

**A PHENOMENOLOGICAL EXAMINATION OF THE INFLUENCE OF CULTURE ON  
TREATING AND CARING FOR HISPANIC CHILDREN WITH AUTISM**

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*Researchers have found that cultural factors may lead to lower rates of diagnosis in Hispanic children with autism and that parents lack the knowledge of therapies and practices used in the treatment of the autism spectrum disorder (ASD). Five research questions guided this phenomenological study. The focus of the first two questions was how culture may affect families seeking assistance; the third question queried how professionals play a part in the choice of therapies ; the fourth question dealt with how do families choose a therapy to aid their child with ASD. The focus of the last question was the involvement of other family members. The major themes 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 aid their children with ASD. These findings will assist professionals to understand the Hispanic culture as it may relate to having a child with ASD and thus assist families to understand how to acquire the services needed.*

The effects of Autism Spectrum Disorder (ASD) pose challenges to all affected families (Hutton & Caron, 2005; Mandell & Novak, 2005; Shulman, 2002; Stoner, Bock, Thompson, Angell, Heyl, & Crowley 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, Listerud, Levy, & Pinto-Martin, 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 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 the children and their families.

One particular problem faced by Hispanic families in this situation is the 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). 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 & Novak, 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, 2002; Shulman, 2002; Overton, Fielding, Garcia de Alba, 2007). The failures to access available services and understand essential rights and responsibilities impacts negatively on the families because they may not receive the support necessary for themselves or their children (Mandell & Novak, 2005; 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, 2002). Many possible factors contribute to the failure to use health care (Collins, Hughes, Doty, Ives, Edwards, & Tenney, 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, 2007; Alvarez-McHatton & Correa, 2005; Bacallao & Smokowski, 2007); (d) fear of deportation because they might be 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; Alvarez-McHatton & Correa, 2005). It is my aspiration that this study, using a phenomenological approach will contribute to the body of knowledge needed to address this problem.

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 (Cantell & Baker, 1984). The families' understandings of educational theories and practices for their children were also addressed.

## **Method**

### *Participants*

There were ten participants in this study, eight mothers and two fathers. The common characteristics shared by the participants were of being of Hispanic ethnicity and being a parent of a child with ASD living in Miami-Dade County. Two participants had children who were not yet in school, two had children who were in elementary, two had children who were about to transition into adulthood, and the last two participants children were adults.

### *Materials and Procedure*

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). Interviews were conducted in English or Spanish and were audio recorded.

Data for this study included demographic data and recorded interviews. 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. Thus, the option of recoding the data if in case the original coding system did not function was available (Creswell, 2003).

### *Procedure*

Interviews were conducted at a location agreed upon with the participant. The purpose of the study was re-stated; participants completed a demographic data form, and participants were reminded of the projected time for the interview. Each interview lasted approximately one hour. The interviews were recorded for accuracy and transcribed within two weeks. The participants were asked questions that were peer reviewed by an expert panel consisting of parents, teachers, and other professionals that have dealt with families living with a child with autism. During the interview, field notes were taken. This allowed for 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. The primary researcher is fluent in both languages and the interviews were conducted in the language of choice of the participants. 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.

## Results

### Themes

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 were 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? 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 included 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? Parents were asked 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. 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 of 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 to 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 time. I really did because even though I knew in my heart – if this is just getting it official you know like stamped but it was just 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 five 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 two 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 were setting their concerns aside.

*P1: No she's oh ok, she's autistic ok, but 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. 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.*

#### *Personalismo*

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

Within the Hispanic culture, personalismo is described as being able to have a warm and trusting relationship with others (Barker, Cook, & Borrego, 2010). There needs to be an ongoing respectful and family like dialogue between professionals and families (Brice, 2002; Barker, et al.). The Hispanic culture tends to prefer to work with professionals who are also Hispanic (Guilamo-Ramos, Dittus, Jaccard, Johansson, Bouris, & Acosta, 2007; McCabe, 2002). If unable to acquire a Hispanic professional, 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., 2010; Guilamo-Ramos, et al., 2007; McCabe, 2002). 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. 2010). This preamble enabled a comfortable setting and ambiance for the parents to be candid with their responses on how their culture influences 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 that 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 to the school.

*P1: No, she's oh- ok she's autistic. Ok but 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 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. Nobody.*

#### *Parent Involvement*

The importance of parental involvement is no different within the realms of this study. The authors found by calculating the responses that seven of the families are 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. 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.

*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 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 go*

*back to the school and she laughed and said no, that means dirty. This is a turkey and this is 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 2:00 am 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 regular 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 a 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.*

*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 son's diagnosis.): 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 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).

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 or educators do not know what ASD is or how to handle it. In this study, 100% of the families did not find some doctors helpful at some point in the treatment of their child.

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 Centers for Disease Control and Prevention (2013) 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 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, 2002; Ell & Castaneda, 1998; Mandell & Novak, 2005; Oyerman & Lee, 2008) due to not having family nearby.

#### *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 participants 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 too 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.

What therapies are Hispanic families choosing to aid their child? According to the demographic survey administered to families, the families used eleven therapies. These therapies are summarized in table 1.

**Table 1. Therapies Utilized at Home**

Therapy Used	Number of Families
Occupational Therapy	3
Speech or Language Therapy	3
Behavior Therapy	2
PECS	1
ABA	2
Floortime	1
Social Skills	1
Music Therapy	1
Faith	7
Physical Therapy	1

Diet	2
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### *Familismo*

Research question 5: To what extent are other family members 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 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. The mother's primary role is that of caring for the children.

According to 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 child rearing. 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 findings of this study manifested familismo most evident in this question. Families tended to rely on each other for shared child rearing. 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 these themes. They pool their money together for finances, they live together in order to facilitate rearing of the child with ASD.

As families, the biggest concern 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 so with second generations (Halgunseth, Ispa, & Rudy, 2006).

### *Frustration with Professionals*

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.

*P8 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 immigrants without money is very stressing. Then, you add the child situation is more frustrating... Our life 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 bear*. Most participants have taken on this view of self-sacrifice for the good of the child. Families have moved across the 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.*

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 concerns related to their child's diagnosis, services, and future. Once data were 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.

#### *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.

#### *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 functioning 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.

#### *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, 2002; Guilamo-Ramos, et al., 2007). 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 child care. 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 want 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.*

#### *Behavioral Familismo*

Within the realm of this study, all participants with family members living in Miami-Dade County share child rearing. 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.

### Discussion

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. Pediatricians should 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 certified 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.

Consistent with previous recommendations, it is the job of the professionals to help educate the families. Professionals need to be cognizant of the parent's 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.

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. Families should 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.

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