

# Family Adjustment Across Cultural Groups in Autistic Spectrum Disorders

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This pilot ethnomethodological study examined perceptions of parents/caregivers of children diagnosed with autistic spectrum disorders concerning actions, norms, understandings, and assumptions related to adjustment to this chronic illness. The sample included 14 caregivers (75% Hispanic of various ethnic groups). Maximum variation sampling was used to compare participants on variables that were inductively derived via constant comparative methods of analysis. The following action categories emerged: "Seeking Diagnosis," "Engaging in Routines to Control behavior," "Finding Therapies (Types of Therapies)," "Finding School Accommodations," "Educating Others," "Rising to Challenges," and "Finding the Role of Spiritual and Religious Belief." **Key words:** *adjustment, autistic spectrum disorders, culture, qualitative, racial/ethnic, services, stress*

## BACKGROUND AND SIGNIFICANCE

The diagnoses of autistic spectrum disorders (ASDs) have increased dramatically in the United States within the last 5 years. There has been a 78% increase in diagnoses since 2007, and prevalence is now estimated to be 1 in every 88 children.<sup>1</sup> Autistic spectrum disorders are characterized by impaired interactive social communication and/or language

that is persistent across contexts, behaviors that are described as repetitive, and some inclusion of restricted interests.<sup>2,3</sup> There are also a number of associated comorbid disorders that have been found in up to 60% to 80% of children diagnosed with ASDs, such as attention-deficit hyperactivity disorder, depression, anxiety, sleep disturbance or sleep apnea, and/or intellectual/cognitive disability.<sup>4-6</sup>

Autistic spectrum disorders have been described as difficult to diagnose and treat by health care professionals both in the United States and internationally because of a number of factors.<sup>3,7,8</sup> These factors may include the perceptions of diagnosticians and families about the symptoms associated with ASDs. Families are the first to recognize that a child may display characteristics associated with disorders. However, diagnosticians around the world may perceive symptoms differently, depending on their interpretations of family descriptions and their cultural perceptions.<sup>7,9,10</sup>

The behaviors associated with these disorders and the comorbidities, which may or may not be present, are seen in the early stages of growth and development. Language and

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behavior are socially constructed and developed within the family milieu or the cultural context. The diagnostic criteria for ASDs and even most of the symptoms associated with the comorbidities include social and behavioral manifestations, which are perceived as medically dysfunctional in the Western society and may be viewed in a different way within a cultural context.<sup>11</sup> The Western societal medical model suggests that certain behaviors or the use of language indicates disease, and interventions associated with this model of disease are targeted at changing the behaviors seen as deviant from the norm.<sup>9</sup> In the Western society, when a pediatrician or school worker, such as a counselor or school nurse, contacts a parent or family member to have a child screened for an ASD, parents may or may not perceive the behaviors in the same way as the health care professional. In other situations, it may be the parent who is the first to observe behaviors that are out of the norm.<sup>12</sup>

Although findings suggest that some similar symptoms may become evident across cultures as the child develops, parents and families within their native country or who have immigrated to a new country (such as the United States) may attribute a different meaning to such symptoms.<sup>13</sup> Help-seeking behaviors among parents also differ on the basis of their worldview and cultural context. International guidelines for diagnosis are becoming clearer with each version of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*; however, clinicians still vary greatly between cultures.<sup>7</sup> For example, children who may be diagnosed with autism by an American clinician would be diagnosed with reactive attachment disorder or lack of parental love by most Korean clinicians. Korean clinicians do report using the *DSM IV* criteria and support diagnoses with instruments such as the Autistic Diagnostic Observation Schedule and the Childhood Autism Rating Scale; however, the impact of cultural held beliefs about poor mothering and parental dysfunction is the basis for diagnosis. Interventions in Korea and for Korean immi-

grants, therefore, may be targeted at fostering increased attachment between parents and children. A review of literature on Korean and Asian parents' cultural perceptions of ASD diagnoses and interventions included findings that whether or not families were in Korea or immigrated to another country; respect and authoritarian parenting were main belief systems for rearing children. Mothers were still generally held responsible for parenting children and, thus, held responsible for behavior. Childhood development was ingrained in cultural context including the use of "honorifics" in language development. Honorifics indicate respect and honor for one's elders and those in authority. A lack of the use of honorifics may be a unique indicator of an ASD in language use for Korean children. Parents and families, therefore, reject the child's behavior, and the mother may be shunned within the family.<sup>7</sup> Navajo communities, on the contrary, may see behaviors associated with ASDs as natural and accept the child and the parent as a part of nature and the natural balance of nature.<sup>14</sup>

Immigrant parents and families may perceive that ASD behaviors are different from behaviors of other children in the community or school but may not perceive the world or community in the same way as other parents or teachers or take actions in the same way to intervene for their children. Whether immigrant or within their own country, it is important to most families where their support and information come from and how they take action to reduce burden and stress. Families from collectivist cultures are more likely to find support from private familial sources than institutional sources. Families from the Western societies such as England, the United States, and Canada rely on institutional supports. Cultural factors also impact the way the family adjusts and adapts to the diagnosis and treatments because there are no universal treatments available. Chinese families have been found to take traditional Western therapies into consideration such as cognitive-behavioral therapy while also using massage and acupuncture

because it is believed that ASDs are a lifelong condition.<sup>9,15</sup>

Parents in Australia have reported poor long-term outcomes. An ethnographic study found that parents reported feeling socially isolated from their communities, ineffective coping mechanisms, and poor access to effective interventions to help their children succeed academically and socially. They also underreported their children's diagnoses and were highly stressed, had many needs and few resources, and usually reported poor long-term outcomes for their children.<sup>16</sup>

Hispanic families are becoming a majority population in the United States, and yet the statistics suggest that the diagnoses of ASDs among Hispanics in the United States are slightly less than the national average. Issues cited by Hispanic parents related to seeking diagnosis and intervention for their children with suspected ASDs have been related to social stigma, access to care, distrust of "system workers" such as social workers, health care professionals, and school workers, as well as language barriers. Perceptions of Mexican Americans with low levels of acculturation have included beliefs that children would "grow out of autism"; however, Hispanic American parents' perceptions of their children's diagnoses have not been well studied. Racial/ethnic subgroups of Hispanic parents of children diagnosed with ASDs have not been consistently well identified in the literature related to the country of origin.<sup>17</sup>

Children with ASDs are identified as Children with Special Health Care Needs (CSHCN) by the Health Resources and Services Division of the United States Government, an acknowledgment they require more than routine care and treatment for acute conditions and are at risk for physical, developmental, behavioral, and emotional health issues beyond that of children in general.<sup>18</sup> Parents of children with an ASD have reported poorer access and more dissatisfaction with school and community health services than other parents of CSHCN and were 3 times more likely to have difficulty in obtaining and being satisfied with

services than parents of other CSHCN controlling for demographics and insurance.<sup>19</sup>

## THEORETICAL FRAMEWORK

Many parents have cited barriers to health care access as a problem in diagnosis and ongoing intervention for their children with ASDs.<sup>20,21</sup> Barriers to health care access and misunderstanding about the need and/or use for services to help parents cope with ASD behaviors in their children cause undue stress and prolong adjustment to the stressors associated with this chronic illness for parents. This may be especially true for those parents who have immigrated to the United States from another country or when the family has multicultural or multiethnic backgrounds.

According to McCubbin and McCubbin,<sup>2</sup> daily life stressors and illness-related hardships place stress upon individuals in the family and tax resources. It is hypothesized that some families may have the resources to manage demands depending on the families' needs, their pileup of demands, caregiver burden, strains, and stresses as well as perceptions. Families assess within their own worldview and attempt to manage stressors as they adjust and adapt to chronic illness. Family appraisal of stressors and the use of resources, however, take place within the context of the families' perceptions of the world around them and their experiences.<sup>2</sup>

When parents are faced with the diagnosis of an ASD (especially in the Western society and within the Western societal social structure), they are forced to assess this as a stressor that has the potential of producing a change in the entire family system. The stressor can deplete resources and disrupt family functioning; however, the perception of the stressor may depend on how the family perceives the disability and the demand it places upon them.<sup>22</sup>

According to McCubbin and McCubbin,<sup>2</sup> the family may become vulnerable from a "pileup" of demands that come from within and outside of the family. There may

be precrisis illness-related hardships and “illness-related hardships” from the illness itself, as well as more stressors that occur from the demands that literally “pile up” after the diagnosis and as the child goes to school. The school may add extra demands from the perspective of the Western society, and the parents may distrust school workers depending on their worldview. These stressors may include the following: (1) normative family transitions, (2) prior (and current) family strains, (3) situational demands and contextual difficulties, (4) consequences of family efforts to cope, and (5) intrafamilial/social ambiguity (that provide inadequate guidelines on how families should act or cope effectively).<sup>2</sup> Social ambiguity may come about when a family becomes integrated into a new society through immigration or a family becomes mixed through intermarriage. Tradition may help in these instances. McCubbin and McCubbin<sup>2</sup> mentioned *Critical Family Resources* necessary to overcome hardships such as economic stability, cohesiveness, flexibility, shared spiritual belief, open communication, traditions, and celebrations. *Organizational Supports* outside of the family are also important and may be composed of friends, neighbors, and community-based agencies and services such as day care centers, respite groups or centers (where care coordination is achieved), and self-help groups.<sup>2</sup> However, as mentioned previously, only some cultures take advantage of these groups, whereas others may not. Mostly Native English and Western societal groups have traditionally liked these types of groups.<sup>9</sup> Problems accessing care, using supports, or using appropriate services can be major roadblocks for any family who has children with chronic illness, but it is particularly problematic for families who have children with ASDs.

Parents experience high levels of stress and strain when they are given the diagnosis of an ASD; however, there may have also been previous illness-related stressors. Research findings suggest that parenting stress in raising a child with an ASD is ongoing, related

to behaviors, discipline, general adjustment, and transitions throughout life.<sup>15</sup> Stuart and McGrew<sup>23</sup> used the double ABCX model (an adaptation of the original model by McCubbin and McCubbin<sup>2</sup>) to study ASD illness-related stressors for parents and found that most families reported high levels of caregiver burden after diagnosis. Additional pileup of demands and passive-avoidant social support were consistent predictors of increased burden. Hall and Graff<sup>24</sup> also used the double ABCX model to study family stress and coping and parents’ perceptions and understanding of their children’s health and found that parents of children with ASDs reported low levels of adaptive behavior in socialization, communication, and activities of daily living. Neither of these studies took cultural worldviews into consideration (Figure 1).

Few studies have been done on how immigrant parents and families seek support and take action for their children to be diagnosed or treated for ASDs in the United States. No studies were found on how parents adjust to this diagnosis and treatment in South Florida, a very multicultural, multiethnic area of the United States, where there are very high levels of immigration.

## PURPOSE

The majority of studies have been conducted on middle-income, predominantly white families in the Western society, and it is unclear how these findings translate to various cultural or racial/ethnic populations, who are already at risk for health disparities. Barriers to health care access and misunderstanding about the need and/or use for services may cause undue stress and prolong adjustment to chronic illness stressors for families. The purpose of this pilot study was to establish data for a larger study on the context of family adjustment when faced with having a child who may have or has the chronic illness of an ASD within the context of the families’ worldview and belief system. The purpose was also to

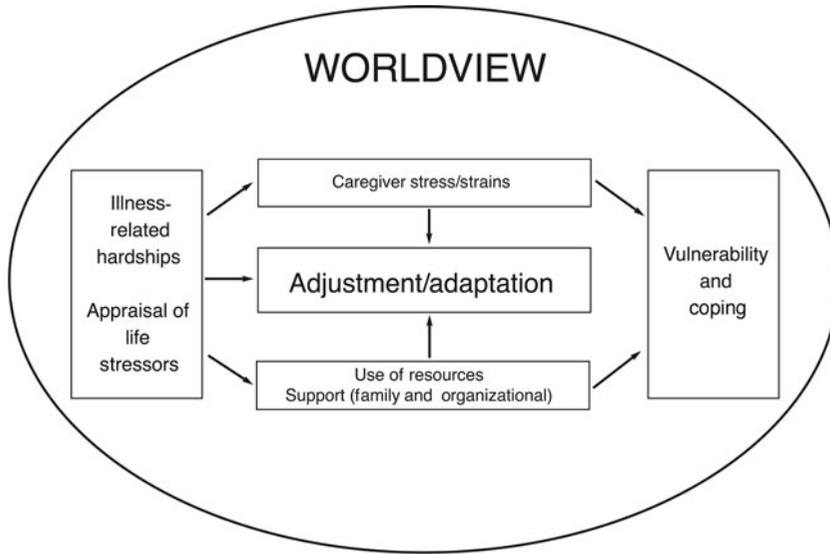


Figure 1. Theoretical framework.

understand norms and the actions of groups of people at risk for health disparities.

**METHODS**

**Design**

The design for the study was ethnomethodology. This approach, rooted in sociology, is used to study norms, understandings, and assumptions about actions taken for granted by groups of people. The method is used to analyze ways in which people “conduct their daily lives.”<sup>4(p2)</sup> Intensive across-case recursive analysis was used to constantly compare cases within and across individual families. Each family or parent is interviewed as a separate case. The case is analyzed individually and compared across cases for concepts and categories and then compared with the model. Thereby, concepts are derived from reading and rereading transcripts in an inductive manner and compared with the model in a deductive manner.<sup>25</sup> In this way, an understanding of the actions taken by certain groups of people can be understood within the context of their worldview. Better interventions for parents’ and children’s adjustment to this chronic

disease may be constructed on the basis of this understanding.

**Setting**

This study took place in South Florida, a multicultural, multiethnic community. Data were collected from 2008 to 2009. The state of Florida exceeds the national averages in persons of Hispanic or Latino origin, black persons, and foreign-born persons. Almost a fourth (23.1%) of Floridians speak a language other than English at home. Miami-Dade County (a site for the Autism Data Monitoring Study) is 65% Hispanic, 15.4% white non-Hispanic, and 18.9% black.<sup>26</sup> Children diagnosed with ASDs in Miami-Dade were similar in number because the national average (1 in 88) in 2008 with a racial/ethnic breakdown of Hispanics being the largest portion of the children represented with 8.2 per 1000, black children 3.0 per 1000, and white children 4.6 per 1000.<sup>27</sup>

**Sample**

Network and maximum variation, purposive sampling were used in this small pilot

study for comparisons. The goal of this type of sampling was to fill out dimensions of the concepts, categories, and themes when comparing cases.<sup>28</sup> Participants who volunteered to participate were from different Hispanic cultural subgroups. Non-Hispanic participants were included to compare and contrast any ethnic belief systems and/or worldviews that seemed to impact perceived actions taken among and between participant cases. Non-Hispanic participants included only white volunteer participants.

Fourteen participants were used in this study. More than 75% ( $n = 11$ ) self-identified as Hispanic. They identified their countries of origin but did not identify when they immigrated to this country or when their parents immigrated to this country. Countries of origin in the subgroup of 11 participants self-identified as Hispanic and were from the Caribbean (Cuba), Central America (Panama), and South America (Brazil, Venezuela, Chile, and Columbia). The majority of these participants were from Cuba and South America. Ten of the 11 interviews were conducted in Spanish, and 1 interview was conducted in a mix of Portuguese and Spanish. Only 3 participants identified themselves as non-Hispanic white (all female). Only 2 participants were male and participated with their wives (although they interviewed separately from their wives). One male participant brought his son to the interview, but the child did not participate in the interview. One grandmother also participated with a mother of a child with an ASD (both from Brazil and included in the previous interview). No participants self-identified as Hispanic or non-Hispanic black or African American.

No children were interviewed in this study. All children of these parents had been diagnosed with ASDs by a physician or psychologist. The children were all verbal and attending school at the time of the study. Children ranged in age between 5 and 15 years.

### Data collection

The study was approved by the university's institutional review board. Data were col-

lected by Spanish- and non-Spanish-speaking research assistants. Once informed consent in English and/or Spanish was signed, the interview was tape-recorded with the permission of the participant (parent(s) or grandparent). After the consent was signed, each participant was asked in which language they would feel most comfortable conducting the interview. Most Spanish speakers chose Spanish. When given the choice of Spanish or English, some Spanish-speaking participants chose to conduct the interview in English. There was 1 Portuguese speaker. This interview was conducted (with the permission of the participant) in a mix of Portuguese and Spanish with a Spanish speaker, where both understood each other (according to the participant and the interviewer).

A semistructured interview schedule was created by the principal investigator (see Table 1) on the basis of the theoretical model and the conceptual definitions. The questions were reviewed by a panel of experts in the field. Interviewers were given instructions on how to use the questions and how to interview participants. The use of English and Spanish conversion questions was discussed in group sessions with research assistants before interviews began. The interviews were mostly conducted in Spanish by a person of the same background as the participant (ie, South American to South American and Cuban to Cuban). If this could not be arranged, then a Spanish speaker conducted the interview.

The process of translation and back-translation is lengthy and can be a paper in itself. For this project, the multicultural, multiethnic student body of the university was used. Students in their research practicum coursework volunteered to be interviewers. They were very excited to be a part of this process and chose this for their research experience. Students were educated on how to interview participants without leading (by the principal investigator). Then, several meetings were conducted about how to translate and back-translate interviews. Professional translators were also used in this process as well. Discussions with translators included

**Table 1.** Semistructured Interview Schedule

<p>Illness-related hardships/stress</p> <p>What is like to be the parent of a child with autism? Or pervasive developmental delay?</p> <p>What does your child need to be successful in life?</p> <p>What do you need so you can help your child to be successful in life?</p> <p>What stresses you? Where do you go to help with everyday stresses?</p> <p>Family/institutional supports/needs</p> <p>Is there anybody in your family that you can count on for help?</p> <p>What types of help does your child need in school? At home? In social situations?</p> <p>What kinds of social activities does your child participate in?</p> <p>Does he/she play any sports? Get invited to parties? Play with other children in the neighborhood?</p> <p>Family? Get bullied?</p> <p>What kinds of health care expenses has your family had?</p> <p>What type of insurance do you have?</p> <p>Do you pay out-of-pocket for any of your family health expenses?</p> <p>Resources</p> <p>What health professionals have you seen?</p> <p>Who made the diagnosis of ASD?</p> <p>What services do you get for your family and child? What helps? What doesn't?</p> <p>Do you use any interventions for your child that your relatives tell you to use?</p> <p>Belief and/or religion</p> <p>Does your family have a spiritual belief system?</p> <p>Have your beliefs helped you to cope with your child's behaviors?</p> <p>Vulnerability and pileup of demands</p> <p>Who takes care of your child when you are at work?</p> <p>Are you asked to come to the school? Why?</p> <p>Do you get help with your child's care at home?</p> <p>How have you coped with this diagnosis?</p> <p>Have you had a lot of demands placed upon you?</p>
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Abbreviation: ASD, autistic spectrum disorders.

the importance of word meaning in interview, analysis, and comparisons. Discussions also included how to stay away from “leading questions” and phrasing of questions should they need to clarify the interview schedule.

### Data analysis

All interviews were done in a setting chosen by the participant (their home, a private room at the support group, or a park). Interviews were tape-recorded in the language most comfortable (chosen by) to the participant. Interviews were transcribed by a Spanish-speaking transcriptionist. All transcripts were also back-translated separately by 2 other Spanish speakers. We have found in other studies that translations differ among ethnic groups from differing Spanish-speaking countries. When doing ethnology, it

is preferred to have more than 1 translation to compare the transcripts with the original language for meaning.

When the investigators were satisfied with translation to English (all of the Spanish speakers [4-8 at a time] came to consensus as to the meaning of the transcripts word by word in English), analysis began. Atlas ti software (GmbH Hardenbergstr. 7, Berlin, Germany) was used to assist in the comparison of the transcripts. Analysis began with each individual case. The first interview was analyzed as 1 case and the next as another case and compared with the first. Transcripts were read line by line to determine concepts, categories, taxonomies, and thematic analysis. Themes are pervasive and go throughout each case. They are the last to be derived in this process. Concepts are built first and

then compared across cases after each case is analyzed, and then concepts that are similar are grouped to form categories. First, an exhaustive description of 1 family is derived, and then concepts (especially about actions) are compared with the next case because categories are built and themes are derived. Categories are formed from similar concepts grouped together into a typology. The across-case comparisons not only maximize variations but also assist in understanding sociodemographic and cultural/ethnic and spiritual dimensions. As mentioned, the themes are derived last because they are woven throughout the experience. Domains and taxonomies are types of experiences that can be used to build an intervention in later work.

## RESULTS

There were many concepts associated with this study. However, although the responses to questions were very typical of other studies of stress and coping by the ABCX model, there were some indications that culture and ethnicity do play a role in how parents respond to their community perception of their children's behavior. Contrary to what the literature has said about support groups, Hispanics from South America did seek support groups in this study and found that early interventions helped ease them into a system that supported their needs. This was contrary to what was found previously about collectivist societies (Hispanic immigrants) as opposed to English, Americans, or Canadians who rely more on institutional supports like support groups and early intervention.<sup>9,15</sup> We did find, however, that even though these parents had similar experiences to those already described by typically "American" parents in the literature related to stress and adjustment, there were some ethnic and/or racial individual comments of note that need further investigation in a larger study.

Ethnomethodology is an inductive, qualitative approach.<sup>29</sup> This was a small pilot study. No domains were found and very small differ-

ences were found in the subgroups because of the numbers of participants. In this section, the categories of actions are described first as they were derived from each of the cases and the comparisons in the data. The pervasive theme is then described as it was derived from the entire description and was ingrained throughout all of the accounts.

The overall purpose of this study was to determine norms, understandings, and assumptions about actions across groups. The types or categories of actions that were found were the following: (1) Seeking Diagnosis, (2) Engaging in Routines to Control Behavior, (3) Finding Therapies, (4) Finding School Accommodations, (5) Educating Others, (6) Rising to Challenges, and (7) Finding the Role of Spiritual and Religious Belief.

*Category 1: Seeking Diagnosis.* The first category of actions was "Seeking Diagnosis" for these parents. There were some subcategories in this small category of actions. All the parents in this study thought that there may be something different in their children than other children (of the same age). Some parents said that they were told by family members and others were told by friends that their children were having a problem. Almost all the "Hispanic" groups (all subgroups) were told by family members. White non-Hispanic groups relied more on nonfamily members.

Children appeared "normal" to their parents at birth. They referred to developmental milestones that their children had achieved as some type of evidence to them that the child was moving along well until something seemed to happen. As 1 parent put it, "He was quick to crawl, able to walk, and say mama and papa."

Diagnosis for parents, in this study, was triggered by changes in the child's behavior. The other reason parents in this study sought diagnosis for their children was for help or services for their children. "He would hit himself against the wall at the sitters—One day he stuck his arm between the bars of the crib and broke his arm" . . . "I kind of knew beforehand . . . I went to a (center) . . . there were a lot of tests . . . he screams a lot."

Diagnosis also helped some parents by putting a name to something that they already suspected. They took action to find out what it was that they suspected that their children had so that they “could do something” (take action). “He had a lot of sensory and social issues and communication issues. When he was diagnosed it made sense for us because we had already been dealing with how he was.” All these parents tried to seek help when stressed by the behaviors; however, some parents were more stressed by the process of diagnosis than others. Most parents did comment on the lack of transportation to the centers for diagnosis.

There were 2 subcategories of actions in “Seeking Diagnosis” because there was more stress described with 1 pathway of action than another. Subcategory 1 of “Seeking Diagnosis” is “Facilitated” and subcategory 2 of “Seeking Diagnosis” is “Non-Facilitated.”

*Subcategory 1: Facilitated.* In the “Facilitated (Seeking Diagnosis)” subcategory, mostly Hispanic subgroups of South Americans (found in a support group for Spanish speakers) had an easier time with diagnosis than some of their Cuban and white non-Hispanic counterparts. They were referred to the Center for Autism and Related Disabilities (CARD) to an Early Intervention program and from there to a “Special School.” The school had set up a specific support group for Spanish speakers led by a Spanish speaker.

*Subcategory 2: Non-Facilitated.* In the “Non-Facilitated (Seeking Diagnosis)” subcategory, mostly Cuban and non-Hispanic white participants had a harder time discovering what was wrong with their children, being shuttled from 1 professional to another. Parents in this group described more stress than parents in the “Facilitated” group.

*Category 2: Engaging in Routines to Control Behavior.* Parents in this study described actions that they took to control behavior. They all noted that behavior was the most difficult problem that they encountered with their children across the spectrum. They stated that people outside the family did not understand their children and they could not

go to any community or social event with their children. This was a consistent across cultural/ethnic groups.

In the home, structure and routine were important to make life livable and behavior controllable. Some parents had to quit their jobs to maintain a routine at home. As 1 mother put it, “When a person is strict with him he adapts better . . . I saw how my son was partial to routine and he felt comfortable following it.” Free time is given within structure to allow for play but most children do not have friends other than family.

Noise is a common distracter and trigger for behavior change in social settings, “When he was younger, he definitely didn’t interact with other children at all . . . He wanted to do his own thing . . . when we wanted to go out somewhere there was too much noise or distraction and he would have a meltdown.”

Again, there was little variation in this category among interviewees. Behaviors varied across the spectrum and among age groups. All the children in this study were verbal and had poor sense of social space, whereas others were described by parents as very self-stimulating (head-banging or rocking) with frequent repetitive behaviors.

New environments are especially unsettling and parents are often confronted by un knowledgeable or frightened school personnel. One mother described her experience as follows: “The school’s director recorded everything and showed me a side of my son’s behavior while he was in class. She then explained to me that his behavior was very [aggressive] toward himself, and that these actions place him and her at risk. She was afraid that one of the other kids will tell their parents, and that the state will call her office to investigate on the daycare.”

Therefore, I took him out of that little daycare school. He had a hard time when he was confronted to a new situation in his life.” This mother stated that “he does well with routine . . . yes, he is different but there’s nothing wrong with being different.”

*Category 3: Finding Therapies.* Once diagnosed with an ASD, parents’ described being

shuttled from 1 referral to another for some type of intervention. However, every case made some mention that these interventions were of no major impact except for speech therapy.

Types of therapies that parents used to intervene with their children included music and sound to calm children, social integration techniques recommended by therapists, pets, and few sports such as swimming or soccer.

Parents in this study denied that there are any interventions specifically used in their cultural or ethnic group or they were told to use by their parents or relatives. Parents did describe a number of interventions that they did use and stated that they were not “covered by insurance” and very costly. They commonly sought “calming” interventions for their children to help with behaviors. Some parents stated that the public school did provide “some speech therapy.” As 1 mother put it, “I had paid over \$30,000 per year only in his private therapies.

These therapies are the occupation, speech, music, sensory-oral, coaching, horse-therapy and others.” Another parent spent more than her yearly salary on similar therapies.

In an additional case, a parent suggested that, among the other therapies for her child, she was interested in summer camp but was perplexed as to how to engage her child in an appropriate setting. She said that she found 2 local college students studying to become special education teachers who had mentioned to her that they were planning to be counselors in a local summer camp. The mother decided that this could be “therapy for free” for her child if she could get her child enrolled with these 2 counselors for the summer in this inexpensive local summer camp. Many other parents found that they had to be creative to find transportation and intervention for their children’s unique needs within the parents’ budget.

When asked about resources for services, parents cited poverty or lack of money as their major concern. One parent described the lack of resources as follows: “I have obtained what

Medicaid gives me, I have obtained very good people but what influences is the money not too much the culture . . . the things there are, there is a club to teach them to ride bike, to swim, that is for rich people, for people like me that don’t have, I can’t go and the Medicaid doesn’t pay, so then you have to find a scholarship, find a waiting list . . . they say my son needs therapy of behavior . . . you have to pay 150 dollars, the Medicaid does not cover. For kids with mental problems, but Autism since it is like a neurological problem, they don’t have it classified and they don’t give . . . you that service.”

*Category 4: Finding School Accommodations.* Children described in this study ranged in age from 5 to 15 years. For maximum variation, older children provided a description of classroom transitions and teacher input in mainstream classes. Some parents stated that finding the “right” teacher was extremely important. This was especially true as the child grew older.

Parents of older children described transitions through school as extremely difficult. Some younger children (aged 5) were in a special school with mainstream children and a majority of children with ASDs. These parents described classrooms more favorably than parents of older children or parents of children in mainstream classrooms. If a child was in a mainstream classroom, parents stated that it was much more difficult to find or get any extra services for their children such as occupational therapy.

One participant parent stated that his own cultural/ethnic heritage (Cuban) did impact his view of how his child was treated in the school. This parent stated that “Hispanic” teachers (teachers who were themselves of Hispanic decent) are not as aware of autism as he thought, they should be and need to be “educated” about autism. This parent stated that this extends to the entire “Hispanic community.” He also stated that his child had much difficulty in school in his neighborhood and had no school accommodations for his needs. He said that he and his wife were called to the school often and could not get any

intervention from the school. He said that he eventually divorced and remarried because of his child's behaviors.

*Category 5: Educating Others.* All participants were focused on school participation and achievement. Finding the "right teacher" was very important, especially for older children. All participants mentioned early intervention; however, some participants still had young children. Parents of older children (aged 10 years or older) said that the effect of early intervention training waned over time and school transitions to mainstreaming were very difficult. Most of the parents interviewed expected their children to achieve normality by saying such things as "they will marry," "become a contributing member of society," or "live a normal life."

All participants stated that they needed to educate themselves about services and their children's needs along the way and that they were still learning. They stated that others in the community and in the schools also needed to learn more about ASDs. All participants felt that teachers were instrumental in autism education among parents and others in both positive and negative ways.

There were some differences between and among cases in this category of educating others. Although white, non-Hispanic parents had some descriptions of behaviors interfering with social outings for families, there were no descriptions of how the specific "community culture" is misinformed or how the parent may seek remedies from the local "culture." A Cuban participant was told that he should seek counsel from *el brujo de la esquina* (the witch around the corner) to help them with their child's ailment. Another parent was very upset about how their child had been called "es un loco (he is a crazy person)" by a person in the park. These parents stated that the community needed to be educated about what ASDs were and why children may act as they do in public places.

*Categories 6 and 7: Rising to Challenges and Finding the Role of Spiritual and Religious Belief.* Challenges for parents are many and most parents mentioned overwhelming

expenditure and insurance as their number 1 issue but noted other challenges to include (1) programs tailored to help the children fit into society, (2) shouldering responsibility on their own (finding help for themselves in the community), (3) poor community perception, (4) little support from the school, and (5) poor to no help with transitions from special classrooms to regular classrooms.

When asked whether their family's belief system had helped them cope with their children's behavior, most participants talked about how church classes had accommodated their children. All participants who self-identified as Hispanic spoke of religion as important and giving strength through prayer. Many Hispanic participants saw their children having this disorder as a gift from God, "accepting God's will" that their children are "special."

Pervasive theme "Taking it One day at a Time": a single pervasive theme was found in the question of "What is it like to be the parent of a child with Autism?" All the parents stated that their "children with ASDs have a hidden potential that is hidden from the public," "They are unique children who do not like to be put aside," "Becomes a part of life, can't imagine life without him, knowing that you are not alone helps," "It is what it is . . . one day at a time," "Great experience . . . little by little . . . day by day . . . don't prevent them from being, living a normal life . . . taking it one day at a time."

## DISCUSSION

This pilot study did have some findings that suggested that worldview and parent or family perceptions do dictate the actions taken on behalf of children who may have what is perceived as an ASD in the Western society. These parents all sought out a diagnosis because they wanted help with the behaviors that they could not control. However, they did have different perceptions about the community around them and about their children's lives as they grow older. Hispanic

participants in this study (particularly Cuban participants) spoke about a community that did not understand their children. The literature suggests that clinicians may not have an understanding of parents or children who have language barriers and communication difficulties.<sup>17</sup> They may speak some English and Spanish and not communicate well in either language. Some Hispanic participants in this study also spoke about poverty and their inability to access services. This has been shown to be a major barrier to care for Mexican Americans who have trouble accessing care from poorer neighborhoods in California.<sup>17</sup>

There is some literature to suggest that there are subgroups of parents or persons who live with certain life circumstances and who become a group through shared understanding of experiences. Some adolescents with ASDs have written that they do not have a disorder but rather have a unique way of communicating and should not be seen as having a disease.<sup>9</sup> Perhaps, this can be said of parents and families of children diagnosed with ASDs who have a shared experience as well, no matter what worldview they have, they share a common goal for their children and have a unique life experience.<sup>30,31</sup> All parents in this study sought diagnosis for their children whether they were Hispanic (across subgroups) or non-Hispanic white. Certainly, parents in this study were stressed by behaviors shown by their children when teachers told them that the child was acting badly or when the child was looked at strangely in a public setting. Hispanic parents (of Cuban descent), however, stated that their community shunned their children because of their behavior and that their community needed to understand how to interact with their children. For some parents, this was more stressful than others. However, their perceptions of

what to do after diagnosis, in the adjustment phase of this model, had much to do with their perceptions of the impact of the behaviors on their children's progression in school and how to reduce the effect of the behavior on the child. All the parents felt that they needed to "Take it One Day at a Time," because they expect normality in the end. What little literature does exist on Hispanic perceptions does state that there is a general mistrust of US system and a social stigma attached to chronic disease.<sup>17</sup>

### IMPLICATIONS FOR FURTHER RESEARCH

Much of the research done on culture and racial/ethnic implications for ASDs and interventions is done using a broad scope. Quantitative studies have assessed the impact of sociodemographic variables such as age of diagnosis and incidence of disease occurrence among certain racial/ethnic groups. Studies of Hispanic parents have been mostly done on Mexican American parents of children with ASDs in the South West. However, no studies have assessed the multicultural milieu of South Florida or looked at the indications of culture and worldview for unique interventions. This small study suggests that all parents and families are isolated and looking for interventions for their children. If they find a support group or family support, it is helpful but does not necessarily help them find interventions that work for their children as they grow older. More research with larger samples of multicultural subgroups is necessary to understand the differences between and among these groups' perceptions to create more appropriate plans for care coordination for these disenfranchised parents.

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