

UC San Diego

UC San Diego Previously Published Works

Title

Amor and Social Stigma: ASD Beliefs Among Immigrant Mexican Parents

Permalink

<https://escholarship.org/uc/item/1jp2b78v>

Journal

Journal of Autism and Developmental Disorders, 48(6)

ISSN

0162-3257

Authors

Cohen, Shana R

Miguel, Jessica

Publication Date

2018-06-01

DOI

10.1007/s10803-017-3457-x

Peer reviewed



Amor and Social Stigma: ASD Beliefs Among Immigrant Mexican Parents

Shana R. Cohen¹ · Jessica Miguel¹

© Springer Science+Business Media, LLC, part of Springer Nature 2018

Abstract

This study examined cultural beliefs about ASD and its causes among Mexican-heritage families. In focus group interviews, we asked 25 immigrant parents of children with ASD to identify words they associated with ASD and its causes. Participants free-listed, ranked, and justified their responses. Mixed methods analyses utilized saliency scores to calculate responses. Deductive interview analyses justified participants' responses. Salient responses for ASD perceptions included specific characteristics about the child (e.g., loving) and perceptions about lack of resources. Salient responses for ASD causes were vaccines, genetics, and a combination of genetics and environment. Inductive analyses revealed distinct beliefs about social stigma, child characteristics, factors supporting development, and parents' emotional stress. Interpretations linked these beliefs to promising adaptations in diagnosis and treatment.

Keywords Latino families · Mexican-heritage parents · Beliefs · ASD cause · Mixed methods analysis

Introduction

Evidence-based autism interventions (EAI) are one of the most effective ways to ameliorate deficits related to autism spectrum disorders (ASD) (Schreibman 2000). EAI, one-on-one, therapist-led interventions, improve child outcomes (Dawson and Burner 2011), and produce significant cost savings to service systems, school districts, and families (Chasson et al. 2007). Studies examining early access to EAI suggest that children reach grade level by first grade, and continue in mainstream classrooms into adolescence (Kasari 2002).

Biomedical approaches to diagnosis and treatment often assume ASD to be a natural, biological phenomenon, rather than contingent upon cultural beliefs or historical context

(Grinker et al. 2015; Ravindran and Myers 2012). This presumption of a shared notion of empirical pathology can conceal the social, cultural, and linguistic components of ASD symptoms (Grinker et al. 2011, 2015; Harrison et al. 2017). Understanding how those factors shape access to diagnosis and treatment of ASD is necessary to enhance early learning opportunities for underserved and understudied populations.

Mexican-heritage children, the largest US Latino group (Lopez et al. 2013), have low ASD treatment participation rates and are at greater risk than White children for certain mental health problems, including more severe ASD symptoms (Blacher et al. 2014; U.S. DHHS 2001). Research consistently shows mental health services (including EAI) are under-utilized among Latino families (Magaña et al. 2013; Stein et al. 2004, US DHHS 2001). With the recent passage of Senate Bill 946, California now mandates state health insurance policies to provide EAI coverage, with families presumably having more access to ASD services and supports (SB. 946, 2011). No studies have examined EAI utilization and access among low-income, Mexican-heritage families in this new political context.

Diminished social and economic resources may further inhibit access to diagnosis and EAI for Mexican-heritage families (Magaña et al. 2013; Zamora et al. 2015). Studies consistently show that socioeconomic status, rather than symptom severity, is a stronger predictor of access to

Electronic supplementary material The online version of this article (<https://doi.org/10.1007/s10803-017-3457-x>) contains supplementary material, which is available to authorized users.

✉ Shana R. Cohen
shanarcohen@ucsd.edu

Jessica Miguel
jlmiguel@ucsd.edu

¹ Department of Education Studies, University of California San Diego, 9500 Gilman Drive #0070, La Jolla, CA 92093, USA

diagnostic and ASD services (Durkin et al. 2010; Harstad et al. 2013). In one large population-based study, Harstad et al. (2013) found that socioeconomic factors (e.g., maternal education, poverty level), rather than ASD symptom severity or behavior problems, predicted access to an Individualized Education Plan¹ (IEP). A report issued by the LA Times found race-based discrepancies in the cost of ASD-related services. The California Department of Developmental Services spent an average of \$11,723 per White child but only \$7634 per Latino child (Zaremba 2011), a disparity that can only be understood by investigating how ASD diagnosis, access and treatment is dependent on racial/ethnic and class status. One possibility is that practitioners, including EAI providers, may be unable to speak Spanish. In fact, Harstad et al. (2013) found that Hispanic children were less likely to receive an IEP. They suggested that this discrepancy may be due in part to language differences between practitioners and families (Harstad et al. 2013). Families may also lack the resources necessary to pay for services, with an average cost of \$40,000 per year, per child (Chasson et al. 2007). Or, families may be undocumented and may decide not to search for or access treatment for fear that they may be deported. Also, many times parents are expected to “prove” that their children need EAI, before an insurance company will cover the service. Some parents may be unable to articulate why their children need ASD treatments. While these deficit-based explanations may be accurate, they do not effectively promote access to timely diagnosis and culturally relevant treatment for ASD. Studies must utilize families’ strengths and assets to identify specific strategies for modifying standardized diagnostic and treatment protocols to be accessible, effective and meaningful for all families.

Mexican-Heritage Families’ Beliefs About ASD

Decades of research among typical Latino families confirms that parents have distinct beliefs about socialization and child development. These beliefs shape parents’ values, expectations, routines, and children’s social and academic outcomes (Reese et al. 1995; Reese and Gallimore 2000; Holloway et al. 2009). In one study, researchers followed 121 Spanish-speaking families for 4 years to understand how their beliefs about education shaped their parenting practices and their children’s outcomes. Parents in the study engaged in purposeful child rearing practices to guide their children along the right path (*buen camino*) (Reese 2002; Valdés 1996). These practices promoted parents’ beliefs about education and development (Reese et al. 1995; Reese

and Gallimore 2000). Similarly, more recent studies found that Latino children displayed higher levels of social engagement and interpersonal skills than their White peers, areas in which parents value cultural models of socialization (Crosnoe 2006).

Beliefs about ASD have been shown to influence parents’ treatment decisions (Blacher et al. 2014; Stahmer et al. 2011; Ravindran and Myers 2012). Specifically, parents’ beliefs about ASD shape parents’ reports of symptoms, the time parents take to seek out treatment, and the type of treatment parents select (Ravindran and Myers 2012). Some Latino parents adopt religion-based explanations for their child’s disability that may shape treatment decisions. For example, Bailey et al. (1999) found that some Latino parents who rear children with disabilities believed that the child was a punishment from God, others believed that the child was a gift from God, still others believed that the child was sent as a test from God (Bailey et al. 1999; Skinner et al. 2001). These beliefs may cause parents to delay seeking treatment, or to seek alternative treatments. In a study examining Latino children with ASD and their families, researchers found that parents endorsed non evidence-based treatments that did not meet efficacy standards (Levy et al. 2003).

In another study, researchers described how some Mexican-heritage individuals viewed illness as biological or spiritual. Doctors cured biological illnesses and *curanderos* (healers) cured spiritual illnesses (Trotter and Chavira 2011). For Mexican-heritage parents who believe that ASD is a spiritual illness, they may select a *curandero*, and not EAI, to “cure” the child of ASD. Practitioners must acknowledge that parents’ beliefs about ASD, and how to treat it, may shape parents’ understanding, implementation, and evaluation of EAI.

In the studies discussed above, researchers identified distinct beliefs about illness and disability among Latino families. The heterogeneity that exists among Latino families may also shape parents’ beliefs about ASD diagnosis and treatment practices. Recent studies have specifically focused on identifying specific groups of Latino families to explore how cultural identity and socioeconomic status differentially shape parenting beliefs and expectations about education, childrearing practices, and child outcomes (Fuller and García-Coll 2010; Galindo and Fuller 2010). A recent meta-analysis suggested that ASD intervention research studies are under-reporting family characteristics and under-utilizing family members as participants (Wolery and Garfinkle 2002). This study is one of the first to examine the strengths of low-income, immigrant, Mexican-heritage families within a sociocultural theoretical framework to understand those families’ specific beliefs about ASD and its causes. Findings from this study will support the development of direct diagnostic pathways and culturally relevant modifications to

¹ An IEP is a legally binding written document and process for individualizing instruction for children with qualifying disabilities (Harstad et al. 2013).

standardized ASD treatment protocols for Mexican-heritage families.

Research Questions

This study contributes to the existing literature by identifying specific beliefs about ASD and its causes among low-income, immigrant, Mexican-heritage families. The first aim of this study was to explore parents' general perceptions about ASD. Because previous studies concluded that Mexican-heritage families' views of illness and disability were based in either biology or spirituality (Trotter and Chavira 2011), we expected parents to have similar general perceptions about ASD. We also expected parents to have distinct beliefs about their children with ASD. Decades of research studying typical children and child socialization identified specific cultural models of education that some Latino parents adopt for their children (García-Coll and Magnuson 2000; Reese et al. 1995; Vygotsky 1967). For example, some studies found that parents expected their children to be *bien educado* (to exhibit strong moral character, and proper comportment), and their educational priorities for their children reflected those beliefs (Bridges et al. 2012; Valdés 1996).

The second aim of this study was to identify parents' beliefs about the causes of ASD. Previous studies have examined Latino families' religious attributions to understanding illness and disability, and their awareness and use of services to support them and their children (Bailey et al. 1999; Skinner et al. 2001). For example, Skinner et al. (2001) sampled 250 Latino families who reared children with developmental disabilities. They found that one-third of the parents made no religious attributions about their child's disability. Instead, the parents adopted biological and scientific causal explanations for their child's disability. However, a majority of these parents (55%) made specific spiritual or religious attributions to their child's disability (Skinner et al. 2001). In the current study we expected some parents to believe in biological or scientific causal explanations, and other parents to believe in spiritual or religious causal explanations.

Theoretical Framework

Building from Weisner's ecocultural framework (Weisner 2002) this study was framed within a critical sociocultural approach to diverse families and ASD (Holloway et al. in press; Skinner and Weisner 2007). There are three fundamental elements to this theoretical approach. First, the professional field of ASD is a community of practice (CoP) with specialized language, practices, and routines that are co-constructed by clinicians, interventionists, and ASD educators that are members of this community (Lave and

Wenger 1991; Nasir and Hand 2006; Odom and Wolery 2003). Practitioners are cultural insiders who share familiar ways of talking about and administering ASD diagnosis and interventions. Second, a CoP is available only to those who have the language and tools to access it. Mexican immigrant families may not have the language and tools of the CoP within the field of ASD to be considered cultural insiders. Third, parents are active, self-reflective individuals with their own perceptions and values about their child's development. Parents use their perceptions to actively construct and shape their child's learning.

Decades of research suggest that Mexican immigrant parents have culturally-specific CoPs for supporting their child's learning (Fuller and García-Coll 2010; Holloway et al. 1997). Specifically, parents' beliefs about development and education influence their expectations and their children's outcomes (Crosnoe 2006, 2012; Reese et al. 1995). Although these beliefs are not unique to this group, many Mexican immigrant parents may expect their children to show respect (*respeto*) for their elders and the parents engage in firm and direct verbal commands to promote *respeto* (Livas-Dlott et al. 2010). Traditional forms of ASD treatment (i.e., Applied Behavioral Analysis Therapy) use verbal commands to teach children to correctly respond to adults in repeated discrete trials (Lovaas 1987). Parents who value *respeto* may appreciate this traditional form of treatment.

Few studies have examined the process of adapting outreach materials, EAIs and standardized ASD treatments to be meaningful for Mexican-heritage families. This study builds upon existing empirical research examining cultural models of socialization among Mexican immigrant families to describe parents' diverse experiences with and knowledge about ASD.

Method

Participants

We recruited families from two sources: (1) a private, non-profit regional center that provides services to individuals with developmental disabilities, including ASD; and (2) a medical clinic located in a border city between the U.S. and Mexico, that provides ASD diagnosis services to immigrant families. Both institutions searched their records and identified Latino families who had a child diagnosed with ASD. The regional center employs psychologists to conduct the ADOS assessment and provide an ASD diagnosis (Lord et al. 2008). The medical clinic

employs developmental-behavioral pediatricians to diagnose ASD. The institutions either hand delivered or mailed out recruitment packets that include a university recruitment letter describing the study, an opt-in card², and a stamped envelope with the university address to each eligible study participant. Interested parents completed and returned the opt-in cards. Upon receipt of the opt-in card, the second author called the interested parent (97% mothers), determined eligibility and interest, and identified a focus group for the parent to attend based on geographic location.

Researchers received 53 opt-in cards. Fifteen of these potential participants were not enrolled in the study because they did not meet eligibility criteria or they were unable to attend a focus group meeting. The final sample included 38 caregivers of children with ASD (86.8% from the Regional Center; 13.2% from the medical clinic), of whom 25 participated in the focus group interviews. In this paper we focus on the 25 participants who participated in the focus group interviews.

After completing the focus group interviews, study participants completed an online demographic questionnaire asking them to report personal background information. All participants were first generation Mexican-heritage mothers with boys ranging in age from 3 to 15 ($M=6.16$). Over 60% of the participants reported a median annual household income of \$35,000 or below. This number is within one standard deviation of the median annual household income for Latinos in California, \$47,180 but not within one standard deviation of the median annual household income for all Californians, \$60,883 (California Senate Office of Research 2014). We highlight the income range because socioeconomic status makes a difference in access to ASD interventions (Chaidez et al. 2012; Durkin et al. 2010; Harstad et al. 2013). The participants' educational attainment was also representative of their limited social and financial capital. Over 70% of the sample reported some college education, or vocational training or less. See Table 1 for demographic characteristics of the target sample.

Procedures

We conducted six focus group interviews between August and October 2016, in immigrant communities in urban and rural Southern California. Two native Spanish speaking moderators led each focus group interview in Spanish. One facilitator led the discussion and the second facilitator supported parent participation (e.g., helped parents write out their individual responses). During each focus

Table 1 Summary of key demographic characteristics (N=25)

	Target child	Parent participant
Mean age	6.16	36.2
Gender		
Male	25 (100.00%)	1 (4.00%)
Female	0 (0.00%)	24 (96.00%)
Country of birth		
United States		4 (16.00%)
Mexico		21 (84.00%)
Employment status		
Currently employed		7 (28.00%)
Currently unemployed		18 (72.00%)
Schooling		
No formal schooling		1 (4.00%)
12th grade or less		10 (40.00%)
Some college, vocational school, or junior college		7 (28.00%)
Bachelor's degree (college graduate)		5 (20.00%)
Graduate or professional degree		1 (4.00%)
Prefer not to answer		1 (4.00%)
Annual household income		
< \$15,000		6 (24.00%)
\$15,001–\$25,000		7 (28.00%)
\$25,001–\$35,000		4 (16.00%)
\$35,001–\$100,000		5 (20.00%)
Don't know/prefer not to answer		3 (12.00%)
Language spoken at home		
Spanish		22 (88.00%)
English		3 (12.00%)

group interview, parents participated in independent and group activities. First, parents used free-listing to write down words or phrases on individual cards in response to two prompts: (1) please tell me what words or phrases you think of when you think about children with autism; and (2) what causes autism? Prompts were open-ended to elicit a range of responses. Next, participants reviewed their cards and the cards of other focus group members. Using all the cards that were generated by that focus group, we asked each participant to write down, rank (e.g., "1" is the most important response), and justify their top five responses for each question.

In the quantitative analysis, we compiled the free-lists and ranked responses. First, we identified a total number of distinct responses for each question. When calculating the number of distinct responses, we grouped together response items that contained the same words or similar words with the same meaning. For example, in response to the question "What causes autism?", we grouped together the following responses: "hereditario," ("hereditary") and "herencia,"

² A postcard asking for the potential participant's name and phone number to request study participation.

Table 2 Saliency score, instances, and definition of level 1 themes

Prompt 1: Please tell me the words or phrases that come to mind when you think about a child with autism				
Category:	SS	N	Subtheme 1	Subtheme 2
<i>Amor</i> (Love)	1	15	Adult efforts to love; The love that parents and other adults have and exhibit to their children	Child expressions of love; Children are loving and affectionate with their parents
<i>Buscar Ayuda</i> (Look for help)	0.84	12	Finding resources; How parents obtain resources for therapy and to better understand their child's symptoms	Difficulty accessing resources; Barriers to accessing supports and services due to label or luck
<i>Niño Especial</i> (Special child)	0.84	7	Label impacts relationships; Family perceptions of child's behaviors and interactions	Child Characteristics; Parents' reports of child's intelligence or independence
Prompt 2: What causes autism?				
Category:	SS	N	Subtheme 1	Subtheme 2
<i>La Genética</i> (The genetics)	3.08	27	Genes; Specific genetic flaws in the child's DNA, or a genetic flaw passed down from a family member	Family history; Family history of developmental disabilities, not tied to genetics
<i>Vacunas</i> (Vaccines)	2	21	Sources of information; Family members or service providers suggest this cause	Vaccines not a cause; Beliefs about how vaccines do not cause ASD
<i>El Medio Ambiente</i> (The environment)	0.88	10	Environment; Chemical contamination like pesticides and pollution	Vaccines led to skill regression; Children exhibit skill regression immediately after receiving vaccines

Saliency scores were calculated by adding the ranked scores for each distinct response and dividing them by the number of participants ($N=25$)

SS saliency score

Table 3 Instances and definition of level 2 categories

Prompt 1: Please tell me the words or phrases that come to mind when you think about a child with autism.

Category	N	Definition
Stigma and education	27	Negative evaluations by members of their community, in parenting skills, or child's behavior; Parents reactions to the evaluation and efforts to educate community and family members
Factors supporting development	12	Support of child's learning and development; Participants mention specific interventions, therapists, and educators, or other parent efforts to support their child's development
Child characteristics	20	Descriptions of children's specific characteristics (e.g., special, different, intelligent); Descriptions of children requiring support to do daily tasks, or children exhibiting certain deficits
Parents' emotional stress	13	Emotional stress, anxiety, and frustration about a child's autism diagnosis; Mothers identified feelings of stress and frustration with challenging behaviors of their child(ren), barriers to securing services, and challenges encountered in communication

N number of instances

("heritage,"). Then we calculated saliency scores for all the ranked responses in a two-step process (Grinker et al. 2015). First, we reverse-coded the ranked responses: we replaced a 5 with the participant's most important response, we replaced a 4 with the participant's next important response, and so on. Second, we calculated an average score for each ranked response. The higher the average, the higher the saliency of that response. Please see Table 2 for the saliency scores corresponding to each question.

In the qualitative inquiry, we conducted two levels of analysis. To understand the rationale behind participants' free-lists and ranked responses, we transcribed and analyzed audio-recordings. In an initial deductive approach, three researchers (the first author, the second author, and a third researcher) read through the original Spanish transcripts that corresponded to each focus group question from all six focus groups and identified examples of participants' justifications for their ranked responses. We categorized these examples into general themes to illustrate the different ways that the salient responses were discussed. We independently coded and discussed the responses for each saliency score to identify recurring themes. We identified the following themes in this deductive analysis: (1) *Amor* (Love); (2) *Buscar Ayuda* (Look for help); and (3) *Niño Especial* (Special Child). Please see Table 2 for number of instances and sub-theme definitions. Please see Online Resource 1 and 2 for tables with original Spanish language quotes and English interpretations.

The first prompt presented to each focus group, "Please tell me what words or phrases you think of when you think about a child with autism", was the most open-ended question and yielded rich and detailed responses that were not captured in the saliency score analysis. In a second level of analysis, we utilized an analytic inductive approach based on principles of grounded theory (Miles et al. 2014), to capture the larger themes from this question across all six focus groups. Independently, we each analyzed the interview transcripts to identify iterative themes and modify

theme definitions. From this process, we discussed recurring themes with specific examples from the transcripts. We then categorized the iterative themes into subthemes that defined and described the larger themes (Miles et al. 2014). We continued the collaborative process of identifying, defining, and refining themes until we agreed on theme definitions. We double coded excerpts that addressed two or more general themes. We identified the following themes in the inductive analysis: (1) Stigma and Education; (2) Factors Supporting Development; (3) Child Characteristics; and (4) Parents' Emotional Stress. Please see Table 3 for the number of instances and theme definitions. Please see Online Resource 3 for a table with original Spanish language quotes and English interpretations.

Results

Level 1 Deductive Analysis: Saliency Scores and Justifications

Prompt One—Beliefs About Children with ASD

We identified 86 distinct responses for the prompt: "Please tell me what words or phrases you think of when you think about children with autism."

Theme 1: Amor. The most salient response for this question was *amor* (love) with a saliency score of 1 (See Table 2). In these responses ($N = 15$) participants discussed the love that children need and desire from their parents, and the love and affection that children expressed to their parents. The first subtheme, *adults' efforts to love*, included instances ($N = 11$) where parents and other adults exhibited love and described a need for love by the child. For example, one mother described her perspective on how love for her child supported her efforts to connect with her child:

They need love. And if they don't like to be touched, but you tell them 'Everything will be fine, calm yourself. Everything will be fine, I love you a lot.' Even though they are responding aggressively, in the end they will also respond with love... Even if they are hitting you in that moment. Repeating often that you care for them, works, it works.

This mother's response to her child's aggressive behavior was to show him love and tell him that he is loved. She believed that this expression of love was useful in mitigating some of his aggressive behavior.

The second subtheme, *child expressions of love*, included instances ($N=4$) in which parents described their children as being loving and affectionate with them. Parents noted that their child's intuition allowed the child to provide comfort to his or her parent if the parent was feeling melancholy. In one example, a mother explained that she believed her son to be sensitive to others' emotional states, and would be loving when he saw a need. Another mother with a newborn at home stated that her son would come over to her when the baby cried, hugging her and offering support.

Theme 2: Autismo, buscar ayuda, todo lo posible. The second most salient response was *autismo, buscar ayuda, todo lo posible* (autism, find help, everything that is possible) with a saliency score of .84. In these responses ($N=12$) participants described how they found resources, and the difficulty that they had in accessing resources. The first subtheme, *finding resources*, included instances ($N=7$) in which parents exerted efforts to obtain resources for therapy at home, or resources that would help the parents to better understand their child's symptoms. One mother explained:

Search for help so that [therapists] will go to your house, go to public places too, they should show [my child] this is correct and this is not correct. They should also show me techniques on how to treat [them], what not to do.

The second subtheme, *difficulty accessing resources*, included instances ($N=5$) in which parents described barriers to accessing support and services either due to the child's label (e.g., the child was considered "functional" and therefore did not need additional services), or because they did not have the same "luck" that other parents had in securing services. For example, one mother described her battle with services, stating that she had been denied interventions in the past because her child was learning "enough," according to her providers. A second mother discussed having to wait for language services due to lack of provider approval.

Theme 3: Niño Especial. The third most salient response was *niño especial* (special child) with a saliency score of .84. In these responses ($N=7$) participants described how the label of *niño especial* impacted family relationships and

described the child's characteristics. The first subtheme, *label impacts relationships*, included instances ($N=5$) where parents described the label of *Niño Especial* as shaping the way they view their child's behavior, and how their extended family views the child and interacts with the child. For example, one mother stated:

On the second point I put a special child, and that also serves as a reminder to myself that when he is doing, well they're called tantrums or behaviors, and I am getting exasperated. To remember that it is not something he is provoking voluntarily, but it is something that he cannot control.

This mother classified her child as "un niño especial" and reminded herself that she should continue supporting her child even during a tantrum because she knows that he cannot always control this behavior.

The second subtheme, *child characteristics*, included instances ($N=2$) where *Niño Especial* was used to indicate children's intelligence or independence. For example, one mother explained that her "special" child was intelligent and "could do thousands of things better than her."

Prompt Two—Causes of ASD

We identified 44 distinct responses for the second prompt: "What causes autism?"

Theme 1: La genética. The most salient response for this question was *la genética* (the genetics), with a saliency score of 3.08. In these responses ($N=27$) participants discussed *la genética* as involving genes, family history, and a combination of causes. The first subtheme, *genes*, included instances ($N=15$) where participants indicated that there was a genetic flaw in their child's DNA. Other participants believed there was a specific gene that helped the child to develop ASD symptoms, and still others believed that certain genes were passed along among family members. For example, one belief, supported by several participants, was the idea that ASD skipped a generation; the "third" generation of children was more likely to receive the gene that causes ASD:

Participant #1: That [explanation] is the third generation, and she thinks that the grandparents, I suppose, of the child... had [the gene]. But they talk about that with cancer and all, that they have a higher propensity in the third generation

Participant #2: of acquiring the genes.

These mothers were building from another mother's explanation that the third generation (the child's grandparents) may have had the gene that causes ASD. This response is nuanced. These mothers do not believe that ASD is inherited. Rather the child retains the ASD gene from the third

generation and exhibits those symptoms, like a person that has a propensity for cancer.

The second subtheme, *family history*, included instances ($N=8$) where the parent described a family history of developmental disabilities, or where one parent exhibited signs of ASD but none of these examples were explicitly tied to genetics. For example, several parents described cousins, parents, and husbands that displayed symptoms of ASD, experienced learning problems in school, or had official ASD diagnoses. Other parents described family members who had different diagnoses (e.g., schizophrenia, dementia) that may have made the child vulnerable to ASD. These beliefs are similar to historical accounts from mid-century child psychiatrists (i.e. Lauretta Bender of Bellevue) who suggested that children with ASD grow up to be adults with schizophrenia (Grinker 2007).

The third subtheme, *combination of causes*, included instances ($N=4$) where participants believed that ASD was caused by a combination of genetics and other factors (e.g., the environment, vaccines). For example, one mother described this combination of factors:

Participant: That it can be a combination, that people are born predisposed to certain illnesses for example, children with cancer, children more prone to the flu, children here... different illnesses. So, there are children predisposed to autism, so there is a, there is a well in what I have read and what I understand is that either vaccines or medications can create a "boom," in these kids.

PI: A boom, what is that?

Participant: It's a boom, it's like, a reaction, not everyone will have a reaction but certain children will have a reaction, and because of predisposition, due to genetics, something, due to nutrition, due to development based on the mother's nutrition. Right now food is very contaminated with everything.

This mother described her beliefs about the cause of ASD as a complicated combination of factors. Just like a child is predisposed to develop cancer, allergies, or other illness, a child may be predisposed to develop the symptoms of ASD through his or her genetic profile, and when he or she is vaccinated or eats contaminated food, there is a reaction that results in ASD.

Theme 2: Vacunas. The second most salient response was *vacunas* (vaccines) with a saliency score of 2. In these responses ($N=21$) participants described how they justified vaccines as a cause of ASD. Some parents said that other family members and service providers suggested that vaccines cause ASD, and other parents described how their child(ren) regressed in their developmental milestones

immediately after receiving a vaccine. Some parents did not agree that vaccines cause ASD. The first subtheme, *sources of information*, included instances ($N=8$) in which parents described conversations with other family members or service providers who suggested that vaccines may cause ASD. A few parents also mentioned reading about a connection between vaccines and ASD in online literature. One mother explained:

Because I have spoken to many educated people and yes...we have arrived at the conclusion that it is the vaccines, the combinations that they do on kids. Because they do not want to poke them the number of times that are required. Because if they give them six, they combine them and they only inject them twice and they combine three [shots]. Many educated people have told me that it is vaccines.

This mother explained that because of conversations with knowledgeable people and through her own personal observations, she believed that vaccines, especially the combination of vaccines (e.g., three different vaccines in one needle), cause ASD.

The second subtheme, *vaccines not a cause*, described instances ($N=8$) in which participants believed that vaccines were not a cause of ASD. One mother explained that she heard that the vaccine causation theory had been disproven. She also said that the theory was unlikely because all children that are vaccinated do not have ASD.

The third subtheme, *vaccines led to skill regression*, included instances ($N=5$) in which parents described child regression in developmental milestones after receiving the vaccines. For example, parents explained that their children had fewer spoken words, would no longer walk, or would no longer maintain eye contact. One participant stated that when her child was born, she made sure to check his developmental milestones, frequently spoke to her son, played games with her son, and used all the tips she learned to help her son succeed. However, she noted that after her son received the vaccine, he stopped progressing, and instead regressed developmentally.

Theme 3: El Medio Ambiente. The third most salient response was *el medio ambiente* (the environment) with a saliency score of .88. In these responses ($N=10$) participants discussed how the environment may be contaminated with chemicals, pesticides and pollution. Parents described how chemicals or contaminants in their food or in the air may have caused ASD. For example, one mother stated:

I also think that it is the environment that is very contaminated, like they were saying the food. Here it's a valley, there are fertilizers, insecticides, all of that... and it stinks, well I am fed up, everytime I go outside I smell it a lot.

This mother explained that living in an agricultural area exposed her and her family to fertilizers and pesticides that contaminated the food. She believed that this contamination caused her son's ASD. Another mother explained that an increase in environmental pollution was the cause.

Level Two Inductive Analysis

In addition to the Level 1 analysis, there were four general themes that did not specifically address the questions but were present throughout all six focus group interviews. This second level analysis was conducted on the responses to the first focus group prompt "Please tell me what words or phrases you think of when you think about children with autism."

Theme 1: Stigma and Education

In the first general theme, parents described instances ($N=27$) where members of their community negatively evaluated them, their parenting skills, and their child[ren]'s behavior. Parents also described their reactions to this negative evaluation and their efforts to educate community and family members. We identified two distinct subthemes that illustrated this general theme. The first subtheme, *societal and family stigma*, included instances ($N=16$) in which participants described rejection, ignorance, and negative evaluations from family and community members. For example, in their responses, many mothers described situations when their children got upset and threw a tantrum in public settings (e.g., a toy store, a park, a restaurant):

I was once in a store and my child was hitting me, mad, frustrated, and [people] keep staring at you. Like how or why did you buy this, or what did you do to him, or did you hit him, no. Now you are judging a behavior.

This mother described how other people examined her interaction with her child, and judged his behavior and her response to that behavior. This mother believed that the people witnessing her child's behavior thought that she did something to cause the behavior.

Many mothers used the same phrase "no juzgar sus comportamientos" (do not judge his behavior), generally asking outsiders and family members to refrain from negatively evaluating their child's behavior. In one instance, a mother linked this negative evaluation of the child's behavior to a common cultural belief about how some parents socialize their children to behave in some Mexican communities. She says:

And for [point] five don't judge his behavior because it is something that as a family we suffer over. To have said that he is badly educated, that he is spoiled, or

asking why is he aggressive? [These are] many words that hurt us in that moment...

In some Mexican families, children are expected to be *bien educado*, to exhibit proper comportment, and display respectful social behavior (Bridges et al. 2012; Valdés 1996). This mother explained that outsiders who share those cultural expectations believed that her child was "mal educado" (badly educated). These negative evaluations were hurtful to her and her family.

The second subtheme, *education*, included instances ($N=10$) in which parents generally explained that others should be educated about ASD. Other parents described exactly how they took the initiative to teach community members and their extended family about ASD. To exemplify parents' general descriptions about how outsiders should be educated, one mother described how she encountered several people who needed more information about ASD. She explained:

Well yes they need more information. Because, um, it is not just us who need more information. Outsiders also need more information...in my own experience, there are people that sometimes see his behavior and they move away. I have encountered people where I say, 'he has autism,' they gasp. they look at him as if he were contagious or [he had] a sickness...

This mother explained a personal experience in which she encountered an "outsider" who needed more information about ASD, particularly how individuals are diagnosed with ASD.

In another set of examples, mothers discussed the specific strategies that they used to educate outsiders (e.g., family members, friends) about children with ASD. For example, one mother described how her son exhibited self-stimulatory behavior in the form of hand flapping. When other family and community members observed this behavior, many of them believed that the child was acting cute or funny. This mother discussed "la ignorancia de la sociedad" (*society's ignorance*) about this child's behavior and how that ignorance motivated her to educate others:

And they think it's funny, right? And there are people that just stare, no? So then you have to tell them that it is a stimulus that the child has to self-regulate. Everything that I have tried to read about why they do certain repetitive things... [I] try to explain to others. I don't know if they understand but my homework sometimes is to explain.

Theme 2: Factors Supporting Development

In the second general theme, parents described ($N=12$) specific ways to support their child's learning and development.

Two distinct subthemes illustrated this general theme. The first subtheme, *interventions*, included some instances ($N=4$) that identified specific interventions, therapists, or educators that supported the child's development. For example, mothers described how interventions like the Picture Exchange Communication System (PECS) (Frost and Bondy 1985) supported their child's language development. Other mothers discussed how their child's ABA therapists supported their child's learning. The second subtheme, *parents' efforts to support development*, included some instances ($N=8$) where parents described their primary efforts to support their child's development. For example, mothers talked about how they exerted significant energy to advocate for the best and most comprehensive interventions for their children and how they attended parenting classes to better understand their child's behavior. In the second focus group, one mother discussed her efforts to advocate for the best services for her child:

But I like it that my child receives the services that he requires...I have fought a lot. I have fought with Special Education. I did not care. I went all the way to the director of Special Education. I have even gone above him and have told him, you must respect my child's IEP. You must give me what the IEP requires for my child. And if I have to be with you at five, six meetings I don't care if I have to keep calling. Sending them "gmails," I don't care having to be on top of it.

In this example, a mother describes her consistent efforts to advocate for her child to receive competent ABA therapists and a comprehensive education plan as required by the child's IEP. She describes multiple strategies to ensure that her voice is heard and her child receives the best education.

Theme Three: Child Characteristics

In the third general theme, parents described instances ($N=20$) where their children exhibited specific characteristics. Four distinct subthemes illustrated this general theme. The first subtheme, *Intelligent*, included instances ($N=5$) in which mothers described their children's intelligence. For example, one mother with two children diagnosed with ASD explained:

My two children are very intelligent. The older one is super intelligent that sometimes although he may not be able to express himself verbally you realize that he has a lot of potential. He is really good with Minecraft, he constructs things—buildings...

Mothers also identified their children as *different*, *special* ($N=5$), and *dependent* ($N=7$). In their descriptions of dependent, mothers described how their children required support to perform daily tasks like dressing and eating.

Other mothers identified their children as dependent but capable of independently performing many tasks. For example, one mother explained:

...the most important point for me, is that they are really dependent of other people because they are very special. It is not that they are incapacitated but that they are different from us but with a lot of capabilities perhaps even more brilliant than us people who are classified as normal.

Notably, in most of these instances, mothers characterized their children as exhibiting numerous strengths and capabilities. There were few instances ($N=3$) where mothers identified their children with certain deficits, like language development and social interaction skills.

Theme Four: Parents' Emotional Stress

In the fourth general theme, parents described instances ($N=13$) where they felt emotional stress, anxiety, and frustration about their child's ASD diagnosis. In the only subtheme for this general theme, mothers identified feelings of stress and frustration when they discussed the challenging behavior exhibited by their children, the barriers to securing services for their children, or the challenges that they encountered in communicating with their children. For example, one mother described her frustration in trying to communicate with her child: "Because I cannot understand him. In that moment there are times that I don't know what he wants, what does he need? And both he and I get frustrated." This mother identified feelings of frustration similar to what she assumed her son to feel when they attempted to communicate.

Discussion

Previous research has shown that understanding parents' beliefs about ASD and its causes shape how and whether parents seek out treatment. For example, a parent with no concerns about their child's development may delay seeking diagnosis and treatment (Blacher et al. 2014). Or, a parent who believes in a biological cause for ASD may seek a biological treatment (e.g., drugs), while parents who believe in an environmental cause may seek behavioral treatments (e.g., Applied Behavior Analysis Therapy) (Ravindran and Myers 2012).

In this study, we used a critical sociocultural theoretical framework as a lens to view and interpret Mexican-heritage parents' beliefs about ASD and its causes (Holloway et al. in press). This framework acknowledges the community of practice (CoP) (specialized language, routines, and practices) that exists among diagnosticians and service providers

in the field of ASD and the difficulty that cultural outsiders may have in accessing these CoPs. This perspective also acknowledges that individuals and families use their beliefs about their child's development to make informed decisions about diagnosis, education, and intervention for ASD. In this study we begin to understand how Mexican immigrant families make sense of ASD. This information should be useful in informing and modifying outreach and intervention practices for some Mexican-heritage children with ASD.

Love (*Amor*)

Findings from Prompt One revealed that *Amor* (love) was the most important answer to the prompt: "Please tell me the words or phrases that come to mind when you think about a child with autism." Similar to other studies that identified themes of love, religiosity, and family support in Latino parents' experiences raising their children with disabilities, including ASD, in this study, parents discussed *amor* in the context of the efforts that they make in displaying love towards their children. When parents talked about the love that they have for their children, many described using love as a tool to mitigate challenging behavior or to overcome the child's diagnosis. Previous studies showed that some Latino parents believed that their children brought about positive changes in their lives including more support and a strong sense of religiosity (Bailey et al. 1999; Casillas et al. 2017; Skinner et al. 1999, 2001).

These findings allow researchers and practitioners to make educated decisions about the types of intervention programs that may be meaningful and sustainable for some Mexican immigrant parents. For example, the prevailing therapy for children with ASD, Applied Behavioral Analysis Therapy, has proven to be efficacious primarily among White children with ASD (Dawson and Burner 2011; Lovaas 1987; Welterlin and LaRue 2007). This therapy requires standardized materials and direct instruction to meet individualized goals (e.g., Johnny will dress himself, or Johnny will request an object using words). For the participants in this study who reported using love and affection to support their child's development, this form of therapy may not be sustainable or appropriate given parents' reported beliefs. Other forms of therapy such as Greenspan's DIR/Floortime intervention may be more appropriate. DIR/Floortime™ is an intervention approach that aims to develop warm relationships with the child, and build upon the child's strengths and abilities. Recent efficacy studies have found that children who participated in DIR/Floortime™ made significant improvements in their emotional functioning, communication, and daily living skills (Pajareya and Nopmaneejumrulers 2011; Liao et al. 2014). These studies included samples of children from Thailand and Taiwan; future research might

explore the efficacy of DIR/Floortime™ techniques with a sample of Mexican immigrant families.

Similar to studies of typically developing Latino children that display higher levels of social engagement and interpersonal skills than their White peers (Crosnoe 2006), parents in this study reported that without a reminder, their children exhibited *amor* (love) and affection to the parent during a difficult time. According to the DSM-5 definition of ASD, children with ASD exhibit "persistent" deficits in social interaction, social-emotional reciprocity and in developing and maintaining relationships (American Psychiatric Association 2013). Contrary to the typical characteristics of a child with ASD, some parents in this study reported their children as affectionate and empathetic. From a sociocultural perspective, these findings would support the notion of utilizing the child's strengths to support areas of weakness. For example, if children in this sample are able to exhibit emotions, practitioners may use this information to develop interventions that exploit this strength but that can be used to support the child's challenges in communication. Researchers have demonstrated the benefits of peer mediated interventions, in an effort to scaffold social interactions among children with ASD and typically developing peers (DiSalvo and Oswald 2002; Wolfberg and Schuler 1999). The integrated peer group model (Wolfberg and Schuler 1999) provides children with ASD the ability to develop play skills in natural settings while also allowing them to form empathetic and affectionate relationships with peers, in addition to parents, as was demonstrated in our findings.

Genetics (*La Genetica*)

For Prompt two, genetics was the most important answer to the question: "What causes autism?" Like the White parents in previous studies examining parents' beliefs about ASD (Goin-Kochel and Myers 2005; Hebert and Koulouglioti 2010; Selkirk et al. 2009), parents in this study discussed genetics in the context of genes that mutate and are passed along to other family members. Most notably, in their complex justifications describing the combination of genetics, epigenetics, and the environment as causes of ASD, some parents in this study provided thoughtful and accurate justifications that represent current explanations (Eskenazi et al. 2007; Hall and Kelley 2014; Persico and Bourgeron 2006). For example, one study by Eskenazi et al. (2007) found a link between pesticide exposure and pervasive developmental disorder in a sample of Mexican American children of farm-worker families. These findings support the beliefs of many parents in this study who identified pesticides in the environment as a cause of ASD.

Future research should explore sources of knowledge and information that these parents used to develop their complex theories about the causes of ASD. Various researchers

discuss the importance of understanding ASD causality and beliefs among different cultural groups (Hebert and Koulouglioti 2010; Mandell and Novak 2005; Welterlin and LaRue 2007). They indicated that parents' beliefs, along with poor consensus on appropriate intervention strategies, can lead parents to differential access to evidence-based treatments (Mandell and Novak 2005). Differential access to interventions can manifest across racial and class disparities, and potentially impact recognition and diagnosis of ASD in diverse cultural communities (Hebert and Koulouglioti 2010).

Stigma

Findings from the deductive analysis revealed stigma as the most prevalent theme throughout the focus group interviews. Previous studies and theoretical analyses identified ASD as an “invisible” condition, distinct from other visible disabilities like Down Syndrome, that may lead to stigma given the lack of understanding about ASD (Grinker 2007). The historical notion that ASD was caused by “refrigerator mothers” may also have generated social stigma and misplaced blame on the mother (Grinker 2007; Holloway et al. in press). This social stigma has been shown to cause emotional distress, depression, and suicidal thoughts in parents of children with ASD (Gray 1993; Green et al. 2005).

Like previous studies that examined how non-ASD parents and community members used words or ideas about ASD that stigmatized individuals with ASD (Grinker et al. 2015), this study found that Mexican-heritage parents felt personal-level social stigma (Holloway et al. in press) when they experienced overt discrimination and avoidance in situations where their children exhibited challenging behavior in a public place or during a large family gathering with extended family members. Notably, parents in this study felt empowered to educate the outsiders that stigmatized them. In an effort to contest the stigma, some parents described the need for outsiders to be educated about ASD, and other parents described specific strategies that they used to teach community members and their extended family about ASD. Similar results have been found in other studies in which stigmatized parents utilized their expertise and medical knowledge to resist stigmatization (Farrugia 2009).

Implications

The results of this study have the potential to inform policy by identifying specific adaptations to outreach materials that address the diversity of beliefs about ASD among some Latino groups. For example, the Spanish version of the 100 Day Kit for newly diagnosed families (Autism Speaks 2014), could include messages for how families can engage with and educate outsiders when they experience personal social

stigma. Rather than assume a shared understanding about the causes, symptoms and treatments of ASD, through this study we encourage practitioners to engage in meaningful dialogue with families in an effort to learn about parents' beliefs and educational expectations for their children. This new knowledge will allow practitioners to individualize EAI content and the process for delivering this content. Future research might explore the origins of ASD beliefs and how those beliefs shape treatment decisions.

Limitations

Sample size may be considered a limitation of this study. Consistent with other research designs, the sample size may vary according to when saturation is observed. In this study, saturation was determined by the point at which participants did not generate new constructs related to each focus group question (Grinker et al. 2015). The $N=25$ participants is consistent with previous studies suggesting that saturation occurs between 20 and 40 participants (Borgatti 1999). A lack of a White comparison group may also be considered a limitation. In accordance with recent calls for a more nuanced understanding of the diversity within Latino families (e.g., Fuller and García-Coll 2010), this study only sampled Mexican-heritage families who rear children with ASD.

Conclusion

This study found that Mexican heritage families have distinct beliefs about ASD and its causes. Parents have positive perceptions about their children with ASD (i.e., love) and they exhibit complex understandings related to ASD causes. Parents' negative perceptions of ASD translate to family and societal stigma that has been buffered by parents' focused energy to educate their families and communities about ASD and the corresponding symptoms.

Acknowledgments The authors would like to acknowledge the Yankelovich Center for Social Science Research: <http://yankelovichcenter.ucsd.edu/> a non-profit foundation at University of California San Diego for partially supporting this study. The authors would also like to acknowledge the families who participated in this study and to the students who participated in data collection and analysis. An earlier iteration of this paper was presented as a Poster at the 2017 IMFAR Conference.

Author Contributions SRC conceived and designed the study. She also participated in coordination, implementation, data interpretation, and she drafted the manuscript. JM participated in the design of the study, data coordination and collection, assisted with data interpretation, and collaborated on drafting the manuscript. Both authors read and approved the final manuscript.

Funding This study was partially funded by the Yankelovich Center at University of California San Diego.

Compliance with Ethical Standards

Conflict of interest Shana R. Cohen has received research grants from the Yankelovich Center at University of California San Diego. Jessica Miguel declares that she has no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Association.
- Autism Speaks. (2014). 100 day kit for newly diagnosed families of young children. Retrieved from <https://www.autismspeaks.org/family-services/tool-kits/100-day-kit>.
- Bailey, D., Skinner, D., Correa, V., Arcia, E., Reyes-Blanes, M., Rodriguez, P., ... Skinner, M. (1999). Needs and supports reported by Latino families of young children with developmental disabilities. *American Journal of Mental Retardation*, 104, 437–451.
- Bailey, D., Skinner, D., Rodriguez, P., Gut, D., & Correa, N. (1999). Awareness, use, and satisfaction with services for Latino parents of young children with disabilities. *Exceptional Children*, 65, 367–381.
- Blacher, J. B., Cohen, S. R., & Azad, G. (2014). In the eye of the beholder: Reports of autism symptoms by Anglo and Latino mothers. *Research in Autism Spectrum Disorders*, 8, 1648–1656.
- Borgatti, S. (1999). Elicitation techniques for cultural domain analysis. In J. J. Schensul & M. D. LeCompte (Eds.), *Enhanced ethnographic methods: Audiovisual techniques, focused group interviews, and elicitation techniques* (pp. 115–151). Lanham: AltaMira Press.
- Bridges, M., Cohen, S. R., McGuire, L. W., Yamada, H., Fuller, B., Mireles, L., & Scott, L. (2012). *Bien educado*: Measuring the social behavior of Mexican American children. *Early Childhood Research Quarterly*, 27, 555–567. <https://doi.org/10.1016/j.ecresq.2012.01.005>.
- California Senate Office of Research. (2014). A statistical picture of Latinos in California: Demographic, income, health, and other social characteristics. Retrieved from <http://latinocaucus.legislature.ca.gov/sites/latinocaucus.legislature.ca.gov/files/Latinos-InCA.pdf>.
- Casillas, N., Vigil, D., & Wang, H. (2017). Latino and non-Latino White parents' experiences raising their child with ASD: An exploratory study. *The Qualitative Report*, 22, 2173–2195.
- Chaidez, V., Hansen, R. L., & Hertz-Picciotto, I. (2012). Autism spectrum disorders in Hispanics and non-Hispanics. *Autism*, 16, 381–397. <https://doi.org/10.1177/1362361311434787>.
- Chasson, G. S., Harris, G. E., & Neely, W. J. (2007). Cost comparison of early intensive behavioral intervention and special education for children with autism. *Journal of Child and Family Studies*, 16, 401–413.
- Crosnoe, R. (2006). *Mexican roots, American schools: Helping Mexican immigrant children succeed*. Palo Alto, CA: Stanford University Press.
- Crosnoe, R. (2012). Studying the immigrant paradox in the Mexican-origin population. In C. García, Coll & A. K. Marks (Eds.), *The immigrant paradox in children and adolescents: Is becoming American a developmental risk?* (pp. 61–76). Washington DC: American Psychological Association.
- Dawson, G., & Burner, K. (2011). Behavioral interventions in children and adolescents with autism spectrum disorder: A review of recent findings. *Current Opinion in Pediatrics*, 23, 616–620. <https://doi.org/10.1097/MOP.0b013e32834cf082>.
- DiSalvo, C. A., & Oswald, D. P. (2002). Peer-mediated interventions to increase the social interaction of children with autism: Consideration of peer expectancies. *Focus on Autism and Other Developmental Disabilities*, 17(4), 198–207.
- Durkin, M. S., Maenner, M. J., Meaney, F. J., Levy, S. E., DiGiuseppe, C., Nicholas, J. S., ... Shieve, L. A. (2010). Socioeconomic quality in the prevalence of autism spectrum disorder: Evidence from a U.S. cross-sectional study. PLoS ONE. <https://doi.org/10.1371/journal.pone.0011551>.
- Eskenazi, B., Marks, A. R., Bradman, A., Harley, K., Barr, D. B., Johnson, C., ... Jewell, N. P. (2007). Organophosphate pesticide exposure and neurodevelopment in young Mexican-American children. *Environmental Health Perspectives*, 115, 792–798.
- Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health and Illness*, 31, 1011–1027. <https://doi.org/10.1111/j.1467-9566.2009.01174.x>.
- Frost, L. A., & Bondy, A. S. (1985). *PECS. The picture exchange communication system*. Newark, DE: Pyramid Educational Consultants.
- Fuller, B. F., & García-Coll, C. (2010). Learning from Latinos: Contexts, families, and child development in motion. *Developmental Psychology*, 46, 559–565. <https://doi.org/10.1037/a0019412>.
- Galindo, C., & Fuller, B. (2010). The social competence of Latino kindergartners and growth in mathematical understanding. *Developmental Psychology*, 46(3), 579.
- García-Coll, C., & Magnuson, K. (2000). Cultural differences as sources of developmental vulnerabilities and resources. In J. P. Shonkoff & S. J. Meisels (Eds.), *Handbook of early childhood intervention* (2nd ed., pp. 94–114). New York: Cambridge University Press.
- Goin-Kochel, R. P., & Myers, B. J. (2005). Congenital versus regressive onset of autism spectrum disorders: Parents beliefs about causes. *Focus on Autism and Other Developmental Disabilities*, 20, 169–179.
- Gray, D. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health and Illness*, 15, 102–120.
- Green, S., Davis, C., Karshmer, E., Marsh, P., & Straight, B. (2005). Living stigma: The impact of labeling, stereotyping, separation, status loss, and discrimination in the lives of individuals with disabilities and their families. *Sociological Inquiry*, 75, 197–215.
- Grinker, R. R. (2007). *Unstrange minds: Remapping the world of autism*. Cambridge, MA: Basic Books.
- Grinker, R. R., Kang-Yi, C. D., Ahmann, C., Beidas, R. S., Lagman, A., & Mandell, D. (2015). Cultural adaptation and translation of outreach materials on autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45, 2329–2336.
- Grinker, R. R., Yeargin-Allsopp, M., & Boyle, C. (2011). ASD and culture: International trends in prevalence and diagnosis. In D. Amaral, D. Geschwind & G. Dawson (Eds.), *Autism spectrum disorders*. Oxford: Oxford University Press.
- Hall, L., & Kelley, E. (2014). The contribution of epigenetics to understanding genetic factors in autism. *Autism*, 18, 872–881. <https://doi.org/10.1177/1362361313503501>.
- Harrison, A. J., Long, K. A., Tommet, D. C., & Jones, R. N. (2017). Examining the role of race, ethnicity, and gender on social and behavioral ratings within the Autism Diagnostic Observation Schedule. *Journal of Autism and Developmental Disorders*, 47, 1–13.

- Harstad, E., Huntington, N., Bacic, J., & Barbaresi, W. (2013). Disparity of care for children with parent-reported autism spectrum disorders. *Academic Pediatrics*, 13, 334–339.
- Health care coverage: mental illness: pervasive developmental disorder or autism: public health. SB. 946, California S. §§ 121022 (2011).
- Hebert, E. B., & Koulouglioti, C. (2010). Parental beliefs about cause and course of their child's autism and outcomes of their beliefs: A review of the literature. *Issues in Comprehensive Pediatric Nursing*, 33, 149–163. <https://doi.org/10.3109/01460862.2010.498331>.
- Holloway, S. D., Cohen, S. R., & Domínguez-Pareto, I. (in press). Culture, stigma, and intersectionality: Towards equitable parent-educator relationships in special education.
- Holloway, S. D., Fuller, B., Rambaudo, M. F., & Eggers-Pierola, C. (1997, 2009). *Through my own eyes: Single mothers and the cultures of poverty*. Cambridge, MA: Harvard University Press.
- Kasari, C. (2002). Assessing change in early intervention programs for children with autism. *Journal of Autism and Developmental Disorders*, 32(5), 447–461.
- Lave, J., & Wenger, E. (1991). *Situated learning: Legitimate peripheral participation*. New York: Cambridge University Press.
- Levy, S. E., Mandell, D. S., Merhar, S., Ittenbach, R. F., & Pinto-Martin, J. A. (2003). Use of complementary and alternative medicine among children recently diagnosed with autistic spectrum disorder. *Journal of Developmental and Behavioral Pediatrics*, 24, 418–423.
- Liao, S., Hwang, Y., Chen, Y., Lee, P., Chen, S., & Lin, L. (2014). Home-based DIR/Floortime Intervention program for preschool children with autism spectrum disorders: Preliminary findings. *Physical and Occupational Therapy in Pediatrics*, 34, 356–367.
- Livas-Dlott, A., Fuller, B., Stein, G. L., Bridges, M., Mangual-Figueroa, A., & Mireles, L. (2010). Commands, competence, and cariño: Maternal socialization practices in Mexican-American families. *Developmental Psychology*, 46, 566–578.
- Lopez, M. H., Gonzalez-Barrera, A., & Patten, E. (2013). *Closing the digital divide: Latinos and technology adoption*. Washington, DC: Pew Hispanic Center.
- Lord, C., Rutter, M., DiLavore, P. C., & Risi, S. (2008). *Autism diagnostic observation schedule: ADOS manual*. Los Angeles: Western Psychological Services.
- Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55, 3–9.
- Magaña, S., Lopez, K., Aguinaga, A., & Morton, H. (2013). Access to diagnosis and treatment services among latino children with autism spectrum disorders. *Intellectual and Developmental Disabilities*, 51, 141–153.
- Mandell, D. S., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews*, 11(2), 110–115.
- Miles, M. B., Huberman, A. M., & Saldaña, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Nasir, N. S., & Hand, V. M. (2006). Exploring sociocultural perspectives on race, culture, and learning. *Review of Educational Research*, 76, 449–475.
- Odom, S., & Wolery, M. (2003). A unified theory of practice in early intervention/early childhood special education: Evidence-based practices. *The Journal of Special Education*, 37, 164–173.
- Pajareya, K., & Nopmaneejumruslers, K. (2011). A pilot randomized controlled trial of DIR/Floortime parent training intervention for pre-school children with autistic spectrum disorders. *Autism*, 15, 563–577. <https://doi.org/10.1177/1362361310386502>.
- Persico, A. M., & Bourgeron, T. (2006). Searching for ways out of the autism maze: Genetic, epigenetic and environmental clues. *Trends in Neurosciences*, 29, 349–358.
- Ravindran, N., & Myers, B. J. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal of Children and Family Studies*, 21, 311–319.
- Reese, L. (2002). Parental strategies in contrasting cultural settings: Families in México and “El Norte”. *Anthropology and Education Quarterly*, 33, 30–59. <https://doi.org/10.1525/aeq.2002.33.1.30>.
- Reese, L., Balzano, S., Gallimore, R., & Goldenberg, C. (1995). The concept of *educación*: Latino families' values and American schooling. *International Journal of Educational Research*, 23, 57–81. [https://doi.org/10.1016/0883-0355\(95\)93535-4](https://doi.org/10.1016/0883-0355(95)93535-4).
- Reese, L., & Gallimore, R. (2000). Immigrant Latinos' cultural model of literacy development: An evolving perspective on home-school discontinuities. *American Journal of Education*, 108, 103–134. Retrieved from <http://www.jstor.org/stable/1085760>.
- Schreibman, L. (2000). Intensive behavioral/psychoeducational treatments for autism: Research needs and future directions. *Journal of Autism and Developmental Disorders*, 30, 373–378.
- Selkirk, C. G., Veach, P. M., Lian, F., Schimmenti, L., & LeRoy, B. S. (2009). Parents' perceptions of autism spectrum disorder etiology and recurrence risk and effects of their perceptions on family planning: Recommendations for genetic counselors. *Journal of Genetic Counseling*, 18, 507–519. <https://doi.org/10.1007/s10897-009-9233-0>.
- Skinner, D., & Weisner, T. S. (2007). Sociocultural studies of families of children with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 302–313.
- Skinner, D. G., Bailey, D. B., Correa, V., & Rodriguez, P. (1999). Narrating self and disability: Latino mothers' construction of identities vis-à-vis their children with special needs. *Exceptional Children*, 65, 481–495.
- Skinner, D. G., Correa, V., Skinner, M., & Bailey, D. B. (2001). Role of religion in the lives of Latino families of young children with developmental delays. *American Journal on Mental Retardation*, 106, 297–313.
- Stahmer, A., Brookman-Frazee, L., Lee, E., Searcy, K., & Reed, S. (2011). Parent and multidisciplinary provider perspectives on earliest intervention for children at risk for autism spectrum disorders. *Infants and Young Children*, 24, 344–363.
- Stein, M. T., Flores, G., Graham, E. A., Magana, L., & Willies-Jacobo, L. (2004). Cultural and linguistic determinants in the diagnosis and management of developmental delay in a four year old. *Journal of Developmental and Behavioral Pediatrics*, 25, S43–S48.
- Trotter, R. T., & Chavira, J. A. (2011). *Curanderismo: Mexican American folk healing* (2nd ed.). Athens: University of Georgia Press.
- U.S. Department of Health and Human Services. (2001). *Culture, race, and ethnicity—A supplement to mental health: A report of the surgeon general*. Rockville: Center for Mental Health Services.
- Valdés, G. (1996). *Con Respeto: Bridging the distances between culturally diverse families and schools*. An ethnographic portrait. New York: Teachers College Press.
- Vygotsky, L. S. (1967). Play and its role in the mental development of the child. *Soviet Psychology*, 5, 6–18.
- Weisner, T. S. (2002). Ecocultural understanding of children's developmental pathways. *Human Development*, 45(4), 275–281.
- Welterlin, A., & LaRue, R. H. (2007). Serving the needs of immigrant families of children with autism. *Disability & Society*, 22(7), 747–760.

- Wolery, M., & Garfinkle, A. N. (2002). Measures in intervention research with young children who have autism. *Journal of Autism and Developmental Disorders*, 32(5), 463–478.
- Wolfberg, P. J., & Schuler, A. L. (1999). Fostering peer interaction, imaginative play and spontaneous language in children with autism. *Child Language Teaching and Therapy*, 15(1), 41–52. <https://doi.org/10.1177/026565909901500105>.
- Zamora, I., Williams, M. E., Higareda, M., Wheeler, B. Y., & Levitt, P. (2015). Brief report: Recruitment and retention of minority children for autism research. *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-015-2603-6>.
- Zarembko, A. (2011). Warrior parents fare best in securing autism services. Second of Four Parts, *Los Angeles Times*. Retrieved from <http://www.latimes.com/local/autism/la-me-autism-day-two-htmlstory.html>.