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A phenomenological examination of the influence of culture on treating and caring for Hispanic children with autism

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COLLEGE OF EDUCATION

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ABSTRACT

A Phenomenological Examination of the Influence of Culture on Treating and Caring for Hispanic Children with Autism

by

Lynette Estrada

M.A., Nova Southeastern University, 1997
B.S., Liberty University, 1994

Doctoral Study Submitted in Fulfillment
of the Requirements for the Degree of
Doctor of Education
Educational Leadership

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ABSTRACT

The purpose of this phenomenological study was to explore and describe the influence culture has on the decisions Hispanic parents make to aid their children with autism. The research problems addressed are the influences culture may have on how professionals and external family members affect the choices parents make. Cultural and family systems theories formed the conceptual framework for the study. Researchers have found that cultural factors may lead to lower rates of diagnosis in Hispanic children with autism and parents' lack of knowledge of therapies and practices used to treat autism spectrum disorder (ASD). Five research questions guided this study. The focus of the first two questions was how culture may affect families seeking assistance; the focus of the third question pertained to how professionals play a part in therapies chosen; the fourth question focused in on the therapies families are choosing to aid their child with ASD. Finally, the focus of the last question was the involvement of external family members. Themes were highlighted, coded, and interpreted using interpretative analysis. The major themes found through triangulation included professional influences, concerns for children's futures as adults, parental involvement, and *personalismo/familismo*. The outcomes of the study demonstrate the influence professionals have on the families and the choices families make to aide their children with ASD. The findings can promote positive social change by aiding to inform professionals of the pinnacle role they play in the lives of Hispanic families with children with ASD. These finding will better aide professionals by helping them to understand the Hispanic culture as it may relate to having a child with ASD and thus assist families to understand and acquire needed services.

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DEDICATION

This doctoral study is dedicated to my children, Lucas and Naomi, as well as my ever-so-patient husband David. The first person I dedicate this to is my son Lucas. Lucas has shown me what true unconditional love, strength, and courage is. My dream of a doctorate began to manifest while Lucas was still in chemotherapy and radiation. He was my genesis. It was during this time I realized life does not have to be so hard. How difficult we all make life to be. Here was an 8-year-old child with autism fighting for his life and telling me, "I'm alright."

To my precious daughter Naomi, who tried to help me in any way she could. She exemplified lessons even adults have yet to master. But through her young years she has learned to value family and others in need. Oftentimes she would sit and do her homework with me. If I were ill or tired, she would volunteer to type my paper. All I needed to do was tell her what to type. Once she even read an assignment so she could summarize it for me- amazing for an 8-year-old. Her empathy and compassion is truly inspirational.

Finally, to my husband David, he came into an instant family, or as he puts it, "a microwave family." He did not need to bear the burden of a child with autism and cancer. He did not have to support his wife pursing a degree a few months after treatment. This patient man learned how to cook (somewhat) and clean. He learned creative ways to entertain the children so mommy could work.

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Earning my doctorate degree has been a life long dream. I would like to acknowledge those people that made it possible. Without them this would still have been just a dream.

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- My husband, David Tobon, his belief and dedication allowed me to complete this.
- Finally, my angels Lucas and Naomi. What more can I say?

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SECTION I:

Overview of the Study

The focus of this study was the cultural perspectives of Hispanics and how these unique perspectives may influence the age of diagnosis and treatments received by Hispanic children who have been diagnosed with an Autism Spectrum Disorder (ASD) in Miami-Dade County. According to the executive director of University of Miami Center for Autism and Related Services, the number of registered families with a child with autism is considerably lower than the national average (Dr. Michael Alessandri, personal communication, December 4, 2007). This is a problem within the county because families are not receiving vital services and assistance available for their children with ASD. For the course of this paper, autism and ASD will be used interchangeably. The paper includes a historical overview of ASD, its relation to the Hispanic culture, and presents the numerous therapies parents could possibly use with their children who have been diagnosed within the spectrum. In addition to focusing on the nuances of the Hispanic culture, the paper includes an exploration of the emotional and economic effects of ASD on families. In the literature review, I will discuss therapies traditionally used for ASD, each with varying rates of effectiveness for the children. With so many therapies to choose from, parents have to make the decision to accept one or more therapies in order to treat their children effectively (Shulman, 2002). It remains to be seen on what basis parents choose therapies for their children. Section 2 will provide more detailed information on this.

The choices parents make at the early ages of their children can have life-altering effects on the future of their children with ASD, on the family nucleus, and on society (Ozonoff & Rogers, 2003). The theories portrayed in this paper are best known to practitioners in the fields of education and psychology. Many professionals assume parents know about these theories and will automatically subscribe to one in order to assist the children's development (Stoner, Bock, Thompson, Angell, Heyl, & Crowley, 2005). Parents need to be educated on the best options available for their children in order to ensure hope for the children and families (Shevell, Majnemer, Rosenbaum, & Arbrahamowicz, 2000). Section 2 will make available more explicit information regarding the local problem and the significance of the problem in Miami-Dade County.

Research Problem

By reading this study, individuals and potential policy makers will gain information regarding the magnitude and effects of ASD on Hispanic families in Miami-Dade County and how their culture affects the theories and practices utilized to contribute to the education of their children. Currently, ASD affects one in 150 children (Monastersky, 2007). It is my intent to increase the awareness of ASD within Hispanic communities and aid in educating the public on cultural sensitivity in order to improve the services provided for these children (Harwood, Schoelmerich, Schulze, & Gonzalez, 1999; Julian, McKenry, & McKelvey, 1994; Mandell, Listerud, Levy, & Pinto-Martin, 2002). Mandell and Novak (2005) stated that little information is available as to why parents choose certain services over others to help their child with autism and even less research exists on how those in the Hispanic community make the same decisions (Guilamo-Ramos, Dittus, Jaccard, Johansson, Bouris, & Acosta, 2007). Mandell and

Novak (2005) recommended that future research be conducted on cultural differences that may lead to decisions families make in terms of medical and educational needs for their child with autism (see also Mandell, et al., 2002).

Problem Statement

The effects of ASD pose challenges to all affected families (Hutton & Caron, 2005; Mandell & Novak, 2005; Shulman, 2002; Stoner et al., 2005; Woodgate, Ateah, & Secco, 2008). The Hispanic population, which is the largest minority group in the United States (U.S. Census, 2006a), is not immune to the effects of autism. Neither is Miami-Dade County (Center for Disease and Control, 2006; Mandell at al., 2002; Overton, Fielding, Garcia de Alba, 2007). In Miami-Dade County, Hispanics count for 61.3% of the population (U.S. Census Bureau, 2006b). It is projected that, by the year 2020, the Hispanic population will grow 46% while the Caucasian population will grow only 24% in the United States (PEW Research Center, 2005). With these statistics in mind, research on Hispanic children and families is imperative, in order to assure proper services and practices to assist these children and families.

One particular problem faced by Hispanic families in this situation is lower rates of diagnosis compared to other ethnic groups (Mandell, et al., 2002; Overton, Fielding, & Garcia de Alba, 2007) and the apparent lack of understanding of therapies and practices used to treat ASD (Mandell & Novak, 2005). Due to a lack of data focusing on the Hispanic family with a child with autism, the study was broken down into segments. These segments included the research of Hispanics as a culture, racial differences in diagnosis, and ASD. Some of the research on the Hispanic family and their child with ASD has been typically quantitative in nature and used in conjunction with a diagnostic evaluation of the child in order to ensure an ASD diagnosis (Mandell, et al.; Overton, Fielding, & Garcia de Alba). The area of concentration of this research has been focusing on the "decision-making process used for differential diagnosis of Hispanic children referred for ASDs" (Overton, Fielding, & Garcia de Alba, p. 1996) as well as examining racial differences in acquiring an ASD diagnosis by use of the Medicaid system (Mandell, et al). Other studies delved into Hispanic practices as a culture by use of qualitative data (Guilamo-Ramos, Dittus, Jaccard, Johansson, Bouris, & Acosta, 2007; Harwood, Schoelmerich, Schulze, & Gonzalez, 1999). Other studies conducted used qualitative methods researching parents', not necessarily Hispanic, coping strategies over an extended period of time (Gray, 1994; Gray, 2006; Montes & Halterman, 2007); other studies also investigated the coping strategies of families using a quantitative approach (Hastings, Kovshoff, Ward, Espinosa, Brown, & Remington, 2005; Hastings, Kovshoff, Brown, Ward, Espinosa, & Remington, 2005).

Without a proper diagnosis, many parents are unaware of potential resources, their rights, community support systems and services, and their responsibilities as caregivers of children with ASD (Mandell & Novak; Shulman; Overton, Fielding, Garcia de Alba, 2007). The failures to access available services and understand essential rights and responsibilities impacts families negatively because they may not receive the support necessary for themselves or their children (Mandell, et al.; Woodgate, Ateah, & Secco, 2008). This problem may also affect society as a whole because society will be supporting the child with ASD as an adult, which in turn may have negative long-term psychological effects on his or her family (Hutton & Caron; Kasari, 2002; Shulman). Many possible factors contribute to the failure to use health care (Collins, 2002; Ell &

Castaneda, 1998), including: (a) the lack of knowledge within the Hispanic community of ASD; (b) the belief that ASD is shameful for the family, brought on by sin or by divine intervention to make one a better parent (Lopez-DeFede & Haeussler-Fiore, 2005; Santana-Martin & Santana, 2005); (c) parents not knowing the English language, thus not understanding their rights (Alvarez-McHatton, 2008; Alvarez- McHatton & Correa, 2005; Bacallao, 2007); (d) fear of deportation because they are illegal aliens; (e) lack of finances or health insurance (Cruza-Guet, Spokane, Caskie, & Szapocznik, 2008); (f) lack of social support (Brice, 2002; Ell & Castaneda, 1998; Mandell & Novak; Oyerman & Lee, 2008); and/or (g) perception of discrimination (Alvarez-McHatton, 2007; Alvarez-McHatton, 2008; Alvarez- McHatton & Correa). It is my aspiration that this study will contribute to the body of knowledge needed to address this problem by using a phenomenological approach.

Nature of the Study

Utilizing the phenomenological approach (Van Manen, 1990) in the form of backyard research, this study provides a description of the experiences of eight families in Miami-Dade County. Participants included 8 Hispanic families with a child diagnosed with one of the five categories within ASD as defined by *Diagnostic and Statistical Manual of Mental Disorders 4th edition Text Revision* (*DSM-IV-TR,* 2000). The eight children were at different stages of chronological development. The families presented documentation of an ASD diagnosis in either the form of an Individualized Educational Plan (IEP), a letter from a doctor, or a psychological report. The first set of families had a child who received a diagnosis within the past year. The next set of families had a child who is receiving services at the elementary school level. The third set of families had a child transitioning to adulthood. The last set of families had an adult aged child who has been living with the diagnosis for more than 20 years. Access to the participants was gained with the assistance of a gatekeeper. Data were gathered and the results analyzed. A combination of closed- and open-ended questions for the parents were created and placed in the appendices (see appendix A and B). Permission to take notes and audiotape the interview to ensure accuracy was requested of the participants. More of the methodology will be explained in detail in section 3.

Notes on observations or written memos is an effective tool to organize reflection or observations attained during the interview process (Hatch, 2002). Throughout the process, data were reflected upon and analyzed. This was done by continually recording ideas or observations within the interview protocol. A summary draft of notes was presented to the participants to ensure accuracy of the information they provided to the interviewer. Information was sorted into categories. Finally, a visual representation of the interpreted data will be provided at the conclusion of this study.

According to Creswell (2003), “multiple strategies of validity to create reader confidence in the accuracy of the findings” (p. 184) should be implemented when the researcher incorporates backyard research. For this particular study, four strategies were used to check for accuracy, including member-checking, rich, thick description, and peer debriefing**.**

Research Questions

1. Does culture play a part in the age of diagnosis for a Hispanic child?
2. How does culture influence the choices that Hispanic families make to aid their child with ASD?

3. What possible effects do professionals have on Hispanic families with a child with ASD?
4. What therapies are Hispanic families choosing to aid their child?
5. To what extent are external family members involved in raising the child with ASD?

Purpose of the Study

The purpose of this phenomenological study was to describe and understand ASD as it relates to the effects it has on Hispanic families and treatment decisions made by Hispanic families within Miami-Dade County. This was made possible through access to families attained through the University of Miami Center for Autism and Related Disabilities (CARD) Center, Parent to Parent of Miami, and Atlantis Academy, a local school tailored to children with disabilities. The effects of autism on the family are generally defined as the way autism affects the families socially and economically. The families' understandings of educational theories and practices for their children were also addressed. An open-ended questionnaire was administered (see appendix B). This enabled families to give their stories and perception of the development and care of their children. This study will ultimately allow professionals, including doctors, teachers, therapists, and policy makers to better understand the Hispanic population, thus reaching and providing accurate assistance for the Hispanic community.

Conceptual Framework

The conceptual basis for this study was cultural theory (Barnes, 2005; Swidler, 1986) and family systems theory (Gabriels, 2002). Cultural theorists acknowledge the "cultural repertoire of 'tool kit' that reflects beliefs, ritual practices, stories, and symbols that provide meaning and impetus for resource mobilization" (Barnes, p. 967; see also Swidler). Culture enables people to make sense and formulate solutions for issues and challenges that may arise within their lives (Barnes; Guilamo-Ramos, et al., 2007). Cultural theory leads to the use of *familismo* and *personalismo* (Guilamo-Ramos, et al.; Magana & Smith, 2006; Mandell & Novak, 2005; Santana-Martin & Santana, 2005; Wilson, Kohn, & Lee, 2000) within the Hispanic community. These concepts may, in fact, be the link connecting a Hispanic family to care giving of a child with ASD. The *familismo* theory accentuates the Hispanic individual's emphasis on the importance of family and culture, even when faced with the added stress of taking care of a disabled family member (Magana & Smith). Staying together for the sake of children or taking care of the family alone would be an indication of this theory (Magana & Smith). *Personalismo* is how an individual addresses a Hispanic person (Santana-Martin & Santana). Hispanics individuals prefer conversations that pertain to personal information in order to gain confidence and trust. In using *personalismo*, Hispanic people expect professionals to share parts of their personal life in order for the family to open up (Santana-Martin & Santana).

Family systems theory recognizes the influences and contributions made by each member of the family, including the extended family. Each member is valued as a unique individual with direct relation with the family. The family systems theory acknowledges the impact family members have on one another (Gabriels, 2002).

I used the cultural theory and the family systems theory as a guide to answer the research questions pertaining to families and how professionals and extended family members living in Miami-Dade County may influence the Hispanic parent. These two theories created a road map for the researcher to use on developing her research within the community.

Definitions

Applied behavior analysis (ABA): ABA is currently the most common educational intervention plan within the autistic community whose fundamentals are deeply rooted in behavior modification (Robledo & Ham-Kucharski, 2005). ABA uses reward and punishment as means for teaching consequences for particular behaviors being encouraged or behaviors to extinguish (Robledo & Ham-Kucharski; Mesibov, Adams, & Klinger, 1997)

Autism Spectrum Disorder (ASD): "Characterized as an impairment of social interaction and communication, along with restricted, repetitive, and stereotyped patterns of behaviors" (Stahmer, Collings, & Palinkas, 2005 p. 66).

Culture: Is a set of values, beliefs and practices respected by a particular group (Alvarez- McHatton & Correa, 2005; Guilamo-Ramos, et al., 2007; Harwood, Schoelmerich, Schulze, & Gonzalez, 1999).

Family: "the basic unit in a society traditionally consisting of two parents rearing their children; also: any of various social units differing from but regarded as equivalent to the traditional family" (*Merriam-Webster online dictionary*, n.d.).

Familismo: Represents feelings of loyalty and solidarity towards attitudes a belief system, and values, amongst family members (Guilamo-Ramos, et al., 2007; Magana & Smith, 2006, p. 347).

Fatalismo: Belief that in some Latin cultures the individual can do little to change their fate (Mandell and Novak, 2005).

Gatekeeper: Individual who gives access to the researcher for the study (Creswell, 2003).

Hispanic: People whose origin is “Mexican, Puerto Rican, Cuban, Spanish Speaking Central and South American countries, or other Hispanic/Latino regardless of race” (U.S. Census Bureau, 2000b).

Machismo: Men are considered to be dominant of women with an air of self-confidence (Guilamo-Ramos, et al., 2007; Stavanas, 2007).

Marianismo: Considered to be the “female self-sacrifice” (Stavanas, 2007, p. 76). Women are expected to emulate the characteristics of virtue and purity like the Virgin Mary (Guilamo-Ramos, et al., 2007; Stavanas).

Personalism: To share parts of one’s personal life in order to open up (Brice, 2002; Guilamo-Ramos, et al., 2007; Wilson, Kohn, & Lee, 2000).

Respecto: Respect given to the elderly and the professionals (Brice, 2002; Guilamo-Ramos, et al., 2007; Wilson et al, 2000).

Sensory integration (SI) dysfunction: “Ineffective neurological processing” (Kranowitz, 1998, p. 8). These children process their environment as an “atypical” individual. The noises and textures within the environment can cause great discomfort to them.

Assumptions

The following assumptions are applicable to this study:

1. Despite cultural stigma of speaking to someone about problems within the home, participants will be open and truthful when answering interview questions.

2. Participants abilities to understand the translation of the survey into Spanish was consistent across different dialects of Spanish. There are words or phrases in English that do not translate well, if at all, into Spanish. The same holds true for the reverse.
3. Participants remembered with little or no effort their child's milestone events, such as when the child first spoke, drank from a cup, etc.
4. The open-ended interview questions in this qualitative study are assumed to provide sufficient data to answer the research questions.

Scope of the Study

This study drew on the experiences of eight different Hispanic families taken from a pool of one of the five categories that fall within the ASD put forth in the *DSM-IV*. The children must have a diagnosis and be of Hispanic descent living in Miami-Dade County, Florida. These families were recruited from local parent resource centers and a local school. Six of the children were enrolled in school; the other two were not.

Limitations and Delimitations of the Study

According to Creswell (2002), a limitation within a study identifies potential weaknesses of the study to the best of the researchers' ability at the time of the proposal. I identified possible weaknesses in sampling, data collection, analysis, or any other section included within the study. This includes uncontrollable situations. The following is a compiled list of potential weaknesses within this study.

1. My bias as a Hispanic mother of a 12-year-old child with autism may influence the study.

2. This study will only examine eight families, which may thwart the external validity and increase the minimal level of significance.

The delimitations in a study are the characteristics that set the boundaries of the inquiry being set forth in a study (Castetter & Heisler, 1977). These boundaries include the decisions of including or excluding a specific variable within the study (Castetter & Heisler). According to Creswell (2003), "the scope may focus on specific variables or a central phenomenon, delimited to specific participants or sites, or narrowed to one type of research design" (p. 148). The delimitations in this study include:

1. Participants were first or second-generation Hispanics.
2. Participants live in Miami-Dade County.
3. This is a phenomenological study and generalizations were limited to only the Hispanic population.
4. Interviewing only caregivers living with children and not all those who are active in the upbringing of the child (example: grandparents, aunts, uncles, siblings, etc.).
5. Interviewing only one guardians.

Significance of the Study

The significance of the study was to increase development of current policies and strategies in assisting Hispanic parents of children with ASD. This study will assist researchers in enhancing current programs targeted toward families affected by ASD, specifically those within the Hispanic community. According to Florida’s Agency for Person’s with Disabilities ([APD], 2006), Florida does not recognize the five levels of autism when determining who is to receive government assistance. However, the Florida

Department of Education (FLDOE, 2007) does recognize the five levels of autism. Asperger's and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) fall within the group not recognized by APD.

The intent of this study was to bring this information to the forefront and educate the Hispanic community on their rights and the importance of their voices by sharing this information with key organizations like University of Miami CARD, local schools that specialize in children with an ASD, and local parent resource centers. According to Mandell and Novak (2005), Hispanic children with autism are six times more likely to be treated by nontraditional methods than American families (Martinez, 2009). Hispanic families are less likely to attribute their children's behaviors to any emotional, psychological, or neurological disorder; whereas American families are more likely to notice developmental delays and thus receive earlier interventions (Mandell & Novak; Mandell, et al., 2002). A study done in 2002 found that the average age a Hispanic child diagnosed with ASD is eight years of age compared to age six for white children and age seven for African American children (Mandell, et al.).

Implications for Social Change

The positive social change implications include the sharing of information found for the development of programs targeting Hispanic families, educators, psychologists, lawmakers, physicians, and other researchers in regards to children with ASD. The research findings will be shared with Parent to Parent of Miami, Atlantis Academy, and the University of Miami CARDS Center. I chose these organizations to share the findings due to the high volume of Hispanic families with a child with autism receiving services from these organizations. Parent to Parent of Miami is an organization which provides workshops and free services for families with a child with a disability. The organization helps to train families to advocate for their children. Atlantis Academy is a school who educates only children with special needs. In the last few years they have had an increase of children with ASD. Finally, University of Miami CARDS Center is the Center for autism in Miami. The changes I seek would be evident with an increase of Hispanic children and parents accessing services at an earlier age (Overton, Fielding, Garcia de Alba, 2007; Shevell, et al., 2000). In Miami, the Hispanic population is the dominant minority culture (U.S. Census Bureau, 2006a; U.S. Census Bureau, 2006b). This domination influences the community and the educational system. Being part of this culture helps individuals identify themselves with others who have similar beliefs and values (Guilamo-Ramos, 2007). Unfortunately, there are cultural misconceptions and fallacies that have created visible barriers for the Hispanic families facing ASD. There needs to be loyalty and mutual commitment. There needs be to a better understanding of the Hispanic culture, why they react and do the things they do. By clarifying this significance, I seek to assist the families and the children with an ASD.

Consistent with previous research on the effects of ASD on the family (Dillon, 1995; Green, 1996; Hutton& Caron, 2005; Kasari, 2002; Mandell, et al, 2002; Mandell & Novak, 2005; National Autistic Society, 2005; Robledo, 2005; Schopler & Mesibov, 1984; Shopler, Mesibov, Shigley & Bashford, 1984; Sicile-Kira, 2004; Zigler, 1984), it is believed that the results of this study will show a difference in services chosen by the Hispanic families in Miami-Dade County. This research will play an important role for future studies by giving an alternative to educating and researching based on cultural differences. According to Mesibov (personal communication, December 4, 2007), "there has not been a lot of work on that topic" (see also Guilamo-Ramos, 2007; Mandell et al., 2002; Overton, Fielding, & Garcia de Alba, 2007). My intention is to contribute to the field of autism specifically for the Hispanic population, which is the largest minority group in the county (U.S. Census Bureau, 2006a).

Summary

The focus of this study was on the effects ASD has on the Hispanic family living within Miami-Dade County. A qualitative phenomenological study was conducted. Data were collected by interviewing eight Hispanic families. This section presented the research problem as how culture plays a role in the diagnosis and treatment chosen for Hispanic children with ASD. The five research questions that focus on culture, families, and professionals led the course of this study. An overview of the study, the purpose and nature of the study, as well as essential definitions that were utilized throughout this study was presented.

Section 2 contains a review of current literature pertaining to ASD and the Hispanic culture. A description of the methodology will follow in section 3. The methodology section will include detailed information for participant selection, data collection, and data privacy. Section 4 will include the data analysis and results, while section 5 will include a discussion of the study, the limitations, recommendations for families affected by ASD, and recommendations for future studies.

SECTION II: LITERATURE REVIEW

Introduction

The primary purpose of this study is to examine the effects of ASD on Hispanic families and how culture influences the theories and practices parents choose to assist their child with ASD. In section 1, there was an overview of the study with information regarding the conceptual framework, definitions, delimitations, limitations, scope, and significance of the study.

This section will contain a review of current literature related to ASD and the Hispanic culture. The review will be organized into five sections: introduction, background information of ASD, current therapies, parental involvement, and cultural influence. This review will bridge the gap in the knowledge between Hispanic culture and actions taken. The literature reviewed was based on searches made through the Education Resources Information Center (ERIC), educational full text, and academic search premier databases through the Walden University Library. The key words searched were autism, families with child with autism, Hispanic with a disability, Hispanic families with a child with autism, and effects of autism on the family. Specific journals that were searched consistently were *Psychological Intervention and Cultural Diversity, Social Forces, Journal of Autism and Developmental Disorder, and Focus on Autism and Other Developmental Disabilities* and *Infants and Young Children.* Literature was also gathered for this study by examining the references listed in journal articles, books, and government documents which were found in the initial search for information.

It is important to recognize the role culture may have when determining the choices families make to help their children with autism. In addition, because this study is focused on ASD, it is important to have clear background knowledge to ensure understanding of the disability before combining it with a cultural factor. With a clear understanding of culture and what ASD is, I hope to make sense of the choices Hispanics make for their children.

Historical Overview of ASD

The study of autism has been a puzzle to many professionals since the beginning of the 20th century (Bettelhein, 1967; Dillon, 1995; Gabriels & Hills, 2002; Rimland, 1964; Schopler & Mesibov, 1984). Kanner described autism more than 60 years ago (Cray, 2006; Gabriels & Hills; Ohta, Nagai, Hara, & Sasaki, 1987; Schopler & Mesibov; Woodgate, Ateah, & Secco, 2008). In a 2002 Congressional hearing, autism was declared a "national health emergency" (Schreibman, 2006b, p. 36). According to quantitative and qualitative longitudinal studies, autism is ranked as one of the most significant stressors in a family's life (Gray, 1994; Gray, 2006). Schieve, Blumberg, Rice, Visser, & Boyle (2006) conducted a quantitative study, which included selected children ages 4 to 17 years of age. Their sample included children with ASD and parents or other caregivers. The data in this study suggests the unique and immense stress caregivers are under (see also Siverb, 2002), especially for mothers (Hastings, Kovshoff, Ward, Espinosa, Brown, & Remington, 2005; Montes, & Hilterman, 2006; Seltzer, Abbeduto, Krauss, Greenberg, & Swe, 2004).

The *DSM-IV-TR* (2000) defines autism as individuals who have "the presence of markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests" (p. 70). In 2005, Stahmer, Collings, and Palinkas wrote that ASD is "characterized as an impairment of social interaction and communication, along with restricted, repetitive, and stereotyped patterns of behaviors" (p. 66; see also Billstedt, Gillberg, & Gillberg, 2007). Today, the United States, Japan, England, Denmark, and France have the highest growth of autism in the world (Cray, 2006). In the United States 1 out of every 150 children will fall under the ASD criteria (Monastersky, 2007).

In the past, autism was perceived by psychologists as a mental or emotional disorder brought on by unemotional, unresponsive, and unattached parents (Bettelheim, 1967; Rimland, 1964). The children were diagnosed with childhood schizophrenia, mental retardation, or parental psychogenesis (Ozonoff & Rogers, 2003; Schopler & Mesibov, 1984). Children were often institutionalized in order to remove them from the cause of their sickness, namely their parents (Schopler & Mesibov; Shulman, 2002). Parents were placed in therapy sessions to acknowledge they had done wrong to their child. The children were regarded as having no hope for a future. Unlike other disabilities, such as cerebral palsy or Down syndrome, where it is physically obvious the child has a congenital or physical disability, the parents of children with ASD have more difficulty explaining their child's odd behaviors to strangers or family members because the child looks normal (Hastings, et al., 2005; Schopler & Mesibov; Shulman; Sivberg, 2002).

The turning point in the study of autism began in the 1960s. Parents were angry for being blamed by professionals for their children's disabilities and began to educate themselves (Rimland, 1964). Rimland challenged the trend of blaming poor parenting. Rimland introduced his theory of autism as being an organic disability and gave parents hope. Today, in many cases, parents are the co-therapists for their children with autism (Gabriels, 2002; Gabriels & Hill, 2002; Shulman, 2002; Schopler & Mesibov, 1984).

Parents were often looked upon as the cause of their children's disabilities. Professionals rarely relied on any input parents had. In fact, in a 2005 qualitative study of 21 parents of a child with an ASD, Hutton and Caron found 100% of mothers felt something was wrong with their child years before a diagnosis was given (see also Montes & Halterman, 2006; Ohta, et al., 1987). Often, parents were told nothing was wrong with their children and/or they were just slow (Schopler & Mesibov, 1984). Parents often found themselves more informed than the professionals, many times going from professional to professional with a number of different diagnosis ranging from emotional disturbance to Attention Deficit Disorder with or without Hyperactivity (ADHD) before acquiring an official diagnosis of autism (Baird, Charman, Cox, Baron-Cohen, Swettenharm, & Drew, 2001; Schopler & Mesibov). Years ago, a diagnosis could only be given if a child displayed symptoms before the age of 30 months (Schopler & Mesibov). Today, the National Autistic Society (2005) states that an ASD diagnosis can be diagnosed at any age. However, there is evidence suggesting that treatment should begin before the age of five (Woodgate, Ateah, & Secco, 2008).

Educators or those in the medical field typically refer children for screening (Hix-Small, Marks, Squires, & Nickel, 2007; Smith, Strain, Snyder, Sandall, McLean, Ramsey, & Sumi, 2002). Once referred, children are then screened using diagnostic tests by therapists or doctors through observations and interviews with the parents, children, and educators (Baird, 2001). Some of the tools used for diagnosing a child with an ASD include:

1. Pre-linguistic Autism Diagnostic Observation Schedule
2. Childhood Autism Rating Scale (CARS)
3. Autism Behavior Checklist
4. Checklist for Autism in toddlers (M-CHAT)
5. Bernard Rimland's Diagnostic Checklist for Behavior-Disturbed Children
6. Autism Screening Instrument for Educational Planning
7. Pervasive Developmental Disorder Screening Test
8. Gilliam Asperger Disorder Scale (GADS; Baird, et al., 2001; Goodlin-Jones & Solomon, 2003)

More than 60 years after autism was first given a name, parents are now included in the decision-making process for their child's needs (Ozonoff & Rogers, 2003; Symon, 2005). The most recent amendments of the Education of All Handicapped Children Act now known as Individuals with Disabilities Education Act (IDEA) of *PL-94*-142 was in 2004 (IDEA; 2004). This law provides children with a disability the right to a free public education (NEA, 2004; Schopler & Mesibov, 1984). Parents have the job of assuring what is best for their children and fighting for their rights rather than giving the sole right to the professionals who seek the most cost efficient route (Shulman, 2002). Recent estimates made by the National Education Association (NEA; 2008) projects the current funding as not being near the 40% promised in 1975 to educate a student receiving special education services. Even with the gains achieved by implementing IDEA, many parents continue to feel ignored and irrelevant in their children's education. According to a 10 year longitudinal ethnographic study, this has caused many parents of children with autism to be at greater risk for depression, anxiety, fatigue, social isolation, and frustration with the system (Gray, 1994; National Autistic Society, 2005; Shulman; Sivberg, 2002).

The race is on to find a cure to ASD. The diagnosis has increased by more than 800% since 1992 (National Autistic Society, 2005). Currently, there is no cure for ASD and the cause is still unknown (NICHD, 2005; Woodgate, Ateah, & Secco, 2008). The speculated causes are: 1-immune system; 2-genetics (Schreibman, 2006b); 3-envirnmental factors (which include vaccines); 4-diet (Elder et al., 2006); and 5-yet to be specified (NICHD; see also Schopler and Mesibov, 1984).

Classic autism

Autism is not as clearly identified as other disabilities (Shulman, 2002). In order to attain an understanding of autism, a clear summary of each category will be defined. As derived from Robledo and Ham-Kucharski (2005), a child diagnosed with classic autism has manifested delay in social relationships, communication, and exhibits repetitive behaviors. A child with classic autism will lack the ability to appropriately reciprocate conversations. They may lack eye contact and the inability to understand social cues. If they are able to speak, their voice intonations and fluctuations may sound robotic in nature. They may interrupt others who are talking and fail to understand meanings of words.

In order for children to be diagnosed with autism they must meet the criteria set forth by the *DSM-IV-TR* (APA, 2000). As found in table 1, the set criteria for an autism diagnosis to be given, a child, must meet 6 out of the 12 symptoms, “with at least 2 coming from the social domain and 1 each from the communication and restricted behaviors/interests categories. At least 1 symptom must have been present before 36 months of age" (APA, 2000).

Table 1. Diagnostic Criteria for Autistic Disorder according to DSM-IV-TR

Impairment	Delays
Impairment of social interaction of two of the following:	1. Impairment of nonverbal behaviors like eye gaze, facial expression, body posture, and social gestures 2. Difficulties in developing age appropriate peer relationships 3. Lack of sharing interests or achievements 4. Lack of social or emotional connection to others
Impairment of communication marked by one of the following:	1. Delay in spoken language 2. If the child is able to speak, there is an inability to sustain or initiate conversations with others 3. Repetitive use of language 4. Lack of make-believe play
Repetitive patterns of behavior, interests, and activities by at least one of the following:	1. An abnormal preoccupation with and intense focus of personal interests 2. Inflexible behaviors in terms of routines and rituals 3. Repetitive motor movements (hand flapping) 4. Preoccupation with parts of an object

Note. As cited in American Psychiatric Association (2000, p.75).

Asperger's Syndrome

Children with Asperger's are often referred to as high functioning autistic. These children do not quite meet all the criteria of a child with classic autism. These children appear to be "atypical" in terms of speech, language acquisition, and intelligence. The markers for these children are the social interaction impairment, restricted and repetitive behaviors (Gabriels & Hills, 2002; Ozonoff & Rogers, 2003).

Asperger's did not make its way into the *DSM* until the fourth edition (Ozonoff & Rogers, 2003). These children may lack eye contact, gestures, facial expressions, show disinterest with peers their age and achievements of others. A child with Asperger's may also exhibit classic autistic behaviors like hand flapping, obsessions, and set routines (Robledo & Ham-Kucharski, 2005). "In the *DSM-IV-TR* diagnostic system, the main point of differentiation from autistic disorder…is that those with Asperger syndrome do not exhibit significant delays in the onset or early course of language non-echoed, communicative use of single words must be demonstrated by age 2 and meaningful phrase speech by age 3" (Ozonoff & Rogers, p. 6). In fact, most parents of children with Asperger's syndrome were not concerned with the speech and language development at an early age. Table 2 depicts a more detailed criterion for a diagnosis of Asperger's Syndrome. It displays the more common impairments and possible delays.

Table 2. Diagnostic Criteria for Asperger's Disorder according to DSM-IV-TR

Impairment	Delays
Impairment of social interaction by at least two of the following:	1. Impairment of nonverbal behaviors like eye gaze, facial expression, body posture, and social gestures 2. Difficulties in developing age appropriate peer relationships 3. Lack of sharing interests or achievements 4. Lack of social or emotional connection to others
Repetitive patterns of behavior, interests, and activities by at least one of the following:	1. An abnormal preoccupation with and intense focus of personal interests 2. Inflexible behaviors in terms of routines and rituals 3. Repetitive motor movements (hand flapping) 4. Preoccupation with parts of an object
Impairment in social, occupational, or other functioning.	
No clinically significant delay in language skills.	
Does not meet criteria for Pervasive Developmental Disorder (PDD) or Schizophrenia	

Note. As cited in American Psychiatric Association (2000, p. 84).

Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

A child diagnosed with PDD-NOS is a child who has failed to meet all the criteria of classic autism and/or Asperger's. Children with PDD-NOS are cases that do not meet all the previously discussed criteria for autism (*DSM-IV-TR,* 2000). The children in this category will experience difficulties in two out of the three "autism-related symptom cluster (clear difficulty relating to others, as well as either communication problems or repetitive behaviors)" (Ozonoff & Rogers, 2003, p. 12). The diagnosis may appear after the age of three due to doctors, parents, or educators not being able to explain certain behaviors with another diagnosis. For example, a child with PDD-NOS may be able to speak but their sentences may lack proper parts of speech. They appear to be ambivalent to the emotions of themselves or others. They may be of average intelligence but lack the ability to communicate their wants and needs (Robledo &Ham-Kucharski, 2005). More detailed diagnostic criteria for PDD-NOS can be found in Table 3.

Table 3. Diagnostic Criteria for PDD-NOS according to DSM-IV-TR

Impairment	Delays
Impairment of social interaction in conjunction with an impairment in either verbal or nonverbal communication skills	Late age of onset, atypical symptomology, and/or subthreshold symptomology
Average impairment	lack of ability to communicate needs

Note: American Psychiatric Association (2000, p. 84).

Fragile X Syndrome

Fragile X Syndrome is a chromosome abnormality that is found through genetic testing (Robledo &Ham-Kucharski, 2005). "A person with Fragile X has a specific gene that isn't able to produce a protein that the brain needs to be able to learn. As a result, his mental faculties are usually severely impaired, and his moods are difficult to regulate" (Robledo &Ham-Kucharski, p.7). Individuals with Fragile X tend to have seizures, their faces are long, ears are large, and their feet are flat. As with autism, boys are diagnosed more often than girls. The girls who are diagnosed with Fragile X tend to display fewer mental impairments than the boys diagnosed (Dillon, 1995; Robledo &Ham-Kucharski). More detailed diagnostic criteria for Fragile X Syndrome can be found in Table 4.

Table 4.Diagnostic Criteria for Fragile X Syndrome according to DSM-IV-TR

Impairment	Delays
Impairments of mental faculties.	Speech and language delays, low muscle tone and balance, and cognitively delayed.
Gene producing Syndrome	Affects more boys than girls

Note: Dillon, 1995; Robledo &Ham-Kucharski, 2005)

Rett Disorder

Rett disorder shares some traits with autism; however, one difference is that it affects only girls and they display normal development for the first 5 months of life (Ozonoff & Rogers, 2003; Robledo & Ham-Kucharski, 2005). These children have the normal milestones of following objects with their eyes, holding up their heads, crawling etc. Suddenly they begin to regress around the age of 18 months. These children begin to lose their ability to control their movements, known as apraxia (Robledo &Ham-Kucharski). “The classic symptom of Rett disorder include unsteady gait; lack of language; lack of functional hand use; almost constant stereotyped hand movements, including repetitive wringing, ‘washing’, twisting, clapping, or rubbing of the hands in the midline; severe cognitive deficits; and lack of typical social interaction” (Ozonoff & Rogers, p. 11). More detailed diagnostic criteria for Rett’s Disorder can be found in Table 5.

Table 5.Diagnostic Rett's Disorder according to DSM-IV-TR

Impairment	Delays
All of the following must be met:	1. Normal prenatal and perinatal development 2. Normal psychomotor development through the first 5 months of life 3. Normal head circumference at birth
All the following must be evident after normal development	1. Deceleration of head growth between 5 and 48 months 2. Loss of hand skills between ages 5 and 30 months with stereotypical and movements 3. Loss of social connection 4. Poorly coordinated 5. Severe language impairment with severe psychomotor retardation

Note. American Psychiatric Association (2000, p. 77).

Childhood Disintegrative Disorder

Ozonoff & Rogers (2003) described Childhood Disintegrative Disorder (CDD) as rare and affects more boys than girls. A child with CDD has normal development for two to ten years. Before the onset of symptoms, the child is able to communicate, have appropriate social relationships, have self help skills, and be of normal intelligence.

When CDD manifests, the child will regress to the point that he or she is unable to communicate and loses motor skills and cognitive abilities. This regression can last between 4 to 8 weeks. Once the regression has taken place, what is left is a child with severe autism and mental retardation. The treatment for CDD has little effects on the progress of the child (Ozonoff & Rogers). More detailed diagnostic criteria for CDD can be found in Table 6.

Table 6.Diagnostic Criteria for CDD according to DSM-IV-TR

Impairment	Delays
Normal development for at least the first 2 years	
Significant loss of skills already acquired before the age of 10 in at least two of the following:	1. Language
	2. Social and adaptive behavior
	3. Bowel or bladder control
	4. Play
	5. Motor skills
Abnormalities in at least two of the following:	1. Impairment of social interaction
	2. Impairments in communication.
	3. Repetitive patterns of behavior, interests, and activities
Does not meet criteria for Pervasive Developmental Disorder (PDD) or Schizophrenia	

Note. American Psychiatric Association (2000, p. 79).

Autistic Savant

A savant "is a person who possesses enormous intellectual abilities or talents even as they try to manage a developmental disorder" (Robledo &Ham-Kucharski, 2005, p.

12). A prodigy savant is rare. Only 10% of children with ASD are also diagnosed as savants (Robledo &Ham-Kucharski). Some famous individuals who were savants were Einstein, Michelangelo (Robledo & Ham-Kucharski), and Newton (Elder, 2006). These individuals showed remarkable talents in their fields, which might be math, writing, science,
or the arts.

Therapies

Along with the numerous speculations to the cause of ASD, I located an abundance of strategies and treatments for a child with ASD within the ERIC database. Care must be taken when deciding the course of treatment for each child with an ASD. No two children with ASD will have the same symptoms or treatment (Dillon, 1995, p. 17; see also Schreibman, 2006a, p. 42) thus complicating the search for a single answer on treatment. According to National Institute of Child Health and Human Development (NICHD, 2005), there is no known cure for ASD. Nevertheless, there are a plethora of treatments. Of the most popular treatments, behavior modification is the *only* current treatment that has empirically demonstrated positive effects on the child with autism (Schreibman). Other therapies that will be presented that have shown positive progress include Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) (Dillon; see also Schopler, Mesibov, Shigley, & Bashford, 1984) and Naturalistic Treatment strategies. Other methods which have had little or no testing for their effectiveness include: pharmaceutical intervention, vitamins, and diet (Mandell & Novak, 2005), social skills training (McConnell, 2002), pivotal response training for the parents (Symon, 2005), sensory integration therapy (Kranowitz, 1998), social stories

(Lorimer, Simpson, Myles, & Ganz, 2002), and comic strips (Rogers & Myles, 2001). It is up to the parent and professionals to choose the most beneficial for an individualized child. Today there are numerous therapies for professionals and families to review and choose to use. Table 7 is a comprehensive list of the most commonly utilized therapies by professionals and families with children with autism.

With so many therapies to choose from, parents and professionals must be sure to be cautious when treating a child with ASD. As was previously said, no two children with autism will display the same symptoms. What works for one child may not work for another. The following sections, the researcher will be presenting more popular therapies that are being utilized to treat ASD.

Table 7.Therapies for the Treatment of ASD

Types of therapy	Name of therapy	Summary of therapy discussed in paper
Language skills	Naturalistic Behavior	1- Child initiates conversation 2- Intrinsic motivators are used 3- Natural environment utilized
	Developmental-Pragmatic	1- Goal is to promote the use of language as a motivator to speak to others as a warm and satisfying feeling 2- The child is the leader in conversations
	Picture Exchange Communication System	1- Based on ABA 2- Communication is through the use of picture exchange
Social competency	Social stories	Stories are written to teach social rules and appropriate behavior
	Visual cuing	Printed cues assist children to socialize and know their schedules to reduce stress and anxiety
	Video modeling	Use of videotapes of a model simulating correct social interaction
Educational	Preschool intervention	Intervention begins early and the family is involved with goals and treatment
Alternative therapy	Bowel-Brain connection	There appears to be a connection between autism and gastrointestinal disturbances (GI)

(table continues)

Types of therapy	Name of therapy	Summary of therapy discussed in paper
	Hippotherapy	Therapeutic horseback riding

Note. Dillon (1995); Hansen & Ozonoff (2003); Mastergeorge, Rogers, Corbett, & Solomon (2003); Robledo and Ham-Kucharski (2005).

Behavioral Approaches

ABA

The Behavior Model of Learning or Applied Behavior Analysis (ABA) is the only treatment which has "empirically demonstrated to be effective for children with autism" (Schreibman, 2006; Woodgate, Ateah, & Secco, 2008). ABA is currently the most common educational intervention plan within the autistic community whose fundamentals are deeply rooted in behavior modification (Lovaas, 1987; Robeledo & Ham-Kucharski, 2005). It was created by Skinner who found: "behavior could be molded through a process called *operant conditioning*" (Robeledo & Ham-Kucharski, 2005, p. 59). Operant conditioning uses rewards as a way of teaching certain behaviors (Green, 1996). These children are taught by setting a goal of a particular behavior, and reaching their goal with consistent practice. These children are given a specific cue or prompt to perform a task. When appropriate responses are obtained, the child would be reinforced with a reward. If the child fails to respond correctly, they would be given a consequence like a time-out (Green, pp. 30-31). Children who successfully reach their goal may be rewarded by verbal praise, a simple smile or pat on the back, or a tangible reward like a visit to a treasure box (Robeledo & Ham-Kucharski, p. 58).

ABA utilizes a highly structured environment (Robeledo & Ham-Kucharski, 2005). A phenomenological study, describes ABA as requiring a commitment by parents of up to 40 hours per week of one to one behavior training. The findings in the study found that parents often felt isolated from society due to a lack of understanding of ASD, feeling "they have no life, we only have a program [referring to the ABA program]" (Woodgate, Ateah, & Secco, 2008, p. 1078), parents felt disconnected from extended family members, and frustrated due to lack of support in the community. In an ABA program, parents are considered part of the treatment sessions for the children. Parental input and professional collaboration on a regular basis is a very powerful tool and should always be considered (Woodgate, Ateah, & Secco).

Discrete Trial Training

Discrete Trial Training (DTT) is associated with direct teaching (Anderson, Taras, & Cannon, 1996). DTT falls under the behavior modification umbrella because the children are taught to “discriminate between and respond appropriately to various stimuli (e.g., questions, requests, or commands)” (Schreibman, 2006a, p. 41). DTT is extremely structured and repetitive in nature. A good DTT program contains four components which include; (a) presenting a question or command to the child; (b) responding to the child’s response no matter what it is; (c) having a consequence; (d) a wait-time; and (e) consequence with the next instruction (Anderson, Taras, & Cannon). The actual nature of the component depends on the “desired effects” (Schreibman, 2006a). This method has been shown to enable the sibling to take part in the treatment of a child with autism (Luce & Dyer, 1996).

TEACCH

The Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) was developed by Schopler for the state of North

Carolina (Mesibov, Shea, & Schopler, 2006). The TEACCH program is an individualized method that focuses on the individuals' skills, interests and needs (Mesibov, Shea, & Schopler). It is considered a one-stop-shop for receiving services (Robledo & Ham-Kucharski, 2005) where a plan is created based on individual needs, parental and professional involvement (Dillon, 1995; Mesibov, Shea, & Schopler; Sicile-Kira, 2004). TEACCH is a highly structured organization that draws upon behavioral procedures to instruct the students and incorporates many different systems into the program (Robledo & Ham-Kucharski, 2005). This program utilizes a highly structured environment, which stresses visual structure and organizational strategies throughout the individual's life (Mastergeorge. Rogers, Corbett, & Solomon, 2003) Although the TEACCH program emphasizes cognitive learning, independent skills, and adaptive behavior, it is a program designed to shelter the child with ASD from the *normal* world in order to promote communication and foster communicational growth while controlling an over-stimulating world (Robledo & Ham-Kucharski). By use of visual cues, the individual with an ASD will be able to relax and know what will happen next without feeling stressed. These visual cues may or may not be color-coded (Mesibov, 2007).

Relationship Approaches

Floor time

Play constitutes one of the most important aspects of childhood (Wieder & Greenspan, 2003). Play is a time of learning and mastering social cues, social skills and a time for utilizing symbolic play (Wieder & Greenspan). Greenspan's theory incorporates parents and therapist together in the developments of a child; the child can attain developmental milestones through one to one experiences with the therapist in conjunction with the parents (Robledo & Ham-Kucharski, 2005; Wieder & Greenspan, 2003).

Floor time allows the opportunity for parents to create experiences that may promote interpersonal, emotional and intellectual growth. Therapists utilize the session by working one to one with the child. By play and interaction the child will learn to get out of their world and feel empathy for others by learning that every action has a reaction. Through this interaction a child learns that a smile will get a smile in return; by reaching out will get them picked up. The children learn that they have an effect on their environment (Gabriels, 2002; Greenspan, 1992; Robledo & Ham-Kucharski, 2005; Wieder & Greenspan, 2003).

Floor time is based on the “belief that emotions give meaning to our experiences, as well as a direction to our actions” (Sicile-Kira, 2004, p. 128). Greenspan believed that parents and caregivers can work as their child’s therapist by encouraging positive interaction with others at home and in other natural environments which make this therapy affordable (Solomon, Necheles, Ferch, & Bruckman, 2007; Wieder & Greenspan, 2003). Parents are encouraged to be animated in their interactions with their child in order to entice a response from them. Some techniques include: following the child’s lead no matter what it is or how repetitive it is, respond to child’s actions no matter how mundane it is, help the child to succeed, intentionally do things out of order or by mistake on purpose, do not interrupt the child at play, use sensory toys and interactions, exaggerate gestures, tone of voice, and body language when speaking to the child, and help your child deal with their emotions (Robledo & Ham-Kucharski, 2005; Wieder & Greenspan).

Solomon, Necheles, Ferch, & Bruckman's (2007) quantitative pilot study on a program called The PLAY (Play and Language for Autistic Youngsters), included sixty-eight children in an 8-12 month regimen with their parents. Parents were encouraged to commit to a 15 hour per week with their child. This study found The PLAY to be cost-effective and 90% satisfying to the families involved. This study stressed the importance of parent involvement since the parent has vested interest in the child's development and the fact that parents spend more time with the child.

Sensory Integration Therapy

Many children with ASD suffer from Sensory Integration Dysfunction (Robledo & Ham-Kucharski, 2005). Ayres first described SID as “ineffective neurological processing” (as cited in Kranowitz, 1998, p. 8). The dysfunction occurs when the brain cannot organize and process specific information traveling to the senses. A child with SID will have difficulties processing the environment and what they need to do (Greenspan & Wieder, 2006; Kranowitz). A child with SID has difficulties understanding the information received from one or more of the five senses. These children spend their lives trying to make sense of a world that is filled with stimulus’ they cannot comprehend. An occupational therapist (OT) who has been trained in SID may assist families in recognizing the types of sensations the child with ASD prefers or avoids (Sicile-Kira, 2004). Knowing this will assist the OT in determining the next course of action (Sicile-Kira).

The principal goal of Sensory Integration (SI) therapy is to assist the child with finding equilibrium with their senses (Kranowitz, 1998). SI therapy targets three areas: “tactile system (sense of touch); vestibular system (sense of body and space); and the proprioceptive system (sense of muscle and joints bending, straightening, pulling and compressing for movement)" (Kranowitz, p. 68). The occupational therapist who works with a child with SI will provide the child with a steady sensory diet in order to assist the child in making sense of their environment. Some of the recommended activities include: playing with things that are squishy and slimy, spinning, somersaults on a mat, eating peanut butter, or rubbing the body with a brush with coarse hair or bumps (Kranowitz; Robledo & Ham-Kucharski, 2005).

Social Skills

Individuals with ASD have difficulty understanding that others might see things differently (Greenspan & Wieder, 2006). These individuals tend not to realize the cause and effect aspect that for every action there is a reaction even if they did not see it coming. To assist these children, qualitative studies found the teaching of social skills to be beneficial (Lorimer et al.; Rogers & Myles, 2001; Sicile-Kira, 2004). These methods include social stories and social skills groups (Gray, 1994; Sicile-Kira).

Social skills may be taught through social play, social stories (Gray, 1994; Lorimer et al, 2002), and comic strips (Rogers & Myles, 2001). Social play and social stories give children the opportunity to interact with peers their age while under the watchful eye of a psychologist (Lorimer et al). Comic strips have pictures in a format depicting a particular situation. Using thought bubbles, children will be able to read and write in a response for the situation (Rogers & Myles).

Social skills groups are clustered according to age and need. Groups tend to be between four and six children. Since social skills development is one of the most difficult challenges faced by a child with ASD, this format allows children to practice everyday skills such as turn-taking and social cues (Gray, 1994; Greenway, 2000; McConnell, 2002). These groups tend to be a safe haven for the child with ASD to have friends that will accept them as they are (Sicile-Kira, 2004).

Complementary and Alternative Medicine (CAM)

Along with the research of empirically tested therapies, parents' desperation for answers and cures has caused them to seek alternatives to the conventional treatments made available (Levy & Hyman, 2002; Nickel & Gerlach, 2001). These alternative therapies are generally referred to as complimentary and alternative medicines (CAMs). CAM has been defined as treatments and products that are not part of conventional medicine (Nickel & Gerlach; Martinez, 2009; Wong & Smith, 2006). The usages of CAMs are to compliment existing therapies as well as offer an alternative to families (Nickel & Gerlach; Wong & Smith). In a quantitative study of 112 families 74% of the families reported using CAM (Hanson, Kalish, Bunce, Curtis, McDaniel, Ware, & Petry, 2007). When asked why parents chose the usage of CAMs, they reported that CAMs were useful in alleviating symptoms without producing side effects or harm to their child (Hanson, et al.). Families consider the treatments useful and natural (Hanson, et al.; Rey, Walter, & Soh, 2008). Currently, children with ASD have the highest prevalence of CAM usage in the 90% range (Hanson, et al.). Of those reported, Hispanics are the most likely to prefer CAMS before choosing contemporary medicine (Martinez,). (More of this will be discussed in the cultural portion of this document.) Another study reported usage are more likely in European American families with higher education (Hanson, et al.; Martinez) yet in Hispanics the higher the education the less likely CAMs would be used (Martinez). What is consistent are families desiring educators and physicians to familiarize themselves with alternative treatments (Levy & Hyman; Shatkin & Koplewicz, 2008). Parents are searching for providers who will listen to their concerns, give them respect for their knowledge about their child, be nonjudgmental, be honest about their own knowledge about treatments, inform parents of alternatives not in the mainstream, and support the families for their choice (Nickel & Gerlach; Wong & Smith). Until then, most families will continue to not express to the professionals the alternative methods being used to treat their child with ASD (Nickel & Gerlach; Wong & Smith).

In a CAM there exists what is known as biologic agents and non-biologics. The biologic agents are those that are to be taken orally. This can include the purchase and the administration of vitamins such as vitamin B6, Vitamin C, and A (Levy & Hyman, 2002) or a change in the child's diet. The gluten-free-casein-free diet is the most common diet discussed by parents with a child with ASD (Grace, Velez, & Chambliss, 1999; Hansen & Ozonoff, 2003; Robledo & Ham-Kucharski, 2005). This diet is very strict: It calls for an elimination of two kinds of protein including gluten which is a product of wheat and other types of grains and casein- derived from dairy products (Elder et al., 2006; Hansen & Ozonoff; Levy & Hyman, 2002; Robledo & Ham-Kucharski). The theory is that children with developmental disorders are unable to process these proteins correctly, thus causing behavior problems (Elder et al., 2006; Hansen & Ozonoff; Levy & Hyman; Robledo & Ham-Kucharski). These behavior problems can be seen as a child just not feeling well. The effectiveness of this diet has come into question (Robledo & Ham-Kucharski). A child with autism may have sensory issues that inhibit their food choices. If a parent decides to follow the strict regiment of a gluten-free-casein-free diet then the child would be at risk of nutritional deficits due to the restrictions (Levy & Hyman, 2002).

Chelation is one of the most recent treatments making headway for parents (Levy & Hyman, 2002). Chelation involves administration of large dosages of different medications into the bloodstream intravenously or orally in order to remove heavy metals (like mercury) from the blood stream (Levy & Hyman). This therapy holds to be true that these children were exposed to high dosages of mercury through their vaccines (Robledo & Ham-Kucharski, 2005) and thus is the cause of their regression (Levy & Hyman). The danger for these children is the damage these medications may cause in the future including kidney failure, heart disease (Levy & Hyman; Robledo & Ham-Kucharski; Sicile-Kira, 2004), liver failure, severe electrolyte and fluid imbalance, as well as hypersensitivity (Levy & Hyman).

There is no doubt that a danger exists when applying some of these drastic diets and over medicating children. The types of diet limitations may create an imbalance of nutrients in an already unstable system. A child with ASD tends to have limitations in what s/he eats. If a strict diet is implemented the child’s choice of food would be reduced drastically (Robledo & Ham-Kucharski, 2005). If a child is over medicated the long term result may be devastating as well (Des Portes et al., 2003).

Another aspect to CAMs is the non-biologics (Levy & Hyman, 2002). The non-biologics are either provided by a therapist or self-imposed by the family of a child with ASD (Levy & Hyman). These CAMs provide manipulation or some kind of movement to the body (Hanson, Kalish, Bunce, Curtis, McDaniel, Ware & Petry, 2007). These CAMs include but are not limited to music therapy (Hanson, et al.), horseback riding, chiropractic therapy, and the facilitated communication. All these therapies are considered noninvasive (Levy & Hyman). Parents are choosing these noninvasive treatments as a personal choice to assist their child with ASD as a form of handling their frustration and stress with more conventional methods (Hanson et al.; Nickel & Gerlach, 2001). Currently, there is no substantiated evidence holding the effectiveness of these therapies. More research must be done (Levy & Hyman; Wong & Smith, 2006).

Medication

In conjunction with diet and vitamin supplements, parents face the decision of using or not using medications. Some of the most common types of medications associated with secondary symptoms of autism include mood stabilizers, neuroleptics or alpha-adrenergic agonists for aggression, agitation, disruptive behaviors, or irritability (DesPortes, Hagerman, & Hendren, 2003). While this list is not inclusive of all the types of medications, it does provide a general overview of the common medications for treatment of the secondary symptoms and not that of ASD. There is currently no known cure.

In Table 8, the trend of combining medications to treat some secondary symptoms associated with a child with autism is displayed (Levy & Hyman, 2002). The children on these medications may face a multitude of medical problems in the future as a direct consequence of the side effects of these medications (Des Portes et al., 2003). Furthermore, the children may develop a tolerance to these medications and new ones will have to be made available to them (Des Portes et al.).

Table 8. Target Symptoms and Types of Medication Used

Target symptoms	Potential medications
Aggression, agitation, irritability	Neuroleptics
	Mood stabilizers
	Alpha-adrenergic agonists
Repetitive/Impulsive behavior	SSRIs
	Opioid antagonists
	Alpha-adrenergic agonists
Disruptive behavior	Alpha-adrenergic agonists
	Neuroleptics
	Stimulants
Affective instability	Mood stabilizers
	SSRIs
Social withdrawal	Neuroleptics
Anxiety, hyper-arousal	Alpha-adrenergic agonists
	SSRIs
	Buspirone
Insomnia	Antihistamines
	Trazodone
	Tricycle antidepressants
	Melatonin

Note. As cited in Des Portes et al. (2003, p. 172).

Summary of Autism Spectrum Disorder and Therapies

As leaders within the context of a professional learning community, a proactive stance to articulate and promote a vision that addresses parental involvement in the education of their child with autism is necessary. A leader in the field must acknowledge the untapped knowledge of the parents that live with the child all year. Parents have natural resources that can assist this growing field (Bunsen, 2002; Gabriels, 2002; Lambert, et al., 2005; Shulman, 2002; Schopler & Mesibov, 1984). Understandably, economics is a concern. With funding so limited, parents and professionals need to take an active role as “life-long learners” (Barth, 2001) in order to educate themselves and the politicians (Zigler, 1984). Autism rates have never been as high as they are now (Stahmer, Collings, & Palinkas, 2005). There is much concern as to what the future will bring for these children and their families. Society must work together to ensure a positive future. By tapping into parents’ knowledge, more efficient ways to work at home is possible. At this moment many parents are clueless as to whether what they are doing is working well or not. Parents must be encouraged to come together and share experiences on how autism has affected their families and what they have found that has helped. By empowering and educating parents we are empowering society (Schopler et al, 1984). Dewey stresses the use of prior knowledge and experience to learn (Lambert, et al., 2002). What better prior knowledge than that of the parents who live 24/7 with these children? Leaders need to allow parents to describe their techniques used at home and give personal insight to autism. Leaders need to encourage parents to educate themselves rather than fear parental knowledge.

Ultimately, any assistance a child receives rests in the knowledge and decision made by the parents. With so many therapies to choose from, parents must be careful to educate themselves on the most effective documented therapies and trusting their own parental extinct.

Parental Involvement

Research shows the importance of incorporating parents in their child's education (Copeland, 2007; Felber, 1997; Padgett, 2006; Parette, Chuang, & Huer, 2004; Tam & Heng, 2005). Under IDEA and the No Child Left Behind Act (NCLB, 2001), a partnership between school and home became more evident and mandated in schools (NCLB). This partnership increases communication between home and school. It provides more information to parents on their child's progress throughout the child's education. Parents will have resources available to them to assist with their child's strengths or weakness (NCLB).

In regards to children with disabilities, the partnership between schools and families is imperative to ensure the child reaches their full potential through positive interventions (Parette, Chuang, & Huer, 2004). This partnership enables the educators to get an idea of the students' lives outside of school (Felber, 1997). A case study found this involvement enables educators to understand better the child. Who better than the families to give information or who have the most vested interest in the success of that child (Tam & Heng, 2005)? Also, the family members involved in the child's lives will be active within the child's educational path for years to come (Tam & Heng). According to Padgett (2006), children have better attendance, achieve academically, and have better behavior at home and at school when parents are involved in their education. As cited by

Padgett, 71% of principals and 59% of teachers value the importance of parental involvement but find themselves frustrated with it.

Another frustration is the assumption that parents do not care which may be perceived from the parent's lack of motivation in education (Copeland, 2007). There is a social stigma when an individual acts or performs different from what is regarded as normal in dominant society (Jahoda & Markova, 2004). Rather than assume a parent does not care, educators must first understand why parents are not more involved, which could be accomplished by simply asking (Padgett, 2006). Copeland made suggestions in how overcoming cultural barriers while enhancing the communication and participation of families in the education of the children:

1. Learn about the student's culture. This would include the educational norm of their particular country.
2. Explain to the parents what the educational goals are and why things are done the way they are done.
3. Assist new students in their transition to America. Let them watch and listen.
4. Recommend some books that may help the families acquaint themselves with the education system in this country.
5. Allow students to answer or participate through writing or in groups.
6. Watch for nonverbal cues for the child needing help. Culturally, the child may not ask for help even if s/he is told it is OK.
7. Introduce the student to a "buddy" to help the child.
8. Call for a conference as soon as possible to facilitate communication with the parents.

9. Explain to the parents the educational goals and the importance of parental involvement. Explain that this could be as easy as cooking or fieldtrips.
10. If the parents are from a more formal background, be sure to be formal in the communication. If they come with a title from their country, address them as such.
11. Always, be respectful of the culture the child and families brings.

A Comparison and Contrasting of Cultural Influences

According to the U.S. Census Bureau (2006c), we live in a society where 27% of Hispanics live within the Unites States, 16.8% reside in Florida. Hispanics living in the U.S. come from Cuba (5.2%), Central America (8.2%), Mexico (2.3%), Puerto Rico (3%), South America (6.0%), and other countries (8.0%). There are over two million Hispanics or 61.3% of the residents in Miami, Florida (U.S. Census Bureau, 2006b). The breakdown of Hispanics in Miami places the Cubans as the majority with an estimated 767,349; Puerto Ricans at 88,579; Mexicans at 41,942, and other Hispanic or Latinos 573,839 (U.S. Census Bureau, 2006b). In Miami, the total number of documented children with autism enrolled in Miami-Dade County Public school for the 2007-2008 school year was 1,846 (Dade County Public Schools Autism Task Force, 2007). Hispanics are the largest and fastest growing minority group in the United States (Alvarez- McHatton, 2007; Brown & Souto-Manning, 2008; McCabe, 2002; Smokowski & Bacallao, 2007). Although they are the largest minority group in the United States, they are the most underrepresented group in public mental health services (McCabe) and have the highest rates of poverty and inferior health insurance (Alvarez- McHatton; Alvarez-Mchatton & Correa; 2005; Cruza-Guet, et al., 2008; Satchell & Pati, 2005).

As a group the Hispanics have the least amount of education and the highest poverty levels. An alarming 45.3% of Hispanics have less than a high school education with a 23.6% graduation rate; of these 6.4% graduate with a Bachelors degree and 3.6% with a graduate or professional degree. These percentages are the highest amongst all ethnic groups including African Americans, Asian/Pacific, American Indian and non-Hispanic White (Aponte & Crouch, 2000).

The Hispanic community is not immune to the devastating diagnosis of autism (Center for Disease Control, 2006; Mandell, et al., 2002; Overton, Fielding, Garcia de Alba, 2007; Seltzer, et al., 2004), however, this was not always believed to be true. Sanua (1984), concluded that autism was an “illness of Western Civilization, and appear in countries of high technology” (p.173). She found the diagnosis rare in the Hispanic population in the United States, Spain, and Latin America. The medical professions in the Spanish speaking countries were not as educated in autism as those of western civilization. She recommended Hispanics be studied more in the United States due to the high population.

Twenty-four years later, based on searches in educational databases, few studies have been done on the Hispanic families living with autism (Mandell, et al., 2002; Overton, Fielding, Garcia de Alba, 2007; Reyes-Blanes, Correa, & Bailey, 1999). To understand the Hispanic culture and how they relate to disabilities one must educate oneself on the cultural framework of the Hispanic community (Mandell, et al., 2002; Wood, Chiu, Hwang, Jacobs, & Ifekwunigwe, 2008). The cultural framework brings an understanding of how and why families behave the way they do. This behavior will either help or hinder the facilitation for families (Hwang, 2006; Oyserman & Lee, 2008;

Rosenthal, Cohen, & Simeonsson, 2001). To acknowledge the power culture has over an individual will better facilitate the reasoning behind actions taken by an individual in a particular culture (Alvidrez, 1999; Hwang, 2006; Martinez, 2009; McCabe, 2002; Swidler, 2006).

> Virtually all immigrants require care that is culturally sensitive. Homogenized health care that ignores personal and ethnic differences magnifies the inequities in access. Migrant workers, refugees, and asylees, and legal immigrants often need language assistance, targeted outreach, and health professionals who are trained to understand special needs. Institutional and professional biases against poor and foreign-born discourages patients from appropriately using health care systems, thereby jeopardizing successful outcomes achieved through appropriate treatment and patient education. (Riedel, 1998, p. 106)

Professionals should use care when encountering a Hispanic student and their families due to the values and culture (Brice, 2002; Guilamo-Ramos, et al., 2007; Martinez, 2009; McCabe, 2002; Harwood, et al., 1999). Table 8 depicts some basic values and implications within the Hispanic culture that may guide awareness of values that may assist professionals attempting to aide these families. When working with these families professionals should keep in mind the premature dropout rates within this community (McCabe; Wood, et al., 2008).

Some guidelines cited by researchers may also be of use to organizations and professionals that work closely with the Hispanic community.

1. Some Hispanics may prefer to organize into extended family support systems.
2. Some Hispanics may tend to be more present-oriented. Immediate reinforcement may have to be built into individualized education plans.
3. Some Hispanics may come to seek help only when they perceive the situation to be in crisis.

4. Use of the Spanish language is an important social tool.

5. To be charming is as important as is the use of humor. To be judged as disagreeable is considered a cultural sin.

6. Hispanics may be more spontaneous than other ethnic groups.

7. Hispanic males tend to display *machismo* (Brice; Guilamo-Ramos, et al., 2007)

8. Hispanic mothers tend to devote their lives to their children thus exemplifying the role of the Virgin Mary- *marianismo* (Guilamo-Ramos, et al.; Stavans, 2007).

There are two underlying premises within the Hispanic community, which guide them with or without their awareness are *familismo* and *personalismo* (Brice, 2002; Guilamo-Ramos, et al., 2007; Santana-Martin & Santana, 2005; Wilson, Kohn, & Lee, 2000). A qualitative study conducted by Bacallao and Smokowski (2007) presents *Familismoas* possibly being the link connecting a family to care-giving of a child with autism. This theory accentuates the Hispanic individual's emphasis on the importance of family and culture (see also Cruza-Guet, 2008; McCabe, 2002; Smokowski & Bacallao, 2007) even when faced with the added stress of taking care of a family member with a disability (Brice, 2002; Guilamo-Ramos, et al.; Thurman et al., 2000). "Staying together for the sake of the children would be an indication of this value" (Magana & Smith, 2006). Family is considered sacred and is a symbol of all that is good (Brice; McCabe; Smokowski & Bacallao). In familism, the individual give up their individual rights and decision making for the benefit of the family (Bacallao & Smokowski; Brice; Guilamo-Ramos, et al.; McCabe; Halgunseth, Ispa, & Rudy, 2006; Smokowski & Bacallao). Family secrets are never to be brought out into the open. The family is a place where an individual of blood line or kin can find solace and acceptance in good and bad times

Table 9. Cultural Values and Implications for Health Care and Educational Professionals in Serving Hispanics

Expected values	Implications
Respect elder, experts, those with curing powers	Recognize elders, greet the family
Circularness, wholeness	Work with the student and the family as a team effort
Silence is valued	Listen. Wait for answers. Think before speaking. Be comfortable with Silence
Privacy with personal matters	Do not start to ask questions; tell why you are asking and why the information is important
Congeniality and graciousness is cherished	When food and drink are offered accept the hospitality
Accept what is. Health problems are the result of past behaviors.	Preventive medicine is not seen as important; the value of prevention may take time to teach
Modesty and reluctance to show pain, suffering, signs of illness.	A heightened awareness of comfort levels are indicated
Illness is supernatural.	Work with traditional practices
Negative thoughts or actions may cause illness to occur	Speak positively
Time is viewed differently	Family events take precedence over appointments
Belief in traditional healers, *curanderos, Santeros*, folk medicines.	Incorporate traditional beliefs whenever possible

(table continues)

Expected values	Implications
Healers give tangible objects	Leave something at the end of a meeting like a pamphlet or a small toy for stimulation

Note. As cited in Brice (2002, p. 7).

(Alvidrez, 1999; Brice; Guilamo-Ramos, et al.; Halgunseth, Ispa, & Rudy; Vazquez, 2004). They are considered warm and loving, yet are viewed as authoritarian or too permissive when it comes to raising their children (Achhpal, Goldman, & Rohner, 2007; Cardona, Nicholson, & Fox, 2000; Halgunseth, Ispa, & Rudy; Julian, McKenry, & McKelvey, 1994). There is evidence suggesting the tendency of *familismo* declining over generations (Halgunseth, Ispa, & Rudy).

Personalismo is how an individual addresses a Hispanic. According to qualitative studies, Caucasians tend get to the point in a conversation (Guilamo-Ramos, et. al, 2007; McCabe, 2002), whereas, the Hispanic relies on personal information in order to gain confidence and trust. For example, a Hispanic would prefer another Hispanic to be their doctor. However, if unable to acquire one, the Hispanic would feel more comfortable with a doctor that would speak to them about their family, their hobbies, where they just had lunch. Counter to this, Caucasians prefer to be in and out of an appointment (Guilamo-Ramos, et al; McCabe). In using personalismo, the Hispanic expects the professionals to share parts of their personal life in order to open up (Guilamo-Ramos, et al.; McCabe). Professionals must acknowledge the stress a child with autism has on a family regardless of race (Seltzer, et al., 2004)

When speaking of Hispanics, the author's data will emphasize three groups in Miami-Dade County- Mexican, Puerto Rican, and Cuban. Although Hispanics share a common language, similar cultural backgrounds, religion, and ancestry, it cannot be assumed they are all the same (De Von Figueroa-Moseley, 2009; Julian, McKenry, & McKelvey, 1994). Each group has a different perspective of how a disability or illness is regarded (Alvidrez, 1999; De Von Figueroa-Moseley). Professionals must be sensitive to the cultures and belief in folk illnesses that permeate the Hispanic culture (Baer, Clark, & Peterson, 1998; McCabe, 2002; Wood, et al., 2008). The researcher will use key elements in the culture and family systems theory to show how they play an intricate role in the diagnosis and treatment of a child with ASD within the Hispanic community living in Miami-Dade County.

Mexican

For the purpose of this research, the term Mexican will be referred to as those individuals who are of Mexican decent living in the United States (Martinez, 2009). In Miami-Dade County, the Mexican populations is generally from low Social Economic Status (SES) and are likely to be uninsured (Collins, 2002; McCabe, 2002; Riedel, 1998, p. 110; Wood, et al., 2008). The Mexican population is the fastest growing group in the United States (Wood, et al.). As a group the Mexicans have the lowest insurance coverage than any other ethnic group (Collins, 2002; Wells, Hough, Golding, Burnam, & Karno, 1987). According to Riedel, this lack of insurance and lack of seeking medical attention lead to unfavorable health (see also McCabe, 2002). The Mexican population tends to work as labor or field workers (Guendelman, 1998). They often relocate for employment often times following the seasonal crops (Bacallao & Smokowski, 2007; Napolitano & Goldberg).

For the Mexican family, it is not uncommon to find more than one family living under one roof in substandard living quarters (Angel, Angel, Lee, & Markides, 1999; Napolitano & Goldberg, 1998). The Mexican families have a deep commitment to their families. There is a strong sense of obligation in keeping the family together and solely relying on the family for support. The Mexicans that come to this country are in the United States to improve their way of life and to help the family that remained in Mexico. For some Mexicans, survival is what is important while education may not be viewed as a priority (Angel, Angel, Lee, & Markides, Guendelman). By contrast, in a qualitative research done by Bacallao and Smokowski (2007) found that others chose to come to the United States in order to increase the chance of their children receiving an education. An education that was likely impossible in their country (Bacallao & Smokowski, 2007)

In the Mexican culture, many remain true to their heritage by holding on to folk therapies (also known as CAM) and spirituality (Bacallao & Smokowski, 2007; Martinez, 2009). This includes their views of illness. For the Mexicans illness can be caused naturally or by witchcraft (Baer, Clark, & Peterson, 1998). Health is considered to be a balance between the "social and spiritual realms" (Baer, Clark, & Peterson, p. 193). Mexicans use a lot of herbal and other home remedies for the sick. In fact 53% of Mexican families admit to treating their children with these remedies (Baer, Clark, & Peterson). The Mexicans place a high emphasis on natural remedies provided by *curandero, santero, or espiritistas* (Martinez). These remedies are dated as far back as the era of the Aztec and pre-Columbian civilization (Martinez).

Puerto Rican

Puerto Rico is a commonwealth of the United States. Puerto Ricans are American citizens but are still considered Hispanics; however, they have all the same benefits of an American citizen (Reyes-Blanes, Correa, & Bailey, 1999; Riedel, 1998). They are able to travel to and from the mainland with no passports. This ease of travel is said to have produced a unique problem with this group (Reyes-Blanes, Correa, & Bailey; Riedel). Since the Puerto Ricans have the ability to move from the island to the mainland as they want, assimilation has become more challenging for this group as compared to others (Reyes-Blanes, Correa, & Bailey; Riedel, p.111).

The Puerto Rican family emphasizes the extended family, which includes aunts (*tias*), uncles (*tios*), grandparents (*abuelos*), (Aponte & Johnson, 2000; Brice, 2002; Guilamo-Ramos, et al., 2007) and godparents (*compadrazco*) (Aponte & Johnson; Guilamo-Ramos, et al.). Everyone in the family helps to raise a child within the family nucleus (Brice; Guilamo-Ramos, et al.). The men are considered to be the authority figures that are responsible for the decisions made within the household. This is known as *machismo* (Guilamo-Ramos, et al.). In contrast to this, 60% of Puerto Rican families have a female head of household which leads to the low SES (Guendelman, 1998; Riedel, 1998). Regardless of the high amount of single family homes, the Puerto Rican have a hierarchy level they call *respecto*. *Respecto* is a way to describe harmony amongst the generations and the self (Halgunseth, Ispa, & Rudy, 2006). The children are taught at a very early age the verbal and nonverbal behaviors that are acceptable to their culture. For example, children are taught when and how to great, when to speak, and never interrupt an adult conversation (Halgunseth, Ispa, & Rudy). *Respecto* is a hierarchy given to authority figures within the community and the family. It is gained with age and status (Guilamo-Ramos, et al.). Children are to respect their parents no matter how old they are (Guilamo-Ramos, et al).

The poverty level of Puerto Ricans living on the mainland is the highest amongst all the Hispanic groups (Porter, 2000). They share with the Mexican population a lower high school graduation rates and lower rates in college attendance. In New York, the drop out rate is from 42 to 80 percent (Porter). Teen pregnancy is highest with this group (14.6%) than any other Hispanic group (Guendelman, 1998). Infant mortality comes in at 7.6%, the lowest healthy births within the Hispanic community (Guendelman). This group is prone to “violence, substance abuse, and HIV/AIDS” (Riedel, 1998, p. 111).

The Puerto Rican believes that good health is a gift from God and illness is viewed as a punishment for past sins committed. In the event of emotional or mental health issues witchcraft may be used to cure the ailment (Alvidrez, 1999; Riedel, 1998). Another effective treatment has been the use of storytelling of Puerto Rican folktales (*cuentos*) as a way of reducing stress, reducing anxiety, and not passing judgment by using a hero or heroine (Alvidrez, 1999; Hwang, 2006; Thurman et al., 2000, p. 227).

Cuban

Cubans represent 55% of the population in Miami (U. S. Census Bureau, 2000b). Education is valued more within the Cuban group (Mcewan & Marshakk, 2004) than the Mexican and Puerto Rican population (Guendelman, 1998). They place an incredible amount of pressure on their children to succeed (Brice, 2002).

Cubans tend to live with their parents until they marry (Skaine, 2003). Marriage is expected after a college degree is achieved. The Cuban mother believe in keeping their children as close to them as possible and in pampering their children. The older sons are seen as the future heirs. Daughters are seen as the ones that will care for smaller children and their parents in their old age (Brice, 2002; Skaine).

For Cubans good health is seen as a "balance of humans with their environment, natural with supernatural, mind with body, and hot and cold (as cited in Baer, Clark, & Peterson, 1998, p. 193). The belief that illness is brought on by evil spirits, magic, or as God's will reigns over this population. The Cubans believe that a person's health can be affected by the evil eye (*mal de ojo)* or by sudden fear (*susto*). The Cubans try to protect their children and women from the evil eye by placing amulets on their children's clothing. These amulets can be in the form of two eyes, beads, a hand, and/or a black stone. Historically, these amulets come from the West African religion combined with Catholicism known as *santeria* and *brujeria* (Baer, Clark, & Peterson, p. 193).

Within the Hispanic community, the family system is one that extends to outside that of father and mother (Marshall, Koenig, Grifhorst, & Ewijk, 1998). The Hispanic community is a unique group, in that, their strong beliefs of the spiritual world influences their daily activity and decisions that need to be made (Marshall, Koenig, Grifhorst, & Ewijk). Practitioners must be sensitive to the culture and the beliefs of folk illnesses in order to improve the diagnosis and treatment of an individual with a disability (Hwang, 2006; Marshall, Koenig, Grifhorst, & Ewijk). Many immigrants come to this country not knowing the language or cultural norms. Many of them are unprepared to make medical decisions on their own due to the reliance they have had on the family system in their native countries (Hwang; Marshall, Koenig, Grifhorst, & Ewijk). In essence there is no

“I”, Hispanics view themselves as “we” or “us”. The family unit sticks together in good and bad times.

Summary of Cultural Influences

This section presented the statistics given by the U.S. Census Bureau regarding the increase in the Hispanic population. The focus was on three dominant groups living within Miami-Dade County, Mexican, Puerto Rican, and Cuban population. Within each group the researcher detailed certain customs and beliefs that may play an integral part in the decisions parents are making in determining the best medical and educational path for their child with ASD. With regards to the best medical and educational path, there are numerous influences for the Hispanic family. All of this will affect the family’s decision to seek help from professionals as well as what services they will use. The psychological functioning, how an illness is expressed is impacted by the belief system of an ethnic group (Aponte & Johnson, 2000, p. 18). The weight of culture of the Hispanic community must be taken into account when determining a specific course of action to be taken with any member of the family- especially a child (Overton, Fielding, Garcia de Alba, 2007).

Summary of Section 2

In summary, section 2 contained a reviewed literature concerning the history of ASD, possible therapies, parental involvements and potential cultural influences that may play a role in why Hispanic families make certain decisions. Included were symptoms and diagnostic tools used to diagnose ASD as well as a comprehensive list of the most popular therapies currently being utilized to treat a child with ASD. This was followed by research on parental involvement as well as statistics on the Hispanic population. For the purpose of this study, I presented three prominent groups living in Miami-Dade County-Mexican, Puerto Rican and Cuban. After an extensive review of the literature on ASD and the Hispanic culture, it is believed that many themes will arise from the data. Some of the themes may include but are not limited to age of diagnosis, family coping strategies, and how therapies are being selected. For example, the theme of age of diagnosis was influenced by Overton, Fielding, and Garcia de Alba (2007). These researchers found that Hispanics have a lower rate of diagnosis and may be under diagnosed. Another theme is family coping strategies which was inspired by Hutton and Caron's, Ex*periences of families with children with autism in Rural England* (2005), as well as Gray's work in 1994 and 2006. They found a vast array of coping strategies families acquire after the initial realization their child has an ASD. Finally, the potential theme of the therapies parents were choosing was impressed upon by Mandell and Novak (2005). They stressed in their research the weight culture plays in determining parental understanding and assimilation of ASD. In fact, Mandell and Novak recommended future research be done on the cultural difference in recognition of symptoms, how decisions are made for medical and educational settings, and possible intervention strategies.

In section 3 a detailed description of the methodology used for this study will be presented. Section 3 will contain the design, restate the research question, and give a description of the researcher’s role, the participants, data collection procedures, and data analysis.

SECTION III: DESIGN AND METHODOLOGY

Introduction

Given the increase of the Hispanic American population and the historically low and late identification of Hispanic children with ASD, it is critical to increase the understanding of what roles cultural factors play in parents' decisions to choose one therapy over another. As stated in section 1, there are two primary purposes of this study. The first is to describe and understand ASD as it relates to the Hispanic families living within Miami-Dade County. The second purpose is to understand the decisions parents make when choosing specific therapies in and out of school to aid their child with ASD within Miami-Dade County. The number of children registered with ASD in Miami-Dade County is considerably lower in than the national average. Parents are either unaware of their children's disabilities or are unaware of services available within the county. This is a problem because these unidentified children are not receiving proper therapies and services available within the community. Since it is the parent or primary caregiver who makes these decisions, a phenomenological qualitative research design affords exploration of their perspectives.

In the previous sections the research topic was introduced and an explanation of its importance to future studies was provided. Section 2 included a review of current literature on autism and Hispanic culture. This section contains detailed information regarding the methodology and the procedures used for conducting this phenomenological study.

Research Design

For this study, the qualitative design is the most useful for facilitating an open dialogue with participants living with a child with ASD. The qualitative design focuses "on a single phenomenon or concept" (Creswell, 2003, p. 106). The qualitative design allows participants more freedom when answering questions (Moustakas, 1994; Van Manen, 1990). Moustakas called for the researcher to be able to write about their personal experiences about a specific subject before being able to describe the experiences of individuals within a study. This method allows for open-ended questions, interviews, observation data, and document data. It allows participants the freedom to tell their own personal experiences while allowing the researcher to collect the data into developing themes (Moustakas; Van Manen).

The design chosen for this study was the phenomenological design (Moustakas, 1994; Sokolowski, 2000; Van Manen, 1990). The phenomenological design is the study of life as it is experienced. It is "a deeper understanding of the nature or meaning of our everyday experiences" (Van Manen, p. 9). It was selected as an inductive approach to engage the participants in a discussion of the phenomenon of *familismo* and *personalismo* as it relates to Hispanic families living with a child with autism. The method of gathering information included interviews, focus groups, discussions, and observations (Moustakas; Sokolowski; Van Manen). This methodology helped to identify the perceptions and lived experiences (Sokolowski; Van Manen) of the Hispanic community. The experiences of the participants were gathered and analyzed as a collective group in order to better understand how one's culture might dictate decisions made (Moustakas; Sokolowski; Van Manen).

Alternatively, there are other qualitative traditions that could have been used in place of phenomenology. Other forms of the qualitative design include Ethnography, narrative, grounded theory, and case study (Creswell, 1998). None of these designs would have been applicable to this particular study. For example, the ethnography method studies a cultural group by observing and collecting data for a prolonged period of time (Creswell). This was not the right moment to conduct a study over an extensive period of time without a larger team of researchers and time. Therefore, ethnography was rejected because of time constraints needed to study a culture in it natural habitat (Creswell, 2003). The next method that was rejected was the narrative research. I would need to study the lives of the participants involved in the study. At the conclusion of the narrative research I would have retold individual stories that may or may not be applicable to a larger population (Creswell, 2003). Thus, the narrative research was rejected. The next option was grounded theory. Grounded theory would have involved multiple stages of data collection and analyses throughout the study. Again, for the time allotted to conduct this study, the ground theory was rejected due to time constraints. Finally, the case study was considered but rejected. The case study would require an in depth study of a program, activity, or process of one or more individuals over a sustained time period (Creswell, 1998; Creswell, 2003). The case study was rejected due to sustained time needed to conduct the study.

Finally, in order to facilitate the research, I chose a qualitative design rather than a quantitative design. A quantitative design would have required an experimental and/or nonexperimental form of inquiry with the intent of using an experimental group to prove theory or hypothesis. In this study the research questions do not form a theory or hypothesis. Furthermore, the subjects would be required to enter into an experiment with treatment conditions. There are no treatment conditions in this study; therefore, a quantitative design was deemed inappropriate (Creswell, 2003).

Research Questions

The questions that guided this study were:

1. How does culture play a part in the age of diagnosis for a Hispanic child?
2. How does culture influence the choices that Hispanic families make to aid their child with ASD?
3. What possible effects do professionals have on Hispanic families with a child with ASD?
4. What therapies are Hispanic families choosing to aid their child?
5. To what extent are external family members involved in raising the child with ASD?

Context of the Study

The population of Miami-Dade County is 61.3% Hispanic, thus accessing Hispanics for this study is convenient (U.S. Census, 2006b). The executive director of University of Miami CARD Center, the executive director of Parent to Parent of Miami, and the principal of Atlantis Academy, all located in Miami-Dade County, ensured access to potential participants for the purposed research study. In addition to location, these organizations were chosen because they provide services to a large number of Hispanic families living with children with ASD. According to Dr. Michael Alesandri, executive director of University of Miami CARD Center, the exact numbers of children with autism living in Miami-Dade County is "tough to know for sure. We have 2,263 individuals registered with CARD in Miami-Dade. But based on a 1/150 rate and a population of 2,387,789, there should be 15,919" (personal communication, June 8, 2009).

Ethical Issues

In preparing to conduct the study, discussions were held with the gatekeepers of the agencies that would assist in accessing participants. Details of the study and procedures for protection of participants were discussed. Copies of the letter of permission to gain access to participants (see appendix A) were submitted with the proposal for the study to the Institutional Review Board (IRB) for permission to conduct the study. Once approval was received from the IRB 10-05-09-0334575, I approached the gatekeepers to gain access to a pool of participants. Then, participants were selected based on purposeful sampling described later in this section. Once potential participants were identified, I communicated with them the purpose of the study and ensured their confidentiality. Once the potential participant communicated interest in the study a time and place to conduct the interview was established. At the beginning of the interview, I obtained signed consent forms to conduct the interviews (appendix B). Finally, interviews were conducted individually.

There were minimal risks to the parents associated with participating in this study. This study focused on the responses of the parents and not that of the child. Participants were told of their freedom to participate in the current study, told of their right to participate and the right to withdraw at any time, know the purpose of the study, know the expected procedures of the study, have the right to ask questions, obtain a copy of the transcript, obtain a copy of the study results, have their privacy respected, and obtain the signature of the researcher agreeing to all the terms specified.

Confidentiality was addressed by assuring the participants that a pseudonym would be used in place of their real names. I signed a confidentiality agreement, which acknowledged and agreed to not disclosing or discussing confidential information with others or in the presence of anyone who could overhear the conversations, even if names were not used. I agreed to not divulge copy, release, or sell any information. No unauthorized transmittals of confidential information would occur. Acknowledgement of the legal implications of violating any and all terms found in the confidentially agreement even after the termination of the research was made.

This informed consent and confidentiality agreement will protect the participants from any physical or psychological harm. All data will be maintained in my home for a period of 3 years from the date of completion of the study.

Role of the Researcher

The researcher's role in this study was as an examiner of the lives of the participants' experiences as Hispanics with a child with autism. There was no tie to any of the participants in terms of professional nor social relationships thus data collection will not be affected. A trusting relationship with the participants through gatekeepers was developed. These gatekeepers included the executive director of Parent to Parent of Miami, the executive director of University of Miami CARD Center, and the principal of Atlantis Academy. My function was investigator of documents or artifacts (journals, diaries, etc.), translator of materials into Spanish, and interviewer of the participants in either English or Spanish. During the interview process and data analysis, I bracketed my personal experience as a Hispanic and mother of a child with autism.

Participants

Participants were chosen using purposeful sampling (Creswell, 2003). This type of sampling enables a group of homogenous individuals who have common experiences or characteristics to come together (Hatch, 2002). For the purpose of this study, the common characteristics were Hispanic ethnicity, and being a parent of a child with ASD living in Miami-Dade County. These criteria aligned with parameters set forth in the research design. Creswell recommends six to eight participants in the interview process (2003). I chose eight as a means to saturate the information being given (Seidman, 2006). There was a point in the interview process where no new information was given and the stories appeared to be the same (Seidman). For example, families had the same experiences with the developmental milestones and personal perceptions throughout the children's development.

Participants in this study were asked to provide documentation of their children's diagnoses to ensure accuracy. Accepted documentation included a psychological evaluations, school reports, or letters from physicians (e.g. pediatrician, psychologist). The families were recruited from local parent resource centers and private school located in Miami-Dade by use of fliers (appendix D). Participants were first and second generation Hispanics with a child diagnosed with an ASD. Families may have children of the same chronological age; however, the children exhibit different developmental abilities due to the broad spectrum of this disorder. This ensured the representation of a variety of families each with a unique experience (Van Manen, 1990). Once volunteer's eligibility for the research was determined, a consent form was mailed to the participant (appendix b) and the consent form was discussed and signed at the time of the interview.

Data Collection and Recording Tools

Upon approval from the Walden University IRB, data collection began. Meetings were held with the gatekeepers' and potential participants in order to give an overview of the study and invite potential participants to take part in the study (Seidman, 2006). I acted as the primary data collector by reviewing documentation and by conducting interviews in English or Spanish. The interview was recorded using a cassette recorder. The recorder was checked before each interview for proper functioning. Extra cassettes and batteries were available in case the need arose (Hatch, 2002). Decisions regarding the interview questions were based on a pilot test administered in spring of 2008 for course number EDUC 8035, Qualitative Research at Walden University under the guidance of Dr. Edward Kim. The participants for the pilot study included close friends and family members who had a child diagnosed with ASD and were willing to assist in the preliminary stages of this study. None of the participants in the pilot took part in the actual study.

Also, the interview questions were designed over a period of 3 years. As peer based studies and books related to autism were reviewed, I would write down a question that would pertain to this study. The questions developed were examined by two peers who are pursuing a doctorate degree from Walden University, experts in the field of autism (professors at Walden University and the executive director of UM CARD), parents who piloted the research study, and special education teachers within Miami-Dade County. Prior to the pilot, I was advised to reword the questions in order to promote open ended discussions. Reliability of the interview questions was addressed when the questions were tested in this pilot study and where peer and expert reviewed. Any questions that were regarded as insensitive or invasive by those that reviewed it were either deleted or revised. Some of the questions might have placed the caregiver under stress by providing their names and feelings towards the initial reaction to the diagnosis, feelings towards educational and medical profession. For example, I removed the following questions due to the experience and expertise of my committee members; I willingly adhered to their suggestions:

1. How did you feel when you received the diagnosis?
2. What was your reaction?

Data for this study included demographic data, recorded interviews and highlight themes from the interview (Smith, et al., 2002). Data were collected and put into an outline format by using Roman Numerals and letters that identified key elements within the interview. Using the outline format allowed the researcher the ability to place important dates of specific events or other notations easily on the margins of the paper (Hatch, 2002). At the end of organizing the data, recurring or similar experiences were grouped and/or clustered together in columns. The topics at the top of these columns were abbreviated with a code. Codes were alphabetized for the researcher to be able to find specific topics with ease (see appendix C). If need be, the option of recoding the data if the original coding system did not function was available (Creswell, 2003).

Interviews

Interviews were conducted at a location agreed upon with the participant. The purpose of the study was restated, complete a demographic data form (appendix E), review consent forms, and reminding the participants of the projected time for the interview. Each interview lasted approximately 1 hour. The interviews were recorded for accuracy and transcribed within two weeks. The participants were asked questions that were peer reviewed and had been viewed by an expert panel consisting of parents, teachers, and other professionals that have dealt with families living with a child with autism (appendix F). During the interview, field notes were taken. As Rubin and Rubin (2005) found the field notes force the researcher to pay attention to key elements in the interview and can be considered a backup in the event the recording device fails. By paying attention, I was able to consider follow-up questions in order to clarify answers being given by the caregivers.

The common language of inhabitants of Miami is Spanish; however, English is also commonly used. Participants in this study spoke English, Spanish, or both at the same time. I was able to conduct the study the language of choice. The interview was composed of the following elements:

1. Setting the stage, review of consent form and ask for anything that needed clarification.
2. Review of documentation verifying diagnosis.
3. Interview questions were given in an open-ended format. This format enabled parents to express their experiences and viewpoints using their own voice (Seidman, 2006).
4. Allowing the participant’s the opportunity to review the transcripts after it had been transcribed in their preferred language prior to analyzing data to ensure accuracy.

Throughout the process, a reflective journal was kept in order to keep the researcher's own beliefs and ideas separated from the actual research (Van Manen, 1990).

Data Analysis and Interpretation Plan

Prior to coding, the participants were given a copy of their transcripts to check for accuracy (Hatch, 2002). Once the participants viewed the transcribed interviews, the interviews were coded for potential themes (Hatch; Moustakas, 1994). As I reflected in my journal and read through the transcripts of the interviews, I highlighted, sorted, and labeled themes and thoughts with codes only known to me. These codes were used to organize data. This ensured confidentiality to the participants by ensuring their identity would not be divulged by responses given. This way no responses can be linked to a participant.

Data obtained will be presented in a table in Section 4. This table will show the common themes and frequency in responses to particular questions. The results of this study will be presented and analyzed in Section 4. Use of the triangulation method in order to ensure accuracy of data and frequency of themes that arose from the interviews was utilized. Triangulation is the "verification or extension of information from other sources" (Hatch, 2002, p. 92) which include the psychological evaluation, school report, or letter from physician (e.g. pediatrician, psychologist) and/or the interview. By using triangulation, I was able to gather information without interrupting the daily lives of the participants. This method enabled me to use different sources to corroborate the perspective within this study (Creswell, 1998; Hatch, 2002).

Data obtained was reviewed and analyzed on an ongoing basis after completing and transcribing each of the 8 interviews. Hatch recommended an interpretive analysis for data collected in phenomenological studies (2002, p. 181). Hatch's model was chosen because of his explicit plan to relate the participant's perspectives to what the researcher had in mind when the study was first developed. I included typologies already in mind as well as any that may have arisen unexpectedly during the analysis. Once the typologies were identified and recorded, a summary sheet was created. At this time I conducted an extensive search for themes and patterns which may or may not be consistent to the outcome I had in mind. All themes and patterns will be coded. Once I reviewed the themes and patterns, I wrote a one-sentence generalization about it as a way of "examining and bringing them together" (Hatch, p. 159). This enabled me to pull data together in a cohesive format by relating the data to the research questions.

Validity

Validity is a term that can be found in quantitative, mix method, and qualitative studies. In a qualitative study, the term validity carries a different meaning. It is considered a strength in a qualitative study (Creswell, 2003). Validity "is used to suggest determining whether the findings are accurate from the standpoint of the researcher, participant, or the readers of an account" (Creswell, pp. 195-196). Creswell lists eight possible strategies to check for validity within a study. I chose five of the eight for this study. The following were used:

1. Triangulation of the themes that emerged.
2. Member checking. Provide the transcript's to the participants to ensure accuracy of the responses given.
3. Peer reviewed the questions in the study a final time.
4. Clarification of any biases brought in by recording in research journals and/or bracketed in protocols and recorded these in memos.

5. Read data, identified impressions, and recorded impressions in memos by use of a rich, thick description.

Summary of Section 3

The purpose of this phenomenological study was to examine the effect of autism on the Hispanic families living within Miami-Dade County. Data was collected by interviewing participants willing to take part in this study. In addition, the role of the researcher, a description of the participants who have a child with ASD, ethical procedures, interview process, and data collection had been discussed in this section. It is my aspiration to give society an insight into the Hispanic culture. This insight may assist in diagnosing children at an earlier age and assist parents with their child's educational and emotional needs. These results may be considered useful when working with Hispanic families with a child with ASD in the fields of education, pediatric, and psychology.

SECTION IV: RESULTS

Introduction

The purpose of this phenomenological study was to explore the ASD diagnosis as it pertained to the diagnostic effects on Hispanic families living within Miami-Dade County. By utilizing the descriptions set forth by Van Manen (1990), the phenomenological approach was applied to this study. This design utilized open-ended questions which permitted parents, who volunteered, the freedom to express through discussion their thoughts and personal experiences of living with a child diagnosed with ASD in an interview setting.

Section 4 of this study contains a description of the qualitative data collected during the eight interviews. Data included the experiences and perceptions of eight Hispanic families with a child with autism in four different developmental ages. Two of the children were not yet enrolled in full-time school. The next group was school aged. The next sample was the group transitioning out of the educational system. The last group consisted of families with an adult child with autism. Section 4 includes data collection and recording procedures, the system of record keeping, a profile of the participants, and discrepant data.

Data Collection and Recoding

On the day of each prescheduled interview, I reviewed the child's diagnosis of ASD through psychological evaluation or school reports. Once diagnosis was verified, the participants were given the consent form in their self-identified preferred language (Appendix B). I reviewed with the participant the consent form, confidentiality agreement, demographic survey, and the projected time of the interview. Once the documents were reviewed and all questions answered, I had the participant sign the necessary forms. Two interviews had more than one guardian present. The researcher had both guardians sign all forms. I then signed the confidentiality agreement and presented each participant with a copy. All forms were labeled as P1 through P8. These forms are located in a folder in a locked cabinet in the researcher's place of residence and will be destroyed after 5 years.

The participants of this study were interviewed between October and December, 2009. Six of the participants elected to have the researcher conduct the interviews in their home in order to facilitate their child's therapy schedules and family commitments. One interview took place at the office of the Parent to Parent organization. Although unexpected, one interview took place in my home because the participant insisted she did not want her son to be present for the interview and it gave her an excuse to take a break.

The semi structured interviews were conducted in person in the participant's preferential language (Appendix F). During this process P1 insisted on conducting the interview in English even though her primary language was Spanish, which did not seem to have an impact on the interview. Interviews with P2 and P6 were done in English and Spanish. P3 and P7 were in English only and finally P4's, P5's, and P8's interviews were in Spanish only. In Table 10 the participant breakdowns including the preferential language of the participant during the interview.

Table 10: Participant Breakdown

Participant	Stages	Country of Origin	Language Spoken
P1	Not yet in school	Cuba	English (with heavy accent)
P2	In school between Kindergarten and 9th grade	Venezuela	English and Spanish
P3	In school between Kindergarten and 9th grade	Cuba	English
P4	In school between 10th and 12th grade	Mexico	Spanish
P5	Ages 18 and up	Colombia	Spanish
P6	Ages 18 and up	Puerto Rico	English and Spanish
P7	In school between 10th and 12th grade	Chile	English
P8	Not yet in school	Cuba	Spanish

During the initial face-to-face meeting, I established a dialogue with the participant. I was often offered coffee or a snack. Parents asked me questions about my personal experiences with autism. This technique was used as a means of personalizing the researcher to the participant by lived experiences. These conversations were not recorded (Van Manen, 1990). By use of the semi structured interviews, participants were able to express their personal stories while using their own experiences and voices. “At the same time, the words are flavored by the style with which we have disclosed the things in question, so they indicate to the reader or listener something about ourselves as well” (Sokolowski, 2000, p. 158). I created open-ended questions that encouraged the participants to tell their stories. In many cases, the participant responses did not need much probing or follow up questions. Most participants were more than willing to tell their stories. In fact, some questions had been answered through the personal stories retold by the participants. Participants discussed areas of concern as it related to their child’s ASD or their experiences with the medical profession and/or educators. Some participants discussed unrelated issues not connected to the research study. I allowed the dialogue to continue in order to continue rapport and dialogue (Van Manen, 1990). These conversations are marked in parenthesis within the transcripts. I would gently guide the parent back to the study by asking the parent what they thought or how they handled the situation. Then I initiated a question in order to have the parent come back to the topic of the study (Van Manen, 1990).

My role in the interview process was to verify the diagnosis of ASD by reviewing documentation with an ASD diagnosis, conduct the interview by asking the pre-approved questions and probing questions, make clarifications as needed while taking field notes, and recording the interviews on a cassette recorder. If the participant asked for clarification of a question, or appeared confused or perplexed, then I elaborated the questions. For example:

Researcher: Describe how the family is involved in your child's treatment. You said grandma and aunt are involved. What is their involvement in helping?
P1: And I do tell them like I sit down my mom and tell her like forget about the mess. Forget about everything
Researcher ok
P1: Like right now you saw the pile of clothes because I had to pick up the house yesterday that was a mess and I wanted to keep the house clean and whatever
Researcher right
P1: But I told her forget about the cloths ok the clothes will be done tomorrow you focus on them like
Researcher: Ok, your family is here helping you for example with chores, watching the children while you get stuff done. When it comes to the therapy if they give you suggestions because I noticed in the bathroom you had the pictures
P1: Uh huh
Researcher: Does the family follow that regimen do they help you with that?
P1: No I have to be on top of them

In other instances, if the participant's responses were mumbled or unclear, I would ask the respondent to restate the response. Each interview was recorded on a separate cassette tape marked P1 through P8. Most interviews lasted between 45 minutes to 90 minutes. This time frame depended on the participant's elaboration of his or her experiences. Upon completion, I transcribed each interview into a Microsoft Word document using the language of the interviewee. Then I translated the Spanish interviews into English. The interviews conducted in Spanish were saved in Microsoft Word at the different stages. For example, the interview of participant 2 was labeled as P2 before the translation. After it was translated it was marked as P2translated, then finally P2coded. If an interview had more than one guardian present, the transcript would read P2m for mom and P2h for dad. These can be found on my computer file and on a flash drive. In order to assure accuracy, transcripts were sent to the participants within a two week time period. Participants were called within 3 days of sending the transcripts in order confirm receipt and verify their accuracy. The only correction was made by P3 in regard to the age difference of her children.

The interview of P1, summary of the interview of P1, codes for the interviews, and individual coded interview of P1 were sent to the committee chair and methodologist to determine if I was on track for IRB purposes and maintaining a clear path to answering the research questions. Both the committee chair and methodologist determined the interview was a success and could continue to move forward. I then continued to conduct interviews, transcribe, and code interviews within 2 weeks in order to keep the interviews fresh in my mind. The interview questions were the same for all the interviews. However, as was previously stated, some responses needed probing and clarification in order to ensure the parent and I understood the answers being expressed. There were instances in which I noticed the parents' confusion with a particular question. Parents would stare at me after the question was asked with a blank look on their faces or they would tell me they did not understand the question. There were times I would elaborate or personalize the question to fit the situation. Interview questions had to be modified and/or rephrased based on the parents' understanding of the question (Rubin & Rubin, 2005). For example, for parents whose children have not yet entered the school system the questions pertaining to education were not asked. It was rephrased as "What are your concerns once your child enters school?" Also, some interview questions were never asked because parents were so eager to tell their story they would answer some of the research questions on their own as they described their journey.

Researcher's Journal

A leather bound journal was purchased in order to maintain throughout the interview process. This journal was always with me in the event I had an idea or thought on a particular participant (Van Manen, 1990). The journal contains some contact information, observations made during the interview, impressions of the participants, ideas and suggestions the participants may need, personal reflection of her own children, a working code, rubric notes for section 4 and 5, and personal feelings.

Through use of the journal, I was able to separate my feelings from what I was trying to accomplish with the study. This method is known as bracketing (Hatch, 2002). In the journal, I expressed concern or distress for particular participants. I expressed correlations between my personal experiences and those of some of the participants. There were times when I had to stop and view the situation from my own experiences, "self-awareness, self-reflection and self-knowledge" (Moustakas, 1994, p. 95) in order to refocus. For example, after completing the first interview, I wrote in the journal, "I could not help to compare myself to P1. It seemed so similar." Upon completing P3, I thought about my daughter. I wrote, "I thought of Naomi. Her life and how it's been affected."

Pilot Study

The pilot study assisted me with the refinement of research questions and the overall format. The Hispanic participants volunteered to pilot the study and did not partake in the final study. The same interview protocols were used. Participants provided feedback on the interview questions and length of the process. The pilot study lasted 90 minutes or more. The pilot study participants felt that the interview questions were more personal and gave the appearance of being "intrusive." Questions were adjusted with the assistance of my committee.

Interviews

Data collection began once IRB approval was received from Walden University. The first step was to gain access to the participants by acquiring permission from Atlantis Academy, Parent to Parent of Miami, and University of Miami Center for Autism and Related Disabilities (UMCARD) to send out fliers advertising the research study. These organizations provided signed letters of cooperation, which were submitted to IRB for approval. Once the fliers were sent, interested participants called me in order to gain more information. During this contact, the approximate time frame for the interview was relayed, and the purpose and significance of the study was explained. Once interest was established, the consent forms and demographic survey were sent by US mail or email. I would call to verify the parent had received the forms, answer any questions or concerns, and establish an interview date, time, and location.

The participants chosen met the criteria set forth at the beginning of this study. I interviewed the parents of eight individuals with ASD. The stages of the children with autism were: children not yet in school, children between the grades kindergarten through ninth grade, children between tenth and twelfth grade, and children 18 years of age and older. Knowledge about the study was ascertained by the participant through a variety of sources. The first, second, and eighth participants were referred by UMCARD. The third participant came from Parent to Parent. Participant four received the flier from a friend whose child attends Atlantis Academy. Participant 7 was a parent at Atlantis Academy.

Finally, participants five and six received the flier from an undisclosed friend associated with one of the aforementioned organizations.

Participants, within this study, came with their own unique experiences and stories. All participants were first and second generation Hispanics; however, they were from different Spanish speaking countries and had different educational backgrounds.

P1. P1 is of Cuban descent. She tries very hard to speak in English refusing to do the interview in Spanish. P1 is married with 2 children. Her oldest is a girl with normal abilities and the youngest was recently diagnosed with ASD. P1 was studying to become a Special Education teacher when she realized something was wrong with her youngest child. P1 has some family support. The family members that help are her mother and sister. They come to help with chores and /or help watch the children so mom can get something else accomplished. P1 has her son in Occupational Therapy, Speech Therapy, Behavior Therapy, and on a special diet. The Occupational Therapy works on Sensory Integration Issues. Behavior Therapy incorporates ABA and Speech Therapy may include Language Therapy as well (mom was not clear). Mom claims that the medical professionals have been "clueless" with what autism is. No one has really explained the diagnosis. What she knows is through her own research and study. “I freaked out and I just started doing the research and everything. I told my husband and he was like yeah but the neurologist told us you know just do this. And that is what I am saying I do not just sit and do what the neurologist and other educational people say. Just that- I want to do that and beyond.”

P2. P2 was a husband and wife team from Venezuela. The mother made initial contact with the researcher. At first the husband was not going to participate but became interested when he heard the researcher explain the purpose of the study. This husband (P2H) and wife (P2W) team have two children. Their eldest is diagnosed with ASD. He is 12 years old. The youngest child is a typically developing child. The mother is more comfortable speaking Spanish and the father prefers English. Therefore, this interview was conducted in both languages. The mother was the first to recognize something was different about her son. She was a teacher's aide in a special education program in North Carolina. This family feels that they educated themselves, despite being involved with organizations that cater to the ASD population. One of the initial programs their son was part of promoted the TEACCH program, which is used statewide in North Carolina (see section 2 for more information). They decided to move to Miami because of the ABA method used in the school system and because Florida has the McKay Scholarship available to children with special needs. This Scholarship grants families the freedom to choose for their child alternatives to public or private education. P2 has tried to keep their son active in sports and therapies. They believe professionals have yet to fully understand what ASD is. ASD seems to be taboo and no one wants to speak of it. They feel rejected by friends and family. They describe themselves as being alone in raising their son.

P3. P3 is first generation Cuban and fluent in English and Spanish. She is a nurse by trade. She considers herself a child advocate. She has two boys (one twelve and one ten years old). Her oldest is the one with ASD. For the most part, her experiences have been positive. She has support from family and friends. P3 feels "lucky" with their experiences in and out of schools. Her main issues have been with neurologists. Her first neurologist never said the word "autism" but it was in his records. The second neurologist was very blunt and abrasive. The first few visits she just "wanted to hit him with the stapler." Currently, her son's therapies in school include speech, language, occupational, behavior therapy, and applied ABA. P3 does integration therapy and floor time privately. For a time auditory therapy was included but it was discontinued because the therapist moved away. Recently the therapist moved back and she is interested in restarting the program.

P4. P4 is a single mother from Mexico with limited English proficiency as well as reading skills. She works in a cafeteria in a local school. She has two high school aged boys. Her eldest was diagnosed with ASD in third grade and is currently transitioning out of the public school system. P4 heard about the study from a friend who was her son's therapist. She thought the researcher could assist her in understanding and translating a letter she received from SSI and Medicaid. She was very concerned and scared because her son is now 18 and she is no longer permitted to make educational or medical decisions for him. P4 claims to never have been told what the process was with a child with ASD. She believed this study would be good because it is "very good for the community. We need a voice from someone who understands us and can explain this to us." Throughout the study the researcher had to re-explain research questions. P4 would often answer something separate to what was being asked. Even though all questions were answered, this was the shortest of the eight interviews lasting approximately forty minutes.

P5. P5 were a Spanish speaking Columbian couple with a 31-year-old son with autism. The son of P5 had numerous diagnoses before finally diagnosed with ASD. The doctors involved said, "…it was the parent's fault; that the parents were from different cultures. That the parents were too cold". P5 believes not much has changed in 25 years.

"Doctors are no closer knowing the cause and treatment now as back then." They had never done an interview before but believed it was time to "let it all out." They believed this study is important for the community. As a couple, P5 are very united with the care of their son. They are the primary caregivers. They worry about the care their son will receive once they are no longer able to take care of him. They do not want to impose the care of their son with ASD on their other 3 children. P5 believe there are no effective training programs available for adults with ASD. P5m believes children such as her son have a lot to teach the world due to their purity and perfectionism- "if only all of society could be like them."

P6. P6 was a mother and aunt duo from Puerto Rico. Mom and aunt share legal custody of the 21-year-old adult with ASD. The interview of P6 was conducted in English and Spanish. P6m and P6a appeared to be angry with the medical and educational system. They believe no one has really helped them. They have had no training. They have learned about living with a child with ASD through "trial and error". He had numerous diagnoses before finally receiving an ASD diagnosis. The 21 year old speaks very little and he cannot function alone. P6m and P6a try to keep him active in sports and outings. However, they live in constant fear of their safety due to the 21 years olds size and rages. P6m are at the verge of institutionalizing the 21 year old with ASD due to his intense rages that have lately led to him being tazzered by the police.

P7. P7 is a mother from Chile. She is fluent in both English and Spanish. Her son currently receives speech and language therapy, occupational therapy, and physical therapy. Her child also uses social stories and piano as a therapy. However, she feels very strongly about the use of an augmentative device. Based on past experience with the device P7 believes her son will benefit from it. P7 heard about the study from her sons school Atlantis Academy. P7 first noticed something was wrong with her son on his first birthday. When she spoke to her pediatrician about it she described the experience as “Classic, we kept asking the pediatrician, something does not seem right xxx does not seem to be reaching his development mile stones at the time that he should have been meeting them and um…. The pediatrician said, "He is a boy, and boys are slower. You have a daughter and she is very advanced. So your son is you know… sometimes in the older sibling, tries to take care of things or get involved, so the second child gets a little lazy; and this is just the way a lot of boys are.” Once her son received a diagnosis, the neurologist said to her “now you go out and you be your child’s advocate. And that’s it. And that was his parting words. Go out and be your child’s advocate.” P7 educated herself on ASD. She has family support. She has hopes for her son but feels society is lacking on good programs that will train the children to work and live independently.

P8. The final interview was an immigrant Hispanic family who just received a diagnosis from UMCARD about 2 weeks prior to the interview. P8h was from Santo Domingo and P8w was from Cuba. P8h stepped out of the interview as soon as the consent forms were signed. He went to care for the children ages 2 and 3. P8w describes the 3-year-old as very hyper. P8w has more concerns with her daughter than her son who was diagnosed just after his second birthday. The observations of P8w are that her son does not speak, only eats rice from a spoon, and eats anything including his diaper and crib. She does not understand PDD-NOS. “Is it or isn’t it autism?” Her understanding is it is not. She has hopes for her son that he will be cured and he will be able to go to a "regular school and live a normal life."

Data Analysis

The data analysis was based on Hatch's (2002) interpretive analysis model for qualitative researchers. Hatch identifies transforming data by emphasizing interpretation. By use of this model, the researcher transforms data by emphasizing descriptions, their analysis, or the interpretation.

Step 1 of the interpretive analysis model required me to read all data collected for a sense of the whole. Step 2, impressions were identified and recorded in the journal. Step 3 required me to review my impressions in a research journal. Step 4, known as data reduction process, I collected impressions made during data collection based on reading of the data. Data reduction was accomplished by repeated reading of all the transcripts. Any repetitive information and/or information that did not address research questions were removed. Step5, once the data was organized according to how they related one to another, data was coded where interpretations are supported or challenged. Step 6 was the writing of a summary draft of the participants and the information they brought to the study. This enables the story of the participants to come together. Subsequent to the draft, participants were able to review the data and identify excerpts that may have been incorrectly transcribed. Known as member-checking, feedback of the summary and transcripts were gathered. I was able to search the data for excerpts that might be chosen for the final report. In this step, I highlighted potential quotes that would help to convince readers that interpretations were well founded.

Research Findings

The following section presents the research findings for this study. The findings address the focus of the research questions and literature review that guided this study.

Salient themes are presented with examples of the statements participants made. All responses convey the lived experiences of the participants in their own words, feelings, and represent their encounters as a Hispanic guardian of a child with ASD.

Data collected for analyzing was based on the research questions (a) Does culture play a part in the age of diagnosis for a Hispanic child, (b) How does culture influence the choices that Hispanic families make to aid their child with ASD, (c) What possible effects do professionals have on Hispanic families with a child with ASD, (d) What therapies are Hispanic families choosing to aid their child, (e) To what extent are external family members involved in raising the child with ASD.

Research Question 1

Data collected for analyzing were based on the research questions which included experiences with professionals, involvement of the parents, and cultural influences.

Experiences with Professionals

For the purpose of the research findings the word professional will include pediatricians, neurologists, teachers, psychologists, social workers, and speech and language pathologists. The first research question, does culture play a part in the age of diagnosis for a Hispanic child? asked parents to share the age in which their child officially received a diagnosis of ASD. Within this study the age of diagnosis had no consistency. The age of diagnosis ranged from 22 months to 10-years of age. Surprisingly to the researcher, the parents all remembered when the diagnosis was given. Some of the parents encountered more challenges than others in order to obtain the diagnosis. In their discussions with the professional, the word "autism" never came up for some families. One family learned of the official diagnosis only after they changed doctors.

> P3: Well, the autism I was at 3 when I took him to Dr XXX At 15 months you know developmental delays, language delays, for early intervention and that was from 15 months ‘til about I think he was 3. I mean I kind of we always kind knew that was probably at 3 that was the official from Dr. XXX. It was kind of a confirmation as to what we kind of suspected all along because he pretty much knew it. He had a previous neurologist and I kept asking him and oh don’t worry about it and sure enough he had already diagnosed him when I go back to the papers he never wanted to tell me. Which is kind of stupid and I got very upset about it because you know it doesn’t make sense but sure enough it was in there when I actually got the paperwork from him afterwards that I asked for copies that I was going go to Dr. XXX and he had it in there.

Most families expressed the stress and confusion they had when they knew something was wrong with their child.

> P3: So I cried the whole entire time I really did because even though I knew in my heart –If this is just getting it official you know like stampeded but it was just so so sad for me.
>
> P8w: I have also investigated, but It’s confusing…

Most families knew long before they received an official diagnosis of autism. The following are examples of parents knowing something was wrong and having to challenge the professionals.

> P1: And there I read that like the only way to diagnose autism is by asking the parents and they ask the 5 famous questions that they ask. And I said yes to most of them and so from there on I did not say anything else to the pediatrician like oh he is not talking. I just went to him and showed him the book and I was like this is it. And I just need you to give me a prescription to go see a neurologist.
>
> P3: At about age one. I was thinking that there was a problem with XXX and that is when I approached the pediatrician at that point.
>
> P5h: Well, I think that it was more or less when he was 2 years and some when we noticed something. We mentioned to the pediatrician and he said not to worry that he was little and he will growing, and that was normal.

Studies have demonstrated similar scenarios where parents had the preconceived notion that something was wrong with their child and the professionals where setting their concerns aside.

> P1: No she she she's oh ok she's autistic ok but she she felt in a way I realized he's autistic he's the neurologist problem he's not my problem.
>
> P7: Classic, we kept asking the pediatrician, "something does not seem right" xxx7 does not seem to be reaching his development mile stones at the time that he should have been meeting them and um…. The pediatrician said he is a boy, boys are slower, you have a daughter and she is very advanced, so your son is you know… sometimes in the older sibling, tries to take care of things or get involved, so the second child gets a little lazy; and this is just the way a lot of boys are.

This finding continues to add to the body of literature that resonates that "parents of children with autism are usually the first to recognize the symptoms and subsequently have difficulty convincing reluctant grandparents and medical personnel of the problem" (Hutton & Caron, 2005 p. 181; see also Gray, 1994; Gray, 2006).

The negative experiences parents continue to have with the professionals continues to be very real.

> P4w: I would like to find a way to solve this problem or find someone that could help me with this problem. Do you understand?... Because this is not normal. This is not something that we bring. We don't ask for it .
>
> P5h: Well, when we got here, we started looking for special programs that the government would offer.
> P5w: Public schools didn't accept him because he was too old.
> P5h: He was too old and they didn't have high school. I took him. We went with the social Worker to see if they had a job for him, but we also found a group that many other problems that xxx didn't have. Once, he saw it, he didn't like it and told immediately that he didn't want stay there. "I don't want, I don't want" he kept repeating. There were kids screaming and doing other things that….
>
> P6a: Me on the phone calling XXX, Medicaid…ect just calling different people telling me to call other people. No you call here you call there. All,

> I write everything down, I call numbers, I need to call back, I called so and so. Like my mom use to say “a drop on the rock until you cause a hole.”

With the exception of P3, all participants have had and continue to have some sort of negative experiences. Once P3 changed neurologists she felt "blessed". Everything fell into place. Although she still frustrated with the neurologist and the educational system, she knows her experience has been very positive compared to others.

> P3: Well we have been lucky again, I think I have you know a guardian angel has been with me all this time, and God has been good. So we have been lucky.

Although all parents expressed concerns with their professional encounters in one way or another, P5's experience was the most extreme and heartbreaking.

> P5: Because they said that it was the parent’s fault, that the parents were from different cultures. Back then they didn’t even know the cause and today they still don’t know; that was the parent’s fault.

Research Question 2

Research question 2, how does culture influence the choices that Hispanic families make to aid their child with ASD?

Culture makes possible for a person to make sense and devise a solution for situations which may arise within their lives (Barnes, 2005). The belief is that the cultural theory of *familismo* and *personalismo* may be the link connecting the Hispanic culture to the decisions they are making to care for their child with ASD.

Literature reviewed in section 2 acknowledged the Hispanic culture and the possible views that they hold may affect how they view professionals and their child's disability.

Personalismo

Within the Hispanic culture, *Personalismo* is described as being able to have a warm and trusting relationship with others (Barker, Cook, Borrego, Texas Tech University, 2010). There needs to be an ongoing respectful and family like dialogue between professionals and families (Brice, 2002; Barker, et al). The Hispanic culture tend to prefer to work with professionals who are also Hispanic (Guilamo-Ramos, et al, 2007; McCabe, 2002). If unable to acquire a Hispanic professionals, then they would prefer someone who understands the language and their culture. The families within this study were no different. Participants expected me to respect and speak their language of preference. Before beginning the interview, all participants initiated a personal conversation. They wanted to hear in detail about my experience with ASD and about my personal experiences outside of ASD (Barker, et al; Guilamo-Ramos, et al; McCabe). Participants were genuinely interested and gracious with their hospitality (Brice, 2002). This technique of allotting extra time at the beginning of a session to discuss other events in a person's life is recommended when working with Hispanic families (Barker, et al). This preamble enabled a comfortable setting and ambiance for the parents to be candid with their responses on how their culture influence the choices made to help their child with ASD.

Personalismo became evident as the emergent theme in this research question as parents described their experiences with the professionals involved in their child's care. As discussed in the literature review, Hispanic families prefer someone who will speak to them one to one. Someone who will sit down and discuss personal information without having a sense of being rushed. The families are aware professionals have a job to do, but they would like to be related to on a more personal level and not by the book all the time. The following are examples of how parents felt rushed or impersonal with professionals. In the first section P1 is discussing her experience with the doctor. In the second example we were discussing how she relates in the school.

> P1: No she she she's oh- ok she's autistic. Ok but she she felt in a way I realized he's autistic. He's the neurologist problem he's not my (the pediatrician) problem. You know, I treat him if he has a cold or he has this but they treat it like two different problems you know… and that's her s that's the pediatrician. Uh the neurologist- you know just typical neurologist he just saying ok this is it and this is he is autistic and you just need to take him into a school or take him to therapy.
>
> They have been nice but they really do not do it because in her program it is a problem because there are other children with other disabilities and for example she does not really do the schedules in school. And I did tell her like mentionally "you know I noticed they have a schedule that works" and she was like "Oh ok but I don't have time to do it." All so nicely but she's not going to do it.

P2h and P2w want to be a part of the school process. However, they continue to face barriers.

> P2: They (the school)brought teachers that were like we really we do not want to be bothered by you guys. You know they had an open house, we were like the only parents who showed up and they were like they acted like they would have been just as happy not to see anybody. And he could not do therapy there. He could not have outside therapy come in. He could not have CARD come in and do anything. No body.

I felt the frustration these families were going through. I documented my reflections in my journal. This experience caused my aspiration to help professionals and parents come together to help the find ways to assist each other.

Research Question 3

Research question 3, what possible effects do professionals have on Hispanic families with a child with ASD? As previously stated, the families interviewed for this study have not had consistently positive experiences with the professionals in their child's care.

Parent Involvement

The importance of parental involvement is no different within the realms of this study. The author found by calculating the responses, that 87.5% of the families not satisfied with the information and/or treatment they are receiving from the educational community. Based on the responses given by the families, they do not feel as if they are being listened to by the educational professionals.

> P1: And there I read that like the only way to diagnose autism is by asking the parents and they ask the 5 famous questions that they ask. And I said yes to most of them and so from there on I did not say anything else to the pedestrian like oh he is not talking. I just went to him and showed him the book and I was like this is it. And I just need you to give me a prescription to go see a neurologist. I did not fight you know I just went and I said to him. Because she was like Oh when I told her like no he does not speak she was like saying like everyone else says no he is too small he is a boy because she spoke really early. I mean if you speak to with her she uses all her verbs and she but he was behind so.
>
> P6a: Well, really, really, really, when it came to sign language we had no instructions. They would teach him one thing and we had to guess what it was over here. One day XXX came home and he was going (movement and sound with hand). I said no it’s turkey. I had to back to school and she laughed and said no that means dirty. This is a turkey and this dirty. I had to bust my hump trying to communicate with him because they would teach him one thing and not let us know what they were teaching.

Families who have had educational or medical training have been able to understand more than the families who come from other backgrounds. P1, P2, and P3 were families that had some knowledge about working with education or medicine. P1 was becoming a special education teacher.

> P1: We wanted to know like we knew something was going on but like everyone else we couldn't like pin point what was so before we had this problems I was studying to become an ESE teacher and I remember at 2am in the morning I was studying to do the finals and there was 1 chapter about autism and there I read that like the only way to diagnose autism is by asking the parents and they ask the 5 famous questions that they ask. And I said yes to most of them and so from there on I did not say anything else to the pediatrician like oh he is not talking. I just went to him and showed him the book and I was like this is it. And I just need you to give me a prescription to go see a neurologist. I did not fight you know I just went and I said to him.

P2w worked in a school in North Carolina that catered to the needs of severely disabled children. Despite her background, she was overwhelmed by having to care for her son. She believes God gave her the care of her son since that is what she did.

> P2w: He was three years old. Exactly at three, because I was working at a school, which contained kids with special education needs, but it, was a combination of normal and special needs kids. The special need kids were with the normal kids. That was until 5 years old more or less. He entered as a regular child at the age of 3. He was with other teachers, as I was working in a different class with other kids. I noticed that x2 was different, as I would observe him through the window. I would see him hide behind the teachers instead of being out and about playing with the other children. It was very unusual. I would confront the teachers as to his behavior being unusual; yet they would just treat him as any other child. And these are educated individuals.

P3 is an active member of the advocate community in Miami-Dade County.

> P3: It was very noticeable for me and as an RN I kind of you know there was something there. You know?

On the other side of the coin, we have the families who are coming into an diagnosis with little to no experience. They are learning the process as they go along if at all. P4 insists she has learned nothing despite her son already turning 18.

> P6a: We learned everything through trial and error
> P6m: Sure sure
> P6a: A lot of trials and a lot of errors…nothing, nothing they only had 1 class where they had this lady and the class was like mentally retarded children that really had nothing to do with autism. She only taught us about where they would masturbate and how to be instructed on where. You can only do it here or there. This was the only instruction that we ever gotten.

P7 shares her vivid recollection of her experience with her sons diagnosis.

> P7: Well that would depend entirely on the teacher… it was very disheartening too because you would come to the classroom with the recommendations then of course the other issue is what that was terrible was this whole issue of a veil of secrecy… So awful. I have to tell you that once I found this out… I called the district. I did the whole line- you know? The region, district no one would listen to me my complaints went unheard there was another mother who did the same thing her son was in that class until finally I had it. I said this is too much. I am going to write an email to Jeb Bush. Who was the governor at that time? … I can tell you they got a lot better for XXX. Yeah because anytime there was a problem they wanted to make me happy. Because you know what I just got to the point I was just fed up.

The involvement parent's have with the medical profession is just as important as the involvement they have had with the educational professionals. The partnership should not be underrated (Osborne & Reed, 2006). As found within this study, 100% of the families were frustrated with the medical profession. Families feel they are not being heard nor taken seriously when they first go to their family doctor or pediatrician. Consistent with studies conducted on the communication with the medical professionals, the anxiety level of the parents are rising since they know something is wrong with their child but no one is giving them any answers as to what is wrong (Goin-Kochel, Mackintosh, & Myers, 2006; Osborne & Reed, 2008). I was stunned at the aggravated tone parents manifested when speaking about the medical profession. Parents expressed their feeling of being disgruntled because the medical professionals continue to struggle with the diagnosis of a child with ASD. P1's child was diagnosed within the last 2 years. This is what P1 stated when asked how her experience has been with the pediatrician and/or neurologist.

> P1: Clueless of what autism is…The neurologist, you know just typical neurologist he just saying ok this is it and this is he is autistic and you just need to take him into a school or take him to therapy.

This was the experience P2 had when she went to the pediatrician with her concerns about the child's development and possibly having autism

> P2w: The pediatrician said he was normal. Told the pediatrician and the pediatrician told me XXX was not crazy and was normal. He was not helpful.

Again, the experience of P3 was a bit different to the rest of the participants. P3 gave a positive report about her pediatrician, however, a more frustrating description when speaking about the neurologist.

> P3: My pediatrician has been very good.
>
> (about the neurologist) And then now actually now I do not mind his visits but at first it was a shock. I literally would say I wanted to hit him with a stapler.

The experience of P5 resonates for me as the most appalling due to the accusations and future they gave the child some 25 years ago.

> P5h: The pediatrician said nothing. Dr. X said that the child walked with the tip of his toes, he does this, that, and that he won't be able to go to a regular school…. The child won't have….You will probably would have to put him in a home when he grows older because these children are schizophrenic. He won't learn to speak normally like the other children. Well, he said a ton of things. Because they said that it was the parent's fault, that the parents were from different cultures. Back then they didn't

> even know the cause and today they still don't know; that was the parent's fault.

The son of P6 is now an adult. The road they have been on has been trying on the family. They believe they have learned the process through "a lot of trial and error". The following is their experience.

> P6a: I kept questioning the doctors and stuff and they kept saying he's lazy he's lazy until finally I was told to go to XXX. He's been going to the XXX since he was 3. They told us he was mentally retarded. They told me he was mentally retarded until we took him to his neurologist Dr XXX he looked at him and said oh, he's autistic.

P7 and P8 were frustrated by being told how boys are different to girls. Boys develop at a different pace.

> P7: Classic, we kept asking the pediatrician, "something does not seem right" xxx7 does not seem to be reaching his development mile stones at the time that he should have been meeting them and um…. The pediatrician said he is a boy, boys are slower, you have a daughter and she is very advanced, so your son is you know… sometimes in the older sibling, tries to take care of things or get involved, so the second child gets a little lazy; and this is just the way a lot of boys are. We probably heard that each time we went and months would go by and we would hear the same thing…
>
> P8w: Everybody and even the doctors would tell me that boys take longer to talk.

The involvement of parents with the professionals that work with families and with a child with ASD has a direct link to the success of interventions being utilized with the child with ASD (Osborne & Reed, 2008). This correlates with previous studies that have reported the need for parents to have a proper diagnosis in order to be able to access potential resources and services (Mandell & Novak, 2005; Shulman, 2002; Overton, Fielding, & Garcia de Alba, 2007).

The role of the parent should not be ignored. No one has more interest in the advancement of a child than the parent. The family will be with the child throughout the child's educational career and will have to live with whatever educational decisions are made by the professionals (Tam & Heng, 2005).

The diagnosis of ASD is possible only after children have met the criteria set forth in Section 2 of this research study. The medical profession plays a key role in the diagnosis and treatment of these children. Therefore, this question is geared to the experiences parents have had with the medical profession as it pertains to the child’s needs. Research has found that Hispanic families tend to be very respectful towards professionals or experts in a particular field (Brice, 2002). However, within this study, most families were eager to discuss the concerns they have had with professionals. Families believe doctors do not know what ASD is or how to handle it. This can be noted in previous statements made by P1, P2, and P7. In this study, 100% of the families did not find some doctors helpful at some point in the treatment of their child. I included in Section 4 all of their responses in order for the readers to fully capture the frustration parents are feeling.

Another profession that is relied on heavily is the field of education. IDEA was created in order to ensure all children will have access to a free and appropriate education. Thus, education plays a pinnacle role in the future of all children. This is no different for a child diagnosed with a disability such as autism. According to educational research, the communication between parents and schools must be effective in order for children to succeed (Parette, Chuang, & Huer, 2004). In this study, participants believe they have not been able to acquire information to assist their child. Participants have described teachers as “nice” but not knowledgeable of what ASD is. Teachers were described as overwhelmed and in need of more training.

The Hispanic culture is not immune to the autism epidemic. Some Hispanic families are finding themselves thrust into the stress of living in a new country with a different culture. The results of this study as to whether culture plays a role in the age of diagnosis are unclear due to the size of the population of the study being eight participants. The study does coincide with the findings of the National Autistic Society (2005) stating that ASD could be diagnosed at any age. The average age of a diagnosis is three years one month (Mandell, Novak, & Zubritsky, 2005). The average age of diagnosis in this study was four years and five months. There is a there is a one year five month age difference in the diagnosis between the study and the national average. This can be due to a result of a lack of knowledge of ASD (Lopez-DeFede & Haeussler-Fiore, 2005; Santana-Martin & Santana, 2005) and a lack of social support (Brice; Ell & Castaneda; Mandell & Novak; Oyerman & Lee, 2008) due to not having family near by.

Concern for the Future

The families within this study continue to forge forward with the therapies chosen more by word of mouth than by professional recommendation. The families believe the Hispanics must stick together and help each other (Calzada, 2010). The participant's in this study do not trust the professionals 100% with the care of their child. Participants' believe that God has given them this and their child with surpass this.

> P1: I'm not trying to think about it to much because I try to focus on my energy. Right now and all the moment, right now and everything, right now top see the future would change. But obviously, I want him to get married I want him to be at least independent

The thought of the future is a concern for 100% of the families. All of the families mentioned to me their desire for their child to be independent. All families want their child to work, have friends, and get married.

Research Question 4

What therapies are Hispanic families choosing to aid their child? According to the demographic survey administered to families (see appendix E), table 12 provides a list of the therapies families in this study are currently using or have used.

Table 12. Therapies Utilized at Home

	OT	Speech or Language	Behavior Therapy	PECS	ABA	Floor Time	Social Skills	Music Therapy	Faith	PT	diet
1					X				X		X
2		X	X	X					X		
3	X	X			X	X			X		
4									X		
5							X				
6	X	X	X						X	X	X
7	X							X	X		
8									X		

Research Question 5

Familismo

The Hispanic community is known for a strong family support system (Brice, 2002). The role of a Hispanic child in the make-up of the family is one of pride, especially for the male child. Children are raised to strengthen and be a part of a larger unit. They are not raised to grow and acquire their own personal goals or foster independence away from their family (Brice, 2002). The parents within this study aspire for their child with ASD to be able to work, perhaps get married, and be independent. Since the mother's primary role is to care for the children (Blacher & McIntyre, 2006; Brice, 2002).

According Calzada (2010), *behavioral familismo* has five themes:

1. Shared finances. Family members support one another out financially.
2. Shared living. Extended family share living arrangements.
3. Shared daily activity. Families are together when they are not working.
4. Shared childrearing. The entire family is vital in raising children.
5. Immigration. Families assist each other in motivation and finances to immigrate to the United States.

With this in mind, the finding of this study manifested *familismo* most evident in this question. Families tended to rely on each other for shared childrearing. Despite the fact some families are out of the country, most participants rely on family for outings, childcare, and transportation. P6m and P6a were a good example of aforementioned themes. They pool their money together for finances, they live together in order to facilitate childrearing of the child with ASD.

As families, the biggest concern possessed is what will happen to the child after they die. Some families admitted to it being the responsibility of the sibling. Only one couple said that they do not want the responsibility to fall on their other children. Within this study, seven of the eight participants share all aspects related to the development of the child with ASD with other family members. Evidence suggests that this is more evident with second generations (Halgunseth, Ispa, & Rudy, 2006).

Frustration with professionals

Research question 5: To what extent external family members are involved in raising the child with ASD? ask families to discuss the way the family assists them in the raising of their child with ASD. Most of the participant's answered this right away. Some had to stop and search for words. The participants reflected on the role their family plays in their lives with a child with ASD. For example: Families within this study rely on those family members who are close by for helping with watching other children, transporting the child with ASD to therapies, or sharing custody of the child with ASD with a non-parental family member, as was the case with P6. This mother/aunt duo has shared custody of the 21 year-old child for many years. This relationship is documented and enforced by both the mother and the aunt who have been living together since the child was a baby. P1 relies on her mother and aunt to watch the children so she can get chores done. With the exception of P3 and P6, most families did not rely on other family members to enforce strategies given by the professionals. In fact, P8w has kept the diagnosis away from her mother who resides in a foreign country. P8w stated the stress her mother was in when she suspected something was wrong with her child.

> My mother was very sad. She had heart problems, but we had to tell her. She used to ask me what does he say? Is he talking? Is he eating with a spoon? So we had to tell her that they were testing him. She saw him and she wants to know his progress. My mother adores him and she asked what was it that they told you? So when I told her that he had a low level of autism, she got very bad. She started lighting up candles and started to pray.

P8w Does not want to worry the family members back home. She continued to express her frustration of being in this country alone with a child with ASD and no job. She expressed the anxiety and stress they are under because they are alone.

> P8w: But we immigrant without money is very stressing. Then, you add the child situation is more frustrating… Our lives at home is horrible.

Within the confines of this study, P8 is not alone. P1 have moved around the country looking for help for their son. They feel alone, with no support. Due to the distance, they do not see their family members often. Neither does P4. Despite her expression of how alone she is she presses forward because she feels this is from God. This is her "cross to bare". Most participants have taken on this view of self sacrifice for the good of the child. Families, have moved crossed country, mothers have stopped their education and/or working in order to care for their child.

> P2h: See being down here he does not see the family at all, that much in NC. He’s been to Venezuela a couple times, maybe once every couple years. So he’s really not there long enough for him to you know be there every day for a long period of time.

A summary of the most common themes can be found in Table 11.

Table 11. Common Themes

Themes	Participants responses
Negative experiences with professionals	8 out of 8
Concerns for child’s future as an adult	8 out of 8
Frustration with professionals	7 out of 8
Personalismo/Familismo	8 out of 8
Parent Involvement	8 out of 8

Discrepant Data

Discrepant data was evident within the findings of this study. The first discrepancy was related to the question: *How old was your child when you were given a diagnosis of an ASD?* Within this study the age of diagnosis had no consistency. I had expected the diagnosis of most of the children to be above age 5, however, the findings to this question coincide with those of the National Autistic Society (2005) stating that ASD could be diagnosed at any age. The next discrepancy was related to the question of who was the primary researcher within the families. Who was the parent acquiring information about autism and possible services within the community? Only one family said the father was the only one who noticed a problem and pursued acquiring information on ASD. Another discrepancy was when participants were asked about the school listening to the concerns about their child’s needs; one parent’s experiences were quite different to other participant’s. At first P7 was trying to elicit help from appropriate channels. Once she felt the interest of her child was not being met, P7 contacted the governor’s office for help. At first, the school system tried to intimidate her but attempts failed. Once the situation was resolved, the parent felt the schools were making full effort in helping her son. The last discrepancy was the therapies chosen by families. Only one family of the eight, do not use any therapies at home.

Evidence of Quality

The evidence of quality was established by the researcher engaging in trustworthiness, which Creswell (2003) described as using a variety of collection tools. Triangulation was used in order to verify information within the study (Hatch, 2002). First, all participants were referred by Parent to Parent of Miami, UMCARD Center, Atlantis Academy, or a friend within one of these community leaders. At the time of the initial contact with potential participants was made over the phone, I asked parents if their child had an official ASD diagnosis. There were instances when parents were in the process of attaining a diagnosis or the parent only suspected the child had ASD. At this moment, I would politely thank the parents for their interest but stated the ASD criteria requirement in order to participate. On another occasion a family with a child with Down's Syndrome called to take part in the study. Again, I politely stated the terms of the study. The interviews were scheduled only when parents who were interested in partaking in the study and had a child with an ASD diagnosis were identified. Parents were advised that I must see proof of diagnosis in the form of a psychological evaluation, IEP, or physician statement at the time of the interview. On the day of the interview, I would ask participants for the documentation before beginning the process. Parents presented psychological evaluations and school reports to ensure a diagnosis of ASD. Once this was clarified, I elucidated my role as a student, special education teacher, and a mother of a child with autism. Next, I collected and reviewed the demographic surveys with the participants in order to ensure understanding of the questions. There were instances when I had to clarify questions and note take on the surveys because the parents had left items blank. Following this, I progressed into incidental conversations with the participants, and conducted an in-depth interview (example in Appendix G). Field notes and bracketing of my personal experience was collected in the leather bound journal purchased to use throughout this process (example in Appendix H). The interviews were recorded on individual cassette tapes. The tapes were then transcribed. Those interviews that had to be translated were done so by myself or by the IRB approved translator (example in Appendix I). Once this was completed, I reviewed the interviews and used member checking for accuracy. The participant determines the accuracy by “taking the final report or specific descriptions or themes back to the participants and determining whether these participants feel that they are accurate” (Creswell, 2003, p. 1996). A minor change was made by P3 in relation to how many months apart her children were.

Summary

Section 4 of this phenomenological study contained a discussion of the effect of autism on the Hispanic families living within Miami-Dade County. Section 4 included data collection, role of the researcher, a summarized description of the participants, analysis of data, and evidence of quality.

Section 5 contains a description of why the study was done. A summary of the findings of the research questions is presented as it relates to the theoretical frame works. It contains my experience and the possible effects it had on the study results. Finally, I conclude with the social change implications and recommendations for future studies.

SECTION V: SUMMARY, CONCLUSION, AND RECOMMENDATIONS

Section 5 contains a discussion of interpretations of findings and an elaboration on the themes developed in section 4, based on the research questions. Section 5 will also include implication for social change, recommendation for action, recommendation for further study, and personal reflections.

The purpose of this phenomenological study was to examine the effect of autism on Hispanic families living within Miami-Dade County. By use of open-ended questions, participants were empowered to express in detail their experiences within the family, with educators, as well as the medical profession. Section 5 includes a review of the purpose of this study and a summary of the findings. Section 5 also contains personal reflection of my experiences as the researcher and a mother of a child with ASD. Finally, this section addresses the implications for social change and recommendations for further study.

One goal of this study was enable families to freely express their personal lived experiences and the choices made as a family for their child. Currently, minimal research exists on the Hispanic population as it pertains to ASD and its effect on the family. Research on ASD as it relates to minority groups (i.e. African Americans and Asians) is available. Interview questions were focused on the lived experiences as they pertained to family, professional interactions, and therapies. Face-to-face interviews were conducted in order to better understand Hispanic families and their culture as it relates to their children with ASD. The findings of data within this study confirm the Hispanic culture as a repertoire in which individuals gain access to how a stressful situation will be handled.

As discussed in the literature review of this study, culture gives a family/individual the tool kit necessary to make decisions based on their own experiences. The findings of this study support the relationship with the theoretical framework of *personalismo and familismo* as the system that drives the Hispanic culture in ascertaining support for their children with ASD.

Interpretation of Findings

This study utilized qualitative research in order to delve into the parental perspectives of living with children with ASD. The interview provided a wealth of information on how parents perceive the influence that the medical and educational professionals have on the decisions they make for their child. Participants shared a lived experience. They expressed concern related to their child's diagnosis, services, and future. Once data was reviewed and analyzed, the interpretation of findings was organized according to the research questions and the thematic units that emerged. These were: (a) negative experiences with professionals, (b) concerns for child’s future as an adult, (c) frustration, (d) personalismo/familismo, and (e) parent involvement.

Research Questions 1 and 3

Does culture play a part in the age of diagnosis for a Hispanic child? and What possible effects do professionals have on Hispanic families with a child with ASD?

Frustration

In speaking to the parents and hearing their stories, the theme of frustration was within all the research questions pertaining to this study. This is why research question 3 was included: What possible effects do professionals have on Hispanic families with a child with ASD?

Frustration with educators

The educations of students go hand in hand with the educations of their teachers (Barth, 2001; Leithwood, 2002; Lieberman & Miller, 2002; Marzano, 2003; Valli & Hawley, 2001). “Evidence suggests a strong link between highly collaborative school cultures and schools’ effectiveness” (Leithwood, 2002, p.99). Parents who come from a diverse cultural and linguistic background "can be challenging"(Tam & Heng, 2005). However, researchers have found that the collaboration between schools and parents have been invaluable to the advancement of a child's educational and emotional skills (Padgett, 2006). In order to maintain positive communication with parents, parents should be treated as partners with valuable knowledge, which may assist professionals in the interventions used for the treatment of their child (Tam & Heng, 2005). This can be made possible by providing personnel who are familiar with their language and cultural needs (Felber 1997; Tam & Heng, 2005).

The majority of the participants reported frustration when working with the educational school system. Parents do not feel they are taken seriously by the educational system. They have been made to feel as if they are in the way. P2h shared, "You know they had an open house, we were like the only parents who showed up and they were like they acted like they would have been just as happy not to see anybody." Participants expressed their lack of support within the schools. As soon as they ask for help or clarification then they (the parents) becomes a problem. P7 shared her experience:

> P7: His IEP’s nothing was being met. It was a just you know it was one of those situations where you know a group of people basically saying they are basically babysitting your child… it was very disheartening too because you would come to the classroom with the recommendations then of course the other issue is what that was terrible was this whole issue of a

> veil of secrecy. They never wanted you to go into to observe your child. no one would listen to me my complaints went unheard there was another mother who did the same thing her son was in that class until finally I had it. I said this is too much. I am going to write an email to Jeb Bush. Who was the governor at that time? So I wrote to Jeb Bush and sent him an email… yeah because anytime there was a problem they wanted to make me happy. Because you know what I just got to the point I was just fed up. It became like a joke don't get Mrs. XXX mad because she is going to call Jeb.

Parents feel that teachers need additional training and understanding in order to be able to work more effectively with the ASD population.

Frustration with medical profession

All participants reported negative experiences with the medical profession. Participants described the doctors as clueless and as having poor bedside manners. P3 remembered:

> P3: I was very upset because I thought he as too straight forward just too much and you know I was really upset at him as well for the way he had his bed side manner but Joe did not see it that way he said you know he has 10 to 15 minutes to be with patience to learn to communicate with the family and he just has to get his point across what you need to do is do it and you know that's it so he had a total different view of it. I wanted to hit him with a stapler.

Most participants reported not being taken seriously by their child's doctor. Most participants either switched doctors or proved to the doctors something was wrong with their child by bringing in documentation on ASD. Once a diagnosis was given, all participants agreed they were left to educate themselves as to what ASD entails and what they need to do with their child. P7 remembers being told by the neurologist, "Now you go out and you be your child's advocate. And that's it. And that was his parting words.

Go out and be your child’s advocate. So I was not given any information at that point. What so ever as to where to go."

Concern for the future

All participants reported frustration with their lack of control and knowledge of what the future will bring. Participants became extremely emotional about this question. They all want to help their children become functional citizens in society but they fear they lack the knowledge as to how to accomplish this. Right before the interview of P3, she was removed from her son's IEP because he had just turned 18. She did not know she had to take legal action in order to continue to help her son. She assumed as his mother and his lack of abilities that there would be no question as to her guardianship. Now, she feels lost and frustrated. Asking, what can be done? P5w and P5h tried to find their son jobs but no one wanted him. The current program available for training people with special needs is not appropriate for their son. He has no wish to return to the program.

Parent involvement

Another aspect of the Hispanic culture is their involvement with their children. All families within this study consider themselves active in their child's lives. All families interviewed included the mother.

The parents who participated in this study attend regular school meetings and meet periodically with teachers and therapists. Parents are eager to learn ways to help their child with ASD to overcome their diagnosis. P6m and P6a attempted to attend a behavioral management class that would help them with their child. They wanted to learn how to communicate with their child. They have questions such as: How can they get him to do homework, become more independent, and write? Instead, they claim to only have been taught the appropriate places the child can masturbate. All participants expressed concern of the lack of support from schools, the medical profession, and the community. They wish to find ways to help their child.

Research Questions 2 and 4

How does culture influence the choices that Hispanic families make to aid their child with ASD? What therapies are Hispanic families choosing to aid their child?

Personalismo

The findings of this study incorporate the theoretical framework of personalismo as the premise for how which Hispanic families choose to aid their child with ASD. Family is key (Guilamo-Ramos, et al, 2007). Within this study four out of eight families had other guardians present during the time of the interview. The families often relied on each other for information and would correct each other if necessary. Only once was it observed that the wife was not as responsive when her husband was in the room. In this study, 100% of Hispanic families interviewed expected a conversation before the interview began. Families offered something to eat or drink as a discussion of my personal connection with ASD began (Brice; Guilamo-Ramos, et al.). Once dialogue was established, I officially began the interview as if they were old friends.

External Support System

The participants who have family in Miami-Dade County rely on the support and services of those family members. Most support came in the form of childcare. This enables parents to work, complete household duties, or for transporting the child to and from school and therapy. Most families expect the siblings to help with the upbringing of the child with ASD as well. The sibling’s role is to help with chores or to entertain the child with ASD so that the parents can get things accomplished.

Faith

All participants expressed an extraordinary faith. They believe they will be able to get through this situation with God's help. Participants believe God will lead them to the right people who will assist them with their child. Participants believe their child was given to them for a purpose and they will endure. They, also, have faith that their child will learn and become good people or perhaps get married:

> P8 I want him to study normally, well, taking into consideration his abilities. I want to have good grades academically and I want him to learn how to live. I worry about school because he is very quiet and if they hit him, he will stay quiet and then people can abuse him. I would not him to go through that. I want him to be able to learn how to live in a society. Mom and dad are not eternal so he needs to understand that.

Marianismo

Marianismo is the tendency of the Hispanic mother to devote their lives to their child, exemplifying the role of the Virgin Mary. Most of the mothers in this study decided to stop working or change careers in order to be able to devote themselves to their child with ASD. Some participants believe that caring for the child with ASD is their duty. It's their calling from God. All the mothers participated in this study.

Research Question 5

To what extent are external family members involved in raising the child with ASD?

Behavioral Familismo

Within the realm of this study, all participants with family members living in Miami-Dade County share childrearing. All participants rely on family to help with day to-day activities like chores and transportation. P6 went as far as to grant guardianship to her sister so that she would have equal say in decisions regarding her son. The involvement of the entire family help to reduce stress by allowing parents to go shopping, go to work, or just have a break. All participants that have family support expressed gratitude to their families.

Also within the behavioral familismo, families share daily activities. Families are together when they are not working. All siblings are encouraged to partake in the lives of the child with ASD. For example, the three younger children of P5 take the eldest brother to the movies or to the store. They assist the parents by entertaining. P7 says her daughter helps by taking her son to therapies and by playing with him. P3 says that grandparents, the aunts and the uncles are active in the care of the child with ASD and help her out. On weekends the families are expected to be together helping around the house or by entertaining the child so that chores and/or work can be done.

Implication for Social Change

Understanding a family's culture can help make enormous positive strides in the life of a child, especially the life of a child with a disability such as ASD. First, fostering a positive relationship between professionals and families with a child with ASD will help relieve a stressor for families. The influence professionals have on a family is one that cannot be taken lightly. The professionals are the ones the family comes to for guidance and support. Next, professionals can help to enable parents to become their child's advocate by assisting parents to feel comfortable in seeking out information despite language barriers and a new country to live in. Finally, by establishing open, positive communication between parents, extended family members, professionals, and other stakeholders. This social change is not only about the knowledge of ASD but rather a motivation for others to see and acknowledge change is necessary in the communication process between families and professionals. By working as a coherent team the child with ASD, families, professionals and the community will ultimately benefit.

Recommendations for Action

Based on the findings of the research questions, the Hispanic parents are concerned with the treatment of their child with ASD. The recommendation for action is broken down into the responses to the research questions.

Does culture play a part in the age of diagnosis for a Hispanic child? What possible effects do professionals have on Hispanic families with a child with ASD? How does culture influence the choices that Hispanic families make to aid their child with ASD?

I combined these questions because the age of diagnosis is relevant to the care the professionals have with the families (Copeland, 2007). The Hispanic culture mandates families need to be respectful to professionals (Brice, 2002). They believe the professionals know best. Based on the responses of this study, the professionals the families rely on are the pediatrician and the educational professionals. This study illustrates a discrepancy with the age of diagnosis of the Hispanic families in Miami-Dade County compared to the national average. I recommend pediatricians be encouraged to participate in community or national workshops on ASD in order to gain a better understanding of how to diagnosis and treat ASD properly. Due to the high prevalence in ASD in schools, I suggest teachers be required to be endorsed or certifies in ASD or as an add on to their SPED certification. This endorsement can be added on to the professional certificate as an endorsement like English as a Second Language (ESOL) is in Miami-Dade County.

What therapies are Hispanic families choosing to aid their child?

Consistent with previous recommendations, I believe it is the job of the professionals to help educate the families. Professionals need to be cognizant of the parents lack of knowledge of how to help their child with ASD due to language barriers, parents not understanding their rights, and lack of support. Professionals should not assume parents do not care or understand everything they are being told. Instead, professionals should assume parents do not know nor understand the ASD diagnosis.

To what extent are external family members involved in raising the child with ASD?

Most families are away from their home countries and away from their families. They are here alone starting a new life with a child with ASD. I recommend families be strongly encouraged to seek out other Hispanic families within the community. Professionals need to give parents community-based information like those found in Parent to Parent of Miami and The University of Miami Center for Autism. I recommend a buddy system for interested families either through use of internet or phone conversations. If a newly diagnosed family does not understand information given to them or if they need someone to talk to, they can call their buddy and acquire the support they may need. I believe a core group of buddies can be trained and be prepared to train other buddies in the future.

Recommendation for Further Study

The current study explored the lived experiences of Hispanic families in Miami-Dade County. This study included only eight families within one community. A similar study can be created to include more counties within the state of Florida and/or other states may be considered. In addition, it may be useful to include other developmental disabilities. It would be interesting to compare the perspectives of parents with a child with ASD to other developmental disabilities (i.e. down syndrome or cerebral palsy). Investigating the age of diagnosis, the stressors, therapies being chosen and family involvement would be the key elements. Also, a longitudinal study could be conducted to investigate the parental perspectives at different stages of development.

Another recommendation for further study is to conduct a quantitative comparison study of Hispanic families and other ethnicities with a child diagnosed with ASD. A comparison study would be able to compare two or more groups simultaneously. It would be fascinating to know how the groups compare with the same questions. Would there be a difference?

Finally, it was evident in this study the importance siblings have on the development of a child with ASD. Most families rely on the assistance of the sibling as a play and homework partner. The researcher recommends a more comprehensive study on the role a child may or may not have on a sibling with ASD. How does the child with ASD affect the "atypical" child socially, emotionally, and academically? A longitudinal study could be conducted to investigate the siblings’ perspective on their influence on the child with ASD. Within the scope of the same study, the siblings' perspective on how the child with ASD has influenced their life would be included.

Personal Reflections

When I first began my dissertation, I knew I would be writing something related to autism. I had been interested in autism since I first heard the term in 1997. I remembered the professor accentuating that these children exist because of "cold parents". I could not fathom such a thing. I recall thinking, "How sad." Little did I know, my son, whom I adored, would be diagnosed with ASD.

Before the birth of my son, many co-workers, fellow classmates, family, and myself blamed parents for their child's diagnosis. All that changed with my child. I was someone everyone knows; a person who was always active. As a special education teacher and Hispanic, I had begun to notice many of the families at school had no idea how to help their child. I observed that in many sessions and therapies, I was only one of a few Hispanics. Why? This question led me on a four-year trip to answer.

My preconceived notions included the idea that Hispanics first relied on their religious faith and folklore for treatment. I had the expectation that there would be more family involvement in the overall decision making for treatment of the child with ASD. As a special education teacher I never took into consideration the fact that parents were not aware of their rights. They were not aware of possible treatment options. I sat in many meetings where the professionals (including myself) assumed a parent miraculously understood everything being said. Parents needed someone to understand their predicaments and guide them through the process with patience. These preconceived ideas affected me as a teacher. It drastically changed the way I communicated with the families I worked with. This process enabled me to truly become an advocate at school and on the home front for interested families.

Summary and Closing Statement

This study exposed how the Hispanic culture may have an influence on the choices Hispanic parents with a child with ASD are making in Miami-Dade County. The Hispanic culture is one filled with folklore and tradition. The study found the heritage itself may play a vital role in the decisions being made as to what therapies or strategies are being used in order to help a child with ASD. Through the course of this study I discovered and wish all who read this study to fully grasp the understanding that Hispanics are extremely personable. Family plays a key role in their lives and decisions they will make. Professionals cannot assume that all the families they are working with fully comprehend or understand what is happening to their families with a child with ASD. Some parents do not understand the terms being given to them. Professionals must realize it may take more than once to explain information. Parents want to help their child. Sometimes, they just do not know how.

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APPENDIX A:
LETTER OF PERMISSION TO GAIN ACCESS TO PARTICIPANTS

Date: yet to be specified

Dear ____________,

My name is Lynette Estrada. I am a student at Walden University. I am currently conducting a study entitled *A Phenomenological Examination of the Influence of Culture on Treating and Caring for Hispanic Children with Autism.* I am aware that your organization assists mother, fathers, or other guardians with a child with an Autism Spectrum Disorder. I am seeking 8 participants in to interview. Participants must be a first or second generation Hispanic parent or guardian of a child with ASD. In addition, participants must be in either of the following categories: be children who have received a diagnosis within the last year, children in elementary school, transitioning into adulthood, and who are adults who have had a diagnosis for 20 years or more. The interview will not last more than 1 hour. Participants will not be reimbursed for their time. They have the right to stop the interview if they feel uncomfortable. The interview will be recorded in order to ensure accuracy. Feel free to let me know via email at lynette.estrada@waldenu.edu or call me at 305-978-1473.

Thank you in advance for your assistance.

Sincerely,

Lynette Estrada

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APPENDIX B:
CONSENT FORM

You are invited to take part in a research study of Autism and it's relation to the Hispanic family. You were chosen for the study because you are a Hispanic individual with a child with autism. Please read this form and ask any questions you have before agreeing to be part of the study.

This study is being conducted by a researcher named Lynette Estrada, who is a doctoral student at Walden University.

Background Information:
The purpose of this study is to create a better understanding of the effects autism has on the Hispanic family. Another purpose is to understand the therapies Hispanics are choosing to help their child with autism.

Procedures:
If you agree to be in this study, you will be asked to:

- Submit to the researcher a copy of your child's psychological evaluation and/ or current IEP stating your child has an Autism Spectrum Disorder.
- Participate in an interview that will last approximately 1 hour.
- The researcher will transcribe the interview within a one week period. Upon completion, the researcher will ask for you to review the content for accuracy.

Voluntary Nature of the Study:
Your participation in this study is voluntary. This means that everyone will respect your decision of whether or not you want to be in the study. No one will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. If you feel stressed during the study you may stop at any time. You may skip any questions that you feel are too personal.

Risks and Benefits of Being in the Study:
Possible risks include parent stress of reliving the emotional state of when you first noticed the developmental delay of your child. The benefit in participation in this study is to help implement a plan to assist Hispanic families in the identification of Autism Spectrum Disorder at a younger age.

Compensation:
There will be no compensation for participation in this study.

Confidentiality:
Any information you provide will be kept confidential under lock and key in the researcher's home. The researcher will not use your information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in any reports of the study.

Contacts and Questions:
The researcher's name is Lynette Estrada. The researcher's faculty advisor is Dr. Aaron Deris. You may ask any questions you have now. Or if you have questions later, you may contact the researcher via 305-978-1473 or lynette.estrada@waldenu.edu or the advisor at 952-390-6978 or

aaron.deris@waldenu.edu. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. Director of the Research Center at Walden University. Her phone number is 1-800-925-3368, extension 1210.

The researcher will give you a copy of this form to keep.

Statement of Consent:

☐ I have read the above information. I have received answers to any questions I have at this time. I am 18 years of age or older, and I consent to participate in the study.

Printed Name of Participant	
Participant's Written or Electronic* Signature	
Researcher's Written or Electronic* Signature	

Electronic signatures are regulated by the Uniform Electronic Transactions Act. Legally, an "electronic signature" can be the person's typed name, their email address, or any other identifying marker. An electronic signature is just as valid as a written signature as long as both parties have agreed to conduct the transaction electronically.

CONFIDENTIALITY AGREEMENT

Name of Signer: ____

During the course of my activity in collecting data for this research: "*A Phenomenological Examination of the Influence of Culture on Treating and Caring for Hispanic Children with Autism*." I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

By signing this Confidentiality Agreement I acknowledge and agree that:

1. I will not disclose or discuss any confidential information with others, including friends or family.
2. I will not in any way divulge, copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant's name is not used.
4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
6. I understand that violation of this agreement will have legal implications.
7. I will only access or use systems or devices I'm officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature: ____ **Date:** _______________

Appendix C:
EXAMPLE OF CODING TO BE USED

I. Background
  a. Culture
    1. Cuban
    2. Puerto Rican
    3. Mexican
    4. Other
  b. Diagnosis received
    1. Autism (classic)
    2. PDD-NOS
    3. Asperger
    4. Unknown
  c. Caregivers
    1. Mother
    2. Father
    3. Step-parents
    4. Grandparents
    5. Aunts/Uncles
    6. Sisters/brothers

II. Effects of Diagnosis
  a. Reaction of self
    1. Confused
    2. Angry
    3. Relieved
    4. Denial
    5. Don’t remember
    6. Stress
    7. Depression
  b. Reaction of spouse
    1. Confused
    2. Angry
    3. Relieved
    4. Denial
    5. Don’t remember
    6. Stress
    7. Depression
  c. Reaction of family
    1. Confused
    2. Angry
    3. Relieved
    4. Denial
    5. Don’t remember
    6. Stress
    7. Depression

        8. Reaction of friends
        9. Confused
        10. Angry
        11. Relieved
    d. Stronger relationships
        1. wife
        2. parents
        3. family members (other)
        4. friends (help)
    e. Strained relationships
        1. wife (separation or divorce)
        2. parents
        3. family members (other)
        4. friends (left)

III. Treatments
- a. Public School
    1. OT
    2. PT
    3. Speech therapy
    4. Language therapy
    5. Behavior intervention
    6. Social Skills
    7. none
- b. Private School
    1. OT
    2. PT
    3. Speech therapy
    4. Language therapy
    5. Behavior intervention
    6. Social Skills
    7. none
- c. External treatments
    1. OT
    2. PT
    3. Speech therapy
    4. Language therapy
    5. Behavior intervention
    6. Social Skills
    7. none

APPENDIX D:
FLYER

VOLUNTEERS NEEDED
for a Research Project

Come and be a part of an exciting innovative research project targeting Hispanics families with a child with autism living in Miami-Dade County. This research is geared towards families and guardians who have a child within the Autism Spectrum Disorder (ASD) from recently diagnosed (within the last year ages 2-5) to adulthood. The information will serve as a guide in assisting parents with a child with ASD in Miami-Dade County.

The premises for this project will be the acknowledgment of the importance of the role the Hispanic culture plays in assisting their child with ASD. The total time for the interview will be no more than 1 hour. The interview location will be set by the participant.

For more information, please contact
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APPENDIX E:
DEMOGRAPHIC DATA FORM

Participants # __ Date:_____________

1. Ethnic Group

Black/Not Hispanic __ White, Not Hispanic__ Hispanic__

2. Country of Origin

Puerto Rico__ Mexico__ Cuba__ Other_____________________

3. Sex: Male__ Female__

4. Marital Status: Married__ Divorced__ Separated__ Single __ Engaged __

Child's Information

5. Child's birthday: __

6. Age ___

7. Years with diagnosis___

8. Which of the 5 categories of autism has your child been diagnosed?

___ Autistic disorder (classic autism)
___ Childhood disintegrative disorder
___ Rett's disorder
___ Asperger's syndrome
___ Pervasive developmental disorder not otherwise specified (PDD)

9. Does you child have an Individualized Educational Plan (IEP)?

___ yes ___ no

10. Is your child currently enrolled in a specialized therapy?

___yes ___no

11. If yes to question 10, what is the specialized therapy?

____

12. Has the family been trained on intervention plans to be used at home?

___yes ___no

Please list any training received:

13. How satisfied are you in regards to the treatment received by educators in regard to your child's needs?

1. Very satisfied
2. Satisfied
3. Neutral
4. Dissatisfied
5. Very Dissatisfied

14. What family members are involved with the care of your child? List as many as necessary.

15. How involved is the family for treatment?

1. Very involved
2. Somewhat involved
3. Involved very little
4. Not involved at all.

16. What type of intervention plans are in place at school? Please check all that apply.

___ Speech therapy
___ Language therapy
___ Occupational therapy
___ Social skills training
___ Behavioral therapy
___ Sensory integration therapy
___ Applied behavioral analysis
___ Music therapy
___ Family therapy
___ TEACCH
___ Unknown

___ Physical therapy
___ Discrete trial teaching (DIT)
___ Lovaas
___ Picture Exchange Communication System (PECS)
___ Facilitated Communication (FC)
___ Social stories
___ Auditory integration therapy
___ Irlen lenses
___ Floor-Time therapy
___ Son-Rise Program
___ Holding therapy

17. What type of intervention plan is put in place at home?

___ Speech therapy
___ Language therapy
___ Occupational therapy
___ Social skills training
___ Behavioral therapy
___ Sensory integration therapy
___ Applied behavioral analysis
___ Physical therapy
___ Discrete trial teaching (DIT)
___ Lovaas
___ Picture Exchange Communication System (PECS)
___ Facilitated Communication (FC)
___ Social stories
___ Auditory integration therapy
___ Irlen lenses
___ Floor-Time therapy
___ Son-Rise Program
___ Holding therapy
___ TEACCH
___ Music therapy
___ Family therapy
___ Special diet
___ Karate
___ Yoga
___ Massages
___ Chiropractor
___ Acupuncture
___ Prayer/Faith
___ Other

APPENDIX F:
INTERVIEW QUESTIONS

Script: Hello, my name is Lynette Estrada. I am a special education teacher for the county. I am a mother of two. My oldest is on the spectrum. I am seeking my doctorate degree with Walden University. My goal is to help other parents with a child with an Autism Spectrum Disorder (ASD). My aspirations are to educate the public on ASD and how culture can influence the choices we make for our children. In volunteering to do this study, you will be helping me getting the word out. I appreciate you being here. Do you have any questions about the consent forms? Now, I would like to ask you some questions.

1. When did you first realize there was something different about your child?
2. How old was your child when you were given a diagnosis of an Autism Spectrum Disorder?
3. Did the diagnosis change your relationship with your spouse? If so, how?
4. Before or after suspecting ASD, who took the lead in acquiring information about ASD in your marriage? Was one parent the researcher? If so, which one and what sorts of things did they do to get help with your child?
5. Did this diagnosis affect the other children in the family? If so, how?
6. Did this diagnosis affect your relationship with your friends? If so, how?
7. Explain your experience with the medical profession in regards to your child’s needs?
8. How have educators helped you in regard to your child’s needs? If so, how?
9. Have educators been open to discuss your knowledge of your child’s needs?

10. Describe how the family is involved in your child's treatment?
11. In your opinion, has the school listened to your concerns about your child's needs? Please give an example of how they listened and/or when they did not
12. Explain the therapies being utilized at home?
13. When you go to the doctor and the school for a discussion about your child's educational needs, do you understand everything being told to you?
14. Explain any concerns you might have for your child's future as an adult.

APPENDIX G:
EXAMPLE OF INTERVIEW

P7

11/29/2009

Le: Disclosures………...

Le Any questions before we begin?

P7 No….. I don't think so.

Le When did you first realize that there was something different about your child?

P7 Probably about at the time of his first birthday.

Le What did you notice?

P7 Well, at the time we probably weren't so aware of it, but it was almost like looking back now, because we had the sense that um, during the festivities the birthday party and the, all the celebratory activity that was going on xxx7 seemed to be very oblivious to it and didn't necessarily seem to be very plugged into it with the happiness of the occasion, didn't really care much about the blowing out of the candles. Just aloofness. A lot of aloofness.

Le We'll it was his first birthday that you noticed. Most people say oh "around" but your sure about the first birthday party.

P7 Yeah, specifically it was hard to say prior to that, but at the first birthday we were kind of surprised that he did not seem, well one is still very little, there young but….. Our daughter which is a year older was really into her first birthday than he was. Xxx7 just you know….. And then we just continued to see that type of aloofness.

Le How old was your child when he was first diagnosed with the ASD spectrum disorder?

P7 He was given that diagnosis at 22 months.

Le From the time he was a year old to 22 months old, what was the process of that. You mentioned something to the pediatrician, the doctor's, what happened there?

P7 Classic, we kept asking the pediatrician, "something does not seem right" xxx7 does not seem to be reaching his development mile stones at the time that he should have been meeting them and um…. The pediatrician said he is a boy, boys are slower, you have a daughter and she is very advanced, so your son is you know… sometimes in the older sibling, tries to take care of things or get involved, so the second child gets a little lazy; and this is just the way a lot of boys are. We probably heard that each time we went and months would go by and we would hear the same thing… no he is not. Thinking back, we'd say he was not really babbling, saying "momma or dada" he really never developed any language… never really developed any words and, um until it came to a point where it became more obvious that there was something wrong…… he actually even fell a few times and really did not have good balance and we noticed it was like dangerous. He would not see like a step and he would miss it. Um and so finally not the pedestrian that was the main pedestrian another associate in the practice I said- I I've had it. There is something wrong. And my mother was also very very involved in XXX life. She noticed it all along and she was particularly worried and concerned.

Le so that pedestrian was the one that wrote you the prescription to get evaluated?

P7 yes he was the one that said ok- we can send you to XXX hospital and we can get a whole battery of tests um with the neurology department there. Um, he did this prescription.

Le so that is how long it took.

P7 yeah, it took probably about 8 months.

Le and you husband was seeing the same stuff as yourself in regards to XXX?

P7 yeah, I think the thing that would really upset my husband was that every day he would get home from work and he would say “hi XX!” and XXX would not look at him and he would stay watching TV or whatever he was doing. And my husband would say “Hi Thomas!!” and XXX wouldn’t move his head wouldn’t move his head. And my husband would be like really upset. He would get really upset and be like “What is wrong with you XXX?! I am talking to you!” and XXX, it went right over his head. So of course then you have the whole question of whether your child is deaf. But we knew he was not really deaf because there were other things he would react to. So, but we did get that checked. But that was the thing my husband really would notice because he was gone all day and he would come home and expect some kind of reaction. And he got no reaction.

Le so he was open then in going to the doctors and he knew something was up.

P7 yeah, he really has his all of his children’s lives and child rearing things exclusively to me. He never interfered with that. He kind of had a feeling something was wrong to. But we had no idea; we had no clue as to what could be wrong.

Le so between the two of you you were the one who took the lead.

P7 yes

Le in terms of the doctors and um the research of it. Now you’re at the doctor getting a diagnosis of autism.

P7 funny enough the pedestrian never mentioned autism. He never mentioned anything. He just said we need to send him for further evaluation and testing so the word autism never came up at all. I am trying to even think during the battery of test we were doing. I think maybe possibly one of the social workers um mentioned the word autism. But up to that point it had never been said. You know the pedestrian never even gave us some type of warning. Or clue for that could have been it. I think they had no clue it was that. So um and no on in my family no one had a clue. No one even mentioned maybe he has autism (whispering). So…

Le ok, I am not sure if you answered this already. So, before or after suspecting the ASD you took the lead in acquiring the information between you and your husband. Did you become the researcher in it? Did you begin to look into it or were you told what to expect by the social worker the doctors… well the doctors no because they did not tell you. Once you had the diagnosis?

P7 once I had the diagnosis, ok so after we went through all the evaluations at XXX hospital um and then they called us to come in for a meeting. And um it is really funny because I can't there is this whole thing I cannot remember so clearly. And I suspect it was because of the emotions involved. But I have this recollection of hearing the word autism and calling my husband from the car and saying they think that XXX may have autism. BUT when we had the final interview with the doctors who was the neurologist at XXX he sat us in his office, my husband was definitely there so I don't know… at that point they basically said, the neurologist said your child definitely has developmental delay that was the way they said it, with characteristics of autism. And I do not believe it was autism spectrum disorder it was just autism. And basically, now you go out and you be your child's advocate. And that's it. And that was his parting words. Go out and be your child's advocate. So I was not given any information at that point. What so ever as to where to go. Because the CARD center was not really operating kind of … there was somebody there but it was not really one of the places they would tell you to go to or anything. After that I called the social worker and asked if they had any information to give me because I had no idea what to do and um at that point she told me about the couple of therapeutic centers so um I called those therapeutic centers and one was full and the other one was actually available in their preschool . So XXX started there. They had a real nice ABA program there. But it was a limited amount of hours. So at that point I started doing all the research. And fortunately I guess, I guess I did it on the internet but I am not really that internet savvy… I just don't know that would have been like 15 years ago. I must have had enough information to get something going. Because at that point I was just none stop doing research. Trying to figure out what to do. Calling all over Miami to try to find places that would provide any type of therapy that we needed. It was a lot of phone calls. There just weren't a lot of people with children with autism at that point. Those 15 ½ years ago…

Le did the diagnosis affect other children in your family? I know you have a daughter. Did it affect her? She is a year older…

P7 no because she would have been just 3 at the time. And I don't think she had a sense of what that was.

Le and through the years she has adjusted…

P7 oh yeah- it is what it is. I think the only time that possibly was when she periodically over the years she might have felt that um that I could have given her a little bit more attention. And that XXX really received most of my attention. And I tried to always be able to do that balance. And I felt I did it the best I could. Um but there were definitely times when she felt that a lot more attention was being given to her brother. And you know?

Le ok that's fine. And sis the diagnosis affects your relationship with friends?

P7 um, well to the extent that we had a lot of friends when the children were little. And we did a lot of thing together with our friends whose children were all about the same age. And it became very problematic because we could not take XXX to a lot of those types of things. It was because when XXX was very young he was very very behavioral. And um he was not really able to function at social activities parties and get togethers. It was really really difficult to go places with XXX. Um even going out to eat and um it was a very I don't know because it made me feel so badly because I did not want to leave XXX. I always wanted XXX to come with us everywhere. It became so chaotic when we would take XXX places and eventually what would happen is my husband would have to leave with XXX or we would all have to leave. Um and our friends were… I think they tried really hard to kind of deal with it but no one was really familiar with it. So I think maybe to some degree we started going less, not really sure we … so it's not like we did not get invited so much but we stopped accepting a lot of those invitations because we really could not do it with XXX. It was a problem.

Le what about with the family? Did it change your relationship with your family itself?

P7 um well I have to say contrary to the myth about the Hispanic families my mother is 100% Latin was extremely accepting of XXX. And felt even more so that she wanted to help XXX. And she really was very very actively involved in XXX life. She would always encourage me to go to her house with XXX. She created spaces in her house for

XXX to have his toys and to feel comfortable there. So he would always be able to be in her house just as he was able to be our house. Um, so my parents were phenomenal phenomenal with XXX. I think they never let it skip a beat with him since he had the diagnosis.

Le What about cousins, aunts…

P7 um my there are no first cousins because my father's family my husband's family lives in Ohio and they have no cousins. Um my brother has no children so there are no cousins really in the United States. Um, my husband's sister in Ohio who never had children, when we went up there it was a problem because she did not understand autism. She was not really… she's great now… but back then… she really did not understand it and she really did not want xxx around her house you know because he really did not do… because he did not behave the way she wanted him to behave. So she was not... we did not go see her for many many years because um that was a problem for her. Um other than that there is no other family. Really here. My family is all in South America and Spain. So they didn't... it was I cannot really… I mean friends became family and that was you know strict family- no.

Le ok that's good- ok explains your experience with the medical profession in regards to your child's needs. Right now before. I know the pediatrcian you had to go through the associate. That took a few months what about after once you got the diagnosis of autism. Did the doctors assist at all with his needs? What what you needed? The speech/ language? Leading you to where you needed to go or did you have to do everything yourself?

P7 I would say I had to do everything myself. I mean the pediatrician had um after we got the diagnosis and the reports were sent to him I think that they … the feeling I had was that they I believe the lead pediatrician there who was an old pediatrician I think he ultimately he just didn't … he was hoping that XXX wouldn't have had autism. Because he did have a child with autism in his practice. And I think that was just unfortunately his feeling. He was really just hoping that something that XXX would outgrow it or something. Um, he, his younger associate was probably a little more cooperate at helping me find a neurologist a specific neurologist because I did not like the neurologist at XXX hospital that gave the diagnosis. But he was helpful in finding me another neurologist. But as far as the therapies the things of that degree the doctors were not really... that was entirely me having to look for those things.

I'm sorry- I feel like have I have to go back to the thing about the family. Because in all fairness to my family as XXX got a little older and we were able to travel with him but that was significantly many years later um I did take XXX with me to visit my cousin in Spain and my 5 cousins and their children could not have been better. Because XXX considers another home for him to be Spain. But this was older when that happened. He started to have that relationship with them when he was about 10 years old.

Le what part of Spain?

P7 Madrid

Le I studied at University of Salamanca and I went I studied at the University there.

P7 really?? University of Salamanca is beautiful…

Le I got my 2nd masters there.

P7 really?

Le I love it there. I dance Flamenco since I was 13.

P7 Oh that's incredible. What a beautiful thing. That's great that's great. I just feel like I needed to say that because they are phenomenal.

Le yeah yeah.

P7 they...everywhere we go they are like XXX is invited and always part of the family.

Le that's so nice that's wonderful. Educators… how have educators met you in regards to your child's educational needs?

P7 um well that would depend entirely on the teacher. Because when XXX was 4 he was allowed to attend a regular pre-school. With that was not a classroom with special needs. It was a private pre-school that was where his older sister had gone. And the speech therapist that was working with XXX thought that XXX would benefit from the social aspect of attending a pre-school. So he would go to the pre-school there then go to his ABA therapy. That was a very wonderful experience for XXX. Because he was the only child with any type of disability and in a completely regular educational pre-school setting which was mostly recreational. But XXX did remarkably well considering um that he was the only child with autism. He learned a lot of proper behavior, listening, following instructions; he was able to do a lot of stuff considering his situation. He attended that pre-school for 1 year. That was a great experience. Thhheeennn we went to the public school system from there and we started in kindergarten in Dade County public School. And the first day of school I cried. We got to the classroom and the classroom was bare. There wasn't a desk there wasn't a chair there wasn't anything in the room.

Le was he is an autistic class?

P7 yes and they had read the IEP- the actual psychological review prepared by FDLRS and um they put in the class with the most behaviorally involved children because they had seen something that led them to believe that XXX was violent. And which was definitely not the case. XXX was has never been violent. But they came to that conclusion without ever asking me for any input from me. And he was put in that classroom.

Le isn't there suppose to be a transition IEP or staffing to put him in there? They didn't? I mean I am a special ed. Teacher and I believe…

P7 I don't remember. I don't remember. I remember the whole thing at the FDLRS but I don't remember, I don't remember having a transitional IEP where we discussed the type of setting that XXX needed. Because I had to do that after that first day. I called… my husband called… I went to the office and I had my husband call and they had to have an emergency meeting. So we had him put into a different classroom. And um so that was not an auspicious way to start. And you know… the first couple of years were not really very good. They were not very good.

Le so he stayed in that school and it was an autistic setting.

P7 right- it was self-contained.

Le yeah back then they had the self contained.

P7 yeah

Le he was in the autistic program?

P7 yeah, it was an autistic program and it was self-contained.

Le then after the 2 years?

P7 after the 2 years then again… well his IEP's nothing was being met. It was a just you know it was one of those situations where you know a group of people basically saying they are basically babysitting your child. That is really all they are doing and that is all they are going to do. So um I got I was able to I had another meeting I had a lot of support from administration it was not lack of support… it was more a lack of an appropriate program. It there was no way to implement a good program, I felt… and the CARD center at that point was already getting actively involved in Dade County Public schools. And they were trying their hardest. They were giving a lot of support to the teachers. To meet with administration. They were giving recommendations that were not being um acted on and that the … it was very disheartening too because you would come to the classroom with the recommendations then of course the other issue is what that was terrible was this whole issue of a veil of secrecy. They never wanted you to go into to observe your child. And they for the whole privacy issue. About not being able to see the other children. That that was like well there was no like HIPPA back then but it was some sort of privacy issue. So you really could never find out… you had to kind of find out from the teacher. Amazingly we found out from the grape vine that there were real problems in that class. This is prior to um when things started getting better. But there were kids in the class that were dangerous, disruptive destroying equipment…and they couldn't remove the children from the class because they had to stay in the class so it was affecting the other children. But they would refuse to do anything about it because we weren't supposed to know about it. We were not supposed to know about the problems. It was all an invasion of privacy.

Le that was told to you by the office?

P7 it was kind of this whole underground system that people would you know a little information would leak out and you would go and try to find someone who may know a little bit more like maybe an aide that would feel like someone needs to know there is a problem. So there was like an aide that would be like…

Le the mole…

P7 the turncoat…ya… the mole. The aide would tell a parent you need to say this because we can't do anything. And that was just amazing. It was just so amazing…

Le it's sad

P7 I only hope that things have gotten better. So awful. I have to tell you that once I found this out… I called the district. I did the whole line- you know? The region, district no one would listen to me my complaints went unheard there was another mother who did the same thing her son was in that class until finally I had it. I said this is too much. I am going to write an email to Jeb Bush. Who was the governor at that time? So I wrote to Jeb Bush and sent him an email. And I referenced 2 of our friends. By first line you know was you don't know me but I am very good friends with Mr. so and so and Mr. so and so. Who are both actual business professional friends of Jeb Bushes and one worked with him. So I said I need you to be aware of the fact that in MDC the programs with children with autism are being run completely ineffectively w/o parent involvement w/o parent's recommendations, w/o the support of the CARD center. It was a very long email. And it took a couple of weeks before I got a response. But before I got the response or around the same time I got a call from district telling me what did I how did I dare write a letter to the governor. To which I said how do you dare run programs such as the programs that you run? Do not dare try to intimidate me because you are the ones that are doing everything wrong that are not following the protocol, who are not providing our children with a free and appropriate education- so I went on that whole legal jargon. And I said don't you dare ever call me and threaten me or tell me that I have done something wrong. If you want to look back and see everything that I did because I spoke to all these different people up and down the chain of command and you guys sis not listen to me and anything ever. My child has been put into situations that are dangerous and you know if there was a problem you were going to you know be held liable and you all did not seem to care. I said so don't you dare tell me that. I was just so upset. I was upset with that them …

Le would talk to you like that…

P7 yeah, so anyways, I got an email from somebody in the governor's office and he assured me that they would be looking into the program…the problem and you know I would like to think things have gotten better. I can tell you they got a lot better for XXX.

Le I can only imagine.

P7 yeah because anytime there was a problem they wanted to make me happy. Because you know what I just got to the point I was just fed up. It became like a joke don't get Mrs. XXX mad because she is going to call Jeb. And so- that was so good with me. IT was great with me!! I called my 2 friends I just wanted you to know that I kind of dropped your name… I 've know these people for a very long time they were like anytime that you need to you just go right ahead. So then fortunately the autism support. The regional autism support specialist said to me let's see what we can do… we are going to walk you around and we are going to see what program will be better for XXX. She took me around. And so I found a teacher at that school that I felt was actually a teacher that really cared. And was like smart enough to know when she had to follow the rules and when she did not have to follow the rules. You can kind of sense she was someone that she wasn't going to let somebody bully her. Um so xxx was moved into that class when he was maybe second, I can't remember if it was second semester of first grade or the somewhere around that time. It might have been second grade. I think we had two totally disaster years. So he was moved into that class which was second, third, fourth, and fifth grade. So he was the youngest and he was the only one that age in that class. But XXX shined. As well as he could do he did in that class. So every year.

Le ok- going back- was at an autism self-contained or was a VE classroom?

P7 no- it was a self-contained classroom with autism. He never was in a VE classroom. I looked at the VE classrooms that were available but they were way too big. They did not have… no they were way too big. Um XXX really needed that small setting. Oh I think one of the issues that happened when he was in that first class they kept on putting more kids in the class. So the class started with like 6 or 7

Le there was no cap…

P7 there was no cap. All of a sudden there were like 12 kids in the class. You know? That was another issue… there were too many kids in the class. Aside from having a child there that really should not have been there.

Le problem is there are no caps on the special Ed programs but yet the regular Ed has a cap.

P7 yeah- I don't get it. There are just so many rules that don't make sense. And regulations, it's just mind boggling. Totally mind boggling. So he was in that class for a long time. And I actually held him back so he had her another year. So he really stayed an extra year. And that um teacher was just phenomenal. I mean she really did the best she could considering … she could have used a lot more support and training and things but she did great. So we left him there. And I really felt like it was ok. Um so…

Le how long was here there? I know you have him in a private school now. After, he was in that classroom…

P7 yeah, he transitioned to middle school

Le so he stayed at that school

P7 he stayed at that school because that was my home school. That was the school we needed to have him in. because it was region 5 and the well I mean there were other schools that were farther away but they weren't any better. There was no sense to move him from that school. Unfortunatley, there weren't any private school options… back then. For a program that was self-contained autism. I mean you can certainly put him in a school. I mean you really could not just put him in a school for children with learning disabilities. So, he went to middle school and he was there for 3 years. And um it was a nice school. It had a very supportive administration. And the teachers I think had some good training. I just think that the IEP's were never really being followed. Because they really just could not really do it. They are not set up to…IEP I mean the IEP as a legal instrument is really a farce. Because you can fight for everything you are asking for on your IEP but if the teacher does not have the support and the teacher are trained because we wanted him to have an augmentative device, no one was trained. And they could not use it. They kept on saying they could not keep spending time on XXX with augmentative device when they had to teach a class. So there wasn't anybody trained to do it with him. So the augmentative device was really the piece that never worked well in elementary school, middle school and by senior high … I mean the augmentative device unfortunately for XXX had he really had an effective augmentative device that everyone knew how to use he probably would have better language skills at this point. That's the one thing that I sometimes really still lose sleep over at night because it was…

Le when you say augmentative device. Can you elaborate on that?

P7 it was …he was given a dinovox. Which was…he went through several. He had some very simple ones that were easy. I cannot remember the name of it. They are like little computers but you have to program them. The child presses buttons based on where they are. They are not used friendly. They are very complicated thing so you have to really need to have an expert program them so they can be used appropriately in the classroom and appropriately in each subject class. And then in transition and for basic bathroom skills and break time. It is all those types of things. It takes a lot of work to program it. But then everyone has to know how to use it. But when you have 1 child in a class of like 10 kids you know which was probably where they were at that point nobody could really take the time to really set it up to sit with him. You almost feel like you need a 1 to 1 person. He did not have a 1 to 1. It became like a struggle for people to use. Because it was something that was a nuisance for them to deal…

Le cumbersome…

P7 yes, cumbersome for them to have to deal with this. I think that augmentative devices a wonderful thing if it is used in a class where almost everyone is using an augmentative device. But one kid… that's the way it always was…just XXX. So, I really kind of felt… I mean I had someone come to the house and set it up at the house and try to do it at the house but… here again they are not user friendly types of devices.

Le so now he is in middle school the 3 years and then???

P7 the middle school he was in was I think a well run school. It actually felt like the administration here were on the ball. They were very well structured. They had 4 classrooms of children with autism. They were segregated in another part of the school like in a separate wing. There were suppose to be mainstreaming opportunities at lunch time and on the PE field and times like that but you know they really did not have any opportunities. It would have been nice because we did discuss on IEP's to please try to give him opportunities to be mainstreamed. Because they had a lot of programs there. Not only the classrooms with autism but they had VE, they had some language impaired, I mean they had more there- it was a bigger school so they had more programs within the ESE areas. But that was an area they were not really able to do that very well. Um, but I would say for public school it was as good as you can get. He had probably 2 very good teachers there. One left in the middle of the school year. And then he had a teacher that was very sweet but not sufficiently trained but she was very sweet and very nurturing. She tried her hardest. I could not say she was a bad teacher. She just did … it's just that some teacher shave good instincts and kind of really understand what to do. This teacher kind of babied the class. She was Hispanic and she was just giving a lot of love. She was always giving lots of hugs and kisses. Make them feel like she was there mother. So she made them feel like she was a mommy thing for them as opposed to a teacher thing. So I always felt like how can you get mad at this lady? She is so sweet and adorable? She loves XXX she loves all her kids. She is so adorable you know like that person. You could not get upset but you knew there was no learning going on. There was no real significant gains. XXX was not learning any real skills. Um they had the ridiculous going out into the community once a week. They would go walk around the mall and you know…that's another story.

Le like whatever

P7 but then his last year there he had a phenomenal teacher who had just arrived in the school. She was just… she was great. She was very well trained she understands autism she was so smart. She was so smart. She had her class running like clockwork. That classroom was broken up into stations. She had stations where they had to do computer time and reading time and like pragmatics… oh she just … you can walk into that classroom at any time because she always use to say you can come whenever you want. You saw that classroom working the kids were all on task. XXX was never like you know misbehaved. He was like great. It was such a wonderful class. I just wanted to clone that woman. She was amazing. Very good very good. That was his 8th grade class. Um, and then we got to 9th grade and that was no good. That was a big public high school very big high school. They had their ESE's in trailers outside. No opportunities really to mingle with the rest of the students. Which was probably not such a bad thing because it was kind of a rough school. Um, very nice teacher was suppose to be XXX teacher but she wounded up quitting a week before school started and they got one of the teachers who had been an aide and here again nice man sweet good you could see he just was a very kind person but really did not have the perspective to change strategies. He did not understand. He really did not get it. And he had an aide and then… so I was in the administration office a lot in the first semester. Very supportive the principal I guess it was… I think it was the ESE specialist of the school .and she was great. She was very supportive. She was on the ball. She knew exactly what I wanted. And she tried to do it for me. They bent over backward. They tried to create a program for XXX.

Le so they would listen to you in the schools after you wrote to Bush.

P7 yeah

Le so they listened to your knowledge and what you had to say. They could not always implement but they tried.

P7 but they tried. I would say there was really just 1 period that XXX was very young and we had those issues. Those first 2 years were very unresponsive principal or was it assistant principal who was in charge of it. But otherwise really I would say that never had problems with administration other than that first time they really did try. When XXX was in elementary school with this teacher he had for 5 years I never really had to go to administration I could just talk to the teacher. The teacher would take care of the issues. She would at least try to figure out what she needed to do. So really had very little contact with administration. Other than the annual IEP meetings when they would send somebody in. frankly I thought it was really nice. I did not have to deal with the beuracacy. Um, in 9th grade what they offered to me was to have XXX leave the self-contained class and go to a VE math class um and go to a VE language arts class. He could not do that on his own because they were in another part of the school so he would have to have a 1 to 1. They had to basically approved. This is what they have to do and you are going to do this for XXX. You have to provide for the 1 on 1 but they could not find the 1 on 1. I have to back track, I believe they approved the 1 on 1 the first semester but they could not find anybody. So I had to find a 1 to 1. XXX had a PCA that he had who was willing to take on his 1 on 1 at school.

Le the PCA is??

P7 a personal care assistant. He is eligible for a personal care assistance. He is eligible for 20 hours a week because of his Medicaid waiver. So the PCA would come in the afternoons and work with XXX. She was a very kind and energetic young lady. She was in college. She said she would be happy to do that for XXX. He only had the 1 on 1 for like 15 hours a week. So they had to structure the class… it was very complicated. At the times the PCA was going to be the 1 on 1 did not jive with the times the classes were going to be. So I had to do it so she would be available those days. So, the administration was like phenomenal, she really tried to make it work. And so we had XXX his PCA was almost not approved by MDCPS because she did not have a degree because she was still in college. So in there infinite wisdom MD said we cannot have her because she does not have a degree and she has to have at least an AA. Wait- she had an AA she did not have …I mean she was still going to school. What is wrong with you guys? We have tried for several months for you guys to find me somebody and you cannot find me somebody a 1 to 1 for XXX to meet his educational goals according to this legal document signed here for an appropriate education so what are you telling? That she can't, so I had to … I forgot who I had to call at that point. I had to call somebody to XXX. You know somebody to say…

Le this is fine.

P7 let this woman do the job because you cannot find someone to do it. So, I think because she did not have a degree she got paid less than someone else. She was not getting paid much anyways with no benefits and they dropped her. I don't know, whatever the minimum payment was she got less because of her degree. So only because this girl was an angel. You know we talked about the angels in our life did we get XXX to be able to do that. She would go with XXX to his math class. She would go with XXX to his language arts class and she would walk him for his safety. He could not walk because it totally would not have been safe. We got through that semester. It was the second semester and um at that point I realized this whole thing was not going to work. First of all she was not going to be able to be his 1 on 1 the following year and this really was not what I wanted for XXX educationally. This was not providing him anything. He really wasn't significantly challenging academics and those social skills they would do out in the community… oh and he would miss them some of the times which is good because they are such a waste of time. They would take them and say we are teaching them to go to the store and pick out black socks. And I would say well he does not need to go to school for learning how to pick out black socks. He lives with us and XXX goes everywhere. I take XXX shopping with me- we go to Dadeland, we go to Marshalls… why…what do I need a school telling me we go to the supermarket and we make a supermarket list. And I say, he goes to the supermarket with me! He goes to the supermarket every week! I don't want the school… That is not something you need to do! So at that point I was just like this is a total waste of time! And um so so my mother had passed away on January of 2008 she had always said if I cannot help XXX in this world I will help XXX from another world. So in February, of XXX 9th grade year I started to ask her to help me and XXX with what I was going to do. I think she just sent me the message to call Atlantis. To call the private school. And because we tried several times prior but they really did not take children with …like XXX because he really did not have good communication skills. So I called and they said oh come on in feel free to come in and I called Dr. Michael XXX. He said I will go with you. He said I know XXX really well and they were very supportive. They said oh we may be able to take XXX. Why don’t you let him spend a day here … by himself…

Le	yeap- that’s the way it is…

P7	I was like OOOHHH Ok and (inaudible) and uh Michael said let him try it. He can really do it. So he did . He did it. He spent the whole day there. They had somebody helping him. A kid from another class. You know someone the same age as him. When I picked him up the other boy said to me XXX doesn’t talk too much ya know but we showed him what he had to do and he seemed like he was ok. I was like Oh my God! I cannot believe this. I just cannot believe that XXX was doing this. So I know that he was because it was right after my mother had passed away. And that was it. And so XXX started that August.

Le	at Atlantis Academy?

P7	yes, at Atlantis Academy and uh for the first time he was not in a self-contained autistic classroom. For the very first time in his life. For the very first time in his life he had to do it on his own. There was no…

Le	he seems to be doing really well.

P7	he does, he still struggles because of the language but the teachers tell me he is doing fine he can stay on task he does his work um and

Le	and you feel they are receptive to you?

P7	oh yes absolutely yeah yeah. We talked about the augmentative device and they said they would really did not use it at the school but if it was something that was very important they would do it. And uh he received speech therapy twice a week there and then once a week afterwards we go after school. I don't know I feel like the augmentative device we would have to like in a summer and do it intensively to see if we can use it. It is very difficult to work with.

Le I find that they are receptive. That is where Lucas goes. This summer they got together and learned about cancer and the germs. And that is why Lucas can go to school. They learned how to do it.

P7 they did

Le they did. I sent them information from livestrong.com that has it for the teachers and they really did. They are very receptive. You speak to Connie or Aballi.

P7 I think so

Le they are open.

P7 yeah, every year I think of things I want to work on with XXX and kind of meet a goal what I think is right for XXX? And every year that goal…not like other ones he needs very well but that one is one we keep on seeing.

Le well, maybe that is something if you bring to the school it might help somebody else. Maybe it will click and you know what maybe it will help this kid.

P7 so I think what I will do is get myself organized to do that. I went down to the district for the walk and we met with Will XXX because we want to get MDC to take on the Autism Speaks walk. You know they really can't do it but if they can get the schools on board.

Le I try to do it. In my school I send out emails all the time.

P7 and nothing?

Le no we have a group of teachers that go or donate. Usually it is the ESE teachers that go…

P7 what school is that?

Le Royal green Elementary. We usually go as a group. Last year we did it under Lucas' name. You can send out an email but you need it more personal. There has to be someone in the school.

P7 yeah so that's the thing. Will XXX said he would try to get principals on board. Then we got an email that said principals can't it has to be through the PTA. So... but in principal he says they are going to try to do it. And uh so united way campaign is over now so they can concentrate on it. They can't do it in the same way as United Way but…

Le so let me know, because the schools have elementary school have FEA Future Educators of America have fundraisers and they do different things in the community so that may be something (more discussion on FEA).

Le the family… I know the family is involved by the demographic survey. The dad, grandfather, sister, and the uncle. What is there involvement?

P7 well, uh my husband takes XXX; he does recreational type things with him. He does not like provide therapy type things. But he will take XXX out on the weekends. He will take XXX out to the movies um go shopping they go to the park.

Le that is great, that is a form of therapy but he just doesn't know it.

P7 right that is true. He takes them out so that is really what my husband does, like on the weekend. And he will do that with XXX. My father, well right now he cannot do a lot…

Le right but before his illness.

P7 but my father will often help me, like when I have to go out my husband and I he will babysit for XXX. XXX will either go to his house or he will come to ours. And he will hang out with XXX. You know, sit there and watch TV or make him dinner um he takes him for walks. He goes for walks with XXX. XXX loves walking and my father likes to walk. So they walk a lot. He … that's about what he does. But he provides a nice safe environment when he is home. And he tries to buy things for XXX. He has the leap pad and he has the little things for XXX to play with the leap pad. He buys him some toys and he has the little Nintendo set up there in his bedroom. XXX is off Nintendo right now. But when he was on Nintendo he tries to have stuff for XXX to be comfortable at his house. He has… when my husband and I took my daughter to college my dad stayed at the house and he kind of watched XXX. So we were able to do that. If not we would not have been able to do that.

Le what about the sister? What does she do?

P7 she is away at school now. But when she is around she watches XXX. She takes him to the movies. She's taken him out places with her. Basically that. I mean she doesn't do therapies with him but she helps. I mean XXX plays piano and since she plays piano sometimes she can play with him. I can't play piano. My husband can't play piano. So she in pass helps him a little bit better than I can because I can barely read music. I mean I can sit there and help turn the pages. Now it's at the point where I tell XXX to turn the page himself because he can read music. So he knows how to…

Le isn't that amazing

P7 yea, XXX played the piano at my mother's funeral at church. He played X? yeah, he plays really complicated pieces.

Le what about the?? I mean my children do the piano thing also…

P7 Lucas plays piano? Aahhh

Le yeah he is funny because he plays piano he is by ear and he just has to watch and he's got it. Yeah, so it took me four different teachers and the fourth one is a friend of mine from church but the problem is (I told her what Lucas does) so she makes him read the music first. And then play it. He says No you play it and I will watch you. So she plays it wrong on purpose and he says that's not it and then he will play it correctly. But he has to like the piece. Otherwise forget it.

P7 yeah, well that's the way it is with XXX. Yeah there are pieces that yeah; there are some pieces that just do not turn him on.

Le yeah, don't even try it.

P7 yeah, it's a major struggle. We just found that he likes to play blues. He really likes that. He is really into it. It's not music therapy anymore.

Le does not matter, it's something, it's music.

P7 when he was younger we did get music therapy and he did get music therapy while he was I n public school. You know ½ hour a week. You know. That was in public school. We lost that when we came to Atlantis. But that did not make any difference. When he was young he started with music therapy and they discovered he can play piano. So the sister is more like a…

Le a buddy?

P7 yeah, a buddy… I would say she loves him tremendously but because XXX is so classic, he is just so much happier when he is on his own he really does not seek out a lot of company. So um she is a companion. She also helps with the care giving.

Le so she becomes like the little mom?

P7 yeah, she is the little mom. Yeah, but she is a terrible cook. She can't really cook. I would not leave her in charge of like XXX meals.

Le that's nice though that he has that.

P7 now my dad can cook. He can cook for XXX but the father and the sister cannot cook.

Le so the uncle cooks?

P7 well, actually the uncle doesn't cook either. But the uncle is really good because the uncle is a football coach. So, he's real athletic. He takes XXX out and he makes XXX run with the dogs. He gets XXX to do real stuff.

Le therapies at home your doing speech?

P7 at home the speech therapist and the occupational therapist come to the home only when there is no school. They provide the therapy at the house. He goes to FIU for speech therapy once a week. It was OT and speech therapy last semester. Now it's just speech. He is doing OT at school.

Le is he part of a program at FIU?

P7 Kinetic Kids.

Le physical therapy?

P7 Physical therapy is now being provided at school. We just started that for the first time.

Le social stories?

P7 well, the speech therapist and the tutor that comes to do the cognitive therapy, they write social stories for XXX. I write it for him sometimes. We use social stories for inappropriate behaviors. Of which there are many.

Le music therapy – is piano?

P7 yes

Le and then parent faith which is something we talked about.

P7 He did his first communion and he did his confirmation last year. Unfortunately, the young lady who was his body, it's her senior year and she is unable to continue with him. So he has not gone back to the youth group. I am kind of sadden.

Le there is no one else there that would …

P7 I don't know. Xxx really understood autism. She was really good. She understood. When she would see XXX get nervous she knew how to handle it. It is hard to find someone their age. XXX is the only child like that. XXX was really good she did not care if XXX was acting the way he was.

Le so when he did the confirmation and the communion he went through the classes?

P7 yes he did he went through everything. He did the class for 1 ½ year. My brother was his sponsor.

Le that is wonderful! So, when you go to the doctor… or the school for a discussion about XXX educational needs you understand everything being told to you now but in the beginning did you understand the word the phrases or acronyms they would throw at you.

P7 yeah, I think so. Nothing was really…

Le can you explain any concerns you have for your child's future?

P7 my concerns, yeah, sometimes I feel like someone who is in AA. It's one step at a time. People ask me all the time, what's going to happen to XXX when he gets older? So, my answer to that is... things in the world of disabilities are moving very rapidly in certain areas because as more children are being diagnosed with autism sadly more services have to be created more programs have to be created. More people have to be trained to do that. My hope is that in the next few years there will be better programs. That we will get FUNDING FUNDING FUNDING specific to the needs of our population. I know that Goodwill has set a wonderful example to the community about how you can find appropriate work for the people with disabilities so they feel rewarded and they feel a sense of accomplishment. The environment is a safe environment. I understand that Easter Seals is starting some great program. My hope is that there will be some programs that XXX can you his God given skills and abilities including his brain so he can do something that is just not doing manual work. That is always my nightmare that XXX will be sweeping the floors at Dad eland. And I really think that XXX has the ability to do much more than that. Um, and that is where I really would like to see him. In something in some type of employment opportunity where he can use that skill that he has because he is a whiz at math. And that there will be appropriate group homes that have staff that are trained and caring and good human beings. That XXX will be able to live as independently as he will be able to be. That is my goal for XXX. It may not happen. He is only …almost an adult. But we will find those things hopefully when we need to use them. And I have also made a commitment to help create some of those opportunities. I am working with Michael and the people at CARD.

Le are you part of the transition team?

P7 no, I am not. But Michael and I are very close friends and he knows that when the time is right when I need to do the things he knows I will do them. So, I will firmly committed to do that. I hope I can find those types of things in Miami. I hope we don't have to go somewhere else cause I know there are programs in other parts of this country. That are run very very well and they provide great opportunities for working and living. But you know…

Le we need to do something…absolutely.

P7 we have to do something… you know and just make it work for their needs and put their needs first and not the government bureaucracy. All the people, when you see all the people and government agencies… when you read the paper today about the department of children and family…

Le it's just too depressing to read the paper.

P7 Oh my God it's unbelievable talk about not having their priorities in the right place. It's unbelievable; it is not putting the children first.

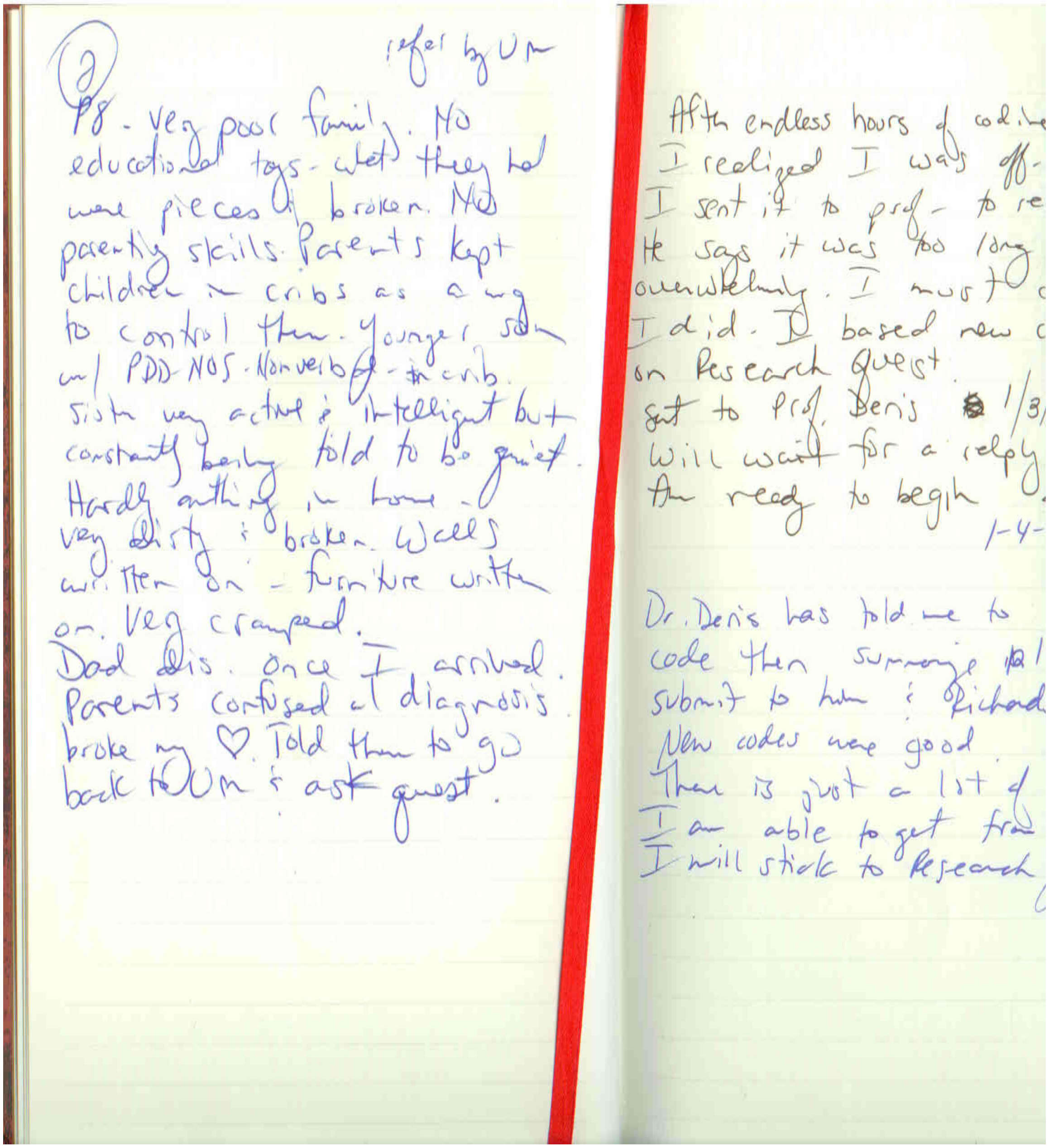
Le no it's not

P7 so…

Le we are done with the interview, thank you sooo much.

APPENDIX H

EXAMPLE OF JOURNAL



② refer by Um

P8 - Very poor family. NO
educational toys - what they had
were pieces of broken. NO
parenting skills. Parents kept
children in cribs as a way
to control them. Younger son
w/ PDD-NOS - Nonverbal - in crib.
Sister very active & intelligent but
constantly being told to be quiet.
Hardly anything in home -
very dirty & broken. Walls
written on - furniture written
on. Very cramped.
Dad dis. Once I arrived.
Parents confused w/ diagnosis.
broke my ♡. Told them to go
back to Um & ask quest.

After endless hours of codi
I realized I was off-
I sent it to prof - to re
He says it was too long
overwhelming. I must
I did. I based new c
on Research Quest.
Sent to Prof. Denis 1/3
Will wait for a reply
then ready to begin
1-4-

Dr. Denis has told me to
code then summarize
submit to him & Richard
New codes were good
There is just a lot of
I am able to get from
I will stick to Research

APPENDIX I:
EXAMPLE OF TRANSLATED INTERVIEW

November 22, 2009
P5

LE First, when was the first time you noticed that something was different with x5? What age?

P5h Well, I think that it was more or less when he was 2 years and some when we noticed something. We mentioned to the pediatrician and he said not to worry that he was little and he will growing, and that was normal.

Le What things did you notice?

P5h He walked with the tips of his toes, he would not look at us straight in the eyes and sometimes, he would get hurt and he would not cry.

P5w undetectable audio

P5h Over there, when he went to the day-care was the first time the teacher called us because the child would hide under the piano and yell while the other kids would play and sing with the piano. Over there, he would not stand the Boise and the movement from the other kids.

Le Was that the first time you noticed something or have you noticed something already?

P5h After that we started going to the doctors…

P5w (wife is cooking in the kitchen as interview is going on) inaudible

P5h No, we had mentioned to the pediatrician and we started going doctors and find out what was going on, and taking him here and there… and well…

Le Was that here in the United States of America or in Colombia?

P5h Here, in the United States.

Le Ok, so the doctors told you not to worry about it because the child was going to grow.

P5h Until finally here in Children's Hospital, Dr. X, who was the department head of children, said right from the back that the child was autistic. That those children no…(unable to understand- both parents speaking at the same time)

P5h Dr. X said that the child walked with the tip of his toes, he does this, that, and that he won't be able to go to a regular school…. The child won't have….You will probably would have to put him in a home when he grows older because these children are schizophrenic. He won't learn to speak normally like the other children. Well, he said a ton of things.

Le and that was in the 70's 75's… 80's…?

P5w No, he was born in 78. That was more or less in the 80's… Anyway, x5 had gone through psychologist, psychiatic, and I have gone through psychiatric as well.

P5h because they said that it was the parent's fault, that the parents were from different cultures. Back then they didn't even know the cause and today they still don't know; that was the parent's fault. Then we Looked at each other and we began to cry.

Le That is was your fault?

P5h That the parents were to cold, they said this and that. And then I started to read and Nico and I don't know who says this and that and today you know that this is not true.

Le You received a diagnosis when the child was between seven and and ten years old? He was like in second grade?

P5w Poor Audio…. We Left in the year 88, x5 was already in Cali, Colombia.

Le But he was born in 75?

P5w No, x5 left when he was 10 years old and we stayed outsider 10 more years.

Le Like third grade? But at that age he should be in 4th and 5th grade.

P5h No, but he didn't attend to a normal class because he was in the group of kids with disadvantages, so he never went to a common normal grade. In that group there were many kids with different categories, conditions, and they were all together with three or four teachers, not small groups. Anyway, some would scream, cry, others would hit each other against the wall and others would drool

P5w x5 spent much time seeing this behavior and going to different schools…

P5h Already he had gone to how many schools? Like four or five schools.

P5w That was a process… a child should be four years old… a child that went for so many schools, many doctors, many diagnosis.

P5h They didn't know where to put him.

P5w They said that they have never had a child that was diagnosed so early, and started school so early. X5 was Adour 4 or 5 years old when he started public schools.

P5h They didn't know what he had at that time.

Le They didn't know what he had?

P5h They didn't know where to put him.

P5w They even said that he had a brain disorder.

Le a brain disorder, schizophrenia what else did they say?

P5w (inaudible). Until came the time that we took him …where was it that we took him? Until finally we took him some papers.

P5h over there by Jackson. Close, but not exactly.

Le And when you were going through all of that, was he the oldest one of your children?

P5h Yes, he is the oldest one.

Le Did you agree with everything that was happening or did you disagree?

P5h no, we disagreed. We knew that something was happening to the child. We were looping for it and how to solve it. We took him here and there.

P5w XXX in a specific moment, xxx walked Fast, and did everything Fast, walking…

P5h and we were happy because he already talked.

P5w in a moment, he lost everything he knew.

P5h The only thing he knew was echolalia. Only repeated. He would repeat a long phrase. We thought he was talking. They had told us that was not echolalia.

P5w He had a lot of changes throughout this investigation process. Changes very….

Le And both of them did it together? Was there one that did it more than the other? Was everything the same?

P5h We were both with the doctors.

Le And how about the family? Did they change with the diagnostic? Did things change among family members and friends?

P5h p5w No

P5h Nothing, everybody loved him.

P5w not even with the uncles, cousins…nothing.

Le and friends? Did everyone loved him the same?

P5h no, nothing changed.

P5h The brother and sister didn’t understand him until much later.

Le And how did they accept him?

P5w They didn’t understand him.

P5h They didn’t accept him, but they didn’t know why he was like that. But later, they understood him and something was different. They accepted him.

Le Like part of life?

P5h Yes

Le Now, in reference to the doctors, they said that xxx …….

P5w The pediatrician said nothing, like we mentioned before.

Le and in reference with education do you thing they helped you?

P5h He had many people that helped him a lot. One lady, there was one that I didn’t like that much. She was very negative. Mrs. Xxx, he was the one that helped us the most. The old lady helped him a lot.

P5w Well, in school, they were very busy, they would tell us his progress. He was like strict one time, but...

P5h Yes, he taught everything, he would make run, everything was so difficult with him. Imagine to write, we spent two years with him to get him to get the pencil right. We had to put him something in his hand so he could feel his hand.

Le Hands weights?

P5h Yes, he didn’t have any attention and would let everything fall a thousand times. I didn’t know why he didn’t pay any attention. And Now look at him nowadays.

Le Look at him. He draws beautiful. Did he graduate here or in Colombia?

P5w and h no, not from any place.

P5w Is that when we went to Colombia he was in a school…

P5h kinder

P5w Which was the only one that received him.

P5h But in kindergarten with children without problems. Were "normal's" and practically dedicated to him. It came to the point the he help teach the class. He would teach the other children how to speak English. And the other kids would teach him how to write and speak Spanish. He talked a little in English and he continued with movies and he by himself…

P5w At that moment, he began to speak because before he didn't speak.

P5h It took him a long time to speak, but he made it.

Le How old was he?

(Inaudible- both parents speaking at once)

P5w He was around 10 years old, when we took him out of the medication "melladir." That was what they had giving him. That was the last medication he took.

P5h What happened was that we took him out without the doctor's permission and against his will. The doctor didn't want, I remember, he told us that is another thing with you guys. Do you remember? I felt bad with the child because he lived constantly drugged up. He lived almost asleep like sedated. We felt bad and said it doesn't matter what happens, we are not going to have him like that his entire life. And we took that stuff away from him and I think from that moment on xxx began to show improvement.

Le without the medication

P5w and p5h meladir (telling me how to spell it)

P5w ten props three times a day. It was too much.

P5h He lived drugged up.

Le Between here and Colombia, when you tried to talk to the teachers, were they helpful? Were they willing to help you?

P5h Everybody.

P5w Yes, since the first moment xxx got to school, they would change him when something didn't work.

P5h They tried to help him a lot. There was only one that problems with him because she said that xxx tried to touch her and kiss her and she didn't like that.

P5w And that was with the Black little girl.

P5h her name was Tracy

P5w or with the one with down syndrome. Remember? that he was suspended.

P5h a Black lady that worked there complained about xxx because xxx had a problem about that. Xxx didn't any problems with any of them.

Le You told me that you are the only two helping with xxx. I know he has the Brothers and the sister. Do they only help to take him out?

P5h The Brothers take him out wherever he wants to go. They get along very well.

Le Do they also help?

P5h Yes, they take him to the movies or wherever he wants to go.

P5w The brothers…yes… He gets along very well with his brothers.

P5h nowadays more than ever.

P5w Now that they are bigger.

Le Then, things have gotten better now that they are bigger.

P5h They understand very well the problems.

P5w What I have noticed is that they treated him normal just like they treat themselves.

P5h Yes, they have treated him the same.

Le Like it was nothing?

P5w They tell him that you can do this, they argue and they talk they make him think. Eventhough, XXX gets mad, he doesn't like to be told but then…

P5h Yes, he gets mad.

P5w But the brothers ask him why and it's very positive.

Le Yes, it's very positive.

P5h He understands and many times. If you ask him things he had done, he understands.

P5h Very normal. He still writes. If you talk to him you can tell, but you can talk to him about anything. He responds but he rathers be by himself alone and tells you stop and go away.

Le Like times up.

P5h Yes, he is like that, he tells you "stop I don't want to talk anymore."

Le You told me that he has a companion that comes and helps him with social skills. Can you explain how is that working twice a week?

P5w Well, the companion takes him wherever he wants to go and stays with him.

P5h They g oto Barnes and Noble, he sees his magazines. He likes comics the most and knows all about them and about the new movies that are coming out. He looks i Barnes and Noble. He goes to the Internet to find out more. The companion takes him here and there.

Le ok- the companion is separate from the person that comes and…

P5h Yes.

Le Then the other person that comes to teach about the Money and how to handle it?

P5h Yes, how to get change when he goes to th estores to buy something.

P5w He has a psychologist and people that comes to give occupational therapy for the past 10 years.

P5h He has learned a lot o f math.

P5w He has learned a lot from them to add, to substratct. They have come to teach him.

Le In the past 10 years he has awaken more?

P5h I would tell that he improved more in Colombia. Here, it was very hard because he would not pay attention. He didn't even know how to talk. He didn't know how to grab the pencil or anything.

P5w (inaudible) XXX walked by at that moment.

P5h But, XXX had several things that he copied from other children. He imitated them in school. He would drool, hit himself against the wall, but those behaviors were from other kids. But when we got to Colombia, it was a different environment with normal children, so that is why he improved walking with the tips of his toes hacia adelante. How do we call that? Well over there he left all of those behaviors.

Le Was he in a regular group?

P5h Yes, in a regular group.

Le Was he in a younger group than him?

P5h Yes, he imitated other children. Maybe he did unconsciously.

P5w I think the fact that he was with other children younger than him, helped him. He benefited because he learned from normal kids.

P5h yes, “normal's”

P5w The normal kids. He had to follow the rules and do everything they had to do.He was 10 years in Hida Abajo. That was the name of the lady. He went through 10 kindergarten and first grade graduations.

P5h Now, his friends are all professionals.

P5w Now, they are men and women married with children and the still know him.

Le Does he remember them?

P5w Of course, he remembers. That part, I think, was very important for him because in those 10 years it was…. It was a small town and xxx learned how to go out by himself.

P5h First he would go out with the Cleaning lady, then he learned to go out by himself. (difficult to hear both parents speaking at the same time).

P5w At the end he went by himself.

Le so there he learned to be independent.

P5h He would go to the bakery to buy his candies and his things sometimes they would give him candies for free. He would go to the bakery.

P5w Also, going to the farm helped a lot because people there knew him. All of my friends, everybody shared with him. He learned many good things and learned from the other kids. They…

P5h It was difficult to play with them, he placed very little with them. He wouldn’t pay attention to the games. But, it was good for him.

Le The last questions. You said a lot already. For the future…

P5h hmm that is very difficult.

Le What are you concerns for the future your son?

P5h Well, when we got here, we started looking for special programs that the government would offer.

P5w Public schools didn't accept him because he was too old.

P5h He was too old and they didn't have high school.

P5w (inaudible) they didn't have high school so they couldn't accept him. In this country they gave us the suggestion about working. And they ask…..

P5h I took him. We went with the social Yorker to see if they had a job for him, but we also found a Group that many other problems that xxx didn't have. Once, he saw it, he didn't like it and told immediately that he didn't want stay there. "I don't want, I don't want" he kept repeating. There were kids screaming and doing other things that….

P5w adults.

P5h adults and almost adults, he didn't like the group and we were not going to force him because we knew that those imitations wouldn't benefit him. We left it like that and we never Looked any more. There were kids that put things in a bag and he didn't want to do it.

Le he never had a job?

P5h no, we also tried with Blockbuster because he loves movies and he would inside Blockbuster and tried to fix the movies. He is a perfectionist He fixes and picks everything that is around the room. Because he loves movies and he would enter Blockbuster and try to arrange the movies where they belong. He is a perfectionist. He would fix it and pick it up what was on the floor and then we tried to see if he can work there but no…

P5w We went there because we had heard that they hire people with disabilities. And we went…but no…

Le What about his future?

P5w I really don't know… the truth is that we wanted to finish high school. But because his age, he couldn't and it's very frustrating. And…

P5h But he doesn't like anything new and to be imposed. But we could try. He is so intelligent.

P5w The only new would be when he will get new homework.

P5h He doesn't' like or want, but he learns. He learns and succeed in whatever he does. We want him to learn.

P5w And more for his life, since he already has his independent. He know how to manage his Money.

P5h I want him to be independent, so he can live by himself.

P5w When his Money gets here, he pays me whatever he thinks he should pay me.

Le aww

P5w He asks me how much Money I will need for my birthday. I let him manage his own money. He has the house's key and his own debit card.

P5h He helps a lot around the house. He helps to cut the grass.

P5w xxx helps a lot.

P5h He mops and does everything.

P5w He organizes his room and knows how to wash his clothes.

P5h He knows many things, he folded his clothes when we went to Colombia. I was surprised to see his clothes folded when I came back. It was good considering that it was his first time. I told him that one of this day he will learn how to clean the bathroom.

Le That is Lucas' favorite. He loves it because he plays with water and he does it very well.

P5w xxx will have to do it with gloves. He needs to learn for the future. He is very organized.

P5h That does not worry me.

Le and you have a guardianship over him?

P5w No papers only Word of mouth. The Word of mouth I am the guardian. In the future I don't know…which of them will be. Because we can't anymore. We can't just give them the load. They wanted to…. (crying) We don't want them to take the problem, but who would do it? We are not going to force them the responsibility. They will take it at the given moment whether they want or not. That is the Harvest part of getting old. Time passes and we won't be here. We will do whatever we can until then.

P5h XXX does not want to grow old. He wants to continue being a kid.

P5w Death hits him hard. We are telling him already because when my father and Alicia died he took it very bad. He doesn't accept it. It is horrible. He hits himself against the wall it is horrible. And he would not accept it and would not accept it!. That is just horrible. He hits himself against the wall- it's horrible. I have told him tree times already that we are old and eventually we can die. We have to tell him.

Le Tell him at this moment because…

P5w I have to tell him so he can remember and it will be easy for him. He can start processing it in his mind.

Le Processed?

P5w He takes his time, so then in the future when it happens, he will know.

When tape was off and I was leaving they were telling me the time had come to help do something. They believe big changes have to take place. The interview was very hard on them but it was good. They feel the president HAS to do more. They believe in sterilizing this population. They have a fear of XXX having children. They asked about guardianship. What it was and how it would help him. They are concerned FI he were to do something no one would know he is disabled.

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EDUCATION

2005- PRESENT	Walden University	Educational Leadership
2003	Universidad de Salamanca	Masters in Spanish culture and language
1997	Nova Southeastern University	Masters in Varying Exceptionalities
1994	Liberty University	BS in Psychology

CERTIFICATION

1999	Florida	Special Education K-12

PROFESSIONAL EXPERIENCE

ACADEMIC

2006 to present	Union Steward
2005 to present	Board Member - Parent to Parent of Miami
2003 to present	Full time special education teacher for Miami Dade County Public School
1996- 1998	Substitute teacher for Miami Dade County Public School
1994-1996	Elementary school teacher for Perrine Baptist Academy, Florida

OTHER WORK EXPERIENCE

1993 to 1994	Paralegal, South Carolina
1992 to 1993	Pre-school teacher for Staten Island Naval Base, New York

1991 to 1992	Store clerk for Staten Island Naval Base, New York

OTHER PROFESSIONAL ACCOMPLISHMENTS

A. SERVICES:

2007 to present	Founder of Dream Team baseball team for children with disabilities.
2005 to present	Habitat for Humanity Volunteer
1996 to present	Locks of Love Hair donations every 3 years
2004 to present	M.S. Society Volunteer rider
1983 to 2005	Flamenco Dancer Volunteer for fundraising within the community

B. PROFESSIONAL AFFILIATIONS:

2005 to present	Parent to Parent of Miami
2005 to present	Phi Delta Kappa
2003 to present	Dade Reading Council
1999 to present	Council for Exceptional Children
1998 to present	University of Miami CARDS

C. MAJOR AREAS OF CREATIVE OR RESEARCH INTEREST

Learning Disability
Autism
TEACCH Program
Social Stories
Hispanic Community
Siblings of child with autism