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Latino and Non-Latino White Parents' Experiences Raising their Child with ASD: An Exploratory Study

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Abstract

There is a dearth of research about the experiences of the Latino population in raising a child with autism spectrum disorder (ASD). This includes a lack of cross-cultural perspectives and perspectives from fathers. Although there are similar experiences in raising a child with ASD among parents, we hypothesize that there will be different experiences due to culture. The current study is an exploratory qualitative research design, where we sought to understand the experiences of Latino and non-Latino White parents who are raising a child with ASD. Results indicated similarities across all families that include: self-efficacy beliefs, challenges, stress and coping, and goals and expectations. Different themes emerged in the Latino families that were not evident in non-Latino White families. Specifically, Latino families emphasized religion and faith, involvement and love, extended family support, Latino pride, and importance of collaboration. Implications are discussed for further cross-cultural family studies, the need to inform healthcare professionals on the early signs of ASD especially with regard to culture, and the importance of collaboration among parents and professionals.

Keywords

Autism Spectrum Disorder, Parents, Exploratory Research, Qualitative Research

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Latino and Non-Latino White Parents' Experiences Raising their Child with ASD: An Exploratory Study

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There is a dearth of research about the experiences of the Latino population in raising a child with autism spectrum disorder (ASD). This includes a lack of cross-cultural perspectives and perspectives from fathers. Although there are similar experiences in raising a child with ASD among parents, we hypothesize that there will be different experiences due to culture. The current study is an exploratory qualitative research design, where we sought to understand the experiences of Latino and non-Latino White parents who are raising a child with ASD. Results indicated similarities across all families that include: self-efficacy beliefs, challenges, stress and coping, and goals and expectations. Different themes emerged in the Latino families that were not evident in non-Latino White families. Specifically, Latino families emphasized religion and faith, involvement and love, extended family support, Latino pride, and importance of collaboration. Implications are discussed for further cross-cultural family studies, the need to inform healthcare professionals on the early signs of ASD especially with regard to culture, and the importance of collaboration among parents and professionals. Keywords: Autism Spectrum Disorder, Parents, Exploratory Research, Qualitative Research

Introduction

Autism spectrum disorder (ASD) is a complex neurodevelopmental disorder with impairments in two core areas: social-communication and repetitive behaviors (American Psychological Association [APA], 2013). The prevalence of ASD in the United States has increased from 1 in 2500 births in the 1990s to 1 in every 68 births as reported by the Centers for Disease Control (Centers for Disease Control [CDC], 2014). Blumberg, Bramlett, Kogan Schieve, Jones, and Lu (2013) investigating parent report of ASD, found the prevalence of ASD in school children ages 6-17 years was 2 percent in 2011-2012 compared to 1.2 percent in 2007. The change in prevalence was greatest for boys and for adolescents aged 14 to 17 years. The reported increase from 2007 to 2011-2012 was due to diagnoses of children with previously unrecognized ASD. This increase in the prevalence of ASD in the general population is concerning. However, even more alarming is that the prevalence of ASD in the Latino population, as reported by the CDC, is 1 in every 126 births and 1 in 98 in the Black population (CDC, 2014). Further, the CDC (2014) reported that non-Latino White children were 30% more likely to be diagnosed with ASD when compared to non-Latino Black children and 50% more likely to be diagnosed with ASD than Latino children. This is quite concerning when ASD symptoms can be identified in children as young as 18 months because these

children can be getting intervention at an earlier time when change can be optimized due to brain plasticity (Zwaigenbaum, Bryson, Rogers, Roberts, Brian, & Szatmari, 2005).

It is not only that minority children are not being diagnosed, it is also reflected in getting the necessary services. A recent study found minority children are disproportionately under-represented in early intervention and early childhood special education (Morgan, Farkas, Hillemeir, & Maczuga, 2012). Further, “racial-ethnic minorities were less likely than Whites to be evaluated and diagnosed by professionals as having communication, attention, or learning problems.” (p. 347). This is true even after considering contextual variables – such as gender, socioeconomic status, low birth weight, relative numeracy and language knowledge, and frequency of problem behaviors.

Because minority children are not getting a diagnosis in a timely manner and not getting the necessary services, it is imperative that healthcare professionals gain an understanding of how minority parents view their children with ASD. This understanding will not only increase knowledge about different cultural beliefs, but can help healthcare professionals ask more poignant questions when interviewing parents about their child’s development that can help to identify possible characteristics of ASD at an earlier age. This study focuses on the Latino population to investigate parent’s perspectives on any possible barriers that might influence when they seek services for their children.

Background

It is known that many parents of various ethnic/racial backgrounds share similar general experiences (e.g., stress and anxiety) in raising their child with ASD (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008; Davis & Carter, 2008; Shtayermman, 2013); however, the extant literature on parents raising their child with ASD fails to demonstrate possible cultural differences with regard to ethnicity and race. The phenomenon of culture was elicited in the present exploratory study to better understand the experiences between possible ethnic/racial background differences of Latino and non-Latino parents raising their child with ASD. Although raising a child with ASD may provoke similar experiences among all parents regardless of culture, we hypothesize that because of culture, differences will be evident in our findings. Culture encompasses ideas such as shared knowledge, assumptions, attitudes, beliefs, and values (Chávez & Guido-DiBrito, 1999; Chiu & Hong, 2006; Mandell & Novak, 2005). According to Schultz and Lavenda (2009), culture is referred to as learned sets of ideas and behaviors that are acquired by people as members of society. Furthermore, people use culture to adapt and transform their environment (Schultz & Lavenda, 2009). Since cultural factors are intertwined with ideas and behaviors, they may influence the way families address variations in their children’s development.

Magaña, Lopez, Aguinaga, and Morton (2013) investigated the disparities in ASD diagnosis and treatment services between 48 Latino and 56 non-Latino White children. Findings indicated that Latino children were diagnosed with ASD approximately one year later than their non-Latino White counterparts. In addition, it was found that Latino children received fewer specialty services and had higher unmet service needs compared to the non-Latino White children. Factors that may have contributed to the disparities include maternal education, and the sources of knowledge regarding ASD. Moreover, Mandell, Listerud, Levy, and Pinto-Martin (2002) examined racial differences in the age at which Medicaid-eligible children first received a diagnosis of ASD and also reviewed mental health treatment until the diagnosis was acknowledged. Non-Latino Black children (8.8 years old) were the oldest to receive a diagnosis, followed by Latino children (7.9 years old), with the youngest being non-Latino White (6.3 years old). In addition, non-Latino White children on average entered the

mental health system at an earlier age than non-Latino Black and Latino children. Findings suggest that racial differences exist in the detection and diagnosis of ASD.

It is critical to understand the disparity of racial differences because an earlier diagnosis leads to earlier treatment and better outcomes. Pitten (2008) suggests that culture may affect how parents view signs and symptoms of ASD. Parents from an ethnic minority background may not be attuned to understanding general developmental delays or language regressions. Mandel and Novak (2005) found that Non-Latino White parents are more likely to see general developmental and language delays before social delays. More specifically to Latinos, Zuckerman et al. (2013) reported that Latino families have poorer access to healthcare and less access to information about ASD. Therefore, having this understanding that parents might see development differently and may not be getting necessary screening for ASD means that these children are not getting the services during that critical period of development. Recent research demonstrates that intervention with children prior to 30 months of age has positive longer-term effects than those children who get little or no early intervention (Estes et al., 2015).

Given that children from Latino backgrounds are diagnosed later than non-Latino children, receive fewer specialty services, and parents from Latino backgrounds lack education related to characteristics of autism, this study may help to educate professionals in how cultural factors can impact whether or not a child gets a timely diagnosis of ASD. Further, studies that have investigated cultural differences have been primarily quantitative. In this study, a qualitative approach is conducted to allow the parents to freely express thoughts and share their experiences, which could define cultural characteristics that will help professionals collaborate with Latino families to help them get the needed services.

Purpose of the Study and Questions

There were two primary goals for this exploratory, qualitative study: (1) Holistically, gain a better understanding of how parents from different cultural backgrounds raise their children with ASD because there is a lack of cross-cultural qualitative studies; and (2) Provide a platform for parents to articulate their experiences so healthcare providers can be aware of how raising a child with ASD can affect their decisions about obtaining care for their children. Research questions that guided the study were:

- 1) What are parents' experiences of raising a child with ASD?
- 2) As a result of those experiences, are there cultural differences between Latino and non-Latino White parents' experiences raising a child with ASD?
- 3) What are parents' beliefs about their children's current status and future outcomes?
- 4) What are parents' goals for their children?

Context of the Authors

Maxwell (2013) makes the point that personal knowledge of the subject in question can influence the validity of a study. For this study in particular, the authors have firsthand knowledge and experience in working with children with ASD. In addition, all of the authors come from linguistically and culturally diverse backgrounds that can help to understand families from more or less the same background. These are both motivating factors because their knowledge and experience can help bridge a relationship to the Latino families. However, it can also be a threat in the interpretation of the results due to possible bias for which we need to remain conscious.

Nicole Casillas. I am an Assistant Professor of Special Education in the School of Education at Seattle Pacific University. I am Latina and have inherent knowledge about the Latino culture. I have roughly 20 years of experience working with children with ASD and their families in the capacity of providing Applied Behavioral Analysis (ABA) therapy in the home, clinic, school, and community settings. In addition, I have a nephew diagnosed with ASD. Having a relative with ASD has provided a unique perspective in regards to children with ASD and the need for early interventions. I have dedicated my educational and career goals to the area of ASD through teaching and conducting research.

Debra C. Vigil. I am an Associate Professor in Speech and Language Pathology and have worked with children with ASD for approximately 25 years. I am bilingual-bicultural Spanish/English and also have the same inherent experience about the Latino culture. I have developed a multidisciplinary team who specializes in the diagnosis of ASD and understand the necessity of early intervention. The fact that I speak Spanish has influenced the number of Latino children that have benefited from an interdisciplinary assessment approach. My experience of working with families of children with ASD has helped to inform the analysis of the data in this study. For example, in my experience of managing an autism assessment clinic in which in-depth assessment is conducted, I have seen Latino families seek help when their children are older and appear to be less informed.

Hui-Ting (Tina) Wang. I am an Assistant Professor in the Department of Special Education at the National Taiwan Normal University in Taiwan. In addition, I am a Board Certified Behavior Analyst Doctoral-level (BCBA-D), and have taught students with special needs in educational, home, and community settings. I have worked with children with ASD and their families in both Taiwan and the U.S. I am invested in research areas, which consist of early intervention, ABA, and cultural linguistic diversity. I am an Asian woman who speaks several different languages.

It is apparent that all of the authors have extensive experience in working with children with ASD and their families. Furthermore, the life situation of each of the authors in being from minority backgrounds helps to provide a cultural diversity lens that can inform the nature of the possible cultural factors. Our investment in this project is our own experience in seeing children from minority backgrounds with ASD, who have not had the benefits of early intervention. Further, we want to educate healthcare professionals with knowledge to help promote early detection of ASD.

Method

The current study is an exploratory qualitative research design, where we sought to understand the experiences of Latino and non-Latino White parents, including fathers who are raising a child with ASD as we are seeking to understand this under-researched area. Creswell (2014) describes qualitative research as “An approach for exploring and understanding the meaning individuals or groups ascribe to a social or human problem” (p. 4). We used semi-structured interviews that provide a platform for the parents to elucidate their views more freely when compared to prepared questions in a survey format or a quantitative study that does not provide opportunities for self-reflection.

Design

Our data collection and data analysis has its basis in constructivist grounded theory which includes the historical perspectives of being open-ended, inductive, comparative, and emergent while acknowledging the subjectivity of the researchers and the researcher’s involvement in the subject (Charmaz, 2014). In developing our conceptual framework, we were

guided by four main sources: (1) experiential knowledge, (2) existing theory and research, (3) pilot and exploratory research, and (4) thought experiments (Maxwell, 2013). First, in the context of this study regarding experiential knowledge, we recognize our own experiences and desire to educate others in the inequities of Latino children getting an early diagnosis of ASD and the concomitant interventions. Our own experiences cannot be ignored because it adds to the general conceptual framework of what we want to know; that is, “Is there something about the Latino culture that precludes parents from seeking necessary early intervention?” Secondly, we were guided by how parent’s experiences and the importance of getting a diagnosis of ASD because it changed their lives. It seemed initially they were, in some sense, lost because they didn’t understand what was happening with their child. Subsequent to that, they could then reflect on their child’s current and future needs. This may have been driven by an unconscious framework to help them help their children. This is defined by Maxwell (2013), who discussed how participants develop their own theories and if their theories are often neglected. Thirdly, this did not obviate the necessity of obtaining information from existent research, which we have reported in the background for this study and highlight more in the discussion section where other researchers have reported on Latino parent’s experiences in raising a child with a disability (Blacher & McIntyre, 2006; Chiu & Hong, 2006; Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Glover & Blankenship, 2007; Olvera & Olvera, 2012; Skinner, Correa, Skinner, & Bailey, 2001). Finally, it is evident that all parents will experience difficulty in raising a child with ASD. However, trying to tease out how it might be different for Latino parents is another story simply because they are also parents raising a child with ASD. This highlights the concept of a thought experiment as it was a true iterative process that included conducting member checks during interviews, drawing on the data, checking with our own beliefs and experiences, and pouring over the literature that guided our thinking in the development of categories.

Participants

The study consisted of six semi-structured interviews that were conducted with eleven parents from Latino and non-Latino White cultural backgrounds. There were five Latino participants (two married couples and one single mother), and six non-Latino White participants (two sets of married couples, and one engaged couple). All participants were raising a child diagnosed with ASD. The participants were all biological parents of the children with exception of the Freeze/Hall family where only Ms. Freeze was the biological parent. However, her fiancé, Mark Hall, served as a father figure to her son. Ages of children with ASD ranged from 2.5 to 13 years. Ages at initial diagnosis ranged from 1.5 to 4 years. Parents were recruited by word-of-mouth (e.g., asking professionals in the field of ASD) and public advertisement (e.g., parent support websites). Having personal contacts for recruitment purposes was important due to the nature of the interview format, the sensitivity of the questions, and the time involved in an interview format. The strength of this format is more personal and informal in the sense that there are no set questions as in surveys or questionnaires. This allows the participants to explore their own thoughts and knowledge based on their experiences. In addition, having both mother and father present provided a unique insight into how both parents relied on each other to develop their thoughts and share their individual views with each other on how ASD has impacted their lives. Further, most research into parent experiences usually focuses on only the mother. These interviews were unique because fathers were also present. All participants and their children were given a pseudonym to ensure anonymity. See Table 1 for a detailed description of participants and their children.

Table 1. *Description of participants and their children*

Participant Name	Marital Status	Biological Parent	Child Name	Age (age at diagnosis)	Ethnicity/Race
Marisol Perez (M)	Married	Yes	Fernando	13(4)	Guatemalan
Hugo Perez (F)		Yes			Honduran
Lorena Quiroz (M)	Married	Yes	Joey	5(2)	Colombian & Costa Rican
Jessie Quiroz (F)		Yes			Mexican
Elizabeth Santos (M)	Single	Yes	Mario	6(2)	Cuban
Krisalyn Freeze (M)	Engaged	Yes	Wade	2.5(2)	White
Mark Hall (FF)		No			White
Tabitha Laver (M)	Married	Yes	Jack	5(1.5)	White
Joe Laver (F)		Yes			White
Gina Wilkenson (M)	Married	Yes	Timmy	5(4)	White
Caleb Wilkenson (F)		Yes			White

Note. M = Mother, F = Father, FF = Father Figure. Pseudonyms used for participant/child names to ensure anonymity.

Procedure

The present study was approved by the Institutional Review Board at the University of Washington. Confidentiality and anonymity were ensured to minimize potential discomfort by participants. The purpose of the study was fully explained to participants and voluntary participation was addressed.

Parents participated in semi-structured interviews that ranged from thirty-five minutes to two hours, with the average time of approximately one hour. Interviews were audio-recorded with permission of participants. All participants chose to be interviewed in their homes with the exception of one participant, the single Latina mother, who chose to be interviewed in a coffee shop. Married couples and the engaged couple were interviewed together. All participants chose to be interviewed in English, although the Latino participants were all bilingual, Spanish/English.

Questions were designed not to be intrusive or highly sensitive for parents, because it was important that the parents be comfortable to answer honestly and freely so they could be more forthcoming. Additional competency to ensure quality of the data obtained from the interviews was to consult with a peer debriefer. Creswell (2014) describes peer debriefing as a process that “involves locating a person (a peer debriefer) who reviews and asks questions about the qualitative study so that the account will resonate with people beyond the researcher” (p. 202). The peer debriefer indicated that the questions were appropriate and would not evoke emotional stress during the interview. The questions are included on the pre-designed interview guide that allowed for probing throughout the interview (Merriam, 1998). Please see Appendix.

During interviews, an effort was made to listen to participants’ stories without asking too many questions and interrupting (Seidman, 1998). In addition, member checks were

assessed during the interview when clarification was required on certain responses from participants or paraphrasing what had just been said by participants when the first author was not sure of the response. Probes were used to deepen the response to a question, increase the richness and depth of responses and give cues to the interviewee about the level of response that is desired (Patton, 2001). An example of a probe was, "Tell me more about *xx*." Because questions were semi-structured in nature (Merriam, 1998), it was in a conversational format, which allowed parents to elaborate if they wanted to provide more information. Questions were asked chronologically, for example, "When did you first notice something developmentally different with your child?" and "What are your goals for your child in five years?" Follow-up questions were asked to determine clarification. For example, "Can you please elaborate on what you mean?" Closing questions were asked to allow for any last minute thoughts or topics that parents felt were important to elaborate on. For example, "Is there anything else you would like to add?" Triangulation in the interview was accomplished by asking participants the same question in multiples ways and asking the same question of each of the participants as recommended by Yin (2014).

Building a rapport with the participants is critical to the outcome of interviews. To help families feel comfortable, the interviewer engaged in casual conversation to help establish a level of comfort. With regard to the Latino families, we believe it made a difference that the interviewer was Latina because there was a shared cultural heritage. The Latino participants freely and frequently asked questions of the researcher pertaining to her Latino background, which seemed to make the participants more comfortable. With regard to the non-Latino participants, they reported that they felt different about the interviewer, because they primarily interacted with healthcare professionals and educators, and the interviewer was a graduate student researcher. So, this possibly helped to develop trust, because there was not a specific relationship with their child.

Data Analyses

In comparative research, memos are used as a "placeholder" for further discussion between researchers to determine whether or not the data showed differences or similarities. It was imperative to conduct comparative research to determine any real differences between groups. Mills (2008) describes comparative research as evaluating similarities, differences, and any association between entities. A category system was utilized to develop themes and codes to analyze the data. Interviews were transcribed verbatim by the first author and thoroughly reviewed multiple times by the first and second authors. This helped us to reflect on our own experiences with being experienced clinicians working with ASD and being minorities. Notes and memos in the data were reviewed multiple times that generated rich discussion between researchers and, in this way, we were able to develop the categories. We verified and clarified themes and subthemes. The themes were placed in charts and we then reviewed our questions to ensure the data addressed the questions. In rereading the interviews, notes, and memos, we were able to compare and contrast the data; and as a result, themes emerged showing similarities and differences across families. Two major charts were created with these similarities and differences. This, in turn, allowed us to reflect on whether the similarities were experiences of having a child with autism and whether differences could be ascribed to culture. We coded the data into the two main themes and rearranged the data according to how the data fit. This was more of an "open coding" procedure that allowed us to capture the insights of the participants (Corbin & Strauss, 2007). The resultant data is how all the participants see themselves in a life changing situation where decisions are made based around a single child with ASD. The Latino parents did reflect on several themes that were more specific to their cultures such as religion and Latino Pride.

Finally, a certain degree of trustworthiness was established with the Latino families because the first author shares the same Latino culture. Parents asked if she was Latina and conversation ensued regarding her Latino heritage. Throughout the interview they insinuated that the researcher knew the culture by making statements that suggested familiarity with the topics of raising children, religion, and family dynamics inside the Latino culture. We believe that this allowed participants to reflect on their experiences that benefited themselves to be able to express themselves in a way that they might not have had a previous opportunity (Charmaz, 2014). Further, familiarity with the Latino culture helped with data analysis because it provided a bridge between the emerging themes and relating these to the experience of raising a child with ASD.

Findings

Two major findings emerged in this investigation. The first major finding was similarities across all eleven participants which all families experienced in raising a child with ASD. These include the following four themes: (1) self-efficacy beliefs, which defined a determination to obtain help and guidance, (2) challenges in getting a diagnosis, (3) related stress of coping with having a child with ASD, and (4) goals and expectations of the future of their children's lives. The second major finding yielded cultural differences between Latino and non-Latino White participants that were specific to the Latino group. These themes include: (1) religion and faith, (2) involvement and love, (3) extended family support, (4) Latino Pride, and (5) importance of collaboration.

Each of these two major findings will be discussed in turn below. In regard to the differences between the two groups the discussion primarily focuses on the Latino families because the non-Latino White families, for instance, did not broach some of the topics. Firstly, we present similarities across all families and, secondly, we present differences between Latino and non-Latino White families.

Similarities across All Families

Self-Efficacy Beliefs. First, most parents held high levels of self-efficacy beliefs. Although the families were quite motivated, they also appeared to have a strong belief in their ability to get the needed services for their children, thereby reaching goals that they developed for their children. They reported that it became clear to them that they had to actively pursue the services as the information was not overtly available. They felt that if they themselves did not pursue the help, they might not have gotten the needed services. Several of the parents made specific statements of self-efficacy in their ability to help their child be successful with educational resources. These comments included, "I am gonna get him the resources," "I'll give up everything to give him what he needs," and, "I'll do it."

Finally, other statements of self-efficacy included parents making statements pertaining to future outcomes such as helping their children improve their skills. These statements included: "I know I can do it," "I'll do whatever it takes to give him whatever he needs," "I'm gonna work hard for my son to get better." Finally, one parent stated "You know, and now I'm strong." Ms. Santos explained that after the initial shock of receiving her son's diagnosis, she then felt empowered to take action and get the needed services for a better prognosis.

Challenges. Parents experienced several challenges in raising a child with ASD. They all had a suspicion prior to the diagnosis that something was different about their child's development. They had difficulty locating resources such as early intervention and, most prominently, obtaining a diagnosis of ASD. Interestingly, they encountered difficulty with their pediatricians. When parents took their children in for their routine check-ups, they

reported that they felt something was “not right” about their child’s development. Despite this concern, most pediatricians did not take action. Parents visited pediatricians multiple times before pediatricians finally referred parents to other professionals such as neurologists and/or hearing specialists.

Four of the families received a relatively early diagnosis with the exception of the Perez and the Wilkenson families. The Wilkenson's noticed something different about their son’s development; he didn't receive an early diagnosis because his pediatrician repeatedly told them to “wait it out.” They were told that boys tend to be slower at developing than girls and that there was nothing to be concerned about. According to Mrs. Wilkenson, the reason it took so long for her son to receive a diagnosis is because the pediatrician would not diagnose him. Mrs. Wilkenson said, “We were fighting our pediatrician.” She also stated that she had to keep fighting and “go to different people’s chain of command to get him the help he needed.” She went on to proclaim that doctors and insurance companies should all work together.

The Laver's also experienced problems with their son's pediatrician. The first time Mrs. Laver remembers telling her pediatrician about her son’s ASD characteristics, such as being “spacey,” and having very little language, the pediatrician simply told her, “We’ll just be watching that.” Mrs. Laver exclaimed; “It's so frustrating that we had that pediatrician.”

Parents were provided with information about resources at the time of the diagnosis, but the families themselves had to do the footwork to get to the resources. Mrs. Wilkenson explained:

We found out ourselves, on the Internet, nobody else would give them to you. I would call up different agencies that handled disabled children. I would just call around. Wasting a whole bunch of time but you know there was not really anybody at his doctor’s office that would give me any resources or anything. I just learned if I’m gonna get by with anything, I’ve gotta do it by myself. I was getting books at the library. I tried to figure out what was going on with Timmy. I would go to the book store and pull out different things and try and pinpoint, you know because I was not getting anywhere with his pediatrician.

All parents independently researched ASD and available resources over the Internet. Parents learned about parent advocacy groups, mandatory educational services such as Individualized Education Program (IEP), ASD conferences, and early intervention services offered at local child development centers.

Following their child's ASD diagnoses, all parents immediately sought early intervention services. At the time of data collection, all six children with ASD were receiving some type of early intervention service. Choice of services varied among families and included ABA, bio-medical intervention, occupational therapy, speech therapy, pivotal response training (PRT), social skills groups, picture exchange communication system (PECS), and horseback riding. In addition, some children attended pre-school, kindergarten, and elementary school.

Stress and Coping. All parents discussed how raising a child with ASD causes a great deal of stress in their daily lives. Four of the six children were nonverbal. This caused a high level of stress because the children had temper tantrums due to their inability to communicate their needs; and it was difficult for parents to provide comfort to their children. The Freeze/Hall family reported problems with sleep. Ms. Freeze stated, “Falling asleep is very hard. He does a lot of crying...he fights it.” She went on to say, “Falling asleep and waking up can be very distressing to him.” Ms. Freeze and her fiancé Mr. Hall did not know when he would wake up fine or be distressed stating “It’s hard to know... There are just those weird days where he just wakes up just inconsolable like yesterday’s nap or is inconsolable going to sleep.”

Most parents also discussed how the diagnosis affected their marriage. Marital issues have been confirmed in the literature, in which there is a divorce rate of 23.5% for parents of children with ASD as compared to a divorce rate of 13.8% for parents of children without disabilities (Hartley et al., 2010). Mr. Laver commented on his marriage; “Yeah, it’s affected our marriage a lot.” The Laver’s child had many medical problems that required a lot of attention. They also took their child to several different therapies each week. In addition, they changed their child’s diet that required them to change their own eating habits. All of these lifestyle changes resulted in a great deal of stress for each of the parents. Mr. Laver stated, “We don’t got time for each other. Our marriage, I mean, we’ve certainly grown further apart over the last two years as opposed to closer together.” Mrs. Laver stated, “We fight a lot.” She further states,

We know that it’s 90% of marriages that don’t make it through this kind of thing. And we know that we don’t have our lives balanced, and we know that we have to keep pushing through that and we see how it’s damaged us in terms of shared exhaustion. And, just the necessity to get mad at somebody (laughs). So, we just get mad at each other because it’s just, you work so hard, and you’re trying to help your child. So, I mean just 24/7 when things don’t go well.

Another area of difficulty in marriage is highlighted by the Quiroz family in terms of discipline. Mr. Quiroz described it as, “A struggle.” Mrs. Quiroz responded with, “We’ve gone to marriage counseling.” They stated that they are not happy with the way each of them disciplines their son. Specifically, Mrs. Quiroz stated, “He thinks I’m too lenient and I think he’s way too harsh.” They also stated that they do not always go to social gatherings together because of their child’s behavior. “It’s always an excuse that we come up with, you know. Yeah it’s tough.” Furthermore, they stated that when they do go to gatherings with their family they find it difficult to socialize together stating, “Both of us can’t sit down and converse with everyone. One of has to be with him, you know, following him, make sure he’s not getting into something that he shouldn’t be or damaging or breaking something.”

When asked about marriage, Mrs. Perez simply replied, “Yeah, we’ve thought about divorce.” They both stated, “We don’t get time for each other.”

Ms. Santos described her stress related to being a single parent and multiple moves between countries. She divorced before her son was diagnosed with ASD. Subsequently, she moved to the United States from Chile. She stated that there was a lot of disagreement between her and her husband during the divorce procedures. In addition, there was stress related to moving countries. She stated, “So, imagine that stress. It was awful. The change, so like a new country, a different language, new people. Very stressful.” She explained that the divorce itself, and the moves compounded stress for her son that then increased her stress. “I got divorced when he was ten months old. Um, so I thought maybe it is too stressful.” Mario’s [Ms. Santo’s son] aware of the situation, he’s feeling my anxiety, and my stress.”

Although there is a great deal of stress in raising a child with ASD, the parents also discussed how they cope with their lives. Mrs. Laver elaborated on her coping strategy: “Our coping strategies, we believe that we could beat this thing. And, we did. That was our main coping strategy for months and years. I mean we were on a sprint, this was no marathon yet.”

Ms. Freeze stated,

I guess I cope by being as involved as I can, working with him as much as I can, and, um, learning as much as I can....at the end of the day I just kind of have my time and I cry or I lay in bed and worry or I talk to Mark [Fiancé] about

things that worry me. Um, but mostly we're just so busy with all the kids and work and doing what we can. I guess that's my way of coping.

Wilkenson's stated that they take time out. She also stated, "If I get too frustrated, you know, I will go play Internet games or I'll write in my journal."

Parents also discussed how their affectionate child keeps them going. Mr. Laver said, "I mean in many ways we are so lucky. We have the most affectionate child in the entire world. No family could get more affection from any kid." With a smile on her face, Ms. Freeze described her son in the following way, "Fortunately for me, Wade is extremely affectionate. He'll slam into me and hug me really tight. And, press his cheek against mine really hard."

Goals and Expectation. Finally, all parents discussed similar goals and expectations for their children. Every family discussed both short-term goals and long-term goals for their children. Short-term goals varied by family, and were specific to each child. For example, the Laver's short-term goals for Jack is to be able to digest food successfully, and to be able to have successful bowel movements, and get into a mainstream classroom. For a long-term goal, Mr. Laver stated, "Just to have him to be able to have meaningful relationships in his life and to be independent of us." They also dream of Jack going to college. Mrs. Laver explains, "Yeah, and we've been assured that it is a possibility, I mean, people have said that, you know, he'll go to college. People have said that to us."

A short-term goal for the Quiroz family is for Joey to start talking. Mr. Quiroz would like his son to say sentences such as, "'Good morning Daddy.', 'Let's go for a bike ride', or 'Let's go to the beach.'" Further, they also discussed having Joey be in a mainstream classroom. In the long term, both parents stated that they want Joey to be self-sufficient and independent.

Mrs. Wilkenson stated, "My short term goal, I would like to see him maybe in a couple of more months being able to speak real, real, real clear." Mr. Wilkinson wants Timmy to get into a good program. A long-term goal for Mrs. Wilkenson is to get him into college.

All parents mentioned short-term academic goals for their children, such as accomplishing the goals stated on IEPs. These IEP goals ranged from writing their names to sorting colors. All parents reported similar long-term goals for their children's future that included a desire for their child to be self-sufficient, attend college, get married, have a family, obtain a job, and ultimately become independent and happy. Ironically, although all participants do have a strong desire for their child to be independent and self-sufficient, they still have doubts. Participants discussed concern for their child after they are no longer living. Mr. Perez stated, "Who's gonna take him after we pass away or something? All the time, I think, and I'm afraid. He has his brother. But, we never know. So, we're afraid about what's gonna happen with Fernando."

Mr. Quiroz said,

Yeah, I think about it every day. What's gonna happen to my son when we're gone? Yes, Joey has an older sister, but is it fair for her? I know she'll take care of him, but it's not really fair to her.

Mrs. Wilkenson commented,

Our plan is to raise [Timmy's brother] to be his mentor when we are not around.... I know that's probably unfair for [Timmy's brother], but you know our plan is to get [Timmy's brother] to take care of his big brother.

Ms. Santos articulated the following:

I'm gonna be gone before him, and I wanna leave him with the skills that he's gonna be able to you know, have a normal life, to be able to be self-sufficient.

There are two issues here. One is that the parents are working very hard to help their child to be independent, but it seems that they really don't know if their child will have the skills to develop self-sufficiency. For example, Mr. Wilkensen stated, "If it's possible for him" and Mrs. Laver said that others told her that "it is a possibility" that her child could be independent. There appears to be an internal struggle between their expectations and the possibility that their child may not ever be independent. As a result of this doubt, most parents' back up plan is to have their other children who are typically developing to be the caretaker once they pass away. This raises the issue of siblings of children with ASD. This is a quandary for these parents. They are cognizant that it's not fair for their other children, but they are unsure what will happen to their child with ASD.

Differences between Latino and Non-Latino White Participants

There were five themes that emerged with the Latino participants that were not found among non-Latino White participants. The five themes that emerged were (a) religion and faith (b) involvement and love (c) extended family support (d) Latino pride and (e) the importance of collaboration.

Religion and Faith. All Latino parents acknowledged religion not only as a way of coping, but also how God has impacted their lives by giving them a child with ASD, and how God helps them. Although they reported that religion helps to relieve stress, they also explained that God is an outside force that a higher being is the cause of the ASD. Below is what Ms. Santos said when asked about her coping strategy:

My religion, I'm Catholic and very close to God. I think that you know he keeps me up every day. That was what helped me a lot. I mean every time I feel a little bit down, I start, you know, I go to church every Sunday and I pray and I read my bible.

Mrs. Quiroz stated,

"I thank God every day. It's going to get better." Mrs. Perez also made a statement about how God helped them to realize that something was wrong and going to church has helped her cope. She said, "I give thanks to my God every day, because I mean, he showed us the way to see what's going on with my son."

On the other hand, Mr. Quiroz expressed anger at God.

I've cursed God many times saying "Why did you do this to my son? What did I do? What did my wife do? What did he do to deserve this?" For a long time, I resented him [God].... Slowly I'm getting back into it [religion]. You know, it's still hard. There are times where I still damn him. You know, I say to everybody, I got no reason to believe in him because, you know, what he did to my son. Why didn't he do it to somebody else?

This situation in which Mr. and Mrs. Quiroz's child has ASD brought Mr. Quiroz to question his religion. He stated,

I wouldn't say I'm a religious person, but I do believe that there's a heaven. I do believe there's a God, but I also believe there's a hell and the Devil, too. It can't be just good. There's also evil, but I do believe in God and I do believe that he does do things for a reason. I guess I won't ever understand until that time comes, but you know, slowly trying to accept the fact that he did this for a reason. But it's a slow process. It's a real slow process. I'm still, like, in a denial stage, in part of, religion wise. As far as him, you know, knowing he's autistic and stuff. I've accepted that. I try to do the best I can. I don't think. I mean, I'm doing the best, but I'm trying. It's an everyday struggle for me.

Mr. Perez also questioned God, not only because he felt helpless, but he wondered why it happened because there was no family history of developmental disabilities. He stated,

I had no idea what ASD was. I asked myself, "Why that happened to us?" I asked God. You know what I mean, because I believe in God. So, I was, like, why that happened to us.... I have all my family, my sisters and my brothers. They have normal kids. Nobody has a problem.... So, I was like, what's going on here? Why me? Why did this happen to me? It has to be a reason. You know what I mean? We have Fernando. He's autistic. We have no idea how we can help him. You know, because we don't have the tools to help him.

Involvement and Love. At the end of the interviews, all parents were asked a wrap up question, specifically if they wanted to share more with the interviewer about their experiences raising their child with ASD. From this last question on the interview protocol, all three of the Latino parents made reference to constant involvement and love in their children's lives, while the non-Latino White parents discussed the etiology of ASD or the importance of getting resources. All of the Latino parents emphasized the importance of involvement and love. Ms. Santos provided the following information:

I gave up everything, my style of life, my everything, that's it. This is my son, this is my goal in my life. And, he will be whatever I can make him, you know, with my effort.

Every speech therapy session and every school day, she observed him and learned from the teachers what they were teaching her son. She borrowed learning materials from his speech therapist and early childhood teachers, and even turned her one bedroom she and her son were living in into a classroom. She described the situation in detail;

I set up in that little room, a small classroom with little tables and chairs and a little blackboard. So, we were doing everything he did at school the day before. We would repeat it the day after in the morning so we will go in the afternoon to school and it was a cycle. He was growing and getting skills like you can't imagine how fast and maintaining the skills.

Like Ms. Santos, Mrs. Perez was heavily involved in her son's education. She explained,

I remember going to the school maybe one or two times a week, and I can see him behind a mirror. You can imagine how many times I cried because I saw him make progress, his first steps, you know. And, I feel proud.

Ms. Santos stated,

It doesn't matter how much therapy you get for your child. If you're not there every single minute for them as if they were a baby all the time and forget about that you have a different child, a disabled child. Just treat them like a regular normal child. Give them all your love, your caring, your support, and you just need to bring force. It takes a lot of persistence.

Mrs. Quiroz said the following: "Be involved. Be involved in your son's education. Be on top of it, with everything. With the teachers, the supervisors, the programmers out there, the regional centers. See them." Mr. Quiroz, added, "Give them love." Mrs. Perez stated the following. "Spend time with your kids. It's one of the most important things. Teach them how to love themselves. It's more easy for them to love everybody else." Her husband, Mr. Perez elaborated, "You know share the love with them, and they're going to share the love back with you."

Extended Family Support. Extended family support was credited by Latino parents with helping to reduce stress. Ms. Santos elaborated:

The other thing is my family. It's a great family. My grandma is Mario's great-grandma. Thank God she's very healthy. She is helping me with Mario. She's living with us. My mom calls every single week, we talk for hours. She is always there for us.

The mother of Mrs. Quiroz takes care of Joey during the weekdays while Mrs. and Mrs. Quiroz are at work. When discussing specifically her mother's help, Mrs. Quiroz stated, "It's a little less stress." The Perez family's extended family members are also very much involved and supportive. The mother of Mrs. Perez lives with them six months out of the year, and when she is not living with them, she visits frequently. Fernando's grandmother is also involved with her grandson's education. His grandmother takes him to school occasionally and communicates with his teachers about Fernando's progress in school.

Latino Pride. The Latino parents acknowledged pride for their Latino heritage and how it impacts their lives. For example, Ms. Santos said,

I think my Cuban blood has help me a lot because we're very optimistic, yeah, and we're very perseverant. If I say I'm gonna do this, I'll do it. It doesn't matter how much time it will take me. I know I can do it.

Mrs. Perez stated,

You know where we coming from in our countries. Our families is our number one thing for everybody. So. we don't need to forget that. Trust me if we don't give love, if we don't share what we got, our kids are gonna be a regular adult with no feelings. When we be older, they not going to take us to a nursing home, like everyone else. We are different. I mean, that's the reason to be Latino, makes me feel so proud because, Latinos, we care about our families.

In response to her child getting a phone call, Mrs. Perez attributed her ethnicity to being protective of her child,

Gosh, I feel like that's the hard part of being Latino. I have to be so nosy and I have to know everything. I feel like this is my job. I want to protect my son, and I want to know who is behind my son.

The Perez family described that in being Latino, working hard is important to help their child with special needs develop skills and to freely express their love. Although both parents worked when they came to the United States, Mrs. Perez stopped working to help their child. Mr. Perez emphasized how hard they work, "Especially Latinos. We just tend to work. Work and work and work."

Importance of Collaboration. All Latino families emphasized the importance of collaborative relationships between school personnel, interventionists, and themselves as it would be beneficial for their child. At the time of data collection, all Latino families were in daily contact with their child's teachers and thought it was important to know about their child's behavior in the classroom so they could implement the same therapies and educational activities at home. Mrs. Quiroz verbalized, "I even have the teacher's cell phone number." Often times, Ms. Santos attends her son's classroom to observe his educational progress. Mr. Quiroz and Mr. Perez both mentioned the importance of being on the same page with school professionals. Mr. Quiroz explained,

I think collaboration is important, because that way, teachers can open up a lot more to you. They might say he's progressing really good. But, they might not tell us that he's doing other [undesired] behaviors. We told the teachers from the get go, if there's anything that you see, tell us, and we'll do the same.

Mrs. Perez stated,

You know, in my case, I feel like the teachers, they try to do their best. Because in my case, I try to be so close to the teachers, to my son.....They try to be in his life. They try to know everything about him because one of the things, I think, they help me a lot.

She explained that there is a two-way street between teachers and parents and elaborated about meeting with the teacher. She said,

I give her ideas, and she gives ideas to me, and we put all these ideas together. They make something really strong. So, for me, it's really important when my son comes from the school. I'd like to know what's going on. I'd like to know if we can do something together.

Discussion

Findings of the current exploratory study showed that there were similarities and differences between Latino and non-Latino White families in their experiences of raising a child with ASD. Firstly, there will be a discussion on the first major finding that all families reported in which they had similar experiences. This will be followed by a discussion specific to themes found with Latino families that the non-Latino White families did not discuss even though the same questions were presented to all families.

Themes across All Participants

The themes across all participants were consistent with some research findings while one theme was a new finding. In a meta-analysis by Hayes and Watson (2013), they found that “parenting a child with ASD is associated with greater parenting stress” (p. 638) when comparing parents of children with ASD to parents of typically developing children and children with other disabilities. Additionally, there were specific challenges with raising a child with ASD, one of which was frustration with pediatricians who did not take parent concerns seriously. dosReis, Weiner, Johnson, and Newschaffer (2006) conducted a study to examine screening practices of general pediatricians. Findings indicated that 82% of pediatricians screen for general developmental milestones, but only 8% screen for ASD. Additionally, the CDC (2005) report that 65% of pediatricians say they do not feel trained to assess children’s developmental status.

From the responses of participants in this study, the parents are efficacious and that ultimately relates to the goals and expectations of their child. For instance, Ms. Santos indicated that she would do everything that she could do in the present to help her child in the future. This includes being self-sufficient and independent. According to self-efficacy theory, self-efficacy makes a difference in how people feel, think, and act (Bandura, 1997). Similar to past studies (Gray, 1994; Piper & Howlin, 1992), some participants expressed relief that seemed to be strongly associated with having the ASD diagnosis, which essentially enabled parents to better comprehend their child’s behaviors. This helped them to understand the necessity of early intervention, where they then actively sought services and resources. In terms of self-efficacy, they were able to exert control of their situation and this helped them to think about the future and make plans.

One theme that falls in the category of self-efficacy that does not seem to appear in past studies is research where participants talked positively about their child in the present and their children’s future. They seemed confident that their children were going to have a worthy future. They mentioned that they would not change anything about their child; participants noted how their fun and affectionate child positively impacted their lives. Despite challenges and struggles, they stated that their child brought joy to their lives. Of course, for parents, they obviously love their children and it makes sense that they would see their child in a positive light. Psychologically, even though they have a child with a disability, the child is still their child and there is parental love. This is an area of research that needs to be further explored to discuss the resiliency of parents of a child with ASD or with any other disability. This can be helpful in teaching advocacy, not only for parents, but for the children as they grow older to be self-advocates. This finding underscores the importance of an organization called the Autistic Self Advocacy Network (ASAN), which created an Autistic Pride Day in 2015. The President of ASAN stated that individuals with ASD have something important to offer and has urged individuals with ASD to live without shame and without concession (Ne’eman, 2015).

Themes across Latino Participants

There appears to be cultural differences in the experiences of raising a child with ASD between Latino and non-Latino White families. For example, none of the non-Latino White families mentioned religion or extended family support as a coping mechanism, unlike the Latino families, who all mentioned their religious faith, and extended family support as being important in their lives. Dyches et al. (2004) assert that Latinos, especially Latina mothers have a strong faith in God. Latinos believe that God is important in life and that practicing religion is also important in raising a child (Chiu & Hong, 2006; Glover & Blankenship, 2007). Two Latina mothers made several comments regarding self-sacrifice for their sons. Dyches et

al. (2004) posit that Latina mothers attribute sacrificing, suffering, and dedication to their religious beliefs. Two Latino fathers expressed anger and frustration and questioned God in asking why God gave them a child with ASD. This questioning of their faith could be related to the suffering that they feel with having a child with ASD. Skinner, Correa, Skinner, and Bailey (2001) found that 55% of Latino parents believe that their child's ASD is a sign from God; and the majority of these parents feel that it is a test to demonstrate their worthiness. Three percent feel that the diagnosis is a punishment for past sins.

All of the Latino families emphasized the importance of extended family support. One possible reason why Latino families elaborated on the influences of their extended family members may relate to the Latino cultural concept of *familismo* (family-centered), where there is a strong family cohesion among Latino families (Dyches et al., 2004; Olvera & Olvera, 2012). In the Latino heritage, family and collectivism is emphasized, and the notion of individualism is not commonly practiced as it is in the non-Latino White culture (Chiu & Hong, 2006). Blacher and McIntyre (2006) report on a concept called "Marianismo" which is a view of raising a family in terms of self-sacrifice and parents give more than they receive. This was reinforced by Ms. Santos and Mrs. Perez who both indicated that they gave up their careers and their way of life to care for their children with ASD.

Involvement and love, as well as Latino pride may be associated with *familismo* in which according to Magaña and Smith (2006) state there is "strong feeling of loyalty, reciprocity, and solidarity among family members" (p. 347). There is a common theme that Latinos "take care of our own." Furthermore, Magaña and Smith (2006) suggest that motherhood in the Latino culture is a woman's main role in life. The Latina mothers in their study reported no negativity with their children in the home. For Latina mothers, the concept of interdependence in the culture is important here as dependency is an aspect of the extended family. The Latino families in the current study discussed the importance of love and involvement, and contended for a reciprocity with sharing love and affection with one another (family members) and others (non-family members). Also, all of the Latino parents expressed the need to teach their children how to love themselves. Each family highlighted the importance of this behavior.

Finally, Latino families collaborated frequently with educational professionals, and found it beneficial. Although collaboration for all parents of children with ASD is important, we can attribute this collaborative aspect to the Latino culture. Olvera and Olvera (2012) emphasize the cultural values of *confianza* (trust), *respeto* (respect), and *familismo* can be important to the collaborative process. *Confianza* is a cultural expression of faith in which there is a trusting relationship, which the Latino participants in this study expressed. For example, Mrs. Perez discussed having the teacher's phone number and explained that she perceived a partnership and working relationship between her and the teacher. This led to *respeto*, which refers to respecting family members; but in this case, there is the mother deferring to the child's teacher and, in the broader context, the school in which she entrusted the care of her child to obtain the necessary educational services and therapies. With regard to *familismo* the families referred to the fact that they had the teacher's phone number and the opportunity to be in the school with their child. This enhances acceptance of collaboration more easily.

Overall, the results of this study highlight how culture affects the way parents view their children with ASD. Although parents from both cultures share similar experiences in raising a child with ASD and expressed some positivity with having a child with a disability, the Latino parents explicitly discussed their religion, and how it relates to their child with ASD, and the impact on the family. They were open to collaboration with teachers and their school, which entails a more personal level with the concepts of *confianza*, *respeto*, and *familismo*. Specifically, the concept of *familismo* is related to the broader theory of interdependence versus independence where interdependence emphasizes collectivism to function as a collective

extended family unit as evident in the Latino culture, while independence relates to individualism as seen in most non-Latino White cultures where the nuclear family is dominant.

Current Study's Contribution to the Field

This study adds a cross-cultural perspective to the importance of understanding how culture affects a parent's view on raising a child with ASD. This is important because Latinos are a growing population in the United States, and there is an increase in the diagnosis of ASD in general. This means children of Latino descent will be requiring the necessary interventions. However, we know that these children are being diagnosed approximately two-years later than their non-Latino White counterparts. Professionals who are able to provide a diagnosis need to understand how culture can affect what parents might report regarding the behaviors of their children. Gaining the *confianza*, *respeto*, and incorporating *familismo* into their interactions will go a long way to gaining the trust of these families that can help in providing a diagnosis and subsequent services. It is not only trust, but gaining the confidence with Latino families by emphasizing religion and inviting extended family members to consultations can lead to better outcomes for these children and their families.

By gathering qualitative information from parents, we can discover various components that are essential, such as the trajectory from an ASD diagnosis to obtaining early intervention services, and educational resources for their children. We can also begin to understand why and how some parents are fully engaged in their child's lives whereas other parents may not be. Finally, this study adds to the inclusion of fathers' involvement in their children's development. Most studies have taken the perspective solely from mothers of children with ASD, thereby excluding the important contributions from fathers. Fathers' perspectives and their experiences of raising a child with ASD is as equally important to the views of mothers.

Limitations

There were several limitations. First, because this study was exploratory in nature, only one type of data source (e.g., semi-structured interviews) was utilized once. Multiple interviews with parents, and perhaps even interviewing parents separately may have captured additional findings. Semi-structured interviews with educators (e.g., classroom teachers) may have offered a different perspective to gain an understanding of how teachers view their relationship with Latinos versus non-Latino White parents. Additional data sources such as home and school observations could have been employed to obtain a richer understanding of raising a child with ASD from different cultural perspectives. Secondly, only six parental semi-structured interviews were conducted. Future studies should include a larger number of participants to ensure a variety of information provided by parents. Finally, it may be that Latino families were more inclined to discuss certain topics such as their religious beliefs, and pride for their Latino heritage because of the mutual Latino culture the first author shares with the Latino participants. Perhaps Latino participants felt comfortable and trusting of the first author because of their shared culture as opposed to the non-Latino White participants.

Implications

The current study offered a glimpse of the cultural differences that exist between parents who are raising a child with ASD. Cross-cultural studies that involve parents of diverse ethnic/racial backgrounds raising a child with ASD should be studied further. Healthcare providers, as well as educators will be able to better understand how families of various cultures, particularly the Latino culture, think about their child with ASD and how their beliefs

affect the way in which they raise their child. There is a need for educating healthcare professionals, and it must start sooner rather than later. Parents will then be able to access immediate resources (e.g., early intervention services), which will ultimately aid in fostering a more positive prognosis. Research has shown that the earlier the diagnosis, the better the outcomes (e.g., Fein et al., 2013). Finally, collaboration between parents, and professionals such as healthcare providers and educators must occur. Parents' voices must be heard when working with professionals. After all, parents know their child best. Collaboration is essential in helping the child with ASD become successful in various realms of life.

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Appendix

Interview Protocol for Parents of Children with ASD

1. When did you first suspect something was different with your child?
2. What were the symptoms or signs?
3. Did you immediately think it was ASD?
4. Were you ever aware of ASD before you suspected something was different or abnormal in your child?
5. When did your child first receive a diagnosis of ASD?
6. Who diagnosed your child?
7. What was the time gap between your initial thought something was wrong or different in your child's development to the day your child was diagnosed?
8. Were you on a wait list just to receive a diagnosis?
9. Did you receive any resources, support or services from the person(s) or institution that diagnosed your child?
10. Did you get resources, support, or services such as referral to a therapist/counselor for yourself or family, such as educational services, Applied Behavioral Analysis (ABA), occupational therapy, speech and language therapy for your child, parent support groups? Regional centers? Others?
11. What was your initial response after your child was diagnosed?
12. How has the diagnosis affected your family (e.g., your other children, & extended family)?
13. How has the diagnosis affected you (e.g., stress, sadness, depression, anxiety, frustration, anger, etc.)?
14. How do you cope with the diagnosis?
15. Any coping strategies?
16. How has the diagnosis affected your life (e.g., marital life, & social life)?
17. How has the diagnosis affected your child's life?
18. Does your child receive therapy outside of the school setting?
19. What kind of therapy does your child receive?
20. How has therapy impacted your child's life?
21. How has therapy impacted your life?
22. How has therapy impacted your other children's lives?
23. What improvements/gains has your child made from therapy?
24. How is your child functioning now as compared to before the diagnosis?
25. What was the time gap from your child's diagnosis to the day your child first received therapy?
26. Who informed you of therapy?
27. Who pays for your child's therapy?
28. If you do, than how has paying for your child's therapy out of your own pocket affected your life?
29. Who do you think is responsible for paying for therapy?
30. What do you think the school districts responsible for?
31. What motivated you to obtain therapy for your child?
32. What are your goals for your child?
33. What are your goals for yourself?
34. What are your expectations for your child's future?
35. What are your expectations for your own future?
36. Where do you see your child 5, 10, or 20 years from now?

37. Is there anything you would like to add/share? Is there anything you feel I have missed that you feel is important for others to know? This is your story.

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