‘Everything is for Him’: Mothers of Autistics as Agents of Social Change at Casa da Esperança

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Abstract

This research project explores mothers of children with autism as social actors. I conducted the research at Casa da Esperança, which is school and therapy intstituion, and social organization, for autistics in Fortaleza, Ceará, Brazil. A group of mothers founded Casa da Esperança based on a policy of inclusiveness towards autistics and their families. Casa da Esperança's structure reflects its collective and communal philosophy, as demonstrated by the family program. Many mothers of autistics participate in this program on a daily basis when they stay at Casa da Esperança while their children are in class. Casa da Esperança is a reaction and answer to social isolation, as both autistics and their mothers encounter social rejection. Going into this project, I wanted to investigate if and how Casa da Esperanca's philosophy and methodology was connected to the mothers' of autistics actions to create social change. From this I hoped to gain insight into the mode through which mothers actively worked to change society. I found that despite the social exclusion that the mothers' described, they still enter into the public sphere in order to fulfill their roles as mothers. In this sense, the mothers become individual actors on a social level in order to provide for their children's needs. These social actions take place through the collective context of Casa da Esperança. By empowering individual mothers to act in society, Casa da Esperança creates social change with mothers as the agents of this change.

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Location of Research

Casa da Esperança is located in Fortaleza, Ceará, Brazil. Ceará is part of the Northeast region of the country. Casa da Esperança's physical infrastructure is the neighborhood of Água Fria. It is in a predominately residential area off of a main highway. All of the components of the institution, including the school, the therapy, the professionals and staff, and the family program, are housed in this one location. Casa da Esperança was started in Fortaleza because where the founders live and raised their families. Though the institution was created in direct response to the treatment towards autistics by society and the public education system in Fortaleza, this mistreatment extends beyond the city's limits. Casa da Esperança moved to its current location in Água Fria seven years ago so it had enough space to serve and support its rapidly growing clientele.

Casa da Esperança looks like a long, extended, one story house. It appears very open with all of the corridors visible. There are lots of trees and grass on the property as well. The house itself is surrounded by a white wall. When a person first walks in, he or she walks down a small path to reach the reception area. The reception area is at the center of Casa da Esperança, and it is where people are always entering, exiting, and waiting. To the right of the reception area is where the classrooms and therapy areas for the autistics are located. There is also a pool that becomes visible on the path towards the classrooms. To the left of the reception area is where the administrative offices, the auditorium, the art room, and the open square are located. I stayed mostly in this general area, as it is where both the staff and the mothers that I was working with were. I spent almost all of my time in the art room, as it gave me easy access to the mothers and provided me with a participatory environment as well. There was a group of mothers that sat in the outside square area and talked, though I had limited interaction with them. These mothers did not participate in the art room or the parents' meetings. The art room was where I could most naturally build relationships, while conducting research. I mostly did embroidery with the mothers, which gave us something to share and was an activity that we could bond over.

Social Relevance

Mothers of autistics as social actors directly relates to this Culture, Development, and Social Justice program, and society at large. A group of mothers created Casa da Esperança in response to the social injustice their children with autism face. The wider cultural mistreatment of people with special needs can act as a broader context for understanding and studying Casa da Esperança. I specifically looked at the how the mothers understood and conceptualized the social injustice that they encountered. Working with a socially excluded population at a social organization allowed me to consider the individual and institutional response to this injustice. My research became a direct investigation of how social change is implemented by the individual actions of the mothers through the collective structure of Casa da Esperança.

Moreover, the mothers' experiences provide an emic perspective of the meaning of motherhood. Their description of their realities, as well as my observations of their behaviors, can help us better understand the cultural script of mothers in Northeast Brazil and how it pertains to mothers of autistic children. In this sense, my research sheds new light on the topic of autism. Autism is a hotly debated subject that has become a "buzz word" within the medical community. However, most of the research to date is based solely around autism as a medical condition; looking at what autism is, where it comes from, and how to treat it. Because autism is a disorder that directly links to social interaction, it is important to broaden the scope of research. By approaching the issue from a social standpoint, I was able to explore the social mistreatment of autistics and their mothers. In order to change society it is imperative to be aware of the current attitude and wrongdoings towards a specific population. Furthermore, it is equally important to see how the socially excluded are creating this change, as is the with the mothers at Casa da Esperança.

Personal and Professional Motivations

This research project gave me the opportunity to explore a variety of my interests through a single lens. I was able to consider the role of mothers, the treatment of those with special needs, and the work of social organizations, all within a cultural context that is different from my own. For many years I have worked with various community organizations in the United States that address the issue of gender, and others that work with people with special needs. These two populations are often subjugated by society, and I have always taken an interest in not only how they are treated but also how this treatment is confronted and overcome. My academic journey thus far reflects this broad-based curiosity in social attitudes and social action. As an Anthropology and International Affairs major, looking at cultural realities through the eyes of those living them has always been of the upmost importance to me. When I came to Brazil I realized how prevalent and visible many of these issues regarding women and motherhood, special needs, and social organizations are, but how infrequently they are addressed or discussed. Thus, not long after my arrival, I came to conclusion that I wanted to find a way to conduct research on something that combined all of these topics. Once I discovered that Casa da Esperança not only addresses but also incorporates in its mission and structure, all of these different issues, I knew it is where I needed to do my research.

Methodology

Because Casa da Esperança is an organized school and social institution, my time there was structured and consistent. As a result, it was easy to implement a schedule for myself. I went to Casa da Esperança four days a week for three weeks for approximately three and a half hours in the afternoon. I often took the bus with the mothers and the autistics to and from the site. There are two school sessions at Casa da Esperança each day, one in the morning and one if the afternoon. Most students went either in the morning or the afternoon, so there were also two different groups of parents that stayed at Casa da Esperança. With the exception of the first day, I only interacted with the group of mothers in the afternoon. I went into the project knowing that I needed to focus on one group of mothers in order to gain the most in-depth and comprehensive insight into their lives. I chose to work with the afternoon mothers because after the first day when I visited with both groups, I felt the most comfortable with the afternoon group.

While I was at Casa da Esperança, I spent a majority of my time with the mothers in the art room. Here the mothers embroidered, did patchwork, sewed, watched television, and read magazines. Though there were mothers in other areas, I found that in the art room I could participate, observe, and converse. Moreover, it was generally the same group of approximately fourteen mothers that stayed in the art room everyday. This consistency allowed me to build relationships with this core group of mothers. Also, because they were engaging in activities that I could partake in, my presence did not seem unnatural or disruptive.

My research consisted of observations, participant observations, and interviews. The observations came from sitting in the art room with the mothers and making note of what was going on. I listened to the mothers' conversations to try to get a sense of how they connected with one another. I was also constantly looking and/or walking around the art room watching what the mothers were doing. The bulk of my observations came from participating. Participating usually meant doing some sort of embroidery. I often would embroider as I observed everything that was taking place around me. By doing art with the mothers, we were able to share an activity, which frequently opened the door to conversations. I also participated in the group meetings every Thursday. Though I never spoke, I was part of the discussion circle. All of my informal interviews came in the form of casual conversations. On many occasions when I sitting next to a mother and we were both embroidering, I would ask her questions about her art, her children, her life, and/or Casa da Esperança. Most of these conversations were short and without much personal detail, as many of the mothers were not comfortable talking about themselves in such a public area. Thus, I gained the most in-depth, personal information from formal interviews.

Most of the formal interviews were conducted in a private office closed off from the public. Four out of the six women that I interviewed, approached me and expressed their interest in being interviewed. These mothers (with the exception of the first interview) were those that I had built the best relationships with and felt the most comfortable with. These two elements were critical to the openness and success of the interviews. I had a list of questions that I wanted to ask all of the mothers, though often only some of these questions were ever directly addressed, yet most of the general topics were almost always covered. I would often ask follow-up questions in response to what they mothers were telling me. So while the interviews resembled somewhat structured question and answer sessions, they were also conversations. All of the mothers (even those that were not formally interviewed) consented to being tape recorded. I used the tape recorder and took notes during the formal interviews. Each night I listened to the recorded interviews and transcribed them. All of the mothers signed a consent form that said that their names would be changed in the final project, thus the mothers have all been given aliases.

In the field my notebook was divided up into events, observations, and interviews, and I took short-hand notes in each of these sections. At night I expanded my notes and wrote down the details. The next morning, when I had access to a computer, I typed-up my field notes and interviews from the day before.

When I was in the field, I listened to and spoke Portuguese. I only conversed in English with my advisor, Alesandre Costa, and the mothers' art teacher, Selma. Aside from this, all of the exchanges I participated in and witnessed took place in Portuguese. Prior to this project, I had six weeks of formal Portuguese language instruction. My other form of training came from living in Brazil for two and a half months before my research began. My grasp of the Portuguese language allowed me to participate with and understand the mothers to a large extent, though the language barrier sometimes inhibited my full comprehension of situations. This was particularly true when I was listening to a group of the women talk with one another; they would usually speak very quickly and use words I did not understand. During my interviews, I usually understood the general ideas of what the mothers were saying, though I had difficulty understanding the details. I often had to listen to parts of conversations many times in order to translate and transcribe what was said. There were also many instances when one of my professors, Valeria, helped me translate the interviews based on the rape recordings. As a result, while I tried to directly transcribe what the mothers told me and capture their voices in full detail, what was written was ultimately my own interpretation (as well as Valeria's interpretation) of what was said based on my intermediate Portuguese skills.

Introduction

Autism is a developmental disorder characterized by a broad range of types, manifestations, and potential causes. While there is currently a great deal of medical research being done on the disorder, many aspects remain unknown. Autism is a "spectrum disorder" that cimprises: autistic disorder, Asperger's syndrome, Rett's syndrome, and childhood disintegrative disorder. All types of autism influence a person's social communication skills ("About Autism"). Because autism is a spectrum disorder, it can affect a person in a myriad of ways and range from mild to severe. Some of the most common behaviors associated with autism include: lack of or delay in spoken language, repetitive use of language and/or motor mannerisms, little or no eye contact, lack of interest in peer relationships, lack of spontaneous or make-believe play, and persistent fixation on parts of objects ("About Autism"). The causes of autism remain unclear and highly controversial. Many professional and non-professionals alike debate whether autism is genetic, environmental, or somewhere in between. In some cases children are born with autism, and in other instances it develops when children are toddlers. In my research, some of the mothers connected autism with genetics, others to accidents, and many were unsure where it came from (ISP Field Journal 26, 69). What *is* clear, is that investigations into autism must continue. This is essential in order to gain a better understanding of not only the disorder itself, but also those most closely affected by it. In my research, I considered the social realities of mothers with autistic children. Considering autism directly impacts social interactions, it is important to study how it functions on a social level.

In order to examine autism through a social lens, I focused on mothers' of autistics relationship with society. When I began my preliminary research on this topic, I was surprised by how little information I could find on the meaning of motherhood in Northeast Brazil. I had assumed that because the family unit makes up such a large component of the culture, that there would be a wealth of published knowledge at my disposal. However, this was not the case. I then realized how difficult it is to capture the meaning of motherhood in the context of Northeast Brazil. From my observations during my time in Brazil, the role of mothers is evident in every aspect of the culture, thus making it hard to separate her from the underlying culture. It also occurred to me that the fact that there has been so little research on mothers implies the extent to which they have been silenced. This truth is hard to come to terms with considering the extensive role mothers play in Northeast Brazil in caring for future generations. Through my discussions with Sonia and the mothers at Casa da Esperança (referred to as "the mothers"), I began to understand how they conceived of the role of the mother. Sonia and all of the mothers emphasized that mothers are the primary caregivers for their children, no matter the situation or circumstances (ISP Field Journal 9, 40, 61). Even if fathers are present and involved, the mothers remain "closer" to their children (ISP Field Journal 54). Society expects mothers' primary job and priority to be taking care of the children. Even though the mothers that I spoke with willingly provided for their children, they were aware of this social expectation (ISP Field Journal 19, 77). In Paula's case, we see the failure of a mother. Paula acts as a mother to her grandson because his real mother abandoned him, which she believes does not make her "real mother," because a real mother loves her children unconditionally and would never abandon them. Paula now assumes the role of mother, and calls herself “mother-grandmother.” (ISP Field Journal 43) From my experience at Casa da Esperança, mothers must place her children above every other aspect of her life in order to fulfill the role that society has set for her.

This expectation of care and commitment is even more drastic for mothers of children with autism. Sonia showed me a study that was conducted at Casa da Esperança to evaluate the parents’ acceptance of autism and the care they provided to their children. Most mothers in both the lower and middle classes accept the diagnosis of autism and like caring for their children. In the lower class, twenty-seven percent of mothers believe that there is no alternative to caring for their children, while thirteen percent of mothers in the middle class think this. In comparison, twenty-two percent of fathers in the lower class and ten percent of fathers in the middle class do not accept the diagnosis and do not care for their children (ISP Field Journal 64). The fact that mothers do not have the option of not caring for their children demonstrates how the stark differences in expectations for mothers and fathers further manifest themselves when parents have autistic children. The mothers at Casa da Esperança consider their roles as mothers of autistics to be distinct from the roles of mothers without children with autism. The mothers of autistics spoke of the increased protection, dedication, and care that their children require (ISP Field Journal 26, 42, 54-55). Lorena used the saying “what the eyes can’t see the heart doesn’t feel” when describing the constant need to be watching over and worrying about her daughter (ISP Field Journal 69). The lives of the mothers of autistics are overtaken by the lives of their children. Gabriela explains how she never imagined her life would have taken the route it did; everything she does now is for her son (ISP Field Journal 77-78). Many of the mothers gave up dreams of professional lives in order to care for their children with special needs. Erica wanted to be a doctor and Lorena wanted to be a teacher, but neither of these women was able to accomplish these goals because of their duties and responsibilities as mothers (ISP Field Journal 25, 68). Mothers of children with autism alter their lives in order to care for their children. As a result, a large portion of their identities is connected to their children.

Casa da Esperança ("the Casa") is an educational and therapeutic institution for people with autism, as well as a social organization working towards social change. Fifteen years ago a group of nine mothers founded the Casa after their children were forced to leave a different school for autistics because they were too old. The Casa became a school where autistics of all ages could attend. The motto of Casa da Esperança is "Education, Therapy, and Life." Professionals work directly with the autistics to tend to all three of these components. These professionals include: educators, speech therapists, physical therapists, psychologists, occupational therapists, psychiatric doctors, and neurologists. The Casa is run by some of the mothers that founded it. The president, Fatima, conceptualized the idea of Casa da Esperança and established the original group of mothers. The Casa consists of four programs for autistics: one for young children to address early stimulation, one for school-aged children to provide academic skills, one for teenagers to assist with self-care and challenging behavior, and one for young adults to aid in professionalization (ISP Field Journal 28-29). Most of the students attend the Casa Monday through Friday for four hours a day, either during the morning or the afternoon. In addition to the school and therapy for the autistics, there is a program to address works with the parents of the autistics. Casa da Esperança believes that the family is critical to autistic's quality of life, and that the involvement of the families in the institution sets it apart from other institutions (ISP Field Journal 62). Many of the mothers and a couple fathers remain at the Casa while their children are in class. They stay in the art room, the open square area, or the reception area. The official family program consists of courses, meetings, lectures, fieldtrips, movie events, and a cooperative (which is called “Casa Encantada”) (ISP Field Journal 63). Though families have always been involved in the Casa, the formal program began ten years ago. Sonia, one of the founders of Casa da Esperança, is the director of the family program. The program is also run by Quenia, the assistant director of the family program. Both Sonia and Quenia ensure that the family program functions on a day-to-day, while also meeting its broader aims. Selma is an art teacher that comes to the Casa every Monday and Tuesday to teache the mother new skills and to introduce new projects. During my time at Casa da Esperança, I also worked closely with Alesandre Costa, a psychologist, psychotherapist, and the technical director. Sonia, Quenia, and Alesandre Costa’s commitment to their jobs working with the families, demonstrates the emphasis and importance the Casa places on not only including the families, but making them part of the institution’s operations and structure. Through Casa da Esperança the lives and realities of mothers of autistic children are able to be seen, heard, and experienced.

Analysis of Findings

Erica does not sleep through the night because she frequently gets-up and checks on her son to make sure he is still sleeping.

Claudia remains married to her husband though she does not have his help or support in caring for their 2 year-old son.

Gabriela moved 8 hours away from her mother and family, and now lives alone because there was not a school or proper medical care in the area they came from.

Lorena must live with the guilt of watching her daughter get in the head and knowing now that she can no longer speak.

Cynthia was 18 years-old when her autistic son was born and she was forced to give up any dream she had of a professional life.

Paula is now financially dependent on her children because she lost her job and her income when she assumed responsibility for her grandson.

These are just a few snapshots of some of the daily realities of mothers of children with autism.

Every mother that I spoke with at Casa da Esperança, explained society as having prejudice towards autistic people. In fact, they each used the word “prejudice” when describing society. It is because of this prejudice that families, and mothers in particular, often keep their children inside the home (ISP Field Journal 66). Cynthia notes how society has certain models for normalcy and because those with autism do not meet this standard they are rejected (ISP Field Journal 53). Autistics are outcaste and labeled as “disabled” and “different.” This discrimination takes place in most public spaces. I rode the bus with the autistics and their mothers almost everyday, and everyday I noted how the faces around me displayed signs of frustration and annoyance as the autistics behaved differently than what is thought to be “normal” behavior (ISP Field Journal 10). The rejection and exclusion of autistics transcends the social realm into public institutions. Nowhere is this more evident than with the public schools.

Casa da Esperança can be an alternative to or be in conjunction with the public schools. Some of the students go to public school for part of the day and go to the Casa for the other part of the day, while others only go to the Casa. Regardless of the situation both the professionals and the mothers at Casa da Esperança discussed the difficulties and challenges of sending autistics to public schools. Alesandre Costa explained how the public schools often fail to provide autistics with a proper education (ISP Field Journal 29). Both he and Sonia noted the lack of structure and preparedness of the public school in working with autistics, and their ongoing dependence on the Casa. The Casa tries to send classroom aids to assist the schools, however, financial resources are not usually available to maintain this for a long period of time (ISP Field Journal 29). While the schools are unable to structurally and institutionally provide for autistic children, the teachers and other children further perpetuate this exclusion. Erica explained that while the schools themselves do not accept her son, neither will the teachers or the other children (ISP Journal 7). In both the classroom and the playground autistics are ostracized and harassed for their differences. This discrimination within the public school system denies autistic children access to the education that rest of society is granted.

Through this structural and social exclusion, autistics are cutoff from society. "Normal" people on the other hand, are given full access to society and its resources, and as a result they can act as individuals and carry-out individual identities within a social context. In this sense, they are free to make choices within society. Autistics, however, are denied what others are inherently given, and thus they are striped of their human agency. This lack of agency restricts an autistic's any individual choice, and inhibits his or her personhood. Autistics are rejected by society because they are not considered full individuals.

Because mothers, and particularly the mothers of autistics, always accompany their children, they too are rejected from society. The mothers also receive demeaning, disparaging looks on the bus, just as they are denied the right to their child's education. In her dissertation, Ruth Rachel Nyland explains that the mothers bear witness to the discriminations that their children with disabilities face. Because of their sense of responsibility, mothers also feel "marginalized."(Nyland 2) Mothers go where their children go, and in the case of autistics, it is to a lower status in society. Cynthia and Erica both commented that children with autism *and* their mothers are discriminated against and rejected by society (ISP Field Journal 26, 52). This demonstrates that while autistics may not always understand their social exclusion, it is clear and notable to the mothers. As a result, mothers feel limited in their abilities to act in society.

None of the mothers that I spoke with conceptualize themselves as possible agents of broad-based social change. Rather, they only see how their actions can change their most immediate and closest realities, not society at large. They said that they worked to put food on the table, to provide their child with an education, and to pay for medical bills, but they were not working to change society. In fact, most of them feel left out from society all together (ISP Field Journal 26, 54). They view society as rigid and exclusive (ISP Field Journal 19, 54). Without social space they cannot act in society, only on its outskirts. However, they must care for their children despite their lowered position in society. The mothers recognize agents of change as people and things other than themselves. When asked how can society's attitudes change, the mothers responded with mechanisms such as: television, newspapers, education, teachers, therapists, and doctors. (ISP Field Journal 20, 42) Never once, however, did they mention mothers. The mothers' understanding of being both unable to act in and rejected from society, illustrates how their identity as individuals is also compromised. Thus, both autistics and the mothers of autistics are disempowered as people and as members of society.

Casa da Esperança was created so the mothers and the autistics could regain this power. A group of nine mothers founded the Casa in response to the social exclusion. Sonia, one of the founding mothers, explained that the founding mothers imagined a place where their children could be tended to and would not be forced to leave (ISP Field Journal 61-62). The Casa's philosophy defined it as a place of inclusion for any autistic person and his or her family, without any exceptions. Both Alesandre Costa and Sonia's emphasis on the importance of this philosophy demonstrates its centrality in the Casa's day-to-day activities. Because the Casa arose from rejection autistics encounter in society, public schools, and other institutions, it provides an alternative (ISP Field Journal 61-62). It is not only an alternative to education, but also an alternative to dismemberment and exclusion. The Casa gives autistics and their families a place to belong, and in doing so improves their quality of life (ISP Field Journal 29-32).

Due to the social rejection experienced by both the mothers and their autistic children, the founding mothers of Casa da Esperança created an all-inclusive environment for their children. The mothers united to form their own community. As individuals the mothers were excluded and powerless, but as a group they created new possibilities and a better future. Moreover, they did so on their own terms. This emphasis on the collective became Casa da Esperança's guiding principle and framework.

The structure and programs at Casa da Esperança exemplify this communitarian, holistic approach. In talking about this approach, Alesandre Costa noted that Casa da Esperança is different from other institutions because they "open many doors" to the families and the autistics. While he was speaking in a figurative sense, this unwavering attitude of inclusion and community is expressed literally with all of the Casa's doors remaining open. I frequently observed that the doors to all of the rooms were open, so staff, students, parents, and autistics alike, were free to move in and out of them. Even when the mothers' meetings and discussions were interrupted by an autistic that had to be escorted out, the door remained open (ISP Field Journal 14, 47, 73). Additionally, the doors to the staff and administrative offices were always left open as well (ISP Field Journal 6). Inclusion is also evident by the importance the Casa places on doing things together; it utilizes teams in all of its programs and approaches. Every education program at the Casa is run by a team comprised of teachers, speech therapists, physical therapists, psychologists, occupational therapists, psychiatric doctors, and neurological doctors. Moreover, the education itself teaches the students to work within a team setting. Students are put into teams that make use of their skills. Alesandre Costa emphasizes that while they may not have the skills necessary to hold down a job, the students are capable and productive team members (ISP Field Journal, 29). When autistics start coming to the Casa and partaking in their programs, "…they start to feel the sense of belonging to a group, belonging to a relationship." (ISP Field Journal 32) This group-centered programmatic approach that lends itself to a sense of belonging epitomizes Casa da Esperança's philosophy of inclusion.

This approach of collective and joint action is further evident in the education model that Casa da Esperança employs, the SCERTS Model. The SCERTS Model helps autistics in social communication and relationship building ("The SCERTS Model"). It uses the "family-professional partnerships" as its basis in working with autistics ("The SCERTS Model"). From this it is clear why the SCERTS Model is the chosen educational method at an institution where families and the community are the foundation; it was its similar philosophy and methodology that led Casa da Esperança to the SCERTS Model. Alesandre Costa explained that, "it's a transactional relationship, that's why the transactional support of the SCERTS model, it's because it's a two-way view, a two-way relationship, I teach them [the families] they teach me, and then we are collectively building knowledge about their kids." (ISP Field Journal 33) Both the SCERTS Model and Casa da Esperança work to connect autistics with their families, communities, and ultimately society at large. Inherently, families play an integral role in this collective ideology.

Just as families constructed Casa da Esperança fifteen years ago, they continue to be a central component to the Casa's current structure. Both the families and the staff (many of whom are parents of autistics) understand that this involvement and emphasis on the families sets Casa da Esperança apart from other similar institutions. The Casa recognizes the importance of families accepting their children. Sonia, who is also the director of the family program, said that the Casa helps families accept their children for who they are, in hopes of creating better lives for the autistics and the families (ISP Field Journal 62). From what the mothers told me and from what I observed, the Casa has been successful in this objective. While the mothers recognize the difficulty and challenges of raising a child with autism, they all accept their children for who they are. During a group meeting, one of the mothers declared that while she hopes some of her daughter's behaviors will change, like the aggressiveness, she would never want a normal child in exchange because that is not her daughter and she loves her daughter for who she is (ISP Field Journal 73). While Casa da Esperança works with families in order to give the autistics more possibilities, it also creates a sense of collectivity amongst the families, and the mothers specifically.

The mothers do not just contribute to Casa da Esperança, but they also become part of the organization. As described earlier, mothers of autistics also face social exclusion. The family program is designed to include these rejected mothers into the Casa's structure. When I asked Sonia when this program for the families began, she responded that it has always been in place because the Casa is based on and was built by families (ISP Field Journal 62). The family program started as an informal meeting place for parents to discuss their challenges and share their experiences, and it has evolved into a formal program with key components that utilize the group setting. The program now includes: a business corporative, an art space, group meetings, a parents course, lectures, films, and fieldtrips. Many of the mothers and some fathers take part in this program everyday when they stay at the Casa while their children are in class. They congregate in the art office, outside square area, and the reception area. In this sense, mothers are given literal space at the Casa.

Both the foundation and structure of Casa da Esperança embody the idea of "parents helping parents," and often mothers helping mothers (ISP Field Journal 33). Many of the administrators and therapists at the Casa are not just professionals, but also mothers and fathers of autistics as well. They draw on this connection to make Casa da Esperança not jut an educational and medical institution, but also a community (ISP Field Journal 62, 67). While some of the mothers see the Casa as a community and others do not, all of the mothers recognized this familial involvement as a unique and positive element of the Casa (ISP Field Journal 53, 75). The sense of belonging to the Casa extends beyond the autistics to the mothers. The family program provides an environment where the mothers can express themselves through both formal components (the course, the lectures, the group meetings, the fieldtrips, the movie events, and the cooperative) and informal discussions and activities. In this sense, the collective structure at Casa da Esperança, is gives voice and power to the individual participants.

Casa da Esperança's collectivity acts as a framework for individual actions and identities to unfold. By being included at Casa da Esperança as equal individuals with agency, autistics and mothers of autistics are able to reclaim their space in society. Through its collective approach, the Casa validates each individual as fully human. The Casa believes that autism cannot be separated from a person because it is inherent to their personhood, so an autistic must be socially recognized as a full and equal individual (ISP Field Journal 31). By recognizing autistics as full people, Casa da Esperança refutes society's claim that they are lesser individuals. The Casa actively works to include and integrate autistics into the public sector (ISP Field Journal 31-32). Much of this work can only be done by the mothers, as it requires the mothers stepping-out into society with their children. In order to do this, the mothers also must be engaging and participating in society. In this sense, the mothers must individually act in order to provide for their children.

I observed the numerous ways in which the mothers at Casa da Esperança asserted identities as individuals to accomplish this task. Kevin Neuhouser claims that it is a mother's commitment to her identity as a mother that drives her to act (Neuhouser, 333). In other words, it is her identity as a mother that prompts her to individually insert herself into society. The mothers at Casa da Esperança will go to any length necessary in order to care for their children, and it is in this context that they perceive their motives for acting. Cynthia explains how everything she does is for her son, it is her job to take care of him (ISP Field Journal 54) So while Neuhouser may be correct in his analysis of the motives behind the mothers' actions, he does not acknowledge the complexities behind the identity of motherhood. He recognizes that "individuals have multiple identities.." (Neuhouser 336), but does not consider the identities behind motherhood. Through my experience at Casa da Esperança, I have come to understand an individual mother and the identity of motherhood as composites of other active identities that she takes on. The mothers at Casa da Esperança act as educators, medical providers, and business women, in order to best care for their children. Essential to this action is the mothers' empowerment as individuals. Selma made this clear when she addressed the group of mothers and emphasized the individual choices that they made to stay at the Casa and what that choice means (ISP Field Journal 21). The mothers must act as individuals in order to meet the needs of their children.

The mothers' of autistic children individual identities unfold in numerous ways and forms. Many mothers become educators by going into public spaces with their children. All of the mothers that I interviewed talked about the specific ways that society can be educated in order in order to overcome the prejudices that exist. Erica belives that parents need to educate their children, Claudia thinking that people need more information, Paula said that more socialization needs to take place, and Cynthia reported that there needs more consciousness and knowledge of autistic people (ISP Field Journal 25, 20, 42, 54). While all of these mothers acknowledged what needs to happen to bring about change, none of them saw themselves as active participants in delivering these changes. When I asked Cynthia if mothers could create these social changes, she responded that it is not really possible because society is too "rigid," so the mothers cannot act (ISP Field Journal 54). However, the mothers *are* acting; Erica *does* educate her children about differences, Claudia *does* bring more information forward by going out with her son, Paula *does* socialize her child by taking him out into society, and Cynthia *does* circulate more knowledge of autism by living with her child outside of the home. All of the mothers that I spoke with are actively engaged in educating society about autistics by bringing their children into society and forcing society to confront its own preconceptions. They all go to public places with their children, whether it is on the bus, to the shopping malls, or to the parks, despite the difficulties and prejudices that they encounter. Through the mothers' engagements in these social endeavors with their children, society sees that these people exist so they must recognize them. It is through these public channels that knowledge and information is dispersed and begins to circulate. Gabriela explained that when she leaves home with her child he drools, screams, and cries in public, but she acknowledged that despite these obstacles she leaves the house anyways (ISP Field Journal 77-78). All of the mothers constantly take actions to provide their children with lives as socially integrated individuals. Erica asked me many questions about the United States' policies towards autistics, the special education, and the social attitude (ISP Field Journal 7-8). She saw it as her job to investigate into other places and situations of autism in order to know of the possibilities for her own child's social environment. Neuhouser points out that this individual action as a mother climaxes when there is a lack of resources (Neuhouser 332-333). Most of the mothers at Casa da Esperança lack the resources to own a car, pay for babysitters, or stay at home, so they are forced to go into society with their children, and they must act and ascertain resources within the public sphere (ISP Field Journal 66). The individual actions that the mothers take within society make them active participants in the process of social change.

Mothers of children with autism must also provide for their medical care to their, which requires entering the public health system. The mothers come into contact with society through the medicine as well. Sonia discussed the difficulties the mothers encounter trying to find doctors, not being able to make appointments, and having to wait for extended periods of time (ISP Field Journal 66). The doctors themselves are often not able to provide the necessary care to the autistic children. Claudia talked about the doctors not knowing what was wrong with her son or how to help him when he was born (ISP Field Journal 18). Cynthia reiterated the point that doctors are generally unaware of and unfamiliar with autism (ISP Field Journal 52). Despite these medical upheavals, the mothers enter into the public realm through the public health system and fight for the proper care. Lorena spoke of waiting in long lines at the hospital and talking to many different professionals before finding one that could properly assist her (ISP Field Journal 68). Gabriela moved with her son eight hours away from her family and life in the interior because of lack of medical care, schools, and therapy (ISP Field Journal 11, 75). These mothers take any necessary action to ensure that their children receive medical attention, both from medical professionals and themselves. The mothers must often deliver the medical care. I witnessed one mother putting hearing aids into her son's ears (ISP Field Journal 72). Despite fighting for and providing this care to their autistic children, many of the mothers maintain that they have limited knowledge of autism. In an informal interview and a formal interview, Gabriela told me that she does not know very much about autism (ISP Field Journal 11, 78). However, she and the other mothers must be constantly ensuring that their children's medical needs are met, as they live with autism as their daily realities. By demanding medical care for their autistic children and being actively engaged in the public health system, the mothers claim space in the medical world and society at large.

The mothers at Casa da Esperança also participate in the public sector of the economy. They established a cooperative called, "Casa Encantada," which sells embroidered, patchworked, and painted merchandise that is made by the mothers in the art office at Casa da Esperança. Some of the mothers founded and run the cooperative, while others only produce the goods to be sold that are sold the cooperative. In this sense, the mothers are individual economic actors that sell, create, and work for a shared business endeavor. Cynthia described the cooperative as people working for the same objective (ISP Field Journal 54). The mothers' personal and individualistic motives led them to engage in this economic activity. The mothers all said that they make and sell the art in order to provide financial help to their families (ISP Field Journal 25, 41, 53, 69). The mothers cannot have jobs because they must stay at the Casa while their children are in class because they live far away and it is too expensive to return. Thus, the money that they make through Casa Encantada serves as their income and constructs their identity as economic providers for their families. These economic transactions take place within a public context. The mothers that designed and organized the cooperative attended a course at the Federal University of Ceará (a public university) so that the business could be officially recognized. In this way, the cooperative was started and implemented through the public system, and it continues to operate on a public level. Gabriela described how the government gives the cooperative money because this business is the mothers' job, thus making it part of the public sector (ISP Field Journal 11). The cooperative also functions in society's formal market. The mothers go to fairs around the city of Fortaleza to sell the cooperative's merchandise to the public. When I asked many of the mothers why they sell their products, they all acknowledged that it helps them personally, within the home, but they did not perceive their actions as participating in society or having a broader scale affect.

As educators, medical caregivers, and economic providers, the mothers execute individual identities to act within society. In this way, these individual actions are social actions that create social change. According to Sonia, “Every time the mothers participate in society and the community they change it, because the public sees that these people exist.” (ISP Field Journal 65) Even though they listed different means through which society could become aware of autistics and autism, the mothers all described this awareness through some form of education (ISP Field Journal 25, 20, 42, 54). To accomplish this increased public awareness and knowledge of autism, Sonia emphasizes that the mothers must “experience,” so that society learns to live with autistics (ISP Field Journal 66). Gabriela, Paula, and Cynthia said that they and/or their families did not know about autism before their children were diagnosed (ISP Field Journal 40, 51-52, 75). Sonia describes this as a general truism in Northeast, Brazil; people do not know what autism is or that autistic people exist, so they do not understand the behavior of autistics As the mothers step into the public realm with their children, society is forced to not only see that autism exists, but that it must also recognize and deal with those that are different and behave differently (ISP Field Journal 65-66). When talking about society’s prejudice and discriminatory attitude towards autistics, Cynthia underscored how the mothers see a different side of society (ISP Field Journal 53). Yet, by witnessing and interacting with this negative side of society, the mothers of autistics are given a window through which to change it.

The mothers *are* social actors that change society at large by going to public places with their children, entering the medical world, and participating in the formal economy. Even if the change is not self-evident at the time, the actions necessary to realize the change are evident. Everyday during the research period I took the city bus with the mothers and their children. The mothers allowed their children to scream, cry, and touch things, while they ignored the looks and reactions of everyone around them (ISP Field Journal 9-10). For the mothers, there children's behavior *is* normal, and thus it can and should take place in public where society can see and accept it. By entering the public health system with their children and demanding care, the mothers force the medical world to take notice, while developing the field's understanding of autism. Moreover, every time someone buys a product from the cooperative there is an business card about Casa Encantada attached. Each buyer learns about Casa Encantada through these cards, which disperse information to the public and prompt a cycle of knowledge. In a similar sense, Paula describes how every piece of art they create tells their life stories, and when these stories are sold, they are communicated and displayed for all of society to see (ISP Field Journal 41). In essence, it is the social ramifications of the mere presence of these mothers and their children within the public sphere that enacts social change. Their presence is a social change in and of itself.

Casa da Esperança provides the literal space for the mothers to assert figurative space in society. It is this space in society that not only creates the change, but also *is* the change. Thus, the individual mother's are given a voice through the collective support and structure that is Casa da Esperança. In his book Women and Social Movements in Latin America: Power from Below, Stephen Lynn writes that individual identities, rather than a common identity such as motherhood, need to be considered as the primary motivating factors behind the formation of the collective in collective action (Lynn, 273). At Casa da Esperança, while individual identities do form the collective, this collective shares the need to care for their children as their motivation to act. Casa da Esperança's main goal with the mothers is to work with them to create openings in society and fight for the necessities, for them to take the initiative to talk with the teachers at the public schools and do things in society (ISP Field Journal 67). In this sense, the Casa provides the foundation for the mothers to be individual actors so they can change society. Sonia noted how the Casa encourages the mothers to push beyond the barriers and the fear that make them want to stay at home with their children, and start living in the outside world (Sonia interview). Thus, the mothers are empowered to act through both the Casa da Esperança's formal and informal forums.

Through the different components of the formal family program, like the lectures, classes, meetings, trips, and cooperative, the mothers have the structural and emotional support to act in society. Sonia emphasizes that the value of the community and the parents' group is in their exchange of stories and experiences that give the mothers the courage to confront society (ISP Field Journal 66). In this sense, it is through both the Casa and through each other that the mothers gain the tools and confidence to enter into the public realm. Casa da Esperança works to provide the mothers with the necessary resources and knowledge to take action. For instance, a lecturer that came and talked to the mothers at Casa da Esperança about overcoming society's preconceptions and prejudices by taking their children to public places so that society is forced to live with and learn from them (ISP Field Journal 66). Every Thursday the mothers take part in a formal meeting led by Sonia or Quenia to discuss autism, their children, and their experiences. In all three of the group meetings that I witnessed and participated in, the women talked openly in a communal format about their triumphs and struggles (ISP Field

Journal 13-14, 46-47, 73-74). They also used the group meeting as a time to pose questions to both the staff and to each other. In one meeting Sandra needed medical advice and Erica gave her the name of a doctor, during Son'as class she shared stories about her own daughter for every point that she made, and in another instance some of the mothers described to one of the new moms the range of differences in autism spectrum disorder (ISP Field Journal 46-47, 73). The Casa also plans fieldtrips, movie nights, and parties for the mothers so that they feel like they have a place to belong and a support system (ISP Field Journal 14, 63).

In a monetary sense as well, the mothers are economic actors within the context of the cooperative's single, unified whole. The cooperative was started as a result of the problems and difficulties the mothers had selling their products as individuals with no structure behind them (ISP Field Journal 63). The cooperative is a communal and collective entity that acts a mechanism through which the mothers can produce, sell, and profit from their goods. The business decisions are made within a group context through which each individual can contribute. This was evident when Selma introduced the mothers to the idea of buying new materials and learning to make new bags to sell. Selma said that it was an ongoing negotiation, as many of the mothers discussed and debated what they should do (ISP Field Journal 49). Quenia also highlighted the importance of all the mothers attending the planning meeting for the cooperative for 2009 because they all had input and the decisions would affect all of them (ISP Field Journal 60). In conjunction with this communal decision making and communal structure, the cooperative's production of goods occurs within a collective format as well. Many mothers collaborate on the products they produce. I watched three mothers work at one table constructing Santa Clause ornaments together, while Paula and Erica made bulb ornaments together (ISP Field Journal 38). The formal programmatic scheme for the mothers at Casa da Esperança emphasizes the collective in order empower the mothers as individuals.

The mothers must support one another because they are the only ones that understand each others experiences. The physical space that Casa da Esperança gives the mothers to converse, engage, and share further empowers them to act. Sonia explained that even though the mothers live far away, that when they are at the Casa they live like a community and share because they have that life in common (ISP Field Journal 64). It is through this commonality that they can talk about their lives and sympathize with one another. On many occasions I listened as casual conversations between the mothers became about their children; they talked about everything from what their children eat, to what their children like and dislike, to the medical needs of their children, to when their children put bugs up their noses (ISP Field Journal 14, 38) I also witnessed the sympathy they exchanged with one another (ISP Field Journal 14). The mothers recognize that the Casa gives them place to share with and learn from one another. Erica said that she liked the mothers' group because when they discuss their experiences they are able to learn (ISP Field Journal 24). Lorena described the group of mothers as her "second family." (ISP Field Journal 69) Through both the formal programs and the informal exchanges that take place, the individual mothers are enabled to act in society through the structure of Casa da Epserança. Casa da Esperança can be characterized as a transformative space in which the worlds of individual, social, and collective action collide to produce social change.

Conclusion

Mothers of autistics report that both they along with their children are rejected by society. Due to their lack of space in society, the mothers do not see themselves as capable of bringing about social change. However, they take action in a variety of social environments in order to fulfill their roles as mothers. The mothers understand their participation in society in general, the medical field, and the economy as being necessary to provide the proper care to their children. By acting in society and bringing their children with them, the mothers are inherently changing society. Every time they engage in this social action, the mothers educate the public on autistics and autism. This increased awareness and preconceptions will change society's preconceptions and prejudices that currently result in social exclusion. Yet, it is only through the collective body of Casa da Esperança that the mothers are empowered to act on a social level. Casa da Esperança gives the mothers a support structure to work through. It is evident that Casa da Esperança is a transformative place where mothers of autistics become social actors and the socially rejected become capable of making social change. Through this inside out approach, Casa da Esperança as a social organization takes an innovative approach to the implementation of social change.

Casa da Esperança provides the mothers with the necessary structure and platform to act on a social level. In doing this, the organization creates internal power that will then deliver social change. In essence, the mothers "work" for the institution by carrying out its mission as a social organization aiming to enact social change. The system in place is a self-sustaining process of social change and empowerment; Casa da Esperança empowers mothers as individual actors within society, and by becoming agents of social change the mothers give back to Casa da Esperança. Through this it is evident how individual and collective action can not only work with one another to create social change, but can also reinforce one another.

Future research should focus on if and how this social change is actually occurring. Due to the limited time period, I was only able to focus on what is happening inside Casa da Esperança. At this point, my ideas concerning this social change exist as academic foresight as a result of what the mothers and the professionals at Casa da Esperança have shared with me. However, it is important to examine this change in the field in order to asses the extent to which it has become a reality. In order to do this, future researchers should get a broader sense of society's attitude towards autistics and the mothers of autistics. This requires the researcher to go into society and observe the treatment of autistics in the public realm. Doing so will provide a more comprehensive evaluation of society's current views, and thus provide a better scale in which to track and consider change.

Furthermore, more research needs to be done on social organizations that use the family structures as its foundation. Looking at such organizations will inherently garner greater insight into the interaction between individual, social, and collective action. It is essential that social leaders, social movements, and social organizations are aware of the sorts of mechanisms in which society will best respond. Considering society is not a static entity, as it is constantly moving and producing new ideas, social organizations need to also be able to transform themselves. In this sense, social organizations must alter their philosophies and methodologies in order to keep up with society. Further research may perhaps reveal Casa da Esperança to be revolutionary in its approach and groundbreaking in its ability to produce social change.

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Appendix

1. Could you have done this project in the United States of America? What data or sources were unique to the culture in which you did the project?

I could not reproduce this same project in the United States, however, I could adapt it in order to execute it there. In order to conduct this ISP in the United States I would have to change my approach, as it would be difficult to find an institution like Casa da Esperança. Casa da Esperança is unique to Brazil in the sense that is functions on the Brazilian education model. This means that most of the students only went to the school for part of the day. As a result, I had easy access to the mothers because many of them stayed at the school due to the short time period and the distance from the houses. In addition, because I worked with mothers in Northeast Brazil, their roles were based on this culture. The meaning of motherhood and how this identity is carried out is uniquely culture, and thus in studying motherhood it is essential to be aware of the cultural context one is studying it in.

2. Could you have done any part of it in the Untied States? Would the results have been different? How?

The only part of this exact project that I could have replicated in the United States was the background research. All of the other information and knowledge that I gained were direct results of my field experience. If I had done this project in the U.S., I would have had to find an institution were mothers were actively involved and engaged. It is likely that this institution would not have been a school, but rather some sort of non-governmental organization. Also, because I was looking specifically at social action and social change, my results would have been different in a different society. I am unsure if I would find that the mothers of autistic children were empowered to act as individuals within society through the context of the organization. Rather, I would likely find other ways in which mothers were creating social change for their children.

3. Did the process of doing the ISP modify your learning style? How was this different from your previous style and approaches to learning?

I have always tried to learn from my real life experiences, and I often try to make connections between what I learn in class and the outside world. However, prior to the ISP, I relied heavily on what I read in books and what I learned from professors, as my framework for understanding most concepts and ideas. Now that I have field experience, I feel like I have a wider repertoire of skills and knowledge at my disposal. So while my learning style may not have been altered because I have always seen the value of putting everything that I learn into a real world context, my understanding of this learning approach is much more comprehensive.

4. How much of the final monograph is primary data? How much is from secondary sources?

A large majority of my final monograph is primary data. While my background research from secondary sources was in the back of my head throughout my research and I often referred back to those ideas when I was in the field, it ultimately makes-up very little of my final, written project. I relied heavily on what I witnessed, observed, and heard when I was in the field. There has been very little published research done on the related subjects surrounding my topic, and no published research to date on my specific topic. Because of this, I knew that my final presentation was going to depend heavily on primary sources and data.

5. What criteria did you use to evaluate your data for inclusion in the final monograph? Or how did you decide to exclude certain data?

I had a very eventful three week research period and a very comprehensive field journal. As a result, I spent a lot of time organizing and evaluating the data that I had collected to try to find common themes and patterns. Every night I went through and looked at what had occurred during that day. As the days went on, I started to take note of the ideas that were evolving. From here I began focusing on the trends that I was seeing. Once I had a general sense of what my analysis was going to be, I went through my entire field journal in detail and pulled-out all of the key information that I was going to use. I then organized this information into the different main sections of my analysis. Then when I began writing my project I had all of the potential data organized and was able to apply the data that was most relevant and appropriate.

6. How did the "drop-offs" or field exercises contribute to the process and completion of the ISP?

The "drop-offs" and field exercises were good ways to practice being in the field prior to the ISP. Through the "drop-off" and the discussion that followed, I became familiar with organizations in Fortaleza, their philosophies, and how they are run. This gave me a strong foundation for my consideration of social justice. It also made me comfortable with being in an unknown area and relying on other people to assist me in my task.

The best preparatory work prior to the ISP came from my community project. The community project provided me with the opportunity to experiment with different methods of note-taking, to analyze field data, and to practice interacting with people in different forums. It also allowed to me to see how I acted in the field. Because of the community project, I was more aware of what I needed for myself during the ISP and what methods worked best for me to gather information.

7. What part of the FSS most significantly influenced the ISP process?

Both the community project and the FSS class discussions significantly influenced the ISP process. As explained earlier, the community project was a good practice course for me to gain a better understanding of the realities of being in the field. In addition, I got the first glimpse of myself as a field researcher. From the community project, I could better foresee what I could accomplish in the given time period. The FSS class discussions also helped to prepare me for the ISP. Through the FSS discussions I developed new ideas on what to do in the field, and was able to brainstorm and converse with the other students about conducting field research. Being able to bounce ideas off the other students was a critical component in the process because I began to think about how I wanted to present myself as a researcher and what I saw myself doing in the field.

8. What were the principal problems you encountered while doing the ISP? Were you able to resolve these and how?

By biggest challenge throughout the ISP was navigating my relationships with the mothers. It was difficult to build rapport and camaraderie with the mothers while maintaining my objective as a researcher. I was constantly struggling to understand my role and where I stood with the mothers. This affected the degree to which I felt I was integrated in their group and was getting a sense of what was going on. This was most often an issue when it came to the way food was distributed. All of the mothers brought their own snacks or sold snacks to one other, there were very few handouts. There was a small group of mothers that traded off days that they brought in food for each other. Most days I was offered and/or forced into taking food. I felt like I could not decline the offer because it would have been rude, but when I did accept the food the other mothers were seemingly resentful. The fact that I was receiving food for free when others had to pay created a clear separation between me and everyone else.

There were also times when I felt like I was losing control of my own project. There were a couple mothers that wanted to decide what I should be doing and who I should be talking to. Furthermore, it took time to understand how the group of mothers functioned internally. As someone researching from the inside by talking and participating with the mothers, it was difficult to make sense of the preexisting relationships and the relationships I was trying to build.

None of these problems were ever completely resolved, though I found ways to work with them and diminish their significance. When it came to the food, I found useful strategies for shifting the focus so I was no longer the center of attention. I also learned when to assert control over my project and when to relinquish control to the people I was studying and allow the project to go where they took me. Furthermore, by constantly observing, listening, and conversing I was able to get a grasp on the "culture" of the art room at the Casa. Ultimately, I think this general challenge of navigating relationships is one of the most delicate and important undertakings in field research.

9. Did you experience any time constraints? How could these have been resolved?

I had a good idea of what I could and needed to accomplish in the given time period. For the most part, I stayed on schedule throughout my project, and never felt like I was running out of time. I struck a balance between participating with the group, talking with the mothers informally, stepping back to observe, and interviewing the mothers one-on-one. I quickly fell into a routine concerning how I would spend my days during the ISP period and my time at the Casa. I think that there was a certain amount of ease when it came to time because of the structured nature of Casa da Esperança; everyday the mothers came and left the Casa at the same time, every Monday and Tuesday Selma came to work with the mothers, and every Thursday there was group meeting. The daily routines at the Casa provided a well-built schedule for me to follow.

The only minor time issue I had was with my interview with the President of Casa da Esperança, Fatima. I talked with Alesandre Costa about conducting an interview with Fatima the day I started my ISP. He told me almost three times a week that an interview was going to happen that day, though it never occurred. I think if there was more time then eventually I would have had an interview with Fatima. However, by the final week I knew that an interview was no longer necessary to my research, and thus I did not insist upon having one.

10. Did your original topic change and evolve as you discovered or did not discover new and different resources? Did the resources available modify or determine the topic?

I did not stray too far from my original topic. While my ideas and thoughts on the issue evolved, it remained an on-topic exploration of my problem statement. Going into the project I had a good idea of the resources that were at my disposable. I was pleasantly surprised when I visited Casa da Esperança a few weeks before the ISP period and discovered that there was a formal program in place for the mothers. Thus, going into the project, I knew I would have access to and be spending most of my time with the mothers. Although I had my topic in mind and had produced my problem statement prior to knowing about the mothers' program, I think the success to which I was able to consider the topic was a direct result of the mothers' program being there. In this sense, the resources guided the direction and depth in which I was able to explore the topic at hand.

11. How did you go about finding resources: institutions, interviewees, publications, etc.?

I found my main resource, Casa da Esperança, through a list compiled by Oélito that was given to me with the names of different institutions in Fortaleza that address special needs. I looked-up every institution on the internet. I took note of Casa da Esperança, and later Valeria called and setup an appointment for us to go and visit. My meeting was with Alesandre Costa, who became my advisor, and from here everything fell into place very easily.

Most of the information I had about Casa da Esperança prior to conducting my ISP came from their website and from the conversations I had with Alesandre Costa. The articles that I read about autism, motherhood in Northeast Brazil, collective action, and the parents of special children, all came from my school database.

The other main resources I had came in the form of people at the Casa. The mothers spent every afternoon at the Casa, so there was easy access to talk with, engage, and participate with them. The other resources were the staff at Casa da Esperança. I met a lot of people just from spending so much time there. By spending almost all of my time with the mothers, I was able to interact with Sonia and Queina, who run the family program. I was also able to use Alesandre Costa as a resource in terms of finding out information and getting to know other people.

12. What method(s) did you use? How did you decide to use such method(s)?

I used observation, participant observation, informal interviews, and formal interviews. I relied equally on data from observations and interviews in producing my final monograph. The environment in which I was researching lent itself to participant observation, conversations about the topic at hand, and formal interviews. I always had my notebook with me, and when I had a few seconds I would jot down quickly what was going on and being said. I tape recorded all of the formal interviews. I decided to use these methods when I started to conceive of my project and how I would execute it. The methods that I predicted would be most useful, in fact were. In the beginning of the ISP I thought that I was going to have trouble with the formal interviews and that I was going to rely heavily on observations and informal interviews, but as time went on I was able to identify the mothers that would be the most helpful informants

13. Comment on your relations with your advisor: indispensable? Occasionally helpful? Not very helpful? At what point was he/she most helpful? Were there cultural differences which influenced the relationship? A different understanding of educational processes and goals? Was working with the advisor instructional?

My advisor, Alesandre Costa, in general was helpful, though he was not very active in my project. I only met with him a couple of times, but when I did meet with him I received great information. I reference him a lot in my monograph because I was able to interview him and find out about the basic structure and philosophy at Casa da Esperança. In this sense, he was incredibly helpful as a source of knowledge and data for my actual paper. As an advisor, however, he did not assist me when it came to thinking through my ideas. He was not a part of my analysis process. Despite this, he was incredibly supportive of my research and always offered his help. Even though it was hard to find times to meet with him, he wanted to ensure that I was having a good experience and was able to accomplish what I needed to. He and I were on the same page in terms of the goals I had for my time at the Casa. In addition, because he speaks English, the couple of times I did talk with him, I felt like I could fully express myself in an intellectual, academic manner. I do not think that my project suffered because of the limited input I had from my advisor. Because I was working through an organized, structured institution, my project was easy to execute and manage without much on-site oversight or assistance.

The only aspect in which the cultural differences were evident between me and my advisor was when it came to setting up times to meet. Would we often arrange for times and I would be scheduled into his planner, but then he would be unavailable when I would go to meet with him. On numerous occasions he gave me time frames in which I was supposed to have an interview with his wife, Fatima, but in the end they always fell through.

14. Did you reach any dead ends? Hypotheses which turned out to not be useful? Interviews or visits that had no application?

I had many ideas of what I could do with the abundance information that I learned through the ISP period, though many of these ideas I did not use in my final paper. When I was in the field, a great deal of the data that I gathered that I thought was going to be helpful and applicable is not part of my final analysis. In this sense, there were many hypotheses that I was working with but ultimately did not use. At no point did I ever feel like I had reached a "dead end." If anything, I felt like I had too many different directions to take my analysis and I needed to focus in on the one that I was going to apply.
There was only one interview that was not helpful and could not be translated. It was the first interview that I conducted and it was with two people at once. The recording is of very low quality, I did not take many notes, I could not understand them well during the interview, their voices are indistinguishable on the tape, and I had not built enough rapport with either of them so the interview was brief and without much detail. In the

end, the interview was not applicable or necessary to my research. I ultimately decided to use the interview as a practice run.

15. What insights did you gain into the culture as a result of doing the ISP, which you might not otherwise have gained?

I gained greater insight into the realities of mothers in Northeast Brazil. Though I had been living in Brazil for two and a half months, and throughout that time I was interested in the meaning of motherhood, I was never given the opportunity to talk with and get to know any mothers on a personal level. Through the ISP, I was able to see and hear about the expectations of mothers in Northeast Brazil. Moreover, I spent quality time with a neglected population, those with special needs. Autistics are rarely seen and never talked about within the culture. By stepping out into public with the autistics and being identified with their institution, I was also able to witness the prejudice of society. My entire ISP experience was spent with those that the mainstream culture rejects.

16. Did the ISP assist your adjustment to the culture? Integration?

For the most part the ISP did not assist my adjustment to the culture. If anything, it opened my eyes to how difficult it would be for me to ever fully integrate myself. The only aspect that I became better adjusted to throughout the ISP was the sensitive nature of talking to the mothers about their children and their roles as mothers. Many of the mothers had trouble openly discussing and articulating their commitment and sacrifices. This helped me better understand why mothers in general cannot always explain their motives.

17. What were the principal lessons that you learned from the ISP process?

I learned to allow the people and the research to take you down new paths, while also asserting yourself when necessary. As someone who likes to control most situations, it was important for me to hand over control in many situations during my ISP. There were many instances when I did not understand what was going on or what the mothers were asking of me, I just followed their lead. I also could not plan out everything in advance, I just had to let it happen. Interviews and activities did not always happen on time, and I had to be okay with that.

I also learned the value in getting to know those that you are studying. I found that the most comfortable and helpful interviews were with those mothers that I had built substantial relationships with. Trust was necessary for the mothers to open-up and talk to me about their lives.

Lastly, I realized the importance of being confident in who I am and what I am doing. Even when situations changed or things did not go according to plan, I had to remain sure that I could accomplish the task at hand. This confidence in myself and my research helped build the mothers' confidence in me and my abilities.

18. If you met a future student who wanted to do this same project, what would be your recommendations to him/her?

I would recommend that a future student should perhaps focus on the morning group of mothers. It would be an interesting comparison, especially because I know there are some large differences between the groups, and even some dissension. Most of the mothers in the morning group run the cooperative. I would also recommend that a future student makes Sonia an advisor as well. Both Alesandre Costa and Sonia are very busy, so if you worked with the two of them I think role of the advisor would be fulfilled. Sonia would also be the best person to discuss your ideas with. When it comes to the staff, I would suggest interviewing Quenia. It would be interesting to see how a staff member that is not directly affiliated with the Casa's founding perceives it. Finally, I would underscore the importance of building relationships with these mothers. It is impossible to get close to all of them, so the future student should find those he or she connects with, and then focus on those mothers' experiences. The student will find that it is the mothers that he or she is closest with is the present and helpful in the research.

19. Give what you know now, would you undertake this, or a similar project again?

I would undertake this exact project again. With the exception of a few minor setbacks, this project was easy to execute and manage. I think working through an organized institution helped me in a myriad of ways. All of my research took place within a confined space so I did not have to worry about travel or getting from place to place. This meant that all the time I spent at the Casa was time well spent because I was researching. The Casa also grounded my research and gave me a structure though which I could work through. This made it easy to meet people, build relationships, and conduct my research. Similarly, my framework was already in place without me having to create it.