a single group?[27]

The very nature of the term 'mental handicap' encompasses a broad range of intellectual, physical, and behavioural particularities. In my three weeks of research I saw those who cannot walk or eat independently, as well as those who communicated well and were socially active. As a result, the care for such persons requires training to be able to deal with these needs as well as a developed infrastructure to address the variety of difficulties.

The specialized centers take into account these diverse characteristics, and develop their programs around such needs. Those with autism at LOB rest in a room with employees who try to 'mother' them with attention and sensorial stimulation. The children and young adults at the center are provided with services according to their needs; those capable of learning how to read are taught, those in need of stability are disciplined, and those who benefit from artistic stimulation attend music therapy sessions.

However, as discussed earlier, these structures require a financial participation that many are not capable of producing. The structures that do exist of a gratuitous nature are most often religious organizations and NGOs offering medical, physical, or spiritual care but have rarely had any training to provide services that would develop and expand the intellectual aptitude of such persons. One explanation for this lack of training results from the fact that of the many professional formation centers in Tana, there is very little concerning the mentally handicapped. The two centers that do provide such training are not well established yet, as they have been in existence for less than 3 years. If one wishes to receive preparation for working with the mentally handicapped, the university does not offer specialized classes; one simply majors in 'social services.'

One example of a benevolent community with little training in the needs of the intellectually deficient is Tongarivo. In visiting this center, one of the first things I was told was that this was not an educational institution, but that they provided food, medical care, and assistance in daily activities as changing clothes and using the restroom.[28] Touring the center, one can see that those who live there are well taken care of, but typically do nothing but sit inside or outside, staring about and occasionally listening to the radio.

They also do not have the training or personnel to deal with behavioural adjustment and end up using isolation structures. When their patients act aggressively or with instability they have such structures as the "lit des betises" where one rests in a bed with a barred enclosure about four feet tall. In viewing three men sitting and pacing in an enclosed area outside, a nun explains to me that this is because the men categorically try to leave the center.

These physical structures can also be used by families who suffer from the lack of supportive infrastructure or training to deal with the behavioural particularities of the mentally handicapped. One woman recounts the unusual case where a child in the countryside was found to be living in a cage outside of the house.[29]

Mme Lucie, employee at LOB, explains that orphanages rarely accept orphaned kids with mental handicaps as a result of the lack of training and personnel to deal with such needs and a fear that child as this would create disturbances with in the social functioning of the center. With the case of Christine*, however, an orphanage was housing a child with intellectual deficiencies. As the personnel did not know how to handle her needs, especially the fact that she still could not walk, they left her unaccompanied with no participation in the daily activities of the orphanage.[30]

By making no effort to address her needs, the orphanage treated this little girl as though she was a burden with which they did not want to deal. Recall the case of Fanilon'i Madagasikara where sponsors abandon the program as a result of viewing their responsibility as a heavy load they no longer wish to carry. Mme Ratsifasoamanana is in charge of a private

school that has integrated 6 mentally handicapped children into their classrooms. When asked why the school had decided to start this program, she exclaims that she likes to help the mentally handicapped children, and that they have the same rights as other children. However, when recounting the situation at the school she notes the difficult experiences as when these intellectually deficient children yell, are aggressive, or disturb the concentration of others. In her descriptions, she did not make not of any positive experiences with these children, treating the integration more as a **burden** with which the school must manage and not as a joy or rewarding experience.

. These behavioural difficulties and influences on the other children's learning environment leads organizations as Handicap International and COPH to maintain that one must integrate mentally handicapped students in the regular educational mileu with adapted programs. These programs allow for encounters with non-handicapped children in recess and dining, while maintaining a special class for the special needs of these children. However, the lack of personnel, legal discrimination, and unfounded belief that the private structures are sufficient for children have resulted in only one school requesting help in starting such an adapted program in Tana.

As these examples illustrate, there is insufficient infrastructure and care for the mentally handicapped population in Tana. The conflict lays in the fact that the very nature of mental handicaps, with a variety of special accompaniment and stimulatory needs, requires a strong infrastructure of trained personnel. The resulting situations leave the families with a child who needs special attention that few are able to give. These families are left feeling as though their children are a **responsibility** and not a blessing. Consider the case of Mme Analamahitsy who was so intent that I understand the difficulties her family experienced as a result of her mentally handicapped brother-in-law, exclaiming that the attention her husband bestowed on his brother rendered them a 'shared couple.'

Retard in Development and Daily Activities

vs. Economy: Productivity in a Developing Nation

A residing characteristic of those who have mental deficiencies is that of a slower rate of development and learning. Mme Micheline, an employee at LOB, remarks the aging process does not necessarily correspond to the improvement of one's behavioural comportment or intellectual capabilities. These individuals need sensorial stimulation, communication and much repetition; even with this, it sometimes takes years to clearly percept development, as with the case of Mamy who started LOB at the age of 14 and did not stop some of his disruptive behaviour as cussing and throwing objects until 4 or 5 years after.[31]

In speaking with those who work directly with mentally handicapped persons, I was often told that the most important quality necessary for such work patience. In a program termed Rehabilitation à Base Communautaire (RBC) which will be discussed in more detail presently, trained agents worked with mentally and physically handicapped children for three years. From the documentation from this project, one can see the recorded evolutions after one agent had worked with 10 children for a year. These evolutions include such statements as "participates a bit in a game of pass-pass" or "positive approach" and "smiles."[32] After a year of specialized attention for these children, these developments are actions that many children would be able to acquire within minutes.

Time required for daily activities is also augmented with some mentally handicapped persons. Seheno remarks that her sister can be frustrating sometimes because it takes her so long to accomplish small tasks. M Martine of LOB explains that this is often the case with persons who have Down Syndrome, and while you can continually encourage them to work, their natural manner is to be "mora, mora, mora, mora" (slow, slow, slow slow).
Further demonstrating the slower nature of the mentally handicapped, M Radafiniantsoa remarks that UNAHM in naturally inferior in productivity in comparison to other businesses,

estimating that the employees at this workshop produce at about 25% the rate of non-handicapped workers.

These reduced rates of productivity clash with Madagascar's current economic state. In 2004, the World Bank declared that Madagascar was the poorest, non-conflict country in the world. Therefore, the government places all priorities in those actions that will help the country develop.[33] The current infrastructure being developed and improved are the roads connecting city to city thus providing a more efficient means to transport goods which aids in the economical development of the nation.

The mentally handicapped, however, do not aid in the development of the nation. M Ramamonjisoa remarks that companies would rather hire an unemployed person with no qualifications that a mentally handicapped adult. The unemployed at least have the qualification of the capability to be productive. Even M Etacelin from Savonnerie Tropicale admits that the company can hire those with mental handicaps as they are a stable company with no desire to expand to the exterior. Therefore, the trade-offs for a lessened productivity are low.

In many cases, however, this retard in development completely separates the mentally handicapped from the occupational system. With little contribution to the productivity of the nation, the public sees them as **worthless**; while families may find the worth of mentally handicapped members in other aspects of their being, they do become **frustrated** with the amount of time necessary for daily task and tangible developments.

Abnormal Appearance and Behavior vs. Collective Identity

Some mentally handicapped persons have a normal appearance with no indication of their state. However, many who have intellectual disabilities present physical suggestions of their handicap. From observing at LOB, some physical differences seem to be more manifest than others, namely open mouths, blank stares, awkward hand positions, and clumsy or stiff movement. Some conditions have specific physical effects, as Down Syndrome, which is a

hereditary mental handicap that causes such corporeal effects as large hands with little fingers, small necks, small noses, and the back of the head is often flat.[34]

When asked what specific quality of mentally handicapped persons perturbed the average Tana citizen the most, *M Analamahitsy asserts that it's the physical disparity. He explains that in Madagascar the value of placing community over individual extends to one's appearance. People don't want to appear different because they don't want to stand out from the community; they want to be a part of it. The mentally handicapped, however, often have physical properties that set them apart from the norm, and render it impossible to blend into society even if merely walking down the street.

Another aspect that places mentally handicapped persons as atypical in comparison to society is the disparity between mental and corporeal age. LOB employee Mme Lucie explains that most mentally handicapped persons do not surpass the mental age of 10 to 15. However, this mental age is determined through sporadic evaluation and trained observation. To meet a 14 year old boy who still cannot speak well appears very atypical even if his mental age may be that of a three year old. The general public cannot look at a person and know their mental age.

Those with mental deficiencies depart from the norm in behaviour as well. When asked what Tahina likes to do for fun, her family explains that she enjoys gathering small bits of paper and handling them or placing them in piles.[35] Edith used to clap her hands when she walked, creating such a strange scene that her parents often left her at home when entering public. However, once she stopped doing this odd action and learned to walk like everyone else, her mother started taking Edith almost everywhere she went.[36]

Sometimes these behavioural differences are not so harmless. Some may demonstrate aggressive or instable tendencies. Four of the ten families that I visited spoke of occasional situations of aggression. Most often these were described as being merely threatening but occasionally included punches or slapping. I witnessed such aggression, watching one young

boy punch his father repeatedly at LOB in frustration after falling in the dirt. Sometimes yet, these behaviours are self-aggressive, as in the case of Michelle who threw herself down on the ground, banging her head when I entered the house for an interview out of categorical anxiety of strangers.

As a manual for handicapped persons used by LOB asserts, these behaviours are often imitations of behaviour the mentally handicapped person has observed when directed against him or her. However, "These problems of comportment sometimes overwhelm the family and the community. Often the family and the community don't want to be responsible for a child with such comportment."[37]

These behavioural challenges create the sentiment that mentally handicapped persons are instable. In interviewing the terms *fou* (crazy), *handicapé mental*, and *malade mentale* (mentally ill) were sometimes used interchangeably. The general public does not know the difference between mental handicaps, which is the result of a physical condition, and mental illnesses which often originate in emotional trauma. Indeed, the Malagasy language does not differentiate from the two mental states, as one can use *marary saina* for both. *Adala*, which technically means crazy can also be used to refer to a mentally handicapped person.[38]

Mentally handicapped persons are, therefore, often believed to be emotionally **instable** and **crazy**. Recall the communal situations described of those who may react violently to mentally handicapped persons in their neighborhoods. They are acting out of protection, protection from a person who may not have control his emotions or actions, a person who is not a part of their community.

Malagasy people are by their culture a people who value being a part of the norm, a part of the community. When signing the informed consent form, one participant remarks that the Malagasy people always put their family name before their first name. She continues that this reflects a societal value, for one always puts family before self.[39]

This emphasis on finding one's identity in community creates the sense that one's actions are a representation of the community to which one belongs. As a result of this cultural value, the sentiment of **embarrassment** occurs not only as a result of one's own actions but can occur from the actions of one's fellow community members. Ando sometimes leaves the house without permission, to which his nephew *Eric responds by immediately finding him and trying to get him to return. He fears that he will do 'embarrassing things' as trying to kiss young girls or touch people. His reaction indicates that he worries that such atypical behaviours would not only be associated with his uncle, but with him and his family as well.

These worries prove to be granted, as the public does devote attention to persons displaying bizarre characteristics. After experiencing the uncomfortable staring the day I went to the market with a group of mentally handicapped persons at LOB, I became intentionally observant of my own trips to the market. I noticed that people on the street often stared at me as well, as a tall white adult walking in a midst of shorter darker skinned persons. In this I recognized that these Tana citizens did not stare at the mentally handicapped group because they believe there is something inherently wrong with such people. They stared because they are *different.*

Psychiatrist Lisy explains that people push away what is different from them because they fear that which they are not familiar with, for they do not know how this unfamiliar individual will behave and worry that this **abnormal** and **bizarre** individual will influence them to be different too. Individuals often laugh and ridicule people they perceive as atypical to set up a definite distance between themselves and that person. In a society where people find identity in being associated with other members of their community, those who pose a threat to the community by being different are as a result mocked and avoided.

Limited Aptitude and Compliance vs. Concepts of Community

Another defining characteristic of the mentally handicapped is that of limited aptitude and compliance. Each has his or her own capabilities as well as intellectually cap. On a

general level, these limitations can be frustrating to those who can accomplish activities with ease that are difficult for the mentally handicapped person. Thirteen year old *Mandry has been trying to learn the difference between green and red for the past couple of monthes, and still has not mastered the skill. While the LOB employee working with him on this skill began the individual session waiting for Mandry to state whether the pinpointed object was green or red, when his comprehension had not improved after fifteen minutes, she began to cross her arms, sigh, and place her hand on her forehead in frustration.

There are, however, certain limitations of mentally handicapped persons that are more detrimental as a result of societal values. Franc is 30 years old, but he cannot speak except for repetition of small phrases.[40] Many of the intellectually deficient have difficulties expressing themselves, especially with the skill of speech. However, "orality is the essential characteristic of the Malagasy culture… as well as the transmission from generation to generation of their wisdom and their philosophy."[41] Many mentally handicapped persons, therefore, cannot partake in this very valued form of communication, placing them once again outside of the norms of the society.

*M Mamory remarks that some members of the mosque continue to tell him that he should try to arrange a marriage for his 28 year old mentally retarded son Mamy because this would help him to be more normal. However, M and Mme Mamory believe that this is not possible for their son. Indeed, Mme Micheline of LOB relays to me that she has attended a marriage between a light level mentally handicapped man and woman, saying that they don't have children yet but the grandparents hope for this. For the majority of intellectually deficient persons, however, marriage and having children is not a possibility. With mental ages of 15 and below, these persons are not psychologically prepared or capable of making such a commitment.

Again, however, this goes against the grain of Malagasy society. When asked what aspects of Malagasy culture affect the social situation for mentally handicapped persons in

Tana, *M Analamahitsy remarks that it's a Malagasy value to found a family; it's important to have kids because you never really die with descendents. You continue to be represented.

This concept of descendents also manifests itself in the negative situations that can sometimes result from giving birth to a mentally handicapped child. Seheno explains that having a child with mental deficiencies can create couple problems as a result of men viewing these children as "bad roots." You cannot build a family tree with roots that can produce no trunk, so the handicapped person is seen as a worthless descendent. Seheno recounted to me the story of a couple who got divorced because their first child had Down Syndrome, and of another whose mother left her mentally handicapped child to be raised by the father alone. Dr. Giacinta-Gobetti of Les Filles de la Charité remarks that occasionally mothers beg the center to accept their children because their husband will divorce them if the mentally handicapped child remains at home.

Beyond lack of ability to partake in communal life through oral tradition and creating a family, some mentally handicapped persons can be uncooperative and incompliant with instructions from those superior in the hierarchy of the community. At LOB I observed an adult group working on motor skills by stepping onto a circular bar structure and then scooting around the construction. One woman resisted and the intern, frustrated with the efforts to get this individual to step upon the structure, turned and pointed her finger at her with a hard stare for about five seconds. Another day, an educator at LOB exclaimed in a loud voice "Sofina!" when the student he was addressing failed to listen to his request to sit down at the desk. While the educators at LOB attempt to develop friendships with the assisted persons, M Ratovohery notes that there is still a level of respect demanded.

The frustration with uncooperative behaviour demonstrated by these educators was also found with families. When speaking of evolutions that they had remarked in their mentally handicapped child's behaviour in the past couple of years, many remarked that they were happy their childe now follows requests. This, too, reflects a Malagasy cultural specificity, the

presence of hierarchy in the family. Undergraduate student Michelle Albert asserts that in Malagasy society parents have demand respect from their children, and that these children respond to this authority by learning the wisdom that the parents pass along.[42] However, mentally handicapped persons often cannot partake in this process, lacking the aptitude to comprehend such wisdom and displaying uncooperative behaviours that defy the authority of the parents.

Parents, however, can sometimes makes the opposite mistake of asking too much of their mentally handicapped children. Sometimes they expect too little. "The family of handicapped persons and members of the community have a tendency to think that handicapped persons can't do what they can."[43] *Mme Mandroseza thought her son Franc **incapable** of education after some unsuccessful experiences with him wetting himself at school, so she quit trying. The family of Michelle does not believe she can go to church without causing problems, having a nervous attack, or inadvertently taking things; she stays at home Sunday morning.[44]

These situations indicate the presence of a common belief found in families with mentally handicapped members: that one must keep them in the circumstances and environments in which they know they succeed. To place them into unknown circumstances invokes unnecessary risks for their fragile children. Mme Anjahana hopes for her child Naly to remain at LOB because 'there she is accepted because it is all the same type of people with the same handicaps'; there she is 'safe.' This "hyperprotection… nourishes at the home of the [mentally handicapped person] a sentiment of dependence, a certain refuge in the sickness."[45] These persons are often protected like young children; the mother of a young adult in a class at LOB does not want her child to handle knives, Mme Martine remarks as the student peels potatoes, 'but look at him. He's already an adult.' This recognition of the mentally handicapped as anything beyond their mental age, however, is rare. All of the educators used

the French word *enfant* in referring to the assisted individuals, even if referring to men over 40 years old. One even used the phrase “un enfant à l’âge adult.”

While it is easy to assume that segregation always results from an outside force refusing a person the right to enter the norm, those who are trying to defend the person from exclusion can just as easily prevent movement toward the norm. It is the push and pull of those who are trying to reject and those who are trying to protect that create such separation.

Therefore, mentally handicapped persons often cannot partake in valued aspects of community including the passing along of oral wisdom, the priority of building a family, and the hierarchy found in social structures. Even further, limited abilities of the mentally handicapped lead families to **hyper-protect** their children resulting in an isolation that renders participation in the community impossible This results in perceptions that mentally handicapped persons are **worthless** in society, creating feelings of **frustration** on the part of family and community members.

Inadequate Understanding of Origins and Comportment

vs. Religious and Traditional Beliefs

Perhaps the strongest factor that contributes to social ostracism in Tana finds its roots in the inadequate understanding of the origins of this deficiency. Even in speaking to those who had studied mental handicaps, whether at the university level or in professional formations, there were contradictions. An educator at LOB explains that if parents are really old and have a child they may be born mentally handicapped as a result of weak chromosomes.[46] Dr. Ranaivoarisoa, a paediatrician that deals with neurology, disagrees with this statement and says that older parents are not factors in mental handicaps. He then denied the beliefs of three of the families with whom I spoke who claim that a strong blow to the head resulted in the mental handicaps of their children by saying that infantile falls can’t cause mental handicaps.

Not only are there conflicting ideas about what causes the mental state, there are many cases with indeterminable causes. "A large part of psycho-motor retards, 40% rest of an undetermined origin, even after thorough radiological, biological, and genetic investigations."[47]

As a result of such puzzling causes of mental deficiencies, M Ramamonjisoa remarks the families are always trying to pinpoint a reason or experience that caused the mental handicap. One family told me three different scenarios that could have caused their daughter's intellectual deficiency. What's more, an deeper reason exists for parents trying to find an origin for their child's mental state: a desire to prove that *their* actions are not to blame for the creation of the handicap.

Many view having a mental handicapped child as a 'sign of culpability.' [48] These persons blame the family for having done something that invoked the anger of God or an ancestor, depending on one's beliefs. As previously discussed, in the Christian tradition some believe mental handicaps to be the presence of evil spirits from the devil that must be exorcised.

In the traditional viewpoint, mental handicaps are seen as a punishment for a social transgression, such as not respecting the *fady* or *famadihana.* [49] of an ancestor or not respecting the community or fihavanana. The ancester, in response to this violation of respect, punishes the family by bestowing this handicap upon the newborn child.

As a symbol of this disrepect for the ancestors, can impede the rights of the mentally handicapped. M Ramamonjisoa recounts that Handicap International once dealt with a case where a young mentally handicapped person had been unwillingly impregnated by a neighbor, but the family would not press charges in the desire to keep the community at peace. Her right to legally pursue her perpetrator was deemed unworthy of creating tension with the neighbor, for she was already a sign of violating the rapport with the ancestors and in this act would have become a symbol of the disrespect of the living community's harmony as well.

This ancestors may also impart mental handicaps on children not as a punishment, but in compliance to the desires of the parents. A parent can approach the ancestors with a proposal and use their children's state of health as a condition of the exchange. Mlle Ivandry recounts the story of a man who visited the cave where an ancestor was believed to live, and bartered his children's intellectual capacities for wealth. He then became rich and his four children mentally handicapped.

Birthing mentally handicapped children can be an indication of other guilty actions. Mme Anjahana* recounts that her husband believes their daughter Naly has mental deficiencies because their union held a weakness. Not by fault of the mother or the father, he believes that the combination of the two persons couldn't create strong descendents. Professor Bernadin explains that a couple could be 'weak' if the union wasn't blessed by the ancestors or if the husband and wife have two different destinies and weren't meant to mix. He continues to say that often, however, the fault is placed on the mother since she carried the child and the society is patriarchal.

Such culpability is revealed in the fact that ometimes people view such a child as an indication that the mother slept with another man.[50] The explanation for this belief lies in the Malagasy traditional charms. Two interviewees mentioned that a person could be born mentally handicapped if another person had used *odygasy* against them.[51] A person who feels wronged from another family, neighbor, or lover goes to the traditional holy man called an *ombiasy* to obtain these *odygasy*. The *ombiasy* then mixes natural objects as plants, small amounts of sand, or sacred water and sometimes require an object from the person at whom the *odygasy* is aimed, as a hair or piece of fabric from an article of clothing; when these mixtures are placed in the path of the targeted person, they can create illness or medical states, as mental handicaps.[52]

While the family who then births the mentally handicapped child may have been the victim in this scenario, it remains an indication that they wronged a neighbor or other

community member. In the case of women, the belief that she may have slept with another man arises from the fact that these intimate contacts would have given ample opportunity to obtain a personal article of hers required for the charm.

Sixty-nine year old *Mme Lucien* remarks that another potential origin of mentally handicaps is *ambalavelona*. This is an illness that results from *odygasy* and makes a person 'cry, scream, and have convulsions where the force of five men can't contain them.' [53] While not all epileptic persons have mental deficiencies, seizures in children can "often occasion a basement of intellectual efficiency and sometimes a mental retardation more or less profound."[54] Sometimes these persons continue to have seizures throughout their lifetime. A LOB employee remembers one time when an assisted person had a seizure in the market, and the necessity of explaining what was happening to the surprised eyewitnesses. [55] Associations of seizures with this *ambalavelona* renders such physical crisis' to be not only a sign of a medical difficulties but of societal conflicts as well.

Mme Mamamonjisoa explains students react with fear if they see integrated mentally handicapped students have seizures, because they believe this comportment is transmissible. Because people believe that seizures find their origins in the power of people, of traditional sorcery, the condition is thought to easily be easily dispersed. If men can create it, they can pass it on. Family members who are pregnant do not expose themselves to Michelle, for fear that their children will catch the sickness. [56] When Handicap International works with schools to integrate mentally handicapped children, they hold meetings with the parents of the school. A common worry they must deal with is that many parents believe that mental handicaps are transmissible. [57]

The results of not having a firm grasp of why mental handicaps occur leads family and community members to search for their own answers. These religious and traditional explanations are found to be viable explanations for the origination of such intellectual deficiencies. As some beliefs have other citizens as the source, they believe men have the

power to transmit mental handicaps through contact. This creates, however, negative conceptions that blame the family for committing some fault that resulted in this handicap. The negative societal perceptions then induce feelings of **shame** and guilt in the family, making them more likely to hide and conceal their children from society.

Conclusion : Suggestions for the Future

We cannot change either of our two opposing forces, the state of being mentally handicapped or the culture and economy in the state of Madagascar. We can however, improve the relationship between the two by addressing the tensions that exist in the rapport. If we put our efforts into resolving these conflicts, we can, and will, succeed in changing the social situation for mentally handicapped persons.

A Malagasy proverb asserts "Make like a chameleon while walking: Look ahead and behind." [58] To be able to move effectively forward, we must look to the past. There are existing projects that address the five previously presented conflicts, yet the perceptions and negative circumstances still persist. We must, therefore, critique and evaluate these methods, in order to more effectively create social change.

Efforts Addressing the Conflicts

Sensibilisation

Many organizations that deal with the mentally handicapped population put their efforts into what is termed *sensibilisation*, which refers to public awareness and education campaigns. The basic principle in these efforts is that if citizens understand the particularities of this population they will be more receptive and accepting.

M Razafindrakero remarks that there are a number of ways to perform *sensibilisation*, from demonstration, to speeches, to participatory measures. He believes that one must use a mixture of these methods to be effective. Currently there are efforts that address the underlying perceptions of the mentally handicapped as useless, shameful, and abnormal

through the use of various types of *sensibilisation*. I will, however, evaluate how to most effectively address these conflicts by tailoring the efforts to the targeted population and the perceptions themselves.

Productivity in a Developing Nation

LOB employee Mme Martine spent about 20 minutes showing me all of the crafts her group had made, often repeating that the assisted individuals had made the object by themselves. Many of the LOB services try to produce things, as an attestation that the mentally handicapped population is capable of being productive. She explains that sometimes they have expositions at the school to sell all of the things, and while she says that members of the public are invited for such expositions, she admits that it's mostly parents who buy the object.

Suggestions: Consideration of Target Population

While this does address Conflict 2 by presenting the mentally handicapped as capable of productivity, the reached population is insufficient. While families benefit from the knowledge of knowing their children's capabilities, those who really need to recognize the capabilities of the mentally handicapped are members of the public. It is Tana's occupational system whose belief in the uselessness of the mentally handicapped renders them excluded from this societal infrastructure. UNAHM president M Radafiniantsoa explains that they have to do demonstrations for the general public, because many do not believe that it is actually the handicapped persons that produce the business suits. Public demonstrations must be developed further to succeed in targeting the population where prejudices of uselessness reside. Thus, those involved in business structures may readjust their perceptions that it would be impossible or unproductive to hire such persons with intellectual difficulties.

Inadequate Understanding of Origins

Handicap International addresses Conflict 5 by trying to collapse the beliefs that mental handicaps result from a mistake of the parents and that it's transmissible. They promote a discussion based format for the meetings they hold with the parents of soon-to-be integrated

schools. This way parents reveal the perceptions they hold of origins and transmission, and the representatives of Handicap International can provide the medical explanations of the handicap.

Suggestions: Expanding the Discourse

I find this process to be effective. The parents are provided an opportunity to voice their own concerns, and by addressing the origins of the handicap they diminish the belief that mentally handicapped children should be hidden because they're a source of shame. This alleviates parents' fear and worries for their own children, making integration a less problematic process.

The process of educating the public about the origins and particularities of mental handicaps is an effort that all organizations with which I spoke found to be extremely important in creating acceptance and understanding. While these efforts do exist, they're not reaching far enough. *Mme Behorika says that today she notices efforts of *sensibilisation* concerning the mentally handicapped; however, before she had her autistic daughter Michelle she didn't notice any attempts at public education, but then again she 'wasn't looking for it then.' If the only people that are benefiting from these projects of *sensibilisation* are those who actively seek the education, those who are apathetic, ashamed, or unaware of the difficulties of mental handicaps and left untouched.

Children: Perceptions and conceptions are created over time, through social learning and experiences. If we can develop an understanding in these children early, we can prevent the formation of negative attitudes later on. Mlle Behorika notes that children are always asking questions about her mentally handicapped sister, curious about why she does certain things or reacts in certain ways. This curiosity should be taken advantage of. The most efficient way to provide this education would be to utilize the national scholastic curriculum. By negotiating with the Minister of the Education, lessons can be developed for primary sciences classes concerning the origins and particularities of mental handicaps. I am convinced

that even with one or two lessons centered on this subject, the seeds of comprehension would be sown in a society where this lack of understanding has influenced the development of detrimental beliefs toward this group.

Pregnant Women: Dr. Annie asserts that the best way to *diminish* mental handicaps is to inform agencies that care for pregnant woman and young children as the Centre de la Santé Mere-Enfant, La Maternité, and La Pediatre as to how to lower the risks for children being born with such intellectual disabilities. I add to the list of these agencies the network of midwives, as many pregnant woman use midwives for birthing their children. With careful attention and strong prenatal care, this can diminish the prevalence of such cases but there is 'no way to completely prevent intellectual deficiencies. It touches all: the poor, the rich, all ethnicities…' [59] I assert, then, that these agencies should not only have informed employees who know how to diminish the possibilities of having such children, but that these agencies should be used for *educating the mothers*.

Pregnant women need to be educated as to the origins of mental deficiencies, signs to look for, and where to find help. This would serve as a catalyst in social change. Many families, even with the recognition that their child has developed difficulties, and the desire to help, do not know where to take their children for care, ending up at local pharmacies. [60] If the child did show signs of being mentally handicapped, they would know where to receive help; then, if the child grew to be mentally healthy, the knowledge of the origins of the handicap would affect their perceptions regarding others who have mental handicaps.

Collective Identity

Psychiatrist Lisy explains that in order to address the existing prejudices, one must *show* that even though the mentally handicapped are different they do things like everyone else. She said even little similarities connect such individuals to the society; demonstrating that they have emotions, desires, and personalities and can succeed in daily activities just like

everyone else can create a basis for acceptance by creating connections with community members.

The adult LOB group going to the market, or as the educators phrase it 'into the exterior,' is intended to fulfil these conditions and as a result address Conflict 3. Mme Edith explains that by partaking in the typical Malagasy activity of shopping for food, the group demonstrates to the outside community that the mentally handicapped population is capable of normal activites. Another employee adds that with such exposure the public can see that they are not aggressive or destructive, as commonly believed. [61]

Suggestions: Recognition of Capabilities

However, in considering the effects of exposure, it is the quality and not the quantity that counts. When I walked to the market with the adults from LOB, I was asked to hold two individual's hands. I feel that this was unnecessary. The assisted persons who held my hand could walk independently, and the handholding seemed nothing more than a precaution.

While this activity is supposed to demonstrate a mentally handicapped person's capabilities and, hence, similarities to the general population, most adults do not walk down the street with a younger woman leading them with a protective handhold. I realize that some with intellectual deficiencies may require such help; after all, mentally handicapped persons do have needs that non-handicapped persons do not and cannot always behave in a 'normal' fashion. Giving a man who has the mentality of a three year old a newspaper to read in a park is neither productive nor helpful. However, this protective measure was not in accordance with the capabilities of these women.

The difficulty for demonstrating to the public the likenesses between them and the mentally handicapped population lies in the fact that many avoid direct interactions mentally deficient persons, so the characteristics that link one to another will never be observed. The responsibility then lies on those who *are* in contact with them to inspire accepting perceptions by treating them like they're normal. Workers, family members, and others who come in

contact with these persons on a regular basis have an advantage in that they already know the capabilities of the mentally handicapped person. The mistake made by many is by trying to avoid risks to a point where they don't allow the person the act according to their capability. If there are adults capable of acting like 'typical' adults, they should be pushed to do so in order that society can see such potential being attained, not hindered. Such interactions will educate the public in the capabilities of the mentally handicapped, allowing them to be considered a part of society because they do 'normal' activities.

Development of Infrastructure

Conflict 1 is being addressed by the development of further infrastructure in plans for the future, present negotiations, and recent advancements. Dr. Annie of IME Equilibre shows me the plan for what she terms a 'dream,' the construction ideas for a larger center than would include class rooms, recreational areas, and workshops. The committee for La Décennie Nationale des Personnes Handicapées, which consists of representatives of the government, civil associations, and federations, started in 2003 and has broad goals to render the legal texts effective that concern this population and to further social inclusion.[62] Akany Riana, a private school opened its doors merely four years ago to accept mentally handicapped children into their regular classrooms.

Suggestions: Inclusive, but Realistic Infrastructure

While any development of infrastructure will help provide structures to alleviate the responsibilities of families to deal with the specialized needs of the mentally handicapped, one must also consider the results of such infrastructure. M Razafindrako notes there is a markable difference in the perceptions of those who live in quartiers with specialized schools and *quartiers* with integrated schools. Mme Ramampjisoa echoes him believing that specialized

centers contribute to perceptions of prejudice, as they fuel the perceptions that such persons need to be separated from the mainstream infrastructure.

The absolute opposite of these specialized centers would be complete integration as in the case of Akany Riana. However, while this social insertion would seem to have a positive effect on perceptions of the mentally handicapped by reinforcing that they do not need to be placed in separate environments, these programs must take into account the ability of the children to be integrated. When I visited this private school, I walked into one of the integrated classrooms to see one of the mentally handicapped students (who was described to me as a bit unstable and in need of discipline) walk around the classroom and turn off the light. While some may benefit from absolute integration as this, the capability of students to handle this must be seriously considered beforehand. If children are going to create disturbances and hinder the learning environment of the other children, they are once again placed as an outsider. While they may be physically with the other students, the extra attention devoted to this student fuels the perception that mentally handicapped children are heavy responsibilities.

I do not mean to suggest, however, the social insertion is impossible; sometimes, however, this process must be taken in stages. "For the best chances of success, insertion uses a progressive approach. To acquire a stable place… transitory stages are essential. Complete entry into the ordinary milieu should take place in a graduation duration and manner because it concerns the complete reorganization of the social order to which the mentally handicapped person is habituated." [63] Currently there are programs being developed with separated classes (Handicap International) and complete integration (LOB). This can be used to create a process where children may gradually move from specialized centers to separated classes to integrated school classrooms; progression into the next step would be contingent upon whether the student is sufficiently prepared and capable of being within the integrated community in behaviour and actions, not just physical presence.

Limited Aptitude and Compliance

The difficulty in the abovementioned suggestion is that this requires institutions that are ready, willing, and capable of such care. However, as public infrastructure requires the compliance of a broad range of persons, the process of development as spoke of in Conflict 4 will take years of diminishing negative beliefs before such structures are deemed necessary or valuable in respect to the community.

I therefore charge the families who must assume the responsibilities of educating and developing the aptitude and abilities of their mentally handicapped children to take matters into their own hands. A community-based organization should be created, where those who deal with the difficulties of mental handicaps do not wait for the help of experts, but help themselves out. Such an association would need to fulfil two purposes: the presentation of ideas and methods for bringing about development and the creation of a network for support and communication.

In 2000, UNISEF funded a program in coordination with LOB called Rehabilitation à Base Communautaire where agents were trained to go into the community to find families who had little or no resources to aid in the development of their handicapped children. The objectives of this program where to provide advice on how to help their children progress, how to integrate them into the activities of the community, and to offer periods where the family could be free from the responsibility of their child.[64] The program was quite successful with an estimated 500 families[65] reached in three years. However, in 2003 the program ended abruptly with no more funding to continue.

However, such programs do not have to end with the loss of involvement of formalized structures as LOB if those who benefited from this education in how to provoke development in mentally handicapped persons spread this knowledge to others. M Analakely remarks that before her involvement in RBC, she did not know how to address the problems of her mentally handicapped son. Now, however, she says that not only did she benefit from the specific ideas of her agent, but she can now think of other ideas to help her child develop. Sharing advice

and information sparks more ideas and the realization of more effective ways to address particular problems.

A community, however, must be developed to provide such communication. M Razafindrakero asserts that one can use the local seats of government called *fokontany* to provide such a network of communication. If a system is put into place where families with mentally handicapped members can register at the local *fokontany,* they can then discover the other families in the surrounding area who have members with similar issues. Families can then come together to support one another through the spread of knowledge, and also for support in caring for the mentally handicapped members.

Mme Micheline explains that LOB is trying to start a program where siblings bring them sisters or brothers to the center a couple of times a month to do activities. This is essentially for the goal of giving the parents a break, she explains. If parents need respite from the constant responsibilities of having a child with intellectual deficiencies, programs as this do not require the involvement of a specialized center. With a supportive community-based organization families can help each other out. Why should two households have parents remain at home with no salary when the presence of one person for both children would be sufficient? Concerned parents can create regular activities to provide relief from the difficulties in having a mentally handicapped child.

A Final Overview

In light of the volume of data presented in this essay, I hope that the threads of connection between these segments have bound the work into a unified whole. Through a carefully structured methodology, I observed and heard testimony to three levels of social segregation: in the family, immediate community, and general public. Such actions are

interlaced with negative attitudes and emotions concerning the mentally handicapped community.

Through looking at the society as a comprehensive whole, these situations and circumstances are rooted in the conflicting characteristics of the state of being mentally handicapped and the Malagasy society as a cultural and economic entity. In focusing our efforts and critical analysis into the existing efforts that could potentially resolve these underlying tensions, changes can occur in the social situation for this marginalized group. It this, it is possible to create an atmosphere of acceptance and a place of value for the mentally handicapped in the overarching society.

Terminology

Abnormal – Atypical – a sociological term referring to behaviours or characteristics that are deemed to fall outside of the normal or typical

Accompanied Person – perons who receive the services of the organization

Autism - a developmental disorder characterized by impaired development in communication, social interaction, and behaviour

Down syndrome – a chromosomal disorder due to an extra chromosome number 21 that causes mental disabilities and has characteristic physical malformation. This affects both the physical and intellectual development of the individual

Epilepsy – a medical state characterized by seizures. If occurs in early developmental stages of life, can result in mental handicaps

Formal or Structured Organizations –establishments with a defined state of existence, often with presence in the legal, economic, or civil society and with physical buildings

Informal or Unstructured Organization –groups as families, neighbourhoods, or ethnicities that society views as bound together by a common characteristic, such as genetics or geographical proximity

Isolation –the lack of contact with those beyond a defined and strictly enforced area

Light handicap – an IQ of approximately 50 - 69

Mental age –the typical age of development in which a persons reasoning, comprehension, and behaviour falls

Mental handicap, Mental deficiency, Intellectual handicap, Intellectual deficiency - These terms are used interchangeably to refer to the difficulties of intellect and comportment described in the section Research Population

Normal – Typical – a sociological term referring to the aspects of the population that the majority displays or is deemed appropriate and correct

Poly-handicap – those who not only have a mental deficiency, but severe physical handicaps as well

Profound handicap – an IQ of approximately 20 or below

Public - members of the population who interact with mentally handicapped persons in brief situations, perhaps on the street or in the store, but are not subject to steady encounters with such persons

Separation and Exclusion – a distance from the mainstream society. This is an imposed state, not a choice of the separated or excluded person

State – a medical condition that cannot be healed or cured

Endnotes

[1] * indicates name changed for confidentiality.
[2] *Mme Miraille, personal interview, 25 October 26.
[3] Precise statistics for the population do not exist.
[4] John Lofland and Lyn H. Lofland, Analyzing Social Settings: A Guide to Qualitative Observation and Analysis (Davis: University of California, 1995) 17.
[5] Ken Wilson, "Thinking about the Ethics of Fieldwork," Fieldwork in Developing Countries, eds. Steven Devereux and John Hoddinott (Lynn Rienner Publishers, 1993) 185.
[6] Lisy Ratsifandrihamanana, "Le Handicap Mental," Les Orchidées Blanches, 14. (both references)
[7] "Definition of Mental Retardation," 4 December 2006, <http://www.medterms.com/script/main/art.asp?articlekey=20174>
[8] The Handicap International document prefaced in this work declares that there are 300,000 mentally handicapped in Madagascar. As Tana holds approx. 20% of the Malagasy population, this gives us approx. 60,000.
[9] Salaire Minimum, the equivalent of minimum wage
[10] JORM Année 117 117 N° 2700, no.2001-162, Ministère de la Population de la Condition Feminine et de L'Enfance, 4 September 2001. See Appendix D.
[11] Edith Ramamonjisoa, personal interview, 16 November 2006.
Single quotation marks throughout the essay indicate that the quote is a paraphrase, translated from French into English.
[12] JORM Année 117 117 N° 2700, no.2001-162, Ministère de la Population de la Condition Feminine et de L'Enfance, 4 September 2001. See Appendix D.
[13] *Mme Antanimena, personal interview, 18 November 2006.
[14] *Mme Anketsa, personal interview, 18 November 2006.
[15] *Mlle Behorika, personal interview, 15 November 2006.
[16] *Mlle Anjahana, personal interview, 18 November 2006.
[17] *Mme Miraille, personal interview, 25 October 26.
[18] *M Analamahitsy, personal interview, 10 November 2006.
[19] *Mme Analakely, personal interview 18 November 2006.
[20] *M Antanimena, personal interview, 18 November 2006.
[21] *M Mamory, personal interview, 21 November 2006.
[22] Field Journal Part I, page 52, 14 November 2006.
[23] Falihery Razafindrakero, personal interview, 9 November 2006.
[24] Lisy Ratsifandrihamanana, "Le Handicap Mental," Les Orchidées Blanches, 2.
Actual text reads « …on note certes des reactions de peur et de mise à distance, mqis il n'y a guère d'aggressivité manifeste. Les cas extrêmes de rejet et d'abandon par la famille sont rares même si le sujet est parfois cache par ses proches. » Trans. by student.
[25] The manifestation of these sentiments are bolded in the following section.
[26] See Appendix C.
[27] Field Journal Part I, page 21, 8 November 2006.
[28] Dr. Giacinta-Gobetti, personal interview, 20 November 2006.
[29] Lisy Ratsifandrihamanana, personal interviex, 23 November 2006.
[30] Lucie Razanatsimiova, personal interview, 23 November 2006.
[31] *M Mamory, personal interview, 21 November 2006.
[32] See Appendix E.
[33] Lucie Razanatsimiova, personal interview, 18 November 2006.

[34] Unknown Author, "La Trisomie 21," Retard Mental (Unknown), 279. Some elements unknown because a copied resource used by LOB.
[35] *Seheno, personal interview, 11 November 2006.
[36] Lucie Razanatsimiova, personal interview, 18 November 2006.
[37] Aider Les Personnes Handicapées Là Où Elles Vivent : Guide pour les Maîtres d'Ecole (Geneva : Organisation Mondiale de la Santé, 1991), 9.
Actual text reads «Les problèmes de comportement bouleversent quelquefois la famille et la communauté. Souvent la famille et la communauté ne veulent pas être responsable d'un enfant qui a un tel comportement.» Trans. by student.
[38] Dama Ravelomanana, personal interview, 11 November 2006.
[39] Lisy Ratsifandrihamanana, personal interview, 23 November 2006.
[40] *Mme Mandroseza, personal interview, 17 November 2006.
[41] Razoharinoro Randriamboavonjy, "La Vie à Anatirova," La Cité des Mille: Antananarivo: Histoire, Architecture, Urbanisme (Antanarivo: Tsipika, 1998) 83.
Actual text reads «L'oralité est la charactéristique essentielle de la culture malgache…ainsi que la transmission de génération en génération de leur sagesse et de leur philosophie.» Trans. by student.
[42] Michelle Albert, "La Sagesse Malgache," ISP, School for International Training, 1993, 17.
[43] Aider Les Personnes Handicapées Là Où Elles Vivent : Guide pour les Maîtres d'Ecole (Geneva : Organisation Mondiale de la Santé, 1991), 3.
Actual text reads «La famille des personnes handicapées et les membres de la communauté ont tendance à penser que les personnes handicapées ne peuvent pas faire ce qu'ils font.» Trans. by student.
[44] *Mlle Behorika, personal interview, 15 November 2006.
[45] Formation des Agents de Rehabilitation à Base Communautaire: L'Epilepsie (Antananarivo : Les Orchidées Blanches, 2001), 14.
Actual text reads «L'hyperprotection…nourrit chez le malade un sentiment de dependence, un certain refuge dan le maladie.» Trans. by student.
[46] Lucie Razanatsimiova, personal interview, 23 November 2006.
[47] Théophile Rakotomanana, "Aspects Cliniaues et Etiologiaues des Retards Psychomoteurs des Enfants de Moins de 5 ans," diss., Univerisity of Antananarivo: Faculté de Médicine, 1999.

Actual text reads «une grande partie de retards psychomoteurs, 40% restent d'origine indéterminée, même après des investigations radiologiques, biologiques, et génétiques approfondis.» Trans. by student.
[48] Annie Raherimalala, personal interview, 14 November 2006.
[49] *fady* - tabou
famadihana – Malagasy ritual involving the celebration of the ancestors, and the rewrapping of dead bodies from the familiar tomb.
[50] Bernadin Rabarijaona, personal interview, 20 November 2006.
[51] *Mlle Ivandry, personal interview, 12 November 2006.
*Mme Lucien, personal interview, 16 November 2006.
[53] Bernadin Rabarijaona, personal interview, 20 November 2006.
[54] Formation des Agents de Rehabilitation à Base Communautaire: L'Epilepsie (Antananarivo : Les Orchidées Blanches, 2001), 10.
Actual text reads «...occasionnent souvent une baisse de l'efficience intellectuelle et parfois une arriération mentale plus our moins profonde.» Trans. by student.
[55] Lisy Ratsifandrihamanana, personal interview, 23 November 2006.
[56] *Mlle Behorika, personal interview, 15 November 2006.
[57] Edith Ramamonjisoa, personal interview, 16 November 2006.
[58] « Ataovy toy ny dian-tana: jereo ny aloha, todiho ny aoriana. »

[59] Lucie Razanatsimiova, personal interview, 23 November 2006.
[60] Dr. Rabeantoandro, personal interview, 22 November 2006.
[61, 62] Lisy Ratsifandrihamanana, personal interview, 23 November 2006.

[63] Unknown Author, "La Réussite d'une Insertion Professionnelle se Conjugue Avec un Ouverture sur la Vie Sociale et Culturelle," Cahiers du Promoteur et du Gesttionnaire N° 9 (Unknown), 22. Some elements unknown because a copied resource used by LOB.
Actual text reads «.Pour de meilleures chances de réussite, l'insertion passe par une démarche progressive. Pour acquérir une place stable…des étapes transitoires sont indispensables.» Trans. by student.
[64] Lisy Ratsifandrihamanana, "Le Handicap Mental," Les Orchidées Blanches, 14.
[65] Faralalao Andrianarivony, personal interview, 23 November 2006.

Resources

Aider Les Personnes Handicapées Là Où Elles Vivent : Guide pour les Maîtres d'Ecole. Geneva : Organisation Mondiale de la Santé, 1991.

Albert, Michelle. "La Sagesse Malgache," ISP, School for International Training, 1993.

*Mme Analakely. Personal interview. 18 November 2006.

Andrianarivony, Faralalao. Personal interview. 23 November 2006.

*M Analamahitsy. Personal interview. 10 November 2006.

*Mlle Anjahana. Personal interview. 18 November 2006.

*Mme Anketsa. Personal interview. 18 November 2006.

*M Antanimena. Personal interview. 18 November 2006.

*Mlle Behorika. Personal interview. 15 November 2006.

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Dr. Giacinta-Gobetti. Personal interview. 20 November 2006.

Etancelin, Gaëtan. Personal interview. 19 November 2006.

*Mlle Ivandry, personal interview, 12 November 2006.

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Lofland, John and Lofland, Lyn H. Analyzing Social Settings: A Guide to Qualitative Observation and Analysis. Davis: University of California, 1995.

*Mme Lucien, personal interview, 16 November 2006.

*M Mamory. personal interview. 21 November 2006.

*Mme Mandroseza. Personal interview. 17 November 2006.

*Mme Miraille, personal interview, 25 October 26.

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Raherimalala, Annie. Personal interview. 14 November 2006.

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Ratsifandrihamanana, Lisy. "Le Handicap Mental." Les Orchidées Blanches.

Ratsifandrihamanana, Lisy. Personal interview. 23 November 2006.

Ravelomanana, Dama. Personal interview. 11 November 2006.

Razafindrakero, Falihery. Personal interview. 9 November 2006.

Razanatsimiova, Lucie. Personal interview. 18 November 2006. 23 November 2006.

*Seheno, Personal interview. 11 November 2006.

Dr. Suzanne. Personal interview. 17 November 2006.

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Unknown Author, "La Réussite d'une Insertion Professionnelle se Conjugue Avec un Ouverture sur la Vie Sociale et Culturelle," Cahiers du Promoteur et du Gesttionnaire N° 9 Unknown.

Appendix A

Formal Structures

#	Date	Organization	Contact	Defining Characteristics	Quartier
1	10/8 – 11/23	Les Orchidées Blanches	Numerous	Medical and Educational Center for Children and Adults ; Workshop	Androhibe
2	11/9	COPH (Collectif des Organisations des Personnes Handicapées)	Mr. RAZAFINDRAKERO	Collection of Organizations for Handicapped Persons (Not just MH)	Ambohijatovo
3	11/14	IME Equilibre	Dr. RAHERIMALALA	Medical and Educational Center for Children (until age 30)	Ambaranjana
4	11/15	MPPSL (Minister de la Population de la Protection Sociale et des Loisirs)	Mr. JBONA	State Office Promoting the Legal Rights of Handicapped Persons	Ambohijatovo
5	11/16	Handicap International	Mrs. RAMAMONJISOA Mrs. RASOARIVELO	International Promotion of Rights of Handicapped; Current Promotion of School Integration	Ambohijatovo
6	11/17	TOBY (supported by SALFA)	Dr. RAFAKAMALALA	Religious Center for Mentally Ill that have also cared for Epileptics and other MH; Patients live at the Center	Ambohibao
7	11/19	Savonnerie Tropicale	Mr. ETANCELIN	Company where 4 MH people work	Ankorondrano
8	11/20	Tongarivo	Dr. Giacinta-Gobetti	Religious and Medical Center where care for MH; Patients Live at Center	Tanjombato
9	11/20	UNAHM (Union Nationale des Associations des Handicapés de MDG)	Mr. RADAFINIANTSOA	Worshop to Make Company Suits for All Handicapped (4 MH) ; supported by Association UNAHM	Behorika
10	11/22	Hôpital Befelatànana Centre de Pediatre	Dr. RANAIVOARISOA Dr. RABEANTOANDRO	Public Hospital that diagnoses children who are showing signs of MH	Befelatànana
11	11/22	Fanilon'I Madagasasikara	Mrs. RASOLOFONIDINA Mrs. RANAIVOSON	Girl Scouts Program with Branch for MH Children	Ampasamadinika
12	11/23	Akany Riana	Mrs.	Private School that Integrates MH Children	Ambohihakeley

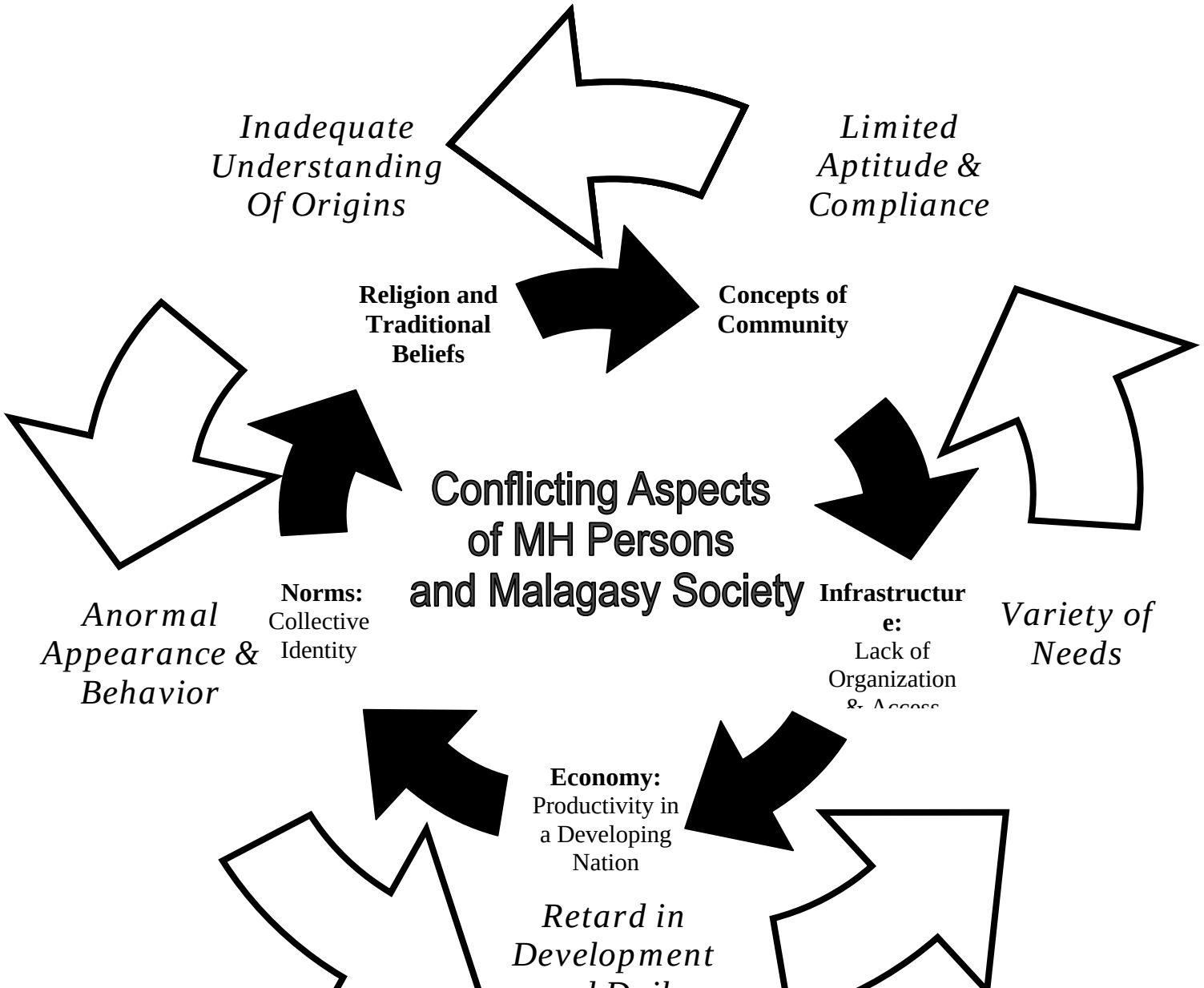
			RATSIFASOAMANANA	Into Préscolaire and Primaire level	

Appendix B

Home Visits

Date	#	Age	Specificities	Contact	Involvement in Infrastructure	Quartier
11/10 11/16	1	20	*Nicole - Mental Retardation, no schooling, seizures and aggression	Mother	None	Andoharanomaintso (village, not quartier)
11/11	2	50s	*Ando - Mental Retardation, went to school until mid Collège, now stays at home	Brother, Sister-in-Law, Mother-in-Law, Nephew	None	Ambanidia
11/15	3	9	*Tahina - Down Syndrome, went to private school until 5, special education	Mother, Sister	ACBHM	Unknown
11/17	4	26	*Michelle - Autistic, Anxiety and Aggression, special education	Mother, Sister, Brother	Les Orchidées Blanches	Ambanidia
11/18	5	30	*Franc - Down Syndrome, Anxiety, no schooling	Mother	None	Ambohibao
11/18	6	9	*Henri - Physical Handicaps, no schooling	Mother	RBC, Now None	Ankadindramamy
11/18	7	13	*Edith - IMC, Unapproachable, no schooling	Father, Mother	RBC, Now None	Ankadindramamy
11/18	8	3	*Naly - Psycho-Motor Retardation, special education	Mother, Sister	Les Orchidées Blanches	Anjanahary
11/21	9	7	*Marie - Psycho-Motor Retardation, special education	Mother	Les Orchidées Blanches	Ambohimanambola Tanjonandriana
11/23	10	28	*Mamy - special education, used to be incompliant and instable	Father	Les Orchidées Blanches	Ankorondrano

Appendix C


Inadequate Understanding Of Origins
Limited Aptitude & Compliance
Religion and Traditional Beliefs
Concepts of Community
Conflicting Aspects of MH Persons and Malagasy Society
Anormal Appearance & Behavior
Norms: Collective Identity
Infrastructure: Lack of Organization
Variety of Needs
Economy: Productivity in a Developing Nation
Retard in Development

Appendix D

Appendix E